



# Towards a world free from leprosy

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**ILEP Strategy**  
2021 – 2025



# ILEP 2021-2025 Strategy at a Glance

**Towards a world  
free from leprosy**

ILEP is a consortium of autonomous, international NGOs working for a world free from leprosy: **zero transmission of leprosy, zero patients without treatment, zero leprosy-related disability and zero exclusion.** This strategy articulates five significant global 'game-changers' that ILEP aims to tackle and resolve through active collaboration.

## KEY STRATEGIC GOALS

Game-changing goals towards which ILEP aims to make significant progress during 2021-2025.

1	2	3	4	5
<b>Global framework and strategy to build and sustain leprosy capacity</b> ..... Global framework in place ..... Comprehensive strategy in operation, normally in integrated Skin NTD context, in > 10 countries	<b>Globally consistent leprosy data standards and data collection methodologies, leading to accurate reporting for improved programme planning and monitoring</b> ..... Initiatives piloted towards more accurate new case data ..... Effective, integrated surveillance systems ..... Widespread digital case-based data reporting ..... Accurate records of patients with disabilities and/or at-risk	<b>Readily available services related to mental wellbeing in leprosy</b> ..... Use of ILEP guides on stigma/mental wellbeing ..... Access to point-of-care and referral services for mental wellbeing	<b>Active engagement by persons affected by leprosy</b> ..... Countries specifically including leprosy in national human rights frameworks: target > 20 ..... 50% reduction in discriminatory laws ..... National organisations representing persons affected by leprosy: target > 30 ..... Regular monitoring of stigma levels in countries	<b>Innovative approaches through research, proof of concept, and application of game-changing technologies and processes</b> ..... ILEP Research strategy and priorities adopted ..... Collaborative piloting/ proof of concept of new initiatives involving multiple ILEP Members

## ENABLING ACTIONS

How the ILEP Federation aims collectively to achieve the key strategic goals

① Strong in-country collaboration between ILEP members | ② Sharing of knowledge and experience and putting into practice mutual learning | ③ ILEP Technical Commission outputs in line with key strategic goals | ④ Input through ILEP Advisory Panel into key strategic goals | ⑤ Effective advocacy within relevant forums of OHCHR and WHO | ⑥ Engagement in the work of the UN Special Rapporteur | ⑦ Increased understanding and capacity in human rights across the ILEP federation.

## MEMBERS

American Leprosy Missions | Associazione Italiana Amici di Raoul Follereau | Damien Foundation Belgium  
Effect Hope | FAIRMED | Fondation Raoul Follereau | Fontilles | German Leprosy and TB Relief Association –  
*Deutsche Lepra- und Tuberkulosehilfe* | Leprosy Relief Canada – *Secours aux Lépreux* | Lepra | NLR International  
St Francis Leprosy Guild | Sasakawa Health Foundation | The Leprosy Mission International.



## IDENTITY AND PURPOSE

ILEP is a consortium of autonomous, international NGOs working for a world free from leprosy, in partnership with others committed to the same goal. Through the programmes of its member organisations and in cooperation with many partners from local to international level, ILEP spans more than 60 countries and 1,000 project locations worldwide.

## STRATEGIC CONTEXT

### Global leprosy situation

In four decades since the introduction of MDT, leprosy prevalence has reduced by 95%, but the very slight downward trend in overall new case numbers over the past decade shows the limitations of strategies reliant mainly on passive case-finding and treatment with MDT. Countries are therefore increasingly investing in active case-finding and in measures aimed at preventing leprosy. But referral systems to deal with the disabling complications of leprosy are often weak, and most countries are doing little to tackle the ongoing physical, mental, social and economic consequences of leprosy, and the closely connected social exclusion and loss of rights.

### Current challenges and wider strategic context

The WHO Global Leprosy Strategy 2021-2030 identifies thirteen significant global challenges. The ILEP strategy primarily addresses six of these.

