Seventy-eighth session
Item 73 (b) of the provisional agenda*

Promotion and protection of human rights: human rights questions, including alternative approaches for improving the effective enjoyment of human rights and fundamental freedoms

Legal framework for eliminating discrimination on the grounds of leprosy

Note by the Secretary-General

The Secretary-General has the honour to transmit to the General Assembly the report of the Special Rapporteur on the elimination of discrimination against persons affected by leprosy and their family members, Alice Cruz, submitted in accordance with Human Rights Council resolution 44/6.
Report of the Special Rapporteur on the elimination of discrimination against persons affected by leprosy and their family members, Alice Cruz

Summary

In the present report, the Special Rapporteur on the elimination of discrimination against persons affected by leprosy and their family members, Alice Cruz, addresses the obligations of States to combat leprosy-related discrimination. It examines the principles of non-discrimination in international human rights law and the need for anti-discrimination legal frameworks. In the report, the Special Rapporteur highlights the importance of adopting specific anti-discrimination laws to protect the rights of persons affected by leprosy, including provisions on positive action and remedies. She also stresses the need to ensure the participation of affected persons and their families in legislative processes.
Contents

<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>I. Introduction</td>
<td>4</td>
</tr>
<tr>
<td>II. The principle of non-discrimination in the framework of international human rights law</td>
<td>7</td>
</tr>
<tr>
<td>III. States’ obligations to respect, protect and fulfil the core principle of non-discrimination for persons affected by Hansen’s disease and their family members</td>
<td>9</td>
</tr>
<tr>
<td>IV. The duty of enacting anti-discrimination legal frameworks, as provided for in the jurisprudence of the treaty bodies</td>
<td>10</td>
</tr>
<tr>
<td>V. Comprehensive anti-discrimination laws and those specific to Hansen’s disease among the priority countries for Hansen’s disease</td>
<td>13</td>
</tr>
<tr>
<td>VI. Ensuring the right to participation for persons affected by Hansen’s disease and their family members in legislative processes</td>
<td>14</td>
</tr>
<tr>
<td>VII. An intersectional approach to anti-discrimination legal frameworks</td>
<td>17</td>
</tr>
<tr>
<td>VIII. Conclusions and recommendations</td>
<td>19</td>
</tr>
</tbody>
</table>
I. Introduction

1. In the present report, the Special Rapporteur on the elimination of discrimination against persons affected by leprosy and their family members, Alice Cruz, focuses on States’ obligations to protect persons affected by leprosy (also known as Hansen’s disease) and their family members from discrimination. At her discretion as an expert on the matter, she henceforth refers to Hansen’s disease instead of leprosy.

2. More precisely, the Special Rapporteur discusses how the provisions of international human rights law and jurisprudence from international human rights monitoring mechanisms bind States to develop and enact both general and specific anti-discrimination legal frameworks in order to fulfil their positive obligations to protect all persons, and especially those in more disadvantaged situations, from discrimination.

3. With this report, which is also her final report to the General Assembly, the Special Rapporteur closes a discussion on legal frameworks that started with her report about discrimination in law against persons affected by Hansen’s disease and their family members (A/76/148) and was followed by her report on legal frameworks for guaranteeing disability rights to persons affected by Hansen’s disease and their family members (A/77/139).

4. In her final report to the Human Rights Council, the Special Rapporteur identifies the development of guidance on anti-discrimination legislation, policies and programmes as important tasks to be included in the mandate of the Special Rapporteur on the elimination of discrimination against persons affected by leprosy and their family members. The present report partially undertakes such a task by focusing on providing guidance on the anti-discrimination legal framework. The Special Rapporteur would like to remind States that she already presented a report that contains a policy framework for rights-based action plans to the Human Rights Council (A/HRC/44/46).

5. With nearly six years’ experience as a special procedure mandate holder, the Special Rapporteur is convinced that the mere fulfilment of States’ negative obligations not to discriminate against persons affected by Hansen’s disease and their family members is insufficient to properly address human rights violations, discrimination and unequal access to opportunities and results for this extremely marginalized and historically ostracized group of people. In order to truly eliminate discrimination on the grounds of Hansen’s disease, States must take positive steps to both protect those who are discriminated against on such grounds and fulfil their rights. To that end, the Special Rapporteur strongly recommends that the relevant States elaborate and enact anti-discrimination legal frameworks, together with affirmative measures that can correct the historical and persistent disadvantage endured by this group of people and which results from systemic discrimination against them.

6. In the present report, the Special Rapporteur only addresses anti-discrimination legal frameworks. Given that the principles and guidelines for the elimination of discrimination against persons affected by leprosy and their family members, of which the General Assembly took note in its resolution 65/215, already provided guidance on the material scope of protection from discrimination, that is to say, the areas of life in which persons affected by Hansen’s disease and their family members should be duly protected from discrimination, which are also the areas more relevant for the implementation of affirmative measures, the Special Rapporteur will not address the material scope of anti-discrimination legal frameworks in the present report. She urges States to use the principles and guidelines for the elimination of
discrimination against persons affected by leprosy and their family members as a road map for monitoring the situation of persons affected by Hansen’s disease and their family members, as well as for implementing measures that, by enforcing international human rights law, can guarantee formal and substantive equality for them.

7. Furthermore, the Special Rapporteur discusses the importance of guaranteeing the right to participation to persons affected by Hansen’s disease and their family members in amending existing laws, as well as in designing, implementing and evaluating new laws. As outlined in her final report to the Human Rights Council, there is more knowledge today about discrimination on the grounds of Hansen’s disease (A/HRC/53/30). Systematic empirical data collected by the Special Rapporteur over the years confirms the vision she outlined in her first report to the Human Rights Council (A/HRC/38/42), in which she affirmed that discrimination on the grounds of Hansen’s disease should be approached and tackled using an intersectional lens. Accordingly, she offers basic guidance in the present report on how to design an anti-discrimination law with an intersectional perspective. In the present report, the Special Rapporteur also analyses the legal frameworks of the 23 global priority countries identified by the World Health Organization (WHO) as priority countries for action on Hansen’s disease, identifying a considerable gap in both general anti-discrimination legislation and that which is specific to Hansen’s disease.

