

towards community partnership
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for leprosy elimination
for leprosy elimination



Vision 2010
ALERT-INDIA

**Towards Community Partnership
for
Leprosy Elimination**

Vision 2010

ALERT-INDIA

Association for Leprosy Education, Rehabilitation and Treatment

1978 - 2004

**Silver Jubilee Commemorative Document
11th October, 2004**

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Foreword

The progress towards achieving the goal of Leprosy Elimination in India at National level, by December 2005 is quite impressive. Barring a few states, all the other States/ UTs also should hopefully reach this goal by that time.

Still lot of work is yet to be done in identified districts and at sub-district level. In urban areas the problem is more complex due to migration of people, multiplicity of service providers and lack of coordination amongst them. Govt. of India has issued a Guidelines in May 2004, for the states to develop urban area wise plan of action and to implement it. The role of NGOs in supporting the leprosy elimination Programme in Urban areas remains high in priority.

ALERT- India, a Leprosy NGO working in Mumbai for the last 25 years is providing great support to the Programme. Their training and utilization of community Health Volunteers of the Municipal corporation of Greater Mumbai is praiseworthy. On the occasion of its Silver Jubilee, ALERT-India has come out with this vision document, highlighting the works carried out in the past and their plan for the future. The vision emphasized on the development of Programmes towards Voluntary Reporting without deformities at the stage of diagnosis. The document will provide inspiration to other Non-Governmental Leprosy Organizations, particularly those working in urban areas.

We hope the Voluntary organizations will continue to play an important role in Leprosy Control and rehabilitation in the next few years even after the elimination is achieved at National level.

Dr. G. P. S. Dhillon
Dy. Director General, Leprosy
Govt. of India, New Delhi

27th September, 2004

Preface

For centuries, the scourge of Leprosy has been a huge socio-economic problem for those afflicted by it – patients and their families, and the communities prone to the disease. Leprosy then was characterized by deformity and mutilation. As identified by modern medicine through anaesthetic patches or early nerve involvement, Leprosy has proven to be a treatable and even curable through multi-drug (chemo) therapy (MDT). If the drugs are taken early, there are good chances of preventing visible deformities, which have been the root cause of the stigma attached to the disease.

With modern drugs it has been possible to launch control programmes and bring the disease to the level of treatability and curability just like with any other disease, without labeling it a public health problem.

Concerted efforts by international agencies, national governments and voluntary institutions have rendered this possible. It is therefore but natural for the government to roll back the “vertical” leprosy programme – and integrate it with the general health care services.

Since the means of transmission of the disease is not completely understood, and since the disease sometimes results in complications, it is felt that leprosy-specialising personnel in the government and in the voluntary sector will continue to have a role in leprosy-related issues.

ALERT-India, a prominent NGLO in Mumbai, has, during the last 25 years, shown sensitivity in dealing with leprosy not merely as a vertical issue but also in attempting to merge it with other urban-related health issues. . Great emphasis has been placed on involving community health volunteers attached to the health posts of the Municipal Corporation of Greater Mumbai.

It is therefore desirable that the 25 years of experience should project the phases after integration is effected. This document has tried to take stock of leprosy-related issues and the role ALERT-India has played as a partner in leprosy control.

The first chapter projects the issues as have been discussed in global and national foras. The second chapter summarizes the work of ALERT-India over the past 25 years. The third chapter provides a vision for the next ten years. I am sure the document will provide food for thought and reflection about the evolution of leprosy programmes as conceived and implemented, as well as project a vision of the scenario for the near future.

September 5, 2004

Prof. R K Mutatkar

Epilogue

Till 1955, there was no extensive leprosy field work in Mumbai, though Allbless & Acworth Leprosy Home existed since 1885 and 1890 respectively. The Greater Bombay Leprosy Control Scheme (GBLCS) came into existence in 1955 under the auspices of Acworth Leprosy Hospital, wherein 13 Health Visitors and two Non-Medical-Assistants were appointed who undertook field work in whole of Bombay and treatment centres were opened-up in all the then teaching medical colleges in Mumbai.

On account of job hunting and other facilities like good treatment for all the diseases, there is an influx of people in Mumbai from other parts of Maharashtra State and other States of India, till today. Bombay gives 1/3 revenue of the whole country to GOI, this indicates sources of business. The Secretariat, Govt. of Maharashtra State is in Mumbai. Being connected by sea, rail, roads to the whole country, entry is made easier for the people in Mumbai. Population explosion has become phenomenal. Paucity of good houses, has added to the accommodation problem, therefore, slums are overcrowded, footpath dwelling has increased. This has brought about the atmospheric congestion and low profile of socio-economic conditions, creating a good ground for breeding of all kinds of communicable diseases, including leprosy. Urban leprosy problem has been recognised as a special national problem of public health and was thoroughly discussed at an international platform in 1974 in Mumbai under the auspices of ALH-RRE Society and IAL.

In 1976, GLRA started 4 field projects in Bombay, namely, Bombay Leprosy Project (BLP), Lok Seva Sangam (LSS), VDC (Vimala Dermatological Centre) and MLSM (Maharashtra Lohita Seva Mandal). In 1977 and 1978 two more projects - Society for Eradication of Leprosy (SEL) and ALERT-INDIA came in to existence respectively. Realising the importance of urban leprosy the State Government started 4 SULUs in Bombay in 1984-85 and the MCGM enhanced the field work by giving 16 more trained workers to A.L. Hospital for more field work in 1978-79. However, because of the peculiar course of leprosy and ever increasing population of Mumbai city, the disease could not be eliminated even with the advent of MDT. Since 1997, LEC, MLEC, VRC and SAPEL types of Programmes were undertaken, yet till today elimination level could not be achieved. Moreover, multiplicity of service providers does not give correct information on PR.

Since July 2004, integration of leprosy services has taken place with GHC system of MCGM. All the stakeholders are involved and with special drives and focal-surveys, it is but natural that the hidden cases will get surfaced. This will help to a greater extent to attain elimination level. The CBR, POD programmes will certainly help in reducing stigma attached to the disease along with integration process. The 'vision' is a 'path' revealing document from that point of view. It will help all the concerned, in the present transitional phase to create awareness, detect cases, treat them with MDT and target the much awaited elimination level !

Dr. V.V. Dongre
Hon. Secretary, The Society for the Eradication of Leprosy, Mumbai.

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Chapter 1

Leprosy Elimination Strategies

1.1 Pioneers :

Leprosy is probably the oldest documented disease in human history. In India, Sushruta Samhita dating 600 B.C. has given clinical features and treatment for leprosy.

Chaulmoogra (Hydnocarpus) oil mentioned as 'tuvarka oil', taken internally and applied externally was the only possible remedy. In China, it was believed that leprosy was supposed to be caused by 'foul' air lodged in blood vessels. Due to incurability, leprosy got associated with 'sin', a concept upheld in all the scriptures and mythologies, leading to social stigma. This was manifested in abnormal practices such as suicides, or isolation, presumably with the consent or persuasion by patient and his family, to end the misery by drowning or cremating or burying the patient, many times, in violation of the prevailing law. Social segregation was legalized in several legislative Acts such as The Indian Lepers Act, 1898, The Indian Railways Act, 1890 and the Marriage Acts of the Hindus, Muslims and Christians of India.

The discovery of penicillin raised hopes about synthetic drugs coming forth for chemotherapy. The first sulphone drug, DDS (Diamino Diphenyl Sulphone) was first used in injection form during 1941 in U.S and subsequently many leprologists used in the tablet form since 1949 in India.

The leprosy patients rejected by the family and community had no other option but to go in wilderness or to take shelter in leprosy homes. The first leprosy asylum was probably built by the Dutch in Kerala near Kochi at Pallipuram in 1728, followed by asyla in Almora in 1854 and several asylums were established in the rest of the country until 1919. Eduljee Framjee Allbless family handed over their hunting house to a German missionary, Fr Murien to start a Leprosy Home at Trombay in 1885. Inturn, Fr. Murien handed over the leprosy home to the Society of St. Vincent de Paul who ever since are running this home. Acworth Leprosy Hospital was established in Bombay (Mumbai) in 1890. The Leprosy Mission (TLM), an International leprosy NGO established leprosy hospitals at Purulia, Miraj, Bilaspur, Bankura and Vizianagaram between 1888 and 1903. The first leprosy home was established by an Indian, Mr. Manohar Diwan at

Dattapur, near Wardha in 1936.

Mahatma Gandhi who took personal interest in leprosy work included it in his constructive programmes. In 1951, Gandhi Memorial Leprosy Foundation (GMLF) was established at Wardha. In 1966, 'Mission to Lepers' (established in 1874) was renamed as The Leprosy Mission. Earlier, Indian Council of BELRA, a British leprosy agency started its Indian chapter in 1950, which was later known as Hind Kustha Nivaran Sangh. Besides these, several other voluntary organizations have helped Government of India to formulate the Leprosy Control Programme in India after independence. Late Smt. Indira Gandhi, then Prime Minister of India extended her strong political will and support to the leprosy programme in India and included leprosy control programme among the 20-point welfare programme.

Leprosy control work at the global level was initiated by WHO at the first World Health Assembly in 1948 by recognizing leprosy as the sixth priority. The first Expert Committee on Leprosy was convened in 1952 and an exclusive leprosy unit was established at WHO, Geneva in 1958. ILEP - the International Federation of Anti-Leprosy Associations – was founded in September 1966 by bringing together 24 international agencies helping leprosy sufferers.

In 1952, the expert committee of WHO recommended the abolition of compulsory isolation of leprosy patients and recommended that leprosy control should be based on early detection and ambulatory regular treatment of patients (H. Sansarricq et.al.: 1978, 15, *Window on Leprosy*)

In 1953, UNICEF/WHO joint committee decided to include leprosy among the diseases for which both organizations would provide coordinated assistance.

1.2 Research :

In India, the scientific work in leprosy started in 1869 with the use of Hydnocarpus oil for leprosy treatment at J.J. Hospital, Bombay. Besides the missionary commitment to provide relief to leprosy sufferers, Dr. Cochrane used DDS in tablet form in 1949. In 1950, Hind Kushta Nivaran Sangh replaced Indian Council of BELRA and Indian Association of Leprologists was founded in 1950. In 1951, Gandhi Memorial Leprosy Foundation (GMLF) was established at Wardha, whose initiatives established National Leprosy Control Programme in the Government Sector as Survey, Education and Treatment (SET) pattern for leprosy control. Another prominent academic NGO, Schieffelin Leprosy Research and Training Centre was established at Karigiri, near Vellore in

Tamilnadu, in 1955.

The pattern in the government as well as voluntary sector was to have a focused vertical programme by establishing Leprosy Control Units exclusively devoted to case detection and case holding through para-medical workers supervised by Non-medical Supervisors under the leadership of a doctor. Attempts also began to undertake research to develop a vaccine by Dr.V.R. Khanolkar at Mumbai and physical rehabilitation through Reconstructive surgery by Dr. Paul Brand.

“The whole problem of leprosy is a chain of problems”

“The whole problem of leprosy is a chain of problems, small and big ones, each linked up with the other, each with its own off-shoots and each demanding separate and full time attention”.

- “(a) In the early state of the disease, persons afflicted by the infectious or non-infectious type of leprosy are not recognised by the patients themselves and the society. These patients need to be detected and put under treatment.
- (b) There are patients having developed minor deformities who are likely to lose their employment as the disease becomes known to the society. In such cases, there is a problem of treating them and ensuring their employment.
- (c) There are deformed patients who have lost their jobs and who are rejected by the society though they are not infectious. The problem is to treat these people, correct their deformities and give them jobs.
- (d) There are patients or ex-patients who have taken to beggary. These beggar patients are illeducating the society about leprosy, thus increasing the stigma attached to leprosy. Most of these beggars are non-infectious.
- (e) There does not exist any protective immunization or vaccine against leprosy. The onslaught of the disease does not give any disturbing or troublesome signs such as fever, body-ache, loss of appetite etc. which are commonly known to people.”

“People do not come forward for early detection due to ignorance and fear. They do not continue treatment for long periods, as desired, because the progress of cure of the disease is slow and because the scientific conviction about the curability of disease is lacking in the patient. The stigma continues to bar the speed and seriousness of the control programme.”

Wardekar: 1964:523

In the decade of '50s, importance of health education was recognized by the WHO. The Expert committee on Health Education of the Public discussed the methods and media of health education (1954). GMLF used health education as the main tool in urban leprosy control work. It was decided to start Health Education centres in 1959 and accordingly ten urban health education units were established by GMLF across the country, during 1962-67. This programme was evaluated by Prof. R.K. Mutatkar and has been presented in a book, "Society and Leprosy" (1979). It brings out that people exposed to health education accept curability but are not yet convinced about the causation of disease, and continue to harbour prejudices against leprosy beggars as spreading the disease. Divorce is also recommended, as also isolation of leprosy patients (1979:150-51).

“The problem with leprosy is not what the disease”

The problem with leprosy is not what the disease is, but what the people believe it to be. For control of leprosy, eradication of social stigma would have to be the main concern of health education.

