ilep India

GOOD PRACTICES


AIFO INDIA

american leprosy missions

foundation India Trust damien

fontilles salud desarrollo

GLRA INDIA

LEPRA
® Registered as LEPRA Society

NLR INDIA FOUNDATION

SWISS EMMAUS LEPROSY RELIEF WORK - INDIA

The Leprosy Mission Trust India
healing.inclusion.dignity

Table of Contents

Sr. No.	Content	Page No.
1.	Rationale	1
2.	About Us	2
3.	AIFO India, ALM, and DFIT	3
4.	Fontilles, GLRA India, and Lepra Society	4
5.	NLR India Foundation, TLMTI and Swiss Emmaus	5
6.	Focus area of ILEP India Members	6
7.	Strategic Approach	7
8.	Capacity Building of Medical Officers & Health Workers (AIFO India)	8
9.	Leprosy Complication Management (AIFO India)	9
10.	Special Surveillance Survey and Focused Leprosy Campaign in Tea Gardens Areas of Dibrugarh (AIFO India)	10-11
11.	Integrating Primary & Tertiary levels in India for custom footwear for people with leprosy anaesthetic feet (ALM)	12-13
12.	Involvement of local community volunteers in Leprosy case detection in the Musahar population (DFIT)	14-15

Table of Contents

Sr. No.	Content	Page No.
13.	Updating the list of persons affected by leprosy with disabilities and assessment of disability status for providing services like footwear, RCS, Disability Certificates, and Livelihood support for sustainable income (DFIT)	16-17
14.	NIRAMAYA II – Comprehensive Leprosy Care through Strengthening and Streamlining Referral Services – A hub & spoke model (GLRA India)	18-19
15.	WaSH My Eyes - Reduction of blindness caused by NTDs through integrated WaSH approaches (GLRA India)	20-21
16.	Accelerating elimination targets through enhanced active case finding and responsive health systems (Lepra Society)	22-23
17.	Empowering Persons with Disabilities (NLR India)	24-25
18.	Community Health Need Assessment for Project Development in Drug (Swiss Emmaus)	26-27
19.	Promotion of accessibility of services for persons in need due to Leprosy in Guntur and East Godavari districts of Andhra Pradesh State, India (Swiss Emmaus)	28-29
20.	Enhanced self-care program to reduce disability in Leprosy (TLMTI)	30-31
21.	Empowering Public Health: Trailblazing Participatory Block-Level Resource Mapping for Enhanced Leprosy Program Management in Chhattisgarh (TLMTI)	32-33

Rationale

Effective strategies towards “Zero Leprosy” demand not only innovative solutions but also well-documented, replicable models that drive sustainable impact. The ongoing work of the ILEP consortium across India demonstrates this approach, as member organizations work collaboratively to establish and refine practices that are proven effective in complex field environments. These practices cover a broad spectrum, including early case detection, disability prevention and medical rehabilitation, mental health support, and socio-economic rehabilitation, all of which are essential to address the multifaceted challenges faced by those affected by leprosy.

Furthermore, documenting these practices enables the development of adaptable, evidence-based models that can be replicated across different regions locally and globally. Such replicable models foster continuity and reliability in service delivery, particularly for vulnerable populations. By systematically recording successful methodologies, ILEP India’s member organizations create a valuable resource that promotes consistency, efficiency, and scalability, allowing future projects to benefit from lessons learned and avoid common pitfalls. In addition to operational benefits, documenting and sharing these good practices significantly enhances the visibility of fieldwork. Raising awareness about these efforts is crucial for advocacy, enabling stakeholders including government bodies, healthcare professionals, and community organizations to recognize the transformative impact of leprosy initiatives. Enhanced visibility also aids in fostering partnerships, and influencing policy changes, all of which are vital to sustaining and scaling up “zero leprosy” efforts. Through robust documentation and widespread dissemination, ILEP India’s initiatives inspire confidence among partners and communities alike, advancing the collective mission toward a leprosy-free India.

In essence, maintaining and promoting good practices not only strengthens current operations but also creates a legacy of knowledge and best practices that will guide future interventions, amplifying the reach and impact of leprosy programs across India and the globe.

ABOUT US

The International Federation of Anti-Leprosy Associations (ILEP) is a consortium of international non-governmental organizations dedicated to eradicating leprosy worldwide. Since its inception, ILEP has acknowledged that achieving a leprosy-free world requires collective effort, collaboration, and shared resources.
ILEP India is committed to the global vision of ILEP: achieving "Zero Leprosy by zero transmission, zero disability, and zero stigma and discrimination." This vision guides all activities and initiatives, aiming for a future free from leprosy through collaboration, innovation, and dedicated efforts.

ILEP member organizations have been involved in India for many decades, a few of them from as far back as the 1870s. Since 1983, ILEP India members have been instrumental in supporting leprosy prevention and services throughout the country as a consortium supporting the NLEP.

ILEP India consortium comprises of nine member organizations:
1. AIFO India - Italian Association of Friends of Raoul Follereau
2. ALM - American Leprosy Missions
3. DFIT - Damien Foundation India Trust
4. FONTILLES - Fontilles, Lucha Contra La Lepra
5. GLRA India - German Leprosy and TB Relief Association
6. LEPRA Society - LEPRA Health in Action
7. NLRIF – Until No Leprosy Remains India Foundation
8. SEI - Swiss Emmaus Leprosy Relief Work - India
9. TLMTI - The Leprosy Mission Trust India

Presence and Impact

ILEP India operates in 18 out of the 36 states and union territories of India, providing comprehensive leprosy services through its member organizations. It has a direct presence in 14 out of 15 high-priority states as per NLEP 2023-24. The federation has 16 consultants who serve as state NLEP (National Leprosy Eradication Programme) consultants, offering strategic support and expertise in the states working in close association with the State Leprosy team. In the northeastern states, AIFO India provides need-based support while continuing its work in Assam.

Amici di Raoul Follereau, affectionately shortened to AIFO, was founded in India in 1998 by Dr. V. Ekambaram. As we said earlier, we are a Non-Governmental Organisation in Bangalore, serving as the Coordination Office for Associazione Italiana Amici di Raoul Follereau, Bologna, Italy. Our inspiration is Raoul Follereau (1903-1977), a social reformer who devoted his life to the upliftment of people with leprosy. His work lives on through many organizations across the world—all honored to call themselves Friends of Raoul Follereau or Amici di Raoul Follereau.

Our objective is to emulate Follereau's approach of sharing love and serving people with leprosy, within different families and communities. While our early vision was focused on the eradication of leprosy through early identification and treatment, our efforts soon grew to include surveys, educational programmes and community-acceptance initiatives.

Our reach expanded to cover the North-east and Karnataka.

ALM Asia Regional Office is located in Hyderabad, Telangana state, India. Its role is to realize ALM's strategy in the Asia region through collaborative development and implementation of innovative, impactful and locally appropriate solutions addressing health and development needs of communities at-risk of and people affected by, leprosy and other NTDs.

Programmes focus on health systems strengthening; leprosy control; health infrastructure and capacity development; health promotion and disease prevention; home and facility based NTD care (MMDP); WASH, community empowerment and mobilization for health and WASH; and disease mapping, data collection and research to influence policy and practice. The programs engage with Ministries of Health, NGOs, hospitals and healthcare facilities, scientific / research centres, government departments for water, sanitation and health, and with community based organizations / groups. The work is enabled through strong in-country partnerships with organizations having the requisite programmatic experience, NTD expertise and good government relations. In Asia, ALM has its presence in four countries through current projects: India , Nepal, Myanmar and the Philippines. ALM has also been involved in Bangladesh through earlier projects.

Damien Foundation India Trust (DFIT) is a charitable Non-Governmental Organization established for Leprosy and TB Control Activities in India. It offers Leprosy and TB related services either directly through its own projects or in partnership with Government and local NGOs. The organization started its chapter of leprosy control activities at a village in South India in 1955, TB control in 1998 and now covers a population of 143.2 million populations across 9 states in India. The main objective is to provide medical and social support for persons affected by Leprosy or Tuberculosis which is done in close partnership with the local community and Government.

Fontilles is a foundation that works for the health and well-being of the most vulnerable and neglected people, work that began with the opening of its sanatorium, in 1909, located between the areas of Vall de Laguar, Murla and Orba (the Marina Alta , Alicante). The institution played a fundamental role in the elimination of leprosy in Spain, an experience that it has exported to other countries where the disease has not yet been eradicated. Fontilles has a history of over 100 years of services to mankind. Fontilles originated in Spain – is a Member in ILEP since 1969. Its international operations were started with its first project at Harapanahalli in Karnataka, India in 1986.

Fontilles in India works with local partners. The focus is on people at grassroots level and in most needy places. The location of Fontilles projects in India has been dynamic with emerging collaborations and promotion of successful models.

GLRA India, a non-profit Indian entity, has been working for the cause of Leprosy/Skin NTDs, Tuberculosis, Disability, and Humanitarian crises since 1966. Its registered office is in Chennai and operates from the head office in Delhi with divisional offices in Chennai, Kolkata, and Mumbai. For the past 5 decades, our constant endeavor has been to provide medical and social rehabilitation to those affected by the above-mentioned diseases and conditions. Through the evolution of our work and the implementation of 382 plus projects in 23 states and 3 UTs, we touched the lives of more than 2.5 million people and enabled them to live a life of dignity. With the constant support of our parent organization, DAHW Germany, several national and international agencies, partner NGOs, hundreds of donors, and well-wishers, GLRA continues its journey with a commitment to a world where 'No one is left behind.'

