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WORKSHOP REPORT

National Workshop on 'Best practices to ensure sustainable quality care for leprosy affected persons at the district level referral centres through general health care system'

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The Context

Recently, in line with the target date of the global Millennium Development Goals (MDG-6), WHO has proposed an 'enhanced global strategy' to sustain leprosy control and to further reduce the global burden of leprosy by 2015.[1] The thrust of achieving the goal of 'elimination' of leprosy as a public health problem at national level by the Government of India (GOI) has changed forever the method of leprosy control work that is being undertaken in the country by all players. The strategic policy for integrating leprosy services with the general health care (GHC) system resulted in the total dismantling of the vertical system and transferring the principal responsibility for leprosy control to the GHC system.

The GHC system at primary level shouldered the basic task of providing MDT to all new leprosy affected people. The secondary and tertiary level centres were expected and relied on to provide quality services to needy leprosy affected people through referrals. Hence, there is a dire need to create appropriate support structures and effective referral mechanisms within the GHC system, both to sustain quality leprosy services on a long term basis, and to ensure the rights of leprosy affected people.

Concerns and Options

In response to the need for sustaining quality leprosy services, the Central Leprosy Division (CLD) implemented the Disability Prevention and Medical Rehabilitation (DPMR)

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programme, as a component of the NLEP that is aimed at providing quality care to all leprosy affected people at primary, secondary and tertiary levels of the GHC system. Furthermore, the GOI has also retained about 25% of trained NLEP staff in most of the States to provide skill development training and technical support to the GHC personnel. A few state units have made efforts to evolve a viable 'referral system' based on the Operational guidelines for DPMR under NLEP formulated by GOI.[2]

ALERT-INDIA, a non-governmental organisation engaged in leprosy control work, has promoted establishing Leprosy Referral Centres (LRCs) under its Leprosy Elimination Action Programme (LEAP) at secondary level within the GHC system in six districts of Maharashtra since 2005 based on a rights approach.[3]

The ILEP Technical Commission recommended that establishing referral and training centres is a priority that needs to be strengthened.[4] The ILEP agencies working in India have also implemented their own models of referral systems at district level in many leprosy endemic districts adopted by them in different states.

The Workshop: Approach and Methodology

To ensure access to quality service as a right of all leprosy affected people, the CLD proposed to define guiding principles to the GHC system for operationalisation and implementation of the referral centres at district level. In this context, it was crucial to identify the infrastructure and facilities existing at different levels within the GHC system and to ascertain what additional resources are required to provide quality leprosy services at district level referral centres within the GHC system.

A National Workshop was organised by ALERT-INDIA in collaboration with the CLD, New Delhi at Mumbai on 21 and 22 October 2009, in order to share the experiences of NLEP and all key partners engaged in leprosy control at different states through a scientific deliberation. This National Workshop was supported by WHO Country Office for India.

The objectives for this National Workshop were clearly defined by the GOI along with terms of reference (TOR) for developing a referral service module with specific operational guidelines that can enable the GHC system to provide adequate services to leprosy affected people at the different levels of health care system.

The following were the specific Objectives:

1. To discuss and analyse the *prevailing referral system* developed at secondary level District Hospitals by the Programme Managers of NLEP and Project Officers of NGO Partners as per GOI directives.
2. To suggest and recommend an appropriate referral mechanism for providing quality care and services to the leprosy affected people in the integrated system.
3. To obtain consensus and draw up a module on 'Leprosy Referral Services' for the GHC system to ensure the sustainability of quality services to leprosy affected people at the secondary level.

Experiences and different models to ensure adequate quality care to leprosy affected people were presented by the key players such as (i) State Leprosy Officers from seven states across the country, (ii) Representatives of ILEP agencies and NGOs, (iii) Leprosy and Public Health Experts from Government and Non-Government institutions and (iv) GOI and WHO during

the Technical sessions. These presentations strongly emphasised that strengthening of secondary level hospitals in the district as a first referral point will raise the credibility of the GHC system as leprosy cases referred from primary levels will get better quality care, while reducing the work load of tertiary care hospitals.

Following the technical sessions, there were three work group sessions to discuss and suggest vital programme components needed to sustain quality leprosy services at district level, and establish an appropriate referral system between different levels of health care institutions.

The deliberations and recommendations will help the NLEP to evolve an intervention strategy – both to programmatic and structural components. The feedback to the policy makers will result in appropriate policy formulation with allocation of adequate manpower and resources to strengthen the referral services at district level. The major recommendations are outlined below:

Summary of Major Recommendations

1. *Establishing a District Leprosy Referral Centre:* At least one ***first referral point*** for the leprosy affected people should be established in every district as a 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 specialised services. More than one DLRC in a district can be established if the need exists in terms of the number of leprosy patients who need specialised services.
2. *Managing District Leprosy Referral Centres by trained personnel:* Each DLRC should be managed by the following trained health personnel equipped with good clinical acumen in leprosy diagnosis and management of complications. They should be officially posted or deputed as a matter of policy:
    i) Dermatologist or Medical doctors
    ii) Physiotherapist
    iii) Laboratory Technician
    iv) Trained leprosy (NLEP) worker or Public Health Nurse
    v) Dresser

    The services of an ophthalmologist, orthopaedic surgeon, counsellor, medical social worker, etc. available at the District Hospital should be easily available for leprosy affected people, 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 district level:* The training of GHC staff (specially for the DLRC team) at secondary level should be conducted for three full days by the faculties from Tertiary care institutions/ILEP agencies/NGOs/GOI training institutes using training modules developed by NLEP or ILEP[4] or ALERT-India. Further, the training must include field postings for practical exposure. The training at 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 the 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 and undertake all required steps to strengthen them with appropriate manpower and the necessary resources. DLRCs are to be effectively linked to tertiary care centres.
5. *Ensuring quality services at District Leprosy Referral Centres:* The services provided at the DLRC should primarily be based on the DPMR Operational Guidelines for secondary level of GOI[5] and should include:
    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 specialised services to Tertiary level centres for 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 Tertiary level centres.
6. *Training of GHC personnel at primary level health centres:* The General Health Care (GHC) staff at primary level should be trained by a faculty from the District Nucleus Team (DNT)/ILEP agencies/NGOs for one full day using DPMR Operational Guidelines formulated by the NLEP, Central Leprosy Division (CLD).[6] The training for GHC at 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 Centres:* 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 the 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 health personnel at the DLRC.
8. *Monitoring and review of District Leprosy Referral Centres:* The Non-Medical Supervisors (NMS) or the Medical Officer of the DNT, wherever it functions as a leprosy expert team, under the guidance of the District Leprosy Officer (DLO) and/or the District Coordination Committee should liaise between 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 supervision of tasks. The DNT must employ wide publicity about the quality services that are available at DLRC and promote referrals. Periodic review of the DLRC should be part of the General Health Care system's routine review on a par with other health care programmes as a priority, at district and state levels.

Conclusion

With the upgrade of existing health facilities, provision of additional inputs, and enhancement of skills of service providers, it is expected that the health facilities at district (secondary) level can comply with the requirements and needs of leprosy affected people for quality services. However, the utilisation of these services depends upon the flow of leprosy patients by way of referrals from 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 accessible to needy leprosy patients.

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

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