



Hear our voice

The change we want to see
2015 – 2020



Easy Read

www.hear-my-voice.org.uk
#HearMyVoice

mencap
The voice of
learning disability

Here are some **important words** that are used in this book



General Election

This is when the member of parliament (MP) for your area will get decided. They will speak up for everyone in your area in parliament. The General Election also decides which political party will be in the next government. The government makes the important decisions about the country.



Councillor

This is someone who speaks up for your area in your local council.



Campaign

When you campaign it means you try to change things that are not working at the moment. For example, go to an event like a protest where you speak up.



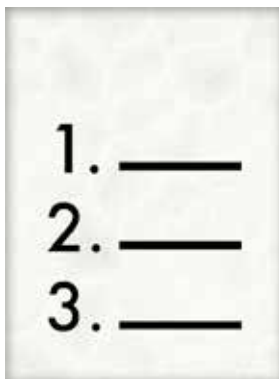
Manifesto

This is a document that says what changes a group want to see happen and how they think the changes should happen.



Politicians

People who are chosen to speak up for people in an area like members of parliament (MPs). They often make important decisions.



Agenda

A list of things that are going to happen



Early childhood

This is the time from when a child is born, to when they turn five and start school.



Diagnosis

When someone is told by a doctor or an expert that they have a health condition or a disability.

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Introduction



My name is Sara Pickard.

I have a learning disability.

This means that I need a bit of extra help with some things.

I am a community councillor in my town of Pentyrch in Wales.



I speak up for the community including people with a learning disability.

People with a learning disability are still not treated the same as everyone else.



Every year, 1,200 people with a learning disability die in hospital because doctors do not give them the right treatment.



More than half of all disabled people have been a victim of hate crime.



Thousands of people with a learning disability are stuck far away from home in places like Winterbourne View. We talk about Winterbourne View on page 27.

These are very serious issues that affect many of the 1.4 million people with a learning disability who live in the UK.



It is shocking that the issues are not more important to most politicians.



Understanding politics can be confusing.



Everyone has the right to know how politics works.



That is why Mencap has made this Easy Read book.

Mencap has a campaign called Hear my voice.



We want to support people with a learning disability to share their stories.



We want politicians to listen to the stories so that they know what people with a learning disability want to see change in the next five years.

We hope this book will help you decide what you want to say to politicians.



We also hope it will help you to share your story.

Politics matters.



It is time for politicians to hear our voice.



What is happening now?

Each year 1,200 people with a learning disability die in the NHS when they should not have died.



Women with a learning disability die around 20 years before women without a learning disability.

Men with a learning disability die around 13 years before men without a learning disability.



People with a learning disability are two times more likely than other people to go into hospital because of an emergency during a year.



What do we want to see change?

The NHS must stop the 1,200 people with a learning disability from dying each year in hospitals when they should not have.

Everyone with a learning disability should get a good health check.



Everyone with a learning disability should have a health plan.

Everyone with a learning disability should be offered a hospital passport. This will make sure doctors know about them when they go to hospital and can give them the right care.



All doctors and nurses must have full training about caring for people with a learning disability and their families.

Early childhood

What is happening now?



There are 200 children born each week who will have a learning disability.

There are around 54,000 children with a learning disability in England who are 5 years old or younger.



Early years is the time from when a child is born, to when they are five years old.

It is a very important time for a child with a learning disability to be with their family.



It is also a time when families will work out what support their child will need.

What do we want to see change?



All children with a learning disability and their families should get the support that is right for them.



Families must get the right support at the right time so their children can grow up and have a good life.

Social care



What is happening now?

Thousands of people with a learning disability are still living in places like Winterbourne View. We talk about Winterbourne View on page 27.

Many of them have lived there for years - this costs the country £500 million a year.



Almost half of people with a learning disability and their families have had their short breaks or respite services cut.



Most family carers of people with a learning disability have reached breaking point because they do not get enough short breaks or respite services.

What do we want to see change?



People with a learning disability and their families must have the support they need to live a good life.

If they do not have the support they could reach breaking point and this could cost a lot of money.



There must be enough money in the care system so that everyone who needs support gets it.



People with a learning disability must get the right support in their local area so they can live the life they want to live.

Nobody should be sent far away from their home to places like Winterbourne View. We talk about Winterbourne View on page 27.

Hate crime

What is happening now?



More than half of all disabled people have been victims of hate crime.



Not many of the hate crimes were taken seriously by the police.



Not many of the people who did the hate crimes were punished.

What do we want to see change?



The law must be changed so that it treats hate crime in the same way as race hate crime and religious hate crime.



