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

## **Elimination of discrimination against persons affected by leprosy and their family members**

### **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, in accordance with Human Rights Council resolution [44/6](#).

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\* [A/76/150](#).



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

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

#### *Summary*

The present report is the first report 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, she 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. She also 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. In order to contribute to the elimination of formal discrimination and to the enforcement of formal equality for persons affected by leprosy, the Special Rapporteur 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.

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## I. Introduction

1. In 2010, the General Assembly adopted resolution [65/215](#) on the elimination of discrimination against persons affected by leprosy and their family members, reaffirming that persons affected by leprosy and their family members should be treated as individuals with dignity and are entitled to all human rights and fundamental freedoms under customary international law, relevant conventions and national constitutions and laws. In the resolution, the Assembly also took note of the principles and guidelines for the elimination of discrimination against persons affected by leprosy and their family members.

2. The principles and guidelines are a non-treaty standard that reinforces international human rights instruments, interpreting and translating legally binding norms in close connection with the conditions and needs of the particular group of persons affected by leprosy and their family members (see [A/HRC/41/47](#)). They provide States with a road map for monitoring the situation of persons affected by leprosy and their family members and for implementing measures that, by enforcing international human rights law, can guarantee formal and substantive equality for them.

3. In its resolution [35/9](#), the Human Rights Council established the mandate of the Special Rapporteur on the elimination of discrimination against persons affected by leprosy and their family members to follow up and report on progress made and measures taken by States for the effective implementation of the principles and guidelines. In its resolution [44/6](#), the Council extended the mandate of the Special Rapporteur to continue to report to it annually, and to report also to the General Assembly.

4. The Special Rapporteur on the elimination of discrimination against persons affected by leprosy and their family members, Alice Cruz, has implemented a people-centred approach to the mandate entrusted to her by the Human Rights Council. The historical and systemic dehumanization of persons affected by leprosy and their family members makes empowerment key for fighting back against their structural and widespread subordination. By promoting active participation, critical reflection, awareness-raising, understanding and access to and control over important decisions and resources, empowerment allows for people in disadvantaged situations to achieve greater control over their lives, furthering their democratic engagement, with enhanced critical understanding of their own settings and their relationship to power relations and hegemonic social structures.

5. With such an approach, the Special Rapporteur seeks to provide a bridge for a group of people living in an extreme vulnerable situation who have been systematically pushed furthest behind within the overall human rights system, and thus ensure the sustainability of efforts undertaken for eliminating both the disease and the stigmatization attached to it, since the empowerment of individuals and groups can contribute to transforming laws, policies, practices, norms and power relations. Such an approach also reflects the spirit of the 2030 Agenda for Sustainable Development, in which it was affirmed that development must go beyond transforming the material conditions of people in disadvantaged circumstances to actually enabling them to have a voice and a choice.

6. Building also on a cooperative approach, the Special Rapporteur has continuously engaged with United Nations bodies and intergovernmental agencies – especially the World Health Organization (WHO) – Member States, political and religious world leaders, academia and the main stakeholders in the field, such as the WHO Goodwill Ambassador for the Elimination of Leprosy, the Global Partnership for Zero Leprosy, civil society organizations working with leprosy and national and grass-roots organizations of persons affected by leprosy, to promote synergies and catalyze systemic change.

7. The Special Rapporteur has contributed to the WHO road map for neglected tropical diseases 2021–2030<sup>1</sup> and to the WHO global leprosy strategy 2021–2030<sup>2</sup> and has proactively promoted the mainstreaming of leprosy within the treaty bodies, especially the Committee on the Rights of Persons with Disabilities, and the universal periodic review. She has also dedicated efforts to make human rights standards accessible to persons affected by leprosy and their representative organizations. She has continuously made herself available to provide technical guidance to key stakeholders for tackling stigmatization and discrimination on the grounds of leprosy.

8. The work of the mandate of the Special Rapporteur has enabled the production of a body of new evidence about discrimination on the grounds of leprosy and increased wider attentiveness to, and engagement with, a gender approach to leprosy-related issues, as well as the participation of persons affected by leprosy and their representative organizations. The Special Rapporteur has presented a policy framework for rights-based action plans and has provided guidance to States and civil society organizations on the context of the disproportionate impact of the coronavirus disease (COVID-19) pandemic on persons affected by leprosy and their family members.<sup>3</sup>

9. In the present report, which is her first report to the General Assembly, the Special Rapporteur examines discrimination against persons affected by leprosy in national legal frameworks. The imperative of legal harmonization as part of global and national efforts to eliminate discrimination on the grounds of leprosy is included in: guideline No. 1 of the principles and guidelines, which affirms that States should take all appropriate legislative, administrative and other measures to modify, repeal or abolish existing laws, regulations, policies, customs and practices that discriminate directly or indirectly against persons affected by leprosy and their family members; several provisions of international human rights law; and strategic pillar 4 of the WHO global leprosy strategy. According to WHO, 21 countries reported that they still had 39 laws in place in 2018 that permit discrimination on the basis of leprosy,<sup>4</sup> which evinces the importance of enforcing formal equality for persons affected by leprosy.

10. The importance and impact of discrimination in law includes: classification of groups of people and framing of identities; access to resources, services and rights; and opportunities for freely and autonomously acting in society. The increasing power of the law to frame public and private dimensions of social life is undeniable. It has been noted by the Working Group on discrimination against women and girls that laws are an essential mechanism for the enjoyment of human rights. Laws determine the operating values and principles through which actions and behaviours are considered acceptable or criminalized and stigmatized (see [A/HRC/35/29](#)). Undeniably, laws play a structuring role in the dynamics of formal, as well as substantive, discrimination in the sense that they codify, regulate and influence social behaviour.

11. If it is true that, in practice, discrimination refers to any unfair or prejudicial treatment of people that leads to loss of opportunities, material deprivation, structural disadvantage, stigmatization and poor access to the State's goods and services, the fact is that an ideological bias always lies at the root of discrimination.<sup>5</sup> Such ideological biases are simultaneously sustained by and sustain unequal power relations. That is why groups discriminated against are usually deprived of the means to fight back against discrimination.

12. The key point in this regard is that institutionalized discrimination against persons affected by leprosy reflects an ideological bias socially produced throughout

<sup>1</sup> See [www.ohchr.org/Documents/Issues/Leprosy/AliceCruz-April2019.pdf](http://www.ohchr.org/Documents/Issues/Leprosy/AliceCruz-April2019.pdf).

<sup>2</sup> See [www.ohchr.org/Documents/Issues/Leprosy/STM\\_WHO\\_consultation.pdf](http://www.ohchr.org/Documents/Issues/Leprosy/STM_WHO_consultation.pdf).

