



# Treat me well

Simple adjustments make a big difference

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



## Thank you

Mencap would like to thank everyone who shared their experiences, and those of their loved ones, for this report – Sue, Monica, Karen, Jen, Desmond, Michelle, Anne, and Angus. Your stories show why change is needed and will help us make that happen.

We would also like to thank the Mencap volunteers with a learning disability, and their families, who agreed to be photographed for the campaign – Rahima and Rina, Brendan, Zarah, Sam and Judith, Chris, Patrick, Catherine, Ellie and Annmarie – you have all helped us bring this campaign to life. Some of the photographs next to case studies are not of the person whose story is being shared, because not everyone was comfortable having their photograph included in the report.

We must also thank the wonderful team at St George's Hospital, London – particularly Padraic, Shevon, Pippa, Paul and Avey – for welcoming us into their hospital and allowing us to use their facilities (and their faces!) in our photographs.

Lastly, we would like to thank the 500 people with a learning disability who took part in our survey – you have informed this campaign and we hope that with your voices we can make an even bigger impact and improve the care people with a learning disability receive in hospital.



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# Treat me well

What's it all about?

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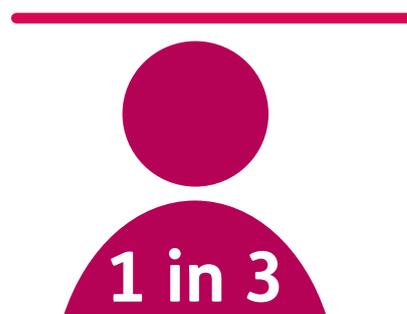
Our new health campaign – *Treat me well* – aims to transform how the NHS treats people with a learning disability. It is focused on finding solutions to healthcare inequalities in hospitals, and bringing about practical changes, so people with a learning disability always get the treatment they need and the equal access to healthcare they deserve.

## What are reasonable adjustments?

Reasonable adjustments are often simple changes that would help the 1.4 million people with a learning disability in the UK get better healthcare. They are also a legal right: laws such as the Equality Act 2010 and the Mental Capacity Act 2005 demand that services adjust the way they work to enable people with a learning disability to access the support they need to gain the same health outcomes as the rest of the population. Reasonable adjustments are person-centred and respond to an individual's particular needs. These adjustments address barriers to healthcare and aim to remedy them by doing things differently. Examples include:

- using more simple language or communication aids
- allowing extra time for appointments
- providing written information in an accessible format (such as easy read).

Simple changes to the care people with a learning disability receive can make a big difference to their health outcomes. Avoiding jargon and explaining things in a way that is accessible to the individual means they can understand more about their health condition and how to manage it. Ten extra minutes in an appointment may give someone the extra time they need to ask questions and check they know what is going to happen next. Providing easy read appointment letters means people are more likely to know when their appointment is and then access the tests or treatment they need.



**1 in 3** healthcare professionals think people with a learning disability receive worse quality healthcare than those without.

Simple changes to the care people with a learning disability receive can make a big difference to their health outcomes.

The issue of healthcare inequalities for people with a learning disability is complex, but the evidence suggests that making reasonable adjustments is one major solution. We know that healthcare professionals see the value in making reasonable adjustments. We also know that there is some truly excellent practice out there, but, sadly, this is not the norm.

At Mencap, we often receive requests for help from people with a learning disability, their families or support staff, in situations where people are not able to access the healthcare they need. These situations often arise in hospitals, which is why we decided to focus our campaign on this part of the healthcare system.

Our experience tells us that when people with a learning disability miss out on the reasonable adjustments they need in hospital, it is often because healthcare professionals are not given the knowledge, skills or resources they need to help them identify that someone has a learning disability, or to adjust their care once this has been identified.

We believe NHS decision-makers and practitioners are ready to make a change, and the time is right for us to work together to transform healthcare for people with a learning disability.

## Anne Grant's story

**Anne has a learning disability and mental health issues. Here, she shares two very different experiences in hospital, where reasonable adjustments were and were not made.**

"I have been to hospital lots of times and had good and bad experiences. These are my stories of how I was treated on two different visits and what made the difference for me.

I had a good experience of going into hospital when having an operation on my knee. The learning disability nurse helped by giving me some easy read information about what would happen. The doctor explained things in a way I could understand and the nurses looked after me. This was a good experience because all the staff communicated well and took the time to help me.

But in 2016, I had to go to accident and emergency, and the receptionist did not understand my needs. I kept having to repeat myself which made me feel very anxious. I asked if I could wait in a quiet space but there wasn't anywhere to go. They told me to wait outside if I wanted to have space. The doctors were not very good and gave me information which was different to what the nurses had told me. They changed my medication and did not clearly explain what I needed to do. It was very difficult to understand the words they used, especially the jargon. If they would just take some time to explain things better, I would know what to do."

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"They changed my medication and did not clearly explain what I needed to do."

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**Treat me well**

Simple adjustments make a big difference

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# Death by indifference

## Ten years on

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Ten years ago, Mencap launched *Death by indifference*: a crucial health campaign in response to the ongoing, poor treatment of people with a learning disability in the NHS. We aimed to highlight the serious consequences of healthcare inequalities through the tragic stories of six people: Emma, Mark, Martin, Ted, Tom and Warren. We wanted to let the world know that their deaths could have been avoided. The campaign was an opportunity for people with a learning disability and their families, whose voices had been ignored for so long, to finally be heard.

In the wake of the report, we were contacted by many families who felt their loved ones had died in hospital because of poor healthcare, and over the following years we supported them in their fight for justice, through complaints and inquests. Every case we examined led us to the same conclusion: the NHS was continuing to fail people with a learning disability and this was costing people their lives. Five years later, in 2012, we published a follow-up report: *74 deaths and counting*.

## Sitting up and taking notice

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The *Death by indifference* campaign proved an essential wake-up call for the NHS.

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The *Death by indifference* campaign proved an essential wake-up call for the NHS and triggered an Independent Inquiry, *Healthcare for all* (2008), which concluded that people with a learning disability were finding it much harder to access healthcare. Two key recommendations of *Healthcare for all* were the inclusion of mandatory, competence-based learning disability training in undergraduate and postgraduate curricula, and for the NHS to ensure systematic provision was made to allow for reasonable adjustments to be made for people with a learning disability. Both of these recommendations were accepted by the government.

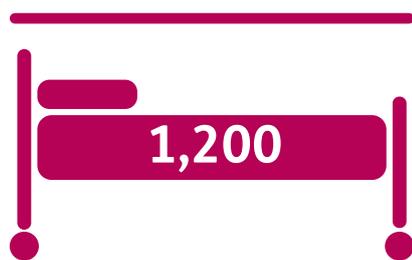
*Healthcare for all* was followed by *Six lives: the provision of public services to people with learning difficulties* (2009), an investigation by the Parliamentary and Health Service Ombudsman into the six cases in the original *Death by indifference* report. In the same year, the government published *Valuing People Now*, an updated three-year strategy on learning disability, which included a commitment to establish a Confidential Inquiry into premature deaths and the Learning Disabilities Public Health Observatory.