- Limited or dwindling **leprosy expertise**, especially clinical skills at all levels.
- Lack of **engagement by stakeholders** including organisations of people affected by leprosy.
- Deeply embedded stigma and discrimination resulting in **social exclusion and denial of rights**.
- Poor **surveillance** systems for hidden cases and post-treatment monitoring of persons at risk.
- Weak **health information systems** and inadequate or under-reporting of data.
- Far-reaching consequences of **Covid-19** include weakened health systems, reduced focus on leprosy, funding uncertainties, a backlog of undiagnosed, untreated and neglected patients, and physical, mental, social and economic problems for people affected by leprosy.

Alongside these challenges, the ILEP strategy takes into account aspects of the wider global context.

- The **Sustainable Development Goals 2015-2030** aim to 'end the NTD epidemic' and thus reduce their health burden and disabling effects.
- WHO's **NTDs Roadmap 2021-2030** is the framework within which leprosy-endemic countries will form integrated plans for disease control or elimination. Key elements of the framework include integrated and mainstreamed approaches, country ownership and sustainability.
- At **country level**, ILEP Members work within national health and disability frameworks, supporting governments and other partners towards more effective leprosy programmes.
- ILEP is in official relations with WHO and is an essential partner in implementation of the **WHO Global Leprosy Strategy 2021-2030**.
- ILEP is a cornerstone partner in the **Global Partnership for Zero Leprosy**, a key vehicle to accomplish ILEP's mission and vision.
- The UN Special Rapporteur<sup>1</sup>, the ILEP Advisory Panel, the Global Forum of People's Organizations on Hansen's Disease (2019) and other factors have contributed to increased empowerment, connectivity and participation of **persons affected by leprosy**.
- A growing range of **digital technologies**, including resurgence of remote working and telehealth during Covid-19, has the potential to revolutionise programmes, communications and training.

1. UN Special Rapporteur on the elimination of discrimination against persons affected by leprosy and their family members.



Each year around 15,000 children are diagnosed with leprosy and face risks of disability and exclusion. ILEP Members are working with governments and other partners to decrease leprosy transmission and combat the stigma that still surrounds leprosy.

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### ILEP COLLABORATION: ACHIEVEMENTS AND LESSONS LEARNED

ILEP Members have greater collective impact when collaborating together and with partners such as governments, other NGOs and civil society organisations, communities and persons affected by leprosy. This section identifies achievements during the past five years at this collaborative level, and lessons to be learned from the experiences in mutual collaboration.

- Regular country-focused workshops are resulting in practical measures to improve **in-country coordination**, but also demonstrating instances where coordination is weak. Work is needed on better communication, participation of all stakeholders, and joint planning and programming.
- ILEP conferences have led to **better knowledge and practice** around 'zero leprosy' (2016), social inclusion (2017), innovative digital applications (2020) and building leprosy expertise (2020).
- **Technical leadership and advice** are provided through the ILEP Technical Commission (ITC), including publication of Stigma and Mental Wellbeing Guides (2020) and guidance on leprosy and Covid-19. After consultation, the ITC has adopted an ambitious workplan for 2021-2024.
- ILEP members have **provided expertise to World Health Organization** consultations on inclusion (2018), management of reactions and disability prevention (2020), contact tracing and PEP (2020), and criteria for the elimination of leprosy (2020-21). ILEP is an acknowledged voice for leprosy within WHO meetings, WHO NTDs department and the WHO Global Leprosy Programme.
- The **ILEP Advisory Panel of women and men affected by leprosy** has brought a distinctive voice into ILEP's decision-making and is a conduit to people's organisations in many countries.
- **Joint research projects** are in place especially through partnership in the Leprosy Research Initiative, a powerful global presence in leprosy research funding and learning.
- There has been a **growing culture of human rights** within ILEP, with advocacy through UN human rights instruments for an end to stigmatising practices and repeal of discriminatory laws.
- ILEP members have had a major impact on the effectiveness of the **Global Partnership for Zero Leprosy** through participation in research working groups, development of the GPZL country model, fundraising groups, the leadership team and other fora.
- ILEP members collaborate in funding the **internationally recognised knowledge platforms** Infolep and InfoNTD, and *Leprosy Review*, the leading academic journal on leprosy.
- There are several joint initiatives towards **leprosy prevention** through post-exposure prophylaxis, active case-finding and other leprosy control activities.
- ILEP is **influencing global practice** by bringing a leprosy voice and perspective within the NGO NTDs Network (NNN), the International Disability and Development Consortium (IDDC) and Uniting to Combat NTDs.