GLRA is one of the founding members of ILEP India, the counterpart of the 'International Federation of Anti-Leprosy Association.' Being a member and the coordinator of the ILEP India consortium, GLRA actively collaborates with the CLD-MoHFW, State Governments, other ILEP members, WHO, APAL, state ILEP/NLEP consultants, and other important stakeholders and provides technical support in the implementation of NLEP. It also collaborate with the NTEP and with several bilateral/multilateral agencies such as The Global Fund, USAID, BMZ, MISEREOR, Deutsche Bahn Stiftung (Germany), and Indian corporates such as Fullerton, DBS India, ATF, etc.

LEPRA (registered as LEPRA Society in 1989), is in existence since 1989 and has earned the reputation of being one of the leading organisations working for people affected by leprosy. In the last three decades, it has provided treatment and care to people affected by leprosy as well as those suffering from lymphatic filariasis (LF), tuberculosis (TB), HIV/AIDS and eye problems. For LEPRA, Leprosy remains the key focus and providing end to end services to the patients especially in hard-to-reach remote areas forms the core of all the projects of LEPRA.

While dealing with leprosy, one of the Neglected Tropical Diseases (NTDs), LEPRA's technical expertise has aided not only in providing case detection, treatment, disability care, rehabilitation, community mobilisation; but also, holistic end to end services and approaches in tackling the diseases through counselling, advocacy and envisaging the welfare of those affected.

NLR India (NLRIF), New Delhi is an ISO 9001:2015 certified, Non-Profit, Non-religious, Non-Government Organization. NLR India works for persons and families affected by Leprosy, other Neglected Tropical Diseases (NTD) and Persons With Disabilities (PWDs). The Foundation has a track record of serving the leprosy cause since the year 1999. With its noble vision and Leprosy oriented efforts spread across a time period of over two decades, NLRIF supports the National Leprosy Eradication Programme (NLEP) in achieving Zero Transmission, Zero Disability and Zero Exclusion. NLR India works in five different thematic areas, namely, Health, Education, Livelihood, Empowerment and Research.

SEI is working towards a world in which no one suffers from leprosy and other neglected tropical diseases (NTDs), discrimination because of disease or handicap. Since 1960, SEI has spearheaded the efforts to eradicate leprosy in India by supporting the NLEP as well as providing services at all levels of health care system and in the community. FM's projects are aligned to Sustainable Development Goals which aims to ensure 'health for all'.

Since initiating work in India, FM has committed itself to working in collaboration with the government at all levels so as to increase its reach and enhance its impact. So far, all programs implemented at the state, district or lower levels have been in consensus with the government and towards further strengthening the government systems to implement its leprosy control program seamlessly and effectively. The organization works directly with the NLEP in various capacities. SEI is also supporting tertiary leprosy care hospitals where out-patient and in-patient services are provided, including reconstructive surgeries, reaction management and disability care services.

The Leprosy Mission Trust India (TLMTI), founded in 1874 as the 'Mission to Lepers' by an Irishman named Wellesley Cosby Bailey, is the largest leprosy-focused non-governmental organisation (NGO) in India. TLMTI is registered as a Society under the Societies Registration Act, 1860 and is headquartered in New Delhi, India. The organisation works with people affected by leprosy and other neglected tropical diseases (NTDs), people with disabilities, and marginalised communities. TLMTI has a diverse set of programmes, namely, Healthcare, Sustainable Livelihood, Community Empowerment, Advocacy and Communication, and Research and Training. These programmes are implemented through 16 hospitals, six vocational training centres, four residential care homes for elderly persons affected by leprosy, nine community empowerment projects, and a molecular research laboratory, spread across 9 states of India.

TLMTI celebrated its 140th anniversary in 2014. What was started in 1874 for giving shelter to persons considered as 'outcasts' at a time when there was no cure for leprosy has become India's largest leprosy-focussed non-governmental organisation (NGO).

Presently, TLMTI has around 900 staff working in various capacities in its institutions and projects. It is a member of The Leprosy Mission Global Fellowship.

Focus area of ILEP India Members

Name of Agency	Focus area
AIFO India	Leprosy & Disability
ALM	Leprosy & other NTDs
DFIT	Leprosy & Tuberculosis
Fontilles India	Leprosy & Community Health
GLRA India	Leprosy, TB, NTDs (LF), Disability Inclusion, Humanitarian Aid, Research and WASH
LEPRA Society	Leprosy, Lymphatic Filariasis, Tuberculosis, HIV, Eye Care, Disability Inclusion, Research (Medical/Operational), WASH, Customized footwear for Leprosy/LF, Mental Health, Training
NLR India Foundation	Leprosy, Lymphatic Filariasis & Mental Health
SEI	Leprosy & General Medical Services, Migration & Leprosy, Mental Health
TLMTI	Leprosy & General Medical Services

Strategic Approach

ILEP India aligns its efforts with national and state strategic plans, annual reports, and evaluation reports. It collaborates with various stakeholders, including the Central Leprosy Division (CLD), the Ministry of Health and Family Welfare (MoHFW), state and local governments, the ILEP Global team, the World Health Organization (WHO), and others. The organization develops a common work plan with yearly activities based on these priorities.

· Strategic Planning and Guidelines: Supporting the development and implementation of guidelines at national, state, and district levels with recent ones including the National Strategic Plan 2023-2027, Guidelines on AMR, and Integrating Mental Health Services for persons affected by Leprosy.

· National Strategic Plan Implementation: Working with stakeholders to implement, monitor, and supervise the National Strategic Plan.

· Training, capacity building, and Review Meetings: Participating in and facilitating trainings and support review meetings at various administrative levels.

· Technical Support: Providing engagement and technical support to states through NLEP/ILEP consultants.

· Active Case Finding and LPEP Implementation: Engaging in active case finding and the implementation of the Leprosy Post-Exposure Prophylaxis (LPEP) initiative.

· DPMR Services: Offering Disability Prevention and Medical Rehabilitation (DPMR) services, including self-care, community-based rehabilitation, and ulcer care kit distribution.

Communication and Advocacy

ILEP India is dedicated to promoting the rights of people affected by leprosy through advocacy and communication efforts. This includes:

1. Large-Scale Awareness Campaigns: Raising awareness about leprosy through Information, Education, and Communication (IEC) materials using Social and Behavior Change Communication (SBCC) approaches.
2. Digital Platforms and Social Media: Utilizing digital platforms and social media to reach a broader audience.
3. IEC Material Development: Preparing and updating IEC materials in consultation with stakeholders.
4. Repealing Discriminatory Laws: ILEP Members together with other partners are involved in researching the existing discriminatory laws towards persons affected by leprosy and actively advocate for repealing the same.

Comprehensive Care and Support

ILEP India's key contributions include:

1. Supporting Tertiary Care Services: ILEP India is operating in 31 hospitals and tertiary care centers across 13 states.
2. MCR Footwear Units: ILEP India through its members manages 44 Microcellular Rubber (MCR) footwear manufacturing and supply units in 11 states, with an annual production capacity of 160,000 footwear for individuals affected by leprosy.
3. Performing Reconstructive Surgeries: ILEP India member hospitals conduct approximately 1300 reconstructive surgeries annually.
4. Socio-economic Rehabilitation: ILEP India members also provide educational support, vocational training, small business assistance, housing support, and more to individuals and families affected by leprosy.
5. Mental Health Services: ILEP India members continue to provide peer counseling, psychosocial support, and innovations in mental health care.
6. Capacity building: To sustain the dwindling leprosy expertise in India, ILEP members actively conduct training for various healthcare cadres beginning from frontline workers to reconstructive surgeons.
7. Apex AMR testing laboratories: The Blue Peter Public Health and Research Centre, Hyderabad, Telangana, and Stanley Browne Research Laboratory, New Delhi mentioned under NSP for AMR surveillance are operated by ILEP India Members.

Capacity Building of Medical Officers & Health Workers (2023)

Project site : Guwahati, Sivasagar, Karimganj, and Hailakandi districts, Assam

Target Population

Medical Professionals and Health Workers of the districts

Key Stakeholders

Medical Officers, Health Supervisors, ASHA Workers, Community Volunteers.

Brief Description

AIFO, in collaboration with district leprosy cells, conducted extensive training sessions in the year 2023, aiming to enhance the skills and knowledge of medical professionals and health workers in managing leprosy effectively. These sessions were held in various locations including Guwahati, Sivasagar District, Karimganj, and Hailakandi. The training focused on equipping participants with essential skills in clinical leprosy, covering areas such as history, identification, examination techniques, reaction management, complication management, and reconstructive surgeries.

Outcomes/Findings

The outcomes of these sessions were significant. In Sivasagar District, 40 medical professionals, 280 ASHA workers in Nilam Bazar, 350 ASHA workers in R. K. Nagar & Durlovpur, and 400 beneficiaries in Srigouri - Kachuadam BPHC demonstrated enhanced proficiency in leprosy detection and deformity prevention. Trained personnel are now actively addressing leprosy-related challenges in their communities, contributing to improved healthcare outcomes.

Key Challenges

The variation in prior knowledge among participants required tailored training approaches to ensure all attendees achieved the desired competency level.

Recommendations

To sustain and build on the progress made, it is recommended to conduct follow-up training sessions and refresher courses. Developing a continuous education program and providing additional resources, such as training manuals and online modules, can help maintain and enhance the skills of healthcare workers. Strengthening collaboration with local health authorities and community organizations will also be essential for ongoing support and resource allocation.

