



Working together towards a world free from leprosy

ILEP ANNUAL REPORT 2021

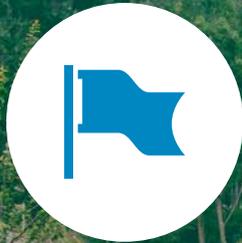


YEAR IN NUMBERS – at a glance



14

ILEP Members



63

Countries we work in



578

Projects in 1,238 locations



127,396*

New cases reported (WHO 2020)



7,198*

New cases with visible disabilities (WHO 2020)



8,629*

New child cases (WHO 2020)



49,208*

New female cases (WHO 2020)



3-4 million

Persons living with visible disabilities (WHO)



~30 million

People at risk of leprosy (WHO)



130

Discriminatory laws worldwide



* These figures are artificially low due to reduced detection of leprosy during the Covid-19 pandemic. The true new case numbers are likely to be around 60% higher.

Working together to stop leprosy, prevent disability and break the stigma resulting from leprosy.

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PRESIDENT'S REPORT

Brent Morgan, ILEP President



New strategy,
new opportunities



“ILEP’s new strategy holds the potential for game-changing collaboration.”

ILEP’s experience during the Covid-19 pandemic has highlighted the value of partnership. From April 2020 onwards, ILEP member CEOs started meeting monthly to share how they were responding to events around them. Even after the Covid situation began to settle, the meetings have continued because of what we are learning from one another’s programmes, successes and experiences.

This attitude of working and learning together has continued to build during 2021. At country level, cooperation is reviewed in online workshops, held over a three-year period, in which we review the performance and level of cooperation in each of the countries where more than one ILEP member is active. These workshops now include specific plans for collaborative projects focused on key activities that would benefit from a joint approach.

At the international level, ILEP’s Strategy 2021-2025, adopted in September, places a renewed emphasis on the need to work together – and with other partners – towards our objectives

of zero transmission of leprosy, zero patients without treatment, zero leprosy-related disability, and zero exclusion. The five key strategic goals all represent game-changing outcomes for the leprosy world: none can be achieved without the active collaboration of all ILEP members. Similarly, the enabling actions described in the Strategy call for the collective energies of all the ILEP members.

We were delighted to welcome St Francis Leprosy Guild into ILEP this year, increasing our number of members to fourteen and expanding the opportunities for mutual learning and on-the-ground cooperation. Moreover, six ILEP members have new CEOs since we last met in person, in pre-Covid days. We are looking forward to the opportunity, finally, to be together in person in 2022, to reignite friendships and build new connections on which collaboration, so vital to our success, will be built.

A handwritten signature in blue ink, reading "Brent J. Morgan".



MESSAGE FROM THE CEO

Geoff Warne



Looking outward,
stronger together

“ILEP cannot hope to achieve its shared vision of a world free from leprosy without looking outward, to foster active partnerships with other organisations.”

Collaboration, co-operation and harnessing collective strengths are some of the keys to ILEP’s impact as we work towards zero leprosy. We see these effects in technical collaboration between members, joint funding of research and other programmes, active coordination at country level, and knowledge exchange. Yet ILEP cannot hope to achieve its shared vision of a world free from leprosy without looking outward, to foster active partnerships with other organisations.

Partnership-building at national level enables ILEP to mobilise other interested participants towards our zero-leprosy goals. By embracing integrated approaches, ILEP members are broadening the range of their engagement into countries’ health systems, disability support services, human rights frameworks and other facets relevant to a holistic approach to leprosy. Supporting the formation of national partnerships for zero leprosy is another means by which ILEP members are helping to unite stakeholders and resources into national roadmaps to zero leprosy. Similarly, ILEP is active in global-level networks not only in the leprosy world (for example, with the Global Partnership for Zero Leprosy), but also

in the Neglected Tropical Diseases community (for example, with members of the NTD NGO Network), and in disability and inclusion.

The ILEP Technical Commission’s working subgroups have brought together a network of technical experts from many countries and organisations, working to resolve some of the ongoing programmatic questions in leprosy. The ILEP Advisory Panel is reaching out to organisations of persons affected by leprosy in different countries, to hear more clearly the voices of people with personal experience of the disease and to bring those perspectives into ILEP’s strategic thinking.

The road to a world free from leprosy is certainly a challenging one. ILEP will continue to strengthen existing partnerships and seek new alliances, towards that goal.



