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Elimination of discrimination against persons affected by leprosy (Hansen's disease) and their family members

Report of the Special Rapporteur on the elimination of discrimination against persons affected by leprosy (Hansen's disease) and their family members, Beatriz Miranda-Galarza

Summary

In the present report, the first since her appointment, the Special Rapporteur on the elimination of discrimination against persons affected by leprosy (Hansen's disease) and their family members, Beatriz Miranda-Galarza, provides an overview of the impact of the mandate since its establishment in 2017, with a strong focus on the views of persons affected; outlines her vision for her work over the coming years; and details the working methods, as well as the areas of concern and priority issues, for her work.

Contents

I. Introduction

1. The present thematic report of the Special Rapporteur on the elimination of discrimination against persons affected by leprosy (Hansen's disease) and their family members is the first of the current mandate holder, Beatriz Miranda-Galarza, since she took up her functions on 1 November 2023. The report is submitted pursuant to Human Rights Council resolution 53/8, in which the Council renewed the mandate.

2. Recognizing the need to respond to the demands that have been made regarding violations of the fundamental rights of persons affected by leprosy and their families, the Human Rights Council, in its resolution 35/9, established the mandate of Special Rapporteur on the elimination of discrimination against persons affected by leprosy (Hansen's disease) and their family members. This pivotal decision underscores the Council's acknowledgement of the long-standing exclusion and discrimination experienced by those affected by leprosy and their families on a global scale, and emphasizes the urgent need to affirm their status as human rights holders and to undertake prompt and decisive measures accordingly.

3. In the present report, the Special Rapporteur provides an overview of the impact of the work of the previous mandate holder and describes her vision for the mandate, her working methods and the strategic themes to be addressed during her mandate.

4. The Special Rapporteur extends her sincere appreciation and gratitude to her predecessor for her pioneering work, as documented in her last report to the Human Rights Council,[1] and to the team working with the mandate in the Special Procedures Branch of the Office of the United Nations High Commissioner for Human Rights (OHCHR). She also acknowledges the work of United Nations agencies and Member States that have supported the mandate and, most importantly, organizations of and for persons affected by leprosy, their families and their allies.

II. Background: from exclusion to recognition as holders of rights

5. Leprosy, also known as Hansen's disease, is a chronic infectious disease caused by the bacterium *Mycobacterium leprae*. It primarily affects the skin, peripheral nerves, mucosa of the upper respiratory tract and eyes. It is known for causing skin lesions, nerve damage and deformities, which lead to impairments, especially in untreated cases. It is not highly contagious but can be spread through respiratory droplets from an infected person, although prolonged close contact is usually required for transmission. Nevertheless, there is still social stigma attached to the disease, leading to discrimination against and the isolation of affected persons and their families. With appropriate diagnosis and treatment using multidrug therapy, it is curable. Such diagnosis and treatment are also crucial in preventing long-term complications and reducing transmission of the disease.

6. In 2010, the General Assembly adopted resolution 65/215, in which it took note with appreciation of the principles and guidelines for the elimination of discrimination against persons affected by leprosy and their family members. The adoption of this resolution was a milestone in the history of persons affected by leprosy: on the one hand, the General Assembly thereby recognized the need for international instruments to promote the consideration of leprosy as a human rights issue; on the other, it encouraged Member States to give due consideration to the principles and guidelines in the formulation and implementation of their policies and measures concerning persons affected by leprosy and their family members.

7. Behind that achievement lies a long history of isolation and exclusion and a continual struggle by persons affected by leprosy to reclaim their status as human rights holders. That history can be understood in a deeper way if seen through the lens of four main approaches: (a) a religious and moral approach; (b) a scientific and administrative approach; (c) a representational and cultural approach; and (d) a human rights-based approach. These diverse

[1] A/HRC/53/30.

approaches have led to varied responses to the disease and, ultimately, to the persons affected by it. Such responses are interconnected and have had an impact on the elaboration and implementation of policies, social programmes and legal frameworks relating to the lives of persons affected by leprosy and their families.

8. The Special Rapporteur recognizes the semantic and political nuances associated with the terms "leprosy" and "Hansen's disease". While some countries and organizations opt to use the latter term in deference to the preferences of members of the social movement of persons affected by leprosy in their localities, the term "leprosy" remains widely recognizable to most organizations and affected persons. Consequently, she will use both terms interchangeably and advocate the use of "Hansen's disease" wherever it aligns with the decisions made by the leprosy rights movement.

9. An understanding and thorough examination of the approaches mentioned above could shed light on the existence of derogatory laws and discriminatory practices that are still present, especially in countries in which leprosy is endemic. In this regard, it is important to recognize the invaluable contribution of the disability rights movement, which has provided the theoretical and conceptual frameworks essential for understanding the complexities surrounding the history of leprosy.[2]

A. Religious and moral approach

10. From a religious and moral approach, the source of leprosy is a divine figure commonly called God. Across various cultures, and influenced by religious interpretations and, at times, misinterpretations, leprosy has often been associated with divine punishment for immoral behaviour. The link between leprosy and sin and impurity has been prevalent in major world religions,[3] such as Judaism, Christianity, Hinduism,[4] Buddhism and Islam. However, while some religious texts contain references to leprosy and recommendations for social treatment, others, such as the Qur'an, refer to the disease in an ambiguous way.[5] It is crucial to acknowledge and understand the ways in which societies have responded to leprosy on the basis of the transmission and interpretation of religious texts. This view of leprosy-related moral wrongdoing has resulted in paternalistic and charity-oriented responses, neglecting the rights of the persons affected and their families.

B. Scientific and administrative approach

11. From a scientific and administrative standpoint, leprosy has been approached as a disease necessitating scientific research and the isolation of affected individuals, often through the implementation of laws and norms. The medical understanding of leprosy began to take shape in the 1840s, with the work of Daniel Cornelius Danielssen and Carl Wilhelm Boeck, and was further advanced in 1873 when Gerhard Armauer Hansen discovered *Mycobacterium leprae*, a significant milestone in understanding its aetiology. Despite scientific scepticism regarding the high risk of contagion and the hereditary theory of transmission, Governments, in collaboration with the global scientific community, enforced compulsory segregation, leading to the establishment of numerous leprosaria worldwide. In tandem with segregation, laws were enacted to strip individuals affected by leprosy of their citizenship. The introduction of sulfone drugs, particularly dapsone, in 1940 revolutionized leprosy treatment, and multidrug therapy later became the standard treatment, significantly reducing leprosy prevalence globally. The World Health Organization (WHO) launched

[2] See Patrick J. Devlieger, "Generating a cultural model of disability", paper presented at the nineteenth Congress of the European Federation of Associations of Teachers of the Deaf, 14–16 October 2005.

