



INCLUSION IRELAND

# **The Experiences of Adults with Intellectual Disabilities in Ireland During the Covid-19 Crisis**

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**September 2020**

Tomás Murphy  
Margaret Turley  
Chris Byrne  
*with*  
Nóirín Clancy  
Harry Browne

**T**  
DUBLIN  
OLLSCOIL TEICNEOLAÍOCHTA  
BHAILE ÁTHA CLIATH  
TECHNOLOGICAL  
UNIVERSITY DUBLIN

## Easy to read summary



This report is a summary of The Experiences of Adults with Intellectual Disabilities in Ireland During the Covid-19 Crisis.



This research was carried out by three people with disabilities with support from TU Dublin and Inclusion Ireland.

Eleven participants were interviewed by Zoom.

We asked them questions about work, supports, independence, what they liked, did not like and the information they got about Covid-19.



### What participants told us

All participants had to stop working in their day services because of Covid-19.

They said not working has been very hard.



All participants said they miss meeting their family and friends at their work or day service.

Many said they were isolated. This made them feel anxious and fearful.



The levels of support participants got from day services was different.

Some got Zoom calls every week.

Others had no contact with their service.

Participants talked about ways to support themselves by walking, writing poetry and doing meditation.



The information participants got about Covid-19 came from TV and information booklets.

Some information was not easy to understand because it was not in an accessible format.

### **What people liked about the lockdown**



- Being able to do things online like meetings and classes on Zoom.

This helped many participants have a feeling of independence.

- Having a sleep-in because they didn't have to get up for work.

### **What people did not like about the lockdown**



- Not being able to meet with friends and family.
- Missing opportunities like taking up studying and going on a holiday.
- Not being able to go anywhere.

### **Recommendations:**



Before returning to work people with disabilities should know about the changes and be able to take their time doing their job.

If services close and reopen again, people with disabilities must be included in these discussions so their voice can be heard.



The Government needs to make information on Covid-19 in more accessible formats.

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## Introduction: The Power of 11

We interviewed 11 people for this project. All 11 people gave some great information about their experiences during the Covid-19 crisis.

Article 11 of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) is about 'Situations of risk and humanitarian emergencies'. It says what the special duties of countries are to people with disabilities during a crisis such as Covid-19:

*States parties shall take, in accordance with their obligations under international law, including international humanitarian law and international human rights law, all necessary measures to ensure the protection and safety of persons with disabilities in situations of risk, including situations of armed conflict, humanitarian emergencies and the occurrence of natural disasters.*

Ireland legally has to comply with the UNCRPD. In this report you can see what 11 people said about what they have been experiencing, and you can see whether Ireland has been ensuring their protection and safety, the way it promises under Article 11.

## How we went about the project

The research for this project was designed completely by three of us who have disabilities ourselves, Tomás, Margaret and Chris.

We put a list of questions together about the lockdown and Covid-19. The questions were in two parts: part 1 had some general personal questions about living and work, and part 2 was questions that were more about the lockdown and Covid-19. We tested the questions in interviews with each other and improved them.

After the questions were put together we then had to find people with intellectual disabilities to interview. Tomás, Margaret and Chris, as well as Nóirín from Inclusion Ireland, all asked our different contacts that we know to find people to interview. We did not want to interview our own friends. The people that we were going to interview had to be able to use Zoom or WhatsApp or have someone who could help them use it.

We sent information about the project in Easy to Read format out to all the possible participants.

When we had our people for interviewing we had to give their contact information to Margaret and Noirin, who put a timetable together of the day and time and who was doing each of the interviews. After that Noirin or Margaret would give the information to Harry who set up the Zoom interviews for recording. Once the Zoom interviews were set up we then did the interviews.

Participants gave their consent in the interviews when we read through an Easy to Read consent form together on the Zoom screen.

The interviews took place in late June and July 2020, when the lockdown was getting a bit less restrictive.

Tomás did five interviews. Margaret and Chris did three each.

The people we interviewed were from all over the Republic of Ireland, including counties Galway, Sligo, Carlow, Dublin, Offaly and Kildare, and they live in a variety of domestic settings. None of them was in a care setting affected directly by Covid-19. Most were affected by the long and continuing closing of day services.

Their names were Jimmy Dooner, Pat Flaherty, Sinead Gilgunn, Sarah Jane Lavin, Peggy McDonnell, Gary McCabe, Mairead McHugh, Phillip O'Donnell, Barry Olwill, Dairine O'Rourke and Kai Tiernan. We call them by their first names in this report.

The report is divided into sections but we have also used selected quotes from each participant talking about their feelings about the Covid-19 crisis throughout the document.