8. While the principle of non-discrimination is recognized in many constitutions, it is less often translated into policymaking and subsequent programmes and strategies. In addition, budget allocation for anti-discrimination policies is rarely sufficient to meet their goals. That is why the Special Rapporteur starts by examining the provisions and jurisprudence with which States parties should comply. After which, she provides basic guidance on the protected grounds that should be present in any anti-discrimination law specific to Hansen’s disease. The guidance provided by the Special Rapporteur is essentially generic, mainly because both the personal and the material scope of protection should be duly detailed in full accordance with the reality of national and subnational local contexts. To that end, persons affected by Hansen’s disease, their family members and their representative organizations must be recognized as experts by experience and their right to participate in all matters that concern their lives duly guaranteed. The fact that, in most countries, oversight institutions fail to monitor discrimination on the grounds of Hansen’s disease and that States are usually highly inefficient in collecting data that can inform anti-discrimination evidence-based policies related to Hansen’s disease, illustrates why the participation of concerned groups is essential to the design, implementation and evaluation of any anti-discrimination law specific to Hansen’s disease.

9. In the present report, anti-discrimination laws refer to a set of norms and rules, which may include national laws, but also other subnational, regional and international normative instruments. They put forward a set of norms and rules aimed at fighting back and eliminating discrimination. The set of rules may comprise: (a) constitutional provisions, as constitutions can contain fundamental rights provisions that affirm equality and prohibit discrimination, in line with international treaties and conventions; (b) international human rights law, as many States are legally bound by regional human rights frameworks, as well as by treaties, conventions and the supervisory bodies of the United Nations system; (c) guidelines from intergovernmental organizations, in the case of the European Union, for example, protection against discrimination is expressed in both European Union law and the Charter of Fundamental Rights of the European Union; (d) specific anti-discrimination laws that provide for the prohibition of discrimination with regard to specific groups, specific grounds, specific areas or themes and specific structural barriers; and (e) comprehensive anti-discrimination laws that aim at eliminating all forms of discrimination and promote equality for all.
10. Anti-discrimination laws, in general, refer to perceived or actual characteristics of individuals and/or groups of people that should be considered protected grounds in order to address patterns of exclusion and social injustice against these same individuals and groups. Examples of protected grounds that may fall under the scope of anti-discrimination laws include, inter alia: age; birth; nationality; Indigenous origin; descent, including caste; language; colour; race; disability; economic status; ethnicity; genetic or other predisposition towards some illness; health status; marital status; maternity or paternity status; migrant status; minority status; political or other form of opinion and expression, including human rights defender status, trade union membership, or political affiliation; refugee status; religion or belief; sex and gender; and sexual orientation.

11. An anti-discrimination law should take into consideration the different attitudes, behaviours and practices that must be prohibited in strict accordance with international human rights standards. Such attitudes, behaviours and practices may include, but are not limited to:¹

(a) Direct discrimination, which occurs when in a similar situation, persons or groups are treated, through detrimental acts or omissions, differently owing to their perceived or actual characteristics and in such a way that creates unfavourable or disadvantageous situations for them;

(b) Indirect discrimination, which occurs when seemingly neutral norms or practices are applied in such a way that denies, in practice, access to what seemed to be equal opportunities and/or causes a disproportionate and unfavourable impact on certain persons or groups;

(c) Harassment, which occurs when a hostile, offensive, degrading or humiliating environment is actively generated in order to target certain persons or groups;

(d) Denial of reasonable accommodation, meaning that a disproportionate and undue burden is imposed on certain persons and groups as a result of the denial and/or absence of modifications, adjustments or support that would have been necessary for these same persons and groups to enjoy the same rights on an equal basis with others;

(e) Segregation, which occurs when persons and groups are subjected to separation from mainstream society and denied equal and fair access to environments, institutions, goods and services owing to their perceived or actual characteristics;

(f) Victimization, which occurs when persons or groups who filed complaints about discriminatory practices or claimed for the rightful application of provisions on equality and non-discrimination are treated in an adverse and undignified manner with significant psychosocial consequences.

12. As can be found in both the thematic and country reports of the Special Rapporteur, persons affected by Hansen’s disease and their family members continue to suffer from direct and indirect discrimination, harassment, denial of reasonable accommodation, and victimization, as well as interpersonal and structural violence. It is the view of the Special Rapporteur that violence should be added to the list of forms of discrimination, since it is too often the consequence of discrimination, in the case of interpersonal violence, but also the root cause of discrimination, as in the case of structural violence. The Special Rapporteur has simultaneously detailed and elaborated on all these forms of discrimination and violence, as they are still

experienced by persons affected by Hansen’s disease and their families, in her reports, and for that reason will neither detail nor elaborate on the same issues in the present report. Furthermore, the Special Rapporteur has identified a major gap in the provision of remedies and reparations for present and past human rights violations against persons affected by Hansen’s disease and their family members, while oversight institutions do not monitor discrimination on the grounds of Hansen’s disease. The foregoing considerations duly justify the need to enact anti-discrimination legal frameworks specific to Hansen’s disease, especially in endemic countries.

13. Any anti-discrimination law should also recognize that discrimination can result either from perception or association. In other words, people can be excluded by reason of being either identified as having certain characteristics or associated with persons or groups that are perceived as having those same characteristics. This is particularly important for the specific case of family members of persons affected by Hansen’s disease, who many times suffer the same patterns of exclusion as the latter. Furthermore, such a law should consider multiple forms of discrimination, that is, discrimination based on more than one ground or resulting from the interaction of different grounds of discrimination which give rise to specific situations of disadvantage, exclusion, discrimination and violence. The law should include provisions for the enactment of specific affirmative measures aimed at guaranteeing de facto equality for the persons and groups protected under the same legal framework. Lastly, the protection provided by anti-discrimination laws should take into consideration a personal scope (the protected grounds) and a material scope (the areas of life to be protected).

II. The principle of non-discrimination in the framework of international human rights law

14. The Human Rights Committee expressly affirms that: “Non-discrimination, together with equality before the law and equal protection of the law without any discrimination, constitute a basic and general principle relating to the protection of human rights.”

15. Equality and non-discrimination, besides being fundamental principles of international human rights law, are essential to the enforcement of the rights provided for in international treaties and conventions. In article 2 (2) of the International Covenant on Economic, Social and Cultural Rights, it is stipulated that each State party must “undertake to guarantee that the rights enunciated in the present Covenant will be exercised without discrimination of any kind as to race, colour, sex, language, religion, political or other opinion, national or social origin, property, birth or other status”. The Committee on Economic, Social and Cultural Rights clarifies that non-discrimination is an immediate and cross-cutting obligation in the Covenant. Under article 2 (2) States parties must ensure “non-discrimination in the exercise of each of the economic, social and cultural rights” and must also ensure the application of these rights in combination with non-discrimination. According to the Committee, “discrimination constitutes any distinction, exclusion, restriction or preference or other differential treatment that is directly or indirectly based on the prohibited grounds of discrimination and which has the intention or effect of nullifying or impairing the recognition, enjoyment or exercise, on an equal footing, of Covenant rights. Discrimination also includes incitement to discriminate and harassment”.

