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including the right to development**

Visit to Japan

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

Summary

In the report on her visit to Japan, from 12 to 19 February 2020, the Special Rapporteur on the elimination of discrimination against persons affected by leprosy and their family members, Alice Cruz, looks into the human rights situation of persons affected by Hansen's disease and their family members in the light of the efforts being made to achieve truth and justice and to guarantee the non-recurrence of human rights violations. Special attention is paid to the role that persons affected by Hansen's disease and their family members have played in bringing about both formal and systemic change. The Special Rapporteur identifies progress, good practices and challenges in eliminating discrimination against persons affected by Hansen's disease and their family members in Japan. She also offers constructive recommendations with regard to reparation schemes, the rights of older persons affected by Hansen's disease and guarantees of the right to the highest attainable standard of physical and mental health in the post-elimination context.

* The summary of the report is being circulated in all official languages. The report itself, which is annexed to the summary, is being circulated in the language of submission only.

** The present report was submitted after the deadline so as to include the most recent information.



Annex

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

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 Japan from 12 to 19 February 2020. The purpose of the visit was twofold: to develop an in-depth understanding of the historical process that framed the current legal and institutional responses to leprosy, known as Hansen's disease in Japan, and to examine the current situation of the enjoyment of human rights by persons affected by Hansen's disease and their family members in terms of progress and remaining challenges.

2. During her mission, the Special Rapporteur met with several representatives of the Ministry of Foreign Affairs, the Ministry of Health, Labour and Welfare, the Ministry of Justice and the Ministry of Education, Culture, Sports, Science and Technology. She also met with the Japanese Goodwill Ambassador for the Human Rights of Persons Affected by Leprosy and World Health Organization (WHO) Goodwill Ambassador for Leprosy Elimination, alongside other representatives of the Nippon Foundation and the Sasakawa Health Foundation. She visited the National Hansen's Disease Museum in Tokyo and had several meetings with its director, Nao Hoshino, and the team of curators, and met with curators from different sanatoriums and with the head of the association of the directors of the 13 functioning sanatoriums in the country. She met with the director and staff of the National Institute of Infectious Diseases, and consulted scholars conducting outstanding work on Hansen's disease at the University of Tokyo and experts who have been collaborating with persons affected by the disease. She visited the Centre for Human Rights Education and Training, where she met with the Centre's president, Shigeki Sakamoto, who drafted the principles and guidelines for the elimination of discrimination against persons affected by leprosy and their family members. She talked to plaintiffs of the 2001 and 2019 lawsuits (see sect. IV below), both persons affected by Hansen's disease and their family members, their lawyers, victims of the eugenics protection law, persons affected by Hansen's disease and their family members living in general society and others living in various communities. She visited the National Sanatorium Tama Zenshōen in the Tokyo area and Nagashima-aiseien and Oku-komyoen Sanatoriums in Okayama Prefecture, where she met with staff and representatives of the residents' committees and of the National Hansen's Disease Sanatorium Residents' Association, Zen Ryo Kyo.

3. The Special Rapporteur expresses her appreciation to the Government for the support it provided and thanks the staff of the public and private institutions and the civil society organizations and the individuals who provided substantive inputs and assistance in the coordination of the visit. She also wishes to pay tribute to persons affected by Hansen's disease, their families and the organizations representing them.

II. Hansen's disease in Japan

4. From an epidemiological point of view, Hansen's disease is now a rare and imported disease in Japan. According to the Government, in 2018, there were 2 new foreign-born and no new Japanese cases, and between 2014 and 2018, there were 16 new foreign-born cases. WHO reported 2 new foreign-born cases in 2018.¹ According to private medical practitioners, there were 5 new foreign-born cases in 2019 and around 27 new foreign-born cases between 2012 and 2019. According to the same sources, between 2000 and 2018,

¹ WHO, "Global leprosy update 2018: moving towards a leprosy-free world", *Weekly Epidemiological Record*, vol. 94, Nos. 35/36 (30 August 2019).

there were 98 new foreign-born cases, most of them from Nepal, the Philippines and Brazil, and 34 new Japanese cases, 20 of which were from Okinawa prefecture.

5. The incidence of Hansen's disease started declining after the introduction of the first available medical treatment for the disease in 1946,² then fell drastically in the 1970s. Until as late as the twentieth century, the modern history of Hansen's disease in Japan involved multiple human rights violations. After the Meiji Restoration in 1868, the development of a national identity together with a drive towards modernization led to the institutional exclusion of persons affected by Hansen's disease, which dehumanized them, robbing them of their personal identities and rights.³

6. In 1907, the first leprosy prevention law was enacted to isolate persons affected by Hansen's disease. That policy was subsequently reinforced through laws passed in 1931 and 1953. It is striking that the second of those laws was passed in the same year as the international community, including Japanese scientists and medical doctors, gathered at the sixth International Leprosy Congress, held in Madrid,⁴ and agreed to abandon the policy of segregation, which had emerged as a global policy in the late nineteenth century. Prior to the enactment of the 1953 leprosy prevention law, medical doctors operating in the field, who were aware of the international trend away from that policy, were consulted by the House of Representatives (the National Diet) and recommended continuing with the policy of segregation. Even more striking is the fact that this law remained in force until 1996.

7. The formal discrimination provided for under that law constituted a systemic violation of the human rights of persons affected by Hansen's disease, accompanied by torture, inhumane treatment and abuse of different sorts. These included breaking family ties, forced labour within the confinement settings, often resulting in the worsening of physical impairments, and the most extreme violation of the right to the continuity of life in the form of forced sterilization (eugenic surgery), which was permitted in 1948 under the eugenics protection law.

8. Today, there are still about 1,200 persons affected by Hansen's disease living in sanatoriums in Japan. Their average age is 86 years old. A considerable number of people have left the sanatoriums. They now constitute an ageing population that is living with physical and psychosocial impairments and disabilities related to Hansen's disease, many of which are very serious. They include visible physical impairments, such as irreversible damage to the skin, nerves, hands, feet, limbs and eyes, and disfigurement, blindness, loss of sensation, chronic wounds and neuropathic pain. Many of these impairments and disabilities are aggravated by conditions related to old age, such as orthopaedic diseases, metabolic syndromes, cancer, depression and loss of cognitive functions.

III. Legal and institutional framework

9. The Japanese Constitution is based on the principle of popular sovereignty and on respect for fundamental human rights. In its preamble, the Constitution affirms the preservation of peace and acknowledges the right of everyone to live in peace, free from fear and want. Article 13 of the Constitution provides that all people shall be respected as individuals. Article 11 provides that people shall not be prevented from enjoying any of the fundamental human rights and article 14 provides that all people are equal under the law and that there shall be no discrimination. Pursuant to article 25, the State shall strive to promote and improve social welfare and security, and public health. Article 98 affirms that the Constitution is the supreme law of the nation and that Japan is obliged to implement the international treaties it has ratified. Pursuant to article 98 (2), the provisions of the international treaties ratified by Japan are juridically framed as part of domestic law.

² G.H. Faget and others, "Present status of prominin treatment in leprosy", *International Journal of Leprosy*, vol. 14, No. 1 (1946).