Leprosy Complication Management

Project site : Dibrugarh and surrounding areas, Assam

Target Population

Individuals affected by leprosy in Dibrugarh and surrounding areas

Key Stakeholders

Medical Officers, Health Supervisors, ANMs, Nursing Technicians, Community Volunteers, Leprosy Officers, Physiotherapists, Government Healthcare Providers.

Brief Description

The team has effectively implemented a systematic monthly visit/call follow-up to manage complications in individuals affected by leprosy. This approach ensures continuous monitoring of their health and tracks their progress over time. The ongoing follow-up is meticulously designed to assess their health status, promptly address emerging complications, and verify the improvement in overall well-being for patients. Currently, 3 patients are undergoing steroid treatment from Assam Medical College. The team has effectively managed a total of 160 individual cases of leprosy-related complications, highlighting the importance of timely intervention and care.

Outcomes/Findings

- Systematic Follow-ups: Implemented systematic monthly visit/call follow-ups to monitor health status and track progress over time.
- Prompt Intervention: Ensured prompt addressing of emerging complications, including reactions and other health issues related to leprosy.
- Collaboration with Assam Medical College: Facilitated timely treatment, including steroid administration, for patients requiring specialized care.
- Management of Complications: Successfully managed 160 cases of leprosy-related complications, demonstrating effective healthcare delivery and patient management.

Key Challenges

Ensuring consistent engagement and participation from patients in follow-up sessions posed challenges. Misconceptions and lack of awareness about leprosy led to improper self-treatment. Reaching remote and marginalized communities required substantial logistical planning and resource allocation.

Recommendations

To sustain and enhance the impact of these initiatives, it is recommended to conduct follow-up sessions and refresher courses for community volunteers and health workers. Strengthen collaboration with local leaders and influencers to leverage existing social networks for disseminating health messages. Explore the use of mobile health clinics and community-based support groups to maintain engagement and support for affected individuals and families. Continued advocacy for policy support and funding is essential to sustain and scale up successful interventions.

Special Surveillance Survey and Focused Leprosy Campaign in Tea Gardens Areas of Dibrugarh (2023 onwards)

Project site : Few blocks of Dibrugarh and Silchar districts, Assam

Target Population

People living in tea gardens, villages, and schools in Dibrugarh and Silchar Districts of Assam (Lahowal, Barbarua, Naharani, Tengakhat, Khowang, Panitola, Sonai, Lakhipur, Borkhola and Kanaikuri blocks)

Key Stakeholders

Medical Officers, Health Supervisors, ASHA Workers, Community Volunteers.

Brief Description

AIFO conducted targeted Special Surveillance Surveys and Screening Drives in 42 tea gardens, 21 villages, and three schools, accommodating 250 students and over 20 teachers in Dibrugarh and Silchar Districts. The initiative aimed to detect leprosy early and raise awareness among a total population of 1,32,843. Additionally, Focused Leprosy Campaigns along with Leprosy Case Detection Campaign (LCDC) were held on Republic Day and World Leprosy Day in Chandigarh TE, Silchar, and Halmari TE, Dibrugarh, with attendance from local people, club members, patients, health workers, and tea estate authorities.

The drive spanned across six blocks in Dibrugarh (Khowang, Barbaruah, Naharani, Lahowal, Tengakhat, Panitola) and six blocks in Cachar (Dholai, Jalalpur, Udharbond, Borkhola, Sonai, Lakhipur), covering a total of two districts. During the drives, the team covered a population of 1,07,478 residing in tea gardens and 25,095 residing in villages.

A comprehensive Special Screening Drive was conducted in 42 tea gardens and 12 blocks of the Dibrugarh and Silchar districts of Assam, reaching 6575 individuals with leprosy awareness and screening 493 individuals who had patches. Disturbingly, some patients were treating leprosy patches with antifungal medication due to a lack of awareness. Among those screened, five suspects emerged, with three confirmed as leprosy cases.

Partners

Local Community Organizations, Health Centres and Tea Estate Authorities

Outcomes/Findings

The initiative led to early detection of leprosy cases and increased awareness among the community. A total of 83 people benefitted from the campaigns in Dibrugarh and Silchar, and 745 people benefitted from the campaigns in Karimganj and Hailakandi (LCDC). Trained personnel now actively address leprosy-related challenges in their communities, contributing to improved healthcare outcomes.

Key Challenges

Misconceptions and lack of awareness about leprosy led to improper self-treatment with antifungal medications. Reaching remote and marginalized communities required substantial logistical planning and resource allocation.

Recommendations

To sustain and build on the progress made, it is recommended to conduct follow-up training sessions and refresher courses. Developing a continuous education program and providing additional resources, such as training manuals and online modules, can help maintain and enhance the skills of healthcare workers. Strengthening collaboration with local health authorities and community organizations will also be essential for ongoing support and resource allocation.

Integrating Primary & Tertiary levels in India for custom footwear for people with leprosy anaesthetic feet (September 2022- to present)

Project site : Kalyanpur Community Health Centre, Samastipur District, Bihar; SIHRLC, Karigiri, Tamil Nadu

american leprosy missions

Target Population

- People with severe leprosy lower limb disabilities

Key Stakeholders

1. People with leprosy and LF lower limb disability in remote areas who require but cannot access specialized footwear services.
2. General healthcare system at the primary level
3. ILEP members in Bihar
4. SIHRLC, Karigiri
5. HRL, PHFI

Brief Description

ALM, LEPRA Society, and the Health Informatics Rapid Lab, Public Health Foundation of India (HRL, PHFI) are collaborating in a 3-year integrated WASH (water, sanitation, and hygiene) and NTDs (neglected tropical diseases) project called Jagruti in 130 villages of Kalyanpur Block in Samastipur District, Bihar. The district is endemic for leprosy and lymphatic filariasis (LF). A digital universal household survey in 2021 and a rapid enquiry survey in 2022 have confirmed and reported to the national programmes, 336 people affected by leprosy and 4,730 people affected by LF living in all 130 villages of the Block, data previously unknown to the Bihar State health system.

One Community Health Centre (CHC) serves the entire Block population of 380,000. Despite over 5000 people with chronic NTDs living in the Block, NTD disability and morbidity care was not available at the CHC prior to the project. Concurrently, ALM and the Schieffelin Institute of Health Research & Leprosy Centre (SIHRLC), Karigiri are collaborating in innovative technologies like CAD/CAM (computer-aided design, computer-aided manufacturing) and pressure sensors in the manufacture of protective insoles for people with leprosy damaged feet.
The project's goal was to make integrated and specialized footwear services accessible to people affected by leprosy and LF, at the primary level.

Objectives

1. To set up and equip a footwear unit at Kalyanpur CHC (primary level healthcare facility) for manual manufacture of custom footwear, including provision for 3D foot scans.
2. To link this unit with SIHRLC, Karigiri (tertiary leprosy centre) having a CAD/CAM facility for the manufacture of custom insoles.
3. To increase compliance in footwear usage by people affected by leprosy and LF (acceptability, comfort).
4. To decrease leprosy plantar ulcer recurrence.
5. To decrease LF lower limb lymphedema.

Key activities

1. Collecting geotagged, photographic data of NTD. Reliable photographic and geotagged data on chronic NTDs formed an evidence base for this new service at the CHC.
2. Signed MoU with District Health Society, Samastipur for health systems strengthening of Kalyanpur CHC for primary level NTD care. This enabled allocation of a room in the CHC and smooth implementation.
3. Persistent evidence- based advocacy through multiple meetings with district and state health authorities. This created the opportunity to build relationships, share the geotagged and photographic data gathered through our universal household surveys, and facilitate collaboration and joint planning with the government programmes.
4. Purchase of equipment and materials for fabricating footwear at CHC Kalyanpur (primary level)

5. Purchase of portable 3 D foot scanner at CHC Kalyanpur (primary level)
6. Appointment and training of shoe technician at CHC Kalyanpur (primary level)
7. Sensitization of CHC staff and frontline workers
8. IEC materials on footcare in leprosy and LF
9. Identification of persons requiring footwear and collecting baseline data (community level)
10. Footwear measurements and manual fabrication of footwear at CHC
11. Foot scans taken at the CHC or in the community are emailed to SIHRLC, Karigiri (tertiary level) for fabrication of CAD/CAM insoles. These are posted back to the primary level and the insoles fitted into the footwear at the CHC.
12. Delivery and fitting of footwear, footcare and gait education, at the CHC or in the community.
13.Regular follow-up (6-month) for data collection and feedback on any modifications for next pair of footwear.
14.Optimal and effective collaboration between all key stakeholders.

Partners

1.District Health Society, Samastipur, Bihar
2.Health Informatics Rapid Lab (HRL), Public Health Foundation of India (PHFI)
3.Schieffelin Institute of Health Research & Leprosy Centre (SIHRLC), Karigiri

Outcome

1.Equipping Kalyanpur CHC in an NTD endemic area with a manual footwear manufacturing unit linked with SIHRLC, Karigiri for CAD/CAM insoles has enabled people with leprosy living more than 2000 kms away from this sort of specialized centre, to receive custom footwear of their choice, at the primary level, close to home.

2.The custom CAD/CAM footwear has advantages over the standard issue government MCR (microcellular rubber) sandals which are, improved first fit accuracy and increased user compliance due to perceived comfort, usefulness, and increased participation and activity levels, thereby decreasing ulcer recurrence and lower limb disability.
3. From our current monitoring, we have documented evidence of healing of ulcer in 94% of leprosy plantar ulcer cases, and 72% reduction of LF lower limb swelling due to a combination of custom footwear usage and regular practice of selfcare.