[3] See Zachary Gussow and George S. Tracy, "Stigma and the leprosy phenomenon: the social history of a disease in the nineteenth and twentieth centuries", *Bulletin of the History of Medicine*, vol. 44, No. 5 (1970).

[4] See A.K. Sinha, B.G. Banerjee and S. Singh, "Leprosy and its socio-cultural perception in Indian religions and ancient texts", *Indian Journal of Leprosy*, vol. 82, No. 1 (2010).

[5] See Rooshey Hasnain and others, "Islam, leprosy, and disability: how religion, history, art, and storytelling can yield new insights and acceptance", *Societies*, vol. 10, No. 1 (2020).

global leprosy control programmes in the mid-twentieth century, focusing on early detection, prompt treatment with multidrug therapy and public health interventions. Despite expectations that leprosaria would close with the introduction of effective treatment, the process of inclusion of individuals affected by leprosy into their communities has been complex and challenging, with a significant impact on their lives and families. In 2001, WHO announced the global elimination of leprosy as a public health problem, but challenges remain, with rates of transmission and the detection of new cases not meeting expectations. This biomedical and administrative approach to leprosy has led some Governments to treat persons affected by leprosy primarily as persons with a disease rather than as persons with rights.

C. Representational and cultural approach

12. A medical and administrative approach to leprosy has proved insufficient in eliminating it. Stigmatization and discrimination have hindered diagnosis, treatment and the fulfilment of civil, political, economic, social and cultural rights, particularly in countries in which it is endemic. Efforts to raise awareness about leprosy have often inadvertently reinforced negative stereotypes, portraying affected individuals as dangerous and perpetuating the myth of leprosy as highly contagious. Cultural and contextual interpretations of religious, legal and medical accounts have influenced representations of leprosy and affected individuals. For example, while the term "leprosy" is widely used, especially in Western cultures, its etymology is complex, with theologians and researchers uncovering potential mistranslations and misinterpretations in sacred texts, such as the Old Testament and the Qur'an.[6] A similar situation can be observed regarding segregation and the violation of citizens' rights, stemming from the disregarding of reports and evidence indicating that leprosy is not as dangerous or contagious as fear and power have led people to believe.

D. Human rights-based approach

13. In the latter half of the twentieth century, leprosy gained recognition as a human rights issue amid the global human rights movement. Advocates highlighted systematic violations of the rights of affected individuals, leading to increased attention to their plight. In 2010, the General Assembly adopted resolution 65/215, on the elimination of discrimination against persons affected by leprosy and their family members, marking a significant step. The rights of those affected by leprosy have since been integrated into the protective frameworks of international human rights instruments, including the Universal Declaration of Human Rights and the Convention on the Rights of Persons with Disabilities. Legal challenges and advocacy efforts, led by organizations such as the International Federation of Anti-Leprosy Associations and the Sasakawa Health Foundation, have been instrumental in advancing the rights of affected individuals. With this approach, emphasis is given to empowering grass-roots organizations and inclusive community programmes.

E. Observations regarding the four approaches

14. The Special Rapporteur emphasizes that the emergence of each approach does not indicate the overcoming of the previous one; rather, they coexist, with one or two sometimes prevailing in certain contexts or cultures. For example, even if persons affected by leprosy are undergoing treatment, their religious beliefs may still lead them to perceive leprosy to be a result of misbehaviour.

15. In addition, it is important to recognize that each approach has made positive contributions, including medical advancements in treatment and the transformation of the approach of various religious organizations from one that is charity-focused to one that is based on human rights approach. The significance of these approaches lies in their utility for analysing how legal, social and political frameworks are developed to address the challenges

[6] See Gilbert Lewis, "A lesson from Leviticus: leprosy", *Man*, vol. 22, No. 4 (1987).

faced by individuals affected by leprosy in their daily lives. By understanding the complexities of medical, cultural, human rights and other approaches, policymakers, lawmakers and advocates can craft more comprehensive and effective strategies to tackle the stigma, discrimination and barriers to health-care access experienced by those affected by leprosy.

III. Work of the Special Rapporteur in the period 2017–2023

A. Overview

16. The first Special Rapporteur on the elimination of discrimination against persons affected by leprosy (Hansen's disease) and their family members held the mandate from 2017 to 2023. During that period, she addressed several pertinent issues, as highlighted in the reports that she submitted to the Human Rights Council[7] and the General Assembly.[8] They included: (a) stigmatization and discrimination based on leprosy; (b) the social determinants of leprosy; (c) women and children affected by leprosy; (d) the right to health and the coronavirus disease (COVID-19) emergency; (e) discriminatory law and policy; (f) disability rights; and (g) the participation and empowerment of persons affected by leprosy.

17. In her last report, the previous Special Rapporteur underlined that she had dedicated considerable efforts to making persons affected by leprosy and their representative organizations aware of human rights standards.[9] Awareness-raising, technical input and collaboration with political and religious leaders from around the world, and especially with grass-roots organizations of persons affected by leprosy, have contributed to changing policies, practices, norms and power relations and have brought about an understanding of persons affected by leprosy as rights holders.

18. An exemplary transformation was achieved by the social movement of persons affected by leprosy and their allies in Brazil. On 24 November 2023, the President of Brazil, in line with the recommendations of the Special Rapporteur,[10] signed a law amending legislation adopted in 2007. The new law provides for a monthly stipend for persons with Hansen's disease of not less than the minimum wage. Children separated from parents affected by the disease may receive the stipend as a form of reparation.

19. The previous Special Rapporteur identified several significant barriers to accomplishing the objectives of the mandate. They included the limited resources at her disposal, which affected the implementation of key activities, such as expert or regional consultations and the examination of additional, intersectional leprosy-related issues, such as race.

20. The previous Special Rapporteur acknowledged factors hindering persons affected by leprosy and their representative organizations from making use of the human rights system. Such factors include language barriers, as the majority of persons affected do not speak any of the six official languages of the United Nations; the digital divide; complex procedures that require a level of literacy and expertise that marginalized groups often do not possess; and the fact that international and civil society organizations with experience and expertise in the system do not have issues faced by persons affected by leprosy, such as access to health care, on their agendas.[11]

21. While adopting a cooperative approach with Governments, the previous Special Rapporteur expressed regret over their limited engagement. The former Special Rapporteur

[7] A/HRC/38/42, A/HRC/41/47, A/HRC/44/46, A/HRC/47/29, A/HRC/50/35 and A/HRC/53/30.

[8] A/76/148, A/77/139 and A/78/173.

[9] A/HRC/53/30, para. 27.

