

# IDA Survey on the Experiences of Persons with Disabilities Adapting to the COVID-19 Global Pandemic Executive Summary and Recommendations

September 2021



*"(The pandemic is) so devastating. Persons with disabilities should be given preference in all COVID-19 interventions."*

Woman with deafblindness, Palestine

*"Because my child is small, I cannot work. I have nowhere to leave him. My child is still isolated up to now, for fear that he will be infected."*

Man with an intellectual disability, Bolivia

*"During COVID-19 I have experienced unstable mental health. I became so anxious and later went into a very bad depression that necessitated me to seek medical attention which was non-accessible, so I only depended on family and peer support."*

Indigenous woman with a psychosocial disability, Uganda

*"Many women with disabilities in underdeveloped or developing countries. Women living in villages or even small towns are still not that literate or tech savvy so that they can get the proper information."*

A blind woman, India

## Introduction

The global COVID-19 pandemic drastically transformed human life, many aspects of which have yet to be normalised. While some countries go through waves of high infection rates, and new variations of the virus are being identified, in other regions life is getting back to a semi-normal state due to successful vaccination plans. Many governments are in the process of developing or implementing recovery plans to mitigate some of the economic and social consequences of the pandemic. These rapid changes and unstable conditions particularly impacted marginalised groups including persons with disabilities.

The IDA COVID-19 survey contributes to the growing body of international evidence documenting the disproportionate impact of the pandemic on persons with disabilities, addressing more specifically the situation of underrepresented groups in underreported regions. It is estimated that 80% of persons with disabilities live in developing countries<sup>1</sup>. Yet, there are considerable gaps in documenting the impact of COVID-19 on their lives at an international level. The survey addresses this gap by mainly focusing on these regions. Developed based on active consultations with persons with disabilities and their representative organisations, the survey adopted plain language, to maximise participation among people who are rarely consulted in research on disability rights, during the pandemic. As an example, 17% of respondents self-identified as having an intellectual disability.

The survey documents the experiences of persons who face multiple and intersecting forms of discrimination, including indigenous groups and racial minorities. It captures the experiences of groups that are not usually consulted, including persons with intellectual disabilities, and parents with disabilities. The survey also highlights the multiple and intersecting forms of discrimination experienced by persons with disabilities in areas where there are natural disasters and humanitarian emergencies.

This report presents the experiences of persons with disabilities, in their own words. It is a mixed methods study, which was conducted in three interrelated stages: descriptive quantitative analysis, thematic qualitative analysis, and statistical testing of hypotheses. The triangulation of the data gives an in-depth insight into the experiences of persons with disabilities during new waves of the pandemic as well as the recovery and reopening phases.

The survey received a total of 600 responses from around the world. The fact that the survey was open only for a short period, combined with digital barriers to accessing the online survey, as well as the multiplication of surveys now proposed can be understood/attributed to have impacted the outreach. However, the diversity of respondents representing different regions and constituencies and also the quality of testimonies shared, resulted in a great source of information about economic and social impact of the pandemic on lives of persons with disabilities around the globe.

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<sup>1</sup> United Nations, Department of Economic and Social Affairs <https://www.un.org/development/desa/disabilities/resources/factsheet-on-persons-with-disabilities.html>

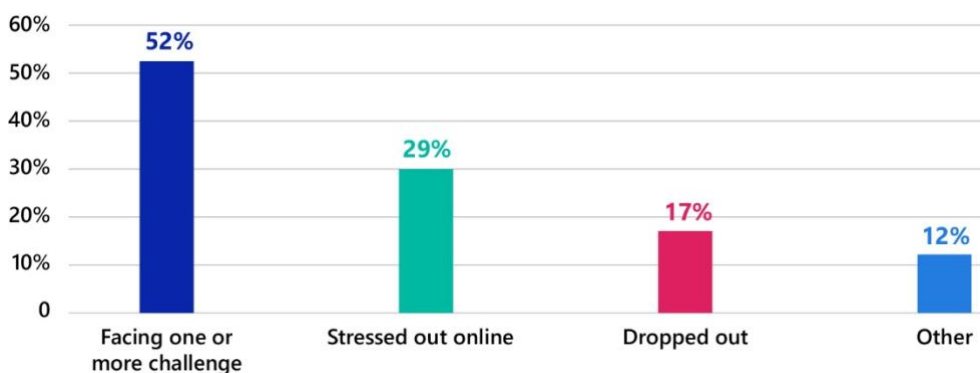
## Main findings

### Impact on social and economic rights

Forty-seven per cent of the respondents said that they lost all or some of their income during the pandemic. Almost two thirds (65%) said that they faced at least one challenge at work since the beginning of the pandemic. Challenges included barriers to communication because of facemasks or income loss.

