



This report has been made from the UK Coronavirus and people with learning disabilities study



## **Living through the pandemic** COVID-19 and people with learning disabilities in Wales

February

2022



I think people with learning disabilities found the study successful. It helped them have a say in the lockdowns and improve things during the hardest times.

I think it will help us continue to have a voice. I just hope the politicians listen because improvements are still needed to help people with learning disabilities to gain greater independence and support when they need it, especially during the hardest times.

- James Tyler, Chair of the All Wales People First National Council

## What is this report about?



This report is about coronavirus (sometimes called COVID-19) and adults with learning disabilities in Wales.



It is part of a research study in England, Scotland, Northern Ireland and Wales. We talked to 183 people living in Wales.

This report is in 2 parts.



1. What we found out about COVID-19 and people with learning disabilities in Wales.



2. How people who make decisions about services for people with learning disabilities might use what we found out.

# Who worked on the study in Wales?

The study in Wales was led by



Professor Stuart  
Todd



Dr Edward Oloidi



Dr Stephen Beyer



University of South Wales



Cardiff  
University

They worked with partner organisations



All Wales  
People First



All Wales Forum  
of Parents and Carers



Learning  
Disability Wales



A small group of people with learning disabilities and a group of family carers were also asked about the important questions in the study.

## How did the study work?



People with learning disabilities were asked questions about coronavirus 3 times.



- in December 2020
- in April 2021
- and in August 21



They were asked questions on the phone and on Zoom.



59 family carers and paid staff also answered questions for people who could not answer for themselves.

# Part 1: What we found out about COVID-19 and people with learning disabilities in Wales

## Who took part in the study?



Half of the people who took part were men.

Half of the people who took part were women.



Half of the people were younger than 35 years old.



Nearly everyone who took part was white.

The researchers tried to find people from Black, Asian and Minority Ethnic communities. Only a few Black, Asian or minority ethnic people took part in the study.

## How many people had coronavirus?



Over half of the people in the study in Wales had health conditions that made them worried about getting coronavirus.



By August 2021, over 1 in 10 people on the study had had coronavirus.



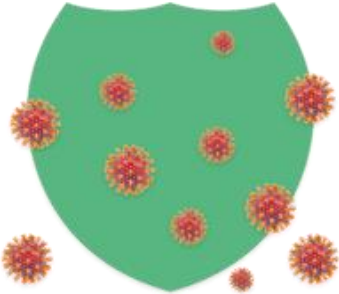
People with learning disabilities were more likely to test positive for coronavirus than people without learning disabilities.



1 in 4 people who tested positive for coronavirus said they had been in hospital.

## Following the rules for coronavirus

Nearly everyone who took part in the study followed the rules.



- In December 2020, half of the people who took part were shielding.



- 9 out of 10 people wore masks.



- Nearly everyone had both vaccine doses and nearly everyone said they would get a booster if offered one.



8 out of 10 people said support staff should have the vaccine.



## Health



Most people we asked said their health was good. This did not change during the study.



Most of the people in the study are offered an Annual Health Check.

During the pandemic only half of these people had an Annual Health Check.



People in the study said they saw their doctor less.



People in the study said they saw their learning disability nurse less.



When they did speak to their doctor or nurse it was mostly by phone or video call. This could mean illnesses they had were not found or treated

## Well-being



During the pandemic people were asked to stay indoors more and not to mix with lots of people. This was called a lockdown.

During the lockdown in January 2021 most people in the study said most or all of the time they felt



- lonely



- worried



- or sad

I'd like to go out again without worrying about dying and giving people coronavirus.

## More about well-being



Family carers and paid staff who answered for people said they were more worried about the person's behaviour.

There is a severe decline in his behaviour. He frequently walks about shouting and rocking. Sleep patterns are completely disrupted, and he has frequent bouts of temper and frustration.



Family carers and paid staff also said they were more sad or worried than before the pandemic.

A third of people on the study said someone they knew well died during the pandemic.

Very few people had support to deal with the loss.



I was and still am in a total mess and shock....I still can't believe it. It was cancer as far as I know.

## Use of services

A third of people said they are getting less support than before.



- Fewer people are using day services



- Fewer people are using respite services



Some people on the study use Direct Payments to get support.

A third of people using Direct Payments said they were paying for services they did not get.

## Relationships



During lockdowns people were told to only spend time with the people they lived with.

This did not change how people felt about who they lived with.



People living in care homes or supported living had rules about who could and could not visit.

Some people had no visitors.

Most people were allowed the same person to visit for a short time.



Before the first lockdown most people did things in the community like shopping and eating out.

Most of these activities stopped during the lockdowns

Even when the rules ended, people were only going out half as much as before.

## More about relationships



Some people talked to their neighbours more.



Before coronavirus 1 in 3 people we talked to had a paid job.  
After the study this dropped to 1 in 5 people.



During coronavirus, lots of people used the phone or the internet to speak to people. Everyone on the study had the internet. Most people had a phone they could use.

Not everyone could use the phone or internet by themselves. This meant they had to wait for someone else to help them.

He finds it difficult to engage fully via zoom.  
Not being able to see his family in person resulted in his mental health suffering, as did the mental health of his family.

## The future



Most people felt their life would not return to normal or it would take a long time.