[10] A/HRC/44/46/Add.2, para. 80. See also communication BRA 15/2019, available at https://spcommreports.ohchr.org/TMResultsBase/DownLoadPublicCommunicationFile?gId=24952; and https://www.ohchr.org/en/press-releases/2020/10/leprosy-brazil-children-sent-preventoriums-long-overdue-justice-says-un.

[11] A/HRC/53/30, para. 25.

visited four countries, namely, Angola, Bangladesh, Brazil and Japan,[12] but 16 countries[13] to which she sent a request for a visit, most of which were countries in which leprosy is highly endemic, failed to accept her request. She stressed that greater cooperation from relevant States would be essential to the success of the mandate.

22. The previous Special Rapporteur issued crucial recommendations relating to: (a) discriminatory laws against persons affected by leprosy at all levels of government; (b) increasing knowledge about leprosy and the right to non-discrimination among State officials and public servants; (c) ensuring the accessibility of legal systems to women affected by leprosy and providing gender awareness training for officials; (d) guaranteeing non-discriminatory access to health-care services; and (e) ensuring comprehensive medical and psychosocial care within the public health system.[14]

23. The current Special Rapporteur is committed to continuing the work started by her predecessor and to making the mandate a people-centred one.

B. Voices of persons affected by leprosy and their organizations

24. In accordance with the underlying philosophy of the mandate, which is that the voice, knowledge and life experience of persons affected by leprosy must guide the work of the mandate holder, the current Special Rapporteur conducted interviews with representatives of organizations of persons affected by leprosy and their allies in Bangladesh, Colombia, Ethiopia, Kenya, India, Indonesia, Japan, New Zealand and Paraguay. The interviews addressed two specific topics: the impact of the implementation of the mandate at the local and international levels; and relevant issues that should be addressed in the coming years.

25. The Special Rapporteur regrets that, due to the short time between her appointment and the submission of the present report, which she primarily spent familiarizing herself with the responsibilities of the mandate, there was insufficient time in which to interview representatives of other organizations, including organizations in other countries. However, she is committed to continuing to elicit suggestions for her work, which will be shared in her next report.

26. International organizations report that, since the establishment of the mandate, there has been increased awareness regarding leprosy as a human rights issue, enabling discussions about the topic to extend beyond the medical domain. In addition, the previous mandate holder provided valuable recommendations to United Nations bodies and Member States to assist them in introducing appropriate legislative, administrative and other measures to implement anti-discriminatory laws, programmes and procedures. That included modifying, repealing or abolishing laws, regulations, policies, customs and practices that promoted discrimination. Those efforts were aimed at ensuring equitable conditions of life for persons affected by leprosy and their families.

27. In the United Nations system and internationally, leprosy has gained more recognition, and awareness has been raised about the concerns of persons affected by leprosy and their allies globally. The mandate has been successful, accompanied by the ongoing efforts of various international organizations to influence some of the United Nations bodies that are directly or indirectly concerned with leprosy. According to the interviewees, the creation of the mandate has reinforced the visibility of leprosy within the United Nations and the involvement of international leprosy donors in activities and dialogues with different United Nations bodies, including OHCHR.

28. The Special Rapporteur was informed that another impact of the mandate was an increased interest within major leprosy donor organizations in amplifying knowledge about

[12] The country visit reports may be accessed at https://www.ohchr.org/en/documents-listing?field_content_category_target_id%5B182%5D=182&field_entity_target_id%5B1275%5D=1275.

[13] Colombia, Ethiopia, Fiji, India, Indonesia, Kenya, Madagascar, Morocco, Mozambique, Nepal, Nigeria, Papua New Guinea, Philippines, Senegal, Sri Lanka and Timor-Leste.

[14] See A/HRC/53/30.

the human rights approach among organizations of persons affected by leprosy and beyond. Representatives of international and local organizations believe that the shift towards recognizing leprosy as a human rights issue at the United Nations was evidenced by the extension of the mandate for three more years. This development instils confidence that the voices of persons affected by leprosy are being heard and are gradually reaching important decision makers, both internationally and locally. According to one of the persons affected by leprosy who was interviewed, "if a person affected by leprosy is heard and seen by somebody coming from an organization such as the United Nations, she feels important and thinks that her problems are important too. That makes a difference in her life." Nevertheless, the view was expressed that there was still a long way to go to eliminate discriminatory practices and laws, especially in some of the countries in which leprosy is endemic.

29. While some changes at the international level have been noted, the impact of the mandate is not yet as visible at the local level as persons affected by leprosy and their allies would desire. Nevertheless, the Special Rapporteur's request for information about the situation of persons affected by leprosy in each country has motivated grass-roots organizations to stay informed about the various violations of the rights of persons affected by leprosy in their own communities. They have noted the scarcity of information available regarding the challenges faced by persons affected by leprosy and their families, with existing data often being outdated and unreliable.

30. Moreover, it seems that, at the country level, major organizations of persons affected by leprosy in urban areas have received information regarding the work implemented under the mandate, but a notable number of smaller organizations in rural and marginal areas have not received such information. This difference could be attributed to challenges in disseminating centralized information to peripheral areas, as well as language barriers, given that English is the language predominantly used and spoken within international leprosy organizations.

31. Organizations of persons affected by leprosy have gained increased recognition at the local and international levels, partly through their participation in human rights events related to leprosy and their engagement with the United Nations. They have become more aware of the importance of their involvement in decision-making processes at the local level, with the mandate playing an encouraging role in this regard. This impact became evident following the country visits undertaken by the Special Rapporteur, which gave persons affected by leprosy a sense of being heard and increased awareness of their rights.

32. The transition to online meetings during the COVID-19 pandemic enabled the Special Rapporteur to have more frequent contact with representatives of grass-roots organizations. As a result of those meetings, information has circulated more widely, leading some organizations to rethink the methods that they use to inform communities about leprosy. In addition, they have shown improvements, potentially influenced by the mandate, in managing funds and conducting democratic elections for leaders.

33. Due to the formal nature of communication procedures within the special procedures system, some grass-roots organizations of persons affected by leprosy have learned to implement more formal systems of work within their organizational structures. This includes the collection of data and the registration of cases to be used as evidence when demanding action from local and international institutions regarding violations of human rights.

34. The work carried out under the mandate has provided hope to persons affected by leprosy, their families and grass-roots organizations, although the impact is not easily measurable. This effect is essential to highlight because, as persons affected by leprosy have historically been discriminated against and excluded, the acknowledgement by their communities and by local authorities of the significant role that they could play in processes of social change has a parallel effect on their personal and family lives. In one of the interviews conducted by the Special Rapporteur, it was mentioned that, "when persons affected by leprosy realize they have rights, like any other person, their self-confidence changes, and also there is confidence in what their organizations can achieve".