Key Challenges

1.Delay (3 -4 weeks) in the delivery of the fabricated orthosis to the CHC, due to delay in courier/ postage services. Hypothetically, foot pressure points could change if plantar ulcers develop or worsen during this period of waiting for the insoles to arrive, fitting the insole into the footwear, and delivery to the patient.
2. Cost per pair of footwear with CAD/CAM customized insole is higher (INR 2,500) than the standard MCR footwear (INR 500). Funding will be required initially. However, there is no disputing the fact that CAD/CAM insoles are more effective in preventing ulcers and disability.
3. Manual footwear making with partial orthotic customization is a diminishing art with a dwindling number of skilled shoe technicians. Finding a suitable person was difficult.

Recommendation

Fragmented or siloed approaches in healthcare are neither cost effective nor sustainable for health systems in low-and middle-income countries. This integrated approach with good collaborations, can be replicated by optimal, effective, and collaborative usage of NGO and government resources in countries, states, and districts endemic for leprosy and other NTDs. Care of the foot in chronic NTDs like leprosy and LF, and NCDs like diabetes, is based on similar principles, practices, and products. When footcare as a service can be integrated for more than one disease where these diseases occur together, it becomes relevant, cost effective, and sustainable.
1.Pilot interventions/approaches that experiment different models of integrating footcare for NTDs and NCDs at the community level, in areas where these diseases occur together. The benefit of CAD/CAM footwear would outweigh its cost, considering its effectiveness in preventing further disability and maintaining an individual's ambulation. Therefore, integrating footwear services for leprosy and LF, which often coexist in rural areas, and including neuropathic (diabetic) feet will increase the cost effectiveness and sustainability of this much needed service at the primary level.
2.Identify and address gaps in integrating footcare services through models that integrate primary and tertiary levels.
3.Pilot innovations in footcare e.g., ulcer care, footwear, that are acceptable, effective, and low cost for the community.
4.Showcase models of successful and sustained government ownership of integrated footcare that can be replicated.

Involvement of local community volunteers in Leprosy case detection in the Musahar population (March 2018 to December 2019)

Project site : Piprakothi and Motihari Sadar blocks of East Champaran district, Bihar

foundation India Trust damien

Target Population

Musahar Population community in parts of East Champaran district

Key Stakeholders

- National Leprosy Program Bihar
- State Leprosy Office
- Health Facilities and Staff at the Secondary and Primary Levels
- ASHA
- Musahar Community Volunteers

Brief Description

Leprosy case detection is improved in the Musahar population in Bihar by involving volunteers from the same community along with ASHA.
Musahar community in Bihar is a part of the scheduled caste (SC) and the most marginalized population, living on a daily wage. It was observed that the leprosy case detection campaigns could not reach this population for several reasons. During the 1st LCDC in Bihar which was conducted in 2016 only 2 cases were detected from the Musahar community in 31 villages in 2 blocks with a population of around 12500.

Soon after the 1st LCDC, DFIT teams identified 40 new leprosy cases during their health education activities conducted in some of these villages during the survey of leprosy patients with disabilities as a part of its project activities. This clearly indicated missing cases during routine and special campaigns.
This was discussed with the program officer, NLEP at the state level, and decided to conduct door-to-door surveys with community volunteers from the same community along with ASHAs supervised by DFIT's Community social workers. Around 12500 population living in 31 villages were covered through 3 different phases (2 special surveys and 2nd LCDC), the final coverage was around 85%, and 232 new leprosy cases were detected in a period of 9 months.

After advocacy by DFIT, NLEP Bihar recognized the problem and decided to conduct a survey mainly focusing on Schedule Caste which is around 10 million population including the Musahar community in Bihar. LCDC was conducted in 2019 January, focusing on the SC population detected nearly 2497 cases in the 10.34 million population. i.e., 24 per 100000 population.

Musahar Population

They do not have any sustainable livelihood options. The literacy rate in the Musahar community is only 6.88% and it is only 3.09% for women. The health status of the Musahar is highly affected by their illiteracy, early marriage, and food habits.

They are dependent on daily wages working in an agricultural field, they consume rats and they still do not seek health care services for delivery or any other ailments. Their children do not go to school and their living conditions are very poor. They are highly vulnerable to any diseases including infectious diseases. So, the incidence of leprosy is higher among this population compared to the general population.

A strategy was developed during LCDC 2 for selected 31 villages in 2 blocks of East Champaran district. This involved meetings with the SLO and concerned DLO, meeting with local ASHAs, and identifying male and female volunteers from the Musahar community in every village. Training sessions were conducted on identifying suspects in collaboration with local ASHAs. Here the best practice is involving community volunteers from the Musahar community for better acceptance and coverage during the survey.

Goal and Objectives

Involvement of local community volunteers in Leprosy case detection in the Musahar population in two blocks of East Champaran district of Bihar in 2018.

- To understand the prevalence of leprosy in the Musahar community.
- To enhance case detection and ensure treatment completion in the targeted community by involving volunteers from the same community.

Key activities

An active search was conducted, involving concerned ASHAs and community volunteers from the Musahar community. DFIT provided incentives, like those offered during LCDC, to ASHAs and Musahar volunteers. Presumptive leprosy cases were examined by District nucleus members, DFIT supervisors, and medical officers on the same day. Confirmed cases were then reported to the respective Primary Health Centres (PHCs), and treatment was initiated.

Outcome

Total Number Of Village screened	Enumerated Population	Population Screened	Cases Confirmed	
			MB	PB
31	12593	10416	67	161

Around 12500 population living in 31 villages were covered through 3 different phases (2 special surveys and 2nd LCDC), the final coverage was around 85%, and 232 new leprosy cases were detected in 9 months (March 2018 to December 2018).

After advocacy by DFIT, NLEP Bihar recognized the problem and decided to conduct a survey mainly focusing on Schedule Caste which is around 10 million population including the Musahar community in Bihar. LCDC was conducted in 2019 January, focusing on the SC population detected nearly 2497 cases in the 10.34 million population. i.e., 24 per 100000 population.

Recommendations

- Identifying the vulnerable population.
- The involvement of volunteers from the same community is necessary for body examination, better coverage, and sustainability of the awareness about leprosy in the community.
- Choosing the right time/season is important to ensure better coverage and examination during the campaign.
- There is a need to develop a good network between community volunteers from the underserved population and local ASHAs for leprosy presumptive identification and referral.
- Special attention is needed during the treatment follow-up since they may stop treatment anytime. Community volunteers should be involved in treatment follow-up.

Updating the list of persons affected by leprosy with disabilities and assessment of disability status for providing services like footwear, RCS, Disability Certificates, and Livelihood support for sustainable income

Project site : Bihar (2017-2021), Jharkhand (2017-2023) and Chhattisgarh (2019-2022)

foundation India Trust damien

Target Population

Persons affected by leprosy with disabilities in Bihar, Chhattisgarh and Jharkhand

Bihar: 28 districts
Chhattisgarh: 04 districts
Jharkhand: 12 districts

Key Stakeholders

- National Leprosy Eradication Program Bihar
- State Leprosy Office
- Government Health Facilities at the District and Primary Level
- ASHA
- Person affected by leprosy

Brief Description

Disabilities and deformities are the key reasons for stigma and discrimination. Medical rehabilitation is essential to prevent the further worsening of disabilities and to improve both functionally and cosmetically. There are two aspects of medical rehabilitation, first by home-based self-care and second by reconstructive surgery.

One of the challenges is the nonavailability of data on persons affected by leprosy after the integration of leprosy into general health services. The total number of G2D patients on the list at the time of implementation of the program in 2017 was 7498 in 28 districts of Bihar. In Jharkhand at the time of implementation in 2017, it was 4803 and in Chhattisgarh at the time of implementation in 2019, it was 1565 cases in 4 districts.
From 2017 our main strategy was to identify and assess the disability status of persons affected by leprosy in selected districts of Bihar, Chhattisgarh, and Jharkhand and provide services along with training in self-care with demonstration, need assessment for MCR footwear and self-care, Re-constructive-surgery-and-social assistance. Also facilitated for disability certificates.

There was an impact on the medical and social aspects of persons affected by leprosy with disabilities in intervention districts (28 Districts in Bihar, 4 districts in Chhattisgarh, and 12 districts in Jharkhand). The updating of the list and disability assessment resulted in the availability of data on the number of persons affected by leprosy with disabilities living in the districts, requirement of MCR footwear, customized footwear, eligibility for RCS, eligibility for disability certificates, and pensions. DFIT assisted NLEP in providing necessary services to persons after the assessment for both medical and social rehabilitation.

- DFIT developed a strategy to address the issue of medical and social rehabilitation of persons affected by leprosy with disabilities in the selected districts.
- The selection of districts was done based on districts with the history of the highest leprosy cases treated so that a greater number of leprosy patients with disabilities benefit after the intervention
- Appointed one Community Social Worker (CSW) in each district for 2-3 years to accomplish the work. An available list of persons affected by leprosy with disabilities was given to them and they were trained in disability assessment, home-based self-care, footwear measurement, and identifying eligible cases for RCS.
- Community Social Workers identified many persons affected by leprosy that were not on the list by covering each block.

- Community social workers (CSWs) were guided by the DFIT-supported DPMR coordinators and district NLEP teams.
- The appropriate services were provided simultaneously after the disability assessment like footwear, RCS, Disability certificate, etc

Goals and Objectives

To identify persons affected with leprosy with disabilities and provide them with the necessary support for both medical and social rehabilitation.

Primary Objective:

- To update the list of persons with disabilities in 28 districts of Bihar, 4 districts of Chhattisgarh, and 12 districts of Jharkhand and to provide medical and social services.
- To identify the persons affected by leprosy with disabilities living in the districts and provide them with necessary services.