<sup>3</sup> See [www.ohchr.org/Documents/Issues/Leprosy/SR\\_leprosy\\_Open\\_letter\\_22May2020.pdf](http://www.ohchr.org/Documents/Issues/Leprosy/SR_leprosy_Open_letter_22May2020.pdf) and [A/HRC/47/29](#).

<sup>4</sup> WHO, "Weekly epidemiological record", vol. 94, No. 35/36 (30 August 2019), pp. 389–412.

<sup>5</sup> Nancy Krieger, "Discrimination and health inequities", *International Journal of Health Services*, vol. 44, No. 4 (2014), pp. 643–710.

time by different cultural systems and explanatory models of leprosy, which has historically subordinated persons affected by leprosy to social structures that deny not only their belonging to local and national communities, but also their humanity. Institutionalized discrimination against persons affected by leprosy has also simultaneously been sustained by and sustained such ideological biases, authorizing and perpetuating their dehumanization by framing what society sees as normal, acceptable and desirable, as well as the opposite, which leprosy came to embody against different cultural backdrops. Undeniably, the institutionalization of discrimination on the grounds of leprosy has prompted and normalized the stigmatization and dehumanization of affected individuals. That is why legal harmonization and formal recognition of persons affected by leprosy as right holders is not only the State's obligation, but also a moral imperative.

13. Discrimination against persons affected by leprosy in law persists in the realm of States that have ratified international human rights instruments and whose national constitutions affirm the rights to equality and non-discrimination. Their mere existence hinders recognition of the human rights of persons affected by leprosy, starting with the most basic one of all: the right to equality. If a State asserts the equality of all persons before the law and at the same time keeps in place laws that discriminate against a certain group of people, then the State is actively denying fundamental rights and freedoms to that group of people and hence violating international and national obligations.

14. In order to map and report on existing discriminatory laws against persons affected by leprosy and to provide technical guidance to States in this regard, the Special Rapporteur consulted Member States and civil society organizations on national laws, regulations, ordinances, resolutions and policies that have discriminatory impacts on persons affected by leprosy and/or their family members, as well as existing customary regulations, including traditional non-written norms, that have discriminatory impacts on them. The Special Rapporteur acknowledges that different legal systems coexist in some societies, and has therefore called for the support of States and civil society organizations to map traditional non-written norms that are part of non-State legal systems. She has also requested information on measures taken to abolish or amend discriminatory laws and norms. A total of 10 States and 22 civil society organizations<sup>6</sup> have responded to her call for cooperation in assessing discrimination in law. The Special Rapporteur has also held in-depth conversations with several persons affected by leprosy and their representative organizations in order to better understand their lived experience with regard to discrimination in law.

15. Information submitted by civil society organizations, which includes the most thorough database of discriminatory laws against persons affected by leprosy that currently exists, put together by the International Federation of Anti-Leprosy Associations,<sup>7</sup> as well as data reported by other civil society organizations, was thoroughly reviewed, with the full texts of the reported laws properly identified and examined. A list with examples of discriminatory laws from different countries will be made available on web page for the present report.<sup>8</sup> The Federation's database alone identifies 130 laws in different countries that directly discriminate against persons affected by leprosy. For the assessment of discrimination in law against persons affected by leprosy, the Special Rapporteur took into consideration laws in both a strict and a broad sense. Laws in a strict sense are normative acts elaborated and approved in parliaments at the central and local levels. Laws in a broad sense are normative acts, such as regulations, decrees and guidelines, established by other regulatory bodies.

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<sup>6</sup> The submissions from States and civil society organizations that were authorized by them to be made public will be available on the web page of the mandate of the Special Rapporteur:

[www.ohchr.org/EN/Issues/Leprosy/Pages/LeprosyIndex.aspx](http://www.ohchr.org/EN/Issues/Leprosy/Pages/LeprosyIndex.aspx).

<sup>7</sup> See <https://ilepfederation.org/discriminatory-laws>.

<sup>8</sup> See [www.ohchr.org/EN/Issues/Leprosy/Pages/DiscriminatoryImpacts.aspx](http://www.ohchr.org/EN/Issues/Leprosy/Pages/DiscriminatoryImpacts.aspx).

16. The Special Rapporteur acknowledges the difficulty of mapping such laws, regulations and norms and of keeping updated information on their status. While she draws on the work of different stakeholders to map discriminatory laws, she welcomes further discussion with Members States on this particular issue and makes herself available for engaging in technical cooperation for their amendment or abolishment. With the present report, she wishes to call attention to a matter of unfinished business: legal harmonization and enforcement of formal equality for persons affected by leprosy.

## II. Looking back to understand current institutionalized discrimination

17. Available data on discrimination in law against persons affected by leprosy show that laws that discriminate against this group of people have been elaborated and put into force since the beginning of the twentieth century. The widespread institutionalization of prohibitions and discrimination on the grounds of leprosy started to be enacted during the first stage in the modern history of leprosy, between 1873 and 1948 (see [A/HRC/38/42](#)), and did not stop there, as will be further demonstrated.

18. The Special Rapporteur recalls that the discovery of the causative agent of leprosy, *Mycobacterium leprae*, in the late nineteenth century led to a unified response by European experts and Governments in 1879 based upon the idea of contagion, which gave rise to the establishment of thousands of places for the segregation and confinement of persons affected by leprosy in what were then the imperial nations, as well as in countries and territories under colonial rule. Leprosy was described by European powers as an imperial danger (*ibid.*).

19. Under these State policies, persons affected by leprosy were separated from their families and communities, and prohibitions on their reproduction were enacted in many countries, while others went as far as to practise their forced sterilization. The same policies were applied in 1923 to children of persons affected by leprosy. Healthy newborns were forcibly separated from their parents and many were also secluded from their communities.

20. There was never any scientific evidence to support the prophylactic segregation of persons affected by leprosy, and yet such segregation was widespread from the late nineteenth century until the late twentieth century – almost half a century after the discovery of a cure for leprosy. The year 1948 signalled the point at which leprosy experts abandoned the policy of compulsory segregation. However, segregation as an official policy persisted in some countries until the late twentieth century. However hard it may be to estimate the number of leprosy colonies in the world that are still active, it is probably well over 1,000.

21. The COVID-19 pandemic has taught the world what persons affected by leprosy have known for decades and centuries, namely that health and illness are not just biological phenomena. Accumulated knowledge in the field of medical anthropology has proved the difference between illness, meaning the bodily process itself, and disease, meaning the nosology produced by a given medical system, which is always culturally grounded. Diseases are biosocial constructs and, as the history of epidemics shows, explanatory models of disease can produce labelling and even give rise to institutionalized and structural stigmatization. For modern nations, biomedicine became central to the definition of the boundaries between the normal and the pathological, as well as to the classification of groups of people under those categories. The very notion of the modern citizen is embedded with biopolitical conceptions about what is normal and desirable.