³ Fujio Ohtani, *The Walls Crumble: The Emancipation of Persons Affected by Hansen's Disease in Japan* (Tokyo, Tofu Kyokai Association, 1998).

⁴ *Memoria del VI Congreso Internacional de Leprología: Madrid, octubre de 1953* (Madrid, Gráficas González, 1954).

10. Japan has ratified many of the international human rights treaties relevant to the protection of the rights of persons affected by Hansen's disease and their family members, including the International Covenant on Civil and Political Rights, the International Covenant on Economic, Social and Cultural Rights, the Convention on the Elimination of All Forms of Discrimination against Women, the Convention against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment, the Convention on the Rights of the Child and the Convention on the Rights of Persons with Disabilities.

11. The domestic legal framework for the protection, promotion and fulfilment of the human rights of persons affected by Hansen's disease and their family members in Japan is in line with the international human rights obligations of the country and reflects some of the principles and guidelines for the elimination of discrimination against persons affected by leprosy and their family members. Of particular relevance are the Act on the payment of compensation to inmates of Hansen's disease sanatoriums (2001); the Act on the promotion of a resolution of issues related to Hansen's disease (2008) and the 2014 and 2019 amendments to that Act; and the Act on the payment of compensation to family members of former Hansen's disease patients (2019).

12. The health system in Japan is based on universal health coverage through a public health insurance system. Citizens are enrolled in at least one of following schemes: the employment-based health insurance system, the residence-based national health insurance system, and the medical insurance system for those aged 75 and over. Together, the ageing population and the low birth rate pose a major challenge for the Japanese health-care system. With the entry into force of the 1982 Act on public aid for the elderly, a substantial part of the health-care costs for older persons became free of charge, the Act requiring that they pay small co-payments.

13. With regard to policies related to Hansen's disease, Japan is endeavouring to put in place a multisectoral approach coordinated by the Ministry of Health, Labour and Welfare, the Ministry of Justice and the Ministry of Education, Culture, Sports, Science and Technology. The Ministry of Foreign Affairs provides on its website an English version of the principles and guidelines for the elimination of discrimination against persons affected by leprosy and their family members, and a summary in Japanese. The Ministry of Health, Labour and Welfare is implementing several strategies, such as organizing annual forums of persons affected by Hansen's disease, their family members and Hansen's disease experts, holding annual celebrations of the day to commemorate the victims of the leprosy prevention law and restore their honour, guaranteeing the availability of health care within the sanatoriums, running annual summer courses on Hansen's disease, and taking steps to preserve the history of the disease with the opening of two national Hansen's disease museums. The Ministry of Justice monitors cases of discrimination, distributes brochures to raise awareness of human rights and holds a national human rights essay contest for junior high school students. The Ministry of Education, Culture, Sports, Science and Technology is engaged in awareness-raising among schoolchildren and teachers on human rights issues related to Hansen's disease. Ad hoc councils, usually convened to address matters that require a particular level of expertise or to gather a broad range of opinions, have been established to consult with persons affected by Hansen's disease, their families and experts with regard to anti-discrimination measures, which is in line with guideline 14 of the principles and guidelines for the elimination of discrimination against persons affected by leprosy and their family members. The Special Rapporteur urges the Government to ensure that the consultations have a meaningful impact in terms of decision-making and policymaking and do not result in merely token consultation.

IV. Progress

A. Access to justice and bottom-up legal and policy change: the 2001 lawsuit

14. The Japanese policy on Hansen's disease was first made into law in 1907, when Act No. 11 provided that homeless persons with Hansen's disease were to be isolated in one of

five sanatoriums to be set up throughout the country.⁵ The leprosy prevention law of 1931 extended the State's control over all persons affected by Hansen's disease, not only those who were homeless, providing for active case detection followed by institutionalization. At that time, public campaigns were promoted by local governments with the support of volunteers, aimed at finding and segregating affected individuals, which boosted stigmatization at the community level. The consequences of that policy can still be felt to this day.⁶ 1931 was also the year in which the first national sanatorium was inaugurated and the already existing sanatoriums were nationalized. As a consequence, as of that year, the number of individuals forcibly interned in the sanatoriums grew exponentially.⁷

15. The National Hansen's Disease Sanatorium Residents' Association, Zen Ryo Kyo, was established in 1951 to unite the voices of those who had been institutionalized in the 13 sanatoriums, following several cases of death and arbitrary punishment of some inmates. In 1916, the Government had given sanatorium directors the authority to arrest and punish residents. The directors had decided to build a special facility to that end, and in 1938, Jukambo prison had been installed in Kuryu Rakusen-en sanatorium. Records show that many prisoners died there as a result of the harsh conditions. Inmates of the sanatoriums also decided to organize themselves into an association in order to pursue their struggle to have access to the new sulfone drug to treat the disease. Thereafter, based on evidence of the curability of the disease, the members of Zen Ryo Kyo demanded the abolishment of mandatory confinement, compensation for their work inside the sanatoriums, an increase in the number of health-care staff, improvement of the health conditions, the use of the term "Hansen's disease", provision for the livelihoods of inmates' families, regulation of punishment in accordance with penal law, and an end to the discriminatory practice of holding special trials outside standard courtrooms.⁸

16. Despite their efforts, the leprosy prevention law was renewed in 1953, reinforcing the isolation policy and giving sanatorium directors more powers. Sterilization became part of the package with the adoption of the eugenics protection law in 1948, allowing doctors to sterilize individuals with a broad range of mental or physical impairments, those with hereditary diseases and those with Hansen's disease. A government guideline from 1953 approved the use of anaesthetics and even deceptive strategies to force sterilizations on unwilling recipients. During her visit, the Special Rapporteur heard reports of persons affected by Hansen's disease who, while living outside the sanatoriums in the 1990s, were advised by medical doctors to undergo sterilization and not to have children.

17. The Act to abolish the leprosy prevention law was not approved until 1996. It provided not only for that law to be abolished, but also established the Government's responsibility for guaranteeing medical and social services for residents of sanatoriums, and provided that persons affected by Hansen's disease had the freedom to choose whether to leave, remain in or return to sanatoriums. Also in 1996, the eugenics protection law was revised, becoming the maternal protection law, eliminating the discriminatory clauses, including the provision for forced sterilization. The preamble of the Infectious Diseases Prevention Act of 1998 establishes the importance of acknowledging the fact that discrimination and prejudice against persons affected by Hansen's disease had been widespread and society should learn from those past experiences.

18. After 1996, persons affected by Hansen's disease came to the view that putting an end to segregation was not sufficient to remedy the harm they had suffered and they started organizing and working with legal experts to access justice. In 1998, a group of persons affected by Hansen's disease went to court demanding an apology and reparation from the State for the discrimination and violations they had suffered as a result of the implementation of the excessively protracted official policy of compulsory segregation. The

⁵ Shuichi Mori and Norihisa Ishii, "A study on the entering and out-going trends at Japan's national Hansen's disease sanatoriums", *Japanese Journal of Leprosy*, vol. 86, No. 1 (2017).

