THE PROBLEM

A. Unnecessary Optimism

1. Since the advent of effective medical cure with multidrug therapy (MDT) for leprosy in 1983, there have been repeated declarations of a deadline for the complete elimination of leprosy. But when the deadline is reached the new cases incidence is still too high. And a new deadline is set:

   a. In 1991, the World Health Organization gave a call for elimination of leprosy. The target was set as year 2000 to bring down the prevalence of leprosy to one case in less than 10,000 population. Each Five year plan, since then, also set targets of achieving elimination within that Plan period. The last of these was the 12th Five Year Plan (2012-2017) that had set out to achieve elimination of leprosy at the district level by 2017.

   b. The Union Finance Minister Shri. Arun Jaitley in his General Budget speech for 2017-18 in Parliament sets a deadline for elimination of Leprosy by 2018. But one year later the cases went up.

   c. So what has the government done? Created a new deadline. The most recent deadline- By October 2nd 2019, the 150th year of Mahatma Gandhi’s birth the government aims to eradicate leprosy.

Recently, the Supreme Court of India has asked the Centre to submit an action plan for eradicating leprosy. This was in response to a petition where the petitioner alleged that the disease was fully eradicable since 1981, but despite this, the government has failed to eradicate it due to the apathy shown by the concerned authorities. In response, Government has supplied such a plan. While the attention such litigation brings the problem is welcome, the wrong directions that it could push the government into achieving the set target, are a reason for concern.

B. The Situation - Growing Neglect

1. 1.35 lakh new cases of leprosy were reported in India in 2016-17. And this was a 6% increase over the previous year. The Annual New Case Detection Rate (ANCDR) is 10.17 per 100,000 population. Leprosy elimination is defined by WHO as a case rate of less than one per 100,000 population.

2. In 2005, Prevalence Rate recorded in the country was 0.95/10,000 population. This reduced to 0.69 in 2010 and has stagnated since then. An ICMR survey (Kiran Katoch 2017) of 147 lakh population reports new cases of 14.6 per 100,000 population; Disabilities 2.05/100,000 population and 13.9 per cent in new cases.

3. Adivasis, who are 8.6% of the population, bear the burden of 18.8% of new leprosy cases during 2016-17. In states like Gujarat and Tripura, two-thirds (more than 64%) of new leprosy patients are adivasis. Alarming, the proportion of districts with prevalence of 1/10,000 population or more has climbed up to 18.8%, up from 15.3% in 2012.

4. Though major deformities due to leprosy are much reduced among new cases detected, the number of those with existing leprosy related disability or developing leprosy related disability is high. Treatment and even cure does not reverse nerve damage where it has already occurred- and therefore even a cured
patient could develop disability a year later. New disabilities can be entirely prevented in those treated for leprosy if there is good follow up care. But in practice there is none.

5. For those with deformity and the few developing new deformity - even after elimination- the long term disability care and services are needed- the availability of both surgical and physiotherapy for cure and rehabilitation are very limited and reducing.

6. A small proportion of leprosy cases may continue to have lesions, or will relapse (disease occurring again) even after they are considered cured and declared RFT (released from treatment). Such cases need sustained follow-up. The system of long term surveillance and follow up was weak even earlier but is now almost non-existent.

THE REASONS FOR THE CRISIS

1. Changing definitions creating false expectations
The decline in prevalence rate from over 5 per 10,000 to less than 1 per 10,000 within a decade was because the treatment duration was decreased from over 2 years for PB leprosy to 6 months and from lifelong for MB leprosy to two years and then one year. Once the duration of treatment stabilized the prevalence rate plateaued. But this artifact of measurement where at the same level of incidence, one could get a dramatic reduction of prevalence rate led to false expectations of early eradication of the disease. However, the new case detection rate had declined much slower and remained constant during the past decade.

2. Premature declaration
The misleading declaration of elimination in 2005 had severed adverse consequences:

a. Decline in funding which contributed to decline in anti-leprosy activity.
b. Frontline workers stopped making household visits to identify undetected cases. Currently new case detection is based only on voluntary reporting, except a few sporadic campaigns conducted in focused areas.
c. Leprosy (specially trained) supervisors were shifted to other programmes.
d. Even young researchers stopped being attracted to an officially eliminated disease.
e. There were very many informal disincentives for reporting leprosy cases.

