mencap
The voice of learning disability

Easy read

Treat me well

Simple adjustments make a big difference

A campaign to change how the NHS treats people with a learning disability

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Treat me well is the new health campaign from Mencap.

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.

We know that lots of people with a learning disability miss out on support and reasonable adjustments.

We want to change how health services support people with a learning disability.

Our campaign is about making sure every person with a learning disability is treated well.

Death by indifference

What has changed since our report 10 years ago

11 years ago, in 2007, Mencap wrote the report, **Death by indifference**.

We told the stories of 6 people who had died because they missed out on the support they needed.

Things have come a long way since then.

We all understand more about the problems people with a learning disability face.

Important research, like the **Confidential Inquiry** in 2013, has told us more about what was going on.

The Confidential Inquiry looked at the lives of lots of people with a learning disability.

The Confidential Inquiry report said lots of people with a learning disability had missed out on healthcare they needed.

The report said that some people had died from things that could have been treated.

The report said there are lots of reasons why people with a learning disability may miss out on healthcare.

There is lots of research still going on to find out more about this problem.

But we already know it would be much better if people with a learning disability got the support and reasonable adjustments they needed.

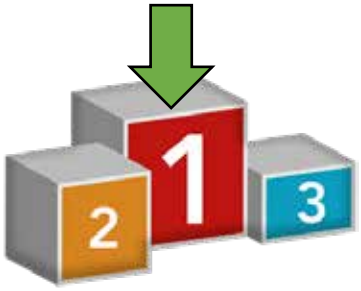
That is why the Treat me well campaign is about people getting the reasonable adjustments and support they need.

There are many organisations that work together to run our health service.

Some organisations are part of the NHS, like **NHS England**.

And some are not, like the **Care Quality Commission** or **CQC**.

They all have lots of managers and bosses.



They all agree that sorting out healthcare for people with a learning disability is very important.

The NHS and other health organisations are doing lots of work trying to make things better.

For example, **Health Education England** has made a plan for training healthcare staff about learning disability.

But it is not being used enough by the other organisations.

NHS England

And NHS England started the **Accessible Information Standard** in 2016.

This said that people with a learning disability should have information they can understand from healthcare services.

But lots of the organisations in the NHS have not been able to make the Accessible Information Standard work yet.

That is why the Treat me well campaign will be about making sure everyone plans and works together.

At Mencap we get lots of calls for help and support about hospitals.

People call us because they have problems getting the reasonable adjustments and support they need.

Sometimes people call us to tell us they had a problem they could not sort out and someone has died.

This needs to stop right now.

Hospitals must be able to support people with a learning disability to get the tests and treatment they need.

That is why Treat me well is about making hospital care better.

Our new research: What we found out

We asked people with a learning disability, healthcare staff – doctors and nurses, universities and hospitals what they think.

What people with a learning disability told us

They need healthcare workers, like doctors and nurses, to explain things in a way they can understand.

They need healthcare workers to support them to have their say in appointments.

They need more time with healthcare workers.

They need healthcare workers to listen to them more.

What healthcare workers, like doctors and nurses, told us

Some healthcare workers have never had any training on learning disability.

Most of them think that more training at work would help them give better support to people with a learning disability.

Most of them think that more time or resources would help them to give better support to people with a learning disability.

What hospital trusts told us

Half of the hospitals had some information on learning disability in their training for new healthcare workers.

Less than half had some information on learning disability for the rest of their staff – like receptionists and porters.

Only a few of them would always offer people with a learning disability a longer appointment or easy read information.

Many hospitals said they had some sort of training just on learning disability.

But it was not for everyone and people did not have to do it.

What the universities that train doctors and nurses told us

We asked universities if they trained their student doctors and nurses about reasonable adjustments.

Most universities said they did.

But this means there are some doctors and nurses leaving university with no training in reasonable adjustments.

More universities for nurses had information on reasonable adjustments in their training than the universities for doctors.

We could not tell how good any of this training was from our research.

What we think about our research

We are worried that lots of health workers are still not getting training on how to support people with a learning disability.

Some people are working in hospitals with no training at all on learning disability.

Most healthcare workers told us they need more resources to give people all the support they need.

That means things like extra time, or communication tools.

We think it is important that they get the things they need and the money to pay for them.

We think healthcare workers will need help from NHS managers to sort this out.

