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**Promotion and protection of all human rights, civil,  
political, economic, social and cultural rights,  
including the right to development**

## **Progress and remaining challenges in eliminating discrimination against persons affected by leprosy and their family members**

**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, examines the progress made and the challenges remaining in eliminating leprosy-related discrimination and provides a comprehensive list of recommendations for States and other relevant stakeholders to overcome these challenges.



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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 all such persons should be treated as individuals with dignity and should enjoy all human rights and fundamental freedoms under customary international law, relevant conventions and national constitutions and laws. 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 adoption of the above resolution was an important milestone in the history of centuries of discrimination against persons affected by leprosy and their families, by which the States Members of the United Nations recognized that leprosy is not only a health issue, but also a deeply rooted human rights issue: the adoption of the resolution was a remarkable achievement, given the decades of persecution and segregation of persons affected by leprosy and their family members, with States being the main perpetrators of such violations.
3. The official policy of forced segregation of persons affected by leprosy was implemented from at least the late nineteenth into the mid-twentieth century, although in some countries it went well beyond that time, into the last decades of the twentieth century. Such policies were never supported by scientific evidence but were rather the product of harmful stereotypes about leprosy and harmful stereotyping of persons affected by leprosy, which were wrongly sanctioned by biomedicine as authoritative truths. Moreover, many family members of persons affected by leprosy were also segregated and forcibly institutionalized. There are still more than one thousand so-called leprosy colonies in the world today. Regrettably, the Special Rapporteur has received reports of people who continue to live in segregated places, continuing the discrimination they experience at the community level, owing to lack of adequate health care, quality mobility aids, assistive devices and rehabilitation close to home.
4. At a minimum, States must provide redress to persons affected by leprosy and their family members since the violations of their rights were both of a permanent nature and also generated widespread fear and stigmatization against people who were wrongfully blamed and persecuted on the grounds of leprosy. In addition, after the global elimination of leprosy as a public health problem in 2000 (often misunderstood as eradication, when it meant prevalence of less than 1 incidence per 10,000 population), efforts and political will to tackle the disease decreased dramatically. In many countries, as a result of ongoing discrimination against them, persons affected by leprosy were forced to turn to charity-based organizations to gain access to health care and livelihoods.
5. The General Assembly, by its adoption of resolution 65/215, not only paved the way for remedies against past and present violations against persons affected by leprosy and their family members, it also placed leprosy on the global human rights agenda. This meant that all States where leprosy, whether endemic or non-endemic, must fully recognize the need to take the steps necessary to eliminate leprosy-related discrimination and to cooperate to ensure the human rights of persons affected by leprosy globally. Resolution 65/215, including the referenced principles and guidelines for the elimination of discrimination against persons affected by leprosy and their family members,<sup>1</sup> also helped to highlight the particular needs of persons affected by leprosy and their family members as a group in an extremely vulnerable situation and in need of special protection. It focused on very specific issues to be addressed by the entities of the human rights system and its mechanisms.
6. Nevertheless, notwithstanding the adoption of resolution 65/215, widespread inaction continued. In response, in 2017, the Human Rights Council, by its resolution 35/9, 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 above-mentioned principles and guidelines. Subsequently, in 2020, by its resolution 44/6, the Council extended the

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<sup>1</sup> [A/HRC/15/30](#), annex.

mandate, requesting that the Special Rapporteur continue to report annually to the Council and to report also to the General Assembly, starting from its seventy-sixth session.

7. As the Special Rapporteur on the elimination of discrimination against persons affected by leprosy and their family members, Alice Cruz, has detailed in her previous reports,<sup>2</sup> the principles and guidelines for the elimination of discrimination against persons affected by leprosy and their family members referenced in resolution 65/215 are a non-treaty standard that reinforces customary law and the normative integration of several international human rights instruments, interpreting and translating legally binding norms, in close connection with the conditions and needs of persons affected by leprosy and their family members. The principles and guidelines 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 help to guarantee formal and substantive equality to this group of people.

8. In her first report to the Council about her vision and methods for the mandate entrusted to her, the Special Rapporteur argued that discrimination on the grounds of leprosy is multiple and intersects with other prohibited grounds of discrimination, including gender, disability, age and race.<sup>3</sup> Over the course of her work as mandate holder, this assertion has been fully borne out by evidence collected both for thematic reports and during country visits.

9. National legal frameworks and policies designed to implement international human rights law and, more particularly, provisions on non-discrimination should expressly recognize persons affected by leprosy and their family members as individuals entitled to protection under those same legal frameworks and policies and all necessary steps should be taken to integrate leprosy into related strategies. In gathering evidence in fulfilment of her mandate, the Special Rapporteur has come to the conclusion that more efforts are needed in this regard.

10. To address this matter, it is important to increasingly detail entitlements for persons affected by leprosy 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, given the vulnerability of their historic, social, political and economic situation, including women, children and persons with disabilities, and with the jurisprudence elaborated by the treaty bodies.

11. On the subject of the nature of the State's obligations to ensure the human rights of persons affected by leprosy and their family members, it is worth noting that States from both the Global South and the Global North have responsibilities in this regard. While leprosy is endemic today in countries of the Global South, the dehumanizing official policy of forced segregation and its stigmatizing corollaries were originally the creation of European nations, which transplanted the policy to the countries and territories under their colonial rule and domination, making institutionalized, formal and direct discrimination against persons affected by leprosy a global reality.

12. As detailed by the Special Rapporteur in her previous reports, while colonialism and its corollaries form the core of many of the stigmatizing beliefs about leprosy, they are also relevant to an understanding of the current social determinants of leprosy and of other neglected tropical diseases in many countries of the Global South. In and of itself, the classification of such diseases as tropical is deeply colonial since not all are tropical. In any case, leprosy and other neglected tropical diseases should be addressed as global issues and should form part of international cooperative efforts to achieve Sustainable Development Goal target 3.3<sup>4</sup> and as part of the commitment of all Governments to the implementation of the 2030 Agenda for Sustainable Development, in particular under Sustainable Development

<sup>2</sup> A/HRC/38/42, A/HRC/41/47, A/HRC/44/46, A/HRC/44/46/Add.1, A/HRC/44/46/Add.2, A/HRC/44/46/Add.3, A/HRC/47/29, A/HRC/50/35, A/76/148 and A/77/139.