ILEP 2021-2025 Strategy at a Glance

Towards a world free from leprosy

The International Federation of Anti-Leprosy Associations (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.

This is a short ‘strategy at a glance’: the full strategy can be viewed on the ILEP website.

KEY STRATEGIC GOALS

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

1

Global framework and strategy to build and sustain leprosy capacity

Global framework in place

Comprehensive strategy in operation, normally in integrated Skin NTD context, in > 10 countries

2

Globally consistent leprosy data standards and data collection methodologies, leading to accurate reporting for improved programme planning and monitoring

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

3

Readily available services related to mental wellbeing in leprosy

Use of ILEP guides on stigma/mental wellbeing

Access to point-of-care and referral services for mental wellbeing

4

Active engagement by persons affected by leprosy

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

5

Innovative approaches through research, proof of concept, and application of game-changing technologies and processes

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.





**Our vision is a world
free from leprosy**



ILEP expertise has continued to inform NGO partners, the World Health Organization, governments, the Global Partnership for Zero Leprosy and others.



STRATEGIC GOAL: Stopping the Transmission of Leprosy – Towards Zero Transmission

How things are

In the 40 years since the introduction of multi-drug therapy for leprosy, disease 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. The WHO Global Leprosy Strategy 2021-2030 urges countries to make plans to interrupt leprosy transmission by investing in active case-finding, contact tracing and other measures aimed at preventing leprosy.

There are numerous obstacles to this objective. Limited or dwindling leprosy expertise is a reality almost everywhere. Weak health information systems can result in leprosy case numbers being under-reported or persons at risk not being followed up. Some countries still rely on manual processes that make it difficult to get timely information or to confidently monitor trends.

As the Covid-19 pandemic continued during 2021, case-finding activities and contact tracing continued to be curtailed. The Covid-related backlog of cases at the end of 2020 was made worse during 2021, when reported new cases were one-third lower than the underlying trend. There is justifiable fear that the backlog of untreated leprosy will lead to ongoing disease transmission.

How we are working for positive change

One of ILEP's primary roles, at both country and global level, is as a source of expertise. During 2021, the ILEP Technical Commission, an appointed group of technical experts, adopted a four-year workplan following wide consultation. The workplan addresses issues where new or updated technical guidance is needed, and the ITC has recruited subgroups of people, from many backgrounds, to work on this.

ILEP expertise has continued to benefit and inform governments, NGO partners, WHO, the Global Partnership for Zero Leprosy and others. ILEP personnel were involved during the year on the Task Force on Criteria for Elimination of Leprosy, established by the WHO Global Leprosy Programme to provide guidance to countries wishing to verify interruption of transmission and elimination of leprosy disease.





ILEP hosted two well-attended webinars on the implications for ILEP members of the new WHO NTD Roadmap 2021-2030 and the related WHO Global Leprosy Strategy.

ILEP remains an acknowledged voice for leprosy within WHO global and regional meetings, the WHO NTDs department, and the Global Leprosy Programme.

At country level, ILEP members work closely with governments and other partners to advise on and model active case-finding and contact-tracing programmes. In some places, ILEP members supplement the work of governments by running case detection activities, especially in hard-to-reach areas. Several member associations are working with governments to implement and evaluate the efficacy of post-exposure prophylaxis programmes as a contribution to leprosy prevention.

During the first half year, ILEP was deeply concerned with ongoing stock-outs of multidrug therapy, posing a major threat to patient wellbeing. Our survey painted a bleak picture, and our advocacy resulted in a summit meeting with Novartis, the WHO supply team, patient representatives and other stakeholders.

Subsequently, ILEP stayed very alert to any indications of supply problems and followed up promptly with WHO. The situation has markedly improved. Towards the end of the year, we undertook a further survey on availability of prednisolone, a vital drug for managing leprosy reactions.

Most ILEP members continued to invest in research during 2021, although some research projects were delayed during the pandemic. Some members invested through dedicated research facilities, specific long-term research projects, or operational research. Some provided grants into the pooled research budgets that enabled the Leprosy Research Initiative to invest around €1.4 million in research projects each year.