⁶ Makiko Kondo and others, "Bioethics and the experiences of Hansen's disease survivors", in *Bioethics: medical, ethical and legal perspectives*, Peter A. Clark, ed. (InTech, Rijeka, Croatia, 2017).

⁷ Hajime Sato and Janet E. Frantz, "Termination of the leprosy isolation policy in the US and Japan: science, policy changes, and the garbage can model", *BMC International Health and Human Rights*, vol. 5, art. No. 3 (2005); and Mori and Ishii, "A study on the entering and out-going trends at Japan's national Hansen's disease sanatoriums".

⁸ In February 2019, Kumamoto District Court declared such trials unconstitutional.

activism of the 1950s and 1970s was strengthened in the 1990s with strategic litigation.⁹ This legal mobilization benefited from partnerships that developed after 1996 between persons affected by Hansen's disease and experts. The previous experience of non-partisan lawyers with collective litigation, the strategic use of the media and volunteer-based activism contributed to the success of the legal mobilization.¹⁰ Also noteworthy is the personal sacrifice and dedication to this process of persons affected by Hansen's disease themselves, who had to face individual trauma to reach a common agreement on the composition of the collective demand. In 2001, Kumamoto District Court ruled that the State's segregation policy was unconstitutional and ordered the State to provide material reparation to persons who had suffered from it.

19. According to the 2001 Kumamoto District Court ruling, there was a lack of grounds to support the reasoning for the isolation provisions of the leprosy prevention law of 1953. This was especially so considering: (a) the evidence of the efficacy of sulfones in Japan and overseas for curing Hansen's disease in the late 1950s; (b) the fact that the number of persons who remained severely ill had dropped sharply in Japan since the introduction of sulfones; (c) the fact that the number of new cases fell remarkably between 1955 and 1960; and (d) the widespread trend noted at international conferences on Hansen's disease, such as the International Leprosy Conference held in Tokyo in 1958, in favour of outpatient care. The court concluded that the unconstitutionality of the leprosy prevention law dated back to at least 1960. It also recognized that the legal and policy framework that had been in place had played a major role in the production and reproduction of stigmatization on the grounds of Hansen's disease.

20. According to the ruling, the Ministry of Health, Labour and Welfare was responsible for not having revised and abolished the isolation policy. Furthermore, the court specified that the Ministry should have taken steps to: (a) ensure that all residents were free to leave sanatoriums; (b) eliminate institutional gaps that hindered outpatient care; and (c) eliminate discrimination and prejudice against persons affected by Hansen's disease in society at large. Likewise, the court pointed out the omission of some members of the National Diet for not having amended or abolished the isolation provisions before or after 1965.

21. If this landmark ruling was achieved thanks to the capacity of persons affected by Hansen's disease for self-organization and strategic litigation, the positive action taken by the State on this matter was to decide not to appeal against the court's decision, to offer public apologies to the survivors and to put in place a large-scale administrative programme for material compensation. In 2001, the State endorsed the Act on the payment of compensation to inmates of Hansen's disease sanatoriums, and in 2008, it adopted the Act on the promotion of a resolution of issues related to Hansen's disease. The struggle of persons affected by Hansen's disease in Japan is testimony to how, in the face of an abusive State that acts as the main perpetrator of human rights violations, human rights defenders played a key role in building a free and just society. As one woman affected by Hansen's disease told the Special Rapporteur, the main lesson for history should be that Governments can be wrong and citizens must always stand up, fight and not be silenced. In the end, their story is one of what democracy should be about and the fact there can be no enjoyment of human rights without the full right to participate in public affairs.

B. Access to justice and bottom-up legal and policy change: the 2019 lawsuit

22. In 2016, family members of persons who had been segregated in Hansen's disease sanatoriums filed lawsuits against the Government, seeking compensation and an apology for their own suffering, claiming that they too had suffered discrimination and prejudice under the isolation policy. As a result of the forced segregation policy, family members, many of them at a very young age, suffered deprivation of family relations, loss of family protection, insufficient means of subsistence (despite the 1953 law providing for welfare of

⁹ Celeste L. Arrington, *Accidental Activists: Victim Movements and Government Accountability in Japan and South Korea* (Ithaca, New York, Cornell University Press, 2016).

¹⁰ Celeste L. Arrington, "Leprosy, legal mobilization, and the public sphere in Japan and South Korea", *Law & Society Review*, vol. 48, No. 3 (September 2014).

families, which was seldom implemented in practice), gaps in childhood development, social aversion, bullying and rejection from peers, social pressure for not having children, and extreme difficulty dealing with childhood traumas in adult life.¹¹ During the 2001 lawsuit, several organizations had been set up, including the Association of families and bereaved relatives of Hansen's disease patients. In June 2019, Kumamoto District Court ruled that the Government had the obligation to compensate the family members of persons who had been forcibly segregated in the sanatoriums.

23. In its ruling, the court acknowledged that the harm resulting from discrimination on the grounds of Hansen's disease suffered by those family members took several forms. They included: the loss of the minimum socialization necessary for personal development as a result of rejection at school and social ostracism; the loss of learning and character-building opportunities owing to rejection at school; the loss of marriage opportunities; the loss of opportunities for self-fulfilment and financial loss caused by limited employment opportunities; the loss of opportunities for personal development and self-fulfilment owing to restrictions in a broad range of life choices regarding careers and friendships, or as a result of keeping secret the fact that a family member was affected by Hansen's disease; and having a family relationship damaged as a result of being unable to live with a family member affected by Hansen's disease in order to avoid discrimination. The court also pointed out that the State's isolation policy was the cause of discrimination against the family members of persons affected by Hansen's disease.

24. In its ruling, the court observed that the Ministry of Health, Labour and Welfare had, since 1960, had the obligation to ensure the normalization of the way society perceived Hansen's disease and to fight prejudice and discrimination. The Ministry also had the obligation to guarantee outpatient care and to duly make that known to the general public. Therefore, the court also found that the Government should make an official apology and take all necessary measures to raise awareness about Hansen's disease. Since the promotion of human rights falls under the responsibility of the Ministry of Justice, the court considered the Ministry of Justice to have had the obligation, from 1996 to 2001, to carry out activities aimed at promoting the human rights of persons affected by Hansen's disease and their family members and eliminating discrimination against them. Through a careful analysis of the Ministry of Justice's endeavour, the court concluded that it had failed to fulfil that obligation.

25. Although the Government did not agree with some parts of the reasoning of the court's ruling, it again decided not to appeal and set up a large-scale administrative programme for providing material compensation. In 2019, it adopted the Act on the payment of compensation to family members of former Hansen's disease patients. The Act acknowledges that the former government policy of forced isolation created an inaccurate understanding of the disease among the public, enhanced discrimination, and resulted in severe hardship for not only persons affected by Hansen's disease, but also their family members. The Act covers spouses, parents, children and siblings of persons affected by Hansen's disease, as well as other close family members and in-laws who lived with individuals who developed the disease by 31 March 1996. Not only plaintiffs but also non-plaintiff family members can receive compensation. Nevertheless, the Act restricts beneficiaries to persons who lived in the past with relatives affected by Hansen's disease.

