An unfinished business: discrimination in law against persons affected by leprosy and their family members

The report is the first submitted to the General Assembly by the Special Rapporteur on the elimination of discrimination against persons affected by leprosy and their family members, Alice Cruz. In the report, the Special Rapporteur:

- identifies more than 100 laws that discriminate against persons affected by leprosy worldwide, examining their roots in biomedical misconceptions about the disease and their provisions and consequences, which are reflected in the persisting dehumanization of persons affected by leprosy and their family members;
- examines the efforts undertaken towards legal harmonization, and her analysis of the impact of discrimination in law against persons affected by leprosy is grounded in the lived experience of the individuals concerned in order to demonstrate why it is urgent to finish the business of formal recognition of persons affected by leprosy as rights holders;
- puts forward constructive recommendations for eliminating discriminatory laws, customs and practices, as well as for fighting against some of the more immediate consequences of extended discrimination in law with regard to the enjoyment of rights and access to opportunities of persons affected by leprosy and their family members on an equal basis with others.

BARRIERS TO RIGHTS

One of the main adverse impacts of remaining discriminatory laws pointed out to the Special Rapporteur by persons affected by leprosy and their representative organizations: the barriers that such laws create to access to rights and the enjoyment of opportunities on an equal basis with others, as well as access to justice and the right to an adequate remedy in the face of discrimination and human rights violations. Another major impact of such laws is that by not being abolished they authorize discrimination and violence. While the State may not enforce such laws, other social players may do so freely, and often do.

Formal discrimination motivates, authorizes and normalizes substantive discrimination against persons affected by leprosy by:

- significantly compromising the livelihoods;
- formalizing harmful stereotypes as lawful labels and normalizing humiliation and violence as authorized practices;
- excluding persons affected by leprosy from political and civic participation and therefore hindering changes with regard to democratic engagement and involvement with decision-making;
- augmenting the State’s negligence towards this marginalized group of people and its lack of commitment to systemic change and accommodation of differences.

GENDER IMBALANCE

As described several times to the Special Rapporteur, given the limited economic independence and autonomy of women affected by leprosy (see A/HRC/41/47), laws such as those allowing for divorce on the grounds of leprosy have a greater impact on them, heightening their already subordinated status. The mere existence of such laws hinders women’s access to justice in demanding enforcement of the rights that are entitled to them after divorce.
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RECOMMENDATIONS TO STATES

In general:
- Review, amend, repeal or abolish all laws, regulations, ordinances, resolutions and policies that discriminate against persons affected by leprosy and deny them the enjoyment of rights on an equal basis with others at both the national and subnational levels of government;
- Prohibit discrimination on the grounds of leprosy and extend such prohibition to the private and public spheres;
- Develop and enact comprehensive anti-discrimination laws and/or statutes, in close consultation with organizations of persons affected by leprosy;
- Eliminate institutionalized discrimination and derogatory language from official documents, laws, regulations, ordinances, resolutions and policies.

To enable systemic change:
- Support and protect the engagement of persons affected by leprosy and their family members in leadership positions in public and political life;
- Take steps to ensure that children affected by leprosy are guaranteed the right to education and to stay in school;
- Enact affirmative measures to guarantee that children affected by leprosy and children of persons affected by leprosy have access to higher education on an equal basis with others.

To eliminate traditional discriminatory customs and practices:
- Carry out participatory research that can enable knowledge of the relation between discriminatory traditional customs and practices and non-State legal systems, while involving local communities, which should be properly recognized as experts;
- Implement effective monitoring systems on traditional customs and practices;
- Make use of intercultural dialogue and mutual learning as effective methods for generating greater awareness of the rights of persons affected by leprosy and their family members;
- Implement awareness-raising programmes that are sensitive to culture, language, gender, age and disability and that are developed in close collaboration with local communities.

To protect women affected by leprosy from violence:
- Eliminate discriminatory laws and/or practices that restrict or deny the rights of women affected by leprosy, including those regarding physical and mental health, sexuality and reproduction, as well as those concerning family issues, such as marriage and divorce;
- Eliminate all laws and/or practices that restrict rights and access to opportunities on an equal basis with others for women who experienced divorce or separation owing to leprosy and guarantee them their share of marital property and custody of their children, as well as housing, property and land rights;
- Prohibit and punish domestic violence against women affected by leprosy, as well as all kinds of violence against them;
- Ensure that the State’s formal legal system is accessible to women affected by leprosy and ensure gender awareness training for government officials who are responsible for enforcing laws that may be harmfully applied against women affected by leprosy;
- Establish affirmative measures for ensuring equality of participation of women affected by leprosy in any decision-making that affects their lives.

To connect restorative justice to prevention:
- Prohibit all laws, norms and official and traditional practices that lead to the segregation of persons affected by leprosy;
- Implement reparation programmes that encompass both material and symbolic reparations;
- Recognize and enforce housing and property rights for persons affected by leprosy who were forcibly segregated into leprosy colonies and ensure the same rights to second- and third-generation family members.