Best practices to ensure sustainable quality care for leprosy affected persons

at the district level referral centre through general health care system

National Workshop

21 & 22 October, 2009

A beginning: Leprosy services provided by the general health care staff across the country

Organised by

in collaboration with

Central Leprosy Division
Govt. of India, New Delhi

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National Workshop

on

Best practices to ensure sustainable quality care for leprosy affected persons at the district level referral centre through General Health Care system

21 & 22 October 2009, Mumbai

A report on the Proceedings and Recommendations

Organised by

ALERT-INDIA

Association for Leprosy, Education, Rehabilitation & Treatment - India

in collaboration with

Central Leprosy Division,
Govt. of India, New Delhi

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New Delhi

Photo Courtesy : Dr. I. Banerjee, Dr. P.K.B. Patnaik, Dr. P. Vijayakumaran and Mr. M.V. Jose

Acknowledgment of need - the first step towards finding a way out!

The logical next step, after the thrust in reducing the disease burden at the national level, is to ensure quality leprosy services, both for short and long term care, within the general health care system. In response to this concern, the Central Leprosy Division (CLD) implemented Disability Prevention and Medical Rehabilitation (DPMR) programme, as a component of NLEP that is aimed at providing quality care to all leprosy affected persons at primary, secondary and tertiary levels of general health care system.

In this context, the rights based approach demands providing quality leprosy services at the district level referral centre within the general health care system. Since the service providers at the primary level care are often not equipped with the required technical skills and material resources, they rely mostly on the secondary and tertiary level centres for quality services through referrals.

In response to this call, NLEP had taken a serious note of this crucial aspect of the programme and given a consent and collaboration to the objectives of this WHO - India sponsored national workshop. One single factor that will help fulfill the objectives is to identify the existing resources and facilities available within the GHC system in the district and make necessary policy directions to effectively orient and utilise the GHC system for providing quality leprosy services. This can explicitly tackle the social ostracism that is at the root cause for stigma associated with leprosy.

Sion, Mumbai - 22
27 November, 2009

A. Antony Samy
Chief Executive, ALERT-INDIA

Need for a vibrant referral system !

A. Antony Samy
Chief Executive, ALERT-INDIA, Mumbai

Mr. A. Antony Samy explained the purpose and the rationale for this National Workshop. He called upon all the NLEP Partners and stakeholders to share the common concern to assure quality services to leprosy affected persons within the GHC system.

He said that the quantum of funds for leprosy control work has come down due to reported decline in number of new leprosy cases. He explained that the quantum of funds should not be determined on the basis of new leprosy cases currently being reported. Also asserted that we all have a collective obligation for treating all leprosy affected persons needing long-term care. Accessing quality care and services at different levels of general health care system is a matter of right of the leprosy affected persons and it should not be considered as a relief to the victims of leprosy out of pity or piety.

He also said that there is an urgency

(i) to identify the existing resources and facilities available at district level;

(ii) to enlist the training needs;

(iii) to strengthen the knowledge, skills and motivation of the health workers in the GHC system; and

(iv) to define major services that are to be provided at the block / district level, based on the need of the leprosy affected persons.

He emphasised the fact that responding to the needs of the leprosy affected persons is the primary concern of this two day National workshop. He justified that such a national level consultation by the Programme Managers and the experts from the field of leprosy and public health can pave way to move a step forward towards establishing a vibrant referral services for the leprosy affected persons in the country. ■

Inaugural Session

An invocation song by ***Mrs. Sunita Vittal,*** *Information and Liaison Officer, ALERT-INDIA* and ***Mr. Kamlesh Chavan,*** *Programme Officer, ALERT-INDIA* blessed the occasion and provided the requisite atmosphere.

Mrs. Veera Rao, *Director,*
Resource Mobilization Unit, ALERT-INDIA
Mrs. Veera Rao extended a warm floral welcome to the Chief Guest, Guests of Honour, Programme Managers from Central and State Governments, Representatives from WHO, ILEP & NGOs and welcomed all the delegates of National Workshop.

Dr. V. V. Dongre, *Sr. Consultant,*
LEAP, ALERT-INDIA, Mumbai
Dr. V. V. Dongre introduced the Chief Guest and the Guests of Honour present on the dias.

Chief Guest: **Dr. B. D. Athani**

Additional Director General of Health Services & Director, All India Institute of Physical Medicine and Rehabilitation, Mumbai

In his inaugural address, Dr. B. D. Athani quipped that how the general health care system has responded to the integration of the leprosy services and need to assess its impact from the point of health care providers and leprosy affected persons.

He mentioned that most district hospitals do not have trained staff to provide rehabilitation services and suggested to integrate the rehabilitation services for people with leprosy and other disabilities and thus establish, redefine and strengthen 'Rehabilitation centres' at the district level.

He proposed that the GHC system at the secondary level, having accepted the responsibility, can begin special clinics for providing a range of leprosy services. He added that these special clinics must create linkages with the District Rehabilitation Centres. He emphasized that the social integration of the leprosy affected persons into the society is utmost important in order to minimize the stigma. ■

Message: **Ms. Catalina Echevarri**

Desk Officer – India & Bangladesh, Anesvad Foundation, Spain

Ms. Catalina informed that the leprosy situation today is different from 20 years ago, yet leprosy is still a public health problem that need to be solved. She stressed the need to reaffirm the political commitment for the development of a referral system by strengthening the referral facilities wherever needed. She added that in the modern times, if a person develops disabilities and deformities due to leprosy, the problems could be ignorance about the disease and delay in prompt diagnosis and treatment with MDT.

She opined that the proposal of the Govt. of India on establishment of district level referral centre within the general health care system is a positive event and requires a will and qualified human resources. She mentioned that the Leprosy Elimination Action Programme (LEAP) implemented by ALERT-INDIA is a good practical example to provide quality care at secondary level. She conveyed wishes to all the participants for a fruitful and successful discussion on behalf of Anesvad Foundation. ■

Guests of Honour: **Dr. Indranath Banerjee, Dr. K. R. Thankappan & Dr. P. P. Doke**

The Guests of Honour stressed the importance of this National Workshop for the national leprosy control programme. ■

Mrs. Stella Mancheril

Director – Finance, ALERT-INDIA, Mumbai

Mrs. Stella Mancheril proposed a vote of thanks to all the guests and delegates of this National Workshop.■

Strategies and best practices adopted for strengthening referral system at the secondary level within the GHC system as per GOI directives

Presentations by Programme Managers of 7 States
(abstracts)

Dr. K. L. Sinha, *Jt. Director of Health Services (Leprosy), Govt. of West Bengal*

Dr. Sai Babu, *Additional Director of Health Services (Leprosy), Govt. of Andhra Pradesh*

Dr. R. N. Verma, *State Leprosy Officer, Govt. of Chhattisgarh*

Dr. P. K. B. Patnaik, *Assistant State Leprosy Officer, Govt. of Orissa*

Dr. N. D. Deshmukh, *Assistant Director of Health Services (Leprosy), Govt. of Maharashtra*

Dr. N. Nagarajan, *Surveillance Medical Officer, Directorate of Health Services, Govt. of Tamil Nadu*

Dr. Nilesh Shah, *District Leprosy Officer, Govt. of Gujarat*

Chairperson:

Dr. Indranath Banerjee
National Professional Officer for Leprosy,
WHO - India, New Delhi

Co-chairperson:

Dr. Ashok Ladda
Joint Director of Health Services (Leprosy & TB),
Govt. of Maharashtra, Pune

Dr. I. Banerjee - Chairperson (R)
Dr. Ashok Ladda - Co-chairperson (L)

