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**Promotion and protection of all human rights, civil,
political, economic, social and cultural rights,
including the right to development****Stigmatization as dehumanization: wrongful stereotyping
and structural violence against women and children affected
by leprosy****Report of the Special Rapporteur on the elimination of discrimination
against persons affected by leprosy and their family members***Summary*

In her report, prepared in accordance with Human Rights Council resolution 35/9, the Special Rapporteur on the elimination of discrimination against persons affected by leprosy and their family members, Alice Cruz, focuses on the situation of women and children affected by leprosy and their family members. She identifies and examines the root causes of their vulnerability to various forms of discrimination and offers recommendations on how to eliminate it.



I. Introduction

1. The present report is submitted pursuant to Human Rights Council resolution 35/9, in which the Council established the mandate of the Special Rapporteur on the elimination of discrimination against persons affected by leprosy and their family members. In its resolution, the Council recognized that specific attention is needed to address all forms of discrimination against persons affected by leprosy and their family members, and mandated the Special Rapporteur to report to the Council on progress made and measures taken by States for the effective implementation of the principles and guidelines for the elimination of discrimination against persons affected by leprosy and their family members (A/HRC/15/30, annex).

2. Following the first report (A/HRC/38/42), in which the Special Rapporteur outlined the vision, priorities and working methods of the mandate, the present report aims at unveiling the multiple nature of discrimination on the grounds of leprosy, focusing on the particular experience of women and children. In order to present a comprehensive description, foster bottom-up participation and promote future evidenced-based policies, the Special Rapporteur methodically resourced more than 600 contributions. She looks into the pervasive structural disadvantage that allocates women and children affected by leprosy to a context of intersecting vulnerabilities and multilayered discrimination, simultaneously acknowledging the shared subordinated status of both groups and rejecting their representation as a composite concept. The Special Rapporteur identifies specific human rights violations against each group, alongside pragmatic and concrete steps for eliminating ongoing institutionalized, structural and interpersonal discrimination.¹

3. As with some historically ascribed identity categories (such as race, gender or sexuality), leprosy, also known as Hansen's disease, has been infused in such a way with moral, religious, cultural and political meanings throughout history that it became a label that unremittingly produces and reproduces a deeply stigmatized social category. Labelling is at the root of discrimination on the grounds of leprosy. It is labelling, and not leprosy itself, that disrupts the social location² of a person diagnosed with the disease and that symbolically homogenizes a group of people within deeply ingrained stereotypes framed by negative attributes.

4. The overlapping of harmful stereotypes, wrongful stereotyping³ and structural iniquities strengthens exclusion, discrimination and violence on the grounds of leprosy and compromises the enjoyment of fundamental rights, such as dignity, equality and non-discrimination, by millions of persons affected by leprosy worldwide, as well as by many of their family members. Stigmatization of persons affected by leprosy remains institutionalized in the State's architecture and functioning: more than 50 countries in the world keep hundreds of discriminatory laws against persons affected by leprosy in force,⁴ while discriminatory practices at the State's administration services endure.

¹ The Special Rapporteur wishes to express her gratitude to the valuable cooperation received from States; national human rights institutions; the World Health Organization (WHO); the Pan-American Health Organization; national leprosy programmes; the International Federation of Anti-Leprosy Associations, in particular the Sasakawa Memorial Health Foundation; the International Federation's panel of persons affected by leprosy; Global Partnership for Zero Leprosy; leprosy and law experts and activists; organizations of persons affected by leprosy and their representatives; and, most of all, to the women and men affected by leprosy, as well as many of their family members, who consistently support the Special Rapporteur's work.

² The Special Rapporteur makes use of the concept as presented in the report of the Special Rapporteur on violence against women, its causes and consequences (A/HRC/17/26).

³ The Special Rapporteur makes use of the conceptual frame developed in the report commissioned by the Office of the United Nations High Commissioner for Human Rights entitled *Gender Stereotyping as a Human Rights Violation* (2013).

⁴ See www.ilepfederation.org/wp-content/uploads/2018/11/Updated-discriminatory-laws-table-Final-1.pdf.

II. Conceptual framework: intersecting stereotypes and human rights standards

A. Dehumanization

5. Harmful stereotypes not only contribute to generating stigmatized categories and identities, but are also drivers for the dehumanization of groups of people. The process through which a group of people comes to be regarded as less human than others has stereotyping at its core. Furthermore, dehumanization and the exercise of abuse and violence are inextricably linked, since they are mutually reinforcing. That is why stereotyping is a paramount mechanism to be addressed in the prevention of violations and the promotion of human rights.

6. Stereotypes are produced through fixity and repetition. Stereotypes fix socially and historically produced patterns of representation on a particular group of people. The repetition of such fixed patterns in different situations allows for its universalization as “natural” truths. Stereotypes also work by excess and default. Labels that deprive people of their identity and of their right to a dignified life are awarded excessive visibility (by social representations from different sources), while insufficient visibility is accorded to the commonalities between the affected individuals and the rest of society. This deprives those individuals of the opportunity to participate in the larger community, and is a violation of their rights.

7. Extreme dehumanization becomes possible when the target group can readily be identified as a separate category of persons who are stereotyped and stigmatized as inferior, dangerous or uncivilized.⁵ Through dehumanization, moral restraints that prevent the exercise of abuse and violence upon certain groups of people lose strength. Dehumanized groups are regarded as disposable and their annihilation (civil or material) is morally established as acceptable.⁶

8. Persons affected by leprosy were historically dehumanized under the harmful stereotype of the leper. Such stigmatizing sign (and its different cultural versions) has been employed throughout history as a label that subsumes a group of individuals under the negative attribute of a disease socially perceived as undesirable, pollutant and dangerous.

9. Protest against the widespread use of the stigmatizing sign of the “leper” arose in the mid-twentieth century, when persons who were forcibly segregated by State policies claimed that as long as stigmatizing language was in use, discrimination would persist.⁷ However, the outcome of this struggle was still largely in the control of the medical community, who decided in favour of the expression “persons with leprosy” to replace the ostracizing sign of the “leper”, using it interchangeably with the noun “patient” and conferring, as such, equal meanings to both terms.

10. It was only in the late twentieth century that representatives of already established organizations of persons affected by leprosy moved against the hegemony of biomedicine in classifying groups of persons by diseases and rejected the expression “persons with leprosy”. In their view, the expression continued to put leprosy at the forefront of their identities and concealed the fact that many persons had already been cured of the infection caused by *Mycobacterium leprae*, even though they continued to live with physical impairments, discrimination and disability.

11. The currently used expression “persons affected by leprosy” was adopted as the first step towards self-identification to simultaneously refer to individuals currently under

⁵ Extreme examples of dehumanization are described in article 7 of the Rome Statute of the International Criminal Court.

⁶ Herbert C. Kelman, “Violence without moral restraint: reflection on the dehumanization of victims and victimizers”, *Journal of Social Issues*, vol. 29, No. 4 (1973), pp. 25–61.