<sup>3</sup> A/HRC/38/42, para. 64.

<sup>4</sup> Communicable diseases: By 2030, end the epidemics of AIDS, tuberculosis, malaria and neglected tropical diseases and combat hepatitis, water-borne diseases and other communicable diseases.

Goal 17, as well as under article 55 of the Charter of the United Nations and articles 3 and 4 of the Declaration on the Right to Development.

13. Furthermore, leprosy and the persistence of discrimination against those affected by the disease, as well as against their family members, reveals to what extent States have made progress in terms of the protection, promotion and fulfillment of human rights, given that this group of people is among those groups furthest behind. The situation of people affected by leprosy is a clear marker of the overall promotion and protection of human rights in a given country. In general, with regard to measures in place to guarantee equality and non-discrimination, as well as the enjoyment of social, economic and cultural rights on a universal basis, the situation of people affected by leprosy is also a clear marker of the degree to which States have provided for the enjoyment of the comprehensive right to development, as set out in the Declaration on the Right to Development.

14. The present report is the final report of the current Special Rapporteur to the Council. For that reason, it contains an overview of lessons learned and an assessment of progress and remaining challenges regarding the elimination of discrimination on the grounds of leprosy. The report also presents a set of key recommendations to States, intergovernmental agencies and non-governmental organizations (NGOs) concerning the elimination of discrimination against persons affected by leprosy and their family members.

15. The Special Rapporteur wishes to thank persons affected by leprosy and their family members for the continuous encouragement and support given to her as mandate holder. During the years of her tenure, her admiration for their resilience and their determination to survive leprosy and its consequences, together with their dedication to support their peers and improve their living conditions, has only increased. The Special Rapporteur finds great hope in the increasing interaction of organizations of persons affected by leprosy with the overall human rights system and she leaves her office inspired by their formidable example.

## II. Overview of the work of the Special Rapporteur

16. The Special Rapporteur implemented a people-centered approach to the mandate entrusted to her by the Council. She delivered her mandate using a bottom-up approach to human rights, always prioritizing inputs from persons affected by leprosy and their family members as the primary source of information and guidance.

17. She consistently recognized persons affected by leprosy and their family members as experts through experience and defended their right to participate and be involved in decision-making in a wide range of settings, from the public to the private. While she endeavored to identify and report on the consequences of deep-rooted stigmatization and discrimination and to elaborate recommendations on how to mitigate and eliminate both interpersonal and systemic discrimination, she always carried out her mandate side by side with persons affected by leprosy and their representative organizations and continued to be guided by them.

18. The people-centred approach adopted by the Special Rapporteur has had an empowering effect among persons affected by leprosy, their family members and representative organizations. The Special Rapporteur considers this to be the most consistent and sustainable outcome of her mandate.

19. Empowerment is key both in fighting the historical and systemic dehumanization of persons affected by leprosy and their family members and in the ongoing struggle against their structural and widespread subordination. By promoting their active participation and critical reflection, including their understanding, access to and control over important decisions and resources, empowerment allows people in disadvantaged situations to achieve greater control over their lives. It also furthers their democratic engagement in public affairs, with an enhanced critical understanding of their own settings and their relationship to power relations and hegemonic social structures.

20. Using this approach, the Special Rapporteur aimed to ensure that her mandate provided a bridge for a group of people living in an extremely vulnerable situation, who have been systematically pushed furthest behind, helping them to gain access to the human rights

system and to relevant intergovernmental agencies, Governments and international organizations working in the field.

21. The goal of the Special Rapporteur has been to ensure the sustainability of efforts to eliminate both the disease and the discrimination attached to it. In the long-term, what contributes the most to transforming laws, policies, practices, norms and power relations is the empowerment and active participation of people affected by leprosy and their family members in public affairs and in all matters concerning their lives.

22. Systemic change can only be achieved by ensuring that affected groups have a voice and choice in all decision-making processes that affect their lives. Their autonomy, active citizenship and ability to defend their interests in public affairs are key to any sustainable action. A free civic space is essential to building just societies and participation means ensuring that Governments, NGOs and intergovernmental agencies are held accountable.

23. Accountability, access to justice and even the justiciability of rights are fundamental mechanisms to guarantee human rights and fundamental freedoms. However important formal equality and recognition of entitlements and rights can be, without the political will to convert such recognition into policies, strategies and practices, laws alone will not have the power to have a transformative impact on people's lives. Participation and accountability are of the essence in order to guarantee that law is put into action.

24. Traditionally, the situation of persons affected by leprosy has been addressed either within medical or charity-based frameworks and they have rarely been recognized as rights holders. The need for a paradigm shift is imperative and the mandate of the Special Rapporteur has played an important role in encouraging the first steps towards such an important change. The global human rights system and the world community must support such a shift by cooperating closely with local and national organizations of persons affected by leprosy and by enabling the participation of such organizations in their work. It is important to note that such participation is still severely compromised by multiple barriers.

25. With specific regard to the human rights system, over the years the Special Rapporteur has come to realize that it is not easily accessed by those who need it the most. Significant factors hindering persons affected by leprosy and their representative organizations from making use of the human rights system include: language (the majority of persons affected by leprosy and their families do not speak any of the six official United Nations languages); the digital divide; difficult-to-use procedures that require a level of literacy and expertise that those who have been marginalized do not always possess; and non-inclusion of the particular issues that affect them on the agendas of international civil society organizations with experience and expertise about the system. These are only a few of the barriers that the human rights system itself should properly identify and remove.

26. The Special Rapporteur, with few resources at her disposal, has used her position to overcome barriers in her collaborative work with persons affected by leprosy and their representative organizations. She regrets not having had sufficient resources to undertake key activities, for example, expert consultations or regional consultations, for a mandate that was new to the human rights system. Such activities might have enhanced further awareness and promoted important synergies.

