



ILEP CEO's speech to advocacy workshop Kathmandu, Nepal: 12 September 2022

Mr Chairman, Honourable Minister of Law and Justice, distinguished guests, colleagues and friends

The 14 member associations of the International Federation of Anti-Leprosy Associations or ILEP, four of which are working here in Nepal, are all committed to a world free from leprosy. By this we mean a world with not only zero transmission of leprosy, but also zero leprosy disability, zero leprosy-related discrimination, zero social exclusion. I am honoured to be invited to bring an international perspective to the issue that we are examining today.

I expect that everyone in the room knows that stigmatisation against people affected by leprosy is a very ancient problem, that remains very real and current today. WHO estimates that 3-4 million people are living with visible impairments from leprosy, especially damage to hands, feet and eyes. But this is only part of the story. For thousands of years, as a result of traditional beliefs and practices and some religious teachings, the word leprosy – and comparable words like *kushtarog* in Nepali – have brought feelings of fear and revulsion. There is no medical justification for this fear and prejudice: it is a social invention based on harmful stereotypes. But it is real. This label of leprosy is associated with the abuse and violation of countless women, men and children – around 5 million of them alive today.

This stigmatisation is not just found at community level. It remains institutionalized. Around fifty countries keep discriminatory laws in force against persons affected by leprosy. There are laws aimed at segregating people who have experienced leprosy. There are laws restricting their employment, laws restricting their immigration, laws related to marriage and divorce like here in Nepal, laws related to public transport, and the right to vote, and more. Some of these laws and regulations are very old, but they are on the statutes of the nation, and people know that these laws can be used against them. Other laws are more recent.

All of these laws are offensive because they're based on the mistaken idea that leprosy is to be feared and somehow isolated. The Nepali public is repeatedly, and correctly, told that leprosy is curable and not to be feared. But this law gives the opposite message to the Nepali people. It tells them that people affected by leprosy need to be excluded and are unfit to be marriage partners. This message is wrong, and it needs to be changed.

Nepal is a signatory to the United Nations Convention on the Rights of Persons with Disabilities, or the CRPD. The Convention lays certain obligations on all signatory countries. I want to bring three of these obligations to your attention today. The first, in Article 4 of the Convention, is the obligation to modify or abolish existing laws and regulations, customs and practices that constitute discrimination against persons with disabilities, including people affected by leprosy. The second, Article 5, is the obligation to prohibit all discrimination on the basis of disability, and to guarantee to persons with disabilities (including leprosy) effective legal protection against discrimination. The third, Article 6, is to recognize that women and girls with disabilities, including those affected by leprosy, are subject to multiple discrimination – women are disproportionately affected by marriage-related discrimination, for example. The obligation is to take particular measures to ensure that they enjoy all human rights and fundamental freedoms. It is important for the government to consider its CRPD obligations as regards to the marriage law that we are discussing today.

The successes in India in recent years, in advocating for the repeal of laws that discriminate against persons affected by leprosy, have often involved multiple parties: the courts, the Law Commission, the national human rights institutions, activists representing the community affected by leprosy, the NGOs, parliamentarians and others. I mention also the repeal, some years ago, of the so-called Lepers Act in Bangladesh that discriminated against people affected by leprosy there. The repeal of that law was championed by a Member of Parliament who saw the deep injustice in it, and I'm pleased to say that he was successful in demonstrating that injustice and denial of rights, and successfully brought a bill to repeal the law.

To conclude, I urge the relevant duty-bearers present, to recognize and acknowledge the harm that is done to the citizens of Nepal – men, women and children – by this section of the marriage law and to work towards its amendment.

At the same time, it is important to recognize that discriminatory laws and regulations are simply the most visible shape of underlying stigmatizing and discriminatory attitudes in society. For that reason, alongside the amendment to the law, I urge you to consult with persons affected by leprosy, through their representative organizations, especially IDEA Nepal, to identify other areas of ongoing discrimination and denial of rights in daily life. And then, to take such actions as are needed to enable people affected by leprosy to play a full part in Nepali society without exclusion, restriction or discrimination. Thank you.