Fifty two per cent of respondents who were in education said that they faced at least one challenge or barrier to education. Twenty nine percent said that they were stressed out with online classes and 17% dropped out of education during the pandemic.

#### ● Barriers and challenges to education



### A mental health crisis

The findings shed light on the socio-economic impact of the pandemic on the mental health of persons with disabilities. We found indications of some crisis in mental health for people with disabilities, many of whom lost their income, support and services during the pandemic. Eighty-two percent of respondents said they were more anxious or worried since the pandemic began, while 74% said they were more sad or depressed. Many people fell into a vicious cycle of losing support services, facing barriers in fulfilling their basic needs, and experiencing mental health challenges without having access to psychosocial support. People who lost their support services or their income were more likely to experience anxiety.

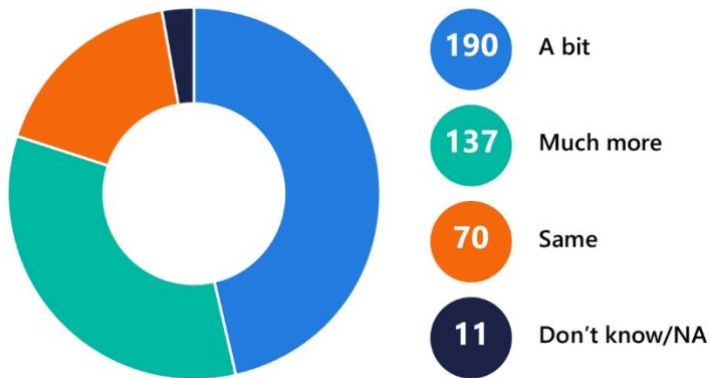
Almost half (48%) of respondents sought support for anxiety or depression. Most people received informal mental health support from family or friends. However, the survey also highlights the breakdown of communication, social supports, and peer networks because of social distancing. Three quarters of respondents said their communication with others was negatively affected by social distancing. Breakdown of communication because of social distancing had a negative impact on the mental health of persons with disabilities with 81% of those who lost communication reported feeling more depressed than before the pandemic.

Some people shared their experience of isolation and loneliness because of social distancing and less communication with other people. This was affecting their mental health.

*"It's extremely isolating and frightening to live alone as a PWD during a pandemic. It triggers my C-PTSD, heightens my anxiety levels, increases frequency of panic attacks and plummets me into helpless moments of depression."*

Woman with a physical impairment, Canada

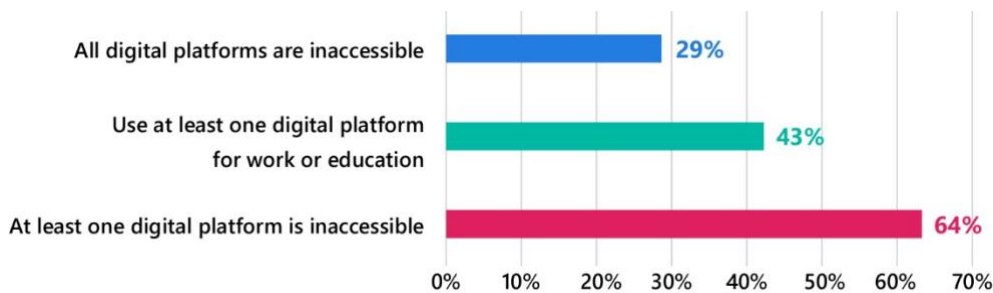
● **Depression among those who have less communication because of social distancing**



**Communication and digital access**

Most people received information about COVID-19 from social media. While digital access was a useful source of information about COVID-19, many respondents faced digital barriers which had a negative impact on employment and education. Only 29% of respondents who use digital platforms for work or education said that all online platforms are accessible to them. Sixty-four percent found at least one platform inaccessible. Parents with disabilities faced digital barriers when supporting their children to do remote schooling. Twenty-four percent said that their children cannot join online classes because they cannot afford internet access, or they have a poor online connection. A further 21% said that the online schooling application was inaccessible.

● **Digital access for work and education**



**The experience of underrepresented groups**

The survey gives a rare insight into the experiences of parents with disabilities during the pandemic. It captures the voices of persons who are rarely represented in research, including parents with intellectual disabilities in the Global South. The survey findings suggest that parents with disabilities were more likely to lose income during the pandemic than other respondents, with 55% of parents losing some or all of their income.

People with intellectual disabilities were more likely to lose their income than other respondents. Several people explained that it is difficult to find a job as a person with an intellectual disability.