27. While she has dedicated considerable efforts to making persons affected by leprosy and their representative organizations aware of human rights standards, as well as to developing and strengthening their awareness of their rights and how to claim them, she still believes that the overall accessibility of the system to those furthest behind is a major issue to be discussed and addressed. In reference to the well-known thought piece on whether those in subordinate positions can speak,<sup>5</sup> the Special Rapporteur would respond that, of course, they can speak, but that it is high-level forums that do not properly listen to them, hindering their right to claim to their human rights. This is an important limitation of the system itself, which requires a greater commitment from States in terms of budget allocation to the overall system and its offices.

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<sup>5</sup> Gayatri C. Spivak, "Can the subaltern speak?", in Patrick Williams and Laura Chrisman (eds.), *Colonial Discourse and Post-Colonial Theory* (Routledge, London, 1993).

28. In always encouraging a cooperative approach, the Special Rapporteur has continuously engaged with United Nations bodies and intergovernmental agencies, especially the World Health Organization (WHO) and the United Nations Children's Fund (UNICEF). During country visits, she has consistently made an effort to interact with relevant agencies, such as the United Nations Development Programme (UNDP), the United Nations Entity for Gender Equality and the Empowerment of Women (UN-Women), UNICEF and WHO. She has also used country visits as opportunities for connecting persons affected by leprosy and their representative organizations with their respective Governments and with intergovernmental agencies working in the country. Awareness-raising has been a major task for her mandate. Moreover, the Special Rapporteur always adopted a cooperative approach with Governments and regrets their very limited engagement with her mandate. The mandate of the Special Rapporteur was, like all others, deeply impacted by the coronavirus disease (COVID-19) pandemic, and she was only able to visit four countries in her official capacity. Nevertheless, she visited three countries in the three most important regions in terms of the incidence of leprosy (Asia, Africa and South America). The three countries, Angola, Bangladesh and Brazil, are also among the 23 WHO priority countries for leprosy. In addition, she visited one country (Japan) that has already eliminated leprosy, which enabled her to elaborate recommendations for a post-elimination scenario. While she commends the willingness of the three countries to assess their national gaps and to improve their responses to leprosy-related discrimination, she regrets that other highly endemic countries did not invite her to visit. Commitments under the Sustainable Development Goals should have inspired States to leave no one behind and cooperate with her mandate.

29. With a view to promoting synergies and catalyzing systemic change, the Special Rapporteur reached out to, and worked closely with, political and religious world leaders, members of academia both from the Global South and the Global North, 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 for persons affected by leprosy and national and grassroots organizations of persons affected by leprosy. Further, she has always been available to provide technical guidance to key stakeholders for tackling stigmatization and discrimination against persons affected by leprosy and their family members.

30. In order to facilitate the implementation of the principles and guidelines for the elimination of discrimination against persons affected by leprosy and their family members, as well as the discussion of such discrimination as part of the work of the universal periodic review and the treaty bodies, the Special Rapporteur has presented a policy framework for rights-based action plans,<sup>6</sup> including specific recommendations in 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. The report also included concrete examples of good practices in the four aforementioned areas for action.

31. The Special Rapporteur contributed to the WHO road map for neglected tropical diseases 2021–2030<sup>7</sup> and the WHO global leprosy strategy 2021–2030.<sup>8</sup> Since she became the mandate holder, the Special Rapporteur has endeavoured to mainstream leprosy within the entire human rights system and has focused, in particular, on raising awareness about discrimination against persons affected by leprosy within the Committee on the Rights of Persons with Disabilities. She made several submissions to the Committee with regard to the Committee's reviews of endemic countries and also contributed to the drafting of the Committee's general comment No. 8 (2022) on the right of persons with disabilities to work and employment, as enshrined in article 27 of the Convention.

32. The Special Rapporteur extends her appreciation to the Committee on the Rights of Persons with Disabilities for its efforts to guarantee the recognition of persons affected by

<sup>6</sup> See [A/HRC/44/46](#).

<sup>7</sup> WHO, *Ending the neglect to attain the Sustainable Development Goals: A road map for neglected tropical diseases 2021–2030*, Geneva, 2020.

<sup>8</sup> WHO, *Towards Zero Leprosy: Global Leprosy (Hansen's Disease) Strategy 2021–2030*, Geneva, 2021.

leprosy as persons with disabilities within national legal and regulatory frameworks and for making recommendations to countries where leprosy is endemic in this regard. She also notes the importance of recognizing the specific experiences and needs of women, children and older people with leprosy-related disabilities, as well as ensuring accessibility to the work of the Committee by organizations of persons affected by leprosy, which, historically, have been excluded from the overall system as a result of the above-mentioned barriers.

33. Throughout the COVID-19 pandemic, the Special Rapporteur has worked tirelessly, reaching out to persons affected by leprosy and their families, to assess the impact of the pandemic on them. Organizations of persons affected by leprosy were key to this work, given the extent to which the digital divide excludes the majority of persons affected by leprosy from engaging with the human rights system. Using the gathered evidence, she elaborated a guidance document for States and presented a comprehensive report on the disproportionate impact of the pandemic persons affected by leprosy and their families.<sup>9</sup> The report examines the root causes of the group's vulnerability to the pandemic and to the crisis that has unfolded. The Special Rapporteur considers that the comprehensive nature of the report, which encompasses both causes, consequences and necessary measures to overcome such a crisis, makes it an important and fundamental document in the event of future crises.

34. The work of the Special Rapporteur has enabled the production of a body of new evidence about discrimination on the grounds of leprosy. Over the past several years, she has extensively documented such discrimination and has presented evidence on the pervasiveness of formal and substantive discrimination against this group of people, including the systemic denial of their right to access to opportunities on an equal basis with others in areas such as education, work, social protection and access to justice. She has also presented evidence on physical, psychological and sexual violence, particularly against women and children affected by leprosy, and how harmful stereotypes about leprosy can threaten the right to life of persons affected by leprosy. All of this work was made possible as a result of the unwavering support of persons affected by leprosy and their representative organizations.

35. The Special Rapporteur has always worked under the principle that leprosy-related discrimination intersects with wider processes of oppression, marginalization, violation and social conflict. She has examined discrimination related to gender, age, health care, disability and legal frameworks from the point of view of the particular situation of persons affected by leprosy, while also contributing to a wider discussion on core topics of the human rights agenda. She believes that social gaps and problems are better identified when society is viewed from the margins. She firmly believes that persons affected by leprosy and their family members, while a minority, have much to contribute to the advancement of the overall human rights agenda, especially in the areas of inclusion and rights enforcement for dehumanized groups and populations living in poverty and extremely vulnerable situations.

