

National Workshop
on
***“Integration and Inclusion in National Leprosy Eradication Programme:
Challenges and Opportunities for ‘Leprosy Free India’***

14th and 15th October 2015, Mumbai

A) EXECUTIVE SUMMARY

- The Centre for Public Health, School of Health System Studies, Tata Institute of Social Sciences, Mumbai and ALERT – INDIA, Mumbai jointly organized a National Workshop on *“Integration and Inclusion in National Leprosy Eradication Programme: Challenges and Opportunities for ‘Leprosy Free India’* on 14th and 15th October 2015 at Mumbai.
- The workshop was attended by 90 delegates from Government and Non-Government Organizations, ILEP partners, Research institutions, World Health Organization and spokespersons of organizations representing people affected by leprosy. Leading academicians, practitioners, activists and authorities working in this domain made presentations reviewing recent developments in the understanding of the disease, and efforts at its control. The changing contexts of health systems and social determinants were also discussed at length. Based on these presentations, the workshop evolved an understanding of the challenges ahead and the coordinated action that is required of different stakeholders- the government, academic community, civil society and persons affected with leprosy to respond to these challenges.
- In the epidemiological dimension, the conference provided evidence that transmission of leprosy is a continuing problem. It called for revising the system of categorisation to locate such hot-spots better and the continued relevance of active case detection. Given the varied quality of case detection, categorization based only on self reporting had its problems. The workshop also noted learning from molecular biology with respect to adaptation and resistance in the causative organism and the implications it has for diagnosis and control. It also paid attention the development of new tools of epidemiological investigation.
- In terms of integration of leprosy into general health services, the failure to achieve the expected gains from such integration relate to two factors- the weak capacity and development of general health services in many states which have the greatest leprosy challenge and the lack of clarity of accountability for outcomes in leprosy control after integration. However, at the current levels of new case detection, horizontal integration is not an option but a mandate.

- Experience of the last ten years shows us that there are three governance pre-conditions for leprosy control to be effective under integration - fixing accountability on who is responsible for overall outcomes as also for specific components, a matching human resource policy which understands the difficulties of retaining essential skills at every level and a sustained financing plan.
- In terms of the design of leprosy programmes, there was a consensus that voluntary self- reporting cannot be accepted as the only strategy in all endemic districts and must be complemented by active case detection methods. Studies showed that active case detection yields best results when it is focused on contacts which include family members, but could also be extended to all villages reporting more than one case.
- While the disability rate among new leprosy cases is a cause of concern, the fact that a good number of cases develop disability after treatment is worse. The workshop deliberated on what it characterized as the non-communicable and neurological character of leprosy, which would have a prevalence rate estimated at close to 20 times the prevalence rate of leprosy as a communicable disease. New approaches such as Leprosy Referral Centres and Leprosy Outreach Camps were required to build the capacity of GHS to deliver quality services that address this dimension of leprosy.
- In the present context, pre-service training as it exists today does not create the necessary skills among the healthcare providers for fulfilling the needs of leprosy cases. The NMA/NMS cadre which had the skills is retiring or already gone, and the new paramedical worker is too sporadic and ad-hoc an arrangement, and inadequately trained and supported to close this gap. The principles of an alternative HR policy were one of the key areas of discussion.
- There was also a crisis in tertiary care for leprosy which included the difficulty in retaining talent and attracting researchers and specialist practitioners in this area, lack of exposure to adequate number of complications, poor two-way referral mechanisms, major financial barriers for the poor to access such tertiary care, etc., – all of which needed a comprehensive plan to address.
- Discussions on social dimensions concluded that though in some spheres there is a decrease in stigma, quite often it has taken less obvious but equally pernicious forms as compared with the past. This highlights the need to acknowledge that stigma and discrimination exist, to expose them and to use all possible means to eliminate them. Social exclusion of people affected by leprosy is underpinned by several discriminatory laws and irrational practices. Therefore, sensitization of the lower judiciary and law enforcement mechanisms is also required.

- Another important dimension of the battle is addressing the needs of leprosy colonies. One conclusion we arrive at is that any high-handed approach to abolish these colonies by administrative fiat is violation of basic rights - as they are their homes and identity. It is also not a feasible option. Pro-active measures to encourage social mingling would also be welcome. Some organization should be assigned this responsibility so that the deformity associated with leprosy could be uniformly quantified.
- The Workshop called for a three-pronged approach to addressing leprosy colonies- one that is focused on improving access to health care, another that is built on empowering them to take care of their own lives through organization and a third that allows them a choice of livelihood and access to higher education and financial support for those too disabled to take to a livelihood.
- All participants of the Workshop reconfirmed its commitment to work together towards addressing the challenges in achieving a 'leprosy-free India'. The Workshop unanimously acknowledged that the issues discussed can form a basis for developing appropriate strategies that can impact the initiatives of NLEP in overcoming the challenges in leprosy control- and towards this end proposed the following key recommendations:

B) RECOMMENDATIONS

1. STRATEGIES FOR SUSTAINABLE IMPACT ON INTEGRATION

- i. **Active case detection and hot-spots:** Insist on annual or even twice a year active case detection in all epidemiologically hot-spots defined as a cluster of villages or blocks where leprosy is endemic. Probe the determinants of disease transmission in such identified hot spots. Include to 'areas' where people live in poverty and in situation of vulnerability such as slum pockets and remote tribal hamlets.
- ii. **Categorization of districts as endemic** – In addition to prevalence rate, use a cut off figure of total number of cases reported- over 500 in small districts and over 1000 in large districts should lead to categorization of districts as high risk. Within an endemic district- focus interventions in epidemiologically identified 'hot-spots' village clusters.
- iii. **In non-endemic districts:** In such districts and blocks strengthen the quality of surveillance through better recording and reporting of "passive case detection," but also plan for an active case search once in three to five years that confirms its non-endemic status.
- iv. **Designated Leprosy Referral Centres (DLRCs):** Designate a sub-set of CHCs and district hospitals as Leprosy Referral Centres and build the capacity of these centres to manage leprosy and its common complication. Such facilities should also have provisions for slit skin smear examination to diagnose people with suspected signs of leprosy (SOS

without skin patch or sensory impairment). Designated staff in these LRCs should be followed up with regular skill retention programmes, both in distance education mode and in contact programmes, the latter being organized along with Leprosy Outreach Camps. Endemic districts would need more DLRCs than non-endemic ones.

- v. **Leprosy Outreach (LOR) Camps** could be organized with the participation of medical officers, lab technicians and physiotherapists of DLRCs to ensure not only confirmation of leprosy in those suspected during active case detection, but also for periodic nerve assessment of leprosy cases at risk for developing nerve damage and providing comprehensive care and physiotherapy services to all disabled (Gr.1&2) cases.
- vi. **Set up Disease Surveillance Teams (technical) with appropriately trained human resources** at district levels in endemic districts and at regional level in non-endemic districts to ensure that the data from both passive and active case detection is adequately captured, analyzed and used to guide action, that referral services and linkages are functional, and that all leprosy cases released from treatment (RFT) are followed up for lepra reactions, relapse, progressive disabilities and other complications.
- vii. **Mandate a human resource policy, recognize and act on the need to strengthen partnerships** with non-governmental which a) ensures that every medical officer and multipurpose workers working in PHCs and CHCs have the skills to detect leprosy and its complications, record and report it, initiate treatment when not complicated and make appropriate referral when it is complicated, b) provides necessary human resources for leprosy referral centres - other than medical officers, paramedics with physiotherapy or occupational therapy qualifications who can be trained and deployed playing roles similar to the earlier NMAs and as leprosy declines they would be available for all other disability and rehabilitation work, c) provides human resources for surveillance units which provide technical guidance for the programme- similar to the leprosy officers of the earlier period and would have accountability for programme's success.
- viii. **Develop a tertiary care plan** that involves not only medical colleges but also NGOs with such professional and technical capacity. Such a capacity is required to retain the core of subject specialists needed both from dermatologists and for reconstructive surgery, train the trainers for programme implementation and pursue research in this area, especially on emerging disease patterns and challenges.

2) STRATEGIES TO PROMOTE INCLUSION

- i. **Promote planned participation of persons affected by leprosy** in awareness generation and encourage their active involvement in planning, implementing and monitoring leprosy control activities at the district level. In particular, they could be a part of meetings to review the progress of the programme and be involved in preparing the project implementation plan for the national programme.

- ii. **Develop pro-active instructions and procedures to recognize the human rights and dignity** of persons affected by leprosy and their family members, and to promote equity and social justice by the healthcare providers in all the health care facilities with an effort to mitigate the bias, prejudice and resultant discriminatory practices.
- iii. **Form a multi-disciplinary technical committee consisting of experts** from fields related to leprosy and disability including representatives of PALs to develop specific guidelines for disability certification of PALs and recommend its implementation by the Ministry of Social Justice and Empowerment and other related ministries of the Government.
- iv. **Evolve a coordination mechanism** with related ministries and departments of the Government to facilitate the socio-economic welfare entitlements and vocational activities at community level for the needy PALs regardless of their disease/disability status and functional capability.
- v. **Advocate strongly with the Ministry of Justice against the criminalization** and discrimination of persons affected by leprosy by means of ordained practices reinforced by the existing discriminatory laws and provisions, and demand their repeal as recommended by Report No. 256 of the Law Commission of India.
- vi. **Promote networking of self-settled colonies** – Networking *at the state level of communities of people affected by leprosy socially displaced* and enlisting them for training in vocational and income generation activities/schemes under Ministries of Social Justice and Empowerment and Labour on par with other vulnerable and disadvantaged groups to ensure social participation and equity; as well as giving scholarships and support for higher education. Such communities also need to be linked to designated leprosy referral centres for continuity of care where needed.
- vii. **Recognize and act on the need to strengthen partnerships** with non-governmental organizations for care delivery in marginalized and vulnerable groups for the advocacy needed to retain leprosy as an important health and political priority, and for motivating those made accountable for leprosy in integrated health systems with the sense of a mission which has been part of the tradition of work in leprosy control.

