ILEP in India
Strategy 2016–2018
1. Background:

ILEP (International Federation of Anti-Leprosy Associations) is a federation of 14 autonomous non-governmental international organisations working together for the common goal of a world without leprosy. In India, nine ILEP Members are active as under:

- Associazione Italiane Amici di Raoul Follereau – AIFO India (Italian Association of Friends of Raoul Follereau)
- Aide aux Lépreux Emmaüs-Suisse - ALES India (Swiss Emmaus Leprosy Relief Association)
- American Leprosy Missions – ALM India
- Damien Foundation Belgium - Damien Foundation, India Trust (DFIT)
- Fontilles, Lucha Contra La Lepra (Spanish Leprosy Relief Association) - Fontilles – India
- German Leprosy & TB Relief Association - GLRA India
- Netherlands Leprosy Relief - NLR Branch Office and NLR Foundation
- The Leprosy Mission Trust India (TLMTI)

These Members through their local bodies and supported NGOs work in close collaboration with the WHO, Government of India and other partners. ILEP agencies active in India are supporting the National Leprosy Eradication Programme (NLEP) in line with the MoU signed with the Ministry of health. In addition to the support to NLEP, ILEP in India is also supporting persons affected by leprosy through direct projects, tertiary care hospitals, supported NGOs, in areas of socio-economic rehabilitation (including CBR), livelihood, education, advocacy, human rights besides involvement in basic and operational research.
ILEP in India strategy 2016-2018

A strategic planning workshop was organized on 2nd and 3rd June 2015 in Delhi, to develop a new strategy for ILEP in India for 2016-2018. In this workshop, besides ILEP representatives in India, a variety of stakeholders participated such as Central Leprosy Division (CLD), Government of India, WHO, people affected by leprosy, etc. This workshop was facilitated by an external facilitator Mr. Arvind Chittewale. Situational analysis, in the form of SWOT (Annex 1), External environment (Annex 2) and stakeholder analysis (Annex 3) was done, key challenges were identified and priorities were set. Discussions were held within ILEP in India to formulate strategic directions to meet the challenges and needs in India. The drafted strategy was further discussed in ILEP in India meetings held on 10th August 2015 at Chennai and 4th November 2015 at Delhi. In these meetings, at least two Members from ILEP global participated. Members of ILEP technical commission assisted the Members in India to draft the strategy. In Chennai meeting, vision and mission of ILEP in India were agreed, a format/template for strategic planning document was developed. During 4th November 2015 meeting, a working group of ILEP Members in India was formed to finalise the draft strategic plan, the group met on 10th and 11th December 2015 at Hyderabad in which strategic goals and objectives were fine-tuned, strategies and indicators were formulated in line with ILEP Global strategy, WHO Global strategy and NLEPs 12th Five year plan. The draft was finalised on 11th January 2016 at Bengaluru, as under:

2. Vision
Leprosy free India.

3. Mission
We work together using strengths of individual organisations, collaborations, partnerships, to engage and influence policy makers and other key stakeholders and demonstrate innovative approaches to stop leprosy transmission, ensure no disability due to leprosy and mainstream people affected by leprosy.

4. Values
- Mutual respect: we respect each other's mandate and priorities.
- Integrity and honesty: we believe in honesty and integrity.
- Transparency: we are transparent.
- Accountability: we are accountable to each other and to the community at large.
- Collaboration: we value collaborations and partnerships.
- Excellence: we strive for excellence in everything we do.
- People centred: our focus remains on persons affected by leprosy and their families.
- Equity: we believe and advocate for equity for people affected by leprosy.
- Justice: we strive to secure justice for people affected by leprosy.
5. Key challenges
   - Consistent occurrence of significant number of new cases with an increase in disabilities.
   - Target oriented elimination affects actual leprosy situation.
   - Lack of awareness and political commitment towards leprosy.
   - Utilisation of allocated funds by government.
   - Decreased international funding. Apprehension for shrinking space for civil society
   - Decreasing leprosy related expertise.
   - Lack of space for people affected by leprosy.
   - Inaccessible geographical areas.
   - MDT logistics.
   - Inadequate attention to nerve damage, reactions and other leprosy related complications.
   - Lack of disaggregated data on number and needs of women and men affected/disabled due to leprosy.
   - Inadequate and ineffective referral system.
   - Continued stigma and discrimination against people affected by leprosy.
   - Insufficient research (basic, implementation and operational)
   - Visibility of ILEP in India.
   - Perceptions about ILEP in India regarding working relationships, focus areas, financial status, etc.
   - Convergence among key Ministries in addressing comprehensive needs of people affected by leprosy.

