



UNITED NATIONS
HUMAN RIGHTS
OFFICE OF THE HIGH COMMISSIONER

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

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





Introduction

The report is based on the work of the UN Special Rapporteur on the elimination of discrimination against persons affected by leprosy, Beatriz Miranda-Galarza. It focuses on the urgent need to adopt a human rights-based approach to care and support for persons affected by leprosy and their families. The report is grounded in interviews with persons affected by leprosy from various countries, alongside consultations with experts and stakeholders. The goal is to integrate leprosy into global discussions on care, human rights, and the Sustainable Development Goals (SDGs).

Care and Support: Semantics and Definitions

The report begins by defining **care** and **support**:



Care is viewed as a fundamental social responsibility, emphasizing empathy, attentiveness, and the fulfillment of others' needs. It moves away from traditional views where care was seen as the sole responsibility of families, particularly women, and encourages shared responsibility among communities, governments, and the private sector.



Support refers to the assistance necessary for persons to participate fully in society. Support goes beyond medical care to include emotional, material, and social assistance, ensuring autonomy and dignity for affected persons. Both care and support are framed within human rights, arguing for their recognition as rights rather than charitable acts.

Care and Support Systems: Normative Frameworks

The section outlines the international human rights instruments and treaties that provide a framework for ensuring care and support for persons with disabilities and chronic illnesses like leprosy. These include:

- The *Universal Declaration of Human Rights* and its recognition of the right to an adequate standard of living, including medical care and necessary social services.
- The *International Covenant on Economic, Social, and Cultural Rights*, which enshrines the right to social security, health, and adequate living standards.
- The *Convention on the Rights of Persons with Disabilities* (CRPD), which calls for community inclusion and support services for persons with disabilities, recognizing the importance of independent living and rehabilitation.
- Other frameworks include regional human rights charters and the *2030 Agenda for Sustainable Development*, which promotes universal health coverage and inclusion of marginalized groups like persons affected by leprosy.
- The report also highlights relevant resolutions from the Human Rights Council, such as Resolution 54/6, which focuses on the centrality of care and support from a human rights perspective, recognizing the critical role of both paid and unpaid care work.

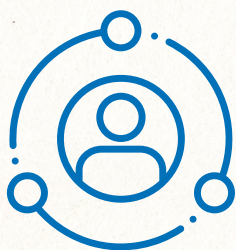
Finally, the United Nations principles and guidelines for the elimination of discrimination against persons affected by leprosy are also mentioned as crucial normative guides, particularly for ensuring non-discriminatory access to services and community-based rehabilitation.

Lived Experience of Care and Support for Persons Affected by Leprosy and Their Families

This section focuses on the lived experiences of those affected by leprosy, highlighting the persistent challenges they face in accessing adequate care and support. Persons affected by leprosy often experience stigma, discrimination, and exclusion from social services, employment, and even within their own families.



Medical Access: Access to medical and rehabilitation services remains inadequate in many countries, particularly in rural areas. Specialized knowledge of leprosy among healthcare professionals has decreased, and many patients report difficulties in obtaining the necessary treatment and support, especially for chronic pain and disabilities caused by leprosy.



Social and Economic Support: Social discrimination hinders affected persons access to social security, education, and employment. Although some countries provide social welfare programs, many affected persons struggle with bureaucratic barriers, preventing them from accessing benefits. The caregiving burden often falls disproportionately on women within families, with little financial or social recognition for their unpaid labor.

From an Institutional Perspective to a Human Rights Approach of Care and Support

The report highlights the historical shift from **institutionalized care** to a more **human rights-based approach**:



Institutionalized Care: Historically, persons affected by leprosy were isolated in institutions like leprosaria and hospitals, which treated them as dependents rather than rights holders. This institutional care, although providing some medical assistance, perpetuated the idea that leprosy-affected persons were passive recipients of charity rather than active participants in their own care. In many cases, patients had to act as caregivers for one another due to a lack of external support.