## STRATEGY 2021-2025

ILEP's vision is a world free from leprosy. Our shared mission is to work together towards that vision: towards zero transmission of leprosy, zero patients without treatment, zero leprosy-related disability and zero exclusion. To that end, this ILEP strategy articulates five significant global 'game-changers', from among the current global challenges, that the ILEP Federation collectively aims to tackle and resolve through active collaboration.

### Our key strategic goals

Game-changing goals towards which ILEP aims to make significant progress during 2021-2025.

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|--|--|
| <p><b>1 Global framework and strategy to build and sustain leprosy capacity</b></p> <ul style="list-style-type: none"> <li>➤ Global framework in place</li> <li>➤ Comprehensive strategy in operation, normally in integrated Skin NTD context, in &gt;10 countries</li> </ul>   | <p><b>4 Active engagement by persons affected by leprosy</b></p> <ul style="list-style-type: none"> <li>➤ Countries specifically including leprosy in national human rights frameworks: target &gt; 20</li> <li>➤ 50% reduction in discriminatory laws: target &lt; 65 (baseline: 130)</li> <li>➤ Number of ILEP-active countries with national organisations representing persons affected by leprosy: target ≈ 30 (baseline: 20)</li> <li>➤ Systems in place to monitor stigma levels in countries at regular intervals</li> </ul> |
| <p><b>2 Globally consistent leprosy data standards and data collection methodologies, leading to accurate reporting for improved programme planning and monitoring</b></p> <ul style="list-style-type: none"> <li>➤ Initiatives piloted towards more accurate new case data in selected countries</li> <li>➤ Effective surveillance systems for leprosy integrated with other relevant health conditions</li> <li>➤ Countries using widespread digital case-based data reporting</li> <li>➤ Countries maintaining accurate records of patients with disabilities and/or at-risk, both during and at completion of MDT treatment</li> </ul> | <p><b>5 Innovative approaches through research, proof of concept, and application of game-changing technologies and processes</b></p> <ul style="list-style-type: none"> <li>➤ Research strategy and priorities adopted by Members' Assembly</li> <li>➤ Collaborative piloting/proof of concept of new initiatives involving multiple ILEP Members</li> </ul>  |
| <p><b>3 Readily available services related to mental wellbeing in leprosy</b></p> <ul style="list-style-type: none"> <li>➤ Usage in national training programmes of ILEP/NNN Guides on Stigma and Mental Wellbeing</li> <li>➤ Access to basic psychological support at points of care, and to referral services to address mental health needs</li> </ul>  |  |



At least 4 million people are thought to be living with leprosy-related disability. ILEP's long-term vision is zero disability, and more accurate recording of at-risk patients is essential.

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## Enabling actions

How the ILEP Federation aims collectively to achieve the key strategic goals

### 1 Strong in-country collaboration between ILEP members

- Regular country planning/coordination workshops with regular progress reviews (target: 30 countries over 5 years)
- Increase in number of joint programming and resource mobilisation initiatives in-country

### 2 Sharing of knowledge and experience and putting into practice mutual learning

- Active Member participation in ILEP conferences and learning events focused on the key strategic goals
- ITC working groups bringing together technical experts globally
- Member working groups carrying forward selected topics into practical application
- Forum for sharing experiences and identifying effective practices to form and sustain national organisations of persons affected by leprosy
- Evidence of capacity development through knowledge exchange across comms officers' and institutional fundraisers' networks
- Monthly informal Member CEO calls building relationships and mutual support

### 3 ILEP Technical Commission outputs in line with key strategic goals

- Proportion of 2021 priority list delivered as completed work products: target > 50%

### 4 Input from, or coordinated by, ILEP Advisory Panel into key strategic goals

- Delivery of results against Advisory Panel workplan
- Strengthening connections with organisations of persons affected by leprosy worldwide

### 5 Effective advocacy on issues related to leprosy and people affected by leprosy within relevant forums of OHCHR and WHO

- Submissions made to more than 60% of scheduled reviews of relevant countries (CRPD, CEDAW, CRC and UPR) and on all relevant calls by CRPD Committee
- Organisations representing persons affected by leprosy supported to build capacity to make direct submissions
- ILEP engagement in WHO GLP country missions, expert consultations and relevant forums
- Engagement through WHO Leprosy TAG