C) RECORD OF PROCEEDINGS

1. INAUGURAL SESSION

The inaugural session was chaired by chief guest **Dr. V. Pannikar**, formerly Team Leader, Global Leprosy Programme, World Health Organization, Office of South-East Asian Region, and guests of honour, **Dr. P. Krishnamurthy**, President and Managing Trustee, Damien Foundation India Trust (DFIT) and **Prof. S. Parasuraman**, Director, Tata Institute of Social Sciences (TISS).

Prof. T. Sundararaman, Dean, School of Health Systems Studies, TISS, **Dr. Mathew George**, Chairperson, Centre for Public Health, School of Health Systems Studies, TISS and **Mr. Antony Samy**, Chief Executive, ALERT-INDIA were present on the dais.

Welcome

Dr. Nilesh Gawde, Assistant Professor, Centre for Public Health, School of Health Systems Studies, TISS and Organizing Secretary welcomed the participants of the National Workshop.

Purpose of the workshop

Mr. Antony Samy highlighted that though India achieved the elimination target of a prevalence of less than one per 10,000 people, new cases continues to occur. The troublesome aspect is that they occur in unknown locations across the country and among them are the young and children, and are associated with deformities at the time of detection itself.

Today, 10 years after integration of the National Leprosy Eradication Programme (NLEP) with General Healthcare System (GHS), it is evident that the latter is missing many new leprosy cases and is not equipped to provide quality services to those who have been diagnosed with leprosy. He pointed out that this is partly because leprosy agencies worked for decades without linking to and building capacities within GHS. After integration, the latter could not deal with issues as they were never equipped to handle them. He called for an authentic review of the ground reality and adopt new strategies under NLEP to deal with the situation.

Inaugural address

Prof. Sundararaman described the chequered history of leprosy control. The pre-eminent scourge of medieval times, leprosy had persisted into the 21st century. He pointed that the social and policy response to the disease in ancient societies has been of social exclusion where 'leper' (as they were referred to) colonies got established in different parts of the world including those on islands where leprosy affected people were deported. Medical advances by means of discovery of 'dapson' and its effectiveness (limited) in treating leprosy brought the first change in public health policy.

It also began to be recognized that deformity could be prevented in all cases. Medical treatment came as alternative to (rather complimentary) to earlier social norm of exclusion. Three decades later, multi-drug therapy (MDT) brought the good news that the disease can be cured with certainty and in much shorter duration of treatment, and early detection and treatment could prevent deformity. Shortening of duration of treatment reduces prevalence rates as a consequence, but the decline in incidence of new cases is modest. With a reduction of prevalence rates below a critical level (elimination target), it became impractical to provide leprosy specific services in a vertical structure.

The NLEP was integrated with general health services, but the latter did not have the capacity or the systems to deal with the cases. This has resulted in issues, as pointed out earlier by Mr. Samy. Stigma and discrimination and even mediaeval forms of exclusion anachronistically persist in modern societies as can be seen in the leprosy colonies and beggar homes. There is a need to discuss and deliberate on these issues. He said that the workshop aimed to bring out new ideas and understanding which would help planning for the future.

Address by the Chief Guest

Dr. V. K. Pannikar discussed challenges and opportunities for leprosy-free India. He started with demystifying ten common myths about leprosy in India. He pointed out that although she does not top in terms of endemicity though given the large population size, it contributes to nearly 60 per cent of the global incidence. He also stated that despite achieving elimination as per its definition, leprosy is not under control and transmission and still occurs.

MDT is effective but not 100 percent and cases of relapse and resistance do occur though it is as yet not a major issue. With respect to India, he brought attention of the audience that 60 districts in eight states contribute to a majority of cases. NLEP does not detect most cases and actual estimated incidence could be three to five times more than reported in Annual New Case Detection Rate (ANCDR). Even for cases that are detected, treatment completion rate is low.

He highlighted the programmatic challenges including poor mapping of high endemic districts, not focusing efforts to the high endemic pockets and loss of skilled human resource for leprosy related services. Some of these challenges have accentuated in integrated delivery of services which is characterized by lack of ownership, accountability, weak supervision, monitoring and evaluation. He prescribed focus on priority areas and specific groups, especially children, the need for active case detection, uniform MDT, stronger monitoring and for what he termed “precautionary advocacy”. Precautionary advocacy is needed to remove the perception that leprosy does not exist, too much talk about achievements and too less about remaining challenges.

Address by the Guest of honour

Dr. P. Krishnamurthy reiterated the global scenario presented by Dr. Pannikar. He highlighted that there is a plateau of case detection over last decade not only in India but across the globe. He felt that it is not merely related to global epidemic situation. Rather, he argued that it is because the operational efficiency of the programmes has reached a threshold across countries.

Address by the Guest of honour

Prof. Parsuraman greeted the conference and endorsed the need for a review of the policy and progress made towards elimination of the suffering and discrimination associated with the disease. He spoke about 'Koshish' project of TISS where he pointed how the leprosy affected are detained in beggars' homes and need for policies to include leprosy affected in societies.

Release of publications

Two publications of ALERT-INDIA, namely, TASK-TODAY (Series 6) and FOCUS (Series 6) were released by the dignitaries on the dais.

Vote of thanks

Dr. Mathew George proposed a vote of thanks.

2. SCIENTIFIC SESSIONS

2.1. Current Epidemiology of leprosy

Chairperson: Dr. P. Krishnamurthy

Rapporteur: Dr. Rajan Babu

- I. **Dr. Nerges Mistry**, *Director, Foundation for Medical Research (FMR), Mumbai* presented a paper on “**Current developments in molecular epidemiology of leprosy**”. She stated that our understanding of leprosy as a disease is limited and there are numerous uncertainties regarding its molecular biology, natural history and the extent to which it gets altered by medical and public health measures. On the one hand, smaller genome with many non-coding regions suggests that the bacterium may be heading for evolutionary extinction. On the other hand, there is clear evidence of extra-human reservoirs and its persistence in environment and how these ecological factors will play a role in the future is uncertain.

Current surveillance scenario indicates that even if this may be true, it may take several decades. On the other hand, it may also be that the bacteria are adapting and may produce different (diffuse) variety of disease (for example *M. lepramatosis* (M Lep M). Lack of genomic diversity also indicates that antigenic drift should be negligible.

Although antibiotic resistance has been reported with dapsons and increasingly with fluoroquinolones, the whole process itself is likely to be slow, making it less likely to emerge in multi-drug resistant forms as in the case of its cousin *M. Tuberculosis*. However, as the disease persists, over a period of time this danger could also increase. She posed questions at the end: Will newer techniques like RNA PCR be able to help in early diagnosis of the disease or of sub-clinical infection? Who will provide resources for the same? Will the research in this regard get limited as leprosy now becomes a neglected tropical disease?

- II. **Prof. Harshad Thakur**, *Faculty, Centre for Public Health, TISS, Mumbai* presented a paper on **“An overview of the disease and its control”**, as well as the global data to highlight that India contributes most cases. Both the prevalence and new case detection have stagnated and there is no remarkable decline over the past decade. He highlighted that although at the national level the prevalence is less than one per 10,000 (elimination target), there are several districts and blocks which have much higher caseloads. He dealt with the evolution of NLEP in India, its current focus and plan. He then presented the issues and challenges to the programme.
- III. **Dr. Vasna Joshua**, *Sr. Scientist, National Institute of Epidemiology, ICMR, Chennai* made a presentation on **“New epidemiological approaches to predict the trends of leprosy and its determinants”**. The research was based on the fact that cases of infectious diseases do not occur as random events, rather they occur in clusters. The spatial dependency and trends can be studied using Bayesian methods which could help identify factors that might explain spatial distribution of cases.

In her study that uses tools based on Geographical Information System (GIS) extensively, the spatial clustering of cases in Vidarbha region of Maharashtra state were correlated with forest cover but not with other variables. However, she noted two limitations of her study; one that the data were based on cases notified to NLEP which is known to under-report, and the variables were available not for individuals but for the blocks whether it be case notification or literacy or employment status.

The Bayesian space period model showed that the incidence was increasing and decreasing in alternate years; whether this is disease phenomenon or reporting in programme due to active search could not be deduced however. The study highlights that endemic pockets exist below block level and may be associated with ecological determinants. The main limitation of this study was that the endemicity was a function of effectiveness of health systems in detection of new cases which was partly attributed to the human resource and strategies employed in these areas including active case detection.