⁷ Perry Burgess, “Shall we change the names leper and leprosy? Eradication of leprosy”, in *Memoria del V Congreso Internacional de la Lepra* (Havana, Cenit, 1949), pp. 818–819.

treatment for leprosy and individuals who had been cured of leprosy. It has also been suggested that this expression encompasses family members of persons affected by leprosy.

12. The Special Rapporteur makes use of the expression “persons affected by leprosy” in accordance with Human Rights Council resolution 35/9 and due to the lack of an alternative terminology emerging from a self-identification process. Notwithstanding, she targets the knowledge gaps that persistently represent persons affected by leprosy as a homogeneous group.

B. The principles and guidelines as a road map towards formal and substantive equality

13. The principles and guidelines for the elimination of discrimination against persons affected by leprosy and their family members simultaneously draw inspiration from the provisions of legally binding human rights instruments⁸ and recognize persons affected by leprosy and their family members as a group of individuals in need of special measures for eliminating the root causes that perpetuate substantive discrimination against them.

14. The principles and guidelines are thus in agreement with general comment No. 20 (2009) on non-discrimination in economic, social and cultural rights of the Committee on Economic, Social and Cultural Rights. The principles and guidelines clarify the normative content of legally binding international human rights instruments, providing guidance on how to enforce human rights in the specific context of the systemic and structural violation of the human rights of persons affected by leprosy and their family members.

15. Firstly, the principles and guidelines are an example of non-treaty standards that reinforce customary law. International human rights norms prohibit inhuman and degrading treatment, as well as arbitrary detention. Such is the point of departure of the principles and guidelines, which recognize the massive violation of the human rights of persons affected by leprosy and their family members through the enactment of discriminatory policies and institutionalized practices. The principles and guidelines condemn the results of the aforementioned policies and practices, which have contributed to systematic and widespread violations.

16. Secondly, the principles and guidelines embody the fundamental values of international human rights norms. Therefore, they reaffirm and seek to reinforce compulsory general principles of human rights as established by several treaties and conventions such as dignity, non-discrimination and equality.

17. Thirdly, the multilayered discrimination on the grounds of leprosy calls for acknowledging multiple intersections of leprosy with gender, ethnicity and/or race, age, disability, migration and poverty. This also means that in order to eliminate discrimination on the grounds of leprosy, persons affected by leprosy and their family members are entitled to the rights established for these different social groups and they should be enforced accordingly.

18. In sum, the principles and guidelines underpin the normative integration of several international human rights instruments, interpreting and translating legally binding norms in close connection with the conditions and needs of the particular group of persons affected by leprosy and their family members. They provide States with a road map for monitoring the situation of persons affected by leprosy and their family members and for implementing measures that, by enforcing international human rights law, can guarantee formal and substantive equality.

⁸ Universal Declaration of Human Rights; Convention on the Elimination of All Forms of Racial Discrimination; Convention on the Elimination of All Forms of Discrimination against Women; International Covenant on Civil and Political Rights; International Covenant on Economic, Social and Cultural Rights; Convention against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment; Convention on the Rights of the Child; Convention on the Protection of the Rights of All Migrant Workers and Members of Their Families; and Convention on the Rights of Persons with Disabilities.

C. Subordination

19. Guideline 3 of the principles and guidelines identifies the adverse impact of leprosy on women and children and recommends the adoption of necessary measures to eliminate discrimination against more vulnerable groups to leprosy-related violations.

20. It is the view of the Special Rapporteur that vulnerability must be approached as a result of disadvantage caused by unequal power relations and not as an ontological feature of a group of persons.⁹ This is particularly important in the case of women and children, who are often silenced as political subjects by essentialist views that overlook their agency in the face of disadvantage and impair their participation in decision-making processes. For such reasons, the pervasive structural disadvantage that allocates women and children to the context of intersecting vulnerabilities and multilayered discrimination is addressed by the Special Rapporteur as subordination.¹⁰

21. Subordination is understood as the historical devaluation of some groups of people under hierarchical social structures that, by producing and reproducing an unequal distribution of power, severely constrain their autonomy and participation. Subordination is the structural landscape where the vulnerability of women and children is framed, with accompanying corollaries of subdued participation, neglected intentionality and unrecognized agency.

22. If a shared subordinate status is the uniting bond between these two groups, women and children should nevertheless not be treated as a composite concept. Such an approach mirrors the widespread and pervasive exclusion of both groups from culture, public life and politics and into their opposites, that is, biology, private life and nature. For this reason, the Special Rapporteur unpicks the composite concept and highlights women and children as distinct social groups.

23. Article 1 of the Convention on the Elimination of All Forms of Discrimination against Women explicitly identifies as its object the elimination of any distinction, exclusion or restriction made on the basis of sex. Anchoring the target group of the Convention thus allows for universalizing protection onto what is a highly diverse group. Not only is gender the product of power relations that, throughout historical dynamics, imprints patterns of difference that are enacted in and by hierarchized social relations; the embodiment of womanhood is also anchored in iniquities and is far from giving rise to a universal experience. Nor is the concept of woman a discrete and unitary category. In fact, a monolithic model of woman can exclude and affirm inequality by rendering invisible other axes of oppression interconnected with structures of power, as shown by intersectionality theory. At the same time, recourse to strategic essentialism¹¹ may be necessary to develop a more positive stance from which common subordination can be interrogated and challenged. The aim should then be that equality becomes compatible with diversity. Therefore, the Special Rapporteur looks at women affected by leprosy as a plural group that, its contingency notwithstanding, experience shared patterns of subordination and structural violence.

24. Article 1 of the Convention on the Rights of the Child defines a child as a person below the age of 18, unless the laws of a particular country set the legal age for adulthood younger. Making use of age to define who a child is allows for universalizing protection, as in the case of the Convention on the Elimination of All Forms of Discrimination against Women. However, it seems to be more difficult to acknowledge the historical dynamics that produce different versions of childhood, which is equally traversed by power relations, than it is to recognize gender as a social construct. Childhood is seldom seen as a subject of articulate scrutiny, reinforcing the lens through which children are seen as weak, vulnerable and incapable; as adults-to-be. The Special Rapporteur approaches children affected by

⁹ On vulnerability, see A/HRC/38/42.

¹⁰ The Special Rapporteur agrees with general recommendation No. 19 (1992) on violence against women of the Committee on the Elimination of Discrimination against Women, which addresses how the subordinated social location of women contributes to gender-based violence.

¹¹ G.C. Spivak, *In Other Worlds: Essays in Cultural Politics* (New York, Routledge, 1988).

leprosy as social beings whose world is constructed within a historical and cultural frame of reference, and childhood is considered as a period in which children function as a category of a social group immersed in unequal power relations that constrain their autonomy, agency and recognition as rights bearers.¹² Children are also regarded as contributors to social thinking and policymaking, and the child's right to protection, as well as to participation, is emphasized.

