



# Achieving a world free from leprosy

ILEP Strategy 2016 – 2018



## Who we are

The ILEP Federation is a consortium of NGOs committed to working together to fight leprosy, in partnership with others committed to this common goal.

## Background and global context

This strategy was developed in 2015, a critical year in the achievement of a world free of leprosy. The United Nations (UN) agreed new Sustainable Development Goals, WHO produced a new global leprosy strategy and ILEP underwent a major restructuring. This ILEP strategy states the direction of the ILEP membership globally and in countries where we are working. It also shows the contribution that achieving our goal of a world free from leprosy, brings to broader efforts in tackling health, disability, development and human rights.

- **Sustainable Development Goals (2015-2030)** In 2015, UN and its member states approved the new Sustainable Development Goals. The references to disabilities, as well as target 3.3 in relation to ending NTDs are welcomed by ILEP, as it joins with others working in NTDs and on disability issues to achieve these critical goals.
- **Uniting to combat NTDs – The London Declaration (2012 – 2020)** In 2012, global public health leaders came together in London, where they pledged to unite in their efforts of the WHO 2020 targets for NTDs, known as the London Declaration. The indicators in this strategy help contribute to measuring progress of leprosy in relation to these targets.
- **Global Leprosy Strategy (2016-2020)** In 2015, WHO led the development of a new Global Leprosy Strategy. ILEP is a critical partner in being able to achieve the goals and targets within the Global Leprosy Strategy. The ILEP strategy is intended to chart our contribution to the wider Global Leprosy Strategy.
- **ILEP's new way forward:** In 2015, ILEP underwent a major restructure at the governance, strategic and operational levels to look at how it can work better with each other and other partners to achieve these goals.

## Purpose of the strategy

- **Combine forces to achieve a world free from leprosy** and recognise the important role that all ILEP Members play in stopping transmission, preventing disability and promoting inclusion;
- **Expand partnerships** globally, regionally and at national level to intensify the engagement to achieve a world free from leprosy;
- **Track progress and promote learning** to achieve the goals the ILEP Federation has set itself, and,
- **Accelerate efforts** and act with urgency to reduce the number of people suffering from a preventable and treatable disease.

### *Our Vision*

*A world free from leprosy*

### *Our Mission*

*To work together to stop leprosy, to prevent disability and break the stigma resulting from leprosy*



## Strategy summary

This strategy was devised during 2015 with extensive stakeholder consultation and working with the ILEP Members. It is divided into three areas with the following aims:

### 1 Strategic Goals

**What the ILEP Federation aims to achieve:**

**Strategic Goal 1:** We will work together and with other partners to stop the transmission of leprosy.

**Strategic Goal 2:** We will work together and with other partners to prevent disabilities from leprosy.

**Strategic Goal 3:** We will work together and with other partners to promote inclusion of people affected by leprosy.

### 2 Enabling Actions

**How the ILEP Federation will achieve these Strategic Goals:**

**Enabling Action 1:** We will improve ILEP collaboration to achieve our Strategic Goals.

**Enabling Action 2:** We will work in partnership with others to achieve our Strategic Goals.

**Enabling Action 3:** We will raise the profile of leprosy and its consequences to achieve our Strategic Goals.

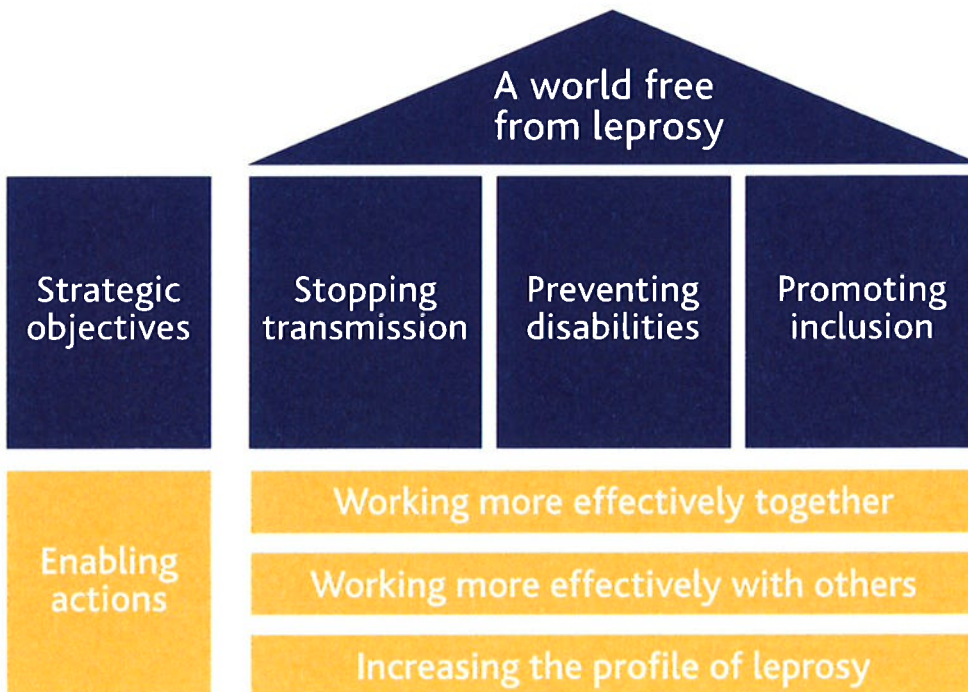
### 3 Operational Strategy

**How the ILEP Office will facilitate this strategy:**

**Operational Aim 1:** ILEP Office will facilitate effective governance of the ILEP Federation.

**Operational Aim 2:** ILEP Office will coordinate the Federation to monitor achievements and promote learning in the attainment of the ILEP strategy at national and global level.

**Operational Aim 3:** ILEP Office will lead the development of policy, advocacy and communication initiatives in collaboration with the Members.



## Strategic Goals: What the ILEP Federation aims to achieve

**Strategic Goal 1:** *The ILEP Federation will work together and with other partners to stop the transmission of leprosy*

**In support of the Global Leprosy Strategy target:**  
"Reduction of new leprosy cases with Grade 2 disabilities to less than one case per million population"

**Objectives** | **Indicators**

- 1.1 Increased early detection of leprosy, with a focus on women and children.
- 1.1.1 Annual new case detection and new case-detection rate (per 100,000 population), disaggregated by sex and age group.
  - 1.1.2 Proportion of contacts screened among registered contacts.
  - 1.1.3 % of child contacts screened among total child contacts.
  - 1.1.4 % of children among the listed contacts screened.
  - 1.1.5 % of female patients among newly diagnosed patients.
  - 1.1.6 Completion rate of MDT in all cases, disaggregated by sex.
  - 1.1.7 Number of countries where sub-district level mapping of leprosy case detection is implemented.
  - 1.1.8 Proportion of MB cases among new cases.
  - 1.1.9 Availability of web-based, case based reporting system allowing disaggregation by age, sex, place of residence and other relevant criteria
- 1.2 Increased evidence of effectiveness of immuno/chemoprophylaxis in stopping transmission.
- 1.2.1 Number of peer reviewed reports on immuno/chemoprophylaxis.
  - 1.2.2 Number of people affected by leprosy that have access to testing for resistance to leprosy drugs.

**Strategic Goal 2:** *The ILEP Federation will work together and with other partners to prevent disabilities from leprosy*

**In support of the Global Leprosy Strategy target "Zero Grade 2 disabilities among paediatric leprosy patients"**

**Objectives** | **Indicators**

- 2.1 Improved data collection of residual morbidity disaggregated by gender and age.
- 2.1.1 % of people (by country) with EHF (eye hand foot) assessed for disabilities, disaggregated by sex and age group.
  - 2.1.2 Number of countries where figures for residual morbidity are available.
  - 2.1.3 Proportion of newly diagnosed leprosy patients with Grade 2 disabilities disaggregated by sex and age group.

**Strategic Goal 2:** Continued

- 2.1.4 Proportion of patients having reactions among new cases, disaggregated by bacillary load (PB or MB).
- 2.1.5 Number of cured patients presenting with new disabilities not present at the end of treatment.
- 2.1.6 Proportion of patients evaluated for disabilities at the end of treatment, disaggregated by sex;

2.2 Improved access to rehabilitative care and support services to address the needs of those with disabilities.

- 2.2.1 % of people with leprosy related disabilities accessing assistive devices among those in need.
- 2.2.2 % of people with leprosy related disabilities receiving rehabilitative surgery among those in need.
- 2.2.3 Proportion of people affected by leprosy in self-care support programmes among patients with Grade 1 disabilities and Grade 2 disabilities.
- 2.2.4 Number of persons with leprosy-related wounds that have access to wound care services among those in need.