Dr. K. L. Sinha, *Govt. of West Bengal*

Dr. K. L. Sinha said that the training for self care and ulcer care at PHC level has been completed and updating of disability registers at the block level is in progress. Except 2 out of 19 districts in West Bengal has reached the level of elimination as on March 2009, i.e. 1 case per 10,000 population. He also said that 4 Sentinel centres are identified under the directives of GOI to investigate drug resistance in relapsed leprosy cases. ■

Discussion: *Dr. Barkakaty clarified that such Sentinel centres are initiated recently under the WHO Global strategy for leprosy.*

Dr. Sai Babu, *Govt. of Andhra Pradesh*

Dr. Sai Babu mentioned that all the districts have reached the goal of leprosy elimination in AP state. He also stated that the staff at District Nucleus, District Hospitals and Temporary Hospitalization Wards (THWs) are involved in the referral system at the secondary level. He said that the referral system is the part and parcel of NLEP and Reconstructive Surgeries (RCS) are done in NGO hospitals and Government Medical colleges. Efforts are being made to make the Community Health Centre (CHC) of the Government as secondary level referral centres for leprosy. He pointed out the issues such as lack of infrastructure at the secondary level institutions, non-availability of trained personnel, vacancy of DLO posts (50%) and inadequate supply of drugs and Physiotherapy materials. He also said that the involvement of the secondary and tertiary level institutions and their linkages with the primary level institutions is the main concern.

As a 'best practice', the referral system practised in Andhra Pradesh State can it be said that "According to us the best practice is one where the GHC has gained confidence of the leprosy affected persons and the local community there by encouraging voluntary reporting and thus to reduce stigma. ■

Discussion: *Dr. Dongre pointed out that continuation of THWs can give rise to stigma and in the integration phase such a set-up should not exist. Dr. Sai Babu replied that the State Government is planning to convert these THWs as Referral centres, however no specific guidelines are issued by the CLD in this regard.*

Dr. R. N. Verma, *Govt. of Chhattisgarh*

Dr. R. N. Verma said that the current prevalence rate (PR) of leprosy is 2.3 per 10,000 population in Chhattisgarh state as on March 2009. He stated that 3,380 persons with Grade II disabilities were assessed since 2001 and 954 cases underwent reconstructive surgery. 78 out of 106 Block Medical Officers were trained in Disability Prevention and Medical Rehabilitation (DPMR) programme and report format were printed and distributed. However the training of Multipurpose Workers (MPWs), Health Supervisors (HS) and Medical Officers (MO) of PHCs is in progress. 18 Laboratory Technicians (LT) and 27 Physiotherapy Technicians (PTs) have been trained for skin smear examination and in pre and post operative care respectively. MCR footwear production has been

started and 511 leprosy affected persons benefited during 2008-09. RCS services are being provided by the Regional Leprosy Training and Research Institute (RLTRI) and NGOs (ILEP) in 3 districts. He expressed concern that only 8 out of 18 District Leprosy Officers (DLO) post are filled and there is no provision for District Nucleus Team (DNT) at the districts. He concluded that (i) a special order issued by the Secretary for Health, Government of Chhattisgarh to the regional Directors of Health and Chief Medical Officers (CMO) to monitor all the national disease control programmes including leprosy on weekly basis and (ii) involvement of Village Health and Sanitation Committee for awareness generation and early referral of leprosy suspects. These can be considered as 'best practices' in Chhattisgarh state. ■

Dr. P. K. B. Patnaik, *Govt. of Orissa*

Dr. P. K. B. Patnaik said that 11 out of 30 districts are tribal and 48% of the population belongs to the category of below poverty line (BPL) in Orissa state. As on March 2009, 20 out of 30 districts have reached the level of leprosy elimination. He said that although 50% of the population live in unapproachable areas, the basic health services are reached through the Accredited Social Health Activist (ASHA) workers under National Rural Health Mission (NRHM). He informed that all 30 districts have full functional District Nucleus Team (DNT) and the Government of Orissa is planning to upgrade all the Medical Officer of DNT as DLOs. Under best practices, the Govt. of Orissa has formed an 'Apex Group' headed by a Dermatologist including a specialist in Medicine, Orthopedics, Ophthalmology, Laboratory Technician, Physiotherapy etc, in all districts who provide appropriate services to leprosy affected persons referred to district hospitals. Additionally, DPMR clinic has been established at every district hospital under MO of DNT and Dermatologist of district hospital has been entrusted to attend DPMR clinic on regular basis and logistics is provided by local Rogi Kalyan Samiti (RKS). ■

Dr. N. D. Deshmukh, *Govt. of Maharashtra*

Dr. N. D. Deshmukh said that 157 referral centres have been established at District Hospital (DH), Sub-District Hospital (SDH), Rural Hospital (RH) and NGOs in Maharashtra state of which 61 referral centres are under support from ALERT-INDIA in 8 districts. He said that the referral system in 3 tier Health Care system is functional in Maharashtra.

Health staff working at each level are well oriented and maintain good communication network. He listed issues like untrained staff at Referral centre, non-availability of logistical support and lack of publicity about referral centres as constraints. He stated that the Project Implementation Plan (PIP) is totally normative and have no scope for innovation. He also called for more flexibility in initiation of new activity and funds are required to enhance basic infrastructure, procurement of equipments for referral centres. ■

Discussion: *Dr. Ladda mentioned that as far as referral services at secondary level, Govt. of Maharashtra has taken a step forward, however he stressed the need to reorganize the human resources as systematically managed under RNTCP.*

Dr. N. Nagarajan, *Govt. of Tamil Nadu*

Dr. N. Nagarajan said that all the 30 districts in Tamil Nadu state have attained the goal of leprosy elimination. He pointed out that about 80% of the District Leprosy Officer posts are vacant in Tamil Nadu and GHC staff are not adequately trained to manage consequences of leprosy.

The District Nucleus Team (DNT) consists of Medical Officer, Health Educator (HE), Non-Medical Supervisor (NMS), Physiotherapy Technician (PT) and Health Inspector (HI), in addition to their routine work, they conduct refresher training for GHC staff to enrich their knowledge so that they can identify and refer suitable cases for required services. He said that funds for infrastructure and logistics are needed to establish referral centres at District hospitals. ■

Dr. Nilesh Shah, *Govt. of Gujarat*

Dr. Nilesh Shah stated that the referral system in Gujarat state is functional as per the DPMR guidelines, however additional funds are required to strengthen referral at secondary level. Referral services must be integrated into the GHC system and make it accessible to leprosy affected persons in need. He said that all vertical staff in Gujarat state has been trained for DPMR activities. Additionally, during 2008-09, GHC staff will be provided training for DPMR activities.

He also said that frequent transfer, non availability of trained personnel, lack of motivation and accountability of GHC staff, insufficient transport facility and inadequate funds are the matter of concern. The services of Dermatologist / Medical Specialist, General Surgeon, Eye specialist, Orthopedic Surgeon, Physiotherapy technician, Laboratory technician and Nursing assistant available at the district hospital can be utilized. He proposed to provide special funds to PHCs for referral of cases towards travel expenses and loss of wages. ■

Release of 'FOCUS'

As a part of ALERT – INDIA's effort to gather informed support for leprosy control, a publication called **'FOCUS - Series 4'** (October, 2009) was released at the hands of Dr. B. D. Athani, the Chief Guest.

This special issue consists of 'operational guidelines' for Selective Special Drives (SSDs) and Leprosy Referral Centres (LRCs) that are the components of Leprosy Elimination Action Programme (LEAP).

The copies of ALERT-INDIA's publications along with the copies of 2 documents – Plan and Operational Guidelines of the WHOs' Enhanced Global Strategy for Leprosy (2010-2015) – were distributed to all participants of the Workshop.