---

16. In article 26 of the International Covenant on Civil and Political Rights it is stated that “all persons are equal before the law and are entitled without any discrimination to the equal protection of the law. In this respect, the law shall prohibit any discrimination and guarantee to all persons equal and effective protection against discrimination”. The Human Rights Committee reinforces that the right to non-discrimination provided for in article 26 of the International Covenant on Civil and Political Rights constitutes an autonomous right. In article 26, “obligations imposed on States parties in regard to their legislation and the application thereof” are established and that it is up to those States to ensure that the content of their legislation is non-discriminatory. Furthermore, the application of the principle of non-discrimination contained in article 26 is not limited to those rights which are provided for in the International Covenant on Civil and Political Rights. The International Covenant on Civil and Political Rights and the International Covenant on Economic, Social and Cultural Rights further establish the equal treatment of men and women in their article 3: “the States Parties to the present Covenant undertake to ensure the equal right of men and women to the enjoyment” of the rights set forth in the respective Covenants.

17. Considering the need for the elimination of discrimination on specific grounds, specific instruments have been created, which include, for example, the International Convention on the Elimination of All Forms of Racial Discrimination, the Convention on the Elimination of All Forms of Discrimination against Women and the Convention on the Rights of Persons with Disabilities. According to article 5 of the Convention on the Elimination of All Forms of Racial Discrimination, the duty to prohibit and eliminate racial discrimination in all its forms and to guarantee the right of everyone to equality before the law should be ensured through a minimum set of specific rights, which span from civil and political to economic, social and cultural rights. Similar provisions can be found in the Convention on the Elimination of All Forms of Discrimination against Women.

18. According to article 5 (2) of the Convention on the Rights of Persons with Disabilities, “States Parties shall prohibit all discrimination on the basis of disability and guarantee to persons with disabilities equal and effective legal protection against discrimination on all grounds.” According to the Committee on the Rights of Persons with Disabilities, article 5 brings with it a set of obligations, namely “obligations to prohibit all discrimination on the basis of disability [including] persons with disabilities and their associates … [and] the obligation to guarantee to persons with disabilities equal and effective legal protection”. The Committee further notes that “persons with disabilities will not be granted more or fewer rights or benefits than the general population” and “States parties should take concrete specific measures to achieve de facto equality for persons with disabilities to ensure that they can in fact enjoy all human rights and fundamental freedoms”.

19. More examples of this commitment to assert the obligation of States to equality and non-discrimination can be found in other international human rights instruments. A few examples are: the Convention on the Rights of the Child (art. 2 (1)) and the International Convention on the Protection of the Rights of All Migrant Workers and Members of Their Families (art. 1 (1)).

---

5 Committee on the Rights of Persons with Disabilities, general comment No. 6 (2018), para. 17.
III. States’ obligations to respect, protect and fulfil the core principle of non-discrimination for persons affected by Hansen’s disease and their family members

20. As a result of their obligations under international treaties and conventions, States are responsible for adopting all the necessary administrative, legislative and judicial measures to implement and enforce the rights set forth in those instruments and to respect, protect and fulfil human rights, as well as to provide remedies for their violations.

21. The obligation to respect is a negative obligation. It refers to the duty of States to refrain from discriminating, whether through laws, policies, practices or the attitudes of its officials. On the one hand, there is the State’s commitment to refrain from any kind of discriminatory act or the promotion of any kind of discriminatory legislation, policy, programme or initiative, whether in its objective or in its result. On the other hand, this obligation refers to the State’s commitment to amend, repeal or abolish any rules that have either the objective or lead to a result that produces and/or maintains discrimination.

22. As a negative obligation, the obligation to respect relates to preventing persons affected by Hansen’s disease from suffering abuses by the State itself and by its public authorities. In this sense, international human rights treaties establish States’ primary obligation not to discriminate against persons affected by Hansen’s disease and their family members. They also hold States responsible in cases where public authorities are the ones perpetrating acts of discrimination. This obligation concerns laws, as well as the activities that States undertake to implement or enforce them. As thoroughly documented by the Special Rapporteur, States continue to formally discriminate against persons affected by Hansen’s disease and their family members, while institutionalized discrimination against this group of people also endures, especially on the part of public servants with insufficient knowledge in relation to Hansen’s disease in several State services, such as education, employment, social protection and justice.

23. The obligation to respect the rights of persons affected by Hansen’s disease and their family members binds States to refrain from interfering directly or indirectly with these individuals’ enjoyment and exercise of their civil, political, economic, social and cultural rights. States must ensure that their actions do not impair the enjoyment and exercise of any rights, either through direct or indirect discrimination. This duty includes the obligation to abolish or repeal discriminatory laws against persons affected by Hansen’s disease that are still in force. By the same token, States must ensure that all public authorities and institutions eliminate discriminatory policies, measures and practices on the grounds of Hansen’s disease.

24. The obligation to respect also concerns States’ obligation not to discriminate against persons affected by Hansen’s disease and their family members in functions and activities where there are responsibilities to be assumed by public authorities and institutions, such as: celebrations and rules related to marriage and divorce; decisions on parental authority; the production of identification documents; the granting of citizenship; access to public schools and training programmes; and the language used by State bodies and in official documents.

25. The obligation to protect persons affected by Hansen’s disease and their family members from discrimination should be understood as requiring States to take measures to prevent third parties from interfering with these individuals’ ability to exercise their rights. Hence, it will not be enough for the State to limit itself to merely not discriminating against this group of people. States must take all the necessary measures to ensure that the principle of non-discrimination is implemented and guaranteed by all, including private actors. Therefore, States have a positive
obligation to fight discrimination in the various areas of life, extending to customary practices based on local and world religions, which, as previously mapped by the Special Rapporteur, continue to be the source of discriminatory attitudes towards persons affected by Hansen’s disease and their family members. This positive obligation requires the adoption of specific legal and policy measures, including legislation. The duty of the relevant States to adopt anti-discrimination legislation specific to Hansen’s disease is therefore implicit in this positive obligation.

26. States must ensure that private organizations, companies, establishments and services eliminate discriminatory measures and practices towards persons affected by Hansen’s disease and their family members. This obligation includes the responsibility to enact and enforce legislation that prohibits discriminatory acts, which includes interpersonal discrimination, institutionalized discrimination and systemic discrimination, as well as any discriminatory acts perpetrated by third parties that may restrict the equal access of persons affected by Hansen’s disease and their family members to services, facilities, transportation and educational and employment opportunities. States are also responsible for ensuring that acts of violence committed against this group of people are duly investigated and punished.

