KIT Royal Tropical Institute

END EVALUATION NLR PROGRAMME INDIA 2012-2016

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EXECUTIVE SUMMARY

For the last few decades, Netherlands Leprosy Relief has been an important and valued partner in India' efforts to eliminate and eradicate Leprosy, and to mitigate the physical, economic, and social consequences of Leprosy. This external review unequivocally notes that this remains true today. Through an analysis of the context, both current and with a view on the future, the review highlights the importance of maintaining and strengthening this commitment. The review makes suggestions for improving NLR's engagement in India.

A key point in NLR India's country policy (2012-2016) was to work with higher level decision makers to catalyse policy change and to facilitate improvements in practice. This review found that this was operationalized primarily as working with higher level decision makers in the Leprosy program itself. This strategy has been effective in helping NLR shape policy at national level, and to some extent in keeping Leprosy control on the agenda of the public health services at state and district level – a success given the low interest in Leprosy and the many competing priorities. This success can be attributed clearly to the many smart, often counterintuitive operational choices that have been made by the NLR India team. This review argues that it is equally important to engage actors outside the Leprosy world, particularly those who exert defining influence over the program's functioning. It recommends that a strategy cognizant of local power politics, including of the state level bureaucracies, be developed and implemented with a view to mobilize and maintain political and managerial will for Leprosy control in India.

Another key point in NLR India's country policy (2012-2016) was to increasingly focus on community based rehabilitation of persons affected by Leprosy and their families. This strategic choice has been translated into action in the form of a pilot initiative (forming self-help groups) in Bihar state; this initiative has tremendous potential and much support amongst Persons Affected by Leprosy and those with disabilities. The review notes that the decision to have within the self-help groups persons affected by Leprosy and those with disabilities, together, is particularly thoughtful; doing so rephrames the social identity of those with Leprosy, and creates alliances with those in similar, albeit different life circumstances – allowing both groups to better claim their constitutional and legal rights. The review also found that the pace of growth and scale up of the initiative, is remarkable. And it is suggested that in the short term, NLR should focus on consolidating the early gains made with the self-help groups initiative in Bihar; in the medium term, NLR should learn from this experience, fine tune operational processes and strategies – before expanding further in the long term.

Overall, NLR India' success during the 2012-2016 policy period is worth appreciation. In many ways it demonstrates the optimal application of efforts and allocation of resources at different levels. Examples include: At the policy level - the contribution that NLR has made to the Leprosy Case Detection Campaigns (LCDC), a cornerstone of Leprosy control in India; at practice level – NLR's role in reinvigorating disability prevention by reinstituting the practice of self-care at facility level; and at the community level – NLR's initiative of bringing together Persons Affected by Leprosy and those with disabilities to work together in self-help groups, for social and economic independence and rehabilitation. These examples, and all of NLR's work in the field is much appreciated by partners for both, the technical soundness of the work, and for the mature partnership oriented approach.

The review notes that at the policy level (2012-2016 policy) the focus on supporting national and state programs and the focus on community based rehabilitation, appeared as a zero sum game, perhaps because the 2012-2016 policy document visualized it as such. The review however found that in practice, the international, national and state level officers alike, recognize that this is not the case. They appreciate that these are complementarity elements of an effective response; they also appreciate that choices need to be made, given the finite nature of resources.

Few considerations deserve particular attention in the next NLR India policy:

- In many ways, the next 15 years are probably the last stretch of the long marathon that Leprosy control has been in India. The conditions (capacities and resources) exist to cover this last stretch successfully – but there are also worrying signals of fatigue and reversal of gains, particularly related to continued transmission and delayed diagnosis. It is critical that all those committed to Leprosy control in India persevere and get this last stretch right – this hold true for NLR too.
- Unless the national Leprosy eradication program, and the state Leprosy departments are effective in fulfilling their tasks and mandates, Leprosy *cannot* be controlled in India: this applies to breaking the chain of transmission of infection, to prevention of delays in diagnosis and disability prevention, and also to the care of those affected with Leprosy.
- The optimal strategy for any (and all) non-state actor who wishes to contribute to Leprosy control in India, is to intervene to ensure that the national and state public health services, fulfil their tasks and mandates.
- How the above should be done, needs to be tailored to the context of each state, and should be informed by a thorough analysis of: capacities, actors, local politics, including but not limited to those within the powerful bureaucracies, and ILEP partners nationally and in particular states.
- How the above should not be done is also clear; the contribution and support should not be such as to create incentives for those responsible to retreat from their responsibilities. This is a delicate balance to strike, and a middle ground, unique to each state context, is the optimal way forward.
- Not all focus should be on the states. Working with national level actors, the National Health Mission (and its state missions), and other high level influencers at national level (parliamentarians, ministers, senior administrators) – to mobilize their support for Leprosy control, will allow the creation of a policy and administrative environment where Leprosy is not at the bottom of policy priorities. This is an arduous task and a missing link in the current NLR India response - it has the potential to exert defining influence on Leprosy control in India.
- NLR India's initiatives towards social and economic rehabilitation of persons affected by Leprosy and their families, are well meant, but require to be thought through better. Indian society has a long tradition of supporting those with Leprosy, and a more strategic approach which focuses less on direct (sometimes ad-hoc) provision of assistance, but on linking, leveraging, and facilitating access to both resources and entitlements (state and non-state) would allow for the best value for money.

LIST OF ABBREVIATIONS

ANCDR	Annual New Case Detection Rate
CBR	Community Based Rehabilitation
CLD	Central Leprosy Division
DDG(L)	Deputy Director General (Leprosy)
DLO	District Leprosy Officer
DM	District Magistrate
DPO	Disabled People Organisation
IO	International Office (Amsterdam)
CO	Country Office (New Delhi)
ILEP	International Federation of Anti-leprosy Associations
LPA	Leprosy Program Advisor
MoH	Ministry of Health and Family Welfare
MTR	Mid Term Review
NLEP	National Leprosy Eradication Programme
NLR	Netherlands Leprosy Relief
NMA	Non-Medical Assistant
NMS	Non-Medical Supervisor
PAL	Persons Affected by Leprosy
PHC	Primary Health Centre
SHG	Self Help Group
SLO	State Leprosy Officer

INTRODUCTION

By 2012, India had achieved major successes in Leprosy control. Of the 35 states and union territories, all but one State (Chhattisgarh) and one territory (Dadra & Nagar Haveli) had achieved elimination status, as had 542 districts. Much of these gains had been made in the preceding decade. The success was the result of the efforts of the National Leprosy Eradication Programme (NLEP) coordinated by the Central Leprosy Division (CLD) under the Directorate of Health, of the Government of India, and its partners. Partners, particularly, the nine members of the International Federation of Anti-leprosy Associations (ILEP), including the Netherlands Leprosy Relief (NLR), working closely with the CLD, state ministries of health, and other collaborators, were instrumental in contributing to this success.