Release of FOCUS Series No. 4 at the hands of Chief Guest & Guests of Honour

Models of referral services being practised in different states: Best practices and norms for providing quality care to leprosy affected persons at the secondary level within the GHC system

Presentations by ILEP Agencies & NGOs working in India

Mr. M. V. Jose
Representative for India, Associazione Italiana Amici di Raoul Follereau (AIFO) - India, Bangalore

Dr. P. Vijayakumaran
Director – Programme, Damien Foundation India Trust (DFIT), Chennai

Dr. Mannam Ebenezer
Director, Schieffelin Institute of Health & Leprosy Centre (SIHLC), Karigiri, Tamil Nadu

Dr. W. S. Bhatki
Executive Director, Maharashtra Lokahita Seva Mandal (MLSM), Mumbai and Coordinator – Mumbai District Monitoring Team, LEAP, ALERT – INDIA, Mumbai

Dr. Atul Shah
Director, Novartis Comprehensive Leprosy Care Association, Mumbai

Chairperson:

Dr. K. R. Thankappan
Prof. & Head, Achutha Menon Centre for Health Science Studies, Sree Chitra Tirunal Institute for Medical Sciences and Technology, Trivandrum

Co-chairperson:

Dr. V. V. Pai
Director, Bombay Leprosy Project, Mumbai

Dr. K. R. Thankappan - Chairperson (R)
Dr. Vivek V. Pai - Co-chairperson (L)

Mr. M. V. Jose

Representative for India, Associazione Italiana Amici di Raoul Follereau (AIFO) - India, Bangalore

Mr. M. V. Jose said that AIFO - India is working in Assam state, which is an important hub for North-Eastern states. The PR was 0.4 as on March 2009. He said that the availability of health personnel and medical specialist vary from state to state, hence he proposed that each state formulate its own referral system. He also said that the District Nucleus Team is not a viable structure to deliver quality services at the secondary level.

To achieve the goal of DPMR, the following are the basic requirements: (i) utilize communication facilities, (ii) provide & utilize mobility (transportation) facilities and (iii) Socio-economic support for the leprosy affected persons. He said that there is no attempt made to collect information on persons needing special services and this justifies the need for a strong, sustainable referral system.

He concluded that efforts to explore and utilize available resources, sustain and develop already existing Referral System and promote equal proportions of priority with other diseases. He stressed not to consider as a place of segregation for establishing a Referral Centre at secondary level – but as a specialized care centre for management of leprosy related complications. He recommended that referral system evolved through NLEP initiatives should become a model in general for any diseases in the coming years. ■

Dr. P. Vijayakumaran

Director – Programme, Damien Foundation India Trust (DFIT), Chennai

Dr. P. Vijayakumaran shared the experiences of DPMR programme in integrated health care system implemented in Tamil Nadu state by DFIT. He said that 200 PHC workers in the Salem district have been trained in delivering POD services during 2001-02. The evaluation of this programme showed that a very few patients practiced self care, general health staff not fully involved and the health workers not willing to take up new or additional work. Therefore DFIT adopted a new strategy to promote capacity of GH staff to implement and sustain DPMR in collaboration with District Nucleus Team and facilitation by the local NGO.

The methodology includes practical training on self care practices with effective network for referral services at PHC, District Nucleus and the NGO centres. The components of self care practice are: Inspection – Soaking – Scraping – Oiling and Dressing (ISSOD). No materials were supplied to the patients (No dependence on health system).

Patients were encouraged to use materials available at home for daily soaking (old pots, bucket, etc); rough stone without sharp edge for scraping; old cloths – washed – dried in sunlight – for dressing the wounds and Neem oil for oiling as it is cheap and repels rodents and insects. 1356 patients with disabilities from 9 UHPs and 20 blocks were trained during 2004 to 2009. It was observed that 80% of the patients practising self care and 75% of the ulcers healed. 2350 MCR

footwear were supplied of which 19% sponsored by the community. The programme was replicated in Trichy and Pudukottai districts with similar results. The challenges observed were labour intensive, difficulty in sustaining motivation among the GH staff, lack of MCR footwear supply, developing recurrent ulcers and lack of RCS facilities at Govt. Medical College. ■

Dr. Mannam Ebenezer

Director, Schieffelin Institute of Health & Leprosy Centre (SIHLC), Karigiri, Tamil Nadu

Dr. Mannam Ebenezer said that the goal of establishing the referral services for leprosy would be to utilize the existing tiered approach in the General Health Care system to treat leprosy and its complications. He said that the role of NGOs in referral services should be towards (i) support in establishing referral system in the GHC system; (ii) capacity building for Trainers in the GHC system and for specific skills at each referral level; (iii) continue to function as a part of the referral system by providing referral services and (iv) carry out Operational research in establishing sustainable systems and best practice methods.

He said that such an attempt will increase the strength and the credibility of the NLEP and there is a need to define the role of District Nucleus and it should facilitate linkage between PHCs and District hospitals. The NGOs should assist NLEP in initiating a functional referral system with technical support that ought to complement and not substitute the GHC system. He stressed that ulcer care is more important than correcting deformity by reconstructive surgery. He suggested that a set of training faculty be identified at State level and these trainers team can be given intensive training at existing leprosy training centres. Subsequently these trained faculties can provide capacity building of the identified health personnel at the district level. Involving the local Rogi Kalyan Samiti, Panchayat Raj Institutions and the Health & Sanitation Committees as well as empowering the community in referral system is crucial. ■

Discussion: *Promoting public – private initiative can be a model for best practice. He emphasized that integrating leprosy affected persons into the community should be the ultimate goal. He questioned that can we enable the district hospitals to treat leprosy on par with other diseases as part and parcel of their routine work.*

Dr. W. S. Bhatki

Executive Director, Maharashtra Lokahita Seva Mandal (MLSM), Mumbai and Coordinator – Mumbai District Monitoring Team, LEAP, ALERT – INDIA, Mumbai

Dr. W. S. Bhatki presented the unique model of referral services being practiced by ALERT – INDIA in collaboration with the NLEP units of Govt. of Maharashtra and NGOs. He said that providing quality services is one of the strategies of NLEP under its Disability Prevention and Medical Rehabilitation programme. He explained that ALERT – INDIA has assisted 62 Leprosy Referral Centres (LRCs) in 7 districts of Maharashtra under LEAP within the GHC system at Sub-District Hospitals (SDH) and Rural Hospitals (RH) as secondary level care. The role of these LRCs are to provide sustained quality care to all needy leprosy affected persons referred by the

primary level institutions and facilitate higher level referrals to tertiary level centres for specialized services.

He informed that ALERT - INDIA has prepared an 'Operational Guidelines' for establishing LRCs at secondary level. He also said that the LRCs can act as a teaching centre for organizing Continuing Medical Education (CME) programmes to all categories of GHC staff as well as promote a platform for conducting advocacy meetings. He mentioned that the functioning of LRCs depend on good coordination between the District Leprosy Officer, District Health Officer and the Civil Surgeon as these officials have administrative control of the GHC system in each districts.

He said that the following factors were considered before establishing referral centres: (i) location at the sub district level Hospital, (ii) available resources - Medical & Paramedical staff and services under GHC, (iii) infrastructure support provided by ALERT - INDIA – furniture, equipment and other logistics; (iv) technical support provided by ALERT – INDIA - Capacity building of GHC staff in leprosy and LRC management; (v) motivation of the GHC staff to take the responsibility of managing LRC; (vi) frequency of operations – weekly / biweekly / daily depending on the case load and (vii) monitoring and supervision by ALERT – INIDA teams and District Leprosy Officers.

He said that considering the above factors the LRCs in Mumbai, Thane, Raigad and Vidarbha region are extended full and partial support by ALERT – INDIA's team. In Nashik and Nandurbar districts, the LRCs are fully managed by the local NLEP and GHC personnel and monitored by ALERT – INDIA's team. He said that lack of priority for leprosy by the GHC, frequent transfer of trained health personnel and inadequate coverage of beneficiaries are the issues that need to be addressed.

