

## Easy Read Report

# My Health, My Life:

Problems getting healthcare for people with a learning disability when coronavirus came.



## A message about this report from the Treat me well steering group



We are a group of people with a learning disability who steer the Treat me well campaign from Mencap.



Treat me well is our campaign to change how the NHS treats people with a learning disability.



This report is about some of the problems people with a learning disability have had when coronavirus came.



We would like the government and the NHS to listen to people with a learning disability and make sure they are not forgotten.



It is important that people with a learning disability get the right access to better healthcare.



We want our Treat me well campaign to continue to give people with a learning disability a voice.



We would like to thank all the people who shared their story with us for this report.

**Treat me well Steering group**

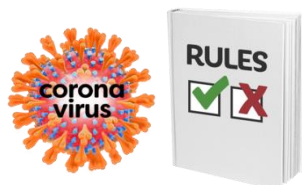
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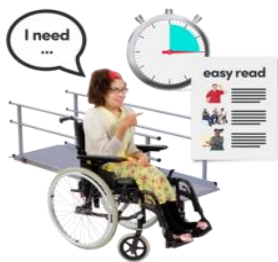


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## What we knew about healthcare before coronavirus



People with a learning disability often need support and **reasonable adjustments** to get the healthcare they need.



**Reasonable adjustments** are helpful changes to the way a service works to make it easier for disabled people.



Reasonable adjustments include things like giving someone easy read information or extra time to communicate.



Another example of a reasonable adjustment is having a carer or family member to stay with them on the ward.



People should with a learning disability have the right to reasonable adjustments because of a law called the **Equality Act**.



People with a learning disability also have the right be included in decisions about their healthcare and try to choose for themselves.



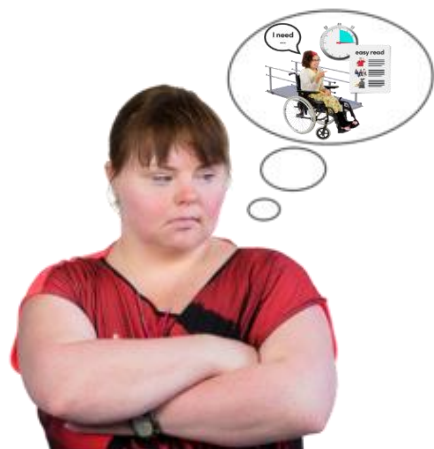
If someone cannot make a decision for themselves, the law says healthcare services must talk to people who know the person well to find out what is best.

This is because of a law called the **Mental Capacity Act**.



We know that sometimes people with a learning disability can miss out on reasonable adjustments, and the support they need.





We know that sometimes people with a learning disability miss out on the support they need to make decisions.

This means they can miss out on the healthcare they need.

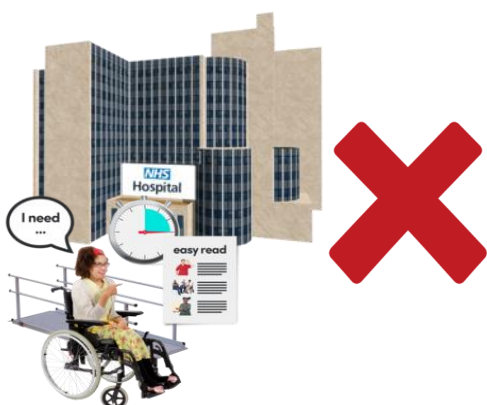


But we know the NHS want to make things better.

The NHS has done lots of work to make healthcare better for people with a learning disability, but there is still more work to do.



There are lots of good changes planned in the next few years that will help make healthcare better, but they had not happened yet when coronavirus came.



This means that when coronavirus came, people with a learning disability were already at risk of missing out on the healthcare they needed.

## How the NHS works



The NHS run services to help us stay healthy, and to help us get better when we are unwell.



NHS services include things like accident and emergency to help when you are very unwell, and ambulances to get you to hospital

NHS services also include the GP, the hospital, and the dentist.