26. The 2001 and 2019 court decisions were key to triggering the Government's recognition of its responsibility for the gross human rights violations of persons affected by Hansen's disease and their family members and in establishing large-scale reparation programmes. As clearly explained by the Special Rapporteur on the promotion of truth, justice, reparation and guarantees of non-recurrence in his report on reparation (A/69/518), reparation programmes, besides turning victims into beneficiaries, have the positive effects of promoting trust in institutions, strengthening the rule of law and encouraging social integration or reconciliation. To the extent that reparations are a justice measure, they rest on general norms and their benefits have important positive spillover effects, one of which is to exemplify the fulfilment of the legal obligation to take the violation of rights seriously. Such historical processes in Japan allowed persons affected by Hansen's disease and their

¹¹ Ai Kurosaka, *Fighting Prejudice in Japan: The Families of Hansen's Diseases Patients Speak Out* (Melbourne: Trans Pacific Press, 2019).

family members not only to receive justice, but also to heal psychologically at the personal level. Afterwards, many felt encouraged to speak openly about their history. The ruling of the courts in their favour meant for all of them that society was able to treat them as equals. This was a considerable step forward in the enforcement of their rights to dignity, equality and non-discrimination.

C. International cooperation and transnational activism

27. The struggle for dignity of the persons affected by Hansen's disease in Japan and the positive responses from both the judicial system and the Government in 2001 triggered the scaling up of a human rights-based approach in the international field. Since 2007, Japan has been the lead sponsor of a series of resolutions on the elimination of discrimination against persons affected by Hansen's disease and their family members that were adopted by the General Assembly and the Human Rights Council. This has been the result of a concerted effort on the part of the Government and Japanese civil society groups, namely the Nippon Foundation and the Sasakawa Health Foundation. Ultimately, however, the wake-up call to recognize persons affected by Hansen's disease as rights bearers came from the grass roots.

28. The Japanese endeavour at the international level concerning Hansen's disease has been led by the Government's Goodwill Ambassador for the Human Rights of Persons Affected by Leprosy and WHO Goodwill Ambassador for Leprosy Elimination, Yohei Sasakawa.¹² Under his leadership, the Nippon Foundation has long been supporting WHO; it provided funding for WHO to distribute multidrug therapy free of charge between 1995 and 1999. That aid was key to achieving the global elimination of Hansen's disease as a public health problem (defined as a registered prevalence of less than 1 case for every 10,000 persons) in 2000. At the beginning of the twenty-first century, Yohei Sasakawa started to draw attention to stigmatization as a social determinant of Hansen's disease. The Nippon Foundation joined forces with the Government of Japan in raising the issue at the United Nations and has been promoting annual global appeals to end stigma and discrimination since 2006. One important strategy pursued by the Sasakawa Health Foundation is the empowerment of grass-roots organizations of persons affected by Hansen's disease worldwide with the provision of funding and capacity-building. In 2019, the Foundation sponsored the first Global Forum of People's Organizations on Hansen's Disease.¹³

29. The struggle of persons affected by Hansen's disease in Japan has reached others overseas. The 2001 lawsuit, together with Japanese lawyers' transnational activism, prompted individuals affected by Hansen's disease in the Republic of Korea and in Taiwan Province of China to demand compensation for their own suffering while under Japanese colonial rule. The ensuing transnational legal battle led Japan to revise the 2001 law and provide, in 2006, for compensation to Korean and Taiwanese persons affected by Hansen's disease. The National Assembly of the Republic of Korea subsequently passed legislation in 2007 to provide for support to the post-war victims of violations related to Hansen's disease. Taiwan Province of China followed suit in 2008.¹⁴

D. Good practices

30. Following the court decisions and laws enacted in response to them, the Government has been pursuing a multisectoral approach to redress stigmatization and the impact of past violations. One important aspect of this policy is the delivery of health care, free of charge, at the sanatoriums. An average of two health workers for each resident is ensured in each sanatorium, alongside the provision of basic needs and housing, all of which are guaranteed for life. Another important dimension is awareness-raising on Hansen's disease in schools, encompassing accurate medical knowledge, the history of human rights violations, and

¹² Yohei Sasakawa, *No Matter Where the Journey Takes Me: One Man's Quest for a Leprosy-Free World* (London, C. Hurst & Co., 2019).

¹³ See www.shf.or.jp/information/6813?lang=en.

¹⁴ Celeste L. Arrington, "Leprosy, legal mobilization, and the public sphere in Japan and South Korea".

human rights capacity-building among schoolchildren. Importantly, the materials produced by the Government make use of the testimonies of persons affected by Hansen's disease, not only giving voice to those who endured such gross violations, but also acknowledging that personal testimonies of the obstacles to a full and dignified life, as well as of how people survive discrimination, are the most effective instruments to systemically change mindsets. Furthermore, Hansen's disease museums have become important sites not only for the preservation of history, but also for the elimination of harmful stereotypes and stigma reduction strategies.

31. The National Hansen's Disease Museum in Tokyo¹⁵ is a landmark example of participatory museography and of the right to truth and memory being implemented from the bottom up. Created in 1993 by persons affected by Hansen's disease themselves, the museum (which became the National Hansen's Disease Museum in 2007) initially consisted of a collection of items from all the sanatoriums in Japan, with the goal of raising awareness about the personal histories of persons who were forcibly segregated. From the outset, the museum was intended to tell the non-official history of these people who were denied their civil and political rights, rendered invisible, silenced and robbed of the right to continuity of life on the grounds of Hansen's disease. Official history usually assumes the viewpoint of elites, while rendering invisible the agency of people with less epistemic and political capital. Official history is always backed up by concomitant processes of public forgetting.¹⁶ Testimonies and oral history are an effective way to counter public forgetting and the partial writing of history, by rescuing the stories of the victims from the private experience of memory.¹⁷ By creating the museum, persons affected by Hansen's disease ensured that their voices were the ones defining the production of the modern history of Hansen's disease in Japan, which has a powerful effect on human rights education and enforcement.

32. Currently, the National Hansen's Disease Museum in Tokyo is run by a professional team that focuses on three areas: curation, awareness-raising and conservation. Significantly, the participatory matrix of the museum is maintained by a steering committee that comprises persons affected by Hansen's disease, members of the community and experts. The restoration of dignity continues to be the core mission of the museum and to that end, visitors are provided with first-hand testimonies, whether through video archives or lectures and talks given by persons affected by Hansen's disease to visitors and groups. The museum staff also perform important work by preserving, studying and displaying the artistic and creative output of persons affected by Hansen's disease, including literature, poetry and painting. A small part of the 13 sanatoriums in the country, including the National Hansen's Disease Museum in Tokyo, is dedicated to raising awareness among schoolchildren, through visits to the museums and lectures at schools. Such good practices should be replicated in the 13 sanatoriums.

