

ENDING DISCRIMINATION AGAINST PERSONS AFFECTED BY LEPROSY IN MYANMAR

Submitted for the consideration of the 22nd 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. Organisations of persons with disabilities took a lead in submissions for the List of Issues during the pre-session. This further submission is made by ILEP on behalf of stakeholders.

Website: www.ilepfederation.org. Email officer@ilepfederation.org. Phone +41 22 940 3412

1. Leprosy remains endemic in Myanmar. Over the years since adoption of the current treatment regimen, the Government estimates that around 300,000 persons have been cured of leprosy. It is estimated that 100,000 continue to live in the community with disabilities due to leprosy. At least double this number have no visible physical impairments but are suffering from exclusion, stigmatisation and societal barriers to participation as a result of harmful stereotypes related to the label 'leprosy'. This stigma and discrimination affect not only individuals with personal experience of leprosy but also their family members.

2. The Nay Pyi Daw Declaration was endorsed by Government, World Health Organisation, NGOs and other disability stakeholders in 2018 at the Myanmar National Conference on Leprosy: To eliminate stigma and discrimination against persons affected by leprosy. The Declaration expresses a shared commitment to change the negative images of leprosy in the community and to eliminate stigma as well as discrimination against persons affected by leprosy and their family members. Further, it pledges to ensure appropriate implementation of the UN Principles and Guidelines for the elimination of discrimination against persons affected by leprosy and their family members (A/HRC/15/30) and to promote inclusion and empowerment of leprosy affected persons and their family members through systemic collaboration among related Ministries, UN Agencies and the private sector. **In accordance**

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.

with Article 5, the government is asked, in consultation with NGO and DPO stakeholders and WHO, to adopt and implement an action plan to put this declaration into effect.

3. Rehabilitation and habilitation services for persons with disabilities, including persons affected by leprosy, are available in a small number of specialised centres. The size of the country makes these centres inaccessible for most persons. **In accordance with Article 19, the government is asked to take measures to provide community-based rehabilitation programs that are accessible from where people live, including rural and remote areas, and to ensure that these programs focus not just on physical aspects but on the broader issues of social inclusion.**

4. Many persons affected by leprosy continue to live in leprosy colonies. Although segregation is no longer enforced as in the past, a combination of poverty, fear, self-stigma and lack of awareness perpetuates the isolation of the colonies. Moreover, because of ignorance and fear of social exclusion, persons affected by leprosy are often kept hidden by family members or are compelled to live apart from other members of the community. **In accordance with Article 8, the government is asked to take action 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. Myanmar Association of Persons Affected by Leprosy (MAPAL) was formed in 2018 as a nationally representative body for persons affected by leprosy. Members of MAPAL are key participants within leprosy awareness campaigns and other mechanisms of public education. **In accordance with Articles 4 and 33, the government is asked to consult with and actively involve MAPAL, along with other organisations of persons with disabilities, in the design and implementation of actions to implement its obligations under the CRPD.**

6. The City of Rangoon Municipal Act 1922 contains discriminatory provisions, especially in s.25, which allow the Municipal Corporation to establish segregated 'asylums' for persons affected by leprosy to whom 'pauper lepers' can be sent. The terminology 'leper' and the provisions for 'asylums' are deeply offensive for persons affected by leprosy. There are also other discriminatory provisions in this Act. **In accordance with Article 5, the government is asked to take urgent steps to amend the discriminatory provisions in this Act, and to review other legislation to ensure that any discriminatory provisions are amended or repealed.**

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 Government of Myanmar, in line with its pledges in the Nay Pyi Daw Declaration of 2018, to implement the Principles and Guidelines as a significant contribution to enabling persons affected by leprosy to live with dignity.**