## **Note on Zoom and communications**

Although we had a backup plan to use WhatsApp, Zoom turned out to be what we used for all 11 interviews.

This software, which few of us had heard of before March 2020, proved to be an important tool for us, as it has been for many people this year.

It allowed people to see and speak to each other, and made it easy to record interviews.

Some participants used Zoom at the offices of a local service or organisation. Most used it at home.

We did not speak to people with no access to this technology. There are many such people, both with and without disabilities. Their experiences of Covid-19 were probably different from the experiences of the people we interviewed.

Most of our participants said "doing Zoom" was one of the skills they acquired during the crisis. They used it to maintain friendships, family relationships and, in some cases, contacts with service providers.

The use of Zoom also highlights the fact that all our participants are verbal to at least some degree.

Also, all have some literacy skills. All of them, for example, could spell their names as the interviewer went through the consent form for the interview.

Again, these capacities are common but not universal, and some people were excluded from being interviewed because certain communications capacities, skills, access and/or supports were necessary.

## **Work**

During the Covid-19 crisis some people in the country have continued to go to work, and some have been able to work from home. Not everyone could work from home, and for people with disabilities it was no different.

The people that we interviewed all lost work because due to Covid-19 they could not go to work. Most of them had worked in centres and services for people with disabilities.

Their work had included helping other service users, cooking, serving in coffee shops, and doing laundry. All of this work was stopped due to Covid-19.

Kai said the start of his internship in Trinity College Dublin was delayed until at least autumn.

Pat no longer works in a factory but has been working online for Galway Advocacy Council.

Gary said he has continued to deliver copies of the Offaly Independent in Clara.

It has been very hard for people with disabilities not working during the Covid-19 crisis.

Several people said that when they go back to work it will not be like

*'My job came to an end... my Special Olympics. My brother couldn't come for my birthday. Couldn't go out for dinner, or go for hot chocolates. And my Gaisce – had to cancel that. I was doing the Gaisce Silver Medal.'*

**Dairine O'Rourke**

before Covid. It will be very different and for people with disabilities that may not be easy to understand.

Before starting back at work people with disabilities should

ask to have a look at the changes in their different workplaces and the new ways of doing the work. On their first day back at work they should take their time doing their job.

Article 27 of the United Nations Convention on the Rights of Persons with Disabilities says that people with disabilities have the right to work on an equal basis with others and *"the right to the opportunity to gain a living by work freely chosen or accepted in a labour market and work environment that is open, inclusive and accessible"*.

It says the State *"must safeguard and promote the realisation of the right to work"*. Last year, the Irish government published a 'Comprehensive Employment Strategy for People with Disabilities': its priorities include *"to build skills, capacity and independence"*; to *"provide bridges and supports into work"*; and to *"make work pay"*.

## Social life

In the interviews we found that many participants were isolated from extended family and friends. This isolation contributed to their anxieties and fears.

*'I don't really find anything hard about the lockdown because I'm listening to the rules and obeying by the rules. I'm wearing my mask and everything... They know how to obey by the rules, people with disability, they know how to listen to the rules. But most people with disabilities, they don't listen to the rules.'*

**Barry Olwill**

They missed the social interaction with people they knew at work, in their day services and with their friends and families. They missed their sports.

For example Dairine missed her brother and dad's visits.

Pat had to stay on his own at night for the first time because his mother was in hospital and no family member or carer could stay overnight with him because of the Covid-19 restrictions that were in place. A carer did come the following morning, as he has cerebral palsy and needed some assistance. This was frightening and stressful for him at the time.

A lot of those interviewed had no connection to their work or care services. One got a Zoom phone call once a week from her work.

Sarah Jane said she felt "isolated and alone" with very little contact from people outside her home.

Mairead said she missed her job and baking with one of the staff but she liked her sleep-ins. She said she has got stressed and finds the lockdown tough.

Gary lives with his dad and keeps in touch with family and friends through social media. He has found Covid-19 very stressful: he misses weekends away, felt panicky and particularly missed a weekend in Limerick with people who had motorbikes, which he loves.

Kai said he found it tough that his internship had been delayed and he felt bored. He missed going to the city centre and going out. He was shocked at the Covid-19 news and found it all very stressful.

A lot of those interviewed said they were very sad for those who had Covid and Barry was sad for people who couldn't fly or get home – he

himself was probably going to miss out on a trip to Canada. Peggy was sad for those who had to isolate.

Dairine was a bit worried about going out. Sarah Jane brought the dog for a walk in the park but was very careful to keep her social distance from others.