As a result of all of the above, the actual number of new cases detected may vary from three times (in a state like Maharashtra) to over 20 times (in a state like Uttar Pradesh) the cases reported as found in many sample surveys. The weaker the healthcare system, the larger the reporting gaps. An analysis report in the British Medical Journal (Lockwood, 2014) pointed out that the difference between the reported and observed estimates suggests that up to half of India's leprosy cases are not being reported and the "true count" of new leprosy cases could greatly exceed the National Leprosy Eradication Programme's (NLEP) report.

3. Epidemiological Consideration
Elimination was promoted as a goal to create political and media interest in a neglected disease, but the limitations of what could be achieved was not adequately communicated.

4. Growing non-communicable neuropathy problem
Given the nature of the disease, cure only means that the disease has now become non-communicable. But without optimal degree of self-care and good quality supportive care, a large number of patients who are declared cured will progress to develop new deformity or the existing ones deteriorate, and sometimes this will lead to socioeconomic consequences as well. Towards this, the much needed follow up care is almost completely absent, even in the planning, let alone the implementation. An estimated 30 lakh persons are living with disability and deformity due to leprosy - and this could increase by about 15,000 each year. We need to measure those at risk, and those who have developed deformity and set deadlines for stopping new deformity and worsening of existing ones.

5. Loss of skills for case detection
A doctor in a PHC may see very few cases of leprosy each year. They may not have seen many cases during their medical education. The skills for slit smear examination have also faded- as program design no longer asks for it. It is the so-called non-medical supervisor of the leprosy program who retains the skills- but this is a dying cadre-with no new replacements coming in. In the regular outpatient clinic there may be only one leprosy case in over 5000 patients- and this could easily be missed since there are many similar skin diseases. Only if there is an effort to diagnose, test and treat every single skin disease will the leprosy cases be detected. This is a problem also in skin camps that follow house-to-house case detection efforts. If these camps have to remain successful, all skin diseases
need to diagnosed and treated. However primary health care today, even in health and wellness centers does not envisage skin disease care as part of its services.

6. Loss of capacity for prevention and management of deformity

- Detection of grade I and II deformity in leprosy patients can be done by any primary healthcare provider. After these are detected, counseling and support to patient for preventive and self care measures can also be done by any primary care providers. But currently neither ASHA, nor ANM, nor MPW nor the Mid Level Care provider is trained on this.
- For patients with established deformity in hands and feet, protective footwear and specific appliances to be provided and that requires a trained physiotherapy technician or occupational therapist. But these are not in position in the blocks and district hospitals. Such physiotherapy is also a must before and after reconstructive surgery- and in its absence even where surgery is available, the results are poor.
- Reconstructive surgery centers itself are decreasing because the skills are shifting from general surgeons to orthopedic surgeons to plastic surgeons, and the modern specialist has little interest in this work- except in very few centers. Bringing new specialists into these skills is also a huge challenge. Incentive based reconstructive surgery with annual targets promoted by Government to clear the 'backlog' disability is a major diversion of resources without a systematic approach and appropriate follow-up mechanism.

7. Renew interest in adequately financing and strengthening public health systems

Funding for leprosy programs has sharply declined. This needs to be reversed. The whole of Ayushman Bharat's 1.5 lakh Health and Wellness centres (HWC) and all publicly funded insurance schemes ignores the problem of leprosy. Part of the reasons for this is the shift of attention to purchasing care from the private sector. But the usual commercial private sector- has no engagement with this issue whatsoever. It is only the public health system that has to be relied on by the needy people, and the neglect of inputs into the public system will result in the neglect of leprosy as a social and rights issue. If Ayushman Bharat is to be a game changer for an oft-eliminated leprosy, the false rhetoric of India achieving elimination needs to stop, and the strengthening of universal access to comprehensive primary health care must be accelerated.

