

Key note speech at the side-event organized by Disabled Peoples' International and Sasakawa Health Foundation in partnership with the Permanent Mission of Japan, Permanent Mission of India, Permanent Mission of Portugal, Permanent Mission of Brazil and Global Partnership for Zero Leprosy on “Work and Employment Situation of Persons Affected by Leprosy amid the Coronavirus Pandemic and Efforts to Resolve the Challenges They Face” on the occasion of the 14th session of the Conference of States Parties to the CRPD, 18th June, 2021

Excellencies

Colleagues and partners

Ladies and gentlemen

Persons with the personal experience of leprosy - which is also called by many people and some States Hansen’s disease as a means, that I personally consider effective, to fight stigmatization associated with wrongful stereotypes and old beliefs – have systematically pointed out to me the barriers to their right to work and rights at work as being simultaneously the result and one of the causes of ongoing discrimination.

Importantly, they also report on barriers to the access to social protection and, more specifically, to disability related social protection benefits; and yet they should be fully recognized by national legal and regulatory frameworks as persons with disabilities in accordance with articles 1 and 2 of the Convention on the Rights of Persons with Disabilities, on the grounds of not only physical impairments and the multiple barriers imposed by society to their full participation, but also on the grounds of discrimination based upon harmful stereotypes.

The connection between the systematic exclusion of persons who have experienced Hansen’s disease from the open labour market and the disproportionate impact of the pandemic on their right to life was clear right from the beginning of the COVID-19 pandemic. That is why I address the right to work, among other economic and social rights, in my forthcoming thematic report to the Human Rights Council, which details the adverse effects of the pandemic and puts forward constructive recommendations for an inclusive recovery.

Unreliable casual labour with low income, unsafe working conditions and without entitlements to social protection or participation in social dialogue defines the livelihoods of the majority of these individuals. If before the pandemic they were already struggling with what one organization’s

representative referred to me as the “prepandemic crisis”, the pandemic became one additional basis for discrimination.

Persons who have experienced Hansen’s disease face formidable, intersecting and multiple barriers to freely choose their work and to enjoy rights at work. The testimony of one individual captures all too well how discrimination simultaneously operates at different levels of social life and is at the root of rights’ violations: while working as a public servant he was dismissed from his job after being diagnosed with Hansen’s disease; he then went back to work as a farmer in a community land, but he was also dismissed by the village committee that administered such land; resorting to growing vegetables in his backyard, he could not sell those at the local market because people were afraid to buy vegetables from him. This testimony represents a shared pattern of denial of equality of opportunities, as well as of denial of equality of treatment.

Some of the formal barriers that have systematically hindered persons who have experienced Hansen’s disease to work at the formal economy are: a) the more than 100 discriminatory laws that are still in force worldwide and that in some countries regard employment; b) institutionalized discrimination in what concerns hiring policies for public jobs; c) the fact that in some countries, traditional non-written customs deny land and inheritance rights to persons who have experienced Hansen’s disease, especially to women; d) discrimination at school, which has pushed too many persons who have experienced Hansen’s disease out of education.

During the current global crisis, persons who have experienced Hansen’s disease lost income-generating activities and safety nets. As one organization’s representative told me: “It is tough to see members [of the organization] dying from lack of food and other COVID-19 issues.” The widespread denial of social protection to persons who have experienced Hansen’s disease and the multiple and intersecting barriers that I map on my report to their access to mitigation measures, has aggravated all this.

Significant improvement is indispensable with regard to recovery plans, but I would like to highlight one in particular: the need to guarantee the right to participation in COVID-19-related plans and recovery, especially to the more marginalized groups. On my report to the Council I consider good mitigation practices the ones that were developed through collaborative work with the people’s organizations, guaranteeing the co-production of health, respecting autonomy, enhancing local capacities and linking relief to development. Indeed, community engagement is a

well-documented key strategy for responding to outbreaks in an equitable, appropriate and efficient manner. And the fact is that the people's organizations were the first ones to sound the alarm about the disproportionate impact of the COVID-19 pandemic and to act in order to ensure the survival of their peers. All this was done with very scarce resources. Very few NGOs implemented a participatory approach to humanitarian aid and only one State, to my knowledge, consulted persons who have experienced Hansen's disease.

To conclude, I would like to mention only a few of the constructive recommendations that I put forward in my report to the Council with the aim of contributing to an inclusive recovery. But first, a word on gender-based discrimination. Denial of inclusive education, furthered by denial of opportunities that can ensure economic autonomy to women with Hansen's disease and related disabilities, makes women more vulnerable to poverty and physical, psychological and sexual violence. Implementing gender-inclusive approaches to ensuring the right to work and ensuring rights at work and which affirm women's rights to inclusive education, vocational training, decent work and equal remuneration, and that also recognize unpaid care work in social protection schemes, is thus crucial.

Furthermore, and while I am preparing my thematic report to the General Assembly, which addresses discrimination in law, I would like to recall the importance of moving forward with legal harmonization and abolishing outdated discriminatory laws, but also of enacting anti-discriminatory legal and regulatory frameworks, in order to ensure both formal and substantive equality to persons who have experienced Hansen's disease. This is an unfinished business that demands urgent action.

Some other recommendations include:

The implementation of a whole-of-government approach that mainstreams persons who have experienced Hansen's disease into macro-level policies aimed at the transition from the informal to the formal economy;

Enabling the right to collective bargaining for persons who have experienced Hansen's disease and opening social dialogue to organized groups of persons who have experienced Hansen's disease working in the informal economy;

The inclusion of persons who have experienced Hansen's disease in public employment programmes;

Fulfilling accessibility and reasonable accommodation rights, including the provision of assistive devices and other disability inclusive mechanisms, to ensure a disability inclusive work environment in all productive sectors and work arrangements;

Recognizing not only visible physical impairments, but also invisible physical impairments, such as neuropathic pain or loss of sensation, as well as psychosocial impairments related to stigmatization as disabilities.

Implementing affirmative measures as a means to correct historical and structural disadvantage.

The COVID-pandemic has brutally revealed how the principle of universality of human rights as provided for in the Universal Declaration of Human Rights has hardly been fulfilled. That is why establishing minimum core obligations of social and economic rights regarding vulnerable groups as a matter of priority, may be a necessity now more than ever, together with anti-discriminatory policies that ensure the enjoyment of rights without discrimination. I am aware that the idea of establishing minimum obligations may be controversial and that is why I also call upon international cooperation for enabling comprehensive and human-centred development policies.

If one thing became clear during the pandemic, it is that "other people's problems" are everyone's problems. On this regard, I would like to recall that persons who have experienced Hansen's disease must be recognized as a vulnerable group with regard to COVID-19 vaccination, given that many of them are immunocompromised. Multilateral action may be key to save their lives.

There is much to learn from the history of leprosy or Hansen's disease that can be applied to the current global crisis, but the main lesson is: there is no building back better if States fail to put those who have been systematically pushed furthest behind at the centre of recovery efforts.

Thank you

Alice Cruz