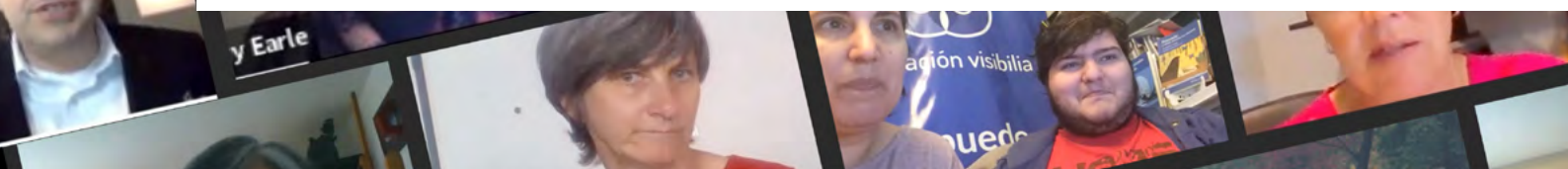




A Global Agenda for Inclusive Recovery:

**Ensuring People with
Intellectual Disabilities
and Families are Included
in a Post-COVID World**



**A Global Agenda for Inclusive Recovery: Ensuring
People with Intellectual Disabilities and Families
are Included in a Post-COVID World**

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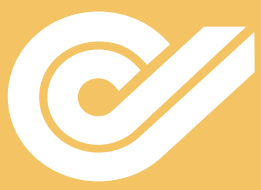
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Table of Contents

Executive Summary	4
Introduction	6
How the Information Was Collected	9
Impact of Covid-19 on People with Intellectual Disabilities and Their Families	14
Access to Information	14
Access to Support	18
Access to Health Care	24
Support for Families	28
Institutions	34
Social Protection Measures	38
Education	43
Employment	52
Summary of Policy Recommendations	54
Acknowledgements	57



Executive Summary

Over the course of the pandemic, Inclusion International has heard from self-advocates, families, and the organizations that represent and advocate for them about their experience of being left behind and ignored during the COVID-19 crisis.

We heard directly from people and organizations that during the pandemic, people with intellectual disabilities lost access to essential services and support, were excluded from education, were excluded from social protection systems, and were denied access to information about the changes happening in their lives due to COVID-19. People living in institutions lost their lives due to their unsafe living conditions, and others were denied access to lifesaving health care due to discriminatory triage practices.

This report documents that experience of exclusion - it tells the story of so many people with intellectual disabilities and their families who were ignored in a global crisis, sacrificed, or deemed less valuable. This report also tells the story of the organizations of persons with disabilities (OPDs) representing people with intellectual disabilities and their families who took action to respond to this exclusion. Despite the families and self-advocates that make up the staff and volunteers of these organizations operating at reduced



This report documents the experience of exclusion - it tells the story of so many people with intellectual disabilities and their families who were ignored in a global crisis, sacrificed, or deemed less valuable.



capacity due to the disproportionate impact of the pandemic on their own lives, they were called on and took action to respond directly to the growing need for direct support from families left without services, without support, and with unmet basic needs.

These experiences reveal pre-existing structural inequalities that affected the lives of people with intellectual disabilities and their families before COVID-19, during the pandemic, and beyond, as well as the human rights violations they continue to experience. This report raises up the voices of those most excluded in a time of global crisis and demands an inclusive COVID-19 recovery.

In developing this report, evidence about these experiences was collected from our global network through our 18-part webinar series which drew people together during the initial outbreak, a survey of our membership, and the COVID 19 Disability Rights Monitor. We learned that where government emergency measures were instituted in response to COVID-19, people with intellectual disabilities and their families were left behind – 54% of Inclusion International members surveyed reported that their country's COVID-19 emergency response was not inclusive of people with intellectual disabilities and their families.

We collected data about the experience of people with intellectual disabilities and families across eight different issues areas. Across these themes, we examined how and why people with intellectual disabilities were left out and excluded in pandemic responses, what pre-existing conditions and inequalities contributed to their vulnerability and exclusion, and how future policy structures could begin to address both this immediate and systemic exclusion.

Together, these experiences and policy solutions form our global agenda for inclusive COVID-19 recovery, an action plan to ensure that government efforts to 'build back better' are inclusive of people with intellectual disabilities and their families.



These experiences and policy solutions form our global agenda for inclusive COVID-19 recovery, an action plan to ensure that government efforts to 'build back better' are inclusive of people with intellectual disabilities and their families.



Our movement calls on governments to take action to:



Present all information in accessible formats, and use partnerships to ensure it reaches the right communities.



Ensure consistent access to support services, including in emergency situations.



Improve awareness and inclusivity within health systems.



Support families and family-led organizations.



Address unsafe living conditions by prioritizing deinstitutionalization.



Design inclusive social protection systems.



Reimagine education systems to ensure education delivery models are fully inclusive of students with disabilities.



Reaffirm commitments to inclusion in employment.

The COVID-19 recovery is an important opportunity for governments to rectify the historical exclusion of people with intellectual disabilities and their families. These recommendations give policymakers the tools to 'build back better' and to ensure that the pandemic recovery works to create more inclusive communities.



Introduction



The COVID-19 pandemic disrupted the lives of billions of people around the world, changing overnight the way that we live, work, study, and socialise. For people who have an intellectual disabilities, their families, and the organizations that represent, support, and advocate for them, the impact of COVID-19 has been devastating. The crisis has revealed the depth of pre-existing marginalization and exclusion experienced by people with disabilities, and it has resulted in many cases in reversal of important progress made towards the fulfillment of the United Nations Convention on the Rights of Persons with Disabilities (CRPD) and the achievement of the Sustainable Development Goals (SDGs).

Inclusion International (II) is the international network of people with intellectual disabilities and their families. As a global network of organizations in over 115 countries spread across all regions of the world, we have been advocating for human rights and inclusion in the community for over 60 years.

During the negotiations of the UN CRPD, Inclusion International through its global network worked to ensure that the issues and perspectives of people with intellectual disabilities and their families were recognized and included in the Convention. Since the CRPD came into force in 2006, II and its members have worked together to draw attention to the continued exclusion experienced by people with intellectual disabilities.



The reality of the that exclusion has been well documented in our global campaigns and reports on poverty (2006), inclusive education (2009), the right to live and be included in the community (2012), the right to decide (2014), and self-advocacy (2016). While we have seen some significant progress in good practices and individual stories of inclusion in different countries and communities, the pandemic has underlined a hard reality: exclusion is structural, systemic, and based fundamentally on societies devaluing people with intellectual disabilities and their families.

As governments make plans for their own country's COVID-19 recovery and identify their strategies to 'build back better', policymakers have an important opportunity to ensure that no one is left behind. 'Building back better' will require recognition of the barriers in place prior to the pandemic, as well as the exclusion that was amplified due to the global crisis. 'Building back better' does not only mean restoring the pre-pandemic status quo, but aims to create a recovery that addresses the systemic issues which pre-dated and were amplified by COVID-19, to ensure that our 'new normal' is inclusive.

Building back better must pay specific attention to groups disproportionately impacted by the pandemic and the lockdowns. Throughout the pandemic, people with intellectual disabilities lost access to their essential support, to inclusive education, to equal access to health care, and to other rights safeguarded for people with disabilities by the CRPD. The crisis resulted in the deaths of people in institutions and other congregate living settings, in the denial of essential information in accessible formats, caused significant mental health impacts, and excluded people from social protection systems – all of which disproportionately impacted people with intellectual disabilities and their families.

During the pandemic, we learned that government emergency response measures failed to include and respond to the needs of people with intellectual disabilities and their families. 54% of Inclusion International members surveyed reported that their country's COVID-19 emergency response was not inclusive of people with intellectual disabilities and their families.

54% of Inclusion International members surveyed reported that their country's COVID-19 emergency response was not inclusive of people with intellectual disabilities and their families.



NOT INCLUSIVE

Self-advocates and families have demanded a response to this exclusion, raising these issues with their governments and calling for urgent action. They have made their voices heard through monitoring and reporting on human rights violations, campaigning, engaging with media, representation and leadership on government COVID-19 task forces, spearheading legislative responses, and other advocacy strategies to ensure that people with intellectual disabilities and their families are included in conversations. Their advocacy has helped ensure access to services for people with disabilities during lockdowns, the introduction of social protection measures, and prioritization of people with intellectual disabilities and their carers for vaccination.

Alongside their advocacy work, our member organizations have also taken action to fill the gaps left by governments; delivering emergency aid to families, producing accessible information about COVID-19, providing peer support and other services to people with intellectual disabilities and their families, and creating opportunities for self-advocates and families to connect virtually. As a global community our network has come together to demand not only urgent action in the moments of crisis but long term strategies to finally address the economic, social and cultural exclusion that people with intellectual disabilities continue to face.

Eliminating exclusion in the COVID-19 recovery and beyond will require governments to take concrete action to ensure inclusion. The COVID-19 recovery is an important opportunity for governments to rectify both the historical exclusion of people with intellectual disabilities and their families, and the disproportionate impact of the pandemic on their lives. They must use the opportunity to build back better, and ensure that the pandemic recovery works to create more inclusive communities through systemic change.

This report presents what Inclusion International has learned from our members about the barriers – both new and historical – that impacted people with intellectual disabilities and families around the world during the COVID-19 pandemic. **It presents our global agenda for inclusive recovery** and presents key recommendations for policy makers, communities, and governments to ensure that the COVID-19 recovery truly contributes to inclusion for all.



As a global community, our network has come together to demand not only urgent action in the moments of crisis, but long term strategies to finally address the economic, social, and cultural exclusion that people with intellectual disabilities continue to face.





How the Information was Collected

3

We invited our member organizations, self-advocates, families, and other allies to tell us about the impact of COVID-19 on their lives. The data we collected comes from three main sources:



COVID-19 Webinar Series



COVID-19 Impact Survey



COVID-19 Disability Rights Monitor



COVID-19 Webinar Series

From April to July 2020, Inclusion International delivered a series of 18 webinars on the impact of COVID-19 on people with intellectual disabilities and their families across a number of different themes, including education, employment, access to information, institutions, gender, and human rights monitoring.

Panellists from 26 different countries from across our 5 global regions led these webinars, sharing stories of how COVID-19 was affecting people with intellectual disabilities in their countries and regions.

Over 1,100 participants tuned in to join the conversation and share anecdotes and experiences from their countries.



education



employment



information



institutions



gender



human rights

18

WEBINARS



APRIL - JULY



26

countries

5

global regions

over 1,100

participants



COVID-19 Impact Survey

Inclusion International collected qualitative and quantitative data from our members through an online survey for member organisations.

It covered key topics including access to education, accessible information, institutions and social protection systems.

Across our global network, 68 member organisations responded to this survey, sharing experiences from 48 countries.



