

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

REFERENCE:
AL BRA 15/2019

21 November 2019

Excellency,

I have the honour to address you in my capacity as Special Rapporteur on the elimination of discrimination against persons affected by leprosy and their family members, pursuant to Human Rights Council resolution 35/9.

In this connection, I would like to bring to the attention of your Excellency's Government information I have received concerning **the grave human rights violations of approximately 16000 children separated from their parents affected by leprosy, also known as Hansen's disease, between the decades of 1920 and 1980.**

An estimate of those 16.000 individuals remain uncompensated regarding the damages suffered due to the compulsory and segregationist isolation of their biological parents with Hansen's disease.

According to the information received:

Due to a public health policy between 1923 and 1986, the Decree 16.300/1923 compulsory discriminated and segregated people with Hansen's disease. It was adopted systematically until the last decades of the twentieth-century (specifically until 1986), even though scientific and medical advances in the disease treatment on the 1940s decade led the international community to abandon prophylactic segregation as a public health policy. That is one of the main reasons why Brazil acknowledged the damage caused by such State policy on the persons affected by Hansen's disease with the 2017's law 11.520.

This segregationist policy was hardened by the Law n. 610 from 1949, which established the compulsory hospitalization for sick people that could not provide the necessary resources for their own subsistence and of people that presented severe Hansen's disease related physical impairments.

The law 610/1949 was repealed by the 5.511/1968 law. Even though it didn't establish the compulsory isolation for the people affected and their children, the Brazilian public policy of segregation was still kept in practice.

As part of the compulsory isolation policy, a large number of the children of persons affected were separated from their parents, many at birth, and grew up without any contact with their biological parents. Furthermore, many were also confined in institutions created by the State for their segregation from society, which were known as "preventórios". Despite the State's obligation to ensure the

children integral protection, many of them were submitted within these institutions to slave labor, sexual abuses and other forms of physical and psychological violence.

In December 2017, the social movement MORHAN (Movement of Reintegration of Persons Affected by Hansen's disease), in representation of all the "separated children" (as they have become known), started a public civil action for the reparation of the damage generated by the Brazilian laws that imposed the prophylaxis policy in the 4th São Paulo's Federal Justice Civil Court. However, to this day, one year and a half after the registration date of the action, it has not advanced due to excessive delay in the action's processing with clear discriminatory features. In fact, on ID 19608521 the Judge extinguished the process and applied a financial penalty to the plaintiff.

Without prejudging the accuracy of the information received, concern is expressed at the above allegations. The absence of preoccupation with priority processing from the Brazilian's state may be regarded as negligence of the judiciary regarding the severity of the fact and the dimension of the violated rights.

We furthermore point to the fact that no compensation to the separated children that suffered human rights violations due to actions committed in the past by the State have yet been given, despite the fact that many of them have an advanced age, remain without knowing their family origin, and live with physical and psychosocial impairments and disabilities resulted from the damage they have suffered.

In connection with the above alleged facts and concerns, please refer to the **Annex on Reference to international human rights law** attached to this letter which cites international human rights instruments and standards relevant to these allegations.

As it is my responsibility, under the mandate provided to me by the Human Rights Council, to seek to clarify all cases brought to my attention, I would be grateful for your observations on the following matters:

1. Please provide any additional information and/or comment(s) you may have on the above-mentioned allegations.
2. Please provide information on the measures taken to ensure the psychological and/or psychiatric treatment for the separated children, as well as support to their full inclusion into the society.
3. Please provide information on the public civil action filed by the social movement MORHAN, in representation of all the separated children as mentioned.
4. Please provide information on the registration process of the separated children that proves their separation from their parents due to Hansen's

disease, and allows for this population to trace their family origins, and the steps towards its wide national disclosure.

5. Please highlight the steps that the Government has taken, or is considering to take, to disclose all the documents regarding the separation policy enforced.
6. Please provide detailed information on the steps that the Government has taken, or is considering to take, to guarantee an effective reparation for the damages caused to the separated children.

I would appreciate receiving a response within 60 days. Passed this delay, this communication and any response received from your Excellency's Government will be made public via the communications reporting [website](#). They will also subsequently be made available in the usual report to be presented to the Human Rights Council.

While awaiting a reply, I urge that all necessary interim measures be taken to halt the alleged violations and prevent their re-occurrence and in the event that the investigations support or suggest the allegations to be correct, to ensure the accountability of any person(s) responsible for the alleged violations.

