

**JUNE 2021**

**“OTHER PEOPLE’S PROBLEMS”**

**ARE**

**EVERYONE’S PROBLEMS**

**FACTSHEET**

**Disproportionate impact of the coronavirus disease (COVID-19) pandemic on persons affected by leprosy and their family members: root causes, consequences and the way to recovery**

**SPECIAL RAPPOREUR ALICE CRUZ’ S REPORT TO THE HUMAN RIGHTS COUNCIL**

## **Disproportionate impact of the coronavirus disease (COVID-19) pandemic on persons affected by leprosy and their family members: root causes, consequences and the way to recovery**

In the report, the Special Rapporteur on the elimination of discrimination against persons affected by leprosy and their family members, Alice Cruz, addresses the disproportionate impact of the coronavirus disease (COVID-19) pandemic on persons affected by leprosy and their family members, exploring the underlying causes and offering constructive recommendations for an inclusive recovery.

There is much to learn from the history of leprosy that can be applied to the current global crisis. While examining the disproportionate impact of the COVID-19 pandemic on the lives of persons affected by leprosy and their family members, another lesson came to light:

**there is no building back better if States fail to put those who have been systematically pushed further behind at the centre of recovery efforts.**

The multidrug therapy crisis revealed **double standards at play in terms of the protection of the right to health in the context of the pandemic.**

Global action to ensure supply channels for delivering essential medicines and goods did not reach persons affected by leprosy, nor did the definition of priority groups for COVID-19 vaccinations include them, despite the fact that many such persons are immunocompromised.

**If one thing became clear during the pandemic, it is that “other people’s problems” are everyone’s problems.**

## KEY POINTS

### Access to livelihoods

- **Exclusion from the formal economy:** Unreliable casual labour with low income, unsafe working conditions and without entitlements to social protection or participation in social dialogue defines the livelihoods of the majority of persons affected by leprosy
- Persons affected by leprosy face formidable, intersecting and multiple **barriers to freely choosing their work and to enjoying their rights at work**
- Such barriers have systematically pushed people into poverty and extreme poverty, forcing many of them to resort to begging
- Persons affected by leprosy are among the 80 per cent of people with severe disabilities who **do not have access to disability-related social protection schemes** in low- and middle-income countries
- With the COVID-19 outbreak, persons affected by leprosy, who were already outside the formal economy and denied employment protection, faced the **loss of jobs, income-generating activities and safety nets**

The pandemic imposed upon them the immoral dilemma of having to choose between dying from hunger or from the virus. If before the pandemic this marginalized group was already struggling with what one organization's representative referred to as the "prepandemic crisis", the pandemic became one additional basis for discrimination, aggravating structural violence and rights violations.

### Access to fundamental goods and life-saving information

- Social determinants of health and illness: Gaps in access to water, sanitation and hygiene and in poverty reduction policies are unmistakably at the **root of the incidence of leprosy, but also of vulnerability to COVID-19**
- The Special Rapporteur has been receiving reports from all leprosy endemic countries about a **food emergency among affected persons**
- And also about a **lack of adequate housing**, clean water, sanitation and electricity, as well as of housing deprivation
- Key **information for COVID-19 prevention has not been accessible** to a considerable number of persons affected by leprosy

Taking into consideration the risks to life associated with the lack of information about COVID-19, the Special Rapporteur considers such information to be fundamental to guaranteeing the right to life in the context of the pandemic and the lack of effective measures taken by governments to make it accessible to all people, especially those who are the most vulnerable, to be a human rights violation.





## KEY POINTS

### Access to health care and essential medicines

- Loss of financial and human resources from national leprosy programmes
- Interruption of key activities for early diagnosis and the concomitant prevention of physical impairments
- The non-availability of leprosy care among health-care services
- Sporadic difficulties in the provision of multidrug therapy
- Generalized difficulties in the treatment and clinical management of leprosy reactions
- Lack of drugs for treating leprosy reactions
- The deferral of complementary care that was essential for the prevention of physical and psychosocial disabilities
- Reduction in and the interruption of disability prevention and rehabilitation
- Reduction in and the interruption of community-based rehabilitation
- Self-diagnosed cases not receiving a diagnosis or treatment at health-care facilities
- Lack of effective national systems in place to monitor COVID-19 infection among immunocompromised persons affected by leprosy
- Older people living in former leprosy colonies being at greater risk of contracting COVID-19
- Unavailability of health care in former leprosy colonies
- Specific cases in which persons affected by leprosy could not receive health care
- Lack of income to buy means of transportation to gain access to health-care services
- Political instability, with forced displacement in some countries, with no measures in place to ensure leprosy treatment.

And **barriers to access to essential medicines**: The Special Rapporteur identified 10 countries with multidrug therapy drug shortages during the period from mid-2020 through the beginning of 2021. The problem was the result of distinct issues affecting the overall supply chain at various times, with the pandemic playing an important role, especially in terms of distribution and delivery to patients.