68
member
organisations



48
countries

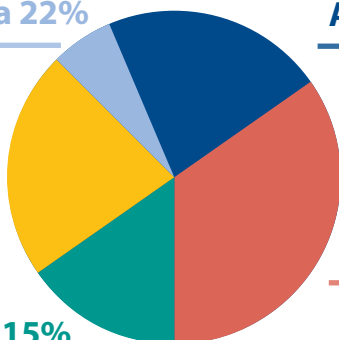
**Middle East and
North Africa 22%**

Africa 21%

**Europe
22%**

Americas 34%

Asia -Pacific 15%

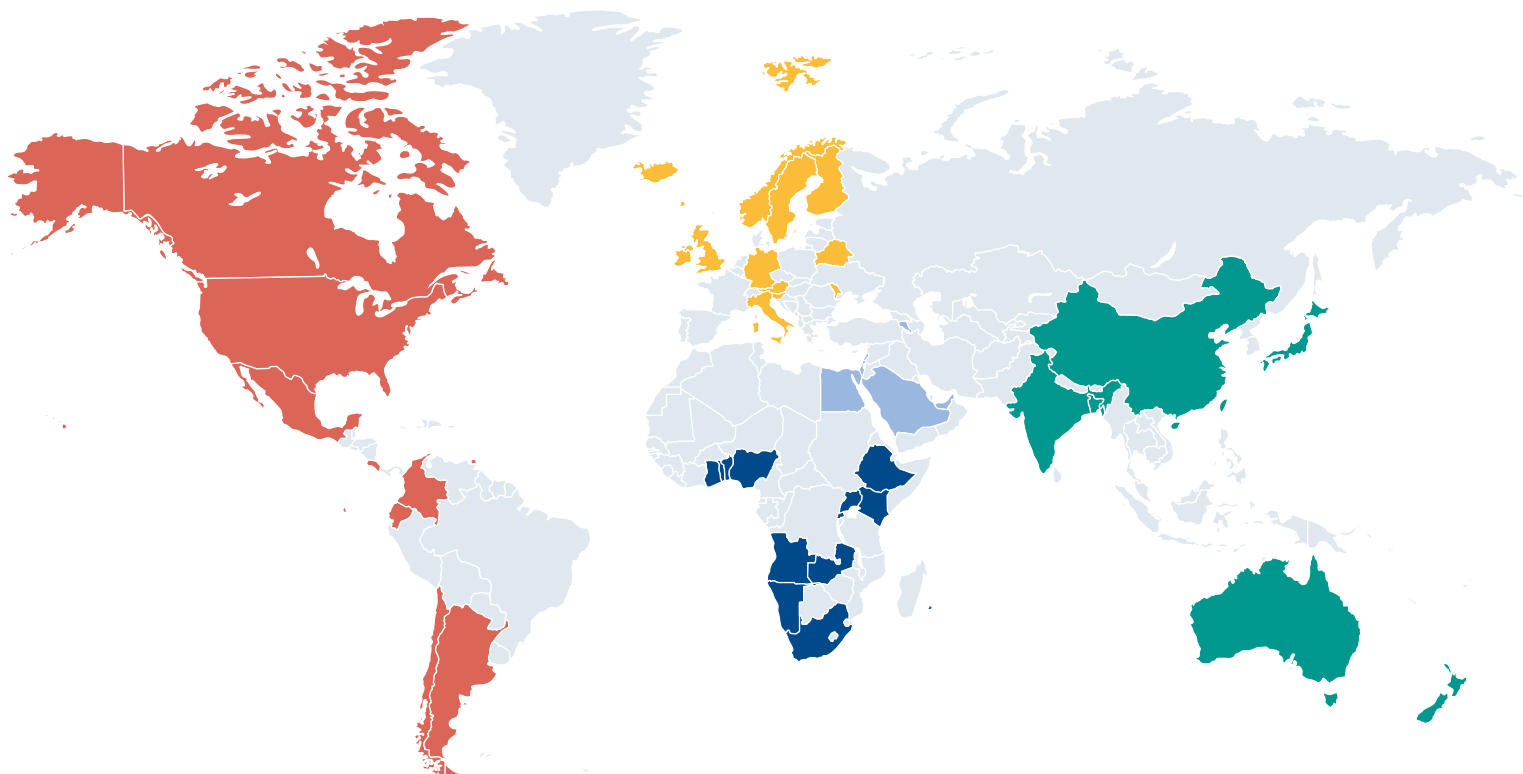


COVID-19 Disability Rights Monitor

This report also presents data reported by individuals with intellectual disabilities and their families collected through the COVID-19 Disability Rights Monitor (DRM), a global survey on the impact of COVID-19 on the disability community.

It was conducted by a coalition of disability organisations including the International Disability Alliance (IDA) and the International Disability and Development Consortium (IDDC). The [final report of the COVID-19 DRM](#) presents findings about the experiences of individuals with disabilities around the world during the pandemic, and presents key recommendations from the cross-disability community.

Countries surveyed



Americas

- Argentina
- Canada
- Chile
- Colombia
- Costa Rica
- Ecuador
- Mexico
- Trinidad and Tobago
- USA

Europe

- Austria
- Belarus
- Faroe Islands
- Finland
- Germany
- Iceland
- Ireland
- Italy
- Moldova
- Norway
- Slovenia
- Sweden
- UK

Middle East and North Africa

- Armenia
- Egypt
- Israel
- Lebanon
- Saudi Arabia
- UAE

Africa

- Angola
- Benin
- Ethiopia
- Ghana
- Kenya
- Mauritius
- Namibia
- Nigeria
- Rwanda
- South Africa
- Togo
- Uganda
- Zambia

Asia - Pacific

- Australia
- Bangladesh
- China
- India
- Japan
- New Zealand



Impact of COVID-19 on People with Intellectual Disabilities and their Families

4



Access to Information

One of the first issues identified by our members at the beginning of the pandemic was the lack of accessible information made available by governments about the virus, about health and hygiene requirements, about lockdown requirements, or about essential support available to citizens.



There is still a lack of resources to help us understand what is going on and how we can be taking care of ourselves and our families in regards to COVID. I haven't seen many pictograms or any guides around the city or on the news that explains to us what is really happening. The resources are inadequate for intellectually disabled people. It is very important for tv broadcast and radio to give information to everyone in simple language, so all intellectually disabled people can understand.

Fernanda Castro

Self-Advocate, CONFE, Mexico



In Inclusion International's member survey, only half (53%) of the respondents reported that service providers were making information available in plain language, easy read, or other formats accessible to people with intellectual disabilities, and only 33% reported that information about changes in service availability specifically were presented in accessible formats.

We heard from self-advocates and families that even where plain language and easy read resources are available, in many cases this accessible information is not reliably reaching people with intellectual disabilities.

People with intellectual disabilities are less likely to have access to the technology needed to access information, may not have access to support to look for information, and where accessible information is available it is often buried in otherwise inaccessible websites.

In the COVID-19 DRM survey, only 32% of people with intellectual disability, Down syndrome or autism reported having enough information about the pandemic.

This lack of accessible information also disproportionately impacted people with more significant barriers to communication.

Did governments provide accessible information?



47%
no

53%
in some
instances

Was the information about changes in services presented in accessible formats?



67% no



“

Having a telephone call to ask what would happen if I became ill or if my Pa became ill does not solve the problem of [...] no assistance with understanding the rules and how to follow them. I have to search for information and then interpret it. I'm given no clear, reliable and easy to follow instructions.

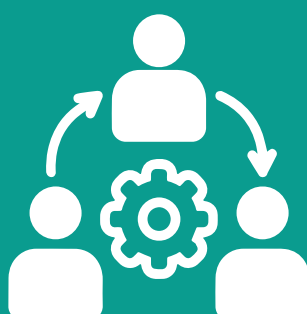
*Person with an intellectual disability,
COVID-19 DRM Survey Respondent*

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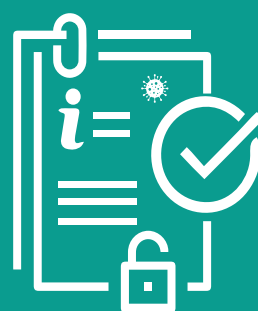
In many cases, organisations of persons with disabilities (OPDs) were forced to fill the gaps left by governments and service providers by creating information in accessible formats. Our global network quickly began creating and sharing accessible resources in different languages. Inclusion Europe developed a resource list with in over 10 languages. Self-advocacy groups in Croatia, Hong Kong, the United States and many other countries worked to create accessible information about COVID-19, to ensure that people with intellectual disabilities understood the situation and the implications of lockdowns and other changes that affected their lives.



Only **32%** of people with intellectual disabilities had enough information about the pandemic.



Organisations of persons with disabilities (OPDs) were forced to fill the gaps



Self-advocacy groups worked to create accessible information about COVID-19.

Recommendations



The COVID-19 pandemic has revealed that governments are still not successfully communicating with their citizens, and that people with intellectual disabilities trying to access information are still being left behind. In the COVID-19 recovery, including during the drive for vaccinations, governments must commit to the consistent delivery of information in accessible formats to ensure that everyone can access essential information.

To ensure that the COVID-19 recovery helps communication systems build back better, governments must:

Produce all information in formats accessible to people with intellectual disabilities

All information that governments share with their citizens must be made available in accessible formats to ensure that people with intellectual disabilities can access that information quickly. Formats accessible to people with intellectual disabilities (such as plain language, easy read, video formats, and diagrams) must be a core accessibility requirement for all government publications and information dissemination, and governments must also ensure that their website, TV, radio communications and other communication channels are accessible and easily navigable so that their accessible information will actually reach people with intellectual disabilities.

Require service providers and other private organisations to produce content in accessible formats

In emergency situations, the delivery of services and the dissemination of life saving information is not solely handled by governments – charitable organisations, service providers, and other organisations involved in emergency response should also be mandated to produce accessible materials in order to ensure that people with intellectual disabilities can access essential information.

Ensure that self-advocates are involved in the design and vetting of accessible materials

Best practice for the creation of communication tools accessible to people with intellectual disabilities requires consultation with people with intellectual disabilities themselves. Governments and other organisations must consult with self-advocates about the design of accessible formats, and all materials in accessible formats must be vetted by self-advocates before being released. In many countries, self-advocates work on a consultancy basis to support the production of accessible materials.

Consult OPDs on acceptable formats for the local context

Local standards for the creation of accessible materials vary by region and by country – governments should approach local organisations of persons with disabilities (OPDs) representing people with intellectual disabilities and their families to identify the accessible formats preferred by people with intellectual disabilities. OPDs are also essential partners for ensuring that accessible information is successfully reaching people.



