



**Universal Periodic Review, Myanmar, 2020  
UN Human Rights Council**

**Submission by The Leprosy Mission Myanmar and the International Federation of  
Anti-Leprosy Associations (ILEP) in collaboration with the Myanmar Association of  
Persons Affected by Leprosy (MAPAL)**

**1. The Leprosy Mission Myanmar**

We are an organisation that works across Myanmar to support people affected by leprosy. We are a part of the larger Global Fellowship of The Leprosy Mission, which has nearly 150 years of experience in tackling leprosy across the globe. Our work in Myanmar includes close collaboration with MAPAL (The Myanmar Association of Persons Affected by Leprosy) and sees us support awareness raising, healthcare intervention, and disability care amongst many other things. The details in our submission are based upon the experiences of people affected by leprosy and people with disabilities in Myanmar over the last four years. This is our first submission to the Universal Periodic Review.

**2. Background**

The issue of leprosy has never been mentioned in the reports of the Universal Periodic Review for Myanmar, but it is an issue that requires attention. As this submission demonstrates, people affected by leprosy in Myanmar are amongst the most marginalised in the country. They regularly face discrimination and are denied access to their human rights. WHO data suggests that there have been between 2,000 and 3,000 people diagnosed with leprosy within Myanmar each year since the last Universal Periodic Review of this country.<sup>1</sup>

These recent figures do not include the many thousands of people who were diagnosed with leprosy in years gone by and are still living with the consequences, which include disability, physical impairments, mental health problems, and social isolation. Estimates by the National Leprosy Control Programme suggest that by 2008 there were 274,277 people who had been released from treatment and since then around 26,000 have been released from treatment. Amongst these persons, it is estimated that at least 30 percent (upwards of 90,000) suffer from disabilities due to leprosy, mostly related to functional loss of eyes, hands, and feet. This population of 90,000 people living with leprosy-related disabilities is out of a total population of around 2.3 million people with disabilities meaning that around 1 in 24 people with disabilities in Myanmar are persons affected by leprosy.

Leprosy is a mildly infectious disease that 95 percent of the world population is immune to. Only 1 in 10 people affected by leprosy is infectious and after 72 hours of

the appropriate treatment, they stop being infectious. To catch the disease requires one of the 1 in 10 infectious people to be in close and prolonged proximity to the 5% of the world population that isn't immune. Despite this, there remains substantial stigma and fear surrounding people affected by leprosy in Myanmar.

Because of this prevailing stigma, leprosy is far more than a disease; it has become, in Myanmar and elsewhere across the world, a profound human rights issue. As this submission demonstrates, a leprosy diagnosis often means that a person will have their human rights stolen from them.

### **3. Participation in social and cultural life**

People affected by leprosy face such stigma and discrimination that they are afraid to take part in everyday activities. When MAPAL meetings take place, the people who attend that are affected by leprosy will refuse to attend restaurants after the meetings. This is because they are worried that the physical consequences of leprosy (clawed hand, drop foot, amongst others) will mark them out as people affected by leprosy and so they will be refused access to the restaurant. Ahead of the World Leprosy Day celebrations in Mandalay on 29 January 2020, a group of people affected by leprosy ate at a restaurant. Even though they had not been infectious for years (because they had undergone the correct treatment) they were told that their plates would be thrown away after they had eaten so that they would not pass on the infection, they were moved to a corner of the restaurant, were treated as beggars and told that they should not pay for their food, but should eat quickly and leave.

Another group of people affected by leprosy was refused access to a hostel in Yangon until they produced a certificate to prove that they are no longer infectious. In another incident, a hotel owner shouted at the manager who accepted a delegation of MAPAL members to the hotel because he was afraid this would turn away other customers.

Meanwhile, on a flight from Yangon to Geneva to attend a session of the CRPD Committee, a person affected by leprosy was asked to move seats on three separate occasions because the other passengers did not want to sit next to him. We have also received much anecdotal evidence of people affected by leprosy being refused access to public transport as a result of their visible disabilities. Many people affected by leprosy will do whatever they can to cover up those signs of physical disability so that they can access public transport uninhibited.

#### **Recommendation**

We recommend that the Government of Myanmar take steps to increase public knowledge surrounding leprosy. Schools, businesses, and public transportation networks should be provided with factual information about the disease. Furthermore, people affected by leprosy should receive opportunities for representation in public awareness campaigns. The Government of Myanmar should also use its social media channels to raise awareness of leprosy as a curable disease and to correct stigmatising attitudes.