The Government and the NHS bosses give hospitals and healthcare staff like doctors and nurses instructions on how to run NHS health services.

Sometimes these instructions are called guidance.



The instructions tell hospitals and healthcare staff how their services should work.





The instructions include rules about how they have to do things.

The instructions and rules might include:



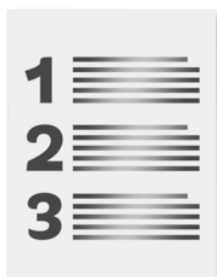
- What healthcare services they have to run



- What support they need to give to disabled people when they use the services.

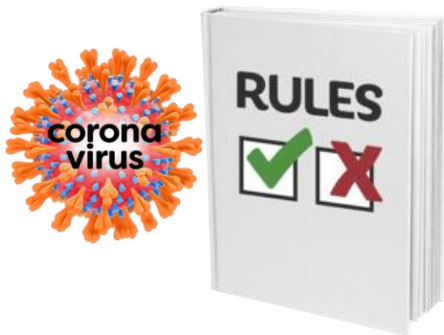


- Things they have to do make sure that patients and staff are safe.



The healthcare services and healthcare workers have to do the things the instructions and rules say.

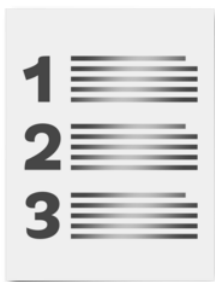
## What happened to the instructions for healthcare services when coronavirus came?



When coronavirus came, the government and NHS bosses had to work quickly to give the healthcare services and healthcare workers new instructions and rules about how to run the healthcare services.



Hospitals, GP surgeries and healthcare staff were told to work in a different way.



The instructions told healthcare workers how to keep themselves and their patients safe from the virus.



For example, things like making sure patients were not too close together and wearing special clothes – like face masks.



The instructions told them to make sure there were more emergency services, because the virus might make lots of people very unwell, and need help with their breathing.



This meant that some other services might need to be stopped for a while.

The new instructions did not always work for people with a learning disability.



The instructions have not always reminded healthcare workers to make reasonable adjustments for people with a learning disability.



For example, when coronavirus first came, if people went into the hospital they were not allowed to have a carer with them.



The instructions did not tell the hospitals to make sure disabled people had support.



This meant some people might not have had a supporter with them when they needed it.



Sometimes when the government or NHS have noticed the rules do not work for disabled people, they have changed them quickly.

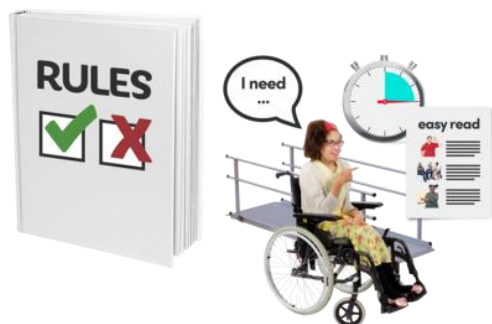


For example, when coronavirus first came, a set of instructions was sent out to doctors about how to decide whether to give someone treatment with a ventilator.



The instructions were written in a way that could have made doctors think that disabled people should not get ventilator.

This was a mistake and should not have happened.



They changed the rules very quickly, and made sure they clearly said that disabled people should get an equal chance of treatment.



But the instructions for healthcare workers and healthcare services keep changing, and sometimes they change very quickly.



Sometimes, even when we have said that a set of rules or instructions does not work for disabled people, the Government and NHS have not done anything to change it.

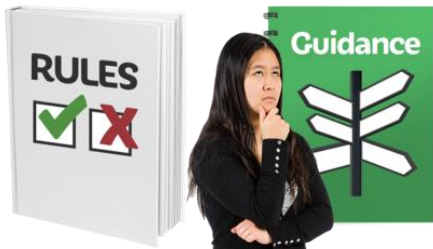


For example, at the moment, while we are writing this easy read, there are instructions about visiting, that could make it hard for disabled people to have a supporter with them when they need it.





We think this is wrong.



The government and NHS is still putting out instructions and rules about how to run things differently.