Going forward, the Programme Implementation Plan (PIP) for 12th Plan Period (2012-13 to 2016-17), of the NLEP, set for itself the target of eliminating Leprosy in all 642 Districts (100%), and to reduce the Annual New Case Detection Rate (ANCDR) to <10/100,000 population in all districts. In 2012, the NLEP and the partners recognized that the successes notwithstanding, India continued to face Leprosy related challenges on multiple fronts: it still had the highest number of new cases of Leprosy in the world; transmission of infections to vulnerable groups continued; new operational challenges were emerging e.g. related to urbanization, and to human resources for health; old challenges, hitherto overshadowed by the urgency of breaking the chain of transmission and treatment of cases, remained insufficiently addressed e.g. Stigma, socio economic rehabilitation of those affected and their families. At another level, and not surprisingly given the diversity of contexts within India, these successes had been unequal across and within states; for example, 209 districts were still far from reaching the elimination status. There was collective recognition that efforts needed to be made to maintain and to sustain the gains made thus far; efforts needed to be intensified to break the chain of transmission of infection in the areas left behind, and to improve the quality of life of those affected by Leprosy. There was also realization that this final stretch would be difficult and that all partners had to do their bit contribute to achieving the PIP targets.

NLR instituted its India country policy for the period 2012-2016 with a view to keep it in aligned with the PIP development process; among other things NLR reiterated its commitment of working closely with CLD and partners towards achieving targets in the 8 result areas set out in the NLEP's PIP. The policy explicated the approach NLR would take and the role NLR would play towards achieving these targets; it also clearly identified the progress markers by which performance towards the actualization of the policy's objectives would be assessed. The purpose of this external review is,

- to evaluate the major achievements of the NLR program 2012-2016,
    - assess the support NLR has provided to the NLEP program.
    - reflect on how thereby NLR has contributed to improving the situation of persons affected by leprosy (and their families) in the intervention areas.
- to critically examine the strategic choices that were made in country policy 2012-2016 and their operationalization,
- and in view of this, to reflect upon the future strategic direction of the NLR program in India.

METHODOLOGY

To achieve the review objectives, a case study approach was considered the most appropriate. While the review's orientation was to evaluate NLR's contribution and added value to the NLEP in India, the case study approach allowed elaboration of some very specific examples of this value addition, and at the same time helped to identify both, possible blind spots, and opportunities, going forward. As summarized below and detailed in Annex 1 and Annex 2, multiple sources of information and multiple methods for getting this information enabled the generation of this insight;

- Review of relevant documents: Country Policy, Annual Reports, Field Reports
- Interviews with
    - Staff from the NLR programmes department at IO and CO;
    - ILEP partners, at national and state levels
    - National level staff of NLEP
    - World health Organisation
    - State/District/Block level staff of NLEP,
    - State/District/Block level staff of state health services
    - Persons with Leprosy; representatives of patients with Leprosy
- Field visits to
    - States/Districts supported by NLR, including all levels of the health services
    - NLR supported CBR program sites
    - Leprosy colonies in two states
- Survey with main stakeholders involved in the NLR programme (2012 -2016) in the country

This review was conducted across 4 districts of two NLR supported states. The states were purposively chosen given NLR's focus; in Uttar Pradesh the focus being on program support, and in Bihar the focus being on community based rehabilitation activities. In all, 42 persons were interviewed, and two Leprosy colonies were visited; details of respondents are included in Annex 1. An online survey consisting of both closed and open ended questions was conducted with all officials responsible for Leprosy control in the districts and states supported by NLR.

A consultative and appreciative approach underpinned the review process. A thorough reading about the context and history of NLR's work in India, the NLEP and its partner's work; experience based insight into the workings of the Indian health system; and intensive initial consultations with NLR IO and CO staff (the latter via email and in person on arrival in Delhi) prior to the two weeks of field visits, allowed the evaluator to appreciate the key concerns, dilemmas and expectations of the NLR team. Follow up interviews and consultations with various interviewees, the daily and end of visit debriefing sessions with the state/district/national teams, and the many informal discussions during the long road journeys, allowed the evaluator to get critical insight into the successes, challenges and bottlenecks on the ground.

The review process has some limitations too. The many constraints and difficulties of getting busy public officials to respond to online surveys were recognised early on, and it was apriori agreed that in case the response rate was low, the survey responses would be treated as qualitative data. Of the 88 persons included in the online survey, only 8 completed the survey[i], and 8 sent it back via email . This is an important limitation of this review; had the survey had a good response rate, it would have improved the validity of the qualitative findings from the interviews and field visits.

Similarly, the field work was conducted in only two states of India (Uttar Pradesh and Bihar). While there are many commonalities across states, India is a large and diverse country, with much diversity across multiple domains – culture, society, economy, polity, infrastructure, health status (including but not limited to as it applies to leprosy), health systems, and the governance of health systems. The ambivalent and often difficult relations between state governments and union governments, and the highly hierarchical and relationship based (compared to rules based) functioning of bureaucracies (including health services) in India, further complicate the picture. Given these complexities, it follows that many of the insights, reflections and conclusions of this report need to be carefully contextualised whenever policy and program inferences are drawn for other states.

[i] During the field visits, some of the reasons for the low response to the online survey were explored; not unexpectedly, this was found to be because of a combination of many of the survey respondents not being computer savvy, and being very busy.

CONTEXT ANALYSIS

The broader context of India and its polity

India is a large diverse country; with many commonalities across its 36 states and union territories, but with many differences too. If one were to look at an aggregate index like the Human Development Index (HDI), states where NLR operates (Uttar Pradesh, Bihar, Jharkhand) consistently rank lowest in India. Within and across states, HDI varies across population groups; according to the United Nations Development Program, entrenched inequalities alone contribute to a 28% loss in HDI in India. Lower castes (scheduled casters and scheduled tribes in particular) have HDIs which are around half the national average; it follows that these communities have the worst population health indicators and are also the most vulnerable to illness and its consequences.

Within the federal polity of India, Health is primarily a state subject - while at the union government broad policy directions and guidelines are defined, it is at the state level that things finally get done. Given the differences in the development of various states, it follows that capacities to execute, also vary across states. The institutional arrangements within the states are however similar; for instance – the health sector is overseen by a state ministry of health headed by an elected minister. The ministers (irrespective of the sector) are supported by a nationwide cadre of powerful administrators whose responsibilities relate to providing policy advise and policy implementation. These administrators oversee the public health services which in turn are led by a director general of health services (DG); the director in turn is assisted by many department heads, one of them, the one responsible for Leprosy, being the State Leprosy Officer (SLO).

Institutional arrangements in relation to public health services

All health departments work through a hierarchy of care providing facilities ranging from health posts, sub-centers, primary health centers, up to the secondary care providing district hospitals. The key operational administrative unit for all public services, including health services, is the district. A typical district in India would be the size of The Netherlands, and would have a population of at least 2-3 million, primarily rural. The district is again overseen by one of the members of the national cadre of administrators whose responsibilities relate to providing policy advice and policy implementation – this administrator is de facto in charge of all public services, including the health services. The district level health services are managed by a district health management team led by a chief medical officer (who reports to the district administrator); the team includes officers in-charge (almost always doctors) of various public health programs and services – one such officer is the District Leprosy Officer (DLO). Each state level departmental head and district level member of the health management team, typically holds responsibilities for multiple programs and departments.

