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Multiple disabilities and fluid self-identification: disability rights of
persons affected by leprosy and their family members and
how they challenge national legal frameworks

Report of the Special Rapporteur on the elimination of
discrimination against persons affected by leprosy
and their family members, Alice Cruz

In **the present report**, submitted pursuant to Human Rights Council resolution 44/6, the Special Rapporteur on the elimination of discrimination against persons affected by leprosy and their family members, Alice Cruz, focuses on **national legal protections available for persons affected by leprosy (also known as Hansen's disease) and their family members**, along with remaining challenges. More specifically, she discusses how the recognition of persons affected by leprosy and their family members as persons who are entitled to the rights provided for in the Convention on the Rights of Persons with Disabilities is an important step in protecting this group of people, eliminating systemic discrimination against them and fulfilling their human rights.

Persons affected by leprosy should be **fully recognized as persons with disabilities in accordance with articles 1 and 2 of the Convention on the Rights of Persons with Disabilities**, not only on the grounds of physical impairments caused by leprosy and the multiple barriers to their full participation imposed by society, but also on the ground of discrimination based on harmful stereotypes about leprosy itself. Furthermore, many family members experience psychosocial impairments and disabilities owing to systemic discrimination on the ground of leprosy. Yet, persons affected by leprosy and their family members have been largely excluded from the global conversation about disability, and society's disabling forces affecting them have been left unexamined.

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The Special Rapporteur adopts **the distinction established by the social model of disability between "impairment"** (referring to any loss or difference of physical, mental, intellectual or sensory functioning) and **"disability"** (referring to the avoidable and imposed restrictions and losses caused by societies' multiple barriers). **It is not impairments, but rather disability that actively marginalizes, excludes and dehumanizes people who experience any physical, mental, intellectual or sensory loss or difference.**



The **World Health Organization (WHO)** global leprosy strategy contains a grading system for assessing and measuring leprosy-related impairments. **Even though such a system uses the term “disability”, it only measures physical impairments**, which contributes to misinterpretations of disability associated with leprosy and to misguided policies and practices. The limitations to the medical approach are clear. For example, owing to systemic discrimination, the majority of persons affected by leprosy work in the informal economy and depend on unreliable casual labour with low income and unsafe working conditions. Physically demanding labour, which for many persons affected by leprosy is the daily reality of sustaining a livelihood, can aggravate physical impairments related to nerve damage. **The interrelation between physical impairments, discrimination and unequal opportunities for decent work illustrates how the medical approach, by focusing solely on physical impairments, overlooks important socioeconomic factors and generates misinterpretations that negatively influence policymaking, and in so doing, contributes to disabling persons affected by leprosy.**

An analysis of the evolution of the number of people diagnosed with already irreversible physical impairments in the 23 WHO global priority countries over the past five years shows that the decrease is manifestly slow. Many people continue to be diagnosed with already irreversible impairments, and efforts to monitor the evolution of impairments after discharge from the health-care services once the bacteriological treatment for the leprosy infection has been completed, together with the provision of rehabilitation, are clearly lacking, as previously documented by the Special Rapporteur.

The interrelation between physical impairments, discrimination and unequal opportunities for decent work illustrates how the medical approach contributes to disabling persons affected by leprosy.



On this report, the Special Rapporteur examines

measures taken by States to recognize persons affected by leprosy and their family members as persons who are entitled to disability rights,

as well as the barriers that hinder them from gaining access to and enjoying those rights, and offers constructive recommendations in that regard. She identifies national institutional barriers to recognition of and access to disability rights, in order to provide States with recommendations aimed at improving their national legal frameworks. She focused less on societal and attitudinal barriers to inclusion, since these topics have been largely examined on her previous reports.



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Apart from South Sudan, the remaining 22 WHO global priority countries for action against leprosy have either ratified or acceded to the Convention on the Rights of Persons with Disabilities. However, a significant number of those States parties have not signed, ratified or acceded to the Optional Protocol. This situation hinders persons with disabilities from gaining access to their right to an effective remedy and reparation.

Constitutional norms, legislation, programmes and strategies in force in some countries where leprosy is relevant create favourable conditions for protecting the rights of persons with leprosy-related impairments and disabilities. This situation notwithstanding, there are important challenges regarding the execution and implementation of such frameworks, as well as significant problems with the content of the aforementioned norms, legislation, programmes and strategies.

While the majority of countries in which leprosy is relevant have legal and regulatory frameworks, effective access to disability-related benefits remain unaddressed.

While the majority of countries in which leprosy is relevant have legal and regulatory frameworks in place that, in principle, recognize visible impairments caused by leprosy, issues around the assessment and recognition of invisible impairments and psychosocial impairments, **disability as the interaction between impairments and society's restrictions, effective access to disability-related benefits, the right to an effective remedy and reparation, the elimination of discriminatory legal and regulatory frameworks, the elimination of harmful stereotypes, the intersection of leprosy with deep-rooted harmful stereotypes and wrongful stereotyping, with poverty and with geographical barriers for people living in remote and rural areas and measures to protect the rights of people living in former leprosy colonies, among others, remain unaddressed.** In essence, disability rights seem to be restricted to social protection, and decisions on who is or is not entitled to such protection remain largely in the hands of the medical professions.