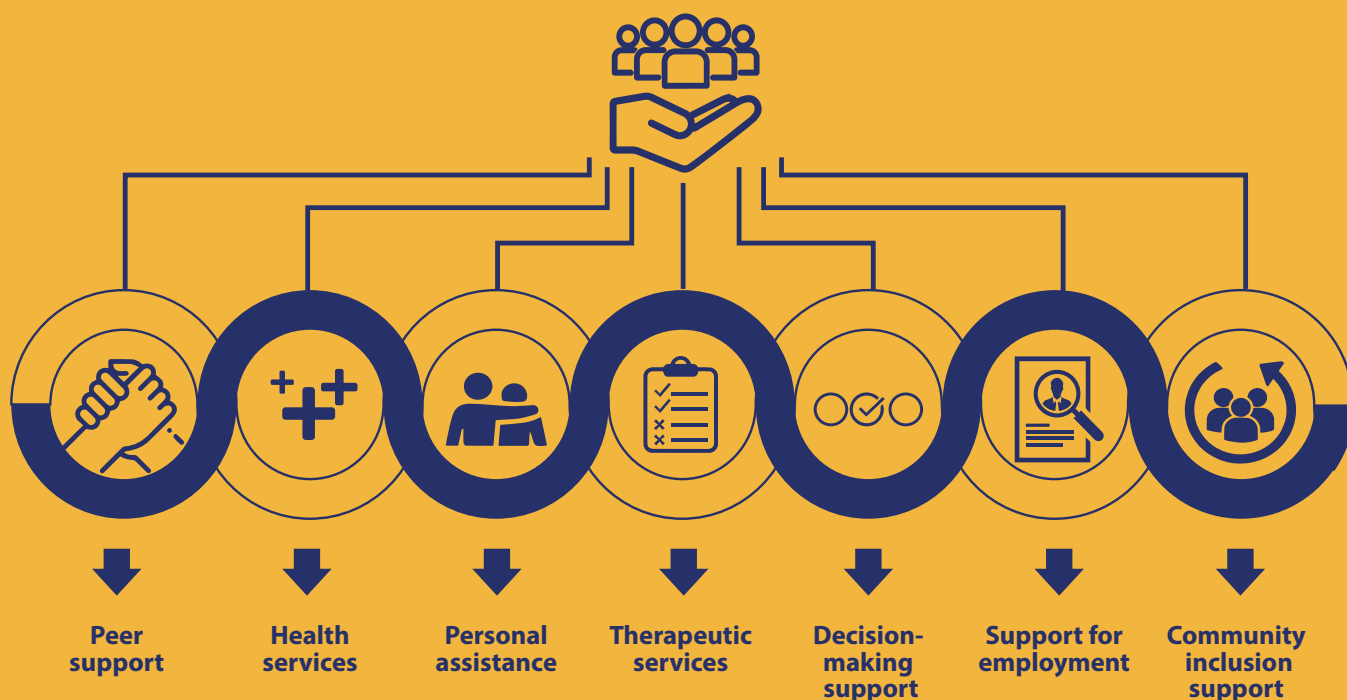


Access to Support

People with disabilities have the right to receive supports and services which enable them to participate in all aspects of society. For people with intellectual disabilities these services and supports may include peer support, mental health services, personal assistance, therapeutic services, decision-making support, support for employment, and other forms of support that allow people with intellectual disabilities to be fully included in their communities.

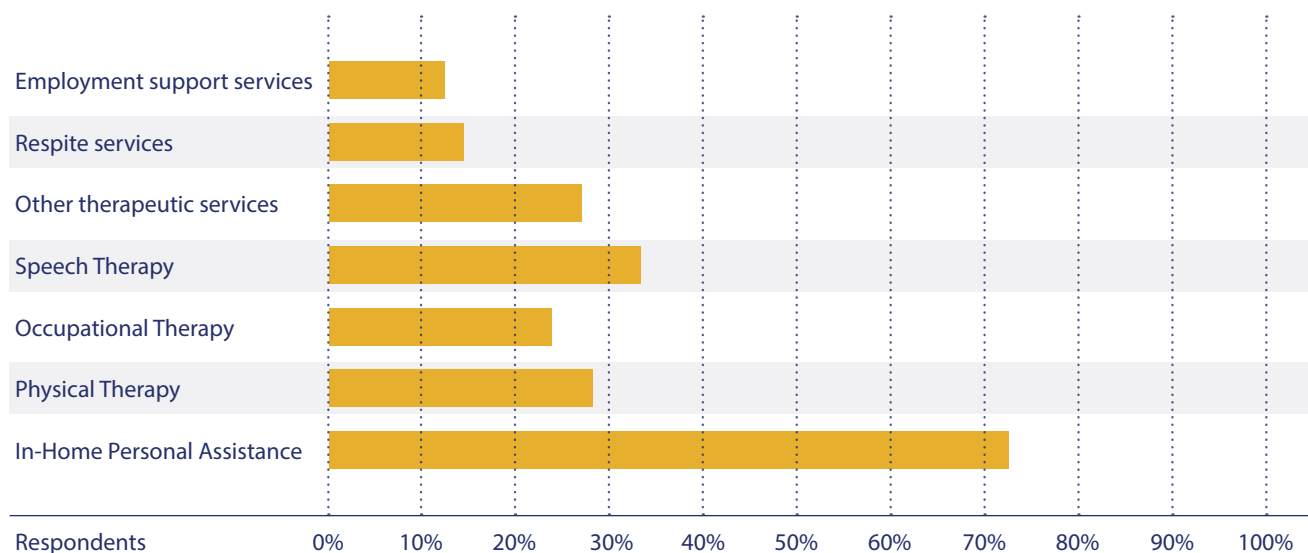
The formal and informal services and supports available and the way they are delivered varies significantly from country to country and across different economic contexts but the common experience of people with intellectual disabilities during the pandemic was that access to these essential supports was significantly reduced or eliminated. In countries where people with intellectual disabilities had access to formal support services prior to the pandemic, 87% of Inclusion International's member survey respondents reported that, as a result of COVID-19, these essential formal support services were either reduced or stopped being available altogether.

Support for people with intellectual disabilities may take a variety of forms and areas of their lives



The forms of support that were maintained during the pandemic varied significantly by country and region, although independent living services tended to be the most likely to continue, while family services were least likely. Among formal services, in-home personal assistance was the support that was most widely deemed essential, with 71% of respondents reporting that this was maintained during the pandemic.

Formal Support Services Deemed Essentials during COVID-19 Pandemic



Support for families was the least likely to be maintained during the pandemic, with only 13% of respondents reporting that respite services were available.

Availability of formal services also depended heavily on the setting in which the service was delivered – services delivered in medical settings were more likely to be reduced or eliminated as medical care settings turned their focus solely to the COVID-19 response.



Although our son is considered extremely complex, we have been offered little support. No one has asked us at any point whether he is still attending services or not, or assessed our level of need.

*Parent of person with an intellectual disability,
COVID-19 DRM Survey Respondent*



“

Whilst services were available, most therapies at hospitals and clinics were suspended and patients were turned away as these facilities were only attending to COVID-19 cases.

Organisation supporting people with intellectual disabilities, African region

”

In many countries, support services are governed by different districts or provinces, meaning that which services were deemed essential varied by region, and people within a country had unequal access to services based on where they lived. In many cases, governments did not make decisions about what services were deemed essential and should continue during the pandemic at all, which meant that service providers had to make their own decisions about what work to cut and what work to continue. This resulted in a patchwork of unequal access to services within cities and even within neighbourhoods. In some areas, it took longer for disability services to be deemed essential, which kept people waiting without access to services or information for long periods. Some services tried to pivot to virtual delivery – for example, personal assistance in some cases was not delivered in person but some people received independent living support virtually.

“

Services were available to very few people, and only those with very high support needs to help maintain the family unit – where the situation was deemed ‘an emergency’.

Inclusion Ireland

”

Many jurisdictions made decisions about who could access services on a case by case basis, based on their understanding of who had more ‘severe’ needs, but in many cases people with high support needs were hit the hardest by cuts to service availability.

“

The federal government refused to define what an essential service was. It was left up to providers to make the call.

Organisation supporting people with intellectual disabilities in Australia

”

We heard that in some cases individuals began to receive more support during the pandemic – in many cases increasing their support to the level that they should have been receiving in the first place – but that these increases are being treated as a stopgap measure and will be withdrawn during the COVID-19 recovery.

As formal support services were being curtailed, people with intellectual disabilities and their families were also turned away from their informal support, such as peer support, self-advocacy groups, and decision-making support. Overall, 90% of respondents reported that informal support was either reduced or stopped altogether during the pandemic.

In the COVID-19 DRM survey, people with an intellectual disability, Down syndrome, or autism reported losing access to informal support at a higher rate than was cumulatively reported for all people with disabilities. In some cases, this informal support pivoted to virtual delivery - 66% of survey respondents said that support was delivered virtually or through other alternative platforms during the lockdown.

In many countries, communities have mobilised in order to address the lack of formal and informal support for people with intellectual disabilities and other community members.

“

In the United States, there has been participation from the corporate sector in providing grants to local, state, and national organisations to address the needs of people affected by the pandemic. In addition, there are many communities in which local volunteers have worked to meet the needs of people who have lost services or who are otherwise in need.

The Arc, United States of America

”

Self-advocacy groups have also taken action to ensure that people with intellectual disabilities still have access to support, including offering peer support and other mental health interventions for people with intellectual disabilities.

Decreased access to formal support services



Inclusion International members reported that formal services were reduced or eliminated in **87%** of contexts.

Decreased access to informal supports



Inclusion International members reported that informal services were reduced or eliminated in **90%** of contexts.

Decreased access to support for families



Only **13%** of Inclusion International members reported that respite services were available during the pandemic.

New platforms for delivering support



66% of survey respondents reported that informal support (including peer support and decision-making support) were able to be delivered through virtual platforms.


Recommendations



Support and services available for people with intellectual disabilities are always essential. Consistent availability of services and support to people with disabilities in their communities should be a hallmark of the COVID-19 recovery, and a standard set by government regulators of service providers.


To ensure that the COVID-19 recovery helps service delivery systems build back better, governments must:

Ensure services that support people to live in the community are deemed essential




Services which people with intellectual disabilities use to live in the community – including personal assistants, support with decision-making and other community-based services – are essential. They must be designed to be flexible and responsive to individual needs, and they must be consistently available in community-based settings, including in rural areas. These services cannot be compromised in any situation.

Ensure that support to families of people with intellectual disabilities is deemed essential



For families of people with intellectual disabilities, who in many cases are the sole carers of their family members, access to services and support are essential in all situations, including emergencies. Respite services and other family support must be consistently available in communities.

Safeguard services for people with high support needs



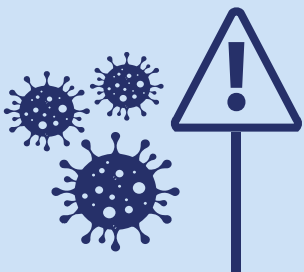
In many cases, services for people with higher support needs cannot be delivered in socially distanced formats. These forms of support for people with high support needs are essential for ensuring that they remain safe and healthy, and these services should not be eliminated or reduced in any capacity, including in emergency situations.



Access to Health Care

Historically people with intellectual disabilities have experienced direct discrimination in accessing health care and health services, including deliberate denial of care, health interventions without consent, and other forms of discrimination. People with intellectual disabilities have also experienced systemic discrimination in the health care system due to economic conditions, and have struggled to navigate inaccessible communications and practices. Health care systems typically work and communicate health information in ways that are inaccessible to people with intellectual disabilities, and often make discriminatory assumptions about the quality of life of people with disabilities which impacts their access to care.

