



# Overcoming Adversity: The Continuing Impact of COVID-19 on People Ageing with an Intellectual Disability in Ireland

What we found from the IDS-TILDA study  
An Accessible Report



Trinity College Dublin  
Coláiste na Tríonóide, Baile Átha Cliath  
The University of Dublin



The Intellectual Disability Supplement to  
The Irish Longitudinal Study on Ageing  
(IDS-TILDA)

# Overcoming Adversity: The Continuing Impact of COVID-19 on People Ageing with an Intellectual Disability in Ireland

What we found from the IDS-TILDA study

An Accessible Report'

By

**Eimear McGlinchey, Darren McCausland, Andrew P. Allen, Mei Lin Yap, Christina Corr, Margaret Haigh, Fintan Sheerin, Eilish Burke, Fidelma Flannery, Niamh Mulryan, Philip McCallion and Mary McCarron,**

Reviewed for accessibility by 'Brain Buzzers', a group of people with intellectual disability who meet to discuss Brain Health

December 2021

---



## The Intellectual Disability Supplement to TILDA School of Nursing and Midwifery (IDS-TILDA)

The University of Dublin, Trinity College  
2 Clare Street  
Dublin 2  
Ireland

### Trinity Centre for Ageing and Intellectual Disability

Tel: + 353 1 8963187 / + 353 1 8963186

Email: [IdsTilda@tcd.ie](mailto:IdsTilda@tcd.ie)

Website: [www.idstilda.tcd.ie](http://www.idstilda.tcd.ie)  
<https://www.tcd.ie/tcaid/>

Copyright © The Intellectual Disability Supplement to  
The Irish Longitudinal Study on Ageing 2022

---

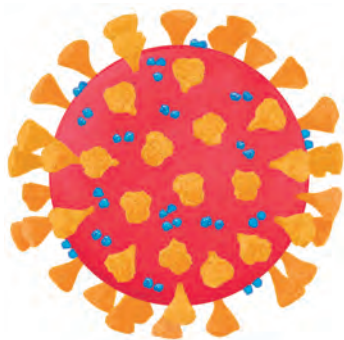
---

## Contents

|  |           |
|--|-----------|
| <b>A Message from Mary McCarron</b>    | <b>2</b>  |
| <b>The Words we Use</b>                | <b>3</b>  |
| <b>Introduction</b>                    | <b>4</b>  |
| <b>COVID-19 Testing</b>                | <b>5</b>  |
| <b>Symptoms</b>                        | <b>6</b>  |
| <b>Vaccines</b>                        | <b>7</b>  |
| <b>Using Healthcare Services</b>       | <b>8</b>  |
| <b>Contact with Family and Friends</b> | <b>9</b>  |
| <b>Community Participation</b>         | <b>10</b> |
| <b>Mental Health and Wellbeing</b>     | <b>12</b> |

---

## A Message from Mary McCarron



In this report we will tell you what we found out about how COVID-19 affected our lives.



We could not do this research without you.



Thank you for all your help and support for IDS-TILDA.

Best wishes,

Mary

## The Words We Use

When we say **‘Hardly any’** we mean **1-4% of people**

When we say **‘Very few’** we mean **5-9% of people**

When we say **‘A few’** we mean **10-19% of people**

When we say **‘Some’** we mean **20-39% of people**

When we say **‘Just under half’** we mean **40-49% of people**

When we say **‘Half’** we mean **50% of people**

When we say **‘A lot’** we mean **51-59% of people**

When we say **‘Most’** we mean **60-79% of people**

When we say **‘Nearly everyone’** we mean **80-99% of people**



**For example,** when we say:

**Nearly everyone** in the study got a COVID-19 vaccine.

This means that **80-99% of people** got a COVID-19 vaccine.

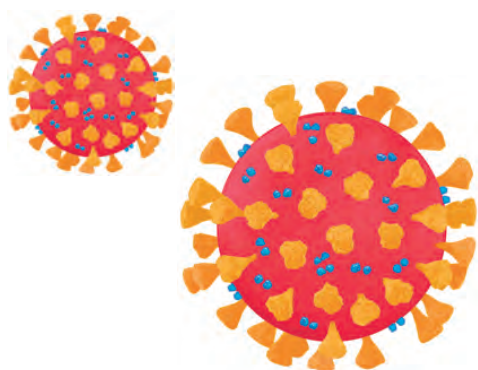


# Introduction



The Intellectual Disability Supplement to  
The Irish Longitudinal Study on Ageing  
(IDS-TILDA)

IDS-TILDA wants to find out about growing older in Ireland with an intellectual disability.



In 2020, we asked people about their experience during the COVID-19 pandemic.



We asked people the same questions again in 2021 to see if things had changed.

We also asked some new questions to find out more information.



This report gives the main findings about COVID-19 from this new survey.

## Covid-19 Testing and Symptoms



Three out of four people got tested for COVID-19.

