

ENDING DISCRIMINATION AGAINST PERSONS AFFECTED BY LEPROSY IN BOLIVARIAN REPUBLIC OF VENEZUELA

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 Venezuela with 840 persons under treatment at the end of 2017. It is estimated that, over the years since adoption of the current treatment regimen, more than 30,000 persons have been cured of leprosy. It is estimated that up to 10,000 continue to live with disabilities due to leprosy and that as many as double this number have no visible physical impairments but are also suffering from exclusion, stigmatisation and societal barriers to participation as a result of harmful stereotypes related to the label 'leprosy'. These persons fall within the category of 'disabled' in the Persons with Disabilities Act. Stigma and discrimination affect not only individuals with personal experience of leprosy but also their family members.
2. 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, within the implementation of the Health Care for Persons with Disabilities Programme, 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.**
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**

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.

ensure that persons affected by leprosy are enabled to access the government's network of rehabilitation service centres and community committees 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 the design and implementation of the forthcoming national policy to promote quality of life and personal autonomy for persons with disabilities.

4. In past days, leprosy colonies were established in Venezuela 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, and in forming its national strategic plan for an inclusive society, the government is asked to specify actions to ensure access to social protection 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. Stigmatisation within the community may result from the existence of physical impairments caused by leprosy or from harmful stereotypes related to the label 'leprosy'. Stigmatisation leads to social exclusion which is disabling to persons affected by leprosy and their family members. Many persons with leprosy related disabilities are not receiving the benefits that are provided by national disability legislation. **In accordance with Articles 19 and 28, the government is asked to ensure that persons affected by leprosy are entitled to the same monthly allowances and other forms of government assistance as are other persons with disabilities.**
6. Because of old fears about leprosy, many countries retain on their statute books discriminatory legislation about leprosy even if those laws are not actively enforced. Laws may also use the terminology 'leper' which is labelling and therefore deeply offensive to persons affected by leprosy. **In accordance with Article 5, the government is asked to take steps to ensure that any legislation containing discriminatory provisions is amended or repealed.**
7. 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.**
8. 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 Venezuelan government to implement the Principles and Guidelines as a significant contribution to enabling persons affected by leprosy to live with dignity.**