Bridging Gaps in Leprosy Care: Field realities and Lessons from District Visits

Presented by

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Introduction

"Leprosy remains not just a health issue, but a social one—with deeply rooted stigma, longstanding service gaps, and hidden cases in vulnerable populations.

The aim of this presentation is to highlight field-level insights drawn from recent district visits, reflecting both systemic challenges and inspiring solutions observed at the ground level.“

Approach:
"Our approach was participatory and collaborative.

- ✓ Field visits across districts, multiple PHCs and sub-centers
- ✓ Interactions with health staff, ASHAs, ANMs, and affected persons
- ✓ Review of records, IEC material, and disability management tools

"This bottom-up perspective is vital to align policy intent with field realities."

Districts covered :

1. NT Rama Rao
2. Eluru
3. Alluri Sita Rama Raju
4. Anakapalli
5. Kurnool
6. Nandhyala
7. Anantapur
8. Bapatla
9. Guntur
10. Tirupati
11. Chittoor
12. Nellore
13. Krishna
14. Vishakhapatnam
15. Vizianagaram
16. West Godavari

Areas covered in the districts

1. District Leprosy Office
2. Government Hospital/Medical College
3. Temporary Hospitalization ward
4. Primary Health Centers (PHC)
5. Health and Wellness Centers (Subcenters)
6. House to House Survey
7. Leprosy Colonies

District Leprosy Office:

1. Prevalence Rate, Grade-1 &2 cases, Child cases etc.,
2. NLEP registers
3. Stock availability

   Multi bacillary-Adult, Child

   Pauci bacillary- Adult, Child

   Expiry date on the drugs
4. Data entry – Nikusth

During LCDC,

1. District Coordination committee meeting were held according to the guidelines
2. Media coordination meeting
3. LCDC cells are available at DLO
4. Medical Officers trainings were up to mark or not
5. Micro plans were available/not especially to Hard to reach Areas.
6. IEC availability and any best practices

Government General Hospital

1. Departments working on Leprosy at district hospital like Department of Dermatology, Microbiology/pathology, Orthopedics/Plastic Surgery etc.,
2. Records and the services are being delivered
3. Slit Skin Smear Test
4. Stock availability
5. Data entry especially new case in portal
6. Follow ups, reaction Management
7. Physio care-Nerve Function Assessments, Ulcer care, MCR etc.,
8. Disability prevention and Medical Rehabilitation (DPMR)-activities like camps etc.,
9. Any Challenges

Temporary hospitalization wards:

1. Total no. of patients admitted
2. Service delivery
3. Ulcer dressing materials
4. Facilities of inpatients- medicine supply, food etc.,
5. Any challenges

Primary Health Centre

1. NLEP registers
   - Suspects registers
   - New case register
   - Treatment register
   - Disability register-EHF score
   - Stock register
2. Stock availability (MB &PB- Adult &Child)
3. IEC availability
4. Slit Skin Smear test and/or referrals
5. Knowledge of the Staff on leprosy-Patient card, NFA, DPMR day on 11th/ 12th of every month.
6. Data entry in state portal and Nikusth

Health and Wellness Center (Sub Center)

1. Referral Mechanisms-Slips availability
2. Records on referrals
3. Knowledge on leprosy to MLHPs, ANMs and ASHA

During LCDC, additionally-

1. Availability of Micro Action plan
2. Staff trainings
3. Percentage of population covered

House to House Survey

1. Markings on the houses
2. Knowledge of ASHA and male volunteer on House marking and leprosy
3. Referral slips and Survey Reports
4. Interactions with the general community
5. Any specific challenges at field level

Leprosy Colonies

1. No. of persons affected and inmates/families
2. Health status
3. Livelihood of the PA's
4. DPMR services- Any Support required from NGOs/PHCs
5. MCR foot wear supply- NGOs/Govt
6. Socio-economic Rehabilitation-educational support to PA or to their children
7. Pension services
8. Any colony issues

Strengths Observed in the Field

"In the spirit of appreciation and acknowledgment, several commendable practices were noticed:"

- **Dedicated field staff:** Many ANMs and ASHAs are actively involved in contact tracing and awareness generation.
- **Drug availability:** MDT was generally available and well-maintained in stock in most facilities.
- **Early referral and RCS coordination:** Some districts have proactively identified Grade 2 Disability (G2D) cases and initiated reconstructive care with support of NGOs.
- **Community participation:** In some areas, Persons Affected (PAs) themselves are peer educators and contributing to stigma reduction.

