

Mandates of the Special Rapporteur on the elimination of discrimination against persons affected by leprosy and their family members; and the Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health

REFERENCE:
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Excellency,

We have the honour to address you in our capacity as Special Rapporteur on the elimination of discrimination against persons affected by leprosy and their family members and Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health, pursuant to Human Rights Council resolutions 44/6 and 42/16.

In this connection, we would like to bring to the attention of your Excellency's Government information we have received concerning **serious risks posed to the enjoyment of human rights of a significant number of persons affected by Hansen's disease in Brazil, known globally as leprosy, including the non-availability of multi-drug therapy (MDT) since August 2020 and the barriers to accessing health care and sanitation. Furthermore, a large number of persons affected by Hansen's disease are excluded from a COVID-19 relief allowance.**

According to the information received:

Since August 2020, Hansen's disease patients in Brazil have not been able to obtain the essential multi-drug therapy (MDT) needed to treat the disease in the public health system. For instance, the Cabo de Santo Agostinho reference center located in the state of Pernambuco has no MDT to treat more than 200 leprosy patients under their responsibility. Since the outbreak of COVID-19, several doctors reported to the National Coordination of Leprosy and Diseases in Elimination of the Secretariat of Health Surveillance (CGDE) about the shortage and their urgent need of MDT, but without success. They recently received a response confirming the shortage of MDT on the state, "a national problem, with no perspectives of solution".

As per the information received, on 26 August 2020, the CGDE indicated that Brazil does not have any stock of MDT due to (i) the temporary shortage of dapsona production in December 2019 and January 2020 and (ii) the difficulties related to the transportation of the drug because of the high prices of airfreight related to the COVID-19 pandemic. Brazil does not internally produce the medicine and it is still dependent on the donations of medicines by the World Health Organization. As per the WHO data (Global Leprosy update), Hansen's disease remains a significant public health problem in Brazil, placing the country as the second highest absolute number of new cases of Hansen's disease in the world. Hansen's disease communities in Brazil have advocated for the domestic production of essential medicine.

According to recent WHO data ([Global Leprosy update, No.36, 2020](#)), new grade 2 disability (G2D) cases linked to Hansen disease have increased in Brazil (1,736 in 2016, 1,949 in 2017, 2,109 in 2018, 2,351 in 2019) due to delays in access to diagnosis and to a high-quality treatment. As stated in the WHO [Advice about leprosy and COVID-19](#), physical impairments caused by Hansen's disease are preventable with timely diagnosis and adequate treatment of the disease, including proper management and distribution of MDT.

Reportedly, many barriers posed by cultural and socioeconomic factors have added up to the lack of access to an adequate treatment for Hansen's disease in Brazil during the COVID-19 pandemic. Many people affected by the Hansen disease in Brazil, especially women and racial minorities, live in restricted spaces and without basic sanitation, such as access to soap and cleaning agents. In addition, their lack of medication increases the risk of transmission of COVID-19. In particular, it is reported that people of African Descent in Brazil are already vulnerable to racial stigmatization and discrimination and they are even more vulnerable to negative health outcomes related to leprosy. Women have also faced more domestic violence during the pandemic and are affected by the lack of governmental action in order to face the challenges related to Hansen disease.

Moreover, it is reported that persons affected by Hansen's disease who receive the lifelong pension provided by Law n° 11.520 are not eligible for the COVID-19 benefit provided by Government of Brazil. A case was brought to the federal court on behalf of those covered by Law n° 11.520 given mounting difficulties for this vulnerable group in the context of COVID-19. This case has not been accepted by the federal court and is now awaiting an appeal at the higher court.

Lastly, Law n° 8,213, of July 24, 1991, related to the Social Security Benefit Plans and other provisions, indicates that some pathologies do not need to meet the minimum grace period to receive sickness/illness or disability benefits, including Hansen disease. On 26 June 2020, the Interministerial Ordinance n° 256 created an Interministerial Working Group (IWO) to review the latest list of diseases and conditions and reportedly, Hansen's disease may be removed from the list of pathologies. This would be allegedly against the National Health Council Recommendation n° 52 of 14 August 2020, which recommends a broad and democratic debate in the IWG for the adequate evolution of the updated table and suggests that the pathologies on the list should not lose any of their entitlements.