33. Memorialization processes are important for guaranteeing non-repetition of gross violations of human rights, as acknowledged in the Durban Declaration of the World Conference against Racism, Racial Discrimination, Xenophobia and Related Intolerance. As pointed out by the Special Rapporteur in the field of cultural rights, memorialization for educative purposes meets at least three goals: recognizing victims, personal and collective healing, and prevention (A/HRC/25/49, para. 13). Memorialization also helps to promote democracy and respect for human rights and is closely connected to freedom of expression and the right to participation, reflecting key provisions of the International Covenant on Civil and Political Rights. Furthermore, as acknowledged by the Committee on Economic, Social and Cultural Rights in its general comment No. 21 (2009) on the right of everyone to take part in cultural life, culture not only mirrors, but also shapes the core guiding values of social life. That is why the right to participate in cultural life closely relates to economic, social and political rights and should duly respect three main components: participation,

¹⁵ There is also the Jukambo National Museum, in Kuryu Rakusen-en, which preserves punishment cells.

¹⁶ Mahamadou Diallo, "People from different backgrounds write different histories: an essay on historiography (Britain and India)", *African and Asian Studies*, vol. 6, Nos. 1–2 (2007); and Georg Gugelberger and Michael Kearney, "Voices for the voiceless: testimonial literature in Latin America", *Latin American Perspectives*, No. 18, vol. 3 (1991).

¹⁷ Margarida Calafate Ribeiro, *África no Feminino: As Mulheres Portuguesas e a Guerra Colonial* (Porto, Edições Afrontamento, 2007).

access to, and contribution to cultural life. The struggle of persons affected by Hansen's disease in Japan to preserve their history and make it available to society at large has therefore greatly influenced the backdrop against which policymaking takes place. Their struggle to preserve their own history and to tell it from their lived experience has been a key component for systemic change in the country. The Special Rapporteur urges the Government to ensure continuity to their pioneering efforts and promote them as good practices at the international level by supporting the efforts to include the Nagashima-aiseien sanatorium on the United Nations Educational, Scientific and Cultural Organization (UNESCO) World Heritage List.

V. Challenges

A. Gaps in the reparation scheme

34. Article 8 of the Universal Declaration of Human Rights affirms that everyone has the right to an effective remedy for the violations of his or her fundamental rights. That right is expanded upon in several international human rights instruments, including article 2 of the International Covenant on Civil and Political Rights and article 14 of the Convention against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment. Additionally, jurisprudence has confirmed that reparation transcends monetary compensation, which should be accompanied by additional measures with regard to: investigation and prosecution; restitution of rights and freedoms, as well as employment or property; legal reform; rehabilitation measures; medical care; symbolic reparation and memorialization; public apologies and official recognition of the State's responsibility for violations.¹⁸

35. Redress should fit the needs of the victims and be proportional to the gravity of the violations. It should also duly compensate for any economically assessable damage that resulted from the violations.¹⁹ 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 include five forms of reparation: restitution, compensation, rehabilitation, satisfaction measures and guarantees of non-repetition. As explained by the Special Rapporteur on the promotion of truth, justice, reparation and guarantees of non-recurrence, reparation programmes are more complex if they distribute benefits of more distinct types and in more distinct ways than their alternatives (A/69/518, para. 30). In order for something to count as reparation, it has to be accompanied by an acknowledgment of responsibility and it has to be linked, precisely, to truth, justice and guarantees of non-recurrence (*ibid.*, para. 11).

36. While the Special Rapporteur considers the measures that followed the 2001 and 2019 court decisions in favour of persons affected by Hansen's disease and their family members to be positive and highly comprehensive, she has identified some gaps in the reparation programmes developed by the Government which she brings to its attention. Aside from the provision of compensation, public apologies and memorialization processes that have already been put into place, additional measures might strengthen the spillover effects of the remedies that have already been provided.

37. First, the aforementioned measures fail to acknowledge the responsibility of particular professional communities, such as the medical, law, welfare and media communities, as was indicated in 2005 by the Verification Committee in its report.²⁰ After hearing several testimonies and examining relevant documentation, the Special Rapporteur believes that the medical community in particular should be held accountable for the implementation of the segregation policies and its anomalous extension over time. She nonetheless recognizes that the medical community is not a homogenous group in any State,

¹⁸ Diana Contreras-Garduño and Sebastiaan Rombouts, "Collective reparations for indigenous communities before the Inter-American Court of Human Rights", *Merkourios*, vol. 27, No. 72 (2010).

¹⁹ Committee against Torture, general comment No. 3 (2012) on the implementation of article 14, para. 10.

²⁰ See www.mhlw.go.jp/english/policy/health/01/pdf/01.pdf.

and that in Japan, a number of medical doctors did oppose the State's policy of segregation, but their freedom of expression was curtailed.

38. In order to ensure guarantees of non-recurrence of such gross violations of human rights, including segregation and change of name and loss of identity, as well as of all civil and political rights, sexual and reproductive rights, and the right to the continuity of life itself in the form of forced sterilization and abortion, it is crucial to ensure that the role played by the medical community is visible, given that it was decisive in establishing the discriminatory legal framework and practices. In its general comment No. 20 (2009) on non-discrimination in economic, social and cultural rights, the Committee on Economic, Social and Cultural Rights established that the protection of public health as a basis for restricting human rights in the context of a person's health status was often a clear violation of the International Covenant on Economic, Social and Cultural Rights. However, public health has long been used as a powerful argumentation to restrict civil and political rights, and the history of modern medicine is indicative of too many human rights violations under the auspices of the State and based upon medical reasoning.²¹

39. In order to ensure non-repetition of gross human rights violations in the name of public health, the Special Rapporteur considers it vital that the Government include reference to the ethical boundaries of medical practice and health policies in medical curricula with direct reference to the history of Hansen's disease in the country. Furthermore, the modern history of Hansen's disease in the country clearly demonstrates the importance of human rights capacity-building among the health-care workforce (A/74/174). The same applies to other professions that have great capacity to influence public opinion, such as the media and legal professionals.

40. Secondly, rehabilitation is largely missing from the reparation programmes put in place by the Government. Rehabilitation is mainly interpreted by international law experts as medical and psychological services, to which the Special Rapporteur adds, for this specific case, psychosocial support. The plaintiffs in the 2001 lawsuit each adopted a new name on entering the sanatoriums, abandoning their own names to stigmatization on the grounds of Hansen's disease. Restoration of their good name and reputation through memorialization processes developed outside the sanatoriums should be included in the reparation package in order to acknowledge the victims of segregation as survivors entitled to the same rights as everyone else. Counselling, rehabilitation and restoration of the dignity and the good names of the persons who were forcibly segregated might also support family members who endured discrimination and assist family reconciliation. Secrecy still shrouds the true identity of many persons affected by Hansen's disease and their family members in Japan, hindering real psychological and social healing, as well as effective systemic change to the way Hansen's disease is perceived by society at large.

41. Thirdly, a vision for the future of the sanatoriums should also be part of the reparation schemes and should focus on reconnecting sanatoriums with the surrounding communities during the lifetime of their residents. It should also duly implement the recommendations from the principles and guidelines for the elimination of discrimination against persons affected by leprosy and their family members with regard to full participation of the sanatorium residents in any decision-making processes that concern the future of those institutions. Good practices already implemented by some sanatoriums in the country aimed at ending the isolation of these facilities, such as providing nurseries and outpatient care to the surrounding community, should be studied for swift replication. The Special Rapporteur agrees with the view of some experts²² who have contended that priority should be given to creating the conditions for the residents to live in peace until their last days, but also to reconnect them with the outside world, instead of making plans for the sanatoriums after they are gone. By the same token, ending the isolation of the sanatoriums should involve not only residents, but also former residents and their families. Such additional measures should also be considered as fulfilling satisfaction measures.