### 6 Engagement in work of the UN Special Rapporteur (SR) on elimination of discrimination against persons affected by leprosy and their family members

- Organised interaction between SR and country teams
- Input into SR's reports to Human Rights Council and UN General Assembly
- Support of requests for official SR country visits

### 7 Increased understanding and capacity in human rights across the ILEP federation

- Member strategies include promotion of dignity, autonomy and participation by persons affected by leprosy
- Member strategies include appropriate support for formation and sustainability of autonomous, representative national organisations of persons affected by leprosy
- Application of ILEP statement on participation by persons affected by leprosy
- Members adopt intentional plans for building staff knowledge and capacity in human rights

## Operational strategy

What the ILEP Secretariat will do to facilitate achievement of the strategy

- 1 Support good governance by Members' Assembly and Executive Board**
  - Satisfaction surveys in 2023 and 2025
- 2 Keep Members informed on significant developments relevant to ILEP**
  - Monthly ILEP Update
  - Ad-hoc information to CEOs on important issues
- 3 Support ITC and ILEP Advisory Panel to function effectively and reflect the ILEP strategy and priorities in their work**
  - Surveys in 2022 and 2024 of Member satisfaction with value added by ITC and Advisory Panel
- 4 Maintain database of national organisations of persons affected by leprosy**
  - Database maintained, and Member attention drawn to gaps
- 5 In consultation with Members, ITC and Advisory Panel, lead in the planning, design, running and evaluation of ILEP learning events**
  - Member satisfaction with learning events and overall trajectory of learning within ILEP
- 6 Report regularly on achievement towards strategic targets**
  - Reports to Members' Assembly and Executive Board
  - Annual Report published on website
- 7 Monitor and take rapid action on MDT stock-outs or shortages**
  - Periodic reviews, and updates to ITC on any warning reports and actions taken or required
  - Regular interaction with WHO Geneva and Novartis on MDT supply issues
- 8 Keep Members informed on the work of LRI and encourage participation in joint research**
  - Reports through ILEP Update
- 9 Initiate and/or support jointly funded country-based and other projects involving multi-member collaboration towards strategic goals**
  - New collaborative ventures at country level
  - Engagement by ILEP members in other jointly funded collaborative ventures
- 10 Organise coordination/collaboration workshops and maintain regular interaction with country representatives to strengthen coordination**
  - Well-prepared, effective workshops
  - Implementation of workshop decisions
- 11 Ensure ILEP representation at relevant WHO global and regional meetings and consultations**
  - ILEP submissions and statements to WHO committees, conferences, NTD-TAG etc
  - Reports to Members' Assembly
- 12 Liaise with UN Special Rapporteur on all aspects of ILEP support and interaction**
  - Appreciative working relationship between ILEP and Special Rapporteur
- 13 Ensure ILEP represented on GPZL leadership team, NNN Executive Committee, IDDC General Assembly, and relevant working groups of these networks**
  - Regular 1-2 monthly reports to Members on GPZL progress and initiatives
  - Maintain overview of ILEP participation in NNN and IDDC working groups
- 14 Support Advisory Panel to maintain strong links with national organisations of persons affected by leprosy, foster collaboration between them, and develop ways of hearing from those most left behind**
  - Evidence of global input into Advisory Panel and effectiveness of Panel's role in building collaboration
- 15 Maintain database of opportunities for OHCHR input, work with Members to maximise the number of submissions, and represent ILEP at OHCHR committees and events**
  - Report to Members' Assembly
- 16 Build internal dialogue on intersection with significant global threats or movements, to keep leprosy on the global agenda**
  - Interested stakeholders engaged
- 17 Maintain up-to-date, informative ILEP website**
  - Website fit for purpose



International Federation of Anti-Leprosy Associations

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#### **MEMBERS**

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Fondation Raoul Follereau | Fontilles

German Leprosy and TB Relief Association – *Deutsche Lepra- und Tuberkulosehilfe*

Leprosy Relief Canada – *Secours aux Lépreux*

Lepra | NLR International | St Francis Leprosy Guild

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