



Including People with Intellectual Disabilities in the COVID-19 Recovery

Inclusion
international | 



Inclusion International is the global network for people with intellectual disabilities and their families.

We are made up of self-advocates and families.

Our members are organizations and individuals around the world who want a world that is more inclusive of people with intellectual disabilities.

Inclusion | 
international

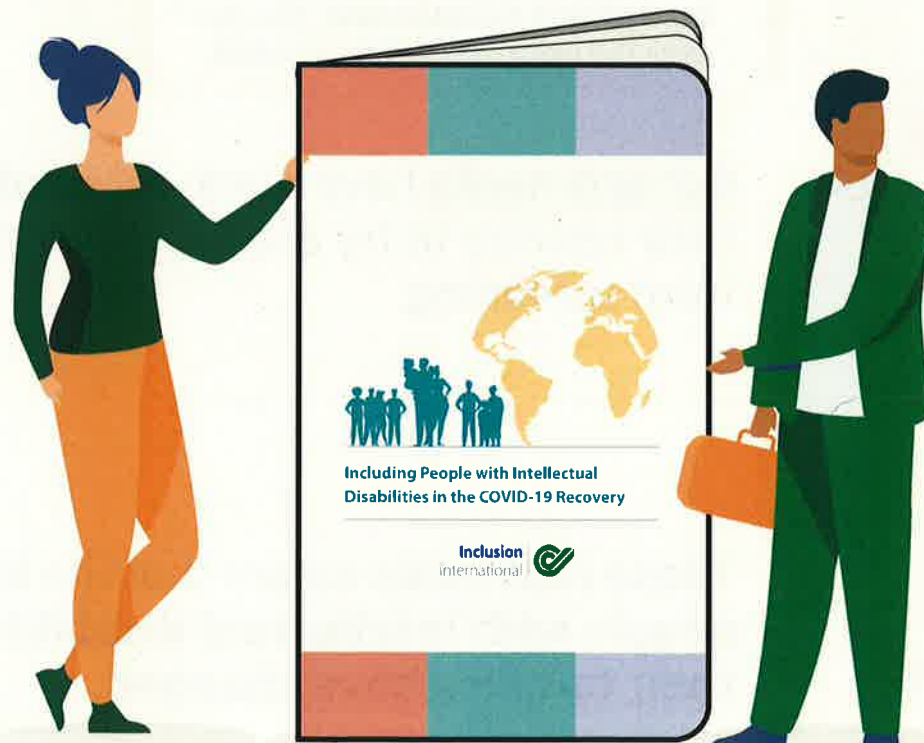




This report is about what countries need to do to include people with intellectual disabilities. This is important because they were not included during COVID-19.

People can use this report to learn what the problems were during COVID-19. They can also use it to learn what governments should do differently.

Self-advocates can use this report to show their governments and ask them to take action.

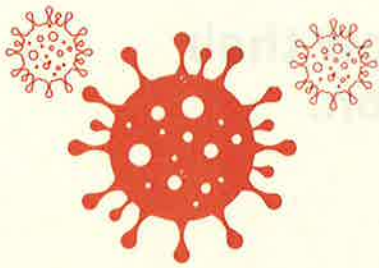




Introduction

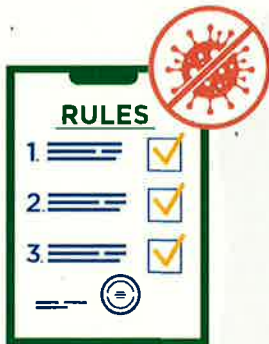


COVID-19 is a health problem that has affected many people around the world.



COVID-19 is also called Coronavirus.

Words that are highlighted in yellow are more difficult to understand. You can click the word to see what it means.



Governments have made **new rules** in their country to try and stop COVID-19 from spreading.



These new rules meant that the **lives of people with intellectual disabilities and their families** have changed.



