

## ***Leprosy Referral Centre: An intervention critical to sustain elimination and support integration***

*A. Antony Samy\**

### **ABSTRACT**

**LRC (Leprosy Referral Centre) centered activities are aimed to augment the services for leprosy affected persons by involving the GHC system to sustain leprosy elimination activities during integration phase. The LRC activities are focused to promote the integration of MDT services within the general health services, strengthening surveillance and monitoring at the local level, supporting special surveys among specific groups of population, enhancing community participation and social communication to increase awareness, entwined with capacity building of the GHC personnel, promotion of prevention of disabilities and rehabilitation activities.**

### **INTRODUCTION**

The 'intermediate goal' for elimination of leprosy, defined as 'reducing the registered prevalence rate to less than 1 case per 10,000 population' by the end of December 2005, has been achieved at the national level. *'This of course does not mean that all supportive components will disappear. It will be important to maintain an effective network of supportive and referral services within the health system to support general health workers in maintaining an acceptable quality of services'*<sup>1</sup> assure the experts. This assurance needs to be translated into a policy driven action on the ground to benefit patients through out the length and breadth of the country.

After five decades of intensive specialised leprosy control efforts, the major thrust on elimination gave birth to the policy of integration. The structural integration of leprosy services into general health care (GHC) system has taken place. The entire GHC service in the country is made responsible to detect, treat and cure leprosy. The availability of MDT through a large network of primary health centres (PHCs) and urban health posts (UHPs) in most parts of the country is a boon to the leprosy patients and will help to reduce social ostracism in due course of time. Indeed, this is a reliable long-term process to achieve the goal of leprosy elimination, provided an active investment is made on

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\* Chief Executive, ALERT-INDIA, B-9 Mira Manion, Sion (West), Mumbai. [alert@bom5.vsnl.net.in](mailto:alert@bom5.vsnl.net.in)

priority for capacity building of the GHC personnel, both medical and paramedical to diagnose and treat leprosy.

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

#### **Epidemiological point of view**

Experts say that '*mathematical modelling of leprosy indicators suggests leprosy is slowly declining but that the rate of decline remains uncertain and a sustained leprosy control is required*<sup>2</sup>. However, '*the picture is different, when NCDR is used instead of PR figures. The NCDR is a better indicator of disease, because it is not affected by changing case definitions or duration of treatment*<sup>3</sup>. WHO presume that, '*from an epidemiological standpoint, an increase in new case detection is compatible with progress towards elimination, however sustaining leprosy control activities in the context of low prevalence conditions will continue to be a challenge in the coming years*<sup>4</sup>. It is difficult to measure the leprosy incidence accurately due to operational and social factors, specially the effectiveness of case finding methods, social stigma and ignorance about leprosy. There may be

areas reported 'zero' case detection, but it does not mean 'zero' incidence of leprosy. Thus, these indicators do not characterize the leprosy burden in a given population. We must take into account disability related parameters to judge the efficacy of leprosy elimination programmes.

According to WHO, '*a number of countries have demonstrated that a significant decline in the annual new case detection rates can be achieved after wide scale application of MDT for several years. The paradoxical trends with relatively stable detection rates reported in some major endemic countries (notably India, which contributes 78% of the global annual case detection) could be the result of several operational and administrative shortcomings, rather than epidemiological factor*<sup>5</sup>. Granting operational and administrative shortcomings, one finds it extremely difficult to agree with the policy makers that the decline in epidemiological trend of the disease has fallen to the aspired limit in prescribed time span at all levels to meet the intermediate goal set for leprosy elimination.