(R.K. Mutatkar: Society and Leprosy)

1.3 Guidelines :

In the decade of '60s, more international agencies started working in India. At WHO, on one hand, the emphasis on integrating leprosy control programmes with public health services was being discussed, while the Expert Committee in 1965 advised countries with limited resources to concentrate their efforts on treatment, follow up of infectious cases and in surveillance of their contacts. In 1966, Guide to leprosy control published earlier by WHO in 1959, was revised.

The Government of India had constituted three Sub-Committees of the Leprosy Advisory Committee in 1962 and 1964, the documents of which have been merged in one volume "Operational Guide and Guidelines of Assessment of Leprosy Control Work in India" published in June 1969. The guidelines are addressed to the needs of para-medical personnel who have been carrying out the Programme due to non-availability of medical men.

“The need for integration should not lead to precipitate action”

The Operational Guide is based on the existence and need for some period at least of a separate leprosy control programme. It is recognized that the ultimate aim should be to integrate the leprosy control into the public health services in general, since leprosy is a public health problem. Eventually, it is neither necessary nor possible to have or continue to have separate control programmes for each individual disease. Efforts have therefore to be made for progressive convergence and ultimate merger of the leprosy control programme with the general health services. The changeover should however be gradual and at the proper time. The need for integration should not lead to precipitate action which may result in the possible loss of the advantages obtained so far. The setting up of SET Centres is a beginning towards integration. At an appropriate stage, a more direct method of complete integration, should be tried in a selected ‘pilot area’, and then extended to other areas with the help of the experience gained. To the extent the integration becomes operative, this guide will become in-operative, and with the final integration of leprosy control with general health work the need for separate leprosy control centres, and consequently of this guide will disappear. (1969)

1.4 Urban Leprosy Control :

1.4.1 The operational guide : The operational guide visualized establishment of urban leprosy centre and has provided guidelines for the functioning of such centres. This kind of centre, if and when established should be located in urban Municipal areas, and attached to a Hospital or Dispensary in the area. It will be conducted by a senior and experienced para-medical worker under the guidance of the Medical Officer. The main emphasis of work will be on health education, surveys will be restricted only to certain groups, and the treatment will be given by Medical Officers in the Public or Municipal Dispensaries and as far as possible by the general practitioners in their private dispensaries. Emphasis has been laid on health education, involvement of general medical practitioners and school surveys and survey of special groups. (1969)

It is to be appreciated that the Directorate General of Health Services Government of India had anticipated the establishment of such centres in early '60s and provided guidelines to that effect about the logistic functioning of such centres.

1.4.2 Leprosy in urban areas : WHO Expert Committee on Leprosy in its fifth report 1977, and subsequent reports has repeatedly, dwelt on the issue of case detection in urban areas. Leprosy in urban areas poses a special public health problem. For socioeconomic reasons, leprosy control in urban areas is more complex than that in rural areas. Effective control work in cities requires good coverage of the rural areas, otherwise treatment opportunity for leprosy may be an added attraction for the migration of patients into the cities from the villages.

Leprosy control is closely linked with other measures that regulate urban planning and the general promotion of health. A limited drug-based approach will not be sufficient unless a community health programme with social, educational and administrative measures for the improvement of the area is also encouraged. Leprosy control workers should become part of the municipal health services and collaborate with other community-level workers, e.g. teachers, social workers, welfare workers, and community leaders.

The three essentials of urban control activity are: case-detection through examination of schoolchildren and contacts of known cases and through the examination of shanty-town communities especially at risk; efficient outpatient treatment in convenient health centres and in all treatment institutions; health education of patients, families, teachers, social workers and members of the medical profession.

There is a general notion that leprosy is primarily a disease of rural areas, but in many countries the prevalence of leprosy is just as high in urban areas. Integration of urban control activities with primary health care should receive particular attention.

Leprosy control in urban areas poses special problems, including the high level of social stigma, the mobility of the population, poor compliance with treatment, multiple registration of patients, difficulties with active case detection, and self-reported cases coming from outside the urban areas. Existing control strategies, particularly for using multidrug therapy, have therefore to be modified for urban areas. The following initiatives are expected to improve the quality of urban control programmes.

- Active involvement of all available facilities, urban health centres, dispensaries and hospitals (skin clinics) in case-detection and treatment after appropriate training of the personnel;
- Orientation of private medical practitioners in leprosy control strategies,

multidrug therapy regimens and reporting of results;

- Supply of antileprosy drugs to participating private practitioners;
- Involvement of peripheral health workers in the retrieval of defaulters from treatment;
- Optimal use of the media to increase community awareness of leprosy services;
- Development of a cross-notification system to trace patients migrating within and outside the urban area;
- Creation of, and publicity for, referral centres; and
- Periodic review of programme activities with the participating agencies.

1.4.3 Basic Strategy : While the basic strategy for eliminating leprosy in urban areas of all categories is no different from that in rural areas, rapid industrialization and the increasing density of migrant population in slums are posing operational challenges.

Coordination between government and nongovernmental organizations, as well as local authorities, dermatologists and general practitioners, should be encouraged, particularly to ensure that the standard WHO MDT regimens are implemented by all agencies and that new cases are reported.

It is important that all existing health facilities, especially those providing first-level care, be actively involved in leprosy elimination activities as this will greatly improve accessibility, case detection and completion of treatment. Full use should be made of the potential of mass media, including television and radio, for promoting community awareness about leprosy, particularly in urban areas.

By and large, the Urban Leprosy Control was initiated as a health education activity. However, the SET pattern control work in urban areas was started only in the decade of 70s. The German Leprosy Relief Association started in 1971 a pilot project in Madras (Chennai) called Greater Madras Leprosy Treatment and Health Education Scheme. The population was divided into three groups: Slum population, school going children and other population, A 3 tier programme of funding was adopted.

1. Slum population to be covered by intensive house to house examination.
2. Systematic physical examination of all the school going children
3. Extensive health education of the remaining population.

4. The city was divided into 5 zones and further divided into Control Units managed by para-medical workers. The clinics were located at the places provided by Madras Corporation, slum clearance Board and other voluntary social welfare agencies. Physiotherapy Unit, laboratory and a shoe department were also established. First phase of slum survey was completed in December 1974. School surveys unearthed sizable number of undetected cases. Resurvey in schools took an year to complete in 1976. Around the same time, healthy contacts were brought under surveillance. Orientation courses for medical practitioners, teachers, selected groups like lawyers, nurses, services clubs, social workers and voluntary organizations were organized. On similar lines as in Madras, Bombay leprosy project was launched in October 1976, supported by GLRA. GLRA sponsored similar projects in several cities including Pune, Visakhapatnam and Kolkata (Calcutta).

1.5. Urban Centres for leprosy :

1.5.1 The Operational Guide of the Government of India (1969) for an urban centre :

The need for an urban centre: In view of the growing realization of the importance of Leprosy in the urban areas, in future a new type of leprosy centre may be established for urban areas where the disease is prevalent. The need for starting this type of centre is that the urban areas differ in certain important respects from the rural areas. As urban people generally do not like to be examined in their own homes by the para-medical workers, surveys for case-detection are therefore not possible except in the slums. Social stigma of leprosy is also more pronounced in these area than in rural areas. In towns and cities there are many general practitioners, who if approached properly, will be willing to treat leprosy patients in their own dispensaries. The plan of leprosy control work for urban areas has to be prepared in the context of the above facts.

1.5.2 The plan of work : In the urban Leprosy Centres the basic principal of detecting the cases early, and making arrangements for their treatment, will remain the same as in the Leprosy Control Unit or in the S.E.T. Centre. However, instead of carrying out surveys for the case finding, and starting special leprosy clinics for the treatment of patients, it will be necessary to achieve the two objectives by intensive health education of the people and the medical men in general practice and government or municipal hospitals. The purpose of the health education should be two-fold : On the one hand, the people, as soon as they see any suspicious signs of the disease, should seek medical opinion from

their own family physician, or Medical Officer of the Government or Municipal dispensary; and on other hand, the medical men should consider leprosy as one of the several other diseases, and treat the leprosy patients in private clinics and in public dispensaries.

1.5.3 Location, staff, etc. : The Urban Leprosy Centres, as the name suggests, are to be located in Municipal towns and cities. The centre will be attached to the Government or Municipal hospitals or Dispensary, and will be conducted by a para-medical worker under the guidance of the Medical Officer. In view of the type of work he has to do, and the type of people he has to deal with, it is necessary that the para-medical workers to be posted at such centres should be senior and experienced workers. With a view that the people should be able to meet him, if they want to, the para-medical worker should be provided with a room for this office, which may be either in the hospital or at some other convenient place.

1.5.4 Duties of the para-medical workers : The nature of duties of para-medical workers engaged in urban centres is different from the duties of those working in rural centres. Because of this, while the duties of para-medical workers in general are described in section 7 along with the duties of other personnel, the duties of para-medical workers to be engaged in urban centres are described here. The work of the para-medical worker in urban areas will be as follows :

- (ii) Do intensive leprosy health education in the population of the town.
- (iii) Carry out surveys in schools and any other special groups when possible.
- (iv) Arrange for treatment of those patients who come to his knowledge, either with a general practitioner or at the Government or Municipal dispensary.
- (v) Try to make arrangements for meeting the social needs of the patients and to help those requiring rehabilitation.
- (vi) Arrange treatment of beggars suffering from leprosy, and persuade them to take treatment.
- (vii) Maintain proper records of his work.

1.5.5 Co-operation of the people : The success of work will depend on the degree of co-operation the para-medical worker receives from the people. It will be advantageous if a local committee is formed to help the para-medical worker. The para-medical worker will of course be able to approach and also influence certain groups of the people, but there will be some others whom he will find difficult to approach or influence. It will, therefore, be necessary that the State Leprosy Officer and the Municipal Officer take steps to introduce the worker to such sections of the community, and help him in his efforts of contacting them whenever necessary. Visits and lectures delivered by some of the well known people and members of the local committee will also help the para-medical worker in influencing the society. With such help, the para-medical worker should meet the groups listed below, explain to them the work he is doing, and the type of help he will need from them.

- (i) Government personnel of all departments.
- (ii) Leading persons of the town.
- (iii) Medical men in general practice and Government or Municipal Hospitals and Dispensaries.

One of the important functions of the Urban Leprosy Centre is to persuade local medical men to diagnose and treat leprosy patients along with patients suffering from other diseases. If, therefore, they need refresher courses the para-medical worker should request the State Leprosy Officer to organize and conduct such courses.

1.6 Referral Centres for Leprosy :

1.6.1 The need for a referral Centre : With increasing number of S.E.T. and Urban Leprosy Centres the number of para-medical workers and medical practitioners doing leprosy diagnostic and treatment work has already increased and is likely to considerable increase further.

Those workers will be able to deal with a vast majority of cases, but they will come across some cases which may present difficulties in diagnosis, either because the lesions are very early or because they simulate skin lesions of other diseases. Similarly, some of the cases may present difficulties in treatment. They will, therefore, need the services of a place to which they could refer these difficult cases for opinion, advice and treatment if necessary.

1.6.2 Existing facilities to be utilized : Existing facilities to be utilized: It should, be emphasized here that it is not visualized to have a separate referral centre as such but to utilize the facilities available at Medical Colleges, Leprosy institutions, selected Control Units and other suitable institutions. It may, however, be necessary to provide additional facilities at the centre selected to function as Referral Centre. One of the important criteria for selecting the centre should be availability of the right type of a Medical Officer. Such a person may already be on the spot or can be easily provided. (1969)

A referral hospital was inaugurated at GMLF Wardha in 1965 by the President of India. A well equipped hospital was already in operation at SLRTC, Karigiri which always functioned as a referral centre at least in South India. Another important development has been the promotion of National Leprosy Organization in 1965, (NLO) a body of voluntary organizations in leprosy, in India.

1.7 Disabilities, Rehabilitation and Social Problems in Leprosy

The Government of Maharashtra had appointed a Committee in 1963 about Rehabilitation of Leprosy Patients, the members of which included Dr. P. Kapoor, special leprosy officer, Dr. R.V. Wardekar, Dr. S.G. Patwardhan, Shri. Baba Amte, Dr. S.D. Gokhale and Smt. K.V. Nimkar. The committee has given the basic concept about rehabilitation.

“In the name of rehabilitation”

The practice of starting settlements or colonies for leprosy patients under the name of Rehabilitation Centres should be given up once and for all. It is not rehabilitation. The committee feels that as long as this practice is not given up, the fear of leprosy and stigma of leprosy will not disappear and these will interfere with the control of leprosy.

Government Committee 1963

“Rehabilitation”

Rehabilitation should be an attempt to keep in or send back the patient to his own normal environment. Attempts to give work and shelter for patients in a secluded environment, however, worthy, result in strengthening prejudice against Leprosy.

Government Committee 1963

“Dehabilitation”

“Dehabilitation” is the process and the state of devaluation leading to the individual not being able to be a fully participatory member of society. Rehabilitation means reversing this process, and restoring a person’s social identity by re-possession of his or her normal roles and functions in society.