III. Overview: leprosy in women and children

A. Leprosy in women

25. An overall male-over-female preponderance in the incidence of leprosy has dominated epidemiological reports of the disease. In 2017, out of the 210,671 new cases reported by 150 countries to the World Health Organization (WHO), only 82,922 (39.3 per cent) were women. Moreover, there are no disaggregated data for women with grade 2 disability¹³ at the time of diagnosis.¹⁴

26. For decades, biomedical readings of such discrepancy placed biology at the centre of the explanation, overlooking the fact that women in different regions of the world generally have less access to health care. Such interpretation of available data may subsidize long-prevailing non-equitable and discriminatory access by women to their rights.

27. The recognition of women's central role in family health care – especially reproductive and children's health – contributed to gender-sensitive approaches in public health. At present, the WHO Global Leprosy Strategy (2016–2020) recognizes women as a priority group. Notwithstanding, generalized underreporting prevails. Lack of a gender framework and gender-sensitive indicators, as well as critical analysis of available data (namely, how the data are collected, its quality – completeness and accuracy – and what they represent) are contributing factors to knowledge gaps.

28. Independent studies in demarcated territories reveal that active-case finding of leprosy at the community level balances the sex ratio, which ascertains generalized underdetection. Independent studies also point to delays in diagnosis and possible higher risk of women to developing leprosy-related physical impairments and disability, which calls for official reporting of disaggregated data on physical impairments at the time of diagnosis for women.¹⁵

29. Some of the institutional barriers to diagnosis and prevention of physical impairments in women result from institutional mediating factors, such as discriminatory legal frames; underfinancing of health care and poorly implemented policies for prevention, care and rehabilitation; status of leprosy services integration into primary care; the reach of health services; and the gender of the health-care workforce in primary care services.

30. However, non-addressed social barriers are also a leading cause of deficient access by women to the highest attainable standard of health (A/HRC/32/44). Some of the aforementioned barriers are harmful traditional beliefs and practices; the low status assigned to women, which is at the root of women's widespread self-concealment of the

¹² J. Qvortrup and others, eds., *Childhood Matters: Social Theory, Practice and Politics* (Avebury, United Kingdom, Aldershot, 1994).

¹³ Grade 2 disability refers to visible impairment. The grading system used by the Global Leprosy Programme consists of grade 0, meaning no impairment; grade 1, meaning loss of sensation in the hand, eye or foot; and grade 2, meaning visible impairment. In the present report, the Special Rapporteur uses the terms "impairment" to refer to the loss of functioning or detriment to the health of persons affected by leprosy, and "disability" to refer to the social responses of discrimination and exclusion due to leprosy-related impairments. This distinction is based upon the social model of disability, which is embraced by the Special Rapporteur in her work.

¹⁴ WHO, *Weekly Epidemiological Record*, vol. 93, No. 35 (31 August 2018), pp. 445–456.

¹⁵ R. Sarkar and P. Swetalina, "Leprosy and women", *International Journal of Women's Dermatology*, vol. 2 (2016), pp. 117–121.

disease; dependency of women's access to health services on third-party authorization; women's limited mobility; illiteracy; and poor knowledge of leprosy.¹⁶

31. Women's socioeconomic life conditions, such as quality of nutrition (suggested by some studies to impact cell-mediated immunity and influence the progression of the disease)¹⁷ or daily household activities (hindering self-care and exposing women to physical trauma that can lead to impairments), influence public health strategy outcomes at the micro social and individual levels.

32. The global health system at the macro level should also be targeted towards improving the well-being of women affected by leprosy. Knowledge gaps are a harsh reality when it comes to the linkage between leprosy and sexual and reproductive health. Such correlation is hypothesized by independent studies on the following topics: (a) pregnancy and lactation may be contributing factors to leprosy reactions and subsequent nerve damage (the main cause of leprosy-related impairments); (b) leprosy may affect women's fertility; (c) the health of newborns and children may be impacted by their mother's leprosy status.¹⁸

33. There is sufficient knowledge on the side effects of available drugs for treating leprosy on women's sexual and reproductive rights: (a) thalidomide, a drug that treats nerve-damaging reactions, if not properly managed with informed consent can lead to malformation in babies; (b) clofazimine, one of the first-line drugs used in multidrug therapy,¹⁹ produces reversible skin pigmentation, which nonetheless may cause adverse consequences on women's social life; and (c) steroids, commonly used for treating nerve damage, can cause dependence and its chronic use can lead to irreversible changes in bodily appearance, decalcification and diabetes, negatively impacting women's quality of life.

34. Lack of gender-sensitive strategies and obsolete drugs reflect the negative synergies between the patriarchal nature of biomedicine as an institution that still fails to take into full consideration sexual and reproductive rights (A/HRC/32/44) and the increasing mercantilization of health, which is responsible for the disinvestment in basic and pharmacological research on diseases with greater incidence among marginalized populations. Unmistakably, one of the cross-cutting effects of the mercantilization of health is the proration of obsolete drugs that can be simultaneously inefficient and capable of generating iatrogenic effects that, given general patterns of gender subordination, marginalization and invisibility, have a greater impact on women.

35. Clearly, leprosy in women is a typical instance of the intersection of the institutional and extra-institutional mediating factors of health, well-being and enjoyment of rights at the different macro, intermediary, micro and individual levels.²⁰ Leprosy in women is also testimony to the need for a human rights approach, based upon the principles of intersectionality/affirmative action, vulnerability/intersectorality and lay knowledge/participation (A/HRC/38/42).

36. Evidence suggests that women affected by leprosy are structurally more discriminated against than men affected by leprosy. Studies point to gender disadvantage in the social, health and/or psychological domain, with a higher percentage of women experiencing stigmatization and lower quality of life.²¹ However, such studies seldom take

¹⁶ U.-B. Engelbrektsson, *Challenged Lives: A Medical Anthropological Study of Leprosy in Nepal* (Göteborg, Sweden, University of Gothenburg, 2012); and I. 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), pp. 60–70.

¹⁷ Sarkar, "Leprosy and women".

¹⁸ Ibid.

¹⁹ Leprosy is curable with a combination of drugs known as multidrug therapy.

²⁰ A. Cruz, "Leprosy as a multilayered biosocial phenomenon: the comparison of institutional responses and illness narratives of an endemic disease in Brazil and an imported disease in Portugal", *Clinics in Dermatology*, vol. 34, No. 1 (2016), pp. 16–23.

²¹ J. Dijkstra, W.V. Brakel and M.V. Elteren, "Gender and leprosy-related stigma in endemic areas: a systematic review", *Leprosy Review*, vol. 88 (2017), pp. 419–440; and R.M. Peters and others, "Narratives around concealment and agency for stigma-reduction: a study of women affected by

into consideration the relation of the intersection of leprosy and gender with other axes of oppression such as ethnicity and/or race, age, disability, migration and poverty, merely highlighting the tip of the iceberg.²²

37. By the same token, if there is a general underrepresentation of women in political and public life, the absence of women affected by leprosy in programmes and policies that directly affect them, as well as in the leadership of civil society organizations and organizations of persons affected by leprosy, is alarming. Giving voice to women affected by leprosy would lead to the recognition of the correlation between leprosy, gender-based violence, civil death and, in some cases, even material death.²³

B. Leprosy in children

38. The age group in which leprosy is most commonly diagnosed in children under 15 years of age is between 10 and 14 years. This is due to the disease's long incubation period following exposure. The next most affected age group is between 5 and 9 years of age. However, cases among younger children have also been found and, more rarely, cases in infants of less than 1 year have also been reported.²⁴

39. Due to the immaturity of their immune system, children appear to be more prone to leprosy than other members of the same household,²⁵ which should raise concerns about their vulnerability to leprosy and prompt special measures to protect them.

