Integrated Approach for Leprosy Elimination in India

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India is one of 14 countries where leprosy is still endemic. It contributes 65% of the world's total cases. Since the disease carried intense social stigma and was linked closely with poverty, the Indian government thought it prudent to hand over responsibility for its control to a separate staff with exclusive facilities. This approach gave a tremendous boost to the program. However, the latest detection trends do not show any appreciable declines and this separate structure may be working against the cause of leprosy. There are a multitude of challenges that remain to be addressed, including the stigma attached to leprosy, lack of community involvement and limited facilities. In addition, the exclusive infrastructure is costly and not sustainable. It is now being debated whether this approach has become counterproductive in terms of outreach and expenditure. This paper makes a case that this approach has outlived its utility, and argues for an integrated model. If the program is not to lose its focus it should address the current challenges so that it can sustain itself in the long run.

In 1921 when Mahatma Gandhi was invited to open the first asylum for leprosy patients, he said he would rather like to come for its closure after it accomplishes its mission.

Introduction
The fight against leprosy in a planned manner started in India in 1955. Since the disease carried intense social stigma and was closely linked with poverty, the government thought it prudent to hand over responsibility for its control to separate staff with exclusive facilities having no connection with the general health care system. This approach gave a tremendous boost to the program but also increasingly isolated leprosy services and patients. Rather than working for the cause of leprosy, the existing establishment started working to protect its turf. It is now being debated whether this approach beyond a point becomes counterproductive in terms of outreach and expenditure. This paper makes a case that this approach has outlived its utility and advocates a model of integration to address the current challenges and ensure program sustainability.

Background
Leprosy (Hansen's disease) is one of the most dreaded of all diseases because even though one may recover clinically, nerve damage can result in lifelong crippling deformities. In some communities, its sufferers are the victims of social prejudice, discrimination and stigma. According to the World Health Organization (WHO), leprosy is a leading cause of permanent disability in the world. Addressing leprosy has three dimensions: medical - the treatment of deformities and complications; social welfare - aspects pertaining to rehabilitation; and public health - containment and elimination. This paper focuses on the public health dimensions.

When leprosy control efforts began after World War Two, the overall outlook was pessimistic due to long treatment times and consequent low compliance rates. Until the year 1950, when Dapsone became available, there was no real cure for the disease (Research in Leprosy 2000 website). Some gains were made but increasing drug resistance dented the initial optimism. Optimism was restored with the advent of Multi Drug Therapy (MDT) and resulting shorter treatment times. This apparent breakthrough emboldened the 44th World Health Assembly in May 1991 to adopt a resolution calling for the global elimination of leprosy as a public health problem by the year 2000. Among the 122 countries considered endemic in 1985, 108 have now achieved elimination at the country level. Of the 14 countries, India alone reports 344,377 cases, representing 65% of the cases worldwide (WHO, 2003 (status report)). This proportion is much higher than the country's global proportion of HIV/AIDS cases (UNAIDS, 2003).

The Indian Scenario
Though the disease has been in existence on the Indian subcontinent for several centuries, leprosy control program got underway only in 1955. The emphasis was on containing the spread of disease in the absence of any effective drug. The magnitude of the caseload and the high prevalence in the country dictated the creation of a vertical structure for rendering leprosy services. In the absence of an effective cure, there occurred a steady increase in the number of leprosy cases through successive decades. In 1951 there were 1.37 million cases and by 1981 four million (Ministry of Health and Family Welfare Annual Report, 2000-01). With the availability of medical intervention in the year 1983, leprosy eradication was established as a high priority by the Prime Minister, and the National Leprosy Control Program was renamed the National Leprosy Eradication Program (NLEP) (Dharmshaktu, 1990). Prevalence started falling drastically. It was only after the World Health Assembly resolution in the year 1991 that the objective of the program was defined to be the elimination of leprosy by the end of the century. With the World Bank assisted Leprosy Elimination Project in 1993, leprosy services were extended to uncovered areas. From 1997, efforts were intensified in high endemic and inaccessible areas involving medical officers, health workers, and volunteers for house-to-house search. As a result prevalence decreased from to 4.2 per 10,000 in 2002 from 57 in 1981, and 12 out of 35 states achieved elimination.
Distribution of the disease is uneven, though it is present throughout the country. In 1981, most states had prevalence of more than 10 per 10,000. However, in 2002 there were only five states with prevalence of more than 5 per 10,000. These five states, Uttar Pradesh, Bihar, Orissa, Chattisgarh and Jharkhand, contribute 62% of the country’s caseload (WHO, 2002, Global Information System). It is no coincidence that they also happen to be the lowest in per capita income.

