

ENDING DISCRIMINATION AGAINST PERSONS AFFECTED BY LEPROSY IN MEXICO

Submitted for the consideration of the 12TH Pre-Session of the CRPD Committee

Submitted by:

International Federation of Anti Leprosy Associations (ILEP)

(The submission may be posted on the OHCHR website)

This submission is made by the International Federation of Anti-Leprosy Associations (ILEP), a federation of 13 member associations working in leprosy-related activities in 69 countries. Its goal is zero leprosy, including zero stigma and discrimination against persons affected by leprosy and their family members. Persons affected by leprosy¹ play a significant role in organisational decisions through the operation of a high-profile Advisory Panel.

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1. Leprosy is a relatively low-endemic disease in Mexico with 377 persons under treatment at the end of 2017. This is down from more than 16,000 in 1989, when the current treatment regime was adopted. It is estimated that, over the years since 1989, more than 25,000 persons have been cured of leprosy. It is projected that between 5,000 and 10,000 are living live with disabilities due to leprosy, a figure that tends to increase over time due to the consequences of nerve damage, and an unknown number suffer from exclusion, stigmatisation and societal barriers to participation as a result of harmful stereotypes related to the label 'leprosy'. Stigma and discrimination affect not only individuals with personal experience of leprosy but also their family members.
2. Leprosy detection and treatment are well managed in Mexico. However, people affected by leprosy may experience difficulties in accessing general healthcare (not specifically related to leprosy) because of stigmatising attitudes in the community and misconceptions of leprosy among healthcare staff. **In accordance with Article 25, the government is asked to ensure that healthcare staff are provided accurate information about leprosy and that persons affected by leprosy are never denied health care or health services on the basis of having experienced leprosy.**

¹ Persons with personal experience of leprosy prefer this descriptive term. The alternative term 'persons with leprosy' is rejected as being more descriptive of persons currently suffering from the disease, rather than its consequential effects in terms of disability, stigma and discrimination.

3. The disabling effects of leprosy are progressive and may require access to rehabilitation services throughout the lifespan. **In accordance with Articles 19 and 26, the government is asked to ensure that persons affected by leprosy are enabled to access government rehabilitation service centres other programs for persons with disabilities, and that these programs focus not just on physical aspects but on the broader issues of social inclusion. The government is also asked to take particular note of the issues faced by persons affected by leprosy in considering national policies to promote quality of life and personal autonomy for persons with disabilities.**
4. In the distant past, leprosaria were established in Mexico to segregate persons suffering from the disease from the rest of the population. Although segregation is not government policy, a combination of poverty, fear, self-stigma and lack of awareness can perpetuate the isolation of people who have experienced leprosy. Because of ignorance and fear of social exclusion, persons affected by leprosy may be kept hidden by family members or compelled to live apart from other members of the community. **In accordance with Article 8, the government is asked to specify actions to ensure access to social services and support for persons affected by leprosy and to take strong affirmative action to build awareness and change negative community attitudes about leprosy. Because women and girls affected by leprosy face harsher discrimination than males, special attention should be given to protection of the rights of women and girls.**
5. There is no registry or monitoring in Mexico of persons with physical or sensory impairments resulting from leprosy. After the completion of the drug treatment regimen, patients are discharged without further follow-up or surveillance, even though the nature of the disease means that, in most cases, there is the risk of progressive impairment and consequential disabling. **In accordance with Article 31, the government is asked to consider implementing follow-up and surveillance for those released from treatment who either have impairments due to leprosy or are considered at risk of developing impairments.**
6. The social stigma about leprosy, medical complications such as ulceration and leprosy reactions, and the long-term disabling effects of the disease all combine to have negative effects on the livelihoods of individuals affected by leprosy and their families. Leprosy is closely associated with poverty. **In accordance with Article 27, the Government is asked to give attention to enhancing socioeconomic opportunities for persons with disabilities, including persons affected by leprosy.**
7. The UN Principles and Guidelines for the elimination of discrimination against persons affected by leprosy and their family members were adopted by the Human Rights Council in 2010. They broadly mirror the CRPD and provide a valuable roadmap for countries seeking to reduce anti-leprosy stigma and promote the human rights of persons affected by leprosy. **The Committee is asked to urge the Mexican government to implement the Principles and Guidelines as a significant contribution to enabling persons affected by leprosy to live with dignity.**