42. Fourthly, the importance of prevention as part of reparation is highlighted in the Basic Principles and Guidelines on the Right to a Remedy and Reparation for Victims of

²¹ Dipesh Chakrabarty, "Postcoloniality and the artifice of history", *The Post-colonial SReader*, Bill Ashcroft, Gareth Griffiths and Helen Tiffin, eds. (London and New York, Routledge, 1995).

²² Kurosaka, *Fighting prejudice in Japan*.

Gross Violations of International Human Rights Law and Serious Violations of International Humanitarian Law. They indicate the need to take appropriate legislative and administrative and other appropriate measures to prevent violations (para. 3 (a)). The Special Rapporteur considers the Government's endeavour to raise awareness about Hansen's disease among schoolchildren to be a good practice in the field of prevention. However, during the visit, she realized that the ways in which the awareness-raising guidelines provided by the Government were being implemented differed at the local level, depending on the interests of both private companies that produce school materials and local government administration.

43. The Special Rapporteur therefore recommends that both the private sector and local governments give priority to Hansen's disease in their human rights programmes and that the central Government place additional emphasis on this important strategy. Furthermore, the Special Rapporteur considers that the Government is not making sufficient use of the impressive fountainhead of artistic production by the individuals isolated in the sanatoriums as a way of guaranteeing their continuity of life (curtailed by the sterilization policy) and of providing the public with a positive image of their capabilities, work and humanity. Further research, accompanied by wide dissemination of the artistic production of persons affected by Hansen's disease, should also be part of the reparation schemes as an effective means to bring about systemic change in the way society regards Hansen's disease and to eliminate harmful stereotypes.

44. Fifthly, the ideal behind a reparation programme is to distribute a set of benefits in such a way as to turn every victim into a beneficiary (A/69/518, para. 23). While compensation should be provided to all victims under the same category of violations rather than through individual calculations of the harm each person suffered, the categorization of violations should be as broad as possible in order to include everyone who suffered a gross violation and the different effects it had. Reparation should also be proportional to the harm suffered. During her visit, the Special Rapporteur heard reports of family members who, while not having lived with the relative affected by Hansen's disease, had suffered from the same pattern of discrimination as those who did, and yet were excluded from the reparation scheme. She also heard testimonies from family members of persons affected by Hansen's disease whose childhood development and opportunities for education and work had been devastated, and who did not consider the amount of the compensation received to be sufficient to remedy the economic damage they had endured. Furthermore, the Special Rapporteur heard from persons who had undergone forced sterilization, who indicated that there had not been sufficient acknowledgement from the State with regard to what was a permanent violation owing to its enduring effects. Some of them therefore continue to demand more substantive compensation, even though their pleas have been denied in the courts on the grounds of the statute of limitation in Japan.²³ The Special Rapporteur also observed with concern the complete absence of any reference to gender both in grass-roots organizations and in the Government reparation programmes and related policies.

45. The first gap, which relates to not ensuring due recognition of all the victims, and the second and third gaps, which relate to a probable lack of proportionality of the compensation provided to the harm suffered, all have significant effects on individuals' lives at the micro level. By contrast, the fourth gap reflects deep-rooted norms and values that undermine the participation of women in public affairs, and thus has far-reaching consequences on the macro objectives of any reparation programme, which, as indicated above, aims at building a just and egalitarian society. Gender-neutral reparation programmes that fail to acknowledge the distinctive impact of harm on women and to provide adequate remedies for women jeopardize the linkage between reparation and the building of more inclusive and equitable societies.²⁴ The extremely limited representation of women in the organizations of persons affected by Hansen's disease cannot be explained by epidemiology. Rather, it reflects the inexistence of an empowering environment that favours the full involvement of women in decision-making processes. The absence of a

²³ Committee against Torture, general comment No. 3; and WHO, *Eliminating forced, coercive and otherwise involuntary sterilization: an interagency statement*, OHCHR, UN-Women, UNAIDS, UNDP, UNFPA, UNICEF, WHO (2014.)

²⁴ Ruth Rubio-Marín, ed., *The Gender of Reparations: Unsettling Sexual Hierarchies while Redressing Human Rights Violations* (Cambridge: Cambridge University Press, 2009).

gender dimension in the Government's reparation programme reinforces this disempowering environment and, by embarking on a gender-neutral programme, the Government misses out on the opportunity to promote gender equality and eliminate gender-based harmful stereotypes. As acknowledged by the Security Council in its resolution 1325 (2000) on women and peace and security, reparation should always recognize the impact of violations on women and girls, but also the role of women in fighting them. In fact, the Special Rapporteur found direct consequences of the lack of a gender dimension in the reparation schemes on the current situation of persons affected by Hansen's disease, as explained below.

46. Sixthly, family reunification was identified by many persons affected by Hansen's disease and their family members as the most pressing and urgent matter. The Special Rapporteur considers family reunification to be a core constituent of restitution. Segregation resulted in the complete disruption and breaking up of family ties and relationships. When entering the sanatoriums, people changed their names in order to protect their families and the rupture was therefore total and definitive. Persons affected by Hansen's disease, but also their family members, submitted themselves to a life of secrecy. The Special Rapporteur witnessed the pain that this still inflicts upon them and the variety of psychosocial disabilities that result from it. She urges the Government to move forward with the urgency required to guarantee the rights of an ageing population, to put in place a comprehensive strategy for the reunification of the families separated by the segregation policy and structural discrimination. True psychosocial healing can only be achieved by filling this gap.

47. While there have been some spontaneous reencounters between persons affected by Hansen's disease and their family members, none resulted from a systematic policy, which is still fairly inexistent. Nevertheless, such incidental reunification cases could aptly be used as positive examples for the implementation of systematic reunification. The principles and guidelines for the elimination of discrimination against persons affected by leprosy and their family members call for the reunification of families separated in the past as a result of policies and practices relating to persons affected by Hansen's disease. The principles and guidelines reflect legally binding provisions concerning the protection of the family in the Universal Declaration of Human Rights, the International Covenant on Civil and Political Rights, the Convention on the Rights of the Child, the Convention on the Elimination of All Forms of Discrimination against Women and, more specifically, articles 9 and 23 of the Convention on the Rights of Persons with Disabilities. Under international human rights instruments, the State is obliged to protect the family, including from any illegal or illegitimate arbitrary interference. The Convention on the Rights of Persons with Disabilities explicitly prohibits the separation of children from their parents on the grounds of disability. Guideline No. 4 of the principles and guidelines affirms that States should, where possible, support the reunification of families separated in the past as a result of policies and practices relating to persons affected by Hansen's disease.