The public health services provide promotive, preventive, curative and rehabilitative services; these services are largely free at the point of care – particularly at the primary care level. Evidence shows that both the poor and the middle classes use the services provided by the public sector. Evidence also shows that both the poor and the middle classes use the services provided by the for profit private

sector (de Costa & Diwan 2008). The private sector is by far the largest provider of curative services (at all levels of care) in India; it accounts for around 75% of all care consumed by Indians (NHA 2014).

Situation vis-à-vis Leprosy

India has had much success in controlling Leprosy; by March 2016, of the total 669 districts in the country, 551 districts (82.36%) had achieved elimination status. While the Annual New Case Detection Rate (ANCDR) and Prevalence Rate (PR) are almost static since 2006 – 2007, India continues to account for almost 60% of all new cases of Leprosy worldwide. What is more worrisome is however is that the percentage of grade II disability amongst new cases detected has increased from 3.10% (2010 - 2011) to 4.61% (2014 - 2015); this means that detection is being delayed, and it signals that there are likely to several undetected cases.

The National Leprosy Eradication Programme (NLEP) coordinated by the Central Leprosy Division (CLD) under the Directorate of Health, of the Government of India, is responsible for the stewardship of Leprosy control efforts in India. It works through and with the state ministries of health, and together with non-government partners, particularly members of ILEP, including NLR to achieve its target of eliminating Leprosy in all 642 Districts (100%), and to reduce the Annual New Case Detection Rate (ANCDR) to <10/100,000 population in all districts. The NLEP has set out to achieve the following 8 results for the period 2012-2016:

> i. Improved early case detection; ii. Improved case management; iii. Stigma reduced; iv. Development of leprosy expertise sustained; v. Research supported evidence based programme practices; vi. Monitoring supervision and evaluation system improved; vii. Increased participation of persons affected by leprosy in society; viii. Programme management ensured.

A key development within the institutional arrangements of the India health system deserves attention here. Prior to 2005, Leprosy control in India was organised through a nationally controlled and reasonably well-resourced vertical program. In 2005, the Government of India declared that it had achieved elimination of Leprosy across the country. As a consequence, among others, steps were initiated to integrate the vast and nationwide network of vertical program processes and personnel into the general health services – across all states, irrespective of the state of Leprosy control in the state.

Some argue that the declaration of elimination was a bit premature – and that the process of integration that followed was insufficiently thought through: capacities to absorb tasks and roles; institutional arrangements in terms of CLD and state MoH relations; processes and resources needed for operationalisation of guidelines; were neither sufficiently tailored to different state contexts nor sufficiently thought through. On the ground the remaining (and dwindling due to retirements and) staff assigned to Leprosy feel alone and insufficiently supported; a frontline Leprosy worker at a primary health centre articulated this sense of alienation rather poignantly by pointing out that while they (the erstwhile Leprosy cadres) are “there to provide all services, there is nobody to take care of Leprosy”. This quote (in Hindi below) crystallises the current context of Leprosy control in India.

“हम तो सब के है … हमारा कोइ नही”

KEY FINDINGS

This section is organized along the lines of the purpose of the review; it sheds light on the different questions as formulated in the TOR. To begin with and building upon the earlier section, the state of NLR's support to the capacity building interventions, both for the NLEP and for self-care, are presented – they are discussed with a view to appreciate NLR's contributions to improving policy and practice in India, and with a view on the consequent benefits for individuals affected by leprosy; reflections on constraints, bottlenecks, and strategic considerations going forward, given the context, are articulated.

The NLR India policy for 2012 – 2016 articulated fourteen qualitative progress markers, across eight content and process domain areas. Normative expectations and targets were also articulated with a view to assess India program's performance over the policy period. As part this review process, the NLR CO team was asked to share their self-reflections, with specific examples, on the state of the progress markers; these reflections are included in Annex 4. The self-reflections show, and the insights from the field trip (as detailed in the following sections) signal few key points. Throughout, the findings section, the situation vis-à-vis the progress markers that were agreed upon as part of NLR India's 2012 -2016 policy is presented and briefly discussed.

NLR's support to the National Leprosy Eradication Program of India

The NLEP through the office of the Deputy Director General (Leprosy) at the Central Leprosy Division of the Ministry of Health of the Govt of India, steers the response to Leprosy in India. The nature of India's federal polity is such that the NLEP depends on the state level ministries of health for implementation of its policies; the states have the decision space to tailor and resource NLEP policies and strategies to their contexts. At the heart of NLR India's approach to Leprosy control is the principle of not duplicating or replacing, but rather supporting the national and state ministries (in the states where NLR operates) to fulfil their public mandate. This principle is consistently reflected in NLR India's Country Policy, in the various annual plans, in the annual reports, and has also been acknowledged (and appreciated) in last external policy review.

NLR's support to NLEP: Accolades from all quarters

There is extensive and universal appreciation of the support that NLR provides to NLEP and to the state Leprosy programs. Unpacking and critically examining what is being appreciated, by whom, for what reasons, allows us to both appreciate the work being done by NLR's India team, and to critically reflect upon the way the support is currently directed and operationalized – doing so can yield insights into possibilities for improvements going forward.

At the national level, within the CLD, there is much appreciation of NLR as a technically sound and reliable strategic partner. On the strategic front, NLR's presence in various advisory, strategic planning, and monitoring fora is considered vital by the CLD; NLR India team's value addition to the NLEP and to Leprosy control in India broadly, stands out, and is recognized as such by the CLD. Over the last 5 years, NLR's role in shaping and supporting the Leprosy response in India, particularly in the conceptualization, design, and operationalization of the Leprosy Case Detection Campaigns (LCDC)

and the Post-Exposure Prophylaxis initiative, were singled out as being critical examples of NLR's value addition. On the operational front, NLR's approach of working closely with the CLD and its ability to work closely with the state ministries of health is seen as a critical asset. This is because NLR is able to play a vital role in overcoming a major systemic weakness whereby the CLD has little effective influence over the state level Leprosy departments. A national level official pointed out that,

"NLR's state staff are the CLD's eyes and ears on the ground"

NLR's state level staff's ability to work closely and seamlessly with state ministry of health officials and to serve as the missing link between the national and state levels was consistently acknowledged and appreciated by national and state level government officials. That the national ministry of health and the NLEP, as a result of NLR's efforts, have issued official ID cards, designating NLR's state level advisors (and other ILEP partner staff as appropriate) as NLEP Consultants symbolizes the success with which NLR India has navigated this delicate relationship; it serves as a proxy for the social capital and influence NLR India has earned over the years.

NLR India team has earned remarkable social capital, and developed strong relations with key health services actors at national and state levels – this capital offers many possibilities for influencing positive changes.

At the state level, in both UP and in Bihar, particularly in the former (given the focus on program support in the state), NLR's state level staff and national level staff are regarded with much respect; their dedicated, diligent, patient and competent, yet firm and critical support, was acknowledged and appreciated by state and district level officials alike. Officials related a wide range of examples to illustrate the kinds of support they and their program receive from NLR's state level advisors (see Table 3.1 in Annex 3 for example from Uttar Pradesh). At the heart of this appreciation is the sense that NLR's team can be counted upon in times of need – for advise, for guidance, and if necessary for help. That the NLR team unhesitatingly steps-in in times of need, is much appreciated – be it helping out for training, supportive supervision, data compilation and analysis, implementation of LCDC.

