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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, v

Leprosy (Hansen's disease) in the 21st century: A human rights approach oriented by ethics of care





Executive Summary::

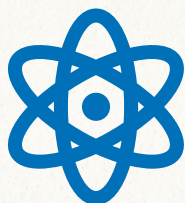
The present report, submitted by Beatriz Miranda-Galarza, the UN Special Rapporteur on the elimination of discrimination against persons affected by leprosy (Hansen's disease) and their family members, is her first since her appointment in November 2023. The report provides an overview of the progress made by the mandate since its establishment in 2017, assesses the current state of discrimination against persons affected by leprosy, and outlines the Special Rapporteur's vision and priorities for the upcoming years (2024–2026).

Background: from exclusion to recognition as holders of rights

Leprosy, also known as Hansen's disease, is a chronic infectious disease that disproportionately affects individuals in marginalized communities. Despite being curable, it carries a heavy burden of stigma and discrimination, often leading to severe social exclusion for those affected and their families. The history of addressing leprosy is marked by four key approaches:



Religious and Moral Approach: Historically, leprosy was often seen as a divine punishment, with religious interpretations contributing to the view that the disease was a manifestation of sin or immoral behavior. In many cultures, persons affected by leprosy were isolated or subjected to charity-based care, reinforcing their exclusion from society.



Scientific and Administrative Approach: This approach has been primarily medical, focusing on controlling the disease through isolation and segregation of affected individuals. Key milestones include the discovery of the causative agent *Mycobacterium leprae* in 1873 and the introduction of multidrug therapy in the 1940s, which revolutionized treatment. However, this approach also led to harsh segregation policies, depriving affected individuals of their rights.



Representational and Cultural Approach: The cultural representation of leprosy has historically stigmatized those affected. The term "leprosy" itself carries negative connotations, often reinforcing stereotypes about the disease as highly contagious and those affected as dangerous. Efforts to raise awareness sometimes unintentionally perpetuated these harmful views.



Human Rights-Based Approach: In recent decades, there has been a shift toward recognizing leprosy as a human rights issue. This approach emphasizes the empowerment of persons affected by leprosy, advocating for their rights to non-discrimination, access to health care, education, and participation in public life. International instruments such as the UN's Principles and Guidelines for the Elimination of Discrimination against Persons Affected by Leprosy (2010) and the Convention on the Rights of Persons with Disabilities have been instrumental in this shift.

These approaches continue to coexist, with the human rights-based framework now taking precedence in global advocacy efforts.

Relevance of the Mandate from the voices of Persons Affected by Leprosy and Their Organizations

Recognizing that persons affected by leprosy are the primary stakeholders, the current Special Rapporteur conducted a series of interviews with representatives of organizations of persons affected by leprosy, as well as their allies, from countries including Bangladesh, Colombia, Ethiopia, Kenya, India, Indonesia, Japan, New Zealand, and Paraguay. The interviews aimed to assess the impact of the mandate's implementation and identify key issues that should be prioritized in the coming years.

Feedback from international and local organizations indicated that the creation of the mandate has significantly raised awareness of leprosy as a human rights issue, shifting the focus beyond the medical domain to include the social, economic, and cultural aspects of the disease.

This increased recognition has led to meaningful discussions on leprosy-related human rights violations at both the international and national levels. For example, the previous Special Rapporteur's recommendations have led to important legislative changes, such as in Brazil, where a law was passed to provide financial reparations to persons affected by Hansen's disease, as well as to children who were separated from their parents due to the disease.

Positive Developments: Despite these challenges, the interviews revealed several positive developments:



Empowerment of Grassroots Organizations: Organizations of persons affected by leprosy have gained more visibility and recognition at both the local and international levels. Their participation in human rights events, including country visits by the Special Rapporteur, has helped to increase awareness of their rights and build their capacity to advocate for themselves.



