MESSAGE FROM DDG (LEPROSY)

It is with great pleasure and humility; I am contributing in the 3rd issue of quarterly newsletter of year 2018, which witnessed the successful introduction of several initiatives under NLEP from various states. The lead story in this issue is about Epidemiological Investigation conducted by a team formed by Central Leprosy Division (CLD) at Salaunikhurd village of Chhattisgarh of multiple cases of Leprosy occurring in one family. Under Best Practice I would like to share the collaboration between CLD and ECHO trust India for establishing a knowledge sharing platform under NLEP. Further, in order to pay homage to our Father of the Nation, Mahatma Gandhi, on his 150th Birth Anniversary, CLD has committed to achieve the new cases with Grade II disability < 1 case/ million population by introducing a yearlong comprehensive campaign called ‘Sparsh Leprosy Elimination Campaign’ (SLEC) till 2nd Oct 2019, it is being rolled out in 36 states. Under success story Meena-a symbol of Girl Empowerment can be transformed into Sapna: A role model for Leprosy Elimination.

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LEAD STORY

Epidemiological investigation of Multiple cases occurring in one family in village Salaunikhurd under Bhatgaon PHC of Bilaigarh Block in Balodabazar district of Chhattisgarh.

A team was constituted by Central Leprosy Division comprising of Dr V. Santaram (Director, RLTRI Aska), Dr Sunil Gitte (Joint Director, RLTRI&ROHFW Raipur), and Miss Latika Rewaria (IEC & Training Consultant, CLD, Delhi) to carry out the Epidemiological investigation of multiple leprosy cases occurring in one family in village of Salaunikhurd of Bilaigarh Block in Balodabazar district of Chhattisgarh between 30.07.18 to 01.08.18. Investigation was further supported by Dr Aparna Pandey (Director RLTRI, Raipur) and Dr Sarosh Jamil (WHO- NTDs).

Chhattisgarh has 2% of India’s population and contributes about 9.31% of total leprosy cases in the country. Out of 27 districts, 24 districts are having >10 ANCDR. District Balodabazar is one of the 24 high endemic districts in the state. Bilaigarh is high endemic block with regard to leprosy contributing 45% of new cases in the district. The Salaunikhurd village has 0.2% of the block population and contributes 6.5% of cases during 2016-17. In one family all ten members were detected as MB cases within a period of three months.

The investigation is carried out in the village to assess the leprosy situation, to find out reasons for high endemcity, investigation of multi case family, assessment of health service delivery along with IEC and awareness.

Methods: House to house survey of village was carried out to find out new cases along with assessment of all patients affected with leprosy. Detailed investigation of two MCF families were carried out. Standard field definitions were used for labeling cases. Assessment of Health service delivery of NLEP from block to the village level by review of records, registers and interview. Assessment of knowledge, attitude and practice was carried out PAL, community members, general health care staff and ASHA in the sampled population. Participatory scale was used to understand the level of participation of PAL and two separate Focussed group Discussion were conducted.

Trend of ANCDR of Bilaigarh Block of Balodabazar (2006-07 to 2017-18)

Results: During survey of the village, 84% of the total population was covered and two new leprosy cases were confirmed. Among the 5UT and 16 RFT cases, three defaulter patients and two G2D case were found. Interview of MCF revealed that the cases were missed during LCDC. All the leprosy cases in the MCF
families are MB cases with infiltrative lesions and nodules. The MCF belongs to low socio-economic status, poor housing condition, high family density, poor sanitation, seasonal migration, poor health seeking behavior and lack of awareness of the disease. There was delay in detection was noted in both the patient and system side. The block is the single window provider of NLEP services with least involvement of PHC in detection, diagnosis, treatment and follow-up. DPMR services were found to be not in priority of the health system. Quality of patient care was compromised. Knowledge was poor among ASHA and their trainers. NMA was having good knowledge of the disease. P score reveals mild to moderate restriction in eleven out of sixteen respondents indicating stigma in the community.