While we do not wish to prejudge the accuracy of these allegations, we express serious concern at the lack of MDT, basic sanitation and access to the allowance to provide COVID-19 relief for persons affected by Hansen's disease. The treatment for Hansen's disease is essential in order to prevent irreversible physical

impairments and stop transmission. As an immunosuppressed population, the lack of treatment is putting persons affected at great risk of infection of COVID.

All Persons affected by Hansen's disease and their family members are entitled to all rights and freedoms enshrined in international human rights instruments. In this connection, I would like to refer your Excellency's Government to article 12 of the International Covenant on Economic, Social and Cultural Rights (ICESCR), to which Brazil acceded on 24 January 1992, that protects the right of everyone to the enjoyment of the highest attainable standard of physical and mental health. In its General Comment 14, the Committee on Economic, Social and Cultural Rights established that States have the obligation to ensure the right of access to health facilities, goods and services on a non-discriminatory basis, especially for vulnerable or marginalized groups (paragraph 12(b)).

In addition, the recognition of persons affected by Hansen's disease leprosy and their family members as a marginalized and mostly forgotten segment of population that experience multiple discrimination and violation is recognized in the General Assembly resolution 65/215 (2010), accompanied by the "Principles and Guidelines for the elimination of discrimination against persons affected by leprosy and their family members". The Principles and Guidelines refer to already existing obligations pursuant to Member States' ratification of international human rights treaties and conventions. In this regard, principle 11.3 enshrines the obligation of all States to ensure that persons affected by Hansen's disease have access to free medication for leprosy, as well as appropriate health care.

In particular, the UN Special Rapporteur on the elimination of discrimination against persons affected by leprosy and their family members issued an Open Letter on COVID-19 and Leprosy addressed to the UN Members. She indicated that, in order to implement the prevention measures during the pandemic, it is necessary to have access, at least, to decent housing, access to clean water and soap, as well as to purchase masks and other protection items. The Special Rapporteur highlighted that persons affected by leprosy and their families are among the furthest behind and are currently experiencing a disproportionate impact of the crisis generated by the COVID-19 pandemic. In addition, she stated that the guarantee of income security, through social security schemes that allow persons affected and their families to acquire minimum healthcare, basic shelter and housing, clean water and food, is urgent and glaring. Furthermore, the right to a continuum of medical and psychosocial care that encompasses the full spectrum of prevention, timely access to multidrug-therapy, proper management of leprosy reactions, complementary care, such as wound care, physiotherapy, rehabilitation, reconstructive surgery, should be guaranteed, alongside service delivery at the community level.

The full texts of the human rights instruments and standards recalled above are available on www.ohchr.org or can be provided upon request.

In view of the urgency of the matter, we would appreciate a response on the initial steps taken by your Excellency's Government to safeguard the rights of the above-mentioned persons in compliance with international instruments.

As it is our responsibility, under the mandates provided to us by the Human Rights Council, to seek to clarify all cases brought to our attention, we would be grateful for your observations on the following matters:

1. Please provide any additional information and any comment you may have on the above-mentioned allegations.
2. Please provide detailed data on Hansen's disease and COVID-19, including number of persons affected among those tested positive for COVID-19, by sex, age and region. Please provide information about those residing in former colonies where the risk of COVID-19 infections might be higher.
3. Please provide detailed information about the measures taken to ensure access to MDT and basic sanitation for persons affected by Hansen's disease in Brazil. Please indicate any emergency actions to respond to the shortage of MDT in the context of COVID-19. Please provide the details on the present situation of MDT stock in the country and the number of blisters requested by Brazil in 2019 and 2020.
4. Please provide detailed information on the measure taken or being taken by the authorities to produce the essential medication for Hansen's disease. If this is not the case, please explain the reason as well as indicate how Brazil will secure the access to essential health care for persons affected by leprosy at all times.
5. Please provide information on the measure taken to ensure the rights to health and social security benefits of persons affected by Hansen's disease, especially in the context of COVID-19.
6. Please provide information on the measures taken to comply with the Advice about leprosy and COVID-19 by the WHO and other relevant organisations as well as the key principles elaborated in the Open Letter by the Special Rapporteur on the elimination of discrimination against persons affected by leprosy and their family members.

While awaiting a reply, we 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 responsible of the alleged violations.

This communication and any response received from your Excellency's Government will be made public via the communications reporting [website](#) within

60 days. They will also subsequently be made available in the usual report to be presented to the Human Rights Council.

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

Alice Cruz

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

Tlaleng Mofokeng

Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health