40. Of the total of 210,671 new cases reported by 150 countries to WHO in 2017, 16,979 (about 8 per cent) were children under 15 years of age, a shamefully high figure. Of the total of 5,591 new cases in children, among priority countries that reported new cases in children under 15 years of age with grade 2 disabilities, 202 presented visible physical impairments, including irreversible damage to the nerves, hands, feet, limbs and eyes, at the time of diagnosis. However, some countries with a high incidence of leprosy, such as India, Nepal, Nigeria and the Philippines, did not provide disaggregated data on grade 2 disabilities at the time of diagnosis for adults and children, meaning that the aforementioned 202 reported cases are a major underestimation.²⁶

41. Still, these data only reflect the situation at the time of diagnosis. Independent studies in delimited territories have found a substantial hidden prevalence of leprosy among children in endemic areas, which also indicates a hidden prevalence among adults. Up to 11 per cent of children with visible physical impairments at the time of diagnosis, increasing to 27.3 per cent during follow-up, have also been found.²⁷

42. Data from independent studies suggest two critical concerns: (a) enduring underdetection of new cases of leprosy in children, accompanied by late diagnosis, are both causal factors of physical and psychosocial impairments and disabilities; and (b) physical impairments that can worsen over time without proper care require follow-up studies, the absence of which hinders a clear understanding of the real conditions faced by children affected by leprosy in the medium and long term.

leprosy in Cirebon District, Indonesia", *Disability, CBR and Inclusive Development*, vol. 25, No. 4 (2014), pp. 5–21.

²² A. Castro and P. Farmer, "Understanding and addressing AIDS-related stigma: from anthropological theory to clinical practice in Haiti", *American Journal of Public Health*, vol. 95, No. 1 (2005), pp. 53–59.

²³ Englebretsson, *Challenged Lives*. See also A/HRC/35/10 for the importance of addressing these intersections and their impact on women and girls.

²⁴ M.B.B. Oliveira, "Leprosy among children under 15 years of age: literature review", *Anais Brasileiros de Dermatologia*, vol. 91, No. 2 (2016), pp. 196–203.

²⁵ *Ibid.*

²⁶ WHO, *Weekly Epidemiological Record*.

²⁷ J.G. Barreto and others, "Leprosy in children", *Current Infectious Diseases Reports*, vol. 19, Issue 6 (2017), pp. 19–23.

43. The outbreak of cases in children and adolescents points to recent transmission, as well as to the failure of the health-care system to control the disease. The number of new cases of leprosy among children with visible physical impairments at the time of diagnosis directly reflects late case detection, alongside the incapacity of the health-care system to identify leprosy. However, such evidence should not be taken as a mere indicator of the strength of the epidemic and should also support effective public health strategies capable of ensuring access to the highest attainable standard of health among vulnerable populations and groups.

44. Diagnosis and treatment of leprosy in children require medical expertise, since both demand adjustments to immature cognition, perception and bodies. This poses a significant challenge in the global scenario of decline in medical expertise to diagnose and treat leprosy.²⁸ Techniques normally used to diagnose leprosy are not fit for children as they require cooperation from the children, and some may even be experienced as violence.

45. Such difficulties and barriers are surely a contributing factor for underdetection and late diagnosis, but they are also a result of the diminished public apprehension of leprosy that followed the global elimination of leprosy as a public health problem (defined as a registered prevalence of less than 1 case for every 10,000 persons) in 2000.²⁹ This situation has been generally misunderstood as eradication, when in fact such a scenario is unlikely in the future.

46. Treatment dropout rates in children range from 10 to 20 per cent in some programmes, the main cause being the child's refusal to cooperate in swallowing tablets and the long duration of the treatment, which can be physically challenging and painful. Child-friendly treatment options like flavoured syrups would provide greater quality to the care of children with leprosy and would also help in securing adherence to the treatment. However, no such paediatric formulations are on the horizon, given the overall lack of funds for leprosy.³⁰ Such lack of biomedical technologies that can provide better care is grounded in the mercantilization of health.

47. Children are not only more vulnerable to leprosy, but also to the harmful stereotypes that still frame many of the local explanatory models about the disease and that also support stigmatization at the community level, as well as institutionalized, structural and interpersonal discrimination. However, lack of comprehensive data on how harmful stereotypes and traditional practices impact the well-being of affected children is a major void in leprosy research. There is also scarce knowledge on the impact of discrimination on the grounds of leprosy against children of persons affected by leprosy.

IV. How discrimination harms women and children

A. Assessing discrimination from below

48. Discrimination on any grounds can be fully understood only if the phenomenological dimension enacted in the daily lives of its victims is properly acknowledged. Such phenomenological dimension allows for uncovering epistemological possibilities that cannot be grasped or generated by representations produced by dominant groups.³¹

49. In order to assess discrimination from below, the Special Rapporteur strived at giving voice to people living in extreme vulnerable conditions and who are, in consequence,

²⁸ N. Mistry and others, "Childhood leprosy revisited", *Pediatric Oncall Journal*, vol. 13, No. 4 (October–December 2016), pp. 83–92.

²⁹ Ibid.

³⁰ Ibid.

³¹ S. Harding, "Rethinking standpoint epistemology: what is 'strong objectivity'?", in *The Feminist Standpoint Theory Reader: Intellectual and Political Controversies* (New York, Routledge, 2002); and D.J. Haraway, "Situated knowledges: the science question in feminism and the privilege of partial perspective", *Feminist Studies*, vol. 14, No. 3 (Autumn 1988), pp. 575–599.

persistently silenced by structural disadvantage, low participation in the public sphere and generalized lack of access to information.

50. The Special Rapporteur undertook an online and individual consultation with persons affected by leprosy, their family members, health workers and non-governmental organization (NGO) personnel. A total of 575 responses were received from the following eight high-burden countries: Brazil, Ethiopia, India, Indonesia, Nepal, Myanmar, Nigeria and the Philippines. Responses were also received from Benin, Cabo Verde, China, Colombia, France, Japan, Mexico, the Netherlands, New Zealand, Paraguay, Switzerland, Timor-Leste, Trinidad and Tobago, the United Kingdom of Great Britain and Northern Ireland, the United States of America and Venezuela. The majority of the responses came from India, Brazil and Myanmar.

51. Women affected by leprosy provided 31.9 per cent of the responses, men affected by leprosy 33.6 per cent, female family members of persons affected 9.8 per cent, male family members of persons affected 8 per cent and other categories, such as health and NGO workers, 16.7 per cent; 72 per cent of the respondents live in a rural area and the majority do not take part in any organization. Due to the limitation of available methods and required ethical procedures for consulting with children, it was not possible to consult with children affected by leprosy, as would have been desirable.

