

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

50th Session of the Human Rights Council

Interactive dialogue with the Special Rapporteur on the elimination of discrimination against persons affected by leprosy and their family members

ILEP strongly supports the Special Rapporteur's report and recommendations.

National leprosy programs typically equate cure with the completion of a course of treatment. But people who have experienced leprosy point to a different reality: ongoing leprosy reactions, a lifelong risk of disabilities caused by nerve damage, and the cruel reality of stigmatisation and social exclusion. Yet the health system classifies them as 'treatment completed' and often fails to provide the physical and mental health and disability services that they need to live a healthy life.

A new narrative is needed: a people-centred approach in which those who have experienced leprosy are active participants in interpreting the right to health from their perspective. As the research shows, this perspective is typically around what it means to enjoy opportunities in life on an equal basis with others, without discrimination and violence, accessing the health-related services that they need, when they need them.

ILEP supports the Special Rapporteur's call for national consultative committees that enable people affected by leprosy to be at the centre and to articulate what the right to healthy lives really means for them: access to ongoing services that tackle the physical and mental complications of leprosy, and to activities that ensure their human rights are respected. We join her in calling on Member States to adopt country-owned political agendas that not only combat leprosy as a disease, but equally protect, promote and fulfil the rights of people affected by leprosy to the highest attainable standard of physical and mental health.