## Timeline

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- 2007**  
Mencap publishes *Death by indifference* to highlight the issue of avoidable deaths of people with a learning disability in the NHS.
  - 2008**  
Sir Jonathan Michael publishes *Healthcare for all* from his Independent Inquiry into access to healthcare for people with a learning disability.
  - 2009**  
The Parliamentary and Health Service Ombudsman publishes *Six lives: the provision of public services to people with learning difficulties*. The government publishes *Valuing People Now*, which commits to establishing the Confidential Inquiry.
  - 2010**  
The Confidential Inquiry into premature deaths of people with learning disabilities starts reviewing deaths in the south west of England.
  - 2012**  
Mencap publishes *Death by indifference: 74 deaths and counting* (an update on the original report).
  - 2013**  
The Confidential Inquiry publishes its final report.
  - 2015**  
The Learning Disabilities Mortality Review Programme launches, which was a recommendation from the Confidential Inquiry.
  - 2016**  
The Care Quality Commission publishes a review of the way NHS trusts investigate deaths in England, which includes learning on deaths of people with a learning disability.
  - 2017**  
The National Quality Board publishes national guidance on learning from deaths, which includes deaths of people with a learning disability.

The *Death by indifference* campaign led to the Confidential Inquiry into premature deaths of people with learning disabilities (CIPOLD), the key findings of which were reported in 2013:

- People with a learning disability were dying, on average, 16 years younger than the general population.
- People with a learning disability were over 4 times more likely, than those without a learning disability, to have died from causes that were amenable to good quality healthcare, which means their deaths could have been avoided through better healthcare.



**1,200** people with a learning disability die avoidably each year.

Using the data from the Confidential Inquiry, Professors Glover and Emerson of the Improving Health and Lives Learning Disabilities Observatory estimated that there were 1,200 deaths of people with a learning disability every year that could have been avoided through good healthcare.

These findings confirmed what we feared: despite some progress, people with a learning disability were still facing shocking healthcare inequalities, they were still dying avoidably, and this was happening on a large scale.

The Confidential Inquiry noted several key problem areas:

- People with a learning disability were not being identified in the NHS.
- The need for reasonable adjustments was not being recognised, particularly in secondary care.
- Healthcare services were not always adhering to key legislation, particularly the Mental Capacity Act 2005.

The Confidential Inquiry also noted that learning disability awareness training for hospital staff was a commonly reported need to help address these problems.

Every new research paper, every new report, and every family we spoke to, echoed that these were the issues to tackle if we were to make progress in eliminating healthcare inequalities for people with a learning disability.

Learning disability awareness training for hospital staff is a commonly reported need to help address the problem of healthcare inequalities.



## Anne Clifford's story



**Anne was admitted to hospital with breathing difficulties. Following serious failings in her care, which included not making reasonable adjustments to enable Anne to be fed, she sadly died. Here, Anne's sister, Monica, tells her story.**

“I will never forget the phone call I received from the doctor when she had been taken into hospital. ‘What would you like me to do for her?’ they asked. I told him to do for her exactly what they would do for me: whatever was needed. I couldn’t believe they would ask such a question.

That was only the beginning. A DNACPR (Do Not Attempt CPR) notice was put on her file – without even discussing it with me first. They claimed she was brain damaged, but everything they described were things she did all the time. They made no attempts to understand Anne as an individual or to make reasonable adjustments to her care.

The staff found it very difficult to feed Anne and she lost a lot of weight. This is because they didn’t adjust how they tried to feed her and she wouldn’t allow a tube up her nose – something I could have told them if the hospital involved me more. She spent days and days without nutrition. Despite my concerns they waited a whole week to try another way. The next morning she became seriously ill. And then she died.

The Parliamentary and Health Service Ombudsman found serious failings in many areas of Anne’s care. A statement from one of the hospital staff read: “She was treated no differently”. That says a great deal. They did not see her as a patient that was in any way different to anybody else, and they didn’t allow for different ways of treating her. I can’t stand injustice, and that’s what I feel has happened. That is why I keep on campaigning – for Anne, and for everybody else in this position.”

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“She lost a lot of weight...they didn’t adjust how they tried to feed her.”

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## What has been achieved so far?

### Increased awareness

Ten years on from the launch of *Death by indifference*, the problem of healthcare inequalities for people with a learning disability is now largely known and recognised by the leaders of the NHS. There are real efforts being made in NHS policy-making to address this issue and provide equal access to healthcare; some examples of which we will discuss in this section. However, there is an urgent need for a joined-up approach across all the organisations that make up the NHS, so efforts are not made in vain and services have the knowledge and resources they need to put policy into practice.

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There is an urgent need for a joined-up approach across all the organisations that make up the NHS.

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### Greater commitment from healthcare organisations

NHS England has made learning disability a national priority, and shown a real commitment to this by setting up a Learning Disability programme. The programme leads on implementing many important NHS England objectives on learning disability – including tackling premature mortality – and has begun to make great strides. However, there is still a very long way to go and the clock is ticking – the programme’s funding is due to end in March 2019, with no guarantee of renewal. We need continued central leadership and joined-up working to tackle healthcare inequalities for people with a learning disability.

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**1 in 3** healthcare professionals believe that a lack of government leadership might be contributing to avoidable deaths of people with a learning disability.

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In mid-2016, Health Education England developed the Learning Disability Core Skills Education and Training Framework in partnership with several other organisations, including Mencap. The framework sets out a number of core competencies for healthcare professionals to successfully support people with a learning disability to access health services and manage their own health. This has the potential to make a real difference to how our healthcare professionals learn about learning disability; however, this framework has yet to be as widely used or well-known as we had hoped.



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Visiting the hospital before a stay or appointment can ensure people with a learning disability understand what will happen, and help to identify all the reasonable adjustments they will need.

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In 2016, NHS England developed the Accessible Information Standard, which put a duty on all health and social care organisations to ensure their written and verbal communications were accessible to disabled people, including people with a learning disability. We celebrated this as a fantastic step forward; however, a recent review of the standard clearly showed that organisations were struggling to understand and implement it, and the people with a learning disability we spoke to were still not noticing any impact. There is a great need for training and resources to make the Accessible Information Standard work successfully across the NHS.

## A closer look at the problem

NHS England has commissioned the Learning Disabilities Mortality Review (LeDeR) Programme: a more detailed, longer-term review into the deaths of people with a learning disability. The LeDeR programme aims to help reduce premature mortality and healthcare inequalities by conducting local multidisciplinary reviews of every death of someone with a learning disability in England – and reviewing these nationally. The hope is that lessons learned from each review will influence individual services, and simultaneously the national team will pass on the learning at a country-wide level. LeDeR faces its own challenges in ensuring that local services have the capacity and skills to conduct reviews, which is vital if the programme is to be a success. Following recent guidance on learning from deaths, every NHS trust is now subject to particular duties when someone with a learning disability dies, including a review of their recent care. The aim of this is to ensure lessons are learned and improvements can be made to future care.

The work of the LeDeR programme is very promising and we look forward to seeing the impact of that learning in the future. We also hope that the new learning from deaths guidance will mean that trusts are able to help identify where improvements need to be made to care. However, we must not forget that much learning has already been done, and there is huge potential for making change happen now, with initiatives such as LeDeR there to show us the way as we move forward.

## What next?

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A change to how we support people with a learning disability in hospital must happen – and we need this change to happen now.

