



Hear our voice

The change we want to see
2015 – 2020





Introduction

Sara Pickard

My name is Sara Pickard, I'm 30 years old and I'm trying to bring about real change in the UK, through politics.

Politics can be messy and inaccessible for everyone, especially people with a learning disability. But it is our right to take part.

That's why Mencap has made this book. It's a collection of stories from people with a learning disability and their families, telling us what changes they want to see from the 2015 General Election.

Like so many people who have joined the Hear my voice campaign, I have a learning disability. What does that mean? It just means that I might need extra help with certain things.

I'm a councillor in my town of Pentyrch. I represent the community, including people with a learning disability.

The General Election is our chance to influence decisions that affect all our lives.

In the last generation we made real progress for people with a learning disability and our families, but we still

have such a long way to go before we are recognised – and treated – as equal and valued members of society.

Every year, 1,200 people with a learning disability die needlessly in the NHS. Over half of disabled people have been victims of hate crime. Thousands of people are stuck in units like Winterbourne View.

These very serious issues affect many of the 1.4 million people with a learning disability in the UK, so it's shocking that they aren't at the top of all political parties' agendas.

We hope this book will inspire you to share your story and tell politicians what matters to you.

We also hope it will help political candidates learn more about the changes people with a learning disability and their families want to see.

Politics matters. It has an extraordinary impact on everyday life. It's time we told politicians to Hear my voice.

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They saw his disability, not his illness.

Jayne, Paul's sister



Hear my voice Jayne and Jonathan

On New Year's Eve in 2008, our brother Paul was in great pain and was taken to hospital. He had a perforated bowel and spent three weeks in intensive care. As soon as Paul came round he was transferred prematurely on to a general ward - but it was way too soon. What happened next was a nightmare.

Paul was severely neglected and a few days later he died.

He died because of his learning disability, plain and simple. He just wasn't treated the same as other patients. Those last few days of Paul's life were horrific.

We knew he was getting worse. We begged staff to do more. After Paul died we were haunted with questions. "Did we shout loud enough? What could we have done differently?"

But the doctors and nurses didn't listen to us. They left him for up to 20 hours without being checked on, despite all of us constantly explaining how much he was deteriorating. His notes went missing and they were giving him diazepam for agitation and saying that his clamminess was all due to his disability. It turns out the medication made everything worse.

Paul died because staff only saw his disability, not his illness. This is what makes his story so tragic.

Paul's death is a scandal. Our fears are that we will see more and more deaths like Paul's in the news.

People with a learning disability deserve equal health care. They are dying too young - this can't be happening in the UK.

It's so important for nurses and medical staff to listen to families. To really understand the person they are trying to treat and care for, to make the right decisions. There's not enough understanding.

We need government leaders across the UK to make changes to protect people with a learning disability. We want it to be the same for everyone across the UK.

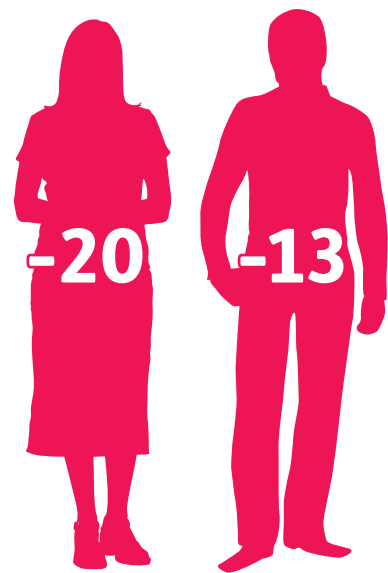
We know that it will be a long road but we will continue campaigning. We won't stop until we see the changes that are required.

Paul had so much joy and warmth for everyone. We were proud he was in our family.

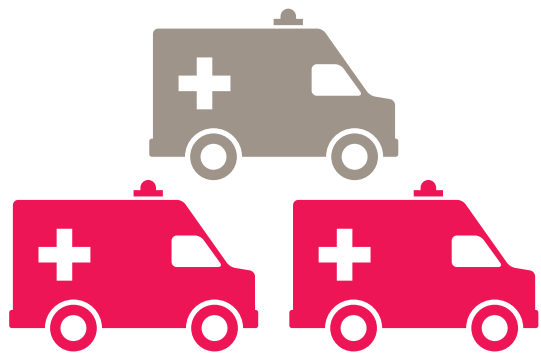
Paul's legacy is to prevent this from ever happening again.