He suggested that to sustain LRCs on long-term basis, the GHC system must accept full ownership of the referral centres that can be achieved by providing proper guidelines and technical support with adequate referral mechanism at the secondary level. ■

Dr. Atul Shah

Director, Novartis Comprehensive Leprosy Care Association, Mumbai

Dr. Atul Shah said that enabling persons with disabilities to get certain services that are not within the ambit of GHC system at primary level to maintain their optimal physical and social function is the process of referral system.

He said that the best practice to achieve this is to establish a well equipped center to offer sustainable care for empowerment and rehabilitation thereby providing the leprosy affected persons with tools to change their lives towards a higher level of independence.

He quoted that the proportion of 'leprosy cured' is included in the 'loco-motor disability', one of categories of disabilities, which is 55%. In reality, he said that the referrals from the mega camps organized at the primary level are directed towards tertiary level centres in Gujarat state.

He also said that tertiary care centres are more important than secondary level and this alone can sustain specialized leprosy services, provided we involve them. He added that to strengthen the referrals at the secondary level, trainings were given and district officials were provided with funds for material supply.

He also said that the secondary level centres depend on tertiary level centres for material support and therefore the secondary centres should screen all the needy patients and refer to tertiary level centres. He pointed out that most of the tertiary level centres are located in urban areas thereby benefiting the urban population.

He said that there are various institution models for providing physical, vocational and socio-economic rehabilitation services to the disabled. He declared that there is a need to integrate the services with other loco-motor disabilities and the 'Novartis' model tag on a holistic approach but many do not welcome it as the services are provided free of cost.

He concluded that it is possible to train health personnel in offering care at all levels to change the perception of patients that care given is to cure the ailments and ensuring their human rights. ■

Situation analysis for drawing up a sustainable referral system within GHC system

Presentations by Experts from the field of Leprosy & Public Health

Dr. K. R. Thankappan
Prof. & Head, Achutha Menon Centre for Health Science Studies, Sree Chitra Tirunal Institute for Medical Sciences and Technology, Trivandrum

Dr. H. K. Kar
Prof. and Head, Dept. of Dermatology, Dr. Ram Manohar Lohia Hospital, New Delhi

Dr. S. N. Pati
ILEP State Coordinator – Orissa, LEPRA Society, Bhubaneshwar

Dr. Anne Mattam
ILEP State Coordinator – Bihar, Damien Foundation India Trust, Patna

Dr. B. N. Barkakaty
WHO National Consultant for NLEP, Central Leprosy Division, Govt. of India, New Delhi

Dr. T. Sreedhar
Orthopedic Surgeon & Chief Medical Officer (NFSG), All India Institute for Physical Medicine & Rehabilitation, Mumbai

Dr. Dhananjay Katkar
Assistant Director of Health Services (Leprosy) - Pune, Govt. of Maharashtra

Chairperson:

Dr. P. K. B. Patnaik
Assistant State Leprosy Officer,
Govt. of Orissa, Bhubaneshwar

Co-chairperson:

Dr. Sharmila Patil
Head, Dept. of Dermatology
Dr. D. Y. Patil Medical College & Hospital, Navi Mumbai

Dr. P. K. B. Patnaik (Chairperson)
Dr. Sharmila Patil (Co-chairperson)

Referral mechanism for leprosy control in the Government Health Care system : A public health perspective

Dr. K. R. Thankappan

Prof. & Head, Achutha Menon Centre for Health Science Studies, Sree Chitra Tirunal Institute for Medical Sciences and Technology, Trivandrum

Dr. K. R. Thankappan said that despite poor health outcomes as compared to neighboring countries, the health status of India has improved. He mentioned that these are determined by what proportion of population is covered by the existing health services as access to health care vary in different States and regions.

He also pointed out that although there is a consistent decline in the prevalence rate of leprosy in all endemic countries; India contributes to 54% of the total global load.

He said that we need to rejuvenate the primary health care in order to break the viscous cycle of ill health and poverty. He stressed the need for training ASHA and PHC workers for strengthening the referral system to different levels and the role of Private practitioners including the other system of medicines should be defined.

He stated that a strong political commitment is needed for adequate resource allocation. He added that areas like slums, lack of trained personnel, inadequate skills of health personnel and logistic issues are the anticipated problems.

Based on the major recommendations of a WHO Report on social determination on health (2008), he proposed that the (i) improved daily living conditions, (ii) tackling the inequitable distribution of power, money, and resources and (iii) measuring and understanding the problem including the gender equity and assessing the impact of action will enable the civil society to organize and act in a manner that promotes and realizes the political and social rights affecting health equity of the people.

He emphasized that the manpower and resource allocation should be more for preventive care rather than tertiary care. He concluded that even though significant progress has been made in controlling leprosy and reducing burden, much remains to be done in order to sustain gains in collaboration with partners and community based organizations. ■

Strategy to involve specialized health personnel at District level hospitals for providing quality care to leprosy affected persons

Dr. H. K. Kar

Prof. and Head, Dept. of Dermatology, Dr. Ram Manohar Lohia Hospital, New Delhi

Dr. H. K. Kar explained the various indications for routine and emergency referral and specified the categories of health and medical personnel to be made available at the referral level. He stressed that the Dermatologists or medical specialists posted at the District hospital should be the main referral point who will act as a nodal officer. He suggested that this

Specialist will have a link with other medical specialists such as Ophthalmologist, Orthopedic Surgeon / Plastic Surgeon, Laboratory Technician for slit skin smear examination, Physiotherapist and a Social worker / counsellor available in the District hospital.

He outlined the activities and tasks that have to be performed for each of these medical specialists. He proposed a road map for the referral system and highlighted that the Social Worker / Counsellor will liaison and create linkage between leprosy patient, specialists and PHC under DHO / DLO. ■

Sustaining technical expertise for managing referrals at secondary level in the general health care system

Dr. S. N. Pati

ILEP State Coordinator – Orissa, LEPRA Society, Bhubaneshwar

Dr. S. N. Pati elaborated on the service components and the indications of referrals that are to be made at primary, secondary and tertiary level care institutions as proposed under DPMR programme. He said that in the integrated set up, the leprosy patients must be cordially received at the PHC, thoroughly examined, counselled and followed up and referred those in need of special treatment to secondary level with referral slip specifying proper instructions on where & whom to report and clinical documentation.

He insisted that at the secondary level, the leprosy patients referred by the primary level must be received properly, examined and investigated, provided appropriate treatment, gave follow-up advise and referred back to primary level with instructions on continuation of the treatment. In order to sustain the technical expertise to manage the cases at the secondary level, he said that the availability of infrastructure, logistics, trained personnel, supervision and monitoring are the key factors.

He stressed that the technical and logistic support provided by WHO, ILEP and NGOs need to be continued at the present juncture. He also proposed that a periodic evaluation of the programme need to be done by independent experts at the end each two-year period and their recommendations should be implemented for further enriching the programme. ■

Operationalising the referral system: Need for adequate linkages between different level of health system for providing quality leprosy services

Dr. Anne Mattam

ILEP State Coordinator – Bihar, Damien Foundation India Trust, Patna

Dr. Anne Mattam emphatically stated that the leprosy programme has not taken its roots at all PHCs in Bihar state and the District Nucleus Team is to be 'notified' as they are used for various purposes. She listed the problems related to staff, materials and capacity building at the primary level that are essential to strengthen the referral system for implementing DPMR activities. She also pointed out that 8 out of 38 districts have regular District Leprosy Officers and only 4 districts have District Nucleus team, which is

a matter of concern to have a uniform strategy in Bihar state. She stated that all the epidemiological indicators are declining since 2005, except the disability rate (Gr.II cases), which is probably due to the special efforts made by ILEP agencies.