52. The data received were not broken down into demographic variables such as ethnicity and/or race, age, disability or socioeconomic conditions, since the consultation merely intended to provide a preliminary assessment able to identify generic areas of concern. Confidentiality was strictly ensured during data collection and processing. Collected data point to ongoing discrimination against women and children affected by leprosy (including female and underage family members) and allow for identifying the main areas where the human rights of both groups are jeopardized, unfulfilled and violated.

1. Harmful stereotypes and wrongful stereotyping

53. When asked about the traditional beliefs regarding leprosy, the majority of responses pointed to the persistence of religious beliefs (grounded in different religious traditions) that classify leprosy as the result of sins committed in current or past lives by the affected person or by the affected person's ancestors; God's punishment on the individual and/or the family; a curse pronounced by ancestors; sorcery; possession by evil spirits; and punishment for adultery and/or sexual promiscuity. Leprosy is also attributed to a particular race or caste and to women. Finally, erroneous misconceptions produced by late nineteenth century "modern" medicine, which held that leprosy was a hereditary disease or a highly contagious one transmitted by touch and without a cure, still prevail. Regarding discriminatory language, 52.3 per cent of the respondents confirmed that it is commonly employed.

54. When asked about the traditional practices regarding leprosy, responses evinced how harmful stereotypes about leprosy can lead to informal segregation and widespread exclusion by treating individuals as untouchable; segregating individuals within the household and also prohibiting them from leaving the house; divorce on the grounds of leprosy and prohibiting marriage with an affected person or any of his/her family members; barring individuals from participating in religious and community activities as well as in economic transactions; dismissing individuals from their jobs; pushing individuals into begging; and banishing individuals from the community. In fact, 42.7 per cent of the respondents confirmed that affected persons face rejection and/or segregation from their families and communities.

55. When asked if these traditional beliefs have a more adverse impact on women affected by leprosy than on men affected by leprosy, 45.5 per cent of the responses confirmed that this is the case, citing the following practices: driving out from the household without financial resources to ensure survival (which is at the root of a considerable number of affected women begging and/or selling sex); abuse within the household as a result of women experiencing difficulties in performing the role expected of them (due to pain and other physical impairments caused by leprosy); and lack of resources to fight against discrimination (including lack of access to justice).

56. When asked if these traditional beliefs have a more adverse impact on children affected by leprosy, respondents identified the following discriminatory practices against this group: expulsion from schools; separation at school from other students; peer rejection; and segregation.

57. Harmful stereotypes and wrongful stereotyping produce and reproduce symbolic violence that, by enacting dehumanizing labelling and accompanying harmful practices,³² sustain informal segregation from community life and denial of fundamental human rights. Harmful stereotypes and wrongful stereotyping have a stronger impact on women and children affected by leprosy due to the low social status attributed to both groups in many societies and to the subordinated position ascribed to them by pervasive and unequal power relations.

2. Interpersonal, institutional and structural violence³³

58. When asked if, as a result of discrimination on the grounds of leprosy, women affected by leprosy experience low self-esteem and isolate themselves, 56.3 per cent of the respondents confirmed that they did, 27 per cent said that they did not and the remaining respondents did not know. The same question applied to children received 40.1 per cent positive responses and 33.1 per cent negative responses. When asked if, also as a result of discrimination on the grounds of leprosy, women experience depression and/or suicidal thoughts, 48.7 per cent of respondents answered positively and 37.4 per cent negatively. The same question applied to children received 41 per cent negative responses and 35.3 per cent positive ones. Such data suggest the internalization of stigmatization as a result of extreme psychological violence.

59. Regarding violence against women on the grounds of leprosy, responses pointed to an intersection of leprosy and gender that amounts to the already ascribed subordinated position of women. The following practices were described: separation from children and not being allowed to feed them; verbal abuse from family and community members; beatings perpetrated by family members who regard women affected by leprosy as sinners and/or indolent due to the difficulties they face in fulfilling household activities when living with chronic pain and physical impairments; sexual abuse and violence perpetrated by the spouse and family members; abuse from medical workers; and suicide attempts.

60. Children affected by leprosy also experience violence on the grounds of leprosy as a result of the intersection of harmful stereotypes about leprosy and the low social status attributed to children. The former reflects, and is strengthened by, the non-recognition of children as autonomous social beings and the bearers of rights. According to the majority of the responses, children affected by leprosy are subjected to bullying; verbal and physical abuse from family members, neighbours and schoolteachers; physical punishments for going into public spaces; sexual abuse; and isolation (mainly driven by their parents and community members). There are many reports of attempted suicide among adults who were diagnosed with leprosy in childhood and who experienced multilayered stigmatization from a very early age, demonstrating how stigmatization impacts the overall life course of children.³⁴

61. Children of persons affected by leprosy can also experience similar patterns of violations. In fact, some of the children of persons affected by leprosy who were forcibly segregated by State policies were also segregated by State policies that were stricter than those applied to their parents and had a greater impact in the overall life course of these

³² The Special Rapporteur grounds her analysis on joint general recommendation No. 31 of the Committee on the Elimination of Discrimination against Women/general comment No. 18 of the Committee on the Rights of the Child (2014) on harmful practices.

³³ For the concepts of interpersonal, institutional and structural violence, see A/HRC/17/26.

³⁴ Children who have been abused or neglected are often hampered in their development, as described in United Nations Children's Fund (UNICEF), *Hidden in Plain Sight: A Statistical Analysis of Violence against Children* (New York, 2014). That is one of the main reasons why the Special Rapporteur considers interpersonal discrimination against children as a violent act.

individuals (A/HRC/38/42).³⁵ This particular group suffered from alienation from their families without consent, imprisonment and other inhumane acts such as torture and physical, sexual and psychological violence within the places built for their confinement, and many live today with severe psychosocial disabilities as well as with physical impairments that resulted from the extreme violence to which they were subjected in such institutions. Their experience shows how institutional and interpersonal violence intersect, generating harmful synergies.

62. The intersection of leprosy with other social conditions was preliminarily mapped on the basis of a question on which categories enhance women's vulnerability to discrimination on the grounds of leprosy. The question allowed each respondent to choose more than one option. Poverty was chosen 412 times, religious affiliation 235, ethnic affiliation 230, marital status 209, race 192 and age 159. With respect to children affected by leprosy, poverty was chosen 364 times, religious affiliation 230, ethnic affiliation 210, gender 191 and race 174. Undoubtedly, poverty seems to be the category that most strongly intersects with leprosy in terms of a discrimination outcome for both groups, highlighting the intersection of leprosy and social inequities.

63. Answers to questions on the traditional role attributed to women, women's work and economic independence varied from region to region, reflecting different cultural patterns and what could be called a "geopolitics of patriarchy". Since the Special Rapporteur only aimed at providing a preliminary assessment, the information gathered is presented in a generic way. Household activities, caretaking of family members and agricultural work predominate in the responses to the question on the role attributed to women, also signalling that women affected by leprosy mainly undertake unpaid care and household work, which greatly contributes to the feminization of poverty and gender inequality (A/68/293).

