

# Strengthening international cooperation and solidarity to protect the rights of persons affected by leprosy (Hansen's disease)

**(A/HRC/59/55), UN Special Rapporteur Beatriz Miranda-Galarza.**

This summary is structured to inform and guide organizations on how to operationalize the report's findings and recommendations.



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## I. Introduction

The report opens with a **call to reinvigorate international cooperation and solidarity for the protection of the rights of persons affected by leprosy and their families**. It emphasizes that while leprosy is curable, its social consequences persist, including discrimination, exclusion, and poverty. The Special Rapporteur argues that global efforts have stagnated due to reduced funding, a shift in global health priorities, and fragmented international responses. The report warns that the withdrawal of financial support from key actors, such as the U.S. government and philanthropic donors, has disrupted coordination and delivery of services, particularly affecting WHO-led programs. This context makes it urgent to rethink cooperation frameworks, not only in terms of funding, but also in ethical and human rights dimensions.

## II. Why Normative and Legal Frameworks Matter

This section highlights how international law mandates **cooperation to realize human rights universally**. States are required under treaties like the International Covenant on Economic, Social and Cultural Rights (ICESCR) to ensure the right to health, **including access to medicines, prevention, and treatment of diseases such as leprosy**. Articles 2 and 12 are specifically relevant, as they **obligate states to take steps** through international assistance to fulfill these rights.

It also emphasizes the relevance of the Convention on the Rights of Persons with Disabilities (CRPD), particularly regarding leprosy-related disabilities. This includes requirements for **accessibility, inclusion, and participation**.

Key instruments and declarations are referenced:



- UN General Assembly Resolution 65/215, which adopted the Principles and Guidelines to eliminate discrimination against persons affected by leprosy.



- The Sustainable Development Goals (SDGs), especially SDG 3.3 (ending the epidemic of NTDs) and SDG 17 (global partnerships).



- The 2022 Kigali Declaration, which specifically calls for renewed commitment to addressing NTDs, with leprosy highlighted as a priority.

The report calls for using these instruments not only as reference points, but as practical frameworks to demand accountability and shape funding, programming, and legal reforms.

## III. Historical Overview of International Cooperation and Solidarity

The evolution of cooperation in leprosy care is analyzed in three phases:



1. Charity- and Mission-Based Responses (colonial period–mid-20th century): Religious organizations and colonial powers established leprosaria. These institutions often isolated rather than empowered affected persons, reinforcing stigma and dependency.



2. Medicalization and WHO Involvement (1950s–1990s): International organizations, especially WHO, shifted the response toward a biomedical model. The introduction of multidrug therapy (MDT) in the 1980s and its global distribution since 1995, in collaboration with pharmaceutical donations (e.g., Novartis), marked a turning point.







3. Human Rights Approaches (2000s–present): From 2003 onward, a more explicit human rights discourse emerged, leading to the adoption of international principles and greater involvement of persons affected. However, this shift remains partial, and many current strategies continue to prioritize treatment over social inclusion and justice.

The report notes that this historical evolution still shapes the way funding, participation, and technical priorities are set today.




## IV. Current Progress and Challenges to a Human Rights-Based Inclusive International Cooperation Framework

This core section presents a detailed analysis across six dimensions:



### A. Policy and Funding

-  • Most funding continues to prioritize case detection and treatment, neglecting key social determinants.
-  • Sectors like education, housing, and livelihood remain underfunded despite being essential to a rights-based approach.
-  • Few donors explicitly support anti-stigma efforts or gender-inclusive programming.
-  • The report underscores the Nigerian MDT crisis (2024) as an example of failing cooperation and planning, where 3,000+ people were left without treatment, with dangerous consequences.




### B. Capacity Building

-  • While WHO and NGOs conduct trainings, many national systems have removed leprosy from medical curricula.
-  • The closure of specialized hospitals, coupled with retirement of experienced staff, is reducing national capacity.
-  • Health systems heavily rely on external funding and expertise.



### C. Knowledge Sharing and Networks

-  • Initiatives like the Global Partnership for Zero Leprosy and the International Leprosy Congress play key roles but often lack representation from affected persons due to linguistic, technological, or financial barriers.
-  • South–South collaborations (e.g., India’s partnership with Brazil and African countries) have promise but need scaling and coordination.

### D. Research and Innovation

-  • The Leprosy Research Initiative (LRI) has helped coordinate efforts, but investment remains low compared to other NTDs.
-  • New approaches—like AI for leprosy detection in Brazil—require better digital infrastructure and ethical safeguards.
-  • Affected persons are rarely part of research design, data governance, or dissemination, raising ethical concerns.

### E. Human Rights and Inclusive Development

-  • The shift from institutional to community-based care is happening, particularly in countries like India, Senegal, and Nepal.
-  • Programs increasingly address psychosocial aspects of exclusion.





- Organizations led by persons affected (e.g., ENAPAL, IDEA) are emerging as key actors, though they struggle with funding and political inclusion.

## F. Ethical Solidarity and Compassion



- Examples from COVID-19 show grassroots responses rooted in solidarity—like providing food, care, and digital support networks.
- New training initiatives based on compassion (especially in Ethiopia, Nigeria, India) are reducing stigma within medical and traditional communities.
- However, disparities in digital connectivity and infrastructure still hinder equal participation.

## V. Conclusions and Recommendations

The report concludes with an urgent appeal to realign international cooperation with human rights principles. It recognizes progress but warns that without structural change, including meaningful funding and inclusion, global targets will not be met.

