Excellencies

Dear colleagues and fellow speakers,

The more adverse effects of climate change and conflicts continue to be mostly felt by people with less political and economic capital. Still, people leading decision-making on these issues are those who suffer a lesser impact. In order to build more equitable, and thus resilient, societies, it is necessary to recognize that there can be no social justice without cognitive justice.

A growing body of evidence has shown that community engagement is a key strategy for simultaneously preventing and responding to outbreaks and natural disasters. Communities have an accumulated and action-oriented knowledge about their territory and people, which can enhance the efficiency of States’ responses to crisis.

Persons with disabilities are among those who face greater threats to their survival and livelihoods in the face of natural and/or human made disasters and they are also the ones who can better identify the risks affecting them, their needs and contribute to solutions. Thus, the implementation of article 11 of the CRPD is inseparable from the participatory principle that frames the entire Convention. Notwithstanding, participation is often used in discourse and seldom put into practice. In order for participation to be meaningful, issues around recognition and access, as well as the barriers that hinder both, need to prioritized.

Persons affected by leprosy are still not recognized as persons with disabilities in many national legal frameworks, but also by many civil society organizations. And, yet, for the consultation I undertook to inform my next report to the GA, 74% of the persons affected by leprosy identified themselves as persons with disabilities.

There are several reasons that explain such limited recognition, here I would like to highlight two: leprosy has been historically dominated by the medical professions and people tend to look at it as a mere disease, and worse, as a mere biological phenomenon; and leprosy is mostly incident among countries of the Global South and the global narratives on disability are still largely framed by the perspectives coming from the Global North. ~

But 30% of family members also identified themselves as persons with disabilities, especially with psychosocial disabilities related to discrimination. I remind you that the Convention does not offer a fixed definition on disability, speaking instead of disability as an evolving concept in its preamble, leaving an open space for self-identification processes. But even when recognized as being entitled to disability rights, persons affected by leprosy continue to face multiple barriers to accessing and enjoying those.

Dear colleagues,

As I move to the final year of my role as mandate holder, I wish the people-centric approach I took for implementing my mandate can take a new step forward. That is why today I have invited Ms Subodha Galahitiyawa, an expert who is also a woman affected by leprosy, to speak in representation of the leprosy mandate.

In the same spirit, I urge States to implement with haste guideline 14.1 of the principles and guidelines for the elimination of discrimination against persons affected by leprosy and NGOs to adopt such a goal as priority in their advocacy work. In order to make systemic change reality, we must fight for a participatory citizenship that is inclusive of all people without any discrimination.

I thank you