**Nearly everyone** living in a residential setting had a COVID-19 test.

**Just under half** of people living independently or with family had a COVID-19 test.



More people with an intellectual disability got tested for COVID-19 than in the general population.

The rate of positive COVID-19 tests for people with an intellectual disability was higher than in the general population.

**Nearly everyone** got easy read information about COVID-19 from the government.

**A lot of people** found it easy to understand.

**Some people** found the information a bit hard to understand.

**Some people** found it really hard to understand.





## Symptoms



**Some people** said that they had symptoms of COVID-19.

This was lower than in the general population.

The symptoms that people in our study reported most often were:

- Cough
- Fever

In total, 63 people from our study tested positive for COVID-19.

Symptoms lasted less than two weeks for **most** of these people.

**Very few** people had symptoms for 9-12 weeks.

**A few** people who tested positive didn't have any symptoms.

**A few** people with COVID-19 had to go to hospital.

3 people from our study died while they had COVID-19.

We do not know if COVID-19 was the cause of their death.



## Vaccines



**Nearly everyone** in the study got a COVID-19 vaccine.

One in three people had minor side-effects from getting the vaccine.

Side effects were gone in 48hours for **nearly everyone**.



The most common side effects were:

- Swelling or redness of the arm
- Feeling tired



**Nearly everyone** who had to self-isolate had a plan in place to manage COVID-19.

Self-isolation is when you have to stay indoors and avoid contact with others.

## Using Services



**Most** people had some change related to their health since the start of the COVID-19 pandemic.

The most common changes were:

- More time sitting
- Doing less exercise
- Less medical care than usual
- More health problems
- Eating more food or eating less healthily.



**Most** people did not make any new healthcare appointments since the start of the pandemic in March 2020.



**Some people** missed their usual health check during the pandemic.

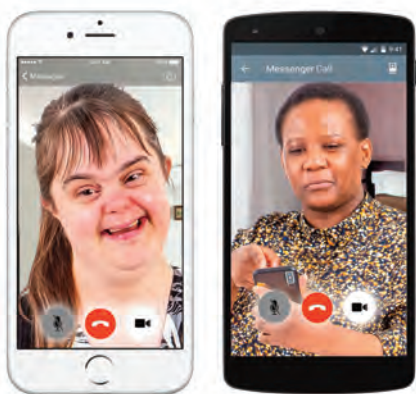


A lot of people had appointments by video instead of going to someone's office.

## Contact with family and friends



During the pandemic **nearly everyone** had less face-to-face contact with **family** that they don't live with.



**Eight out of ten** people had less face-to-face contact with **friends** that they don't live with.



About half of the people in the study used technology more.

They used technology to speak to their family and friends during the pandemic.

## Community participation



**Nearly everyone** said that they:

- Had enjoyable hobbies they could not do
- Were separated from family

**Most people** said that:

- They had less hours in work or day service
- Religious activities were cancelled



**A lot of people** said that

- Travel plans were canceled
- They could not take part in social clubs or sports team
- They could not volunteer



**Some people** told us that:

- There were more arguments at home
- They could not go to a funeral





## Community participation



A few people told us that:

- They could not visit a relative in a care home
- They could not be with a family member when their family member was very sick

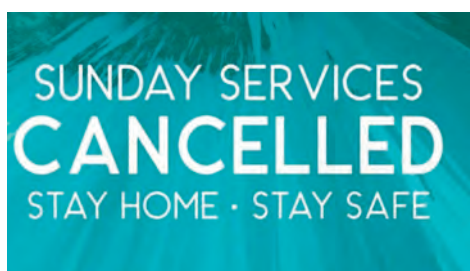


Younger people were more affected by:

- Less work or day services
- Fewer family celebrations
- Cancelled travel plans.

Older people were more affected by:

- Less religious or spiritual activities.



COVID-19 infection control measures affected people living independently or living with family the most.

COVID-19 infection control measures affected people living in a residential setting the least.

## Mental health and well being



**Most people** said that their mental health was either excellent, very good, or good.

**Just over half** of participants who spoke for themselves said they felt lonely during the pandemic.



The things that caused the most stress were:

- Isolation
- Not being able to see family or friends
- Not being able to do usual activities.



One in five people knew someone who died during the pandemic.



**Nearly everyone** said there were some positive experiences during COVID-19.

## Mental health and well being



Some positive things that people told us about were

- Starting a new activity.



- More rest and relaxation
- Spending more time or having a better time with staff.



- Using technology to communicate.

People told us that they are looking forward to:



- Being able to see family and friends
- Eating out and going to the pub
- Going back to work



- 'Just getting back to normal'
- Going on holiday.





Trinity College Dublin  
Coláiste na Tríonóide, Baile Átha Cliath  
The University of Dublin



The Intellectual Disability Supplement to  
The Irish Longitudinal Study on Ageing  
(IDS-TILDA)

