

# **Statement by the Special Rapporteur on the elimination of discrimination against persons affected by leprosy and their family members, Alice Cruz**

## **Sasakawa Health Foundation Webinar “Issues in Leprosy amid the Coronavirus Pandemic”, 2020**

It's a great honour to participate in the first webinar of SHF as the United Nations Special Rapporteur on the elimination of discrimination against persons affected by leprosy and their family members.

The COVID-19 pandemic has changed the world. After more than half a year living with its health, economic, social and political consequences, we are now looking at recovery.

As the crisis generated by the COVID-19 pandemic unfolded, the emergence of a humanitarian crisis became rapidly obvious. After a thorough consultation process that I undertook together with the GPZL, I wrote a letter to governments on the disproportionate impact of the COVID-19 among persons affected by Hansen's disease and their family members that also included 5 key recommendations to them.

The global trends of such impact range from access to health to sustenance of livelihoods. Lockdown measures have brought additional barriers in the access to healthcare by persons affected by Hansen's disease, with the loss of financial and human resources from national Hansen's disease programs to the fight against COVID-19; interruption of key activities for early diagnosis and prevention of physical impairments; non-availability of Hansen's disease care in healthcare service. The continuum of care for persons affected by Hansen's disease has been seriously threatened and, for that reason, we can expect a setback in the interruption of transmission and early diagnosis. As the situation evolved in most countries, healthcare services started to resume some of their activities related to Hansen's disease. However, some of the problems have been aggravated, such as the lack of MDT – the treatment for Hansen's disease - in key countries.

Access to fundamental goods, such as food, energy for cooking, clean water, soap, masks and other protective items, were lacking for a substantive number of persons affected by Hansen's disease and their families during the first 6 months of this crisis. The impossibility of many persons affected by Hansen's disease, who have been structurally excluded from the formal labor market, to guarantee any income, together with the loss of safety nets essential for their survival, in the context of the quarantine and other exceptional measures enacted by the States, has determined that many persons affected by Hansen's disease and their families have been left to live in extreme poverty.

In order to respond to this humanitarian crisis, I called upon States to implement social security schemes that would allow individuals and families to acquire minimum healthcare, basic shelter and housing, clean water and food. Many organizations of persons affected by Hansen's disease have been advocating for social protection measures in their countries as well. In the cases where States have implemented cash transfer programs to ensure minimum standard of living for vulnerable populations during the crisis, such benefits have been in great measure inaccessible to persons affected by Hansen's disease for different reasons. So far, out of all countries that I was able to monitor, only Myanmar reported action taken by the government to specifically meet the needs of persons affected by Hansen's disease. In most countries, temporary food aid was the most common measure, but many of these measures have expired after the initial outbreak response, although the needs of the people persist.

In the case of the more vulnerable groups within the overall population affected by Hansen's disease, older people living in former Hansen's disease's sanatoriums were from the start at higher risk. There are still up to two thousands of such places in the world today and there is a great number of issues of concern, such as generalized institutional neglect leading to lack of food, clean water and hygiene and protective items, but also lack of biosecurity plans that can prevent the spreading of COVID-19 within these places; there is also the fact that some countries have turned parts of these sanatoriums into field hospitals for COVID-19 patients, putting the elderly population at a great risk. An even more disproportionate impact of the current crisis within the population affected by Hansen's disease is found among women, refugees, persons with disabilities, people living in remote areas, among which children are of the greatest concern.

In my letter to the governments, I present five key principles that should guide responses to the consequences of the crisis in the medium and long term. Here, I would like to highlight the

fourth principle. As I tell the governments, in the face of their limited action to ensure that information about COVID-19 is accessible to those left furthest behind, in order to achieve public health education's goals that are central to containing the novel coronavirus, the participation of grassroots organizations is critical for ensuring that relevant information reaches all people. Such key participation should be supported with proper funding. Such organizations play a key role in mainstreaming good practices, fulfilling institutional gaps and providing support services. Meaningful participation of the organizations of persons affected by Hansen's disease in policy-making, monitoring and evaluation is essential to ensure an inclusive response to the crisis. By the same token, building autonomy through empowerment, is vital for marginalized persons to achieve greater control over their lives and further their democratic engagement. The agenda for the Sustainable Development Goals is built upon the recognition that development is not only about transforming the material conditions of people in disadvantaged circumstances, but that also implies providing them with a voice and choice.

This was also the spirit of the recommendations to Non-Governmental Organizations presented in the report that I have issued together with the GPZL. There, I recommend NGOs to: develop and put in place a participatory framework for humanitarian aid that links relief to development; support grassroots organizations with funding and capacity building, and work with them to share information about COVID-19 and existing national social protection schemes to persons in the community. As we begin rebuilding our societies in the context of the crisis generated by COVID-19, we need to make sure that sustainability leads each and every one of our actions. Only through the empowerment of persons affected by Hansen's disease will systemic change be made possible.

That is why I congratulate SHF for creating a grant programme aimed at redressing the impact of the COVID-19 crisis, which is built upon the principles of ownership and promotion of autonomy. SHF's grant programme aims at recognizing and respecting local knowledge and expertise, while at the same time strengthening capacity of organizations of persons affected by Hansen's disease. By simultaneously linking relief to development, and by respecting their autonomy in implementation, this grant programme responds to the need to enable the leading role of persons affected by Hansen's disease as protagonists of change.

I wish SHF and the organizations involved in this new programme a great success in the defence of the rights of persons affected by leprosy and their family members.