WHO 1998

The WHO Study Group revised the objectives of leprosy control to add prevention of associated deformities and the definition of the case of leprosy to include those who needed assistance due to disabilities.

1.7.1 Strategies for prevention and management of disabilities :

Diagnosis of the disease at an early enough stage, adequate treatment of cases, and effective detection and management of neuritis and reactive phenomena constitute the best strategy for primary prevention of impairment. Even in patients who present with permanent sensory loss or other disabilities and in whom impairments and disabilities have occurred during treatment, further deterioration can and should be prevented by proper instruction regarding protection of insensitve extremities and by monitoring the patients. The necessary techniques exist but too few leprosy control programmes are structured to carry out the tasks that are involved in disability prevention. The expert committee recommends that prevention and management of impairments and disabilities, which have long been recognized as essential components of leprosy control programmes, should be implemented effectively.

1.7.2 Managerial steps for disability prevention : Six specific managerial steps are recommended for the practical implementation of disability prevention and management at the peripheral level.

1. The team leader, normally a physician, accepts responsibility for prevention of primary and secondary impairments and disability as part of his or her responsibility for patient care.
2. Specific, limited, measurable objectives are set for preventing and limiting disability, and activity plans based on these objectives are formulated.
3. Impairment and disability records are included in the clinical recording systems.
4. Arrangements are made for the provision of protective footwear and other aids.

5. Patients are instructed in self-care and in behavior designed to prevent further disability.
6. Staff are trained to implement the disability prevention programme, to teach patients self-care and to monitor and support the practice of self-care by patients. (WHO: 1988)

“Deformity is not an inevitable part of leprosy”

Fifth and Sixth Report of the Expert Committee “It cannot be stressed too strongly that deformity is not an inevitable or necessary part of leprosy... In a well conducted leprosy control programme, almost no leprosy patients on first diagnosis will be suffering from some deformity attributable to neglected disease” (1977 & 1988)

“Peoples’ Participation”

All control programmes and tool development programmes should aim at reducing deformities to break the association of leprosy with deformity and social death which is the root of social stigma. Stigma and fear hinder people’s participation in control activities.

Pontifical Academy of Sciences, 1984

“Social Science Research”

The gap between “what the disease is” and “what people believe it to be” needs to be understood by social scientists, medical anthropologists and sociologists, educational psychologists, management and communication experts. Social science research should be encouraged to find better tools for health education and attitudinal changes.

Pontifical Academy of Sciences, 1984

1.8 Social problems in leprosy

1.8.1 Stigma of leprosy : The importance of social and structural factors in leprosy control, and the serious and sometimes catastrophic impact of these factors on individual leprosy patients are now generally recognized.

At one time, in efforts to prevent the spread of disease, patients were commonly isolated and relatively little attention was paid to their social problems. In fact, the practice of compulsory isolation helped perpetuate the stigma of leprosy in

many countries. Since chemotherapy and domiciliary care have become the accepted methods of leprosy control, it is being increasingly recognized that the customs, culture, social attitudes and restrictive laws that still exist in some countries have a great impact on leprosy control activities as well as on the social and economic well being of the patients.

1.8.2 Social and economic research : Priority needs in the area of social and economic research include studies directed towards assessing the social costs of leprosy, improving awareness of leprosy, enhancing compliance with treatment, increasing family and community support for leprosy patients, and improving the motivation of health providers towards leprosy. The role of such research in improving the utilization of available health technology for leprosy control should not be underestimated. However, it is important to ensure that the research is multidisciplinary and goal-oriented. It should be recognized that, although most of the results are site- or culture specific, they can provide an insight into issues of wider significance.

With the development of social science theory and methodology, social aspects should include besides social and economic, cultural, religious, management and communication aspects. Since leprosy afflicts humans and is transmitted by humans amongst each other, understanding life styles of people such as mating patterns of endogamy and exogamy, food habits, rules permitting physical proximity and group interaction becomes relevant for understanding factors favouring transmission of the disease.

Poverty and health consciousness are usually found in inverse ratio. For the poor, health disorganization is yet another area of disorganization in life. It is thus neglected until it threatens their basic social and economic securities. In leprosy, this happens with the onset of deformities and it is too late. So people resign themselves to their fate adopting lower levels of aspirations in life and the psychology of defeat.

1.9 Role of NGOs and other contributing agencies

It is important to accept the principle that health care of the people is the prerogative of the people themselves and the responsibility of national governments as their representatives. The role of external NGOs should therefore be to support the efforts of national governments and national NGOs.

The main role of national NGOs is to advocate leprosy control activities and to promote community participation in the national control programmes. Because

of their flexibility, NGOs are uniquely placed to experiment with novel solutions to problems which, if successful, could later be incorporated into government programmes.

1.10 Definition of a case of leprosy :

At present, leprosy patients needing or undergoing treatment, those who have completed multidrug therapy and require or are under surveillance, as well as those with deformities and disabilities resulting from leprosy in the past and needing care, are grouped together as “cases of leprosy”. Lack of distinction between these categories continues to be a source of error in computing and comparing prevalence and other statistics necessary for planning and organizing leprosy control programmes.

A “case of leprosy” is a person showing clinical signs of leprosy, with or without bacteriological confirmation of the diagnosis, and requiring chemotherapy. It is recommended that this definition be adopted by all countries so that information on prevalence can be meaningfully interpreted. It is also recommended that separate lists of the other two categories (patients who have completed their treatment but require, or are under, surveillance, and those who have deformities and disabilities due to past leprosy) be maintained.

For operational purposes, those who have or have had leprosy will therefore fall into one of the following three categories.

1. Those requiring or receiving chemotherapy;
2. Those who have completed chemotherapy and require, or are under surveillance; and
3. Those released from surveillance but in need of care or assistance because of disabilities.

A fourth category of individuals, who need not be maintained in any register or list, are those released from surveillance and not in need of further attention.

Prevalence of leprosy should be computed on the basis of the first category of patients. (WHO: 1988)

1.10.1 Objectives of leprosy control

The objectives of leprosy control are threefold:

1. to interrupt transmission of the infection, thereby reducing the incidence of disease so that it no longer constitutes a public health problem;
2. to treat patients in order to achieve their cure and where possible, complete rehabilitation;
3. to prevent the development of associated deformities.

1.11 Integration of antileprosy activities within general health services

1.11.1 Approaches to eliminate the disease

There are at least two major approaches of eliminating the disease:

- A vertical programme, i.e. the exclusive undertaking of all the activities against the disease down to the community level in specialized setting.
- An integrated programme, in which the elimination activities are conducted mostly in multipurpose settings by health workers within the general health service.

Nonetheless, integration does not mean that specialized components are completely abolished; in fact, they will always exist in the integrated programme at the national level, may also be available at the intermediate level or even the district level, and they play a vital role in the coordination, planning, technical support and monitoring of the programme.

1.11.2 Fully integrated programmes : Consequently, fully integrated programmes would be more appropriate to strengthen leprosy elimination activities rather than vertical programmes. The key issue is how to improve the performance on integrated programmes.

This may be done by :

- Informing the community about the main features of leprosy, the curability of the disease and the availability of free treatment, and improving the community's participation in case finding, ensuring that patients complete their treatment and the delivery of MDT drugs.
- Improving capacity building within general health services. In order to ensure the basic quality of diagnosis, classification, treatment, recording and reporting, the training of general health workers at different levels is needed.

In general, the number of workers to be trained is significantly greater than in vertical programmes, but there is no need to train all staff. The training course must be concise and task oriented, and it should be as short as possible.

- Ensuring regular supervision and technical support by workers from higher levels of the general health service and by specialized leprosy workers.
- Ensuring the availability of adequate referral services.

1.11.3 Leprosy control through primary health care : In almost all countries where leprosy is endemic, leprosy control activities were started as vertical programmes. Over the past decade the specialized, vertical services have been increasingly integrated into the general health services, most commonly by progressive transfer of direct responsibility for leprosy control activities to the general health service staff.

The rationale for this policy is that optimal health care, including that for leprosy patients, should consist of comprehensive, continuous and integrated care, which is best delivered through multipurpose, decentralized health services. Integration also ensures the widest possible coverage of patients for leprosy control.

Integration of leprosy control into the primary health care system does not imply that all specialized elements should disappear from the health services. Indeed, in many countries where integration has been implemented, elements such as technical supervision, referral of patients, drug supply and financing have necessarily remained specialized.

“Involvement of General Health Workers”

In order to improve case detection, MDT coverage and completion of treatment, a key strategy for elimination is to involve general health workers and community health volunteers in leprosy elimination tasks down to the village level.

WHO 1998

Chapter 2

ALERT-INDIA - As a Partner in Leprosy Elimination

2.1 The Global Leprosy Scene

When MDT was introduced in the 1980s, leprosy was prevalent in 122 countries in Asia, Africa, America and Europe. There were more than 12 million leprosy cases in the world. In 1982, WHO adopted MDT and implemented it globally. This focused on early case detection, thereby changing the negative image of leprosy. In collaboration with governments and voluntary organisations, WHO has reduced the prevalence rate. The success of MDT led the World Health Assembly in 1991 to commit to the goal of reducing the prevalence of leprosy in all countries to a level of less than one case per ten thousand of population by AD 2000. In May 2001, WHO proudly claimed to have achieved this target globally.

Major achievements at the beginning of 1999 at the global level were

- Ten million leprosy patients cured
- Prevalence of leprosy reduced by 85%
- The number of countries where leprosy is a public health problem came down from 122 to 24.
- Relapse cases are only 0.1% a year; hence negligible from the public health point of view
- Resistance to MDT has not been reported.

By end-2000, twenty-four countries could still not reach the target, as the new case detection rate was high and therefore the prevalence rate was high. They were mostly third-world countries, from Africa and south-east Asia and a couple from the Americas and one from the Western Pacific. The elimination target for these countries was extended to 2005. The situation in Asia, with over five million cases, was a matter of serious concern.

However, MDT had brought about significant changes — and many countries achieved the elimination target except India, Nepal, Indonesia and Myanmar, which could not reach the target. Although countries like Bhutan, Bangladesh, Maldives, Sri Lanka and Thailand touched the target nationally, they needed to

work on it sub-nationally. Despite all this progress, today 78% of global cases are in Asia, of which 61% are in India. Greater emphasis is being given to countries which still have not achieved the elimination level (1 per 10,000) at both national and sub-national levels. The strategy now focuses on community involvement and awareness building.

2.2 India's Fight Against Leprosy

In India, the National Leprosy Control Programme (NLCP) was launched in 1955. Dapsone was the only satisfactory drug then available. Though it proved effective, much progress could not be made mainly because of lack of patient compliance, lengthy and prolonged treatment, and too many relapses as drug resistance developed. In 1981, about four million people in India were affected by leprosy and the prevalence rate (PR) was 57 per 10,000. This constituted almost 60% of global cases. At that time, leprosy was highly prevalent in TamilNadu, Andhra Pradesh, Pondicherry, in South and Orissa in East. These states had a PR of more than 100/ 10,000. The turning point came with the advent of a combination of powerful drugs in the form of multi-drug therapy (MDT). Following this, since 1982-83, India has adopted the MDT programme under the National Leprosy Eradication Programme (NLEP). MDT was initially introduced in all leprosy endemic districts and gradually extended to the entire country in a phased manner. India partnered WHO in 1991 to meet the leprosy elimination target of 1 per 10,000 by 2000 at the national level.

Leprosy work in India has a long history and the Government of India in collaboration with several international leprosy relief agencies and many local voluntary organizations have obtained remarkable results. In India, about 290 NGOs have been working in this field for many years; of them, 54 receive grant-in-aid from the Government for work on the SET (Survey, Education and Treatment) pattern.

Major achievements in 2000 at the national level were

- Prevalence rate declined from 57 per 10,000 in 1981 to 5.2 per 10,000.
- 4.4 million new leprosy patients were detected and cured with MDT.
- Visible deformities were reduced from 8-12% in 1981 to 3.12% in 2003.
- Elimination levels have already been achieved in 13 states (Nagaland, Haryana, Punjab, Mizoram, Tripura, Himachal Pradesh, Sikkim, J&K, Rajasthan, Manipur, Assam and Kerala).

Despite these achievements, India could not reach the elimination target (1 per 10,000) at the national level, as there was no appreciable decline in the new case detection rate (NCDR). At present, the problem had shifted from the south to the northern and eastern states (Bihar, Orissa, Madhya Pradesh, West Bengal, Uttar Pradesh, Jharkhand, Chhattisgarh and Uttaranchal), which have a high prevalence rate. These states contribute about 64% of the country's caseload.

Hence, the Government of India adopted a phase-wise elimination campaign programme throughout the country. The focus continues to be detecting new cases and public awareness. The programme is carried out in rural and urban areas with the involvement of NGOs. The government also proposed integrating leprosy services with the general public health system, especially in rural areas.