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THE PEOPLES HEALTH MOVEMENT DEMANDS

1. Stop declaration of deadlines or targets for eradication of leprosy. Instead call for an end to deformity due to leprosy. Zero disability due to leprosy among new cases detected is a more feasible target. Continued watchfulness to prevent the re-emergence of the disease by reintroducing active surveillance of all 'risk' prone cases (multi-bacillary) for a minimum period of 3 to 5 years.

2. Ensure periodic active case detection activity including contact examination by frontline health workers working as team with more focus on adivasis (tribal areas) and child population. Include care for all common skin infections – acute and chronic in the assured set of services for health and wellness centers / primary health centers- and ensure that primary care providers have the training and support for the same. Speedy implementations of the HWC initiative in the true spirit of comprehensive primary healthcare approach can help address the problem of leprosy in a successful and sustainable way, taking healthcare to the last person.

3. Strengthen sub-centers with a four person team as envisaged for health and wellness centers- with all the four trained in case detection of leprosy, deformity prevention and in the entire range of primary skin disease care.

4. Create a position of occupational therapist or physiotherapy technicians post in every CHC and district hospital specially trained in management of leprosy neuropathy. In endemic blocks such a post should be in place under the NLEP- but often lies vacant. This technician would renew the role currently played by non-medical supervisors of leprosy and in addition ensure that care for leprosy neuropathy is optimized. In blocks where the number of leprosy cases and deformities are already low, or decrease over the years, this cadre, would address a much wider range of disability far beyond leprosy. Where it is not possible to create such a unit in every CHC, one must begin by starting one up for every 5 lakhs population at least.

5. Designate special tertiary care units for leprosy referral services in a selection of medical colleges in each state. These should not be limited to reconstructive surgery, as they are now, but be able to handle the entire range of leprosy complications for referrals from every level and sustain research and training in leprosy. This team requires including occupational therapists, dermatologists, and plastic surgeons/dedicated leprosy reconstructive surgeons.

6. Partnerships and active engagement with Not for Profit organizations involved in leprosy care- both for research (with linkage to tertiary care units) and for field support and for advocacy is a must.
7. The introduction of new programs must not lead to a reduction of funding and support to existing programs. New moneys have to be found - not diversion of existing resources. Ensure that public health budgets are increased annually on par with other developing countries in South-East Asian region.

8. There are concerns regarding the introduction of new technologies like immunoprophylaxis through 'vaccines' and chemoprophylaxis for contacts through single dose Rifampicin. Concerns relate both to cost effectiveness of these approaches and diversion of resources from more evidence based and tested approaches. No new technologies may be considered without a transparent, competent and participatory consideration of the same organized by a statutory national institution, like the Health Technology Assessment- India Board. In particular, one should be cautious about adopting it merely on the basis of recommendations of international technical agencies, due to possible conflicts of interest.

While there was a 16% decline in funding for the leprosy eradication program, there was a 36% increase in leprosy cases nationwide. Over the last five years, funds released from the Centre to the states under the three main programs–National Vector-Borne Disease Control Program (NVBDCP); Revised National Tuberculosis Control Program (RNTCP); and National Leprosy Eradication Program (NLEP)–has been declining; it dropped from Rs. 947 crore in 2011-12 to Rs. 395 crore in 2015-16. In 2012-13, states received only half the funds budgeted for vector-borne diseases and leprosy.

9. Till date, at least 119 laws and rules, that are discriminatory against those affected by leprosy, still exists in different states of India. Government should enact a comprehensive legislation to repeal various discriminatory laws against people afflicted with leprosy and penalize all discriminatory practices against leprosy on the lines of Mental Health Care Act 2017 that is in force from July 2018. This process has been initiated following a PIL filed in the Supreme Court, by the NGO - Vidhi Centre, but it needs to be prioritized.

10. All leprosy patients with disability and deformity, should be given assistance towards socio-economic upliftment under India’s The Rights of Persons With Disabilities ACT, 2016 and India’s international obligations in pursuant to the Convention on Rights of Persons with Disabilities, 2006 including its optional protocol.

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