Remarkably for the Indian context, while the state officials know and recognize NLR's state level staff as the CLD's eyes and ears on the ground, they do not view NLR's staff as a threat, but rather as a genuine partner. They acknowledge that the NLR staff are infact a welcome deterrent that helps them maintain attention on Leprosy. A state level official elegantly encapsulated this sentiment by drawing on a local phrase used by watchmen who patrol residential areas late in the night, reminding people to "stay alert and stay awake" (quote below, in Hindi) –

"जागते रहो --जागते रहो"

This sentiment was recognized by state and district level officials in both UP and Bihar; the point that they all recognized (and also rued) was that today in India Leprosy has the lowest priority of all public health programs. They pointed out that there is fatigue, disinterest, and widespread misunderstanding among members of the health services that Leprosy has already been eliminated. According to state and district level officials, NLR's state level staff serve to remind people within the health services, including the SLOs and DLOs (both of whom are often overworked and responsible for multiple public

health programs), the work that still needs and remains to be done to tackle Leprosy. Again, this appreciation can be understood to be the function of the kinds of persons who have been appointed as state level advisors by NLR – the older, experienced, former public health officials chosen by the CO team are ideal for this role, however counterintuitive the choice might appear at first sight.

> NLR's choice of profiles of state level advisors is ideal for the context and for the nature of support NLR provides to state Leprosy programs.

Capacity development and support to NLEP as a cornerstone of NLR India's work

Strengthening of and supporting the NLEP was a key tenet of the NLR India policy for 2012 – 2016; progress markers towards this area (1,2, 8,9,12,13) show, and insights from the field (above) indicate that NLR India made substantial progress on this key tenet. Field insights indicate that on many aspects (eg. strategy and guideline development, training related support at state level, data for decision making related support at state level, mentoring and coaching of DLOs, support for LCDC implementation) performance exceeded what NLEP expected or was envisaged in the NLR India policy for 2012 – 2016. The self-reflection by the NLR CO also highlights progress markers where not much progress could be made (eg. promotion of a results based management approach within the NLEP) – and insights from the field testify to this lack of progress. This lack of progress is understandable and in some ways inevitable given the aforementioned highly bureaucratic nature of health and civil services in India; this lack of progress is however clearly not because of insufficient efforts.

Reflections on capacity development

Many of the areas where NLR's support is appreciated, are what can be considered to fall within the responsibilities of state level officers of the ministry of health. On being challenged about this being so, Ministry officials conceded that sometimes they turned to NLR's staff because they could not get things done through ministerial processes, or because they did not have enough support and staff to do these tasks. In Uttar Pradesh it was clear that the state ministry had enough personnel, with enough experience, at all levels (primary care, district, and state) to fulfil the needs of the Leprosy program; the problem lay with the inability of the state and district level Leprosy officers to commandeer and mobilize the Leprosy program staff to fulfil the program requirements – this was for two reasons: i. Many Leprosy program personnel were seen as not having enough workload and were increasingly assigned by facility in-charges to do other tasks (thus undermining Leprosy work); ii. Even where personnel were available, there were not enough material resources (vehicles, fuel etc) to do the field work. Officials at the state and district level Leprosy offices expressed their frustration with this situation; facility in-charges also accepted that this was a common problem and argued that they were understaffed overall and had but no choice to commandeer anybody who was available in their facilities to do whatever tasks that needed to be done.

The above conundrum begs the question 'Is there really a capacity gap (to respond effectively to Leprosy) at the state level?' In response to this question, in Uttar Pradesh, officials at facility, district, and state levels unanimously responded that they (still) had the personnel and the capacity to discharge their duties vi-a-vis Leprosy. They added that what was constraining this was the lack of

managerial and political will; this meant that Leprosy was the lowest priority of all health programs. They indicated that Leprosy was at the bottom of the agenda of facility in-charges, because it was at the bottom of the agenda for key power centers: CMOs of the state, health secretaries, mission directors, and the district magistrates. They were categorical and unanimous in saying that if the importance of Leprosy was paid attention to by these higher-ups, facility in-charges and the rank and field health workers would fall in line. The example of Polio was repeatedly cited; one official said,

> "If there is one case of paralysis (AFP due to Polio), the whole system, from top to bottom convulses … and there is not even a flutter, in spite of so many, including children presenting with Grade II disabilities due to Leprosy."

Insights from the field support these views for the context of Uttar Pradesh; however this only perhaps partly holds for the context of Bihar. Unlike Uttar Pradesh, Bihar has a dwindling number of Leprosy cadres – with few remaining NMS's, NMA's and PMWs (the frontline and backbone of the program), and very few new recruitments in the pipeline. In Bihar, while perhaps there is still reasonable capacity in relation to systems, processes and roles (due to the embeddedness within the health bureaucracy), the performance capacity (staff and skills capacity) is weak and deteriorating fast as staff with skills retire, and are not replaced.

Two conclusions emerge from this analysis: Different states are likely to be at different stages of development and different levels of capacity in terms of their Leprosy programs – and instead of a nationwide strategy, NLR should tailor its approach to each state's context. The current model of state level program support in Uttar Pradesh, while clearly appreciated, is insufficient – unless it is complemented with higher level interventions to mobilize political and managerial will behind the Leprosy control, these efforts can yield very limited results. In the context of Bihar, the current model (of providing support at state level and district level Leprosy staff) is clearly a case of well-meaning, yet too little effort (relative to need); given that unlike Uttar Pradesh, Bihar simply does not have the dedicated cadres of NMSs, NMAs and PMWs, merely supporting the state level and district level Leprosy staff is unlikely to yield much results. Similar to Uttar Pradesh, higher level interventions to mobilize political and managerial will behind the Leprosy control, could get facility in-charges and the rank and file health workers to start paying attention to Leprosy.

> At national level, NLR India could have guiding principles for its functioning, however strategies for program support need to be tailored to state contexts.
>
> A high level approach which mobilizes political and managerial will for Leprosy control can optimize and amplify the effectiveness of the current strategy.

This focus on higher level decision makers is not new; it was one of the six areas of support within the NLR India policy for 2012 – 2016. The self-reflection report reveals that this was hitherto understood as working with higher level decision makers within the Leprosy world, particularly the higher echelons of the Leprosy program itself. This report however argues that while higher level actors in the Leprosy world are important, it is the actors outside the Leprosy world who exert defining influence over the program's functioning – they should be the focus of attention. A well thought through strategy, cognizant of local power politics, including of the state level bureaucracies, can help mobilize and

maintain political and managerial will for Leprosy control; such a strategy if effectively executed can optimize and amplify the effectiveness of the current strategy of technical and operational support to NLEP.