She declared that the training to staff at primary and district level, financial support to RCS at PMR departments of Medical colleges and socio-economic assistance to needy leprosy patients were provided by ILEP agencies like DFIT, NLR, TLM and LEPRA Society, however material support was not provided by the state government.

She stated that sensitization of Dermatologists including the Private Practitioners and PG Medical students were also undertaken in Patna district. She mentioned that the referral services in urban areas are provided by NGOs and Private hospitals. She also said that the formation of Self Care Group involving ASHA and ANM of the PHCs was fruitful in identifying the needs of the leprosy affected persons. ■

Monitoring the quality of leprosy services provided at secondary level under NLEP: Prospects and achievements

Dr. B. N. Barkakaty

WHO National Consultant for NLEP, Central Leprosy Division, Govt. of India, New Delhi

Dr. B. N. Barkakaty said that the District hospital will function as a 'primary level' centre for those patients reporting directly and as a 'secondary level' centre for those patients referred by PHCs.

He stated that there is a distinction between District referral centre and the District Nucleus as the later will function under the District Leprosy Officer. He emphasized the need for linkages with the District Rehabilitation Centre and make services available to leprosy affected persons on all working days.

He told that the District Nucleus will provide logistic support and coordinate the activities between primary, secondary and tertiary level centres.

He proposed the following 5 indicators for assessing the quality of services at district level.

1) % of district hospitals with properly trained specialist;
2) % of district hospitals providing Leprosy services at OPD on all working days;
3) % of district hospital where Physiotherapy unit available;
4) % of district hospital that send samples of suspect relapse cases to the Sentinel Surveillance centres for confirmation and
5) % of District Nucleus that spends 90% or more of allotted budget for procurement of drugs and materials, footwear and on RCS incentives.

He mentioned that the prospects are very 'bright' as the required funds are made available under NRHM and the NLEP partners are willing to extend support for capacity building. He announced that the achievements made so far in NLEP need to be assessed through an evaluation in future. ■

Role of PMR institutions in strengthening DPMR activities under NLEP: Present scenario and the missing link between the primary, secondary and tertiary level institutions

Dr. T. Sreedhar

Orthopedic Surgeon & Chief Medical Officer (NFSG), All India Institute for Physical Medicine & Rehabilitation, Mumbai

Dr. T. Sreedhar elaborated on the evolution of DPMR programme in India under the 11th Five Year Plan that was primarily aimed at preventing the disabilities and deformities due to leprosy.

He stated that the Government of India constituted a group of Experts from Govt. and NGOs and discussed the service components and the levels of service delivery through a consultative meeting based on 6 specific Terms of References (ToR).

1) Prepare list of major components;
2) Describe activities of each component (training requirement, logistics / supply, referral-coordination / linkages, supervision & monitoring, etc.);
3) Identify the functionaries responsible for each of the activities in the first, second and third level of service providing institutions;
4) Prepare job responsibilities of above functionaries in relation to the subject under consideration;
5) List out the resources required and
6) Mention timeframe, wherever applicable.

He reported that the core group made the following specific recommendations:

(i) PMR institutions are to be facilitated with proper equipment for RCS,
(ii) Training of medical and paramedical staff are to be conducted,
(iii) NGO's to refer the cases requiring surgery to the tertiary referral centers,
(iv) Referral centers to conduct the RCS and rehabilitation programme as per the protocol and
(v) Review the work done and the balance of POD cases among new cases are to be identified and assessed. ■

Quality control tool: leprosy case tracking application for programme monitors

Dr. Dhananjay Katkar

Assistant Director of Health Services (Leprosy) - Pune, Govt. of Maharashtra

Dr. Dhananjay Katkar said that following the integration, the reporting system under NLEP is simplified and does not facilitate to assess the true impact of NLEP. He demonstrated a user friendly application software based on WEB 2.0 technology, which can enhance the recording and reporting process of leprosy indicators at various stages that are useful in tracking the treatment completion status of newly registered leprosy cases.

He stated that this new innovation is field tested in Pune district of Maharashtra and is planning to introduce in all the districts after a few enhancements.

He said that the collection, maintenance and analysis of data is time consuming and may not be available at any point of time. He stated that in the present Management Information System (MIS) for NLEP, the flow of information is not standardized and there is no scope for validation of data.

He also said that this application makes the data organization, updating and compilation easy and quickly without any procedural error. He said that the output of data analysis in terms of indicators and projection with reporting features will help the programme managers to monitor with a view to improve the quality of the programme.

He concluded that this application software also aims to introduce an effective referral system by automating the referral process thus it acts as a supportive tool for evolving referral system under NLEP. ■

Discussion: *Dr. P. K. B. Patnaik suggested that this software application can have additional enhancements before wider dissemination and implementation into the programme for data validation.*

Discussion: *Dr. P. P. Doke complemented the State Leprosy Office, Govt. of Maharashtra for developing a useful method to monitor the programme and opined that this application software can be made available online for the programme managers at the district level for monitoring.*

Guiding principles on referral services: Sustainability and future perspectives for quality services to the leprosy affected persons within GHC system

Presentations by Govt. of India & WHO - India

Dr. P. L. Joshi
Dy. Director General of Health Services (Leprosy), Ministry of Health & Family Welfare, Govt. of India

Dr. Indranath Banerjee
National Professional Officer for Leprosy, WHO - India, New Delhi

Chairperson:

Dr. P. P. Doke
Executive Director,
State Health Systems Resource Centre, National Rural Health Mission (NRHM), Govt. of Maharashtra

Co-chairperson:

Dr. M. V. Jose
Representative for India,
Associazione Italiana Amici di Raoul Follereau (AIFO) - India, Bangalore

Dr. Prakash P. Doke - Chairperson (R)
Mr. M. V. Jose - Co-chairperson (L)

Sustaining quality care and referral system at secondary level within GHC system: Policy Options and Opportunities

Dr. P. L. Joshi

Dy. Director General of Health Services (Leprosy), Ministry of Health & Family Welfare, Govt. of India

Dr. P. L. Joshi said that the (i) expectations of the beneficiaries, (ii) availability of resources, (iii) competence of general health care staff, and (iv) provision of appropriate services that are patient centric and comprehensive are the prerequisite for quality services under NLEP.

He added that the service providers must observe the rights and privacy of the leprosy patients. He insisted that the equity and social justice must be ensured to the leprosy affected persons at all levels of health delivery system.

He stated that the medical, physical and social problems related to leprosy including other health problems are the conditions that require referral to higher level care. He said that the District hospital along with NGOs must provide quality leprosy services. He also elaborated the quality leprosy services to be made available at the primary, secondary and tertiary level including the conditions for referral.

He concluded that the outcome of this National Workshop is vital in developing a practical norms and guidelines for implementing referral services at the district level. He also complemented the support extended by all NLEP partners in ensuring the rights of the leprosy affected persons. ■

Feedback:

At the beginning of this Session, Mr. Antony Samy, Chief Executive, ALERT - INDIA welcomed Dr. P. L. Joshi, Deputy Director General of Health Services (Leprosy), Central Leprosy Division, Govt. of India and presented a 'recap' on the highlights of the presentations made by various speakers in the technical sessions on Day 1 of National Workshop.

Response by DDG (Leprosy):

In response to the issues raised during the technical sessions on Day 1, Dr. P. L. Joshi clarified that the CLD has already issued clear guidelines for Temporary Hospitalization Wards and the responsibility is with the state government to adhere the guidelines.

He also stated that the ***NGOs should mobilize the leprosy patients to voice their concern for ensuring their rights*** *for access to prompt treatment, quality services and rehabilitation schemes.*

WHO's Enhanced Global Strategy for leprsoy control : Referral services as one of the priority

Dr. Indranath Banerjee

National Professional Officer for Leprosy, WHO - India, New Delhi

Dr. Indranath Banerjee said that the 'Enhanced Global Strategy for Further Reducing the Disease Burden Due to Leprosy (2011-2015)' is meant to help the leprosy programs worldwide to provide equitable and sustainable quality leprosy services in an integrated environment.

