**How to fight against stigma and discrimination**

ILEP CEO’s speech, Bergen International Conference on Hansen’s disease, June 2023

As I begin, I want to express appreciation to Alice Cruz, not only for what she has presented to us today, but for the deep understandings, insights and challenges that she has brought to ILEP and ILEP members over the past six years as Special Rapporteur. Alice, every time I’ve heard you speak has been a mind-opening experience. I salute you.

The question before us is how to fight stigma and discrimination, and I want to bring to this the perspective mainly of ILEP and its members, who work either directly or through partners in around 60 endemic countries. How can ILEP members and other NGOs participate in the fight against stigma and discrimination? I’m going to briefly suggest six ways in which we can contribute to this goal.

First, NGOs need to insist on, and train their staff in a people-centred approach. We all know that early diagnosis and prompt MDT treatment are essential: we want to reduce the risk of nerve damage and disability, we want to keep patients safe. But a person-centred approach requires so much more, thinking about the wider issues that the person is likely to face especially in stigmatizing societies. Restrictions or exclusion as regards jobs and livelihoods, education, participation in social and religious life, loss of friendships, rejection by family. The list of risks to the individual is very long and if we are taking just a disease-centred approach, we are not meeting the person’s needs. Indeed there’s the very real risk that health personnel will tell the patient ‘now you’ve completed your course of treatment, you’re cured!’ whereas in reality the person’s only just beginning to experience the multiplicity of damaging physical and psychosocial consequences that leprosy is bringing to their life and the life of their family.

Second, and very much related, is to encourage all front-line staff to develop listening skills, which are the essence of basic counselling. My wife, who is a professional counsellor, has often repeated that we don’t need everyone to become a trained counsellor but we do need everyone to become a good listener. More than any other skill, good listening initiates positive change for the individual. Very often in healthcare settings, no one asks the person how they’re feeling: everyone just tells them what to do. That whole mindset has to change. Good listening empowers people to understand and manage their own situation, including experiences of discrimination and social exclusion, and helps people to build the resilience to better cope with the changes that leprosy is bringing into their lives.

The third thing that the NGOs can do is to support the birth and development of civil society organisations that represent persons affected by leprosy. We all ought to know by now that by far the most effective advocates are people affected by leprosy, or Hansen’s disease, speaking for themselves. Artur will be sharing in a moment some of the remarkable things that Morhan has been doing in that regard. Organisations like self-help and self-care groups are needed at the local and community level: the evidence is clear that these groups have a tremendously empowering effect for persons affected by leprosy. But also, we need organisations of persons affected by leprosy operating at regional and national level, through which they can raise their voice among the holders of power and the decision-makers. Taka has been describing the important contribution Sasakawa Health Foundation has made to enabling some of these organisations to develop and thrive. One of our strategy groups in ILEP, along with the ILEP Panel of persons affected by leprosy, is also focusing on how all ILEP members can do better in this regard, recognizing that the majority of endemic countries don’t yet have any credible national organization of people with direct experience of leprosy.

My fourth observation is that empowered organisations are usually connected with empowered individuals. So it’s relevant for ILEP members and other NGOs to be identifying and supporting leadership development among persons affected by leprosy, including especially among future women leaders. Some ILEP members, for example, have supported the efforts of organizations like IDEA International in developing what we might describe as leprosy champions who may, in due time, become leaders of local or regional or national organisations. One ILEP member association has focused particularly on what it terms ‘mental motivators’ especially associated with community based groups. Mental motivators can support people who have indicated they would like someone to talk to, and also actively find group members who are becoming withdrawn, quiet or upset, all tell-tale signs that a mental health issue may also be part of their condition.

In addition to that, the fifth thing NGOs can do is themselves to be actively involved in advocacy and education. I am especially thinking about advocacy at country and local level. We need to continue to press governments and other stakeholders to see leprosy not just as a disease to be cured, but as a human rights issue. As well, we need to be prepared to respond to examples of stigma, discrimination and abuse of rights as and where they occur. To be effective in this we need to make sure that discrimination and social inclusion are on the agenda in all training and capacity development activity, and that all staff and partners have an understanding of these issues. In planning stigma reduction interventions, NGOs need to be thoughtful about the sources and levels of stigma in the community or environment, so that it’s clear what or whom they are targeting. Then, focus on the desired outcomes, what change in ideas, attitudes and behaviour we want to see, who or what needs to be influenced to make this change happen, and who are our allies in this process, especially people affected by leprosy themselves.

Finally, a brief word about the important place for international-level advocacy. This is another area in which NGOs can amplify the voice of persons affected by leprosy in combatting stigma and discrimination, and influencing States to ensure that their rights are upheld and assured. ILEP maintains a global database of laws and regulations that discriminate against persons affected by leprosy, but of course international-level advocacy needs to go a long way beyond that, advocating for countries to act on instances of structural discrimination and to put in place the sorts of frameworks and provisions that the Special Rapporteur has been urging during the past six years.

**What is preventing the elimination of discriminatory leprosy laws around the world? Is it the attitude of governments or the public’s awareness? What are your thoughts on this**?

**ILEP response to panel question**

I respect that others, like the Special Rapporteur, have pondered this issue in greater depth than I have done. But I want to offer three ideas on this.

First, leprosy and discrimination associated with leprosy are not a priority for most governments. In those situations, it takes a great deal of energy and lobbying from *within the system* to produce legislative change. By ‘within the system’ what do I mean? Firstly the work of the courts: strong statements by the Indian Supreme Court are a good example, which resulted in action at central level but, so far, not at state level. Secondly, action by concerned parliamentarians: Bangladesh is a good example, where one Member of Parliament persistently argued for the repeal of an old, discriminatory law and was eventually successful in it. Third, action by organisations of persons affected by leprosy, whether through quiet advocacy with policymakers or indeed though very vocal advocacy in the public space.

Second, many of the discriminatory laws and regulations are very old. In India, which has the majority of discriminatory laws, most were passed in colonial times. Many of these laws are not being actively put into effect and so the attitudes of governments may well be ‘these are redundant laws, they’re not being applied, and so there’s no urgency to repeal them’. But ILEP completely rejects that point of view. For one thing, under the CRPD Convention, States have an obligation to repeal or amend discriminatory laws, and the age of the law is irrelevant. Another point is that many people affected by leprosy suffer daily discrimination at community level, and it’s completely anathema to have that discrimination legitimised by legislation. And, we simply don’t know when and if a regime may dust off and use old legislation in ways that are hostile to persons affected by leprosy.

Finally, I do think that public awareness is a factor. Very often, people are amazed to find that these laws actually exist in their country. So I want to make the point again that where organisations of persons affected by leprosy exist, and are empowered, and are able to raise their voice and obtain the ear of duty-bearers and media and religious and community leaders and the general public, awareness can be raised and people can be convicted by the need for change.