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تعزيز وحماية جميع حقوق الإنسان، المدنية والسياسية والاقتصادية والاجتماعية والثقافية، بما في ذلك الحق في التنمية

الزيارة إلى البرازيل

تقرير المقررة الخاصة المعنية بالقضاء على التمييز ضد الأشخاص المصابين
بالجذام وأفراد أسرهم**

موجز

تستكشف المقررة الخاصة المعنية بالقضاء على التمييز ضد الأشخاص المصابين بالجذام وأفراد أسرهم، أليس كروز، المسائل المتعلقة بالإنجازات التي حققتها البرازيل في القضاء على التمييز ضد الأشخاص المصابين بالجذام وأفراد أسرهم، والتحديات التي يواجهها البلد في هذا الصدد، بما في ذلك الثغرات المتبقية. وتقدم أيضاً توصيات بناءة تهدف إلى مواصلة الجهود وتحقيق تغيير منهجي.

* يُعمَّم موجز هذا التقرير بجميع اللغات الرسمية. أما التقرير نفسه، المرفق بهذا الموجز، فيُعمم باللغة التي قُدِّم بها فقط.

** اتُّفق على نشر هذا التقرير بعد تاريخ النشر الاعتيادي لظروف خارجة عن إرادة الجهة التي قدمته.



الرجاء إعادة الاستعمال

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Annex

Report of the Special Rapporteur on the elimination of discrimination against persons affected by leprosy and their family members on her visit to Brazil

I. Introduction

1. The Special Rapporteur on the elimination of discrimination against persons affected by leprosy and their family members, Alice Cruz, undertook an official visit to Brazil from 7 to 14 May 2019. The purpose of the visit was to evaluate the improvements made and the challenges the country faces in eliminating discrimination against persons affected by leprosy and their family members and to provide the Government and key stakeholders with constructive recommendations. Given that leprosy is referred to as Hansen's disease in Brazil, that term will be used in the present report.

2. During her mission, the Special Rapporteur visited the capital, Brasília, in the Federal District. She also visited Pará, a highly endemic state, and Rio de Janeiro, a state with a low incidence of Hansen's disease. The aim was to assess the main factors sustaining ongoing discrimination against persons affected by Hansen's disease and their family members with regard to the distinct epidemiological, socioeconomic and cultural realities within the country.

3. The Special Rapporteur met with federal and local government representatives in the cities of Brasília, Rio de Janeiro and Belém, with the Federal Public Defender and with staff of the public defenders' offices at the federal and state levels. She also met with the United Nations resident coordinator and country team; the Pan American Health Organization coordinator for Hansen's disease in the region; the more prominent academics in the fields of hansenology (leprology), public health, history and social sciences at the leading South American public health research centre (Fundação Oswaldo Cruz); law and health-care professionals and public health managers; members of civil society organizations and national and international non-governmental organizations (NGOs); and members of MORHAN, the national Movement for the Reintegration of Persons Affected by Hansen's disease, both its national coordination and regional branches. In addition, the Special Rapporteur visited several communities and former Hansen's disease colonies, where she met with persons affected by the disease and their family members. She made every effort to make the visit interdisciplinary and to give all stakeholders a voice. She also endeavoured to make the visit a catalyst to enable dialogue and to build bridges between different stakeholders in order to foster more effective responses to discrimination.

4. The Special Rapporteur expresses her appreciation to the Government of Brazil for its initial invitation and for the support it provided in the organization and facilitation of the visit, in close coordination with the regional and local authorities. She also thanks the public and private institutions and civil society organizations that provided valuable substantive inputs and assistance in the coordination of the visit. She is particularly grateful to MORHAN, to the persons affected by the disease and their families.

II. Hansen's disease in Brazil

5. Hansen's disease, known globally as leprosy, remains a significant public health problem in Brazil. Brazil is the world's fifth largest country by both population and total area, and the largest and most populated Latin American country. It is composed of 26 states and one federal district. According to World Bank indicators on poverty and inequality, in 2017, 26.5 per cent of the population of Brazil was living in poverty, and 7.4 per cent was living in extreme poverty. Over a third of the population had restricted access to basic sanitation and 15 per cent had no access to the water supply network. Such data is relevant for understanding the epidemiological features of Hansen's disease in the country.

6. According to the World Health Organization (WHO), Brazil has the second highest absolute number of new cases of Hansen's disease in the world. In 2018, Brazil accounted

for about 13 per cent of new Hansen's disease cases detected globally and 93 per cent of new cases in the Americas. Brazil has the highest rate in the world by percentage of the population.¹

7. Although there was an overall reduction in 2018 in the number of new cases detected in global priority countries compared to the previous year, the countries in which the new cases were detected included Brazil. New cases of Hansen's disease are not distributed evenly in Brazil, with areas of higher risk mainly located in the Midwest, North and North-East regions. The prevalence of the disease has significantly decreased over the years.² In 2018, Brazil had 1,107 more new cases than in 2017, which probably reflects the improved capacity of the health system to detect the disease.³

8. New cases of Hansen's disease in patients diagnosed with severe and irreversible impairments⁴ point to the limited capacity of health-care systems to recognize and treat the disease on time. According to WHO, a decrease in the number of new cases with visible and irreversible physical impairments at the time of diagnosis was reported globally, which is consistent with the overall decrease in the number of new cases over the past 10 years. Nevertheless, in 2018 an increase was reported in a few countries, including Brazil, with 2,109 new cases diagnosed with irreversible physical impairments at the time of diagnosis.

9. Hansen's disease is not only a significant endemic disease in Brazil. It has also been an important scientific subject in Brazilian medical history. In the context of Brazilian collective health, which since the 1970s has undergone a paradigmatic shift in terms of public health, much later adopted by WHO with the concept of social determinants of health, scientific research on the medical and historical aspects of Hansen's disease has flourished. Evidence of this is the introduction in the 1960s of rifampicin⁵ in the treatment of Hansen's disease by the Brazilian doctor Diltor Vladimir Araújo Opromolla.⁶ WHO subsequently included rifampicin in multidrug therapy⁷ in the 1980s. This involvement of the scientific community with Hansen's disease has contributed greatly to framing the governmentality⁸ of the disease in Brazil. By the same token, the participatory profile of the 1988 Constitution paved the way for a politics of recognition headed by MORHAN, created in 1981, which also has significant corollaries in the governmentality of the disease in Brazil.

¹ WHO, "Global leprosy update, 2018: moving towards a leprosy-free world", *Weekly Epidemiological Record*, vol. 94, No. 35 (30 August 2019).

² Data on the prevalence of Hansen's disease per 10,000 inhabitants, provided by the Ministry of Health. Available at <http://portalarquivos2.saude.gov.br/images/pdf/2018/julho/13/Taxa-de-prevalencia-de-hanseniose-1990a2017.pdf>.

³ Matheus Moreira, "Após 13 anos em queda, hanseníase volta a crescer no Brasil", *Folha de São Paulo*, 13 July 2019.

⁴ According to the grading system used by the WHO Global Leprosy Strategy to assess physical impairments caused by Hansen's disease at the time of diagnosis, 0 means no impairment, 1 means loss of sensation in the hand, eye or foot, and 2 means visible impairment, including irreversible damage to the nerves, hands, feet, limbs and eyes. In the present report, the Special Rapporteur uses the term "impairment" to refer to the loss of function or the detriment to the health of persons affected by leprosy, and the term "disability" to refer to the social responses of discrimination and exclusion to leprosy-related impairments. This distinction is based upon the social model of disability, which is embraced by the Special Rapporteur in her work.