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Despite a much greater awareness of the problem at a national level, our new research shows that healthcare professionals are still not consistently getting the training or resources they need to give good care to people with a learning disability in hospital, and whilst progress has been made, we can do much more. We are still learning about healthcare inequalities for people with a learning disability. The LeDeR programme, and other initiatives, will be vital in ensuring we continue to act on that learning.

Mencap understands very well – from the *Death by indifference* cases we presented ten years ago and from the calls for help we still regularly receive from families in the same terrible situations – that for too many people with a learning disability, healthcare is still not good enough. A change to how we support people with a learning disability in hospital must happen – and we need this change to happen now.

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## Communication

Hospital passports can be a great way of helping healthcare professionals know the communication and support needs of a person with a learning disability.

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## Nick's story



**Nick was just 27 years old when he was admitted to hospital – and less than a month later he died. Here, his mother, Sue, shares how concerns she voiced about a lack of adjustments were not listened to, and how that's left her feeling today.**

“My son was an inspirational, vibrant, extremely brave young man. And like many others with a severe learning disability, autism and a complex health condition, he needed high levels of support. At home he got this, but in hospital – when he needed it most – he did not.

Nick had been in hospital for surgery on a ruptured kidney, and became seriously unwell shortly afterwards. During the weeks that followed, Nick's dad and I voiced our concerns to staff about the care Nick was receiving, and the lack of adjustments being made. We asked if we could stay overnight to make sure Nick got the extra support he needed, but we were told there was no provision for this. They viewed us as a nuisance rather than accepting that we were experts in understanding Nick's needs.

We lost Nick on 17 December 2014. He had suffered cardiac and respiratory arrest, and could not be resuscitated – a result of a mucus plug which blocked his airway. On the day he died, I noticed something was very wrong, and pleaded for hospital staff to do something – but they ignored my concerns. The coroner's conclusion showed what we have always believed: things could have been different for Nick if he had been given the care he needed.

Every day we wake up to the pain and realisation that we have to try and carry on without him. All we can hope for now is that in some small way Nick's story can help prevent another person with a learning disability, and their family, from ever going through what we have.”

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“We asked if we could stay overnight, but there was no provision for this.”

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# Our research

How we shaped  
the campaign

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People identified that relatively simple reasonable adjustments would improve their hospital experience.

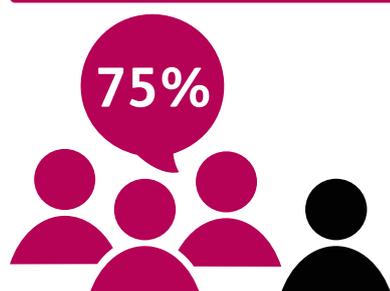
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As part of our new campaign, we carried out research to find out how people with a learning disability felt about their experiences of going to hospital. We also sought the views of healthcare professionals, acute hospital trusts and universities teaching medical and nursing students. We will continue to find out about people with a learning disability and their families' experiences of being in hospital throughout the campaign.

### What people with a learning disability told us

We asked 500 people with a learning disability about their experiences of going to hospital and what reasonable adjustments they needed to improve their experiences of hospital care.

The survey results were consistent with what we hear when working with people with a learning disability, people we support directly, and those involved with our campaigns work as part of self-advocacy, local Mencap and other groups.



**75%** of people with a learning disability said that hospital staff explaining things to them in a way that is easy to understand would improve their experience of going to hospital.

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Many people found hospital staff and the information they provide difficult to understand, and many told us about experiences of not being listened to, or feeling rushed. People identified that relatively simple reasonable adjustments would improve their hospital experience. These included hospital staff improving how they explain things, listening more and allowing more time.

- **3 out of 4 (75%)** said that hospital staff explaining things to them in a way that is easy to understand would improve their experience of going to hospital.
- **Over half (55%)** told us that hospital staff supporting them to have their say in appointments would improve their hospital experience.
- The same number (**55%**) told us that having more time in appointments would improve their experience.

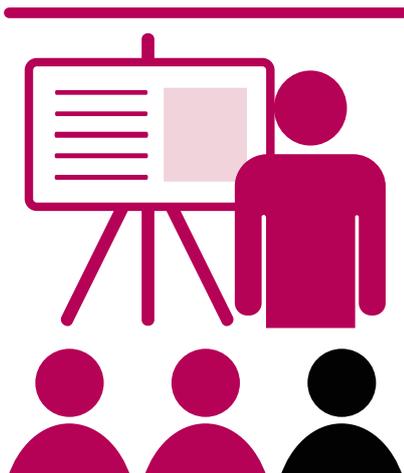


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Not feeling listened to can be a common experience for people with a learning disability and their families. Training can help healthcare professionals feel confident to listen and include people in decisions about their care.

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## What healthcare professionals told us



Two-thirds (**66%**) of healthcare professionals want more learning disability training.

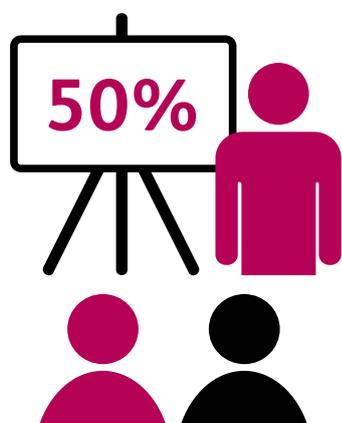
We can only make a real difference to healthcare inequalities if we collaborate with those who are on the front line of the NHS. In March 2017, YouGov – on behalf of Mencap – carried out a survey of 500 healthcare professionals, to find out about their experiences of working with people with a learning disability and what they thought about the quality of healthcare people with a learning disability receive. Of those surveyed, **74%** worked mostly in a hospital setting, **71%** were nurses and **14%** were doctors.

**Over a third (37%)** of healthcare professionals thought that people with a learning disability received worse quality healthcare than those without.

### What is causing the problem?

Training appears to be at the heart of the problem, as our findings revealed:

- Almost **one quarter (23%)** had never attended any training specifically on learning disability.
- **Two-thirds (66%)** wanted more learning disability training.
- **Over half (57%)** thought that more on-the-job learning disability training would enable them to provide better support to people with a learning disability.



**50%** of healthcare professionals suggest that a lack of knowledge around learning disability might be contributing to avoidable deaths.

When told about the 1,200 avoidable deaths each year, almost **6 out of 10 (59%)** agreed that the issue of avoidable deaths of people with a learning disability does not receive enough attention from the NHS.

Reflecting on what might cause such significant healthcare inequalities, **50%** suggested that a lack of knowledge around learning disability might be contributing to the problem of avoidable deaths. **Almost half (45%)** thought that a lack of training for nursing and medical students might be contributing to this problem, and **42%** thought a lack of continuing professional development training might be having the same negative effect.

Almost **two-thirds (64%)** said a lack of practical resources for

themselves and their colleagues might also be contributing to the problem, and – perhaps most concerning – more than **a quarter (26%)** thought negative attitudes towards people with a learning disability might be a contributing factor in avoidable deaths.

Almost **a third (30%)** believed that a lack of government leadership might also be part of the cause of avoidable deaths of people with a learning disability.

### **How can we respond to this problem?**

Our research shows that many healthcare professionals don't feel they've had enough training on learning disability, but, positively, there is a big appetite to learn more about how to work with people with a learning disability. These findings show immense honesty and concern from healthcare professionals about the issue of healthcare inequalities, which is what we would expect from the hard-working, committed people who keep our NHS running.

