

Introduction

The World Federation of the Deaf is a member of the International Disability Alliance. Together, we make up a network of over 1,100 organisations of persons with disabilities and their families from across eight global and six regional networks.

We <u>promote the rights of persons with disabilities</u> across the United Nations' efforts to advance human rights and sustainable development. We <u>support organisations of persons with disabilities</u> to hold their governments to account and advocate for change locally, nationally and internationally. The cornerstone of our work is the <u>United Nations Convention on the Rights of Persons with Disabilities</u>. We promote the effective and full implementation of the UNCRPD, and compliance by governments and the UN System, through the active and coordinated involvement of representative organisations of persons with disabilities at the national, regional and international levels. The 2030 Agenda and its Sustainable Development Goals are also integral to IDA's work to promote inclusive, sustainable development in line with the UNCRPD.

We advocate for a more inclusive global environment for everyone. I'm glad that this go-around for this meeting, we will be able to converse with one another.

I'm going to start with a few of the human rights violations against persons with disabilities we have observed in the course of the pandemic, then talk about the importance of participation, and end with some of our recommendations for vaccine rollout.

Pandemic Rights Violations

When the pandemic hit over one year ago, our alliance hit the ground running. One of our first concerns was that persons with disabilities were unable to access vital information about COVID-19 on equal basis with others. Daily briefings by the World Health Organization and national governments around the world were not accessible.

International Sign interpretation, closed captioning, written or audio description of graphs and videos, and documentation in plain language (easy-to-read) were not included. This excluded huge proportions of us from accessing the vital information we needed to protect ourselves and those around us.

So, we campaigned for all COVID-19 responders (including the UN, WHO and national governments) to work with representative organisations of persons with disabilities to distribute fully-accessible public health information.



In article 21 of the Convention on the Rights of Persons with Disabilities (the CRPD), we have the right to freedom to seek, receive and impart information and ideas on an equal basis with others; we have the right to access to information. This is a fundamental component of the right to health.

We have also faced discrimination through the use of "stereotypes about an individual's disability to ration care.^{1"} This is discrimination has taken place under the guise of triage. Organizations of persons with disabilities around the world sprang into action as hospital systems determined life-or-death based on their analysis of our quality of life.

Governments did not follow a human rights-based approach to access to health care, based on the principle of non-discrimination² when developing assessment and determination processes for eligibility. We campaigned against such practices that discriminated against our access to live-saving health care services. The Siracusa Principles on the Limitation and Derogation Provisions in the International Covenant on Civil and Political Rights state that for states party, non-discrimination is an obligation that cannot be suspended, even in times of emergency.³

Our Right to Participation

This never would have happened if states party to the Convention on the Rights of Persons with Disabilities had respected our rights to participation. and experience is absolutely vital to ensure governments protect, respect and fulfill our rights. So much so that organizations of persons with disabilities are included as one of the main vehicles in Article 29 for states parties to actively promote an environment in which persons with disabilities can effectively and fully participate in the conduct of public affairs.

The pandemic has made our participation in public affairs a stark life-and-death matter for many of us.

¹ Singh S. Disability ethics in the coronavirus crisis. J Family Med Prim Care 2020;

^{9:2167-71.}file:///C:/Users/erina/OneDrive/Documents/IDA/Disability%20ethics.pdf

² OHCHR. Policy Guidelines for Inclusive Sustainable Development Goals FOUNDATIONS. 2020.

https://www.ohchr.org/Documents/Issues/Disability/SDG-CRPD-Resource/policy-guideline-foundations.pdf

³ The Siracusa Principles on the Limitation and Derogation Provisions in the ICCPR, https://www.icj.org/wp-content/uploads/1984/07/Siracusa-principles-ICCPR-legal-submission-1985-eng.pdf



Article 4.3 of the Convention says: "States Parties **shall closely consult** with and actively involve persons with disabilities, including children with disabilities, through their representative organizations."

And the UN Disability Inclusion Strategy for all UN entities and country teams requires "Systematic close consultation with and active involvement of, organizations of persons with disabilities on all disability-specific issues and broader issues" to meet its requirements.

Vaccines

And now, we are campaigning for the prioritization of persons with disabilities in vaccination campaigns around the world. We are calling on all governments, United Nations agencies and the private sector to immediately take all measures to ensure that:

COVID-19 vaccinations are available in free or low-cost targeted programs to all people including persons with disabilities and support networks of their choice. To reach the furthest behind first, persons with disabilities must be prioritized; vaccinations are not of much use if the people supporting an individual get sick. Prioritization must include personal assistants, family caregivers, and persons working in disability-related services. This is in line with the WHO guidance.⁴

Specific outreach should be conducted to ensure that persons with disabilities know of the availability of vaccinations, and all information campaigns are inclusive and accessible to persons with disabilities, including gender and age-appropriate information. Organizations of persons with disabilities have been stepping up to help provide this information.

Receiving a COVID-19 vaccination must be based on **free and informed consent** of persons with disabilities, as outlined in Article 25 of the CRPD on the right to health. Autonomy and legal capacity of all persons with disabilities including persons with intellectual disabilities, persons with psychosocial disabilities and autistic persons must not be undermined with justifications such as public good or the best interest of the person;

International organizations and government should ensure that persons with disabilities and their representative organizations **meaningfully participate in policy-making and planning** on distribution of COVID-19 vaccinations and related processes;

⁴ April 21, 2021 WHO Guidance



And such processes cannot be done successfully if all information systems related to vaccinations are not collecting **data disaggregated by age, gender and disability** as well as other relevant areas. Article 31 of the CRPD requires States Parties undertake to collect appropriate information, including statistical and research data, to enable them to formulate and implement policies to give effect to the convention.

In closing, the pandemic has laid bare that we have a very long way to go to realize our rights under the CRPD. It has also steeled our resolve to support one another, pushing for an equality firmly rooted in human rights.