- IV. **Mr. Prabhavalkar, Head, Programmes (Leprosy), ALERT-INDIA and Mr. Rajeev Dudhalkar, Senior Project Manager, ALERT-INDIA** presented a paper on '**ALERT-INDIA's experience in active case detection**'. These campaigns termed as 'Selective Special Drives' (SSD) were implemented through partnership with local NGOs which recruited volunteers as 'community spokespersons' for the drive. House to house communication by community volunteers and community level IEC activities were carried out. This led to identification of suspects that were referred for diagnosis to PHCs.

The data on new cases detected during campaigns were cautiously analysed and compared with routine cases detection of NLEP as campaigns detect single lesion cases which self-heal. However, these SSDs (35.5) found an incidence (NCDR) about thrice higher than Special Search Activity (SSA) reported by NLEP (11.3).

It is important to note was that nearly 40 per cent were MB cases and 10 per cent were children, disability among new cases was 2.6 per cent and among old cases 14.6 per cent. The study provides proof that passive case detection is not enough and active case detection is needed in endemic areas to trace out all new cases.

- V. **Dr. V. R. Pemmaraju, Technical Officer – Global Leprosy Programme, WHO–SEARO** made a presentation on "**Need for revisiting criteria for deciding endemicity and its application in optimizing control strategies**". He presented global and Indian scenarios. He highlighted that although the WHO and member countries aimed at reducing the proportion of new cases with disabilities, the reported disabilities were actually rising globally as well as in India.

In Maharashtra there is an increasing trend of prevalence, new case detection as well as grade 2 disabilities. He presented priority districts not by ANCDR but by absolute number of cases and showed that 11 districts in India report more than 1000 cases whereas other 60 report 500 to 1000 cases. Categorisation of leprosy endemicity based on the numbers of cases reported is needed in addition to categorization by high prevalence rates for prioritizing action, achieving results and gives a concerted and focused approach. Such prioritization of areas for action improves accountability and inclusivity.

While the magnitude may be measured as new cases detected, cases among children and disability among new cases are sensitive indicators of transmission and delay in detection respectively. Therefore, a priority should not be based on prevalence or incidence alone, but on counts and presence of higher number of child and new disability cases. He then presented strategies to address specific challenges in areas with varying burden of leprosy.

2.2. Integrating leprosy in Primary Healthcare

Chairperson: **Dr. Sunil Anand**

Rapporteur: **Mr. John Kurien George**

- I. **Dr. Rajib Dasgupta**, Professor, Centre of Social Medicine and Community Health, School of Social Sciences, Jawaharlal Nehru University (JNU) presented a paper on '**Health policy and planning gaps relevant to leprosy control**'. There are certain social dimensions that need to be factored in. They include core aspects in the elimination in leprosy as inclusion, the response to migration and the rising problems of urban leprosy. In terms of health systems, the challenge is to recognize that certain aspects will need to be provided as vertical, while many aspects could have a horizontal integration. But there is a need to strengthen general health services and this is a pre-condition for integration. Much of the crisis which leprosy control faces is only reflective of the crisis in primary health care services, its financing and implementation.

- II. **Dr. Anil Kumar**, Deputy Director, JALMA Institute of Leprosy and Other Myco-bacterial Diseases (ICMR) presented on "**New Case Detection in Uttar Pradesh**". His study assessed the burden of new cases in two states (UP and Haryana) through population-based surveys and compared the results with cases detected by the general health system, and especially the role of ASHA in the same. The study highlights that Accredited Social Health Activists (ASHAs) (volunteers in villages with limited qualifications) have not been equipped to identify leprosy cases. They could detect only a few cases compared with expert teams from ICMR which could detect 15 to 20 times more cases. The study also found that the incidence of leprosy was the highest among contacts of MB cases, followed by those in contact with PB cases and lowest among those who were not in contact with a leprosy case within the past five years.

He argued that in the absence of active case detection, many districts in UP and Haryana (and rest of India too) are labelled as low endemic despite having high endemicity. He also argued that ASHA will not be able to play a role in case detection. (Contrary to this, Dr. Pai pointed out that ASHA's role was far better in Mahasamund, highest endemic district in Chhattisgarh). ASHA may have a limited role but it may also be a function of how strong the health system is in a particular state, higher or lower endemicity, and how much emphasis health system is giving to leprosy work in that district or block. In using the village as a unit to measure progress towards elimination, the JALMA study reports that there are villages which did not report cases for five years in row and now have incidence. This leads to several unanswered questions. Is it persistence? Is it a failure to detect new cases? Is it re-introduction in the community?

III. **Dr. Vanaja Shetty**, *Deputy Director, Foundation for Medical Research (FMR)* presented a write up on “**Epidemiological Features of Leprosy in Maharashtra**”. The study found that many new cases were undetected by general health system with significant proportions of multi-bacillary (MB), child and disability cases which could be identified by survey. MDT has not been able to affect transmission of leprosy as cases continue to occur even among children. The treatment completion rates are poor and patients develop deformities while on and after treatment.

The study also found considerable cases of neuritis (63 per cent), relapse (58 per cent), and grade 2 deformity – G2D (31 per cent) among those “Released from Treatment” (RFT). These data are not being captured by NLEP. Leprosy Referral Centres (LRCs) were started by Government of Maharashtra but the study found that they were ill-equipped to handle the cases and that the quality of services provided by them was poor with respect to special services for leprosy like skin smears, physiotherapy, treatment of reactions, etc. Active case detection, strengthening of LRCs, examination of patient at the time of RFT (to confirm cure/deal with disability), regular nerve-function tests, post-RFT surveillance for 10 years, etc., were some of the key recommendations by this study for the programme.

IV. **Dr. Aashish Wagh**, *NLEP Consultant, Damien Foundation India Trust* presented a paper on “**Situational Analysis of Leprosy Elimination Programme from Bihar**”. This state has a lot of challenges and opportunities for leprosy at Primary Health Care level. The challenges such as unavailability of NLEP staff, dependence of medical officers on non-medical assistants (NMAs) for diagnosis, no specified referral centres for reaction and disability management and poor supervision and monitoring at all levels affect the programme.

There are opportunities such as support from CLD in provision of additional human resources, availability of five International Non-Governmental Organizations (INGOs) providing their services in the State, appointment of new medical officers who will be responsible for leprosy programme in the districts and pension schemes provided by the State Government to the persons affected. However, all of this reflects the verticality of NLEP in Bihar compared with other states where there is a considerable degree of integration. Even in the presence of central support, the decline in human and financial resources is noteworthy, putting doubts regarding its sustainability.

As found in NLEP data, the new case detection in Bihar has reached a plateau, while there is an increase in the case of detection among women and children with increasing reporting of deformities. There is a major role of NGOs for interventions in leprosy programme in the State. One of them could be to develop designated referral centres which can deliver

primary, secondary and tertiary care services to affected persons. Recommendations such as involvement of local NGOs, community volunteers and persons with disabilities (PwDs) should be effectively utilized in the programme. Nerve Function Assessment (NFA) of new cases and contact screening were also recommended.

- V. **Dr. V. K. Rokade**, *Assistant Director of Health Services (Leprosy), Government of Maharashtra* presented a write up on “**Achievements and challenges in leprosy control of the state of Maharashtra**”. He shared positive experiences with involvement of ASHA. However, the numbers contributed by ASHAs were small- about 10 to 15 per cent of the state’s case detection and 5 to 10 per cent of treatment completion of total patients. He presented data from the cases detected through examination of household contacts that showed that the yield was far better than the community survey (about 1 to 2 per cent contacts had leprosy).

The State also has invested in information, education and communication (IEC) which has resulted in improvement in voluntary reporting of new cases but contributes to only about 5 percent of the total cases detected. This also provides a proof that active case detection may be needed in high endemic pockets and voluntary reporting cannot be relied upon.

2.3. Operational challenges in leprosy control

Chairperson: Dr. Atul Shah

Rapporteur: Dr. Rajbir Singh

- I. **Prof. R. K. Mutatkar**, *Medical Anthropologist, Interdisciplinary School of Health Sciences, Savitribai Phule Pune University, Pune (Maharashtra)* presented a study of “**Experiences from the mid-term evaluation of NLEP in Assam**” conducted during 2014. He stated that other than ASHA and NLEP staff, no GHC personnel were involved in leprosy work. Social stigma was not a problem with leprosy patients having only skin patches. But the problem is with those leprosy patients with visible deformities. A majority of newly detected leprosy cases are MB type of leprosy that indicates delayed detection. IEC activities and materials are visible as an exception. Community participation as a programme is non-existent.

Infrastructure such as computer and support staff for programme monitoring is lacking at the district level. Health personnel in supervising cadre such as Zonal Leprosy Officer (ZLO) and medical officers (MO) of PHCs are not yet formally trained in leprosy. It is reported that some community members report directly to Medical College Hospital for confirmation of diagnosis and treatment. There was scope to bring in many more partners and to involve elected local bodies and their leadership into this work. Specific recommendations relate to

involving local bodies more systematically, in better focus and use of IEC, use ASHA more effectively in disability prevention and support for advocacy.