35. It is important to stress the importance of acknowledging that the impact of the mandate on the lives of people and organizations is intertwined with various factors, such as the widespread adoption of new digital strategies for outreach and communication,

accelerated by the COVID-19 pandemic; the groundwork laid by international leprosy donors; collaboration with the Committee on the Rights of Persons with Disabilities; and the partnerships formed between organizations of persons affected by leprosy and disability rights organizations. The changes that have occurred in the past six years have been the result of collaboration between the Special Rapporteur, international leprosy organizations, the Governments that have supported the mandate and persons affected by leprosy.

36. However, there is still a need for clarification of the Special Rapporteur's role at the local level, as expectations on the ground may exceed the capacity of the mandate. Many grass-roots organizations might assume that the Special Rapporteur can take more direct action at the local level, without realizing that her role is primarily informational and advisory as opposed to action-oriented.

37. International leprosy organizations believe that, although international attention has increased, it is not yet sufficient. There is a greater need for the implementation of policies and guidelines on the ground, which is primarily the responsibility of Member States. Governmental institutions could rely more on the advice and support of organizations of persons affected by leprosy and the Special Rapporteur to take leading actions to guarantee the protection of the rights of persons affected by leprosy and their families.

38. Civil society organizations and affected persons welcomed the decision of the Human Rights Council to extend the mandate. The existence of the mandate signifies – for persons affected, their families, their communities and their allies – that leprosy is in the spotlight of the international community. This marks a significant step in the long history of violations of the rights of persons affected by leprosy. For this reason, one of the Special Rapporteur's requests is that Member States and the members of the Council continue to support the existence of the mandate and its work.

39. Such support would include facilitating the production of accessible human rights information materials, fostering collaboration with mandates that are directly or indirectly related to leprosy (such as those in the areas of health and disability) and allowing the dissemination of information about leprosy-related human rights issues within the United Nations system and among Member States.

40. Furthermore, the interviewees called for active collaboration on the part of Member States to accept and implement the recommendations made by the Special Rapporteur, ensuring that the measures adopted benefit not only persons affected by leprosy but also their families, communities and countries.

IV. Leprosy in the twenty-first century: key priorities for the mandate

41. The second topic raised by the Special Rapporteur during her discussions with various representatives of international leprosy organizations and grass-roots organizations concerned the pertinent issues that, in their view, she should address in the coming years. Their responses aided the Special Rapporteur in identifying the priorities among the numerous unresolved issues concerning the elimination of discriminatory practices against and violations of the rights of persons affected by leprosy and their families. Many of the issues presented to the Special Rapporteur had already been discussed with representatives of the organizations concerned in initial meetings held as part of the process of introducing the new mandate holder. Similarly, they were noted by her predecessor in her reports. Regrettably, this underscores the fact that there remains a long journey ahead to guarantee and protect the rights of persons affected by leprosy.

42. Taking into account these key priorities, the Special Rapporteur will ensure that her various thematic reports are designed to inform and give rise to regional or domestic debates about practical steps that can be taken to bring about a cultural shift towards respect for the values and rights enshrined in the principles and guidelines for the elimination of discrimination against persons affected by leprosy and their family members, to advance law and policy reform and to ensure that systems change in order to enable the enjoyment of human rights by persons affected by leprosy and their families. Each thematic report will be

informed by a gender perspective, will cover the accumulated disadvantages faced by children, youth and older persons and will illustrate the different circumstances that persons affected by leprosy face in different localities and contexts.

43. The Special Rapporteur emphasizes that one of the key objectives of her mandate is to propel the understanding of leprosy as a human rights issue into the twenty-first century. This involves emphasizing that the issue is inherently societal rather than individual, meaning that it implicates States, Governments, institutions and organizations and not only persons affected by leprosy and their families. As both a human rights and a social problem, it evolves alongside global developments; consequently, the primary challenges confronting humanity are echoed in the experiences of persons affected by leprosy, often with a magnified impact.

44. The Special Rapporteur has categorized the issues presented to her into five clusters: fundamental rights and support and care systems; crucial intersectional issues and marginalized groups; social, political and cultural considerations; legal and economic dimensions related to leprosy; and conflict-related and environmental considerations.

A. Rights-based support and care systems

45. According to WHO,[15] in 2019, 161 countries submitted information regarding leprosy. A total of 202,256 new cases were detected in 118 countries. Of those cases, 96 per cent were reported by the 23 global priority countries, and 79 per cent by Brazil, India and Indonesia. Sixty-six countries reported fewer than 100 cases. It is important to mention that the true number of cases could be higher due to underreporting.

46. Considering that statistics regarding leprosy cases should be multiplied by four, as leprosy has an impact not only on the affected individuals but also on their family members, it becomes evident that the discussion surrounding support and care for leprosy within the familial and communal context is crucial. This recognizes the substantial burden borne by families and communities, which is often worsened by the limited support offered by Governments in many countries.

47. Historically, care has been perceived through a paternalistic lens, leading to the relegation of the rights of the individuals affected. Slogans such as “taking care of” or “being cared for” have typically characterized settlements, leprosaria and hospitals, reflecting paternalistic and segregationist paradigms. This approach has tended to medicalize care and relegate persons affected by leprosy to the status of dependent subjects as opposed to active rights holders.

48. The social movement of persons affected by leprosy challenges the medicalized approach to care, pushing for a transition towards a human rights framework in which support, care and assistance are positioned as inherent rights rather than as patronizing gestures. Aligned with this framework, and supported by the principles and guidelines on the elimination of discrimination against persons affected by leprosy and their family members, the Convention on the Rights of Persons with Disabilities, Human Rights Council resolution 54/6, on the centrality of care and support from a human rights perspective, the 2030 Agenda for Sustainable Development and the WHO 2011 guidelines for strengthening participation of persons affected by leprosy in leprosy services, the community of persons affected by leprosy and their families demand an appropriate support system that guarantees their full participation at all levels and the fulfilment of their daily life activities.

49. Support and care for persons affected by leprosy encompass a wide range of formal and informal interventions, including live assistance and intermediaries, as well as personal assistance; living arrangements services for securing housing and household help; treatment, medical assistance and follow-up; and community services. Persons with leprosy-related disabilities may need support in accessing and using general services, such as health, education and justice support; support in decision-making; mobility and support aids, such as assistive technology and devices; and communicational assistance.

[15] WHO, “Towards zero leprosy: global leprosy (Hansen’s disease) strategy 2021–2030”, 2021.

