

Emerging needs and priorities in leprosy: The role of ILEP
Speech by ILEP CEO, Geoff Warne, to opening plenary event of International Leprosy Congress
Hyderabad, November 2022



Our vision:
A world free from leprosy

Ladies and gentlemen –it's great to be here together at the 21st International Leprosy Congress. I've been to five of these Congresses over the years – some of you have attended far more than that – and they never fail to inform and to inspire. I want to congratulate the International Leprosy Association, and Dr Narasimha Rao and Dr Sujai Suneetha and their team, for getting us to this point with an excellent three day programme ahead of us.

ILEP is one of the official sponsors of this year's Congress. As Chief Executive it is my pleasure and privilege to bring the greetings of all ILEP member associations – all of whom are represented here in Hyderabad – and to extend our warmest wishes for a successful and productive Congress.

ILEP, as most of you will know, is a consortium of international NGOs, currently 14 in number. We share a commitment to achieving a world free from leprosy. And let me be very clear that, in ILEP's terms, a world free from leprosy includes not just zero transmission but also zero new disability caused by leprosy, and zero leprosy-related stigma and discrimination. Triple zero.

ILEP was founded more than 60 years ago – back in the days of dapsone monotherapy. Over those 60 years we have seen many developments in the treatment and management of leprosy, and have made



14 Member associations | 63 countries | 578 projects | 1,238 project locations

many changes in the way in which we approach the disease and the people who experience it. So although the zero-leprosy goal has remained constant, a continual adjustment is going on to new thinking, new evidence, new tools, new understanding of the needs, and agreement on new priorities.

As that adjustment takes place, ILEP members also engage in ongoing reflection and discussion about what is their role.

There's no single answer to the question 'what is our role'. ILEP members are autonomous. They each make their own decisions on what should be their approach and their priorities. But we can see general trends. For example:

- less of direct service delivery and more of support to the country program
- a shift from vertical programs to more mainstreamed approaches
- a shift from single-disease to more integrated approaches
- an increasingly holistic focus on medical treatment, rehabilitation, disease prevention, disability prevention, livelihoods, advocacy, research, capacity development, empowerment and more.

These sorts of themes are prominent in the WHO NTD Road map, but they have been under way among ILEP members for a long time. And as you can see, they are reflected today in a large number of very diverse projects in more than 60 countries.

So, looking at the leprosy world today, what are some of the emerging priorities for ILEP, and what do these priorities say about the role of ILEP in the coming two or three years?

I want to answer that by talking about four projects which the ILEP Members agreed, earlier this year, to fund from the joint ILEP reserve. These are all collaborative projects involving several ILEP members. These projects do not represent the totality of what we see as emerging needs and priorities. Don't get the wrong impression about that. But they illustrate what we consider to be strategically important at present as regards what's needed in the leprosy world. If you'd like to read more about ILEP's strategy, then please come to the ILEP table in the display area and pick up our one-page 'strategy at a glance'.

Lift leprosy learning

Halt and reverse dwindling leprosy expertise



- Promote a coordinated approach and resources to address leprosy capacity building, usually in an integrated setting.
- Develop new, updated and modern training materials, methods and tools and make them easily accessible, attractive and adaptable to specific contexts.
- Pilot this coordinated and modernised approach in seven countries that have varying levels of endemicity and different health systems.

The first project is about leprosy expertise: it's ILEP's **Lift Leprosy Learning** project.

Many of us – many of you – have been deeply concerned for many years now with the loss of leprosy expertise, especially clinical skills at all levels. This is listed in the WHO Global Leprosy Strategy, and also in most national leprosy strategies, as one of the most pressing challenges in the leprosy world today. We

looked at this problem in an ILEP online conference in 2020, which was reported in *Leprosy Review* last year. We saw that many of the current approaches to capacity development are intermittent, and not cost-effective, and not sustainable.

One of ILEP's key goals by 2025 is to work towards a global framework and strategy to build and sustain leprosy capacity. The ILEP Technical Commission is contributing to this by identifying as many leprosy training materials as we can, evaluating them and considering what needs to be done to make them fit for purpose. But Lift Leprosy Learning goes much further than this. It's a three-year project with three main workstreams:

- The first is to promote a coordinated approach to address leprosy capacity building, usually in an integrated setting. This involves Ministries of Health, ILEP members, training institutes, persons affected by leprosy and other stakeholders.
- Second, to develop new, updated and modern training materials, methods and tools and make them easily accessible, attractive and adaptable to specific contexts.
- And third, to pilot this coordinated and modernised approach in seven countries that have varying levels of endemicity and different health systems.