**Need for Leprosy Elimination**

Eliminating leprosy has far more than public health implications. Poverty is both a cause and a result of leprosy. It is a cause because poor people are more prone to acquiring the disease due to weaker immune systems and higher transmission rates created by living in close proximity. It is a result because leprosy is one of the leading causes of permanent disability, often inflicting individuals at the most productive stage of their lives, preventing them from generating income (Neira, 2001). In order to enhance equity and accelerate human development of the poor, leprosy needs to be eliminated. Fortunately, leprosy is one of the few infectious diseases that meet the especially demanding criteria for elimination: practical and simple diagnostic tools, availability of an effective intervention to reduce its transmission and a single reservoir of infection—humans (Neira, 2001). About 95% people are immune to the disease and only 20% of leprosy patients are of the infectious type. However, from a public health point of view, leprosy poses several problems. It is a chronic non-fatal disease leaving untreated patients infectious for several years. Even where patients have access to treatment, the delay between the onset of the disease and the start of the treatment is considerable. This delay contributes to transmission of infection. Also, there is no primary preventive approach available, chemotherapy remaining only a secondary preventive approach (Noordeen, 2000).

**Challenges to Fighting Leprosy**

1. *High detection rates:* Although the prevalence of leprosy is falling, the detection of new cases has remained constant at around 600,000 cases per year (Research in Leprosy 2000 website). It was hoped that with the widening coverage of leprosy elimination campaigns, there would ultimately be a decrease. However, that has not happened.

2. *Restricted facilities:* Leprosy services are only available through specialized clinics, for a specified period of time, and not through the general health services on a daily basis. This limits awareness of the early signs of leprosy not only among the general public but also among health care providers.


4. *Shifting prevalence:* Some low endemic areas are likely to become high again due to the free movement of the population from high to low endemic areas. For example, a large number of people move from the endemic states of Bihar and Uttar Pradesh into Haryana and Punjab seasonally as farm labor.

5. *Poor governance:* High endemic states happen to be poorly governed and lacking in infrastructure and trained manpower.

6. *Lack of community involvement:* There is a problem of compliance as treatment completion rates are found to be no more than 85% to 90%. In an evaluation in Jharkhand, it was found that even after house to house visits, one third of cases remained undetected, awareness among the community was only 67% and re-registration was only 8.6% (Damien Foundation, 2002).

7. *Sustaining political will:* The World Health Assembly passed a resolution in 1991 and leprosy elimination became a global issue. However, India was nowhere near the target as the year 2000 approached. Even the 2005 target year of elimination at the national level now looks optimistic. Medical intervention is available. What is needed is sustained political will. WHO took the initiative and a Global Alliance for the Elimination of Leprosy was formed. Its first meeting was held in New Delhi in 2001 where the Prime Minister of India reaffirmed his commitment to give the highest priority to elimination (WHO Delhi Declaration, 2001). A meeting in Tokyo in 2002 followed where ministers and senior officials from most endemic states reiterated their resolve (WHO Tokyo Declaration, 2002).

8. *Epidemiology of the disease:* There is incomplete understanding of the epidemiology of leprosy, and consequent limitations of indicators used for its surveillance. It is widely accepted and agreed upon by leprologists and epidemiologists that not much can be said with certainty about the incidence of the disease. It is a disease with a long incubation period whose onset is highly difficult to predict. Hence the indicator used for measuring the incidence of leprosy in the community and progress toward the elimination goal is point prevalence. This indicator is dependent on detection and cure rates. There is uncertainty about the degree to which it is a proxy for incidence of leprosy and, therefore, the extent to which it can reflect reduction in transmission. Hence both indicators are required to understand the issue in correct perspective.

**Addressing the Problem**

Case detection trends in India are not showing any appreciable decline, and there is no clear explanation for the persistence of this situation in spite of the highly specialized and expensive vertical program in operation for close to 50 years (WHO Status Report, 2002). This was the first warning signal that there could be something fundamentally wrong with the centrally controlled vertical program. In the final push, the solution may lie in integration of leprosy services. The questions are: what is integration, what are its benefits and can it meet all the
challenges?