50. The complexity of adopting a human rights-based approach to leprosy support, care and assistance stems from the recognition that, while leprosy is a curable disease, the journey does not end with the elimination of the bacteria. Post-treatment health complications and reactions may persist, necessitating ongoing support that extends beyond the treatment period and often lasts for the remainder of the individual's life.

51. The implementation of a human rights-based system of support and care must be guided by reliable and relevant data regarding the mental, social and economic impact of leprosy on affected persons and their families. There are limited data on the economic burden borne by the families of persons affected by leprosy.[16] A study undertaken in rural India demonstrated that the impact on households of *Erythema nodosum leprosum*, a common immune-mediated complication of lepromatous and borderline lepromatous leprosy, was predominantly through indirect costs, which accounted for 65 per cent of total household costs. By comparison, indirect costs accounted for only 21 per cent of total household costs for those in the control group. Indirect costs, in the study, referred to the reduction in household productivity resulting from the interruption of the normal or preferred activities of household members.[17]

52. A similar study carried out among migrant and resident patient populations in Guangdong Province, China, concluded that the median yearly total expense after diagnosis amounted to 15 per cent of migrant and 38 per cent of resident patients' annual income. Among migrant patients, the median cost before diagnosis was $131.6, the median yearly cost of leprosy treatment after diagnosis was $300.6 and the median yearly cost of leprosy complications was $69.5. By comparison, among residents, the median yearly costs were $152.4 pre-diagnosis, $309.7 after diagnosis and $91.9 for leprosy complications.[18]

53. Equally important is to assess existing support and care policies in each country in order to understand the measures implemented, identify gaps and determine the necessary steps forward. This comprehensive analysis should help to rethink care and support services as human rights-based support services.

54. The central obstacle to achieving the goal of leprosy elimination revolves around securing access to quality and compassionate health-care services.[19] This entails the operation of services in a way that is interlinked with other essential services. The far-reaching effects of this challenge significantly hinder strategies aimed at prevention, detection, treatment and subsequent follow-up. Crucially, this includes the consequences of delayed detection, inadequate post-treatment monitoring, falling numbers of well-trained health-care personnel and obstacles in accessing essential medicines. Similarly, there is a need to consider in this context the impact of investment in medical and social research, which seems to be falling.

55. In a recent report, entitled "Good practices of support systems enabling community inclusion of persons with disabilities",[20] OHCHR reiterated the importance of adopting a rights-based approach to disability. In the report, OHCHR provided a diverse range of good practices for support and care systems that were enabling persons with disabilities to live independently and ensuring their inclusion in the community. Such examples show how progress can be made in meeting the demand for human rights-based health, care and support systems for persons affected by leprosy and their families to bring about change in their lives.

56. Support and mental well-being are undoubtedly connected to what has been mentioned above. The Special Rapporteur acknowledges that the implications of the disease extend beyond the physical and social spheres for those affected and their families. Mental

[16] See Syahroni Bahtiar, Tantut Susanto and Dewi Rokhmah, "People affected by leprosy needs during rehabilitation in community: study of health care provider perceptions", *NurseLine Journal*, vol. 5, No. 2 (2020).

[17] David J. Chandler and others, "Household costs of leprosy reactions (ENL) in rural India", *PLOS Neglected Tropical Diseases*, vol. 9, No. 1 (2015).

[18] Mingzhou Xiong and others, "Evaluation of the economic burden of leprosy among migrant and resident patients in Guangdong Province, China", *BMC Infectious Diseases*, vol. 17, No. 1 (2017).

[19] Issues regarding access to health services were raised in a thematic report by the previous Special Rapporteur (A/HRC/50/35).

[20] A/HRC/55/34.

health concerns caused by the disease's effects on the body, coupled with discrimination and exclusion, have historically been disregarded. The shared and personal histories of individuals affected by leprosy and their families have led to emotional and psychological challenges, which can be recognized as forms of collective and individual trauma. There has been a notable lack of accountability on the part of States and Governments in addressing these critical issues, the burden on persons affected by leprosy and their families and the lack of strong and committed public support and care systems.

57. To illuminate this demand for human rights-based support and care systems, including with regard to mental health, the following case of a person affected by leprosy in Indonesia was relayed to the Special Rapporteur:

> Hadi, 32 years old, is a construction worker with a wife and two children. He was initially treated for leprosy for 12 months (2021/22). After treatment, he began to suffer from recurrent reactions. He was given prednisone by the health centre, but the reactions recurred whenever he tapered off the prednisone. The health centre staff did not know what else to do, so he was eventually told to take multidrug therapy treatment again for six months. At this point, he was already dependent on prednisone. He is now (February 2024) still on multidrug therapy and still taking prednisone. The recurring reactions led to persistent exhaustion, which left him unable to work. His eyes are affected by prednisone, meaning he can no longer ride a motorcycle from his remote home to the town where he worked. He is at home and has no income. His wife now works in a small kiosk but does not earn enough to cover the small family's expenses. He is under stress and pressure due to this situation; he feels useless, as he is unable to provide for his family. This is likely what caused his reactions to persist, causing him to continue taking prednisone and his health problems to worsen, leaving him unable to work.

B. Crucial intersectional issues and marginalized groups

58. When left untreated, leprosy can lead to deformity and resultant disabilities. In 2019, 10,816 persons, including 370 children, in 94 countries presented with a grade 2 disability[21] at the time of diagnosis, which is an indication of late diagnosis and lack of community awareness. The number of children with grade 2 disabilities is likely to be significantly higher, as some countries did not report data on grade 2 disabilities in children. The overall grade 2 disability rate was 1.4 per million population.[22] In the same report, it is estimated that between 3 and 4 million people are living with visible impairments or deformities due to leprosy. Of the new cases, 38.9 per cent were in women and 7.4 per cent in children. Detection of cases in children is considered an indicator of recent community transmission. Globally, the new case detection rate for those aged under 14 years was 7.9 per million children.

59. There is very little information available on the kinds of problems faced by persons with leprosy-related disabilities, the resulting needs that they have for services[23] and violations of their rights to access those services. However, they encounter challenges in their daily lives that span a spectrum of material and emotional issues. In addition to these challenges, the need for rehabilitation services and medication must be considered, with many persons requiring lifelong treatment. When discussing disability issues related to leprosy, it is crucial to address leprosy reactions, which are frequently mentioned by individuals who have completed their treatment and have been declared cured.

[21] In leprosy, disabilities are categorized into different grades based on their severity. "Grade 2 disability" refers to visible impairment of the hands, feet or eyes due to leprosy. These impairments can include clawed fingers, dropped feet or visual impairments. Grade 2 disability indicates a more advanced stage of disability compared with grade 1 disability, which refers to less visible impairment. It is an important measure used in assessing the severity and progression of leprosy-related disabilities.

[22] WHO, "Towards zero leprosy".