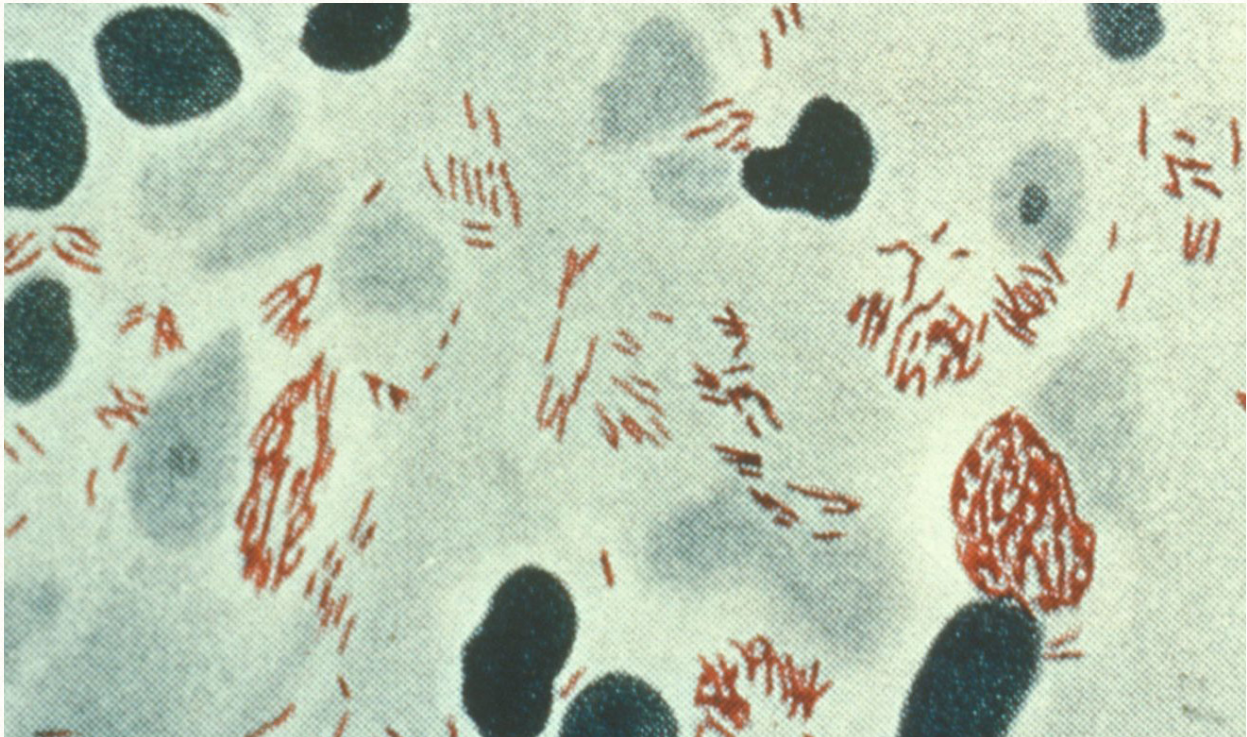
Strengthened Advocacy: The mandate has played a role in strengthening the advocacy efforts of grassroots organizations. These organizations now have a better understanding of the importance of participating in decision-making processes and are more empowered to engage with local authorities and international bodies. The increased engagement of grassroots organizations with international leprosy donors has amplified their capacity to influence policy and practice at the national level.



Access to Resources and Capacity Building: The Special Rapporteur's request for information on the situation of persons affected by leprosy in each country has motivated many grassroots organizations to stay informed about violations of the rights of persons affected by leprosy. This has led to an improvement in their organizational capabilities, including better data collection and case registration, which are essential for advocating for legal reforms and other necessary changes.



Building Hope: One of the most significant impacts of the mandate has been the sense of hope it has instilled in persons affected by leprosy and their families. For many, the acknowledgment of their rights and the international recognition of their struggles have been empowering. The mandate has given affected individuals a platform to share their stories, and many now believe that their voices are being heard. As one interviewee put it, "When persons affected by leprosy realize they have rights, like any other person, their self-confidence changes, and also there is confidence in what their organizations can achieve."



Unmet Expectations: Despite the successes, many grassroots organizations feel that there is still a long way to go to eliminate discriminatory practices and laws, particularly in countries where leprosy is endemic. In addition, there is some confusion at the local level about the role of the Special Rapporteur, with some organizations expecting more direct action from the mandate, such as intervention in individual cases of human rights violations. The Special Rapporteur's role, however, is primarily informational and advisory, which can sometimes lead to unmet expectations.

Global and Local Perspectives: The mandate's success at the international level, particularly within UN systems and international organizations, has not yet fully translated into visible change at the local level, particularly for grassroots organizations and communities. While major organizations in urban centers have received information about the work under the mandate, smaller organizations, especially those in rural or marginalized areas, often lack access to this information due to language barriers and difficulties in disseminating centralized information.