## Experience of people with disabilities living in humanitarian settings

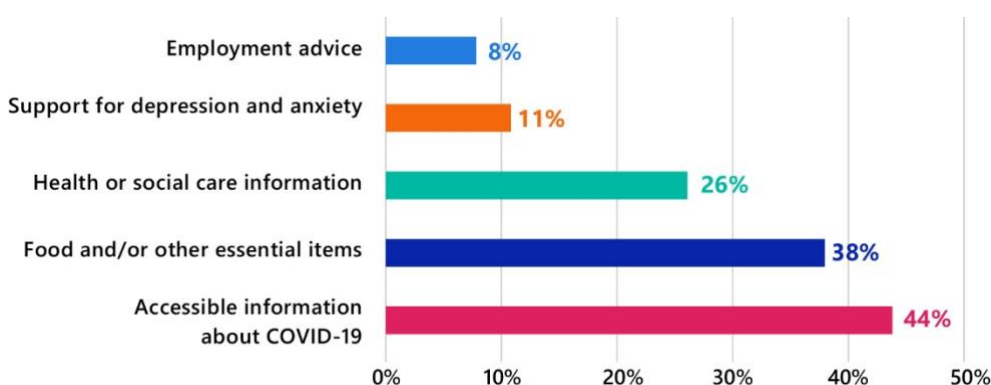
The findings serve as a stark reminder of other natural disasters and humanitarian emergencies that took place during the COVID-19 pandemic. One quarter of respondents said there was a flood, a war or armed conflict, a cyclone, an earthquake, or other crisis in their country. Most respondents in these areas were women. Humanitarian emergencies and natural disasters combined with the barriers created by the COVID-19 pandemic have a devastating impact on the rights of persons with disabilities in these areas. For example, 64% of people from these areas faced at least one barrier to access healthcare and medicines, making them more likely to experience deteriorating health during the pandemic.

## The role of OPDs in the pandemic response

Near half (41%) of respondents said that they received at least one type of support from their local organisations of persons with disabilities (OPDs). In many cases, OPD support and capacity building moved online. While digital platforms provided a way for people to keep in touch with OPDs and peer networks, there is a digital divide between those who have internet access and those who can not afford or can not access signal in their areas.

OPDs played a key role in bridging the gap between public COVID-19 service providers and persons with disabilities including by acting as information hubs. OPDs also were significantly impacted by funding cuts and were operating on reduced staff of mostly volunteer time. The impact of the pandemic on the sustainability of OPDs has been immense. In many cases, the priorities of OPDs have shifted from advocacy to service delivery – also impacting how disability rights are advanced in the longer term. There is the risk of OPDs becoming providers of services to persons with disabilities that should be essentially the role of the State.

### ● Support from OPDs



OPDs sometimes played a critical role in getting vital supplies to persons with disabilities during the pandemic.

*"My organisation has been managing the donation of food and cleaning packages, with the Government the prioritisation of People with Disabilities in the delivery of food, online support groups and the collection of experiential experiences of women with disabilities in times of coronavirus."*

Woman with physical impairments, El Salvador

## Key recommendations

The International Disability Alliance (IDA), as a global representative network of persons with disabilities and their organisations from various regions and constituencies, urges all States around the world to take the following measures:

1. Ensure that all national or local studies and assessments on the impact of COVID-19 collect information on the experience of persons with disabilities, including under-represented groups, and are available in all accessible formats;
2. Design and implement specific studies to document the impact of the pandemic on human rights of persons with disabilities and their families;
3. Ensure close consultation with and active involvement of persons with disabilities and their representative organisations including organisations of underrepresented groups in designing, implementing and monitoring COVID-19 socio-economic recovery plans;
4. Include specific measures in national and local recovery plans to ensure addressing negative consequences of the pandemic on persons with disabilities including the under-represented groups;
5. Mandate different sectors of the government including social security, employment, health, support systems and other relevant sectors to mainstream disability in their recovery plans, and introduce disability-specific plans as appropriate;
6. Introduce a detailed plan to transform national emergency response systems to enhance disability-inclusion, accessibility and transparency based on close consultation with persons with disabilities and their representative organisations;
7. Take all appropriate measures to ensure that different layers of emergency responders are sensitised and properly informed of the rights and needs of diverse groups of persons with disabilities, and are prepared to provide emergency support to them in case of future emergencies on equal basis with others; and
8. Dedicate sufficient resources and make strong commitments through international cooperation to ensure enhanced international funding for OPD capacity-building as well as disability-inclusive and accessible emergency response plans.