[23] See Wim H. van Brakel and others, "Disability in people affected by leprosy: the role of impairment, activity, social participation, stigma and discrimination", *Global Health Action*, vol. 5 (2012).

60. While the above-mentioned issues include the circumstances of children, women, young people and older persons – groups whose rights are often the most vulnerable – there remains a demand for a more comprehensive examination of the specific challenges faced by these groups. A study conducted in Indonesia concerning women with leprosy-related disabilities reveals that most of them were unable to contribute to the family income, although they did undertake household duties.[24] Overall, women with leprosy-related disabilities often find themselves responsible for their own care, as well as caregiving for other family members, leading to stressful situations that can exacerbate their health conditions.

61. Women affected by leprosy face negligence and discrimination when seeking medical attention.[25] The following case of a young woman affected by leprosy in India, which was relayed to the Special Rapporteur by an activist for the rights of persons affected by leprosy, exemplifies their situation:

> Due to the closure of some leprosy hospitals and the integration of specialized medical staff into hospitals located far from villages, reconstructive surgeries for leprosy patients are often conducted in camps. However, after such surgeries, patients require ongoing therapy and rehabilitation, posing challenges for follow-up care. I know of the case of a young pregnant woman who is also a double amputee and a mother of a child. She recently underwent surgery and received care from a skilled doctor at a distant hospital. However, she had to endure a difficult eight-hour journey alone, surrounded by strangers, due to the lack of support from her husband, who may leave her at any time because they are poor people. This case is just one example of the many similar situations faced by women worldwide in similar circumstances.

62. During the interviews and initial meetings with leprosy donor organizations, the Special Rapporteur received information about issues concerning children affected by leprosy and the medical treatment and attention provided to them. While studies have been conducted regarding the complex situation of children between the ages of 10 and 15,[26] there is a recognized need for further research to understand the specific challenges faced by children under the age of 10. These include the effects of the medical treatment provided. Similar demands have been made regarding young people affected by leprosy, who may face consequences after completing treatment. However, there is often a lack of post-treatment follow-up, which, in some cases, has resulted in a recurrence of the disease in affected individuals. According to one study, it is time to consider the mortality rates associated with leprosy in countries in which it is endemic in the twenty-first century and, specifically, to determine whether, even today, those diagnosed with lepromatous leprosy (in particular young people and those with *Erythema nodosum leprosum*) have a shortened life expectancy compared with the general population.[27]

C. Social, political and cultural considerations

63. One of the successful steps taken during the twenty-first century is the strengthening of the social movement of persons affected by leprosy. As previously mentioned, this development marks the initiation of a human rights approach to leprosy. Small, grass-roots organizations have notably expanded their efforts, often forming alliances with disability organizations. Their funding typically stems from the activities that they undertake or from international donors. The various challenges that these organizations encounter in their efforts to sustain themselves hinder their ability to emerge as influential political voices both locally and internationally. Ensuring the political engagement of persons affected by leprosy

[24] Ilse Schuller and others, “The way women experience disabilities and especially disabilities related to leprosy in rural areas in South Sulawesi, Indonesia”, *Asia Pacific Disability Rehabilitation Journal*, vol. 21, No. 1 (2010).

[25] See A/HRC/41/47.

[26] See Álisson Neves Santos and others, “Epidemiological profile and tendency of leprosy in people younger than 15 years”, *Revista da Escola de Enfermagem da USP*, vol. 54 (2020).

[27] C. Ruth Butlin, “Excess of deaths of leprosy-affected people”, *Leprosy Review*, vol. 91, No. 2 (2020), p. 222.

across various levels within their communities and countries and on the global stage remains an unfinished task.

64. The actions undertaken by activists for the human rights of persons affected by leprosy and their allies to amplify awareness about the situation of persons affected by leprosy have consistently encountered obstacles due to inadequate governmental allocation of resources towards enhancing their political and organizational capabilities. Examining the nature of these organizations and their difficulties and obstacles and assessing the extent of the support that they receive from governmental, national and international bodies will shed light on their essential role in addressing leprosy through a human rights lens.

65. Another important issue raised by persons affected by leprosy concerns the preservation of leprosy history, which has often been viewed solely as a moral obligation. However, it is crucial to recognize that communities and collectives have a right to safeguard their memory, particularly when their history involves rights violations by Governments and societies. Hence, it is imperative to advocate the protection of archives, sites and the oral history and artefacts intrinsic to leprosy history, seeking their active safeguarding by States and Governments.

66. Historically, numerous leprosy settlements have been established worldwide, often because of segregation policies. Many of the settlements have undergone transformations over time, with some being converted into integrated communities or repurposed for other uses. While the number of active leprosy colonies has decreased over the years due to advancements in treatment, some continue to exist, particularly in regions where leprosy remains prevalent or where affected persons face challenges in living in mainstream society.

67. A study conducted in one of the settlements in Ghana revealed that persons affected by leprosy and their families who continue to reside in the area expressed dissatisfaction with their living conditions, particularly due to their limited and sometimes neglected access to health-care services. Similar complaints have arisen from so-called former colonies, for instance in Brazil,[28] Ethiopia,[29] India[30] and Thailand,[31] where insecurity is a prevalent issue. Governments have not granted land ownership rights to these individuals, despite their long-standing residency, leading to concerns about security of tenure. In addition, inadequate access to essential amenities, such as electricity and sanitation, compounds the challenges faced by these communities. It is worth noting that a significant portion of the population in these settlements comprises older individuals struggling with health difficulties, which further complicates their lives.

68. Migration is another contemporary issue that deserves consideration in relation to leprosy. Numerous studies conducted in countries such as Brazil, India and Indonesia have shed light on the role of internal migration and rural development trends in the spread of leprosy. Migration and displacements often correlate with the exacerbation of poverty and inequality, contributing to the transmission of the disease. Furthermore, international migration emerges as another significant factor to consider in twenty-first-century discussions. Research on leprosy and immigration in the United States of America has highlighted several knowledge gaps within the broader medical community regarding the disease. Similar concerns have been raised regarding cases in Canada and countries in Europe.[32] These studies indicate that individuals migrating from low-prevalence regions may experience delays in receiving treatment compared with patients from nations where leprosy is endemic and who are more familiar with its early symptoms. In addition, there is a

[28] See Raissa Mariah Ferraz Moreira Barcelos and others, “Leprosy patients’ quality of life: a scoping review”, *Revista da Escola de Enfermagem da USP*, vol. 55 (2021).

[29] See Hunegnaw Ayele, “Leprosy stigma and its effect on the marriage experience of leprosy affected people and their descendants: the case of Addis-Tesfa Hiwot settlements in Ethiopia”, *Leprosy Review*, vol. 93, No. 2 (2022).

