

International Federation of Anti-Leprosy Associations (ILEP) Strategy 2021-2023: Consultation paper

Introduction

ILEP is a consortium of international non-governmental organisations with a shared desire to see a world free from leprosy (Hansen's disease). Their mission is to work together to stop the transmission of leprosy, to prevent disability and to break the stigma resulting from leprosy. Through the programmes of its member associations, and in association with many partners from local to international level, ILEP spans more than 60 countries and 700 project locations worldwide.

ILEP's current strategy expires at the end of 2020. Through this consultation paper, ILEP invites input from stakeholders and interested persons on the design of its 2021-2023 strategy, which will be adopted by the ILEP Members' Assembly in March 2021.

Previous strategy

The three 'pillars' of ILEP's 2016-2020 strategy¹ outline the primary ways in which ILEP has sought to achieve its mission during the past five years.

Working collaboratively together

Collaboration between member associations has continued to be at the heart of ILEP. ILEP's biggest achievement is the effective coordination of responsibilities within countries in which two or more ILEP members are working. An ongoing series of coordination workshops has focused on improving this practical collaboration. Conferences on operationalising 'triple zero' (2016), social inclusion (2017), innovative digital applications (2020) and retaining leprosy expertise (2020) have brought together a wide range of participants: the 2020 conferences involved almost 200 people from 38 countries. The objective of these conferences, and other joint learning events, is to tackle challenging issues together, learn from one another, and apply the findings. Learning objectives are supported by the ILEP Technical Commission, whose advice on leprosy-related issues – for example, the Stigma and Mental Wellbeing Guides published in 2020 – benefits not only ILEP members but the leprosy world at large. Several ILEP members have engaged in joint research projects, including the five core partners in the Leprosy Research Initiative which, since 2014, has supported more than 45 different projects in six continents. ILEP members have also continued to collaborate in co-funding Infolep and InfoNTD, the online knowledge centres for leprosy and NTDs, and *Leprosy Review*, the leading academic journal on leprosy.

Working effectively with others

The road towards the 'triple zero' goals of zero transmission, zero disability and zero stigma and discrimination is a challenging one. At country level, ILEP members have continued to work with governments, other NGOs, academia, community leaders and organisations of persons affected by leprosy, and to advocate for coordination structures such as national partnerships for zero leprosy which have the potential to unite stakeholders and resources. ILEP has also fostered partnerships at the global level. It has official relations with the World Health Organization and has engaged not only with the WHO Global Leprosy Programme – including participation in review missions, technical guides and other consultations – but also with WHO Neglected Tropical Diseases unit and WHO regional forums. ILEP was a co-founder of the Global Partnership for Zero Leprosy, launched in 2018, and remains a cornerstone partner through member contributions to GPZL working groups and its budget. ILEP has become increasingly active as a well-regarded partner in the Neglected Tropical Diseases NGO Network (NNN) and the International Disability and Development Consortium (IDDC).

¹ The full 2016-2020 strategy is at <https://ilepfederation.org/wp-content/uploads/2020/02/ILEP-Strategy-2016-20.pdf>

The formation of the ILEP Advisory Panel, which consists of women and men with personal experience of leprosy, has not only brought a 'voice' of persons affected by leprosy into ILEP's thinking and decision-making, but has also enabled a conduit to organisations of persons affected by leprosy in many countries.

Raising the profile of leprosy

Factors such as stigmatisation, misleading statements about 'elimination', inadequate focus on post-treatment disability and weak grasp of the dire human rights consequences of leprosy have all contributed to the disease having an unduly low profile. ILEP has used various means to raise this profile. During the past five years ILEP has radically increased its engagement with the Office of the UN High Commissioner for Human Rights (OHCHR). The ILEP Office advises on, coordinates, and sometimes write submissions to the Committee on the Rights of Persons with Disabilities (CRPD), other OHCHR treaty bodies and the Universal Periodic Review, with the aim to submit information on leprosy-related human rights issues wherever ILEP members are working. ILEP welcomed the appointment in 2017 of the UN Special Rapporteur on the elimination of discrimination against persons affected by leprosy and their family members and has sought to work in increasingly close cooperation with her mandate. ILEP manages the world's leading database of legislation that discriminates against persons affected by leprosy and, through advocacy, has seen a welcome reduction in the number of laws during the past five years. Internally, the website has been updated, ILEP specialist networks of communications officers and institutional funding officers have worked together, and ILEP has used World Leprosy Day as a major focus for broadening leprosy awareness.

