



## **For a World without Leprosy: Remaining Challenges and What is Needed Now?**

### **Background:**

For ILEP, the last decade has seen the re-establishment of official relations with WHO; collaboration on two WHO (World Health Organisation) Global Leprosy Strategies and their Operational Guidelines; guidelines for improving participation of persons affected; increased synergy and collaboration with those working in CBR (Community Based Rehabilitation) and the disability movement; increasing human rights based approaches to leprosy and inclusive development; and support for organisations of persons affected. Major international legal instruments exist and are vital tools for promoting advocacy.

The key leprosy stakeholders remain in place - WHO, ILEP, the Nippon Foundation and the WHO's Goodwill Ambassador for Leprosy Elimination, the Novartis Foundation for Sustainable Development (NFSD); key, motivated national programme managers in the major endemic countries, academia and research institutions and, perhaps most importantly, national and international networks of persons affected.

It is well understood by all stakeholders working in leprosy that there will be new cases of leprosy beyond 2020 and that there will continue to be a need for residual morbidity management, prevention of disability work and stigma reduction efforts for the foreseeable future. Implementation of new evidence on early case detection contact management could reduce the incidence of leprosy but it is recognised that there will continue to be a need for further research and development of new tools to break the transmission of leprosy.

Continuing, and even closer, collaboration among key leprosy stakeholders is the first essential track to ILEP's preferred approach to addressing the remaining challenges in leprosy. But a disease-specific, single-track approach is no longer enough and indeed would only serve to marginalise even further the efforts to achieve a world without leprosy. In ILEP's view, a multi-tracked, multi-sectoral approach is required.

Of all the global health trends in the last decade, perhaps the highest profile has been the growing interest and involvement in Neglected Tropical Diseases (NTDs). The inclusion of leprosy in this grouping of neglected diseases presents important opportunities. There has been a rapid growth of collaborative networks of key stakeholders involved in NTDs and there have been positive initiatives taken to bring these key players together through events such as the London Declaration and WHO regional plans to promote integrated approaches to NTDs. ILEP and its members have begun to play an increasingly active role in national and international networks of NGOs and others working in the NTD field and have clearly voiced the importance of coming together on the many cross cutting issues encountered, particularly in relation to the promotion of more patient-centred intensive disease management, morbidity management and prevention of disability, inclusive, rights-based approaches and the reduction of stigma and discrimination.

## **What is needed now?**

With this background, and an apparent plateau of around 250,000 new cases of leprosy reported each year, ILEP perceives the time to be right to take firm action to address the remaining challenges. One possible approach would be to bring the key stakeholders in leprosy work together to discuss the potential synergies and collaborations that can address the so called 'Last Mile' and bring about interruption of transmission and the ending of leprosy and its consequences. It will be important to consult with all stakeholders to determine their differing perspectives on what they see as their particular 'unfinished agendas' and to engage them in an open and frank discussion about what needs to be prioritised if we are to genuinely achieve a world without leprosy. Part of this consultation and discussion will necessarily have to focus on what form a new collaborative initiative might take. It would have to acknowledge the continuing needs in leprosy, the comparative advantages of the different groups that are involved, and the desire to carry out collaborative efforts in an efficient and effective way, with clear roles and accountabilities.

The expected outcome of this proposed 'overture' discussion with key stakeholders would be a revitalized global, collaborative alliance to end leprosy and its consequences. A proposed stakeholder dialogue, perhaps in a 'Chatham House Rule' setting\*, would provide for an open exchange of views on policy, strategy, operational matters and best practices. It could create sub-groups and review particular issues. Collaborators will have to work in open, collegial and inclusive ways. Achieving our common goal of a world without leprosy depends on such collaborative approaches.

## **What is ILEP's position and focus?**

ILEP's three priority challenges (which are also key cross-cutting themes with other Neglected Tropical Diseases) are how to achieve and build upon:

- 1. Innovative and Intensive Disease Management**
- 2. Research & Development**
- 3. Advocacy and Rights**

### **1. Innovative and Intensive Disease Management**

ILEP considers as priority, the promotion of collaborative approaches to:

- Sustainable Control
- Morbidity management and Prevention of Disability
- Community Based Rehabilitation
- Stigma reduction
- Advocacy with persons affected
- Accessing funding

ILEP and its Members currently support work to help make leprosy control sustainable. Our aspirational goal remains the elimination of leprosy (interruption of transmission) and as signatories of the London Declaration we remain committed to achieving progress towards this by 2020. ILEP shares the view of the WHO Technical Advisory Group and WHO 8<sup>th</sup> Expert Committee that leprosy is not an eradicable disease.