- II. **Mr. S. Kingsley**, *Head – Knowledge Management, ALERT-INDIA* presented his paper on **“Sustaining leprosy expertise during post-integration in Maharashtra”**. He clarified that the transfer of ‘responsibility’ to general health services needs to be done in a phased manner taking into consideration all its limitations. The need for training and capacity building of healthcare providers at all levels of general health services is crucial to provide quality care to persons affected by leprosy. Uninterrupted availability of resources such as drugs and other rehabilitation services for those with disabilities and deformities must be ensured. He highlighted the need to define organizational responsibilities with a clear accountability of healthcare providers along with the participation of people affected and a strong political commitment in order to sustain leprosy expertise during integration phase!

Narrating ALERT-INDIA’s experience to sustain leprosy expertise in Maharashtra State, he described their programme called LEAP, launched to strengthen ‘integration and to ‘sustain’ leprosy control in 13 endemic districts. The main innovations in this approach were developing Leprosy Referral Centres (LRCs) and Leprosy Out-reach (LOR) Camps as key intervention strategies of LEAP. He said that the establishment of 123 LRCs within the Community Health Centres (*CHCs – referred as Rural Hospital (RH) or Sub-District Hospital (SDH) in Maharashtra*) at the block level enabled provisioning and accessibility to specialized leprosy services. These LRCs have created linkages between different levels of general health services for referral services, thereby strengthened the referral system under Disability Prevention and Medical Rehabilitation (DPMR). Trainings conducted for medical and health personnel of CHCs have enhanced their capacity with adequate support services that has improved accountability in delivering leprosy services.

263 LOR camps were conducted in PHCs and they contributed to improving the knowledge and skills of medical and health personnel and sustained leprosy expertise. They also promoted referrals of leprosy cases to LRCs for specialized leprosy services and adherence to DPMR guidelines. The LOR camp thus becomes a vehicle that facilitates transfer of responsibility to PHC staff after their capacity building and increasing their ownership for NLEP. Other lessons were the need to ensure active participation of persons affected by leprosy (right holders) in preparing annual Programme Implementation Plans (PIPs) for NLEP as per National Health Mission (NHM) guidelines and the need to include general health services personnel in review and evaluation of NLEP and fix accountability for assuming greater responsibility under NLEP in the form of key ‘administrators’ or ‘duty bearers’ for the people affected by leprosy.

III. **Dr. Nilesh Gawde, Centre for Public Health, TISS** presented on **“Alternative service delivery models for integration of leprosy into general health services”**. He stated that the integration of leprosy faces certain challenges with respect to sustaining expertise and to provide health services for leprosy affected. Hence, there is a need to rethink about the structure of service delivery for the coming decade. He discussed advantages and disadvantages of three healthcare delivery models for providing leprosy services at three levels of GHC system as recommended by DPMR. These are i) NLEP model for high endemic districts (ANCDR > 10 per lac); ii) NLEP model for low endemic districts (ANCDR < 10 per lac); and, iii) Leprosy Referral Centre (ALERT INDIA) model (ANCDR > 10 per lac). At primary level, the NLEP staff (NMA) is basically responsible for delivering leprosy services in high endemic districts, whereas it is the responsibility of GHC staff in low endemic districts. In secondary and tertiary levels, the District Leprosy Cell (DLC) and medical colleges/Physical Medicine and Rehabilitation (PMR) institutions are responsible for delivering leprosy services.

In ALERT-INDIA’s LRC model, the PHC personnel are involved through LOR camps at primary level and through LRCs by a partnership of NGO/NLEP and GHC staff at the secondary (block) level. An analysis of data from NLEP reports and LRC reports (ALERT-INDIA) for the period 2011-12 to 2013-14 revealed the ratio of leprosy patients developed ‘lepra reactions’ per 100 new cases detected to be 9.8 and 13.1 respectively which is statistically significant. The proportion of G2D among new cases detected per million population is showing an increasing trend since 2007-08. There is a lack of disability prevalence data - both new and old cases- which make it difficult to build an estimate of cases who would require services other than MDT. Only 20 per cent of disabled leprosy cases accessed specialized leprosy services once a year. A few case studies have demonstrated that the disability management after cure is still a challenge in sustaining leprosy services for a long term. Building capacities and sustaining them is easier said than done, however mobile team approach may help in reducing the cost and improving service delivery.

The recommendations were that leprosy services at district level may be provided by regular physiotherapist at District Hospital (DH - outside NLEP) and in the districts where no physiotherapist position is sanctioned, it may be made available under NLEP. The physiotherapist also provides services for people with other conditions. The DLC role is in training and supervision rather than provision of leprosy services. One worker at each block/CHC would also be required to provide physiotherapy services for all conditions including leprosy (from general health services). Government - NGO partnerships would be critical to build capacity of village/PHC/CHC level staff (focus to be on hands-on rather than formal training) to retain their attention on this programme. The possibility of mobile teams to improve outreach services can be explored.

- IV. **Dr. Vivek V Pai**, *Director, Bombay Leprosy Project* presented his paper on **“Continuing challenge of disability management in leprosy”**. Based on the experience of the project in providing prevention of disability care in rural areas of Thane district (Maharashtra), he described how the project had deployed trained local community volunteers linked to mobile service units that supplied dressing kits, splints, Micro-Cellular Rubber (MCR) footwear and physiotherapy measures like wax therapy and hospital care. In some areas ASHAs have been sensitized involving them in the programme for community care. Community volunteers were selected from local villages and leprosy affected and this was a part of their rehabilitation.

The impact of these services was found to be maximum in patients with foot ulcer who were 56 per cent of those requiring care and in mobile claw hand, which were 40 per cent. Improvement in their disability was achieved using conservative line of management. This campaign showed that when all disability due to leprosy was counted- past leprosy, presently under treatment, and those who were recently RFT- a very high prevalence of persons affected with leprosy-related disability in the rural areas results - at about 22 / 10,000. There is a need to systematically assess the magnitude of problem, train the GHC staff in identification of high risk cases and silent nerve damage as well as establish quality referral services.

He recommended that the policy focus, which deals largely with the ‘communicable’ aspect of leprosy in terms of early detection and cure with MDT, should now expand to address the non-communicable aspect of the disease in terms of reducing the occurrence of nerve damage, and preventing and managing its consequences. There is a need for a well planned strategy to provide disability care services to those suffering from leprosy-related disabilities eventually reducing the disease burden in the community. Early identification and management of Lepra reaction with or without nerve damage in leprosy patients will go a long way in preventing development of new disabilities and will help to a great extent in reducing the morbidity of the disease and contribute to the efforts of reaching the goal of “World without Leprosy”.

- V. **Dr Sunil Dogra**, *Additional Professor, Department of Dermatology, Venereology & Leprology Post-graduate Institute of Medical Education & Research, Chandigarh* read a paper on **“Re-thinking tertiary healthcare in leprosy”**. Sharing the experiences on the role of tertiary care hospital in NLEP, he highlighted the ‘after effects’ of post-elimination situation that have serious implications on patients, doctors and society. At the tertiary care centre, the new cases have broadly a similar clinical pattern and number of new cases over past 35 years with frequently encountered leprosy reactions and deformities. Over the last few years

there has been an alarming rise in the number of highly bacillated MB cases and child cases with grade two deformities. The absence of skin smears in routine control programmes makes it difficult to ascertain exact relapse/resistance cases. There is an increased number of 'treatment failure' cases among high BI / MI positive MB cases noticed over the last five to seven years at PGI Leprosy Clinic, Chandigarh.

He stated that a stigma still persists and there is a need to provide rehabilitation services and address the issues of colonies and homes. He predicted an increased role of dermatologists in treatment and need for greater coordination with other stakeholders in the near future. He listed the negative impact of recent trends in encouraging leprosy research and specialization. These 'drifting' scenarios include dismantling of vertical leprosy control programmes, greater visibility (glamour) of other national disease control programmes, declining number of designated "leprosy officers", more interesting and lucrative career options, and limited funding and research avenues for leprosy.

He warned that the "next generation dermatologists" have inadequate training/expertise in leprosy. Thus, it will become more difficult for people with leprosy to access expert and timely care both for the initial diagnosis and management of complications. Several studies have proved that leprosy, reactions and relapses including all other problems and complications will continue to occur in a setting where leprosy experience is greatly diminished.

He called for a better utilization of dermatologists and tertiary care service centres for leprosy as a part of the referral chain under NLEP. The importance of consultation with such centres of expertise before changes in treatment policy by WHO or government should be acknowledged. He cautioned against any further shortening of WHO-MDT MBR from one year as disastrous for leprosy control in India. A special grant support for post-graduate medical students could attract candidates to work in this neglected field. A Special Interest Group (SIG) of Indian Association of Dermatology, Venereology & Leprology (IADVL) is working past few years to increase awareness about leprosy among health care professionals.

2.4: Stigma, discrimination and integration of people affected

Chairperson: Dr. V. R. Pemmaraju

Rapporteur: Dr. W. S. Bhatki

- I. **Ms. Jayashree, CEO, iBAS Consulting, Bangalore** presented her paper on "**Challenges and opportunities to address leprosy stigma in the present context**". It was mainly based on her -experience and those of close associates. The stigma associated with leprosy still exists

and is ever increasing. It is difficult to define it, however it is a state of “*Non-acceptance*”, “*Disrespect*” and full of “*Negative Attitude*” towards people affected. Leprosy is not accepted like any other disease by general public and even by the medical fraternity. There is a lack of information about it in the public domain and the media is not too keen to cover the leprosy-related issues, while other diseases were given a ‘respectful’ status with celebrity endorsement. People affected could still be denied public transport and are stigmatized in institutions.