22. During the early shaping of modern nations, leprosy came to embody all that was considered to be antithetical to the modern project, namely the structural backwardness that was to be purged from modern nations. It is not an exaggeration to say that stigma was the *dolus* behind the State's policy of forced segregation, since it resulted more from an ideological bias than from scientific evidence, while it aimed at nothing less than banishing leprosy by banishing the people who were infected by it. But if this ideological bias was harboured in central nations, it was also transplanted into the countries and territories under colonial rule and domination, turning institutionalized discrimination against persons affected by leprosy into a global reality. Moreover, the policy continues to have an impact on the lives of persons affected by leprosy and their family members who were subjected to it, therefore comprising a continuous violation.

23. This ideological bias and its power to shape institutionalized discrimination endured over time, even after the discovery of a cure for leprosy in the mid-twentieth century. Even after being debunked, the biomedical concept that affirmed the need for prophylactic segregation continued to influence national legal and regulatory frameworks in fields as varied as those concerning freedom of movement, participation in political and social life, family life, work regulations and immigration and visa regulations. These legal and regulatory frameworks give legal legitimacy to, and reinforce, structural and interpersonal discrimination on the grounds of leprosy, endorsing and normalizing the dehumanization of persons affected by leprosy and denying them any possibility of enjoying a life with dignity.

### III. Discriminatory laws throughout the world

24. Laws that discriminate against persons affected by leprosy were identified in both endemic and non-endemic countries. According to the International Federation of Anti-Leprosy Associations, discriminatory laws persist in the Bahamas, Barbados, Dominica, Egypt, India, Jamaica, Malaysia, Mali, Malta, Myanmar, Namibia, Nepal, the Niger, Pakistan, Papua New Guinea, the Philippines, Senegal, Singapore, Sri Lanka, Taiwan Province of China, Thailand, the United Arab Emirates and the United States of America.<sup>9</sup> According to both the Federation's database and the information submitted by other civil society organizations, Asia is the continent where discriminatory laws against persons affected by leprosy are most prevalent. The existence of discriminatory laws has been reported by civil society organizations, including the Federation, in Ethiopia, India, Myanmar,<sup>10</sup> Nepal, Papua New Guinea and Sri Lanka.<sup>11</sup> India alone counts for approximately 77 per cent of the discriminatory laws mapped worldwide, with more than 100 such laws having been identified, according to the Federation's database.<sup>12</sup>

25. In the countries where at least one discriminatory law was mapped, they encompass: (a) public health-related laws that establish forced isolation, hospitalization and segregation of persons affected by leprosy; and (b) immigration-related laws that deny admission, visas and residence and work permits for persons

<sup>9</sup> See table 1 on the report web page at: [www.ohchr.org/EN/Issues/Leprosy/Pages/DiscriminatoryImpacts.aspx](http://www.ohchr.org/EN/Issues/Leprosy/Pages/DiscriminatoryImpacts.aspx).

<sup>10</sup> Civil society organizations of Myanmar emphasized that they had doubts as to whether or not the laws were still in force.

<sup>11</sup> See table 2 on the report web page at: [www.ohchr.org/EN/Issues/Leprosy/Pages/DiscriminatoryImpacts.aspx](http://www.ohchr.org/EN/Issues/Leprosy/Pages/DiscriminatoryImpacts.aspx).

<sup>12</sup> The number of laws that discriminate against persons affected by leprosy in India varies in the different submissions for the present report, which also demonstrates the complexity of discrimination in law against persons affected by leprosy in the country and contributes to calls for robust action to identify formal and institutionalized discrimination in the country that has the highest absolute number of cases of leprosy in the world.



affected by leprosy. In the countries where more than one discriminatory law was mapped, it is possible to identify a multifaceted system that separates persons affected by leprosy from the rest of society through the application of laws in different fields of social life. Such multifaceted systems are formed by different laws and norms that regulate the relation between society and persons affected by leprosy under the ideological bias (totally debunked by current science) that classifies persons affected by leprosy as a health risk to the rest of society. Hence, laws are employed to separate persons affected by leprosy from situations of public, professional and family conviviality, radically excluding them from work settings, political representation and active participation in different sectors of society. In some cases, the laws go as far as to include sanctions for public authorities when they fail to remove persons affected by leprosy from public spaces and transportation.

26. In the specific case of India, the large number of laws that discriminate against persons affected by leprosy in the country suggests the existence of a highly complex system in which discrimination spreads over several dimensions of life, encompassing both public and private spaces and ranging from public health regulations, the organization of cities and places of detention, access to management and decision-making positions in public and private settings and work regulations to the criminalization of begging. It is worth highlighting that the proliferation of such laws in India is also a result of the country's complex administrative and territorial organization, under which both the central and the local governments have legislative powers. Discriminatory mechanisms have thus been multiplied at the different levels of government and administration, with the abundant production of similar laws and regulations by different government bodies and administrations.

27. Notably, many of the discriminatory laws that have been mapped throughout the world present compelling examples of how legal and regulatory frameworks that discriminate against persons affected by leprosy are shaped by ideological biases that simultaneously reproduce and maintain stigmatizing labels. Not only is the content of such laws discriminatory, but also the language adopted, which reproduces, gives legitimacy to and keeps in force harmful stereotypes. Indeed, many of the mapped discriminatory laws adopt derogatory language – identifying persons affected by leprosy as “lepers”, which is prohibited by guideline No. 9 of the principles and guidelines, which explicitly affirms that States should remove discriminatory language, including the derogatory use of the term “leper” or its equivalent in any language or dialect, from governmental publications and should revise expeditiously, where possible, existing publications containing such language – even though many of the States that use such language in their legal texts have endorsed the principles and guidelines. Moreover, in some of the legal texts that frame these laws, leprosy is wrongfully described as virulent, contributing to the persistence of misconceptions about its transmission. Lastly, rules that establish the ineligibility of persons affected by leprosy to take positions as civil servants make stigmatizing associations between different groups of people, including persons affected by leprosy, who are described as inferior and inept.<sup>13</sup> Such examples clearly show the power of the law to frame identities and generate stigmatizing labels.

#### **IV. Timeline of discriminatory laws**

28. In 1943, Dr. Guy Faget of the United States discovered a drug with a reasonable degree of efficacy in curing leprosy, despite its long-term use and severe iatrogenic effects. The efficacy of dapsone in curing leprosy led to a transition from a policy of compulsory segregation to a policy of decentralization to general health-care services.

<sup>13</sup> See table 3 on the report web page at: [www.ohchr.org/EN/Issues/Leprosy/Pages/DiscriminatoryImpacts.aspx](http://www.ohchr.org/EN/Issues/Leprosy/Pages/DiscriminatoryImpacts.aspx).