Specific Objective:

- To update the list of persons affected by leprosy in the districts with disability assessment
- To provide appropriate services to persons affected by leprosy after the assessment like training in home-based self-care, RCS, Footwear, and Disability certificate.
- To sustain the activities in the districts by improving the capacity of the general health staff and district nucleus team.

Key activities

- Community social workers (CSWs) were selected and provided institutional training in DPMR.
- CSWs were provided with the list of Grade 2 disability patients of their respective districts which was available with the govt. HFs.
- CSWs visited all the villages in their assigned areas and interacted with the G2D patients, ASHA/Mitanin/Sahiya, AWW, PRI members & and local RMPs to locate and identify persons with disabilities in their locality who were not on the list.
- CSWs assessed each person with disabilities regarding disability status and need assessment was done
- Based on need assessment CSWs provided services such as training in self-care which was demonstrated along with family members and ASHA/Mitanin/Sahiya. They also facilitated MCR, Self-care materials, RCS, Disability certificates, Disability pension, and Livelihood support.
- The details of the persons with disabilities were entered in disability software and a hard copy of that list was provided to concerned HFs and updated in the NLEP disability register which is being maintained by the healthcare staff even today.
- DPMR coordinators (one for 3-4 districts) appointed by DFIT provided guidance and support to CSWs throughout.

Outcome

- Disability status assessment of the Persons Affected with Disability.
- Persons affected with disabilities were trained along with one family member/ASHA/Mitanin/Sahiya in home-based self-care.
- Persons affected with disabilities were provided MCR footwear based on the requirement from the list.
- Persons affected with disabilities were assessed and identified for RCS and they were mobilized for RCS.
- Persons affected with disabilities were facilitated for a disability certificate, disability pension, and other govt. entitlements.
- Persons affected with disabilities were identified with severe social constraints for Livelihood support under the Livelihood Enhancement program by DFIT.

Bihar	Jharkhand	Chhattisgarh
Total Number of G2D patients in the list at the time of implementation of the program (baseline)		
7498	4803	1565
Updated list of G2D patients at the end of Project Phase and G2D patients trained for Self care by involving family members/ASHA/Mitanin/Sahiya		
18221	6981	3182
G2D patients Eligible for RCS		
1542	1071	300
RCS done among eligible		
765	627	185
Facilitated disability certificate		
3202	1806	620
G2D patients with foot disabilities are provided with MCR footwear		
8317	13447	1542
G2D patients provided with LEP support		
364	291	49

Key challenges

The retention of CSWs was difficult, because of a labor-intensive job, we need to identify new CSWs and train them.

Recommendations

- Selection of the Community social workers should be carefully done from the local areas.
- Involving the local stakeholders (PRI members, Cured persons of leprosy) for data collection.
- Validation of persons identified by Community Social Workers by leprosy supervisors is an important aspect.
- Well-versed with Govt. entitlements for linking the persons affected with disabilities with the facilities.

NIRAMAYA II – Comprehensive Leprosy Care through Strengthening and Streamlining Referral Services – A hub & spoke model (2021 – 2023)

Project site : Salem-Tamil Nadu, Nalgonda-Telangana, Kukatpally-Hyderabad, Santacruz-Mumbai, Versova-Mumbai, Palghar-Maharashtra, Dallirajhara-Chattisgarh and 17 districts of West Bengal

GLRA INDIA

Target Population

Salem, Tamil Nadu, Nalgonda, Telangana, Medchal, Hyderabad, Telangana, Santacruz, Mumbai, Versova, Mumbai, Palghar, Maharashtra, (Dallirajhara, Balod, Chhattisgarh) and 17 districts of West Bengal

Key Stakeholders

1. Persons affected by Leprosy and their families
2. Community Health Workers (ASHA, ANM)
3. General Population in Endemic Areas
4. Medical Professionals (Doctors, Nurses)
5. Central Leprosy Division (CLD)
6. State Leprosy Programs and State Leprosy Officers
7. District Leprosy Officers (DLOs)
8. Primary Health Centers (PHCs)
9. Community Health Centers (CHCs)
10. Resource hub hospitals
11. Partner hospitals in target states
12. ILEP India
13. Local NGOs and Social Welfare Offices
14. Medical Training Institutions (Medical Colleges, Nursing Schools)

Brief Description

Project NIRAMAYA II was 3 years (2021-2023) time-bound project implemented in 7 locations aimed to provide quality management of leprosy-related complications at the secondary and tertiary hospitals by strengthening early case detection, improving treatment adherence, and streamlining referral mechanisms by involving local government health facilities. The foremost focus of the project NIRAMAYA was to provide quality care for leprosy-affected persons through referral centers. The partner hospitals in 5 states are recognized centers for leprosy care and collaborate well with the respective state/district health authorities. The project offers a wide range of activities such as specialized leprosy care, skin clinics, physiotherapy, reconstructive surgery, and general health care, promoting early case detection, disability prevention camps, and addressing the affected person's social/economic rehabilitation needs. The project also supported the National Leprosy Eradication Programme (NLEP) in 17 districts of West Bengal

Outcome

Year	New Cases Diagnosed	Reaction Management	Reconstructive Surgeries	Footwear Supply (MCR)	Aids & Appliances	Skin & Disability Camps
2021	476 (85% of target)	301 out-patients (130%)	76 surgeries (126%)	1,801 pairs (138%)	306 devices (117%)	33 camps (55%)
2022	609 (109% of target)	515 out-patients (224%)	106 surgeries (176.6%)	1,832 pairs (141%)	781 devices (300%)	63 camps (105%)
2023	742 new cases (132.5%)	301 lepra reactions (130.8%)	98 surgeries at tertiary hospitals (163%)	2,008 pairs (154%)	685 devices (263%)	67 camps (111%)

Over the three-year period, the program demonstrated remarkable success in diagnosing new cases, managing lepra reactions, and providing comprehensive care for both minor and severe complications. The achievements in these areas reflect the program's commitment to achieving zero transmission, zero disability, and zero stigma associated with leprosy.

Key Challenges

1.Pandemic Delays (2021): The COVID-19 pandemic delayed the project start by two months, shortening Year 1 and limiting activities. Restricted movement also impacted patient access to healthcare services.

2. Capacity Building: Gaps in training for healthcare professionals in leprosy management persisted, requiring continued investment in capacity building to enhance early detection and treatment.

3. Community Outreach and Screening: While outreach was effective, expanded screening and gender-sensitive approaches were needed to address underserved communities and disparities in healthcare access.

4. Data Management: Improving data accuracy and reporting systems was deemed to be essential for better decision-making and tracking outcomes.

Recommendation

1. Early Detection is Crucial: Proactive early case detection is essential to prevent disabilities and reduce severe cases as witnessed in the project sites. This needs further coordination with the local program authorities to strengthen case detection activities.
2. Community Outreach: Outreach medical camps are vital for reaching marginalized communities and increasing case detection. Skin camps played a vital role in NIRAMAYA II, especially in tribal regions.
3. Continuous Training: Sustaining and expanding training programs for healthcare workers is necessary to maintain leprosy expertise.
4. Customized Interventions: Tailoring interventions based on the context and needs of target populations leads to more effective outcomes. A few activities did not yield a greater outcome, particularly in relation to case-finding approaches in NIRAMAYA II and the evaluation suggested focusing on targeted interventions that are cost-effective and time-efficient.
5. Addressing Stigma: Developing and implementing robust SBCC strategies is crucial to overcoming stigma and improving community participation. These SBCC approaches supported in mobilizing communities in attending skin camps and voluntary reporting.

WaSH My Eyes - Reduction of blindness caused by NTDs through integrated WaSH approaches (December 2020 to April 2024)

Project site : Sitapur, U.P., Kaimur, Bihar and Malda, West Bengal

GLRA INDIA

Target Population

300,000 rural population in 6 administrative blocks residing in 73 Gram Panchayats & 100 villages

Key Stakeholders

- Health Service Providers, PHCs & CHCs
- Private Sector institutions
- Village Sanitation Committees (VSCs)
- Village Panchayats/ PRI
- Sanitation workers
- Self-help Groups (SHGs)
- Village, Block and District Authorities
- Community-based Organizations (CBOs)
- Other government eye hospitals

Brief Description

Project Wash My Eyes aims to improve the living conditions of vulnerable populations affected by Leprosy, Lymphatic Filariasis (LF), Eye complications by reducing WASH-associated diseases among 300,000 population. The project is a resolute commitment to the holistic well-being of those affected by leprosy and LF. Our dedicated efforts focus on comprehensive morbidity management, striving to prevent and alleviate the disabilities caused by these diseases and conditions. A focus on awareness and capacity building involving stakeholders and healthcare workers ensures a lasting impact. With a focus on marginalized groups, the project aligns with state development efforts while targeting the people affected by LF, Leprosy, and eye complications. Through this initiative, we aspire to empower these communities with improved healthcare, knowledge, and lasting change.

Partners

Lions Deutschland & The Federal Ministry of Economic Corporation and Development (BMZ)

Outcome

1. High Community Engagement: The project achieved 93% community engagement, indicating effective communication strategies.

2. Reduced Diarrhea Incidence: Diarrhea incidence dropped to 10%, showing significant improvements in sanitation and hygiene.

3.Improved Access to Resources: 90% of the community accessed safe drinking water, and 80% regularly used toilets, improving living conditions.

4.Enhanced Support for NTD Patients: The project improved treatment access (69%), reduced stigma (89%), and increased health literacy (65%) among persons affected by NTDs.