27. In addition, it is also the responsibility of States to fulfil de facto the rights to equality and non-discrimination. Guaranteeing these rights in practice requires that deliberate and purposeful concrete steps are taken to ensure that the structural disadvantage and violence experienced by persons who are structurally discriminated against, like individuals affected by Hansen’s disease, are duly addressed. This positive obligation includes developing and implementing evidence-based public policies, plans, programmes and strategies, for which systematic data collection is essential and must include disaggregation, not only by demographic, environmental, socioeconomic and cultural variables, but also by the various grounds of discrimination recognized in international human rights law, and must respect the principles of participation and privacy.

28. Likewise, the provision of remedies for ongoing human rights violations, as well as reparation measures provided within the framework of transitional justice for past violations perpetrated by States in the name of public health, are fundamental to ensuring that society as a whole commits to the principles of fairness, equality and non-discrimination, and also to promoting free and fair societies.

29. With respect to positive obligations to develop and implement policies, programmes and strategies for eliminating discrimination on the grounds of Hansen’s disease, the Special Rapporteur recommends that States adopt her policy framework for rights-based action plans as guidance, which focuses on four main areas: adequate standard of living and economic autonomy; non-discrimination, independent living and inclusion in the community; elimination of stereotypes and the right to truth and memory; and empowerment, with a focus on vulnerable groups.

IV. The duty of enacting anti-discrimination legal frameworks, as provided for in the jurisprudence of the treaty bodies

30. Within the scope of their competence, the treaty bodies have reinforced the duty of States to take concrete measures to ensure the right to non-discrimination. The Human Rights Committee, in its general comment No. 18 (1989) on non-discrimination, states that “It is for the States parties to determine appropriate measures to implement
the relevant provisions. However, the Committee is to be informed about the nature of such measures and their conformity with the principles of non-discrimination and equality before the law, and equal protection of the law.” The Human Rights Committee called the attention of States parties to the fact that the Covenant sometimes expressly requires them to take measures to guarantee the equality of rights of the persons concerned. Such steps may take the form of legislative, administrative or other measures.9

31. In its general comment No. 20 (2009) on non-discrimination in economic, social and cultural rights, the Committee on Economic, Social and Cultural Rights establishes that, in addition to refraining from discriminatory actions, States parties should take concrete, deliberate and targeted measures to ensure that discrimination in the exercise of Covenant rights is eliminated. The adoption of legislation to address discrimination is indispensable. States parties are therefore encouraged to adopt specific legislation that prohibits discrimination in the field of economic, social and cultural rights. Such laws should aim at eliminating formal and substantive discrimination, attribute obligations to public and private actors and cover the prohibited grounds.10 The Committee on Economic, Social and Cultural Rights further reinforces the importance of involving groups targeted by discrimination in decision-making processes regarding anti-discrimination measures to be taken by States parties, as well as the obligation to monitor the effectiveness of such measures: “Individuals and groups of individuals, who may be distinguished by one or more of the prohibited grounds, should be ensured the right to participate in decision-making processes over the selection of such measures. States parties should regularly assess whether the measures chosen are effective in practice.”11

32. In its general comment No. 6 (2018) on equality and non-discrimination, the Committee on the Rights of Persons with Disabilities provides guidance on the adoption of anti-discrimination laws that are based on the human rights of persons with disabilities. The Committee establishes the positive obligation of States to protect persons with disabilities from discrimination, which implies enacting comprehensive and specific anti-discrimination laws. The Committee further stresses the importance of creating effective responses to make anti-discrimination legislation effective. According to the Committee:

“Equal and effective legal protection against discrimination” means that States parties have positive obligations to protect persons with disabilities from discrimination, with an obligation to enact specific and comprehensive anti-discrimination legislation. The explicit legal prohibition of disability-based and other discrimination against persons with disabilities in legislation should be accompanied by the provision of appropriate and effective legal remedies and sanctions in relation to intersectional discrimination in civil, administrative and criminal proceedings. Where the discrimination is of a systemic nature, the mere granting of compensation to an individual may not have any real effect in terms of changing the approach. In those cases, States parties should also implement “forward-looking, non-pecuniary remedies” in their legislation, meaning that further effective protection against discrimination carried out by private parties and organizations is provided by the State party.12

33. In discussing the implementation of the Convention on the Rights of Persons with Disabilities at the national level, the Committee on the Rights of Persons with Disabilities, general comment No. 6 (2018), para. 22.

---

9 See Human Rights Committee, general comment No. 18 (1989), paras. 4 and 5.
10 Committee on Economic, Social and Cultural Rights, general comment No. 20 (2009), paras. 36 and 37.
11 Ibid., para. 36.
12 Committee on the Rights of Persons with Disabilities, general comment No. 6 (2018), para. 22.
Disabilities explicitly highlights the State’s obligations to enact anti-discrimination legislation. The Committee reinforces the importance of ensuring that the legislation has a broad personal and material scope, provides for legal remedies and has a broad definition of impairment-related disability, indicating that States parties should:

Develop anti-discrimination laws where they do not exist and enact disability-inclusive anti-discrimination laws that have a broad personal and material scope and provide effective legal remedies. Ensure that non-discrimination legislation extends to the private and public spheres, covers areas including education, employment, goods and services, and tackles disability-specific discrimination, such as segregated education, institutionalization, denial or restriction of legal capacity, forced mental health treatment, denial of the provision of sign language instructions and professional sign language interpretation, and denial of Braille or other alternative and augmentative modes, means and formats of communication.13

34. Women’s right to non-discrimination is the pillar of the Convention on the Elimination of All Forms of Discrimination against Women. The Committee on the Elimination of Discrimination against Women stresses the comprehensive nature of State obligations to ensure non-discrimination against women in its general recommendation No. 28 (2010) on the core obligations of States parties under article 2 of the Convention:

States parties must address all aspects of their legal obligations under the Convention to respect, protect and fulfil women’s right to non-discrimination and to the enjoyment of equality. The obligation to respect requires that States parties refrain from making laws, policies, regulations, programmes, administrative procedures and institutional structures that directly or indirectly result in the denial of the equal enjoyment by women of their civil, political, economic, social and cultural rights. The obligation to protect requires that States parties protect women from discrimination by private actors and take steps directly aimed at eliminating customary and all other practices that prejudice and perpetuate the notion of inferiority or superiority of either of the sexes, and of stereotyped roles for men and women. The obligation to fulfil requires that States parties take a wide variety of steps to ensure that women and men enjoy equal rights de jure and de facto, including, where appropriate, the adoption of temporary special measures ... This entails obligations of means or conduct and obligations of results. States parties should consider that they have to fulfil their legal obligations to all women through designing public policies, programmes and institutional frameworks that are aimed at fulfilling the specific needs of women leading to the full development of their potential on an equal basis with men.14

35. It is clear that the jurisprudence of the treaty bodies clearly affirms the positive obligation of States to develop and enact anti-discrimination legal frameworks as part of the measures they must take to enforce the core human rights principle of non-discrimination and guarantee the universality of human rights.