36. There is more knowledge available today about the nature and root causes of leprosy-related discrimination. It is also possible to put together a narrative about leprosy-related discrimination and the steps necessary to tackle it. Furthermore, persons affected by leprosy and their representative organizations have increasingly taken ownership of the leprosy-related narrative, as well as of the activities for claiming their rights, especially at the subnational and national levels.

37. While the Special Rapporteur has been able to extensively map the intersections of discrimination on the grounds of leprosy with discrimination based on gender, age and disability, she did not have resources to examine its intersection with discrimination based on race, although, in some contexts, there are a few cases pointing in that direction. She believes that further research is needed in this area.

38. Another issue that, in the view of the Special Rapporteur, deserves further attention concerns what she referred to in the introduction to the present report as the need to increasingly detail entitlements for persons affected by leprosy and their family members

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<sup>9</sup> See [A/HRC/47/29](#).



under an expanding framework that aligns more closely with the comprehensive nature of core human rights instruments and jurisprudence elaborated by the treaty bodies.

39. In practice, this could be converted into, at least, three important tasks: (a) to ensure continuity in the mainstreaming of the question of leprosy into relevant human rights mechanisms, together with developing and strengthening the capacity of the organizations of persons affected by leprosy to interact with those mechanisms; (b) to develop guidance on anti-discrimination legislation, policies and programmes; (c) to ensure that relevant States, at both the national and subnational levels, cooperate more closely in examining their legal frameworks and policies and in the assessment of both opportunities and gaps in such legal frameworks and policies. The Special Rapporteur stresses, once again, that greater cooperation between relevant States will be essential in undertaking the above-mentioned task.

### III. Progress in eliminating discrimination against persons affected by leprosy and their family members

40. Only two countries in the world have implemented reparation measures for the harm done to persons affected by leprosy and their family members by official State policies of segregation. As thoroughly detailed in the Special Rapporteur's country reports on Brazil and Japan, laws were enacted by both countries to provide reparations to persons affected by leprosy who were segregated in the past by the State and a law was enacted by Japan to provide reparations to family members who were also the victims of State segregation. Remedies, compensation and reparations for violations on the grounds of leprosy suffered both by persons affected and their family members are justice measures which, through general acknowledgment of the unfairness of violations and of the legal obligation of States to take such a violation of human rights seriously, can lead to positive spillover effects, raise awareness and guarantee the non-repetition of such violations.

41. Brazil has also enacted an anti-discriminatory law that officially changes the name of leprosy to Hansen's disease (*Hanseníase* in Portuguese). The official change of the name to a more dignified term in the last decades of the twentieth century in Brazil has produced positive results in mitigating stigmatization against persons affected by the disease in the country. It is important that such a change be legally formalized, not only in practice, since it obliges the entire administration of the State to fully comply with it.

42. While the Special Rapporteur appreciates the complexity of the issue, and that pejorative negative vernacular terms for leprosy are used in some countries and that Western-centred language should not be imposed on non-Western countries, she considers the change of the name of leprosy to a more neutral one to be a best practice for eliminating the harmful stereotypes attached to leprosy, as witnessed in the recent change by WHO of the name of monkey pox to mpox. In another report, the Special Rapporteur presented data suggesting that a large number of persons affected by leprosy prefer the term Hansen's disease.

43. Since the Special Rapporteur took office, there has been further progress with regard to legal frameworks. Noting ongoing discriminatory practices, in 2018, the Supreme Court of India, in its judgment in the case of *Pankaj Sinha v. the Union of India and others*,<sup>10</sup> directed entities of the State to address various forms of discrimination against persons affected by leprosy. In the same judgment, the Supreme Court took note of a writ petition filed by the Vidhi Centre for Legal Policy in its case against the Union of India,<sup>11</sup> 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. The Court also took note of the report of the Law Commission of India, in which the Commission expressed its concern over the number of Indian laws that continue to discriminate, directly and indirectly, against persons affected

<sup>10</sup> Supreme Court of India, Writ petition (civil) No. 767/2014, Judgment, 14 September 2018.

<sup>11</sup> *Ibid.*, para. 8.

by leprosy. Since then, up to 20 or more laws<sup>12</sup> have been either repealed, modified or abolished.

44. In Brazil, three regional States have transferred the usufruct and ownership of properties of former colonies to persons affected by leprosy and their family members who were once segregated there. One regional State approved reparations to individuals who were segregated because their parents were affected by leprosy, although the monetary compensation given to the victims was shamefully low given the permanent nature of such violations. Some victories in terms of reparations from the State were achieved by individuals who suffered similar violations of their rights, although the Federal Government has yet to approve a reparation law that includes all individuals who were victims of the official State policy.

45. Strategic litigation and access to justice have been increasingly incorporated into the agendas of some civil society organizations working for persons affected by leprosy, with important victories in favour of their rights.

46. In addition, progress has been made regarding a gender-sensitive approach to leprosy, especially on the part of civil society organizations for persons affected by leprosy, as well as by WHO and through national leprosy programmes. Increasingly, women, who had largely been excluded from leadership positions in such civil society organizations, have been taking over leadership positions and pushing for greater awareness on the specific issues faced by women affected by leprosy.

47. There has also been progress in the recognition of persons affected by leprosy as persons who are entitled to disability rights, especially with regard to greater openness on the part of national and subnational governments to dialogue with organizations of persons affected by leprosy as part of their disability agendas. By the same token, persons affected by leprosy have developed a deeper understanding of the Convention on the Rights of Persons with Disabilities and have increasingly incorporated its principles into their action plans and advocacy work, especially in supporting the efforts of their peers to access disability-related social benefits. They have also deepened their relations with the overall disability community.

48. Significant progress has been made on the interaction between civil society organizations for persons affected by leprosy and other organizations of persons affected by leprosy with international monitoring mechanisms, with several submissions being made, *inter alia*, as part of the universal periodic review process as well as to the Committee on the Rights of Persons with Disabilities and to the Committee on the Elimination of Discrimination against Women.