5.Effective Community Mobilization: High awareness of sanitation committees (87%) and the Bhagidari model (64%) underscores strong community mobilization.

6.Stakeholder Confidence and Sustainability: Stakeholders express confidence in the project's sustainability (66%) and alignment with government policies (69%).

7.Positive Community Feedback: 78% of the community reported improvements in sanitation facilities, highlighting the project's effectiveness in reducing open defecation.

Key Challenges

- Follow-up for disease control and WASH is difficult due to large, scattered populations, migration, and livelihood demands.
- Community focus on material benefits hinders active participation in health initiatives.
- No accountable person or group manages cleanliness, leading to poor sanitation and waste disposal.
- Poorly designed toilets, limited water access, and few community toilets worsen hygiene issues.
- Low literacy and health awareness, especially in remote areas, prevent the adoption of good health practices.

Recommedations

- Promote culturally relevant BCC strategies to sustain positive health outcomes through community-led campaigns.
- Strengthen health systems, expand coverage, and improve access to healthcare services with effective referral pathways.
- Integrate mental health support to reduce stigma and enhance overall well-being in interventions.
- Invest in capacity building for community health workers, leaders, and officials on sustainable health practices.
- Utilize technology and community monitoring to enhance transparency, accountability, and service delivery.

Accelerating elimination targets through enhanced active case finding and responsive health systems (July 2021 to present)

Project site : 10 Rural and Tribal blocks in Jamui District, Bihar

LEPRA
® Registered as LEPRA Society

Target Population

- Children, Women, Elderly and Institutionalized people (prisoners, old age home, orphanage, etc.)

Key Stakeholders

1. Executive Director of State Health Society, Bihar
2. District Health Society, Jamui, Bihar
3. Chairperson of the State-Level Disability Forum
4. WHO Consultant-Bihar
5. State Programme Officer (SPO – Lep.)
6. NLEP Consultant - Bihar
7. District Magistrate Jamui
8. State Coordinator, Bihar (LEPRA Society)

Brief Description

Rapid Enquiry Surveys (RES), aimed at screening 60% of the total population in Jamui district in minimum time by 20 trained field officers assisted by ASHA workers, who screen for signs and symptoms of leprosy, as well as 4 other skin-NTDs (LF, CL, PKDL and scabies). RES consisted of a one-off screening visit to every listed household.

One day prior to screening, skin-NTD awareness messages are disseminated in each village, using an Information, Education and Communication van.

Screened members of the population who are suspected of any skin NTD are referred to the skin NTD days organised twice a month at each PHC for confirmatory diagnosis, treatment and triage. ASPIRE project staff support patients at the PHCs during skin NTD days, ensuring continuity of care and support. People with complex needs are referred to newly formed Morbidity Management and Disability Prevention (MMDP) centres allocated at district hospital for footwear and complication management.

Before RES commenced, PHC health workers were trained by LEPRA Society using validated diagnosis and treatment protocols.

Objective

1) Evidence-based treatment is available at each PHC and target diseases are managed appropriately through all points of care.
2) Skin NTD control strategies are coordinated and implemented.

Main Activities

1)Development of an RES protocol for active case finding activities.
2)Training of search teams (N=10).
3)Development and validation of diagnosis and treatment protocols for the 5 target diseases.
4)Training of health workers in PHCs[1] (All PHC staff in target staff).
5)Conduct active case finding through Rapid Enquiry Survey (Phase 1: November 2022 to December 2023). This will transition to Mass House-to-House (MH2H) surveys starting in early 2024 (Phase 2). It is assumed that in Phase 2, leprosy will be fully controlled and that vertical activities can transition to horizontal practice within routine health systems (contact tracing). This Best Practices only concentrates on the first phase of the whole process (i.e. RES)
6)Referral of suspect cases to PHC
7)Support to PHC staff with Skin NTD days two times per month in each PHC. Skin NTD days are specific days planned with government officials at PHC level, to receive, diagnose and triage all suspects of target skin-NTDs and any other skin condition to avoid overburdening the public health facilities.
8)Referral of people needing self-care to pre-established community-based groups
9)Provision of secondary care and footwear at MMDP centres

Outcome

Through Rapid Enquiry Survey (RES), all villages were screened for target diseases, reaching 80% of total households and over 60% of total population of Jamui district. Screening was conducted just once during each household visit.

A total of 884 leprosy, 3,397 LF, and 2,979 scabies suspects were referred to the nearest PHC for disease confirmation between November 2022 and October 2023. More than 70% of suspects were confirmed in less than 1 month after they were referred to PHC services, including:

	Leprosy	LF	Scabies
Suspected through RES	884	3,397	2,979
Confirmed at PHC	680	2,344	2,559
% confirmed out of suspected	77%	69%	86%

Out of newly diagnosed cases of leprosy, 4% had grade-2 disability, 30% were MB leprosy, 45% were women and 13% children (about half of which were under the age of 10). Out of those diagnosed with LF, 70% had stage-2 or higher. Out of those diagnosed with scabies, over 13% had crusted scabies or any sort of severe complication. Approximately 400 people affected by leprosy, LF and scabies, in need for self-care, were allocated in about 35 self-support groups.

Key Challenges

Initially, It was noticed that the proportion of suspect cases who presented to the PHC for assessment and diagnosis was not as high as we had anticipated and thus the ratio of suspect cases: patients assessed at PHC was lower than anticipated.

The project subsequently implemented a system whereby counsellors call suspect cases who have not presented at PHC. Subsequently, the proportion of suspect cases presenting at PHC has improved.

The project did not identified any cases of CL or PKDL.

Recommendation

- Ensure that local cultural norms (e.g. Seasonality, daily routines) are considered in the design of screening.
- Ensure that training of healthcare workers and field officers is undertaken.
- Ensure robust MIS systems for collection and monitoring of data.
- Initiate health system strengthening and advocacy activities with government officials right from the beginning.
- Develop strong community networks and self-support group models in parallel.
- Coordinate and plan with sufficient anticipation for the transition of active case finding activities to a more horizontal surveillance approach with government and other decision-making officials.

Empowering Persons with Disabilities (2016 - 2027)
Project site : Aurangabad, Bihar

Target Population

- Persons with Disabilities (PWDs)

Key Stakeholders

- Government, Vihar Viklang Adhikar Manch (VVAM) /Organization of persons with disabilities (OPDs)

Brief Description

Considering the poverty and discriminations faced by the persons with disabilities especially by those affected by leprosy; empowerment of the affected persons, and their socio-economic upliftment constitute high priority for their overall development and rehabilitation.

NLR India (NLRI) has established a pathbreaking project by involving the persons affected by leprosy, and persons with disabilities in a multi-stakeholder engagement process. NLRI showcases this as a model project which is called disability inclusive development (DID).

NLRI has been implementing this DID project since 2016 in all the 11 blocks of Aurangabad district of Bihar.

Objectives

The objective of the DID project is “to empower the community-based peoples’ institutions to an extent that they are able to stand before the duty bearers for their rights and entitlements, in a collective manner”. While the project still continues, it has been able to achieve success because of the way NLRI planned and implemented its activities and approaches it adopted.

Good Practices

The good practices resulting into the achievement of the desired outcomes include the following:

- Memorandum of Understanding (MOU) was signed with Vihar Viklang Adhikar Manch (VVAM) in 2016. VVAM is an organisation of persons with disabilities (OPD).
- The needs assessment (NA) of the persons with disabilities was done by the DID Coordinators, supervised by NLR India. Needs assessment helped in planning expected outcomes and targets for the project
  a. Mobilized government and other stakeholders for the cause of PWDs across all 11 blocks of Aurangabad
  b. Establish 22 model disability friendly villages (DFVs)
  c. Form Divyang self-help groups (DSHGs), village development committees (VDC), block development committees (BDCs), and registered organisations of persons with disabilities (OPDs)
  d. Empower PWDs for their rights and entitlements. Within the limited resources available with the project, the target was set at 3500 PWDs and their families
  e. Support PWDs and their families in their needs related to health, livelihood, access to social welfare services etc

- NLRI worked towards establishing and strengthening the community-based peoples’ institutions by involving Persons affected by Leprosy and Persons with Disabilities and capacitated them so that they are able to voice for their rights and entitlements.
- Worked with the duty bearers in the sector of health, social welfare and education to facilitate relevant platforms and opportunities of interaction between duty bears and right holders.
- Women’s empowerment, in terms of motivating and supporting women to take leadership role, joining Self-help groups (SHGs), setting up sewing center, hiring female teacher for tailoring training, and training adolescents’ girls and young women for 3 months

Outcome

- NLR India has been able to mobilize a large number of government officials, Panchayati Raj members, community leaders, and the persons with disabilities
- 169 Government (duty bearer) staff trained on leprosy or issues related to leprosy
- NLRI has been able to form the following institutions:
- 231 Self-help Groups (SHGs) with 3695 members who have a total savings of Rs.69,28,645/-
- 11 Block Development Committee (BDCs) have been established.
- 22 Village Development Committee (VDCs) have been established.
- 13 Disabled People Organisation (DPOs) with 91 members including 40 female members
- 4016 PWDs trained on organization development, advocacy, Right to information (RTI), Rights and entitlements, Rights of Persons with Disabilities (RPWD) Act, and leprosy
- 79 Places made accessible (by improving infrastructure) for person with disabilities:
- Facilitated 3040 Disability Certificates, Disability Pension to 2272 persons, 2636 UDID Cards, 2468 Assistive Devices, 1302 SHG members in doing business or other livelihood activities, 403 persons with disabilities oriented on Basic Psychological Support for persons with Neglected tropical diseases.
- More than 110 persons with disabilities have contested local elections and 37 have won
- The model on disability-inclusive development (DID) has reached out to around 28,000 PWDs and their family members.
- The model project in Aurangabad has been shared with the stakeholders including government officials in other places and states. NLR had initially planned to develop one model DID in one select block of West Bengal, Uttar Pradesh (Varanasi region) and Rajasthan. Because of the encouraging impact, it is actually being scaled up in all states where NLR is working.