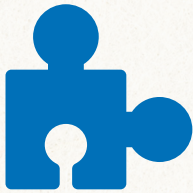
Human Rights Approach: Over time, there has been a shift towards integrating persons affected by leprosy into communities, closing institutions, and advocating for community-based care. However, this transition placed the burden of care on families, who were often ill-equipped to handle the medical and psychological complexities of leprosy. A human rights-based approach demands that persons affected by leprosy be recognized as active participants in the design and delivery of their care, with governments ensuring access to medical, social, and economic support systems.



Lessons from the Past: The report underscores the importance of learning from the self-care practices that arose within institutional settings, where patients, often left to fend for themselves, organized and supported each other. The experience of those affected by leprosy as both caregivers and receivers offers valuable insights into how care systems can be more inclusive and effective.

Access to Medical and Rehabilitation Services

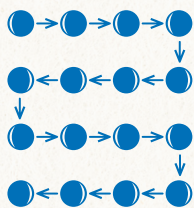
Persons affected by leprosy often face a multifactorial range of physical and mental health challenges. These challenges include skin lesions, nerve damage, deformities, and chronic pain, compounded by complications such as malnutrition and poor access to health care. The report emphasizes the need for specialized medical care and rehabilitation services, which are increasingly scarce in many countries. Delays in diagnosis and treatment exacerbate these problems, leading to preventable disabilities and economic hardship.



Challenges in Treatment: Despite progress in medical treatment, many persons face challenges such as relapses, reactions to the disease, and misdiagnosis. Furthermore, limited access to medications and the lack of mental health services aggravate the physical and psychological burdens faced by leprosy patients.

Discrimination vs. Social and Economic Support: The Role of the State and Families

This section outlines the critical role of governments in creating supportive environments for persons affected by leprosy. Despite some progress in implementing social welfare programs, gaps remain:



Bureaucratic Barriers: Many affected persons struggle to access social benefits, particularly because their impairments may not be recognized as “disabilities” under national law. The lack of accurate data and proactive government measures further marginalizes persons, particularly those in remote areas.



Caregiver Burden: Women disproportionately shoulder the caregiving responsibility, often without financial or social support. This contributes to burnout and economic hardship within families, especially when caregivers are also affected by leprosy.







Community Engagement, Advocacy, and Awareness

Advocacy and awareness are critical in combating discrimination against persons affected by leprosy. Grassroots organizations in countries like Brazil, India, Indonesia and Colombia have been successful in raising awareness and involving affected persons in community decision-making processes. The report stresses the

importance of integrating persons affected by leprosy into leadership roles and building partnerships between grassroots organizations and government bodies to enhance advocacy efforts.

Rethinking Care and Support for Persons Affected by Leprosy and Their Families from a Human Rights Perspective

This section proposes key measures for governments to adopt in order to create inclusive, human rights-based care systems:

-  **Good Governance:** Governments must involve affected persons and their families in designing and implementing care systems. This approach promotes accountability, transparency, and equality.
-  **Accurate Assessment of Needs:** Care systems should be built on comprehensive assessments of the needs of persons affected by leprosy, considering their medical, social, and economic challenges.
-  **Comprehensive Social Protection:** Social protection systems should include financial assistance, access to healthcare, and support services that reduce the economic burden on affected persons and their families.
-  **Cultivating a Skilled Workforce:** There is a need for trained professionals who can provide quality care and support, especially in rural areas where healthcare services are limited.
-  **Human Rights-Based Investment:** Governments should prioritize investments in care systems that respect the rights and dignity of affected persons, ensuring that care systems are sustainable and inclusive.
-  **Ethical and Compassionate Policies:** Care systems must be compassionate and culturally sensitive, recognizing the unique needs of persons affected by leprosy while promoting dignity and respect.

Annual Activities of the Special Rapporteur

Beatriz Miranda-Galarza has participated in numerous international meetings and consultations with various stakeholders, including UN agencies, academic institutions, and civil society organizations. She continues to raise awareness about the rights of persons affected by leprosy through media interviews and social media platforms.