These are some of the ways the lives of people with intellectual disabilities and their families changed because of COVID-19:



Some people have **got sick from COVID-19**



Students have not been able to learn because **schools have closed**



People who live in institutions, like group homes or care homes, have **not been able to see their families**



People have **lost their jobs**



Services that people used, like **day centres, have had to close**



Some people with intellectual disabilities **have not been able to get health care**

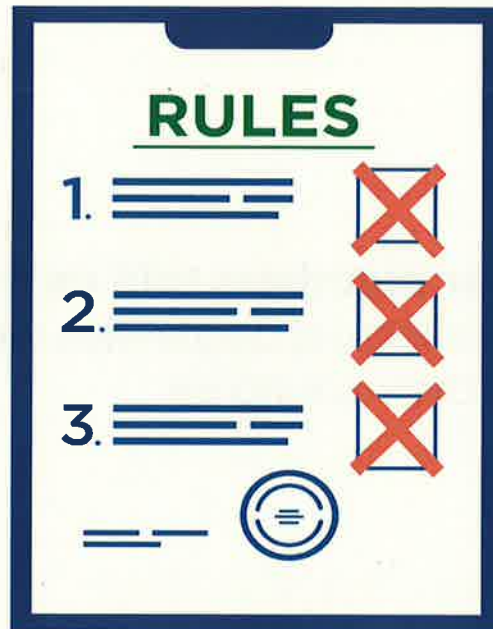


People have felt **isolated and alone**





The new rules that governments made usually did not consider people with intellectual disabilities and their families.





We asked Inclusion International member organizations if new government rules in their countries about COVID-19 were inclusive.



Our members told us that people with intellectual disabilities were not included in their countries



Inclusion International members **have been doing advocacy** to make sure their governments include people with intellectual disabilities.



Governments are making plans for how to fix things in their country after COVID-19.

They want to fix the problems that COVID-19 caused.





This plan is called “building back better.”

Building back better means that governments should try and make things even better than they were before COVID-19 happened.





This report is about the ways that COVID-19 has caused problems for people with intellectual disabilities and their families.

There are 8 parts about different topics.

You can read the whole report, or you can click on the topic to read just one section



Access to Information



Access to Support and Services



Access to Health Care



Support for Families



Institutions



Social Protection



Education



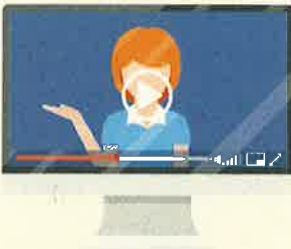
Employment



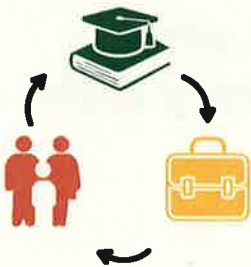
Where did the information in this report come from?

The information in this report came from three different places.

1. COVID-19 Webinar Series



Inclusion International held **18 webinars** about COVID-19.



The webinars were about **different topics** like education, employment, and families.



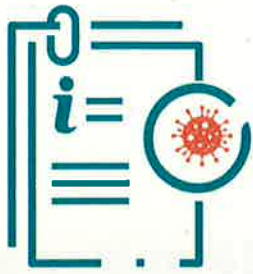
Over 1,000 people joined these webinars.



Some of the information that people shared on the webinars is in this report.



2. COVID-19 Survey of Inclusion International members



Inclusion International did a survey about COVID-19 for our member organizations.



The survey asked them about **what was happening in their country with COVID-19.**



Organizations in 48 countries answered the survey.



3. Disability Rights Monitor



A group of 7 organizations joined together to run a survey about COVID-19.



People with disabilities, families, and organizations could answer the survey.



Information that people with intellectual disabilities, Down Syndrome, Autism, or their families answered in the survey **is in this report.**



How were people excluded during COVID-19?



Access to Information



During COVID-19, **there was lots of new information being sent out** every day about health and about new government rules.



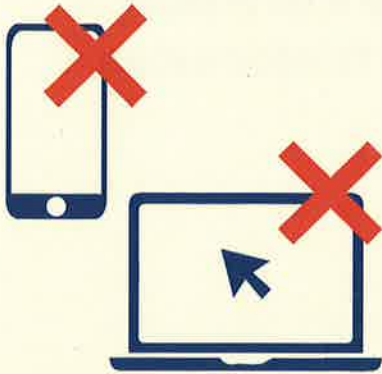
This information was usually not in accessible formats like easy read, plain language, or videos.

Fernanda, a self-advocate from Mexico, said:



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.



Sometimes accessible information is produced, **but not everyone has a phone or computer they can use to find it.**



One survey of people with intellectual disabilities, Down Syndrome, and Autism learned that **only 3 out of 10 people felt like they had enough information about COVID-19.**





What the Government Should Do

Governments should always make information accessible. This is true for COVID-19 information and for all other information.

This is what governments should do:



1. All government information should be accessible

Governments must make their information in plain language, easy read, videos, and other formats. They should ask self-advocates which formats are best in their country.