⁵ Rifampicin is the most important drug in the medical treatment of Hansen's disease and the only one with a bactericidal effect.

⁶ L. de Souza Lima and D.V.A. Opromolla, "First results on the treatment of leprosy with rifampicin SV", *Chemotherapy*, vol. 7, No. 6 (1963).

⁷ Hansen's disease is curable with a combination of drugs known as multidrug therapy, which WHO has been supplying free of charge since 1995.

⁸ Governmentality, a concept introduced by the French philosopher Michel Foucault, encompasses not only formal government, but also all the related social practices, including rationalities and techniques, that regulate the subject, bodies and human conduct.

III. Legal and institutional framework

A. Legal framework

1. International legal framework

10. Brazil has ratified several international human rights treaties, including the International Covenant on Economic, Social and Cultural Rights, the Convention on the Elimination of All Forms of Discrimination against Women, the Convention on the Rights of the Child and the Convention on the Rights of Persons with Disabilities, which are of particular importance for the protection of persons affected by Hansen's disease and their family members.

11. In 2010, Brazil voted for General Assembly resolution 65/215, in which the Assembly explicitly reaffirmed that persons affected by leprosy and their family members are entitled to all human rights and fundamental freedoms. In accordance with article 5 (2) of the Brazilian Constitution, which states that the rights and guarantees enshrined in the Constitution do not exclude others provided for in the international treaties that Brazil has ratified, Brazil is obliged to respect, protect and fulfil the human rights of persons affected by Hansen's disease and their family members. In this regard, the principles and guidelines for the elimination of discrimination against persons affected by leprosy and their family members (A/HRC/15/30, annex), cited in resolution 65/215, provide support in the context of domestic law and policies.

2. National legal framework

General

12. The Brazilian Constitution provides that building a free and fair society, eradicating poverty and reducing social and regional inequalities, and promoting equality without distinction on the basis of race, sex, colour, age or any other grounds for discrimination are the guiding principles for the rule of law in the country. The right to education, health, food, work, housing, transport, leisure, security, social security and protection of motherhood and childhood are recognized as social rights under article 6 of the Constitution.

13. Health protection, promotion and rehabilitation, as well as the organization and functioning of the health services within the public Unified Health System (Serviço Único de Saúde) are regulated by Law No. 8080/1990. Decree No. 7508/2011 regulates that law and specifies how the Unified Health System is organized, including how entities at the federal, state and municipal levels should coordinate their work and plan for the provision of health care.

14. Public participation in the management and monitoring of the Unified Health System is ensured by two bodies at the federal, state and municipal levels: health councils and health conferences. The councils have a permanent and deliberative character, while the conferences meet periodically and have a consultative profile. Both foresee parity of participation between the beneficiaries of the Unified Health System and health providers.

15. Under this legal framework, which guarantees de jure universal, equitable and decentralized access to health care, the health care of persons affected by Hansen's disease is to be provided by multidisciplinary health teams in public services at all levels of the Unified Health System, with particular focus on primary health care.

16. In accordance with the Constitution, especially article 203, the Government of Brazil has an obligation to set up a social security regime⁹ and provide welfare.¹⁰ Brazil has adopted legislation to combat femicide (Law No. 13104/2015), gender violence (the "Maria da Penha" Law, No. 13827/2006) and to protect vulnerable groups, including children and adolescents (Law No. 8069/1990), older persons (Law No. 10741/2013) and persons with disabilities (Law No. 13146/2015). Those laws are applicable for the protection of persons

⁹ Law No. 8213/1991 provides for the establishment of benefit plans within the Brazilian social security system.

¹⁰ Law No. 8742/1993 provides for the establishment of social assistance benefits.

affected by Hansen's disease and their family members. More specifically, the Brazilian legal system provides for a set of basic rights under which persons affected by Hansen's disease are to be protected:¹¹

- Right to free health-care services, under Law No. 8080/1990;
- Rights to adequate treatment in a timely manner, to privacy and confidentiality about one's health, to an enabling and humanized service, to information on and access to participation mechanisms, and to participate in health councils and conferences, under Ministry of Health Ordinance No. 1820/2009;
- Right to rehabilitation and inclusive labour rights for persons with disabilities, under Laws No. 8213/1991 and No. 13146/2015;
- Right to social security benefits for persons with disabilities, under articles 42 and 59 of Law No. 8213/1991;
- Right to a continuous instalment benefit, under Law No. 8742/1993;
- Right to tax exemptions, under Laws No. 7713/1988, No. 8989/1995 and No. 8383/1991;
- Right to full and free legal assistance, under Complementary Law No. 80/1994, as amended by Complementary Law No. 132/2009.

Special measures

17. Brazil has been leading in the adoption of anti-discrimination laws and special measures¹² for the protection of persons affected by Hansen's disease and their family members. Its legal framework is in accordance with principle No. 2 and guideline No. 2 of the principles and guidelines for the elimination of discrimination against persons affected by leprosy and their family members, which concern non-discrimination and reaffirm legally binding provisions from several international treaties. Brazil no longer has any laws in place that discriminate against persons affected by Hansen's disease.

18. Brazil prohibited language that discriminates against persons affected by Hansen's disease under Ordinance No. 165/1976, replacing the term "leprosy" with "Hansen's disease" in all official documentation. That Ordinance later became Law No. 9010/1995. Brazil has played a pioneering role in implementing guideline No. 9 of the principles and guidelines, which concerns the prohibition of discriminatory language. It has also played a key role in acknowledging the relationship between stereotyping and discrimination, which are referred to in article 8 of the Convention on the Rights of Persons with Disabilities, articles 2, 4 and 5 of the Convention on the Elimination of All Forms of Discrimination against Women, and article 7 of the International Convention on the Elimination of All Forms of Racial Discrimination, and in other international human rights instruments.

19. In 2007, Brazil recognized the damage that had been caused by the State policy of forced isolation of persons affected by Hansen's disease, which had been in place between the 1920s and the 1980s. It established an administrative programme to provide for material reparation under Law No. 11520/2007. This Law authorizes the executive branch of the Government to grant special lifelong monthly non-transferable pensions to persons affected by Hansen's disease who were subjected to compulsory isolation in segregated colonies up to 31 December 1986. An application must be submitted for the pension; its receipt does not exclude access to other social benefits. It is a special measure of a permanent nature.¹³

20. The explanatory statement of Executive Order No. 373/2007 (subsequently Law No. 11520/2007) details the historical background of the Brazilian policy of institutional

¹¹ See Rafael Monteiro Teixeira, "Direitos e garantias da pessoa atingida pela hanseníase", master's degree dissertation, Universidade Estadual Paulista "Júlio de Mesquita Filho", 2017.

¹² See Committee on the Elimination of Discrimination against Women, general recommendation No. 25 (2004) on temporary special measures, and Committee on the Elimination of Racial Discrimination, general recommendation No. 32 (2009) on the meaning and scope of special measures in the Convention.

¹³ According to the Committee on Economic, Social and Cultural Rights in its general comment No. 20 (2009) on non-discrimination in economic, social and cultural rights, special measures may, exceptionally, need to be of a permanent nature (para. 9).

segregation. Officially, the compulsory isolation of persons affected by Hansen's disease in Brazil was abolished in 1962 under Decree No. 968. However, the pace at which secluded persons were released differed as a result of local and regional realities, hence de facto segregation continued until as late as 1986.