The instructions and rules they put out sometimes still do not work for people with a learning disability.



We think this is very wrong.

We want the Government and the NHS to learn from what has happened.



We want them to make sure that from now on the instructions always work for people with a learning disability and make sure they can get the healthcare they need.



Public Health  
England

## What can the research tell us about what has happened?

**Public Health England** works with the government to collect information about coronavirus.

**Public Health England** wrote a report. It showed lots of people with a learning disability who have sadly died from coronavirus.



The report used information from the **National Learning Disabilities Mortality Review**. They collect information about people with a learning disability who have died.



The first time people with learning disabilities sadly died with coronavirus was in February and March this year.



Most people with learning disabilities with coronavirus sadly died in hospitals.



Care homes for people with learning disabilities were less likely to have coronavirus than care homes for older people.



This is probably because they have fewer people living in them. This means infections don't spread easily.

## What have Mencap seen happen since coronavirus came?

When coronavirus came we think some of the problems that people with a learning disability have using healthcare services got worse.



When coronavirus came the changes of the rules have been very confusing and sometimes difficult to understand.



Some people called the Mencap helpline to ask for help because they needed support in hospital.



Sometimes staff working in the Mencap services had to ask for help because they were worried someone we support could miss out on care.

Some people were worried about decisions that had been made about someone's care.



Some people were worried because they were not able to be with a person who needed support in hospital.



People with a learning disability who had to be on their own may have found it harder to communicate with a doctor or nurse because their carer was not there to help them say what was wrong.



Learning disability nurses told us they had seen lots of people with a learning disability who were not allowed to have a family member, carer or supporter in hospital with them



Some people asked for help because they were worried because they thought someone was missing out on the treatment they need.

There were also lots of changes to the way appointments with GPs and hospitals worked.



Lots of people had to speak to their GP or hospital doctor over the phone or online.

More people had to phone 111 when they needed help.



Video and phone appointments can be difficult for many people.

Some people may find it very hard to explain what is wrong on the phone.



Some people may struggle to use the phone to book an appointment, or get stuck using a phone system that asks you to press lots of different numbers before you can speak to someone.





Healthcare staff were asked to wear **Personal Protective Equipment** or **PPE** to keep everyone safe and help stop the spread of the virus.

Personal Protective Equipment or PPE for short, includes things like glasses, aprons, gloves and face masks.



This meant it was harder for some people with a learning disability to communicate.



PPE has made it harder for healthcare staff to understand what some people with a learning disability were saying.



Some people found it hard to use healthcare services because they were scared of PPE.



## What has worked well

There were also good examples of care given to people with a learning disability.



Learning disability nurses told us that hospital passports were a good way of understanding the person's health needs.



Some people said that talking to their doctor on the phone made it easier to get help quickly when they needed it.



We know that some people have had excellent care during coronavirus.

Not everyone with a learning disability has missed out.



Hospital staff helped people stay in touch with their family members by using Skype.



But we think the new rules have meant that people with a learning disability were more likely to miss out.

Here are some real life stories about people's experience of being in hospital.



## Peter's Story

My name is Peter. I live in Northern Ireland.

I have been in hospital many times in 2020 due to my disability.

Usually when I stay in hospital I am able to have a family member with me.

This makes me feel safe and happy.

They can help me deal with questions from doctors and nurses.

I was in hospital when coronavirus started. I was suddenly not allowed to have my family visit me. I found this very hard.





The only way I could talk to my family was through Facetime or telephone.

The hospital visitor rules in Northern Ireland did allow people with a learning disability to have a visitor.

But some hospital staff didn't understand this.

Sometimes when my family came to visit me, they were told they weren't allowed in.



After a few weeks I was able to see my family. But only one person for 1 hour per day.

The hospital visitor rules are still causing problems for some people with a learning disability.



My friend has no family. He needs his carers to help explain things to him. When he first went into hospital, his carers were not allowed to go with him into the ward.



It was hard for him to understand what was happening.