2. Service providers must make information accessible

Governments should make a rule that other organizations should also make their information accessible. This includes service providers, like housing or support providers.



3. Work with self-advocates to make accessible materials

Governments should work together with self-advocates to make information accessible. Self-advocates should help design the information. They should also give the government advice on how to reach people. Self-advocates should be paid for this work.



Access to Support and Services



People with intellectual disabilities and their families **access different support in their lives.**



Some examples are personal assistants, peer support, support with decision-making, respite services, or employment support.



During COVID-19, **these services and supports stopped being offered.**



Governments decided that some services were important enough to stay open. **These were called “essential services.”**



An example of an essential service is a hospital. They stayed open during COVID-19.



In some places, services for people with disabilities were essential and **stayed open.**



In other places, the government decided that disability services were not essential.



This meant that people with intellectual disabilities **did not get the support they needed.** This also meant that families did not get the support they needed.



People who have the highest support needs **were the most affected by services closing.**



Self-advocacy groups helped to make sure that people still had some forms of support.



They delivered peer support and kept people with intellectual disabilities connected to each other.



What the Government Should Do

Services and support are important for people to live independently. This is true during COVID-19 and during normal times.

This is what governments should do:



1. Make services for people with disabilities “essential”

Services that people with disabilities use to live independently should be essential. This means that the government would make sure that they can always access it, even during emergencies like COVID-19.



2. Make support for families “essential”

Services that help families should be essential. This means that the government would make sure that they can always access it, even during emergencies like COVID-19.



3. Make sure people with higher needs always have support

Services and support for people with higher needs are important for making sure they are safe and healthy. These services should never be cut, even in emergencies like COVID-19.



Access to Health Care



People with intellectual disabilities have many barriers to good health care. These got worse because of COVID-19.



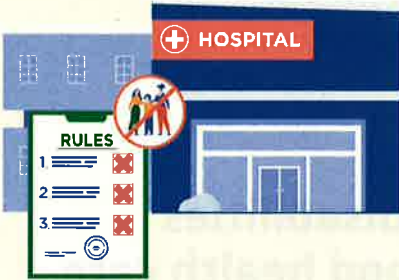
People with intellectual disability have a **much bigger risk of getting very ill or dying of COVID-19.**



Even though people are more at risk, **most governments did not do enough** to make sure people with disabilities stayed safe.



When people got sick, their families also could not come with to them to the doctor's office or the hospital. This was a problem because doctors do not talk in an accessible way.



Some hospitals also made rules that meant that people with intellectual disabilities could not get health care.



The rules said that people with intellectual disabilities should only get health care after other people without disabilities.



These rules are called “triage policies.” **People died because of these policies.**



Even though people with intellectual disabilities are more at risk, they are not being given the vaccine first in most countries.



What the Government Should Do

Everyone needs health care to stay safe and healthy. This is very important during a global health problem like COVID-19. Health systems must be inclusive and accessible to everyone for everyone to stay safe.

This is what governments should do:



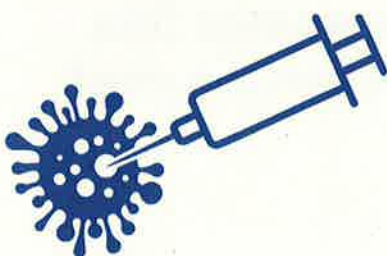
1. Make health services inclusive

Doctors, nurses, and other people who work in health care need to understand people with intellectual disabilities. They need to learn how to talk about health in a way that is accessible to everyone. Health information must be in accessible formats.



2. People with intellectual disabilities need equal access to care

There should not be any rules that say people with disabilities only get care after everyone else. People with intellectual disabilities need equal access to health care.



3. Give people with intellectual disabilities early access to vaccines

People with intellectual disabilities and their families should have early access to vaccines. This is important because they are more at risk for COVID-19.



Support for Families



Families of people with intellectual disabilities have also had a lot of changes in their life because of COVID.



Services that families use to help them in their lives have stopped because of COVID-19.



Many family members (like parents or siblings) have had to leave their jobs because they have to care for their family member or help them with school.



Family members who are women (like mothers and sisters) have been the most affected.



Many family members report a lot of stress and mental health issues because of COVID-19. This is because they are worried about their family getting sick. They also worry that if they get sick, their family member who has an intellectual disability will not have any support anymore.



COVID-19 has also been very difficult for people with intellectual disabilities who have children of their own. They have lost the support they would normally have to help them with their children. Information about COVID-19 and the changes happening is also not accessible to them.