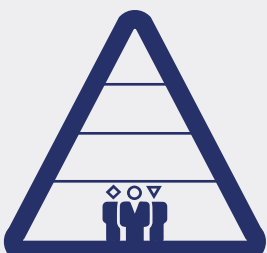
This pre-existing inequality and discrimination was compounded by the pandemic. As a result, people with intellectual disabilities were at significantly higher risk of dying from COVID-19 than the general population.



People with intellectual disabilities had a higher risk of death from COVID-19 than the general population.



Access to health care during the pandemic was denied to people with intellectual disabilities.

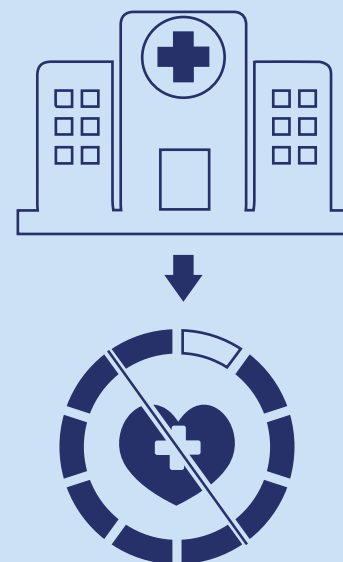


Triage protocols identified tiers for priority access to health. People with intellectual disabilities were identified as low priority for care.

Data in the United States showed that, as a group, people with intellectual disabilities were the second most likely to die as a result of COVID-19 after older people¹, and data from the United Kingdom suggests that people with intellectual disabilities are 6.3 times more likely to die of COVID-19 than the general population².

In the COVID-19 DRM survey, 90% of respondents with an intellectual disability, Down syndrome or autism said that their government had taken either no or insufficient measures to ensure that people with disabilities could access general and specialised medical health care during the pandemic.

Self-advocates told us about their experiences of being denied access to health care during the pandemic. In the COVID-19 DRM survey, only 25% of people with an intellectual disability, Down syndrome or autism reported that they felt their access to health care was equal to that of people without disabilities. Similarly, 75% of people with an intellectual disability, Down syndrome or autism reported that they had evidence of people with disabilities being deprived of or denied access to health care in their country, compared to only 52% in the cross-disability dataset.



90% of DRM survey respondents with an intellectual disability, Down syndrome, or autism said that their government had taken either no or insufficient measures to ensure that people with disabilities could access general and specialised medical health care during the pandemic.



75% of people with an intellectual disability, Down syndrome or autism reported in the COVID-19 DRM survey that people with disabilities were being deprived of or denied access to health care in their country during the pandemic.

For people with intellectual disabilities who did contract COVID-19, triage protocols that were developed for health care systems in many cases substantially decreased the likelihood that they could access lifesaving care. Health care systems identified tiers for priority access to health care during the pandemic as a strategy to manage limited health care resources, where people with intellectual disabilities were identified as low priority for care. These triage policies are rooted in discrimination and devaluing assumptions about the quality of life of people with intellectual disabilities.

¹Gleason, Jonathan et al. (March 2021) The Devastating Impact of COVID-19 on Individuals with Intellectual Disabilities in the United States. NEJM Catalyst Innovations in Care Delivery. <https://catalyst.nejm.org/doi/full/10.1056/CAT.21.0051>

²Public Health England (November 2020) Deaths of People identified as having learning disabilities with COVID-19 in England in the spring of 2020. https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/933612/COVID-19_learning_disabilities_mortality_report.pdf

Triage policies resulted in these patients being denied access to lifesaving care in favour of other patients, resulting in the unnecessary deaths of people with intellectual disabilities.

Due to hospitals and other medical care settings imposing lockdown restrictions, in many cases people with intellectual disabilities were forced to navigate health care systems without the supporters or family members that would typically accompany them, as they were not permitted to enter. The lack of recognition of the need for support in accessing and navigating health services causes a great deal of anxiety and trauma for both people with intellectual disabilities and their families, who fear being put in the position of accessing health care alone.

“

What will happen to my autistic son should either of us need hospitalisation? We live only the two of us, and he is non-verbal. Are the nurses equipped (to) be able to look after autistic individuals since we are not allowed to visit the facility during lockdown?

COVID DRM Survey Respondent, family member of an Autistic person

”

As vaccination campaigns begin, it is essential that people with intellectual disabilities and their carers be prioritised as a response to their increased risk of contracting and dying from COVID-19. People with intellectual disabilities in low- and middle-income countries with less access to vaccinations are at no less risk of COVID-19 than people with intellectual disabilities in high-income countries, and equitable vaccination distribution should be taken into account to ensure that high risk people in all areas of the world have access to vaccinations.



Recommendations



During the pandemic, public health plans failed to take the increased risk factors for people with intellectual disabilities into account, and people with intellectual disabilities continued to be left behind and denied access to care.

Government COVID-19 recovery plans are an important opportunity to ensure that health care systems are accessible and equipped to reach people with intellectual disabilities.

To ensure that the COVID-19 recovery helps health systems build back better, governments must:

Ensure that health services are inclusive of people with intellectual disabilities

Health care professionals must understand the needs of people with intellectual disabilities and the social determinants of health that impact them. They must be equipped to communicate information to individuals about their health in an accessible way, and public health authorities must produce all health information in accessible formats.

Eliminate disability as grounds for lower triage priority

Prior to and during the COVID-19 pandemic, people with intellectual disabilities were given lowest priority for access to health care on the grounds of their disability. Governments must take urgent action to ensure that having an intellectual disability is not grounds for decreased access to care through triage protocols.

Ensure priority access to vaccinations

Given the increased risk of death due to COVID-19, people with intellectual disabilities and their paid or unpaid carers must be prioritised in global vaccination rollout. This must include people with intellectual disabilities and their families in low- and middle- income countries, who are at equal risk of COVID-19 but have decreased access to the COVID-19 vaccination.



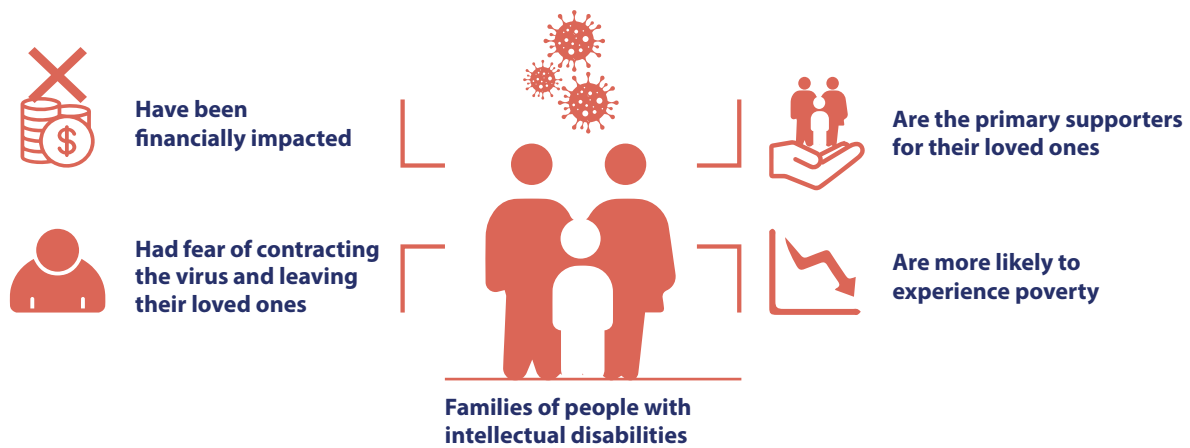
Support for Families

We know from many years of listening to families that they play a key role in supporting children and adults with intellectual disabilities as caregivers, advocates, community organizers, and as loved ones. The vast majority of adults with intellectual disabilities wherever they live in the world, live at home with their families. The CRPD recognizes the importance of the role of families in advancing and supporting the human rights of people with disabilities, yet in most countries even prior to the pandemic, support to families has not been a priority of governments.

During the COVID-19 pandemic we witnessed significant pressure and impact on families, who were completely abandoned by governments. They were left to care for their children with intellectual disabilities (often full time) without support, and they lost access to other forms of support and services for their adult family members. Families have always been the primary supporters for their loved ones with an intellectual disability, but with increased caring responsibilities and the decrease in service availability as a result of COVID-19, families report being at the breaking point.



In addition to managing care and support, stay at home orders and lockdowns have resulted in lost jobs and increased financial insecurity. Many families around the world are without internet access, food, or social protection. Others have had to leave their jobs in order to care for their family member full time as a result of school closures, the loss of access to services for their family member, and lockdown requirements.



Fear and isolation were common experiences for families in countries where food and water shortages were impacting communities. Mothers reported to us that they were not able to leave their homes to get food and water because of their child with a disability could not be left alone.

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My son is high risk for getting COVID-19. I have had to retire from work to look after him. It's my biggest fear that if he contracts the virus that I will not be allowed to be with him.

*Parent of a person with an intellectual disability
COVID-19 DRM Survey Respondent*

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The expectation of leaving work to care for a family member during lockdown has also disproportionately impacted female family members. Women tend to be more concentrated in the informal sector and have less secure jobs, may have lower paying jobs, and have caregiving responsibilities that male family members typically do not. During the pandemic, sectors of the economy where women are disproportionately represented were harder hit, and many informal sector workers were unable to work during the lockdown.

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Women have a double burden of care, and now, the lockdown has even increased the burden on women due to child caring. And if you're looking at a woman with children with disabilities, this burden of care has become maybe even tripled.

*Fauzia Haji
Zanzibar Association of People with Developmental Disabilities (ZAPDD)*

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Families managing job losses and loss of income sources alongside increased caregiving responsibilities are reporting significant increases in stress and mental health issues. For many, there is a significant negative mental health impact surrounding fear of contracting the virus and leaving their loved one with an intellectual disability without family support.

“

Although our son is considered extremely complex, we have been offered little support. No one has asked us at any point whether he is still attending services, nor to assess our level of need.

*Parent of a person with an intellectual disability,
COVID DRM Survey Respondent*

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For family members of people with intellectual disabilities, the lack of support is felt more strongly than for those family members of people with other disabilities. The COVID-19 DRM survey found that 55% of respondents reported no support for families of children with disabilities during the pandemic – this increased to 67% among respondents who were family members of people with intellectual disabilities.

In Inclusion International’s survey of members, only 13% of respondents reported that respite services were retained during the pandemic. Governments failing to treat these services for families as essential has created an increased risk of re-institutionalisation of people with intellectual disabilities currently living with their families without support.

“

I have removed my son from all day services and respite provisions but have received very little in support. Two phone calls and no offer of any extra support for us at home. We’ve been left to get on with it.