Being the cornerstone of leprosy control, multidrug therapy gaps increase transmission, transmission within households, including to children, neuropathic pain, physical impairments and mental health problems as a result of the extreme physical, mental and social suffering caused by leprosy.

Another issue that characterizes the impact of the pandemic is the **slowdowns in the reduction in the incidence of leprosy**. The Special Rapporteur received reports from civil society organizations working in various countries that pointed a 50 per cent decrease in the diagnosis of new cases.

### Women and children

Root causes that aggravate the vulnerability of women and children affected by leprosy to the adverse effects of the pandemic:

- Customary law that denies land and inheritance rights, which **affects women more than men**
- **Discrimination in law** disproportionately affects women
- Women bear the brunt of **unpaid care and household work**
- Women have been the hardest hit among those engaged in business and agriculture activities, and initiatives for **economic empowerment have been put on hold** due to the pandemic
- Household isolation during lockdown measures has left them more vulnerable to **domestic violence**

## RESPONSES TO THE CRISIS

- The resources employed were **only a fraction** of what was needed to fill the social protection gaps in developing countries
- The Special Rapporteur received a considerable number of reports that pointed to **multiple and intersecting barriers** to access for persons affected by leprosy to social protection benefits before and during the pandemic
- **Grass-roots organizations** have been at the forefront of responding to and mitigating the disproportionate impact of the pandemic on their peers and communities
- All of that was done with **scarce support** from governments

The Special Rapporteur considers good practices to be the set of strategies put in place through collaborative work with persons affected by leprosy and their representative organizations, respecting autonomy, enhancing local capacities and linking relief to development.

## RECOMMENDATIONS

### On the right to the highest attainable standard of physical and mental health for persons affected by leprosy

- **Health systems should be strengthened** and the efforts of national leprosy related programmes sustained
- A rights-based strategy for leprosy within health-care systems must be **people-centred**, having as a priority the well-being of persons, communities and populations, and should ensure the availability, as well as physical and economic accessibility, of health-care services
- Access to health care should be guaranteed on a **non-discriminatory basis** through strategies that fight discrimination in health-care settings, ineffective public policies and geographical isolation
- The scope of national leprosy-related programmes should be expanded to **include targeted action on the social determinants of leprosy**, which should be based on a comprehensive multisectoral policy with coordinated interventions between the different sectors of government
- The **right to a continuum of medical and psychosocial care** that encompasses the full spectrum of prevention, timely access to multidrug therapy, the proper management of leprosy reactions and complementary care, such as wound care, physiotherapy, rehabilitation and reconstructive surgery, should be guaranteed, alongside service delivery at the community level, and access to essential medicines should be ensured through national and international efforts, while also guaranteeing the right to access to information
- Persons affected by leprosy must be recognized as a **vulnerable group with regard to COVID-19**, given that many of them are immunocompromised, and leprosy should be recognized as grounds for priority in COVID-19 testing, COVID-19 vaccinations and access to health care.



## RECOMMENDATIONS

## On the right to work of persons affected by leprosy

- **Abolishing discriminatory laws** that hinder persons affected by leprosy from enjoying the right to work and enjoying their rights at work
- Recognizing persons affected by leprosy as **active economic agents**, respecting their legal capacity and realizing their rights to equal work opportunities in the open labour market and to equal remuneration
- Guaranteeing the **right to education** through the creation of an inclusive and enabling education system
- Implementing **gender-inclusive approaches** to ensuring the right to work and ensuring rights at work that fight the intersection of gender with leprosy-related harmful stereotypes and disability
- **Fulfilling accessibility** and reasonable accommodation rights in all productive sectors and work arrangements
- Implementing **affirmative measures** as a means to correct historical and structural disadvantage

## On the right to social protection of persons affected by leprosy

- Social protection measures to respond to the current crisis should act as building blocks for founding national social protection floors and contribute to the **realization of universal health coverage** and to **universal social protection schemes**
- This **comprehensive social protection policy** should also target active citizenship by promoting training opportunities and formal employment, while guaranteeing support as needed
- In the design of social benefits, the **real needs** of the target population, including the additional costs of disability, should be taken into consideration
- Specific measures for short-term actions in relation to the adverse effects of the pandemic should include **broadening social protection** for persons affected by leprosy and simplifying both eligibility criteria and administrative requirements

**The pandemic became one additional basis for discrimination, aggravating structural violence and rights violations.**

Such a fact calls for legal and policy frameworks that can ensure de facto universal access to economic, social and cultural rights for the most vulnerable.

The Special Rapporteur recommends that States put **those who are furthest behind at the centre of an inclusive recovery by eliminating double standards in the response to the current crisis**, ensuring non-discrimination and the right to participation for the most marginalized. The principle of progressivity should be applied in a reasonable manner and that guarantees minimum core obligations in a way that is proportional to the needs of vulnerable groups and groups that have been discriminated against.