The interviews revealed that while the mandate has brought greater visibility and recognition of leprosy within the United Nations and increased dialogue between leprosy-affected organizations and international bodies, there remains a gap in terms of grassroots involvement and impact on local policies and practices. Many of the smaller, more marginalized organizations expressed frustration over the slow pace of change and the lack of resources needed to implement recommendations and programs that address the specific challenges faced by persons affected by leprosy.

Looking Forward: While much progress has been made in raising awareness and empowering organizations of persons affected by leprosy, the interviews underscore the need for continued efforts to ensure that the voices of affected individuals remain at the center of the mandate's work. The Special Rapporteur is committed to continuing to listen to and collaborate with these organizations, ensuring that their perspectives shape the future of the mandate.

In the coming years, it will be essential to address the remaining gaps in access to information and resources for grassroots organizations, especially those in rural and marginalized areas. The mandate will also focus on ensuring that governments take more active steps to implement the recommendations and policies needed to eliminate discrimination against persons affected by leprosy.

Key Priorities for 2024–2026:

There have been identified five major areas of concern for the next phase of the mandate:

1

Rights-Based Support and Care Systems: A key priority is the transformation of care systems from a paternalistic, medicalized approach to a human rights-based framework. This includes recognizing the long-term health needs of individuals affected by leprosy, particularly for those who suffer from disabilities or mental health issues caused by stigma and discrimination. Support systems must ensure access to medical care, mental health services, economic opportunities, and social participation.

2

Intersectional Issues and Marginalized Groups: Women, children, and individuals with disabilities face compounded discrimination in addition to the stigma of leprosy. The Special Rapporteur calls for more comprehensive data collection and policy measures to address the specific needs of these vulnerable groups. For example, women affected by leprosy often face neglect within the healthcare system, and children may face lifelong social exclusion if not diagnosed and treated early.

3

Social, Political, and Cultural Considerations: The report emphasizes the need to strengthen grassroots organizations of persons affected by leprosy and ensure their political inclusion. While there has been progress in some areas, many such organizations lack sufficient resources and political recognition. Additionally, the preservation of the history of persons affected by leprosy, including archives, oral histories, and cultural artifacts, is seen as essential for recognizing their contributions and struggles.

4

Legal and Economic Dimensions: Discriminatory laws continue to affect persons with leprosy in several countries. The mandate aims to address these legal barriers while also tackling the economic hardships faced by affected individuals and their families. Poverty and lack of access to resources exacerbate the challenges of leprosy, creating a cycle of exclusion and deprivation.

5

Environmental and Conflict-Related Considerations: The report highlights the impact of environmental factors, such as poor housing and sanitation, on the spread of leprosy. In conflict zones and areas affected by climate change, individuals with leprosy are particularly vulnerable, often lacking access to healthcare and other basic services. The Special Rapporteur calls for greater attention to these issues within the framework of global development and humanitarian efforts.

Vision and Fundamental Pillars of the mandate:

The Special Rapporteur envisions a future where persons affected by leprosy are fully recognized as rights holders, actively participating in shaping the policies that affect their lives. Her vision is built on three fundamental pillars:



Ethics of Care: This approach emphasizes care as a central value in human rights work. Rather than viewing care as a paternalistic act, the Special Rapporteur advocates for an ethics of care that respects the dignity and autonomy of individuals. Care should be understood as a shared responsibility that sustains individuals, communities, and societies. This perspective highlights the need to rethink care systems in a way that prioritizes the human rights of individuals affected by leprosy.



Culture of Listening: Listening is at the core of the Special Rapporteur's mandate. She stresses the importance of hearing the voices of those affected by leprosy and integrating their experiences into the creation of policies and practices. A culture of listening requires active engagement with affected individuals, ensuring that their perspectives are central to decision-making processes.



Cooperation and Co-Production: The mandate aims to foster cooperation between governments, civil society, and international organizations to co-produce policies that address the needs of persons affected by leprosy. The Special Rapporteur advocates for closer partnerships with other UN bodies, academic institutions, and grassroots movements to advance the human rights of affected individuals.

In her role, the Special Rapporteur will continue to promote the elimination of discrimination and the creation of inclusive, rights-based support systems for persons affected by leprosy and their families. Her vision is rooted in ensuring that all stakeholders work collaboratively to “leave no one behind,” with the active participation of affected individuals in all levels of decision-making.



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