Conclusions and Recommendations

The Special Rapporteur, Beatriz Miranda-Galarza, concludes the report by stressing the **urgency** of implementing care and support systems for persons affected by leprosy that are grounded in **human rights principles**. This approach represents a shift from traditional, disease-centric models to a person-centered approach that emphasizes **dignity, autonomy, and compassion**. Below are the detailed conclusions and recommendations:

- 1. Urgent Need for a Human Rights-Based Care and Support System**
States must develop **integral care and support systems** that go beyond medical treatment, incorporating **psychological, emotional, economic, and social services**. These systems must be designed to protect and promote the **human rights** of persons affected by leprosy, ensuring they are active participants in decisions that affect their lives.
- 2. Shifting from Disease-Centered to Person-Centered Models**
States must adopt a **person-centered care model** that views persons affected by leprosy as **rights holders**, not merely as patients. This involves developing **legal, policy, and institutional frameworks** that guarantee access to a broad range of services, including **healthcare, social protection, education, housing, and employment**.
- 3. Combating Stigma and Discrimination**
Governments must implement **anti-discrimination laws** and **equal opportunity policies** to protect the rights of persons affected by leprosy. This includes ensuring that national policies address the **specific needs** of leprosy-affected persons and their families. **Public awareness campaigns** should be launched to combat myths, raise awareness, and reduce stigma. Collaboration with **religious leaders**, civil society, and the media is essential to transforming societal attitudes.
- 4. Comprehensive Legal Frameworks**
States should establish or strengthen **legal frameworks** that guarantee **just and equal access** to care and support services for persons affected by leprosy. These frameworks must align with **international human rights standards** and include provisions for **monitoring and evaluation** to ensure accountability.
- 5. Sustainability and Funding Mechanisms**
States must develop **sustainable funding mechanisms**, including **public-private partnerships**, to ensure the availability of long-term care and support systems. Funding should cover **healthcare costs, social services, and social protection schemes**. Collaboration between **international agencies, donors**, and local governments will be key to ensuring equitable access to resources.
- 6. Comprehensive and Inclusive Care Systems**
Governments should establish **inclusive care systems** that recognize the contributions of **unpaid caregivers**, particularly women, and provide financial compensation and support. Care systems should incorporate **mental health services, vocational training, and social safety nets** to support affected persons and their families. This also includes

extending care to **rural and remote areas** where leprosy-affected persons may have limited access to services.

7. Data Collection and Research

Governments should invest in **interdisciplinary research** to gather data on the economic, social, and medical impacts of leprosy. Accurate data collection is essential to understanding the **scope of the problem** and ensuring that policies are informed by evidence. States should also prioritize the **inclusion** of affected persons in **data-gathering processes** to ensure their voices are heard.

8. Ethical and Compassionate Care

Care and support systems must incorporate a **compassionate approach**, recognizing the unique cultural, social, and emotional needs of persons affected by leprosy. States should implement **ethical guidelines** for healthcare professionals and caregivers that emphasize the importance of **respect, empathy, and dignity** in providing care. Additionally, **community-based care** models should be promoted, allowing families and local communities to play an active role in the care process.

9. Participation of Persons Affected by Leprosy

States must ensure the **active participation** of persons affected by leprosy in all stages of the development and implementation of care and support systems. This can be achieved by establishing **consultation mechanisms** and **advisory bodies** that include representatives of persons affected by leprosy. Their lived experience provides invaluable insight into the design of effective, inclusive policies.

10. Gender Equality and Addressing Caregiver Inequality

States must adopt **gender-responsive policies** that address the **caregiver inequality** faced by women and girls. This includes providing **financial support, respite care, and vocational training** for women caregivers. Governments should also promote a **redistribution of caregiving responsibilities**, ensuring that families, communities, and the State share the caregiving burden equitably.



UNITED NATIONS
HUMAN RIGHTS
OFFICE OF THE HIGH COMMISSIONER



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