Another issue of concern is the limited participation of persons affected by leprosy and their representative organizations in institutional matters

relating to them, as well as in umbrella organizations for persons with disabilities.

Unarguably, **there are numerous systemic barriers to the full and meaningful participation of persons affected by leprosy and their family members.** Such barriers include:

institutionalized discrimination; illiteracy and low educational qualifications; legal impediments; inaccessibility of administrative procedures and requirements; inaccessibility and unintelligibility of the information being provided; physical and environmental barriers; and a lack of support mechanisms for overcoming structural disadvantages reflected in unequal and unfair socioeconomic and education status.

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Not only are **persons with disabilities a diverse group of people**, but their problems and needs may also differ from those of other persons with disabilities, which emphasizes **the importance of recognizing diversity and consulting all groups of persons with disabilities.**



The Special Rapporteur, in line with her working methods,

has consulted persons affected by leprosy and their family members on issues such as self-identification and disability when preparing the present report.



While **the majority of persons affected by leprosy identify as persons with disabilities (74 per cent), others do not.**

Discussion about the recognition of persons affected by leprosy and their family members as persons with disabilities challenges any fixed definition of disability, as well as **dichotomic frontiers between “disabled” and “non-disabled”**. Fluidity is at the heart of the preamble to the Convention, in which it is affirmed that disability is an evolving concept.

It is also affirmed in **article 1 of the Convention that persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments** which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others, thereby not restricting coverage to any person. Such definition accommodates **family members of persons affected by leprosy who self-identify as persons with psychosocial disabilities owing to stigmatization and discrimination on the ground of leprosy (30 per cent).**

In total, **61 per cent of persons affected by leprosy reported having been discriminated against on the ground of their impairments**, as did 57 per cent of family members of persons affected by leprosy. A total of **36 per cent of persons affected by leprosy mentioned not being recognized as a person with disabilities by doctors** as a barrier to disability-related protection, while **32 per cent said that they did not know about any possible benefits** and another 32 per cent complained about the absence of any benefit. Medical jurisdiction over the assessment of disability and a lack of information seem to be the major barriers at work with regard to access to disability-related social protection.



States must do more to effectively implement the provisions of the Convention on the Rights of Persons with Disabilities

While progress made in the elaboration of norms at the national level that recognize equality for persons with disabilities is well known, **States must do more to effectively implement the provisions of the Convention on the Rights of Persons with Disabilities**, given the fact that, in practice, the implementation of such norms reproduces paternalistic approaches that largely fail to promote systemic change.

Importantly, **it is clarified in the Convention on the Rights of Persons with Disabilities that States' obligations include not only non-discrimination but also taking all the steps necessary to eliminate barriers and promote enabling environments** that guarantee the right of persons with disabilities to enjoy opportunities on an equal basis with others. Undoubtedly, systemic change requires more than what is provided for in existing national legal and regulatory frameworks.

By the same token, recognition of the diversity of persons with disabilities is limited, and more marginalized groups of persons with disabilities, such as persons affected by leprosy and their family members, are overlooked in national policymaking.

Issues that demand much more attention from policymakers include those surrounding the definition and assessment of disability, the removal of institutionalized and extra-institutional barriers hindering access to rights, the relationship between poverty and disability, the provision of remedies and reparation, and the establishment of specific measures with proper budget allocations that can promote active and participatory citizenship.



RECOMMENDATIONS



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In order for States to develop and implement leprosy-inclusive disability laws and policies, **the Special Rapporteur recommends that they adopt and implement the measures set out below.**

- establishing a framework to promote and monitor the implementation of the Convention that recognizes persons affected by leprosy and their family members as persons with multiple disabilities;
- making use of a concept of disability that is in line with the Convention and guarantee that recognition of rights holders is based on encompassing standards that acknowledge the disabling effect of discrimination, integrate self-identification and accommodate the complexity and fluidity of people's experiences and identities;
- reviewing administrative procedures for gaining access to disability rights and benefits and guarantee their accessibility; and ensuring that persons affected by leprosy, their family members and representative organizations are fully involved in such a reform;
- putting forward measures that guarantee equality and non-discrimination, access to health and rehabilitation, decent work and employment, social protection, justice and the right to an effective remedy.

The Special Rapporteur also recommends that intergovernmental agencies:

- use leprosy as a case study to fill the evidence gap on the relationship between disability and poverty;
- review the definition of leprosy-related disabilities in line with the human rights model;
- recognize the diversity of persons with disabilities;
- and ensure leprosy inclusiveness in intergovernmental agencies and human rights monitoring mechanisms when addressing disability-related issues.

