

ILEP statement SHF-DPI side event

Thank you for the invitation to participate on the panel discussion for this important topic.

ILEP's thirteen member associations work in 60 countries for the benefit of persons affected by leprosy. Our experience is that, everywhere, people affected by leprosy are among those most left behind, because of the savage combination of the physically disabling effects of leprosy plus discriminatory attitudes to the disease. These individuals and families have been deeply impacted by the *additional, compounding* crisis generated by Covid-19.

I will focus on the challenge around loss of livelihoods. Generally, people affected by leprosy are poor, sometimes extremely poor, and engaged in the low-paid, fragile, informal economy. The reasons for this are inter-related. Children from a leprosy background find that fear, discrimination and hatred, directed at them, are a powerful barrier to education. The result is low literacy. Combine this with pre-existing poverty and stigmatization by employers, and the result is easy to imagine. Employment opportunities are scarce. When times get difficult, such as during Covid lock-downs, people with disabilities including those with leprosy are among the first to be retrenched. So they find themselves in unreliable casual labour with low incomes, unsafe working conditions, no social protection or entitlements, and the risk that their work may be terminated at any time.

How can supporting organisations work with governments to change this picture – to promote the financial independence of people affected by leprosy so that they are not even more left behind? I suggest six interlocking approaches, all of which require action by governments, supported by action by the NGOs and civil society organisations.

First, discriminatory laws. Of 130 known discriminatory laws worldwide, 25 relate to leprosy and typically bar persons affected by leprosy from obtaining work permits, from gaining certain sorts of employment-related licenses, and from holding certain types of jobs. Governments need, without delay, to repeal *all* these laws. Where they existed, there needs to be a swing of the pendulum: the enactment of laws that explicitly protect and guarantee the rights of people affected by leprosy along with the rights of persons with disabilities. Vigilance is also needed to ensure that other laws and regulations are not misused to prevent access by people affected by leprosy.

Second, there needs to be a programme of leprosy awareness in schools, targeting students, parents, and staff. Around 15,000 children are diagnosed with leprosy each year, any tens of thousands more come from families with leprosy or simply live in a leprosy 'colony' but have never had the disease themselves. They are not a risk to anyone. And yet, once it is known that children have some association with leprosy, that label has immediate consequences. They may be avoided by other school children, and teachers pay less attention to them or to their caregivers because of stigmatizing attitudes. There should be zero tolerance for any actions or attitudes that prevent children with leprosy connections from completing their schooling, and a combination of effective awareness programs, clear government policies, and ongoing vigilance is needed to ensure this.

Third, there needs to be access to vocational training, particularly for young people whose education has been compromised in the ways I have just mentioned. Vocational training can be a lifeline for those seeking to enter employment in the formal economy. Governments need to ensure that young people affected by leprosy face no prejudicial barriers to access to mainstream vocational and skills development programmes. However the NGOs may also have a role here, because low educational attainment may mean that young people affected by leprosy don't qualify. So some ILEP member associations have invested heavily in bespoke vocational training programmes in many countries, for

their benefit. These programmes need to be accompanied by placement activities because – for people affected by leprosy – the attitudinal barriers are so great that even fully certificated vocational training, on its own, is not enough.

Fourth, people affected by leprosy are liable to discrimination by prospective employers, and harassment in the workplace, if their previous experience of leprosy is revealed. There need to be well-organised information programmes for employers, the workforce and the community at large, correcting misconceptions about leprosy and breaking down the attitudinal barriers that prevent so many people affected by leprosy from moving into and staying in formal employment. If not, the patterns of exclusion and harassment are likely to be repeated. These actions with employers, and in access to vocational training, will progressively enable a shift of persons affected by leprosy, of working age, from the informal to the formal economy.

Fifth, ILEP member associations are engaged in many countries in the formation, promotion and support of self-help groups. These are focused primarily on empowerment and livelihoods through self-employment or cooperatives. Many groups embark on small savings schemes, which along with access to microfinance from with government or the private sector, enable group members to invest in livelihood development. Livelihood decisions are usually vetted by the group, which increases the likelihood of success. However the major effect within the groups is empowerment, which opens up many positive effects including the possibility of employment, personal development and effective social and political advocacy. While NGOs are much involved in this space, government policy settings need to facilitate access to microfinance, encourage group formation, set frameworks in place that enable the formal registration of these groups and collectives, and be responsive to any situations where people affected by leprosy are excluded from access.

Finally, governments need to foster social dialogue between duty bearers and organisations of persons affected by leprosy at national and local levels. Discrimination against persons affected by leprosy is so pervasive that, as I have suggested, vigilance is needed to promptly combat any evidence of barriers or denial of rights of access to education, employment, vocational training and so on. This vigilance is hugely boosted by a pattern of respectful dialogue in which government officers are rapidly informed of situations which they can then readily take action on.

As you've seen, a common feature of these various measures is government and supporting organisations working together. Too many times, socio-economic development of persons affected by leprosy, community sensitization about leprosy, and action against discrimination are left to the NGOs. This needs to change, and NGOs like ILEP members are ready to work to support state parties to do what is needed.