

**United Nations Special Rapporteur on the Elimination of Discrimination Against Persons
Affected by Leprosy and their Family Members, Alice Cruz**

Tokyo, 19 February 2020

Members of the Press

Ladies and gentlemen,

I conclude today my first official visit to Japan as the United Nations Special Rapporteur on the elimination of discrimination against persons affected by leprosy (known by Hansen's disease in Japan) and their family members, which took place between the 12th and 19th of February.

As an independent expert, I was mandated to monitor and promote the implementation of the Principles and Guidelines for the Elimination of Discrimination Against Persons Affected by Leprosy and their Family Members, approved by the General Assembly in 2010.

I would like to begin by extending my warmest regards to the Government of Japan for inviting me to assess, in a spirit of dialogue and cooperation, the enforcement of the human rights of persons affected by Hansen's disease and their family members in the country. I would like to thank the support provided by the Government before and during the visit. Such open cooperation enabled me to gather all the information relevant to the focus of the visit. Given the historical and epidemiological reality of the country, I focused on the following topics: access to justice and reparation measures; preservation of history and awareness-raising; disability rights; older persons' rights with a focus on gender; healthcare of foreign-born cases; participation; international cooperation. I would also like to thank the directions of the Hansen's disease institutions that I have visited and that made significant efforts to provide, with full transparency and openness, detailed information, as well as to accommodate for meetings with the institutions' workers and persons affected. I was particularly impressed by their eagerness to serve the best interests of persons affected by Hansen's disease and to continuously improve their work with that goal in view.

I would like to pay my tribute persons affected by Hansen's disease, their families and the organizations representing them, who have trusted me and shared with me their time, their life stories, testimonies, wisdom, knowledge, concerns and demands, many with great concerns about their identity being known, with attests how deep rooted stigma is. To them, I extend my deepest respect, admiration, and gratitude.

During the visit, I consulted with different ministries and government institutions working with Hansen's disease, as well as with civil society representatives, members of the academia, and health, assistance, and law professionals. I have talked to plaintiffs of the 2001 and 2019 lawsuits, their lawyers, to the group currently working on reparation due to the Eugenic Protection Law, to persons affected by Hansen's disease and their family members living in general society and others living in various communities, such as National Sanatorium Tama Zenshōen in Tokyo area, Nagashima-aiseien and Oku-komyoen Sanatouriums in Okayama Prefecture.

I am very pleased to share some of my preliminary reflections, and also take the opportunity to highlight that my findings and recommendations will be published in a report to be presented to the Human Rights Council in June of 2020. These preliminary reflections do not make justice to the vitality and diversity of the issues, as well as to the scope of the measures put in place by both the government and committed professionals in the field, nor are they conclusive remarks. These are thoughts that invite to a joint discussion aimed at the improvement of the responses to Hansen's disease related issues at the national and global levels.

During this visit, I aimed at understanding the multidimensional aspects of Hansen's disease in a country that has already eliminated it from an epidemiological view, but that still struggles with the effects of a very recent history of gross violations. The depth of the experience of the persons affected by Hansen's disease and their families in Japan demands a more thorough analysis that can reach the deep linkage between the enforcement of rights and the restoration of humanity to people who have been historically dehumanized, as well as what this process means for the building of a free and just society.

The history of the struggle for the restoration of humanity by persons affected by Hansen's disease in Japan truly testifies to how critical it is to move from a medical and/or charity based approach to groups such as persons affected by Hansen's disease, but also many

others, to a human rights approach that recognizes full citizenship on the grounds of autonomy, independent living and freedom of choice and expression. The good practices implemented to remedy for such recent history of gross violations were elaborated in respect of the voice and choice of persons affected by Hansen's disease and family members, for which I wish to commend the government. Japan is today the first country to have provided for remedies to persons affected, but also to their family members, due to past official segregation and accompanying violations.

I would also like to express my positive evaluation of the endeavor of the Government to take the issue of guaranteeing the rights of such historically and systemically discriminated population to the field of international cooperation. At the same time, I would like to note the importance of maintaining this effort on a post-elimination context in the future. As I have witnessed during my visit, in such situation, persons affected, but also their family members, are ageing and a dignified life in their late years must be ensured. Moreover, the full enjoyment of freedom of expression, informed consent, autonomy and participation, as well as elaboration of strategies to implement them, must also be ensured.

I thus conclude by presenting how the visit enabled me to gather first-hand information on the need for a human rights treaty on the rights of older people, as demanded by some stakeholders, and take the opportunity to call upon the government of Japan (a country where ageing is a core issue) to consider supporting this important global human rights cause.

