

A/HRC/53/30

HOW FAR  
WE STILL HAVE TO GO

FACTSHEET



June/2023

Progress and remaining challenges in eliminating  
discrimination against 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](#)

# RECOMMENDATIONS

Both **leprosy-endemic and non-leprosy-endemic States** should commit themselves to **ending formal, substantive, interpersonal, direct, indirect, systemic and intersectional discrimination**, as well as violence against and the dehumanization of persons affected by leprosy and their family members, which persist today.

As affirmed in general comment No. 20 (2009) of the **Committee on Economic, Social and Cultural Rights**, **States parties** should ensure that **a person's actual or perceived health status does not constitute an obstacle to the realization of his/her rights** and should also adopt the necessary measures to address widespread stigmatization of persons on the basis of that his/her health status, including diseases such as leprosy.

Furthermore, as clarified by general comment No. 6 (2018) of the **Committee on the Rights of Persons with Disabilities**, the mere recognition of formal equality is not sufficient to combat deep-rooted attitudinal barriers, including those related to leprosy. As also detailed in general comment No. 6, **States parties** are not only obliged to modify or abolish existing discriminatory laws, regulations, customs and practices, but **must also take positive measures, on the one hand, to prevent discrimination, and on the other hand, to tackle it through specific measures aimed at accelerating or achieving de facto equality, non-discrimination, dignity and integrity for groups of people who experience structural disadvantage based on their actual or perceived differences.**

In order to **eliminate all forms of discrimination** against persons affected by leprosy and their family members, **the Special Rapporteur recommends that**

## **leprosy endemic States**

- (a) **Review, amend, repeal or abolish all laws, regulations, ordinances, resolutions and policies that discriminate against persons affected by leprosy** at both the national and subnational levels of government;
- (b) **Prohibit discrimination** on the grounds of leprosy and extend such prohibition to **the private and public spheres**;
- (c) **Develop and enact comprehensive anti-discrimination laws and/or statutes**, in close consultation with organizations of persons affected by leprosy, **to criminalize and punish by effective, proportionate and dissuasive criminal penalties violence and discrimination on the grounds of leprosy**;
- (d) **Include leprosy as prohibited grounds for discrimination in existing monitoring mechanisms and oversight institutions** and systematically collect data disaggregated by demographic, environmental, socioeconomic and cultural variables, with full respect for the principles of participation and privacy;
- (e) **Provide accessible mechanisms for filing complaints about the violation of rights** on the grounds of leprosy, as well as accessible and effective redress mechanisms and free legal aid, and **ensure access to justice, on an equal basis with others**, for persons affected by leprosy and their family members;
- (f) **Reformulate policies and bodies for the protection of vulnerable groups**, in a manner that recognizes and addresses the specific realities and needs of persons affected by leprosy and their family members, with **a proper budget allocation at the national and subnational levels**, with targets, indicators and benchmarks;

(g) **Increase knowledge in all parts of society**, including among State officials and public servants working in different areas of the State administration, particularly in health care, education, work and justice, as well as in the private sector, **about updated scientific evidence on leprosy**, as well as on **the rights to non-discrimination and equality** of persons affected by leprosy;

(h) **Develop and enact comprehensive affirmative measures as a means of correcting historical and structural disadvantage**, in line with general recommendation No. 25 (2004) of the **Committee on the Elimination of Discrimination against Women**, in which the Committee affirms that the duration of a temporary special measure should be determined by its functional result in response to a concrete problem and not by a predetermined passage of time; ensure that affirmative measures are defined in consultation with persons affected by leprosy, their family members and representative organizations; and ensure that affirmative measures come with targets and key performance indicators, as well as effective enforcement mechanisms and remedies; **affirmative measures should recognize the intersectional discrimination against women and children affected by leprosy**;

(i) **Guarantee the right to education for children and teenagers affected by leprosy** through the creation of an inclusive and enabling education system that is non discriminatory and that ensures the availability of education services, accessibility at all levels of education and the promotion of life-long training and skills development opportunities; education services should ensure both accessibility and reasonable accommodation;

(j) **Prohibit and punish domestic violence against women affected by leprosy**, as well as all kinds of violence against them, including institutionalized violence in relation to State services, such as health care, education, social protection and employment, as well as all forms of interpersonal violence;

(k) **Ensure that the State's formal legal system is accessible to women affected by leprosy** and ensure gender awareness training for government officials who are responsible for enforcing laws that may be harmfully applied against women affected by leprosy;



**(l) Establish minimum core obligations for guaranteeing fundamental access to economic and social rights** for vulnerable groups and groups that have been discriminated against, including persons affected by leprosy and their family members, as part of national development plans;

**(m) Guarantee access to health-care services at all levels of the health system by persons affected by leprosy on a non-discriminatory basis;** and ensure their 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, including wound care, physiotherapy, rehabilitation and reconstructive surgery in the public health system;

**(n) Invest in mitigating suffering caused by neuropathic pain and stigmatization through high quality pain management and effective referral** within national health-care systems for mental health care, under a recovery-based paradigm and through services that are ethical, respectful, culturally appropriate, gendersensitive and empowering to individuals; and ensure access by family members of persons affected by leprosy to mental health care;

**(o) Provide, free of charge, assistive devices for protection** and assistive devices for the facilitation of activities of daily life for persons with leprosy-related impairments and disabilities;

**(p) Partner with organizations of persons affected by leprosy to strengthen peer-to-peer counselling,** as well as family-based counselling, and extend counselling to family members of persons affected by leprosy;