She said that the determinants of stigma are mainly due to physical deformity and fear of rejection. Many times people perceive in themselves the negative effects of stigma. There is a constant fear whether they would be accepted in the society which is a form of self-stigma. These are not documented adequately, particularly in the urban context. Leprosy affected individuals are entitled to human rights accorded to people with other disabilities and have the unrestricted opportunity for economic freedom, right to a family and societal life. She ended her presentation by the statement that there is always a state of apathy among everybody about this sensitive issue of stigma.

She recommended providing affected individuals with ‘restorative justice’ where anyone who has experienced being discriminated/been a victim of gross violation of human rights could give testimony and await reparation and rehabilitation. States should engage in creating opportunities for healing and inclusive lifestyles for the affected individuals by making the society aware and responsible for the atrocity committed against the individuals who have been victims of the effect of the disease. Sensitization of health workers through workshops in order to ‘eliminate’ the last of the medical/leprosy workers who are not willing to lend dignity to the patient can yield results.

She emphasised the need to develop a rights based approach where the understanding of rights included freedom from stigma, link with nutrition and living conditions, need for investment in appropriate human resource, adequate compensation and basic rights of access to health care. It should include the right to be heard by the decision makers and policy makers in an open and participative environment, and it should actively and specifically include people affected with leprosy.

- II. **Dr. P. K. Gopal**, *President for International Relations, IDEA (Integration, Dignity & Economic Advancement of PAL) India, Tamil Nadu* presented a paper on “**The dynamics of leprosy colonies and their possible futures**”. Though there was no such law to segregate the people affected, historically people with leprosy were abandoned or forced by the family and community to leave their families. To cope with this, they joined together as a group and

started to live away from the community which is called a leprosy colony or leprosy village in different nations. These persons had to resort to begging for their living and also married among themselves and had children. There are 778 leprosy colonies in India. It is positive to note that no new colonies have come up and no new cases detected from the colonies in last 15 years. Old cured patients and their families live in the colonies as they find it advantageous. But the second and third generations grow up to face problems of stigma and discrimination even though they are healthy and never had leprosy. Networking among the existing colonies is poor. Most of the colonies lack health facilities and general utilities like electricity, water supply, drainage and good environment. They are weak in developmental activities due to lack of support from the Government and NGOs.

To pursue these demands, an Association of Affected Persons has been formed at national and state levels. IDEA India is creating network among these colonies through workshops and facilitating socio-economic empowerment of the residents. They have helped to create leadership qualities and to take up the responsibility to work for themselves. He strongly voiced his opposition to any plan to remove or close down leprosy colonies. He said that colonies will stay as they are the homes of leprosy-affected people and their families for many decades and it is their basic human right to live there. He also pointed out the existence of discriminatory laws and advocated repealing these provisions in view of the recent advances in leprosy treatment. He noted that the Government is taking steps in this regard. The way forward included ensuring basic amenities, proper networking and empowerment of people living in these colonies, and a more caring and supportive attitude amongst service providers and authorities.

- III. **Ms. Kabita Bhattarai**, *Director, Little Flower Leprosy Welfare Association, Ruxaul, Bihar* presented a paper on “**Replicable model and positive example of how leprosy rehabilitation**” could be shaped. “Little Flower” is a consortium of 22 colonies with 4,000 inhabitants which began as a leprosy colony but is much more than that today. It comprises components of prevention and awareness about leprosy, providing treatment through a 140 bed hospital and vocational rehabilitation through several sustainable income generation trades such as spinning, weaving and dairy farming - all of which are gone to scale and generating incomes for individuals and for the project.

She mentioned innovations in clinical care using local plant and earth materials that could be used for healing of planter ulcers in leprosy patients and they are trying to commercialize these products for mass application. The project provides for a family monthly income of Rs.10,000/- and for a family income of Rs.15000/- if there are children who pursue quality/higher education. All the residents live in a structured home with two rooms as well

as kitchen and toilet with piped water and other benefits. This was facilitated by the university students from Austria and other international sponsors. Government support is there but it is either inadequate or delayed and even getting essential anti-leprosy drugs could be a problem. She said that these colonies have self governance mechanism with participation of PAL in all levels of decision making. Hence, it has achieved a status of a financial self-reliant organisation. Colony dwellers elsewhere in India would love to replicate this model. Finally, she stated that if we give the affected people in colonies a healthy home and higher education, they we will overcome the restriction and will show us the future of Leprosy Free India.

- IV. **Mr. Mohd Tarique**, *Koshish Project, School of Health System Studies, TISS, Mumbai*, presented a paper on **“Issues related to human rights and leprosy”** against the criminalization of leprosy as happens under the anti-beggary laws. The Koshish Project deals with the illegal detention of beggars including those people affected by leprosy in beggars’ remand homes. He referred to the Anti-Beggary Act and the provisions therein which is a violation of basic human rights. He said that some form of the Anti-Beggary Act exists in twenty-four states of India. These laws have draconian provisions: anybody found begging in a public place can be arrested, punishment for which is imprisonment from one to ten years, dependents of the offender can also be detained under the same Act, and having leprosy is treated equivalent to begging, etc. Those arrested are sent to beggars’ homes established under the Anti-beggary Act.

He raised some valid questions on the human rights of people affected by leprosy, viz., is begging offense? Is leprosy a crime? According to the study conducted, the leprosy affected beggars are sent to leprosy homes for treatment. But at such places, instead of receiving active treatment, PALs are detained indefinitely. PALs should be considered as patients and not offenders, and there is an urgent need to join forces to decriminalize leprosy by applying pressure from all fronts. He proposed that a specific recommendation should be made to repeal this Act in this workshop.

- V. **Mr. V. Narsappa**, *President, Association for People Affected by Leprosy, Hyderabad* presented a paper on **“Leprosy and community”**. He stated that stigma is not just a matter of using a wrong word or action. Deformity is the main cause of stigma which is a state of non-acceptance, disrespect and barrier. The fear of stigma and resulting discrimination discourages individuals and their family members from getting the help they need in social, economic and psychological terms. This prevents them from taking a part in social activities and to find a safe place to live. Due to their poor economic condition, the people affected and their families are bullied in schools and colleges, thus depriving them of education and

further employment opportunities. When they are rejected by their families and local community, they are forced to stay in rehabilitation homes or colonies that are away from their homes.

He explained the problems and difficulties faced by PALS in colonies in Hyderabad. They were the same. The perspectives of other colony dwellers and the community should be changed. He claimed that the basic health services are not provided and the hospitals do not dress the wounds of people affected by leprosy. He stressed that the process of achieving the acceptance of the leprosy patients in the community along with social status as well as cultural acceptable in the absence of disease/illness should be treated as stigma reduction. He recommended that if we enable an affected person to have good health without any disability, have strong will power and economically well settled with a high education level, then he will not face much stigma and discrimination.

- VI. Mr. Soumik Sau, MPH student of TISS, Mumbai, presented a “Case study of leprosy colonies in West Bengal”.** Even after achieving the elimination of leprosy in 2005, there are still over 742 leprosy colonies in India. This is a contradiction and paradox. It is only a policy gap that explains the existence of leprosy colonies even after the elimination of leprosy. In West Bengal, there are 29 leprosy colonies of which six colonies, two each from metro city, semi-urban areas and rural areas were taken up for the study. Information on the number of inmates, their health and disability status including socio-economic benefits given to the inmates were collected from the Government reports, key informants including officials as well as the office bearers of the NGO named Sara Bangla Kusth Kalyan Samiti.

One finding was that there was a small but significant number of patients on MDT in these colonies, highlighting the need for continued active detection and control measures. Government data underestimated the population living in colonies, and the numbers affected and requiring care. Access to self-care and to was an issue. Stigma, discrimination and access to basic services, employment and higher education were worse in the rural colonies as compared with the urban ones. Discrimination was persistent and rampant in government offices and hospitals. Some of them stated that they are treated like cows and buffalos. Get-togethers in the colonies are attended only by the colony dwellers. Ninety-six per cent marriages take place only within the colony dwellers. He put forth a set of recommendations that could help transform and mainstream the leprosy colony and its inmates into contemporary society - categorising these into healthcare related (self-care, a dedicated ASHA and designated referral facilities), self governance and empowerment (a local committee with powers and linkages) and vocational training or, if disability prevents, gainful employment and financial support.

VII. Ms. Nikita Sara, Head - Advocacy & Communications, The Leprosy Mission India Trust, New Delhi expressed her views on **“Leprosy and the law”**. She presented an overview of all the discriminatory laws on the grounds of leprosy. Beginning with the Lepers’ Act, 1898, there are a host of civil laws that carry discriminatory provisions against people affected by leprosy. These laws are mainly based on age-old misconceptions about incurability, contagion and inevitability of deformity that were instrumental in promoting stigma and discrimination. These laws, however, have been repealed in most of the states. They still exist in four states. Although the Lepers’ Act has been rendered obsolete, many other laws with discriminatory provisions remain.