What is Integration?
District health administration in India on average oversees between 10 and 15 hospitals, 30 to 60 primary health centers (PHC) and 300 to 400 health sub centers (HSC). With 500 districts, the infrastructure of general health care is huge. Integration will mean that all health facilities of the general health care system should be able to provide leprosy services on all working days, not only on fixed days as organized by the vertical staff. This means that the medical officer of the system makes the diagnosis, classifies the patient and initiates the treatment, and subsequent doses are distributed at the health sub-center level, close to the patient’s home. This will necessitate dismantling of the exclusive infrastructure and re-deployment of staff to general health care facilities. However, an exception will have to be made for endemic states. In addition, the monitoring system should remain vertical.

Why is it Essential?
The leprosy staff did very well when the prevalence was high, as general staff would not have been able to meet this responsibility. However, at certain junctures in public health initiatives a shift needs to occur towards horizontal integration. The advantages are many:

1. Better decision-making and greater local priority: Health being a state rather than central government subject, a top-down vertical program is incompatible with decentralized decision-making. Also, integrated health services allow greater control for prioritizing these services, particularly at the local level. In addition, ownership by local leaders can change the way people work, increasing motivation, coordination, accountability and sustainability, as everyone takes more interest in how funds and services are managed.

2. Cost-effectiveness: Employing a conventionally trained staff to take care of the small number of leprosy patients who are geographically widely dispersed is prohibitively expensive and not sustainable. In a survey carried out in one of the slums of Mumbai in 1996, the detection cost per case came out to be $300, an amount which a developing country with declining prevalence can ill afford (Naik & Ganapati, 1998). In addition, under integrated services, unit cost falls as economies of scale exist in the provision of health services, activities concentrated in the same place can benefit from more support services, and bulk purchasing is possible for medical supplies and drugs.

3. Extended reach of leprosy services: With a wide network of primary healthcare centers, integration will make leprosy services available at the grassroots level. It will enable people to receive treatment through routine services. Thus voluntary reporting will pick up and transmission of disease will be curtailed expeditiously. Also, identification of female patients has been a major problem since almost all leprosy workers are male. Integration will make it easier to involve female providers and community based workers in helping detect female patients.

4. Helps combat stigma: The stigma attached to having to attend leprosy clinics will be eliminated.

5. Better management: Integrated services avoid the complex task of having to coordinate basic health services with a vertical program.

6. Improved community involvement: Integration will help in normalizing the disease. Persons will themselves seek diagnosis and treatment. This openness will be shared and encouraged by the community leading to better detection of new cases and treatment compliance.

7. Better capacity to address post-elimination problems: Integration will facilitate the detection of hidden cases, community-based supervised treatment, the identification of reactions and relapses and the field management of disabilities.

Following several decades of running the vertical program, its proponents are understandably concerned about the post-integration scenario. They argue that integration leads to loss of technical expertise as special staff are merged with general health care staff.

Also special dispensation to high risk and inaccessible groups in remote pockets becomes difficult as the disease no longer commands exclusive attention. Another argument is that eliminating separate management information systems compromises quality of monitoring. Apprehension is also expressed that integration may turn out to be a non-starter due to resistance by the vertical staff against redeployment.

Implementing Integration
These apprehensions are well founded and cannot be brushed aside lightly. Strong political will and administrative skill will be needed to make the transition. Operationalizing integration will require:

1. Willingness of the states to take over the expenditure of about 30,000 leprosy workers and laboratory technicians: A number of states with no financial resources may find this difficult. Moreover, higher pay scales and incentives have been given to the vertical staff, and these special privileges are naturally hampering the integration process (WHO Status Report, 2002). So the Indian central government will have to enter into an understanding with the states to protect the salary and allowances of these workers by continuing the grant, so far as poor states are concerned. Otherwise staff may enter into litigation, jeopardizing the entire process. Even in the case of well-off states, a portion of the burden may need to be shared by the central government if their willingness and commitment is to be secured. With funding assured, states may not find it difficult to place them in the regular setup, as gaps there need to be filled up for improvement in all health programs. Ultimately, however, expenses will be reduced with integration.

2. Raising skill levels for leprosy staff in handling all health services, and skill levels of general health care employees in the
early detection and management of leprosy patients: WHO has a number of schemes for capacity-building. Even the World Bank lends assistance for such purposes. So a composite proposal can be made and these agencies tapped for necessary funding.