2.3 The Leprosy Situation in Mumbai

Mumbai is a megapolis, covering about 600 sq. km. with a population of 11.5 million (2001 census) - a density of 16,432 people per sq. km. Over 65% live in the eastern and western suburbs and over 50% in slums and tenements. The NLEP is being implemented through the Mumbai District Leprosy Society. The state government, NGOs and the MCGM are the three partners involved in leprosy elimination.

The city's 24 municipal districts (wards) are divided among seven voluntary organisations, four government-run units and one municipal organisation. About 65% of the area is covered by voluntary organisations, which also work in self-settled leprosy colonies. There are five major leprosy settlements, namely PushpaVihar Colony in Dahisar, DattaNagar Colony in Trombay, Sanjay Gandhi Colony in Sion-Chunabhatti and Bharat Mata Colony in Wadala. Kopri Colony on the Mulund-Thane border is also one among the smaller settlements.

In 1991, the prevalence rate was about 12.2 per 10,000. This was reduced to 2.02 in 2000, following the successful implementation of MDT. The main credit for this goes to early detection and a reduction in the duration of treatment. The practising dermatologists administer MDT in private clinics and these cases do not show on the register of known cases. However, despite this significant fall in overall prevalence, there is a steady occurrence of new cases in the city, especially in slums. New cases arise partly because of the movement of people into the city from endemic states and from rural Maharashtra. Another cause for the rise in new cases is the extreme overcrowding and poor hygienic conditions persisting in all the slums.

In 1999-2000, 14% of the newly registered cases were found to be skin-smear positive (infectious), mainly among slum dwellers, leprosy colonies and people residing on pavements and tenements. The leprosy problem is greater in the suburbs which have a preponderance of slums (4.5 per 10,000) than in the city area, which has fewer slums (2.6 per 10,000).

2.4. ALERT-INDIA - An Overview

2.4.1 Origin : During 1976-77, Mr A. Antony Samy, the present Chief Executive of ALERT-INDIA, visited a leprosy colony at Chunnabhatti for field work as a part of his Master's Programme in Social Welfare Administration at the Tata Institute of Social Sciences (TISS) in Mumbai. After seeing the plight of leprosy patients who had developed various grades of disabilities before they were detected and treated. He realised the need for initiating community-based leprosy control work, which would aim at detecting leprosy patients at an early stage and treated before they become visibly disabled. The Lok Seva Sangam, a NGO, which was engaged in leprosy relief work in this Chunabhatti colony, offered him a most challenging task of implementing a community based leprosy programme in L Ward - Kurla, Mumbai. After gaining ground experience, he established an NGO called ALERT-INDIA to fulfil his vision to serve the leprosy afflicted people in the uncovered areas of the city. With these objectives, ALERT-INDIA was formed under the Chairmanship of the late Prof. N. G. Joshi on 11th October 1978 at R. M. Bhatt High School Hall, Parel, Mumbai.

The Association for Leprosy Education, Rehabilitation and Treatment (ALERT)-India, a registered, secular, voluntary organization, was born, with the dream of eradicating leprosy. A full-fledged leprosy control programme was launched in 1981 in the N, S and T Wards of Mumbai covering a population of approximately 11 lakhs, with the primary objective of creating awareness through education campaigns.

To achieve the ultimate goal of leprosy eradication, it was necessary for the team to operate on different levels depending on the meagre resources available. Uncertainty and flagging spirits did not shatter the determination of leprosy workers, who kept all the hurdles at bay by their concerted effort and optimism. Undauntedly, the team kept knocking on doors and initiated a variety of fund-raising programmes. Through the dusk of dark years, new developments took place gradually and the dawn of bright years have brought great hope and renewed strength to continue efforts to eradicate leprosy.

2.4.2 Objectives : ALERT-INDIA has been progressing with set objectives to be achieved in phased manner.

- To **detect** all infectious cases of leprosy in the community and reach the goal of total case detection by house-to-house surveys of the entire population as also examination of school children and industrial workers. Also to **establish** a surveillance and follow-up network of all detected cases and their contacts.
- To **treat and cure** all new leprosy-affected persons without segregation, within the milieu of the community.
- To **create** leprosy consciousness among all sections of the community through intensive health-education programmes.
- To **work** ardently towards total prevention of debilitation and promote socio-psychological and economic rehabilitation of leprosy affected persons in the milieu of their own family and community.
- To **undertake** and promote study as well as research in leprosy and related sciences.

From 1988, ALERT has expanded its role beyond leprosy control and included other major public health problems like TB within its range of activities. Regular campaigns and promotions are held at the community level through community health volunteers (CHVs) for greater impact, especially on reproductive and child health as well as in AIDS prevention programmes.

ALERT-INDIA has also implemented a community-based tuberculosis control programme under the National Tuberculosis Control Programme (NTCP) in collaboration with the Navi Mumbai Municipal Corporation (NMMC) from November 1998 to December 2000. This resulted in curing 1676 TB patients. Subsequent collaboration in RNTCP from January 2001 to July 2004 resulted in curing 1591 TB patients.

It has trained many CHVs to impart information related to reproductive and child health and held several promotion campaigns among slum communities. ALERT has successfully conducted several campaigns in liver and liver-related disorders, body literacy, etc, with special emphasis on health issues relating to women.

2.4.3 Area of Operation and Target Population

ALERT-INDIA works in the N, S and T Wards (the north-eastern suburbs: Vidyavihar, Ghatkopar, Vikhroli, Kanjurmarg, Bhandup and Mulund) with a population of 16 lakh. The target population lives in slums, chawls and low-income group housing colonies. In addition, it also has another major urban leprosy control project in Navi Mumbai. Work is undertaken in five townships (Vashi-Turbhe, Nerul, CBD Belapur, Airoli and Koper Khairane) along with 44 villages with an approximate population of 9 lakh. In all, ALERT-INDIA covers a population of over 25,00,000.

2.4.4 Achievements

ALERT-INDIA is committed to controlling and eradicating leprosy by identifying early cases, treating them and enlightening the public. In the past 26 years, it has cured 21,414 leprosy sufferers as of June 2004. The majority of the cases were detected in the early stages and hence were not socially known as leprosy patients. Among these, 30% are children and only 5% have disabilities or deformities. The prevalence rate in slum communities was 11 to 15 cases per 1,000. when ALERT-INDIA's work began. Annually, it continues to detect 800 to 1,000 cases.

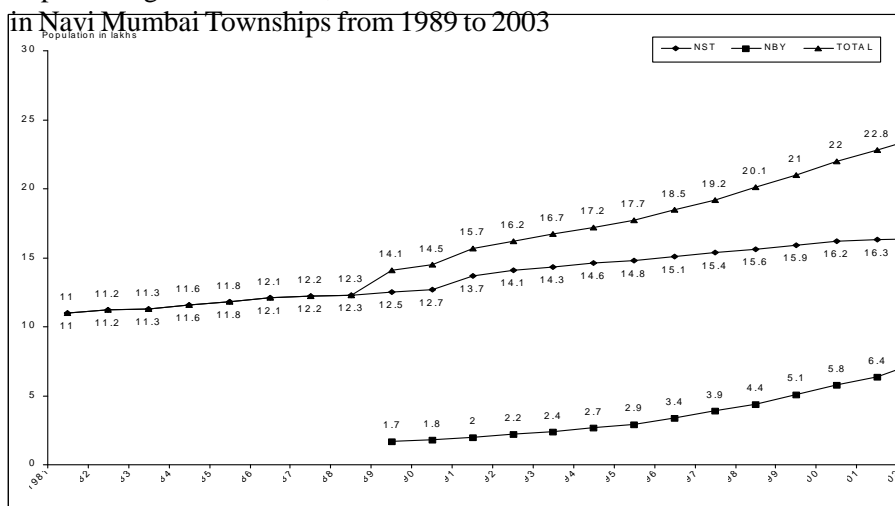
Case cured with MDT

Sr.No	Details	Total
1	Cases cured till 2003	21,414
2	Cases under treatment till 2003	472
3	Cases under surveillance till 2003	1,810
4	Deformed cases under care	475

Graph No. 1

Population growth in the N, S and T Wards of Mumbai from 1981 to 2003 and

in Navi Mumbai Townships from 1989 to 2003

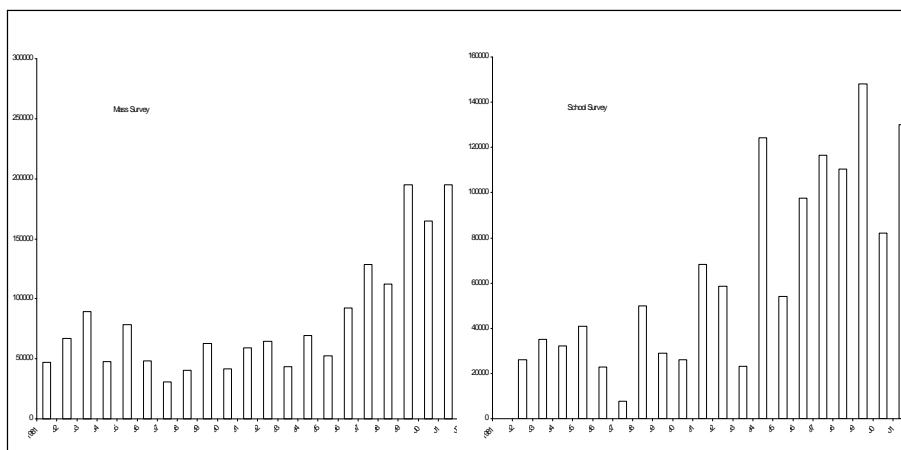


Since 1981, the population at the N, S and T Wards has increased by 40%, whereas the population of Navi Mumbai has grown by more than five times since 1989. In spite of the population growth, both these areas have recorded a gradual decrease in the new case detection rate.

Early detection and prompt treatment of leprosy patients are the only means to eliminate leprosy. To achieve this, ALERT-INDIA had conducted several new case detection campaigns by consistently engaging young men and women who were specially trained as leprosy technicians. They not only undertake community and school level case detection (survey) work but also follow up with the patient at the family / community level and establish a vital link between the patient and the doctor at the clinic. The planning and implementation of community-level programmes are de-centralised to provide greater efficiency at the zonal level in the project areas. From the disease control point of view, greater emphasis was given to early detection of smear positive cases (infectious), as they are the sources for the spread of the disease in the community.

Graph No.2

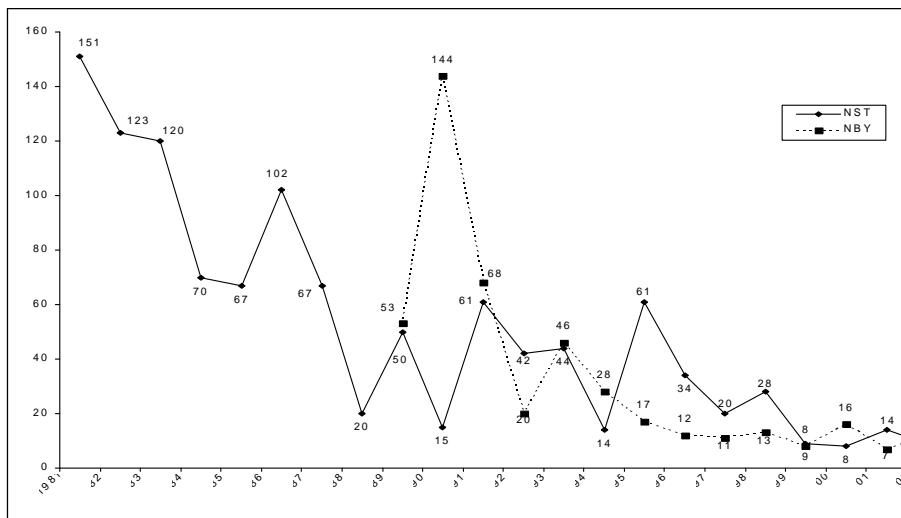
Year-wise population examined in slums and schools of the N, S, and T Wards of Mumbai from 1981 to 2003 and in the Navi Mumbai townships from 1989 to 2003.



Year by year, a higher population was surveyed.

Graph No. 3

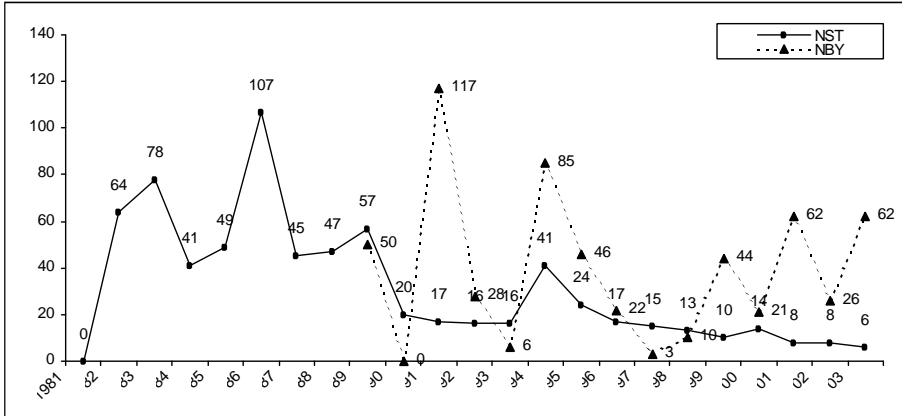
Year-wise new case detection rate (NCDR/ 10,000) among the slum population examined from the N, S, and T Wards from 1981 to 2003 and in the Navi Mumbai townships from 1989 to 2003.



