

# FactSheet: Special Rapporteur Alice Cruz's report to the Human Rights Council, June 2018 (A/HRC/38/42)

## What is it?

Leprosy, also known as Hansen's disease, is a neglected chronic infectious disease caused by *Mycobacterium Lepae*. Leprosy has a long incubation period and symptoms may appear between 2 and 20 years after infection. Leprosy can occur from early infancy to very old age. The disease mainly affects the skin, the peripheral nerves, the mucosal surfaces of the upper respiratory tract and the eyes.

See more details in:

[www.who.int/en/news-room/fact-sheets/detail/leprosy](http://www.who.int/en/news-room/fact-sheets/detail/leprosy)

## Is it Curable?

Leprosy is curable with a combination of drugs known as multidrug therapy. Despite being curable, if not detected early and treated, leprosy can cause irreversible damage to the skin, nerves, limbs, and eyes, leading to disfigurement, blindness, loss of sensation, chronic wounds and neuropathic pain.

See more details in:

<http://www.who.int/mediacentre/factsheets/fs101/en/>

## LEPROSY

### Does it still exist?

In 2016, 214, 783 new cases were reported to the World Health Organization (WHO) by 145 countries.

Despite the impressive decrease in the number of cases since the introduction of multidrug therapy three decades ago (from over 5 million cases in the mid-1980s to approx. 200,000 cases at the end of 2016), there are still: (a) considerable and concerning rates of incidence and transmission; (b) a high proportion of late diagnosis which explains why in 2016, 12,437 new cases were reported with already advanced visible impairments; (c) underreporting which means that the reported cases are not exact, especially among women; (d) a shamefully high figure of new cases among children; and e) emerging new challenges, such as reported and possibly many underreported foreign born cases, in countries that no longer have the expertise to diagnose and treat leprosy, resulting in increasing transmission.

Most recently, an increase in new cases from 2015 to 2016 has been reported. The global elimination of leprosy as a public health problem in 2000 may hide the fact that there are still endemic countries, as well as highly endemic pockets within countries, and that there is still ongoing transmission. There is still worrying prevalence in 22 countries that have been identified by WHO as global priority countries for leprosy control.

The countries with more than 1,000 new cases in 2016 were: Bangladesh, Brazil, Democratic Republic of the Congo, Ethiopia, India, Indonesia, Madagascar, Mozambique, Myanmar, Nepal, Nigeria and Philippines. In endemic countries, leprosy mainly affects poorer communities and regions.

### How is it transmitted?

Contrary to the social representation of leprosy as a highly contagious disease, leprosy is not highly infectious, and most persons (around 95 per cent) who are in contact with the disease do not develop it.

Leprosy is most likely transmitted through droplets, from the nose and mouth, and during close and frequent contact with untreated cases.

## HUMAN RIGHTS VIOLATIONS AND DISCRIMINATORY PRACTICES

### What kind of human rights violations have been impacting persons affected by leprosy and their family members?

Persons affected by leprosy have historically been deprived of their civic, political, economic, social and cultural rights.

Women, men and children affected by leprosy, but also their family members up to the second and third generation have been consistently subjected to: stigmatizing language; segregation;

separation from their families and within the household; separation from their children; denial of care; denial of the means of subsistence; denial of a place to live; denial of education; denial of the right to own property; impediments to marry; impediments to have children; restrictions on their freedom of movement; denial of their right to participate in community, public and political life; physical and psychological abuse and violence; compulsory internment; forced sterilization; institutionalized silencing and invisibility; and removal from history.

### Are there still discriminatory practices and legislation in force?

Laws that discriminate against persons affected by leprosy still exist in more than 20 countries in the world, covering segregation, immigration, marriage, vote, public transportation, employment and housing.

These laws disregard and disrespect international human rights standards, in particular the principle of non-discrimination as stipulated in the Universal Declaration of Human Rights, the International Covenants and subsequent human rights instruments. In addition to law, jurisprudence and public

policies, discrimination is also a reality in the administration of the State, particularly in health services, education, State benefits and reaches extra-institutional settings, such as work, employment opportunities, marriage, community and family life.

Given the generalized vulnerability of persons affected by leprosy, the gap between *law in books* and *law in action* is severely exacerbated trapping persons affected by leprosy in a spiralling chain of disadvantage. But not only are persons affected by leprosy discriminated against, their families are equally impacted by stigma. In many social and cultural contexts, entire families are discriminated against.