NLR's support to people affected by leprosy & support to general disabilities

Support to people affected by leprosy & support to general disabilities also featured prominently in NLR India policy for 2012 – 2016. It was envisaged that during this policy period NLR's focus would progressively shift away from program support to community based rehabilitation and support to general disabilities. With this in mind, a strategic decision was made to revitalize the NLR India Foundation – with a view to locate non program support activities under this institutional unit. Progress markers towards assessing the progress on NLR's support to people affected by leprosy & support to general disabilities, were defined in the NLR India policy for 2012 – 2016.

This strategic shift, was slow to take off; but the progress markers towards these areas (10, 11) show, and insights from the field indicate that during the policy period, NLR India has made a solid start in this new direction. Activities for comprehensive rehabilitation of persons affected by Leprosy and of their dependents are being tried; these take the form of: education support to children, vocational trainings, micro-finance etc. Details are included in Annex 3, Tables 3.2. Recent independent evaluations indicate the potential value of these initiatives.

Similarly, one of the key areas of focus with a view on disability prevention, has been the promotion of self-care among those affected with Leprosy. While traditionally, self-care has been an integral part of the theory of tertiary prevention in Leprosy control, its practice has always been a challenge, and it has also been neglected. While prima facie it might appear counterintuitive to call the promotion of self-care and the formation of self-care groups amongst PALs, an innovation – it perhaps represents precisely the kind of practice innovation that is much needed in the field of Leprosy in India; it has the potential to yield great benefits to PAL. Across both the states, frontline providers, Leprosy program staff, and patients – all expressed appreciation of NLR's revival of the classic tradition of self-care. The results, well documented with pictures and pictograms, present a convincing picture of the remarkable gains that one can make by promoting something as simple as self-care. Annex 3, Tables 3.2 present the numbers and details about self-care across villages in Bihar. NLR's state teams deserve accolades for the patient and diligent work they are putting in to take this forward.

A much more detailed and aggressive approach underpins the work in the field of general disability; a pilot project in Aurangabad district entails the formation of self-help groups (SHG) involving persons with general disability and Leprosy. To date, 204 SHGs consisting of 3720 members, have been formed, and are in different stages of operationalisation (See Table 3.3 in Annex 3). These SHGs have been planned in close collaboration with the Vihar Viklang Adhikar Manch, a disabled people's organisation. Field insight reveals a very enthusiastic response to the SHG initiative; while it is a complex exercise, the potential of this activity is clearly immense.

Reflections on NLR's support to people affected by leprosy & support to general disabilities

The NLR India policy for 2012 – 2016 envisioned a shift away from program support to community based rehabilitation and support to general disabilities. This shift has begun, albeit slowly; among

others because of the context of India, and because of NLR's wish to have all concerned fully on board, and to ensure that the right choices are made. Discussions during this review also reveal that this shift is not seen by NLR IO as a zero sum game; discussions with various stakeholders and an analysis of the Leprosy situation in India affirm the need and importance of both, of efforts to improve the performance of NLEP, and of community based rehabilitation initiatives. In the earlier section, a recommendation is made to revisit where NLR India should focus its attention to optimize state level Leprosy program performance; the proposed high level approach which mobilizes political and managerial will for Leprosy control can also collaterally facilitate efforts for community based rehabilitation and general disabilities – through, at the minimum, raising awareness about the issue amongst those who wield authority and power and thereby improving the chances of better coordination between the two line ministries involved (Ministry of Health for Leprosy Control program, and Ministry of Social Welfare for CBR) .

> A high level approach which mobilizes political and managerial will for Leprosy control can also facilitate CBR activities.

NLR India's work on disability prevention through promotion of self-care among PAL deserves plaudits not only because it makes such a big difference to PAL's dignity and quality of life, but also because NLR dares to invest efforts and resources in an area of work which is seriously neglected and unglamorous within the public health world. Prima facie, NLR's approach on this front seems to have potential – both in terms of effectiveness and in terms of sustainability. Field insights show that NLR is able to add value on this front; little efforts from NLR (in terms of investment in person time and money), seem to be yielding quite some tangible benefits. Patients seem to be satisfied with the attention and clear benefits they are getting; health workers also seem to realize that some efforts towards teaching and facilitating self-care today, helps prevent problems (repeat and delayed care seeking) in the long run. In many ways this is an example of how behaviours change, albeit for different reasons, among different parties, and help achieve the same desired result. This, in many ways is the ideal situation to have for one to be able to improve systemic capacities and to achieve sustainable change at the practice level.

Therefore one can reasonably argue that the current approach of NLR India - intensive involvement of NLR in the beginning to get all parties to realise the feasibility and appreciate the benefits of self-care, and the gradual hand over of tasks to patients and health workers, is an example of optimal use of resources. It also harbors well for the prospects of sustainability. NLR should maintain investments in this area. It would be good to learn from what is being practiced –reflect upon it, systematize and fine tune the approach to formalize it – and to ultimately embed the practice into NLR's national strategy and policy.

NLR India's work on the comprehensive rehabilitation of persons affected by Leprosy and of their dependents through education support to children, vocational trainings, micro-finance etc, are equally appreciate by PAL and their family members – the latter in particular. This focus is important because it looks to the future, and serves to protect children of PAL from paying the price of misfortune experienced by their parents.

Field insights however reveal that the needs on this front are massive and NLR can barely scratch the surface with its direct contributions. A more strategic approach which focuses less on direct (sometimes ad-hoc) provision of assistance, but on linking, leveraging, and facilitating access to both resources and entitlements (state and non-state) would allow for the best value for money; NLR should consider developing such a strategy.

> A linking, leveraging, and facilitating oriented strategy for comprehensive rehabilitation of PAL and their dependents could optimize returns on investments.

As regards NLR India's pilot project of formation of self-help groups (SHG) involving persons with general disability and Leprosy, the field visits, discussions with those involved, and with members of the SHG's, provide clear evidence of the great potential that this initiative has. The SHGs have grown rapidly in terms of membership and in terms of geography, in the last year; it also appears that there is intention to continue to grow and scale up at this rate. This energy is appreciable; a word of caution is however due – the energy and the enthusiasm need to be channelled cautiously. Reducing the rate of growth (# of SHGs), and instead focusing in the short term on consolidating the gains, will allow experience and expertise to mature, for systems to develop, processes to be refined, and the groups to gain in confidence. NLR India would do well to revisit its current short term targets for the SHG initiative, and to take a pause to consolidate, reflect and learn – this in some ways would be an ideal scenario for a small scale qualitative operational research project.

At another level, such a process of consolidation would allow NLR CO to identify complementarities and develop synergies between the broader linking, leveraging, and facilitating oriented strategy (if it were to be developed) for comprehensive rehabilitation of PAL and their dependents.

> The SHG initiative has elicited an enthusiastic response, and has grown rapidly. At this stage taking a pause to consolidate, reflect and learn from this experience – before expanding further, would be a worthwhile consideration.

