Disability Rights Monitor Report Presentation

February 24, 2021

Stakeholder Group of Persons with Disabilities’ Disability Data Webinar

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I am so glad to be here with you today to talk about the Disability Rights Monitor Report “Disability Rights During the Pandemic.”

It was produced by a group of organizations, including **The Validity Foundation – Mental Disability Advocacy Centre, The European Network on Independent Living, Disability Rights International, The Disability Rights Unit at the Centre for Human Rights, University of Pretoria, The International Disability and Development Consortium (IDDC),** The **Disability Rights Fund (DRF)**, and its sister organization, the **Disability Rights Advocacy Fund (DRAF), and my organization, the International Disability Alliance.**

**We are** an Alliance of 14 global and regional organisations of persons with disabilities. Together, the IDA Members promote the rights of persons with disabilities across the United Nations' efforts to advance human rights and sustainable development. IDA supports organisations of persons with disabilities to hold their governments to account and advocate for change locally, nationally and internationally.

We all supported this survey to gather the data necessary to sound the alarm about the catastrophic impact of the COVID-19 pandemic on persons with disabilities worldwide and to catalyse urgent action.

Covid-19 is everyone’s problem. But it effects persons with disabilities in specific ways. Persons with disabilities face increased risk of contracting Covid-19 due to existing health conditions, inequities in underlying health conditions and social determinants of health, as well as contact with support service providers, just to give a few examples. This is why we have the Convention on the rights of Persons with Disabilities – the CRPD; to articulate persons with disabilities’ specific equal rights.

# Overview of Importance of Report

This report is really important. It shows we haven’t gained as much ground as we thought CRPD came into force. It reveals approaches specifically prohibited by the CRPD. It reveals the fragility of support systems for persons with disabilities.

The survey collected 2,152 responses from 134 countries between April 20, and August 8, 2020. The report was launched in October. Nearly all, over 2,000 were responses from persons with disabilities, their representative organisations, and family members, making it the largest internationally comparable data set on the experiences of persons with disabilities during the COVID-19 pandemic.

And this gives us evidence-based recommendations for change.

# Explanation of Methodology

In addition to over 2000 responses, individuals wrote more than 3,000 testimonies. They varied in length from a short sentence to long paragraphs. The testimonies were then coded and thematically analysed.

The combination of qualitative and quantitative data provides a nuanced, in-depth insight into the experiences of persons with disabilities, and state measures to protect their rights during the pandemic.

The survey was initially intended to triangulate the data from the three stakeholder groups: persons with disabilities, governments, and national human rights institutions. But, we did not end up with equal representation among these groups. Despite the best efforts of DRM to disseminate the survey among governments and human rights institutions, the survey received a very low number of responses from these stakeholders (26 governments and 12 human rights institutions).

The survey also had some of the same shortcomings of other online surveys: overrepresentation from wealthy countries, speaking one of the languages it was translated into. Each network sought to minimize this with outreach, and print versions were made available.

# Further Detail of Some Findings

## Deinstitutionalization:

The first is that the pandemic has highlighted the dangers of institutionalization in a new way:

The survey findings shed light on the deadly conditions that resulted in the high death rates within large-scale and small-scale institutions. Thirty-three percent (476) of the respondents who knew about the situation in institutions said that their government took no measures to protect the lives, health, and safety of persons with disabilities in institutions.

In the words of Special Rapporteur on the rights of persons with disabilities, Gerard Quinn: “These places should not exist.” Deinstitutionalization is not just an issue of the human rights being realized. This shows it should be a public health priority.

### Older persons with disabilities in institutions

The situation is dire for older persons with disabilities in institutions: One-third (506) of the respondents who knew about the situation said that their government took no measures to protect the life, health, and safety of older persons. Respondents were also concerned for the effects that the isolation was having on the mental health of older persons in institutions.

### Restrictions on right to privacy, deprivation of liberty, impacting right to health:

This was particularly pronounced with bans on visitors and bans on residents leaving. Of those who knew about the situation, the majority, 69% (819), said that persons with disabilities were restricted or banned from leaving the institutions (refer to Figure 5 on the right). A further 84% (1,172) said that the government had banned, or restricted visits from family, friends or others in social care settings, and 82% (984) of those who knew about the situation in psychiatric health facilities said that their government had banned visits.

## Breakdown of community supports

The survey reports a breakdown in community supports, as well. Many of the essential services that persons with disabilities rely on to live independently in the community were not available during the pandemic. For example, as outlined in Table 3 below, 38% (809) of the survey respondents said that persons with disabilities did not have access to personal assistance. Thirty-three percent (708) said that persons with disabilities did not have access to informal care. A further 23% (490) said that persons with disabilities did not have access to assistive technologies.

### Access to information

This included inadequate access to information. Almost one-third (621, 30%) of respondents said that persons with disabilities did not receive enough information about the prevention of COVID-19.

## Access to food

The survey has revealed that persons with disabilities around the globe did not have access to food and adequate nutrition during the COVID-19 pandemic. Almost one third (633) of the survey respondents in 81 countries said that persons with disabilities in their country could not access food. The ten countries where the highest percentage of respondents reported no access to food were Uganda, Nigeria, Kenya, Bangladesh, India, Colombia, Côte d’Ivoire, Tanzania, Rwanda, and Peru. Several high-income countries were also among those with high proportions of people who said that they could not access food. More than 25% of respondents from Belgium, Canada, France, the United States of America, and the United Kingdom said that persons with disabilities did not have access to food during the pandemic. The findings indicate that the vast majority of governments did not take the appropriate steps to safeguard and promote the right to access food.

## Police harassment

There were also more overt reports of harassment from law enforcement. Around the world persons with disabilities and their family members have had no choice but to break curfew rules to access food and essential medical supplies, because no exceptions were made for them. Public information campaigns were inaccessible to large populations during this period. The majority of respondents (77%, 1105) said that they did not have information about penalties resulting from breaking state of emergency rules (fines, sanctions, arrest) imposed on persons with disabilities.

## Denial of health treatment for COVID-19 and triage discrimination

The last specific area I’ll mention today is access to health services. The majority of respondents who knew about access to healthcare for COVID-19 (52%, 390) said that they were denied or deprived of healthcare for COVID-19 during the pandemic.

Several written testimonies from Canada, the United Kingdom, the United States of America, Austria, Luxembourg, the Netherlands, Georgia, France, and South Africa said that hospital triage procedures indicated discrimination against COVID-19 patients with disabilities in the event of a shortage of hospital places.

And all of these areas: interactions with police, access to healthcare, access to food, institutionalization, hit marginalized persons with disabilities, those facing racial or gender discrimination, LGBT persons with disabilities, those with intellectual disabilities, and those with psychosocial disabilities, and their families, especially hard.

# Where to go from here

So, what is the answer? Consultation and participation, as Mr. Viera and Ms. Nuta have already discussed. Governments have to hear this.

The CRPD requires it. And policy makers working with organizations of persons with disabilities about decisions that affect them drives efficiency.

While this report has highlighted some examples, it cannot do justice to the crucial work undertaken by many organisations to make up for governments’ failings. If there is a lesson to be learned, it is that persons with disabilities and their organisations are key to the planning, preparation and implementation of any emergency response, and their crucial role must be adequately acknowledged and supported and they must be integrated into further response.