



Written submission by International Federation of Anti-Leprosy Associations (ILEP)
to the UN Committee on the Rights of Persons with Disabilities

CRPD General Comment on Article 27

March 2021

Contact information

International Federation of Anti-Leprosy Associations
Route du Nant-d'Avril 150, 1217 Meyrin, Switzerland
www.ilepfederation.org

Geoff Warne, CEO
Email: gwarne@ilepfederation.org

Introduction

1. The International Federation of Anti-Leprosy Associations (ILEP) is a federation of 13 member associations working in leprosy-related activities in 60 countries. Its goal is zero leprosy, including zero stigma and discrimination against persons affected by leprosy and their family members. Persons affected by leprosy¹ play a significant role in organisational policymaking and lobbying through the operation of a high-profile Advisory Panel which is, in turn, a conduit to national organisations of persons affected by leprosy in many countries.
2. Leprosy is an ancient disease but still present today in more than 100 countries. There are more than 200,000 new cases of the disease each year. Leprosy is rapidly curable if treated promptly, but there are estimated to be 3-5 million people with visible impairments to hands, eyes or feet caused by leprosy, and for people with early nerve damage there is a life-long risk of additional impairment. However, this is only part of the story. For thousands of years, as a result of traditional beliefs and practices and some religious teachings, the word *leprosy* has brought feelings of fear and revulsion. A spokesperson for the UN High Commissioner for Human Rights remarked in 2019 that there is no medical justification for this fear and prejudice: it is a social invention, but nonetheless it is real. This label of leprosy is associated with abuse and violation of the rights of countless women, men and children alive today.
3. ILEP appreciates the CRPD Committee's recognition of persons affected by leprosy as persons with disabilities under Articles 1 and 2. The basis of this recognition is that – whether they have visible impairments or not – they suffer exclusion, stigmatisation and denial of rights as a result of attitudinal barriers that are based on false stereotypes about leprosy. These attitudinal barriers impede full enjoyment of the right of persons affected by leprosy to work, as demonstrated through negative attitudes in the workplace and among employers and the community, and through discriminatory legislation.
4. Considering the importance of the right to work to the dignity, autonomy and independence of persons affected by leprosy and persons with disabilities, ILEP welcomes the action by the CRPD Committee to develop a General Comment on Article 27. Because of the uniqueness of some of the barriers facing persons affected by leprosy, which are described in this submission, ILEP asks the Committee to consider including specific reference to leprosy in its General Comment.

Normative content

5. ILEP supports and emphasises the Committee's call for States parties to modify and repeal discriminatory laws and policies and to enact anti-discrimination legislation. This should be designed to explicitly incorporate protections for persons affected by leprosy within disability-specific law, as well as guaranteeing their rights along with the rights of persons with disabilities in mainstream legislation.

¹ Persons with personal experience of leprosy prefer this descriptive term. The alternative term 'persons with leprosy' is rejected as being more descriptive of persons currently suffering from the disease, rather than its consequential effects in terms of disability, stigma and discrimination.

6. In this context, ILEP draws the Committee's attention to the fact that, amongst the 130 published that currently discriminate against persons affected by leprosy, 25 laws relate to the employment context. These include laws in India (22), Thailand, Pakistan and the Bahamas. Typically, these laws bar persons affected by leprosy from obtaining work permits, from gaining certain sorts of employment-related licenses, and from holding certain types of jobs. These laws need to be modified or repealed without delay. More positively, Vietnam, Tanzania, Colombia and Bangladesh present examples of laws that encourage and support the rights of persons affected by leprosy.
7. Regarding Article 27(b), ILEP draws the Committee's attention to the fact that people affected by leprosy are liable to harassment in employment settings when and if their previous experience of leprosy is revealed. This liability for harassment is amplified in cases of intersectionality between leprosy and other vulnerabilities such as gender, race, age, mental health status or degree of physical impairment. ILEP acknowledges the broad definitions of harassment adopted by the UN Committee on Economic, Social and Cultural Rights (General comment 23, 2016) and the ILO Violence and Harassment Convention, and urges the Committee to go beyond considering harassment against women, migrants and refugees with disabilities and explicitly add or incorporate statements related to harassment directed at people affected by leprosy.

In 2014, a woman who is a teacher in a private elementary school in North Sulawesi, Indonesia, received discriminatory treatment and was expelled from the school by the Teacher and Parents Forum after it was learned that she had previously had leprosy.