Development of new methodologies and operational research

Development of new methodologies and operational research featured prominently in NLR India policy for 2012 – 2016; progress markers towards this area (3,4,5,6) show, and insights from the field indicate that NLR India made substantial progress on this front. As the NLR CO's self-reflections (Annex 4) show, and as testified by various independent sources and NLEP, NLR India has made valuable contributions to the development of new methodologies and approaches for leprosy control. Partners, both NLEP and ILEP appreciate the role played by NLR's national and state teams in: developing, testing and improving the Leprosy case detection campaigns (LCDC); in developing strategies for involvement of community health workers for Leprosy control at village level; development, testing and scale up of the use of single dose Rifampicin for breaking the chain of transmission of infection; and development of guidelines and training materials for self-care.

Reflections on NLR's focus on research

The authorities are generally appreciative of NLR's knowledge generation and translation related contributions to improving operational effectiveness of the Leprosy program; they are also however cautious about it. In the absence of insight into how the various research projects are being funded, some expressed worry that perhaps NLR's investments in research were happening at the expense of support to the program and/or the community based rehabilitation initiatives. That being said, not many are aware of NLR's efforts in this domain; of the actors who are aware, most were of the view that one should not occur at the expense of other; some argued that if NLR has to focus on research then NLR should rather do so on small scale studies which help improve programmatic effectiveness, efficiency, equity. This lack of awareness about NLR's role and contribution may in some ways signal something positive about how NLR CO operates in India. Unlike some ILEP partners, and like many research institutions, NLR, by choice functions in the background – supporting NLEP and state Leprosy departments in these activities, and explicitly not seeking to take credit; this, some would rightly argue is the correct approach to work to improve systemic capacities.

> NLR's contributions in generating and translating knowledge are appreciated. NLR would do well to maintain focus on small scale studies which help improve programmatic effectiveness, efficiency, equity.

Other issues emerging from the review, and deserving of attention

Beyond the many issues discussed so far, certain cross-cutting issues emerged during the review process, and deserve attention.

Capitalizing on current interests: driving the LCDC agenda forward

Given the combination of low prevalence, the continued presentation of new cases, and often delayed presentation of new cases – an intensive active case detection based strategy clearly makes for a sound public health approach for breaking the chain of transmission. There is no doubt that unless transmission is interrupted new cases will continue and given the low priority to Leprosy, things might worsen and gains made thus far could well be undermined. The Central leprosy Division, and the state level Leprosy program staff are convinced about both, the technical appropriateness and the feasibility of implementing the LCDC strategy. Such a strategy, if implemented properly, can overcome many of the issues related to human resources, low prioritization, and ongoing resource allocation. The key words here, consistently reported by NLR field staff, NLEP program managers, facility based NLEP staff, and by ILEP partners, are "if implemented properly".

Going forward, NLR India should critically examine and learn from the experience of implementing the LCDC campaigns in different contexts; drawing on these insights, an action plan should be developed, if possible together with ILEP partners, CLD and state Leprosy departments, to ensure that LCDCs are implemented properly. Such an action plan, where all ILEP partners align and harmonize their efforts towards jointly agreed activities and approaches, and work with the CLD and states to achieve

common national/state objectives, would be the ideal situation to work towards. NLR India has been key to developing the LCDC approach of the NLEP; by focusing on ensuring that it is implemented properly, NLR India would be effectively closing the loop on what it has helped initiate. Doing so has the potential to help India achieve its Leprosy eradication ambitions. A strategic combination of approaches – continuing to work with state programs and concurrently mobilizing political will, could make this a reality.

Moving out into uncharted territories

Working with the national and state level public services is clearly the comfort zone for NLR India. The ground reality however is that in India, more than 75% of all care encounters (encounters where individuals are seen and examined by a health worker, irrespective of the reason for examination) occur in the for profit private sector. These encounters represent and offer critical opportunities for timely leprosy case detection; these opportunities remain untapped throughout India. The NLEP policy recognizes this gap, and seeks to do something about it – but ground realities reveal little, if any efforts to leverage the possibilities. NLR India would do well to step outside its comfort zone, and explore ways and means to work with for profit private providers; while it is beyond the scope of this review to delve into details, NLR could build upon the existing strong relations with the state level ministries of health to identify the most optimum approach to achieve this end – possibly, but not necessarily, through getting involved in implementing such an approach. Doing either would also help maintain and enhance its status amongst the ILEP partners, as the operational innovator.

Focusing on the most vulnerable

A consistent narrative across the two states related to the identities of the new cases and those presenting late and with deformities. While the data does not necessarily provide reliable insight, according to program staff and health facility staff, persons who hailed from the lower castes, and lived in communities which were predominantly lower caste, were the most vulnerable. They correctly recognized that multiple structural disadvantages (social status, economic status, education levels, gender) intersected to amplify the vulnerability of lower caste communities to acquiring Leprosy infection and to presenting late.

Structural inequalities are a well-established social determinant of health and illness. NLR, as a Dutch organization committed to social justice would do well to systematically examine the distribution of new cases and those presenting late and with deformities, and if appropriate focus its efforts towards infection control among the most vulnerable. This would be particularly appropriate for the states where NLR operates, as in many of these states caste based disadvantages continue to be important factors in social, economic and health development.

RECOMMENDATIONS

This review recognises and appreciates the multifaceted and unique contribution and value addition made by NLR India towards Leprosy control, and towards improving the lives of persons affected by leprosy and their families in India. This section presents some of the recommendations that have emerged from the review – it is expected that going forward, these recommendations will help NLR India to fulfil its mission more effectively.

Recommendation: Maintain emphasis on breaking the chain of transmission. Continue to work actively with the NLEP to support the effective and intensive implementation of early case detection and treatment initiatives like LCDC.

Recommendation: Revisit the strategy of working with the public services. Complement current program support strategy with a more power and politics aware, and contextualised strategy to mobilise political and administrative will for Leprosy control in India.

Recommendation: Initiate action, working closely with partners and influencers, at international and national levels towards a final (10 year) strong push for Leprosy eradication in India, through an aggressive case detection and management approach modelled on the LCDC approach.

Recommendation: To optimally apply NLR's social capital and limited financial resources, develop and implement a linkage, leverage, and facilitation oriented strategy, based on exploiting existing resources, opportunities and entitlements, for comprehensive rehabilitation of PAL and their dependents.

Recommendation: Maintain focus on knowledge translation, and prioritise small scale studies which help improve programmatic effectiveness, efficiency, equity.

Recommendation: In the short term, consolidate the early gains made with the SHG initiative in Bihar. In the medium term, reflect and learn from this experience – before expanding further in the long term.

Recommendation: Make explicit efforts to further exploit and simultaneously enhance the remarkable social capital that the country team has accrued over the years – this capital offers many possibilities for influencing positive changes for PAL and their dependents.

Recommendation: NLR India should step outside its comfort zone, and explore ways and means to work with for profit private providers, to achieve the goal of eradication of Leprosy.

Recommendation: For its next policy, NLR India should give further conscious attention to influence the NLEP to better serve those most vulnerable to - getting infected with Leprosy, getting delayed with diagnosis and treatment, and ultimately suffering from the social and economic consequences of Leprosy.

Recommendation: For its next policy, given the vast diversity of contexts across states, NLR India should consider developing tailor made strategies and plans, per state.