In October, the Members' Assembly adopted ILEP's 2021-2025 Strategy. Addressing two of the key challenges around zero transmission, we intend to implement a global strategy to build and sustain leprosy capacity; and to work on initiatives towards more accurate new case data and the establishment of effective surveillance systems for leprosy integrated with other relevant health conditions.



1

CASE STUDY: Banashankari's story

Banashankari's story starts at age 22. She hails from Padarayanpura, a densely populated, mainly Muslim suburb Bangalore, India, which shot to prominence as a Covid-19 hotspot.

Banashankari was pregnant and in her third trimester. She went, as usual, for her regular antenatal check to her nearest government health centre. After the routine examination, which seemed to be very normal, she casually asked the Medical Officer about a few red patches on her face. The doctor examined these lesions and diagnosed leprosy, or Hansen's disease. Overloaded with Covid-19 responsibilities, the doctor did not have confidence even to initiate the routine multi-drug therapy (MDT), as she was in late pregnancy. So she called SJJ, a local partner organisation of ILEP member Fontilles, for expert opinion and further management.

It turned out that Banashankari had been living with a form of leprosy reaction which had gone a long time unnoticed. In spite of the Covid-19 lockdown and movement restrictions, SJJ was able to intervene and initiate the crucial reaction treatment for Banashankari. This course of treatment has helped reduce the risk of impairment or prolonged illness, as so often associated with leprosy reactions.

Banashankari's husband is a small time mechanic. The government-imposed Covid lockdown greatly impacted his business and therefore their lives. They were at this time isolated, with no friends and relatives coming to comfort and support them.

It was a relief for Banashankari that this prompt intervention by SJJ ensured her appropriate treatment and other follow up support, and especially that that she was saved from developing any visible disability.

Relief for Banashankari and her family as accurate diagnosis, treatment and support has avoided the risk of prolonged illness or disability.

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**Our mission
is to work
together to
stop leprosy,
to prevent
disability
and break the
stigma resulting
from leprosy**



Due to the Covid-19 pandemic, we may experience a surge in new patients already with physical damage to hands, feet and eyes, with potentially life-long consequences.

2

STRATEGIC GOAL: **Preventing Disabilities from Leprosy** **– Towards Zero Disability**

How things are

In line with the WHO Global Leprosy Strategy 2021-2030, many countries are investing in active case-finding and other measures aimed at interrupting transmission of the disease.

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.

The bacteria that cause leprosy attack nerve endings, reducing a person's ability to feel pain and avoid injury. Nerves controlling muscles can also be damaged, leading to weakness and paralysis of hands and feet, and sometimes to blindness. The body's immune response can also cause damage through inflammatory reactions that are notoriously difficult to treat and can result in very severe pain along with sickness and swelling. Changes to the skin also leave the person susceptible to ulcers, which if left untreated, can cause visible disfigurements. These consequences of leprosy represent a very high cost to individuals, families and communities, and are thought to affect the lives of at least 3-4 million people alive today.

