

DECEMBER 2020



**BUILDING A
PEOPLE-
CENTERED
MANDATE**

FACTSHEET

UN SPECIAL RAPPORTEUR ON THE
ELIMINATION OF DISCRIMINATION AGAINST
PERSONS AFFECTED BY LEPROSY AND THEIR
FAMILY MEMBERS, ALICE CRUZ

The Special Rapporteur on the elimination of discrimination against persons affected by leprosy (also known as hansen's disease) and their family members, Alice Cruz, began on November 1, 2020 a new cycle of her mandate, extended for another three years by the UN Human Rights Council (UNHRC). The first three years (2017-2020) included two official visits to Brazil and Japan and the preparation of four reports. The next report, to be released in 2021 and will address the disproportionate impact of the crisis generated by COVID-19 on persons affected by leprosy and their families. The preparation for the second term of the mandate included an extensive consultation with organizations of people affected by the disease, Non-Governmental Organizations working in the area and other important partners. A work that seeks to bridge between people who have experienced leprosy and national and international decision-making agencies.

IN THIS FACTSHEET: ABOUT SPECIAL PROCEDURES OF THE HUMAN RIGHTS COUNCIL / HOW TO SUBMIT INFORMATION / ACTIONS AND REPORTS OF THE FIRST TERM / A WORD FROM THE SPECIAL RAPPORTEUR

ABOUT SPECIAL PROCEDURES OF THE HUMAN RIGHTS COUNCIL

Human rights are one of the three pillars of the United Nations – the other two are: peace and security; and development. The international area of human rights is anchored in a series of treaties and other instruments adopted since 1945 that have provided a legal format to the inherent human rights. The understanding, implementation and development of this area also include the contribution of statements, guidelines and principles (*such as the Principles and Guidelines for the Elimination of Discrimination against Persons affected by Leprosy and their Family Members*).

International human rights law has provisions with obligations that States must:

- **Respect (refrain from interfering or restricting the benefit of human rights).**
- **Protect (individuals and groups against human rights abuses).**
- **Fulfill (take positive measures to facilitate the enjoyment of basic human rights).**

The Office of the High Commissioner of the United Nations for Human Rights is the UN's leading human rights entity. Geneva headquarter supports the Human Rights Council (OHCHR), the Treaty Bodies, the Universal Periodic Review and the Special Procedures.

Special Rapporteur on leprosy: One of the Special Procedures.

The Special Procedures of the Human Rights Council are independent human rights experts with mandates to report and advise on human rights from a thematic or country-specific perspective. Those independent experts (known as Special Rapporteurs, Independent Experts and members of the Working Groups) are appointed by the Human Rights Council and serve in their personal capacities. This position is honorary and the expert is not an official of the United Nations or paid for his/her work.

The Human Rights Council established the mandate of the Special Rapporteur on the elimination of discrimination against persons affected by leprosy and their family members in June 2017 (resolution 35/9) and appointed Ms. Alice Cruz (Portugal) as Special Rapporteur in November 2017. In July 2020, the Human Rights Council extended the mandate for another three years (resolution 44/6). The Special Rapporteur is mandated to monitor and report on the progress made and the measures taken by States to effectively implement the Principles and Guidelines for eliminating discrimination against persons affected by leprosy and their family members and to make recommendations to the Human Rights Council in this regard.

The Special Rapporteur

Send **communications** (urgent appeals and letters of allegations) to States and others, concerning alleged violations of the rights of persons affected by leprosy and their family members.

Conducts **country visits** to investigate in loco the situation of countries and makes recommendations to their governments.

Submits annual **reports** to the Human Rights Council (In her second term, the Special Rapporteur will also submit annual reports to the General Assembly).



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HOW TO SUBMIT INFORMATION TO THE SPECIAL RAPPORTEUR

Any relevant sources, including persons affected by leprosy and civil society organizations, can submit information to the Special Rapporteur. There are no formal requirements for sending information about alleged violations.

To submit information:

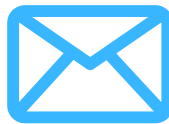


You are encouraged to use the Special Procedures Submission online form, website: <https://spsubmission.ohchr.org/en>

If you are not able to complete the form online, you may:



Send your submission via e-mail to:
urgent-action@ohchr.org;
srleprosy@ohchr.org
With the subject:
Communication about [country]



Or post to:
Special Rapporteur on the Elimination of
Discrimination Against Persons Affected by
Leprosy and Their Family Members
c/o OHCHR-UNOG
8-14 Avenue de la Paix
1211 Geneva 10, Switzerland

Submissions need to be an accurate account of the ALLEGED VIOLATION and include the following information:

- ✓ **Name(s) of the alleged victim(s)** (may be individuals, groups or organizations)
- ✓ **Alleged violation/abuse committed against the victim** (What happened? Where? When? What is the current situation? Are there other victims?)
- ✓ All available information about **who allegedly committed the violation** or abuse.