*Parent of a person with an intellectual disability,
COVID DRM Survey Respondent*

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The nature of support for families is also often different for family members of people with intellectual disabilities. In the COVID-19 DRM survey, fewer families of people with intellectual disabilities reported that personal assistance had been lost during the pandemic than the overall dataset, which may reflect that families were already providing this support themselves prior to the pandemic.

People with intellectual disabilities who have their own children were significantly impacted by this reduction in services and the lack of availability of support, which created new challenges for them to support their children. The closure of schools resulted in parents with intellectual disabilities being required to home-school their child or support them through virtual schooling, and manage their children's other needs, without clear accessible information about the pandemic or other forms of support.

“

[The pandemic] made it hard for my own mental health, and also I was feeling a bit lonely. There were challenges around online school and understanding the information sent by the school, and supporting my daughter to engage with the schoolwork. Supporting my daughter through her own challenges like socialisation, fears around the pandemic.... [I] needed to find new ways of doing things [with] limited support from other parents due to concerns around the pandemic.

Sonia Hume, Self-Advocate and Parent, Australia

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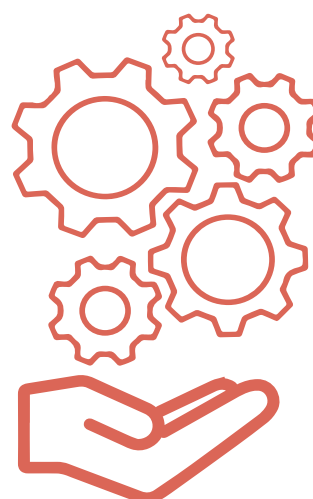
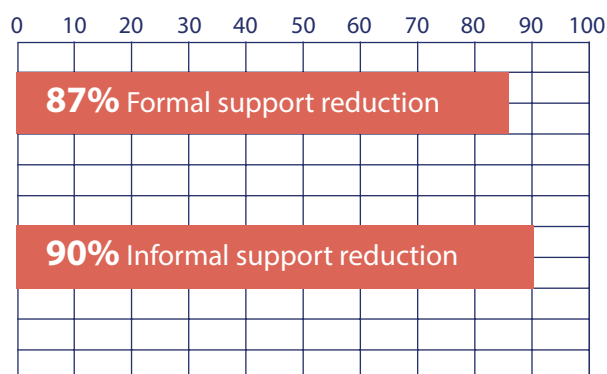
Despite the lack of government support for families, networks of parents of people with intellectual disabilities and organisations in the Inclusion International network have been responding to the mental health concerns and other needs of families. This has included organising virtual meetings and conferences to share information, providing direct support and resources to parents, and supporting families to engage in advocacy through media and other means. In Inclusion International's member survey, 36% of respondents reported that some type of new service was created for families in their country - examples include more flexibility in the use of individualised funding, and family counselling provided by phone. Family organisations and service providers provided the majority of these new services for families, in many cases creating new strategies for family support focused on mental health.

Inclusion International's member organizations have quickly responded to the needs of families to connect and to support each other virtually. We heard from families about how this has shifted understanding of the way to support good mental health from a more traditional medical understanding (involving counselling and formal support) to a broader definition which includes community building and social activities. Organizations are employing informal support, like parent or self-advocate peer support groups, to help improve mental health during the pandemic, and organizations are delivering virtual activities to keep their communities connected.

An inclusive COVID-19 recovery must also be responsive to the needs of family carers, who have been disproportionately impacted by the pandemic. Governments have a responsibility to ensure that families are supported, and organisations of persons with disabilities (OPDs) representing people with intellectual disabilities and their families are not abandoned to manage alone and without support.



67% of family members of people with intellectual disabilities reported in the COVID-19 DRM survey that there had been no support for family members during the pandemic.



36% of Inclusion International members responded that some type of new service or support was created for families in their country, although these were generally created by family networks, not by governments.

Recommendations



The COVID-19 recovery provides an opportunity to rethink the way that families are supported in their role as carers, community organizers and advocates.

To ensure that the COVID-19 recovery helps families build back better, governments must:

Deem the services that support families to be essential services

Services which people with intellectual disabilities use to live independently in their communities – including personal assistants, support with decision-making and other community-based services – are essential. They must be designed to be flexible and responsive to individual needs, and they must be consistently available in community-based settings, including in rural areas. These services cannot be compromised in any situation.

Ensure access to mental health support

Family members of people with intellectual disabilities who are acting as carers, providing support to their family member without access to services or support of their own, face a significant impact to their mental health. Access to mental health services and support for family members is essential to ensure that families are well equipped to support and advocate for their family members.

Support OPDs to deliver family programming

Organisations of persons with disabilities (OPDs) representing people with intellectual disabilities and their families created new programming during the pandemic in order to connect families and foster solidarity. Governments should support OPDs in this work to provide peer support and solidarity building for family members as an accompaniment to providing formal support and services to families.





Institutions



Article 19 of the CRPD outlines the right to live and be included in community, yet we know from many years of advocacy by our members in their own countries that people with intellectual disabilities continue to be segregated and institutionalized. Institutionalization takes many different forms, from large residential institutions to smaller segregated settings and congregate living facilities. We are only just learning the full extent of the failure by governments to support and protect people who live in those institutions during the pandemic.

The combination of outbreaks of the virus, lack of understandable information for residents, lack of personal protective equipment, isolation from family, and reduced supports and services meant that people in congregate living were among the groups most negatively impacted by COVID-19.

We heard from people with intellectual disabilities living in institutions that they felt abandoned and isolated.

They were at high risk for COVID-19 transmission without accessible information about the virus or how to protect themselves, the supports and services they require were dramatically reduced, and in many cases they could not communicate with their family or friends outside of the institution.

“

In Romania, if those people who died in institutions would have lived in the community, they would be alive now. The risk to infect other people is higher in institutions because if one person brings the virus inside, the risk is high to infect another 50 or 100 people. I discussed with a few people from institutions and I asked them about their experience in the pandemic – it was very hard for them, and they were very angry. They couldn't go out from the institutions, and many of them lost their jobs because they are the first who are fired because of their intellectual or physical disability. I think with this pandemic it is important to urge the states to take people out from institutions.

*Eli Moldovan, self-advocate and former resident of an institution,
Asociatia Ceva de Spus, Romania*

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“

It was outrageous that people with disabilities living in residential settings did not see their families for over three months. [They] were kept as prisoners with no facilitated connections with family, and were highly distressed and lonely, particularly [people with] intellectual disability.

COVID-19 DRM Survey Respondent

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With decreased access to technology in institutional settings, many residents were unable to connect with anyone outside of their institution for months on end, leading to feelings of loneliness and isolation. The response by governments to the situation of people living in institutional settings was inadequate, slow, and poorly executed.

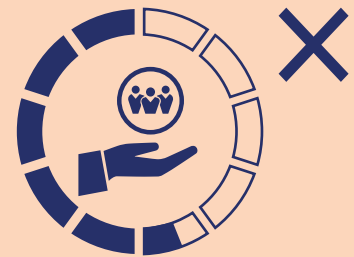
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I don't think the government is doing anything. There are a lot of care homes, and social places didn't get considered until it was raised by the people that were in the homes.

*Phil Hughes, self-advocate
Sunderland People First*

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In some cases, efforts were made to move people out of institutions during the pandemic. 9% of Inclusion International's survey respondents reported that this strategy was used in their countries.



56% of Inclusion International members reported that essential services and support were cut for people living in institutions.



54% of Inclusion International members surveyed reported that people with intellectual disabilities in institutions were not receiving any support to communicate with their family and friends during lockdown.



84% of people with intellectual disabilities who responded to the COVID-19 DRM survey reported that they felt the government had taken either no measures or insufficient measures to protect the life, health, and safety of people with disabilities living in institutional settings.

People with intellectual disabilities living in institutions during COVID -19



Some members reported that emergency deinstitutionalisation was undertaken without planning, which resulted in people with disabilities being moved into communities without any support, access to services, or sufficient transition planning, placing those individuals at risk. Most countries responded to the pandemic in institutions by providing personal protective equipment (PPE) to staff members in institutions (reported by 78% of Inclusion International survey respondents), and fewer countries (only 42%) also provided PPE to residents.

Despite the emerging picture of the failure of congregate settings to effectively protect and support people, there is no evidence that governments are taking action to address this public health risk and human rights violation as part of their COVID-19 recovery plans. In a survey of Inclusion International members in countries where governments were not already working towards deinstitutionalisation, 67% of respondents reported that there were no indicators that the virus outbreaks and high death rates in institutions had made their government any more likely to pursue deinstitutionalisation as a long-term strategy.

“

There is not enough investment in community-based responses. We still do not see the support that is needed for people with disabilities to participate in the community, whether that is specific support or making the services that are available to anyone else inclusive. [...] This is simply unacceptable.

Catalina Devandas Aguilar

Special Rapporteur on the Rights of Persons with Disabilities, 2014-2020

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Recommendations



Prior to the pandemic, institutions were not safe places for people with intellectual disabilities and others facing institutionalisation to live. The pandemic made the dangers of congregated living settings even more visible and made it evident that both from a public health management perspective and a human rights perspective, there is no place for institutions in a post-pandemic world.


To ensure that the COVID-19 recovery helps communities build back better, governments must:

Prioritise deinstitutionalisation




The closure of institutions is an essential step in the recovery from COVID-19, both to ensure the safety of people who have been institutionalised and as a future 'pandemic proofing' measure to eliminate settings that are more likely to have outbreaks in future health crises. The closure of institutions, both large and small scale, is a necessary strategy for reducing the disproportionate impact of health crises on people with disabilities, and to ensure that all people with disabilities are living in safe environments. Deinstitutionalisation measures must be accompanied by a transition plan to ensure the safety of people with disabilities moving out of these settings.

Fund the transition to community living



Deinstitutionalisation is a transition process, not a singular action. The closure of institutions requires coordinated planning over time to ensure that individuals living in institutional settings have the support they need in their communities to live independently. Funding that went towards the expansion of institutions prior to the pandemic must be redirected to systemic change through supporting the transition away from these living settings.

Ensure that adequate community support is available



For people formerly living in institutions to be empowered to lead independent lives in their communities, support and services must be available in their communities. As part of the COVID-19 recovery, closure of institutions must be accompanied by funding inclusive community-based services, ensuring the availability of support services for families, and ensuring that social protection systems are inclusive of people with disabilities living in the community.