We believe training is vital if we are to turn things around; negative attitudes must be tackled and staff must be given the skills and knowledge they need to treat people with a learning disability well. However, training alone will not completely solve the problem, healthcare professionals have told us loud and clear that they need the right leadership and resources too.

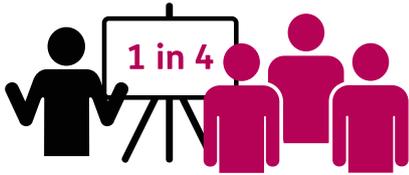
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Training is vital if we are to turn things around.

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### **What universities and hospital trusts told us**

There are two main opportunities to educate and support healthcare professionals to understand learning disability and provide better treatment: either as part of an educational programme, or as part of continued professional development. We ran Freedom of Information (FOI) requests to universities providing undergraduate medicine and/or adult nursing degrees in England and hospital trusts providing acute services in England. We had a high response rate from both requests; **86%** of universities and **75%** of trusts. However, information given to us was not always in a consistent format, and so comparing data was difficult. We have included all information that was provided by a large enough sample of universities and trusts.



**1 in 4** medicine courses do not include training on reasonable adjustments.

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## Universities

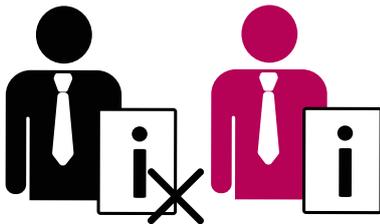
All undergraduate medicine and nursing courses reported the inclusion of some content on learning disability. Furthermore, all medicine, and **98%** of adult nursing courses, told us they include content on the Mental Capacity Act 2005. This is positive; however, we know that the content varies significantly between universities.

When asked about other key content, there were clear differences between nursing and medical courses:

- **86%** of adult nursing courses included teaching on reasonable adjustments compared to **74%** of medicine courses.
- **Only 41%** of nursing courses included teaching on the Accessible Information Standard, despite this standard being mandatory in every health and social care setting in England. And for medicine courses this was even lower, at **35%**.

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**Only half (52%)** of hospitals **include information on learning disability in their induction** training for clinical staff.



This is very worrying, given that reasonable adjustments are key to ensuring people with a learning disability receive equal access to healthcare. Our research did not tell us how, or if, attendance was monitored or learning on these subjects was evaluated in any of the courses. In the past, the government has accepted recommendations that learning disability training for healthcare staff should be both mandatory and competence-based. It is clear this is far from being put into practice.

Whilst there were some efforts being made in undergraduate education, our research indicated this was not enough. We wanted to know if this vital training was being given on the job by hospital trusts.

## Acute hospital trusts

Despite the Accessible Information Standard, and NHS England's pledge to reduce the number of avoidable deaths of people with a learning disability, only just over **half (52%)** of hospital trusts include content related to learning disability in their induction for clinical staff.

In addition, even though there is a requirement for non-clinical staff to be aware of their duties under the Equality Act 2010 and Accessible Information Standard, just **over a third (38%)** of hospital trusts provide learning disability content in their staff inductions for non-clinical staff.

### Learning disability training exists – but not for all, and it’s not compulsory

Many trusts reported they provide specialist learning disability training for staff; however, this appeared to be largely optional and in some cases only offered to specific groups. We do not have information on the quality or content of this training, but based on the evidence we have, it is almost certain it will vary hugely.

Many trusts referred to safeguarding training when we asked them about learning disability training. Safeguarding training is vital to keeping people with a learning disability safe from abuse; however, it is unlikely to cover the topics we believe to be most important to improving the healthcare people with a learning disability receive. For example, this is unlikely to cover reasonable adjustments or the Accessible Information Standard. Furthermore, we know that a failure to provide reasonable adjustments to people with a learning disability can lead to situations where we have to raise safeguarding alerts in our case work. If safeguarding is important to hospital trusts, reasonable adjustments must be too.

### Specialist learning disability staff

We want all those working with patients in hospitals to know how to make reasonable adjustments for people with a learning disability. Many hospitals rely heavily on learning disability liaison nurses, or other specialists in learning disability, to support staff to make these adjustments. Learning disability liaison nurses often play a big role in training other staff, though the exact role of the learning disability nurse will differ between trusts. It is clear that learning disability nurses can have a really positive impact on the care people receive, but often they work alone and can even be stretched across several hospitals.



**Only 41%** of nursing courses and **35%** of medicine courses **include teaching on the Accessible Information Standard.**

The Confidential Inquiry found that learning disability nurses can be effective, but critically, only really during the hours they are in post. In most hospitals there are long periods in the week, such as during the night and weekends, where the learning disability liaison nurse may not be present. Furthermore, more than a **quarter (27%)** of hospital trusts told us they have no specialist learning disability staff at all.

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## The learning disability nurse workforce has fallen by a third.

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Research in 2013 showed the learning disability nurse workforce had fallen by a third. Together with the Royal College of Nursing we have serious concerns about falling numbers of learning disability nurses. We encourage hospitals to employ learning disability specialists as champions to support all staff to make the reasonable adjustments patients need. However, it is important that all staff know how to treat people with a learning disability well – they should not have to rely on learning disability nurses to identify people with a learning disability and make basic adjustments to care.



## Ronnie's story



**Ronnie missed out on the support he needed when he was in hospital. He was fed incorrectly and his communication needs were not understood. Here, Ronnie's nieces, Karen and Jen, describe what happened.**

“Our Uncle Ronnie was a real personality who adored barge holidays and Saturday nights with a takeaway. He had a severe learning disability and didn't have much language, and he needed a lot of support with his OCD. Change was upsetting for him, he needed total stability from people who understood him.

In 2015 Ronnie went into hospital with a suspected urine infection and stayed there for two months. The issues began immediately. Ronnie was moved to six different wards during his first fortnight. He was in pain, he was scared, and they just didn't know how to deal with him – but they weren't listening to anything we or his support workers suggested.

We saw that Ronnie was being fed incorrectly; he needed support to eat as he was at risk of swallowing food the wrong way. On day seven we found out he was being treated for pneumonia – a throwaway comment from one of his nurses. Pneumonia can occur easily if food is ingested into the lungs and we think this is probably what happened to Ronnie.

The hospital staff did not take his specific needs into consideration. For example, his favourite items were his zips. He used to sit, zipping and unzipping – it soothed him. But during one of the many ward moves, they lost all his possessions – including his zips. It might sound insignificant, but without his zips Ronnie began lashing out, and simple things like putting an oxygen mask on him became impossible. But the attitude from staff was, ‘they're only zips’.

Eventually, Ronnie was discharged, but he was never the same again, and he died a year later. Training on learning disability and reasonable adjustments should be compulsory for all staff: from the doctor to the person who brings the teas and coffees. Reasonable adjustments don't need to be huge things to work. It's just thinking about what a person will need and remembering everybody is different.”

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“He was in pain, he was scared, and they just didn't know how to deal with him – but they weren't listening to anything we or his support workers suggested.”

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## Reasonable adjustments: are they being made?