**Strategic Goal 3:** *The ILEP Federation will work together and with other partners to promote inclusion of people affected by leprosy*

**In support of the WHO Global Leprosy Strategy target:**  
"Zero countries with legislation allowing discrimination on basis of leprosy"

**Objectives** | **Indicators**

- 3.1 People affected by leprosy are empowered to understand and take up their rights.
- 3.1.1 Number of affected people or associations of affected people with a role in care (i.e. for advocacy, health education, detection or treatment).
  - 3.1.2 Number of countries that use the participation scale score to assess the social participation of persons affected by leprosy.
- 3.2 An end to discriminatory practices towards people affected by leprosy.
- 3.2.1 Number of countries with discriminatory laws and policies against those affected by leprosy.
  - 3.2.2 Number of countries with norms and/or regulations facilitating the inclusion of persons affected by leprosy and their communities.
  - 3.2.3 The number of countries that assess the level of stigma in the community and among patients and healthcare workers.



## Enabling Actions: How the ILEP Federation will achieve its Strategic Goals

This is how the ILEP Federation has agreed to work to implement and achieve its Strategic Goals.

### Enabling Action 1: *We will improve ILEP collaboration to achieve our Strategic Goals*

#### Objectives | Indicators

1.1 ILEP Members share and utilise learning; actively participating in ILEP thematic Working Groups.

1.1.1 Members able to demonstrate that learning from Working Groups has been applied to programmes and services.

1.2 ILEP Members share and utilise learning; actively participating in ILEP country platforms.

1.2.1 Number of annual country reports (supported by ILEP) on country strategy progress.

1.3 ILEP Members are contributing to an active and well organised ILEP Knowledge Platform.

1.3.1 Number of Knowledge Platform contributions.

1.4 ILEP Members measure progress against ILEP strategies.

1.4.1 Number of annual reports showing progress.

Advisory	Panel of women and men affected by leprosy		ILEP Technical Commission		
Governance	Members' Assembly				
	Executive Board				
Coordination	ILEP Office			Country Coordinators	
Membership cooperation	Working Group Stopping transmission	Working Group Preventing disabilities	Working Group Promoting inclusion	Comms network	Country level collaboration

**Enabling Actions:**  
**How the ILEP Federation will achieve its Strategic Goals *continued***

**Enabling Action 2: We will work in partnership with others to achieve our Strategic Goals**

**Our Objectives | Indicators**

2.1 ILEP and other stakeholders working on leprosy collaborate to deliver shared advocacy and policy messages at the global and national level.

2.1.1 Number of MoUs developed at the global level and national level.

2.2 The ILEP Federation is recognised as a credible partner in policy and programme implementation with other partners working on neglected tropical disease issues.

2.2.1 Increased number of programmes being implemented with other NTD partners.

2.2.2 Increased advocacy initiatives with other NTD partners.

2.3 The ILEP Federation is recognised as a credible partner in policy and programme implementation with other partners working on disability issues.

