

Submission by The International Federation of Anti-Leprosy Associations (ILEP)

53rd Session of the UN Human Rights Council
*Interactive dialogue with the Special Rapporteur on the elimination of
discrimination against persons affected by leprosy and their family members*

The International Federation of Anti-Leprosy Associations (ILEP) is a consortium of 14 international non-governmental organizations working in 63 countries towards zero transmission of leprosy, zero leprosy-related disability, and zero stigma and discrimination.

ILEP welcomes the report to the 53rd session of the Human Rights Council by the Special Rapporteur on the elimination of discrimination against persons affected by leprosy and their family members.

Discrimination in leprosy

UN General Assembly resolution 65/215 (2010), on the elimination of leprosy-related discrimination, recognised the centuries-old but ongoing reality of discrimination, stigmatisation and denial of human rights of persons affected by leprosy and their family members.

Around 200,000 people worldwide are diagnosed with leprosy, also known as Hansen's disease, each year. The vast majority will be treated and experience no complications from the disease. Yet, for most people, the mere diagnosis causes fear. Persons affected by leprosy still face multiple forms of discrimination in their households and communities, stemming from age-old religious and ideological beliefs, cultural practices and misconceptions. Family members, especially children, also find themselves victims of stigmatising attitudes with potentially severe effects in terms of depression and mental illness, loss of livelihoods and consequential poverty.

Negative social attitudes are aggravated by laws and regulations that discriminate against persons affected by leprosy. 130 such laws are known to be in force in 23 countries. Despite the fact that these laws contravene international human rights conventions such as the CRPD Convention, progress on repeal or amendment is slow. Even in countries with a legal framework that should protect their rights, persons affected by leprosy continues to experience inequality, especially in the areas of adequate standard of living, inclusion in the community, elimination of stereotypes, and empowerment of particularly vulnerable groups.

Impact of the Special Rapporteur's mandate

Resolution 65/215 referenced the UN Principles and Guidelines for the elimination of discrimination against persons affected by leprosy and their family members. These provide States with a road map that would help guarantee access to human rights by persons affected by leprosy. However, States have generally not responded with the sorts of actions envisaged in the Principles and Guidelines to safeguard such access. One response to this inaction, warmly welcomed by ILEP, was the establishment in 2017 of the Special Rapporteur's mandate, and then its renewal in 2020.

The Special Rapporteur's current report provides an excellent retrospective reflection on the achievements of her mandate. From the perspective of the international NGOs that are members of ILEP, we highlight the following significant impacts of the mandate during the past six years.

Mainstreaming of leprosy within the UN human rights system

From the outset, the mandate has had a steadily growing impact in sensitising UN Member States, and the committees and instruments of the OHCHR, to the vital importance of addressing leprosy-related issues from a human rights perspective. The High Commissioner for Human Rights has publicly stated that there is no medical justification for anti-leprosy prejudice, describing it as a social invention. The CRPD Committee has acknowledged that, because the very label of leprosy is stigmatising, the disease is intrinsically disabling. Country reports by the CRPD Committee, and by the Human Rights Council through the UPR mechanism, have begun to include recommendations to States to combat leprosy-related discrimination, which was seldom mentioned previously.

Adoption of a gender approach to leprosy-related discrimination

The Special Rapporteur's 2019 report to the Human Rights Council focused on the dehumanising effect of harmful stereotypes and structural violence against women and children affected by leprosy. It thus established a new framework for evidence on discrimination on the grounds of leprosy. The report also offered recommendations for the recognition and enforcement of the rights of women and children. By giving voice and visibility to women affected by leprosy, the report crucially introduced the gender approach to the fight against leprosy-related discrimination.

Country visits

During the six years of the mandate to date, the Special Rapporteur has made, and reported on, country visits to Brazil, Japan, Angola and Bangladesh. Her reports have offered these States constructive recommendations for sustaining and improving ongoing efforts and achieving systemic change, in order to prevent discrimination and safeguard the rights of persons affected by leprosy and their family members. The visits have been extremely empowering for organisations of persons affected by leprosy in each of these countries, and have provided the foundation for ongoing political engagement.