Geo location (spatial location) of PAL in the Salaunikhurd village

Conclusion: Overall scenario in case detection trend in the block across the years indicates smouldering epidemic of leprosy. The large number of cases being detected in the village indicates hidden cases, transmitting the disease silently within the community. Linkage failure between the ASHA, community and Sub-center is a crucial factor in the progression of the disease in the village. Involvement of PHC in providing quality NLEP services could definitely improve the programmatic implementation to achieve universal health coverage and elimination goals.

Clinico-epidemiological factors leading to Multi Case Family (MCF) in the surveyed village

Delay in detection: Duration of delay from the appearance of signs and symptoms and reporting to HCF among MCFs was 13-24 months.

The patient related delay can be attributed to the characteristic of the disease, the symptoms were not worrisome and the patient hoped that it will be cured on its own. There was a definite lack of awareness about the disease among the family members. The migratory nature of the family and Lack of information about the health provider also delayed in seeking health care as the decision maker was not usually present with the whole family at a time. It was not clearly indicated but there can be fear of stigma and discrimination by the villagers that might have prevented the family members to seek care.

Health system delay can be attributed to the lack of interest and involvement of Mitanin (ASHA) of the village. The subsequent case detection campaigns implemented by Mitanin failed to detect suspects of leprosy in the village. There was lack of involvement of PHC Bhatgaon and SC Salaunikala in detection, diagnosis, record keeping, treatment and follow-up of the cases of Salaunikhurd. This
indicates reduced engagement and capacity of general health system in leprosy control.

Nature of disease spectrum In the MCF were De-Novo MB spectrum of cases, thereby delay in appearance of signs and symptoms.

**Best Practice**

**Collaboration with ECHO Trust India to Establish Knowledge Sharing platform under NLEP**

SPARSH Leprosy Elimination Campaign (SLEC) has been introduced by Central Leprosy division (CLD) in the month of Sept 2018. Where in several activities have been planned to be implemented in all the states to bring about a reduction in annual new cases of Grade II Disability to less than 1 case per million population, at National level. To implement this campaign CLD requires frequent communications with the states and continuous monitoring. In this regard CLD has proposed to establish collaboration with ECHO trust India to have zoom platform, which will be utilized as knowledge sharing platform by connecting with all the states at a time like multipoint video conferencing.

This collaboration will be utilized in terms of Video Conference and ECHO clinics, which will address the complex issues of administration, sharing best practices, GoI guidelines and suggesting the best treatment solution by combining the knowledge of participants and experts. This platform will also be utilized for sharing latest changes, updations and reporting formats in the guidelines by CLD among states (SLOs). ECHO trust India will provide the Zoom platform, which works on the principals of Hub & Spoke model wherein Nirman Bhawan, DDG (L) office, Delhi will become hub and all the states will act as spokes. This will be an excellent opportunity for all the state to share the state specific issues directly with ministry on routine basis. First interaction session is planned to be conducted in the month of Nov 2018.

**SUCCESS STORY**

Success of UNICEF’s Meena-a symbol of Girl Empowerment can be transformed into Sapna: A role model for Leprosy Elimination.

Meena is an imaginary cartoon character, relevant to any South Asian region, who is a spirited, nine-year-old girl, striving to change the present situation of children for better world where their rights are fully realized in terms of education, health, protection or participation. Meena stories revolve around the adventures of Meena, her brother Raju, her pet parrot Mithu and members of her family and community. They form the core element of Meena Communication Initiative (MCI)—a mass communication project of UNICEF to change the perception and behaviours that stand in way of realizing survival, protection and development rights of girl children in South Asia The MCI arose to address a strong need to find culturally appropriate ways to communicate messages to empower girls in one of the world’s most challenging and gender insensitive environments. The use of an
attractive, healthy and passionate child who could actively and constructively engage with her family and community members to help overcome barriers to access school education, health care services and overcome stigma and discrimination against girl child has been extremely successful experiment in communication and social mobilization. The essential features of Meena Communication Initiative should guide the use of “Sapna” – a role model proposed for creating awareness and social mobilization for leprosy elimination.

How is Meena Used?

