

## Oral statement by International Federation of Anti-Leprosy Associations (ILEP) CRPD Committee opening session, March 2021

Mr President

Persons affected by leprosy are among the most left behind. This is because of the savage combination of the physically disabling effects of leprosy plus discriminatory attitudes to the disease. Leprosy affected individuals and families, who were already facing social exclusion, poverty and poor health outcomes, have been deeply impacted by the crisis generated by the pandemic. We collaborated in a survey of organisations of persons affected by leprosy in 15 countries to hear their main concerns around Covid-19. They told us:

- about limited access to healthcare. In some countries, the number of newly registered patients has fallen by 60%, meaning large numbers of people remain untreated and at greater risk of disability. Also, the drugs to treat leprosy were sometimes not available.
- about social protection services like food aid and income support often not reaching persons affected by leprosy due to stigmatisation, transportation issues or information gaps.
- about difficulty obtaining basic goods like food, clean water and soap for handwashing.
- about loss of livelihoods. Persons affected by leprosy often work in the informal economy and are especially vulnerable to economic instability.
- and about limited access to information about the pandemic, due to travel restrictions, geography, or illiteracy.

Even more significant was how Covid-19 worsened the pre-existing intersections between leprosy and other forms of vulnerability. I'll give six examples:

- Age. Many people affected by leprosy are elderly and at higher risk of Covid infection. But we found that in some countries older people do not have identity cards, so they are not eligible for government food aid. Also, older people often have less access to telehealth resources.
- Gender. Many women affected by leprosy said that the burdens of health protection, education and maintenance of family life fell heavily on them during this crisis. This became even worse when livelihoods were lost and supportive care services were disrupted.
- Clean water. In some communities, families affected by leprosy already had limited access to clean water because of poverty or stigmatisation, and this was made worse during the crisis.
- Stigma. Persons affected by leprosy already faced extreme health-related stigma, and as a result they often received less health and social assistance than others. Where this intersected with increasing stigma against people affected by Covid-19, it was even more difficult to get assistance.
- Mental health. People who have had leprosy have deep personal experience of quarantining, isolation, loneliness, lost livelihoods, and fear of transmission. Some of the people surveyed described the trauma of reliving their experience of being isolated because of leprosy.
- Finally, isolation. Some governments increased the isolation of leprosy settlements or colonies to keep them insulated from Covid-19. This did protect vulnerable residents, but it also impacted mental wellbeing. Also, settlements are supported by a patchwork of aid from government, NGOs and private donors, so it is unclear whether all needs are being met.

These issues highlight the particular vulnerability of persons affected by leprosy during the pandemic. The pandemic has not only led to new challenges for them, but it has also compounded these other issues that they had already been facing, often due to stigma and discrimination. Many

problems are still under-documented, such as long-term effects on mental well-being of isolation and these intersecting vulnerabilities. All of this raises key issues to be addressed by governments, NGOs and inter-governmental agencies. Attention must shift to building stronger social safety nets that will support persons affected by leprosy and other vulnerable populations.

Thank you