Field Challenges Observed

"These challenges are shared in the spirit of strengthening the program through collective effort"

- **Register Maintenance:** Some facilities lacked updated disability registers or had incomplete stock entries. This might be due to overlapping program responsibilities or staff turnover.
- **Nikusth Portal:** Entries were pending or not real-time in several PHCs. Challenges cited included poor internet connectivity and limited training.
- **Follow-Up of Suspects:** A gap exists between referral and confirmation—some cases referred by field workers remain unverified at PHC level.
- **IEC Material:** Lack of standard, updated IEC materials on disability care, RCS, and stigma mitigation hampers awareness-building.

Ground Realities in Tribal and Remote Areas

"In tribal belts and hilly terrain:"

- **Human resource gaps** (e.g., absence of lab technicians/pathologists) delay diagnosis.
- **Transport challenges** affect patient access to RCS or tertiary care.
- **Stigma and misinformation** are still barriers to disclosure and early treatment.
- **Coordination gaps** between PHCs and higher centers need to be bridged for timely referrals and surgeries.

Voices from the Field

"In speaking with persons affected and frontline workers, a few powerful messages stood out:"

- *'We want to be seen as normal people, not patients.'*
- *'Awareness camps in schools and villages will help remove fear.' by Community Health Officer*
- *'We need more training to guide patients confidently,'* said one ASHA.

"These voices emphasize the human side of programmatic interventions."