Meena is used as a tool to impart important messages on gender, child rights, education, protection and development. The Meena stories present many positive images of a girl succeeding against odds to gain equal treatment, love, care and respect. Creative and exciting story lines have promoted social issues in an appealing and provocative way.

Building on learnings from MCI and transforming Meena character to serve social mobilization and communication objectives of other health and development programmes, especially National Leprosy Elimination Programme

Keeping in view the wide acceptance of Meena for promoting rights of the girl child and the effective communication approaches adopted under MCI, the need to apply learnings from MCI to support implementation and outreach of other National Health and Development programme cannot be over emphasized. Since the Meena character has been identified with the issues related to the rights of girl children, it would be prudent not to distort this image of Meena while planning to replicate the successful experiences of MCI in other programmes. This has also been recommended by the evaluation team of Meena Communication Initiative when they discouraged any attempt to diffuse the focus of Meena character away from rights of girl children. Therefore, the initiative proposed under the guidance of Central Leprosy Division of Ministry of Health and Family Welfare to use an imaginary south Indian girl character “Sapna” as a role model to bring about social mobilization for Leprosy elimination and set aside stigma and discrimination associated with the disease is most welcome. However, it is extremely important for “Sapna” to build on the implementation experiences of Meena Communication Initiatives and abide by the proven communication approaches adopted by Meena. This is necessary for success of Sapna model of communication proposed under Leprosy elimination programme. In short, following critical issues must be duly considered while presenting ‘Sapna” to the community to bring about desired changes in behaviour to meet objectives of National Leprosy Elimination Programme

It must be emphasized, that effective communication and social mobilization are critical determinants of success of any health or development programme. Identification and use of appropriate approaches and tools for communication can bring about desired behaviour change in the community to meet the objectives of the programme. This has been demonstrated by Meena Communication Initiative of UNICEF to improve the situation of girls in community and the experience gained and lessons learned can be suitably adapted to work out communication strategy and tools for Leprosy Elimination programme as well.

- Satish Kumar-Adjunct Professor, IIHMR, Delhi and Ex Advisor, NHSRC, MoHFW
HIGHLIGHTS

SPARSH Leprosy Elimination Campaign (SLEC): Orientation Meeting at Tamil Nadu

One day orientation meeting was held at Tamil Nadu state office by Dr. Anil Kumar, DDG-Leprosy, DGHS, M/O H&FW on 24th Sept 2018. Shri, Darez Ahamed, Mission Director, Tamil Nadu, Dr. Rupali Roy, DADG-Leprosy, DGHS, Dr. Chhadha Director – CLTRI, State leprosy officers – Tamil Nadu and various officers attended the meeting. State NLEP activities and planning of Leprosy Case Detection Campaign (LCDC) was also reviewed by DDG-Leprosy.

MEETINGS & GATHERINGS

National Annual Review meeting of State Leprosy Officers at Goa, India

A three days National Review Meeting of National Leprosy Eradication Programme was conducted from 11th to 13th July 2018 at IBIS hotel, Goa with the support from World Health Organisation. First day of meeting, inaugural session was attended by Shri Vikas Sheel, Joint Secretary, Ministry of Health and Family Welfare, GoI, and Dr. N.S. Dharmshaktu, Pr. Adv. to Secretary (Health), Dr. Anil Kumar, Deputy Director General (Leprosy) and Dr. Rashmi Shukla, National Professional Officer - WHO. Review meeting continued for 3 days under the chairmanship of Dr. Anil Kumar, Deputy Director General (Leprosy) wherein 6 comprehensive sessions were there in which all the states presented their status of implementation of NLEP and various experts also presented the latest development in the field of Leprosy.

Internationally renowned experts like Dr. Erwin Cooreman, Team Leader – Global Leprosy Programme, Presidents of IADVL, representatives of IAL, National Professional Officer for Leprosy – WHO, State Leprosy Officers (SLOs), WHO NTD & Zonal coordinators, NLEP state consultants, Central Leprosy division consultants and various NGO representatives & experts from the Field of Leprosy like Dr. Ashok Kumar, Ex Additional Director General of Health services, Dr. Avi Kumar Bansal, Scientist D JALMA institute, Dr. Satish Kumar, Adjunct Professor IIHMR, Delhi attended the three days comprehensive review meeting. Simultaneously opportunity was also utilized for launching the user manual of revamped Nikusht software by Joint secretary, principal advisor, DDG-Leprosy, WHO NPO-India officer and Add. DDG-Leprosy.