49. Good practices targeting the economic empowerment and the mental health of persons affected by leprosy and their family members have been strengthened by NGOs, as well as by organizations of persons affected by leprosy and local groups and associations of persons affected by leprosy. The Special Rapporteur considers strategies implemented by the aforementioned civil society organizations in the field of solidarity economy to be a best practice for people in overcoming the intersection of poverty with discrimination on the grounds of leprosy and in changing the way communities think of and interact with them.

50. While there has been undeniable progress on the right to participation of persons affected by leprosy over the last few years, the Special Rapporteur worries that, in many instances, participation is still mainly tokenistic and that, while relevant intergovernmental agencies, international organizations and Governments seem to be keener to listen to the representative organizations of persons affected by leprosy, the extent to which people's demands are effectively incorporated into their work plans is still limited.

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<sup>12</sup> It is difficult to estimate with precision the number of laws since this is an ongoing movement happening at the subnational level of government.

#### IV. Remaining challenges in eliminating discrimination against persons affected by leprosy and their family members

51. Despite progress, persons affected by leprosy and some of their family members continue to experience discrimination in law and in practice. There are still around 100 laws in place that actively discriminate against persons affected by leprosy. India alone accounts for the majority of such discriminatory legal frameworks. Laws that discriminate against persons affected by leprosy violate a wide range of rights through policies including: compulsory segregation and isolation of persons affected by leprosy; prohibitions on their participation in elections and their holding of public office; restrictions on their freedom of movement and the use of public transportation; dissolution of marriage on the grounds of leprosy, which, as many women affected by leprosy shared frequently with the Special Rapporteur, contributes to their subordination, poverty and the interpersonal and structural violence perpetrated against them; prohibition on the exercise of a large number of jobs; and denial of rights to migrants affected by leprosy. There are also cases of the discriminatory application of laws that appear neutral at face value, as already documented by the Special Rapporteur in one of her previous reports.

52. As the lived experience of persons affected by leprosy indicates, discrimination under the law promotes substantive discrimination by significantly compromising their livelihoods, formalizing harmful stereotypes as lawful labels and normalizing humiliation and violence against them. Some laws also exclude them from political and civic participation, therefore hindering their chances of defending their interests and rights. Women are particularly harmed by such laws. As an example, in countries where leprosy is legal grounds for divorce, such laws can not only lead to divorce, but also hinder women's access to justice in demanding enforcement of the rights that are entitled to them after divorce, such as their share of marital property and custody of their children, which leaves many women living in poverty.

53. Traditional non-written customs and practices that discriminate against persons affected by leprosy, often grounded in beliefs from world or local religions, persist in some societies, especially where religion strongly frames social interaction. Such customs and practices, mostly unaddressed and unexamined, are a leading cause of interpersonal discrimination at both the family and the community level.

54. Interpersonal discrimination against persons affected by leprosy is not restricted to endemic countries, as evidenced by the fact that the Special Rapporteur has received worrying reports from countries that have reached nearly zero cases of leprosy. As an example, the Special Rapporteur recently received reports about a young man living in a country with nearly zero cases, who cannot go to the health-care services to get his medication because taxi drivers will not take him. People have taken photos of him and published them on social media to bully him. Neighbours have set fire to his house and have demanded that he and his entire family leave the neighbourhood because, in their view, leprosy is a curse. This person is not, however, an isolated case, showing the need for greater attention to leprosy issues by non-endemic countries.

55. Institutionalized discrimination within State services is a shameful reality that often results from public servants not being educated about leprosy and acting based on prejudice and harmful stereotypes, especially in the fields of health care, education and social protection. The Special Rapporteur has also received complaints about a lack of understanding about leprosy and discriminatory attitudes on the grounds of leprosy within the justice system in Brazil. One example concerns a case that is still pending in a civil court in São Paulo. Demonstrating very limited knowledge about leprosy, its history in Brazil or the violations suffered both by persons affected by the disease and by their children, the judge has refused, without justification, to listen to the testimonies of the aggrieved and has excluded the national organization of persons affected by leprosy from taking part in the case, accepting its participation only as *amicus curiae*. Furthermore, the judge has imposed a fine on the organization.

56. Another issue of concern is the limited integration of the subject of leprosy-related discrimination into the work of national oversight institutions. While the visit of the Special

Rapporteur to Brazil promoted greater synergies between the office of the federal public defender and representative organizations of persons affected by leprosy, in the majority of countries, oversight institutions fail to monitor leprosy-related discrimination. Quasi-judicial systems and human rights protection systems in general fail to ensure justiciability, availability, accessibility, good quality, provision of remedies and accountability for persons affected by leprosy and their family members. Furthermore, and as the Special Rapporteur has stated in several reports, there is a data gap concerning the multiple dimensions of living with leprosy, from health to socioeconomic and discrimination variables. Such a data gap hinders the ability of States to develop evidence-based policies to address discrimination against persons affected by leprosy and their family members.

57. More efforts are necessary to guarantee accessible mechanisms for persons affected by leprosy, their family members and representative organizations filing complaints on discrimination and violations on the grounds of leprosy. Complaints on human rights violations on the grounds of leprosy should be duly investigated and punished. Lastly, access to justice should be enabled and guaranteed to persons affected by leprosy, their family members and representative organizations on an equal basis with others facing discrimination, to which end multiple barriers, from physical barriers to information barriers, should be removed.

58. Leprosy-related discrimination does not impact everyone in the same way. In fact, it affects different persons in different ways according to his or her social status and capital. The Special Rapporteur has already demonstrated how women and children are particularly vulnerable to leprosy-related discrimination. While the Special Rapporteur commends the growing understanding of the need to integrate a gender-sensitive approach to leprosy-related discrimination among key stakeholders, she worries that girls, children and teenagers affected by leprosy still lack adequate protection of their rights. The Special Rapporteur recommends that both States and private stakeholders, including the health industry, ensure child-friendly health-care services, appropriate medical expertise and public policies to treat leprosy in children. Children affected by leprosy must also be recognized as rights-holders and their meaningful participation in relevant policy-making processes must be duly enabled.