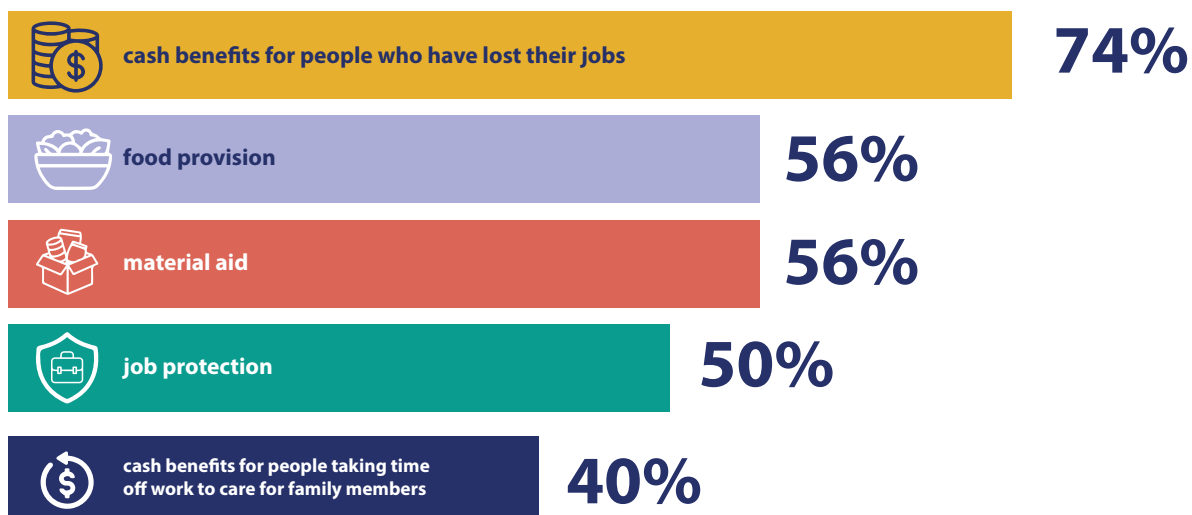
Social Protection Measures

Prior to the pandemic, people with intellectual disabilities and their families in some countries had access to government benefits that were designed to compensate for disability related costs and income support programmes. These social protection mechanisms include cash transfers, tax credits, housing subsidies, child allowances, and other benefits. We know from the experience of people with intellectual disabilities and families that where these systems exist, they have largely been inadequate in addressing income support needs.

As the COVID-19 pandemic worsened, governments introduced new social protection measures to support people impacted by the pandemic: cash benefits for people who have lost their jobs, food provision and material aid, job protection, cash benefits for people taking time off work to care for family members. Despite being disproportionately impacted, people with intellectual disabilities and their families were often unable to access those benefits.

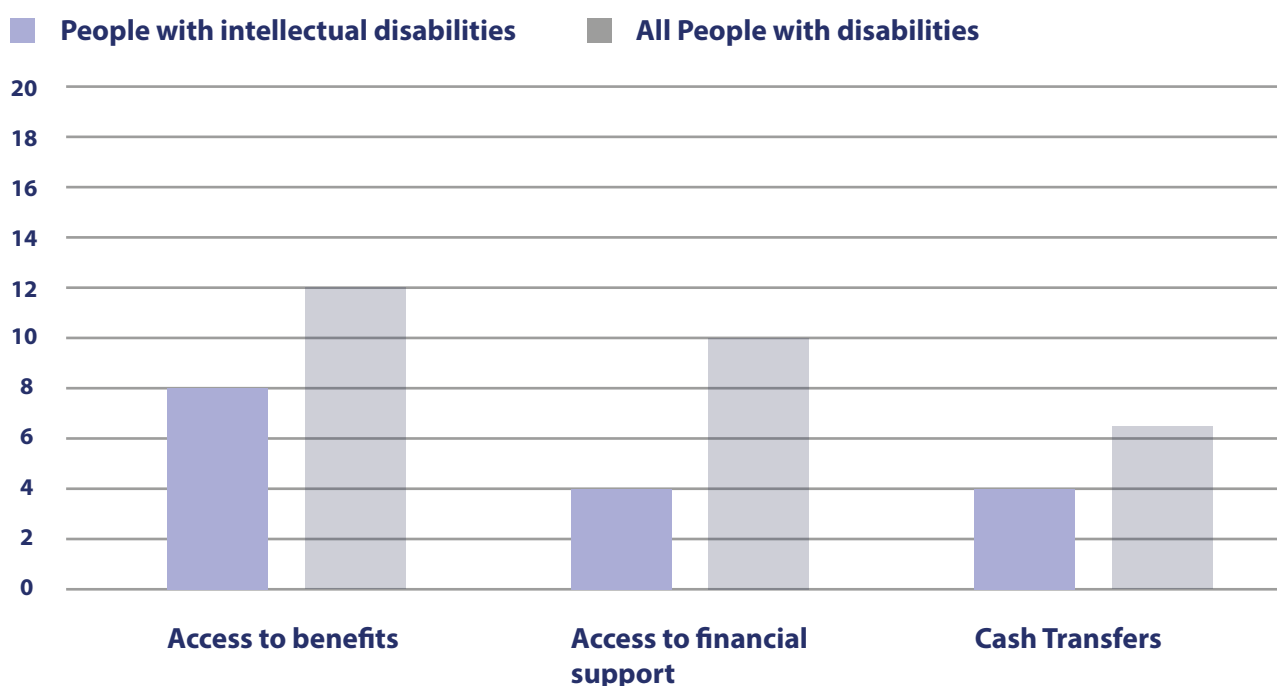
Despite the creation of new social protection mechanisms in some countries, Inclusion International members report that families and people with intellectual disabilities have not consistently been able to access these new forms of social protection; 42% of respondents said that the new COVID-19 social protection measures were inaccessible. This was confirmed in the data from the COVID-19 DRM survey, where fewer people with intellectual disabilities reported being able to access social protection (including benefits, cash transfers, and other financial support) than other people with disabilities. Families of people with intellectual disabilities had similar barriers, and reported in the DRM survey that they had less access to cash transfers and financial support than families of people with other disabilities.

Inclusion International members reported the creation of these new COVID-19 related social protection programmes in their countries:



Some countries created cash allowances specifically for people with disabilities, but member organisations report that the amounts paid out for these benefits were insufficient for the need, and failed to cover both cost of living and disability-associated costs.

Access to Social Protection System Reported in COVID DRM Survey



For people with intellectual disabilities, there are a number of reasons why these COVID-19 social protection systems were inaccessible. People with intellectual disabilities are less likely to be employed, and, in many countries, people working in jobs that paid them less than the minimum wage or a stipend did not qualify for benefits. People without valid ID cards were not able to access these measures in some countries, and if people were not previously accessing specific disability tax credits, then they may not have been eligible for the COVID-19 specific social protection measures.

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The mechanism used to give out the supports was how people fell through the cracks.

People First Canada

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Even in cases where people with intellectual disabilities and their families were eligible for these social protection systems, the information about how to benefit is rarely available in accessible formats and the application process is complicated and inaccessible. Without support to navigate complicated bureaucratic procedures, many people with intellectual disabilities could not access social protection measures.

For families of people with intellectual disabilities, many of whom were forced to leave work to take on caring responsibilities as a result of the pandemic, social protection measures for those temporarily leaving the workforce to care for loved ones were a particularly important form of government support. 50% of Inclusion International members surveyed reported that these social protection programs were created in their country.

The lack of resources redirected from service providers was also a major gap in social protection systems for families during COVID-19. With the loss of services that individuals previously had access to, to families took on delivering that care directly without the additional resources that service providers are afforded to do that same work.

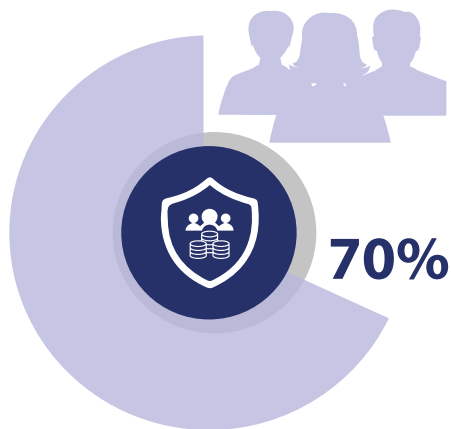
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[After] the termination of day services/support/transport available pre-COVID-19, [there was] no redirection of funds to the service user than would enable the family to employ assistance. Government funds are still provided to the service provider.

*Family member of a person with an intellectual disability
COVID-19 DRM Survey Respondent*

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Inclusion International members also reported uneven application of social protection measures during COVID-19, with people in lower income areas, rural areas, and areas with fewer services being left out from accessing these benefits.



70% of members surveyed reported that the government in their country created new social protection mechanisms due to the pandemic.

Were Social protection measures accessible for people with intellectual disabilities?



Why were social protections measures not accessible for people with intellectual disabilities?



Recommendations



As governments consider how to support the most vulnerable and marginalized in economic recovery, there is a unique opportunity to reimagine social protection systems that will support and enable people with intellectual disabilities to participate and contribute to their communities, and for systems to ensure that families are supported in their roles as carers and advocates.

To ensure that the COVID-19 recovery helps social protection systems build back better, governments must:

Design social protection systems to be flexible, and consider diversity



Social protection systems must be responsive to the fact that no two people with intellectual disabilities have the exact same needs or require the same level of support. Social protection systems must be designed in a way that consider the diversity of the disability community – they must be flexible, adaptable, and avoid ‘one size fits all’ solutions.



Ensure that social protection systems protect family carers

Income supplements for families who cannot work due to care responsibilities are an essential component of social protection systems.



Ensure that social protection mechanisms are accessible and easy to use

Creating social protection systems for people with intellectual disabilities to access will not be effective if the systems necessary to apply for them are bureaucratic, complicated to navigate, and inaccessible. Social protection application systems must be designed for ease of use.



Ensure that social protection systems that aim to cover disability-related costs are not tied to work

Social protection systems that aim to cover disability-related costs cannot be tied to work, minimum salaries, or number of hours worked. Disability-related costs apply to all people with disabilities of all income levels, and work requirements create a barrier to social protection that in many cases prevents people with disabilities from accessing work.



Education



Since its founding, a key priority of Inclusion International and its member organizations has been inclusive education. Many of the member organizations of Inclusion International were founded 50 or 60 years ago by parents whose children were denied access to education. Since the adoption of Article 24 of the CRPD and the global commitment to inclusive quality education in SDG 4, governments have begun to recognize inclusive education as a human right and as a social and economic imperative. Yet we know that children with intellectual disabilities continue to be among the most excluded and segregated in education.

Prior to the COVID-19 pandemic, children with disabilities were 2.5 times more likely to have never been in school³. Member organizations in both high and low income countries reported that the exclusion experienced by children with disabilities was compounded by

the lockdowns and the pandemic. The World Bank reported that 40 percent of disadvantaged learners in low and lower-middle income countries were left entirely unsupported in their education⁴.

With the closure of in-person schooling and the transition to online learning, the inaccessibility of our education systems for students with intellectual disabilities has been made more visible. As countries introduced national lockdowns, schools were closed in favour of remote education in a variety of formats – the majority of which were not accessible to learners with intellectual disabilities. As teaching methods became less accessible, students also lost access to the individual support that they benefited from in the classroom.

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Children with intellectual disabilities were the furthest left behind before the pandemic, but in the move to remote education as a result of COVID-19, children with intellectual disabilities were disproportionately impacted.