Six appreciation awards also distributed during the meeting for their performance. Bihar, Jharkhand and Gujarat received for outstanding implementation of LCDC activities, Haryana received for 1st time...
implementation of PEP, Dadra Nagar Haveli for implementing all the innovations under NLEP in last 2 years and Odhisa received for implementation of 1st LCDC in Country in introductory year. *State wise photos are present in the gallery.*

**Research Group meeting at Nirman Bhawan, Delhi**

A Research Group meeting was held under the Chairmanship of Dr. Anil Kumar, Deputy Director General (Leprosy) on 9th August, 2018 at Nirman Bhawan, Delhi to discuss five research proposals, submitted to the Central Leprosy Division for comments. Dr. Vineet Kumar Chadha, Director, CLTRI, Chengalpattu, Dr. K.S. Baghotia, State Leprosy Officer, Delhi, Mr. John Kurian George, Country Coordinator, ILEP in India, Dr. Rupali Roy, DADG, Leprosy, Dte. GHS, Dr. P.R. Mangalani, NLR Foundation, and Dr. Utpal Sengupta, (Expert Lab In-charge) “The Leprosy Mission” participated in the meeting and put forwards their views.

In addition it was decided by the committee that priority areas may be contributed by research group members will be discussed at quarterly basis.

**NEWS AROUND**

**Supportive supervision for implementations of NLEP activities: Uttar Pradesh**

Leprosy Case Detection Campaign (LCDC) undertaken in 39 selected districts of Uttar Pradesh in 2018, out of which 9 districts are situated in Western UP. Accordingly to ensure the quality implementation of LCDC and supportive supervision of those 9 districts, Dr. Anil Kumar, DDG (Leprosy) and Dr. Rupali Roy, DADG (Leprosy) visited 5 districts of Western UP namely Gautam Budh Nagar, Bulandshahr, Aligarh, Hathras, Agra from 23rd July to 25th July 2018.

![Research Group meeting at Nirman Bhawan, Delhi](image)

**Recommendation:**

- Suspect Case Definition should be available to all team members in advance.
- Following Suspect Case Definition, ASHA should revisit the house, where physical examination of all family members had not been done.
- Team should be well informed about the marking of houses.
- Sensitivity testing should not be done by the field team.
- Effective Coordination and monitoring mechanism should be established between state / district / block level team and involvement of all stakeholders should be there.
- Field level monitoring should be more effective, as at present is not being done.
- Adequate IEC should in place before organizing the campaign.
- Micro planning should be done properly before conducting the activity.
- Copy of micro planning should be available with all supervisors and Medical Officers In-charge.
SPATIAL DATA

G2D (%) of 2015-16

G2D (%) of 2016-17

Legends
- 0%
- 0.1% to 5%
- 5.1% to 10%
- 10.1% to 20%
- Above 20%

Non-LCDC States
- 0%
- 0.1% to 5%
- 5.1% to 10%
- 10.1% to 20%
- Above 20%

LCDC States
- 0%
- 0.1% to 5%
- 5.1% to 10%
- 10.1% to 20%
- Above 20%
Jharkhand State received the appreciation award for outstanding implementation of LCDC activities.

Bihar State received the appreciation award for outstanding implementation of LCDC activities.

Dadra Nagar Haveli, UT received the appreciation award for implementing all the innovations under NLEP in last 2 years.

Odhisa State received the appreciation award for implementation of 1st LCDC in Country in introductory year.

Gujarat State received the appreciation award for outstanding implementation of LCDC activities.
Facilitation of Crowd at Balodabazar district by Dr. Santaram, Director RLTRI, Aska

IEC for Leprosy programme with key message from Dr. APJ Abdul Kalam

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