One of our research team, Margaret, has suggested that the sort of

*'It was mayhem. We couldn't get back at all with this Covid-19. I was very panicky... annoyed, upset, anxious – can't see staff, can't see friends.... It's lonely, and scary, and worried. I miss my friends, I miss my family, I miss my loved-ones. [When hearing the news about the crisis] I go mad, and pull out my hair.'*

**Gary McCabe**

arrangements that make it possible to, for example, reopen a gym in restricted ways for a few people – which makes her feel more comfortable in herself – could also be done in services and in work for people with

disabilities, and allow people to get out and see each other.

All participants said they miss the physical socialising with people from all the different parts of their lives – their work, services, sports, friends, extended family (grannies) etc. A lot of people have learned about Zoom and social media but it's not the same as meeting in person.

As we come out of lockdown, we hope that people with disabilities are given the supports they need to socialise safely with friends and family and get back into a safe routine. There should certainly be no extra delay in achieving this for people with disabilities.

## **Independence**

Participants were asked if the lockdown has made a difference to their independence – things they cannot do any more which affects their sense of independence, or things that enhance independence.

Things they cannot do included not being able to go to their day service, not being able to do activities like horse riding, swimming or meeting their friends. Many talked about simply not being able to go out and feeling worried about it. One participant spoke of sitting in the car while family members did the shopping.

For one participant, Pat, the crisis helped his independence in a way. As noted above, his mother had to go into hospital so he had to stay on his own for the first time.

*'I was doing work before this problem started about friendship: what can you do to make new friends? I came up with good stuff without the staff helping me.... I love doing the poetry, it's great like that, I'm good at doing the nice things in my head, myself... One time when I was really annoyed and cross I wrote out a long page.... I like when every second line rhymes.'*

**Sinead Gilgunn**

Some participants said their independence had not changed. "I'm still quite content at the moment anyway," Jimmy said.

"My independence is really, really good. I do the cleaning, my friend does all the

cooking, we clean up after ourselves," Barry said.

"I go out for a walk in the evening when it's quieter," Sinead said.

Being able to do things online seemed to help people's sense of independence – things like learning how to do Zoom and online classes.

"I can set up Zoom calls myself. I couldn't do that before," Dairine said.

Maintaining or losing independence was largely dependent on people's supports and living circumstances.

## **Support**

Everyone needs support, but many people with disabilities need more support than others.

During the crisis and lockdown the government has kept saying to look out and support each other; for people with disabilities that was more important than ever.

However, some support staff in disability services have been reassigned to other work during the crisis.

Our participants have mostly had support, but have experienced different and uneven levels of support.

Sinead said her two support workers “ring me most of the time....

*‘My mother was hospitalised during lockdown for three or four days. I have supports to assist me in the morning... but it was my first time ever to live a few nights on my own. It was something I had to do, something I was nervous about it, but I had to do it because of Covid.’*

**’ Pat Flaherty**

Sometimes we do the video call or on Messenger, they’re good and helpful. Sometimes I play jokes on them and they believe me as well – if I’ve problem they help me.”

Phillip said services

staff “support me when I need support”, though he would like more. He said he was “getting plenty of support from my mother and sister”.

Gary, as we mentioned in ‘Work’, above, has continued to deliver newspapers on a Friday during the crisis. “I have a key worker and she supports me every Friday,” he said. “She came out with me last Friday to see how many businesses were closed.

“I do the paper work all by myself, flying around the block. Staff come out, we go for takeaway tea or coffee, something like that,” Gary said.

Dairine gets a Zoom call once a week from a support worker.

Pat experienced a loss of support when his mother was briefly hospitalised, his “first time ever to live a few nights on my own”, while Sarah Jane said she had only had her mother to support her.

## Likes

We asked participants if there was anything they liked about the lockdown. There were a few things people liked about it.

Two people said they liked it because they could have a sleep-in.

“I like all of it, cause you can have a have sleep in the morning and get up when you want,” Peggy said.

It is not surprising that people liked their sleep-ins. Usually people with intellectual disabilities have a very routine life; this is okay for some but others like to have a choice about their daily routine. (See ‘Boredom’, below.)

Other things people like are the new ways of keeping in touch – they learned how to use Zoom and online classes.

"I like doing my Zooms," Dairine said. Kai said they had "good laughs" in his online classes.

## Dislikes

We asked participants what they don't like about the Covid-19 crisis and the lockdown in particular – their complaints were many and familiar.