It was in this period that WHO took up leadership in what was then called the eradication of leprosy, with funds from the United Nations Children's Fund. This new policy also called upon States to amend discriminatory legislation, arguing that such legislation was a barrier to the eradication of leprosy. It was also in this period that the first calls emerged from leprosy colonies demanding recognition of the dignity and rights of persons affected by leprosy. In the spirit of the International Conference on Primary Health Care, held in Alma-Ata (now Almaty, Kazakhstan) in 1978, leprosy was progressively reframed under the right to health (see [A/HRC/38/42](#)).

29. Nevertheless, the analysis of existing discriminatory laws in the present report shows that from a legal perspective the biomedical concept of prophylactic segregation of persons affected by leprosy as a means to protect society from leprosy continues to be fully in effect in some countries. Appallingly, laws establishing the mandatory isolation of persons affected by leprosy have not yet been repealed or abolished from some national legal frameworks, while laws that restrict the rights of persons affected by leprosy and actively promote discrimination against them are still being elaborated and promulgated.<sup>14</sup>

30. Public health-related laws establishing the compulsory isolation of persons affected by leprosy that were promulgated during the period prior to the 1950s prevailed over time in some countries without being amended or abolished. It is also possible to identify laws that regulate both public and private dimensions of life and that impose the same biomedical concept of prophylactic segregation on distinct dimensions of social life. Hence, before the 1950s, city laws, regulations for the management of places of detention and universities, anti-begging laws, public transportation regulations and family laws that reproduced the misconception about the need for prophylactic segregation of persons affected by leprosy had already been enacted.

31. From the 1950s to the present day, mechanisms establishing segregation, prohibitions on the grounds of leprosy and restrictions on the rights of persons affected by leprosy have been reiterated in the proliferation of laws that regulate the operation of various public and private dimensions of social life, as well as institutional bodies.<sup>15</sup> The incidence of such phenomena has been particularly high in India, where this type of legislation started to be elaborated and established by different local governments after the 1950s.

32. According to the International Federation of Anti-Leprosy Associations database, some examples of laws approved after 1950 include: laws restricting political rights, such as the prohibition of participating in elections, holding office or occupying certain positions of authority and decision-making positions; laws restricting freedom of movement, with prohibitions regarding the use of public transportation; laws establishing leprosy as grounds for divorce; restrictions on migrants' admission, visas and residence and work permits; and restrictions on the right to work, with prohibitions on the practice of certain professions. The production of laws after 1950 occurred in at least the following countries: Barbados, Dominica, India, Mali, Namibia, Nepal, Niger, Pakistan, Philippines, Senegal, Singapore, Taiwan Province of China, Thailand and United Arab Emirates. Submissions from other civil society organizations also point to the production of discriminatory laws against persons affected by leprosy after 1950, up to the present day.<sup>16</sup>

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<sup>14</sup> See table 4 on the report web page at: [www.ohchr.org/EN/Issues/Leprosy/Pages/DiscriminatoryImpacts.aspx](http://www.ohchr.org/EN/Issues/Leprosy/Pages/DiscriminatoryImpacts.aspx).

<sup>15</sup> See table 5 on the report web page at: [www.ohchr.org/EN/Issues/Leprosy/Pages/DiscriminatoryImpacts.aspx](http://www.ohchr.org/EN/Issues/Leprosy/Pages/DiscriminatoryImpacts.aspx).

<sup>16</sup> See table 6 on the report web page at: [www.ohchr.org/EN/Issues/Leprosy/Pages/DiscriminatoryImpacts.aspx](http://www.ohchr.org/EN/Issues/Leprosy/Pages/DiscriminatoryImpacts.aspx).

## V. Rights violated by discriminatory laws

33. The analysis of the types of laws that discriminate against persons affected by leprosy allows for the identification of spheres of life in which such laws radically exclude persons affected by leprosy, as well as the rights that the laws violate.

### **Discriminatory laws violating political rights through the prohibition of participation in elections or of holding public office**

34. These are laws and normative acts that regulate the operation of city bodies, as well as private and religious institutions. In these cases, leprosy is considered grounds for the prohibition of participation in elections for some positions, as well as for removing persons affected by leprosy from positions that they already occupy.<sup>17</sup>

### **Discriminatory laws restricting freedom of movement by prohibiting or restricting the use of public transportation**

35. These laws regulate the use of public transportation and, as a rule, prohibit use by persons affected by leprosy or condition it upon the presentation of a medical certificate that attests that the individual is non-infectious.<sup>18</sup>

### **Laws allowing for the dissolution of marriage on the grounds of leprosy**

36. These are civil laws, as well as laws regulating marriage in different religions. According to these laws, the dissolution, annulment, separation and non-conclusion of marriage are allowed in cases in which one of the individuals entering the union is affected by leprosy.<sup>19</sup>

### **Discriminatory laws denying rights to migrants**

37. These are laws or regulations by State bodies responsible for migration and national security affairs. According to these laws, leprosy can underpin decisions against the granting of visas, work permits, residence and citizenship.<sup>20</sup>

### **Discriminatory laws restricting access to certain jobs**

38. Laws hindering the practice of certain occupations by persons affected by leprosy extend to a large number of jobs, including: handling food and drinks; providing services in courts and universities; driving public transportation vehicles; working as magistrates; occupying positions of authority in cooperatives, universities and assistance and religious entities; and providing bookkeeping, typing, legal, medical, nursing and domestic services. The laws also prohibit persons affected by leprosy from obtaining certain professional licences and having access to certain positions and careers.<sup>21</sup>

<sup>17</sup> See table 7 on the report web page at: [www.ohchr.org/EN/Issues/Leprosy/Pages/DiscriminatoryImpacts.aspx](http://www.ohchr.org/EN/Issues/Leprosy/Pages/DiscriminatoryImpacts.aspx).

<sup>18</sup> See table 8 on the report web page at: [www.ohchr.org/EN/Issues/Leprosy/Pages/DiscriminatoryImpacts.aspx](http://www.ohchr.org/EN/Issues/Leprosy/Pages/DiscriminatoryImpacts.aspx).

<sup>19</sup> See table 9 on the report web page at: [www.ohchr.org/EN/Issues/Leprosy/Pages/DiscriminatoryImpacts.aspx](http://www.ohchr.org/EN/Issues/Leprosy/Pages/DiscriminatoryImpacts.aspx).

<sup>20</sup> See table 10 on the report web page at: [www.ohchr.org/EN/Issues/Leprosy/Pages/DiscriminatoryImpacts.aspx](http://www.ohchr.org/EN/Issues/Leprosy/Pages/DiscriminatoryImpacts.aspx).