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

Fig. 1: The trend of PR & NCDR in India <sup>6</sup>

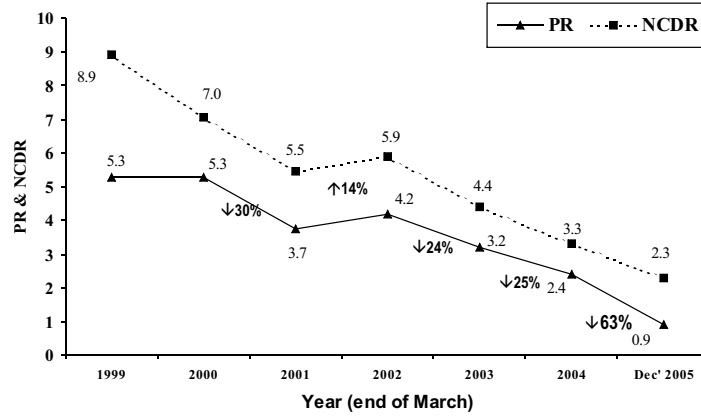


Fig. 2: The trend of PR & NCDR in Maharashtra state <sup>7</sup>

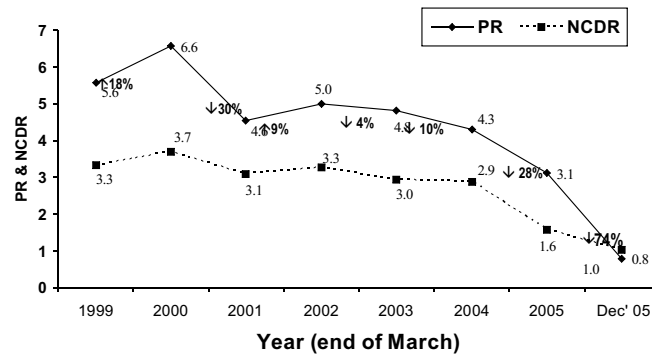
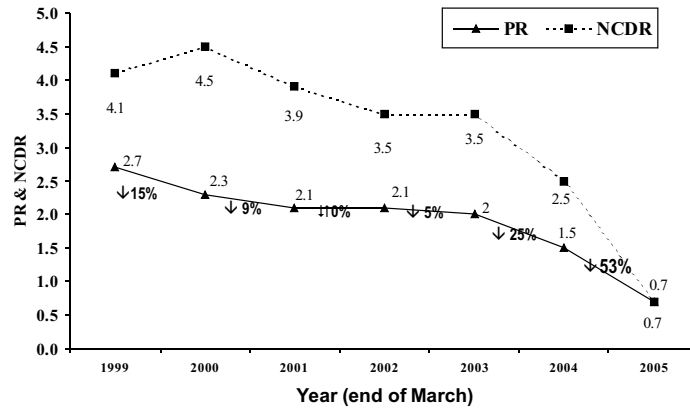


Fig. 3: The trend of PR & NCDR in Mumbai <sup>8</sup>



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

**a. Undetected new leprosy cases contribute to leprosy transmission**

The incidence of new leprosy cases are geographically varying in different regions across the country. *'It is a fact that leprosy patients newly diagnosed may have transmitted the disease to others in their family or community long before the disease is detected'*<sup>3</sup>. The WHO asserts that *'a lack of appropriate tools makes it impossible to measure the true incidence of leprosy which would be the best indicator for monitoring the impact of elimination efforts on leprosy transmission in the community'*<sup>4</sup>. The GOI recommends intensive information, education and communication (IEC) activities to promote voluntary reporting of new cases in the integration phase. However, lack of skills, manpower, motivation and education materials to carry out effective IEC campaigns defy easy answers to educate the community about leprosy. This calls for special interventions during integration phase in the absence of active case detection

activities. However, one cannot expect voluntary reporting of new leprosy cases will happen to its fullest extent in the given socio-economic situation in which the rural and urban poor live.

Even with the entire anticipated positive outcome from integration, the GHC system is overloaded with number of other public health priorities and will take a long time to play a 'primary' role in timely detection of new leprosy cases in the community. Hence, the integration phase requires reliable intermediary steps that will help to sustain elimination. LRC linked Selective Special Drives (SSDs) to reach out to all the undiagnosed cases among the new migrant population to the cities and towns, urban and rural pockets, remote tribal areas and other such population groups with high prevalence will ensure early detection, diagnosis and prompt treatment with MDT<sup>9</sup>.

**b. Significant number of new leprosy cases detected among contacts**

On examining the contacts of all new leprosy cases detected in 3 wards of Eastern suburbs of Mumbai (ALERT-INDIA's project area) during 2003 to 2005, it was revealed that more number of new leprosy cases are detected among the 'family contacts' than general population (Table 1). Although, the overall NCDR in the entire project area is only 5.1 / 10,000, the NCDR among the contacts is 71 / 10,000 during 2005. LRC linked surveillance of all new leprosy cases and their contacts definitely help to unearth a

reasonable number of new leprosy cases. LEAP plans to reach out to such known potential population group with the help of Mumbai Corporation, Government and Non-Governmental Organizations (NGLOs).

### c. Accumulation of disabled persons due to leprosy

Government of India (GOI's) reports that 'there are 6.7 lakhs (5.8%) out of 11.5 million leprosy patients registered during the last 2 decades (1984 to 2005) had visible (Grade II) disability in India'<sup>10</sup> Increase in the proportion of disabled among the new cases detected during 2004-2005 (Table 2) is causing a concern. This may be an indicator of delayed diagnosis and start of treatment.

**Table 1: A comparison of NCDR in general population and among contacts**

General population	2003	2004	2005
Population covered	2,80,036	2,85,746	2,23,085
New leprosy cases detected	279	310	113
NCDR / 10,000	10.8	10.0	5.1
Contacts of new cases			
Contacts examined	5,654	4,687	2,686
New leprosy cases detected	62	43	19
NCDR / 10,000	110	92	71

**Table 2: Trend of disabled cases compared with the trend in NCDR**

Year	NCDR per 10,000 (% of change)	Disabled among new cases
2000-01	5.5 (21%)↓	12,955 (2.5%) ↓
2001-02	5.9 (07%)↑	12,951 (2.1%) ↓
2002-03	4.4 (25%)↓	8,545 (1.8%) ↓
2003-04	3.3 (25%) ↓	5,302 (1.4%) ↓
2004-05	2.3 (30%)↓	4,145 (1.6%)↑

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

### Operational point of view

The WHO believes that, 'the problems facing disabled people at the community level need to be considered in their entirety, whatever the primary cause of the disability. Thus, access to all existing programmes that provide for the social and economic welfare of the disabled, including community-based rehabilitation, should also be available to leprosy-affected persons'<sup>11</sup>. This is ideal, but

the ground reality is different. Equipping the GHC personnel with adequate knowledge and skills especially at the district level hospitals and institutions is a long term objective to be accomplished. Disabled leprosy patients today cannot wait until the GHC system is fully enabled to cater the needs of leprosy patients with disabilities and deformities. LRC will serve as a 'vehicle' located amidst GHC facilities as a 'reliable expertise' and 'multi-service unit' for prevention and care of deformities in addition to confirmation of diagnosis (when needed), smear facilities, management of complications (reactions / neuritis) today and equip the GHC personnel for tomorrow<sup>2</sup>.