We asked what would be important for future lockdowns.

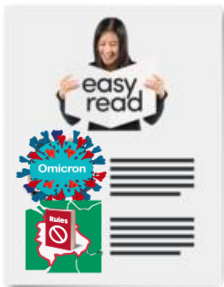
People said



- Help with shopping



- Help to see a doctor and get medicine



- More accessible information about the changes to rules



- Help to use a mobile phone and the internet

Small things. Going for coffee with a friend. I want to watch the rugby but my mum isn't ready to let me.

## How has coronavirus affected carers?



We asked family carers and paid support staff how the pandemic had affected them.

Most carers and paid staff said they felt



- Stressed



- Tired and found it hard to sleep



Nearly half said they felt depressed.



How carers and paid staff felt did not get better by the end of the study.



## More about family carers and paid support

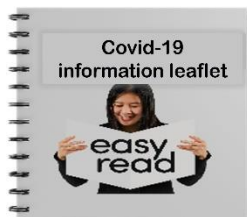


We asked family carers what would help in future lockdowns.

They said



- More help to find things to do for the person they support



- Better information about coronavirus



- Help to see a doctor



- Paid staff to have the vaccine

As a family, we have worked around the clock to minimise the negative impact on our son. We are absolutely exhausted.

## Part 2: How people who make decisions about services for people with learning disabilities might use what we found out.

### The Learning Disability Action Plan



When this report was written, Welsh Government were writing a 5 year plan.

The plan is how services for people with learning disabilities should work.

The plan is called the Learning Disability Strategic Action Plan.



Many of the things we asked about in the study are the same as things in the action plan.



We hope Welsh Government will use our study when planning how services should work.

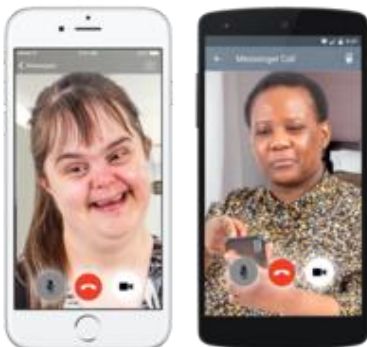
## Things we found out and how they might be useful to the new action plan



- We need new ways to find and talk with people with learning disabilities who are Black, Asian or from an ethnic minority community. This will make sure decisions include everyone.



- We need to find out more about the lives of people with learning disabilities in Wales. This will help with planning better services.  
Working together as a partnership of researchers and different organisations helped to make this study happen. Future research could learn from this.



- Many people with learning disabilities feel lonely and isolated. The pandemic made this worse.  
Using phones and the internet to speak with people helped. But people prefer to meet others in person.  
Help to use phones and the internet should be part of day to day support, not an extra.



- People with learning disabilities need to be included when planning help for people whose loved ones have died.

## More things we found out and how they might be useful to the new action plan



- Lots of people took part in this study. They wanted to have their say. Many decisions were made for people during the pandemic, even decisions people can make for themselves. It is important that people with learning disabilities are included in future decision making.



- People with learning disabilities were worried about their paid jobs during the pandemic. More support is needed to help people stay in jobs and for people to get the chance to work.



- During coronavirus people with learning disabilities did not feel they were thought about when decisions and rules were made.

In future health emergencies decision makers need to think about



- How to support people with learning disabilities to keep seeing loved ones
- How to support the mental health and wellbeing of people with learning disabilities
- How to help people keep the same quality of life
- How to make sure people with learning disabilities' rights are respected as much as other peoples.
- How to include people with learning disabilities, their family carers and paid support staff in reviewing rules about coronavirus.
- All new rules and information should be in easy read.
- Plans should be made so people with learning disabilities do not lose support.

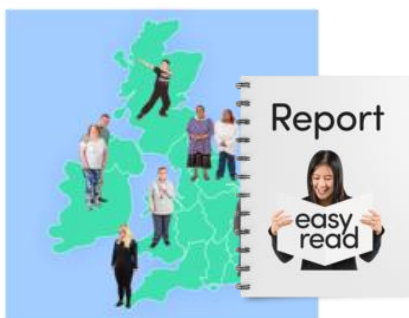
## What we have done to tell people about the study



We held 3 online events to tell people about the study. We would like to hold more events.



We have written about what we have found out in easy read.



We have worked with others across the UK to write reports.



We are still meeting with important people in Wales to tell them about what we found out.

## Thank you



We would like to thank people who helped to make this study a success



- Thank you to people with learning disabilities who talked to the researchers



- Thank you to family carers and paid support who talked to the researchers



- Thank you to the team of interviewers who talked to people with learning disabilities and the people who support them.

## Find out more



If you want to find out more about the study, you can email Dr Edward Oloidi.

[Edward.oloidi@southwales.ac.uk](mailto:Edward.oloidi@southwales.ac.uk)



Or you can click on these links to read more about the study findings.

[Risks and Coronavirus](#)

[Vaccinations](#)

[Digital lives](#)

[Access to health and social care services](#)

[Impact of caring \(1\)](#)

[Impact of Caring \(2\)](#)

[Restrictions](#)

[Impact on physical and mental health](#)

[Access to support and services](#)

[Bereavement](#)



