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WHAT PEOPLE CREATE, PEOPLE CAN CHANGE

FACTSHEET

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Right to the highest attainable standard of physical and mental health for persons affected by leprosy and their family members

Report of the Special Rapporteur on the elimination of discrimination against persons affected by leprosy and their family members, Alice Cruz



[full report](#)

With this report, **the Special Rapporteur** aims to posit people centred elements that can encourage States, intergovernmental agencies and international, national and local stakeholders to produce knowledge that places **people's experience at the centre of the analysis**.

Few human rights have such intricate, controversial and uncertain features as the right to health. In its Constitution, **the World Health Organization (WHO)** defines health as a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity, whereas article 25 of **the Universal Declaration of Human Rights** presents a more overarching concept that connects health and well-being to the guarantees to a dignified and secure standard of living, encompassing access not only to food, clothing and housing, but also to medical care and social security.

Yet **the majority of global and national health narratives and strategies** continue to be dominated by **the biomedical narrative on human suffering**, which narrows diseases to mere biological phenomena, and thus remain disease centred. Although they include recommendations on ensuring universal and affordable access to water, sanitation and hygiene in order to tackle diseases related to poverty, **global health policies do not address the structural violence that is at the root of many of such diseases** and much of the human suffering and economic loss they cause.

Commodification of health, neglected tropical diseases and gaps in leprosy care

Because they mainly affect the poorest, **neglected tropical diseases present no market opportunities**, hence the pharmaceutical industry does not invest in products to address them. Governments, through tax incentives and patent protection, contribute to these market-driven choices, leaving the poorest with few or no treatment options.

In practice **public-health strategies continue to be disease-centred**, as they maintain focus on the individual body and sideline knowledge that is able to address both the psychosocial dimension of the human being and the collective dimension of health and illness.

The Special Rapporteur aims to posit people centred elements



State strategies to ensure the highest attainable standard of physical and mental health are, in most cases, restricted to **guaranteeing access to free medicine for treating infection**, whereas the other elements of the continuum of care, which include reaction management, psychological care, physiotherapy, occupational therapy, group therapy, wound care, surgery, provision of assistive devices and rehabilitation, and also the right to participation, are largely unattended to.

Unequal power relations convert people into passive beneficiaries without the means to overcome the unintentional harm that misguided policies and practices may, and often do, cause.

44% did not feel cured.

Victims of a disease or of a system that overlooks people's needs and suffering?

In order to promote bottom-up knowledge, the Special Rapporteur developed **an online questionnaire with 52 questions** on the right to the highest attainable standard of physical and mental health for persons affected by leprosy. A total of **44 per cent did not feel cured**. About 83 per cent stated that leprosy, its complications and the associated stigma affected their feelings, self-esteem and well-being.

An emphasis on infection seems to lead to neglect of individual case management and care after bacteriological cure. However, for many people **the more serious issues they experience are leprosy reactions**, neuropathic pain, nerve damage and physical and psychosocial impairments and disabilities that may appear during treatment and/or after bacteriological cure.

83% stated that leprosy, its complications and the associated stigma affected their feelings, self-esteem and well-being.



An emphasis on delivering multidrug therapy leads to shortages of drugs to treat reactions, but also of other supplementary medicines. The limited availability of psychosocial and mental health care, diagnosis and treatment of leprosy reactions, information on self-care, rehabilitation and reconstructive surgery, and limited prevention of impairments and provision of assistive devices, together with persisting discriminatory practices perpetrated by the health-care workforce, violate people's rights.

Socioeconomic empowerment and rehabilitation, rarely promoted by government policies, **are essential to restoring people's right to a healthy standard of living** and to promoting their physical, mental and social well-being; they are also key to stopping leprosy's transmission within families and communities.

Conclusion: what people create, people can change

Metrics employed by global health and national health programmes tell us little about structural violence as a cause, and human suffering as a consequence, of leprosy. In order to fulfil the right to the highest attainable standard of physical and mental health for the most disadvantaged, **diseases must be acknowledged as political issues and action to tackle them must be subjected to accountability mechanisms** at all levels of human agency – from the global to the local.

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The Special Rapporteur urges States, especially those where leprosy is endemic, **to develop a country-owned political agenda for fighting leprosy** and protecting, promoting and fulfilling the right to the highest attainable standard of physical and mental health for persons affected by leprosy and their family members, and **recommends that they:**



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a. Put people at the centre of health production, and to that end:

- . Implement guideline 14.1 of the principles and guidelines for the elimination of discrimination against persons affected by leprosy and their family members;**
- . Ensure that planning starts with a needs assessment.**

b. Start with the community and strengthen community-based support systems.

c. Invest in health education and guarantee people's right to access to information.

d. Prioritize primary prevention through multisectoral policymaking and action.

e. Bet on multiservice integration without discriminating against leprosy.

f. Guarantee social protection and, to that end:

- . Ensure food security and cash transfers for people under medical treatment for leprosy.**

g. Empower women affected by leprosy through income-generation programmes, creation of cooperatives and continued education and support women to enable them to engage in health promotion activities.

h. Ensure democratic engagement and, to that end:

- . Provide legal aid and accessible mechanisms for filing complaints of rights violations at primary health-care services.**

The Special Rapporteur also recommends that non-endemic States fulfil their international cooperation obligations, in particular with regard to target 3.3 of the Sustainable Development Goals. She urges States to accept responsibility for drug development, taking it into the public sector, and facilitating access by the world's poorest to high-quality medicines.