Sonia, a self-advocate from Australia who is a parent said:

[I had] challenges around online school and understanding the information sent home 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.



Family organizations have been helping to try and connect families to make things less difficult. They have done peer support and shared information between families.



What the Government Should Do

Families need to be included when the government responds to COVID-19.

This is what governments should do:



1. Make services for families essential

Services that help families should be essential. This means that the government would make sure that families can always have these services, even during emergencies like COVID-19.



2. Help families access mental health support

Family members should be able to get services and support for their mental health. This is important for making sure families are able to support and advocate for their family member.



3. Support family organizations to do programming for families

Organizations that are led by family members are helping families. Governments should make sure they have the money to do this important work.



Institutions



Institutions are places where people with intellectual disabilities live together, but **away from their families and separate from the community.**



Some institutions are big and have many people. **Other institutions are small** and have only a few people (these are sometimes called group homes).



COVID-19 was very dangerous for people who lived in institutions.



Because many people live in one space, the people who live there were more likely to get sick from COVID-19.



In many countries, **people who lived in institutions died.**



When COVID-19 started, **the people who lived in institutions were not allowed to leave.**



This meant that they **couldn't see their families and felt alone.**



Inclusion International asked our members if the people who live in institutions in their country **could talk to their families.**



More than half said that the **staff at institutions were not helping the people who live there to use Zoom** or other technology to talk to their family and friends.



Inclusion International members also told us that people who live in institutions **stopped getting as many services because of COVID-19.**



Many institutions also had less staff. This meant that people did not get enough support.



Eli, self-advocate from Romania who used to live in an institution said:

[For people who live in institutions] 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.



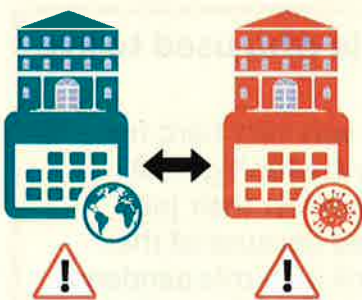
People with intellectual disabilities believe that the **government did not do enough** to make sure people who live in institutions are safe.



In the COVID Disability Rights Monitor survey, **8 out of 10 of people** with intellectual disabilities, Down Syndrome, and Autism said this.



During COVID-19, people in institutions were not safe. This is because institutions are not safe places for people to live.



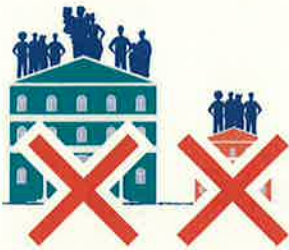
This was also a problem before COVID-19 started.



What the Government Should Do

When governments make their plan for how to make things better after COVID-19, institutions must be part of their plan.

This is what governments should do:



1. Close institutions

Both big and small institutions should be closed.



2. Make sure people can move out of institutions safely

Governments need to plan to make sure that people can move out of institutions safely. People will need support, and the government must pay for this.



3. Make sure there are services in communities

For people to be independent, there must be support and services in their community. This is important for people to live independently.



If governments do these three things, people with intellectual disabilities will be able to live away from institutions and in their communities. This means they will be safer if something like COVID-19 happens again.



Social Protection



Social protection is how governments support people.



Some of these things are part of social protection:

- **Giving people enough money to live**
- **Giving housing to people who cannot afford it**
- **Giving people health care**



Social protection is important for people who are more vulnerable. This can include people with disabilities, who are more likely to be poor.



During COVID-19, many people lost their jobs and stopped earning money. This made social protection programmes even more important.



Lots of countries created new social protection programs, like giving cash benefits to people who lost their jobs.



For families and people with intellectual disabilities, these new programs were not enough to help them.



People with intellectual disabilities also **had more challenges getting the benefits than other people with disabilities.**



Our members told us that the new social protection programmes in their countries were not accessible



Sometimes people could not get these programmes because they did not have jobs before COVID-19. **Some people also couldn't get social protection because the application was not accessible.**



Many people had these problems before COVID-19. **The new COVID-19 social protection programmes had the same problems the old ones did.**



What the Government Should Do

Social protection is important for making sure that people can live safe and healthy lives. Social protection programmes need to fully include people with intellectual disabilities.

This is what governments should do:



1. Social protection should be fit everyone's needs

People with disabilities have different needs. Social protection programmes must be flexible so everyone can get what they need.