1,200 people with a learning disability are dying prematurely in the NHS every year.¹



Women with a learning disability die on average **20 years earlier** and men **13 years earlier** than the general population.²



People with a learning disability are nearly **twice as likely** as other people to be admitted into hospital in an emergency.³

Key asks

- 1** The NHS must take action to stop the scandal of 1,200 preventable deaths of people with a learning disability in hospitals every year.
- 2** Everyone with a learning disability should get a good quality annual health check and a health plan to help keep them well. Everyone should be offered a hospital passport so doctors and nursing staff understand their needs when they go to hospital and can give them good care.
- 3** All GPs, doctors and nurses must have training on the reasonable adjustments they need to make to give quality care to people with a learning disability and their families.

Paul's death is a scandal. Our fears are that we will see more and more deaths like Paul's in the news.

Jayne, Paul's sister



¹ Glover, G. & Emerson, E. (2013) *Estimating how many deaths of people with learning disabilities in England could be prevented by better medical care*. Tizard Learning Disability Review. 18, 3, p. 146-149

² Norah Fry Research Centre, University of Bristol (2013), *Confidential Inquiry into premature deaths of people with a learning disability*

³ Improving Health and Lives (2011), *People with learning disabilities in England*

The diagnosis hit us hard. The huge challenges that lay ahead for Oisin and our family, were terrifying.

Natalie, Oisin's mum



Hear my voice Oisin

When we planned to have a baby, we expected a crawling, walking, talking child like everyone else. Then we were told that's not going to happen, your baby isn't normal. I'll be honest - it was devastating. Some people say it's like grieving.

My pregnancy was brilliant. My scans and screens were all normal. Then the day Oisin was born they noticed he had some different features. His jaw was very far back, he had clenched hands and one of his feet was bent right back.

The initial diagnosis was terrifying for us. They told us it was Edward's syndrome and that we should say goodbye to our son and call the priest.

After hearing that, we didn't care what the final diagnosis was, as long as we got to keep our baby, as long as it wasn't fatal.

Our son Oisin is three and a half now. He has a learning disability and a syndrome so rare that it has no name. I had to let go of my plans for my son, we had to make new plans.

Oisin is a very special boy with special needs and we want him to have the same opportunities as every other child. We found out quickly that there is no childcare for children like Oisin in Belfast. Crèches and child minders are reluctant to look after him. There is also a lack of staff, facilities and knowledge.

People were quick to offer us grants but it wasn't money we needed.

For us, Mencap's Segal House Nursery has been a godsend. I really don't know how we would have managed without it. The type of childcare Oisin gets there just isn't available for children like him elsewhere. He has physio, speech and language workers and the play environment is so wonderful. He can play like all the other children now. Without this support I wouldn't be able to work and we wouldn't be able to cope with the stigma we unfortunately face as a family.

It was so difficult at the beginning but we are such a happy family now. We go on family trips, we do everything any other family might do and I don't feel sorry for us at all. We are lucky and Oisin is just happy as Larry, so we are too.

I'll always remember my mum saying to me:

"You know, it's hard today but tomorrow you're going to get on with this and this kid will give you more than you could ever imagine."

She was right.

Early years is the period of time between a child's birth and their 5th birthday.

It is a crucial time in the life of a child with a learning disability, both in terms of their development and also bonding with their family. It is also a time when families get to know their child and identify the support they need to help their child achieve their potential.

200

There are **200 children** born each week who will have a learning disability and an estimated **54,000 children** with a learning disability in England who are 5 or under.¹

Three quarters of local councils do not have enough childcare for disabled children.²



92% of mothers of disabled children say finding childcare for their child is more difficult compared to non-disabled children.³

33% don't use childcare because staff don't have the right experience.³

Key asks

- 1** There should be a wide range of local advice, information and practical support for families at the point of diagnosis, or when it is clear a child has a learning disability.
- 2** Families must get the right support and intervention at the right time to ensure their child is able to develop to their full potential.



¹ Papworth Trust, (2010) *Disability Facts and Figures*

² Family and Childcare Trust, (2014) *Childcare Cost Survey 2014*

³ Contact a Family, (2014) *Childcare Affordability Trap* http://www.cafamily.org.uk/media/773401/childcare_affordability_trap_research_june_2014.pdf

Caring for my son became too much. We were at breaking point.

Paul, James's dad

James is 13 and has a severe learning disability. He has seizures in the night - which means that sleep is rare in our house and emotions are fraught. My health has been affected - I have sudden attacks of Meniere's disease brought on by stress and my wife and I have no family in the area to support us.

Eventually, we came to a crisis point where we thought we couldn't go on anymore.

