

# The lives of disabled people during COVID-19



### Contents

|                                  | Page |
|----------------------------------|------|
| Introduction                     | 3    |
| How people feel about themselves | 4    |
| Uncertainty                      | 9    |
| Challenges                       | 13   |
| Independence and choice          | 17   |
| Time                             | 20   |
| Good things to come out of it    | 22   |
|                                  |      |



In this easy read document, difficult words are in **bold**. We explain what these words mean in the sentence after they have been used.

### Introduction







The Government has been looking into the issues that disabled people have faced in their daily lives during **COVID-19**.

**COVID-19** is also called Coronavirus. It is an illness that is spreading around the world. It can affect your lungs and breathing.

We met with 9 disabled people from around the country.



We talked with them for a long time to find out more about the issues they faced in their daily lives during COVID-19.



We hope to use this information to improve the way the Government helps disabled people.

## How people feel about themselves



We have all had to change the way we live during COVID-19.

### Feelings of shame and guilt

People said that they felt embarrassed and guilty about being disabled.

People said they felt more shame and guilt during COVID-19.



### Shielding

**Shielding** means staying at home away from other people to keep yourself safe from COVID-19.



People said they were embarrassed to be shielding.

People said that being called disabled made them feel different.



At first, carers didn't understand what shielding meant. They didn't wear masks or other equipment to keep people safe.

### **Social Care**

**Social care** is support you need to look after yourself. Social care workers include nurses, care home workers and social workers.

People didn't always feel safe when they were getting social care services during COVID-19.

Some personal assistants had not wanted to come to work.

This meant that the disabled person had no care.

It was a difficult time for people who employ their own carers.

### **Healthcare services**

People were not happy with having telephone appointments with doctors.



People with complicated health issues needed to see the doctors face to face.

People were always having to explain their health issues again and again to new people.

### Work and money

Some disabled people had difficulty working from home during the time of COVID-19.

There wasn't enough space for the equipment they needed.

Other people tried new ways to make money.



### Shopping

Disabled people had difficulties going to the shops during COVID-19.

People had been used to using Dial-aride, but that had stopped during COVID-19.



It took a while before people knew how to order food online.







Wearing face masks

Face masks were difficult for some disabled people.

Some people were used to lip reading and couldn't do this with people in face masks.

People who couldn't wear masks for health reasons got shouted at by other people.

Some people wore a mask even though they didn't need to, because they felt scared without it.



### What other people think about disabled people

Other people don't notice disabled people. They have no idea what things are like for disabled people during COVID-19.



### What should happen

The Government should think about how to:

- protect people who are likely to become seriously ill if they catch COVID-19
- keep services going during COVID-19
- make sure that care is always the same good quality
- help people get their shopping and the other services they need
- talk to all the different services
- help other people understand what disabled people need.

### Uncertainty



**Uncertainty** means you are not sure what might happen.

During COVID-19, people did not know what would happen if they went out and about, or tried to access a service.



### Confusion

People said they didn't really know what you were allowed to do and what you should not do.





### The guidelines

The Government wrote guidelines for what we should do during COVID-19.

But people did not understand these guidelines.



People didn't know how the guidelines affected disabled people.

### **Health services**

People didn't know which health services they could access during COVID-19.



People didn't know whether they should phone their doctor, NHS 111 or 999.



In hospitals, some disabled people felt scared because no-one would come near them. Everyone was wearing masks.



### Travel

People didn't know if they would be allowed to use the bus with their wheelchairs and other equipment.

People felt worried about using public transport.











### Worry about the future

People were worried about the future.

They didn't know when COVID-19 would end.

They were worried about people who live in other places. Would they be able to see them again?

#### Mental health

During COVID-19 disabled people were more likely to say that:

- their mental health was getting worse
- they were feeling lonely
- they were spending time alone
- they had worries about the future.



### Coping

One person said it helped to:

- drink plenty of water
- eat regular meals
- sleep properly.

Another person went out for a drive.

Another person relied on her faith to help her.

### What should happen

The Government should think about:

- how to write guidelines that are clear and everyone can understand
- how easy it is for people to find the guidelines
- how to support people with mental health issues which are worse because of COVID-19.



### Challenges











People had to do things in different ways because of COVID-19.

People had to find new ways to get the things they needed during COVID-19.

The rules about COVID-19 stopped people going to places that they used to go to.

People felt trapped in their houses.

People had to keep away from family members.

#### Accessibility

The rules about COVID-19 meant that people had to go into places that weren't very accessible.

Ordering food online was difficult and not very accessible for some disabled people.







Some people didn't feel safe in their homes because care workers were coming in and out.

People didn't feel safe going out because other people weren't keeping to the rules.



### **Breaking the rules**

Some people broke the rules. One person who was shielding let his daughter in because he needed her support.



Another person hugged her mum. She needed to for her mental health.



### Other people and the rules

Some disabled people thought that other people were choosing which rules to follow and which they would break.



Sometimes a support worker might not explain that you could do something because it would be extra work for the support worker.

Another person was surprised at how many people were allowed to get on the bus, when they were supposed to be keeping their distance.



#### Harassment

**Harassment** is behaviour that upsets someone.







But sometimes these people were harassed by people who didn't understand that they were allowed to travel without a mask.

The harassment made people even more scared of going out.

15



### What should happen

The Government should think about how to:

 make sure the rules do not stop people getting the support they need



make sure the rules are being followed fairly



tell people that the things they do affect other people's lives.

### Independence and choice



#### Less choice and independence

The changes to the way we had to live during COVID-19 meant that people had less choice and less independence.



People needed support to put on a face mask and use hand sanitiser.



You couldn't see some of the people you were used to seeing.



Some services closed which meant that people had less support.













#### Same as usual

For some people there was no difference with COVID-19.

Some people had been staying mostly indoors for a long time before COVID-19.

They had always had difficulties doing the things they wanted to do or going out.

### Helping each other

Many disabled people are caring for someone else.

Some people live as a couple and support each other.

Helping someone else helps you to cope with the problems of being disabled during COVID-19.



### What should happen

The Government should think about how to:

- listen to disabled people and understand their needs
- understand how people can be more independent
- support people in the way that is best for them
- offer the right health services for people
- help people have the right place to live
- learn from people who have had to stay indoors well before COVID-19.

### Time



#### Slowing down

People talked about their lives slowing down.

This is because there was less that they could do because of the rules about COVID-19.

Having more time made people more bored.

People said that it might take a long time to get back to normal after COVID-19 has finished.



### Waiting

People told us they had to wait longer for health appointments.

People also had to wait for their treatments.



People didn't have the support they were used to, to organise going to appointments.

People who had a health condition had to wait. They couldn't get on with their lives until the health professional had seen them.

### What should happen

The Government should think about how to:

- respect people's time it's not fair to make them wait
- consider what disabled people need from health treatment
- deal with people's health needs quickly during COVID-19
- give people the right support during COVID-19.



## Good things to come out of it



The changes that have come with COVID-19 have been positive for some disabled people.

Some people have found new ways to live.

Some people have had more time to think about things.

#### **New independence**

During the time of COVID-19, some people realised they wanted more independence in their lives.

Other people realised how easy it was to get food delivered. It made life much easier.

Some people realised that it was much better to work from home.



### Using time differently

For some disabled people it was great to do different things.

It was great not to have everything organised for you. You had time to choose what you wanted to do.

### What should happen

The Government should think about how to:

- change the way we care for people so disabled people have more control
- keep the positive things that happened during COVID-19
- work with companies so people can do more online
- make sure that bosses let people work in a way that is best for them.

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