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ANNEX 1: PERSONS INTERVIEWED/MET

#	Position	Name	Date/Place
1.	Head of Program	Gerrit de Vries	Amsterdam
2.	Program Officer	Mathilde Vandebooren	Amsterdam
3.	Technical Advisor	Liesbeth Mieras	Amsterdam
4.	Deputy Director General – NLEP India	Dr. Anil Kumar	New Delhi
5.	CR NLR India	Dr. MA Arif	New Delhi
6.	Technical Advisor NLR India	Dr. Manglani	New Delhi
7.	Former Deputy Director General – NLEP India	Dr. Agrawal	New Delhi
8.	Leprosy Program Advisor – Delhi, Uttarakhand, Rajasthan	Dr. JB Singh	New Delhi
9.	CEO NLR Foundation India	Mr. Sushil Kumar	New Delhi
10.	ILEP National Coordinator	Mr. George	New Delhi
11.	Medical Officer WHO	Dr. Laura	New Delhi
12.	SLO Uttar Pradesh	Dr. Sunil Bhartiya	Lucknow
13.	LPA Uttar Pradesh	Dr. Siddiqi	Lucknow
14.	NMS Hardoi	RS Gupta	Hardoi, UP
15.	PMW CHC Sandila	M Irshad	Sandila, Hardoi, UP
16.	NMA CHC Sandila	UC Rawat	Tiloniya, Hardoi, UP
17.	PWL	Babu Lal	Sandila, Hardoi, UP
18.	PWL	Babu Ali	Hakimgarh, Hardoi, UP
19.	ASHA	Neetu Devi	Kodrahar, Hardoi, UP
20.	Superintendent, CHC Sandila	Dr. S. Vaish	Sandila, Hardoi, UP
21.	DLC Hardoi	Dr. S. Agnihotri	Hardoi, UP
22.	DLO Hardoi	Dr. A. Singh	Hardoi, UP
23.	DLO Kanpur	Dr. Yadav	Kanpur, UP
24.	PWL	Soni Sonkar	Kanpur, UP
25.	PWL	Chandrashekhar Sharma	Kanpur, UP
26.	NMS	David Paul	Kanpur, UP
27.	DLC Lucknow	Dr. S.Yadav	Kanpur, UP
28.	NMA Lucknow	J. Yadav	Kanpur, UP
29.	CBR Coordinator (NLR)	M. Mahato	Lucknow, UP
30.	SLC Bihar	Dr. Pande	Patna, Bihar
31.	DFIT Patna (ILEP Partner)	Mr. Ramanujan; Mr. Sugadhan	Patna, Bihar
32.	CBR Coordinator Bihar	Mr. Tiwari	Patna, Bihar
33.	LPA Bihar	Dr. Chandra Mani	Patna, Bihar
34.	VVAM President	S. Singh	Aurungabad, Bihar
35.	Block Coordinator	B. Kumar	Aurungabad, Bihar

36.	Block Coordinator	J. Singh	Aurungabad, Bihar
37.	Haspura Prakhand Commitee	14 members	Haspura
37.	Block Coordinator	Sagar	Haspura
38.	MOIC	Dr. V.P.Singh	Buxar, Bihar
39.	Communicable Disease Officer	Dr. A.N. Singh	Buxar, Bihar
40.	NMA, PHC Chaugai	Hari Ram Singh	Buxar, Bihar
41.	PMW, PHC Chaugai	Chandan Kumar	Buxar, Bihar
42.	PWL	Kuni Ram	Chaugai, Bihar
43.	PWL	JK Paswan	Chaugai, Bihar
44.	Leprosy Colony Lucknow	Residents	Lucknow, UP
45.	Leprosy Colony Khagol	Residents	Khagol, Bihar

ANNEX 2: TRAVEL SCHEDULE / PLACES VISITED

Date	Activity	Location/Stay
Saturday 10th June	- Arrival by Jet airways flight 9W 0233 arriving at 23:15 hrs.	Stay at Hotel ibis, Aerocity, Delhi
Sunday 11th June	- Rest	Stay at Hotel ibis, Aerocity, Delhi
Monday 12th June	- Visit NLR India and NLR Foundation office for discussion - Lunch - Travel to Lucknow, UP in evening by 9W-639 Dep: 16:45 hrs.	Stay at Hotel Sarover –Portico, Lucknow
Tuesday 13th June	- UP state level: Interview SLO - Interview mission director- State rural health mission - Visit NLR field office + presentation by Dr A Siddiqi - Observe NLR activities in Leprosy colony at Lucknow	Stay at Hotel Sarover –Portico, Lucknow
Wednesday 14th June	- UP district level: travel to Distt. Hardoi - Interview DHO - Interview DLO and NMS - Observe NLR activities/ support in health centers/ hospitals - Travel back to Lucknow	Stay at Hotel Sarover –Portico, Lucknow
Thursday 15th June	- UP district level: Distt. Kanpur Nagar - Interview DHO - Interview DLO and NMS - Observe NLR activities/ support in health centers/ hospitals - Travel back to Lucknow - Debrief to NLR state team	Stay at Hotel Sarover –Portico, Lucknow
Friday 16th June	- Travel back to Delhi by Flight 9W-647 Dep: 10:50 hrs. - Meeting with DDG Dr Anil Kumar at 15:00 hrs.	Stay at Hotel ibis, Aerocity, Delhi
Saturday 17th June	- Debrief findings to team NLR India, Delhi in the morning	Stay at Hotel ibis, Aerocity, Delhi

Sunday 18th June	- Rest	Stay at Hotel ibis, Aerocity, Delhi
Monday 19th June	- Meeting with ILEP coordinator - Meeting with WHO - Other meetings - Travel to Patna, Bihar by Flight AI- 415, Dep at 18:40 hrs.	Stay at hotel Gargi Grand Patna
Tuesday 20th June	- Bihar State level: - Interview SLO and State rural health Mission Director - Visit ILEP partners, LEPRA & DFIT - Travel to Aurangabad	Stay at hotel Sarswati inn, Aurangabad
Wednesday 21st June	- Bihar district level: Aurangabad - Meeting at VVAM office with Block Coordinator, Aurangabad, SHG Meeting - Field visit to two blocks of Aurangabad to meet SHG Members - Stay at Aurangabad	Stay at hotel Sarswati inn, Aurangabad
Thursday 22nd June	- Travel to Buxar, Bihar Distt. - Observe Integrated Self-care at health center level + interview Med. Officer at Buxar - Travel to Patna - Observe NLR activities in Leprosy colony at Patna - Debrief to NLR state Team	Stay at hotel Gargi Grand Patna
Friday 23rd June	- Travel to Delhi by flight Indigo- 6E-4367 Dep. at 10:50 hrs. ; Arrival at 12:40 hrs. - Follow up/ continuing meetings at Delhi that were planned for 19th June - Debrief findings to local team NLR India	Stay at Hotel ibis, Aerocity, Delhi
Saturday 24th June	- Rest/ Report writing	Stay at Hotel ibis, Aerocity, Delhi
Sunday 25th June	- Departure by 9W 0234 departing at 02:35 hrs.	