Key Recommendations:

### For States:



- Prioritize human rights in all national and international leprosy strategies.
- Reaffirm commitments under ICESCR, CRPD, and SDGs.
- Ensure access to medicines, and establish independent monitoring bodies.
- Involve persons affected in planning, budgeting, and service delivery.

### For Donors and Multilateral Agencies



- Restore and increase funding for comprehensive leprosy responses, including stigma reduction, housing, and legal reform.
- Adopt intersectional approaches—incorporating gender, climate justice, and indigenous rights.
- Fund autonomous organizations of persons affected to participate in regional and global policy spaces.

### For Civil Society and Affected Persons' Organizations:



- Strengthen collective advocacy to influence national and international decision-making.
- Invest in leadership development, knowledge sharing, and digital inclusion.
- Promote alliances with other NTD and disability movements.

## Conclusion

The report concludes that unless urgent collective action is taken to strengthen international cooperation and solidarity, the goal of eliminating leprosy-related discrimination will remain out of reach. The current funding crisis is not just a technical problem—it is a political and ethical failure that risks erasing decades of hard-won progress.



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# Report of the Special Rapporteur on the elimination of discrimination against persons affected by leprosy (Hansen's disease) and their family members,

**Strengthening international cooperation and solidarity to protect the  
rights of persons affected by leprosy (Hansen's disease)" (A/HRC/59/55)**

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# What is in this report

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# 1. About the report



This report is about the need to strengthen international cooperation and solidarity to protect the rights of persons affected by leprosy (Hansen's disease) and their families. The report calls for a human rights-based approach, not charity. It emphasizes the importance of dignity, participation, and ethical solidarity. It gives guidance to governments, donors, and international organizations on how to work together to fund projects that protect the rights of persons affected by leprosy.



The United Nations is a group of 193 countries that work together to make sure that the rights of every person in the world are protected.



In 2017 the United Nations approved the creation of the Mandate on the elimination of discrimination against persons affected by leprosy (Hansen's disease) and their family members.



The Special Rapporteur is Beatriz Miranda-Galarza. Her work is to promote the defence of the rights of persons affected by leprosy/Hansen's disease and their family members by advocating and providing information to governments, international organizations, and UN bodies and offices.



As part of her work, she presents two reports about the rights of persons affected by leprosy a year. One in New York and another in Geneva.



To write them she consults governments, local and international organizations of persons affected, as well as experts in different topics related to leprosy.



The terms 'leprosy' and 'Hansen's disease' are used in these reports as they are commonly used by persons affected worldwide.



This report focuses on making sure persons affected are treated as equal human beings with rights.

## 2. Why is international support important?

Leprosy **mostly affects poor and excluded communities**. People still face a lot of discrimination, fear, and lack of support.

Although the disease can be cured, many people:



- Do not get diagnosed on time
- Do not receive the right treatment
- Live with disabilities caused by the disease
- Are excluded from jobs, schools, or their communities

Fighting leprosy requires countries working together to make sure no one is left behind.

## 3. Why is funding a problem?

Persons affected by leprosy shared their experiences:

Many countries and organizations have cut their support for leprosy programs.

This is making things worse, especially in places like Nigeria, where people waited for months without receiving medicine.

There is not enough money for:



- Training doctors and nurses
- Helping people with disabilities
- Supporting families and communities
- Educating people to reduce stigma

## 4. What does international law say?

Countries have legal duties to help each other protect human rights. This includes:



- The right to health
- The right to education
- The right to live without discrimination

The United Nations and other bodies have already agreed on rules to protect persons affected by leprosy. But not enough is being done to follow these rules.

## 5. What happened in the past?

In the past, people with leprosy were often sent to special hospitals or isolated from society.

Religious groups and medical charities tried to help, but they often treated people as poor victims, not as people with rights.

**Today, we know that the best approach is to:**



- Include affected persons in decisions
- Respect their stories and rights
- End all forms of exclusion

## 6. What progress has been made?

Some good things are happening:



- More people are speaking out and organizing
- Research is helping to improve diagnosis and treatment
- Digital tools are used to share information
- South-South cooperation (for example, Brazil and India helping other countries) is growing

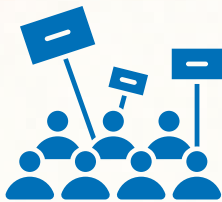
But challenges remain:



- Most decisions are still made without the voices of affected people
- There is little focus on women, mental health, or life after treatment
- Not enough is done to make people feel included and respected

## 7. What do persons affected by leprosy want?

They want:



- A seat at the table – to be part of decisions that affect them
- More funding for health, education, jobs and housing
- Respect for their experiences and history
- End to laws and practices that isolate or punish them
- Stronger health systems that don't forget about them

## 8. What should governments and organizations do?

Governments should:



- Guarantee healthcare, medicine, and support
- Include people affected in national policies
- Work together across borders
- Repeal discriminatory laws

Donors and international groups should:



- Fund more than just medicine, also fund inclusion, housing, mental health, and education
- Support organizations led by persons affected
- Focus on justice and equality, not charity

Grassroots and community organizations should:



- Share experiences and work together
- Ask to be included in funding decisions
- Use technology and storytelling to raise awareness

## 9. Final message from the report

Leprosy is not just a medical issue, it is a human rights issue.

People affected by leprosy deserve respect, participation, and dignity.

We must act together, in solidarity, to end discrimination and ensure that no one is forgotten.