ILEP, in line with the WHO Enhanced Global Strategy, pushes for quality interventions with measurable targets focused on reducing disability. The targets associated with this are as follows: to reduce by 35% the rate of new cases with

grade 2 disabilities per million population by 2015 from a base line at the end of 2010 and to reduce the rate of new patients with disability due to leprosy to one per million by 2020 at a global level.

## **2. Research and Development**

ILEP promotes and supports leprosy related research and has developed a Five Year Research Strategy in which the leprosy research themes are as follows:

1. Prevention of leprosy
2. Early detection
3. Chemotherapy
4. Nerve function impairment and reactions
5. Prevention of disability
6. Community Based Rehabilitation
7. Stigma reduction and advocacy
8. Health and social care integration

ILEP Members are already supporting high quality research initiatives in a number of these fields. These include the ongoing surveillance of drug resistance and relapses, vaccine and diagnostic test development, improving prevention of nerve damage and reducing stigma and discrimination.

A recent ILEP Temporary Expert Group has identified as a priority focus, the development of a Contact Centred Strategy to Reduce Leprosy Transmission - see work-package at:

[http://www.ilep.org.uk/fileadmin/uploads/Documents/ILEP\\_RESEARCH/New\\_leprosy\\_contact\\_centered\\_strategy\\_February\\_2013 .pdf](http://www.ilep.org.uk/fileadmin/uploads/Documents/ILEP_RESEARCH/New_leprosy_contact_centered_strategy_February_2013.pdf). This strategy recognises that breaking the transmission of leprosy will require new tools and ILEP is therefore particularly interested in developing and implementing such tools as chemoprophylaxis.

## **3. Advocacy and Human Rights**

People affected by leprosy have the same human rights as all people. Inclusive, rights-based development refers to the participation of *all* stakeholders in development processes. This includes those affected by leprosy.

International legal instruments exist which have a direct relevance to leprosy work. ILEP's rights-based approach to leprosy work means utilizing the full range of instruments such as the UN Convention on the Rights of persons with Disabilities and the UN Resolution on Elimination of discrimination against persons affected by Leprosy and their families

ILEP supports persons affected by leprosy, the community, health providers and governments to work as partners in a positive and open relationship with a view to improving leprosy related care and enhancing the effectiveness of the diagnosis, treatment and rehabilitation process. This allows for all parties to be held more accountable to each other, fostering mutual interaction and a positive partnership.

ILEP believes that specific advocacy for the reduction of stigma and discrimination and promotion of legislative reform will be particularly important. But the overarching need is for the promotion of broader collaboration between those who are marginalized, disabled or oppressed, including those affected by leprosy, in order to

promote the rights of *all*. Initiatives focusing *only* on the human rights of those affected by leprosy will risk failure and their advocates will themselves continue to be marginalized and excluded from the development process unless a more inclusive and universal rights-based approach is taken.

## **Conclusions**

Within these core areas ILEP believes that renewed global, collaborative efforts are required but that partnerships will need to be flexible and creative if we are to find new ways to reach our goal of a world without leprosy. ILEP is actively searching for synergies with other partners and with other diseases where there are similar needs for innovative and intensive disease management. ILEP advocates for local solutions and for collaboration with governments, local partners and donors to find such synergies.

In 2003 the Evaluation report of the Global Alliance for the Elimination of Leprosy was published. The evaluation panel recommended that NGOs and foundations involved in leprosy take the lead in organising a collaborators' forum and that this should be maintained continuously in a virtual manner with various collaborators meeting physically as needed. This recommendation is still as valid today as it was in 2003.

We need to find new and innovative ways to work together so that we can complete the Last Mile together.

Doug Soutar  
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\* <http://www.chathamhouse.org/about-us/chathamhouserule>