<sup>21</sup> See table 11 on the report web page at: [www.ohchr.org/EN/Issues/Leprosy/Pages/DiscriminatoryImpacts.aspx](http://www.ohchr.org/EN/Issues/Leprosy/Pages/DiscriminatoryImpacts.aspx).

**Discriminatory laws combining restrictions on the right to work with restrictions on the right to significant political participation, and prohibiting persons affected by leprosy from occupying positions of authority in public or private entities**

39. These are laws that regulate the operation of institutions, especially universities. They abound in India and have been multiplied by several bodies at the State administration. Under these laws, leprosy is considered grounds for excluding applications for higher-level work positions and for removing people from such positions as well as on councils, committees and other collegiate decision-making bodies. In some cases, leprosy is also considered grounds for removing people who work as providers of non-teaching service in universities.<sup>22</sup>

**Discriminatory laws determining the compulsory segregation and hospitalization of persons affected by leprosy as part of anti-begging measures**

40. These are laws adopted to fight mendicancy, with the definition of offences and application of sanctions by courts. Such laws determine the isolation of mendicants affected by leprosy and authorize their imprisonment or segregation in asylums or special centres or shelters. The detention of mothers and fathers may also apply to their children. In other cases, detention leads to the separation of parents and children.<sup>23,24</sup>

**City organization laws restricting political and work rights and limiting the freedom of movement of persons affected by leprosy**

41. These are laws that regulate the operation of city bodies and public spaces. Such laws include prohibitions on persons affected by leprosy taking up positions or participating in city-level elections. A common mechanism in these laws is the establishment of the city authority's duty to remove persons affected by leprosy from public markets.<sup>25</sup>

**Discriminatory laws promoting the compulsory segregation of persons affected by leprosy as part of penitentiary system regulations**

42. These laws regulate the operation of the penitentiary system and establish the duty of its managers to remove persons affected by leprosy to separate places for hospitalization.<sup>26</sup>

**Public health discriminatory laws establishing policies for compulsory segregation and isolation of persons affected by leprosy**

43. These laws maintain segregation as the State's official applicable policy for the control of leprosy. Some of the measures covered by such laws are isolation, compulsory hospitalization, detention and prohibition on attending school and entering other public spaces for persons affected by leprosy.<sup>27</sup>

<sup>22</sup> See table 12 on the report web page at:

[www.ohchr.org/EN/Issues/Leprosy/Pages/DiscriminatoryImpacts.aspx](http://www.ohchr.org/EN/Issues/Leprosy/Pages/DiscriminatoryImpacts.aspx).

<sup>23</sup> Anubhuti Jain, "Discrimination against persons afflicted with leprosy as a violation of their international human rights", *PEOPLE: International Journal of Social Sciences*, vol. 5, No. 2 (2019), pp. 454–470.

<sup>24</sup> See table 13 on the report web page at:

<https://www.ohchr.org/EN/Issues/Leprosy/Pages/DiscriminatoryImpacts.aspx>.

<sup>25</sup> See table 14 on the report web page at:

<https://www.ohchr.org/EN/Issues/Leprosy/Pages/DiscriminatoryImpacts.aspx>.

<sup>26</sup> See table 15 on the report web page at:

<https://www.ohchr.org/EN/Issues/Leprosy/Pages/DiscriminatoryImpacts.aspx>.

<sup>27</sup> See table 16 on the report web page at:

<https://www.ohchr.org/EN/Issues/Leprosy/Pages/DiscriminatoryImpacts.aspx>.

### **Indirect discrimination of persons affected by leprosy through the discriminatory application of laws that appear neutral at face value**

44. Reports about indirect discrimination by means of the application of national laws, regulations and policies that appear neutral at face value in a manner that discriminates against persons affected by leprosy point to another dimension of institutionalized discrimination.

45. In India, persons affected by leprosy who need to undergo amputation surgery may face barriers in their access to benefits owed by health insurance plans and may need to cover all the costs of the surgery, depending on the place in which they undergo surgery, and specifically on whether or not the hospital has an orthopaedic specialist centre. Likewise, the Special Rapporteur's attention was called to the fact that the Rehabilitation Council of India Act of 1992 and the Persons with Disabilities Act of 1995 may not be inclusive of all persons affected by leprosy.

46. In Ethiopia, leprosy may be used for the dissolution of marriage, since family law considers becoming ill with an incurable disease to be a fundamental error that justifies the dissolution of marriage.

47. In Papua New Guinea, discrimination against persons with disabilities affected by leprosy is not acknowledged in the Discriminatory Practices Act of 1963. Although national plans recognize the importance of protecting and promoting the human rights of persons with disabilities, the law does not recognize disability or leprosy as prohibited grounds for discrimination.

48. From Brazil the Special Rapporteur received information about the discriminatory effects of the application of two norms. Resolution No. 130/2001 of 8 October 2001 of the state of São Paulo establishes guidelines for the control of Hansen's disease in the state and, based on this norm, the state has required the eviction of persons affected by leprosy or their family members living in its former leprosy colonies that do not fulfil the requirements of the resolution. Law No. 23.137/2018 of the state of Minas Gerais, which establishes reparations for persons who, as children, were forcibly segregated and confined on the grounds that a parent was affected by leprosy, is being enforced through monetary compensation, the amount of which is strikingly low and far from proportional to the gravity of the violations suffered by the victims, which goes against the core principles of the right to remedy and reparation provided for in international human rights law (see [A/HRC/44/46](#)) and explicitly encoded in the Basic Principles and Guidelines on the Right to a Remedy and Reparation for Victims of Gross Violations of International Human Rights Law and Serious Violations of International Humanitarian Law, as well as under the current practice for Brazilian national remedies.

## **VI. Traditional discriminatory customs and practices**

49. The information available to the Special Rapporteur in the contributions from States and civil society organizations is insufficient to affirm the existence of norms that are part of non-State legal systems and that discriminate against persons affected by leprosy. By the same token, a review of the relevant literature does not put forward any data that indicate discrimination related to the exercise of justice by non-State systems and their corresponding justice operators. Hypothetically, this may be the result not so much of the non-existence of such norms but rather of the scarcity of systematized knowledge about the social and cultural dynamics that frame leprosy in countries and regions where different legal systems coexist and operate.

50. One thing that is clear from the information submitted for the present and previous reports (see, for example, [A/HRC/41/47](#)) is the persistence of traditional non-written

customs and practices that discriminate against persons affected by leprosy and are sustained by deep-rooted harmful stereotypes that are, in turn, interconnected with structured systems of traditional beliefs about leprosy, many of which come from world or local religions. This connection between customs and practices that systematically discriminate against persons affected by leprosy and religious beliefs indicates that there is a strong need for States to enable knowledge of the relation between discrimination on the grounds of leprosy and local traditions, through effective monitoring systems that involve local communities, which should be properly recognized as experts on legal pluralism and/or local norms framing collective behaviour. Notably, such discriminatory customs and practices are still the standardized manner in which local communities respond to leprosy, leading to the segregation of persons affected by leprosy from private and community spaces, as previously mapped by the Special Rapporteur (*ibid.*). Some examples are provided below.