**(q) Recognize 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, and include persons affected by leprosy in public employment programmes;

(r) **Open social dialogue to organized groups of persons affected by leprosy working in the informal economy** and enable their right to collective bargaining, including by making available a defined interface with the institutions and government bodies with which the organizations must hold dialogues;

(s) **Fulfil accessibility and reasonable accommodation rights in all productive sectors and work arrangements**, including agriculture, husbandry and fishing, and recognize visible physical impairments related to leprosy as well as invisible ones, such as pain or loss of sensation, and psychosocial disabilities related to stigmatization, in the provision of reasonable accommodation;

(t) **Ensure both work and education opportunities for persons affected by leprosy**, which should come with targets and key performance indicators, as well as with effective enforcement mechanisms and remedies, while also following **paragraph 11 (i) of recommendation No. 168 of the International Labour Organization (ILO)** concerning vocational rehabilitation and employment;

(u) **Ensure that social protection measures and social benefits are implemented** through administrative services and bureaucratic procedures that **guarantee full accessibility to illiterate or poorly educated populations**, as well as to populations living in remote areas; such comprehensive social protection policies should also target active citizenship by promoting training opportunities and formal employment, while guaranteeing support, as needed;

(v) **Recognize**, in the design of social benefits, such as unconditional cash transfers, **the real needs of the target population, including the additional costs of disability**, as well as the specific challenges faced by women, children, teenagers and older persons affected by leprosy, and **ensure a universal basic income for persons affected by leprosy** in order to guarantee them a minimum standard of living and to break the cycle of poverty, disease, disability and discrimination;



(w) **Establish a framework to promote and monitor the implementation of the Convention on the Rights of Persons with Disabilities** that recognizes persons affected by leprosy and their family members as persons with multiple disabilities;

(x) **Implement awareness-raising programmes that are sensitive to culture, language, gender, age and disability** and that are developed in close collaboration with organizations of persons affected by leprosy in order to ensure both accessibility and efficacy, address barriers created by the digital divide and **invest in community media in order to reach as many people as possible**, raise awareness among community leaders, traditional leaders and healers, religious leaders, local pharmacists and schoolteachers with regard to leprosy and engage them in further awareness-raising, and reinforce the positive image of persons affected by leprosy and their family members as rights holders;

(y) **Duly recognize the damage perpetrated by both official and non-official historical segregation through the enactment of reparation measures** that can simultaneously redress harm at the individual level and eliminate leprosy-related segregation and violations;

(z) **Recognize and enforce housing and property rights** for persons affected by leprosy who were forcibly segregated into leprosy colonies and ensure the same rights to second- and third-generation family members;

(aa) **Implement participatory planning and management of former leprosy colonies** and ensure that health care and rehabilitation, including psychosocial support, are available to current residents;

(bb) **Provide urgent symbolic and material reparation, as well as rehabilitation**, at the national level, to **individuals who as children were separated** from their parents affected by leprosy and segregated from society .



The Special Rapporteur recommends that

## intergovernmental agencies

- (a) **Use leprosy as a case study to fill evidence gaps** on the relationship between disease, disability, poverty and discrimination;
- (b) **Ensure leprosy inclusiveness in addressing discrimination**, as well as issues concerning women, children, older people, disability, minorities and development;
- (c) **Make sure to consult with organizations of persons affected by leprosy** when working in leprosy endemic countries on cooperation plans and programmes;
- (d) **Discuss with WHO and consult with organizations** of persons affected by leprosy **the possibility of changing the name of leprosy to a more neutral one, such as Hansen's disease**, in order to address harmful stereotypes attached to the term leprosy.

The Special Rapporteur recommends that

## **international civil society organizations for persons affected by leprosy**

- (a) **Establish measures** to ensure that **persons affected by leprosy** are **included in decision-making** on all relevant programmes and action plans;
- (b) **Establish measures** ensuring **equality of participation of women affected by leprosy in decision-making** with regard to all relevant programmes and action plans;
- (c) **Develop measures** for proper **consultation with children and teenagers affected by leprosy**, assess their real needs and ensure they are included in decisionmaking with regard to all relevant programmes and action plans;
- (d) **Establish quotas** for the employment of persons affected by leprosy in order to **ensure their representation at the organizational level**;
- (e) **Provide training to members of national and local organizations of persons affected by leprosy about their rights and how to claim them**, as well as on basic organizational issues, in order to promote the development of such organizations;
- (f) **Establish**, with sufficient material and technical resources, **an international platform for monitoring the rights of persons affected by leprosy and their family members**, find prompt solutions to urgent needs and provide the human rights system regularly with information about discrimination on the grounds of leprosy .

While sensitive to the epidemiological heterogeneity of leprosy worldwide, **the Special Rapporteur reminds all States** of their commitments under the

**Declaration on the Right to Development and the Sustainable Development Goals**, in accordance with which both leprosy endemic and non-endemic States should:

(a) **Allocate sufficient resources to removing any barriers to the participation of marginalized and vulnerable populations in the human rights system** and ensure accessibility of procedures for the submission of information to the human rights mechanisms;

(b) **Use a more neutral term than leprosy, such as Hansen's disease**, in future resolutions;

(c) **Remove any obstacles to development, recognizing human beings as the central subject of development and ensure that individuals actively participate in and enjoy the benefits of development** and formulate international development policies that complement the efforts of developing countries in the search for solutions that are equitable, inclusive and sustainable; **development policies**, both national and international, **should include non-discrimination as the guiding principle of both processes and outcomes.**