13 Ibid., para. 73 (b) and (c).
14 See Committee on the Elimination of Discrimination against Women, general recommendation No. 28 (2010) on the core obligations of States parties under article 2 of the Convention, para. 9.
V. Comprehensive anti-discrimination laws and those specific to Hansen’s disease among the priority countries for Hansen’s disease

36. Anti-discrimination legal frameworks in the 23 WHO global priority countries for action on Hansen’s disease were examined in order to understand whether or not Hansen’s disease is included in comprehensive anti-discrimination laws and if there are any anti-discrimination laws in place with provisions specific to Hansen’s disease. This exercise aims at supporting the relevant States in assessing the state of their positive obligations towards the protection of persons affected by Hansen’s disease and their family members. It does not pretend to be an exhaustive exercise and the Special Rapporteur is always open to dialogue, in case some information was missed. The fact is that, over the years, the requests by the Special Rapporteur for Member States to provide input were quite often dismissed by the majority of States.

37. WHO global priority countries for action on Hansen’s disease are derived from a composite index using parameters such as prevalence, new case detection, the proportion of females and children affected, and irreversible physical impairments at the time of diagnosis. The 23 priority countries are: Angola, Bangladesh, Brazil, Comoros, Côte d’Ivoire, Democratic Republic of the Congo, Egypt, Ethiopia, Micronesia (Federated States of), India, Indonesia, Kiribati, Madagascar, Mozambique, Myanmar, Nepal, Nigeria, Philippines, Somalia, South Sudan, Sri Lanka, Sudan and United Republic of Tanzania.

38. It is important to note that Hansen’s disease also affects countries that are not among the 23 priority countries, especially in South America, Africa and Asia. One of the four pillars of the WHO global leprosy strategy 2021–2030 concerns combating stigma and ensuring that human rights are respected. In that regard, States should report to WHO annually on their efforts to combat stigma and ensure that the human rights of persons affected by Hansen’s disease are respected. The Special Rapporteur recommends that States make use of the standards she has developed over the years to: (a) define the criteria for assessing stigmatization and discrimination on the grounds of Hansen’s disease; and (b) document good practices for combating both stigmatization and discrimination on the grounds of Hansen’s disease with a view to sharing best practices among States.15

39. All 23 countries have some constitutional provisions regarding the right to equality and non-discrimination, but very few translate such provisions into domestic law. According to the sources that were consulted,16 only Bangladesh has a comprehensive anti-discrimination law, which is still under discussion in the Parliament.

40. The Special Rapporteur discussed the anti-discrimination bill of 2022, elaborated by the Law Commission of Bangladesh, in her country visit report and has specifically called upon the Government to include Hansen’s disease as a prohibited ground of discrimination in that bill.17

41. Other than the bill in Bangladesh, there is no information available about any comprehensive anti-discrimination law in any of the 22 remaining countries. Nevertheless, there are several examples of legal frameworks that address

---

15 The Special Rapporteur would like to thank the Global Leprosy Programme of WHO for the discussions on pillar IV of the global leprosy strategy 2021–2030 for the present report.


17 See A/HRC/53/30/Add.2.
discrimination, although not in a comprehensive manner, but merely focusing on a few specific grounds of discrimination. Only one country, Brazil, enacted what might be considered an anti-discrimination law specific to Hansen’s disease, although its scope is extremely narrow, only prohibiting what the same law considers to be discriminatory language. The text in question is Law No. 9010/1995, which protects persons affected by Hansen’s disease from discriminatory language, by officially replacing the term leprosy with “hanseníase”.

42. The research raised important concerns about the fact that, in many of these countries, there are provisions in force that either discriminate on certain grounds (the most frequent one being sexual orientation) or fail to fully protect some groups of people (such as women or persons with disabilities), which include persons affected by Hansen’s disease.

43. The obligation to not discriminate extends to all groups of people, without exception. Reservations to the provisions of international human rights instruments continue to act as a major barrier to enforcing human rights in accordance with the provisions of the Universal Declaration of Human Rights and the principles endorsed by the Vienna Declaration and Programme of Action, which affirms that all human rights are universal, indivisible, interdependent and interrelated.

44. The present analysis shows that non-discrimination, while being a core human rights principle, together with equality as one of the more fundamental pillars of the Universal Declaration of Human Rights, is still far from being duly enforced.

45. Existing laws and norms with non-discriminatory provisions should be reviewed and amended to include all grounds of discrimination, including Hansen’s disease. States must do more to comply with paragraph 32 of the Vienna Declaration, which reaffirms the importance of ensuring the universality, objectivity and non-selectivity of the consideration of human rights issues. Human rights are universal and must be enjoyed on a non-discriminatory basis by all people, including persons affected by Hansen’s disease and their family members.

VI. Ensuring the right to participation for persons affected by Hansen’s disease and their family members in legislative processes

46. The Special Rapporteur has continuously drawn attention to the centrality of the right of persons affected by Hansen’s disease and their family members to participate in decision-making processes that affect them. This right is even more essential considering the multiple barriers faced by persons affected by Hansen’s disease and their family members to enjoying effective civic and political participation.

47. The principles and guidelines for the elimination of discrimination against persons affected by leprosy and their family members reiterate the need for full participation of persons affected by Hansen’s disease and their family members, with autonomy, in all aspects of life. The same instrument emphasizes their right to defend their own interests in decisions about policies, programmes and other measures that directly involve them and have an impact on their lives.

48. The difficulties faced by excluded or underrepresented groups in exercising the right to participation include the following: outdated paternalistic approaches; harmful stereotypes; stigmatization; inaccessibility (physical, cultural, linguistic, infrastructural and informational); legal and administrative barriers (restrictions on their legal and political capacity); formal and informal segregation (in schools, workplaces and public institutions); and a lack of support.
49. The participation of persons affected by Hansen’s disease and their family members should be fully ensured in any legislative process aimed at discussing anti-discrimination law or provisions, both general and specific to Hansen’s disease, for several reasons. First, their participation adds political legitimacy to such a law, while also increasing the chances of it being successfully implemented. Second, guaranteeing their involvement and participation ensures that the law will be passed by a parliament that has strived to be more inclusive in the decision-making process and that can therefore gain greater trust from society and also share responsibility with society for the implementation of the law. Third, in addition to the more obvious advantage of ensuring greater accountability and transparency in the law-making process, the effective participation of persons affected by Hansen’s disease and their family members ensures that the text of the law truly speaks to their legitimate interests.