Strategic context for the 2021-2023 ILEP strategy

The new ILEP strategy is being developed in the light of significant contextual features.

- The Sustainable Development Goals 2015-2030 aim to end the 'NTD epidemic': this is a long-term focus for the work of ILEP and others working in NTDs and on disability issues.
- In 2020 WHO adopted the NTDs Roadmap 2021-2030, with leprosy among twenty diseases profiled. Integration of leprosy within wider health systems, and especially within skin NTDs as a whole, is one of the cross-cutting themes of the Roadmap.
- In alignment with the NTD Roadmap, WHO is launching the Global Leprosy Strategy 2021-2030 in early 2021. ILEP has partnered in the formation of the strategy and will be a key participant towards its achievement.
- As a cornerstone partner in the Global Partnership for Zero Leprosy, ILEP influences and is influenced by its policies, strategies and actions, including within its priority countries.
- The work of the UN Special Rapporteur, a global forum in 2019 and other factors have contributed to increased empowerment of organisations of persons affected by leprosy.
- GPZL and the Leprosy Research Initiative have collaborated in 2020 on establishing a consensus set of research priorities in leprosy, for which funding will be sought from 2021.
- The COVID-19 pandemic has led to a significant reduction in case-finding activities, and the resulting backlog in diagnosis and treatment has dire consequences for the affected people. Weakened health systems will be a challenging context for ongoing programmes.

Key assumptions and elements of the 2021-2023 ILEP strategy

1. ILEP's vision and mission will remain unchanged. ILEP members will advocate for and support a 'triple-zero' focus in all countries in which they are working. The three 'pillars' of the previous ILEP strategy will continue at the heart of the new strategy.
2. ILEP will lobby and work with all relevant stakeholders to intensify case-finding activities as soon as possible in order to identify and treat all persons with a recent onset of leprosy.
3. ILEP will continue in close and active cooperation with the WHO Global Leprosy Programme, and in overall support of the global leprosy strategy as adapted by governments with whom ILEP

members are partnering. In a departure from its previous practice, ILEP will not necessarily adopt the WHO strategy performance indicators within the ILEP strategy.

4. ILEP will maximise the reach, impact and 'value-add' of the ILEP Technical Commission and the ILEP Advisory Panel.
5. Working with relevant stakeholders, ILEP will support the establishment and capacity of organisations of persons affected by leprosy in all countries in which its members operate.
6. ILEP will continue to play a leading role in contributing to the success of the Global Partnership for Zero Leprosy, including the formation of national partnerships for zero leprosy and design and implementation of zero leprosy roadmaps.
7. ILEP will engage with all relevant instruments of the OHCHR, building the capacity of organisations of persons affected by leprosy to make submissions and to engage directly, and seeking to ensure that well-grounded submissions or reports are produced whenever countries where ILEP members are working come up for review.
8. ILEP will collaborate supportively with the mandate of the UN Special Rapporteur on the elimination of discrimination against persons affected by leprosy and their family members.
9. The ILEP secretariat will consult with ILEP member associations in the planning, design, running and evaluation of learning events, both virtual and face-to-face.
10. ILEP will use the learning from its 2020 conference on leprosy expertise to develop, promote and implement innovative approaches to building and maintaining leprosy capacity at country level and within ILEP member associations.
11. ILEP will continue to advocate for the repeal or amendment of all discriminatory laws, and advocate and support governments to implement policy frameworks that protect the rights of persons affected by leprosy.
12. The ILEP secretariat will continue to support the external communications of members and of GPZL, rather than maintaining its own dedicated communications function.

Consultation

Stakeholders and interested persons are invited to provide feedback on this consultation paper and on any other aspects of ILEP's strategic direction. The ILEP secretariat is particularly interested in responses to the following questions:

1. In the 'Previous strategy' section, have any significant achievements been overlooked? Are there any areas in which ILEP has failed to achieve what it should have done in regard to that strategy?
2. In the 'Strategic context' section, are there any other significant contextual features that ILEP needs to take into account in developing its 2021-2023 strategy?
3. Do you disagree with any of the key assumptions and elements listed for the 2021-2023 strategy? What other key assumptions, strategic elements or strategic priorities should be added?

Responses to these questions, and any other feedback or comment, should be emailed to officer@ilepfederation.org by 25 January 2021. ILEP appreciates and will pay careful attention to feedback from all sources. Thank you for your participation!



Geoff Warne
CEO

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