Best Practices Worth Scaling Up

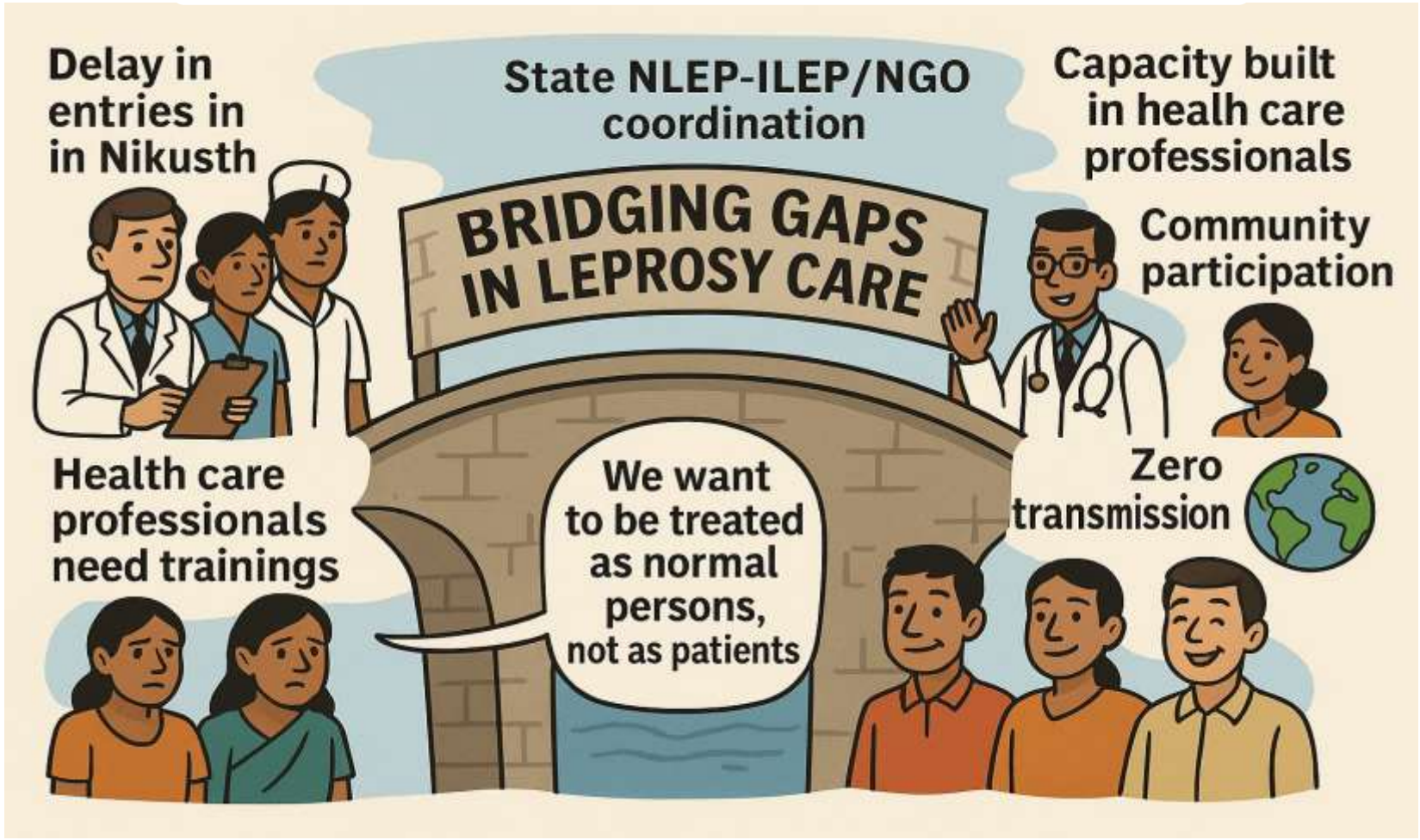
- RCS orientation and referral mechanism in GGH Vijayawada, NTR district
- Use of peer support groups in motivating others
- Cross-program convergence: involving RBSK for school screening and disability assessment
- Use of WhatsApp groups for real-time case reporting and follow-up coordination in some districts
- DPMR camps in the colonies and at some PHCs

Lessons Learnt

"From the visits, a few key lessons emerged:"

1. **Supervision matters:** Simple follow-up visits improved compliance with register maintenance.
2. **Training is empowering:** Where refresher trainings occurred, case identification and data entry improved.
3. **People-centric approach works:** Affected individuals responded positively when they felt involved and respected.
4. **Interdepartmental coordination is critical:** Linking leprosy work with disability services, and Pension government schemes and Socio-Economic Rehabilitation support has the potential to offer holistic care.

"Better Care, Leprosy-Free Future



Picture explaining State and ILEP coordination can Strengthens the Leprosy Care for a Healthier Tomorrow

Gaps identified	Proposed solutions
Knowledge on Leprosy - Patient cards - Voluntary muscle testing - EHF score calculation - Deformity correction - DPMR	Training programs to Medical officers and health care professionals by covering these topics with practical demonstration by mobilizing the persons affected.
Records at PHC level	Conduct refresher trainings
Insufficient services for disability prevention and rehabilitation.	Set up specialized clinics (Weekly clinics at PHC) offering physiotherapy and referring to reconstructive surgery on need basis.
Lack of psychological support for affected individuals	Integrate mental health services into leprosy programs.

Steps which can make a real difference

Identifying the districts which need trainings

Scheduling the in-person trainings for a day or two days

Conducting the pre test

Covering topics on

- Patient cards
- Voluntary muscle testing
- EHF score calculation
- Deformity correction
- DPMR
- Practical Demonstration with patients if possible Child case which can help the participants understand the real world scenario in an empathetic way

Conducting the post-test

State NLEP

ILEP/NGO-Technical resource

Expected Output:

- 100% participation in pre- and post-test.
- Improved post-test scores by at least 30–50%.
- Practical skills demonstrated confidently in DPMR and VMT.
- Increased understanding of empathetic patient handling through real-world case demo.