59. In some countries, children have also experienced separation from their parents and segregation from society on the grounds of leprosy. In Brazil, it is reported that approximately 16,000 children were separated from their parents as a result of the State segregation policy; they were sent to institutions known as preventorios between the 1920s and the 1980s. There are also reports of illegal adoptions, forced disappearances and even executions. As a result, many people who suffered from such violations currently lack access to an adequate standard of living and economic autonomy and many suffer from psychosocial disorders and disabilities that impair their rehabilitation and inclusion in society. These people should be guaranteed remedies and reparation for the violation of their rights and the suffering incurred as a result of the compulsory isolation of their biological parents, in particular the abuse and violence that they were subjected to within State facilities.

60. Although it is difficult to estimate how many leprosy colonies remain active in the world, there are probably around one to two thousand, mostly in Africa, Asia and South America. While some colonies were created by States in order to segregate persons affected by leprosy, others were the result of deep-rooted stigmatization against persons affected by leprosy, who were forced to leave their home communities.

61. In institutions created by States, the majority of the population comprises older persons affected by leprosy, who have special needs resulting from the psychosocial effects of the multiple forms of discrimination and violations they have been subjected to throughout their lives, in particularly the absence of family ties and the internalization of stigmatization, as well as physical impairments and disabilities related both to leprosy and to ageing. This population demands proper comprehensive health care, which is largely missing in the majority of State institutions. Furthermore, older persons affected by leprosy and related disabilities should never be denied their rights to legal capacity on the grounds of their age or mental health and should be ensured of their rights to make decisions on budgeting and financial planning, making wills, health care, palliative care and end-of-life care. Older persons should have the right to receive support in decision-making under all circumstances. Their needs may include mobility aids and assistive technologies, as well as access to

participation in leisure activities and in other social, religious, cultural, political or educational activities, including the enjoyment of personal relationships on an equal basis with others.

62. People living in both State created and non-State created leprosy colonies and/or institutions face similar problems and should be provided with the same rights and conditions, however, in both instances it is important to emphasize that second and third generations of persons affected by leprosy and their families have been born and grown up in such places, and that they have become their homes. They should, as such, enjoy fundamental housing rights. According to the Committee on Economic, Social and Cultural Rights, the seven components of the right to an adequate housing are: legal security of tenure; availability of services, materials, facilities and infrastructure; affordability; habitability; accessibility; location; and cultural adequacy. Over the years, the Special Rapporteur has received a few reports about the imminent eviction of these populations. Forced eviction is considered a *prima facie* violation of the International Covenant on Economic, Social and Cultural Rights. Decisions regarding staying or leaving leprosy colonies and/or institutions, including the future of such locations, should always be made with the inclusion of the inhabitants at the centre of decision-making.

63. The most generalized problem faced by persons affected by leprosy concerns the multiple barriers they face in accessing opportunities on an equal basis with others, especially work, health care, education, higher education and social protection, as well as fundamental disability rights, such as participation, accessibility, reasonable accommodation, independent living, inclusion in the community, habilitation and rehabilitation. Deficient access to and limited enjoyment of an adequate standard of living, including access to decent housing, clean water, sanitation and proper and high-quality health care are also important social determinants of leprosy.

64. Substantive discrimination resulting from entrenched and systemic ostracization and marginalization stands out as a leading cause of the persistent denial of the enjoyment of rights by persons affected by leprosy and their family members on an equal basis with others. Persons affected by leprosy have been trapped in a cycle of disadvantage. Leprosy is a disease of poverty, leading to discrimination and disability, which enhances vulnerability and thus leads to further poverty. The enforcement of economic, social, cultural and disability rights for persons affected by leprosy are of the essence to break this cycle of disadvantage.

65. The Special Rapporteur recalls that, according to the Committee on Economic, Social and Cultural Rights, merely guaranteeing equality in law does not necessarily ensure substantive equality, since the effective enjoyment of rights is often influenced by whether a person is a member of a group characterized by prohibited grounds of discrimination. According to the Committee, eliminating discrimination in practice requires paying sufficient attention to groups of individuals who suffer historical or persistent prejudice instead of merely comparing the formal treatment of individuals in similar situations.

66. Throughout the COVID-19 pandemic, persons affected by leprosy and their families have suffered disproportionately as a result of the long-term structural violence they have been exposed to. For example, they have been denied access to decent work and have been excluded from the formal work market due to systemic stigmatization and, as a consequence, lack access to social protection schemes. These multiple exclusions have posed continuing life-threatening menace to persons affected by leprosy and their families during the COVID-19 pandemic.

67. The principle of the progressive realization of economic, social and cultural rights means that those rights are often neglected in national budgeting and that universality is rarely guaranteed, leaving those who already experience structural discrimination, such as persons affected by leprosy and their families, furthest behind and largely unprotected. Poverty, together with structural and systemic discrimination, contributes to the dehumanization of persons affected by leprosy and their family members. The Special Rapporteur strongly recommends that the principle of progressivity should be applied in a reasonable manner that firmly recognizes poverty as a human rights violation and that guarantees minimum core obligations in a way that is proportional to the needs of vulnerable groups and groups that have been discriminated against.

68. One related issue of great concern is the clear set back on the right to the highest attainable standard of physical and mental health, as witnessed by the Special Rapporteur during her country visits and reported to her by organizations of persons affected by leprosy from a great number of countries. In addition to factors explaining the limited enjoyment by persons affected by leprosy to same rights as others, as detailed in a previous report of the Special Rapporteur,<sup>13</sup> she realized, especially during country visits, that the global elimination of leprosy as public health problem in 2000 has contributed greatly to the deterioration of services, as well as to a decrease in both financial and human resources guaranteeing the right of persons affected by leprosy and their families to health.