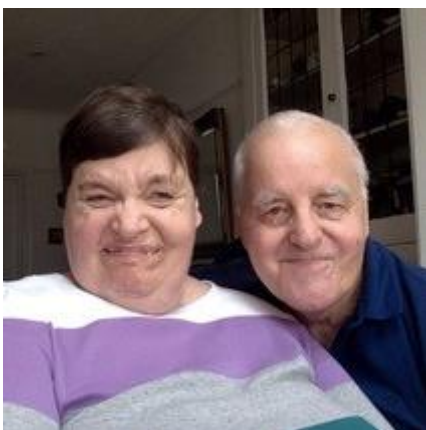
## What we need to see change:

Peter's story shows that it can be hard for some people with a learning disability without support from a carer or family member.

Doctors and nurses need to listen and understand what people with a learning disability need.



We think all staff in hospitals should have learning disability awareness training.



## Roy's story about his daughter

My daughter is 49 years old. She has learning disabilities, is blind and had an organ transplant a few years ago.

She takes medication every day. She has lots of hospital appointments.





Her regular appointment was cancelled. This might have been due to coronavirus rules. But they didn't tell us why.



In April, we had to take her to Accident and Emergency because her legs were swelling up.

The experience was stressful.



We asked the receptionist if she could be seen quickly. My daughter gets upset if she has to wait a long time but we were ignored.



After 2 hours, they noticed my daughter was very upset.

A nurse let us wait in a quiet area.

We were then seen quickly.

The doctor was caring. But my daughter would not let him look at her body. They did a blood test.





We came back the next day for a scan. The person who did the scan was not very caring.

He said he didn't like dealing with children.

My daughter is an adult and does not like being called a child. She felt sad.



We then went to the main hospital. My daughter gets less upset there because she knows the staff well. They are nice to her.

We didn't have to wait. We were seen straight away.

She had a liver scan. The nurse was great.



She spoke directly to my daughter about what tests she was going to do. This helped my daughter feel calmer.



My daughter needs support to make her feel safe and comfortable at hospital.



But since our bad experience at Accident and Emergency, she is now nervous of hospital staff.



### What we need to see change:

Roy's story shows that healthcare staff need to treat people with a learning disability with respect.



People with a learning disability should have access to all tests and treatments if they are feeling unwell.



People should not be ignored if they have a learning disability.



### Steven's story

Steven is 43 years-old and has Down's Syndrome. He lives in supported housing. He has carers to support him at home.



In March, Steven became unwell. An ambulance came. They thought Steven had COVID-19.



His dad was not allowed to see Steven. This meant he couldn't help Steven understand what was happening.

After a long wait, he was allowed into the corridor near Steven's hospital bed. But he was only able to speak to him for a few minutes.



Steven's dad went home. He came back the next day. He was allowed to see Steven in his hospital bed. He had to wear a mask and gloves to protect himself.

The hospital staff were nice and kind to Steven.



Steven seemed to be getting a bit better.

A few days later he was able to go home.



But then he became unwell again.

He was taken to a different hospital this time.



His dad said the staff were not as nice and friendly. They did not make reasonable adjustments.



They did not give him clear information about how Steven was.

A doctor called his dad and said if Steven needed a ventilator to help him breathe, they would not give him one.



Steven's dad was shocked and very upset.

So he phoned a doctor who knows Steven really well. She was shocked too.

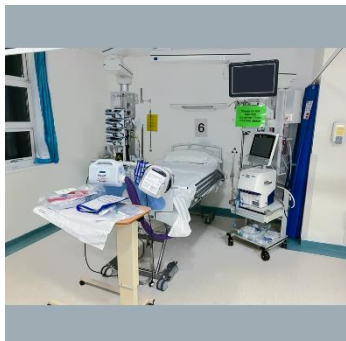
She asked a colleague of hers to check in on Steven and speak to the doctor treating him for COVID-19.

The new doctor then changed their mind and agreed Steven could have a ventilator if he needed one.

Steven's dad was happy to hear this. Steven got much better and is now home and doing well.







## What we need to see change:

**Steven's** story shows people with a learning disability should have access to a ventilator to help them breathe if they need one at the time.