#### **Integration point of view**

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

meet the special needs of leprosy afflicted persons<sup>12</sup>.

#### **Social commitment point of view**

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

Leprosy patients must have equal access to appropriate treatment on par with other diseases. Services for early diagnosis, management of complications and disabilities by special services and trained manpower are made available at equipped places at district or zonal level and are easily accessible for patients. In other words, LRC can serve as a 'sign post' for the public and patients during

integration phase, located in publicly known places, providing comprehensive and quality care to all leprosy patients in a patient-friendly environment<sup>12</sup>.

#### **Capacity building point of view**

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

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

#### **Policy point of view**

WHO recognizes the '*need for "referral" services to sustain quality services in the integrated setting*'<sup>4</sup>. GOI proposes '*to develop a suitable referral system for providing quality services by involving established NGO / Institutions*'<sup>11</sup>. One takes consolation by the fact that the GOI's policy is categorical in asserting that '*it is necessary to extend the NLEP up to March 2007 for reaching elimination of leprosy in most of the districts, i.e. till the end of 10<sup>th</sup> Plan and the programme will continue with NLEP partner organizations*'<sup>11</sup>. The activities proposed under this plan will be crucial to sustain the intermediate goal achieved with lot of extraordinarily active official policy changes and interventions. Ideally, at least one LRC need to be established at regional and district level in the country. LRCs can offer timely, comprehensive and quality services to leprosy patients during Integration phase and beyond.

#### **Need for a practical intervention strategy**

Despite bringing down the overall prevalence of leprosy, new cases continue to surface. Among the new leprosy cases, a significant number of them are detected / reported with early disabilities and deformities. There is a huge backlog of leprosy cured persons with residual disabilities and deformities in addition to leprosy patients prone to develop new disability and deformity. WHO admits that '*the main principle of leprosy control is "morbidity control", i.e. timely detection of new cases, their treatment with effective chemotherapy in the form of*

*multi-drug therapy (MDT), prevention of disability and rehabilitation. This will not change over the coming years. The emphasis will remain on providing diagnostic and treatment services that are equitably distributed, affordable and easily accessible*<sup>12</sup>. Therefore, 'elimination' is not an appropriate goal for leprosy and leprosy is better seen as a chronic disease that requires long-term planning and control. The new challenge is to build on the success of the leprosy campaign and deliver sustainable care for leprosy patients<sup>3</sup>. Continuing transmission and increasing burden of disability due to leprosy will remain as a challenge for many years to come unless a renewed strategy with active approach to leprosy management is pursued by all stakeholders.

This calls for a practical intervention strategy that support integration and sustain leprosy elimination in a real sense of the term. **Leprosy Elimination Action Programme** (LEAP), promoted by ALERT-INDIA during integration phase, is a planned transition from the predominance of vertical leprosy programme and services to an action programme, focussing on community partnership strategies.

The objective of LEAP is to meet all the needs of leprosy affected persons by utilising the best potentials available today with the NLEP and dovetail with the services and facilities in the public health system through a partnership approach. Leprosy referral centres together with continuing medical education, information, education & communication, selective special drives

and epidemiological monitoring and evaluation are identified as scheme of interventions under LEAP<sup>13</sup>.

Establishing LRC in partnership with public and private health care providers, NGLOs and NLEP institutions is an immediate possibility to meet the needs of leprosy patients in the present phase. LEAP promotes such partnerships. LEAP promoted and assisted Government, Municipal Corporation and other NGLOs to establish seven LRCs in urban, rural and tribal areas of Mumbai, Thane and Raigad districts based on the principle of sharing resources, expertise and manpower. In future, LEAP proposes to establish LRCs in four backward and tribal districts of Maharashtra in partnership with district NLEP units. ALERT-INDIA has also established, in its project areas at Mumbai and Navi Mumbai, six LRCs since 2004, out of which five are located in the municipal hospitals / dispensaries and medical colleges.

#### **THE FUTURE**

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

LRC should promote partnership with GHC. The expertise of professionals such



as surgeons, ophthalmologists, dermatologists, physiotherapists and rehabilitation experts available with GHC can be utilised for LRC by exchange and / or interaction programmes. This will pave way for continuation of services to the leprosy affected in the general health sector and provide for sustainability. The dependence on specialised leprosy personnel should be eventually minimised. Finally, LRCs can help us to make leprosy elimination sustainable and enduring.

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