When I found my local short breaks service everything changed. Now we get a full night's sleep once a month and just that little bit of help saved my family from falling apart. There's no doubt about it, if we didn't have the overnight respite, we wouldn't have James with us now.

In 2012 I heard the service was going to close. I couldn't believe it - it was our lifeline. I got together with other parents to launch a campaign to save it. We just couldn't face the thought of losing it.

We fought the closure and in January 2013, we won. NHS Surrey decided to continue funding Beeches. Our hard work paid off.

But that wasn't the end of it. This year we find ourselves in exactly the same position; fighting plans to close our service once again.

Raising a child with a learning disability like James can be extremely challenging and I've learned that you have to fight for the services you believe in, the ones that really truly change lives.

Without breaks, we'd no longer be able to care for our son, and the thought of that is devastating.

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

Ann, Simon's mum

When Simon was 18 he was living in a small care home near to our house and was a well-known and loved part of the community. But social services would not fund the level of support we needed, so things got worse and worse for Simon and he was sent to an assessment and treatment unit. Suddenly life for our family, changed forever.

The staff there didn't understand him and said he was dangerous. They were physically restraining him numerous times a day, he had never been restrained before.

His behaviour deteriorated quickly. They were completely unable to cope with him. This was when he was sectioned and sent to Winterbourne View.

Simon spent 15 months in Winterbourne View where he suffered abuse and neglect that BBC's *Panorama* programme exposed. He has never been the same since.

After this ordeal, his old home welcomed him back with open arms and Simon was able to return to the community he loved. It was an unbelievably happy occasion.

However, when Simon came home his behaviour was different. He was visibly more stressed and frustrated. We needed to come up with a solution to make Simon feel in control and safe again. We worked with the care home and Simon got his own flat attached to the home where he

could have his own space and the support he needs.

His staff have learnt to manage his challenging behaviour in an amazing way - they keep their training up-to-date and they never physically restrain him.

I don't see how sending someone with Simon's needs away to a unit can ever be justified.

There is not even a 'money' argument - Simon's package of care now costs about half as much as it did for him to be in Winterbourne View.

Simon is now safe and living a full life. It is peace of mind for me to know he is not at risk anymore.

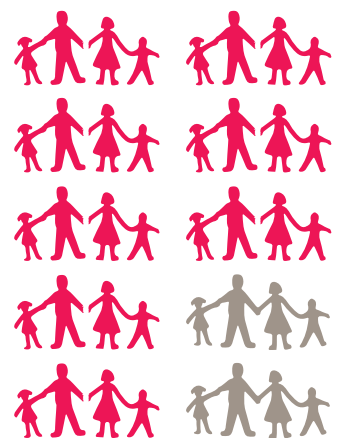


£500m

Thousands of people with a learning disability are living in units like Winterbourne View, many for years, at a cost of around **£500m a year**.¹



For every **£1 spent** on support for people with moderate care needs, **£1.30 will go back** to the NHS, local and central government because people with a learning disability and their families are better supported, need less hospital treatment, and are able to access the community and employment.²



8 out of 10 family carers have reached, or are close to reaching, breaking point due to a lack of short breaks.³

Key asks

- 1** People with a learning disability and their families must have access to the support they need to live a good life. Failing them will lead to families reaching crisis point and society will face huge avoidable costs.
- 2** There must be enough funding in the care system to ensure that everyone who needs support gets it.
- 3** People with a learning disability must get the right support in their local community, so they can have a safe home and live well, and not be sent to places like Winterbourne View.

Without breaks, we'd no longer be able to care for our son, and the thought of that is devastating.

Paul, James's dad



¹ Estimate by Eric Emerson, Professor of Disability and Health Research at Lancaster University

² Scope, Mencap, National Autistic Society, Sense, Leonard Cheshire Disability (2013) *Ending the other care crisis*

³ Mencap, (2013) *Short breaks support is failing family carers*

It all started with shouting names and stealing my things. Over the years it's got more serious. I get nervous, shake and have panic attacks.

Kelly



Hear my voice

Kelly

I'm Kelly and I've been a victim of hate crime. At first the bullies at school used to call me names because I wasn't as fast as other kids at learning things. Once I went to the park with my brother and they stole my walkman and cassettes from me.

It got worse and worse from that day. Now I'm 41 and I still get called nasty names, now it's on the street. I try to walk straight down the road, try not to listen to what they are shouting. They follow me home, ring my bell, wake me up and bang on my door.

It causes me stress and makes my blood pressure high. I just want them to stop, it's not fair.