21. Article 4 of Law No. 11520 provides for full rehabilitation and ensures free access to orthotic devices, prostheses and other assistive devices and technologies for the beneficiaries of the special pension.

22. As part of the compulsory isolation policy, a large number of the children of persons affected by Hansen's disease were separated from their parents and grew up without any contact with their biological parents. These children were sent to orphanages, nurseries and "preventoriums" – institutions created by the State for their segregation from society immediately after birth. Minas Gerais was the first state to adopt a law granting reparation to persons who were separated from their parents owing to this official policy (state Law No. 23137/2018). Minas Gerais Decree No. 47560/2018 establishes the criteria for the concession of this benefit. These norms are applicable in the State of Minas Gerais only.

B. Institutional framework

23. The two governmental bodies directly involved with Hansen's disease in Brazil are the Ministry of Health, which is responsible for the health care of persons affected by Hansen's disease, and the Ministry of Women, Family and Human Rights, which is responsible for the implementation of Law No. 11520.

24. The development and monitoring of the National Hansen's Disease Strategy 2019–2022 is the responsibility of the National Office for Hansen's Disease Coordination, under the Secretariat of Health Surveillance of the Ministry of Health. In accordance with the WHO global strategy,¹⁴ the National Hansen's Disease Strategy is based on three strategic pillars: strengthening management of the programme at the three levels of governance; fighting Hansen's disease and its complications; and fighting discrimination and promoting inclusion.

25. Guidelines for the surveillance, care and control of Hansen's disease and on preventing its transmission are based on active case detection, timely treatment, prevention of physical impairments and contact tracing. The National Office for Hansen's Disease Coordination encourages the participation of both persons affected by the disease and experts in the field, which has contributed to the quality of technical responses to the disease in the country. Brazil has sometimes diverged from WHO policy in the past, researching the WHO guidelines in-depth before implementing them nationally, as in the recent case concerning chemoprophylaxis with a single dose of rifampicin (post-exposure prophylaxis) for individuals who had been in contact with persons diagnosed with Hansen's disease. The concerns over possible resistance to rifampicin and stigmatization of such individuals that were raised by experts and persons affected by Hansen's disease were duly taken into consideration when deciding on this matter. Private-public partnerships are also a core part of the national strategy. Projects implemented by partnerships between the Ministry of Health and MORHAN, Novartis Brazil, DAHW Brazil, the Sasakawa Health Foundation and the Pan American Health Organization are currently under way. Both state and municipal authorities are responsible for the implementation of the strategy.

26. Health councils at the three levels of administration are key mechanisms for monitoring the proper implementation of the strategy. The Special Rapporteur became aware of this fact during her visit, especially given the level of autonomy of the states and the municipalities in the management of resources and the disparate implementation of the national strategy within the country.

27. Presidential Decree No. 9759/2019 regulates and limits the councils, which are federal public collegiate bodies, and restricts the exercise of fundamental freedoms and rights, such as participation in decision-making, monitoring and accountability. Such councils have been critical for guaranteeing the civil and political rights enshrined in the International Covenant on Civil and Political Rights, to which Brazil is a party, and have

¹⁴ WHO, *Global Leprosy Strategy 2016–2020: Accelerating towards a leprosy-free world* (New Delhi, 2016).

also paved the way for the participation in public affairs of marginalized groups, such as persons affected by Hansen’s disease.¹⁵ The elimination of these key mechanisms would reinforce the exclusion of these individuals, constituting a major setback to their enjoyment of social, economic and cultural rights, and a retrograde step with regard to the enforcement of core international human rights.

28. An interministerial pension evaluation committee within the Ministry of Women, Family and Human Rights, composed of experts and representatives of MORHAN, oversees the special pensions provided for under Law No. 11520. According to the available data, the committee had received around 12,997 applications by October 2018, of which 9,011 were granted and 3,986 were rejected, resulting in a successful applicant rate of around 70 per cent.¹⁶

29. One example of good practice aimed at enforcing the human rights of persons affected by Hansen’s disease that was documented during the visit was the creation of the National Observatory on Human Rights and Hansen’s disease. The Observatory receives reports of and monitors human rights violations of persons affected by Hansen’s disease. Its mission is to fight institutional discriminatory practices. The initiative is the result of a partnership between the Public Defender’s Office of the State of Maranhão, MORHAN and the Sasakawa Health Foundation. This institutional experiment is fit for replication at the national and state levels.

IV. Main challenges and opportunities

A. Social determinants of Hansen’s disease

30. Hansen’s disease is classified by WHO as a tropical neglected disease closely linked to poverty.¹⁷ According to WHO, infectious diseases contribute to lifelong disadvantage, perpetuating the vicious cycle of poverty and infection.¹⁸ There is evidence demonstrating the socioeconomic and environmental root causes of Hansen’s disease in Brazil. Independent research shows the linkage between the incidence of Hansen’s disease, poverty rates and inequality indicators, such as household crowding.¹⁹ Independent research also points to the socioeconomic profile of persons diagnosed with Hansen’s disease, who often have a low level of education, a low income and precarious work, and live in areas with poor infrastructure and poor access to goods and services.²⁰

31. At the Special Rapporteur’s meeting with the Minister of Health, he highlighted the close linkage between Hansen’s disease and poverty as an issue of concern, reflected in the

¹⁵ In its general comment No. 25 (1996) on participation in public affairs and the right to vote, the Human Rights Committee defines the conduct of public affairs as a broad concept covering all aspects of public administration and the formulation and implementation of policy at all levels (para. 5).

¹⁶ See www.mdh.gov.br/navegue-por-temas/pessoa-com-deficiencia/programas/hansenise.

¹⁷ See www.who.int/neglected_diseases/diseases/en/.

¹⁸ WHO, *Global Report for Research on Infectious Diseases of Poverty* (Geneva, WHO, 2012).

¹⁹ Leila Posenato Garcia and Gabriela Drummond Marques da Silva, “Doenças transmissíveis e situação socioeconômica no Brasil: análise espacial” (Brasília, Instituto de Pesquisa Econômica Aplicada, 2016); Lúcia R.S. Freitas, Elisabeth C. Duarte and Leila P. Garcia, “Leprosy in Brazil and its association with characteristics of municipalities: ecological study, 2009–2011”, *Tropical Medicine and International Health*, vol. 19, No. 10 (2014); Lorena Dias Monteiro and others, “Determinantes sociais da hanseníase em um estado hiperendêmico da região Norte do Brasil”, *Revista de Saúde Pública*, vol. 51 (2017); Carlos Souza, “Hanseníase e determinantes sociais da saúde: uma abordagem a partir de métodos quantitativos – Bahia, 2001–2015”, PhD dissertation, Instituto Aggeu Magalhães, Fundação Oswaldo Cruz, Recife, 2018.

²⁰ Marli T.C. Duarte, Jairo A. Ayres and Janete P. Simonetti, “Perfil socioeconômico e demográfico de portadores de hanseníase atendidos em consulta de enfermagem”, *Revista Latino-Americana de Enfermagem*, vol. 15 (2007); Viviane A.S. Lopes and Etuany M. Rangel, “Hanseníase e vulnerabilidade social: uma análise do perfil socioeconômico de usuários em tratamento irregular”, *Saúde Debate*, vol. 38, No. 103 (2014); Lúcia M.F. Helene and Maria J.L. Salum, “A reprodução social da hanseníase: um estudo do perfil de doentes com hanseníase no município de São Paulo”, *Cadernos de Saúde Pública*, vol. 8, No. 1 (2002).

delay in diagnosis in remote areas where the public health system has limited coverage. The Minister of Health also expressed concern about the limited access residents of remote areas had to rehabilitation and reconstructive surgery. He highlighted the need to broaden the perspective of Hansen's disease from an infectious disease to a disabling and chronic condition which is not yet suitably addressed by the health system.