Hansen's disease in Japan

From an epidemiological point of view, today Hansen's disease is a rare disease in Japan. With regard to new cases being reported, there were 3 foreign born cases in 2018 and 4 Japanese and 7 foreign born new cases from 2014 to 2018. I will develop this issue further on my final report.

But this was not always the case. The modern history of Hansen's disease in Japan is made up of multiple violations, as the government recognizes. After the instauration of the Meiji restoration, the development of a national identity together with a modernizing drive, led to the

institutional exclusion of persons affected by Hansen's disease to the opposite site of citizenship, ending up with dehumanizing them and robbing them of their personal identities and rights.

It was that in 1907 that the first leprosy prevention law was enacted to isolate persons affected, subsequently reinforced by the 1931's law and by the 1953's law. What is striking about the Japanese case, is the reinforcement of the leprosy prevention law on the year of 1953, the same year in which the international community was putting down the policy of segregation (that emerged as a global policy on the late nineteenth-century) at the international leprosy congress in Madrid, and which was attended by Japanese scientists and medical doctors. It is noteworthy that for the enactment of the 1953 (new) leprosy prevention law, medical doctors operating in the field, and widely in touch with the international scientific arena, were consulted by the Diet, and recommended the continuity of segregation alongside stricter measures to controls the residents. The 1953's law increased the restrictions inflicted upon the residents of the sanatoriums and it was accompanied by sanctioned violations, such as forced sterilization, on a time in which there already was a cure for the disease (discovered in the mid of the 1940s decade). Even more striking is the fact that such violating law was kept in force into as late as 1996. I have also listened to testimonies of persons affected who, while living outside the sanatoriums on the 1990s decade, were advised by medical doctors to get sterilized and not to have children.

Such formal and substantive discrimination represented a systemic violation of the human rights of persons affected in the country, accompanied by torture, inhumane treatment and abuse of different sorts, including - to name just a few-, breaking up of family ties, forced labor within the settings of confinement known as sanatoriums with harsh consequences on the worsening of physical impairments, and the most extreme form of violence against the right to the continuity of life in the form of forced sterilization, sanctioned by the 1948 Eugenic Protection Law. Stigma was the *dolus* behind this State's policy. I consider this violation as a permanent one, since it perpetuates itself in the lives of the persons affected by Hansen's disease and their children, many of whom still suffer from psychosocial disorders and disabilities that impair their rehabilitation and inclusion in society at large. But I also heard from many people, including persons affected, experts and workers in the field, how the campaigns in favour of

isolation at the prefecture's level produced such an ingrained stigmatization that it still continues to lead to the separation of families and discrimination at the community level.

Against this dehumanizing backdrop, persons affected by Hansen's disease began organizing themselves when they discovered that joint coordination and action could produce positive outcomes. This happened after they demanded in a unison voice access to the first effective drug on the treatment of the disease, that had been discovered in the mid-1940s as aforementioned above, and succeeded. They then started an organization of the residents of the 13 sanatoriums in the country, aiming at the abolishment of forced segregation. Seeing their efforts defeated with the 1953s law, residents redirected their struggle to the improvement of life conditions within the sanatoriums, entailing minimum standard of living within the sanatoriums, including the hiring of health workers to perform nursing tasks that had been performed by them until then. Their struggle reached to a successful conclusion as late as 1996 when the official segregation police was finally put down. After 1996, they came to a view that putting an end to segregation wasn't sufficient to remedy the harm they have suffered and went into justice to demand for an official apology from the Japanese government. The persons affected's struggle is proof to how even the more dehumanized populations have a strong sense of the interlinkage between the right to life and the right to dignity. Same struggle is also a testimony of 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 for the building of a free and just society.

As one woman affected told me in her words, the main lesson to history here should be that governments can be wrong and citizens must always stand up, fight and not being shut up. In the end, their story tells us all what democracy should be about and that there can be no human rights' enjoyment without the full right to participate in public affairs.

Today, persons affected by Hansen's disease still living in sanatoriums count to around 1100 with an average age of 86. There is also a considerable number of people who left the sanatoriums, and they are also an ageing population living with physical and psychosocial impairments and disabilities related to Hansen's disease. One of the enduring suffering felt by this group is the lack of the continuity of their life due to forced sterilization and the loss of family ties due to the fact that when entering the sanatoriums they abandoned their identities, changed their names and involved their lives with total secrecy in order to protect their families

from the stigmatizing effects of Hansen's disease. Some persons affected in their late age who have left the sanatoriums before to live an independent life, chose to return to the sanatoriums, not only because of medical needs, but especially out of fear of their families discovering the truth about their medical history. Families, up to the second and third generations, also suffer painfully with the effects of having lost their parents to forced segregation, restrictions during childhood development and discrimination on the grounds of being related to persons affected by Hansen's disease. Secrecy is still veiling the true identity of many persons affected and family members, hindering true psychological and social healing and effective systemic change on the way Hansen's disease is perceived by society at large.

