

Care and support for persons affected by leprosy (Hansen's disease) and their family members from a human rights perspective

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

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About the report



This report looks at how to improve care and support for persons affected by leprosy (Hansen's disease) and their families. Leprosy is not just a disease; it also brings discrimination, poverty, and social problems. The report says that we need to go beyond just treating the disease and focus on helping people live full, happy lives with respect and dignity.



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.

1. What is Care and Support?



Care: This is more than just medical treatment. It means looking after someone's physical, emotional, and social well-being. For example, helping with daily activities, providing emotional support, and making sure they are included in society.



Support: This is the help a person needs to live their life, like assistance with moving around, communicating, or getting access to work, education, and health services.

The report says that care and support should not be seen as charity but as a right. Everyone should have access to these services, no matter their background.

2. Experiences of Persons affected by Leprosy

Persons affected by leprosy shared their experiences:



Medical Needs: Many people need regular medical care to deal with problems like nerve damage, disabilities, or mental health struggles.



Stigma and discrimination: People affected by leprosy are often treated badly by their communities or even their families. This makes it harder for them to live normal lives.



Lack of Help: In many places, there aren't enough services to support them. Families, especially women, often must do all the caregiving without any outside help.

3. Challenges and Solutions



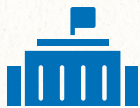
Healthcare access: There aren't enough trained doctors and nurses, and medical services for leprosy are hard to reach, especially in rural areas.



Economic burden: The financial burden of taking care of a family member affected by leprosy can be overwhelming, and many governments don't provide enough financial support.



Discrimination against: The biggest barrier is discrimination against persons affected by leprosy. They often face shame and rejection, which prevents them from getting the care and support they need.



The report suggests that governments must provide more financial help, better healthcare, and education to fight stigma.

4. Rethinking Care and Support for Leprosy from a Human Rights Perspective

The report calls for a new way of thinking about care and support:



Good Governance: Governments must create fair laws and policies that involve persons affected by leprosy in decisions about their care.



Accurate Assessments: It's important to understand the real needs of people affected by leprosy and provide personalized care.



Social Protection: This means financial help for medical costs, rehabilitation, and access to assistive tools like crutches or wheelchairs.



Trained Workforce: Caregivers, whether family members or professionals, should receive training on how to best help people affected by leprosy.

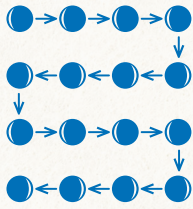


Investing in Care: More money should be spent on care and support services that respect human rights.



Compassionate Policies: All care systems should be built on kindness and respect for the dignity of those affected.

5. Activities of the Special Rapporteur



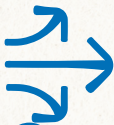
The Special Rapporteur spent the year meeting with governments, organizations, and persons affected by leprosy to raise awareness and push for change. She spoke at conferences, gave interviews, and used social media to spread the message that leprosy is not just a medical issue, but a human rights one.

6. Conclusions and Recommendations

The report finishes by urging governments to:



Create better laws to protect people affected by leprosy from discrimination.



Include persons affected by leprosy in making decisions about their care.



Provide more financial help and better healthcare services.



Raise awareness to reduce stigma and make sure people affected by leprosy are treated fairly.



Support families: especially women, who often bear most of the caregiving responsibilities.



The report emphasizes that all these changes must respect the dignity and rights of persons affected by leprosy. They deserve the same opportunities as everyone else, including good health, education, and a life free from discrimination.