32. During the Special Rapporteur's meetings at the former colony of Marituba, now the Marcello Candia specialized reference unit in sanitary dermatology in the State of Pará, persons affected by Hansen's disease shared their testimonies about the living conditions in the Amazonian region and areas where people are more vulnerable to disease than elsewhere. They referred to the lack of proper assistance available near places of residence, owing to the limited reach and capacity of primary health-care services. That resulted in many people going undiagnosed and not receiving treatment for years, and their concomitant development of irreversible physical impairments that are highly detrimental to them at the psychosocial and economic levels. They also spoke of needing to travel at their own cost to the state capital, Belém, to receive medical care during and after completing multidrug therapy²¹ at the Marcello Candia specialized reference unit (which is proof of the failure of primary health-care services to diagnose and treat Hansen's disease), which is difficult for them owing to their limited finances and the lack of safety nets. Other concerns they expressed were the barriers they faced in terms of access to assistive devices, some as basic as adapted shoes. Such devices can simultaneously prevent the worsening of physical impairments and promote independent living. They also mentioned the lack of availability of reconstructive surgery and rehabilitation. All those factors are exacerbated by an already extremely disadvantaged socioeconomic situation.

33. On her visit to Rocinha, a vulnerable community in Rio de Janeiro and one of the biggest informal settlements (favelas) in Latin America, the Special Rapporteur met with persons affected by Hansen's disease. They spoke of the barriers they faced in accessing goods and services from the State in general, and early diagnosis, timely treatment and comprehensive care of Hansen's disease in particular. Health workers expressed concern about the loss of medical expertise to diagnose and treat the disease in an epidemiological scenario of post-elimination of Hansen's disease. That could result in a worsening in the state of health of many affected individuals and their development of severe physical impairments, as well as an increase in transmission among the population.

34. At the Special Rapporteur's meeting with members of the Brazilian Society of Hansenology, concerns were shared with regard to the limited capacity of the public health system to diagnose Hansen's disease and properly treat it at the primary, secondary and tertiary levels of care, and coordination difficulties between those levels. She also heard about the lack of equal treatment provided to different social classes. Indeed, despite the fact that multidrug therapy is provided free of charge, at private consultations patients can receive drugs with diminished iatrogenic effects (see A/HRC/38/42), which are not available to the general public. Concern was also voiced about the high percentage of late diagnosis, with the accompanying irreversible physical impairments that tend to worsen over time; underdiagnosis rates, which may be related to syndemics²² and to the limited capacity of health workers to recognize Hansen's disease; the limited availability of reconstructive surgery; and the significant decrease in public funds for research on Hansen's disease.

35. At the Special Rapporteur's meeting with scholars, researchers and health experts in the field of Hansen's disease at the Fundação Oswaldo Cruz in Rio de Janeiro, the view that was consistently put forward was that the main obstacle to ensuring a country free of Hansen's disease and the well-being of persons affected by Hansen's disease is the persistent social inequality that hinders the access of a substantive part of the population to fundamental rights and freedom from want. Despite the impressive efforts of government authorities to promote health education, train health workers and develop high-quality technical guidelines, the critical gaps with regard to addressing the social determinants of Hansen's disease in a country where a significant number of people live below the poverty

²¹ Medical treatment and care for persons affected by Hansen's disease is not restricted to curing the infection, as the Special Rapporteur indicated in a previous report (A/HRC/38/42). The disease can turn into a chronic and disabling condition that requires lifelong health care.

²² See Merrill Singer, *Introduction to syndemics: a critical approach to public and community health* (San Francisco, Jossey-Bass, 2009).

line keep the disease very much alive and compromise the rights and well-being of those who are affected. The permanent rotation of health workers within the public health system in the more remote areas of the country, which are not as attractive to health workers as the central areas, was also pointed out as a determining factor in the diminished capacity of the system to diagnose and treat the disease on time.

36. In accordance with the evidence gathered during her visit, the Special Rapporteur recalls that guideline No. 11 of the principles and guidelines for the elimination of discrimination against persons affected by leprosy and their family members provides for guidance to States on the enforcement of the right to health of persons affected by leprosy and their family members. This reflects the core provisions of article 25 of the Universal Declaration of Human Rights, article 12 of the International Covenant on Economic, Social and Cultural Rights and articles 25 and 26 of the Convention on the Rights of Persons with Disabilities, all of which Brazil has ratified. Of particular importance to understand the obligations of Brazil to protect, promote and fulfil the right to health is general comment No. 14 (2000) on the right to the highest attainable standard of health of the Committee on Economic, Social and Cultural Rights. In that general comment, the Committee interprets the right to health as both the right to the enjoyment of a variety of facilities, goods and services, and to the underlying determinants of health, such as access to safe and potable water and adequate sanitation, an adequate supply of safe food, nutrition and housing, and healthy occupational and environmental conditions. The Committee also draws attention to article 25.1 of the Universal Declaration of Human Rights, which affirms that everyone has the right to a standard of living adequate for their own health and that of their family, including food, clothing, housing and medical care and necessary social services.

B. Discrimination

1. Institutionalized and interpersonal discrimination

37. Although there are no discriminatory laws against persons affected by Hansen's disease and their family members in Brazil, institutionalized discrimination is reported in the administration of the State, as is interpersonal discrimination against persons affected by Hansen's disease and their family members.

38. The Special Rapporteur received reports about ongoing discrimination at the hands of public services both in high-burden and low-burden states. Reports submitted by civil society organizations provided two examples (one from Pará and one from Maranhão) of discriminatory practices in hiring policies for public jobs, in which Hansen's disease was considered an eliminatory criterion. Another discriminatory practice was reported in the State of Mato Grosso, where patients undergoing medical treatment for Hansen's disease were forced to sign an agreement committing not to stop their treatment under threat of being prosecuted under article 267 of the Brazilian Penal Code.

39. During several of her meetings with persons affected by Hansen's disease, the Special Rapporteur also heard testimonies of discriminatory practices within public health and social assistance services, most of which reflect a lack of knowledge about the disease among civil servants. This is exacerbated by bureaucratic procedures that are impenetrable or difficult for marginalized groups to comply with. One striking example is that of a woman who, having been diagnosed with Hansen's disease while pregnant, was advised by her health team to terminate the pregnancy because of the disease.

40. Enduring institutionalized discrimination appears to be based on harmful stereotypes (see A/HRC/41/47) which, despite all the efforts made in previous decades, continue to result in stigmatization. The Special Rapporteur received reports of good practices for raising awareness which, instead of making use of medicalized language and a top-down approach, encourage cooperation between health workers, persons affected by Hansen's disease, traditional leaders and healers. The aim is to provide the public with key information through accessible channels and language, thus effectively changing mindsets with regard to Hansen's disease.

41. During one of the Special Rapporteur's meetings in Rio de Janeiro with national civil society organizations and international NGOs, some of the key issues to emerge were the social invisibility of, and institutional gaps on, the sexual and reproductive rights and

the right to the highest attainable standard of mental health of persons affected by Hansen's disease.