8. Regarding Article 27(f), ILEP member associations are engaged in many countries in the formation, promotion and support of self-help groups that are focused primarily on empowerment and livelihoods through self-employment or cooperatives. These groups include persons affected by leprosy but also people who are vulnerable for other reasons including general disabilities. Many groups embark on small savings schemes, and these savings along with external seed funding may be deployed into loans that enable group members – either as individuals or as a cooperative cluster – 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. Some self-help groups have amalgamated into federations, magnifying their political and social impact.
9. A review of the effect of microfinance programmes on self-help groups involving persons affected by leprosy observed these effects:
 - Reduction of stigmatisation and social exclusion. This was the most significant impact reported. It was demonstrated through greater social inclusion of people affected by leprosy following increased community awareness, productive economic engagement, and valued contributions of people affected by leprosy to society.
 - Empowerment, especially where the microfinance interventions start with resources (small savings) that group members have already mobilised themselves, even if supplemented with

external resources. This effect is increased where group members gain the capacity to develop business plans and loan applications in which they are seen as partners.

- Self-employment, through a very wide range of microenterprises, enabling people affected by leprosy to be autonomous, independent and net contributors to family and society wellbeing.
- Food security, where microfinance interventions have enabled participating people affected by leprosy to engage in agricultural activities such as crop production, vegetable growing and livestock.
- Education, where participants have been able to earn the income needed for paying for their children's education including school fees, school uniforms, and learning materials.
- Improved overall health standard, associated with gaining the resources to pay for medicines, improved quality nutrition and improved frequency of food intake.
- Investment in home improvement, resulting in overall rise in the standard of housing including utilities such as electricity, water and sanitation.
- New or improved financial, business, and technical (vocational) skills and general knowledge.
- Creation of an asset base through the use of resources to buy land, equipment, goods and infrastructure.
- Financial inclusion. Conventionally, people affected by leprosy have been excluded by the financial sector in that no lender (formal or informal) is willing to engage with them because of association with the label of leprosy. Microfinance changes that picture.
- Improved accountability and responsibility, associated with the need to keep financial records, manage loan applications, mobilise savings, distribute dividends and provide periodic reports.

10. However, ILEP agrees with the Committee's observation that, in most countries in the developing world, persons with disabilities are overrepresented among those that earn their living through self-employment, especially in the informal sector. This factor is even more pronounced for leprosy, since negative attitudes to the disease hold young people affected by leprosy back from both educational attainment and employment. As long as the livelihoods of persons affected by leprosy remain predominantly in the informal sector, their rights are not acknowledged and therefore vulnerable to abuse. Efforts are needed to move people affected by leprosy to the formal economy.

In Brazil, a woman named Maria recounted her and her husband's experience after a diagnosis of leprosy. "Before the disease, we lived well and had a little shop and a bakery. Afterwards, no one bought anything that came from us, not even the machinery they wanted when we left for Rondônia".

11. One mechanism for doing so is the provision of, and access to, vocational training (Article 27d). This can have powerful impact for people affected by leprosy. At school, once it is known that children have some association with leprosy either through parents or through place of residence, the labelling of leprosy has immediate consequences. They may be avoided by other school children, and teachers pay less attention to them, or to their parents or caregivers, because of stigmatizing attitudes related to their leprosy background. As a result, the majority of children from leprosy-affected families have a very low level of education. Opportunities for

vocational training, both institutional and community-based, become a lifeline for those seeking to enter employment in the formal economy.

12. ILEP agrees with the Committee's concerns about the lack of vocational training opportunities to enable persons with disabilities, including persons affected by leprosy, to gain access to employment. ILEP supports the Committee's call on States parties to implement vocational and skills development programmes to facilitate their entry into the job market. Although enrolling people affected by leprosy into mainstream vocational training programmes may be the preferred option, the Committee should be aware that, as a result of low educational attainment and anti-leprosy prejudice, this is often not possible. Some ILEP member associations have therefore invested heavily in bespoke vocational training programmes in many countries, for the benefit of young men and women with personal experience of leprosy or from leprosy-affected households, or with other disabilities.
13. These programmes need to be accompanied by placement activities (Article 27(e)). The draft General Comment does not provide an explanatory interpretation of Article 27(e), but ILEP submits that – for people affected by leprosy – the attitudinal barriers are so great that even fully certificated vocational training, on its own, is not enough. ILEP would welcome an additional interpretive comment stressing the importance of placement programmes and advocacy with employers, if the purposes of Article 27(d) are to be achieved.