50. Sherry Arnstein presented a sort of ladder for citizen participation, ranging from more elementary forms to more complex ones. Among the types of involvement and participation described by Arnstein, the following are emphasized:

   (a) **Informing.** This is a basic first step in ensuring participation, by informing citizens about their rights and responsibilities. The limitations of this step for participation are made evident in the fact that information is often given in one direction, without room for individual involvement in the issue or the power to intervene in it. On the other hand, it is common for lay people to feel intimidated by the technical nature of terms and procedures;

   (b) **Consultation.** Providing a space for citizens to give their opinion is a second important step for ensuring participation. It also has limitations, however, when there is no guarantee that these opinions will actually be taken into account. In practice, consultation often provides an abstract statistical number of meetings that have been held and the number of people involved, without being accompanied by effective mechanisms that can ensure that opinions and viewpoints are actually taken into consideration;

   (c) **Placation.** This occurs when some citizens are guaranteed a limited degree of influence in a process. An example of this might be when power-holders choose certain citizens, who are already aligned with them, to make up committees or working groups, merely to show that citizens have been involved in the process.

51. Informing, consultation and placation may very well be merely tokenistic strategies and, in the cases observed by the Special Rapporteur over the years regarding the participation of persons affected by Hansen’s disease and their family members, in Governments, intergovernmental bodies and civil society organizations, they usually are.

52. Increased degrees of actual influence on policymaking include the following:

   (a) **Delegated power.** Whereby public institutions, officials or administrators give up some degree of control, administration, decision-making authority or funding to be managed and administered by the citizens themselves, such as the administration of some community programmes;

   (b) **Citizen control.** Such that citizens effectively manage or have power over certain programmes or institutions. To have power means to make decisions about political and managerial aspects, and to have control over the conditions under which there can be a change in programmes or in the ways the institutions operate.

---

53. These categories are important for identifying the possible stages of citizen involvement in a legislative process responsible for drafting an anti-discrimination law. The passing of new laws and the monitoring of existing laws and programmes, that may have a discriminatory impact on persons affected by Hansen’s disease, are examples of opportunities for participation that should afford those persons meaningful capacity to influence decision-making, by making use of delegated power and citizen control.

54. Another critical aspect in the promotion of participation by persons affected by Hansen’s disease and their family members is mentioned in the Convention on the Rights of Persons with Disabilities. Inarguably, there are several systemic barriers to the full and meaningful participation of marginalized groups, which persons affected by Hansen’s disease and their families often face. Such barriers include: illiteracy and low levels of educational qualifications; legal impediments; inaccessibility of administrative procedures and requirements; inaccessibility and unintelligibility of the information being provided; physical and environmental barriers; and the lack of support mechanisms for overcoming structural disadvantages that are reflected in unequal and unfair socioeconomic and education status.

55. In article 29 of the Convention on the Rights of Persons with Disabilities, with the acknowledgement of those multiple barriers, the obligation of States to actively promote enabling environments, ensuring equality and guarantees of the freedom of expression, accessibility, accommodation of procedures and support is affirmed. Accessibility is an indispensable condition for the fulfilment of the right to participation related to information, communication, infrastructure and transport.

56. In order to strengthen the conditions under which participation can become effective, legislative bodies and other public agencies should make all efforts necessary to educate citizens and raise awareness about opportunities for their engagement in legislative activities, as well as provide incentives to encourage citizens to participate in the same legislative processes. According to ParlAmericas, examples of measures that can be adopted to encourage citizen participation in legislative processes are:

   (a) **Awareness-raising programmes and campaigns.** Parliaments can conduct awareness-raising campaigns to educate citizens as to the function of the parliament and expose them to existing participation mechanisms and/or promote participation in a specific process. Campaigns can also be launched in collaboration with civil society organizations;

   (b) **Citizen participation offices and communications departments.** A citizen participation office or communications department can have various mandates, from educating citizens regarding the role of the parliament to disseminating information on the work of the parliament and collecting direct input from citizens into the legislative process;

   (c) **Parliamentary websites.** As a hub of information, parliaments’ websites can include a section to educate citizens about their role, work and impact, as well as other explanations of the mechanisms through which citizens can participate in the legislative process;

   (d) **Educational programmes for children and youth.** Learning about the role and value of parliament at an early age can prepare children and youth to become politically active citizens. Such programmes can be virtual or in-person and include interactions with parliamentarians, games, simulations of parliamentary processes, prizes and interactive materials tailored to children and youth;

---

19 See ParlAmericas, *Citizen Participation in the Legislative Process* (Ottawa, 2018).
(c) **Meetings, public hearings and public forums.** Meetings can be held to invite citizens to participate in a particular legislative process, and they can also be useful mechanisms to educate citizens regarding the role and functions of the parliament, explain the day-to-day impact of legislative issues on citizens’ lives and share how citizens can get involved;

(f) **Supporting the work of independent civil society organizations.** Parliamentarians can contribute to building a strong and independent civil society by promoting and supporting the work of civil society organizations, including parliamentary monitoring organizations, by participating in their activities, contributing to their projects and encouraging citizens to work with them;

(g) **Incentives for participation.** Parliaments can provide incentives to citizens to encourage their participation. These can include awards, prizes, public records of input or even providing online users with special benefits based on the frequency of their use of a particular participatory mechanism;

(h) **Media.** Through its own parliamentary television and radio channels, collaboration with State-owned or private channels, online or printed newspapers, and new digital platforms such as video-sharing platforms and podcasts, the parliament can develop content to inform citizens of its role and functions and mechanisms that are available for citizens to participate in its work, as well as livestream its proceedings.

57. The steps set out in paragraph 56 above are some of the fundamental steps States should take to fully guarantee the right to participation on a non-discriminatory basis to citizens in general, but also to individuals entitled to the provisions of any anti-discrimination law to be drafted and enacted. Governments and parliamentarians have a duty to seek to be informed about discrimination and its impact on the people affected, to raise awareness among other public servants, members of the judiciary and law enforcement officers, to facilitate committees of parliamentarians aiming to promote good laws that advance the well-being and fundamental dignity of all and to call for a review of the legislation when needed.

58. Actions that could be taken by civil society organizations with a view to changing laws and enacting new ones include, but are not limited to: (a) building evidence with which to raise awareness among legislators and working with parliamentarians with a view to undertaking the necessary reforms; (b) strategic litigation undertaken by either individuals and organizations; and (c) advocating the holding of public consultations and referendums.