He stated that the 'referral services' need to be integrated and must be available within the GHC system, just like a surgeon or gynecologist is available in the district hospital.

He clarified that an adequate referral service means that specialist services should be accessible and available to any patient who needs them. He stated that the quality leprosy services are to be delivered at peripheral and referral level, however the country programmes to decide at which level of health system these services can be provided to leprosy affected persons. He suggested that the levels of referral can be based on the endemicity of leprosy and mobile units can be used for service delivery.

He said that the (i) health facilities should be close to the patients' home and be open on all working days, (ii) at least one trained staff should be available to provide leprosy services, (iii) adequate drug stocks need to be ensured and IEC materials / treatment register should be available, and (iv) peripheral workers should be able to effectively refer patients should be the basic principles for strengthening the referral system.

He explained the conditions for emergency and non-emergency referrals and the health personnel required at the referral level including rehabilitation services.

He concluded that the referral services are vital for providing quality leprosy services that is accessible to the patient as possible and need to be integrated in partnerships with NGOs and private health sector. ■

Developing norms and guidelines for establishing a 'District Referral Centre' within the GHC system

Chairperson:

Dr. P. L. Joshi
Dy. Director General of Health Services (Leprosy),
Central Leprosy Division, Govt. of India, New Delhi

Co-chairperson:

Dr. Indranath Banerjee
National Professional Officer for Leprosy,
WHO - India, New Delhi

Panelists:

Dr. B. N. Barkakaty
Dr. P. P. Doke
Mr. M. V. Jose
Dr. Mannam Ebenezer
Dr. K. R. Thankappan
Dr. S. N. Pati
Dr. Ashok Ladda
Mr. Antony Samy

Panelists: (l to r) Dr. Mannam Ebenezer; Dr. B. N. Barkakaty; Dr. P. L. Joshi; Dr. I Banerjee; Dr. P. P. Doke and Dr. Ashok Ladda

On invitation by the Chairman, the co-chairperson of 3 Work groups presented the draft recommendations for open discussion and to obtain a consensus.

In his concluding remarks, Dr. P. L. Joshi said that most of the recommendations proposed can be implemented at district level as we have leprosy trained personnel in place. He also said that the NLEP partners and NGOs should have equal 'footing' in building a viable referral system.

Dr. I. Banerjee stated that a functional referral system at any level of GHC system is essential to provide quality services. Dr. Mannam said that let us develop a model that can effectively deliver quality services at the district level.

All the Panelists and a few participants gave their views and suggestions on the draft recommendations.

Mr. Joy Mancheril, Director, Programmes, ALERT-INDIA, Mumbai proposed a vote of thanks.

Proposal for action:

As proposed, the technical team of ALERT-INDIA prepared a draft report along with the recommendations based on the proposed suggestions. The draft was circulated among the experts in each Work Group for finalization.

This final report and recommendations are submitted to Central Leprosy Division, Govt. of India and WHO - India for consideration and implementation under NLEP in India.

Objective:

Develop norms for establishing a district level Referral Centre and define the basic requirements to institute a sustainable referral mechanism under GHC system.

Chairperson:

Dr. Mannam Ebenezer
Director,
Schieffelin Institute of Health & Leprosy Centre,
Karigiri, Tamil Nadu

Co-chairperson:

Dr. W. S. Bhatki
Executive Director,
Maharashtra Lokahita Seva Mandal, Mumbai

Terms of Reference:

1. Outline minimum space and personnel required to manage the district level referral centre.

   Dr. Kirubakaran
   Regional Coordinator – South India, German Leprosy & TB Relief Association India, Chennai

2. Define source of manpower from the GHC system and initial support from NLEP partners.

   Mr. Kamaraj Devapitchai
   National Consultant – Rehabilitation (Leprosy), WHO-India, New Delhi

3. Capacity building need for each category of GHC staff and training support from the NLEP partners.

   Mr. A. B. Prabhavalkar
   Director, LEAP – Vidarbha region, ALERT-INDIA, Mumbai

4. Linkage with the District Nucleus component and the need for additional resources.

   Dr. Anne Mattam
   ILEP State Co-ordinator for Bihar, Damien Foundation India Trust, Patna

1. **Establishing and managing District Leprosy Referral Centre (DLRC)**

   - District Hospital / Civil Hospital / Sub-district hospital that are centrally located and easily accessible can be identified to function as a District Leprosy Referral Centre at the secondary level in the district.
   - Each district should have atleast one District Leprosy Referral Centre. More number of District Leprosy Referral Centres may be established in a district depending on the number of leprosy patients needing referral services, availability of specialized services and trained medical personnel.
   - Adequate space allocation – a suitable well lit room preferably in the OPD block or Dermatology department with basic amenities such as electric and water supply – is to be made available by the Official of the District Hospital to function as District Leprosy Referral Centre.
   - The District Leprosy Referral Centre will also serve as the first referral point for the leprosy patients reporting directly and as the secondary referral centres for the leprosy patients referred by the primary level centres.

2. **Manpower for District Leprosy Referral Centre**

   - Each District Leprosy Referral Centre will be managed by the following personnel who are officially posted or deputed from the District hospital to the District Leprosy Referral Centre.
     a) Dermatologist or a Medical specialist (1);
     b) Trained Health Worker – preferably an ex-NLEP worker or a Public Health Nurse (2);
     c) Laboratory Technician – preferably a pathology technician from the Sputum Examination Centre of RNTCP (1); and
     d) General Dresser (1)
   - The services of Ophthalmologist, Ortopedic Surgeon, Physiotherapist and Medical Social Worker available at the District Hospital can be availed as and when needed.
   - Initially, ILEP agencies or NGOs working in the district can depute their trained personnel for managing District Leprosy Referral Centres.

3. **Capacity building of the GHC staff**

   a. Primary level:

   - The content of training should include
     (i) orientation on leprosy,
     (ii) Identification of leprosy cases with specific conditions who are to be referred to secondary level (District Leprosy Referral Centre),
     (iii) management of special conditions and consequences of leprosy at different levels
     (iv) location of the referral centre and the type of services available and
     (v) follow up of cases referred back from the secondary level.

- The resource material for the training would be the DPMR Operational Guidelines published by the NLEP, Central Leprosy Division for Primary level care centres.
- The duration of training must be a full day of minimum 6 hours and the training can be organized in the GHC centre at the sub-district or block level.
- The faculties for training the GHC staff can be from the District Nucleus Team or from the ILEP agencies or NGO working in the district.

b. Secondary level:

- The content of training should include (i) orientation on leprosy, (ii) Identification of leprosy cases with specific conditions who are to be referred to secondary level (District Leprosy Referral Centre), (iii) location of the referral centre - Tertiary level and the services available and (iv) follow up of cases referred back from the tertiary level.
- The resource material for the training would be the training modules developed by NLEP or ILEP training guide with suitable modifications.
- The duration of training must be 3 full days of minimum 6 hours and the training can be organized in the GHC centre at the district level.
- The faculties for training the District Hospital staff can be from the Tertiary care institutions or from the ILEP agencies or NGO working in the district.