Key Challenges:

- Linking disability to past sins affects their participation in DID project
- Lack of disabled friendly accessibility is a major challenge
- Poverty often prevents access of services

Recommendation;

- Work on the sustainability of the OPDs
- Undertake major livelihood generating initiatives
- Zero exclusion, rights, gender equity and basic survival needs to be the drivers
- Generate resources for scaling-up the operations, the need is large, both in Aurangabad and other districts/ states
- Continue advocacy with government, donors and other stakeholders for replication

Community Health Need Assessment for Project Development in Drug (2023)

Project site : Durg District, Chhattisgarh

SWISS EMMAUS LEPROSY RELIEF WORK - INDIA

Brief Description

Swiss Emmaus India plan to start a new project to improve the health and wellbeing of targeted marginalised communities in the District of Durg through health system strengthening and community development to contribute towards achieving zero disease, zero disability and zero discrimination and stigma for leprosy and other NTDs. The SEI team hence plan to carryout a community need assessment to have a clear understanding of the needs, expectations, and challenges faced by various stakeholders, including the system, the institutions and the community.

SEI can gain a better understanding of the resources required to meet the identified needs. This enables SEI to allocate resources strategically, ensuring that they are directed towards the most critical areas. By optimizing resource allocation, organizations can maximize the impact of their investments and achieve desired outcomes more efficiently.

Goal

Increase inclusive and adequate access to quality basic public health services focusing leprosy and potentially other NTDs for targeted marginalized communities.

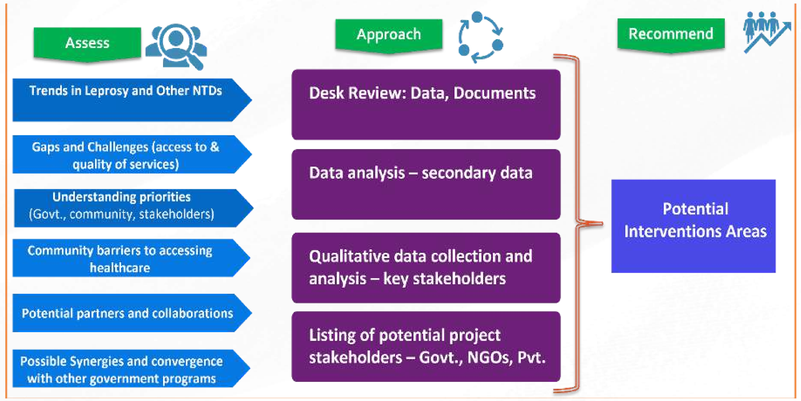
Core Approach

Implementation to be in consensus and collaboration with State Health Department, District Health Dept., other depts, NGOs, ILEP, APAL, public and private sector health providers, communities etc.

Key Stakeholders

State Level	▪ National Health Mission (NHM) ▪ World Health Organization (WHO) ▪ State Health Resource Centre (SHRC), Raipur ▪ Regional Leprosy Training and Research Institute (RLTRI), Raipur ▪ Damien Foundation India Trust (DFIT), Raipur ▪ Association of People affected by Leprosy (APAL), Raipur
District Level	▪ District Health Department, Durg ▪ District Leprosy Team, Durg ▪ Viklang Manch, Durg
Health Facility & Community	▪ Community Health Centre (CHC) ▪ Health & Wellness Centre (HWC) ▪ Mitanins ▪ Leprosy Colony ▪ Person with leprosy (PWLs)

Scope of the Study



Methodology

The Health Needs Assessment used a mix-methods design (Qualitative & Quantitative) and primary and secondary data available in the public domain and from the NLEP program.

The methodology can be grouped under three heads

1. Literature Review:

The team reviewed various guidelines of National Leprosy Eradication Program, National Strategic Plan and Road map for Leprosy 2023-27 and the concept note developed by Swiss Emmaus India for this specific project.

2. Quantitative Review:

The NLEP data from secondary sources from state and district Durg were reviewed.

3. Qualitative Assessment:

The team planned to have KIIs with Govt. officials both at the state and district level, WHO, NGOs, ILEP agencies, APAL, healthcare providers, FGD with Mitanins, Community leaders and representatives of Chhattisgarh Viklang Manch

Outcomes/ Findings

As per the plan, the team interviewed 45 respondents, carried out 15 KII (Key informant Interview) and 3 Focussed Group Discussion (FGDs). The key findings of the need assessment are as follows;

1. Leprosy was integrated with General Health Care services in 2005, however the RHOs / MPWs (male) yet to initiate formal leprosy service provision.
2. State has recently approved selection of 'Kusth Mitra' as a volunteer cadre and the corresponding guidelines.
3. State is in the process of making 'leprosy' a notifiable disease so as to promote reporting by private sector and improve early identification and tracking.
4. The district does not have Slit Skin Smear facility in any Lab in Durg. The cases are diagnosed based on cardinal signs. Lack of lab facility at the district may lead to incorrect diagnosis of the cases (especially when there are no visible patches on the skin).
5. Medical Officers are not directly involved in diagnosis and treatment.
6. Acute staff shortage at district level for managing, coordinating and service provision leading to overburdening of existing of staff.
7. NHM and NLEP not aligned for phasing out of NMS/NMA and on-boarding RHOs/ MPWs (Male).
8. Capacity building/ refresher training required for MOs and RHOs/ MPWs.
9. Monitoring field visits by state and district officials are limited.
10. The comprehensive services under DPMR are not being provided in the district.
11. Post treatment follow-up are not being done in the district.
12. Awareness generation activities limited to special programs and campaigns. Thes includes, wall writings, posters, pamphlet distribution, street plays, quiz activities at school and colleges, community meetings, etc.
13. No IEC material observed at any of the health facilities visited.
14. No IEC material or job-aid (posters, flip book, audio-video materials) available with NMS/NMA and Mitanins.
15. There is a general lack of awareness about signs and symptoms of the disease – community members preferred going to local private doctors when they observed skin discoloration and lack of sensations.

Key Challenges

1. Service data not available for detailed assessment
2. Respondent selection was purposive, and Interviews were done as per availability and time limitation

Conclusion

A needs assessment is a critical step in any organizational or strategic planning process. It helps identify and address the gaps between the current state and the desired future state of an organization or system.

Each new project should be based on the need of the community and the system so that the resources can be best utilised as per the need.

Promotion of accessibility of services for persons in need due to Leprosy in Guntur and East Godavari districts of Andhra Pradesh State, India (2014-2018)

Project site : East Godavari and Guntur District of Andhra Pradesh State

SWISS EMMAUS LEPROSY RELIEF WORK - INDIA

Key Stakeholders

- Persons affected by Leprosy
- The state and district NLEP staffs
- RISDT and GRETNALTES (both FAIRMED supported local NGOs)
- Swiss Emmaus India/FAIRMED INDIA

Brief Description

The post leprosy elimination period in India observed a gap in general health care system accepting leprosy into the mainstream service delivery system. With a shift from a well-supported, high priority specialized program to one integrated with GHS, leprosy elimination faced problems of sustainability. After elimination of leprosy as a public health problem, other health priorities tend to become relatively more important for national health administrations with reduction in focus for leprosy control.

The extent of the problem on the population can be captured as

- Delay in early identification leads to deformity.
- The needs of the patients are not considered and fulfilled by the General Health Services.
- Absence/lack of POID services in the peripheral health centers leading to an increase in the burden of leprosy on the population.
- Lack of self-care material supplies further worsen the deformity and add to the woes of the people.
- Incapacitated health care staff were unable to provide quality services.

Primarily, this project contributed to the 2nd Objective “stop leprosy and its complications”. However, this project further adds value to the 1st objective of “strengthening government ownership, coordination and partnership” thus finally contributing to the 3rd objective of “stop discrimination and promote inclusion”.

Partners

1. Rural India Self Development Trust (RISDT)
2. GRETNALTES

Goals and Objectives

Goal: The quality of life of the leprosy affected persons is improved.

Objective 1: To improve POID services in the primary health care system

Objective-2: To strengthen POID services at community level

Objective-3: To develop project management system for effective implementation of the project

Methodology

1. Strengthening the existing public health care delivery system for detection of new cases of leprosy as well as reaction and neuritis cases early enough before development of any deformity.
2. Generating community level participation and strengthening home-based care for rationalization of tertiary care.
3. Provision of best practice tertiary care in the referral hospital.
4. Providing technical support in terms of capacity building and monitoring for the Program.

The design of the POID project has been based upon the lesson learnt from the previous project DISPEL (Disability Prevention and Education in Leprosy) launched between 2001 -2009 and AP-POID from 2010-2013, in 2 high endemic districts of Andhra Pradesh. However, in the meantime FAIRMED sent their Indian Technical Coordinator to Nepal to study some best practices Model at Lalgadh Leprosy Hospital & it was thought that a strategy shift from the present service delivery model to a prevention model, that is community based.

The lessons learnt during the planning stage of this new project are that early detection of new / hidden cases of leprosy, ensuring complete treatment, and timely identification of cases with reaction / neuritis and prompt management hold key to prevention of impairment and disability in leprosy cases.