## Thematic recommendations

### Healthcare services

Considering the findings, we call on States and all relevant stakeholders to take the following measures to respect, protect and fulfil the right of persons with disabilities to enjoy the highest attainable standard of physical and mental health:

- Ensure that persons with disabilities and support networks of their choice have priority access to COVID-19 vaccinations;
- Resume the provision of accessible and quality medical goods, information and services that were suspended during the pandemic;
- Ensure that persons with disabilities in areas with humanitarian crises or natural disasters have access to medicine and healthcare during and after the pandemic;
- Address the negative impact of the pandemic on the mental health of persons with disabilities by ensuring access to a range of disability-inclusive mental health supports and services, on the basis of free and informed consent; and
- Design and implement national health transformation plans to ensure that persons with disabilities, in particular the under-represented groups, may access emergency health services on an equal basis with others, and are not subject to discrimination and exclusion in the case of scarcity of resources.

### Support services and networks

We call on governments and international organisations to ensure that they fulfil their commitments under international law. In particular, Article 19b of the UN Convention on the Rights of Persons with Disabilities requires State Parties to ensure that persons with disabilities “have access to a range of in-home, residential and other community support services, including personal assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community”. Considering the findings, we recommend that governments:

- Resume the support services that were disconnected during the pandemic;
- Recognise that loss of support has a devastating impact on the mental health of persons with disabilities and plan to ensure that such a large-scale loss of support is avoided in any future emergencies;
- Ensure that persons with disabilities have access to a range of services during disasters and other emergencies;
- Ensure that the data collected from disability assessment or other sources is well used for case management or provision of support services during disasters and afterword;
- Ensure that persons with disabilities have access to financial assistance to guarantee an adequate standard of living during disasters or other emergencies; and
- Ensure that the criteria for accessing emergency government support does not discriminate on the basis of disability.



## Livelihood and income

Considering the findings, we call on governments and global actors to take the following measures in accordance with international human rights rules, particularly Articles 27 (work and employment) and 28 (adequate standard of living and social protection) of the UN Convention on the Rights of Persons with Disabilities and the Sustainable Development Goals (poverty eradication):

- Guarantee that persons with disabilities have an adequate standard of living including access to food, housing, medication, and other essentials in times of disasters or other emergencies;
- Support persons with disabilities in finding, maintaining and/or returning to employment after the pandemic, ensuring accessibility and provision of reasonable accommodation to ensure that persons with disabilities do not face discrimination and exclusion in remote working or other new modalities of work;
- Provide financial assistance to persons with disabilities who lost their job or income during the pandemic, including those working at informal sectors, and ensure all poverty reduction programmes are inclusive of persons with disabilities; and
- Provide support to persons with disabilities and their informal support networks to cover the disability related costs during disasters and beyond.

## Education

Considering the findings, we recommend that governments take the following measures, particularly in relation to their obligations under national law, including the Sustainable Development Goals, the Convention on the Rights of the Child, and the UN Convention on the Rights of Persons with Disabilities, in particular Article 24:

- Ensure that persons with disabilities have access to education on an equal basis with others and that reasonable accommodations are provided during disasters or emergencies;
- Provide necessary supports, including financial supports, assistive technologies, and human resources to ensure that persons with disabilities are not left behind at any level of the education system;
- Ensure that remote classes are accessible for students with disabilities and for parents with disabilities who need to support their children in remote education; and
- Facilitate persons with disabilities returning to school after the pandemic and consider any additional barriers that they may face when returning.

## Information and communication

Considering the survey findings, we recommend that State Parties respect their obligations under international law, in particular under Article 9 of the CRPD which requires that State Parties “take appropriate measures to ensure persons with disabilities access, on an equal basis with others, to information and communications, including information and communications technologies and systems, both in urban and in rural areas”. We recommend that State Parties:

- Continue to ensure access to all information and communications on the status of the pandemic, limitations imposed, and changing regulations for persons with disabilities in all accessible formats including by provision of sign language interpretation, online captioning, interpreter-guides, and easy-to-read plain language; and
- Ensure that healthcare systems, education systems, legal systems, and other public services provide information in all accessible formats, and are prepared to facilitate accessible and safe communication for all persons with disabilities requiring their services during and post pandemic.

## Engagement with OPDs

Considering the findings, we recommend that governments take the following actions in line with their obligations under international law, particularly Article 4 of the UN Convention on the Rights of Persons with Disabilities which requires State Parties to “closely consult with and actively involve persons with disabilities, including children with disabilities, through their representative organisations”:

- Actively involve OPDs representing diverse demographics of persons with disabilities in COVID-19 response and recovery planning;
- Recognise and support the expert role of OPDs and peer support in protecting the rights of persons with disabilities during the pandemic and afterwards; and
- Provide adequate funding and other forms of support to OPDs to support capacity building and relief efforts during disasters or other emergencies.