3. Placing technical expertise in the central government: Under the vertical program, a number of leprosy research institutions belonging to the central government are also supported. They have been sharing technical expertise. Even with ownership of the program passing to the states, this component should remain with the central government in order to ensure that technical expertise is not lost. In fact, with freeing of resources after integration, research activities can be stepped up to understand the epidemiology of the disease and develop indicators for measuring incidence.

4. Strong oversight by the central government: Integration should never mean hands off policy by the central government, especially when it comes to communicable diseases. To consolidate the gains, a leprosy division at the central government with reduced staff needs to be continued in order to strengthen the capacity of the states to manage the program and become a source of technical expertise themselves. Moreover, the division should monitor the elimination on a country and state basis and provide policy guidance and goals for the country in the international context. The role of the central government will only change from implementer to that of a facilitator.

5. Direct involvement of states to manage the problem adequately: So far the strategy and funding mechanisms provided for a facilitator role for the states in leprosy elimination. The program was centrally sponsored and controlled and implemented through District Leprosy Societies which received money directly from the central government. As a result, the states have had insufficient involvement in the program. The direct supervision of the districts by the central government also limited the development of the technical and supervisory capacity of the states. It is important to prepare the states to administer and manage leprosy control (World Bank, 2001). For this, states need not set up any particular body. The same infrastructure can be made use of for monitoring the program through District Level Societies. The idea is to retain special focus and not to merge the program monitoring with general health care.

6. Continuation of special interventions: Special instruments like house to house visits will continue to be relevant and need to be used on a selective basis for reaching pockets of high prevalence and inaccessible areas, not only in the five high endemic states but in other states as well. These may be in tribal pockets or urban slums. District Level Societies will be the nerve center for planning such activities.

7. Special attention to endemic states: A special dispensation needs to be made in the case of five highly endemic states: Uttar Pradesh, Bihar, Jharkhand, Chattisgarh, and Orissa. Unfortunately, these states are not only poor but also their other state-run programs are in shambles due to poor governance. An inter-state comparison in Table 1 clearly shows that since 1981 these states have not shown expected reduction in prevalence.

Table 1.
India Inter-state Comparison on Leprosy Prevalence

<table>
<thead>
<tr>
<th>Prevalence per 10,000</th>
<th>1981</th>
<th>2002</th>
</tr>
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<tbody>
<tr>
<td>Less than 1</td>
<td>Haryana, Assam, Haryana, Himachal Pradesh, Jammu and Kashmir, Kerala, Manipur, Meghalaya, Mizoram, Nagaland, Punjab, Rajasthan and Tripura</td>
<td></td>
</tr>
<tr>
<td>1 to 2</td>
<td>None</td>
<td>Arunachal Pradesh, Gujarat, Sikkim</td>
</tr>
<tr>
<td>2 to 5</td>
<td>Delhi, Rajasthan</td>
<td>Andhra Pradesh, Goa, Karnataka, Madhya Pradesh, Maharashtra, Tamil Nadu, Uttarakhand, West Bengal, A and N Islands, Chandigarh, Daman and Diu, Delhi, Lakshadweep and Pondicherry</td>
</tr>
<tr>
<td>5 to 10</td>
<td>Jammu and Kashmir, Meghalaya</td>
<td>Orissa and Uttar Pradesh</td>
</tr>
<tr>
<td>More than 10</td>
<td>All Other States</td>
<td>Bihar, Chattisgarh and Jharkhand</td>
</tr>
</tbody>
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Source: Leprosy Division of Ministry of Health and Family Welfare, Government of India.

* Prevalence is average for the entire state. The geographical distribution of leprosy differs considerably not only from state to state but also at the district and village levels.

Can and should the central government run a program where the responsibility lies with the state? This is difficult to answer. However if gains are to be sustained, an exception is required in these five cases, as handing over the program will surely be a setback. Considering that just five of these states contribute 62 % of cases and many laborers from these states migrate seasonally to other states, it will be advisable not only to maintain centrally funded vertical structures but also to strengthen the staff component by diverting excess staff from low endemic areas. However, the vertical staff should reposition itself in general health care facilities and operate from there so that accessibility can be widened. It may not be a good solution from the efficiency point of view but from an equity perspective, it is very much desirable.