42. In the course of her visit, at several meetings, persons affected by Hansen's disease, their family members, scholars, health workers and members of civil society organizations and NGOs reported discrimination against persons affected by Hansen's disease and their family members. This included discrimination and violence within their families, including gender-based violence, job losses and impediments to work, and barriers to rehabilitation. Moreover, anticipated stigma seems to act as a barrier for the full participation of persons affected by Hansen's disease in community life and society at large, leading to self-isolation, loss of self-esteem and deterioration of mental health. As the Special Rapporteur indicated in a previous report (A/HRC/41/47), the internalization of stigma is an extreme form of dehumanization. Self-care groups promoted by health services and NGOs were reported as an effective measure for overcoming trauma, as was participation in public affairs through membership of social movements.

43. The intersection of Hansen's disease with poverty also hinders access to justice as a critical means of combating discrimination, as was pointed out to the Special Rapporteur in her meetings with the federal and state public defenders. She wholeheartedly welcomed the Federal Public Defender's engagement on the issues discussed during the meeting. While acknowledging the structural invisibility of persons affected by Hansen's disease, the Federal Public Defender committed his office to supporting this marginalized and vulnerable group in the enforcement of their rights. One of his commitments – to launch an educational campaign on the rights of persons affected by Hansen's disease and their family members – has already been fulfilled. The Special Rapporteur also welcomes the commitment made by the public defenders she met at the state level and hopes that this will help lift the veil of invisibility surrounding Hansen's disease and enable the individual and collective protection of persons affected by Hansen's disease and their family members.²³

44. The core problem of both institutionalized and interpersonal discrimination seems to be that formal equality, mentioned above as *de jure* equality, which is ensured by the Brazilian legal system, is not sufficient to ensure *de facto* equality of a group that has historically been discriminated against in what the Committee on Economic, Social and Cultural Rights referred to as systemic discrimination, given its entrenchment in social behaviour and organization.²⁴

45. Notably, discrimination against persons affected by Hansen's disease in Brazil is a clear example of what the Committee on Economic, Social and Cultural Rights points out about substantive discrimination in its general comment No. 20. Moreover, as detailed by the Special Rapporteur on extreme poverty and human rights (A/72/502), equality of opportunity does not ensure anything like equal outcomes, since available opportunities will often be effectively inaccessible to those living in poverty. Hence, in order to understand discrimination on the grounds of Hansen's disease in Brazil and to tackle it, it is critical to take into consideration the observation of the Committee on the Elimination of Racial Discrimination in its general recommendation No. 32, that to treat in an equal manner persons or groups whose situations are objectively different will constitute discrimination in effect. Discrimination rooted in a history of systemic violations requires application of what the Committee on the Rights of Persons with Disabilities refers to in its general comment No. 6 (2018) on equality and non-discrimination as a substantive model of equality based on a redistributive dimension, aimed at simultaneously addressing socioeconomic disadvantages and fighting stigmatization.

2. Groups in vulnerable situations

Women affected by Hansen's disease

46. The Special Rapporteur acknowledges the fact that in Brazil, from a merely epidemiological perspective, it can take more time for men to be diagnosed than women, and men may even be infected in larger numbers. Many men may experience Hansen's

²³ Committee on the Elimination of Discrimination against Women, general recommendation No. 33 (2015) on women's access to justice, para. 32.

²⁴ See Committee on Economic, Social and Cultural Rights, general comment No. 20.

disease as a stigmatizing condition that affects their physical and social performance with regard to stereotypes of masculinity, causing feelings of social inadequacy and depression.

47. Nonetheless, strictly in accordance with the testimonies shared with the Special Rapporteur during her visit, the intersection²⁵ of gender stereotypes – on the role of women and their social positioning – with harmful stereotypes related to Hansen’s disease increases the burden of Hansen’s disease in women’s lives and makes them more vulnerable to discrimination and violence. This is also corroborated by several independent studies on the matter.²⁶

48. During interviews and group meetings in Rio de Janeiro, on Combu Island (a vulnerable community in the State of Pará), Marituba and in a large meeting in Belém with a group of women from MORHAN, several women shared experiences of the same structural pattern of interpersonal discrimination. The pattern is manifested especially in the household and within the family, in some cases evolving into psychological and physical violence, mainly perpetrated by spouses. It is also manifested in work relations, mainly in the case of unqualified domestic workers,²⁷ with job losses which are exacerbated by the fact that, according to these women, welfare benefits are insufficient and do not guarantee them a minimum standard of living.

49. Such experiences cause severe pain and suffering, which can result in a deterioration of mental health and lead to depression, self-isolation and suicidal thoughts. Moreover, apart from a few cases of discrimination against women at the hands of health service personnel on the grounds of the intersection between gender and Hansen’s disease, the majority of the suffering described to the Special Rapporteur relates to one of two scenarios. Firstly, the Special Rapporteur heard reports of cases of what she has already identified as the perverse consequences of the mercantilization of health (A/HRC/41/47), which are at the root of a substantive number of the difficulties associated with the medical treatment of the disease, such as neuropathic pain, Hansen’s disease reactions and the iatrogenic effects of some of the drugs employed in treating the disease, such as clofazimine, which can produce changes in skin colour, becoming a stigmatizing mark of the disease for these women, and thalidomide, which affects sexual and reproductive health. Second, she heard reports of stereotypes about the appearance of the female body, which relate to a global somatic culture that objectifies women’s bodies.

50. Bodily changes associated with Hansen’s disease cause feelings of shame and loss of self-esteem that can result in self-isolation and reluctance to participate in community life or be in public spaces. Furthermore, as a result of the social roles that continue to be attributed mainly to women, many women described how physical impairments, sometimes invisible ones like neuropathic pain and loss of sensation, made the performance of house work, childcare and care of other family members increasingly painful.

51. None of the women interviewed mentioned access to justice as a means available to them to address domestic violence, abusive work relations or violations of their right to mental and physical health. This reflects the extreme vulnerability of their social position

²⁵ On the concept of intersectionality, see Patricia Hill Collins, *Black feminist thought: knowledge, consciousness, and the politics of empowerment* (Boston, Unwin Hyman, 1990) and Avtar Brah and Ann Phoenix, “Ain’t I a woman? Revisiting intersectionality”, *Journal of International Women’s Studies*, vol. 5, No. 3 (2004). On the use of the term “intersectionality” with regard to discrimination on the grounds of Hansen’s disease, see A/HRC/38/42.

²⁶ C.M. Varkevisser and others, “Gender and leprosy: case studies in Indonesia, Nigeria, Nepal and Brazil”, *Leprosy Review*, vol. 80, No. 1 (2009); Marcela Gonçalves and others, “Trabalho e Hanseníase: as mulheres em suas dores, lutas e labutas”, *Revista brasileira de enfermagem*, vol. 71, No. 1 (2018); Lidiane Mara de Ávila e Silva and Reni Aparecida Barsaglini, “‘A reação é o mais difícil, é pior que Hanseníase’: contradições e ambiguidades na experiência de mulheres com reações Hanseníase”, *Physis*, vol. 28, No. 4 (2019); Maria Helena Pessini de Oliveira and Geraldo Romanelli, “Os efeitos da Hanseníase em homens e mulheres: um estudo de gênero”, *Cadernos de Saúde Pública*, vol. 14, No. 1 (1998); Adriana Kelly Santos, Ana Paula Goulart Ribeiro and Simone Monteiro, “Hanseníase e práticas da comunicação: estudo de recepção de materiais educativos em um serviço de saúde no Rio de Janeiro”, *Interface – Comunicação Saúde Educação*, vol. 16, No. 4 (2012); Leilane Dias Santana and others, “Significado da doença para mulheres com Hanseníase”, *Revista de Enfermagem da UFSM*, vol. 7, No. 1 (2017).