Progress and good practices

Japan has ratified the international human rights treaties relevant to the protection of the rights of persons affected by Hansen's disease and their family members, in particular International Covenant on Civil and Political Rights (ICCPR); International Covenant on Economic, Social and Cultural Rights (ICESCR); Convention on the Elimination of All Forms of Discrimination Against Women (CEDAW); Convention against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment (CAT); Convention on the Rights of the Child (CRC), and Convention on the Rights of Persons with Disabilities (CRPD) .

Domestic legal framework to protect, promote and fulfill 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 particularly reflects many of the principles and guidelines that accompany the 2010 UN resolution 65/215.

In 1998, a group of persons affected by Hansen's disease went into court demanding for reparation from the State for the discrimination and violations they have suffered as a result of the implementation of an excessively protracted official policy of compulsory segregation. In 2001, the Kumamoto District Court ruled that the State's segregation policy was unconstitutional and ordered the State to provide for material reparation to persons who have suffered from it.

If this landmark ruling was achieved due to the capacity of persons affected for self-organization and strategic litigation actions, the positive action taken by the State on this matter

was of deciding not to appeal against this decision, offering public apologies to the victims and putting in place a large-scale administrative programme for providing material compensation. In accordance, the State endorsed in 2001 the Act on Payment of Compensation to Inmates of Hansen's Disease Sanatorium and in 2008 the Act on Promotion of Resolution of Issues Related to Hansen's Disease.

In 2016, family members of persons who were segregated filed lawsuits against the government, seeking compensation and an apology for their own sufferings, claiming that they too had suffered discrimination and prejudice under the isolation policy. In June 2019, the Kumamoto District Court decided that the government should compensate the family members as well. Also in this occasion, the government decided not to appeal and moved forward to set up, as before, a large-scale administrative programme for providing material compensation. In 2019, a new law was enacted to compensate family members of former Hansen's disease patients. Not only plaintiffs but also non-plaintiff family members can receive the compensation. However, the compensation law restricts beneficiaries to people who have lived in the past with the relatives affected by Hansen's disease, not covering all people who were discriminated against on the grounds of being relatives to persons affected by Hansen's disease.

As clearly explained by the Special Rapporteur on the promotion of truth, justice, reparation and guarantees of non-recurrence, programmes such as these 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 justice measures, they rest on general norms and their benefits have important positive spillover effects, one of which is to exemplify the fulfilment of legal obligation to take the violation of rights seriously. Such historical process in Japan allowed for persons affected and their family members not only to receive justice but also to psychologically heal at the personal level. Afterwards, many felt encouraged to speak openly about their history. The ruling of the courts in their favor meant for all and each one of them that society was able to look at them and treat them as equals. This was a considerable step forward on the enforcement of their right to dignity, equality and non-discrimination.

The struggle of persons affected and the positive responses from both the judicial system and the government, triggered the scaling up of a human rights approach to the international

field. The recognition of persons affected as right bearers, enhanced action taken by Japan at the international level, resulting in several resolutions, of which the most important one is the 2010's resolution 65/215 that is accompanied by a set of Principles and Guidelines for the Elimination of Discrimination against Persons Affected by Leprosy and their Family Members. This effort on the international cooperation's field was led by a concerted action between the government and Japanese civil society groups, namely the Nippon Foundation and Sasakawa Memorial Foundation. But ultimately, the wakeup call to recognize persons affected by Hansen's disease as rights bearers and as full citizens came from the grassroots. However, while talking to many persons affected and families, I realized they have not been sufficiently informed of this fact, and I would like to recommend the government to provide them with detailed information about this achievement.

At the policy level, Japan, in full respect of the courts' decisions, is endeavoring to put a multisectoral approach into place with joint coordination between the Ministry of Health, Labor and Welfare, Ministry of Justice and Ministry of Education, Culture, Sports, Science and Technology. Diverse strategies such as annual forums, guarantee of comprehensive healthcare within the sanatoriums, annual summer courses on Hansen's disease, preservation of history with two national Hansen's disease's museums and several museums within the sanatoriums, mechanism for receiving complaints on discrimination and providing remedies, awareness-raising among school children are being put in place. There is also an intention for reuniting families, which I encourage to be concreted into clear strategies with the utmost urgency due to the ageing of the target population. I would like to emphasize the good practice of the government of calling for the participation of persons affected, families and experts on the field to engage in decision-making and policy-making, in line with many of the provisions ratified by the country in international human rights instruments, and urge the government to ensure that such participation is meaningful and not just a token one.