She added that the 20th Law Commission recommended repeal of the Lepers’ Act for being in violation of Article 14 of the Constitution owing to the forcible exclusion and segregation of persons affected by this disease under the Act. Currently, this proposal is under consideration of the Parliament. Additionally, the beggary law while making beggary a punishable act pays no heed to the living realities of people affected by leprosy for many of whom beggary has been the sole means of survival for years.

Apart from the directly discriminatory nature of these provisions is the use of the term ‘leper’ in the beggary law, which in itself is highly derogatory, discriminatory and stigmatizing. The use of such terms in laws provides their use a legal as well as cultural sanction. Thus, their removal from legal parlance becomes a necessary step in ensuring their general disuse in the broader cultural context.

The TMI through ‘CALL’ Project aims at Engagement - Empowerment and Capacitating of people affected by leprosy and their communities to access rights and entitlements. Besides, the project also focuses on awareness of legal instruments/practices which leads the community to raise its voice against any violation of human rights and provides platform with the larger community by building a network with larger disability networks. The collective movement and effort by all the like-minded people and agencies has resulted in Report No. 256 of the Law Commission which is a significant step forward.

She also said that to address the laws connected with leprosy; the disease should be looked into a holistic manner and not just as a medical problem. For this we need to understand the existing laws and propose amendments or deletions of the discriminatory provisions in them in view of the medical advancements with regard to leprosy and sensitise duty bearers and rights holders to ensure rights and entitlements of the leprosy affected. There is a need to engage the Ministries of Health & Family Welfare and Social Justice & Empowerment with the support of national and international community to bring a change.

3. ILEP & NLEP PARTNERSHIP: GOOD PRACTICES & LEARNING

Chairperson: **Dr. A. K. Puri**

Rapporteur: **Dr. V. V. Pai**

I. **Dr. Rajan Babu, Member, ILEP Technical Commission (ITC)**

ILEP strategy for 2015-18 guides the work of the members in the Federation. The vision is to work together for a world free from leprosy that is based on goals such as 1) stop leprosy, 2) prevent disability due to leprosy, and 3) break the barriers to promote inclusion. Each of these goals has specific objectives and interventions to support governments. He said that to achieve goal 1, the strategies are early detection of the disease with a focus on women and children, increased detection and reduce Grade 2 disability. To achieve the goal 2, the strategies are addressing residual morbidity after MDT, prevent disability, and address unmet needs including community-based rehabilitation (CBR) and livelihood programmes. To achieve the goal 3, the strategies are strong associations of people with disabilities including those affected by leprosy, ending discriminatory practices and laws, respecting rights and promoting inclusion. These intervention strategies will focus on three enabling actions such as 1) Improving ILEP collaboration, 2) Improving collaboration with others, and 3) Raising the profile of leprosy.

II. **Mr. John Kurien George, Swiss Emmaus Leprosy Relief Work – India (SEI)**

The core competence of Swiss Emmaus is in managing five tertiary referrals leprosy hospitals across four states in India and on an average 27,454 patients were treated per year for various leprosy-related problems such as ulcer care and Lepra reactions. Besides, it has field based programmes that include Disability Prevention and Education in Leprosy (DISPEL) project and Prevention of Impairment and Disability (POID) project in five districts of Andhra Pradesh. Moreover, it provides NLEP Coordination in five States (Andhra Pradesh, Chandigarh, Haryana, Himachal Pradesh and Punjab). He said that it is important to combine both hospital-based and field work approach to reach out to the last case of leprosy.

He stated that the Swiss Emmaus has implemented a Comprehensive District Leprosy Control Project (CDLCP) in two districts of AP during 2014-17 with the goal of improving the quality of life of the affected people. The key objectives of the project are to improve and provide POID services in the primary health care, at referral hospital and at community levels as well as to develop project management system for effective implementation of the project and undertake operational research. He elaborated the approaches by combining tertiary care services along with field-based POID intervention that promotes early diagnosis to prevent deformity. The following are the lessons learnt and the way forward: The combination approach is one way to

reach out to the last case of leprosy. Routine active survey is essential in high endemic blocks/districts. Currently, SEI India implements POID model in five districts (three in Andhra Pradesh and two in Maharashtra). While the AP model focuses on primary level intervention, the Maharashtra model looks at all the three levels of intervention. It is planned to design and implement the same POID projects in two additional neighbouring districts in AP.

III. Dr. Sunil Anand, *The Leprosy Mission – India (TLMI)*

TLMI currently focuses on healing, inclusion and dignity of people affected by leprosy. While looking back, TLMI has made a change in their themes from disease focus to person focus, from implementing to Implementing and Influencing, and from activity focus to outcome focus. The approach to healing facilitates a holistic approach, thereby making a shift from disease to person – beyond ‘only medical’ to social realities, entitlements, etc., and from Institution to community accessible and relevant as well as right to access for treatment and referrals.

The strategy for inclusion is breaking the barriers and it is a right and not a privilege. These are aimed to be achieved through *integrated programmes* in the disability movement, women’s empowerment and poverty alleviation, vocational education, livelihood and sports. Inclusion also promoted *increased awareness through Media Advocacy*, involving Disability Organizations; Champions/role models for mainstreaming and students as basic communicators for the cause of leprosy. This has a *policy influence by engaging in* National Consultation on Rehabilitation, providing inputs for Right of People with Disability (RPD) Bill as well as to Law Ministry and Law Commission including National Commission for Women (NCW) and National Human Rights Commission (NHRC).

The strategy for dignity is aimed at restoration by realization of rights and promotes participation, positive behaviour and respect for the people affected. It was also aimed to render justice with equity rather than equality. TLMI also strives towards rights of the people affected in medical, social, educational, livelihood and empowerment terms. The future priorities of TLMI are early and appropriate treatment of leprosy, effecting a change in the societal mindset, actions that empower the affected communities, provision of a favourable policy environment and building a team of responsive duty bearers. TLMI wishes to see that *people affected by leprosy live with dignity in a transformed and inclusive society that has overcome leprosy.*

IV. Mr. M. V. Jose, *Associazione Italiana Amici di Raoul Follereau – India (AIFO)*

Realising only on medical interventions alone is not sufficient for the management of leprosy. Therefore, Community Based Rehabilitation (CBR) approach was adopted across all AIFO projects. CBR approach enables us to partner with other organizations and multiple

stakeholders, harnessing their best practices and skills, enabling us to optimize our time and resources. All across there are many CBR and development agencies in India, and so there is a need to find means to convince them to include leprosy into their programmes. Many are willing to do it with little external technical and financial support. This stage - Quality of Life - can be achieved only when all the members of the community are capable of realizing this.

We have the responsibility of sustaining and preserving the healthy community for the future generation. Self-help Groups, especially women SHGs, play a constructive role. When we ask them to include leprosy in their programme, we have to participate in their programme too. To realize it, this SHG plays a crucial role in organizing and facilitating opportunities for lobbying and for IEC activities. Talking about absolute numbers, it is alarming to note that 130,000 new cases are detected every year (every four minutes one new case). Of these 5,800 new cases are with deformity (every day 15 persons disabled due to leprosy). Of the total new cases, 13,000 child cases (every day 35 children get leprosy) are detected of which 600 children are with disability (every month 50 children become disabled due to leprosy). These numbers speak the problem of leprosy.

It is a wrong notion that leprosy is not a problem as North-East is branded as non-endemic, hence less attention can be given. The challenges in North East are that there are many children and youngsters with deformities. Difficult terrain, political disturbances and lack of resources (both money and personal) add to the problems. There are many affected children, young and adults waiting for leprosy services. There are non-leprosy NGOs and now some state health officials are convinced and committed to the cause. New opportunities are being explored with the utilization of all available resources in partnership with LEPRO society and support from TLMI and DFIT for requirement of MCR footwear, surgery and training including Clofazamine / Thalidomide as crisis management. Now ALERT-INDIA has planned to come and we welcome it. Basic level consultation – at the peripheral level (started with Meghalaya as a trial) – to encourage involvement and participation of persons affected by leprosy – rather than just for formality, which does not provide the true representation. Extending the support for provision of socio-economic rehabilitation to the most needy identified by the District Programme Officers is required. This activity is done for not taking the responsibility but to stimulate the health system to visualise the needs for housing, financial support to buy livestock and education for children of persons affected by leprosy and pension schemes.

V. Dr. Rajbir Singh, German Leprosy & TB Relief Association – India (GLTRA)

The mandate of this Organization is leprosy control with focus on disability prevention and rehabilitation. Besides, GLTRA supports programmes on TB control and other NTDs with focus on child, technology and research. The strategy includes coordination with national

programmes and support to 35 NGOs through technical guidance and direct participation spread across four states and four UTs in India. He elaborated the results of three operational studies, the contribution made to develop NGO schemes under NLEP and the participation in Joint Monitoring Mission and Mid-term Evaluation of NLEP. He shared the experience on DPMR initiatives in the integrated settings in selected blocks of Malda district of West Bengal. This project has resulted in providing quality leprosy services to PALs as well as promoted active participation of GHC staff in DPMR services and strengthened the referral mechanism. He said that although the sustenance of self care camps is a challenge, several opportunities are being explored including engaging the people affected by leprosy.