Outcome

Key Results:

1. A capacitated GHC staffs ensures the quality POID services at the PHCs through
- Early identification and referral to the PHC for diagnosis and treatment.
- Improved documentation of people receiving services
- Availability of other services including counselling, MDT (Multi Drug Therapy), steroids, MCR (Micro Cellular Rubber), self-care kits, referral etc at the service delivery centres.

2. Access of POID services at community level
- Elderly & immobile people were provided services at their doorstep.
- Various government social schemes were provided to the people affected by leprosy was worth noting.
- Active involvement of people in improving self-care was the highlight of the project.
- Regular supply of self-care materials was a key aspect of the project.

3.Strengthening the project management system:

Data management through Hospital Information System (HIS) at the project head office and the data collection through android based technology (TIS-Tablet Information System) complement each other. Apart from these two systems, the regular reporting systems, back stopping exercises, mid-term evaluation as well as End evaluation altogether contributed to the conclusion of best practice.

- The primary care health staff including the outreach staffs (ANMs, Multipurpose Health Workers (MPWs) and ASHAs) involvement in delivering the services is highly motivating and encouraging.
- The people practicing self-care at home is highly praiseworthy and the family support to the people have been enhanced.
- People receiving social security benefits are one of the key achievements of the project.

Key Challenges

There is a gap of early identification due to migration issue. Though stigma has been reduced, it cannot be generalized. Shortage of government fund for refresher trainings to the health care staffs is a challenge. Irregularity in releasing the incentives to ASHA and supply of MCR by the government are still few areas of concern.

Recommendation

The long-term effects could be

1. Program could be largely owned by the General Healthcare System (GHS) ensuring greater probability of sustainability
2. A facilitative and non-discriminatory relationship between community and health system staff can be established making services more likely to sustain.

This project has been highly beneficial to people as disability prevention and management has been the center piece of this project. While early diagnosis has been the focus point with prevention of disability as central theme of this project. The success is contingent on sustaining the gains from the project with dynamic synergy between both the person and the health system.

The involvement of the government health system in preventing, treating, and managing disability with complimentary efforts of the person/community has been the hallmark of this project.

Active engagement of the Government health systems and the community is the paramount to extend this good practice in other endemic areas as it significantly contributes towards self-sustenance.

Enhanced self-care program to reduce disability in Leprosy (2022-2024)

Project site : Nawagarh, Champa and Akaltara Block, Champa-Janjgir district, Chhattisgarh

The Leprosy Mission Trust India

healing.inclusion.dignity

Target Population and Key Stakeholders

- All persons affected with leprosy having Grade 1 and 2 disability in the chosen blocks.
- Mitanin trainers and Mitanins

Brief Description

There was a need for revising the existing national and state program activities to improve self-care practices and reduce disability among the leprosy affected population. Implementing an enhanced self-care intervention through the public health system and community health workers (CHWs), called Mitanins in Chhattisgarh, could prove to be effective and sustainable. Therefore, the specific aim of the evaluation is to assess the effectiveness of enhanced self-care intervention in the prevention and reduction of the disability among persons affected by leprosy.

The research team developed a set of international self-care guidelines for programmatic usage. These were contextualized and co-produced by the community of people affected by leprosy, CHWs, community leaders and clinicians as an enhanced self-care program. This was implemented through the Replicability Model (RM) project, a public health systems-strengthening initiative for the leprosy program in Chhattisgarh. The enhanced self-care intervention which is community-based was facilitated using the existing public health system and Mitanins for the prevention and reduction of leprosy-related disability. The enhanced self-care intervention was embedded into the National Leprosy Eradication Program through the RM project and rolled out in three blocks.

Training was done in a cascade manner involving two levels of training . The content of the training was be on leprosy related disability prevention and management including enhanced self-care intervention. The curriculum for training of MTs was pilot tested before implementation.

Outcome

- Training was imparted to Mitanin trainers which is then cascaded into their respective teams of mitanins. In the cascade approach, Community Development Officers (CDOs) of the RM project will train the Mitanin Trainers (MTs) and the Mitanin Trainers will train the Mitanins under their supervision, supported and supervised by the CDOs. The Mitanins would then deliver the enhanced self-care intervention to the identified leprosy affected persons with neuropathy and at risk of disability in the community where the patient is.
- The mitanins provided door step self care training and demonstration
- Individual booklets were developed for care of eyes, hands and feet with both written and illustrations using images. This self care was taught by Mitanins – frontline workers from the village where the patient is from. There was monthly follow-up by Mitanins and documentation of progress of impairments using simple form. This was a community based self-care teaching, Footwear with different models for female and male which is at par with the market was provided. Involvement of family members during the training / demonstration of patients. There was also provision of assistive devices such as walking stick, crutches.

Key Challenges

- Linking disability to past sins affects their participation in DID project
- Lack of disabled friendly accessibility is a major challenge
- Poverty often prevents access of services

Recommendation

- Insertion of self-care intervention in the Mitanin training curriculum will enable the patient to have self-care teaching at their own homes

Empowering Public Health: Trailblazing Participatory Block-Level Resource Mapping for Enhanced Leprosy Program Management in Chhattisgarh

Project site : Janjgir Champa and Sakti Districts of Chhattisgarh

The Leprosy Mission Trust India

healing.inclusion.dignity

Brief Description

In a significant departure from conventional approaches, the National Leprosy Eradication Program (NLEP) and the Replicable Model Project Team of The Leprosy Mission Trust India (TLMTI) spearheaded a pioneering initiative in Janjgir Champa and Sakti Districts of Chhattisgarh. This initiative marked a paradigm shift by integrating Participatory Rural Appraisal (PRA) tools with Block-Level Resource Mapping (BLRM) to revolutionize leprosy program review, planning, and implementation.

Outcome

The BLRM process, rooted in Participatory Rural Appraisal (PRA) tools, engaged stakeholders at all levels, fostering inclusive decision-making and community involvement. Under the guidance of the Senior Management Team and with the dedicated support of project staff, the exercise was meticulously executed. Key contributors included Mr. George Abraham Former Operation Director TLMTI, Dr. Famkima Darlong, Health Head TLMTI, District Leprosy Officer Dr. Sing, Project Manager Jyotiprakash Bag, Mr. Navdeep, Khoobchand Sonant Community Development Organizer, Puran Chandra, Community Development Organizer Mr. Ashish, and grassroots health service providers.

Results

The adoption of BLRM facilitated not only a comprehensive review but also a nuanced understanding of leprosy program dynamics at the grassroots level. The integration of data visualization techniques enabled stakeholders to gain actionable insights, empowering them to make informed decisions. Furthermore, the participatory planning approach ensured that community voices were heard and local contexts were adequately addressed. The success of the initiative has sparked interest among Block Medical Officers, who recognize its potential applicability to other National Flagship Health Programs, underscoring its scalability and relevance.

Conclusion

The convergence of data visualization, participatory planning, and stakeholder engagement has redefined the landscape of leprosy program management in Chhattisgarh. This innovative approach, guided by collaboration and community empowerment, serves as a blueprint for future public health interventions. As we celebrate the success of this initiative, it is imperative to recognize the pivotal role played by the District and State NLEP teams in piloting and pretesting this groundbreaking exercise. Moving forward, the legacy of BLRM will continue to inspire us to embrace innovation and inclusivity in our quest for a healthier, more equitable society.

Learning and Applicability

The initiative yielded invaluable lessons in harnessing data visualization and participatory planning for enhanced program management. By leveraging data visualization techniques, stakeholders were equipped with the tools to identify trends, gaps, and opportunities within the leprosy program. This not only facilitated evidence-based decision-making but also enhanced accountability and transparency. Moreover, the participatory planning process fostered a sense of ownership and commitment among stakeholders, laying the groundwork for sustainable interventions tailored to local needs.

ADDRESSES OF ILEP INDIA MEMBER'S OFFICES

AIFO India

No. 58, 4th cross
Kavery Layout Thavarekere
Main Road, Dharmaram
College, Post, Bangalore -
560029
www.aifoindia.org

American Leprosy Missions (ALM)

#301, Shiloh House, 6-3-
907/5, Kapadia Lane,
Somajiguda, HYDERABAD
500082. Telangana. India
www.leprosy.org

Damien Foundation India Trust (DFIT)

DFIT-14, Venugopal
Avenue, Spur Tank Road,
Chetput, Chennai- 600031,
Tamil Nadu
www.damienfoundation.in

Fontilles

Thazhayil veedu,
Vattapoil, MES College P O,
Mampad
Nilambur, Kerala – 676542
www.fundacionfontilles.org

German Leprosy & TB Relief Association - India

4,Gajapathy
St,Venkatasamy Nagar,
Shenoy Nagar, Chennai,
Tamil Nadu - 600030
www.glraindia.org

LEPRA Society

Plot No 17, Krishnapuri
colony, West Marredpally,
Secunderabad, Telangana –
500026
www.leprasociety.in

NLR India Foundation (NLRIF)

C-4/139,1stF, Safdarjung
Development Area, New
Delhi-110016
www.nlrindia.co.in

Swiss Emmaus Leprosy Relief Work-India

K-7, South City-1, Gurgaon-
122007, Haryana State
www.fairmedindia.in

The Leprosy Mission Trust India (TLMTI)

CNI Bhawan, 16 Pandit
Pant Marg, New Delhi-
110001
www.leprosymission.in

https://ilepindia.com/
ilep.india@gmail.com

We are also available on

ILEP India
141, Pushpanjali Enclave, Vikas Marg Extension,
Delhi 110092 IN