



# Time to be Counted: COVID-19 and Intellectual and Developmental Disabilities

June 2021  
RSC Policy Briefing



COVID-19 has been hard on people's health, school, work, and getting help in the community.



COVID-19 and following all of the COVID-19 rules has been extra hard for people of all ages with Intellectual and Developmental Disabilities (IDD). It has been hard for their families too.



*"I am not OK if my son is not OK. And he is not OK during COVID-19. We lost the life we had before."*

**Pamela L., mother of a son with IDD**



This report is about how to make things better for people with IDD during COVID-19 and after it is over.



We need to think about IDD when deciding about how to deal with COVID-19 and when we plan how to make things better when COVID-19 is over.



The recommendations in this report are trying to make Canada better for people with IDD and their families now and later. This will be good for everyone.



*“Whenever there’s policies being made or whenever we are trying to, as a society, learn how to be more inclusive, it’s really just...a pointless exercise if you have a certain group of experts making recommendations and policies without actually including...the people who have that lived experience...right now it is probably more important to make sure that decisions and policies...are made with our okay and with our input.”*

**Jake Anthony, self-advocate**



## Policy Recommendations

There are two main ideas on how to make things better:

1- “Nothing about us without us” – people with IDD need to be part of the planning to make things better.



2- COVID-19 policies need to remember and help people with IDD, and not just people who do not have disabilities.



Accessible

This report talks about what is important to people with IDD and makes 19 recommendations.



*“We have to be able to accommodate everybody and not have a ‘one size fits all’ approach.”*

**Jake Anthony, self-advocate**



## List of Recommendations

### Recommendation 1

Make sure people with IDD can get the vaccine early with other groups of people who can get very sick from COVID-19.



### Recommendation 2

Make all information about COVID-19 so people with IDD can understand it – use video, audio, print, with pictures.



### Recommendation 3

Make sure no matter how bad things get with COVID-19, people with IDD can see their workers, and get their therapies, and other kinds of help. These services are ESSENTIAL – that means they have to happen and can't be stopped.





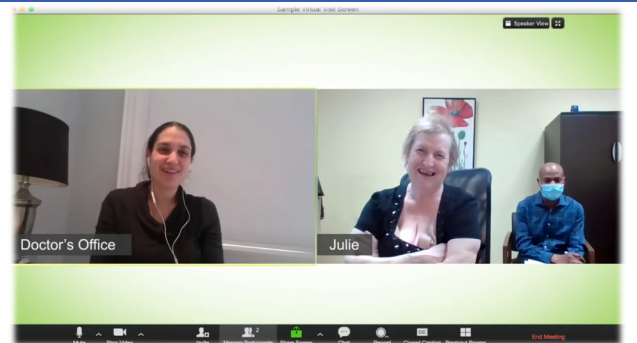
## Recommendation 4

Make it easier for people with IDD to use health care during COVID-19 – they need more time, they need the people who can help them to be allowed to be with them, they need information they can understand.



## Recommendation 5

Using the phone or video can be a good way for people with IDD to get health care and keep them safe, but they need help to do this. Teach them how and make sure people who can't use phone or video can get health care in person.





## Recommendation 6

The mental health of people with IDD is worse because of COVID-19. Give people with IDD proper mental health help that understands their disability.



## Recommendation 7

Make a list of the different activities for people with IDD to do in the community. Find out where programs are missing, then make those programs.



*“I rarely go out because I am more at risk. Isolation has definitely had an impact on my mental health.”*

**Youth with developmental disability**



## Recommendation 8

People with IDD should be able to have fun and be part of our community even when it is COVID-19. Make a guide that helps everyone know how to make in person and virtual activities easier to do.



## Recommendation 9

People with IDD need extra money so they can do activities in the community when it is COVID-19 and after COVID-19.





## Recommendation 10

Make sure people with IDD can be part of school activities and classrooms with kids who do not have disabilities. This is important when going to school and when school happens online.



*“[It’s] harder for students with disabilities, [when] you don’t have that person interaction. It would be harder online.”*

**Self-advocate**

## Recommendation 11

COVID-19 has been hard for kids with IDD who go to school. Find out what happened to kids with IDD because of COVID-19 and schools, and help kids who had a hard time do better with school.







## Recommendation 12

Make sure that everyone with a disability gets enough money to help them manage ok – A National Disability Income Benefit.



## Recommendation 13

When government gives money to help people during COVID-19, think about what people with IDD need. They need money to pay for extra things like PPE, for people who come to help them, and using the internet.



## Recommendation 14

Some of the families of people with IDD had to stop going to work so they can take care of them during COVID-19. The government needs to give money to these families who can't go to work.





## Recommendation 15

Lots of people with IDD have not been able to go to work since COVID-19. They will need help to get new jobs and have people helping them to learn these jobs after COVID-19.



## Recommendation 16

People with IDD have a right to be able to see people in their families who are closest to them if they live in long-term care or a group home.



*“Even before COVID-19 some people had a hard enough time to find a job, but now it’s going to be double hard to find a job—not just because of a disability but for other people too because so many people got laid off—it’s not just going to be hard for us but for everybody.”*

**Joanne Gauthier, self-advocate**



## Recommendation 17

The government needs to count and report about what is happening to people with IDD during COVID-19, including people who live in long-term care homes, and group homes.



## Recommendation 18

Governments need to make safe homes that people can afford where they live with support so they don't have to live in long-term care homes.



## Recommendation 19

Make sure that hospital rules (“triage”) do not stop people with IDD from getting the help they need if they are very sick in hospital.



**You can read the full report here:**

<https://rsc-src.ca/en/covid-19-policy-briefing/time-to-be-counted-covid-19-and-intellectual-and-developmental-disabilities>



## Acknowledgements

This easy-to-read summary of the  
**Time to be Counted:**  
**COVID-19 and Intellectual and Developmental Disabilities**  
**Policy Brief by the Royal Society of Canada**  
was developed in partnership with  
Health Care Access Research in Developmental Disabilities  
(H-CARDD) program and the  
Azrieli Adult Neurodevelopmental Centre at the  
Centre for Addiction and Mental Health (CAMH), Toronto, ON,  
as well as the CHILD-BRIGHT Network.



Health Care Access Research  
and Developmental Disabilities

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Neurodevelopmental Centre

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