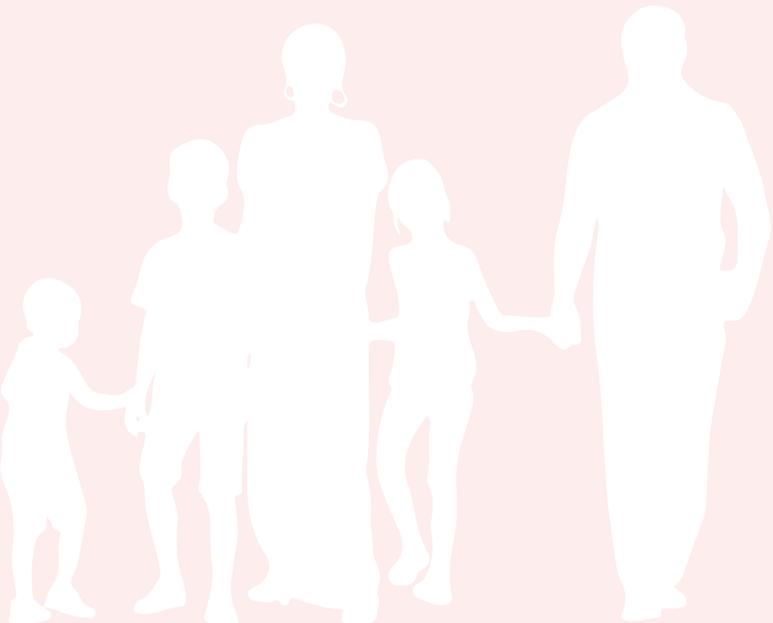
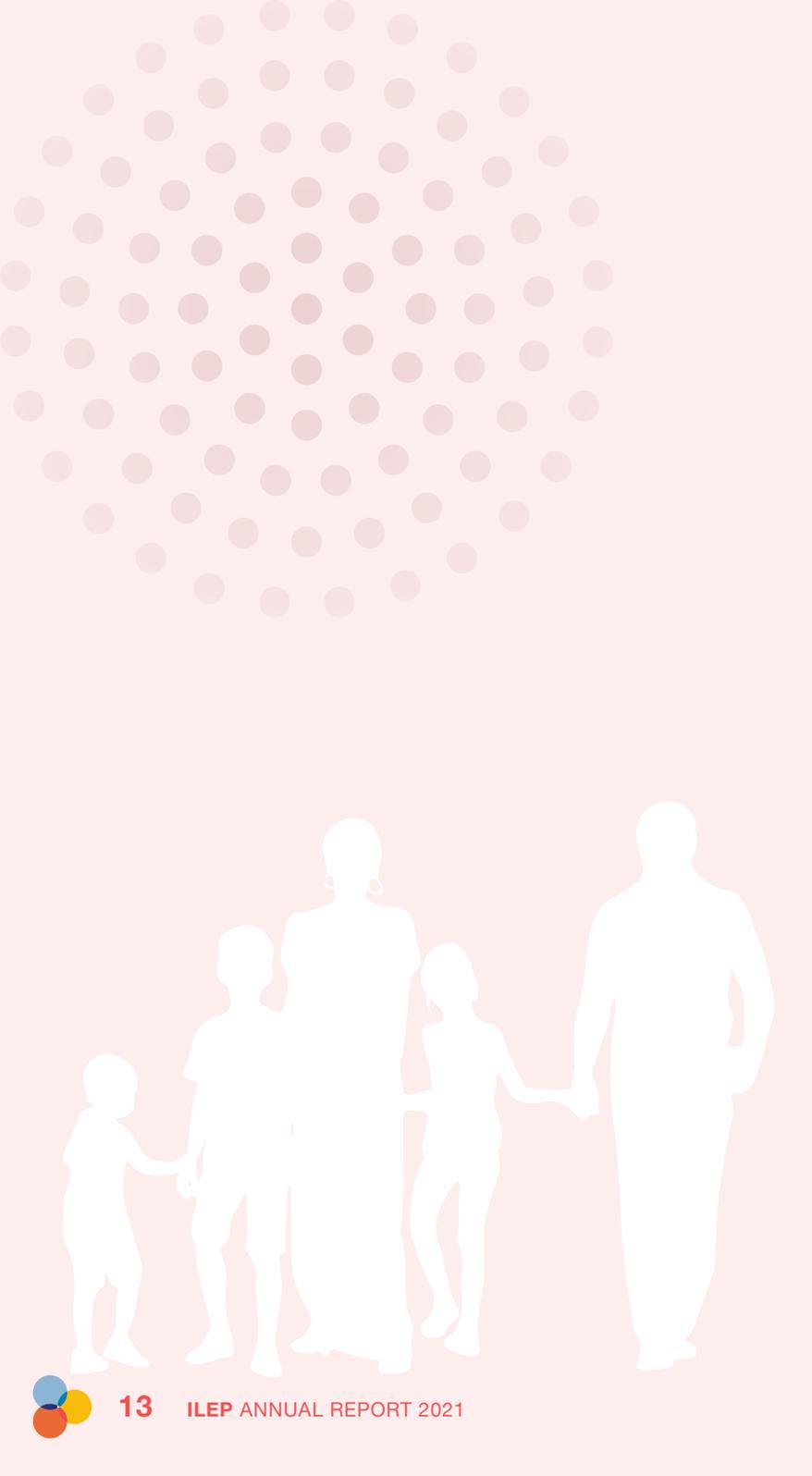
The WHO Global Leprosy Strategy emphasises the need for ready access to comprehensive, well-organised referral facilities where these consequences can be managed, and where patients can be encouraged and supported into self-care habits and lifestyle modifications designed to prevent further injury. It also stresses attention to the mental wellbeing of patients. But in many countries, these services are not easily accessible by the people that need them, and the skills to test for nerve function impairment and for loss of sensation – key indicators of risk – are sporadic.