ANNEX 3: DATA TABLES

Table 3.1: NLEP support activities Uttar Pradesh in 2016

Activities	#
No of supervision visits	9
Trainings	12
SLO Office Visits	52
Meetings with different stakeholders	12
LCDC Support	18
Self Care Camps	1
Evaluation Visit Self Care	2
Post LCDC Evaluation	1
Anti-Leprosy Day Support to NLEP	1

Tables 3.2

Self-Care in Villages, Bihar

Year.	Name of District	No of Blocks/ PHCS	#.of Beneficiaries
2012	Aurangabad, Buxar.	2	58
2013	Nawada, Bhoj pur	2	130
2014	Patna, Bhojpur, Buxar, Aurangabad.	4	240
2015	Patna.	3	106-Lep, 60-L.F.
2016	Buxar	4	105-Lep, 49- L.F.

Self-Care in Villages, Bihar

Year	Beneficiaries.	Persons with Ulcer	Ulcer Healed	Referred for RCS.
2012	58	28	27	Nil
2013	130	56	52	Nil
2014	240	107	93	3
2015	106	36	32	4
2016	105	47	36	Nil

Aids and appliances for PAL

Year	Foot Wear	Crutches	Wheel Chair	Tri Cycle	Grip Aids	Goggles
2012					3	5
2013	108	1		1		5
2014					1	1
2015	60				2	2
2016	109					1
Total	277	1		1	6	14

Education Support to family members in Bihar

Year.	Primary School	Middle School	High School	Higher Education.	Total
2012	189	69	11	8	267
2013	203	65	12	5	285
2014	184	56	17	3	260

2015	150	84	26	9 3-ITI	272
2016	130	95	37	3 2-ITI	267

Vocational Training Support (VT) in Bihar

Year	**#. of persons supported for VT**	**#. of persons started earning after VT,**	**#. of persons still under VT**
2012	2	2	
2013	7	7	
2014	27	12	15
2015	31	12	4
2016	8	1	7

Table 3.3: Self Help Groups in Aurungabad, Bihar – status in 2016

Target # of SHGs for 2016	**# of SHGs Formed in 2016**	**# of Members in SHGs**	**#. of Leprosy Persons in SHGs**
204	204	3720	Data to be collected.
10	10	200	Data to be collected.

ANNEX 4: NLR CO SELF REPORT

Status on progress markers set out in the 2012-2016 policy

Area of support	Progress marker	Status (Y/N/S)	Reflections/Explanations as appropriate: Elaborate as necessary
Capacity development	1. State training system developed, field tested and operational in 3 yrs.	Yes	It's very difficult to change the whole system however efforts were made. "Training of trainers" workshops were organized in states of UP, Bihar, Jharkhand which included how to do "Training need Assessment" and "Curriculum development" This lead to conduction of courses by their own staff at district level without dependence on NLR
	2. Technically competent District Nucleus (DNs) available	Yes	District nucleus (now district leprosy cell) were trained many times in clinical and managerial courses in each of 6 states. These class room trainings and workshops were followed by on the job support by NLR LPAs. This led to better planning, monitoring and supervision of the program. Use of checklist for monitoring and supervision introduced and now used by the DLOs. Chapters on planning, monitoring, supervision contributed by Dr. Arif included in medical officers' manual of training, chapter on upgraded simplified information system (USIS) contributed by Dr. Manglani in a text book for dermatologists.
Development of new methodologies/ operational research	3. Improved case detection methods will be identified and included in the guidelines for DC supervision within four years	yes	Contact management introduced in the program and included in the routine reporting system (i.e. USIS). Active case detection to reduce disability promoted, technical support provided to CLD for development of guidelines for leprosy case detection campaign (e.g. LCDC). Involvement of ASHAs for case detection promoted in NLR supported areas
	4. Self-care group methodology and guidelines developed. NLEP embraces SCG concept and approach, time frame two years	yes	Self-care in groups promoted in colonies, at PHCs, in camp approach. Jharkhand state used NLR guidelines to promote self-care from NLEP funds. Similar training guidelines/methodology/module will be followed in a scheme developed for Rehabilitation council of India
	5. Urban leprosy control guidelines amended and made operational in New Delhi. Guidelines discussed	yes	Discussed in Technical Resource Group, workshop supported by NLR, new guideline issued. Urban situations were assessed by rapid assessment teams (RATs) including members of NLR India, national workshop on urban leprosy was

	and accepted by NLEP for wider application within three years.		conducted and letter of revised guidelines was issued. Workshops at state level e.g. WB and Delhi were conducted.
	6. Study on chemoprophylaxis started	Yes	At Dadra & Nagar Haveli, 22,613 contacts given SDR with no side effects NLEP accepted and adopted same SDR approach and operational guidelines developed by NLR were modified a bit and issued by central leprosy division
Increased attention of decision makers to leprosy	7. Improved district NLEP functioning, shown in better coordination within the District Health Society and timely release of funds	yes	With close coordination, a letter from DDG was issued to all state and ILEP agencies indicating not to spend funds for trainings or IEC. Now all expenditures on training, IEC, MCR footwear etc. which were earlier done by NLR are being done by NLEP. This area needs further improvement because National Rural Health Mission (NRHM) sometimes is a barrier for fund flow . NLR LPA now acting as consultants NLEP have direct contact with CLD and facilitate fund utilization
Strengthening NLEP programme management (by support for RBM and CLD capacity)	8. Better and more efficient fund utilisation	N	Same as above
	9. Improved result based state plans and timely release of funds	yes	Result based annual state district plans were facilitated, implemented and monitored with the help of NLR staff. NLR LPA now acting as consultants NLEP have direct contact with CLD and facilitate fund release
Support to people affected by leprosy	10. NLR becomes a recognised partner in SER and the CBR approach is embedded in NLR India	Yes	Comprehensive & holistic rehabilitation of persons affected and their dependents was tried e.g. education support to children, vocational trainings, micro-finance etc.
Support to general disabilities	11. Pilots in the field of general disability established	Yes	Under Priority Fund (PF) a project “Voice” has been started by formation of self-help groups (SHG) in Aurangabad district in which persons with general disability and leprosy have been included.
More generally, the strategy lays out that “Next to a gradual but distinct reduction in the deployment of LPA ‘s and NMA ‘s, expertise in new areas will be built up. This will be measured by:			
12. The number of LPAs placed by NLR at state level reducing gradually to zero by the end of five year.		Yes	LPA from Uttarakhand withdrawn in 2012, from Dumka, Jharkhand withdrawn in 2013, LPA from Bareilly zone withdrawn in 2014 and from Ballia in 2015
13. On the other hand at least one technical staff for CBR is in place by the end of two years.		Yes	One CBR expert is in place and Voice project is on

Similarly, the policy states that "It is expected that after 3-4 years the technical expertise in the field will be taken over by routine NLEP activities and some technical support will remain at national level."	
14. What is the progress on this front?	Progress & Reflections: No routine activities are supported by NLR now as indicated above. Support remains of advisory character. Activity supported are now Chemoprophylaxis, PEP++, LCDC, SPARSH, Integrated self-care, development of innovative IEC material, Web based training course, training for "Nikushth" i.e. web based information and reporting system etc.