#### **4. Access to healthcare**

According to the aforementioned WHO data, around 10 per cent of people in Myanmar who were diagnosed with leprosy in 2018 were also diagnosed with Grade 2 Disability as a consequence, meaning they already showed signs of physical damage to their hands/feet/eyes due to leprosy at the time of their leprosy diagnosis. This indicates that people affected by leprosy are not receiving treatment fast enough. Leprosy is a curable disease, but if the treatment is not administered fast enough, the person affected is at risk of developing disabilities as a result.

Our experience in Myanmar is that leprosy knowledge is not mainstreamed within healthcare provision. This means that doctors do not recognise the symptoms of leprosy when they see them, and so patients are not being placed on the appropriate treatment fast enough. Furthermore, there is insufficient leprosy expertise within the country so that treatment is not available to people affected by leprosy who require delicate ulcer care and reconstructive surgery.

##### *Recommendation:*

The Government of Myanmar should improve leprosy knowledge within the healthcare community so that people affected by leprosy can receive early identification and intervention as appropriate to treat leprosy and prevent the subsequent disabilities. Doctors should be provided with the appropriate literature on leprosy so that they can recognise the disease and arrange for the appropriate treatment. Further, the Government should provide funding for the training of medical professionals so that they can perform specialised treatments, such as the treatment of ulcers or reconstructive surgery. This medical training would not just benefit people affected by leprosy, but also people with diabetes, neuropathic conditions and other disfigurements.

#### **5. Access to education**

Our experience in Myanmar is that children affected by leprosy and the children of adults affected by leprosy face many difficulties in accessing education, particularly primary education. Their experience is linked closely to people with disabilities, a community within Myanmar with whom we also have close ties.

Many children with personal experience of leprosy and disability are rejected from schools because the school fears that they will not be able to integrate with the other pupils and/or because the school does not have the appropriate facilities to allow a person with disabilities to access their buildings. Like with restaurants and public transport, children affected by leprosy have also faced rejection from schools because of the fear and stigma that surrounds leprosy in Myanmar.

##### *Recommendation*

The Government of Myanmar should ensure that no person affected by leprosy and no person with disabilities should be turned away from the education system of Myanmar. Where school facilities are not sufficient to allow access to buildings, the

Government should make the appropriate funding available so that accessibility requirements can be met.

## 6. Legal discrimination

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.<sup>ii</sup>

### Recommendation

We recommend that the Government of Myanmar immediately repeal the discriminatory provisions in *City of Rangoon Municipal Act 1922* and repeal or amend all legislation at the union or state level, and any subordinate legislation, that discriminates specifically against people affected by leprosy.

## 7. Final recommendations

The Nay Pyi Daw Declaration was endorsed by the Government of Myanmar, the WHO, NGOs, and other disability stakeholders in 2018 at the Myanmar National Conference on Leprosy. It called for the elimination of stigma and discrimination against persons affected by leprosy, expressing a desire for a shared commitment to changing the negative images of leprosy in the community. It pledged to ensure appropriate implementation of the UN *Principles and Guidelines for the Elimination of Discrimination Against Persons Affected by Leprosy and their Family Members* (below) and promote inclusion and empowerment of leprosy affected persons and their family members through systemic collaboration among related Ministries, UN Agencies, and the private sector. We encourage the Government of Myanmar to continue the excellent momentum that they began by signing the Nay Pyi Daw Declaration through implementing its provisions.

Following this the Government of Myanmar should take steps to implement the United Nations’ *Principles and Guidelines for the Elimination of Discrimination Against Persons Affected by Leprosy and their Family Members* throughout the country. Alongside this, the Government should set up the committee recommended within Principles and Guidelines. This committee will be responsible for ensuring the Government has implemented the Principles and Guidelines. People affected by leprosy should be well represented on any such committee.

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<sup>i</sup> <https://apps.who.int/iris/bitstream/handle/10665/326775/WER9435-36-en-fr.pdf?ua=1>

<sup>ii</sup> [https://www.mlis.gov.mm/lsSc.do?menuInfo=2\\_1\\_2&query=lepers](https://www.mlis.gov.mm/lsSc.do?menuInfo=2_1_2&query=lepers)