4. Linkages with the District Nucleus Team

- A Non-Medical Supervisor of the local District Nucleus Team must be posted at the District Leprosy Referral Centre, who will also liaison with the primary, secondary, Tertiary level institutions in the district.
- The District Nucleus Team should train and involve ASHA or PHC workers to update the list of leprosy cases with disabilities living in the district and also promote referrals between different levels.
- The District Nucleus Team should create linkages with the identified Tertiary level institutions or departments for specialized services such as RCS and MCR Footwear. ■

Objective:

Defining the functions and responsibilities of the health workers in the GHC system for providing quality leprosy services at the district referral centre

Chairperson:

Dr. B. N. Barkakaty

WHO National Consultant for NLEP,
Central Leprosy Division, Govt. of India, New Delhi

Co-chairperson:

Dr. Pramila Barkataki

ILEP State Coordinator for Maharashtra,
The Leprosy Mission India Trust, Poladpur

Terms of Reference:

1. Types of functions and service components that are needed to provide in the District referral centre.

   Mr. S. Kingsley

   Coordinator, Epidemiological Monitoring Unit, ALERT-INDIA, Mumbai

2. Linkage with other Departments of the District level Hospital and possible support required.

   Dr. H. K. Kar

   Prof. & Head, Dept of Dermatology, Dr. Ram Manohar Lohia Hospital, New Delhi

3. Linkage with Tertiary level institution for referral of cases from the District referral centre.

   Dr. Anil Kumar

   Deputy Director, National JALMA Institute for Infectious and Communicable Diseases – ICMR, Agra

4. Logistic support required for functioning of the District referral centre and source.

   Dr. P. K. B. Patnaik

   State Leprosy Officer, Govt. of Orissa

1. The following functions and service components must be made available at the District Leprosy Referral Centre to all the leprosy cases reporting directly or referred by the primary level centres in the district.

   a) Examine and make accurate diagnosis of all new leprosy cases and refer the confirmed leprosy cases back to primary level centre for MDT treatment and follow-up.

   b) Advice or perform skin smear examination / Biopsy of leprosy cases with smooth, oily and shiny skin or nodules or hypo-pigmented skin patch with normal sensation.

   c) Identify and manage cases presenting with severe or repeated Lepra reactions / suspected relapse / adverse effects of MDT.

   d) Assess the nerve functions of all MB cases (risk for developing new disability) and treat if there is recent sensory loss and early muscle weakness (Silent neuritis).

   e) Assess and treat all leprosy cases presenting with ulcers on the foot as well as provide dressing kits for self dressing at home.

   f) Assess and teach self care practice to all cases with sensory loss on hands, feet and eyes (Grade I disability).

   g) Assess and treat the leprosy cases with physical disability on hands, feet and eyes (Grade II disability).

   h) Assess and provide appropriate aids such as MCR Footwear / Hand splints / Goggles / Crutches / Grip aids etc.

2. The District Leprosy Referral Centre must have linkages with the departments of Dermatology, Ophthalmology, Orthopedic / Plastic Surgery, Pathology and Physiotherapy / Occupational Therapy available at the District hospital and integrate the leprosy services as a part and parcel of their routine services.

3. The District Leprosy Referral Centre must have linkage with Tertiary level institutions including identified Sentinel surveillance centres by the Govt. of India at district or state level for referral of suitable cases and ensure regular follow-up.

4. Any leprosy case with the following conditions should be referred to the designated Tertiary level centres at the district or regional level only after ensuring the availability of specialized services.

   a) Cases with recurrent reaction and not responding to steroids or with other serious systemic involvement for alternate therapy like Thalidomide.

   b) Cases requiring Skin and Nerve Biopsy for confirmation of diagnosis or with suspected signs of relapse.

   c) Cases with complicated ulcer with evidence of Sqamous cell carcinoma and secondary infection.

   d) Cases requiring reconstructive surgery (nerve and corrective surgery) including septic surgery.

5. The logistic support required for functioning District Leprosy Referral Centre and its source are as follows:

   a) Medicines & supplies:

   i) Dressing materials and supportive medicines

   Source of funds: District Hospital

   b) Equipments & consumables:

   ii) Physiotherapy Equipments / protective aids / Dressing instrumentsNLEP - State

   iii) Laboratory equipments / reagents / consumables

   Source of funds: NLEP - State

   c) Records & registers:

   iv) DPMR Guidelines for Secondary level prepared by CLD, GOI, New Delhi NLEP - GOI / State

   v) Training Manual for Medical Officer prepared by CLD, GOI, New Delhi NLEP - GOI / State

   vi) Register / Patient card / Report form / Referral slip (DPMR guideline) NLEP - GOI / State

   Source of funds: NLEP - GoI / State

   d) Education materials:

   vii) Pamphlets / Booklets for Patient and community education

   Source of funds: ILEP / NGOs

6. The District Leprosy Society (DLS) should estimate the expenses required for the above and include in the Project Implementation Plan (PIP) for the District Health Action Plan (DHAP) in line with NRHM guidelines. The District Nucleus must ensure regular supply of all the required materials to the District Leprosy Referral Centre. Wherever possible, the funds from RKS can be availed.

7. The District Nucleus or DLO should prepare the list of leprosy services and facilities that are available at the designated Tertiary level centres including District Rehabilitation Centres and provide to the District Leprosy Referral Centre for promoting referral of cases. ■

Objective:

Draw up the content of technical guidelines, Record and reports, referral slip and monitoring system of the District referral centre

Chairperson:

Dr. Indranath Banerjee
National Professional Officer for Leprosy,
WHO - India, New Delhi

Co-chairperson:

Dr. P. Vijayakumaran
Director – Programme,
Damien Foundation India Trust (DFIT), Chennai

Terms of Reference

1. Discuss technical guidelines available in the operational guidelines on DPMR for Secondary level institutions and suggest if any changes or additions are needed.

   Dr. S. N. Pati
   ILEP State Co-ordinator, Orissa, LEPRA Society, Bhubaneshwar

2. Records and reports in DPMR guideline – suggest if any changes are required.

   Mr. P. R. Dewarkar
   Director, LEAP (Thane & Raigad), ALERT-INDIA, Mumbai

3. Referral slip from PHC / CHC – District Hospital – Tertiary Centres – back – discuss and indicate if any changes are needed.

   Mr. Rajeev Dudhalkar
   Programme Officer - LEAP, ALERT-INDIA, Mumbai

4. Monitoring mechanism to assess functioning of the district referral centre within the GHC system.

   Dr. Rajendra Prasad
   District Leprosy Officer, Govt. of Andhra Pradesh, Visakhapatnam

1. The content of the DPMR Operational guideline for secondary level published by CLD is elaborate and practical, provided the guideline is implemented at the District level by the trained service providers with proper commitment.

2. The records and reports as suggested by CLD under DPMR guidelines for the secondary level can be used and maintained by the health personnel at the District Leprosy Referral Centre with suitable modifications. The formats and records being used by ALERT – INDIA may be considered with suitable modifications.

3. The referral slip and referral registers suggested by CLD under DPMR guidelines for the secondary level can be used at the District Leprosy Referral Centre. The same referral slip can be used with required information for back referral to primary level.

4. Supervision of the activities carried out at District Leprosy Referral Centre is to be done by the District leprosy officer assisted by the Non-Medical Supervisor of the District Nucleus Team and should be included in the monthly report for review.

5. Monitoring of the District Leprosy Referral Centre to be done by District coordination Committee by way of review of referrals from primary level and analysis of reports from District Leprosy Referral Centre during the monthly review meeting at the district level on priority. ■

1 **Establishing a District Leprosy Referral Centre :** At least one ***first referral point*** for the leprosy affected persons should be established in every district as District Leprosy Referral Centre (DLRC), preferably at the OPD or Dermatology or Physiotherapy department of the District Hospital / Civil Hospital / Sub-district Hospital (Secondary level) that is centrally located and easily accessible (geographically) with leprosy trained manpower and the specialised services. More than one DLRC in a district can be established, if the need exists, in terms of number of leprosy patients who need specialised services.