Even where these services are available, they have not operated to capacity during 2021 due to the Covid-19 pandemic, and we may experience a surge in new patients already with physical damage to hands, feet and eyes, with potentially life-long consequences.

How we are working for positive change

Several ILEP Members are involved in the provision or support of leprosy referral services, such as specialist hospitals, in endemic countries. Typically, these facilities can manage reactions, offer wound care, deal with complications such as damage to the eye, supply footwear or other assistive devices along with training and advice on self-care, and offer reconstructive surgery with associated physiotherapy services.





ILEP members are often involved in helping persons at risk, and their family members, to know about the signs of possible nerve damage and to do what is needed to reduce injuries and protect limbs and eyes. In some countries, ILEP members support the formation of self-care groups in the community, which include people suffering not only from leprosy but also from other conditions needing self-care. ILEP members also support people to develop new livelihoods if the risk of physical damage means that their previous work cannot continue. Self-help groups of people affected by leprosy, and sometimes other marginalised people, can have a powerful effect in encouraging solidarity and also enabling new livelihoods through small savings and loan schemes.

Aware of how a diagnosis of leprosy, and the experience of stigmatisation, can damage people's mental wellbeing, ILEP members also advocate for the provision of basic psychological first aid at points of care, and referral services to address mental health needs.

In keeping with this key goal in ILEP's 2021-2025 strategy, we intend to scale up this advocacy and strive to normalise the use in national training programmes of ILEP's published Guides on Stigma and Mental Wellbeing.

At the international level, ILEP again engaged in 2021 with the UN Committee on the Rights of Persons with Disabilities (CRPD) which recognises that leprosy falls under its mandate. Although the Committee's work slowed during the year due to the pandemic, ILEP made submissions on the impact of Covid-19 on people affected by leprosy, and on protecting their right to work. ILEP members participated in the Global Disability Summit and ILEP took the opportunity to lodge its own statement of commitments to the rights of persons experiencing disability through leprosy.

2

CASE STUDY: Joaquina's story



Joaquina, from Mozambique, first started noticing the symptoms of leprosy many years ago. She didn't know anything about leprosy and the disease spread quickly enough for her to lose her fingers before it was diagnosed.

Her neighbours in the village responded badly to Joaquina's symptoms. She was told she was not wanted and was forced to live on the edge of the village. People wouldn't speak to her or respond when she addressed them. Thankfully, her husband stayed with her, in circumstances when many husbands may have left.

But over time, the stigmatising attitudes in her village have disappeared as ILEP member The Leprosy Mission (TLM) provided community education and raised awareness of the disease. The TLM team also diagnosed Joaquina's leprosy and provided her with multidrug therapy (MDT), the cure for leprosy. Tragically, Joaquina's husband died shortly after this and she was left to raise their eight children on her own. Her only source of income was farming.

Entrepreneurial farmer Joaquina, who has turned her life around following the experience of social rejection after a diagnosis of leprosy.

© Ricardo Franco

This was particularly difficult for Joaquina because the disabilities caused by leprosy made it much harder to work in the field.

Her life changed for the better when she joined TLM's Farming School. She learnt sustainable farming methods, which have made a big difference in the yield and quality of her produce.

She also joined the savings and loans group, which encourages farmers to save some of their income and gives micro-loans to members in need. Through this she has been able to save money for the first time in her life, and to hire workers to help her with the farming. This is important because it is becoming more and more difficult to work in the field due to her age and disability. Through this, Joaquina hopes to live a comfortable, semi-retired life as well as providing jobs for local people.

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National organisations representing persons affected by leprosy are an empowered force for change, in challenging stigmatising attitudes and defending human rights.

3

STRATEGIC GOAL:

Promoting Inclusion of People affected by Leprosy – Towards Zero Discrimination

How things are

Negative, sometimes hateful, community attitudes can be the most troubling and the most disabling consequences of leprosy. The constant exclusions that people affected by leprosy face in the daily business of living result in poverty, dehumanisation, mental torture, despair, even suicide. This is the reality for up to 5 million women, men and children today.