Sue Swenson,

President of Inclusion International

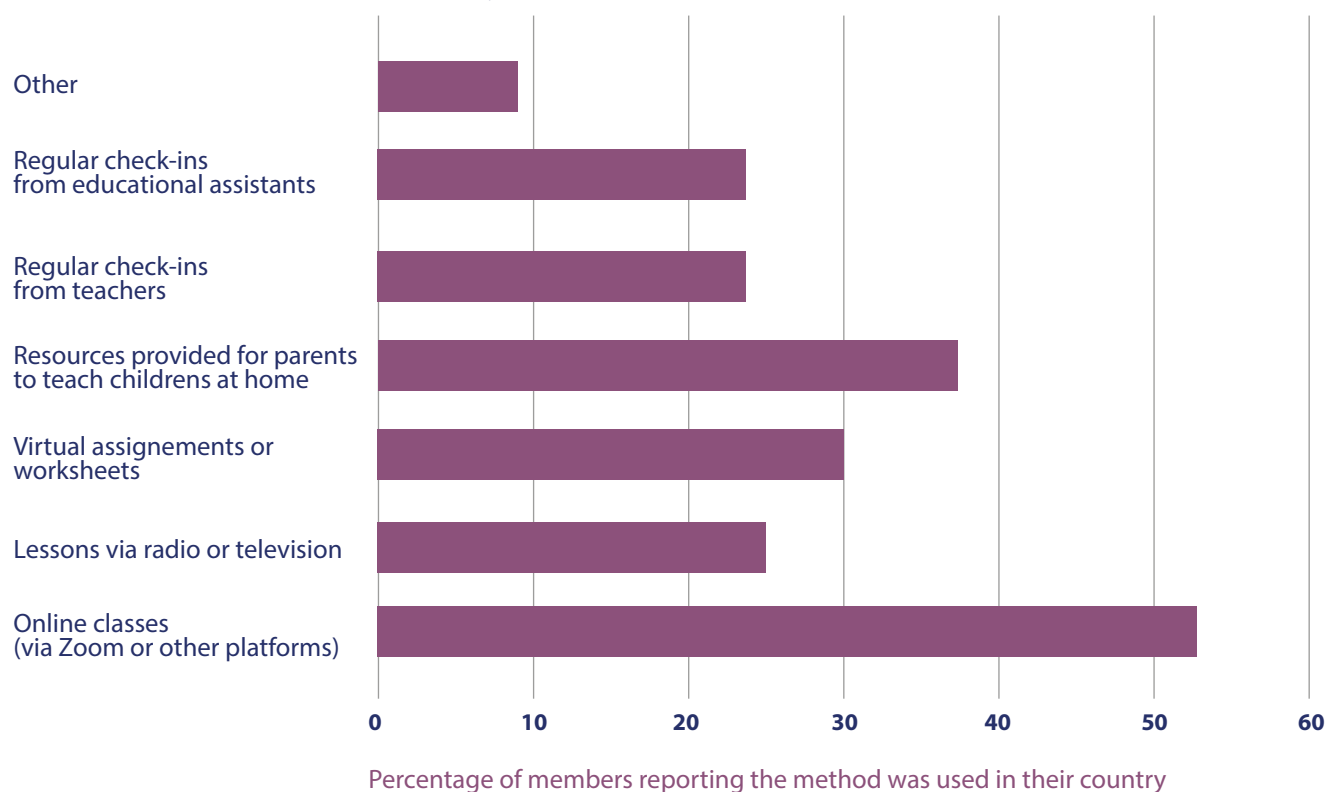
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³ Global Education Monitoring Report (2020). Inclusion and Education: All Means All. <https://unesdoc.unesco.org/ark:/48223/pf0000373718>

⁴ World Bank (2020). Pivoting to Inclusion: Leveraging Lessons from the COVID-19 Crisis for Learners with Disabilities. <https://www.worldbank.org/en/topic/disability/publication/pivoting-to-inclusion-leveraging-lessons-from-the-covid-19-crisis-for-learners-with-disabilities>

Inclusion International members reported a variety of alternative learning formats delivered during the pandemic, ranging from online lessons to delivery of education through television or radio. Delivery of classes through online platforms was the most common alternative lesson format reported by Inclusion International members, with 88% of respondents indicating that this method was used in their country.

Methods of Education Delivery during the COVID-19 Pandemic



The degree of exclusion from education that learners with intellectual disabilities faced during the pandemic was highly dependent on the model of education delivery in that country. While students with intellectual disabilities in inclusive education systems were likely to face accessibility barriers and a lack of individual support with learning, students with intellectual disabilities in segregated education environments were less likely to access education during the pandemic at all. 19% of respondents to Inclusion International's global survey said that segregated schools in their country did not make any online or alternative learning options available to students during the lockdown. Some also reported that government public schools did not attempt to deliver any kind of lessons through alternative means, but private schools were more likely to try and pivot to other delivery models for lessons.

There are many reasons why alternative delivery models were not accessible to students with intellectual disabilities. Inclusion International members reported that in many countries support workers and educational assistants were laid off at the beginning of the pandemic, and teachers were not making the necessary accessibility adaptations to their materials to ensure students with intellectual disabilities could participate.

Families of people with intellectual disabilities are also more likely to be experiencing poverty, which meant that many families did not have access to a computer or a stable internet connection for learners with intellectual disabilities to participate in online lessons.

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It is difficult to reach out to children in marginalised communities like children with intellectual disabilities due to the lack of accessibility in digital devices like smart phones, tablets, and computers, and access to the internet. It is not possible to conduct online classes for all. [In Bangladesh] about 80% of children with intellectual disabilities are left behind.

Organisation supporting people with intellectual disabilities in Bangladesh

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Individual support for students with intellectual disabilities was also lost as a result of COVID-19. Within contexts where students with intellectual disabilities were accessing education prior to the pandemic, 77% of members surveyed reported that students with intellectual disabilities were also accessing some form of individual support in the classroom prior to the pandemic. During the pandemic, learners with disabilities saw their individual support disappear – only 41% of Inclusion International members surveyed reported that teachers were checking in with students with intellectual disabilities in their country, and 21% reported that educational assistants were checking in with students with disabilities about progress. A majority of students were getting no direct support from educators and, in many cases, schools were failing to monitor the progress of their students with disabilities.

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All of the adjustments from in-schooling to schooling via internet were dependent on the teachers themselves [...] There were no systems or resources for teaching children with intellectual disabilities without physical presence, therefore this group was simply forgotten and left out.

*Norsk Forbund for Utviklingshemmede/
Norwegian Association for Persons with
Intellectual Disabilities (NFU)*

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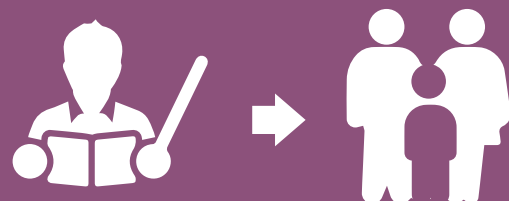
45% of Inclusion International members reported that alternative education delivery models were not accessible to learners with intellectual disabilities



19% of Inclusion International members reported that segregated schools in their country did not deliver education at all during lockdown.



Online classes via Zoom or other platforms were the most common education delivery model, reported by 88% of Inclusion International members.



60% of Inclusion International members reported a shift in responsibility for teaching students with intellectual disabilities from teachers to parents and other family members.

Our members told us that where students with intellectual disabilities did get regular check-ins and other forms of virtual support from their teachers and educational assistants, this was based on the initiative of the individual teacher and not based on the responsiveness of the school or measures put in place by the education system. Due to the failure of schools to identify systemic solutions for ensuring support and accessibility within school boards or national education systems, student support was delivered in an ad-hoc way and unevenly applied across students. The lack of a clear system for teachers to virtually monitor student needs and provide consistent support resulted in many students with intellectual disabilities being left behind.

With the lack of support available to students, family members of people with intellectual disabilities have taken on support roles to ensure that their family member can access education. As a result, families are playing multiple roles as carers, educators, and parents, with no support and with no respite. Parents have reported that the shift to online learning has added stress financially, with routines, and with a lack of time.

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Families have said that they are tired. They have had to adjust the [educational] material and try to teach their children, because the teachers do not make the adjustments.

Asdown Colombia

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Self-advocates have been speaking up about the barriers that the COVID-19 pandemic has created for their learning, reporting that they struggled with using virtual learning platforms and lacked access to the technology or stable internet connections needed to participate in the classroom. Many people also reported experiencing difficulty with losing the social aspect of school.

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Inclusive schools are where we feel good – it is where we make networks of friendship for life, and it is where we are respected and valued as we are. Inclusive education helps for others to value us and have us be part of the community.

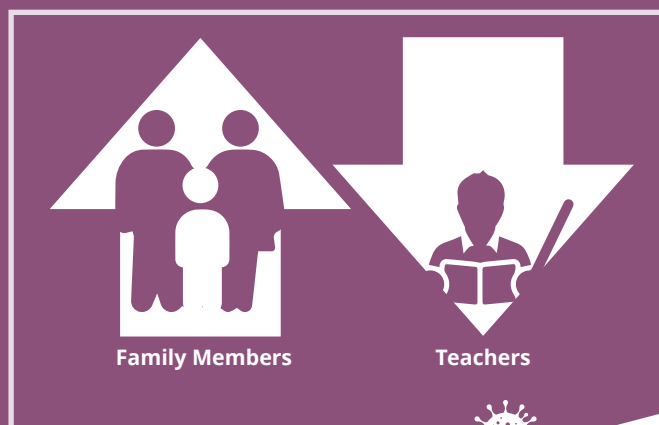
Laura Ximena González Varela

Self Advocate, Asdown Colombia

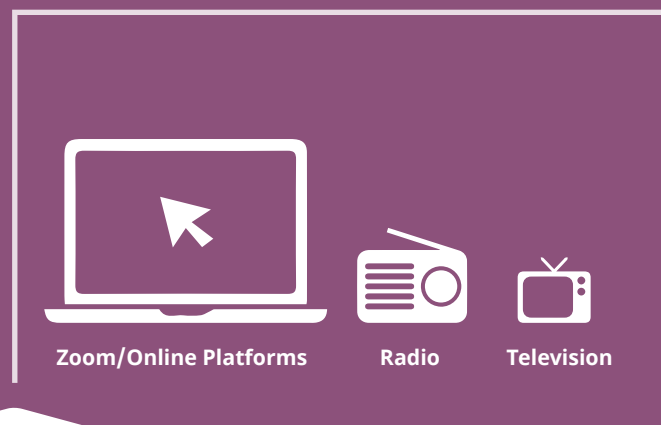
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Impact Of Covid-19 And Education Of Students With Disabilities

Education Responsibility



Education Delivery Model



Social And Financial Gap

Loss Of Support



For students with intellectual disabilities, inclusive schools are the place where they build friendships and connections in their communities. Many students told us stories about feelings lonely and isolated because they could no longer go to school.

Prior to the COVID-19 pandemic, learners with intellectual disabilities faced significant barriers to inclusion in the classroom. The shifts in our education systems caused by COVID-19, and the transition to online and unsupported learning, has disproportionately impacted students with intellectual disabilities, exposing and amplifying the inadequacies of education systems to meet the needs of all learners.