²⁷ Committee on Economic, Social and Cultural Rights, general comment No. 23 (2016) on the right to just and favourable conditions of work, para. 47.

and their low awareness of their rights and how to claim them. There are two key tools to enforce articles 5 and 12 of the Convention on the Elimination of All Forms of Discrimination against Women and prevent gender-based discrimination against women affected by Hansen's disease in Brazil. They are general recommendation No. 25 of the Committee on the Elimination of Discrimination against Women, which highlights the importance of an enabling environment that empowers women, and the Committee's general recommendation No. 19 (1992) on violence against women, which indicates that under general international law and specific human rights covenants, States may be responsible for private acts if they fail to act with due diligence to prevent violations of rights or to investigate and punish acts of violence, and for providing compensation.

Children affected by Hansen's disease

52. As the Special Rapporteur pointed out in a previous report, the outbreak of new cases of Hansen's disease in children and adolescents points to recent transmission and to the failure of the health-care system to control the disease (A/HRC/41/47, paras. 43–46). Transmission in children under 15 years of age occurs mainly among people living in the same household, which points to a failure of health systems to routinely establish contact surveillance as a standard procedure.

53. In 2017, there was a total of 22,940 new cases of Hansen's disease in Brazil, of which 1,718 were in children under 15 years of age. In 2017, 54 children were diagnosed with visible and irreversible physical impairments in Brazil and in the past five years, the percentage of children under 15 years of age diagnosed with irreversible damage ranged from 2.9 per cent in 2013 to 4.1 per cent in 2017.²⁸ Notwithstanding the great concern caused by these figures, the Special Rapporteur welcomes the transparency Brazil has demonstrated in reporting to WHO not only new cases in children, but also new cases in children with irreversible impairments at the time of diagnosis.

54. A child diagnosed with Hansen's disease is always a matter of great concern. Hansen's disease can easily develop into a chronic disease that causes serious sensory loss and severely restricts people's activities and participation in society. During her visit, the Special Rapporteur received reports from civil society organizations and health experts on children affected by Hansen's disease that point to a shared pattern of socioeconomic vulnerability. In fact, a statistically significant link was found between greater coverage of the Bolsa Família cash transfer programme and a reduction in detection rates of Hansen's disease. This reinforces the need for strategies that act on the social determinants of Hansen's disease and protect the families caught up in a cycle of poverty and disease that is difficult to break.²⁹

55. The Special Rapporteur draws attention to the impact of Hansen's disease at an early stage in life, which is even more serious in the case of children belonging to families living in poverty and extreme poverty. Some of these children face difficulties in making progress at school due to the sometimes physically demanding medical treatment, development of impairments and/or experiences of stigmatization that will result in an endless cycle of poverty and discrimination.

56. During her visit to Combu Island, the Special Rapporteur received first-hand reports of how the disease in children places a huge burden on families with financial difficulties and poor access to public services. Care of children affected by Hansen's disease can imply loss of income, since the family member responsible for the child, usually the mother, cannot continue working and yet does not receive any support for her unpaid work as caregiver. Families living in remote areas also reported the difficulties they encounter in accessing health services, including the additional financial burden, since they have to pay the transportation costs to reach the nearest health facility that can ensure proper care for

²⁸ Brazil, Ministry of Health, "Indicadores epidemiológicos e operacionais de hanseníase: Brasil 2000–2017"; Michelle Christini Araújo Vieira and others, "Leprosy in children under 15 years of age in Brazil: a systematic review of the literature", *PLOS Neglected Tropical Diseases*, 2 October 2018.

²⁹ Joilda Silva Nery and others, "Effect of the Brazilian conditional cash transfer and primary health care programs on the new case detection rate of leprosy", *PLOS Neglected Tropical Diseases*, 20 November 2014; Kaio Vinicius Freitas De Andrade and others, "Effect of Brazil's conditional cash transfer programme on the new case detection rate of leprosy in children under 15 years old", *Leprosy Review*, vol. 89, No. 1 (2018).

children affected by Hansen's disease. Indeed, medical care of children affected by Hansen's disease sometimes requires expertise that is not available in primary health-care services. Although health services and medicines are free of cost, poor families endure extra costs related to childcare and disease management that often result in a reduction in household resources.

57. Hansen's disease reactions and the effects of medical treatment can be harsh on children. Aggravated by bodily changes, the experience of Hansen's disease can negatively affect the mental well-being of children and have a negative impact on their school performance and their relationships with their peers. Prolonged exposure to suffering and uncertainty can result in toxic stress, especially in children. The Special Rapporteur heard a few reports of cases in which children affected by Hansen's disease, and also children of persons affected by Hansen's disease, had been forcibly suspended from school at the discretion of teachers who were fearful of the disease, rather than at the instigation of the peers of children affected by Hansen's disease. Such cases constitute a gross violation of articles 28 and 29 of the Convention on the Rights of the Child.

58. According to WHO, the three elements for healthy child development are stable, responsive and nurturing caregiving; safe, supportive environments; and appropriate nutrition.³⁰ As the Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health has explained, children's rights to health and development are intrinsically linked, and early childhood interventions must focus on development as well as survival. This calls for primary health care and paediatric interventions that go beyond the biomedical model and employ psychoeducational and psychosocial methods that promote emotional health and social development from the very start of life (A/70/213). This is made clear in article 6 of the Convention on the Rights of the Child and article 12 of the International Covenant on Economic, Social and Cultural Rights.

59. Schools and health services are privileged entry points for detecting children affected by Hansen's disease and their needs, and for responding swiftly with the necessary measures. These include education about the disease at school, reasonable accommodation at educational facilities and social protection for the children's families, to protect the children's rights.

Persons with disabilities related to Hansen's disease

60. In 2018 alone, a total of 14,322 new cases of Hansen's disease were diagnosed in persons with already severe and irreversible physical impairments. As the Minister of Health said during the meeting with the Special Rapporteur, the high number of persons living with impairments and disabilities related to Hansen's disease calls for an institutional approach that recognizes the burden of the disease in people's lives beyond the cure of infection. Comprehensive care should encompass self-care techniques to prevent impairments, monitoring nerve damage to prevent further impairments, reconstructive surgery and access to assistive devices. Such an approach is in line with the legal framework regulating health-care delivery in Brazil, but requires both expertise and resources to be implemented and is not yet available to all.

61. Effective access to disability rights as provided for in national legislation and policies was a key concern raised by persons affected by Hansen's disease during the visit. The Special Rapporteur heard several testimonies about the difficulties these persons experience in accessing social protection benefits granted to persons with disabilities. Access to such benefits is dependent on medical evaluation of physical impairments and doctors are not always duly equipped to diagnose physical impairments related to Hansen's disease. This can result in people being denied appliances, while their impairments, whether visible or invisible (such as loss of sensation or chronic pain), may severely limit their activities and ability to work. Difficulties with bureaucratic procedures were also reported as barriers to access to disability rights.