### VII. An intersectional approach to anti-discrimination legal frameworks

59. As a rule, anti-discrimination law and jurisprudence focus on a single ground of discrimination. Human rights bodies, mechanisms and courts either concentrate on a sequential analysis of multiple grounds of discrimination, trying to separate the discrimination suffered on each ground, or strategically choose a ground of discrimination, taking into account the strongest evidence available about the concerned act of discrimination. In other situations, the grounds of discrimination are added up, and one ground is seen as aggravating the discrimination already enacted on another ground.

60. Sandra Fredman conceptuallyizes three categories of discriminations that occur on the basis of more than one ground: (a) sequential multiple discrimination, which

---

occurs when a person suffers discrimination on different grounds on separate occasions; (b) additive multiple discrimination, which occurs when a person is discriminated against on the same occasion but in two different ways; and (c) intersectional discrimination, meaning discrimination that does not simply consist of the addition of two sources of discrimination. A specific and distinct form of discrimination results from the simultaneous combination of two or more discrimination grounds that operate synergistically.

61. That was the original concept of intersectionality. It originated from the need to understand the discrimination against black women through an analysis that simultaneously encompassed gender and race. Intersectionality is not an additive approach. Accordingly, different categories do not accumulate, but interrelate in dynamic ways that always have a particular system of domination as a background. This means that intersectionality stands for the numerous effects that result from the intersection of distinct differential axes in specific historical contexts. It also means that different dimensions of social life cannot be artificially separated into pure phenomena.

62. In practice, this means that discrimination on the grounds of Hansen’s disease affects individuals in different ways according to their social status and capital, often by intersecting with gender-based discrimination, discrimination against children, discrimination against older people or disability-based discrimination, but also with other grounds, such as race, caste or social class. That concept is fully supported by the evidence collected for both the thematic and country reports of the Special Rapporteur.

63. In the case of persons affected by Hansen’s disease, the legal framework for anti-discrimination must adopt an intersectional perspective because the traditional rationale for addressing discrimination based on Hansen’s disease is based on a single-ground approach. That is one of the areas where the principles and guidelines for the elimination of discrimination against persons affected by leprosy and their family members might be expanded. As affirmed by the Special Rapporteur in another report, while the aforementioned instrument has many strong points, discrimination on the grounds of Hansen’s disease, especially as it is experienced by younger generations, calls for detailing the rights of persons affected by Hansen’s disease and their family members under an expanding framework that aligns more closely with the comprehensive nature of core human rights instruments on civil, political, economic, social and cultural rights, as well as with rights elaborated for groups historically discriminated against or in need of special protection, and with the jurisprudence elaborated by the human rights treaty bodies. This should be done through an intersectional approach to discrimination.

64. Traditionally, persons affected by Hansen’s disease and their family members have been approached as victims of discrimination with what can be called an essentialist approach, meaning they have largely been seen as a homogeneous group that suffers from the same patterns of discrimination. The reality is much more complex than that. There are different levels of vulnerability to discrimination on the grounds of Hansen’s disease among different individuals, requiring consideration of overlapping layers of protection. Often occupying the bottom of the social pyramid, persons affected by Hansen’s disease tend to be the victims of intersecting and aggravated forms of discrimination and are often affected by the larger structural inequalities of society, especially those manifested by gender, age, disability and oppressive poverty.

---

65. Based on the guidance note on intersectionality prepared by the United Nations network on racial discrimination and protection of minorities,\textsuperscript{22} taking intersectionality seriously in anti-discrimination laws and provisions aimed at protecting persons affected by Hansen’s disease involves measures, such as:

(a) Paying specific attention to individuals who are insufficiently protected from human rights violations, including but not limited to women, children, older persons, persons with disabilities, people of African descent, Indigenous people and people from marginalized castes and communities;

(b) Recognizing that persons affected by Hansen’s disease are not a homogenous group of people and making every effort to increase the visibility and active participation of those who, within the same community, are more marginalized and face more barriers to making their voices heard and taken into account;

(c) Stressing that addressing discrimination is interconnected with the empowerment of concerned groups, which should always include their critical understanding of the forces that disable them, and also their greater control over decisions and resources, including matters that concern the development, implementation and monitoring of policies and programmes that have an impact on their lives; in this regard, it is important to ensure that decision-making processes are gender-, child- and disability-sensitive, and also inclusive of local languages;

(d) Developing policies and programmes that recognize intragroup diversity and avoiding homogenizing approaches while respecting, protecting and ensuring the exercise of human rights for all and responding to the unaddressed needs of all;

(e) Enhancing the availability and analysis of disaggregated data as the basis for effective policy development and programming;

(f) Advancing systemic change by addressing the structural causes of the inequality and disadvantages that are associated with intersecting forms of discrimination, including sociocultural and religious norms and harmful stereotypes that perpetuate and/or aggravate the exclusion of certain individuals, groups and communities, as well as the substantive discrimination that keeps those discriminated against in poverty and extreme poverty, as is the case of the majority of persons affected by Hansen’s disease and their family members.

VIII. Conclusions and recommendations

66. In order to fulfil their obligations of non-discrimination under international human rights law, States should enact comprehensive anti-discrimination legal frameworks that are inclusive of all individuals and groups in order to guarantee the universal enjoyment of human rights. There cannot be double standards in the enforcement and enjoyment of the right to non-discrimination. Already three decades since the Vienna Declaration and Programme of Action was adopted, human rights for all has yet to be achieved and selectivity, which is contrary to article 32 of the Declaration, is still occurring both in law and in practice. Greater commitment to the core principle of non-discrimination is required.

67. In order to combat systemic discrimination against persons affected by Hansen’s disease and their family members (which is persistent and encompasses direct and indirect discrimination, harassment, denial of reasonable accommodation, victimization, as well as interpersonal and structural violence) States should take all the necessary steps to fulfil their positive obligations to

\textsuperscript{22} United Nations network on racial discrimination and protection of minorities, \textit{Guidance Note on Intersectionality, Racial Discrimination and Protection of Minorities} (Geneva, 2022).
protect this group of people and guarantee them both formal and substantive equality.

68. States should begin by reviewing, amending, repealing or abolishing all laws, regulations, ordinances, resolutions and policies that discriminate against persons affected by Hansen’s disease and that deny them the enjoyment of rights on an equal basis with others at both the national and subnational levels of government.

69. States in which there is still a high incidence of Hansen’s disease should make every effort to ensure that individuals affected by the disease, and their family members, enjoy human rights on an equal basis with others, and to that end they should develop and enact anti-discrimination laws and/or statutes specific to Hansen’s disease, involving organizations of persons affected by Hansen’s disease in the overall process, as detailed by the Special Rapporteur in the present report. Such laws or statutes should be guided by the principles set out below.