In 2008 the government accepted a recommendation in the *Healthcare for all* Independent Inquiry to ensure systematic provision was made to allow for reasonable adjustments for people with a learning disability. We wanted to know whether some specific reasonable adjustments were being made by hospital trusts. Here are our findings:

### Communication

Staff need to know when a patient has a learning disability, in order to adapt their communication and better understand their needs. **88%** of trusts reported having a 'flagging system' to achieve this; however, given that only **71%** of trusts were able to tell us how many patients with a learning disability had been treated in the last year, this makes us doubt how effective these systems really are. If these systems are ineffective, people with a learning disability will miss out on the reasonable adjustments they need.

Where hospitals are not expecting someone with a learning disability, for example when they visit accident and emergency, we would expect them to have a process in place to ensure basic questions are asked so that their needs can be met. This can include checking if they have a hospital passport, how they communicate, what support needs they have, or if there is a support worker or family member to support the person. More than **a quarter (27%)** of trusts reported they have no procedure in place for the unplanned admission of a patient with a learning disability.



More than a quarter **(27%)** of trusts reported they have **no procedure in place** for the unplanned admission of a patient with a learning disability.

## Time

Longer appointments are an important adjustment to help ensure that people with a learning disability have time to communicate, understand information and have the support they need to make decisions. Disappointingly just over **a third (34%)** of trusts responded that they routinely offer longer appointments for patients with a learning disability. More than **half (55%)** said that they could offer them if requested by the patient. And **10%** said they do not routinely do this.

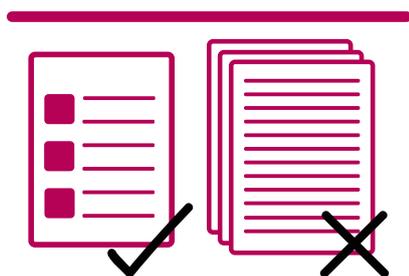
## Information

Easy read and other forms of accessible information can enable someone with a learning disability to understand when their appointment is or how to take their medication. It is also a requirement of the Accessible Information Standard. Disappointingly, **only 23%** of hospital trusts said they routinely offer patients with a learning disability accessible information, such as appointment letters or leaflets, in an easy read format. **21%** of hospitals said that they can offer personalised correspondence in easy read when requested by a patient or consultant.

## Person-centred care

These are all examples of specific reasonable adjustments which can make a big, positive difference to the healthcare people with a learning disability receive. However, this is not an exhaustive list. As the real-life stories in this report show, adjustments can be something small, such as providing easy read information or explaining things using simple language. They can also be something much bigger, such as adjusting how someone is fed or arranging a visit to the hospital before an appointment.

Making reasonable adjustments is about delivering person-centred care; adjusting practice so every person gets the treatment they need, ensuring nobody is disadvantaged because they have a learning disability. This requires not just training for healthcare professionals, but also adequate resources and capacity to support them day-to-day in adjusting their care for people with a learning disability.



Only **1 in 4** hospital trusts routinely offer patients with a learning disability information in an easy read format.

**Making reasonable adjustments is about delivering person-centred care.**

## Desmond's story

**Desmond has a learning disability, which his local hospital has always accommodated well. But when he was referred to another hospital that didn't understand his support needs or make adjustments to his care, it was a completely different experience.**

“My eyesight has been bad for a very long time. When I was young, I used to watch the television very close. This was the first sign that my eyes were not good. My mum and my grandma also have eye problems so that's why I am affected. I have had three operations on my eyes for cataracts and glaucoma, and I have been completely blind in one eye for about four years. My learning disability means I grasp things more slowly and I need people to communicate clearly.

Normally I go to my local hospital for my eye care – they are good with me. But in 2013 they referred me to another hospital to get an operation. That is where the problems began. I had a new doctor looking at my eye before the operation and he didn't explain anything to me about what would happen. In the past, the hospital staff sedated me for operations on my eyes. I thought this would happen again. But instead, the doctor immediately started operating on me, while I was still awake. I was scared, and they were telling me not to close my eyes. It was a horrible feeling. I didn't have a chance to explain what would make me feel more comfortable. There was no-one to talk it through and no time for the doctors to get to know me.

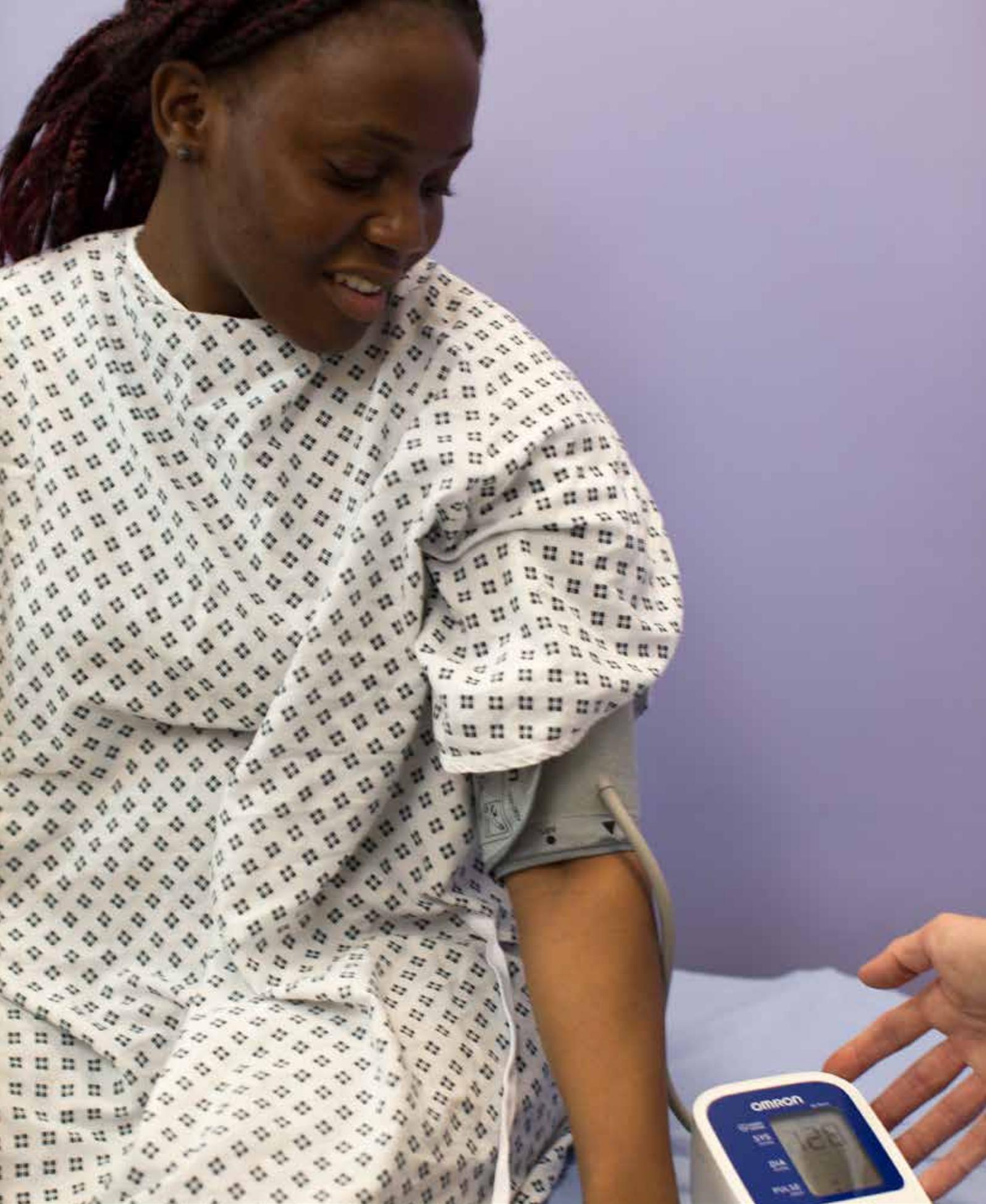
I wish the doctors could have told me what was happening and why – it's what anyone should expect. I hope staff get better training in the future to make sure they communicate better with people with a learning disability.”