Challenges and recommendations

State obligation to provide reparation is not restricted to financial compensation and should be accompanied by additional measures with regard to investigation, restitution of rights and freedoms, rehabilitation measures such as restoring the good name of victims, symbolic

reparation and memorialization, public apologies. 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 sets out five forms: restitution, compensation, rehabilitation, satisfaction 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.

The acts that followed the 2001 and 2019 court decisions in favor of persons affected and family members are very comprehensive, but somehow fail to acknowledge the responsibility of particular professional communities, such as the medical, law, welfare and media, as signaled by the Verification Committee Report. After hearing several testimonies and going through documentation, I believe that the medical community (even though I recognize that this is not an homogenous group and that there were a number of medical doctors who opposed the State's policy of segregation, but whose freedom of expression was shortened) should be held accountable for the implementation of segregation policies and its anomalous extension over time. It is important for the guarantee of non-recurrence of such gross human rights violations (including segregation; change of name and loss of identity, as well as all civil and political rights; violation of sexual and reproductive rights, but also of the right to the continuity of life itself in the form of forced sterilization and abortion) to give visibility to the role played by this particular community. For the sake of future generations, I would like to recommend the government to consider including reference to the ethical boundaries of medical practice in the medical curriculums with direct reference to the history of Hansen's disease in the country.

Moreover, additional measures, besides from the provision of allowance, public apologies, and memorialization processes that are already in place should be considered to strengthen the spillover effects of the remedies provided. As preliminary recommendation, I would suggest the following: restoration of the good name of the victims, psychosocial support to the victims and their families accompanied by the restoration of family ties (this should be implemented with urgency due to the ageing of the concerned groups), memorialization sites outside the sanatoriums in order to acknowledge the victims of segregation as survivors entitled to all the rights as everyone else. Further research and wide dissemination of the artistic production of persons affected within the sanatoriums should also be encouraged as an effective means to

produce systemic change on the way society looks at Hansen's disease. First hand testimonies are always the more effective way to break down the mental barriers that sustain discrimination and unequal treatment at society at large. Good practices already implemented by some sanatoriums in the country aimed at de-isolation these facilities, such as providing kindergartens and outpatient care to the surrounding community should be for replication. During the visit, I realized that the guidelines provided by the government on awareness-raising among school children may have distinct implementation at the local level, depending on the interest of both private companies that produce school materials and local administration. I recommend both the private sector and local administration to give priority to Hansen's disease in their human rights programmes and the central government to put additional efforts to this important strategy, but also to consider making use of the impressive fountainhead of artistic production by the affected as a way of guaranteeing their continuity of life (interrupted by the sterilization policy) and of providing the public with a positive image about their capabilities and work. In conclusion, I strongly recommend the government to continue taking this issue as seriously and committedly as it has been doing and considering expanding its comprehensive approach to try to reach true and effective systemic change at the society level.

Persons affected by Hansen's disease in the country are an ageing population. This calls forth an approach that simultaneously address the psychosocial effects of multiple discrimination and violations throughout life (in particular the current absence of family ties and the internalization of stigmatization), physical impairments and disabilities related both to Hansen's disease and to ageing. But it also calls forth breaking down data into gender differences and clearly defining gender-based approaches that can also give visibility to women's stories, experiences and needs. I observed with great concern the complete absence to references to gender both at the grassroots struggles and the government policy-making, which I will further develop on my final report.

Targeted strategies for each of these conditions (ageing, psychosocial and physical disabilities, gender) should be developed in closed consultation with the target group and put in place under a holistic approach. Such measures should be accessible to all, including those living within, but also 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 free expression on health matters.

Older people affected by Hansen's disease and related disabilities should never be denied the right to legal capacity because of their age and/or mental health. Instead, older people should always have the right to receive support in decision making on circumstances in which 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/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 people affected by Hansen's disease and related disabilities have the right to personal autonomy to make decisions, to determine their life plans and to lead autonomous and independent lives in line with their will and preferences and on an equal basis with others. These are rights to autonomy, independence and legal capacity in older age provided by article 19 of the Convention on the Rights of Persons with Disabilities that establishes the right to independent living for persons with disabilities and which applies to older persons with disabilities. For the enjoyment of this right, support services, such as mobility support, assistive technology, communication support, support for daily activities, participating in leisure activities, and participating in other social, religious, cultural, political or educational activities and personal relationships on an equal basis with others, support in decision-making - including the possibility of making decisions in advance around budgeting and financial planning, the making of wills, healthcare, and end of life care-, may be required.