2. Social protection must be easy to access

It must be easy to get information about social protection programmes. It must also be easy to apply for them.



3. Social protection programmes should not have work requirements

Many social protection programmes help people to pay for the costs of their disability. These programs should not be connected to whether or not someone has a job.



Education



Before COVID-19, many people with intellectual disabilities **were not included in school.**

During COVID-19, this problem got worse.



Because of COVID-19, **many schools closed.**



In some countries, schools closed for students who do not have disabilities, **but students with disabilities still went to school, even though it was dangerous because of COVID-19.**



Many classes switched to being online, over the radio, or over the television.



These new ways of teaching classes were usually not accessible.



Students also lost the support they had in the classroom.



Because the new ways of teaching were not accessible and because there was no support, family members had to help act as teachers.



Self-advocates have reported that the **changes have been difficult.**



They told us that **online learning was not accessible.**



Many self-advocates told us that **people do not have access to technology** so have not been able to learn online.



Schools closing has also been difficult because inclusive **schools are places where people feel included.**



Laura, a self-advocate from Colombia, said:



Inclusive schools are where we feel good.

It is where we make friendships for life.

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.



Schools closing have made people with intellectual disabilities **feel alone and excluded.**



What the Government Should Do

When governments make their plan for how to make things better after COVID-19, education must be part of their plan.

This is what governments should do:



1. Make sure school is always accessible

What we learn in school should be accessible to everyone. Governments must make sure that their schools and the ways students learn always include everyone



2. Make sure students always have support

Direct support for students with disabilities in classrooms is important for making sure they can learn. Governments must make sure that the funding for these supports do not get cut.



3. Include self-advocates and families in planning

Governments should ask self-advocates and families what they think about education. They must involve self-advocates and families in their planning.



Employment



COVID-19 is a health problem, but it has also caused problems for businesses. **Many people have lost their jobs.**



Many people with intellectual disabilities work in restaurants or in shops. **These types of workplaces had many people lose their job because of COVID-19.**



Many people who lost their job **were not given accessible information about what was happening and why.**



For people who did keep their jobs, they had to start working from home. **It is harder to get support from others at your job when you are working from home.**



Luis Gabriel, a self-advocate from Colombia said:



Many of the self-advocates mentioned that this situation has complicated their lives since they cannot go to work as they used to do. Others can work from home. I had to take an early vacation period and an unpaid leave before returning to work. An unpaid leave is when I stayed at home agreed with my company without receiving any kind of payment.

Harry, a self-advocate from England said:



Recently, during the pandemic, working from home has been a big change for me. I've had to get used to a new way of working every day. How can I keep in contact with my colleagues when we aren't have team meetings face to face, I had to think about how I could communicate with my colleagues.



What the Government Should Do

Inclusive work is an important part of independent living. When people start to get their jobs back after COVID-19, it is important that people with intellectual disabilities are included.

This is what governments should do:

1. Make sure that real jobs for real pay are the only option



Many people with intellectual disabilities have lost their jobs. This does not mean we should put them in **sheltered workshops**. Sheltered workshops are places where only people with disabilities work. When people start to work again, it must be real jobs for real pay.



2. Think of new ways to hire people

Usually, the way that companies hire people is not accessible. Because of COVID-19, many companies are trying out new ways of hiring people. new ways of hiring should make it easy for anyone to apply and get hired.



3. Make sure everyone gets support at work

People with disabilities have a right to have support at work. This is called **reasonable accommodation**. Governments must make sure everyone has this, even when they work from home.



Right now, governments are spending money and making lots of changes to make countries better after COVID-19.

If governments follow this advice, their countries will be more inclusive of people with intellectual disabilities.





Glossary

A glossary is a list of words. It explains the meaning of words that are more difficult to understand.

Accessible - Accessible means easy for everyone to understand or use.

Community - A community is a group of people who are connected to each other. For example, people who live in the same neighbourhood together are a community.

Government - Governments are the official group of people that lead and make decisions about our lives.

Institutions - Institutions are places where people with disabilities live. They live with other people with disabilities but they are separated from their families and from their communities.

Reasonable Accommodation - Reasonable accommodation is an adjustment that makes it easier for someone to do something. People with disabilities who have jobs will sometimes get adjustments made to help them do their job.

Sheltered Workshop - Sheltered workshop is a place where all of the workers are people with disabilities. Usually the people who work at sheltered workshops get very low pay or no pay.

Webinar - A webinar is a presentation that happens over the internet instead of in-person.



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the COVID-19 Recovery**

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