What I want to demonstrate, in talking about this project, is that ILEP sees one of our roles as to pick up some of the very challenging and difficult-to-solve operational problems in the leprosy world – like this one – and to apply innovative thinking in an effort to make some progress towards resolving it. We certainly don't expect to have fixed this problem by 2025! But we do confidently expect to have made some progress towards it.



Global leprosy mapping initiative

Tools, processes and best practices to map leprosy

- Recommend global strategy for leprosy data management (including indicators, process for collection, standardization, and verification).
- Build national capacity for data collection, management, mapping, and analysis.
- Develop initial maps for eleven pilot countries based on available data.
- Provide model examples of improved data-driven decision-making processes.

The second project is ILEP's **global leprosy mapping initiative**. A core goal in the WHO Global Leprosy Strategy is interruption of transmission of leprosy. Pillar 2 of the strategy says that this should be achieved through contact tracing, preventive chemotherapy, and active case-finding in targeted populations – often in integrated settings. Better data, and better data management, are crucial in this

regard, and for that reason the WHO NTD Road map calls for standardized mapping to give a detailed view of disease epidemiology and progression. This is especially important in leprosy as it's a clustered disease: uniform approaches to active case finding, for example, waste resources. Managers need to know which are the critical areas to be targeted more intensively.

The goal of ILEP's global leprosy mapping initiative is to develop tools, processes, and best practices to support Ministries of Health to scale up the mapping of leprosy. The project will analyse where countries are in terms of leprosy data collection, reporting, analysis and database management, and it will provide tools, guidance, and standardized approaches for improved mapping and better-informed decision making. In most cases, the project will collectively map all known leprosy cases registered in at least the last five years and develop a systematic approach for recording and mapping future cases. You can hear more about this project during the session in Hall 5 at 4.30 this afternoon.

We expect by the end of the three-year project:

- to recommend a global strategy for leprosy data management (including indicators, process for collection, standardization, and verification)
- to build national capacity for data collection, management, mapping, and analysis
- to develop initial maps for eleven pilot countries based on available data
- and to provide model examples of improved data-driven decision-making processes.

These deliverables will be of great value not only to the more endemic countries but also to low-endemic countries that plan to seek WHO verification that they have achieved interruption of transmission. The dossiers that they'll need to prepare for that include requirements around data management, tracking and surveillance.

What I want to demonstrate, in talking about this project, is that ILEP sees one of our collective roles as to research best practices, help national programmes to identify how best to apply those best practices to their work, and support the scaling up of these practices so that they are part of the country's strategy, policy and standard operational procedures.

The third project is to do with the **active engagement of persons affected by leprosy**. This is another of the key objectives in the ILEP strategy. As I said earlier, ILEP's goal is not just zero leprosy transmission but also zero stigma and discrimination. As part of that, we want to be ensuring that persons affected by leprosy have wider inclusion and meaningful participation. And that includes participation in

organisational policies, processes and programmes that impact their lives. ILEP strongly endorses the call in the WHO Global Leprosy Strategy for initiatives that will strengthen the capacity of organisations of persons affected by leprosy, so that they can provide meaningful engagement on issues relevant to them, at all decision-making levels.

Now, one of the key elements of ILEP's structure is an Advisory Panel consisting of seven people with personal experience of leprosy. They are all here at this Congress and at this week's Global Forum organised by ILEP member Sasakawa Health Foundation. This Advisory Panel has initiated formal statements of commitment to enabling the participation of persons affected by leprosy, and also other NTDs. These statements of commitment have been adopted by the NGO NTDs Network (or NNN) and by ILEP Members. I encourage you to pick up a copy of ILEP's Statement on Participation at the ILEP display booth and think about how you might apply this in your organisation. I also encourage you to listen at this Congress to what people affected by leprosy are saying about their own lives and their desire for participation, for example in the session in this Hall from 3.30 this afternoon.



From words to action

Assessing participation by persons affected by NTDs

- Develop NTD Inclusion Scorecard, an organisational self-assessment tool for meaningful participation.
- Pilot Scorecard in 10 organisations (including ILEP members).
- Publish and disseminate piloted tool throughout NTD world.
- Support leprosy and the wider NTD community to take accountability for the inclusion and meaningful participation by persons affected by leprosy/NTDs.