The NCDR is falling year after year after initial peaks (showing accumulated figures), but remains more or less constant since 1996.

Graph No. 4

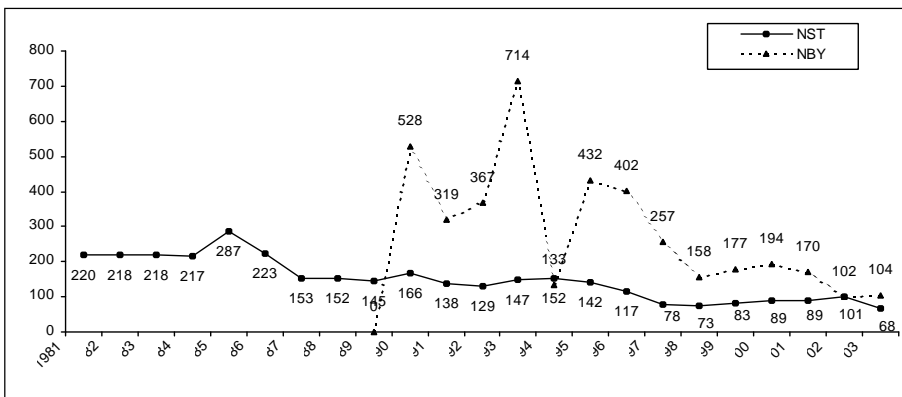
Year-wise new case detection rate (NCDR/ 10,000) among children examined in schools in the N, S, and T Wards of Mumbai from 1981 to 2003 and in Navi Mumbai townships from 1989 to 2003.



The NCDR among school children waxes and wanes, depending upon rates of activities

Graph No. 5

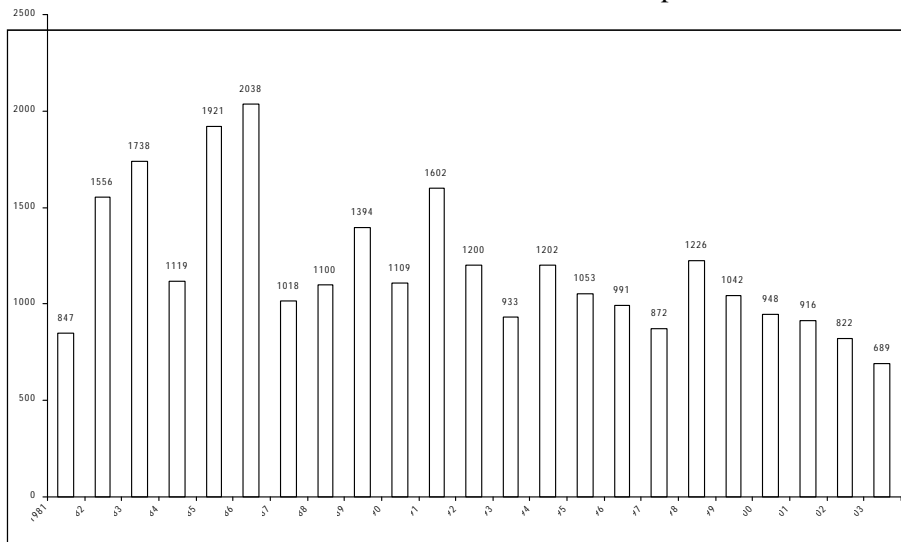
Year-wise new case detection rate (NCDR/ 10,000) among family members examined of detected new cases from the N, S and T Wards of Mumbai from 1981 to 2003 and in Navi Mumbai townships from 1989 to 2003.



This graph indicates the importance of family contacts' survey, where new cases surface.

Graph No. 6

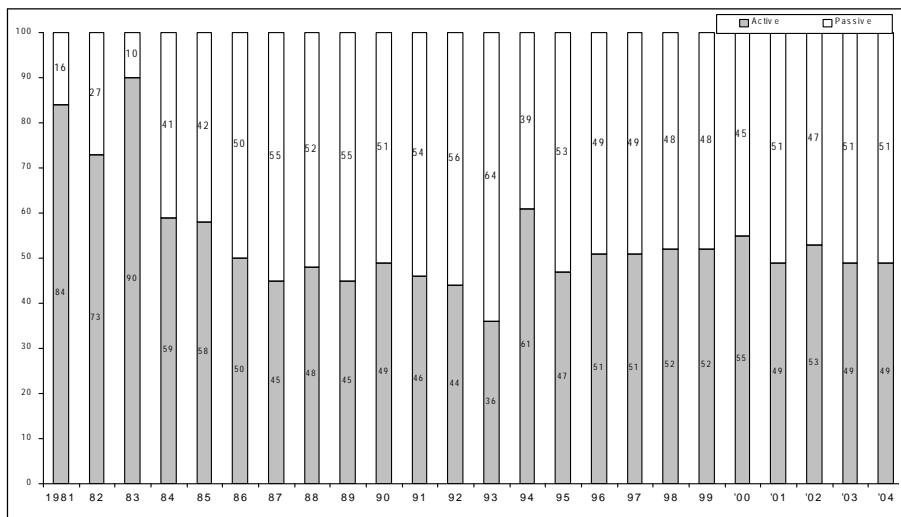
Year-wise new cases detected by all modes from the N, S and T Wards of Mumbai from 1981 to 2003 and in Navi Mumbai townships from 1989 to 2003.



The graph indicates gradual fall in new cases detection due to sustained educational campaigns and active case detection and surveillance activities.

Graph No. 7

Year-wise proportion of new cases detected through active and passive modes of case detection in the N, S and T Wards from 1981 to 2003 and in Navi Mumbai townships from 1989 to 2003

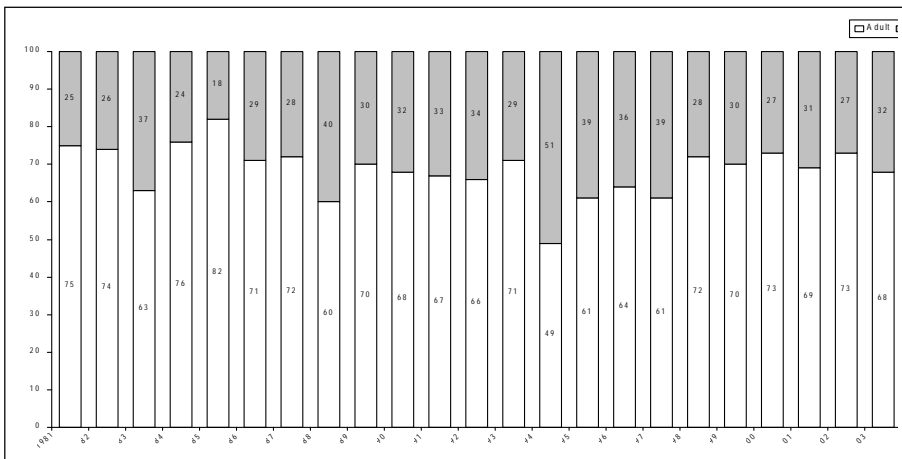


Over a period of time, passive surveys appear highly effective – in terms of cost and energy spent.

Regular multifaceted community-based leprosy education campaigns resulted in an increase in voluntary reporting and referral. (45% to 55% of new cases reported voluntarily or came through referrals from health-care workers or by CBOs involved in the campaign areas).

Graph No. 8

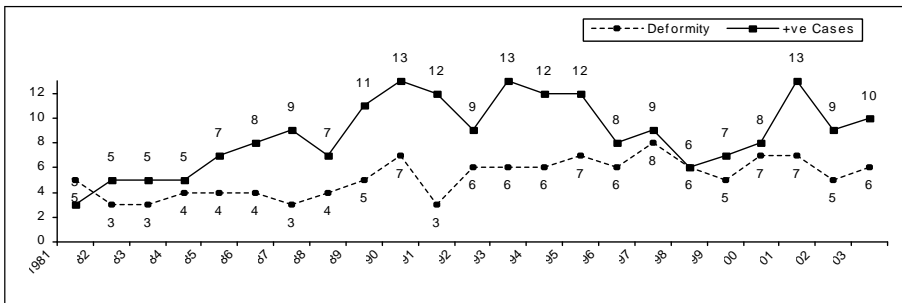
Year-wise proportion of child cases among new cases detected in the N, S and T Wards from 1981 to 2003 and in Navi Mumbai townships from 1989 to 2003



The proportion of child cases remains more or less the same even though the NCDR and PR show a decline.

Graph No. 9

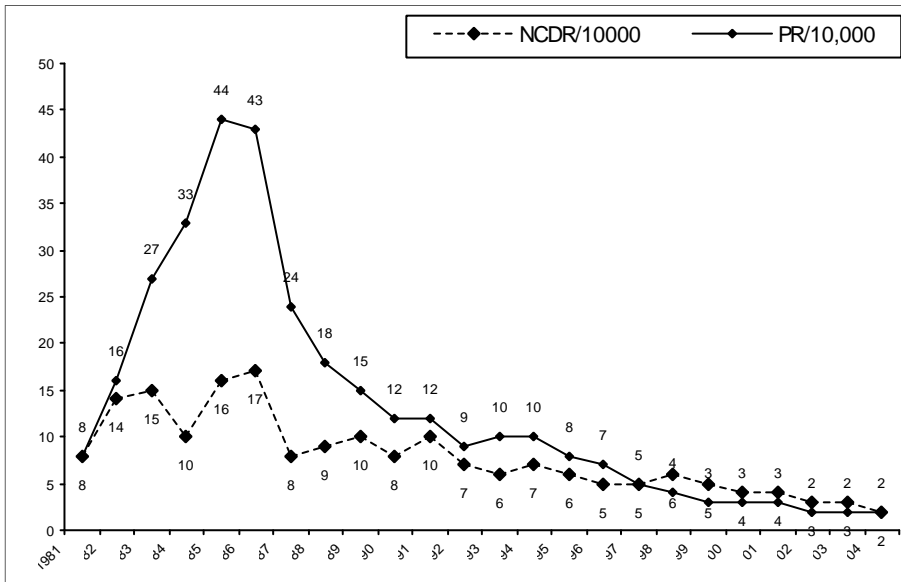
Year-wise proportion of deformed and smear positive cases among new cases detected in the N, S and T Wards from 1981 to 2003 and in Navi Mumbai townships from 1989 to 2003



There is an upward trend in smear positive patients and grade II deformity patients.

Graph No. 10

Year-wise new case detection rate and prevalence rate / 10,000 population in the N, S and T Wards from 1981 to 2003 and in Navi Mumbai townships from 1989 to 2003



The NCDR in the N, S and T Wards has been static for the past few years; since 2000 a gradual decrease has been observed in Navi Mumbai. The prevalence has also been gradually decreasing in the N, S and T Wards and in Navi Mumbai.

2.4.5 Spectrum of Activities

- Before integration, till July 2004, ALERT-India managed 27 free treatment centres in Mumbai and Navi Mumbai
- Successfully treated and cured more than 21,414 cases with MDT
- Reduced the prevalence rate of leprosy from 11-15 per 1,000 in 1981 in the slum areas covered to 3 per 10,000 today
- Conducted slum, community and school surveys through specially trained leprosy technicians, as also follow-ups with patients at the

family/ community level

- Creating awareness and dispelling wrong beliefs about the disease, through slide-shows, films, album talks, exhibitions and video shows were a consistent part of all anti-leprosy campaigns in the community
- Placing emphasis on early detection to prevent deformities and to cure the disease without deformity
- Physiotherapy services were organised to correct any visible deformity and help patients with mild or severe deformities to lead a meaningful life.
- Establishing an aids and appliances unit at the Acworth Municipal Leprosy Hospital, Wadala, Mumbai, to provide special protective footwear of micro-cellular rubber (MCR) for people with foot problems due to leprosy. This unit also produces pre-fabricated splints to prevent and correct hand deformities.
- Leprosy is closely linked with poverty and typically affects young people and children, particularly the poorest of the poor. The disease is clearly in retreat, yet problems remain. While ALERT-India is concerned about the welfare of leprosy-affected persons and their dependent children, emphasis was given towards the formal education of the children to promote self-reliance in future.
- Since 1993, ALERT-India has been providing education sponsorship to children affected by leprosy and also to children of leprosy-affected persons.
- Leprosy-affected people require a comprehensive approach to enjoy equal rights in the economic, social and cultural spheres. The disease morbidity and disability in leprosy-affected persons impose severe economic hardship. There is a need to enhance the socio-economic status of poor leprosy-affected people.
- At every juncture, ALERT-India was quick to grasp opportunities to help those deprived of benefits and eager to take advantage of schemes available elsewhere. Realizing the need, ALERT-India initiated a special scheme and supported several poor people affected by leprosy or their families. It also provided guidance to these people at all stages of the process involved in income-generation.