64. However, collected data also suggest a tendency towards an increase in the double working day for women affected by leprosy in all regions. By the same token, responses consistently pointed to unreliable casual labour, low wages and unsafe and degrading working conditions. In fact, most responses indicated that work falls mainly outside the formal economy, without an entitlement to social security benefits.

65. Notwithstanding, when asked if the work performed by women provides for independent means of subsistence, 47.1 per cent of the respondents answered no, 38.4 per cent answered yes and 14.5 per cent declared that they did not know. In fact, 65.9 per cent of the respondents affirmed that affected women are not economically independent and identify the family as the main source of income, along with begging, government annuities and international NGOs.

66. Particularly relevant to the well-being of women affected by leprosy (especially when considering that for the majority of women affected by leprosy daily activities encompass physical labour that can have an adverse impact on the physical impairments caused by leprosy) was the question on access to adequate utensils (for instance, cooking utensils that can prevent women who have lost sensation from being burned and in consequence develop wounds that can ulcerate and lead to permanent trauma), rest periods and self-care practices that allow for preventing physical impairments, as well as worsening them. Most responses pointed to an intersection with class, declaring that very few women have the means to prevent physical impairments and its negative evolution, which considerably hinders their enjoyment of the highest attainable standard of health and well-being.³⁶

³⁵ See also J. Robertson, "Leprosy's untainted child", *Bulletin of the History of Medicine*, vol. 92, No. 2 (2018), pp. 261–286; G. Maricato and A.M.S. Custódio, "Sequestro e negligência como política de Estado: experiências da segunda geração de atingidos pela hanseníase", *Saúde em Redes*, vol. 4, No. 1 (2018), pp. 153–168; and F. Othani, *The Walls Crumble: The Emancipation of Persons Affected by Hansen's Disease in Japan* (Tokyo, Tofy Kyokai Association, 1998).

³⁶ The Special Rapporteur adopts in her work the concept of the right to health as enshrined in article 25 of the Universal Declaration of Human Rights and deepened by general comment No. 14 (2000) on

67. By the same token, responses to the question about protection by work legislation during treatment in the case of physical impairments and disability evinced a low awareness of rights, with 31.6 per cent affirmative answers, 30 per cent negative replies, and as many as 38.4 per cent of responders affirming that they did not know. Concomitantly, the same question applied to mothers of children affected by leprosy, asking whether work legislation allows them to care for their children affected by leprosy during treatment, received 29.4 per cent positive replies and 29.4 per cent negative answers, while 41.2 per cent did not know the answer.

68. In turn, when asked if women affected by leprosy-related disabilities have access to social security benefits, 56.4 per cent of the respondents replied yes, 25.7 per cent no and 17.9 per cent did not know, which is an encouraging indicator. However, the question on which impairments are recognized by State policies and administrations as disability highlighted a knowledge gap and low awareness of leprosy's characteristics among State policymakers and workers that fails to acknowledge non-visible physical impairments as falling under the umbrella of disability rights.

69. With regard to social protection of children affected by leprosy, the responses to the question whether there are any measures in place for protecting the rights of children affected by leprosy-related disabilities were mainly "don't know". Accordingly, the responses to the question on the existence of measures in place to ensure that children affected by leprosy-related disabilities can proceed with their studies with reasonable accommodation evinced low awareness of rights as well as deficient access to enshrined international human rights, with 35.6 per cent of the responses being affirmative, 34.5 per cent negative and 29.9 per cent answering "don't know".

70. With respect to health care, the majority of responses pointed to the existence of a health system in place that provides medical care for leprosy. The main gaps, according to the responses received, occur due to the inability of the system to address extra-institutional barriers to the right to the highest attainable standard of health and also to provide complementary care, especially after bacteriological cure. Many responses also pointed to practices of medical pluralism and ongoing recourse to traditional healers to treat leprosy with religious healing and exorcising, among other practices. When asked to choose from among several barriers to access to health services, those most frequently chosen were the lack of health facilities near the home and lack of financial resources.

71. Finally, participation was also assessed, and collected data point to very low participation of women affected by leprosy, and even less by children affected by leprosy, in health services and settings, outreach activities, organizations of persons affected by leprosy and NGOs, as well as in the design, target-setting, prioritization, delivery or monitoring of local/regional/national planning for leprosy.

72. Lack of access by persons affected by leprosy and their family members to substantive equality is a result of the structural violence imposed upon this group that keeps the group enclosed in a spiral of disadvantage. Structural violence reflects the systematic restrictions that impair people who occupy the bottom rungs of society from meeting their basic needs and that may even cause harm in a way that leads to deprivation and denial of fundamental human rights. This is even more the case of women and children affected by leprosy who, due to the intersection of leprosy with gender and age, experience widespread and systemic structural violence.

the right to the highest attainable standard of health of the Committee on Economic, Social and Cultural Rights.

V. Progress and bottlenecks in eliminating discrimination

A. Public responses to leprosy-related discrimination

73. With a view to supporting the work undertaken by Governments and civil society organizations to eliminate discrimination on the grounds of leprosy, the Special Rapporteur attempted to map institutional and public responses to leprosy and related violations with respect to women and children by means of a consultation with States and leprosy organizations.

74. Thirteen States responded to the call by the Special Rapporteur, providing detailed information on measures in place to tackle leprosy and discrimination on those grounds. Contributions were received from Argentina, Brazil, Bolivia, Burundi, Côte d'Ivoire, Ecuador, Georgia, Guatemala, Japan, Montenegro, Paraguay, Peru, the Philippines and Tunisia. The majority of the responses came from non-priority countries, with the exception of Brazil, Côte d'Ivoire and the Philippines, which still have a high burden of leprosy. Such a gap calls for sturdier cooperation from priority countries.³⁷

75. Sixteen civil society organizations provided valuable inputs from high-burden countries (Bangladesh, Brazil, the Democratic Republic of the Congo, Ethiopia, India, Nepal and Nigeria) and low-burden countries (Cambodia, China, Colombia, Japan, Malaysia, Pakistan and Papua New Guinea).

76. Four national human rights institutions, from Azerbaijan, India, Nigeria and Uganda, also responded to the appeal of the Special Rapporteur.

77. Approximately half of the responses obtained from Governments and civil society organizations confirmed that there are existing monitoring systems for leprosy in place. The following countries reported statistical data on women and children affected by leprosy: Bangladesh, Bolivia, Brazil, Burundi, Cambodia, Côte d'Ivoire, Colombia, Ecuador, Ethiopia, India, Japan, Nigeria, Pakistan, Paraguay, Peru and the Philippines. The data provided confirm overall male-over-female preponderance in the detection of leprosy.