We think NHS managers will need support from healthcare workers to sort this out.

We think the NHS managers and the healthcare workers will need support from all the other organisations in our health service to sort this out.

We need everyone to plan and work together.

Your stories

People told us their stories about going to hospital.

Your stories

Your stories are the reason behind the Treat me well campaign.

The next pages are stories from people with a learning disability and their families.

They are about people's good and bad experiences of hospitals.

The stories are here to help us think about what the right support looks like.

When something is in “speech marks” it means it is the same words the person used when they told us their story.

Desmond's story

Desmond has problems with his eyes.

He has had three operations on his eyes.

Most of the time he goes to a hospital near where he lives.

The staff there know him well and are good at supporting him.

In 2013 Desmond had to go to a different hospital for an eye operation.

There are different ways of doing eye operations.

In the past, Desmond had been put to sleep for his eye operations.

The staff in the new hospital were going to do the operation while Desmond was awake.

But the new doctor did not make sure Desmond had understood what was going to happen.

“I had a new doctor and he didn’t explain anything to me about what would happen.”

So Desmond was very scared and confused when he had his operation.

“There was no one to talk to and no time for the doctors to get to know me.”

“I wish the doctors could have told me what was happening and why.”

“I hope staff get better training in the future to make sure they communicate better with people with a learning disability.”

Anne's story

Anne has been to hospital lots of times.

Sometimes it has been good and she got the right support.

But sometimes she has not got the support she needs.

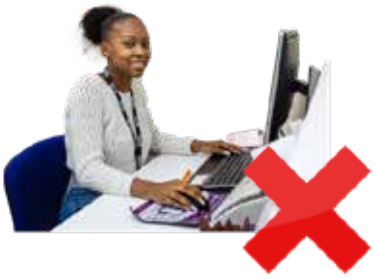
When Anne had an operation, the hospital treated her well.

The learning disability nurse helped Anne by giving her easy read information about what would happen.

The doctor explained things in a way Anne could understand.

“I had a good experience when all the staff took the time to help me.”

But then one day, Anne had to go to hospital in an emergency.

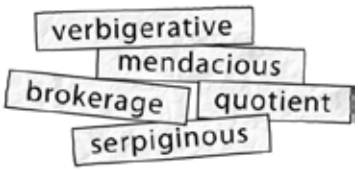


The receptionist did not understand her needs.

Anne asked if she could wait in a quiet space but there wasn't anywhere for her to go.

The doctors changed the medicine Anne was taking.

But they did not clearly explain what she needed to do.



"It was very difficult to understand the words they used, especially the jargon."

Anne just wanted the doctors to take the time to explain things better.

Michelle's story

Michelle has a health condition that affects her kidneys.

She always knew one day she would need a **kidney transplant**.

A **kidney transplant** is an operation to give you a new kidney.

When Michelle was told she had to get ready for the transplant operation, she was really worried and scared.

But the staff at the hospital gave her good support.

They showed her round the hospital and let her see the room where the operation would happen.

Michelle met the nurses.

They went through exactly what would happen on the day.

In 2016 Michelle had a kidney transplant and it went well.

The staff at the hospital made reasonable adjustments so that Michelle got the care she needed.

After the operation Michelle was in pain and had to use a wheelchair for a long time.

The healthcare workers made sure that Michelle understood why she was in pain, so she was not worried.

“I often think about the amazing team who cared for me in hospital. I am so grateful.”

“That kidney transplant changed my life. I have loads of energy now!”

The stories show how important it is for healthcare workers to be able to explain things in a way people can understand.

Healthcare workers must have enough time to spend with patients to get to know them.

All the stories show what a big difference the right support can make.

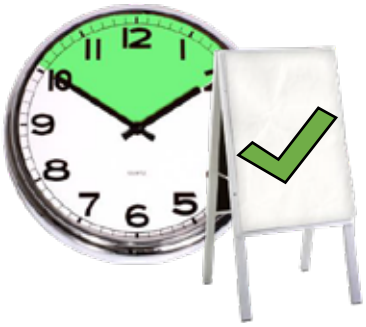
Treat me well: Our new campaign

This part of the report will tell you about the changes we want to make happen.

We want well-trained healthcare staff

We want good learning disability training to be part of all university courses for healthcare staff, like doctors and nurses.

We want all NHS hospitals to make sure all their staff have good training about learning disability.