Exposure of discriminatory laws and regulations

The Special Rapporteur's 2021 report A/76/148 to the UN General Assembly identified the laws and regulations that discriminate against persons affected by leprosy, noting their roots in biomedical misconceptions about the disease. By formalising harmful stereotypes as lawful labels and by normalising humiliating regulations as authorised practices, these laws and regulations significantly compromise livelihoods and contribute to the exclusion of people who have experienced leprosy from social and civic participation. The report's constructive recommendations for eliminating discriminatory laws, customs and practices, and combatting the immediate consequences of ongoing discrimination in law, remain an essential pillar for organisations and individuals challenging these laws through the courts and other mechanisms.

Framework for legal protections

The Special Rapporteur's 2022 report A/77/139 to the General Assembly, echoing elements of her 2020 report to the Human Rights Council, showed that many countries maintain a solely medicalised approach in their regulations as regards disability and leprosy. Even in countries with regulatory frameworks in line with the social model of disability and the CRPD Convention, forms of systemic discrimination continue to prevent people knowing their rights and gaining full access to them. The report urged States to improve access to information, to health and rehabilitation services, to decent work and employment, to social protections, and to justice and effective remedies. NGOs and civil society organisations are able to use these recommendations as a framework for their own supportive, ongoing advocacy.

Building back better from the Covid-19 pandemic

The Special Rapporteur's 2021 report to the Human Rights Council described how persons affected by leprosy were experiencing a disproportionate impact of the crisis generated by the pandemic. The principles she cited, around building back better, are pertinent not only to leprosy but to other health issues that are associated with social exclusion. Examples include ensuring continuous access to leprosy health-care; expanding the scope of national leprosy programmes to include targeted action on the social determinants of leprosy; social protection policies that guarantee full accessibility to persons affected by leprosy; and building up grassroots organisations of persons affected by leprosy, as a way of ensuring that relevant information about pandemics and other emergencies reaches all people.

Empowerment of organisations of persons affected by leprosy

During the past six years, the Special Rapporteur's mandate has progressively empowered individuals and organisations of persons affected by leprosy, worldwide. International NGOs working in leprosy applaud the stronger voice during these years of civil society organisations representing people affected by leprosy in their own countries and, increasingly, internationally. Some national organisations are now engaging directly with the UN human rights mechanisms, for example through reports to the CRPD Committee and the Universal Periodic Review.

Ongoing challenges

The Special Rapporteur's report rightly states that, despite progress including the achievements listed above, persons affected by leprosy continue to experience discrimination in law and in practice. Section IV of her report constitutes a lamentably long list of ongoing challenges. Discriminatory laws remain in force. Institutionalised discrimination persists in education, healthcare and social services. Remedies and reparations are not awarded to persons whose rights were violated by State-mandated segregation. Large numbers of persons living in 'leprosy colonies' lack basic property rights and face risk of eviction. Multiple intersecting barriers prevent people affected by leprosy from accessing work, health care, education and social protection on an equal basis with others. People affected by leprosy could add to and exemplify this list through myriad examples of exclusion, lack of access, and denial of rights.

In view of these continuing challenges, ILEP echoes the Special Rapporteur's reference to general comment No. 6 of the CRPD Committee. To combat such deep-rooted attitudinal barriers as we see related to leprosy, States must take positive measures not only to prevent discrimination, but also to tackle it directly through specific measures aimed at accelerating or achieving de facto equality, non-discrimination, dignity and integrity. ILEP welcomes the Special Rapporteur's recommendations to States as a well-stated summary of essential actions to address, and bring redress to, centuries of dehumanisation and denial of rights.

Finally, ILEP expresses its heartfelt appreciation to the Special Rapporteur for all that she has undertaken in the past six years. Furthermore, ILEP takes the opportunity to remind States parties that, although there has been commendable progress in terms of the expectations when the mandate was established, much remains to be done.