78. Contributions received from Governments, national human rights institutions and civil society organizations confirmed ongoing discrimination against women and children affected by leprosy and referred to practices that align with the results of the individual consultation. The same contributions pointed to the absence of institutional segregation. However, segregation was referred to as a past policy that nevertheless continues to have an impact on the lives of persons affected by leprosy and their family members, including the children and grandchildren of persons affected by leprosy who were forcibly segregated into leprosy colonies. Those violations include generalized informal segregation and lack of property rights in the case of former leprosy colonies.

1. Challenges in enforcing formal equality

79. A significant portion of the responses reported the lack of a national plan for the implementation of the principles and guidelines. Nevertheless, responses from countries such as Bangladesh, Brazil, Bolivia, Burundi, Colombia, Ecuador, India, Peru, Paraguay and the Philippines highlighted interventions in the field of care, rehabilitation, assessment of discrimination, awareness-raising and outreach activities that are in line with the WHO Global Leprosy Strategy (2016–2020). Moreover, non-endemic countries, such as Japan, referred to efforts in raising awareness on leprosy as a human rights issue. Lastly, civil society organizations from India and Japan mentioned strategic litigation activities as a means to achieve legal harmonization in the former country and reparation measures for

³⁷ WHO priority countries for leprosy are: Angola, Bangladesh, Brazil, Comoros, Côte d'Ivoire, Democratic Republic of the Congo, Egypt, Ethiopia, Micronesia (Federated States of), India, Indonesia, Kiribati, Madagascar, Mozambique, Myanmar, Nepal, Nigeria, Philippines, South Sudan, Sri Lanka, Sudan and United Republic of Tanzania.

children of persons affected by leprosy who were forcibly separated from their parents in the latter.

80. The majority of the responses reported the absence of discriminatory laws in place, which also reflects the fact that most Government's responses came from health programmes that are seldom acquainted with such legal frames. Notwithstanding, reference was made to the maintenance in some countries of obsolete laws (with a particular emphasis on the more than 100 discriminatory laws in place in India) that severely constrain the rights of persons affected by leprosy, sustaining stigmatization and impairing their access to justice. Some responses mentioned recent progress in abolishing a number – albeit small – of the overall discriminatory laws in place worldwide, in particular in Bangladesh and India.

81. By the same token, the majority of the responses pointed to the absence of a specific plan of action for amending or abolishing discriminatory laws, norms and practices against persons affected by leprosy and their family members. Some countries, such as Argentina, Bolivia, Brazil, Ecuador, Paraguay and the Philippines, were referred to as undertaking efforts to eliminate general discrimination against persons living in vulnerable conditions. Examples go from general actions (such as anti-discriminatory laws, creation of institutional bodies and national plans dedicated to anti-discrimination policies) to leprosy-specific ones (educational materials and campaigns).

2. Challenges in enforcing substantive equality

82. When asked to describe the steps taken by States to ensure autonomous and comprehensive access to the highest attainable standard of health, the majority of the responses mentioned recognition in the national constitution of the aforementioned right. Specific measures adopted in relation to the treatment of leprosy (such as delivering of multidrug therapy, monitoring systems, strategies for ensuring timely diagnosis, awareness-raising activities and implementation of the WHO technical standards) are reported from Argentina, Brazil, Bolivia, Côte d'Ivoire, Ecuador, Guatemala, Japan, Montenegro, Paraguay, Peru and the Philippines.

83. Responses from civil society organizations allow for identifying the following barriers in the access to the highest attainable standard of health: (a) lack of complementary health services after bacteriological cure; (b) lack of personal income among persons affected by leprosy; (c) lack of health workers, including health workers properly trained in leprosy and leprosy-related health complications; (d) lack of a consistent supply of multidrug therapy in peripheral health settings; and (e) lack of health education-awareness strategies addressing how to identify the signs and symptoms of leprosy, which can facilitate early diagnosis.

84. With regard to the fulfilment of the right to education, the majority of the responses from States referred to general provisions on the right to education and on the principles of equality and non-discrimination in national constitutions. General laws for ensuring the right to education to children in general, and to children with disabilities in particular, were also mentioned. There was no mention of specific measures for ensuring access to education to persons and children affected by leprosy, as well as to provide the former with training opportunities, skills development, accessibility and reasonable accommodation.

85. When asked about the access of persons affected by leprosy to the right to dignified work and economic independence, civil society organization identified the following barriers: unemployment; underemployment; unreliable casual labour; job insecurity; lack of access to job opportunities; unequal pay; and insufficiency of the pensions provided by some States. Some examples of the steps taken by States to overcome the aforementioned barriers were also provided, as follows: training opportunities; disability laws that determine a percentage of jobs reserved for persons with disabilities in India; and lifelong pensions, provided by law 11.520, to persons affected by leprosy who were forcibly segregated in Brazil.

86. When asked to describe the steps taken by States to ensure civil rights with respect to family life, marriage, community and public life, as well as participation in decision-making processes that impact the lives of persons affected and their family members, a

significant part of the responses did not provide information on the topic, except for references to constitutional provisions and general laws that guarantee the principles of equality and non-discrimination.

Challenges in protecting women affected by leprosy

87. The responses from Governments, civil society organizations and national human rights institutions allow for establishing a complete lack of specific plans to address the needs of women affected by leprosy, as well as discrimination and violence against them. Some responses provided information on legal frames for promoting gender equality and eliminating gender-based discrimination (constitutional provisions, ratification of the Convention on the Elimination of All Forms of Discrimination against Women, laws to eliminate gender-based violence and general anti-discrimination laws) in countries such as Bolivia, Cambodia, Côte d'Ivoire, Ecuador, Georgia and India. Others referred to education and empowerment programmes aimed at disadvantaged women in countries such as Côte d'Ivoire, Ethiopia and Bangladesh.

Challenges in protecting children affected by leprosy

88. A substantial part of the responses from Governments, civil society organizations and national human rights institutions did not provide information about measures in place to ensure the rights of children affected by leprosy, or about the overall framework for the protection and care of children. However, some examples of generic laws, programmes and initiatives designed for the protection and care of children (especially with regard to the rights to health, education and information) were referred to as being in place in Bolivia, Cambodia, Côte d'Ivoire, Ecuador and Ethiopia. The responses also provided examples of measures specifically related to leprosy, such as educational materials being distributed and leprosy-related projects being implemented in schools in Paraguay; awareness-raising activities among schoolteachers and students, preventive care focused on zero disability in children affected by leprosy and family counselling in Bangladesh; and priority access to health care among vulnerable children in Colombia. There was no mention of measures adopted for enforcing the rights of the children of persons affected by leprosy, except for the reference to an ongoing lawsuit in Japan aimed at reparation for past State offences.