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 life-threatening illness, is provided by the work of some treaty bodies (both the Committee on Economic, Social and Cultural Rights in General Comment No. 14 and the Committee on the Elimination of Discrimination against Women in General Recommendation No. 27 have asserted that states must ensure access to palliative care as part of the right to health) and the Independent Expert on the enjoyment of all human rights by older persons in her 2015 thematic report, that affirm the need for States to ensure the availability and accessibility of palliative care in public and private settings. Older people affected by Hansen's disease should have the right and opportunity to make free and informed decisions on their palliative care and it may be necessary for the government to regulate and properly monitor the work of all palliative care providers in line with their professional obligations and standards.

All the aforementioned measures to ensure a good standard of living to older persons affected by Hansen's disease should be guaranteed both within and outside the sanatoriums. I have listened to many testimonies that indicate that a higher quality of treatment is being provided within the sanatoriums and that some persons affected chose to go back to these facilities in the face of more limited attention to their needs at the community level. I have also listened to testimonies that state that, besides from the different levels of quality of care within and outside the sanatoriums, main reason for some people going back is their fear of having their medical history on Hansen's disease known at the community and family levels. Even though I understand the difficulty of addressing this issue within the health system, I recommend that all necessary measures must be taken to avoid people going back to the sanatoriums, given the negative effect that such experience can have upon them. Moreover, many of the testimonies that were shared with me point to the fact that in order not to reveal the past medical record, many of these persons voluntarily leave everything behind when returning to the sanatoriums, including family relationships and property.

As such, I recommend that support services should be available on an equal basis in home, community and residential settings, but also that counselling should be provided on a routine basis to older people affected by Hansen's disease. Effective access of older persons affected by Hansen's disease to a wide range of community-based support services and arrangements, including counseling and personal assistance; support for decision-making; assisted living arrangements; mobility aids; assistive devices and technologies; palliative care; and community services should be ensured.

Also given the ageing of this population, but more fundamentally the type of effects that systemic violation has caused both on persons affected and their family members, I urge the government to recognize the internalization of stigmatization as a form of discrimination. While I praise the Ministry of Justice for having develop a mechanism for receiving complaints on discriminatory practices and properly follow-up (a best practice of outstanding meaning, given its lack worldwide), I believe the full scope of discrimination has not been properly grasped by the conceptualization of this key instrument. Many persons affected and family members will be more in need of redress of the psychosocial effects of discrimination than of complaining about ordinary discriminatory events and practices. I recommend, as such, that this mechanism's scope can be extended to include psychosocial counselling, support, especially peer support, as a means

to redress the internalization of stigmatization and support people to be open about their personal history and reunite with their families and communities.

By the same token, segregation brought with itself 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 total and definitive. Children were many times left without sufficient subsistence means, despite the 1953's law that provided for welfare, but that was seldom put into practice. Persons affected, but also their family members, submitted themselves to a life of secrecy. I witnessed the pain that such fact still imposes upon them and the variety of psychosocial disabilities that result from it. I urge the Government to move forward, with the urgency required for guaranteeing the rights of an ageing population, and to put in place a strategy aimed at the reunification of families. True psychosocial healing can only come with this outcome.

During the visit, I was impressed with the quality of the museography work done in the country with regard to the preservation of history of Hansen's disease, especially with the guiding purpose of giving visibility to the people's lives, experiences and knowledge. I found this to be a very vital field for sustaining the efforts of Japan in eliminating discrimination on the grounds of Hansen's disease. As such, I would like to make some preliminary recommendations on this regard. Firstly, I would like to mention the importance of supporting the application of Nagashima-aiseien to UNESCO world heritage. Secondly, I would like to suggest expanding the scope of the work of the museums to include recording of medical and nursing knowledge with a view of preserving, but also of training health workers on the specificity of the medical and nursing care associated with such a complex disease. Such strategy may respond to the difficulties rare diseases impose to health systems, as Hansen's disease does in post-elimination contexts. And thirdly, I strongly recommend further study and widely dissemination of the artistic production left by the sanatoriums' residents as a way to remedy for the violation of their right to the continuity of life by past forced sterilization and achieving for systemic change on the way society looks at Hansen's disease.

Members of the Press

Ladies and gentlemen,

Due to the positive efforts and set of good practices that Japan has developed and currently implements, the country is undoubtedly a leading protagonist in the global elimination of discrimination against persons affected by Hansen's disease and their family members. I commend the Government of Japan for such efforts and urge it to strengthen, double, sustain and expand them onto North-South and triangular cooperation relations, but also in supporting the due recognition of older people's rights in international human rights law.