

ENDING DISCRIMINATION AGAINST CHILDREN FROM FAMILIES AFFECTED BY LEPROSY IN VIETNAM

**Submitted for the consideration of the 87th Pre-Session of the
Committee on the Rights of the Child**

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 low-endemic disease in Vietnam. In 2018, the most recent World Health Organization reporting period, there were only 96 reported new cases of leprosy, and no child cases were included. It is unclear whether the disease surveillance system is robust enough to provide total assurance of no child cases, but the consistency of the data is good evidence that active leprosy disease is steadily disappearing in Vietnam. This may be attributed to good public health systems, reduced poverty and better awareness of the disease.
2. However, disease incidence is not the whole story with leprosy. Thousands of Vietnamese people continue to live with visible impairments and deformities caused by leprosy, and they are still subject to abhorrence, social stigma and exclusion. Moreover, although integrated community care has been the model for treatment for some decades, many people who were treated for leprosy in past years continue to live in the leprosaria. These were institutions set up specifically for leprosy patients more than a century ago, when it was believed (wrongly) that segregation was necessary to protect public health. That official policy persisted until the second half of the 20th century, and in the mind of the general public, the segregationist attitudes behind the policy exist to this day.

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. Several of the leprosaria which continue to operate today can accommodate up to 1,000 people or more than 100 households, others between 400 and 700 people. Unlike in earlier days, there are no state-enforced barriers to entry and exit. But history, poverty, fear of the reactions of others, and internalized stigma all combine to the effect that people affected by leprosy continue to live in and adjacent to the leprosaria – as do their family members. Children who have never had the disease, but who are sons, daughters and grandchildren of leprosy-affected people, live inside the premises of the leprosaria with their parents and/or grandparents.
4. At school, once it is known where these children live, and once it is understood or assumed that they are from families with leprosy, other school children will not make friends with them anymore. Educators or teachers pay less attention to them because of stigmatizing attitudes as regards their leprosy background – even though these children have never experienced the disease themselves. Their parents and grandparents also have little interaction with teachers: they rarely leave the leprosaria, partly because their disabilities make it difficult for them to move or travel, and partly because of their own internalized stigma – the sense of personal loss of worth and dignity that results from leprosy. As a result, the majority of children from these leprosy-affected families have a very low level of education. Often, children from leprosy-affected families go on to attend vocational training programs and work as hired workers in industrial zones.
5. After school hours, these children often play with each other inside the leprosaria premises rather than outside with other children, both because of the social exclusion that they experience from other children and because the leprosaria are isolated from residential areas. When they reach marriageable age, usually they will get married to those who are also from leprosy-affected families, as stigma and discrimination around the label ‘leprosy’ make it difficult for them to get married to outsiders. Once married, they usually live nearby their workplace but, once they have children, many of them send back their children to the grandparents as caregivers. This is a regular practice in Vietnamese society, but when the grandparents live in leprosaria, it is a recipe for stigma even for the younger generation.
6. There is compelling research and anecdotal evidence from many countries that the harmful stereotypes and wrongful stereotyping, which result in the issues described in the previous paragraphs, impact severely on the mental health, well-being and enjoyment of citizenship by children affected by leprosy.
7. In view of the above, we make the following recommendations.
8. First, **in accordance with Article 28, the government is asked:**
 - a. **to specify and mandate actions that will ensure that school policies remove all barriers to education experienced by children from leprosy-affected families;**
 - b. **to ensure that schools promote a correct understanding of leprosy through behavior change and awareness activities at school assemblies and school events, and through school curricula, contests and competitions to boost awareness and eliminate stigma and exclusion; and**
 - c. **to take steps to ensure that teachers and educators are provided accurate information about leprosy so that children from leprosy-affected backgrounds are never denied school education or vocational training on the basis of having family connections with leprosy.**

9. **Second, in accordance with Article 31, the government is asked to regulate to make local authorities responsible for increasing participation and presence of children from leprosy affected families in communities, including in creative events and activities such as Children's Day, Mid-Autumn festivals, and sport competitions. This aims to increase interaction and socialization with children from non-leprosy affected families so that they can understand each other better, thus reducing and eliminating discriminatory attitudes and enabling children from leprosy affected communities to participate fully in cultural and artistic life and in recreational and leisure activities.**

10. **Third, in accordance with Articles 28 and 39, the government is asked:**
 - a. **to ensure that psychological counselling and recovery facilities are offered to enable the social integration of children who are victims of the stigmatizing attitudes particularly in the education system**
 - b. **to ensure that special educational assistance is offered to those children who have achieved, or are achieving, an unduly low level of educational attainment that may be attributable to stigmatizing attitudes within the education system.**

11. **Fourth, in accordance with Article 23, the government is asked to take active steps to promote the rights and entitlements of children from families affected by leprosy to a full and decent life and active participation in school and in the wider community and society, and to actively endorse policies and programs to reduce stigma and discrimination against these groups in Vietnamese society.**

12. **Fifth, because a number of leprosaria remain in Vietnam, and because a combination of poverty, fear, internalized stigma and lack of awareness perpetuates the isolation of these leprosaria, in accordance with Article 2, the government is asked to specify action to ensure access to social protection and support for persons affected by leprosy within the leprosaria and adjacent villages, and to take strong affirmative action to build awareness and change negative community attitudes about leprosy.**

13. **Finally, 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 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 Vietnam government to implement the Principles and Guidelines as a significant contribution to enabling persons affected by leprosy to live with dignity.**