2.3.1 Increased number of programmes being implemented with other disability partners.

2.3.2 Increased advocacy initiatives with other disability partners.

**Enabling Action 3: We will raise the profile of leprosy and its consequences to achieve our Strategic Goals**

**Our Objectives | Indicators**

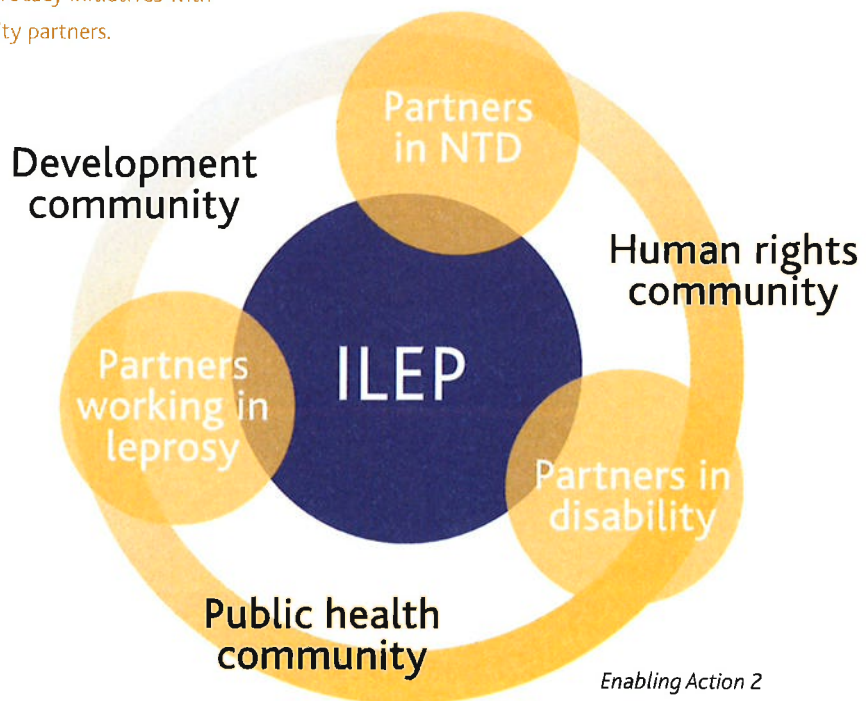
3.1 Policy and funding decision-makers hear a consistent and strong ILEP voice.

3.1.1 ILEP key messages are produced and regularly updated.

3.1.2 News stories and other PR materials are shared and promoted through the network.

3.2 An ILEP communication strategy is endorsed and followed by all ILEP Members.

3.2.1 Increased social media presence.



## Operational Strategy – How ILEP Office will facilitate this strategy

The ILEP Federation is supported in delivering this strategy by a small office, based in Geneva. The aims of the ILEP Office are:

### Operational Aim 1: ILEP Office will facilitate effective governance of the ILEP Federation

#### Objectives | Indicators

- 1.1 ILEP's governance bodies are effectively overseeing and guiding the Federation.
  - 1.1.1 Annual Membership Survey showing positive results.
- 1.2 ILEP's Advisory Boards are providing feedback to the ILEP Federation.
  - 1.2.1 Annual Membership Survey showing positive results.
- 1.3 ILEP has produced and is delivering a new Membership Strategy.
  - 1.3.1 New Membership Strategy is approved and reported on.

### Operational Aim 2: ILEP Office will coordinate the Federation to monitor achievements and promote learning in the achievement of the ILEP strategy at national and global level

#### Objectives | Indicators

- 2.1 ILEP Office monitors and reports on progress against the strategy.
  - 2.1.1 ILEP annual reports charting progress.
  - 2.1.2 Mid-term evaluation report.
- 2.2 ILEP Office facilitates country level planning and reporting.
  - 2.2.1 Number of ILEP country plans and reports.
- 2.3 ILEP Office is maintaining a well organised and up to date ILEP Knowledge Platform.
  - 2.3.1 Increase in contributions to the Knowledge Platform.
  - 2.3.2 More than 10 people attend strategic Working Group meetings.

### Operational Aim 3: ILEP Office will lead the development of policy, advocacy and communication initiatives in collaboration with the Members

#### Objectives | Indicators

- 3.1 ILEP Office formalised exploration of developing a leprosy alliance with partners working on leprosy.
  - 3.1.1 Leprosy Partnership ToR developed.
- 3.2 ILEP Office has led an increased number of policy, advocacy and communication initiatives with members of partners.
  - 3.2.1 Number of initiatives reported on.
- 3.3 ILEP communications strategy in place and being followed.
  - 3.3.1 ILEP communication strategy in place and reported on.
  - 3.3.2 Increase in ILEP branding through the Federation.
- 3.4 ILEP Office systems and processes are in place to enable it to deliver on above.
  - 3.4.1 Quarterly Board reports showing progress on the Operational Strategy.
  - 3.4.2 Mid-term evaluation findings.





**International Federation of Anti-Leprosy Associations**

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Leprosy Relief Canada • Lepra • Ordre de Malte • Netherlands Leprosy Relief • Sasakawa Memorial Health Foundation  
The Leprosy Mission International