62. Moreover, many persons affected by Hansen's disease are not included in the formal labour market.³¹ They often undertake physically demanding work that can aggravate

³⁰ See www.who.int/maternal_child_adolescent/topics/child/development/10facts/en/.

³¹ Committee on Economic, Social and Cultural Rights, general comment No. 23, para. 47.

physical impairments over time. The Special Rapporteur heard many testimonies on the unavailability of assistive devices and support, as provided for in article 4 of Law No. 11520, which is still awaiting regulation. The urgent need for its regulation was widely debated. Many of the rehabilitation needs are fulfilled by NGOs, which also launch most of the initiatives for the labour inclusion of persons affected by impairments related to Hansen's disease.

63. Eligibility conditions in social protection programmes cannot rely on a narrow medical focus, nor be limited to work capacity or medical assessments. They should follow the principles and provisions of the Convention on the Rights of Persons with Disabilities (see A/70/297). With regard to disability rights, a gap between law in theory and law in practice may be pushing part of the population affected by Hansen's disease into social exclusion and poverty.

Persons affected by Hansen's disease in remote areas and in detention centres

64. During the meeting with the Minister of Health and the visit to Combu Island, concerns were raised about the diagnosis of Hansen's disease among persons living in remote areas. On Combu island, the Special Rapporteur learned of cases of persons and almost entire families who had been living with the disease for years without diagnosis. Another cause for concern was the incidence of Hansen's disease among persons deprived of liberty. In a meeting with the Federal Public Defender, the importance of collecting data on the health status of this group was discussed.

V. The trauma of past segregation

A. Current situation of former Hansen's disease colonies

65. In Brazil, prophylactic isolation as a State policy to control Hansen's disease endured in practice until 1986. Since the 1980s, the focus of health policy in Brazil has turned to providing health care in ambulatory treatment centres, alongside the deactivation of isolation settlements known as colonies. The process of deactivation and the social reintegration of the people who had been segregated was not straightforward and there currently remain around 30 colonies with residents from the generation of persons who were segregated as a result of the State policy, as well as second and third generations. Moreover, in some of these places, entire neighbourhoods have informally settled around former colonies.

66. The jurisdiction of former colonies is extremely complex and sometimes hard to identify amidst different levels of federal, state and municipal administration, and amidst distinct sectors, including health and bodies responsible for territorial management, including provision of water, light and other basic resources, often with no clear coordination among them. Another key issue is the ownership of lands and property. This complexity results from the anomalies created by the segregation policy and requires administrative and legal clarification.

67. As the Special Rapporteur has explained in previous reports, past segregation policies continue to have an impact on the lives of persons affected by Hansen's disease and their family members. Stigma was the *dolus* behind this global policy, which was a gross violation of the civil and political rights of persons affected by leprosy (see A/HRC/38/42 and A/HRC/41/47). The violations are of a permanent nature, since they are perpetuated in the lives of these persons and their children who suffer endless trauma and restrictions on their enjoyment of social, economic and cultural rights.

68. The Special Rapporteur had four meetings with representatives of persons who had been subjected to forced segregation and their descendants. One was at the State Institute of Sanitary Dermatology in Rio de Janeiro, known as the former colony of Curupaiti and currently one of the reference centres for Hansen's disease, where multidrug therapy was first tested in Brazil. Another was at the Marcello Candia specialized reference unit, and the other two were at civil society organization meetings, one in Rio de Janeiro and one in Belém. This provided for very different spaces, the differences seeming to relate to the proximity or lack thereof to the administrative centres. Particularly in former Hansen's

disease colonies on the periphery of these centres, an alarming level of institutional neglect was reported, with high levels of poverty, limited or no access to health care, assistive devices or materials, or to basic services and resources, but also cases of relapses and ongoing transmission. The threat of eviction was reported in some regions which, according to the Committee on Economic, Social and Cultural Rights in its general comment No. 4 (1991) on the right to adequate housing, is a prima facie violation of the International Covenant on Economic, Social and Cultural Rights.

69. Nevertheless, good and best practices in the fields of research, care, assistance, land regulation and preservation of history were observed. The Special Rapporteur highlights the quality of international research and rehabilitation provided at the Lauro de Souza Lima Institute in São Paulo; the regulation of land and property, resulting in the transfer of the usufruct and ownership of property to persons affected by Hansen's disease and their family members in the States of Acre, Rio de Janeiro and Minas Gerais; the health-care programme of persons affected by Hansen's disease, but also of their family members, provided at Santa Izabel (Minas Gerais); and interventions on history preservation also at Santa Izabel. Many such practices are the result of participatory administration that included MORHAN as a partner. In some of the former colonies, Brazil is undoubtedly leading the implementation of guideline No. 5.4 of the principles and guidelines for the elimination of discrimination against persons affected by leprosy and their family members. Such efforts should be extended to all former colonies in the country, benefiting from the already good and best practices in place.

B. Separated children of persons affected by Hansen's disease

70. It is reported that approximately 16,000 children were separated from their parents, who were affected by Hansen's disease, as a result of the segregation policy; they were sent to institutions known as preventoriums between the 1920s and the 1980s. There are also reports of illegal adoptions and even executions. Accurate data about those children is not yet available and the whereabouts of many of them remains unknown. In addition, these people do not have access to their medical files and records for the period during which they were at the preventoriums. These children grew up without any contact with their biological parents and many of them experienced imprisonment, inhumane treatment and torture in the preventoriums, such as forced labour, sexual abuse and other forms of physical and psychological violence. As a result of these violations, many of these people do not have access today to an adequate standard of living and economic autonomy, and many suffer from psychosocial disorders and disabilities that impair their rehabilitation and inclusion in society.

71. Public interest litigation cases have been filed in the States of São Paulo, Maranhão and Amazonas demanding reparation measures, but they are still pending. The delay in some cases has been excessive and unjustifiable. They are: collective action filed at the State of São Paulo Federal Court in 2017, *MORHAN vs. Federal Government*,³² collective action filed at the State of Maranhão Federal Court in 2011, *Federal Public Defenders' Office vs. Federal Government*,³³ and collective action filed at the State of Amazonas Federal Court in 2017, *Federal Prosecutor's Office vs. State of Amazonas Government, Institute of Artistic and National Heritage and the Federal Government*.³⁴

72. During her visit, the Special Rapporteur heard testimonies from these separated children, who are now adults deeply marked by a traumatic childhood. One of them told the Special Rapporteur, "I was taken away from my mother as a baby and they put me in the preventorium. There was a shoe store there, for the boys to learn something. When I was 7, the shoemaker said that I was a cute girl, so he would be my father. I was happy because I missed my parents a lot. The shoemaker then made me sit on his lap and started to grope my body. I felt uncomfortable, but he told me to be quiet and he made me smell shoe glue, which made me feel dizzy. He raped me. They toyed with my life." These persons have

³² See www.justificando.com/wp-content/uploads/2017/12/Petic%CC%A7a%CC%83o-Inicial-ACP-MORHAN-1.pdf.

³³ See www.dpu.def.br/images/stories/acao-civil-coletiva/ACP_DPU-MA_filhos_separados_hansenise_politicas_compensatorias.pdf.

³⁴ See www.mpf.mp.br/am/sala-de-imprensa/docs/acp-hansenise.

received no reparation for the damages they suffered owing to the compulsory isolation of their biological parents and the abuse and violence they suffered within State facilities.