51. In the Plurinational State of Bolivia, women continue to be dependent on third-party authorization, especially from their husbands, to obtain medical care, owing to the country's strong patriarchal social structure. Stigmatization and a lack of correct knowledge about the disease are reportedly interrelated in the country as well. In Burundi, traditional and wrongful beliefs about leprosy have an impact on the children of those affected in several life dimensions, such as marriage. There, as in other countries such as Cameroon, leprosy is considered to be a curse. This belief gives way to several prohibitions and discriminatory regulations that segregate persons affected by leprosy from social interaction and community life. In Nigeria, leprosy is also considered to be a curse and the result of an abhorrent offence that justifies treating persons affected by leprosy as outcasts, who are discriminated against in settings as varied as health care, schools, public transportation, restaurants and even within the family. Most persons affected by leprosy in the country are living in separate communities, known as leprosy colonies. Derogatory terms are also used to label persons affected by leprosy in the country. In Nepal, discriminatory practices against persons affected by leprosy include exclusion from festivities, community life and schools and people not buying goods or products from persons affected by leprosy. The Special Rapporteur heard striking reports of people being forced to live in caves and other isolated places in Nepal with no conditions whatsoever to ensure their living and survival after being diagnosed with leprosy. There, as in Papua New Guinea, leprosy is considered to be a curse that passes from one generation to another.

52. With regard to a more direct linkage between discriminatory customs and practices and religious systems, in Ethiopia the Orthodox Church reportedly restricts access by clergy who are affected by leprosy to church activities and services. In India, it has been noted that a major obstacle to the upliftment of the status of persons affected by leprosy is the stigma associated with it. These stigmatizing beliefs about leprosy are reportedly associated with ancient Hindu scriptures, such as the Atharva Veda, the Manusmriti and the Sushruta Samhita. Reports point to wrongful stereotyping, with the employment of derogatory language, as practices are attached to a deep-rooted system of beliefs. In Myanmar, the persistence of beliefs that classify leprosy as the result of bad deeds in past life and justify the marginalization of affected persons is reportedly associated with Buddhism.

53. Importantly, deep-rooted systems of beliefs can motivate not only discriminatory practices but also violence on the grounds of leprosy, as previously noted by the Special Rapporteur (*ibid.*). Deep-rooted systems of beliefs play an important role in the dehumanization of persons affected by leprosy. Dehumanization becomes possible when the target group can readily be identified as a separate category of persons, who are stereotyped and stigmatized as inferior, dangerous or uncivilized. Through dehumanization, moral restraints that prevent the exercise of abuse and violence against certain groups of people lose strength. Dehumanized groups are regarded as

disposable and their annihilation (civil or material) is established as morally acceptable. Extreme cases of violence being perpetrated against persons affected by leprosy and leading to their summary execution have come to the knowledge of the Special Rapporteur. Recently, in a country in Western Africa,<sup>28</sup> a person affected by leprosy was accused of witchcraft due to having leprosy and was brutally murdered. All the persons who witnessed the crime were also murdered.

## VII. Efforts towards eliminating discrimination in law

54. Some States, such as Colombia and Japan, reported efforts that led to the abolishment of public health-related discriminatory laws that determined the forced segregation of persons affected by leprosy. Others, such as Sri Lanka, mentioned ongoing efforts to amend laws that discriminate against persons affected by leprosy. India referred to recent and ongoing efforts towards the elimination of a multifaceted system of laws that discriminate against persons affected by leprosy in different areas of life. India specifically alluded to the abolishment of the Lepers Act by the central State in 2016 and to how the central State had led the process that finally modified provisions of personal laws that affirmed leprosy as grounds for divorce. India also mentioned the efforts undertaken by the Law Commission of India in identifying all existing discriminatory laws in the country and putting together recommendations for their abolishment.<sup>29</sup>

55. Some States reported the adoption of laws and programmes that protect the rights of persons affected by leprosy. In Brunei Darussalam, the Old Age and Disability Pensions Act provides a pension to older persons affected by leprosy that extends to their dependents and also covers a period of six months for the rehabilitation of individuals affected by leprosy. Colombia provides an economic allowance to persons affected by leprosy-related disabilities.

56. Other countries referred to anti-discriminatory laws that simultaneously protect the rights of persons affected by leprosy and prohibit discrimination on the grounds of leprosy. In Japan, several acts were enacted with such a purpose, including the Act on Payment of Compensation to Inmates of Hansen's Disease Sanatorium of 2001, the Act on Promotion of Resolution of Issues Related to Hansen's Disease of 2008 and the Act on Payment of Compensation to Family of Former Hansen's Disease Patients of 2019. Under these acts, a complex reparation programme that includes compensation for persons affected by leprosy and their family members has been put in place (see [A/HRC/44/46/Add.1](#)). The 2008 act specifically prohibits discrimination on the grounds of leprosy and, as a whole, the acts include measures for consulting with persons affected by leprosy and guaranteeing their rights, as well as measures for investigating allegations of human rights abuses and providing remedies accordingly.

57. In India, the Rights of Persons with Disabilities Act is applicable to persons who have been cured of leprosy and have valid disability certificates. It mandates the appropriate administrative and government bodies to develop schemes and programmes in the areas of social security, health, rehabilitation and skills development. It prohibits discrimination on the grounds of disability and recognizes "leprosy-cured persons" as persons with disabilities who are entitled to social benefits and access to positions in government and higher education institutions. The Special Rapporteur calls attention to the fact that the terminology employed in the Act ("leprosy-cured persons") may exclude, in practice, people undergoing treatment and

<sup>28</sup> In order to protect her sources, the Special Rapporteur wishes to keep the name of the country and the individuals confidential.

<sup>29</sup> Government of India, Law Commission of India, *Eliminating Discrimination against Persons Affected by Leprosy*, Report No. 256 (April 2015).



who already live with leprosy-related physical impairments and disabilities, as well as to the problems that have been systematically raised by persons affected by leprosy with regard to the narrow classification and assessment of a 40 per cent disability grade as the basis for entitlement to the rights provided for in the act.