48. The Special Rapporteur urges the Government to fulfil its obligation to reunite separated families and to implement a strategy based on the full participation of the individuals concerned, alongside key mechanisms that are able to ensure: participatory design of an action plan; data collection with guarantees of the right to privacy; monitoring and accountability devices with transparent information-sharing; proper budget allocation with targets, indicators and benchmarks; and community-based strategies. In order to provide preliminary guidance, the Special Rapporteur advises the Government to examine and properly discuss with individuals affected by Hansen's disease and relevant experts, positive examples that already exist in the country, as well as good practices developed in other fields.²⁵ As an example, the Special Rapporteur recalls strategies undertaken with regard to indigenous peoples that have been developed under the principles of: providing access to all government archival records pertaining to the individuals concerned; family history research; guarantees that in the longer term, individuals concerned have an opportunity to manage their own historical documentation; community-based family tracing and reunification services; support and counselling for the individuals concerned, family

²⁵ Human Rights and Equal Opportunity Commission of Australia, *Bringing them home: National Inquiry into the Separation of Aboriginal and Torres Strait Islander Children from Their Families* (1997).

members and community members in the reunion process; and the establishment and management of a referral network of relevant professionals as required by concerned individuals. The Special Rapporteur adds peer counselling to this package.

B. Intersection of Hansen's disease with ageing

49. The persons affected by Hansen's disease in Japan are an ageing population. Moreover, many of their family members are also ageing. This calls for an approach that simultaneously addresses the psychosocial effects of multiple discrimination and violations throughout life (particularly the current absence of family ties and the internalization of stigmatization), physical impairments and disabilities related both to Hansen's disease and to ageing. It also calls for acknowledgment that the ageing process can be different for women and men and that, therefore, gender-based approaches that can give visibility to women's stories, experiences and needs are a fundamental part of any rights-based policy on ageing. Including a gender dimension in policies for guaranteeing the rights of older persons means, among other things, taking the following measures, which also fit the reality of women affected by Hansen's disease: building friendly environments for older women, especially those related to health care; recognizing the role of ageing women as caregivers and providing support for caregivers as part of community-based primary health-care services; training relevant groups of health-care workers to enable them to respond to the health-care needs of ageing women, and training older women themselves to promote self-care; promoting the involvement of older women in research that addresses their concerns; developing appropriate and relevant indicators of older women's health; educating health-care providers to recognize and address the specific needs of older women; and supporting the participation of older women in educational opportunities for sharing personal experiences, histories and accumulated observations.²⁶

50. Targeted strategies for each of the aforementioned dimensions (ageing, gender, psychosocial and physical disabilities) should be developed in closed consultation with the target group and put in place using a holistic approach. Such measures should be accessible to all, including those living in and outside the sanatoriums, and should be solidly grounded on the rights to living, and not just surviving, to autonomy and independent living, to long-term care and palliative care, as well as to freedom of expression on health matters.

51. The Special Rapporteur heard many testimonies that indicate that a better quality of health care is being provided in the sanatoriums than outside, and that some persons affected by Hansen's disease have chosen to go back to those facilities in the face of more limited attention to their needs at the community level. The Special Rapporteur also heard testimonies that affirm that, aside from the different levels of quality of care in and outside the sanatoriums, the main reason why some people go back is their fear of having their medical history on Hansen's disease disclosed at the community and the family levels. Moreover, many of the testimonies that were shared with the Special Rapporteur point to the fact that, in order not to reveal their medical records, many of these individuals voluntarily leave everything behind when returning to the sanatoriums, including family relationships and property.

52. The Special Rapporteur also heard concerns from health professionals about what they regarded as the low quality of some of the health-care workforce at the sanatoriums. Although residents are guaranteed medical services free of charge for life, the monetary and professional incentives for working at the sanatoriums might not be enough to ensure a high-quality health-care workforce. Moreover, some health professionals shared great concerns about what they referred to as subtle forms of physical and mental abuse perpetrated by health-care workers against the elderly residents. As it remains undetected and therefore unpunished, it can escalate into more serious forms of abuse. The Special Rapporteur recalls that abuse of older persons includes both harmful actions and lack of action,²⁷ and that older persons affected by Hansen's disease are a vulnerable group that is entitled to special measures, if needed, to guarantee their human rights.²⁸

²⁶ See www.un.org/womenwatch/daw/csw/aging.htm.

²⁷ Ibid.

²⁸ Committee on the Elimination of Discrimination against Women, general recommendation No. 25

53. Older persons affected by Hansen's disease and related disabilities should never be denied the right to legal capacity on the grounds of their age or mental health. Instead, older persons should always have the right to receive support in decision-making in any circumstance they may need it. Support in decision-making can take different forms, such as having someone who is fully trusted by the concerned individual to assist her or him with a decision, having information provided in an accessible way or being able to say in advance the type of care or medical treatment the individual would like to receive in the future. Older persons affected by Hansen's disease and related disabilities have the right to personal autonomy in making decisions, in determining their life plans and in leading autonomous and independent lives in line with their will and preferences and on an equal basis with others.

54. These rights to autonomy, independence and legal capacity in older age are enshrined in the Convention on the Rights of Persons with Disabilities, article 19 of which provides for the right to independent living for persons with disabilities, and applies to older persons with disabilities. For the enjoyment of this right, support services may be required in areas such as mobility, assistive technologies, communication, daily activities, participating in leisure activities and in other social, religious, cultural, political or educational activities and personal relationships on an equal basis with others, and decision-making, including the possibility to make decisions in advance on budgeting and financial planning, on making wills, on health care and on end of life care.

55. By the same token, palliative care, understood as an approach that improves the quality of life of patients and their families who are facing problems associated with a life-threatening illness, has been recognized by several treaty bodies. Both the Committee on Economic, Social and Cultural Rights in its general comment No. 14 (2000) on the right to the highest attainable standard of health, and the Committee on the Elimination of Discrimination against Women in its general recommendation No. 27 (2010) on older women and the protection of their human rights, have asserted that States must ensure access to palliative care as part of the right to health. Furthermore, the Independent Expert on the enjoyment of all human rights by older persons has affirmed the need for States to ensure the availability and accessibility of palliative care in public and private settings (A/HRC/30/43, para. 131). Older persons affected by Hansen's disease should have the right and opportunity to make free and informed decisions on their palliative care.

56. All the aforementioned measures to ensure a good standard of living for older persons affected by Hansen's disease should be guaranteed both in and outside the sanatoriums. To that end, support services should be available on an equal basis in home, community and residential settings, and counselling should also be provided on a routine basis for older persons affected by Hansen's disease. Moreover, steps should be taken to ensure the effective access of older persons affected by Hansen's disease to a wide range of community-based support services and arrangements, including counselling and personal assistance; support for decision-making; assisted living arrangements; mobility aids; assistive devices and technologies; palliative care; and community services.