When I tell the police they just say: "Walk away Kelly," or "just ignore them Kelly." But I want it to change. I want people to be nicer to me. That's why I want to tell the government, because this is serious.

I know that there are lots of people with a learning disability that are suffering from hate crime and nothing is being done - they get away with it because police don't take it seriously.

Sue (Kelly's mum): Kelly has been hassled, called vicious names and has come home in distress many times. We report things to the police and she has made video statements. Nothing ever happens.

Hate crime affects all of us. It's sleepless nights, anxiety, worrying whenever the phone rings, my stomach clenching. Is she ok? Has something happened to her again today? It's living on a knife edge.

The police, the courts, the judges, the magistrates; everyone should have proper learning disability awareness training because I know they don't understand what disability hate crime is.

I want to start seeing, real, open education of young people starting from tiny tots, right through to adulthood.

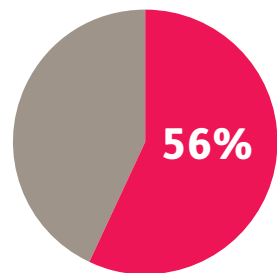
Anybody with any difference, learning disability, mental illness, should be accepted just as everybody else is.

This needs to be higher on the agenda, for law enforcement and education. Kelly and all the other victims of hate crime don't deserve this.



In the last two years there were **124,000 disability hate crimes**.

Only **3%** of these were recorded by the police, and only **1%** resulted in prosecutions.¹



56% of disabled people say that they have experienced hostility, aggression or violence from a stranger because of their condition or impairment.²

Key asks

- 1** The law must be changed so it treats hate crime against disabled people as seriously as it does race or religious hate crime.
- 2** Everyone working in the criminal justice system – the police, judges and the prosecution service – must take disability hate crime seriously and apply the full strength of the law.
- 3** The whole criminal justice system must be more accessible for people with a learning disability, so they are able to report crimes, give evidence and get justice like anyone else. Training is key to achieving this.
- 4** Learning disability awareness must be taught in all schools, so children understand why it is wrong to target someone for having a learning disability.



I will carry on fighting so the children of the future with learning disabilities don't have to wear the same shoes that we have.

Dee, Jack's mum



Hear my voice Jack

Most days Jack was dropped off at the school door and I hadn't even got down to the bottom of the road before I got the phone call to take Jack home

Jack just didn't understand what was being asked of him at school and they didn't understand him - he couldn't communicate and so he behaved differently.

He spent most of his time standing facing the classroom wall as punishment for being the 'bad boy'. He wasn't being taught, his teacher just wanted him quiet and sitting still - when he didn't, she sent him home.

We suspected something might be different about Jack. Everyone kept saying he was just a 'tortured soul' with 'middle child syndrome'. We went to see a specialist and they confirmed what we had started to think - Jack has autism.

It took Jack four years to get the confidence to go back to school again after the trauma of his first years in a classroom. But as soon as he did, his anxiety levels went through the roof and it all happened again.

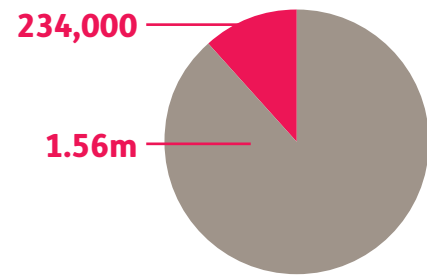
We were losing our son. He was self harming. One morning he mentioned ending his own life, because life for us would be easier without him. He was becoming more isolated and secluded. Jack didn't understand what people wanted from him. And he hated himself.

There were no alternatives because we couldn't get a SEN statement to get the support he needed.

Children with a learning disability are treated like criminals. It's not their fault if their environment distresses them.

As Jack's parents we have had to learn how to speak to our son, how to listen to him through his behaviours and manage his anxieties. It has enabled Jack to become the son we knew was there.

At the end of the day there has to be accountability. Somebody has to answer for what's going to happen to our children, because they're being discriminated against daily. It's nothing short of abuse.



There are **1.8 million pupils** in England with Special Educational Needs (SEN), of which **234,000** have a diagnosis associated with learning disability.¹



Pupils with SEN are **eight times more likely** to be permanently excluded than their peers who do not have these needs.²



By the age of 19 young disabled people are **three times more likely** not to be in education, employment or training (NEET) than non-disabled young people.³

Key asks

- 1** The education system must be set up so mainstream schools and further education provision fully include children and young people with a learning disability.
- 2** No child or young person with a learning disability should face being illegally excluded from their school.
- 3** Young people should be supported to gain the right skills to prepare them for adulthood and have access to learning opportunities throughout their lives.