2.4.6 Prevention of Disabilities : Leprosy and its disabilities are visibly still with us though on a reduced scale. Also, it carries with it a severe social stigma, compounding the pain and suffering that those affected by the disease already have to live with. Some cases continue to be detected only at a late stage after irreversible disabilities have set in. Simple testing of sensory and motor loss makes it possible to detect more cases at an early stage when a complete cure is possible. Disability could easily be prevented by early detection of nerve-function impairment.

Prompt access to effective treatment to prevent disabilities is one of ALERT-India's major strategies to lower the disability burden in the community. Experienced doctors manning ALERT-India's treatment centres routinely examine all leprosy patients and treat those who might develop new disabilities, with appropriate treatment. About 5% to 7% of the patients were detected with visible disabilities and deformities. All of them are given physiotherapy and taught self-care to correct early disabilities/ deformities and prevent further deterioration of existing deformities.

2.4.7 Aids and Appliances – Footwear and Splint Unit : In 2002, ALERT-India established an aids and appliances unit on the premises of Acworth Leprosy Hospital, Wadala. This unit produces special protective footwear made of micro-cellular rubber (MCR) for those with foot problems due to leprosy or from other causes. This protective footwear with MCR insoles is 'made to order' on a 'no-loss, no-profit' basis. It is ideal for feet with sensory loss and is available in different models to patients. Since 2001, ALERT-India has produced and supplied over 6,600 pairs of MCR footwear to leprosy patients at subsidized rates. Beneficiaries include leprosy patients referred from other leprosy agencies run by NGOs, the BMC and the government of Maharashtra as well as dermatologists. This unit also produces pre-fabricated splints to prevent and correct hand deformities due to leprosy and other peripheral neuropathies.

2.4.8 Economic Assistance : Rehabilitation is an integral part of our treatment programme so that leprosy-affected persons are not socio-economically displaced. Since 1998, ALERT-India in collaboration with SREDHA (Society for the Rehabilitation of the Disabled and Handicapped) has been providing rehabilitative and educational empowerment programmes to affected persons in Mumbai and its suburbs. Financial assistance was provided to affected persons/ families to start any kind of income generating activity or to hygienically improve their residences by carrying out necessary repairs or to acquire needed skills to raise their economic status in society. Educational assistance was also provided to school-going children of leprosy-affected families

in the form of sponsorship. Further financial assistance to needy students is given from time to time to overcome crisis situations. Aged sponsorship scheme takes care of the needs of the aged, and helpless leprosy patients were also provided with help to meet urgent needs such as medical treatment, hospitalisation or even death in the family. In addition to these, workshop-based training in trades like fret-work and screen-printing and continuous employment to selected leprosy patients were also offered.

2.4.9 Rehabilitation : ALERT – INDIA has provided rehabilitation services benefiting leprosy affected persons and families from August 1998 to March 2001.

- Financial assistance to start self-employment or for income-generating activities, and to repair houses/ rooms, work premises, etc.
- Financial assistance for emergencies: medical treatment, hospitalization/ death in the family, etc., and an old-age sponsorship scheme
- Workshop-based training-cum-production unit and training-cum-employment
- From February 1999 ALERT-India has been running a *balwadi* in Dattadham Leprosy Colony, Pachubunder, Vasai.
- From August 1998 to March 2001, educational assistance to 43 students who are pursuing professional or technical courses (studies) was offered under this programme.
- CHILD SPONSORSHIP : ALERT-INDIA has also been directly supporting the cost of education of leprosy patients' children or children with leprosy since 1993. 257 children benefit from this programme at any given point of time. These children are carefully selected by leprosy workers based on the family's economic background.

2.4.10 Health education and awareness campaigns : An ambitious leprosy education campaign was launched by ALERT-India in 1999. This includes the use of the mass media and health personnel. By portraying leprosy as just another disease, the campaign helped motivate people with suspicious signs of leprosy to come forward for early diagnosis and free treatment available at all the ALERT INDIA's treatment centres. This strategy recognized the importance of stepping up public health education campaigns to reduce the

stigma of leprosy, spread the word that it is now just like any other curable disease. This encourages awareness regarding the first signs of leprosy and the fact that treatment is widely available in the areas adopted by ALERT-India. It is assumed that these campaigns have resulted in voluntary reporting of cases at an early stage.

The Health Education programmes of ALERT- India always made use of AVs and multimedia very effectively. Slide shows, pictorial albums, exhibitions and video shows were conducted for school or college students or community groups. At all programmes very many brochures on facts about leprosy and the MDT treatment centres were distributed.

In addition to the above regular programmes, extensive and varied media-level programmes and publicity was organized to reach out to the general public during the anti-leprosy week.

2.4.11 Partnership in Leprosy Elimination : When ALERT-India began 25 years ago, leprosy eradication was only a distant dream. Leprosy was then considered a dreaded disease and afflicted patients were looked down upon and treated as outcasts. ALERT-India felt the pressing need to educate people about leprosy and thus shatter some of the myths surrounding the disease. With the aid of modern drugs and an intensive education programme, ALERT has successfully treated and cured over 27,000 leprosy patients till date. The distant dream is thus becoming a tangible reality.

The World Health Organisation (WHO) has set as deadline end- -2005 to eliminate leprosy in all developing countries. In India, though leprosy is no longer the terror it once was, new cases are being continually identified.

It is heartening to note that our efforts over the years have borne fruit. More and more people are now becoming aware of the disease and leprosy-afflicted patients are slowly being accepted back into society. All of this would not have been possible without the dedicated efforts of our team of doctors, paramedics and volunteers.

2.4.12 Challenges for the Future : As a result of MDT, the prevalence rate has dramatically fallen over the past ten years. However, prevalence is no longer a useful indicator. The reported prevalence excludes those who have not been registered for treatment and those treated by private practitioners. To determine progress in elimination we need to know the incidence of leprosy cases. Detected new cases reflect the incidence of leprosy, i.e., the cases

detected over the past year include patients who had been struck by the disease many years ago. Hence, importance needs to be given to new case detection rate over the prevalence rate within the city, region and country.

Leprosy elimination in a metropolis like Mumbai can be achieved only when we can identify all high-risk areas where skin-smear positive cases appear. This requires continuous efforts to survey all new slums and the fresh populations especially in slums. In the period of integration, the SET (survey, education treatment) vertical pattern has been officially given up. MDT is made accessible to patients in all public health facilities. We need to evolve newer strategies. That will take us closer to the elimination target of less than one case per 10,000 population.

It is also important to concentrate on the growing satellite towns in and around metropolitan cities and on new industries where a large concentration of labour has migrated from various states in India. This could be better achieved by involving the public health personnel, community level groups and volunteers in efforts to identify new cases. This also calls for continuing education and campaigns at the community level.

Integration of leprosy with public health services is not the final solution. Special strategies are still required to detect new cases. Adequate and prompt multi-drug therapy to all known cases should be promoted. Specialised leprosy services and care at the district and regional levels need to be established to cater to patients with disabilities and deformities.

Chapter 3

Lessons from ALERT – INDIA’s Community Health Experience

3.1 Community Education Unit (C.E.U.)

In 1993, ALERT-INDIA team had decided to expand its role beyond leprosy control in N, S & T wards (the leprosy control project area since 1981). The decision was to play a catalyst role and bring to the fore important health issues, in addition to leprosy survey, education and treatment. Hence the team decided to take up campaigns on issues of public health concern and take up promotion activities at the community level through Community Health Workers (CHWs) attached to Health Posts of GBMC, for greater impact and reach.

Since ALERT was working in the N, S, T wards of Mumbai Municipal Corporation, it was aware of the health post role and its functioning in the area. Health Posts (the Community Outreach Programme of the Corporation) had great potential and possibilities to reach out to people in the slums. The Corporation authorities extended full co-operation and support to this programme involving the CHWs who are women volunteers derived from the local slums.

3.1.1 ALERT INDIA’s Community Education Unit and work with CHWs : Training and helping CHWs was identified as a direct means of helping people to get access to knowledge and information to improve their health and living conditions. ALERT had started with the general objective to sensitize CHWS to become a catalyst of community’s health care promotion through a systematic process of awareness creation and education (as they fulfil their job requirements as CHWs in the Health Post Community Outreach Programmes). In short, the unit plays an effective, meaningful supportive and promotive role to all the public health programmes and other special campaigns. This is aimed to be achieved through skill and knowledge development of the CHWs in particular and local groups of women in slum communities, in general.

3.2 Specific Objectives

In the light of the above and other felt needs of the slum communities, the CEU’s specific objectives were aimed :

To promote educational activities related to health, education, environment and gender justice among community groups that can bring the positive change in the slum community and help the community groups to assert their right – through participatory training and community level education campaigns.

- 1) To assist CHWS to enhance their skills and knowledge to improve their interactions with other women in the community, in fulfilment of the outreach programme tasks entrusted with them under the public health programme.
- 2) To help, understand and probe in to medical, legal and traditional systems and practices that affect women in the present socio-economic and cultural context and take steps to counter/alter them in their favour.
- 3) To encourage and facilitate individual and collective action by slum women through their own independent forums/organisations.

3.2.1 The Approach : Keeping with the focus of the above objectives, CEU had devised a series of training workshops and campaigns for CHWs. These training's and campaigns were formulated to help CHWs in particular and people in general to discover for themselves and analyze the reality around them and evolve their own strategy to change it in their favour. Towards this end the unit had adopted several approaches in training the CHWs asserting the following.

- Health need to be seen from the holistic point of view.
- Participation of trainees in the process of learning is the pre-requisite to bring about a critical awareness.
- Skill Development should be purposeful and should have relevance to the socio-economic and cultural context in which people live.
- Self assertion and community action can only become a reality with an understanding the socio-economic realities and acknowledgement of the need for change by the people. The change is always related to the consciousness of people and their collective response and action.
- The strategies for action arising out of this approach can sow the seeds for the real long lasting change in people's lives.
- Women have a pivotal role to play in all changes desired to be achieved in the community.

Nine years of Committed Efforts and Outcomes an account of the CEU's work over the nine years since it began in 1993-94.

3.3 Summary of CEU Work :

Key Processes and Features

The CEU team members have been involved in the following key processes

- Training of CHWs
- Community Health Education
- Participatory Research and Analysis
- Educational Media Development, and
- Local collective Health Action.

In each area they have been making constructive and innovative contribution. We highlight the outstanding features of the CEU project:

a commitment to *work in the established Municipal Government Health System*, tapping the resources within it and evolving viable community healthcare alternatives.

a *focus on empowerment of women* as health workers and community members to access women's health rights and to activate the health system in their favour.

a *paradigm of health practice* known as 'self-help' and 'self-exam' that lets women reclaim control over their own bodies.

a challenge to top-down notions of health bureaucracy and professionalism through *developing grassroots skill, attitudes and knowledge* of women.

a *provocation to the existing health system* to positively respond to the expanded role of women

3.3.1 Changes following assessment : Since the assessment and recommendations at the end of 2000, several notable actions have been taken, namely,

- Recruitment of 3 team members, (2 women field co-ordinators and a female doctor)
- Provision for the staff training and skill development through regular 'refresher' training.
- Identification of talented CHWs and holding 'TOT' with them, forming a group of CHW trainers for Health Post level trainings.

- Initiation of community group work with teenage girls and boys.
- Involvement of CHWs in developing and testing new learning aids and in reassessing old ones for reproduction.
- Giving importance to documentation and data collection for future planning.

The most significant step taken by the CEU – both programmatically and logistically – is the

- Implementation of the new strategy of Health Post Level Training (HPLT) of the CHWs, involving the Health Post staff, too.

This marks a bold shift from the former pattern, Earlier, training was conducted in large centralized training shibirs of a few days, facilitated by the CEU team with outside resource persons, and held several times a year. Now, training is conducted in smaller, local (HP-level) sessions, facilitated by the ‘CHW trainers’ and CEU FCs, held on one day every month.

Thus, in various ways, the CEU team has demonstrated its dynamicity and resilience in rising to challengers and making the best use of resources within the system to pursue the goals and the team morale in high. With this confidence, we submit the fresh recommendations.

3.3.2 Need for refined Assessment : From the point of view of detailed and effective planning for the future, and for the fulfillment of social responsibility, it is important to assess the project gains and limitations accurately. It is not enough only to record the process and list outcomes, no matter how faithfully and exhaustingly it is done.

From what we observe, the CEU has come a long way in its attempt to attain the goal of ‘promoting women’s access to knowledge and information for bringing about positive changes in health and the quality of life for themselves, their families and their communities’.

But what do we actually mean when we say this? What indicators could have been set to state this more substantially? It requires a more rigorous exercise than has been possible for us. In planning the future work, the CEU must select the key areas of intervention and set proper indicators – qualitative and quantitative – for what would be considered the desired progress towards the objectives. Within each key area, the process begins with specific questioning and probing before deciding how to go about answering in measurable terms.