3. Good practices for the elimination of discrimination

89. The majority of good practices developed by States fall within the health sector, namely delivery of care and awareness-raising activities. At the international level, Japan mentioned action undertaken to ensure the inclusion of leprosy in the human rights agenda at both the Human Rights Council and the General Assembly. At the national and subnational levels, responses pointed mainly to awareness-raising activities, campaigns and actions for improving health-care services (separated into new case detection, early diagnosis, quality treatment and rehabilitation), alongside the health worker's expertise, to provide care for persons affected by leprosy. Such activities are driven by health programmes in countries such as Bolivia, Brazil, Burundi, Côte d'Ivoire, Ecuador and Paraguay. Schools as priority places for awareness-raising were referred to in countries such as Brazil, India and Japan. Also with regard to awareness-raising activities, examples of decentralized actions within States that bring together different stakeholders (traditional and religious leaders, politicians, teachers, care providers, etc.) were mentioned in countries such as Brazil and Burundi. Finally, in respect of the autonomous development of the persons affected by leprosy, responses highlighted the role played by civil society organizations in community-based rehabilitation; formation of associative, self-help and self-care groups of persons affected by leprosy (with positive examples of successful advocacy led by such groups); as well as the participation of family members in health services, income generation and education opportunities (with a focus on women) in countries such as Bangladesh, Cambodia, the Democratic Republic of the Congo, Ethiopia, Nigeria and Pakistan.

VI. Conclusions and recommendations

A. Conclusions

90. The main underlying causes of ongoing discrimination against women and children affected by leprosy, including family members are: (a) at the macro level of global health, the association between the limited public apprehension of leprosy, on the one hand, and the mercantilization of health and the patriarchal nature of biomedicine on the other; (b) at the intermediate level of State governance, discriminatory laws, widespread absence of reparation and awareness-raising measures to counter the iatrogenic stigma created by past State prophylactic segregation, lack of a multisectoral approach to leprosy and persistence of social iniquities that have not been addressed; (c) at the micro level of social life, pervasive harmful stereotypes, wrongful stereotyping and violence; (d) at the individual level, the internalization of stigma as an extreme form of dehumanization.

91. Harmful stereotypes and traditional practices and institutionalized, structural and interpersonal discrimination intersect with the already subordinated social location of women and children in many societies, with severe manifestations of physical, sexual and psychological violence and systemic informal segregation. The low participation of both social groups in civil society organizations, health services, decision-making processes and institutional bodies enhances the weakness of the responses from State monitoring systems and policies to map and address discrimination and violence on the grounds of leprosy, strengthening women's and children's structural invisibility, social subordination and institutional neglect. The narrow understanding of leprosy as a biological condition hinders much-needed efforts to tackle the social, economic, cultural and political dimensions of leprosy as a social category that, throughout history as well as in contemporary societies, has been used mainly to exclude. Without the de facto recognition that all human rights are inalienable, indivisible, interdependent and interrelated and that they all must be fulfilled on a non-discriminatory basis, alongside a multisectoral strategy that can disaggregate leprosy-related discrimination into the distinct realities of different groups and cultural backdrops, women and children affected by leprosy will surely continue to be left behind.

B. Recommendations

1. General recommendations

92. **The Special Rapporteur calls upon States to take all necessary measures to:**

(a) **Review existing legislation to ensure that it is in line with international human rights standards and abolish and/or amend all discriminatory laws in force as an immediate obligation;**³⁸

(b) **Implement the principles and guidelines for the elimination of discrimination against persons affected by leprosy and their family members as a road map for enforcing enshrined international human rights and achieving substantive equality;**³⁹

(c) **Systematically approach, consult and involve in decision-making processes that directly affect their lives persons affected by leprosy and their representative organizations, with the guarantee of all measures for ensuring the**

³⁸ In line with general comment No. 6 (2018) on equality and non-discrimination of the Committee on the Rights of Persons with Disabilities.

³⁹ In agreement with general comment No. 20 of the Committee on Economic, Social and Cultural Rights.

participation of women, children and men affected by leprosy-related impairments and disabilities;⁴⁰

(d) Establish reparation measures for persons affected by leprosy, as well as for their children when appropriate, who were forcibly segregated by State policies, in order to address the continuous nature of the violation;

(e) Eliminate the iatrogenic stigma generated by prophylactic State segregation, with dissemination of accurate information on leprosy and preservation of its history;

(f) Develop awareness-raising programmes at both the national and subnational levels, with a focus on providing accurate information about leprosy to the general population as well as on the human rights of persons affected by leprosy. Such programmes should provide for dialogue with all relevant population groups (including those possessing non-scientific knowledge and non-official authorities); involve persons affected by leprosy; and be sensitive to local languages, gender, age and disability;

(g) Improve monitoring systems for leprosy, comprising disaggregated and equality data that may support anti-discriminatory policies. Leprosy health services should include easy-to-access mechanisms for making complaints of discrimination;

(h) Implement multisectoral governance, and affirmative measures when necessary, in order to tackle the multiple nature of leprosy-related discrimination and vulnerability. Multisectorality should also be reflected in leprosy health services, guaranteeing accessibility, comprehensive care and peer counselling.

2. Recommendations for enforcing the human rights of women affected by leprosy

93. The Special Rapporteur recommends that States, national human rights institutions and civil society organizations take all necessary measures to:

(a) Ensure that human rights monitoring of gender-based discrimination and violence includes the particular situation of women affected by leprosy. Leprosy monitoring systems and public health strategies should also make use of a gender framework that ensures autonomous, affordable and effective comprehensive care (A/HRC/32/44). Primary care, especially in high-burden areas, should include female health workers. Leprosy services should provide training on self-care techniques and peer counselling;

(b) Include women affected by leprosy in national plans for gender equality, gender violence prevention and women's access to justice and raise awareness on gender equality in leprosy services, high-burden communities and priority groups;

(c) Empower women affected by leprosy to know their rights and how to claim them, including through income-generation programmes, creation of cooperatives and continued education, in order to secure for them economic independence and access to dignified work, which should guarantee reasonable accommodation;

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

3. Recommendations for enforcing the human rights of children affected by leprosy

94. The Special Rapporteur recommends that States, national human rights institutions and civil society organizations take all necessary measures to:

⁴⁰ In line with general comment No. 7 (2018) on the participation of persons with disabilities, including children with disabilities, through their representative organizations, in the implementation of the Convention of the Committee on the Rights of Persons with Disabilities.

(a) Recognize that the child is a rights holder and not a beneficiary of benevolent activities of adults, always consulting the child and respecting their agency in the design and implementation of any framework for addressing discrimination on the grounds of leprosy; this should also be done in accordance with the child's age and evolving capacities;⁴¹

(b) Undertake further research into the risk factors that may perpetuate violence against children affected by leprosy, alongside the formation of integrated partnerships of experts, parents, teachers and young people that can respond effectively to such violence;

(c) Guarantee child- and youth-friendly health care and information, as well as comprehensible information guidance for parents. Provide a safe and supportive environment for children that ensures the opportunity to participate in decisions affecting their health, to build life skills, to acquire appropriate information, to receive counselling and to negotiate the health behaviour choices they make. Affirmative measures regarding work and social security should be in place for parents of children affected by leprosy in order to ensure proper care and support;

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

(e) Recognize that children's participation is a key element for self-protection. With suitable methods, participation of affected children should be ensured in research and the implementation of public programmes. The same applies to participation in relevant non-governmental organizations, epistemic communities and policy-making affecting them.

⁴¹ As enshrined in article 19 of the Convention on the Rights of the Child.