58. Civil society organizations reported on strategies mainly directed at tackling discriminatory customs and practices. In Brazil, NHR Brasil has been implementing activities in line with WHO health policies for leprosy in the fields of access to health care, promotion of mental health and socioeconomic empowerment. In Burundi, the Damien Foundation has been working closely with the Government on awareness-raising activities, reaching out to religious and community leaders to increase their awareness of leprosy-related issues, training health-care workers and promoting joint awareness committees to support grass-roots organizations. In Papua New Guinea and South Africa, The Leprosy Mission undertakes efforts in the field of awareness-raising, as does the Ethiopian National Association of Persons Affected by Leprosy in Ethiopia.

59. Actions taken by civil society organizations regarding discrimination in law encompass both advocacy and strategic litigation. In Nepal, The Leprosy Mission, together with groups and organizations of persons affected by leprosy, has been calling on the Government to abolish a remaining law that discriminates against persons affected by leprosy.

60. Strategic litigation has been employed mostly in India, with important achievements in the courts. In 2014, the Supreme Court asked the central and local governments to take steps towards the inclusion of persons affected by leprosy. In 2015, the Law Commission of India submitted its report No. 256 entitled *Eliminating Discrimination against Persons Affected by Leprosy* to the Union Minister of Law and Justice and proposed a comprehensive new anti-discrimination law, referred to as the Elimination of Discrimination against Persons Affected by Leprosy Bill. Noting ongoing discriminatory practices, the Supreme Court in 2018 gave directions in its judgment in the case of Pankaj Sinha *versus* Union of India and others (writ petition (civil) No. 767/2014) to address the various forms of discrimination against persons affected by leprosy. In the same judgment, the Supreme Court took note of writ petition (civil) No. 1151/2017, filed by the Vidhi Centre for Legal Policy in its case against the Union of India, which listed 119 central and local laws that violate the fundamental rights of persons affected by leprosy under articles 14, 19 and 21 of the Constitution. It also took note of the report of the Law Commission of India, in which concern was expressed over the number of Indian laws that continue to discriminate, directly and indirectly, against persons affected by leprosy.

61. Notably, the case of India shows not only the importance of access to justice and strategic litigation as a key means of fighting formal discrimination, but also the difficulties in moving forward with formal equality when there is no agreement between, or firm decision by, central and local governments to finish the business of legal harmonization.

## VIII. Conclusions

62. **In the words of one of the representatives of the global community of persons affected by leprosy, Amar Timalina,<sup>30</sup> the global network coordinator for IDEA International, who was forced to sign divorce papers owing to the discriminatory law kept in force in his home country, persons affected by leprosy feel “anxious to breathe the air of dignity”.**

<sup>30</sup> The individual is identified in the present report with his full authorization.



63. Dignity robbed from persons affected by leprosy through formal discrimination has also fuelled their dehumanization. The analysis of formal and institutionalized discrimination against persons affected by leprosy enabled the uncovering of ongoing direct discrimination against this group of people. It also identified indirect discrimination against persons affected by leprosy resulting from the discriminatory enforcement of laws, regulations and policies that appear neutral at face value. Furthermore, many States that keep discriminatory laws in place did not report on them, which suggests a lack of knowledge and updated data on discrimination in law in relevant countries, and thus contributes to calls for action to both monitor discrimination in law and move forward with harmonizing national legislation and practices. Lastly, and equally importantly, the derogatory language employed in many of the texts of the laws that were mapped and that discriminate against persons affected by leprosy can be a driving cause of hate speech against such persons.

64. Traditional customs and practices that discriminate against persons affected by leprosy also abound and, if not directly connected to legal pluralism and the exercise of non-State systems of justice, nevertheless seem to be grounded in deep-rooted systems of beliefs that reinforce discrimination and dehumanization as the standardized responses to leprosy. The limited knowledge available on how such systems (encompassing both local cultures and world and local religions) structure discriminatory customs and practices leads to calls for in-depth studies that take local communities as experts and make use of dialogue and mutual learning as a key method for eliminating harmful stereotypes on the ground.

65. If during the consultations undertaken by the Special Rapporteur with persons affected by leprosy and their representative organizations for the present report no evidence of the recent application of discriminatory laws that determine isolation and segregation on the grounds of leprosy was mentioned, the application of discriminatory laws that regulate social relations, such as family relations, was indeed reported. Furthermore, institutionalized discrimination, encompassing both State administration and the discriminatory application of laws, was frequently alluded to. Lastly, from the consultations with persons affected by leprosy and their representative organizations, it is possible to affirm that the impact of discrimination in law on the enjoyment of rights and access to justice, legal remedies and reparation is enormous. By the same token, formal discrimination has been at the root of widespread substantive discrimination, which continues to keep persons affected by leprosy excluded from access to opportunities on an equal basis with others.

66. Before describing the impact of formal discrimination, a word on the gender imbalance of both the application and adverse effects of discriminatory laws against persons affected by leprosy is required. 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. Likewise, 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.

67. This was in fact 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. As pointed out

systematically to the Special Rapporteur, in the face of discrimination and/or violence against them, persons affected by leprosy cannot take legal action. 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.

68. Lastly, formal discrimination motivates, authorizes and normalizes substantive discrimination against persons affected by leprosy by, inter alia: (a) significantly compromising the livelihoods of persons affected by leprosy; (b) formalizing harmful stereotypes as lawful labels and normalizing humiliation and violence against persons affected by leprosy as authorized practices; (c) excluding persons affected by leprosy from political and civic participation and therefore hindering changes with regard to democratic engagement and involvement with decision-making; and (d) augmenting the State's negligence towards this marginalized group of people and its lack of commitment to systemic change and accommodation of differences.

69. International provisions violated by these laws are abundant but the foundational principles of equality, dignity and non-discrimination that sustain international human rights law and are affirmed in articles 1 and 2 of the Universal Declaration of Human Rights, as well as in article 8 that upholds the right to an effective remedy by the competent national courts in the face of acts violating recognized fundamental rights, stand out. Importantly, many of the rights provided for by the International Covenant on Civil and Political Rights are directly violated by discriminatory laws and practices. The same is true for many of the rights provided for by the International Covenant on Economic, Social and Cultural Rights.

70. Article 4 of the Convention on the Rights of Persons with Disabilities establishes the obligation of States to take all appropriate measures, including legislation, to modify or abolish existing laws, regulations, customs and practices that constitute discrimination against persons with disabilities, while the Committee on the Rights of Persons with Disabilities, in its general comment No. 6, affirms that promoting equality and tackling discrimination are cross-cutting obligations of immediate realization and are not subject to progressive realization. Importantly, persons affected by leprosy should widely be recognized as persons with disabilities, in accordance with articles 1 and 2 of the Convention, on the grounds not only of physical impairment and the multiple barriers imposed by society to their full participation, but also of discrimination based on harmful stereotypes of leprosy itself, and are entitled to the rights provided for by the Convention. Likewise, the Committee on Economic, Social and Cultural Rights, in its general comment No. 20, while explicitly stating that States should adopt measures to address widespread stigmatization of persons on the basis of their health status, including diseases such as leprosy, also affirms that discrimination must be eliminated both formally and substantively and that non-discrimination is an immediate and cross-cutting obligation in the International Covenant on Economic, Social and Cultural Rights.