## Katie's Story

Katie\* runs a Mencap service where people we support live.



In March, when coronavirus was really bad, we were shocked when letters from the local GP surgery first arrived for the people we support.



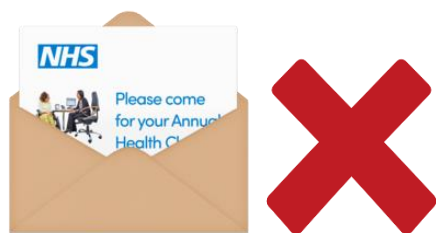
The letter said that if the people we support caught coronavirus then we should not try to contact the emergency services.



The people we support are older people but none of them have any serious health problems.



The same letter was sent to every person who was receiving care from our service.



The letter did not talk about the person's own health needs or say what health problems they had.



The GP surgery called us to ask what the people we support could and couldn't do. For example, if people could use the stairs.



Some of the people we support are wheelchair users so of course they can't use stairs but that doesn't mean that they aren't fit and healthy.



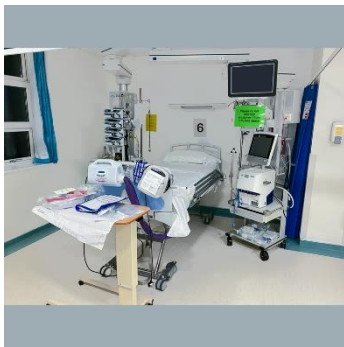
It really felt they were being ignored because they had a learning disability. They made a decision about the people we support because they need care and support.



We were pleased when the GP surgery said sorry and the issues were solved. The people we support are safe and well.



However it is worrying that this happened in the first place. People with a learning disability deserve to get treatment like anyone else – their lives are just as important as anyone else.



### **What we need to see change:**

People with a learning disability should have access to treatments just like anyone else if they are unwell.



People should not be ignored if they have a learning disability.



When you leave hospital to go home, this is called being **discharged**.



Lots of learning disability nurses told us that healthcare staff did not always have enough time to make sure the right support was in place for people when they were ready to go home.



They said their discharge plans for going home were made quickly to free up hospital beds.



This was difficult for disabled people because people who have care and support could not be arranged at short notice.

Leroy's story talks about being discharged from hospital quickly.



## Leroy's Story

Leroy is 58 and has a learning disability and was admitted to hospital with coronavirus in March after feeling out of breath having a very high temperature.



After a week in hospital, I wasn't happy because I said I'm not well enough to go home but they said I was ready to be discharged.



I was having problems with walking and still feeling out of breath. Me and my sister knew that that it was too early.



When he returned home, Leroy continued to have problems breathing properly and eventually his sister had to call an ambulance.

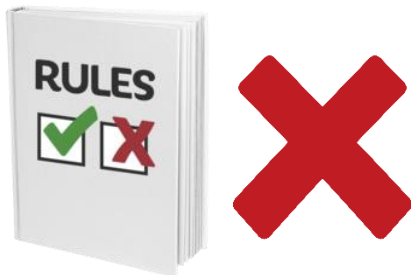


The hospital staff didn't listen to me and I feel it should have never happened. If they had they wouldn't have discharged me too early.





After 3-4 more days in hospital, Leroy was discharged again and started to do better.

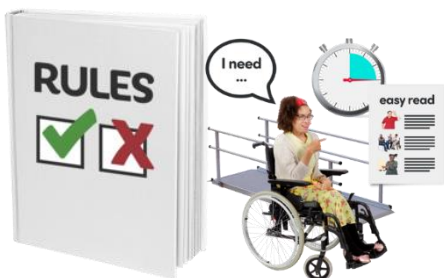


## What we need to see change:

Leroy's story show us the instructions they put out about going home sometimes did not work for people with a learning disability.



Discharge plans need to planned properly with the person and their carer.



The instructions and rules should think about the importance of having support from a carer or family member.



## Bradley's story

Bradley is 27 years old. He has a learning disability, epilepsy, cerebral palsy and is autistic.