6. Key Priorities
   - Retaining and sustaining leprosy related expertise.
   - Early case detection.
   - Improve case management.
   - Reduce stigma and discriminatory practices.
   - Restore dignity of people affected by leprosy.
   - Voices of people affected by leprosy are heard: facilitate the formation of CBOs/DPOs involving people affected by leprosy.
   - Result-based management.
   - Advocacy Influencing Policy and practise.
   - Strategic partnerships.
   - Learning.
   - Image building and visibility of ILEP in India.

7. Strategy
   **Strategic goals:** What ILEP in India aims to achieve:
   - Strategic Goal 1: Stop leprosy transmission.
   - Strategic Goal 2: No disability due to leprosy.
   - Strategic Goal 3: People affected by leprosy mainstreamed.

   **Enabling actions:** How ILEP in India will achieve its goals:
   - Enabling Action 1: Improving ILEP collaboration and coordination.
   - Enabling Action 2: Work in partnership with others.
   - Enabling Action 3: Raise the leprosy profile.
## Vision

Leprosy free India

<table>
<thead>
<tr>
<th>Strategic goals: What ILEP in India aims to achieve?</th>
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<tbody>
<tr>
<td>Goal 1: Stop leprosy transmission</td>
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<tr>
<td>Goal 2: No disability due to leprosy</td>
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<tr>
<td>Goal 3: People affected by leprosy mainstreamed</td>
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### Enabling actions: How ILEP in India will achieve its goals?

<table>
<thead>
<tr>
<th>Action 1</th>
<th>Action 2</th>
<th>Action 3</th>
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<tbody>
<tr>
<td>Improving ILEP collaboration and coordination</td>
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<tr>
<td>Work in partnership with others</td>
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<tr>
<td>Raise the leprosy profile</td>
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### Goal 1: STOP LEPROSY TRANSMISSION

#### Objective 1.1

**Promote early case detection and ensure treatment.**

**Strategies**

- Technical support to NLEP for mass awareness campaigns.
- Influence NLEP to promote active case detection methods.
- Influence and support NLEP in implementation of leprosy control in urban, low endemic and difficult to reach areas.
- Research in innovative case detection methods and in transmission of leprosy.
- Sustain leprosy knowledge and skills among the health workers.
- Implement outreach programmes.

**Indicators**

- Proportion of G2D detected among new leprosy cases.
- Proportion of contact examination.
- Proportion of child cases detected among new leprosy cases.
- Proportion of children with G2D among new cases detected.
- Proportion of new cases of leprosy detected through active methods.
- Proportion of new cases reported voluntarily.
- Treatment completion rate.

#### Objective 1.2

**Provide specialised leprosy services**

**Strategies**

- Specialised leprosy referral services.
- Establish centres of excellence.
- Sustain leprosy knowledge and skills among the health workers.
- Implement outreach programmes.

**Indicators**

- Proportion of cases on which EHF scoring conducted showing worsening of disability.
- Proportion of cases with reaction treated with complete course of steroids.

#### Objective 1.3

**Generate evidence to break the infection cycle**

**Strategies**

- Research in primary prevention of leprosy.

**Indicators**

- Number of peer reviewed evidences promoting primary prevention.
## Objective 2.1
Prevent disability due to leprosy.