71. To conclude, it is vital to note that laws can also be a means of preventing and remedying stigmatization, harm and violence.<sup>31</sup> They can endow individuals with instruments to fight back against discrimination. Equal and effective legal protection against discrimination means that States have positive obligations to protect persons affected by leprosy from discrimination. Affirmative measures and comprehensive anti-discriminatory laws and acts are some of the means through which States have been fulfilling their obligation to protect other groups

<sup>31</sup> Scott Burris, "Stigma and the law", *The Lancet*, vol. 367, No. 9509 (2006), pp. 529–531.

from discrimination and should be applied for eliminating discrimination on the grounds of leprosy, especially in countries with a leprosy endemic. States are faced with a key choice: whether to keep formal discrimination against persons affected by leprosy in place and thus continue to violate international human rights law and contribute to persistent dehumanization and substantive discrimination against them, or to take an active approach to eliminating systemic discrimination against this group of people. Eliminating interrelated de jure and de facto discrimination on the grounds of leprosy is without doubt an unfinished business that States must actively and urgently address.

## **IX. Recommendations**

72. The Special Rapporteur recommends that States, at both the national and the subnational levels of government and administration, adopt and implement the measures set out below in order to enforce formal equality for persons affected by leprosy, as well as to fight against the consequences of extended discrimination in law with regard to the enjoyment of rights by persons affected by leprosy and their family members on an equal basis with others.

73. In general, States should:

(a) 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;

(b) Prohibit discrimination on the grounds of leprosy and extend such prohibition to the private and public spheres;

(c) Develop and enact comprehensive anti-discrimination laws and/or statutes, in close consultation with organizations of persons affected by leprosy, especially in endemic countries, that criminalize and punish by effective, proportionate and dissuasive criminal penalties violence and discrimination on the grounds of leprosy, provide for victims to be offered an assessment of their potentially specific protection needs and protect the right of persons affected by leprosy to equal opportunities and treatment in both the public and private spheres, spanning health care, education, work and employment, justice and social protection;

(d) Ensure the recognition and inclusion of persons affected by leprosy as being entitled on an equal basis with other groups to the protection granted by mainstream equality policies and strategies in both endemic and non-endemic countries;

(e) Include leprosy as prohibited grounds for discrimination in existing monitoring mechanisms, while involving organizations of persons affected by leprosy, and systematically collect data disaggregated by demographic, environmental, socioeconomic and cultural variables, as well as by the various grounds for discrimination recognized in international human rights law, with full respect for the principles of participation and privacy;

(f) Provide accessible mechanisms for filing complaints about the violation of rights on the grounds of leprosy, as well as accessible and effective redress mechanisms, and ensure access to justice, on an equal basis with others, for persons affected by leprosy and their family members;

(g) Reformulate policies and bodies for the protection of vulnerable groups, in a manner that recognizes and addresses the specific reality and needs

of persons affected by leprosy and their family members, with proper budget allocation at the national and subnational levels, with targets, indicators and benchmarks, especially in endemic countries;

(h) Increase knowledge in all parts of society, including among State officials and public servants working in different areas of the State administration, particularly in health care, education, work and justice, as well as in the private sector, about updated scientific evidence on leprosy, as well as on the rights to non-discrimination and equality of persons affected by leprosy, especially in endemic countries;

(i) Eliminate institutionalized discrimination against persons affected by leprosy and their family members by monitoring and preventing the discriminatory application of laws that appear neutral at face value;

(j) Eliminate derogatory language from official documents, laws, regulations, ordinances, resolutions and policies.

74. With regard to eliminating traditional discriminatory customs and practices, States should:

(a) 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;

(b) Implement effective monitoring systems on traditional customs and practices that discriminate against persons affected by leprosy and their family members at the local level;

(c) 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 and eliminating harmful traditional customs and practices based on leprosy at the local level, with the full participation of organizations of persons affected by leprosy;

(d) Implement 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;

(e) Engage with public authorities, the media, State officials from all branches of the government, State and non-State justice operators and traditional and religious leaders in the prevention and elimination of leprosy-related violations.

75. With regard to connecting restorative justice to prevention, States should:

(a) Prohibit all laws, norms and official and traditional practices that lead to the segregation of persons affected by leprosy and duly recognize 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 leprosy-related segregation and violations;

(b) Implement 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;

(c) Put in place comprehensive prevention structures that make use of education, arts and culture, archives and documentation, linking reparation

programmes with memorialization processes that should also educate communities near former leprosy colonies;

(d) 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;

(e) Implement participatory planning and management of former leprosy colonies and ensure that health care and rehabilitation, including psychosocial support, are available to current residents.

76. With regard to enabling systemic change, States should:

(a) Support and protect the engagement of persons affected by leprosy and their family members in leadership positions in public and political life by eliminating all laws, regulations, ordinances, resolutions and policies that hinder access for persons affected by leprosy to positions of power and/or holding office, and/or elaborate 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;

(b) Encourage and promote the participation of persons affected by leprosy and their family members at the community level and in all public affairs that directly concern their life;

(c) Take steps to ensure that children affected by leprosy are guaranteed the right to education and to stay in school, raising community awareness of leprosy and of the rights of persons affected by leprosy at school and providing families with incentives to allow their children to complete their education;

(d) Ensure that children with leprosy-related disabilities participate on an equal basis with others in education services and recreational, leisure and sporting activities. Education services should ensure both accessibility and reasonable accommodation;

(e) 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, including the provision of financial incentives to allow them to finish their studies.

77. With regard to protecting women affected by leprosy from violence, States should:

(a) 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, and provide for adequate solutions, remedies and reparation measures;

(b) 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;

(c) Prohibit and punish domestic violence against women affected by leprosy, as well as all kinds of violence against them, including institutionalized violence in relation to State services, such as health care, education, social protection and employment, as well as any forms of interpersonal violence;

(d) **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;**

(e) **Empower women affected by leprosy to know their rights and how to claim them, including through income-generation programmes, the creation of cooperatives and vocational continuing education, in order to secure for them economic independence and access to decent work and equal remuneration, as well as guarantee rights at work, including accessibility and reasonable accommodation for them, and recognize unpaid care work in social protection schemes;**

(f) **Establish affirmative measures for ensuring equality of participation of women affected by leprosy in any decision-making that affects their lives, as well as in the mechanisms of representative and participatory democracy, non-governmental organizations, epistemic communities and health-care services.**

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