2 **Managing District Leprosy Referral Centre by trained personnel :** Each DLRC should be managed by a team consist of (i) Dermatologist or Medical doctors; (ii) Physiotherapist; (iii) Laboratory Technician; (iv) Trained leprosy (NLEP) worker or Public Health Nurse; (v) Dresser, who are trained and equipped with good clinical acumen in leprosy diagnosis and management of complications and be officially posted / deputed as a matter of policy. The services of ophthalmologist, orthopaedic surgeon, counsellor, medical social worker, etc. available at the District Hospital should be easily available for leprosy affected persons, so that the DLRC need not be managed by separate staff in the future. Initially the same can be provided by ILEP agencies / NGOs.

3 **Developing the skills of GHC personnel at the district level :** The training of the GHC staff (specially for DLRC team) at the secondary level should be conducted for 3 full days by the faculties from Tertiary care institutions / ILEP agencies / NGOs / GoI training institutes using training modules developed by NLEP or ILEP or ALERT-INDIA. Further, the training must include field postings for practical exposure. The training at the secondary level should consist of orientation on leprosy with skills in management of cases referred from the primary level, identification of cases with special conditions to be referred to the tertiary level. DLRC should know the availability of services at the tertiary level centres and liaise.

4 **Assessing the infrastructure and resources available with GHC system :** A specific assessment of existing tertiary care centres is urgently needed to take stock of their present status on the availability of infrastructure and expected multiple services and to suggest, undertake all required steps to strengthen them with an appropriate manpower and the resources. DLRCs are to be linked to tertiary care centres effectively.

5 **Ensuring quality services at the District Leprosy Referral Centre :** The services provided at DLRC should be primarily based on the DPMR Operational Guidelines for secondary level of GOI that includes:

(i) clinical diagnosis of difficult to diagnose cases,

(ii) skin smear (AFB) examination for confirmation of diagnosis and relapse,

(iii) management of complications e.g. lepra reactions, neuritis, suspected relapse, complicated ulcers and early eye complications,

(iv) physiotherapy including provision of MCR footwear, splints and other aids for prevention and management of deformities,

(v) timely referral of cases requiring specialized services to the Tertiary level centres for the management of recurrent reactions, non-healing ulcers, correction of deformities by reconstructive surgery (RCS) and specialised investigations such as skin / nerve biopsies and EMG. These services should be made available at the Tertiary level centres.

6 **Training of the GHC personnel at primary level health centres :** The General Health Care (GHC) staff at the primary level should be trained by a faculty from District Nucleus Team (DNT) / ILEP agencies / NGOs for one full day using DPMR Operational Guidelines formulated by the NLEP, Central Leprosy Division (CLD). The training for GHC at the primary level should include orientation on leprosy, identification of cases with specific conditions required to be referred to the secondary level. The GHC staff must know the locations of the DLRCs and the services provided and also undertake follow up of the cases referred back, from DLRC with specific instructions.

7 **Providing logistic support for District Leprosy Referral Centre :** For effective functioning of the DLRC, the logistic support i.e. laboratory equipment, reagents, consumables, dressing material & instruments, supportive medicines, physiotherapy equipments, protective aids, records and registers should be provided by the District Hospital or the District Leprosy Society. Adequate budget provisions should be made in the District Programme Implementation Plan (PIP) under National Rural Health Mission (NRHM), as a matter of policy. Formats, reports and records suggested by the CLD under DPMR guidelines with suitable modifications based on those being used by ALERT-INDIA should be used by the health personnel at the DLRC.

8 **Monitoring and review of District Leprosy Referral Centre :** The Non-Medical Supervisors (NMS) or the Medical Officer of the DNT, wherever it functions as leprosy expert team, under the guidance of District Leprosy Officer (DLO) and / or District Coordination Committee should liaison between the primary and tertiary level centres as well as with the different departments of GHC in which the DLRC is a part, in addition to their overall monitoring and the supervision of tasks. The DNT must make wide publicity about the quality services that are available at DLRC and promote referrals. Periodical review of DLRC should be part of the General Health Care system's routine review in par with other health care programmes on priority basis, at the district and state levels.

Proposal for follow-up

With the upgradation of the existing health facilities, provision of additional inputs, and enhancement of skills of the service providers, it is expected that the health facilities at the district (secondary) level can comply with the requirements and needs of the leprosy affected persons for quality services.

However, the utilization of these services depends upon the flow of the leprosy patients by way of referrals from the primary level centres in the district.

It is thus imperative to have a good referral system with adequate support so that quality leprosy services are made available in a comprehensive manner as far as possible and easily accessible to the needy leprosy patients.

For developing a comprehensive referral module, an operational guideline for service norms at the secondary level in relation to primary and tertiary levels will largely depend on the type of services that can be guaranteed at the secondary level.

It is proposed that an appropriate module for leprosy referral services can be formulated through an intensive discussion by a consultative group of experts from the field of leprosy and general health. ■

Acknowledgement

We wish to express our thanks to the Officials at Central Leprosy Division, Ministry of Health & Family Welfare, Govt. of India for their active collaboration as well as for their guidance and thoughtful advice.

We convey our profound thanks to the WHO Representative to India and other Officials at WHO Country Office - India for their generous support to this National Workshop.

We extend our thanks all the resource persons for sharing their rich experiences and all the participants for their useful inputs.

We also thank all the Panelists, Chairpersons and co-chairpersons of the technical sessions for their intelectual contributions made during the session.

We would like to show our gratitude to the health officials at the districts and State for their ongoing support and by standing in solidarity with ALERT-INDIA to provide quality services through Leprosy Referral centres (LRCs) under Leprosy Elimination Action Programme (LEAP) in Maharashtra.

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Finally, we are indebted to all the leprosy affected persons whose concerns are shared and represented in order to ensure their rights for accessing quality leprosy services in the general health care system. ■

AFB	Acid Fast Bacilli
ANM	Auxiliary Nurse Midwife
ASHA	Accredited Social Health Activist
BMO	Block Medical Officer
BPL	Below Poverty Line
CHC	Community Health Centre
CLD	Central Leprosy Division
CME	Continuing Medical Education
CMO	Chief Medical Officer
DCC	District Coordination Committee
DH	District Hospital
DHAP	District Health Action Plan
DHO	District Health Officer
DLO	District Leprosy Officer
DLRC	District Leprosy Referral Centre
DLS	District Leprosy Society
DNT	District Nucleus Team
DPMR	Disability Prevention & Medical Rehabilitation
EMG	Electro Myography
GHC	General Health Care
GoI	Government of India
HE	Health Educator
HI	Health Inspector
HS	Health Supervisor
IEC	Information, Education & Communication
ILEP	International Federation of Anti-leprosy Associations
LEAP	Leprosy Elimination Action Programme
LRC	Leprosy Referral Centre
LT	Laboratory Technician
MCR	Micro Cellular Rubber
MDT	Multi Drug Therapy
MO	Medical Officer
MPW	Multipurpose Worker
MSW	Medical Social Worker
NGO	Non-Governmental Organization
NLEP	National Leprosy Eradication Programme
NMS	Non-Medical Supervisor
NRHM	National Rural Health Mission
OPD	Out-Patient Department
PG	Post Graduate
PHC	Primary Health Centre
PHN	Public Health Nurse
PIP	Project Implementation Plan
PMR	Physical Medicine & Rehabilitation
POD	Prevention of Disability
POP	Plaster of Paris
PR	Prevalence rate
PT	Physiotherapy Technician
RCS	Reconstructive Surgery
RH	Rural Hospital
RKS	Rogi Kalyan Samiti
RLTRI	Regional Leprosy Training & Research Institute
RNTCP	Revised National TB Control Programme
SDH	Sub-District Hospital
SLO	State Leprosy Officer
SSD	Selective Special Drive
THW	Temporary Hospitalization Ward
ToR	Terms of Reference
VHSC	Village Health & Sanitation Committee
WHO	World Health Organization

ALERT-INDIA

strives towards
programmes focussing on
community partnership strategies
to achieve the goal of leprosy elimination
during the integration phase,
in alliance with all stakeholders,
to make elimination a reality for people.

VISION

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