### Strategies
- Develop POD models.
- Influence and support NLEP at national, sub-national level in implementing POD activities.
- Develop models for effective referral system.
- Influence and support NLEP for establishment of functioning and effective referral system.

### Indicators
- Proportion of patients developing new disability.
- Number of states where functional referral system exists.
- Number of states showing mapping of disability.
- Proportion of patients not showing increase in EHF score.
- Number of meetings held between different ministries to discuss convergence.
- Number of states showing mapping of disability.

## Objective 2.2
Prevent worsening of existing disability.

### Strategies
- Influence NLEP for mapping of residual disability.
- Effective disability management.
- Capacity building of health staff.
- Facilitate convergence of Ministries of Health and Social Justice & Empowerment.

### Indicators
- Proportion of patients not showing increase in EHF score.
- Number of meetings held between different ministries to discuss convergence.
## GOAL 3.
PERSON AFFECTED BY LEPROSY MAINSTREAMED

<table>
<thead>
<tr>
<th><strong>Objective 3.1. Create discrimination free environment</strong></th>
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<tr>
<td><strong>Strategies</strong></td>
</tr>
<tr>
<td>Advocate for convergence of Ministries of Health, Social Justice &amp; Empowerment, Law and other relevant ministries.</td>
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<td>Work for repeal of discriminatory laws.</td>
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<td>Sensitise the community through government sponsored mass awareness campaigns.</td>
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<tr>
<td><strong>Indicators</strong></td>
</tr>
<tr>
<td>Number of discriminatory laws repealed.</td>
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<tr>
<td>Number of positive actions resulting from convergence of ministries.</td>
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<td>No discrimination known in employment, travel or social functions etc.</td>
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<th><strong>Objective 3.2 Facilitate inclusive development</strong></th>
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<tr>
<td><strong>Strategies</strong></td>
</tr>
<tr>
<td>Facilitate participation of affected people in their communities and society at large.</td>
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<td>Facilitate sustainable livelihoods for affected people.</td>
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<tr>
<td>Sensitise relevant ministries for inclusive development.</td>
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<tr>
<td>Sensitise the community through relevant ministries to promote inclusion of persons affected by leprosy.</td>
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<tr>
<td><strong>Indicators</strong></td>
</tr>
<tr>
<td>Positive experiences of people affected by leprosy.</td>
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<td>Number of affected people provided with skill based trainings/placements.</td>
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<th><strong>Objective 3.3 Enable peoples’ voice to be heard</strong></th>
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<tr>
<td><strong>Strategies</strong></td>
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<tr>
<td>Formation of collectives of and champions among people affected by leprosy.</td>
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<tr>
<td>Build their capacity including leadership skills.</td>
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<tr>
<td><strong>Indicators</strong></td>
</tr>
<tr>
<td>Number of collectives established.</td>
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<td>Number of representations made by the collectives.</td>
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<tr>
<td>Number of affected people represented in different committees.</td>
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8. Enabling Actions

Enabling action 1: Improving ILEP collaboration and coordination

Action points:
- Strengthen the federal structure of ILEP India: collaboration and communication among Members will be strengthened and streamlined. Common areas for collaboration will be identified. Attempts will be made to work as consortium for specific interventions.
- Strengthen national ILEP India leadership: full time Coordinator to be identified by coordinating agency.
- Joint plan of action (MoU with relevant ministries of GOI).

Enabling action 2: Improving collaboration with others

Action points:
- Identify core thematic areas where collaborative initiatives can be undertaken.
- Develop strategic partnerships with key entities (WHO, Ministries of GOI, NGOs, and CBOs etc.)
- Marketing our technical expertise in relevant areas (clinical, case management, POD, Rehabilitation, Programme management, IEC, monitoring, supervision and evaluation and research etc.)

Enabling action 3: Raising the profile of leprosy

Action points:
- Develop and implement communication strategy for ILEP in India.
- Influencing policy makers to increase commitment and funding for leprosy (13th five year plan; discriminating laws)
- Campaign to raise awareness about leprosy.