Sustaining Political and Social Priority
Elimination of leprosy is very much on the national agenda thanks to initiatives taken by the World Health Organization. Whether it remains so, after integration, when leprosy will no longer command special status, should not be a cause of concern. Concern for leprosy can be meaningfully institutionalized as the proposed integration does not involve dismantling the separate
monitoring mechanism from the district level and above. It only means dismantling vertical facilities like Survey, Education and Treatment Centers, Urban Leprosy Centers, Leprosy Control Units and the merger of Temporary Hospitalization Units. These are all below district level facilities. District Level Societies at the district-level and other vertical programs at the state level will continue to monitor and support the work of the general health staff offering leprosy services. The center will continue with its oversight functions.

Also, the media and NGOs will play a major role in making the elimination attractive to the public, decision makers and politicians. No public health program can be solved satisfactorily without the active involvement of the communities served and ignoring the socio-psychological dimensions of the disease and its treatment. Thousands of years of prejudice against leprosy coupled with lack of effective cure until recently cannot be ignored in any elimination strategy (Rao, Gift, Rao, Samuel & Bushanam, 2002). Raising awareness is critical in this final push not only in high endemic areas but also in low ones; in particular ensuring that migrant labor get themselves screened at the nearest primary healthcare center. A media campaign aiming to dispel myths surrounding the disease and speed up its elimination has been launched in India. It involves the national government, the state broadcasting networks, and the BBC World Service Trust (Woolridge, 2002).

Integration is more of a structural and managerial issue. Nonetheless there are certain logistical and technical issues which also need to be addressed simultaneously. First, supervisory roles and indicators for monitoring the performance of the program should be defined, designed and instituted before integration takes place. Second, the community and patients should be informed well in advance regarding the forthcoming changes and specific information be provided to the current patients about the place and person to contact for continuation of treatment after integration. Third, records of old and current patients should be transferred to the respective primary healthcare centers and the staff familiarized with these records.

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 program, including patients and representatives of the community.

Conclusion

Communicable diseases are still major health problems in India. Besides leprosy, there are certain other diseases including tuberculosis, malaria and HIV/AIDS for which vertical structures are maintained. At some point during the course of implementation, it becomes imperative to dismantle vertical structures. However, there is a need to exercise caution. Integration should be evolutionary and take into account the specific conditions of the states. Moreover, efficiency alone cannot be the criteria for this.

Controlling communicable disease has an element of positive externality. In addition there is an equity issue as the burden is mostly on the poor and socially vulnerable. The approach suggested in the case should hold good for other diseases.

Thanks to technological development, increased awareness, political commitment and generous funding from various agencies, leprosy is on the verge of becoming a relatively insignificant problem. The progress made so far is more than just in numbers and statistics alone. Advancements made in relation to reduced physical, psychological and social suffering are truly immeasurable. With significant decline in the prevalence of leprosy over the past two decades, integration of the vertical leprosy program into the general health system is a practical necessity and therefore an essential strategy to eliminate the disease. This change requires careful planning so that the general health system is capable of owning the new responsibilities. It will take time to achieve elimination: to reach the magical target of one in 10,000 prevalence set by the World Health Organization. However, leprosy elimination is well within sight, and when accomplished will be a great achievement in public health.

References


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End Notes

1 Leprosy is a communicable but curable disease. It is caused by the bacillus Mycobacterium Lpraei, discovered by G. A. Hansen in 1873. Still not much is known about mode of transmission and we do not have any test to predict who will get the disease. It can incubate in the human body for up to 20 years before the telltale signs - insensitive patches on the skin - are observed. Leprosy is transmitted via droplets from the nose and mouth, during close and frequent contacts with untreated infected persons. Leprosy mainly affects the skin and nerves, and if untreated can cause progressive and permanent damage to skin, nerves, limbs and eyes.

2 The most pertinent way to manage health programs in developing countries is horizontal integration, which in this article refers to a merger of inputs, organization, management and delivery of leprosy services provided at the same level with that of general health care.

3 MDT is a multi drug therapy consisting of a combination of three potent drugs (Dapsone, Clofazamine and Rifampicin), which need to be taken by patients for six months for Paucibacilliary cases and 12 months for Multibacilliary cases.

4 Elimination is defined as attaining a level of prevalence below one case per 10,000 people.

5 Vertical structure here refers to an exclusive infrastructure of staff and facilities solely meant for leprosy services.

6 Prevalence can be point prevalence or period prevalence. Point prevalence is generally used in leprosy literature, and refers to the number of cases on record in a given area at a given point in time.

7 Incidence is the number of new cases of a particular disease that occurs in a defined population during a specified period of time.

8 District is the lowest administrative unit. The entire country is divided into 35 States/UTs and each state into districts. There are around 500 districts.