For many participants not being able to go anywhere was the thing they

*'Sometimes I get sad and agitated, but then I say to myself that it's okay to feel that way.... There are certain things I can do something about, there's other things I can do nothing about. If I can do nothing about it there's no point in stressing out. ... Let's face it, I've been self-isolating, cocooning, for donkey's years.'*

**Sarah Jane Lavin**

didn't like. This included not being able to go to their day service, or go far for a walk.

You can't go anywhere safely or in comfort," Pat said.

"It's kind of sad not having a reason to get up in the morning, waiting for

the bus to come and take us to day service," Peggy said.

"It's really really frustrating that we're not back in the day service," Barry said.

"Lockdown is really hard, Mairead said. "I'm dying to get back to work, it's been very tough."

'From the end of March to June 8<sup>th</sup> I didn't go out of the house at all, except around the green with the dog," Sarah Jane said.

For some the lockdown meant missing out on plans to travel and take up other opportunities. Sarah Jane said she and her mother were suffering because of a "lost holiday and lost money".

"I thought I would crack up because I couldn't go to Limerick," Gary said.

*'Well, the only thing that I don't feel is for not being able to meet the other parties that I'm fairly close to and some of the family members as well. There's one or two out of the town so, and they're not coming in or out either – so other than that everything is okay.'*

**Jimmy Dooner**

"It's been tough, especially in relation to my delayed internship," Kai said.

Participants said not meeting friends was hard but also knew why it was important not to do so. "Not meeting up with friends, it's hard,"

Phillip said. "But you have to do what's best for the people who have Covid-19, and stay safe."

## **The hardest parts**

We asked participants what they missed about their previous lives and what they found hardest about life during the crisis.

Participants missed many things during the lockdown. This included going to work or their day centre and doing different activities or weekends away. However, the most common thing participants missed was meeting friends and family.

"I really miss all of my friends, to talk to them, and can't wait till it's all over to give them all a big hug," Peggy said.

"I miss hanging out with friends, miss my centre, miss talking to my keyworker – but I can email him," Mairead said.

Some participants were aware that some people were more isolated than themselves. Jimmy spoke of people who are not in town but "out in the sticks" and how things could be harder for them.

Participants talked about missing getting out and about and being involved in different activities. Phillip said he missed horse riding and swimming.

Sinead missed her arts and crafts and "getting out to places... being up and being out at work".

For people with intellectual disabilities many activities and forms of work they do are part of their day service; for some this may also be the only place where they meet friends.

As a result the day service being closed makes a big difference to their lives.

## Boredom

There is a perception that people with intellectual disabilities are attached to structured routine, and more prone to (and intolerant of) boredom.

*'Lockdown has changed most of my life but I will have to get on with life either with Covid or Covid not here. I can't go swimming or horse-riding and I can't go to the day service. I am sad and emotional.'*

**Phillip O'Donnell**

In this view, changes to routine are a source of stress and anxiety.

This is true for many people. Some members of our team have an aversion to

unstructured time and intense negative feelings about boredom.

However, people with intellectual disabilities have the same wide range of reactions to forced inactivity and breaks in routine that have been seen during the Covid-19 crisis in the broader population.

In our interviews, many participants said they missed work and services. They were much more likely to explain this in terms of missing people rather than missing routine.

Jimmy said missing work was "not too bad as I'm out in the community, so more or less meeting with a few of the people that I work with that are in the town."

Sinead said it felt different to "be on my own a lot of the time" and that she wrote poetry when she was angry.

Others did more painting, baking, and making rugs.

Peggy said: "it's kind of sad because you've nothing to look forward to getting up in the morning."

Two people, on the other hand, mentioned the pleasures of sleeping late and not facing the same old routine.

Sarah Jane Lavin decided to opt out of regular classes available online

*'I really miss all of my friends, to talk to them and can't wait till it's all over to give them all a big hug. It's kind of sad because you've nothing to look forward to getting up in the morning – not waiting for the bus to come to take us to the day service.'*

**Peggy McDonnell**

through her service because "the stuff was for five-year-olds they were giving us".

There is a high level of knowledge and concern about Covid-19 among the research

participants. This means that most of them are aware that they cannot expect a simple restoration of old routines in the near future.

A return to workplaces and day services with new routines, and new arrangements of people and spaces, may be a source of anxiety for some. (See 'Work', above.)

## **Getting information on Covid-19**

Most participants said they were getting information on Covid-19, mostly from news (TV and to a lesser extent radio) and the internet. Some participants mentioned government information booklets.

The crisis "has woken us all up," Jimmy said. "We're getting the information – and at least by abiding by it, we'll get over it anyway."

Pat said that for a time early in the crisis he got very agitated as he followed the daily Covid-19 numbers closely.

All participants strongly agreed, however, that the Government needs to make the COVID-19 information in more Easy to Read form – with images.