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“I didn't have a chance to explain what would make me feel more comfortable.”

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**Treat me well**

Simple adjustments make a big difference

## Final thoughts on our findings

Overall, our research findings indicate that there is currently much variation in the training that healthcare professionals receive. As a result, people with a learning disability often miss out on the treatment they need.

We can see that solving this problem cannot be achieved by one person or one organisation; we must all work together to get this right. These findings have strengthened our resolve that action is needed right now at all levels; nationally from the government, national health bodies and regulatory organisations, locally from hospital trusts and commissioners, and individually from healthcare professionals.

Many trusts tell us adjustments will only be made if a patient requests them, but we know that it can be very difficult for people with a learning disability to navigate the healthcare system and ask the 'right' questions. It is important that we make sure people with a learning disability feel empowered to ask for the support they need. However, it is absolutely vital that healthcare staff are able to support people with a learning disability to identify potential adjustments to care and to ensure these are then provided. We must ensure that healthcare professionals have the resources and training they need to treat people with a learning disability well.

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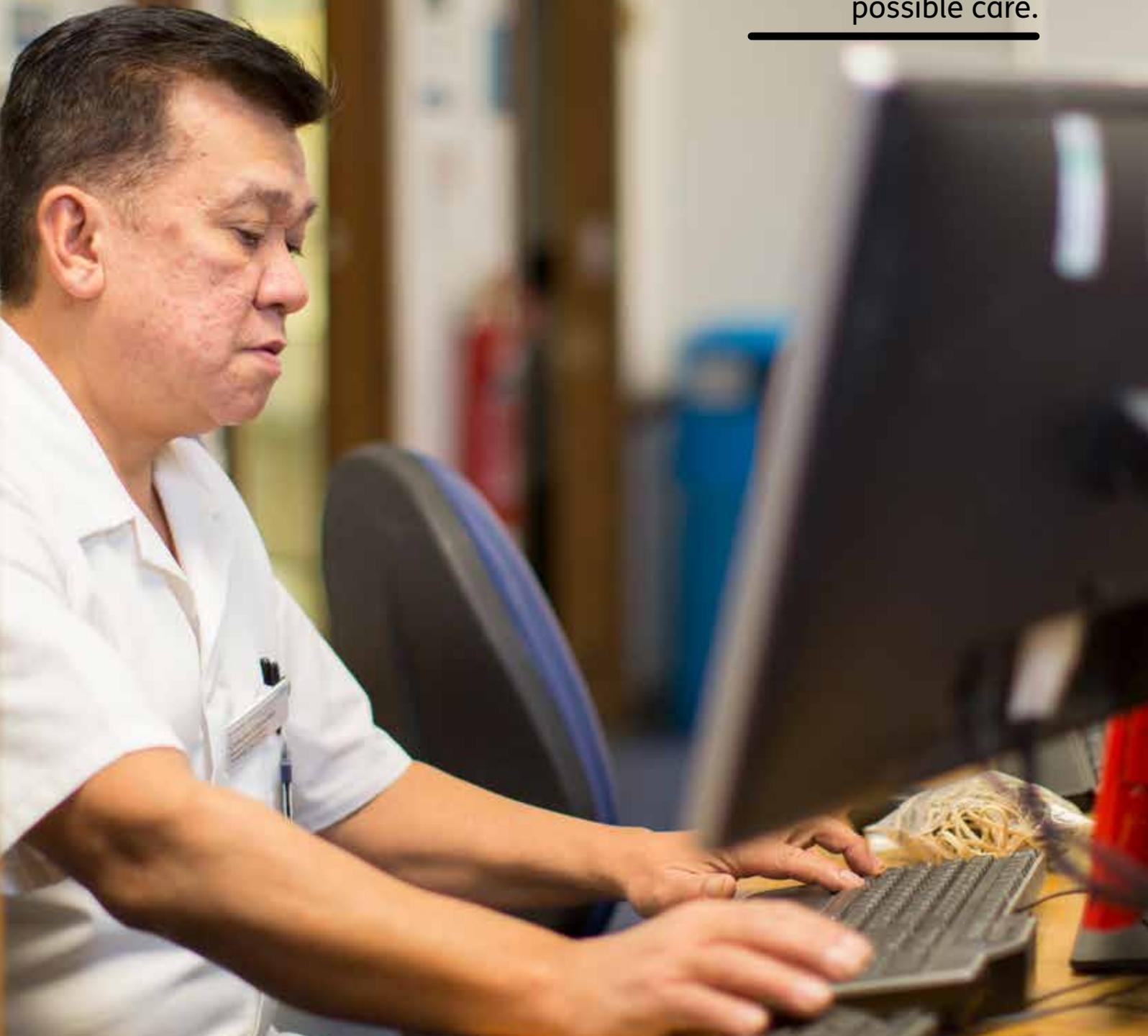
We must ensure that healthcare professionals have the resources and training they need to treat people with a learning disability well.

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Keeping a record of the adjustments someone needs saves time and, importantly, helps everyone who treats the person to provide the best possible care.

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## Angus's story

**Angus Gavin is the safeguarding adults nurse at University College London Hospital. Here, he shares how training transformed his understanding of learning disability, and how it's already making a huge difference in his day-to-day work.**

"In 2014 we had a one-day training session on learning disability for all staff in the hospital who wanted to be 'learning disability champions'. The session was run and facilitated by people with a learning disability, and it was the best training I've ever had – it was fantastic!

The training showed us the importance of supporting people with a learning disability to make decisions and do things for themselves. Previously, my colleagues and I may have lacked full understanding of the needs of people with a learning disability. This could have led to assumptions being made about people's abilities. So our discussions about their individual needs and involvement in decision making may not have been fully person-centred.

The training made me re-think how I communicate – with all patients, not just patients with a learning disability. I began exploring other communication tools, and now I am much more confident in communicating in more creative ways than I would have before.

