

Interactive Dialogue with the UN entities on the CRPD implementation

Dec, 3rd 3pm-5pm EST

Sue Swenson, President of Inclusion International

Excellencies, Distinguished Delegates, ladies and gentlemen,

I'm honored to join today's interactive dialogue among the chair of the Committee on the Rights on persons with disabilities, the Special Rapporteur on the Rights of Persons with Disabilities, the Special envoy of the Secretary General and the UN system representatives. It is my further honor to speak on behalf of the civil society organizations.

Earlier this year, when I sent my application to be a speaker for this session, I planned to speak about the remaining challenges faced by people with intellectual disabilities and their families, such as being included in school with other children, having real jobs and being paid fairly, and closing institutions.

I was also ready to highlight the continuous marginalization of the role of families and the lack of support for and recognition of their roles by the disability community in order to achieve the realization and the full enjoyment of rights by persons with disabilities.

I was prepared to highlight the main achievements of the past year such as the adoption of the UN Disability Inclusion Strategy, the adoption of the UN Security Council Resolution on situation of person with disabilities in armed conflict and humanitarian crises which are important achievements that show real progress in the implementation of the CRPD and the Agenda 2030 and in the recognition of the rights of people with disabilities by the global community.

These are the main topics I wanted to address through my remarks to you before the apparition of the pandemic.

Today, less than a year after and after the global pandemic that affected more than 55million persons and killed more than one million persons in the world, my speech will raise the most fundamental rights of people with disabilities. This pandemic has set us back a few decades. Even though the pandemic did not create new problems for people with disabilities, rather, it has magnified them and made them more visible. It shows us that the progress we thought we had achieved is in fact not sufficient because it is not systemic.

This pandemic revealed the failure of the education systems which consider themselves to be inclusive while many learners with disabilities found themselves out-of-the curriculum due to the non accessibility of the solutions provided. It has shown the weaknesses of the health services in most of the countries where people with disabilities were excluded from receiving care through the triage schemes. The pandemic has also emphasized how on the precarious are the lives shared by people with disabilities and their families. We know that

disability and poverty are strongly linked, the pandemic amplified the poverty of the ones who were already poor but it has put hundreds of people and families in a difficult economic situation due to the loss of their jobs and the weakness of social protection systems.

If nothing else, we have learned that around the globe, governments can not respond to ordinary difficulty or universal crisis without relying on families and families— including parents, spouses, grandparents, siblings, and children with and without disabilities—are the last best hope when government programs fail to meet a crisis. It makes sense that families should have the tools they need to understand the CRPD and the human rights of a disabled family member. Human rights are, after all, universal. They do not depend on the challenges, whims, or principles of governments or families. DPOs strive to make this a reality. It has been a difficult road this year.

We have heard from Inclusion International's network that:

- Learning options provided for school-aged children with disabilities during the pandemic were not accessible (44% of respondents)
- Essential formal support services either stopped being available or were reduced in their country in response to COVID (87.1% of respondents said this), and informal supports were reduced or no longer available (89.82% of respondents reported this)
- People with intellectual disabilities and their families were not able to access new social protection mechanisms introduced in response to COVID (from 42% of respondents)
- Government did not release information about the pandemic or lockdown measures in plain language or easy read (from 51% of respondents)

Several studies, reports, and statements developed by civil society organizations raise the alarm about the horrific situation and the impact of this pandemic on people with disabilities worldwide.

Recalling the overarching theme of this year's conference 'A decade of action and delivery for inclusive sustainable development: implementing the CRPD and the 2030 Agenda for all persons with disabilities', a lot still to be done by Governments in order to fully implement the CRPD and the 2030 Agenda.

As a global DPO representative, we call on States Parties and other stakeholders:

- To develop a pandemic response which is inclusive of all persons with disabilities,
- To consult with people with disabilities, their families, and their representative groups in building the short-term and longer term pandemic recovery strategies, and empower them to participate in policymaking and emergency response planning.
- To adopt systemic changes which are key to ensure a full inclusion of all people with disabilities (such as in education, deinstitutionalization, health care, and social supports), including people who are marginalized in multiple intersecting ways.

- To use the full breadth of data systems, including census counts and the Geographic Information Systems that serve other areas of the SDGs, to allow policymakers to see the us more clearly: where we live, who we are, and what we need in our own homes, cities, and nations and around the world.

Thank you