Further guidelines on the essential and useful information you should provide in your complaint is available on the website: <https://www.ohchr.org/EN/Issues/Leprosy/Pages/Complaints.aspx>

Consent and Confidentiality

The Special Procedures are guided by the principle of “do no harm” For this reason, the CONSENT of the victim or the victim’s representative (family member or legal counsel) is required to send communications.

The identity of the source of information about the alleged violation is kept confidential unless the source agrees that it can be disclosed. When submitting information, you can indicate if there are any other details that you would like to keep confidential.

What the Special Rapporteur can do after the complaint

In the face of a violation communication, the Special Rapporteur will assess the reliability and urgency of the reported situation. From this analysis, it is the time for the mandate to communicate, this time with the Government(s) in question. This communication can be:

Urgent appeal: when the reported situation requires an urgent action.

Letter of allegation: when the situation does not require urgent action, but is related to violations that have already occurred and/ or general patterns of violations.

Other letters: concerns relating to bills, legislation, policies or practices that do not comply with international human rights law and standards.

All communications sent to and responses received from States or others (if any) are confidential until they are made public in joint communication reports presented to the Human Rights Council and in the communications site at: spcommreports.ohchr.org.

The purpose of the communication sent by the Special Rapporteur to Governments is to request clarification on the complaints, with a view to establishing a constructive dialogue aimed at ensuring the elimination of discrimination against persons affected by leprosy and their family members.

For further information,
please see the OHCHR website:
<https://spsubmission.ohchr.org/en>
or Leaflet on Special procedures
communications:
<http://bit.ly/SPPpresentation>



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ACTIONS AND REPORTS OF THE FIRST TERM

The reports of the first three years of the Special Rapporteur's mandate were developed to fulfill two roles at the same time: providing guidance to States and making an instrument of rights' claiming available. Access the documents (by clicking on the icons) and learn more about the process that has been built:



Integration of the leprosy topic into the UN human rights system, seeking a cross-cutting action, from an intersectional perspective

The basis for this process was established in the first report of the mandate, 2018. The document also describes the vision, priorities and working methods of the Special Rapporteur. Among the described strategies is the promotion of social and public participation of persons affected by leprosy and their family members, focusing on empowerment, self-organization and direct engagement with the overall Human Rights system.

New evidences on discrimination and adoption of a gender approach

The 2019 report, with the theme "Stigmatization as dehumanization: harmful stereotypes and structural violence against women and children affected by leprosy" established a new framework for evidences on discrimination on the grounds of leprosy. The document focuses on the discrimination against women and children affected by leprosy and their female and underage relatives, seeking to identify the causes and consequences of their vulnerability to discrimination based on leprosy and the various forms of violence associated with it. Also, it offers recommendations for the recognition and enforcement of their rights. By giving voice and visibility to women affected by leprosy, the report introduces the gender approach to fight against leprosy-related discrimination.



A people-centered approach for building public policies

The 2020 report promotes the structuring of rights-based policies with a people-centered approach. It seeks to promote a consistent Human Rights approach to leprosy, encouraging technical cooperation with States, in particular regarding the adoption of multisectoral rights-based policies, and the mainstreaming of a human rights approach among private stakeholders, such as Non-Governmental Organizations. One of its objectives is to promote the paradigmatic change from a medical and/or charitable model to a rights-based one that recognizes persons affected by leprosy and their family-members as as rights-holders.



Country visits reports

Also in 2020, the Special Rapporteur presented her reports on the country visits made to Brazil and Japan - respectively, a country in which leprosy is still endemic and another one characterized by the post-elimination of the disease -, which evince the heterogeneity and relevance of leprosy worldwide. Such reports show the cooperative and propositional approach of the Special Rapporteur's visits, which aim at catalyzing action, offering constructive recommendations for sustaining and improving ongoing efforts and achieving systemic change.



Brazil



Japan



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A WORD FROM THE SPECIAL RAPPORTEUR



“

The extension of my mandate is a result of the participation of persons affected by leprosy in the work of my mandate during the first two and a half years. It is also a result of the cooperation between the main stakeholders in the field. Our joint work has sensitized the UN Member States to the vital importance of addressing leprosy's issues from a human rights perspective. I feel encouraged, but I also feel the added weight of responsibility. Our expectations can now be more substantial and so my own work needs to live up to such expectations. I expect a lot of hard work in the next three years, which I will undertake with a great sense of personal honor for serving our community and for which I hope to continue to receive the key support from the leprosy community.

”

Alice Cruz

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



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