VI. Dr. Aashish Wagh, Damien Foundation India Trust (DFIT)

DFIT contributes towards strengthening of NLEP services in three states and facilitate referral services including re-constructive surgeries through own centres, Medical college hospital and other ILEP supported projects. These projects facilitate the involvement of persons affected by leprosy and socio-economic rehabilitation including community involvement through the participation of civil society organizations. DFIT provides support in training technical staff in NLEP and participates as a member of Joint Monitoring Missions (JMM) and Independent Evaluations. DFIT provides technical inputs to each state to assist the State Programme Officer in planning, implementation and evaluation of NLEP. He said that the mobilization of funds from the state to districts and districts to blocks is a challenge due to frequent change of Programme Officers at district as well as state levels that has resulted in poor utilization of funds. Ensuring sustainability and continued participation of the general health staff and ASHAs in NLEP as well as continued participation of other stakeholders and persons affected by leprosy in NLEP needs special attention. He mentioned that inadequate referral centres in the state for managing complications related to leprosy is a setback as medical college hospitals are not keen in referral services for leprosy.

VII. Dr. Vineeta Shankar, Sasakawa India Leprosy Foundation (SILF)

SILF's goal is to increase social acceptance of leprosy cured people and their families through dissemination of scientific information, and to create conditions that will enable them to have equal access to economic opportunities. It works towards enabling those cured of leprosy to regain independent and sustainable means of livelihood through measures that enhance their skills and abilities to access market opportunities. It does this by helping leprosy affected people and their children to gain access to education, training them in feasible livelihood streams, arranging microfinance opportunities for them and putting self-help groups in touch with other NGOs and charitable organizations. SILF also raises awareness among different sections of the society against social and economic discrimination of leprosy affected people.

4. CONCLUDING SESSION

Chairperson: **Dr. A. K. Puri**
Rapporteur: **Dr. V. V. Dongre**

All the rapporteurs of the four scientific sessions presented details of the proceedings. **Dr. A. K. Puri**, Assistant Director General of Health Services (Leprosy), Government of India presented a paper on “**Current scenario of leprosy control, programme strategies and achievements of NLEP so far**”. He presented the plan of Central Leprosy Division called Leprosy Case Detection Campaign (LCDC). Fifty districts with prevalence of higher than 1 per 10,000 have been identified and will be targeted under LCDC. The campaign will be with the same intensity as pulse polio and house to house search for leprosy cases will be done by trained teams with supervisory support. He also disclosed that GOI is planning online reporting system (Nikustha). **Ms. Harsha Mukherjee** made a presentation on mainstreaming Corporate Social Responsibility (CSR) for the cause of leprosy.

The workshop concluded with a vote of thanks by **Mr Antony Samy**.

5. SUMMARY OF THE KEY LEARNING

Prof. Sundararaman and Mr. Antony Samy

Based on the reports of rapporteurs, the key learning is summarised from the National Workshop and is listed as follows:

a) Epidemiological and disease control perspective:

- i. Even after the declaration of elimination, leprosy persists as a public health problem. The campaign for elimination by WHO that marked the earlier two decades (1991 to 2011) has brought great benefits by way of the control of this disease. But they would be lost if there is an under-estimation of the remaining gaps or an over-estimation of achievements.
- ii. Levels of annual case detection could be anywhere from three times to twenty times more than the currently projected rates. The weaker the public health system, the lesser the quality and quantity of human resources deployed at the frontline and hence larger the variations. This estimation is based on scanning a number of reliable file level studies from non-governmental organizations and academic institutions.
- iii. Although the persistence of leprosy is due to operational failure, a part of it is also due to long incubation period of the disease - ranging from a few months to over 20 years. Many new cases will continue to rise of which many would self-heal but a significant proportion would remain untreated, develop into the disease and deformity. The presence of disease in children and in multi-bacillary forms, however, is a clear indication of persistent transmission.

- iv. The leprosy bacterium has a very low infectivity rate which is a favourable characteristic from public health point of view. Recent developments in molecular biology bring hopes that the bacteria would attenuate further. However there is also a concern that it is developing non-human reservoirs¹ and adapting to changing environments.
- v. Resistance to modern drugs (MDT), a form of adaptation, is slow to develop which is a complimentary feature from disease control point of view. But given our expectation that the disease would persist much longer, it is a possible scenario. Reports from tertiary care centres and from follow-up studies of those leprosy cases released from treatment (RFT) alert us to the possibilities and call for a greater surveillance effort.
- vi. Studies show significant rates of relapse in those leprosy cases released from treatment - as well as inappropriate categorization. There is also a risk to develop new deformities that can occur even after RFT of which neither the patient nor healthcare provider is aware. Follow-up mechanisms of those released from treatment are currently non-existent and urgently require to be put in place.
- vii. There is potential scope for developing epidemiological methods and tools based on GIS which it would identify hot-spots, probe determinants of disease transmission and guide the health systems to focus the interventions in a more effective manner.
- viii. There is also a need to perceive leprosy as a non-communicable disease - a cause for peripheral neuropathy - with prevalence currently at about 20 per 10,000 persons which would require its own strategy of early detection, secondary prevention and management of complications - like most other non-communicable diseases (NCDs).

b) Organization of service delivery and health systems perspective:

- i. Leprosy is essentially a part of primary health care systems and how well it performs under integration depends on the way they perform in that state.
- ii. Where ASHA programme is functional and ASHAs are well supported and paid in time, their contribution to leprosy control is impressive. But where the ASHA programme is weak, leprosy programme gains very little from it.
- iii. Integration should help if all the primary providers are sensitized and trained on detection of leprosy, on counselling those who are detected, and recognition of complications requiring referral. Well organized leprosy outreach (LOR) camps where primary providers participate, but those with experience also are present and leading the process is one effective way of sensitization and capacity building for this purpose. Mobile clinics which bring the more specialized human resources could be linked to LOR camps to achieve capacity building and case detection expected.
- iv. For management of complications, whether lepra reactions or disability due to neuropathy, there is a need for some degree of expertise and constant exposure to a larger number and wider types of cases. These functions are best organized as a part of

- leprosy referral centres (LRCs) which can be located at block level - usually CHC as mandatory in endemic districts.
- v. The medical and nursing personnel in the LRC would require sensitization in training, but the key HR would be a physiotherapist or occupational therapist who could require a much more intensive training on all aspects of leprosy with subsequent mentoring and follow-up. The paramedical worker sanctioned under NLEP does not have sufficient clarity either as a part of HR policy or in terms of where and how they would be deployed and contribute.
 - vi. It was noted that both LORs and LRCs did well on the small scale by NGO on a pilot basis but effectiveness decreased on scaling up. Managing scaling up more carefully is a part of the challenge of taking these two strategies to scale.
 - vii. In all districts validation of estimates by special surveys is essential. In non-endemic districts, surveys could be done once in three to five years. Categorization by prevalence rates has the inherent problem that districts with large population sizes have low rates but contribute a greater burden of disease. This needs to be addressed by having an additional categorization based on absolute number of new cases detected per year- and then drilling down to identify the hot-spots within these districts.
 - viii. Grave absence of lack of skills/knowledge for the management of leprosy-related disability in physiotherapy course was highlighted making in-service training for it mandatory. It was mentioned that 12th Plan of NLEP had proposed the appointment of a physiotherapist at the district level under NLEP which needs technical and practical inputs.
 - ix. A number of medical college departments, NGO hospitals and government leprosy research institutes which have the skills and tradition must be designated as tertiary care sites for leprosy control. Every LRC should be linked to and mentored by these centres. Such tertiary care centres would be able to access and treat lepra reactions that require Thalidomide, disabilities that require a consultant's guidance or reconstructive surgery, cases of non-response, relapse and suspected drug resistance.
 - x. These designated tertiary care centres for leprosy would also need to sustain their own capacity by networking, research and post-graduate and doctoral educational programmes. Innovative and visionary financing of such organizations is essential. The importance of creating dermatologists, pathologists and plastic surgeons with special interest in managing this disease is both an essential requirement and an outcome of these centres.

c) Social dimensions of leprosy and its consequences:

- i. Stigma associated with the disease has persisted into the 21st century in all its four essential forms- discrimination, social exclusion, segregation and diminished sense of

self-worth. It is not the persistence of leprosy per se that undermines our aspirations to modernity and recognition as a world leader but the persistence of stigma that is our true shame.

- ii. One important dimension of the battle against discrimination is legal. The anachronistic laws that criminalize leprosy and those that stigmatize and discriminate against the person affected with leprosy must be repealed or amended forthwith.
- iii. The workshop heard four insightful presentations on addressing the needs of leprosy colonies. One by an NGO organizing and empowering the leprosy colonies, second by the representative of the association of people living with leprosy, third a positive case study of the Bihar - Nepal border, and the fourth a case study of leprosy colonies in West Bengal.
- iv. In terms of health care in leprosy colonies, the strategies suggested include having a community health volunteer or ASHA for each colony from amongst those living with leprosy, encouraging self care and organizing community level care for all inmates and designating an LRC and one leprosy tertiary care centre for the referral service needs.
- v. In terms of empowerment a management committee/association for the colony and a network of such colonies represent the way forward. But this must be supplemented by capacity building which in turn requires good networking with NGOs for which financial support is required.
- vi. Certification of disability in people affected by leprosy based on the severity was also an issue. There was concern that though there are many schemes in which monetary support is given to the LAPs with deformity, there are no uniform policies and methods for quantifying deformity.

d) Governance and priority issues:

One of the central challenges is to retain prevention/cure of leprosy in the priorities of governments. A disease with no mortality and relatively invisible, almost exclusively affecting the poor and the most marginalized misleads media and diverts public attention, resulting in misplacing political prioritisation. The workshop deliberated on these issues and called for the following measures:

- i. Planned advocacy and championing an understanding that the elimination of leprosy is feasible, even though it is likely to take many more years, and that successful elimination of leprosy requires significant changes of strategy. Failure to do so is fraught with the dangers of its comeback on the lines of MDR-TB, undermining our aspiration to be counted as one of the modern and developed nations of the world.
- ii. A focus on making disability amongst children unacceptable, as happened for polio, where even a single child with neurological deficit was unacceptable. Leprosy causes

disability in several hundred children currently and this could be prevented with much less cost than expenditure incurred for polio eradication.