The whole law system must be more accessible for people with a learning disability. It should be easier for them to report crimes, to talk to the police, to be listened to and to get justice like anyone else.

The police need to have better learning disability training.



Children should be told why it is wrong to pick on anyone for being different including having a learning disability. They should be told in school.

Education

What is happening now?



There are 1.8 million children in England with Special Educational Needs (SEN).

234,000 of these children have a type of learning disability.



Some schools have sent a child with a learning disability home for behaving badly without it being written down. Some schools have sent children with a learning disability home because their classroom support like a teaching assistant is not there. These are both against the law.



Young people without a learning disability are much more likely to be in education, in training or to have a job than young people with a learning disability.



What do we want to see change?

1. All schools must fully include children with a learning disability.



2. Children with a learning disability must not be sent home from school for the wrong reasons. This is against the law.



Training Room

3. Young people with a learning disability should be supported to get the right skills for when they are adults and for the rest of their lives.

Benefits and welfare reform

What is happening now?



There are more than 400,000 people with a 'learning difficulty' claiming Disability Living Allowance (DLA) in the UK.



In 2013 the Government spent £66 million on Work Capability Assessment (WCA) appeals.

An appeal happens when someone asks the government to pay them Employment and Support Allowance and the government says no but the person does not agree and asks them to change their decision.



Approximately 8 out of 10 working age people with a learning disability could work, but less than 2 in 10 people are in work.

What do we want to see change?



Getting support when you have a learning disability can be expensive. Benefits should be there to support people with a learning disability.



People with a learning disability must not have their benefits taken away unfairly.



Everything should be explained clearly if there is a change in the benefits someone gets so they are not left confused.

Real life stories



Here are some of the real life stories people with a learning disability and their families have told us.

These stories are about the problems that people with a learning disability face.

They are stories about what they think needs to change so people with a learning disability have a better life.

Paul and James



My name is Paul. I have a son called James.



James is 13 and has a severe learning disability.



James sometimes has a seizure during the night. A seizure is when a person suddenly becomes ill or has a fit.



This means sometimes the whole family can't sleep for the whole night when James is ill.

My health has been affected through stress and not getting enough sleep.



My wife and I have no family in the area to support us when this happens.

Eventually, we reached breaking point.

We could not take any more.



When I found my local short breaks service, everything changed. Now we get a full night's sleep once a month.



It's amazing how just a little bit of help saved my family from falling apart. If we did not have the overnight respite, we would not have James with us now.



In 2012 I heard the service was going to close. I could not believe it. The short break service had become our lifeline.



I got together with other parents to launch a campaign to save it.

We just could not face the thought of losing it.



We fought the closure and in January 2013, we won.

NHS Surrey decided to keep it open. Our hard work paid off.



But that wasn't the end. This year we are in exactly the same position again. We are fighting plans to close our service once again.



Having a child with a learning disability like James can be very difficult.



I have learned that you have to fight for the services you believe in, the ones that really truly change lives.

Without breaks, we would not be able to care for our son, and the thought of him not being able to live with us anymore is horrible.



Ann and Simon

My name is Ann. When my son Simon was 18 he was living in a small care home near to our house.



He was known and liked by everyone in our community.



Social services would not fund the level of support Simon needed, so things got worse and worse.



So he was sent to an assessment and treatment unit. Suddenly life for our family, changed forever.



The staff there did not understand Simon and said he was dangerous because of this.

They were physically holding Simon down to stop him moving many times a day. He had never been treated like this before. His behaviour got worse. They were not able to cope with him anymore.



This was when he was sent to Winterbourne View.

Simon spent 15 months in Winterbourne View where he was abused and not looked after. *Panorama*, the TV programme, did a special report on it that told the world what was happening.

Simon has never been the same since.



When we found out what was happening we got Simon out. His old home welcomed him back with open arms.



It was an extremely happy time.



We worked with the care home and Simon got his own flat next to the home he was in. It meant he could have his own space and the support he needs.



The staff there are amazing. They have proper training and never hold him down.

His care is cheaper now than when he lived at Winterbourne View.



Simon is safe and living a full life. I am so happy that he is not at risk anymore.

It is time to make our voices heard.

At the next General Election we can help to choose the people who will run the UK for the next five years.

Together we can tell our politicians what matters to us.

There are 1.4 million people with a learning disability in the UK - and millions more who support them.

Most politicians do not understand how issues like poor health care and hate crime can affect our lives.

These issues should be taken seriously. Not ignored.

Now it is time to share your story and help make our country better.

Your voice counts.

Join the Hear my voice campaign.

#HearMyVoice

If you would like to know more about this campaign go to

www.hear-my-voice.org.uk

Or you can email us on

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