One symptom of the prevalence of stigmatising attitudes is the presence of discriminatory laws. More than 20 countries keep such laws in force against persons affected by leprosy, and it is an ongoing challenge to get them amended or repealed. Organisations that represent persons affected by leprosy are active in some, but by no means all, endemic countries, meaning that people have limited influence over policies and decisions that affect their lives.

In theory there are protections against discrimination. The WHO Global Leprosy Strategy 2021-2030 strongly emphasises the United Nations *Principles and Guidelines for the elimination of discrimination against persons affected by leprosy and their family members*, an excellent guide for governments on how to

assure the human rights of persons affected by leprosy. But in order to have effect, they need to be incorporated into countries' general human rights protection frameworks.

How we are working for positive change

During the year, ILEP adopted a Statement of Commitment to the participation of persons affected by leprosy. The statement, shown on the next page, commits ILEP and its members to enable people affected by leprosy to participate in a wide range of organisational processes and decisions.

We plan in 2022 to develop a tool to assess our performance against these commitments.

We also reported on findings from a three-year project, funded by the Leprosy Research Initiative, on building resilience in individuals and families affected by leprosy.

National organisations representing persons affected by leprosy are an empowered force for change, challenging stigmatising attitudes and defending human rights.





During 2021, ILEP collaborated with IDEA International in a global survey to identify countries where no national body adequately reflects the voice of persons affected by leprosy. The ILEP Advisory Panel is beginning a series of consultations with national organisations that represent people affected by leprosy, as one way of ensuring that ILEP is informed by a wider range of perspectives.

ILEP continued to support the mandate of Alice Cruz, the UN Special Rapporteur on the elimination of discrimination against persons affected by leprosy and their family members. Practical aspects of support included providing information and evidence for her reports to the Human Rights Council and the UN General Assembly. In 2021, these reports were respectively about the disproportionate effect of Covid-19 on people affected by leprosy, and on the urgent need to repeal discriminatory legislation wherever it exists. ILEP continued to catalogue discriminatory legislation in all countries.

At year-end, 130 laws remained in place, unchanged from a year earlier. ILEP's 2025 goal, to see the number of these repugnant laws halved, presents as a major challenge.

ILEP was pleased to support organisations of persons with disabilities, including persons affected by leprosy, to prepare and lodge submissions on their country's human rights record. In 2021, organisations in Papua New Guinea and Timor Leste produced reports to the Universal Periodic Review, a function of the UN Human Rights Council. ILEP also reported to the Council on the need for a whole-of-government approach to ending anti-leprosy discrimination in healthcare, education and employment. These reports and statements contribute to keeping the reality of leprosy on the radar of the United Nations, and complement advocacy by ILEP members in-country to bring human rights abuses to an end.



3 CASE STUDY: Surya's story

At ten years old, Surya loved playing cricket with his friends and learning in school. But, unknown to him or his family, Surya also had early symptoms of leprosy. Although his mother had leprosy five years before, they didn't recognise the signs of the disease in Surya.

Fortunately Akkivarapu Ardilakshmi saw the early symptoms in Surya, and she knew what to do. Akkivarapu is a community resource person with the women-led WASH project supported by ILEP member American Leprosy Missions.

Villages like Surya's have limited resources for safe water, sanitation and hygiene (WASH).

Community resource persons help their neighbours understand sanitation and hygiene practices to reduce disease, and at the same time they look for signs of illness so people can seek medical care. When Akkivarapu was in Surya's village, she recognized his symptoms as leprosy and referred him for treatment.

Surya has completed the six month multi-drug therapy (MDT) treatment to cure leprosy. Because he started treatment promptly, he won't suffer any long-term effects, like disability, from the disease. Thanks to Akkivarapu, Surya's family are also making changes in their daily lives: they boil water before they drink it, wash their hands before preparing food, and clean their home differently. Taking these steps keeps Surya's family safer from disease.

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Community resource person Akkivarapu Ardilakshmi suspected leprosy and had no hesitation in bringing Surya to the local health centre for confirmed diagnosis.
© Tom Bradley



ILEP statement of commitment to the participation of persons affected by leprosy

The involvement of communities and persons affected is not a new concept in primary health care and disease programs. Human rights-based approaches to NTDs, including leprosy, emphasise that any interventions should be based on the principles of participation, non-discrimination and accountability. WHO has issued specific Guidelines for strengthening participation of persons affected by leprosy in leprosy services. However, the active participation of persons affected by leprosy is not always a reality.