The NHS must make sure that their healthcare staff have enough time to go to training.

On the next page there is a list of things that we think make good training.

1. The trainers should include people with a learning disability.

2. The training must include learning disability awareness and communication skills.

3. The training must help students understand how people with a learning disability can miss out on healthcare.

4. The training must make sure students understand how to support people to make choices.

5. The training must make sure students understand how to make reasonable adjustments.

6. Students must learn in a group and be able to talk about the way they work.

We want everyone to work and plan together

There are lots of different people and organisations in our health services.

We think people who work in our health services want to give people with a learning disability the care they need.

We know that some organisations have done some really good work already.

Now is the time to plan and work together to make sure we really make a difference.

We want strong leaders

For change to happen we need good leaders in the government, in the NHS and in health organisations.

We need leaders who will make sure everyone remembers that this change is important.

We need leaders who will include people with a learning disability.

We need leaders who will make sure that everyone is planning and working together.

Treat me well

We know that there is some really good work happening in the NHS.

But if we all work together, we can make sure all our hospitals are able to support people with a learning disability.

We can make sure that every person with a learning disability gets the reasonable adjustments they need.

We can make sure that all of our hospitals treat people with a learning disability well.

About this report

Hard words and what they mean

What words mean

We had to use some hard words in this report.

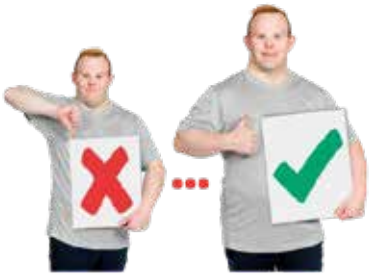
This is because they are names of things.

The next pages are a list of hard words in the report and what they mean.

Reasonable adjustment

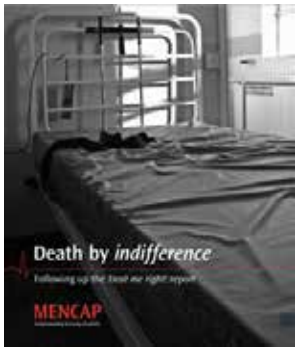
Reasonable means something that is ok to ask for.

An **adjustment** is a change to how something works.



A **reasonable adjustment** is a helpful change to the way things are done for someone with a learning disability.

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



Death by indifference

This is the name of an old Mencap campaign.

Indifference means that something does not really matter to a person.

Death by indifference was about people we thought had died because health services did not think they were important.

Confidential Inquiry

Confidential means keeping important information secret.

Inquiry means to find out what happened.

The **Confidential Inquiry** looked at the lives of people with a learning disability who had died.

The **Confidential Inquiry** kept the details of the people a secret.

But the **Confidential Inquiry** report told us about the ways that people with a learning disability can miss out on the healthcare they need.

NHS England

NHS England is in charge of the National Health Service (NHS) in England.

It decides what is important for the NHS in England.

NHS England makes sure that there is enough money to run the health services we need, like hospitals.

NHS England has its own learning disability team.

We want to work with **NHS England** in our campaign.

Care Quality Commission or CQC for short

A **commission** is an organisation that is given a job by the government.

The **Care Quality Commission's** job is to make sure that people can get good, safe care in places like hospitals and care homes.

The **Care Quality Commission** looks at how well hospitals are run.

If a hospital is not doing well, the **Care Quality Commission** tells them how to get better.

We want to work with the **Care Quality Commission** in our campaign.

Health Education England

Health Education England is in charge of the training for healthcare workers in England.

They come up with ideas for how healthcare workers can get better training.

They wrote a plan about what training healthcare workers should have about learning disability.

The plan is called the Learning Disability Core Skills Education And Training Framework.

We want to work with **Health Education England** in our campaign.

Accessible Information Standard

The **Accessible Information Standard** is the law for health and social care services, like hospitals.

The law says health and social care services have to do their best to communicate with everyone in a way they can understand.

For people with a learning disability, this might include giving easy read information or extra time to communicate.

We want all health services to follow the **Accessible Information Standard**.

Treat me well

Find out more and join our campaign

There are lots of ways to do this:

On our website www.mencap.org.uk/treatmewell

On our Twitter page @mencap_charity
Our hashtag is #TreatMeWell

On our Facebook page facebook.com/Mencap

You can contact us:

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