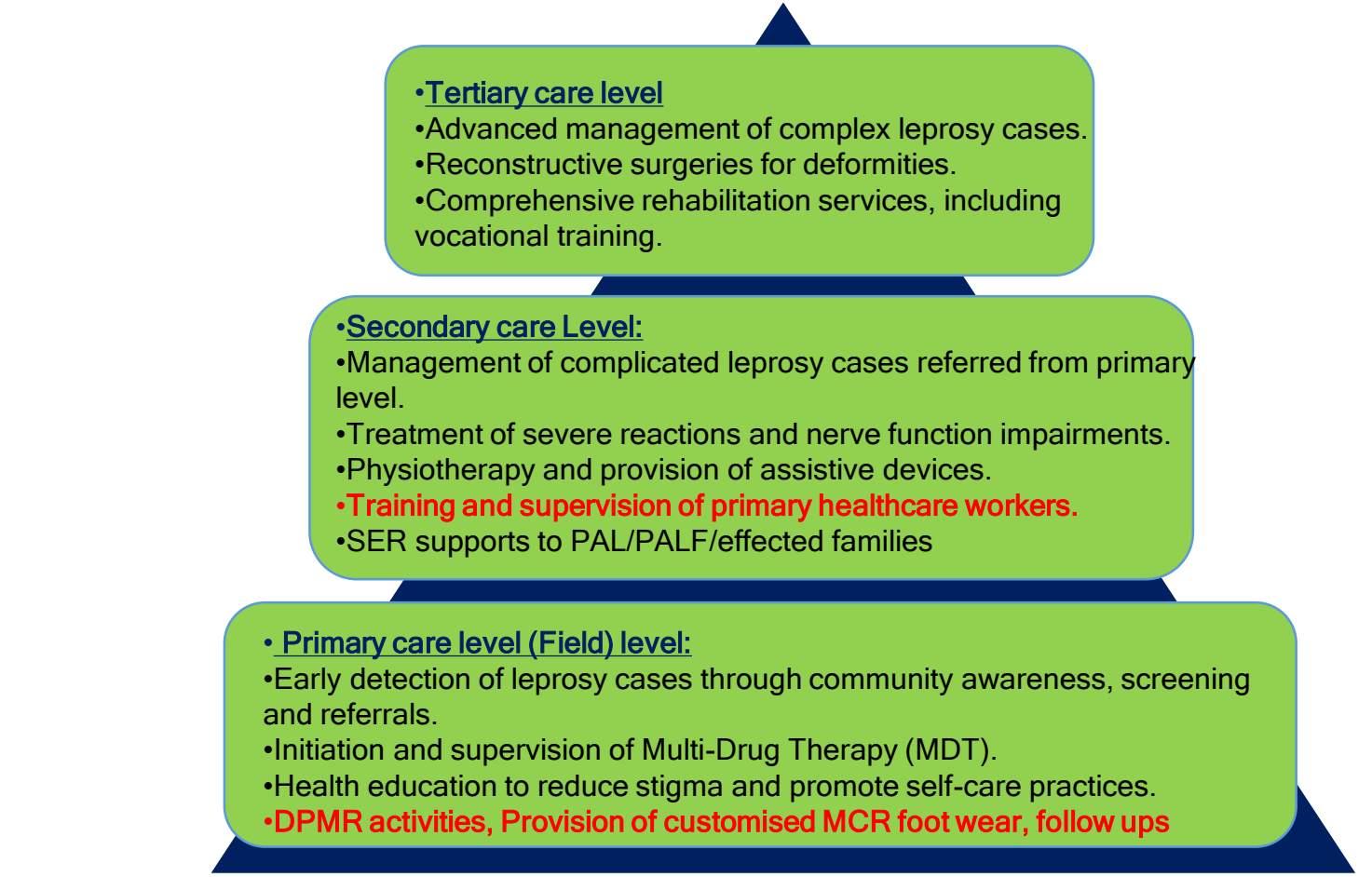
Expected Outcome:

- Health workers gain confidence in:
  - Identifying Grade 1/Grade 2 disabilities.
  - Calculating EHF score accurately.
  - Using patient cards systematically.
  - Educating patients on self-care.
- Better referrals for deformity correction and RCS.
- Enhanced documentation and follow-up at PHC/CHC level.