### What kind of human rights should be protected and implemented by States in defence of persons affected by leprosy and their family members?

In 2010, the United Nations General Assembly adopted resolution 65/215 and took note of the principles and guidelines on the elimination of discrimination against persons affected by leprosy and their family members. In so doing, it established leprosy as a human rights issue and stressed that persons affected by leprosy and their family members should be treated as individuals with dignity and entitled to all human rights and fundamental freedoms under customary international law, the relevant conventions and national constitutions and laws.

Given the cross-cutting nature of leprosy related discrimination, relevant conventions, such as the International Covenant on Economic, Social and Cultural Rights (CESCR); International Convention on the Elimination of All Forms of Racial Discrimination (CERD); International Convention on the Elimination of All Forms of Discrimination against Women (CEDAW); International Convention on the Rights of the Child (CRC); International Convention on the Rights of Persons with Disabilities (CRPD); International Convention on the Protection of the Rights of All Migrant Workers and Members of their Families (CMW) protect persons affected by leprosy and their family members.

# FactSheet: Special Rapporteur Alice Cruz's report to the Human Rights Council, June 2018 (A/HRC/38/42)

## How will the Special Rapporteur work?

### Under the following principles:

- **Civic engagement:** The Special Rapporteur will engage and hold regular dialogues with States, United Nations agencies, funds and programs, civil society organizations and other relevant partners including persons affected by leprosy and their family members and their representative organizations.
- **Participation:** Openness, consultation and participation will remain the driving principles of the Special Rapporteur's working methods and she will actively involve local actors, civil society activists and organizations of persons affected by leprosy in her work.
- **Inclusiveness:** The Special Rapporteur will work in an inclusive manner and will give attention to groups that are more vulnerable to leprosy related discrimination, in particular women, children and persons affected by leprosy related disability.

### The Special Rapporteur will:

- Make annual reports on the activities undertaken in the fulfilment of her mandate and thematic issues to the Human Rights Council
- Undertake country visits at the invitation of Governments for following-up on the implementation of the Principles and Guidelines, identifying good practices and providing technical advice in policymaking and capacity building
- Engage on communications with relevant stakeholders including the States for gathering, requesting and exchanging information on violations of human rights
- Identify and disseminate good practices in the elimination of stigma and discrimination against persons affected by leprosy and their family members and in guaranteeing their fundamental rights and inclusion;
- Build cooperation with and among the United Nations human rights mechanisms and relevant actors and stakeholders in the promotion of awareness raising on the rights of persons affected by leprosy and their family members and to combat stigma, prejudice and harmful traditional practices and beliefs that hinder their enjoyment of human rights and fundamental freedoms

## THE MANDATE

In June 2017, the Council adopted resolution 35/9, establishing the mandate of the Special Rapporteur on the elimination of discrimination against persons affected by leprosy and their family members. The Human Rights Council appointed Alice Cruz to lead the mandate and she assumed her duties on 1 November 2017.



## PROMOTING THE HUMAN RIGHTS OF PERSONS AFFECTED BY LEPROSY AND THEIR FAMILY MEMBERS

### What are the Special Rapporteur's main strategies?

- Make leprosy a positive symbol of the Sustainable Development Goals agenda ensuring that persons affected by leprosy and their family members are not left behind
- Harmonize domestic laws and practices with international law, as well as guarantee effective access to rights, in order to tackle the structural disadvantage of persons affected by leprosy and their family members and empower them
- Eliminate stigmatization and prejudice through strengthened awareness-raising
- Promote the social and public participation of persons affected by leprosy and their family members and empower them to become the leading protagonists in the elimination of leprosy related stigma and discrimination and ensure its sustainability in the long-term

### What does the Special Rapporteur intend to achieve?

- Approach leprosy related human rights violations in their multiple dimensions
- Defend the strategic role of affirmative action for tackling stigmatization and discrimination
- Address the multiple vulnerabilities that impact the lives of persons affected by leprosy and their family members through a multi-sectoral approach based upon the implementation of the Sustainable Development Goals
- Acknowledge the lay expertise of persons affected by leprosy and their family members and to foster their participation in society at large and at all levels of decision-making

## THE REPORT

### What is the report about?

In the report, the Special Rapporteur outlines her vision, priorities and working methods for the next three years.

### Where can I find the report?

The report (A/HRC/38/42) and the translated versions will be available on the following link: <https://www.ohchr.org/EN/HRBodies/HRC/RegularSessions/Session38/Pages/ListReports.aspx>