69. Over the years, it has become increasingly evident to the Special Rapporteur that the limited enjoyment of persons affected by leprosy and their family members of social, economic and cultural rights, mainly due to systemic discrimination, are intertwined with the multiple barriers to their participation in public affairs and in making decisions that affect their lives, which limits their capacity to defend their interests. Moreover, the Special Rapporteur has realized how the dramatic decrease of international funds for fighting leprosy and its consequences has contributed to a worrying exclusion of leprosy from the global health agenda and from national budgeting. The few efforts that remain in place to fight leprosy and its consequences are undertaken by international NGOs under a development framework. The above developments call for a clarification of the basic principles for action under a rights-based approach to development in order to build a sustainable approach to leprosy as well as to other neglected tropical diseases.

70. The Declaration on the Right to Development affirms that development is a comprehensive economic, social, cultural, and political process, which aims at the constant improvement of the well-being of the entire population and of all individuals on the basis of their active, free and meaningful participation in development and in the fair distribution of benefits resulting therefrom. In preparing the present report, the Special Rapporteur sent a questionnaire to States and civil society organizations on the situation of the right to development for persons affected by leprosy, in particular concerning article 3 of the Declaration, and inquired about measures taken to ensure that persons affected by leprosy can participate in, contribute to and enjoy economic, social, cultural and political development. Only four States, together with 17 civil society organizations, responded to the invitation of the Special Rapporteur for submissions to the present report. Responses were received from Brazil, Cambodia, the Democratic Republic of Congo, Ethiopia, India, Indonesia, Italy, Japan, Mauritius, Mozambique, Nepal, Togo, Uganda, the United Kingdom of Great Britain and Northern Ireland and the United Republic of Tanzania.

71. Overall, there were just a few submissions that described any kind of development policies or strategies implemented by States. The submissions received describe more social-protection type measures rather than rights-based approaches to development that guarantee the enjoyment by persons affected by leprosy an adequate standard of living as well as their empowerment as participants in development. Further, development strategies are being mainly implemented by civil society organizations for persons affected by leprosy, which have also been increasingly adopting a participatory dimension to traditional income-generation activities and self-care practices.

72. The analysis of the responses received, including the data gathered by the Special Rapporteur over the years, points to a deficit in the development of State policies guaranteeing the right to non-discrimination. In essence, development is still largely approached from an economic growth framework and core principles of a rights-based approach to development are side-lined. Such an approach leads to an inability of both international and national development policies to reach those who have been hardest hit by deeply disabling forces, such as colonialism, capitalism, patriarchy, economic inequalities and, more recently, climate change. Climate change is already impacting persons affected by leprosy and their families, who mainly live in countries in the Global South and who oftentimes rely solely on agriculture for their livelihoods.

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<sup>13</sup> [A/HRC/50/35](#).

73. The particular situation of persons affected by leprosy and their family members indicates that the principles of the right to development, such as equity in the enjoyment of the benefits of economic growth, self-determination, participation and justice, are still not being met. Their situation also shows the importance of integrating a non-discriminatory dimension to international and national development policies, together with the right to participation, both as a means and a goal of development. Development strategies should empower those who have faced systemic discrimination and both the outcomes and processes of all development policies should always be monitored in a transparent manner in order to ensure that this is the case.

## V. Conclusions and recommendations

74. Both leprosy-endemic and non-leprosy-endemic States should commit themselves to ending formal, substantive, interpersonal, direct, indirect, systemic and intersectional discrimination, as well as violence against and the dehumanization of persons affected by leprosy and their family members, which persist today.

75. As affirmed in general comment No. 20 (2009) of the Committee on Economic, Social and Cultural Rights, States parties should ensure that a person's actual or perceived health status does not constitute an obstacle to the realization of his/her rights and should also adopt the necessary measures to address widespread stigmatization of persons on the basis of that his/her health status, including diseases such as leprosy.

76. Furthermore, as clarified by general comment No. 6 (2018) of the Committee on the Rights of Persons with Disabilities, the mere recognition of formal equality is not sufficient to combat deep-rooted attitudinal barriers, including those related to leprosy. As also detailed in general comment No. 6, States parties are not only obliged to modify or abolish existing discriminatory laws, regulations, customs and practices, but must also take positive measures, on the one hand, to prevent discrimination, and on the other hand, to tackle it through specific measures aimed at accelerating or achieving de facto equality, non-discrimination, dignity and integrity for groups of people who experience structural disadvantage based on their actual or perceived differences.

77. In order to eliminate all forms of discrimination against persons affected by leprosy and their family members, the Special Rapporteur recommends that leprosy endemic States:

(a) Review, amend, repeal or abolish all laws, regulations, ordinances, resolutions and policies that discriminate against persons affected by leprosy 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, to criminalize and punish by effective, proportionate and dissuasive criminal penalties violence and discrimination on the grounds of leprosy;

(d) Include leprosy as prohibited grounds for discrimination in existing monitoring mechanisms and oversight institutions and systematically collect data disaggregated by demographic, environmental, socioeconomic and cultural variables, with full respect for the principles of participation and privacy;

(e) 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 free legal aid, and ensure access to justice, on an equal basis with others, for persons affected by leprosy and their family members;

(f) Reformulate policies and bodies for the protection of vulnerable groups, in a manner that recognizes and addresses the specific realities and needs of persons affected by leprosy and their family members, with a proper budget allocation at the national and subnational levels, with targets, indicators and benchmarks;

(g) 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;

(h) Develop and enact comprehensive affirmative measures as a means of correcting historical and structural disadvantage, in line with general recommendation No. 25 (2004) of the Committee on the Elimination of Discrimination against Women, in which the Committee affirms that the duration of a temporary special measure should be determined by its functional result in response to a concrete problem and not by a predetermined passage of time; ensure that affirmative measures are defined in consultation with persons affected by leprosy, their family members and representative organizations; and ensure that affirmative measures come with targets and key performance indicators, as well as effective enforcement mechanisms and remedies; affirmative measures should recognize the intersectional discrimination against women and children affected by leprosy;

(i) Guarantee the right to education for children and teenagers affected by leprosy through the creation of an inclusive and enabling education system that is non-discriminatory and that ensures the availability of education services, accessibility at all levels of education and the promotion of life-long training and skills development opportunities; education services should ensure both accessibility and reasonable accommodation;

(j) 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 all forms of interpersonal violence;

(k) 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;

(l) Establish minimum core obligations for guaranteeing fundamental access to economic and social rights for vulnerable groups and groups that have been discriminated against, including persons affected by leprosy and their family members, as part of national development plans;