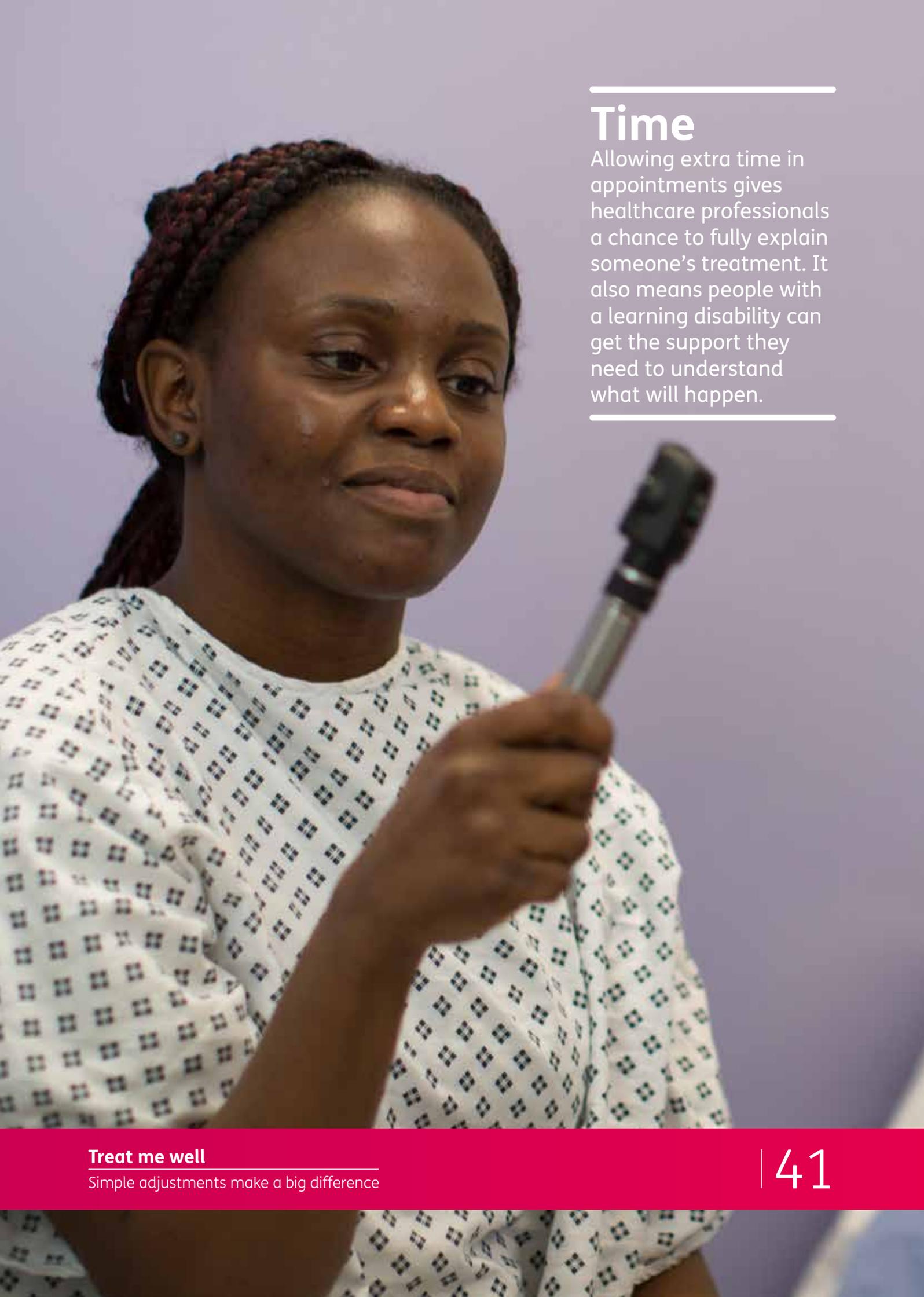
Recently, a man with a mild learning disability came into hospital. Using my new skills and experience, I asked him what support he needed. I worked with the team to make sure that he got the right support and was involved in all decisions about his care. We created an easy read guide on what to do if there were any issues with his health condition or treatment. He found this so useful, we are now going to use it as a template for other patients.

All healthcare professionals need to be aware that a one-size-fits-all approach does not work for patients with a learning disability. The key is to find out what they need to communicate, and who else they might want or need to be involved, then you can give them the same standard of care you give anyone else – in a way that works for them."

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"The training made me re-think how I communicate – with all patients, not just patients with a learning disability."

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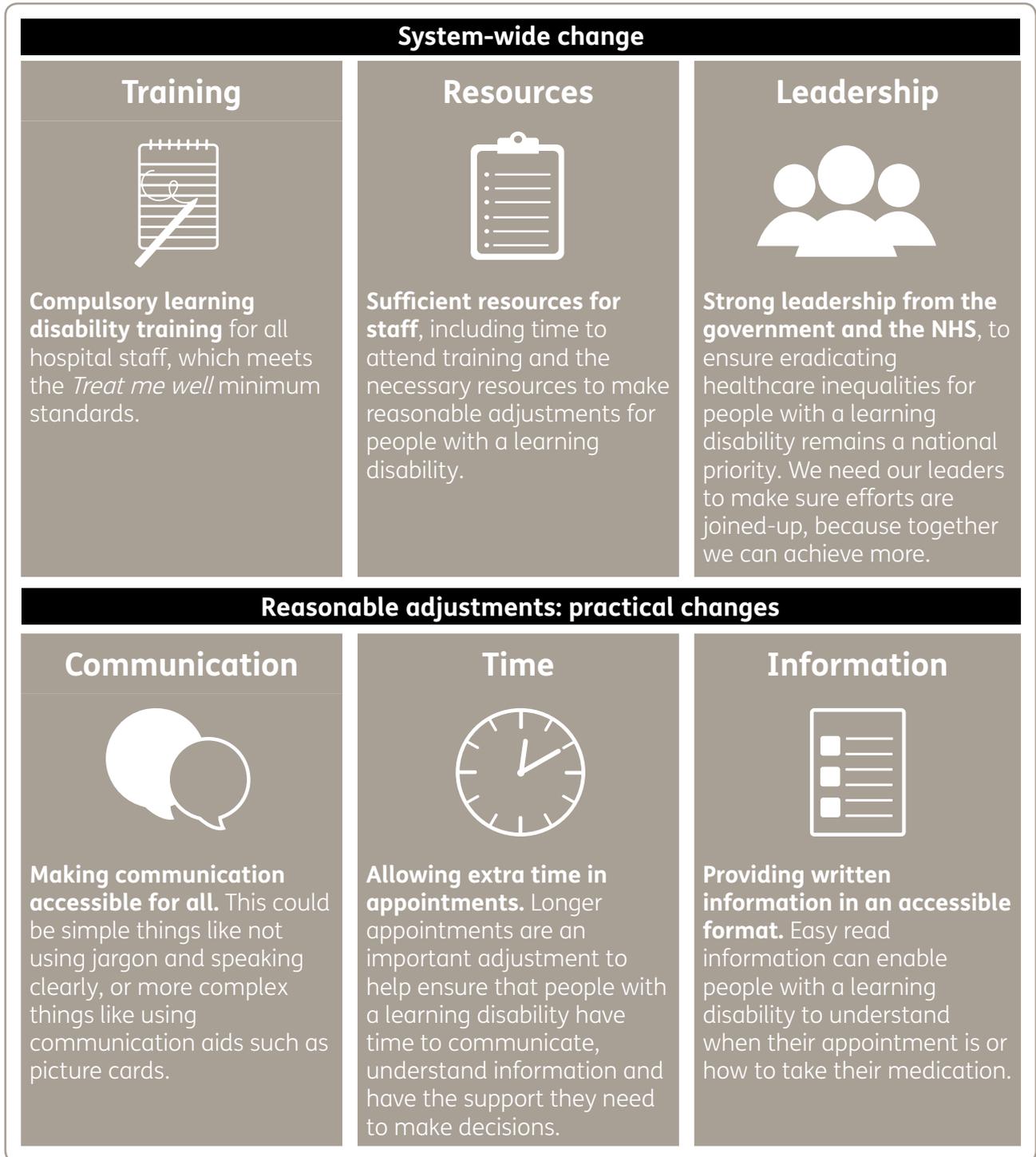
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## Time

Allowing extra time in appointments gives healthcare professionals a chance to fully explain someone's treatment. It also means people with a learning disability can get the support they need to understand what will happen.