[30] See James Staples, “Communities of the afflicted: constituting leprosy through place in South India”, *Medical Anthropology*, vol. 33, No. 1 (2014).

[31] See Nils Kaehler and others, “Perceived stigma towards leprosy among community members living close to Nonsomboon Leprosy Colony in Thailand”, *PLOS ONE*, vol. 10, No. 6 (2015).

[32] See Cassandra White and Carlos Franco-Paredes, “Leprosy in the 21st century”, *Clinical Microbiology Reviews*, vol. 28, No. 1 (2015).

suggestion that physicians may be more inclined to consider leprosy as a possibility when treating individuals from countries where the disease is highly prevalent.

D. Legal and economic dimensions

69. Two ongoing demands made by persons affected by leprosy relate to the persistence of discriminatory laws that impede their rights and those of their families and to the economic and financial hardships that they encounter in their daily lives. The issue of discriminatory law has already been addressed in a previous report under the mandate.[33] While changes have been implemented in various countries, there remains much work to be done, particularly in documenting the tangible impact of these laws on people's lives. Further research in this field is imperative, alongside the provision of legal assistance and advice to support the efforts of the social movement of persons affected by leprosy.

70. Leprosy is a disease entrenched in societies characterized by structural inequalities, where poverty serves as one of numerous barriers to prevention, transmission mitigation and timely treatment and follow-up. Comparative research spanning Brazil, China, India, Indonesia and Nepal[34] has highlighted geographical location and socioeconomic status as primary factors influencing leprosy prevalence. Furthermore, researchers have underscored the existence of a structurally rooted vicious cycle, wherein poverty contributes to leprosy incidence, while leprosy, in turn, exacerbates poverty conditions or fosters its onset.

71. The Special Rapporteur emphasizes that the economic dimensions of leprosy intersect with every issue raised by affected persons, including both the physical and the social determinants of income generation.[35] On the basis of the interviews held, she acknowledges that socioeconomic empowerment could not only enhance quality of life for individuals and their families but also boost their self-esteem. Empowerment facilitates engagement in productive work, fulfilment of social roles and recognition by families and communities.

E. Environmental and conflict-related considerations

72. While it might not seem immediately apparent, the consequences of war, conflict and violence linked to perpetuating the rights of powerful groups, as well as issues such as drug trafficking, significantly affect the lives of individuals affected by leprosy. In countries such as the Congo, Ethiopia, Liberia, Myanmar and the Sudan, those living with leprosy face increased risks to their safety and well-being.[36] During times of national crisis, they are often overlooked, left behind and denied access to basic services crucial for their survival. This oversight exacerbates their exposure and underscores the urgency of addressing these systemic gaps during times of conflict.

73. War and political instability have had a significant impact on rural areas and persons affected by leprosy, resulting in food insecurity and limited access to essential services. In conflict-affected countries, individuals with leprosy face disruptions in logistics, early detection and treatment services, amplifying their health and economic fragility and isolation. Furthermore, conflicts and wars may compel Governments to divert resources and attention away from leprosy and other neglected tropical diseases, further exacerbating the already precarious living conditions of these communities.

[33] A/76/148.

[34] Yu-Ye Li and others, "Factors influencing leprosy incidence: a comprehensive analysis of observations in Wenshan of China, Nepal, and other global epidemic areas", *Frontiers in Public Health*, vol. 9 (2021).

[35] See Messono O. Omang and Simplice A. Asongu, "Historical prevalence of infectious diseases and entrepreneurship: evidence from 125 countries", *Journal of Entrepreneurship in Emerging Economies*, 21 November 2023.

[36] See Laura Dean and others, "A syndemic born of war: combining intersectionality and structural violence to explore the biosocial interactions of neglected tropical diseases, disability and mental distress in Liberia", *PLOS Global Public Health*, vol. 2, No. 6 (2022).

74. Given that climate change is a paramount concern for human existence and has wide-ranging effects, it is crucial to examine its impact on individuals affected by leprosy. This entails exploring how, for those affected, the rights of access to clean water, sanitation and a safe environment have been integrated into policies and procedures. For instance, according to information provided to the Special Rapporteur about the situation in Ethiopia, severe drought in the southern part of the country has aggravated hunger, and organizations of persons affected by leprosy have been aiding marginalized populations, including those affected by leprosy.

75. Furthermore, understanding the role of environmental factors and their function in the continued transmission of the bacteria should be taken into consideration when analysing the rights to safe drinking water and sanitation, as well as the right to a clean, healthy and sustainable environment. Moreover, endemicity in India and Indonesia has been shown to be linked to environmental factors and housing conditions.[37] Measures to improve environmental health (including measures relating to housing, nutrition, access to clean water and sanitation) would not only be relevant for leprosy but also contribute to a life free from many diseases.[38]

V. Envisioning change in the period up to 2026

76. In the present section, the Special Rapporteur articulates her understanding of her role and methods of work and delineates the central pillars of her vision for the mandate. This encompasses the core values that will steer her efforts: implementing an ethics of care, fostering a culture of listening and advocating cooperation and co-production at various levels.

A. Methods of work

77. The Special Rapporteur intends to undertake her tasks in accordance with the mandate established by the Human Rights Council in its resolution 53/8. With regard to facilitating cooperation and fostering connections, she envisions her role as one that facilitates cooperation among stakeholders and the building of bridges between projects, initiatives, stakeholders, countries and continents. This entails creating platforms for the exchange of good practices and lessons learned. With regard to providing advisory services and support, she will aim to facilitate and support the provision of advisory services, technical assistance, capacity-building and international cooperation to boost national efforts aimed at effectively realizing the rights of persons affected by leprosy.

78. The Special Rapporteur acknowledges the following as among the fundamental instruments that will support her work: the principles and guidelines on the elimination of discrimination against persons affected by leprosy and their family members; the Convention on the Rights of Persons with Disabilities; the 2030 Agenda for Sustainable Development; the International Covenant on Economic, Social and Cultural Rights; the International Convention on the Elimination of All Forms of Racial Discrimination; the Convention on the Elimination of All Forms of Discrimination against Women; the Convention on the Rights of the Child; the United Nations Educational, Scientific and Cultural Organization Convention for the Protection of the World Cultural and Natural Heritage; the WHO "Towards Zero Leprosy" Global Leprosy (Hansen's Disease) Strategy 2021–2030; and the WHO guidelines for strengthening participation of persons affected by leprosy in leprosy services of 2011.

[37] See Flora Ramona Sigit Prakoeswa and others, "Environmental factors and leprosy in mother and child: a study in endemic areas in East Java, Indonesia", *Indian Journal of Forensic Medicine and Toxicology*, vol. 15, No. 2 (2021).