For example,

- What if the CHWs' outreach> How to specify the 'effective coverage' for a 'community' to be reached? To what extent are marginalized women and communities included?
- How effective is the information that is conveyed, and how do we assess that?
- What exactly are the positive changes in health and quality of life that we are looking for? And are they only material, or are the changes cultural and social as well?

For assessing each aspect, the team needs to spell out parameters and indicators against which gains or shortcomings will be measured.

3.4 Compelling Reasons to Continue and Grow in Outreach

The CEU's clear priority is health education in its own fields area. Even so, with nine years of experience, it has much to offer other organizations concerned with health training, education and services. Some of the CEU's assets – human, material and conceptual- are rather unique. Together they are reason enough for continuing and developing the project.

The 'Assets'

The CEU has built up assets that we can group into five categories, as follows:

1. **Training:** 1) CHW trainers, 2) HP-level approach, 3) involvement of HP staff, 4) need-based content, 5) participatory method.
2. **Outreach:** 1) gender-sensitive, reality-based approach to communities, 2) linkage with leadership development and health action.
3. **Health work:** 1) unusual 'self-help' approach 2) SHHWs' (Self Help Health Workers) practice (detecting women's health disorders, spotting causes, using healing remedies), 3) referral system.
4. **Materials:** 1) learning aids 2) booklets, 3) Sakhi newsletter, 4) video film, 5) Learning Resource Wing for production / distribution.
5. **Research:** 1) community-based health data, 2) data on women's reproductive health disorders found by SHHWs.

At the same time, the work is evolving, and it needs by sustained and continued in a planned way over the next five years.

3.4.1 Who would be interested?

We know there is interest about various aspects of the CEU Project from several quarters.

- Within the *BMC system* there appears to be interest in engaging ALERT-India's help for training CHWs of the HPs in the other wards.
- Since the *Health Post-level* training, the other staff (Doctors, ANMs, MPWs) are showing interest in the new topics and approach.
- In the *State health system*, the CEU's urban experience is relevant to the debate over a CHW-based scheme for PHC in rural areas.
- *Anganwadi workers* are eager to get Sakhi.
- Numerous *NGO groups* subscribe to Sakhi. And use the aids. Recently the team has conducted training for workers of 2 NGOs.
- Both *Marathi-speaking* and *Hindi-speaking* communities are interested in the materials, and production in Hindi is being planned.

On the other hand, we feel there is potential interest from others in the following aspects:

- The *reproductive health data* generated by the SHHWs may interest the BMC Health Department and other health institutions.
- The innovative pattern of *Health-Post Level Training* could interest those concerned with management and training in PHC systems.
- The adolescent health program for teen girls and boys, that includes a 'body literacy' approach, will grow in general importance.

Chapter 4

Leprosy after Integration

4.1 Integrated social system :

Culture is an integration of social practices relevant to the local socio-economic environment. Every human being is an integrated organism and therefore, human society should function as an integrated social system. Although the diseases may affect any part or organ of the body, it also affects the anatomical, physiological and mental system, which severely hampers the functioning of the affected persons at the physical, social and mental levels. A chronic disease like leprosy, which had no treatment and cure for centuries, has created tremendous social consequences than any other disease. With the development of effective and modern drugs and the bacterial cure is in sight, the health programmes have responded favourably to eliminate the disease in the shorter possible time. Initially, the hypothesis of containing the spread of infection by early detection and prompt treatment could not make quick progress mainly due to fear and ignorance about leprosy in the society. The urban situation has become more complex as routine house-to-house surveys are not feasible in elite urban society except in the slums, where the density of population is abnormally high because of constant influx of migrants from rural areas or from small towns to mega city that results in the spread of infection.

4.2 Programme goals vs peoples' concern :

Integration of health programmes has always been propagated basically for economic and logistic reasons and to achieve optimal results. It has been realized that the patients' confidence and compliance to treatment would be ensured by proper understanding and willingness of General Health Care system. In leprosy, the Integration was visualized as a sequential activity to be followed after achieving the low level of prevalence of leprosy in an area. Activities related to prevention of disability (POD) and rehabilitation are also to be integrated with the General Health Care system through a planned inter-sectoral co-ordination. Even after sustained work for several years and achieving positive statistical / quantitative results, in terms of lowering of prevalence, leprosy related problems are likely to remain in the community unless the programme focuses on active community participation. The vertical leprosy programmes have been so far concentrating mainly on achieving the goals of leprosy elimination at various

levels and not adequately addressing to the peoples' concerns of social exclusion through an effective health education or IEC activities using social marketing techniques.

4.3 Integration :

In principle, the Integration of leprosy programme into the general health care system has been advocated by the Government and accepted by all health agencies since long. The appropriate time, preparation to transfer the responsibility to the general health care system and the stages through which integration was to be achieved has been already formulated. However the issues and strategies pertaining to Integration in urban areas need to be refined in the context of health facilities and priorities.

On the subject of integration:

Lastly, I feel impelled to dwell a little bit on the subject of integration. As we all know the Government of India has taken the decision to abolish all vertical health programmes, including leprosy, and bring everything within an integrated set up. There is no doubt that this is the ideal arrangement in view of the social stigma attached to the disease that keeps patients away from the leprosy treatment centres for fear of identification. We plan vertical programmes for particular health problems in order to bring down the intensity of the problem to a manageable level whereby it can be tackled as any other community disease through the general health care and delivery system i.e., the primary health centres. One need not re-emphasize the fact that we fight the leprosy problem on two fronts, the medical, and the social. This unique situation is peculiar to leprosy. I have a strong conviction that treatment of leprosy in an integrated set up may be neglected unless there is adequate social acceptance of leprosy.

(Wardekar: 1978: A Window on Leprosy)

4.3.1 Misgivings about Integration : The protagonists of the vertical leprosy programme have the apprehension that the specialized and focused attention paid by the trained experienced leprosy staff would not be available if the programme is integrated with the general health care system. On the contrary, the integrationists strongly profess that there would be more health workers available for the programme, once they are trained in leprosy. The positive side of the integration is by making the leprosy services available nearer to the place where the leprosy patients live. The negative side, as perceived by the leprosy patients, is about the reduced attention by the general health care

system. There are certain issues in the process of integration, which are applicable to general health care staff and others applicable to the leprosy patients and community, are to be considered. The government's perspective in respect of financial aspects have created mixed reactions among the vertical leprosy staff that there will be less work for them once the prevalence rate has declined to elimination level.

4.3.2 Community Volunteers perform better : It has been well acknowledged that before integration, the vertical leprosy programme have functioned better in respect of new case detection, wherever the Community volunteers were trained and involved in population screening for suspecting leprosy and later confirmed by the trained leprosy staff. In 2002, an evaluation of DANLEP supported programme in Kirnapur block of Balghat district in Madhya Pradesh has brought out the fact that less number of cases were suspected by trained community volunteers in their respective villages, whereas more leprosy cases were confirmed by the vertical leprosy staff. While the report also states that under Modified Leprosy Elimination Campaign (MLEC) more leprosy cases were suspected by general health staff and MLEC volunteers (not in their respective villages), only a fewer leprosy cases were confirmed by the vertical leprosy staff. This proves that the confirmation rate (48% by Community volunteers against 6.29% of MLEC [II] and 39.7% of SAPEL) has been far better in cases newly detected by the volunteers trained in suspecting early signs of leprosy in their respective villages. It is important to know 'what is not leprosy', than to suspect every sign and symptom as that of leprosy unless otherwise proved. Suspecting all skin patches is a target driven programme in vertical approach, but excluding all non-leprosy cases (differential diagnosis) during population screening is an integrated approach. The vertical approach is likely to perpetuate the fear in the minds of the community, where as the integrated approach makes the people at ease since not every person is suspected for leprosy and identified as a leprosy patient. It must be emphasized that the surveyor or searcher need to explain the differential diagnosis to the family during survey and a sound IEC strategy is required to achieve this.

4.3.3 Integration does not mean new additions : Some NGOs have integrated other disease control programmes, such as TB and HIV into their leprosy control programmes. Obviously this is not a right approach for integration, but just increasing the workload of the staff engaged in the routine vertical leprosy programmes. Ideally, the Integration of leprosy programme into the GHS stresses that the general health system will take care of all the health related issues of the people, including leprosy under their health services programmes.

A number of countries have combined their leprosy elimination programme with programmes for other diseases such as tuberculosis; in such situations the combined programmes remain vertical, WHO: 1998

The primary health care approach focusing on inter-sectoral coordination is an ideal integrated approach for health and development which has been accepted at all levels. The PHC approach should go beyond the scope of curative health services and engulf other issues such as education, transport, sanitation, power, water supply, nutrition etc.

4.4 Evaluation of Integration – Lessons from Tamilnadu Experience

In July 1997, Tamil Nadu was the first State in India to effect integration of NLEP with the PHC system. A study conducted by Experts from the Community Health Department of Christian Medical College, Vellore, which evaluated the 'Process and Impact of interpretation of leprosy with Primary Health Care programme' in 2000 in Tamil Nadu have brought out several important issues that has to be taken into account while practising integration in any other area or State of the country.

4.4.1. The study reports that although all stakeholders have accepted the concept of integration in principle but have expressed dissatisfaction about the short time made available for the process to accomplish by itself. Some of the short comings in the process of Integration were identified as:

1. Inadequate training of workers to take up integration work.
2. Transfer of patient records from LCU to the PHC.
3. Inadequate information to patients and community about the availability of leprosy services at the PHC.
4. Disruption of established referral channels of treatment of complications and rehabilitation needs.
5. Limitation of the role of voluntary agencies.

Comparison of key programme indicators assessed during the pre and post integration period have revealed that the performance levels of rapid survey, school survey, contact survey, group survey, skin camps and voluntary reporting are not satisfactory. Moreover the report observed that the proportion of cases with grade II deformity (WHO, 1988) has increased marginally among all new cases and about half of the new cases detected were single skin lesion (SSL)

cases in the post integration phase.

It was also noted that generally the health workers of vertical programme were critical about the undue haste shown in implementing the integrated programme and also expressed reservation about the quality of leprosy services at the PHC level and about referral services for specialized care. Leprosy patients with ulcers, reactions and visible deformities felt that the services available at PHC level are inadequate. However, the community appreciated the availability of leprosy services at the PHC level after integration.

4.4.2 The evaluation team has recommended the objectives for consolidation phase

- Strengthening the coordination, supervision and monitoring of the leprosy programme at the district level.
- Facilitation of leprosy-related work at the PHC level.
- Establishment of well-defined referral systems and linkages with voluntary institutions to manage aspects of leprosy related services that are not feasible at the PHC level
- Improving the knowledge, skills, attitudes and motivation of workers by identifying training needs and organizing such training
- Raising the level of awareness of the community regarding the leprosy control programme

4.4.3 There has been a general feeling about losing the experience and commitment of NGLOs. The evaluation team has recommended to use the strengths of voluntary institutions:

- Utilizing their facilities and expertise in training health workers to perform leprosy work.
- Utilizing their facilities to provide hospitalization and rehabilitative care to leprosy patients
- Involving them in prevention of deformity activities at the community level.
- Involving them in identification and treatment of cases in areas with poor coverage by the government health infrastructure like urban areas, tribal areas and other hard-to-reach areas.

4.4.4. Recommendations :

General recommendations for other States that are considering integration of the leprosy programme with Primary Health Care.

It is recommended that both the process of integration and the protocols following the integration be carefully planned well in advance, with the involvement of all the stakeholders of the programme, including patients and representatives of the community.

- Necessary training should be imparted and the health workers should be suitably equipped for the performance of their duties before the commencement of the process of integration.
- Supervisory roles and indicators for monitoring the performance of the programme should be defined, designed with care and instituted before integration takes place.
- The community and patients should be informed well in advance regarding the forthcoming changes and specific information should be provided to the current patients about the place and person to contact for continuation of treatment after integration.
- Records of old and current patients should be transferred to the respective PHCs before integration and the PHC staff should be familiarized with these records.
- Referral mechanisms should be established and all the personnel should be familiarized with indications and mechanisms of referral before integration.
- Whenever possible, the PHC level personnel proposed to be involved in leprosy work after integration should accompany the leprosy programme personnel on their daily round of activities in their respective areas in the month preceding integration.
- As far as possible, discrepancies in the cadre, remuneration, allowance, promotion and job roles of personnel that would arise post-integration, should be carefully identified, analyzed and normalized before integration.

4.5 Voluntary Reporting by community

Despite all efforts made towards achieving the target for elimination of leprosy, the new cases will continue to occur, particularly in urban areas, since the estimates on incidence could not be defined in the wake of several deficiencies in the knowledge about transmission process. No programme could cope up with such a huge magnitude of disease burden and the low socio-economic situations in order to do full justice to all aspects of leprosy, such as new case detection, timely treatment preventing and correcting nerve damage and rehabilitation. Voluntary reporting by community members suspecting some pathological conditions is the lasting solution for any disease treatment and control management. However, this issue presupposes thorough knowledge and awareness about the process of causation and cure, the consequences of delay in treatment and the availability of treatment for various stages of the disease including the costs involved. When such knowledge internalizes, it becomes a part of culture system which is transmitted to the next generation by the family and kin groups through the process of enculturation and socialization.