The pandemic has exposed both system level weaknesses in the approach to inclusion, as well as real issues around accessibility.

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With a pandemic that has left even more children with intellectual disabilities out of school, and with few or no supports in accessing remote learning, after COVID, how can we change the way that we offer education to *all*?

Diane Richler

Chair of the Catalyst for Inclusive Education

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Recommendations



The pandemic has created an important opportunity for governments and education systems to re-evaluate how students with intellectual disabilities and other marginalised groups access education, remove barriers, and design new systems where equal access to education is available for *all*.

To ensure that the COVID-19 recovery helps education systems build back better, governments must:

Create standards that ensure online and in-person education spaces are developed through universal design for learning



Education systems must be designed to be accessible to all students, always. This includes education delivery in emergency situations. All governments must set standards for their education departments to ensure explicit inclusion of students with intellectual disabilities in education delivery. This requires designing curricula to be inclusive of all students and ensuring that the delivery models are fully accessible and inclusive of all students in the school system.

Safeguard the support students with disabilities use in the classroom



When governments identify services as 'essential', the staff and services that allow students with intellectual disabilities to fully participate in the classroom must be safeguarded. Support for students with disabilities are essential for meaningful inclusion – these services must be secure in the face of budget cuts, and their delivery models must be maintained and adapted in emergency situations such as COVID-19. Budget cuts cannot come at the expense of students with intellectual disabilities. As governments plan to strengthen education systems as part of the COVID-19 recovery, safeguarding support for students with disabilities is essential.

Consult self-advocates and families on national education plans



The COVID-19 recovery is an opportunity to reimagine inclusion in education. As governments plan for these transitions they must recognise that students with intellectual disabilities and their families are the experts on what they need. National education planning will not be inclusive without active consultation with, and involvement of, self-advocates, families, and their representative groups (organisations of persons with disabilities).



Employment

The COVID-19 pandemic has caused unprecedented job losses and business closures around the world. People with intellectual disabilities were less likely to be in paid work prior to the pandemic, and those who do have access to formal sector employment were disproportionately employed in sectors that were hardest hit by COVID-19, including the retail and hospitality sectors.

People with intellectual disabilities around the world reported losing their jobs or being furloughed due to the pandemic, in many cases without being given accessible information about why this was happening. People with intellectual disabilities are also disproportionately involved in the informal sector, which has been particularly hard hit due to the pandemic.

People with intellectual disabilities who did retain their jobs during the pandemic often had to adjust to working remotely, which has made it more difficult to access the support from their supervisors and colleagues and other reasonable accommodations that enabled them to do their jobs in their physical workplaces.



Recommendations



People with intellectual disabilities faced significant barriers to access paid work prior to the pandemic, and COVID-19 resulted in the few gains that had been made in employment of people with intellectual disabilities being lost in many countries. COVID-19 economic recovery is an important opportunity for people to return to work with more inclusive workforces and workplaces.

To ensure that the COVID-19 recovery helps economic systems build back better, governments must:

Affirm commitments to inclusive employment

With mass layoffs of people with intellectual disabilities from inclusive workplaces, governments may face pressure to support sheltered workshops and other segregated employment options as a bridging mechanism until economies recover. Sheltered workshops remain a human rights violation even in emergency situations, and governments must affirm their commitment to ensuring inclusive employment options for people with intellectual disabilities. Real jobs for real pay are always the only option.

Reimagine recruitment to ensure inclusion

As workforces have transitioned to be remote, recruitment processes are changing to accommodate the lack of face-to-face hiring. Recruitment systems have always been inaccessible to people with intellectual disabilities, and the reimagining of recruitment and onboarding provides an opportunity for business leaders and Departments of Labour to model good practice in accessible formats for applications, interviews, and other recruitment tools.

Safeguard reasonable accommodation and other support during teleworking

Reasonable accommodation in the workplace is a right for all people with disabilities, and working from home does not change the responsibility of the employer to ensure reasonable accommodation is in place. Governments must monitor access to reasonable accommodation as businesses transition their working models or make the decision to maintain remote workforces in the long term, and governments must ensure that businesses have the support to deliver these accommodations remotely.



Summary of Policy Recommendations



As a global movement, Inclusion International's members came together during the pandemic to draw attention to the exclusion and discrimination against people with intellectual disabilities and their families, to share strategies and resources, and to support each other in the face of devastation and loss.

The experience of exclusion is not new, but the pandemic has uncovered the reality of how devalued people with intellectual disabilities are in their societies and has compounded their marginalization. This reality has been felt from the denial of access to inclusive education, employment, and health care to the gaps in social protection systems and shifting care responsibilities.

Our consistent experience throughout the pandemic has been widespread human rights violations - there has been a lack of access to information, education, and services, denial of social protection measures, as well as other rights violations. The COVID-19 crisis has resulted in an increase in restriction, isolation, and coercion for people with disabilities, particularly those living in institutions.

Self-advocates and families have come together to develop an agenda for inclusive COVID-19 recovery that draws from the experience of our network, pre- and post-pandemic, across economic, health and education systems.



Pandemic recovery efforts by governments must address the disproportionate impact of COVID-19 on people with intellectual disabilities and their families. But it also gives policymakers an opportunity to reflect on the pre-pandemic systems that made this exclusion and disproportionate impact possible, and to reimagine and work towards more inclusive systems to help communities 'build back better'.





A Global Agenda for Inclusive Recovery:

Ensuring People with Intellectual Disabilities and Families are Included in a Post-COVID World

Summary of Policy Recommendations



Making information accessible to all

- ✓ **All information shared** by governments must be produced in formats accessible to people with intellectual disabilities, including plain language and easy read, video, and other formats
- ✓ **Require** service providers and other private organisations to produce content in accessible formats
- ✓ **Involve** people with intellectual disabilities in the design and vetting of accessible materials
- ✓ **Work** with organisations of persons with disabilities (OPDs) representing people with intellectual disabilities and their families to ensure that accessible content is reaching people



Ensuring consistent access to support services

- ✓ **Ensure** that services which support independent living, services which support families, and services for people with high support needs are deemed essential.



Improving inclusivity in health systems

- ✓ **In partnership** with organisations of persons with disabilities (OPDs), train health care workers to better understand the social determinants of health that impact people with intellectual disabilities and to share health information in an accessible way.
- ✓ **Eliminate** disability as grounds for lower triage priority for access to health care.
- ✓ **Prioritise** people with intellectual disabilities and family carers in vaccination drives.



Supporting families

- ✓ **Provide** support services to families, including during emergency
- ✓ **Ensure** access to mental health support.
- ✓ **Support** organisations of persons with disabilities and their families (OPDs) to provide peer support and other family-led services.



Deinstitutionalization

- ✓ **Plan** for the closure of institutions and the transition of residents to communities
- ✓ **Ensure** residents of institutions are supported through individual transition planning
- ✓ **Fund** community-based services and support for independent living



Designing inclusive social protection systems

- ✓ **Create** responsive, adaptable, and individualised social protection systems that avoid 'one size fits all' solutions.
- ✓ **Ensure** social protection systems which aim to cover disability-related costs are not tied to work requirements, minimum salaries, or the number of hours worked.
- ✓ **Social protection systems** must be easy to understand, apply for, and receive.
- ✓ **Family caregivers** must also have access to social protection systems.



Reimagining educational systems

- ✓ **Create** standards that mandate the use of universal design for learning in all in-person and online education delivery
- ✓ **Safeguard** the support that students with disabilities use in the classroom
- ✓ **Consult** self-advocates and families on national education plans



Supporting inclusive employment

- ✓ **Affirm** commitments to inclusive employment.
- ✓ **Reimagine** recruitment strategies and onboarding practices for new employees to be more accessible.
- ✓ **Safeguard** reasonable accommodation, even in teleworking situations.



It is only through work to ensure that recovery efforts break down the barriers faced by people with intellectual disabilities that governments can confidently ‘build back better’.



“

COVID-19 recovery efforts are not only about building immunity to COVID-19 and future health crises – if governments take action to ensure their pandemic response includes people with intellectual disabilities and their families, the COVID-19 recovery period is also an opportunity to build a more inclusive post-COVID world.

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COVID-19 Impact Survey Participants:

AKIM Israel

Alexandria Self-Advocacy Resource Group

Anffas Onlus

APAPE Togo

Arc of the United States

Arts Project Australia

Asdown Colombia

Associação Angolana de Apoio a Pessoas Autistas e Deficiente Intelectual

Asociacion Azul

Asociacion sindrome de Down de Costa Rica

Asociación Síndrome de Down de la República Argentina

Belarusian association of assistance to children and young people with disabilities

Bridge of Hope

Bundesvereinigung Lebenshilfe e.V.

Caritas Egypt - SETI Center

Children and Young People with Disability Australia

Collectif Tubakunde

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Community Living Toronto

Down Syndrome Association Mauritius

COVID-19 Impact Survey Participants:

Down Syndrome Family Network	Keystone Moldova
Down Syndrome Foundation Nigeria	La Chrysalide
Down Syndrome Society of Bangladesh	Landssamtökin Þroskahjálþ
Down Syndrome South Africa	Lebanese Association for Self-Advocacy
FDUV	Lebenshilfe Österreich
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Fikir-Ethiopia National Association on Intellectual Disability	Midland Mencap
Fundación Descúbreme	Namibia Association of Children with Disabilities
Help Centre	New Inclusion Japan
Inclusion Alberta	Norsk Forbund for Utviklingshemmede
Inclusion Australia	PARIVAAR
Inclusion Beijing	People First Canada
Inclusion Ghana	People First New Zealand
Inclusion Ireland	Royal Mencap Society
Inclusion Mauritius	Sharjah City for Humanitarian Services
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Keystone Human Services	YAI Network
Keystone Institute India	Zambia Association for Children and Adults with Learning Disabilities
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COVID-19 Webinar Series Speakers:

AKIM Israel	British Council
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Arc of the United States	Centre for Inclusive Policy
Asdown Colombia	Ceva de Spus
Asociacion Azul	Chosen Power
Asociacion Civil por la Igualdad y la Justicia	CONFE
Books Beyond Words	Inclusion Africa

COVID-19 Webinar Series Speakers

Inclusion Canada	Royal Mencap Society
Inclusion Europe	Self-Advocates Becoming Empowered (SABE)
Inclusion Ghana	Sightsavers
Inclusion Ireland	Sociedad Peruana de Síndrome Down
Inclusion Scotland	Society for Education and Inclusion of the Disabled (SEID)
Kenya Association of the Intellectually Handicapped (KAIH)	Speak Out Self-Advocacy
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Plena Inclusion	

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Validity Foundation
European Network on Independent Living (ENIL)
International Disability Alliance (IDA)
Disability Rights International (DRI)
Disability Rights Unit, Centre for Human Rights, University of Pretoria
International Disability and Development Consortium (IDDC)
Disability Rights Fund and Disability Rights Advocacy Fund

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