Please accept, Excellency, the assurances of my highest consideration.

Alice Cruz

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

Annex

Reference to international human rights law

In Persons affected by leprosy and their family members are entitled to all rights and freedoms enshrined in international human rights instruments. The enjoyment of human rights by persons affected by leprosy and their family members must be fulfilled under the principles of dignity, equality and non-discrimination. In this connection, I would like to refer your Excellency's Government to the main legal obligations arising from the Universal Declaration of Human Rights (UDHR), the Covenant on Civil and Political Rights (ICCPR), the Covenant on Economic, Social and Cultural Rights (ICESCR), the Convention on the Elimination of All Forms of Racial Discrimination (CERD) and the Convention on the Rights of Persons with Disabilities (CRPD) adopted and ratified by Brazil on 10 December 1948, 24 January 1992, 27 March 1968 and 1 August 2008 respectively, as some of the international human rights instruments that protect persons affected by leprosy and their family members.

In particular, article 23, par. 4 of the Convention on the Rights of Persons with Disabilities (CRPD) lists, among effective and appropriate measures to eliminate discrimination against persons with disabilities, the obligation of States Parties to “ensure that a child shall not be separated from his or her parents against their will, except when competent authorities subject to judicial review determine, in accordance with applicable law and procedures, that such separation is necessary for the best interests of the child. In no case shall a child be separated from parents on the basis of a disability of either the child or one or both of the parents”.

In addition, article 6 of the Convention on the Elimination of All Forms of Racial Discrimination (CERD) establishes that “States Parties shall assure to everyone within their jurisdiction effective protection and remedies, through the competent national tribunals and other State institutions, against any acts of racial discrimination which violate his human rights and fundamental freedoms contrary to this Convention, as well as the right to seek from such tribunals just and adequate reparation or satisfaction for any damage suffered as a result of such discrimination”.

I would also like to refer that the recognition of persons affected by leprosy and their family members as a marginalized and mostly forgotten segment of population that experience multiple discrimination and violation is recognized in the resolution 65/215 on the elimination of discrimination against persons affected by leprosy and their family members adopted in 2010 by the General Assembly, accompanied by the “Draft set of principles and guidelines for the elimination of discrimination against persons affected by leprosy and their family members”

The “Draft set of principles and guidelines for the elimination of discrimination against persons affected by leprosy and their family members” make reference to already existing obligations due to Member States that ratified international human rights treaties and conventions. In accordance, it clarifies the normative content of the international human rights instruments and provides guidance on how to enforce human rights in the

specific context of systemic and structural discrimination and violation of this particular population.

As such, it aims at putting into practice the General Comment n.º 20 of the Committee on economic, social and cultural rights about substantive discrimination that acknowledges: “(b) Substantive discrimination: Merely addressing formal discrimination will not ensure substantive equality as envisaged and defined by article 2, paragraph 2. The effective enjoyment of Covenant rights is often influenced by whether a person is a member of a group characterized by the prohibited grounds of discrimination. Eliminating discrimination in practice requires paying sufficient attention to groups of individuals which suffer historical or persistent prejudice instead of merely comparing the formal treatment of individuals in similar situations. States parties must therefore immediately adopt the necessary measures to prevent, diminish and eliminate the conditions and attitudes which cause or perpetuate substantive or de facto discrimination.”

Similarly, the “Draft set of principles and guidelines for the elimination of discrimination against persons affected by leprosy and their family members” provides that persons affected by leprosy and their family members should have the same rights as everyone else with respect to marriage, family and parenthood. To this end, a child should not be separated from his or her parents on the grounds of leprosy (principle I.3.c). By the same token, Guideline nº 4 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 diagnosed with leprosy, in close connection with 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 that put forward the following measures: (a) adoption of appropriate legislative and administrative and other appropriate measures to prevent violations; (b) effective, prompt, thorough and impartial investigation of violations and adoption of measures against those responsible; (c) ensuring victims have equal and effective access to justice and effective remedies.

Hence, the Draft set of principles and guidelines aims to provide guidance to States on the promotion, protection and the guarantee of the full realization of all human rights and fundamental freedoms for all persons affected by leprosy and their family members without discrimination on the grounds of leprosy, including those enshrined in the core international human rights instruments.