This order of transformation cannot be achieved by the vertical and target oriented programme to identify and eliminate the causative organism without involving or informing the community. The community or leprosy patients do not think of leprosy alone but even in affliction, they think or act in accordance with the likely negative impact in their total lives. Voluntary reporting of cases without the onset of deformity is the ideal desired condition and the ultimate effect of the IEC programmes.

4.6 Statistical reduction blurs the outlook on social issues

Having realized fully that vertical programmes by its inherent logic continues or accentuates social stigma and that such programmes have been implemented provides only statistical reduction in the prevalence of leprosy without addressing the human and social issues, integration of leprosy programme with the General Health System has been propagated. Incidentally, even health services cannot be isolated as an aspect of culture?

4.7 Primary Health Approach

The Primary Health Care Approach enunciated by WHO as the Alma Ata declaration of 1978 recognizes and promotes the integrated nature of health, culture and society to be implemented through inter-sectoral coordination.

4.8 Issues of integration in urban setting

The leprosy scenario in urban area after total integration is likely to be a bag of sour and sweet fruits. It is expected that the general health staff will treat all the new cases that would surface through voluntary reporting as the active surveys have been abandoned as a routine. The vertical leprosy staff would gradually merge with the GHS and look after the relatively complicated services such as managing relapse, drug resistance and nerve damage. It is an advantage that there is more female staff in GHS, hence the proportion of female leprosy cases may increase in the initial period. If the spirit of integration is followed in its true sense and spirit, the quality of life of leprosy patients will improve and the stigma will decrease in due course of time.

Different kinds of problems might emerge due to multiple service providers and occasionally non-availability of free drugs. It has always been difficult to get feed back about the patients from private health service providers. The private health sectors are likely to play an increased role in the post integration scenario and it is the time to involve them in the process, particularly the dermatologists. Even the retired leprosy PMW and NMS may be involved in the special campaigns and to render specialized treatment so as to utilize their skills.

4.9 ALERT INDIA's response

After witnessing the pros and cons of the Integration in other parts of the country, ALERT INDIA felt the need for a planned and co-ordinated strategy that would help to overcome the limitations and difficulties posed, especially in the growing urban context.

Chapter 5

ALERT-INDIA's Vision

5.1 The role of ALERT-INDIA as an NGO

There will be very few NGLO players in the field after integration – ALERT will be one of those few. ALERT INDIA's intersectoral holistic vision goes beyond leprosy in the arena of general health, poverty alleviation and development, more precisely women's development and will continue to play a creative role in leprosy related issues during and after the Integrated scenario.

The process of Integration of leprosy does not warrant to close down the NGOs engaged in vertical programme or to abandon the existing treatment centres established to provide care and services for leprosy patients. It also does not call for reducing the vertical staff or for finding an alternative work to compensate the work load. The need is for absorbing new strategy for interventions by the NGOs in tune with the Integration policy recommended by the Government that would strengthen the process of integration. In order to fulfil this, ALERT INDIA has envisioned its future programme called **LEAP, "Leprosy Elimination Action Programme"**, which is based on a community partnership strategy. The primary objective of LEAP would be to meet all the needs of leprosy affected persons through a community partnership. A well defined road map has been drawn out after due consideration of the priority issues to be addressed during Integration and Elimination and also taking into account of all the spheres of leprosy activities in the form of Vision Statement.

5.2 Integration for Leprosy Elimination is the focus

It has been now realized that the Integration of leprosy programme will pave a way to achieve the goal of leprosy elimination within a set timeframe by pooling all the health resources to tackle the disease burden that prevail in a given community. The strategy for Integration implies that leprosy will no longer be dealt by specialized centres exclusively working for leprosy. However the focus of the leprosy integration must include urban areas to achieve the desired goal of elimination. More so, the treatment will be dispensed through public health network in the cities and towns of Maharashtra and through PHCs in rural areas. The process of Integration has been already initiated in the Maharsahtra State since July 2004. The transfer of responsibility from the vertical programme

to the General health Care system is taking place in a phased manner.

5.3 Leprosy scenario after Integration – Advantages & disadvantages

Today the integration makes for the first time in history the drugs that can cure leprosy are made available through a large network of public health outlets. The entire medical fraternity especially medical personnel in public health are made responsible to treat leprosy. Rough estimation of leprosy (however, defective and inaccurate) in region wise is now available, though no estimation is available on the actual number of patients treated by private health sector, particularly General practitioners and Practising Dermatologists all over the country. There is also a new thrust to incorporate leprosy as a public health issue in medical teaching and curriculum, though there is a long way to go.

During the Integration phase, active early case detection is officially given up – we do not have definite answer to the questions like will not this lead to late detection – more deformed patients, with gross deformities – misery for the individual - more social visibility - reinforcement of stigma and fear? The poverty condition in which most of the leprosy affected persons dwell leads to gross deformities resulting in economic loss, unemployment and occupational hazards. The consoling factor is “gross deformities” are not common. The fear is will this scene be maintained during integration phase? Public visibility of leprosy – socially known leprosy patients are at the root of social stigmatization, fear and ostracism.

5.3.1 Community awareness and Education : ALERT INDIA proposes to strengthen the IEC (Information–Education–Communication) activities with the help of NCC, NSS, Scouts, School children and women groups using Inter-Personal Communication (IPC) techniques. An effective awareness campaign about leprosy will be carried out in the community with the help of hoardings and pamphlets prepared in local languages and suitable to local socio-cultural beliefs as well as by involving mass media communication tools.

5.3.2 Advocacy and communication campaigns : ALERT INDIA proposes to organize Workshops and Seminars focussing the new approaches for leprosy elimination through integration by involving all the partners of LEAP to reinforce liaison with the Government health agencies. Advocacy and consultative meetings with the Health Programme managers of various health sectors will facilitate smooth implementation of the programme. Various publications and News letters will be brought out to improve the communication skills.

5.3.3 Capacity building of General Health personnel and Medical fraternity :

It is mandatory that the skills of the vertical manpower need to be transferred to the general health personnel in order to maintain the quality of services to the leprosy patients. ALERT INDIA recognized the need for conducting a task-oriented certified short term training at periodical intervals during the integrated phase emphasizing mainly on diagnosis of early leprosy cases, treatment and management for FTMOs and MOs dispensary/hospitals in the urban areas and the MOs of hospitals and Health Centres in rural areas. A standard training curriculum is being formulated by drawing on the expertise available with NGLOs. Continuing Medical Education (CME) is one of the LEAP strategy. ALERT INDIA supports the initiative by the Joint Directorate of Health Services (Leprosy), Government of Maharashtra. Special training programmes for General Medical Practitioners (GMPs) including the medical interns in Medical colleges will also be part of this initiative. This is aimed to cover all the medical fraternity in the State of Maharashtra in a phased manner. The medical students can be involved in the leprosy elimination programmes.

5.3.4 Community approach for leprosy elimination :

The greatest challenge in urban areas is the difficulty in detecting all the hidden cases in the growing slum areas and tackling the migrant population. ALERT INDIA has proposed a strategy for detecting new cases by specially surveying hard to reach population including migrants, floaters, slum dwellers, fishermen and high income group people. These campaigns are to be carried out by deploying trained community level volunteers and the various health personnel in the Health Post or Urban health Post and PHC and village level health workers who are part of the health delivery system in the rural areas. Even after such campaigns, these community level trained personnel will continue to act as a guides and spokesman who will promote spread of awareness and encourage voluntary reporting in the long run.

Besides, school surveys with a special focus on children as an epidemiological indicator to be carried out during rainy season. Priority to be given to schools located in slums and economically weaker sections housing areas. Experience shows that the high incidence of new cases among the contacts, hence survey of family contacts of leprosy patients have to be undertaken. As a good proportion of cured leprosy cases are likely to develop post-treatment complications, it requires active vigilance of RFT (Released From Treatment) cases. Retrieval of defaulters at the local Health Post level need to be promoted.

5.3.5 Creation of district and state level Referral centres : ALERT INDIA recognizes the need for establishing referral centres / facilities for confirmation of diagnosis, management of reactions, physiotherapy and care at regional / district / zonal levels at various locations in the cities, towns and also in rural areas. Simple POD measures such as physiotherapy exercises and home self care will be taught. Assistive aids such as MCR footwear, Crutches, Goggles and hand Splints will be provided to all the needy deformed leprosy patients. Technical guidance to manage complications such as of re-current lepra reactions, neuritis, trophic ulcers will be offered. Suitable and eligible cases for corrective surgery will be referred to the collaborative Re-Constructive Surgery (RCS) Units with due consultation. Specialized services such as Skin Smear, Biopsies, EMG studies will be undertaken for cases that are posing difficulty in management.

5.3.6 Strategies for strengthening Integration : Re-planning and effective deploying of the leprosy specialized man power available today (medical & paramedical) for training, supervision and coordination of referral centres, deformity prevention and control, training of community level volunteers and health personnel, organizing awareness campaigns at community level is crucial in the first phase of integration, when the learned contingent of experience and manpower is available. If not appropriately and adequately reoriented and deployed this manpower will not be available after five years. NGOs (both leprosy specialized and others) come together to form a consortium with specific objectives and strategies to work together and strengthen the process of integration. A common strategy and a common plan of action, short term and long term will set the direction for achieving the goals of integration through public health system and the community participation.

5.3.7 Central registry and Epidemiological Monitoring Unit : NGOs should augment and compliment the efforts taken by the Govt. and the Municipal Corporations at the District level towards leprosy elimination in a perspective. Throughout the *integration phase*, more than it was required in the previous decades, the epidemiological trends viz. new cases, child cases, deformity, ulcers of the disease and community participation need to be documented/studied and results are to be reported, besides for the purpose of basic monitoring (MIS).

This perspective is i) to streamline an authentic recording and reporting system to avoid duplication and re-cycling, ii) to review the progress and provide feedback, iii) to analyze and study the interventions and their relevance in the integration phase and iv) to study and evaluate the outcome and impact. To accomplish this, ALERT INDIA has established an Epidemiological and

Monitoring unit in collaboration with the District Leprosy Society, BrihanMumbai Municipal Corporation and other NGOs, wherein all the information from the health functionaries are collected and computerized. This unit will provide feedback to the stake holders and guide them in planning future perspective of LEAP.

5.3.8 Social concerns assume special significance : Socio-Economic Rehabilitation (SER) and Community Based Rehabilitation (CBR) requires investigations and initiatives to suit the need of those who are afflicted. Welfare schemes have to be an add-on to these rehabilitation schemes. Priority should be given to the self help groups of patients.

Linkages to be established with the service clubs for financial assistance to the need based programmes benefiting the leprosy patients.

Gender issues (The special problems related to women leprosy patients) deserve special attention. A social advocacy and campaigns are required to correct the legal discords on behalf of community in the best interest of leprosy patients to banish legalized ostracisms.

5.4 Special drives in the community

Integration is based on achieving a sustained new case detection and treatment of all leprosy cases by the General Health System. Voluntary reporting from the community is pivot for the success of Integration. Voluntary reporting cannot happen in void without community awareness and their active participation. Promoting voluntary reporting through community level campaigns with full involvement and guidance of leprosy personnel available today is one of the ALERT INDIA's strategy. Selected Special Drives (SSDs) and the Targeted Special Drives (TSDs) are the new tools designed to achieve the elimination target in the integration scenario. The criteria for selection of focus areas to implement these special drives should comprise of selective community groups or urban pockets where multibacillary leprosy (infectious) cases are reporting or new migrant settlements in cities and towns or areas with large number of child cases. All these special drives must be accompanied with community level awareness campaign, which will ensure sustained voluntary reporting of new cases.

5.5 Partnership for LEAP

In the process of integration the key to success lies in building partnership with the community, NGOs, CBOs, concerned public health functionaries and above all the NGLOs. The geographic reach and the scope of operation will be determined by creating linkages with them. Every partnership and linkage will be promoted and assisted to enhance the continuity of the service and care for the leprosy affected individuals. The partners with their roots in a given geographical location and socio-cultural context will be the best suited service providers. All those who share the concerns of LEAP will be the partners. Pooling and sharing resources together with partners will be key to an effective implementation of a common programme for action. Appropriate organizational structure will be developed for coordination and monitoring of the programme.

The ultimate goal of leprosy elimination is the eradication of fear of leprosy and its consequences, in terms of ulcers, deformity and threat of debilitation. If the community can be involved in suspecting the early signs of leprosy including nerve involvement, voluntary reporting will eradicate the fear and stigma. The information about diagnosis and treatment of leprosy has to become the common knowledge of the community, which is only possible through community action in leprosy elimination.

VISION STATEMENT

ALERT INDIA

will strive **towards**

programmes focussing on

community partnership strategies

to achieve the goal of **leprosy elimination**

during the integration phase,

in alliance with all stakeholders,

to make elimination a reality for people.



ALERT-INDIA

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