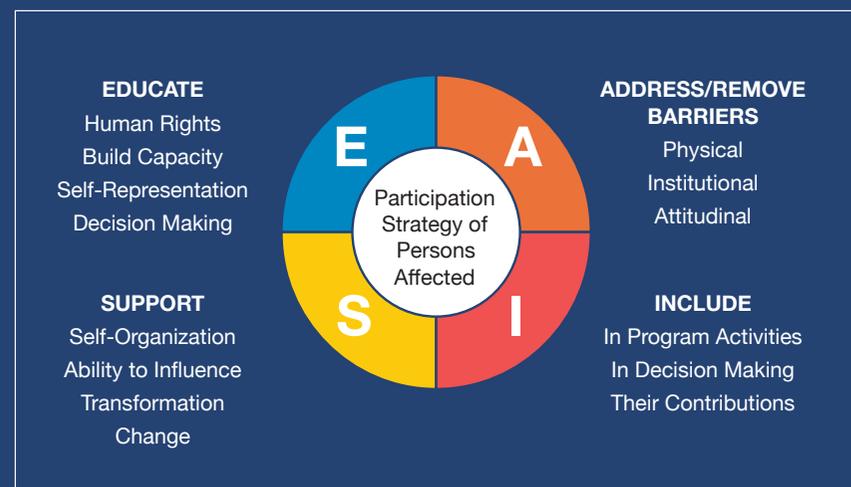
THE EASI STRATEGY

Engaging persons affected by leprosy is essential to the success of leprosy programs. Having experienced the disease, disability and associated discrimination, they have a unique voice and perspective, they bring passion to the work and take the programs closer to the communities they are designed to benefit. ILEP and its Members adopt the EASI strategy to ensure that persons affected by leprosy have the space and the support for meaningful and effective participation.

ILEP COMMITMENT

In relation to the EASI strategy, and within their sphere of influence, ILEP and its Member associations commit to work towards the following outcomes:

- **Policy-making:** Persons affected by leprosy are supported to participate in the development, monitoring and evaluation of leprosy-related policies, guidelines and preferred practices at all levels.
- **Programs:** Persons affected by leprosy systematically participate in all stages of leprosy programs from planning, to implementation, monitoring and evaluation. Their knowledge, skills, experience and connections are valued in these roles.
- **Leadership, networking and sharing:** Persons affected by leprosy are supported to take on leadership roles in self-care groups, support groups and other relevant local, national and international networks; to seek resources and build local capacity; to encourage participation of new members; and to share their experience with others.
- **Advocacy:** Persons affected by leprosy actively participate in advocacy for participation of persons affected, human rights, the removal of all discriminatory laws, regulations and practices and universal access to quality services that are fully integrated into strengthened local health systems.
- **Public representation:** Persons affected by leprosy are supported to actively participate at local, regional and global fora and to become spokespersons in leprosy and related campaigns or speakers at public events.
- **Research:** Persons affected by leprosy are supported to participate in the planning and execution of leprosy-related research.
- **Gender:** Specific attention is paid to ensuring equal participation by women affected by leprosy in each of these actions.





ILEP continues to focus on the stigma surrounding leprosy



FINANCIAL HIGHLIGHTS 2021

The income and expenditure highlights on this page are in Swiss francs (CHF). The audited financial reports are available on request.

	2021	2020
Staff costs	95,253	183,859
Services from third parties	107,201	89,449
Rent, maintenance and insurance	3,891	8,209
Administrative expenses	12,085	14,663
Comms and IT expenses	10,091	12,217
Travel and meeting costs	-417	21,560
Financial expenses and Taxes	-2,500	4,121
Total Expenditure	CHF 225,604	CHF 334,078
Membership contributions	298,519	342,887
Reimbursements and other income	0	2,474
Total income	CHF 298,519	CHF 345,361
Financial result	CHF 72,915	CHF 11,283

In addition, ILEP Members contributed CHF 305,515 (2020; CHF 289,013) towards the operation of the Global Partnership for Zero Leprosy.

ILEP MEMBERS

ILEP is a consortium of international non-government organisations (NGOs) with a shared desire to see an end to leprosy, and an acknowledgment that none of us can achieve this on our own.

Through mutual collaboration and partnership with others, we will achieve our ultimate goal of a world free from leprosy.

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





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