Bradley has to go to hospital a lot because of his epilepsy.

Sometimes when he's in hospital, other patients complain because he makes a lot of noise.



He can't help making noises. It's part of his disability.

His mum always asks the hospital staff if she and Bradley can wait in a quiet room instead.



But the hospital staff ignored her requests.



Some hospital staff have been uncaring too.

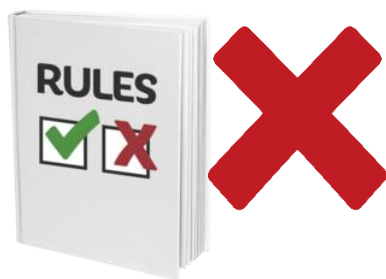
They've asked her, 'Why can't you just control him?'

This really upsets Bradley's mum.



## What we need to see change:

Bradley's story show us why it is important for people with a learning disability who need extra help and support to use healthcare services.



The extra support could help them a lot, otherwise they may miss out on healthcare they need.

We want to learn from and help prepare for the future.



## What has been done about it?

Mencap have continued to raise their concerns with the government and the NHS.

We have been worried that some people have missed out on care and treatment.



It is important that people still ask for reasonable adjustments because they are helpful changes to the way a service works to make it easier for disabled people.



These simple changes could help them a lot, otherwise they may miss out on healthcare they need.

We want the Government and the NHS to learn from what has happened.



We want them to make sure that any new instructions always work for people with a learning disability and make sure they can get the healthcare they need.

## What do we want to happen now?

### Better instructions and rules



We want the Government and the NHS to make the instructions and the rules to think about people with a learning disability.



The instructions need to remind healthcare workers to make reasonable adjustments for people with a learning disability.



The government must give clear instructions about reasonable adjustments.

The instructions should tell hospitals to make sure disabled people have support.

## Reasonable Adjustments



At the moment, while we are writing this easy read, there are instructions about visiting, that could be easier for disabled people to have a supporter with them when they need it.



The instructions and the rules should think about people with a learning disability having support from a carer or family member.



The instructions and the rules should think about the right support is in place for people when they were ready to go home. It should not be rushed.





## Face to face appointments

Video and phone appointments have been difficult for many people.

Some people may find it very hard to explain what is wrong on the phone.

We want to see more people with a learning disability offered face to face appointments safely so they don't miss out on accessing healthcare.



## Access to tests and treatments

People with a learning disability should have access to treatments just like anyone else if they are unwell.



People with a learning disability should still be offered their full annual health check.



Doctors and nurses need to listen and understand what people with a learning disability need.

People should not be ignored if they have a learning disability.

## Vaccine



There is a priority list for people who should get the coronavirus vaccine first.



People with a learning disability should be offered the new coronavirus vaccine.

## Training



We think all staff in hospitals should have learning disability awareness training.



## What you can do

It is really important that you get help from healthcare services when you need it.

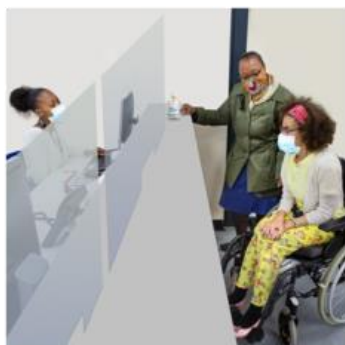


You should still ask for help from healthcare services like the doctor, or the hospital when you need it.



You should still ask for reasonable adjustments if you need them.

Remember that the way the NHS works has had to change because of coronavirus, so the support you need to ask for might be different too.



For example, you may now have to ask for someone to come with you to an appointment.

When you ask for support, make sure you tell the hospital you have a learning disability.



Always ask for help if you are not sure about something.



If you are at the hospital ask to speak to the learning disability nurse.



You can also call your local learning disability team for help to use healthcare services.



You can call the Mencap helpline on 0808 808 1111 if you need advice or support



Check the Mencap website for up-to-date information and advice on coronavirus.



You can also join our Treat me well and campaign with us! Read our supporters pack!

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