For example, there should be more pictures on how to put on a mask. "There needs to be more information on masks, how to do them," Sarah Jane said, adding that she and her mother had been wearing them in shops through most of the crisis.

Picture-based information would help people to understand more generally about the virus.

Peggy, who has worked with many people with disabilities, said "some of them doesn't understand. Some of them do and some of them doesn't,

we need to get some pictures and show them to them and make signs through the hands.”

As Jimmy said, “The picture tells the story.”

## Conclusion and recommendations

Covid-19 has changed our lives and the way we do things and for people with disabilities it is no different. The Government has a particularly important obligation is to look after people with disabilities.

Article 4 of the UNCRPD says that Ireland undertakes *“to ensure and promote the full realisation of all human rights and fundamental freedoms for all persons with disabilities without discrimination of any kind”*.

*‘I am having a very tough life because of lockdown. I’m feeling like pissed off and everything but thing is I’ve been doing meditation to help me feel better. I’ve also been going out for walks – I haven’t been out for walks for couple weeks but did go out with my granny yesterday and did have a little walk around.’*

**Kai Tiernan**

It says the State must *“take into account the protection and promotion of the human rights of persons with disabilities in all policies and programmes”* and *“take all appropriate*

*measures to eliminate discrimination on the basis of disability by any person, organization or private enterprise”*.

With that in mind, we make several recommendations.

**Workplaces** and the employers who run them will need to make things easier for people with disabilities returning to work as the crisis eases. It will be very different and for people with disabilities that may not be easy to understand.

Before starting back at work people with disabilities should ask to have a look at the changes in their different workplaces and what is the new way of doing the work. On their first day back at work they should take their time doing their job.

This needs to be made possible by workplaces.

In general, **reopening** should not be something that goes ahead first for people without disabilities, while those of us with disabilities have to wait.

The sort of arrangements that make it possible to, for example, reopen a gym or a restaurant in restricted ways for a few people could also be done in services and in work for people with disabilities.

**Information** about Covid-19 is very important and people with disabilities should not be left behind in this area either.

The Government needs to make the COVID-19 information in more Easy to Read form – with images. As wearing masks get more important, there should be picture-based information everywhere about how to put on a mask.

**Consultation** with people with disabilities was severely lacking when services closed down in March 2020. While this is understandable in a situation when there was near-panic in many sectors, there is no excuse for the same failures over the coming weeks, months and possibly years.

It is likely that services will be closing and opening again in future, but it

*'It's really hard. I really missed work to be honest with you, miss the baking on the Monday with Chris. I suppose it's important, we all want to keep safe, we don't want to get sick. All those people that have died it's just unbearable – do you know it's very tough on them, even the families. All the people that died from corona 19, it's unbearable like.'*

**Mairead McHugh**

must happen with the active consultation and participation of service users.<sup>1</sup>

Not every adult with a disability is attached to a regularly used service provider. As a society we must listen to people with

disabilities outside the framework of 'services', and consider how they're coping in areas as diverse as work, sports, socialising and other activities.

Ireland, having ratified the UNCRPD, must act to promote the **equality and human rights** of people with disabilities. This year the Government

<sup>1</sup> See the survey and report, 'Covid-19 and the impact of the closure of day services on people with intellectual disabilities', Inclusion Ireland, July 2020.

is required to report to the UN on how it is complying with its obligations under the Convention.

That report to the UN must include an honest reckoning of the widespread failures to ensure equity for people with disabilities during the Covid-19 crisis, not just for people in full-time care settings but in society more widely.

We hope that our own report will help people with disabilities in Ireland cope better with their experiences during the Covid-19 crisis, by understanding what other people have gone through.

And we hope that the Government acts to help people with disabilities during the ongoing Covid-19 crisis – as Covid-19 could be with us for some time.



## Acknowledgements

The research team would like to thank everyone who took part in the interviews. We would also like to thank everyone that has been involved in the project, with a special thanks to Deborah Brennan who was involved at the start – this work would not have been possible without her.

The HSE and Brothers of Charity Services Ireland helped us to recruit participants for the project.

The research was approved by the Research Ethics Committee at Technological University Dublin. Thanks to TU Dublin and Inclusion Ireland for their support.



INCLUSION IRELAND

### **Inclusion Ireland**

The National Association for People with Intellectual Disabilities

Unit C2, The Steelworks, Foley Street, Dublin 1, Ireland.  
Phone: 01 8559891

Email: [info@inclusionireland.ie](mailto:info@inclusionireland.ie)

Website: [www.inclusionireland.ie](http://www.inclusionireland.ie)



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