SEGAL
HOUSE



¹ Emerson, E. and Hatton, C. (2008) *Estimating Future Need for Adult Social Care Services for People with Learning Disabilities in England*

² Children's Commissioner for England, (2012) *They never give up on you* http://www.childrenscommissioner.gov.uk/content/publications/content_561

³ Tunnard et al, (2008) *One in Ten - key messages from policy, research and practice about young people who are NEET*. Research in Practice. Dartington.

I can work and I want to work, but nobody will give me a chance anymore. I am on Jobseekers' Allowance.

Denise



Hear my voice Denise

My name is Denise. I have a learning disability and mental health problems. I also have a little one - Kyle is six.

I can work and I want to work, but nobody will give me a chance anymore. I am on Jobseekers' Allowance.

I had a job at a school for deaf kids before I had Kyle. I was there for four years. I also worked at a crèche where I did my NVQ 1 and 2 in childcare. Since I left to have Kyle nobody ever calls me back.

I really want to work. The benefits I get aren't enough but my learning disability puts off employers and even more now that I am also a mum.

A few months ago I signed something I shouldn't have and I lost half my benefits. I didn't understand what I was doing - nobody explained it to me properly.

I was lucky because Dave, my support worker explained it all to me. He helped me to apply to get my benefits back and he also helps me to use the computer to look for different jobs, which I find really hard.

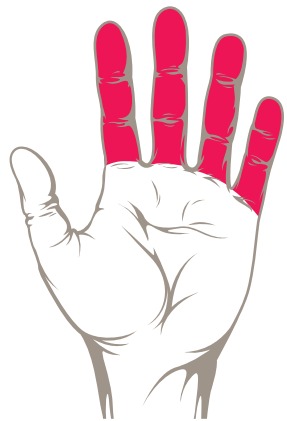
Even though I always tell people about my learning disability, I don't think they get me right. It's just like talking to a brick wall.

As Kyle gets older he needs more and more things that I can't afford.

It's hard for me to make sure I'm getting the right benefits and it's also really hard to apply for jobs without help.

I want to get a job and earn money so my little boy doesn't have to suffer.

There are **over 400,000** people with a 'learning difficulty' claiming Disability Living Allowance (DLA) in the UK.¹ By 2018 the Government has estimated that **600,000 fewer** people will get Personal Independence Payment (PIP) than under DLA.²



During the first 3 months of 2014, people on Employment and Support Allowance (ESA) were **over 4 times more likely** to be sanctioned than in the same period in 2013.³

£66m

In 2013 the Government spent **£66m** on Work Capability Assessment (WCA) appeals.⁴



Approximately **8 out of 10** working age people with a learning disability have a mild or moderate learning disability and could work, but **less than 2 in 10** are in employment.

Key asks

- 1** DLA / PIP should be there to support people with a learning disability with the extra costs they face. The system must work effectively.
- 2** The Work Capability Assessment for ESA must be changed. It must better understand the barriers faced by people with a learning disability.
- 3** The benefits sanctions regime is unfair to people with a learning disability and traps them in poverty. Their benefits must not be taken away unfairly. What is asked of people with a learning disability must be reasonable, with support provided.



¹ DWP Tabulation Tool http://83.244.183.180/100pc/dla_ent/disabled_new/careawd/a_carate_r_disabled_new_c_careawd_feb14.html

² House of Commons Library (2014) *Introduction of Personal Independence Payment* www.parliament.uk/briefing-papers/sn06861.pdf

³ BBC News (13 August 2014) <http://www.bbc.co.uk/news/uk-28776102>

⁴ Letter from Mike Penning MP, Minister of State for Disabled People, to Sheila Gilmore MP, 9 June 2014.

It's time to make our voices heard.



At the next General Election our votes will decide who will run our country for the next five years. We have a chance to stand up together and tell politicians what matters to us.

There are 1.4 million people with a learning disability in the UK - and millions more connected to them - but politicians don't understand how issues like poor health care, hate crime and social isolation affect our lives. These hugely important issues should be debated, not ignored.

Let's make sure that in the run up to the 2015 General Election - and beyond - learning disability is firmly on all political parties' agendas.

Have your say, share your story and help shape our country.

My voice counts. Yours does too.

Join the Hear my voice campaign.

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

Politicians, tell us
you're listening

If you're an MP or candidate tell us you're listening. Go to www.hear-my-voice.org.uk, show your support and read what your constituents are telling you they want to see change in the next parliament.

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