57. Given the ageing of this population, but more fundamentally the effects that the systemic violation of their rights has had both on persons affected by Hansen's disease and their family members, the Special Rapporteur urges the Government to recognize the internalization of stigmatization as a form of discrimination. While the Special Rapporteur acknowledges the effort the Ministry of Justice has made to develop a mechanism for receiving complaints of discriminatory practices and to provide suitable follow-up, as a good practice, the full scope of discrimination may not have been embraced when this key instrument was conceptualized. Many persons affected by Hansen's disease and their family members will be more in need of redress for the psychosocial effects of discrimination than with regard to ordinary discriminatory events and practices. The Special Rapporteur therefore recommends that the scope of the mechanism be extended to include psychosocial counselling, support, especially peer support, as a means to redress the internalization of stigmatization and to support people to be open about their personal history and to reunite with their families and communities.

(2004) on temporary special measures.

58. Moreover, in order to protect older persons affected by Hansen's disease from any type of abuse, it is necessary that the Government establish standards to regulate and monitor the work of caregivers and care providers dealing with issues related to Hansen's disease. Training health-care workers to acquire structural competence (A/74/174) and overcome discriminatory and abusive attitudes should be implemented as a top priority, alongside the monitoring of health-care services and health-care delivery and ensuring the accountability of the health-care workforce, with adequate indicators.

C. Responses from the health system to a rare disease

59. Hansen's disease in Japan today has the epidemiological and sociological profile of a rare disease. This means that persons affected by Hansen's disease encounter difficulties in obtaining an accurate diagnosis and proper treatment within the health system, and that accessibility and reasonable accommodation measures, as well as social protection strategies, are inexistent. This can ultimately hinder these persons' full inclusion in society.²⁹

60. The Special Rapporteur observed a significant lack of knowledge within the health system on key issues, such as: the therapeutic itineraries of persons with Hansen's disease when seeking medical assistance; the complementary care needs of persons with Hansen's disease, such as psychological counselling, prevention of impairments, rehabilitation or reconstructive surgery; and the psychosocial and economic impact of the disease. By the same token, the Special Rapporteur observed the inexistence of a formal referral system within the public health system. Moreover, according to private medical practitioners, very few medical doctors are qualified to diagnose and properly treat Hansen's disease in Japan, which can result in delayed diagnosis and development of impairments and disabilities.

61. Hansen's disease is a highly complex disease from a medical point of view and often requires multidisciplinary expertise and care. As is the case with most rare diseases, Hansen's disease is chronic, progressive, degenerative and disabling. Given that it is an imported disease in the country, it might impose an additional burden on immigrants who may already suffer from the difficulties associated with their status, even more so in the event that their legal or economic situation may exclude them from the public health insurance system. However, given its history, Japan is well equipped to develop a multisectoral response to the epidemiological and sociological profile of Hansen's disease as a rare disease in the country. It is therefore well equipped to implement guarantees with regard to the right to the highest standard of mental and physical health of persons with Hansen's disease, which should include accessibility, availability and quality of multidisciplinary health-care services, alongside proper monitoring and accountability measures.

62. In order to preserve the very specific nursing and medical expertise on Hansen's disease in the country, the Special Rapporteur suggests expanding the scope of the work of the relevant museums. This could include recording medical and nursing knowledge with a view to preserving it, but also training health workers on the specificity of the medical and nursing care associated with such a complex disease. Such a strategy might respond to the difficulties rare diseases impose on health systems, as Hansen's disease does in any post-elimination context.

VI. Conclusions

63. Japan became a leading protagonist in the global elimination of discrimination against persons affected by Hansen's disease and their family members by acknowledging the voices and the choices of all of those persons in the country. During her visit, the Special Rapporteur identified several good practices that are in place and provided advice on remaining challenges concerning the reparation schemes, the rights of older persons affected by Hansen's disease and the guarantee of the right to

²⁹ See www.ngocommitteerarediseases.org/wp-content/uploads/2018/05/NGO-CfRDs-Submission-The-Right-to-Health-in-Rare-Diseases_Feb-15-2018.pdf.

the highest attainable standard of physical and mental health in the post-elimination context, in which Hansen's disease acquired the epidemiological and sociological features of a rare disease.

VII. Recommendations

64. The Special Rapporteur recommends that the Government:

(a) Connect restorative justice to prevention. Concrete strategies should be threefold:

(i) Hansen's disease should be employed in a systematic way as a powerful and multilayered case study for human rights education through its mandatory mainstreaming into all levels of education and within all levels of the educational system's administration;

(ii) Human rights education based on the history of Hansen's disease should employ first-hand testimonies, personal and collective memories of the struggle for dignity, and the artistic production of persons affected by Hansen's disease, in order to promote awareness of the experience, capabilities and contributions of affected individuals as the most effective instrument for achieving systemic change of mindsets;

(iii) Memorialization processes should be developed outside the sanatoriums; ending the historical isolation of sanatoriums during the lifetime of its residents should be promoted; and awareness-raising among schoolchildren should be mainstreamed into all the Hansen's disease museums in the country;

(b) Guarantee the non-recurrence of human rights violations through human rights education and capacity-building of all members of the professions identified in the Verification Committee report as responsible for the past violations, particularly the medical community. Ethical standards for medical practice should be included in medical curricula with direct reference to the history of Hansen's disease. Proper regulation, monitoring and accountability of health professionals working with persons affected by Hansen's disease should be implemented as a priority so as to ensure those persons the right to the highest attainable standard of physical and mental health. The activities of the human rights bodies under the Ministry of Justice should be revised and broadened to include additional needs and characteristics of persons affected by Hansen's disease, including their family members, and the widespread internalization of stigmatization with provision of psychosocial counselling and peer counselling. The same mechanism should be duly publicized in all health-care settings where persons receive medical treatment for Hansen's disease;

(c) Implement additional reparation measures, as follows:

(i) Ensure that rehabilitation, including psychosocial support, is available to persons affected by Hansen's disease and their family members as part of the reparation schemes;

(ii) Ensure that the voices of women affected by Hansen's disease and their female family members, including their artistic expressions, are collected and heard in order to ensure a gender dimension to awareness-raising and follow-up to existing remedies;

(iii) Consult with the beneficiaries of existing compensation schemes for the isolation and sterilization policies, and with family members who were not included in those schemes, and ensure that the remedies provided include all victims and are proportional to the gravity of the violations and continuous suffering;

(d) Fulfil the obligation of restitution by creating an enabling environment and adopting the necessary measures to support family reunification. Strategies should focus on: the participatory design of an action plan; data collection, with guarantees of the right to privacy; monitoring and accountability devices with transparent information-sharing; proper budget allocation with targets, indicators

and benchmarks; community-based strategies; the availability of counselling and peer counselling; and the establishment of a referral network of relevant professionals;

(e) Respond to the current and varied needs of persons affected by Hansen’s disease, encompassing those who have been cured and those undergoing treatment, taking a human rights-based approach by simultaneously enforcing the rights of older persons affected by Hansen’s disease in three core dimensions – ageing, psychosocial and physical disabilities, and gender – and enforcing an efficient and comprehensive response from the public health system to the contemporary epidemiological and sociological profile of Hansen’s disease as a rare disease;

(f) Provide resources to register existing good practices and scale them up into the field of international North-South and triangular cooperation relations. Support the application to include the Nagashima-aiseien Sanatorium on the UNESCO World Heritage List. Support the due recognition of older persons’ rights in international human rights law.
