

Statement by International Federation of Anti-Leprosy Associations (ILEP) RC73 Agenda item 8.2: Monitoring progress on UHC and health-related SDGs

“The moment the pandemic hit, the principles of ‘leave no one behind’ and ‘reach the furthest behind’ evaporated into thin air”.

Persons affected by leprosy are consistently among the most left behind. Their health, livelihoods, community participation and physical and mental wellbeing are negatively affected not only by the physically disabling effects of leprosy but, even more, by stigmatising and discriminatory attitudes to the disease. The 2030 Agenda for Sustainable Development calls for special attention to those most left behind. Yet leprosy affected individuals and families, already facing social exclusion, poverty and poor health outcomes, have now been deeply impacted by the crisis generated by the COVID-19 pandemic. Such realities threaten achievement of UHC and especially SDG-3.

A working group of the Global Partnership for Zero Leprosy, of which the International Federation of Anti-Leprosy Associations (ILEP) is a founding partner, gathered the perspectives of persons affected by leprosy, in many countries, on their needs and challenges during the COVID-19 health crisis. The working group found that some major concerns were consistently being talked about:

- access to health care
- access to basic goods like food, clean water and soap
- access to government support
- access to stable livelihoods
- access to information about COVID-19
- leprosy-related vulnerability made worse by age, gender, stigma, degree of physical impairment, and mental health issues

Regarding these country experiences and lessons learned, ILEP recommends that governments:

- Support grassroots organizations of persons affected by leprosy and liaise with them to not only share information about COVID-19 solutions and resources, but also develop strategies for improving health outcomes and fostering social inclusion for those most left behind.
- Give due consideration to the social determinants of leprosy in the design of responses to the crisis and future delivery of services, in order to ensure access to healthcare. Barriers to be considered include lack of transportation to healthcare services, lack of income, and dependency on third party authorisation in the case of women.

Regarding transition to the ‘new normal’, ILEP recommends urgent action by WHO and Ministries of Health to work with national leprosy programme managers on how to safely and effectively deliver the services needed by persons affected by leprosy in order to work towards the goal of Universal Health Coverage. These include prompt diagnosis and treatment, contact tracing, active case-finding in hotspot areas, management of complications, surgical programmes, effective self-care, provision of assistive devices and referral to community-based rehabilitation programmes. ILEP recommends that Ministries consider innovative approaches to ensure ongoing access to the continuum of care during the pandemic, including:

- Increasing the use of digital technology in leprosy control activities, especially in hard-to-reach places or areas of low endemicity where workforce capacity is low.
- Increasing use of mobile phones for diagnosis, advice on ulcer care and complications, and other forms of follow-up including counselling for mental wellbeing of patients.
- Engaging family members to take an active role, including examining household contacts.