70. The personal scope of these legal frameworks should refer to Hansen’s disease, prohibiting discrimination on that ground and extending such prohibition to all areas of the private and public spheres. Prohibition of discrimination on the grounds of Hansen’s disease should always reflect the fact that the majority of persons affected by Hansen’s disease and their family members are the victims of structural violence and that their experience results from the intersection of Hansen’s disease with other prohibited grounds of discrimination, thereby expressly recognizing the aggravated discrimination suffered by women, children, older persons, persons with disabilities, people of African descent, Indigenous people and people from marginalized castes and communities, and including special measures to respond to intersectional discrimination.

71. Discrimination should be prohibited both on the basis of perception and association. Consistent definitions of all forms of discrimination faced by persons affected by Hansen’s disease and their family members should be provided and in line with what is recognized in international human rights law. Direct and indirect discrimination, harassment, segregation, denial of reasonable accommodation, victimization and interpersonal violence, among other prohibited behaviours identified by persons affected by Hansen’s disease, their family members and representative organizations, should be properly prohibited.

72. Discrimination on the grounds of Hansen’s disease by public authorities, public servants and the entire administration of the State, at both the national and subnational levels, should be expressly prohibited, investigated and punished. Discriminatory language should be monitored and removed from any material published by the government. Public servants in key sectors, such as education, public employment, social protection and justice, should receive training on the rights of persons affected by Hansen’s disease and their family members.

73. Third parties should be prohibited from interfering with the rights of persons affected by Hansen’s disease and their family members and measures for monitoring discrimination in the private sector should be enacted.

74. Effective monitoring systems on traditional customs and practices that discriminate against persons affected by Hansen’s disease and their family members at the local level should be implemented; and communities, community and traditional leaders, as well as women, should be mobilized for the
elimination of harmful traditional customs and practices based on Hansen’s
disease at the local level, with the full participation of organizations of persons
affected by Hansen’s disease, including women and children affected by
Hansen’s disease; traditional customs and practices that discriminate against
persons affected by Hansen’s disease and their family members should be
criminalized when needed.

75. Awareness-raising programmes that are sensitive to culture, language,
gender, age and disability and that are developed in close collaboration with local
communities in order to ensure both accessibility and efficacy should be
implemented.

76. Discrimination on the grounds of Hansen’s disease should be criminalized,
prevented, investigated and punished by effective, proportionate and dissuasive
criminal penalties. Redress should be guaranteed and the specific protection
needs of victims should be assessed as part of redress measures. Victims should
never be victimized in the process.

77. Domestic violence against persons affected by Hansen’s disease, especially
women, children and older people, should be prohibited, investigated and
punished.

78. Hansen’s disease should be included as prohibited grounds for
discrimination in existing monitoring mechanisms and oversight institutions,
with the participation of organizations of persons affected by Hansen’s disease,
and data should be systematically collected and disaggregated by demographic,
environmental, socioeconomic and cultural variables, with full respect for the
principles of participation and privacy.

79. Accessible mechanisms for filing complaints about the violation of rights on
the grounds of Hansen’s disease should be provided, while guaranteeing that
those filing complaints would never experience any form of victimization or
retaliation.

80. Remedies and redress should be duly provided to victims and access to
justice should be enabled by removing all the barriers that persons affected by
Hansen’s disease and their family members face in accessing justice. It should be
fully recognized that access to justice is one of the main instruments for
protecting civil, political, economic, social and cultural rights. It is through the
equal and effective guarantee of access to justice that people may stand up in
defence of their rights, objecting to situations of discrimination and violation and
holding policymakers accountable. Equal access to justice for all and capacity-
building with respect to legal rights and legal aid should be fully guaranteed and
made available to persons affected by Hansen’s disease and their family
members. States should implement the necessary measures for: removing
economic barriers, with the provision of legal aid; removing linguistic and
cultural barriers, with the provision of translation and interpretation services;
providing assistance to illiterate individuals and intercultural interpretation;
developing partnerships with traditional justice systems to ensure that a rights-
based approach to Hansen’s disease is taken in contexts of juridical pluralism;
systematically recording discrimination for supporting research and analysis of
risk factors; training judicial staff on issues related to Hansen’s disease; and
providing quick, adequate, holistic, efficient and proportional remedies.

81. Restorative justice should be connected to prevention, through the
prohibition of all forms of segregation of persons affected by Hansen’s disease
and the recognition of the damage perpetrated by both official and non-official
historical segregation through the enactment of reparation measures that can
simultaneously redress harm at the individual level and eliminate segregation and violations related to Hansen’s disease. Reparation programmes that encompass both material reparations, aimed at redressing structural disadvantages, and symbolic reparations, aimed at enabling systemic change, with effective remedies, including compensation, reparation, restitution and rehabilitation, should be implemented.

82. The engagement of persons affected by Hansen’s disease and their family members in leadership positions in public and political life should be protected and promoted through affirmative measures that can correct the historical and structural disadvantage that has curtailed their rights and those of their family members to participate in public and political life.

83. The material scope of anti-discrimination laws or statutes should encompass all the areas of life regulated by law and the behaviour of both public and private actors. The material scope of anti-discrimination laws should also emphasize the areas of life identified by the principles and guidelines for the elimination of discrimination against persons affected by leprosy and their family members, in which measures for ensuring substantive equality for persons affected by Hansen’s disease and their family members, as well as access to fundamental rights on an equal basis with others, should be implemented.

84. In order to accelerate de facto equality, affirmative or special measures should be expressly permitted and their development and enactment required, and in all cases, guaranteeing the meaningful participation of organizations of persons affected by Hansen’s disease. They should be temporary in principle, but in some cases, they may need to be permanent in nature and should be implemented by the public sector and their implementation promoted for replication in the private sector.

85. A proper institutional framework will be needed for the implementation of anti-discrimination laws, which may include the creation of an equality body responsible for assessing the enjoyment of equality by persons affected by Hansen’s disease and their family members, as well as discrimination against them. The same equality body should make every effort to: educate persons affected by Hansen’s disease and their family members as to their rights; establish mechanisms for receiving complaints on discrimination that should be accessible and sensitive to local languages, disability, age and gender; monitor the degree to which the laws in question are effective in partnership with representative organizations and groups of persons affected by Hansen’s disease; systematically publish data collected, with full transparency and in accessible formats; mainstream the protection and fulfilment of the rights of persons affected by Hansen’s disease and their family members into the different sectors of government, especially in education, public employment, social protection and justice; and make evidence-based proposals for changes to laws and policies. The equality body must guarantee the meaningful participation of persons affected by Hansen’s disease, their family members and representative organizations in all its activities. Governments must ensure proper budget allocation to the work of the equality body.