In 2017 the national organisation of people affected by leprosy in Angola undertook a survey of the experiences of people affected by leprosy. It heard accounts of dismissal or denial of work opportunities affecting a driver in Lunda Norte, a young man in the security service, a teacher in a private school who was dismissed on the demand of parents of the other students, police in Cunene, a young man in the restaurant business, a bricklayer, a coastal fisherman, and a member of the Armed Forces who was demobilized on account of having leprosy, without access to veteran's subsidy etc.

14. Some of the key learnings from evaluations of vocational training programmes in countries like India, Bangladesh and Nigeria include the need for:
 - a. Advocacy with primary and secondary educational facilities to ensure children from leprosy-affected backgrounds are not disadvantaged in schooling. Vocational training programmes may nevertheless need to offer remedial education classes.
 - b. Continuous advocacy with mainstream vocational training providers to counter discriminatory attitudes towards student applicants. ILEP agrees that, although disability-targeted employment services do need to exist, certainly in the case of leprosy, they should be connected to the mainstream employment services for mutual referral.
 - c. Continuous scanning of the market so as to align job training, life-skills development and placement with the emerging external opportunities. This needs to be accompanied with ongoing relationships with key commercial/industrial sectors.
 - d. Post-placement mentoring and alumni associations both for the student's benefit and to ensure ongoing provision of information and advice to employers.
 - e. Ongoing action towards the goal of remuneration levels for female graduates being commensurate with males, whether as employees or as self-employed entrepreneurs.

15. Many employers, reflecting attitudes in the community, discriminate against potential employees from leprosy-affected backgrounds. Vocational training needs to be accompanied by well-organised information programmes for prospective employers and their staff teams, correcting misconceptions about leprosy and disability and offering ongoing support and advice as needed. Moreover, because vocational training programmes can, at best, bring only a fraction of people affected by leprosy into the formal economy, these programmes need to be accompanied by determined advocacy among policy-makers and employers to remove the intrinsic attitudinal barriers that prevent so many people affected by leprosy from obtaining jobs, and assert the right to move into work and to stay in work.

A person affected by leprosy in Cirebon, West Java, Indonesia received a recommendation from the Governor of West Java to work in the PLKB (Family Planning Field Officer), but the discriminatory treatment by the person in charge resulted in this person affected by leprosy deciding to quit his/her job.

16. Regarding Article 27(g), ILEP supports the Committee's observations, and adds that in the case of disabilities like leprosy involving social exclusion, efforts towards employment in the public sector need to be accompanied by intensive efforts at education and awareness of the workforce. If not, the patterns of exclusion and harassment are likely to be repeated.
17. Similarly, affirmative action programmes (Article 27(h)) need to be accompanied by well-planned programmes for employer and community awareness. ILEP notes positively the Committee's recommendation of special programmes that target persons with intellectual and psychosocial disabilities as well as other marginalised groups of persons with disabilities, and asks the Committee to explicitly state that these marginalised groups include people affected by leprosy.
18. Regarding Article 27(i), ILEP welcomes the explanatory comment about reasonable accommodation. One of the effects of nerve damage caused by leprosy is loss of feeling in hands and feet, which leads to damage unless the person learns vigilance. ILEP member associations offer physio and occupational therapy, training in self-care and advocacy for or provision of certain aids and appliances that enable the individual to function independently and maintain employment. In many cases, reasonable accommodation involves relatively low-cost provision of protective footwear and gloves or other simple devices that enable anaesthetic hands to be used for employment without damage.

Relationship to other provisions of the CRPD

19. For people affected by leprosy, the right to work is intrinsically connected to other rights in the Convention, such as the general right to non-discrimination (Articles 5 and 8.1b), freedom from all forms of violence (Article 16), right to inclusion in the community (Article 19), right to education (Article 24), right to health and healthcare (Article 25), right to habilitation or rehabilitation (Article 26) and right to social protection (Article 28). ILEP wishes to emphasise the pervasive effect of leprosy-related stigmatisation and discrimination on the enjoyment not only of the right to work, but of all of these rights and freedoms.

Implementation at national level

20. ILEP draws the Committee's attention to the *Principles and Guidelines for the elimination of discrimination against persons affected by leprosy and their family members* adopted by the Human Rights Council in 2010. The Principles and Guidelines translate legally binding human rights norms into leprosy, but they are not legally binding and therefore not effective as a protection for people affected by leprosy until incorporated within each country's own binding human rights legislative framework.
21. The explicit inclusion of leprosy within the Committee's General Comment on Article 27 is therefore vitally important to people affected by leprosy, as a tool or lever to ensure that their employment-related rights are protected with legal force.