- iii. The thrust on elimination of leprosy should be used for strengthening population based primary health care where the health status of everyone in the population is documented and the primary health care team takes responsibility for prevention, promotion and cure of leprosy and related complications in its area of operation.
- iv. The fight against stigma and discrimination cannot be done by the government alone and partnership with NGOs working in this sector is a key to realizing this objective.

The draft record of proceedings was circulated and incorporates inputs from every participant before finalisation and submission of recommendations to the Ministry of Health and Family Welfare (MoH&FW) through Central Leprosy Division (CLD), New Delhi.

PROGRAMME SCHEDULE

Day 1: 14.10.2015 Registration (08.30 am to 09.00 am)

Inaugural session	09.00 am to 10.40 am
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- Welcome address : Dr. Nilesh Gawde, *Assistant Professor, Centre for Public Health, School of Health Systems Studies, Tata Institute of Social Sciences, Mumbai*
- Theme of Workshop : Mr. A. Antony Samy, *Chief Executive, Association for Leprosy, Education, Rehabilitation & Treatment (ALERT) –INDIA, Mumbai*
- Inaugural address : Prof. T. Sundararaman, *Dean, School of Health Systems Studies, Tata Institute of Social Sciences, Mumbai*
- Keynote address : Dr. V. Pannikar, *Formerly Team leader, Global Leprosy Programme, World Health Organization, Office of South-East Asian Region, New Delhi*
- Address by Director, TISS : Prof. S. Parasuraman, *Director, Tata Institute of Social Sciences, Mumbai*
- Current leprosy scenario : Dr. P. Krishnamurthy, *President and Managing Trustee, Damien Foundation India Trust (DFIT), Chennai*
- Release of “LEAP” publications : By the Chief Guest / Guest of Honour
- Vote of thanks : Dr. Mathew George, *Chairperson, Centre for Public Health, School of Health Systems Studies, Tata Institute of Social Sciences, Mumbai*

Tea (10.40 am to 11.00 am)

SCIENTIFIC SESSIONS

Session 1	Current Epidemiology of Leprosy (11.00 am to 01.00 pm)
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Chairperson: Dr. P. Krishnamurthy	Rapporteur: Dr. Rajan Babu
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- Molecular epidemiology – new tool for an old disease : Dr. Nerges F Mistry, *Trustee and Director, The Foundation for Medical Research (FMR), Mumbai*
- Critical appraisal on current status of Leprosy : Prof. Harshad Thakur, *Faculty, Centre for Public Health, School of Health Systems Studies, TISS, Mumbai.*
- Contemporary epidemiological tools to predict the trends of leprosy : Dr. Vasna Joshua, *Sr. Scientist, National Institute of Epidemiology (ICMR), Chennai*
- Case detection campaigns – relevance and design : Mr. Ashutosh Prabhavalkar, *Head, Programmes (Leprosy), ALERT-INDIA, Nagpur, Maharashtra*
- Revisiting criteria for categorisation of leprosy endemicity to optimise control strategies : Dr. V. R. Pemmaraju, *Technical Officer – Global Leprosy Programme, WHO -SEARO, New Delhi*

Open forum	: Discussion : views from participants
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Lunch (01.00 pm to 02.00 pm)

Session 2	Integrating leprosy in Primary Healthcare (02.00 pm to 03.30 pm)
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Chairperson: Dr. Sunil Anand	Rapporteur: Mr. John Kurien George
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- Health Policy and Planning relevant to leprosy control : Dr. Rajib Dasgupta, *Professor, Centre of Social Medicine and Community Health, School of Social Sciences, Jawaharlal Nehru University, New Delhi*
- Healthcare workers and detection of leprosy : : Dr. Anil Kumar, *Deputy Director, National JALMA Institute of Leprosy and Other Mycobacterial Diseases (ICMR), Agra, Uttar Pradesh*
- Unseen leprosy burden in rural areas of Maharashtra –its policy implications : Dr. Vanaja P Shetty, *Deputy Director, The Foundation for Medical Research (FMR), Mumbai*
- Integrating leprosy in primary health care: the Bihar experience : Dr. Aashish Wagh, *NLEP Consultant – Bihar, Damien Foundation India Trust (DFIT), Patna, Bihar*
- Role of ASHA and leprosy control : Learning from Maharashtra : Dr. V. K. Rokade, *Assistant Director of Health Services (Leprosy), Govt. of Maharashtra, Pune, Maharashtra*

Tea (3.30 pm to 04.00 pm)

Session 3	Operational challenges in Leprosy control (04.00 pm to 05.30 pm)
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Chairperson: Dr. Atul Shah	Rapporteur: Dr. Rajbir Singh
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- Challenges in leprosy control – Anthropologists’ perspective : Prof. R. K. Mutatkar, *Medical Anthropologist, Interdisciplinary School of Health Sciences, Savitribai Phule Pune University, Pune, Maharashtra*
- Sustaining leprosy expertise in post integration : : Mr. S. Kingsley, *Head – Knowledge Management, ALERT-INDIA, Mumbai*
- Disability prevention and management – healthcare model for next decade : Dr. Nilesh Gawde and other *Faculty members, Centre for Public Health, TISS, Mumbai*
- Continuing challenge of disability management in leprosy : Dr. Vivek V Pai, *Director, Bombay Leprosy Project, Mumbai*
- Rethinking tertiary healthcare in leprosy : Dr Sunil Dogra, *Additional Professor, Department of Dermatology, Venereology & Leprology Post Graduate Institute of Medical Education & Research, Chandigarh*

Open Forum	: Discussion : views from participants
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Day 2: 15.10.2015 Breakfast (08.30 am to 09.30 am)

Session 4	Stigma, discrimination & integration of people affected (09.30 am to 11.30 am)
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Chairperson: Dr. V. R. Pemmaraju	Rapporteur: Dr. W. S. Bhatki
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- Leprosy stigma in 21st century : Ms. Jayashree, *CEO, iBAS Consulting, Bangalore, Karnataka*
- Dynamics of leprosy colonies and possible futures : Dr. P. K. Gopal, *President, International Relations, IDEA (Integration, Dignity & Economic Advancement of PAL) India, Erode, Tamil Nadu*

- Replicable model for leprosy rehabilitation : Ms. Kabita Bhattarai, *Director, Little Flower Leprosy Welfare Association, Ruxaul, Bihar*
 - Leprosy and Human rights : Mr. Mohd Tarique, *Koshish Project, School of Health System Studies, TISS, Mumbai*
 - Leprosy and community : Mr. Narsappa, *President, Association for People Affected by Leprosy, Hyderabad*
 - Leprosy colonies in West Bengal- a case study : Mr. Soumik Sau, *MPH student, Centre for Public Health, TISS, Mumbai*
 - Leprosy and the law : Ms. Nikita Sara, *Head - Advocacy & Communications The Leprosy Mission India Trust, New Delhi*
- Open Forum : Discussion : views from participants

TEA (11.30 pm to 12.00 noon)

Session 5	ILEP & NLEP Partnership: Good practices & learning (12.00 noon to 01.00 pm)
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Chairperson: Dr. A. K. Puri	Rapporteur: Dr. V. V. Pai
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- **Mr. John Kurien George** : Swiss Emmaus Leprosy Relief Work India
- **Dr. Sunil Anand** : The Leprosy Mission - India
- **Mr. M. V. Jose** : Associazione Italiana Amici di Raoul Follereau
- **Dr. Rajbir Singh** : German Leprosy & TB Relief Association - India
- **Dr. Aashish Wagh** : Damien Foundation India Trust
- **Dr. Vineeta Shankar** : Sasakawa India Leprosy Foundation

Lunch (01.00 pm to 02.00 pm)

Concluding session (02.00 pm to 03.30 pm)

Chairperson: Dr. A. K. Puri	Co-Chairperson: Dr. V. V. Dongre
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- Summary of learning and discussion on way forward : Presentation by Rapporteurs of scientific sessions
- Mainstreaming Corporate Social Responsibility for the cause of leprosy : Ms. Harsha Mukherjee, *Managing Director, International Institute of Corporate Sustainability and Responsibility (IICSR), Mumbai*
- Valedictory address : Prof. T. Sundararaman, *Dean, School of Health Systems Studies, Tata Institute of Social Sciences, Mumbai*
- Concluding remarks : Chairperson and Co-Chairperson
- Vote of thanks : Mr. Antony Samy, ALERT-INDIA

TEA