(m) Guarantee access to health-care services at all levels of the health system by persons affected by leprosy on a non-discriminatory basis; and ensure their right to a continuum of medical and psychosocial care that encompasses the full spectrum of prevention, timely access to multidrug therapy, the proper management of leprosy reactions and complementary care, including wound care, physiotherapy, rehabilitation and reconstructive surgery in the public health system;

(n) Invest in mitigating suffering caused by neuropathic pain and stigmatization through high quality pain management and effective referral within national health-care systems for mental health care, under a recovery-based paradigm and through services that are ethical, respectful, culturally appropriate, gender-sensitive and empowering to individuals; and ensure access by family members of persons affected by leprosy to mental health care;

(o) Provide, free of charge, assistive devices for protection and assistive devices for the facilitation of activities of daily life for persons with leprosy-related impairments and disabilities;

(p) Partner with organizations of persons affected by leprosy to strengthen peer-to-peer counselling, as well as family-based counselling, and extend counselling to family members of persons affected by leprosy;

(q) Recognize persons affected by leprosy as active economic agents, respecting their legal capacity and realizing their rights to equal work opportunities in



the open labour market and to equal remuneration, and include persons affected by leprosy in public employment programmes;

(r) **Open social dialogue to organized groups of persons affected by leprosy working in the informal economy and enable their right to collective bargaining, including by making available a defined interface with the institutions and government bodies with which the organizations must hold dialogues;**

(s) **Fulfil accessibility and reasonable accommodation rights in all productive sectors and work arrangements, including agriculture, husbandry and fishing, and recognize visible physical impairments related to leprosy as well as invisible ones, such as pain or loss of sensation, and psychosocial disabilities related to stigmatization, in the provision of reasonable accommodation;**

(t) **Ensure both work and education opportunities for persons affected by leprosy, which should come with targets and key performance indicators, as well as with effective enforcement mechanisms and remedies, while also following paragraph 11 (i) of recommendation No. 168 of the International Labour Organization (ILO) concerning vocational rehabilitation and employment;**

(u) **Ensure that social protection measures and social benefits are implemented through administrative services and bureaucratic procedures that guarantee full accessibility to illiterate or poorly educated populations, as well as to populations living in remote areas; such comprehensive social protection policies should also target active citizenship by promoting training opportunities and formal employment, while guaranteeing support, as needed;**

(v) **Recognize, in the design of social benefits, such as unconditional cash transfers, the real needs of the target population, including the additional costs of disability, as well as the specific challenges faced by women, children, teenagers and older persons affected by leprosy, and ensure a universal basic income for persons affected by leprosy in order to guarantee them a minimum standard of living and to break the cycle of poverty, disease, disability and discrimination;**

(w) **Establish a framework to promote and monitor the implementation of the Convention on the Rights of Persons with Disabilities that recognizes persons affected by leprosy and their family members as persons with multiple disabilities;**

(x) **Implement awareness-raising programmes that are sensitive to culture, language, gender, age and disability and that are developed in close collaboration with organizations of persons affected by leprosy in order to ensure both accessibility and efficacy, address barriers created by the digital divide and invest in community media in order to reach as many people as possible, raise awareness among community leaders, traditional leaders and healers, religious leaders, local pharmacists and schoolteachers with regard to leprosy and engage them in further awareness-raising, and reinforce the positive image of persons affected by leprosy and their family members as rights holders;**

(y) **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;**

(z) **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;**

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

(bb) **Provide urgent symbolic and material reparation, as well as rehabilitation, at the national level to individuals who as children were separated from their parents affected by leprosy and segregated from society.**

78. **The Special Rapporteur recommends that intergovernmental agencies:**

- (a) **Use leprosy as a case study to fill evidence gaps on the relationship between disease, disability, poverty and discrimination;**
- (b) **Ensure leprosy inclusiveness in addressing discrimination, as well as issues concerning women, children, older people, disability, minorities and development;**
- (c) **Make sure to consult with organizations of persons affected by leprosy when working in leprosy endemic countries on cooperation plans and programmes;**
- (d) **Discuss with WHO and consult with organizations of persons affected by leprosy the possibility of changing the name of leprosy to a more neutral one, such as Hansen's disease, in order to address harmful stereotypes attached to the term leprosy.**

79. **The Special Rapporteur recommends that international civil society organizations for persons affected by leprosy:**

- (a) **Establish measures to ensure that persons affected by leprosy are included in decision-making on all relevant programmes and action plans;**
- (b) **Establish measures ensuring equality of participation of women affected by leprosy in decision-making with regard to all relevant programmes and action plans;**
- (c) **Develop measures for proper consultation with children and teenagers affected by leprosy, assess their real needs and ensure they are included in decision-making with regard to all relevant programmes and action plans;**
- (d) **Establish quotas for the employment of persons affected by leprosy in order to ensure their representation at the organizational level;**
- (e) **Provide training to members of national and local organizations of persons affected by leprosy about their rights and how to claim them, as well as on basic organizational issues, in order to promote the development of such organizations;**
- (f) **Establish, with sufficient material and technical resources, an international platform for monitoring the rights of persons affected by leprosy and their family members, find prompt solutions to urgent needs and provide the human rights system regularly with information about discrimination on the grounds of leprosy.**

80. **While sensitive to the epidemiological heterogeneity of leprosy worldwide, the Special Rapporteur reminds all States of their commitments under the Declaration on the Right to Development and the Sustainable Development Goals, in accordance with which both leprosy endemic and non-endemic States should:**

- (a) **Allocate sufficient resources to removing any barriers to the participation of marginalized and vulnerable populations in the human rights system and ensure accessibility of procedures for the submission of information to the human rights mechanisms;**
- (b) **Use a more neutral term than leprosy, such as Hansen's disease, in future resolutions;**
- (c) **Remove any obstacles to development, recognizing human beings as the central subject of development and ensure that individuals actively participate in and enjoy the benefits of development and formulate international development policies that complement the efforts of developing countries in the search for solutions that are equitable, inclusive and sustainable; development policies, both national and international, should include non-discrimination as the guiding principle of both processes and outcomes.**