[38] See Vishwa Mohan Katoch, "Eradication of leprosy from India: reflections on past, present and future", *Indian Journal of Medical Research*, vol. 159, No. 1 (2024).

B. Vision and fundamental pillars

79. The Special Rapporteur will promote the protection of the rights of persons affected by leprosy and their families and their participation at different levels in the national and international arenas. To this end, her mandate will be supported by three main principles: (a) an ethics of care; (b) a contribution to a culture of listening; and (c) promoting cooperation and the co-production of policies and strategies.

80. To support the efforts of leprosy rights activists and affected persons and families, the Special Rapporteur shares the views of care and disability thinkers who have contributed to reshaping the understanding and application of both "ethics" and "care". She emphasizes that a mandate aimed at eliminating discrimination against persons affected by leprosy would be ineffective without continual reflection on, and the application of, the foundational principles of ethics as the knowledge of how to lead a fulfilling life, extending to all individuals. This perspective acknowledges that care has often been undervalued and misconstrued in contemporary societies, reduced to a patronizing and gender-biased definition, and that care permeates every aspect of daily life, institutional frameworks and governmental structures. For this reason, the Special Rapporteur advocates an ethics of care as one of the pillars of the mandate, highlighting care as a fundamental aspect of human life. The Special Rapporteur underscores the need to change the overall public value associated with care. In this context, an ethics of care encompasses "everything that we do to maintain, continue, and repair our 'world' so that we can live in it as well as possible. That world includes our body, our selves, and our environment, all of which we seek to interweave in a complex life-sustaining web."[39]

81. An ethics of care is intrinsically connected to a culture of listening, in this case to persons affected by leprosy. Listening is the profound act of acknowledging and appreciating the presence of others, while recognizing one's own presence. As Evelyn Glennie, the renowned deaf percussionist, noted, listening "isn't always about sound; it's often about no sound … It's the presence. It's the presence of two people being there together. So, no words are necessarily spoken at all. But it is the presence and the acknowledgement and, actually, the volume of that person. And we have to hang on and appreciate the value that we have ourselves and the value of other people and exchanging this feeling and therefore respect."[40] The right of persons affected by leprosy to participate at every level of public and private life will not be realized unless listening is embraced as a practice that evolves into a culture. A human rights approach to leprosy must be founded upon a culture of listening that supports the advancement of persons affected by leprosy, their families and their allies in their struggle to protect and ensure their rights.

82. An ethics of care and a culture of listening would promote a practice of cooperation and co-creation to achieve not only the objectives of the mandate, but also the goals set by the leprosy rights movement, such as "leaving no one behind". The Convention on the Rights of Persons with Disabilities is explicit in its requirement that the voices of persons and their representative organizations be heard. It emphasizes that persons, in this case those affected by leprosy, should be closely consulted on and actively involved in the development and implementation of legislation, policies and other decision-making processes that affect them. Applied to the field of leprosy, articles 4 and 33 of the Convention provide for the active engagement of civil society, organizations and persons affected by leprosy in any process that affects their lives and at any level. The Special Rapporteur aims to establish collaborative partnerships with other mandates relevant to her role and with United Nations bodies and Member States. She is looking to promote collaboration with academic institutions, local and international human rights and development organizations and representatives of social movements that are linked to leprosy. This cooperative approach will facilitate the development of strategies to enhance the lives of persons affected by leprosy. She intends to focus her efforts on co-creating materials and information with the leprosy rights movement

[39] Bernice Fisher and Joan C. Tronto, "Toward a feminist theory of care", in *Circles of Care: Work and Identity in Women's Lives*, Emily K. Abel and Margaret K. Nelson, eds. (State University of New York Press, 1990), p. 40.

[40] Oscar Trimboli, "Teaching the world to listen with Evelyn Glennie", *Deep Listening: Impact beyond Words*, podcast, episode No. 70.

to promote the defence of their rights. Similarly, she will advocate the participation of persons affected by leprosy in shaping policies, programmes and legal frameworks that have an impact on their lives.

C. First steps forward

83. Since taking up the mandate, the current Special Rapporteur has held numerous meetings and bilateral consultations with representatives of organizations of persons affected by leprosy and other civil society organizations, States and regional organizations, academics, representatives of the United Nations system, donors and other stakeholders. Those with whom she met included representatives of international leprosy donors and local grass-roots organizations of persons affected by leprosy; representatives of WHO, in India and Geneva; representatives of the Pan American Health Organization and OHCHR, in Mexico; representatives of the National Commission of Human Rights of Mexico; representatives of the Permanent Missions of Ecuador, Japan and Mexico to the United Nations Office and other international organizations in Geneva; representatives of the Committee on the Rights of Persons with Disabilities, in Geneva and Mexico; and other mandate holders. In addition, she has entered into conversations with academics at the University of Copenhagen, the University of Toronto, Canada, and the University of Leeds, United Kingdom of Great Britain and Northern Ireland.

84. She has participated in numerous events focused on human rights and leprosy, including the launch of the Global Appeal 2024 to End Stigma and Discrimination against Persons Affected by Leprosy and the thirtieth session of the Committee on the Rights of Persons with Disabilities, both in Geneva.

85. The Special Rapporteur is advancing discussions on leprosy beyond the confines of the field by initiating a series of radio programmes on leprosy in the twenty-first century.[41] In these programmes, guests share their experiences with leprosy and offer insights on the necessary work ahead. In addition, she is facilitating the dissemination of information about grass-roots organizations worldwide through the editorial platform of 17, Institute of Critical Studies, in Mexico.[42]

86. During this initial period, the Special Rapporteur has crafted public statements and communications. In addition, she has endorsed statements prepared by other special procedures addressing issues relevant to the scope of the mandate. She has collaborated with different news outlets to disseminate information about leprosy and her mandate.

VI. Conclusions

87. **In accordance with her mandate, the Special Rapporteur will promote a human rights approach guided by an ethics of care that places people's voices at the centre and as the primary source of evidence, thereby contributing to the construction of a culture of listening and more equitable and just societies. The Special Rapporteur underlines the particularity of leprosy (Hansen's disease) as a catalyst of social, political and cultural change, serving as a beacon for a more democratic, humane and diversity-respecting world. In the present report, she underscores the significant transformation for individuals affected by leprosy, as well as their families, organizations and allies, brought about by the implementation of the mandate.**

[41] See https://17radio.org/index.php/episodios/la-lepra-en-el-siglo-xxi-memoria-y-re-escritura/.

[42] See, for example, https://diecisiete.org/actualidad/the-transformative-power-of-grassroots-initiatives.