Expected Impact:

- Early detection and prevention of deformities.
- Reduced disability burden among leprosy patients.
- Empathetic care culture promoted within health system.
- Strengthened DPMR implementation at the field level.

In the view of NGOs-Scope for Strengthen



ILEP and other NGOs

NGOs-Scope for Strengthen in Strengthening NLEP

District Leprosy officer and Team

Recommendations

1. **Capacity building:** Quarterly skill-refresh sessions for Medical officers and Other health care functionaries on NLEP indicators, registers, and Nikusth.
2. **Digital mentoring:** Use of mobile-based microlearning or guided videos for field-level functionaries.
3. **Enhanced RCS support:** Facilitate pre and post-operative physiotherapy by connecting with physiotherapy colleges or NGOs.
4. **Improved IEC material:** State-supported printing and timely supply of disability care posters, booklets, and visual aids.
5. **Community Involvement:** Encourage self-care groups, peer educators, and survivor stories during awareness campaigns.
6. **Infrastructure & Logistics:** Ensure basic equipment like splints, MCR footwear, and disability aids are available and tracked.

Interacting with inmates of Bethasda Leprosy Colony at Done, Nandhyala District

Field visit with Joint Director of Leprosy and District medical and Health Officer at Alluri Sita Rama Raju District

IEC at Kodavaluru PHC and interactions with ASHA on the clinical symptoms and house marking ay Kammapalem subcentre at Nellore district

Discussions with the Persons Affected in Grace Leprosy Colony, Bapatla District

PHC Visits at Krishna District

కుష్ఠు రోగులు మందులు సక్రమంగా వాడాలి
: డాక్టర్ ప్రియదర్శిని

పాలకొల్లు,మేజర్‌న్యూస్: లంకలకోడేరు ప్రాథమిక ఆరోగ్య కేంద్రాన్ని రాష్ట్ర నాన్ గవర్నమెంట్ ఆర్గనైజేషన్ లెప్రసీ కన్సల్టెంట్ డాక్టర్ ప్రియదర్శిని. సందర్శించి డాక్టర్ అడ్డాల ప్రతాప్ కుమార్‌ని లెప్రసి కేసుల వివరాలను అడిగి తెలుసుకుని.రికార్డులను పరిశీలించారు. అలాగే కొత్త కేసులను గుర్తించి వారు మందులు సక్రమంగా వాడేటట్లు చూడాలనిసలహాలుసూచనలుఇచ్చారు.

ఈకార్యక్రమంలో పీఎంవో ఎంపీ రమేష్.డిపిఎంలు జక్కంపూడి రాంప్రసాద్, జివిఎస్ఎన్ మూర్తి. ఆరోగ్య విస్తరణ అధికారి గుదాల హరిబాబు. పీహెచ్ఎన్పి ఎలిజబెత్. ఫార్మసి అధికారి పివి స్వామి.స్టాఫ్ నర్స్‌లు ముత్యవల్లి, సౌజన్య, ఎల్‌టి ప్రసాద్. హెల్త్ అసిస్టెంట్ టి.హరిబాబు తదితరులు పాల్గొన్నారు.

PHC Visits at west Godavari District

Conclusion

"Leprosy eradication is not just a technical goal—it is about inclusion, equity, and dignity.

The field presents both obstacles and opportunities.

By listening to ground-level voices and promoting practical solutions, we can bridge gaps and deliver better, more humane care to every person affected."

THANK YOU