So, the project is called **From Words to Action** and it's a one-year project. The purpose is to develop, test, pilot and launch the NTD Inclusion Score Card. The Scorecard is an organisation self-assessment tool. People will use it to assess meaningful participation by persons affected by leprosy in the programs and actions and decisions that are being made about them. The Scorecard

will be a way for any organisation to honestly assess where it stands in terms of compliance with this statement of commitment and whether it is really fostering inclusion and participation by persons affected by leprosy.

What I want to demonstrate, in talking about this project, is that ILEP sees one of our collective roles as to take a lead in fostering participation, firstly by committing to doing that in our own organisations, and then by encouraging others to do the same. I want to emphasise that we do not claim to have mastered this – far from it, we are still growing and learning. As regards the Words to Action project, along with enabling development of the Scorecard, we intend to advocate for its widespread adoption and use in the leprosy and NTD world.

The last of the ILEP collaborative projects I'm highlighting today is called **UPLIFT**. This project is about the effectiveness of Community Based Groups such as self-help groups and self-care groups that are a big part of the leprosy landscape. The WHO Global Leprosy Strategy says that persons affected by leprosy should be encouraged and supported to form these community groups for mutual support and resilience, advocacy, and the development of livelihoods and socioeconomic advancement. We see these groups as having huge potential to make leprosy a 'disease of no consequence', with no disability, no associated prejudice and no quality-of-life impact. These are all key elements of ILEP's vision of a world free from leprosy.

What the UPLIFT project will do is to study the key success factors for these groups and develop a harmonized community groups model that integrates self-care, self-support and self-help practices with



UPLIFT

Harmonised community-based groups model

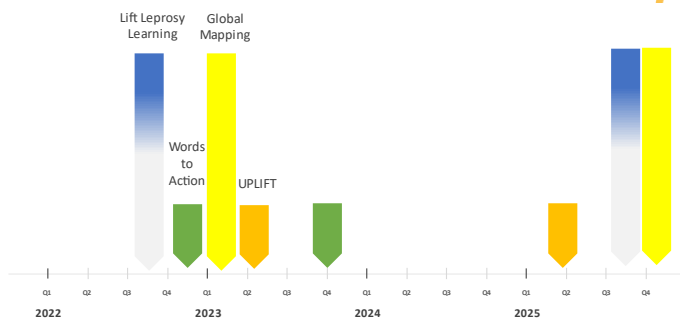
- Study key success factors for communitybased selfhelp and selfcare groups.
- Develop harmonised model integrating selfcare, self-support and selfhelp practices, including focus on mental wellbeing
- Test and validate as startup package with new community groups in India, Bangladesh and Ethiopia.
- 2-arm study, one arm including enhanced mental health component.

a particularly strong focus on mental wellbeing. This mental wellbeing aspect is important to ILEP: one of our five key strategic goals is to advocate for readily available point-of-care and referral services related to mental wellbeing in leprosy. The scientific programme this week has numerous sessions related to mental wellbeing, like at Hall 5 this afternoon.

The community groups model will be designed in consultation with ILEP members, local NGOs, government stakeholders and, most importantly, people affected by leprosy and other NTDs. This is going to be delivered as a start-up package that will be tested and validated on new community groups in India, Bangladesh and Ethiopia. The testing will be through a cohort 2-arm study, where one arm includes an enhanced mental health component involving trained mental health peer counsellors.

What I want to demonstrate, in talking about this project, is that ILEP sees one of our collective roles as to research, publish and demonstrate best practices for the benefit of the leprosy world as a whole. For this project, that includes an emphasis on inclusion of mental wellbeing. We intend to offer the completed work to governments, NGOs and civil society organisations – especially organisations of persons affected by leprosy – that are establishing community groups for empowerment, livelihood, disability prevention and mental wellbeing.

Timeline



Here is the timeline for these four projects. The colour-coding shows the beginning and end dates for each project. You can see they're all starting this quarter and next quarter, and most are finishing in mid-to-late 2025. You can expect to see the results published in Leprosy Review or other journals and disseminated in other words. And, no doubt, reported on at the next ILC.

Ladies and gentlemen, thank you for your attention. I conclude by reminding you of what we're striving to do as ILEP: Working together to stop leprosy, prevent disability and break the stigma resulting from leprosy. You're welcome to come and visit the ILEP booth in the display area, and I wish each of you an inspirational Congress.



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