73. These separated children suffered abuses and violence from birth, which severely compromised their psychological, physical and social development. The State is thus fully responsible for their current situation as persons living with psychosocial disabilities and without access to a minimum standard of living. The Special Rapporteur calls upon the State to enforce guideline No. 4 of the principles and guidelines for the elimination of discrimination against persons affected by leprosy and their family members, and the Basic Principles and Guidelines on the Right to a Remedy and Reparation for Victims of Gross Violations of International Human Rights Law and Serious Violations of International Humanitarian Law. There is an urgent need for a complex reparation programme (see A/69/518) that encompasses material and symbolic reparations, guarantees of non-recurrence, a memorialization process, and rights of access to information and rehabilitation, given the ageing of this population.

VI. Conclusions and recommendations

A. Conclusions

74. During the last decades of the twentieth century, Brazil led the way in the elimination of discrimination against persons affected by Hansen's disease and their family members. Key for such a pioneering role has been the rights-based Constitution, the high level of expertise about Hansen's disease among health researchers in the country, and a sturdy organization of persons affected by the disease, which attests to their resilience and civic engagement in public affairs. The Brazilian normative and institutional framework is qualified to protect, promote and fulfil the rights of persons affected by Hansen's disease and their family members. Of particular relevance are laws that combat discriminatory language and compensate for past damage with a permanent and special measure based on material reparation.

75. Notwithstanding *de jure* equality, *de facto* discrimination endures in institutionalized practices and interpersonal social relations. Structural barriers act as powerful social determinants of the incidence of Hansen's disease in the country, heightened by the regional and local autonomy in resource administration in this quasi-continental and highly diverse country. Mechanisms that can ensure accountability, accessible channels for addressing complaints to relevant authorities, effective access to justice and strengthening of already existing participatory collegiate bodies are key to ensure equitable access to health, social protection and interrelated rights.

76. Moreover, groups that are already in vulnerable situations are disproportionately affected by stigmatization on the grounds of Hansen's disease. The Special Rapporteur identified gender, age and disability as categories that continue to intersect with discrimination related to Hansen's disease, generating restrictions on the enjoyment of the rights to non-discrimination, equality, health, education, decent work, accessibility, reasonable accommodation and support, full inclusion and independent living in the community, and freedom from want and violence. Such groups are in need of targeted interventions aimed at empowerment, capacity-building and generation of safety nets. Such strategies require improved data collection with disaggregation of socioeconomic and demographic variables. The data cannot be put forward by a single institutional body, such as the Ministry of Health, but demand an intersectoral approach and interministerial coordination.

77. Discrepancies were found with regard to the status of the approximately 30 former Hansen's disease colonies. Some of the former colonies have developed outstanding best practices in the fields of research, care, assistance, land regulation and preservation of history, while others, especially on the peripheries of the administrative centres, suffer from alarming institutional neglect. Pending issues, such as the situation of individuals who were placed in confinement institutions as children on the grounds that their parents were affected by Hansen's disease, demand urgent

action to put in place a complex reparation programme based upon symbolic and material reparation, memorialization and guarantees of non-recurrence.

78. The registration and replication of the good and best practices that are already in place are highly recommended, not only in order to implement at the national level a rights-based policy to address barriers to full inclusion related to Hansen's disease, but also to scale it up to the field of international cooperation.

B. Recommendations

General

79. The Special Rapporteur recommends that the Government:

(a) Make every effort to redress persistent substantive discrimination, both in the social determinants of Hansen's disease and the root causes of systemic discrimination. Efforts should simultaneously target socioeconomic disadvantage through redistributive measures that ensure a minimum standard of living, and stigma reduction strategies, through permanent awareness-raising programmes that should include non-scientific knowledge, involve persons affected by Hansen's disease and be sensitive to local languages, gender, age and disability. Efforts should also include guarantees for the autonomous development and independent living of persons affected by Hansen's disease and their family members, with special measures in the fields of education and vocational training, decent work and social protection. Such efforts require multisectoral governance and interministerial cooperation;

(b) Ensure that the health system is capable of guaranteeing for all persons affected by Hansen's disease and their family members in all regions of the country: availability of good quality health services; accessibility without discrimination; physical and economic accessibility; accessibility of health information; active and informed participation of individuals and groups of persons affected by Hansen's disease in health services as peer health promoters and peer counsellors, and in decision-making about health policies and programmes; monitoring and accountability mechanisms on the performance at all levels of the administration of effective, transparent and accessible health programmes designed to ensure early diagnosis of Hansen's disease, prevention of impairments and sustainable reduction of new cases among children; and education of the health workforce on the rights of persons affected by Hansen's disease and their family members;

(c) Enforce access to justice and human rights literacy for this group, which struggles with financial, physical and knowledge restrictions in this regard, and ensure equitable access to local legal aid, accompanied by training of public defenders and judicial staff on issues related to Hansen's disease. Ensure the safety and accessibility of courts, quasi-judicial bodies and other bodies, providing non-discriminatory and timely responses based on adequate and effective remedies. Provide for systematic recording of discrimination to support research and analysis of risk factors, with easy-to-access mechanisms for making complaints of discrimination. Provide capacity-building on core human rights and rights provided for in the Brazilian legal system to persons affected by Hansen's disease and their families;

(d) Ensure that sufficient public resources are mobilized, allocated and effectively utilized to fully implement approved legislation, policies and programmes at the national and subnational levels of the State. Guarantee sufficient resources to sustain expertise on Hansen's disease in the country and to ensure high quality research and teaching on Hansen's disease at universities. Improve monitoring systems for Hansen's disease, comprising data disaggregated by socioeconomic and demographic situation to support anti-discrimination policies and protection of specific groups that are more vulnerable to discrimination related to Hansen's disease.

Protection of specific groups

80. The Special Rapporteur recommends that the Government:

(a) Actively include, through special measures if necessary, women, children and older persons affected by Hansen's disease, and persons affected by disabilities

related to Hansen's disease in existing policies and programmes aimed at protecting women, children, older persons and persons with disabilities;

(b) Foster empowerment, vocational and human rights training, and ensure freedom from want and violence for women affected by Hansen's disease;

(c) Ensure the rights of children affected by Hansen's disease to survival and development, and ensure social protection for their families, guaranteeing that counselling and psychoeducational methods are available at health services, reasonable accommodation is available at schools, and that both services cooperate to protect children's rights;

(d) Regulate article 4 of Law No. 11520, ensuring effective access to assistive devices, support and reconstructive surgery. Take measures to reduce the burden of disability-related costs on persons affected by Hansen's disease and ensure accessibility, reasonable accommodation, support, disability-inclusive social protection, and functional access to information as key disability rights. Provide community-based support services to older persons affected by disabilities related to Hansen's disease;

(e) Use former Hansen's disease colonies as privileged sites for implementing memorialization processes and historical preservation. Guarantee that residents enjoy property and health rights, and access to basic infrastructure and services;

(f) Provide for urgent symbolic and material reparation at the national level to individuals who as children were separated from their parents affected by Hansen's disease and segregated from society.

International cooperation

81. The Special Rapporteur recommends that the Government provide resources to register good and best practices from both the public and the private sectors in fighting discrimination, ensuring the full and meaningful inclusion of persons affected by Hansen's disease and their family members. The aim is to streamline and implement a rights-based approach in the country, and to promote it at the international level in the spirit of Sustainable Development Goal 17, within South-South relations and the Community of Portuguese-speaking Countries.