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# Our solution: what we want to see



**We know the NHS already agrees how important it is that we improve healthcare for people with a learning disability. Now is the time for us to push things forward and work together to really make this change happen, so every person with a learning disability gets the reasonable adjustments they need, and the good healthcare they deserve.**

## Training

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No healthcare professional should set foot in a hospital without good quality learning disability training.

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We want properly trained staff, ready to do the job of treating people with a learning disability well. No healthcare professional should set foot in a hospital without good quality learning disability training.

Training works, and we know healthcare professionals themselves want it. That's why we're calling for learning disability training to be compulsory for all healthcare professionals.

There are three key changes needed:

**1. Include information on learning disability in training, assessment and revalidation.**

The regulatory bodies, medical schools and nursing schools must ensure key knowledge and skills relating to learning disability are referenced in syllabuses and related guidance, and taught throughout all aspects of UK professional healthcare education. Medical licensing assessment and revalidation – a process doctors and nurses go through regularly to show their knowledge is up-to-date and they are fit to practise – must include core requirements which ensure knowledge and understanding of learning disability law and practice.

**2. Provide training on learning disability for all front-line staff at trust level.**

We want to see mandatory continuing professional development training for front-line staff, both clinical and non-clinical at a level appropriate to the role, based on the Learning Disability Core Skills Training and Education Framework. For people working in non-clinical roles, this will include learning disability awareness training, enabling them to communicate

with people with a learning disability effectively, as well as the ability to identify and flag reasonable adjustments to clinical staff. Clinical staff must be able to put these reasonable adjustments into practice and identify further ways of supporting people with a learning disability with their care.

For this training to provide the necessary depth of knowledge and understanding, it cannot be rushed, nor can it be solely delivered in an e-learning format. In our experience of delivering learning disability training to healthcare professionals, a key objective is to achieve a 'switch on' moment for staff, where they gain a deeper understanding of learning disability and see it as their role to change their practice. In our experience, to cover the necessary material, training should be held over two days for clinical staff, and a minimum of half a day for non-clinical staff, depending on their role. This training should be updated on a regular basis. We recommend 'refresher' training every two or three years. Trust-specific information should be part of both inductions and learning disability training for all staff.

### 3. Make sure training meets the *Treat me well* minimum standards.

The Learning Disability Core Skills Training and Education Framework should form the basis of the content of learning disability training. From our experience of delivering training to meet this framework, we have learned that to maximise its impact, training should meet certain standards with regards to delivery and content.

We believe that training should:

- Be co-delivered and co-produced by people with a learning disability.

The inclusion of people with a learning disability in training delivery is a powerful way to challenge negative attitudes or assumptions, and build understanding, which is the route to improving practice. Furthermore, it helps to ensure that the training is relevant and gets to the heart of the issue.



**1 in 4** healthcare professionals have never had any training on learning disability.

Inclusion of people with a learning disability in training is a powerful way to challenge negative attitudes or assumptions.

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## Good learning disability awareness training focuses on accessible communication skills.

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- Include general learning disability awareness.

This includes what a learning disability is, how to identify someone has a learning disability and, crucially, learning about what life is like for someone with a learning disability and the barriers they may experience from day-to-day. Good learning disability awareness training also focuses on accessible communication skills.

- Focus on the Mental Capacity Act 2005.

This is about correctly applying the five principles of the Act to support decision-making, assess capacity and where necessary make best interest decisions. It should also include Deprivation of Liberty Safeguards (DoLS).

- Focus on reasonable adjustments.

This includes the kind of adjustments that might be needed by someone with a learning disability, how to provide these, and the legal duties set out in the Accessible Information Standard and the Equality Act 2010.

- Be 'learner-centred', interactive and allow discussion.

It is important to avoid lecture-style sessions and computer-based lone-study but instead to encourage discussion, ensuring attendees fully engage with the issues and 'switch on' to learning disability. This should include discussion on the initiatives and schemes in the hospital(s) where the attendees work, so they know how they can apply their learning. Training should offer a 'safe space' for professionals to highlight poor practice and share ideas for improving practice.

## Resources

We want enough resources in the system to make change possible.

This includes more time for staff to attend training and tailor care to patients, and more resources to support the delivery of reasonable adjustments.

The work of healthcare professionals is often busy and highly demanding. We're calling on NHS decision makers, commissioners and trusts, to support their staff to treat people with a learning disability well, by treating their staff well too and making sure the necessary resources are available to them.

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We all have a role to play in eradicating healthcare inequalities for people with a learning disability.

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## Leadership

We all have a role to play in eradicating healthcare inequalities for people with a learning disability. Strong leadership is needed from the government and the NHS to ensure the issue remains a national priority. If we all work together and combine our efforts, we can make a bigger impact.

There are many agencies within the NHS, those involved in the regulation of healthcare professionals and those that train them. We recognise and welcome the initiatives that these agencies have already developed, but we also see an urgent need for effective co-ordination, communication and co-operation between organisations in order to ensure these initiatives really work.

We need national leadership to back our call for the compulsory learning disability training and resources that healthcare professionals need to provide good quality, adjusted care for people with a learning disability across the country.

At the same time, we need this leadership to encourage local organisations to find innovative ways of working and to share their own good practice so it can be replicated elsewhere. We must place real value on the inclusion of people with a learning disability and those that support them. And, importantly, we need leadership that listens to everyone's ideas.

## Together we can make real change

For too long the healthcare inequalities faced by people with a learning disability went unnoticed. Ten years ago we helped to expose this problem, and since then we have worked with the NHS to learn what can be done to solve it. Good quality training for healthcare professionals, so they can make the reasonable adjustments people with a learning disability need, is a key part of this solution.

These adjustments are often small, and can be done by individual staff members in hospitals. But where bigger, systemic adjustments are needed, the NHS workforce needs the support of the trusts, commissioners and decision-makers around them.

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We can create a system that treats everyone well.

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If the government and NHS commit to making change happen, we believe together we can transform how the health service treats people with a learning disability. We can create a system where every healthcare professional steps into work with the training they need, ensuring they can give every person with a learning disability the reasonable adjustments they need in hospital and the equal access to healthcare they deserve – a system that treats everyone well.



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## Information

Providing written information in an accessible format, such as easy read, makes a real difference to people with a learning disability.

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## Michelle's story



**Michelle received exceptional, person-centred hospital care when her health problems reached a critical point. We want everyone to be able to share more positive stories like this.**

“I was born in 1979 with a learning disability and lots of health problems, including a genetic disorder that normally makes people’s kidneys fail before they are 50. So I have always known kidney failure was going to happen.

My health started to get really bad in my 30s. I was feeling unwell, no energy – not myself. The doctors said I would need to get ready for dialysis. When they explained what this meant, I said I didn’t want to have to go to hospital every day. That would have made me very unhappy. The doctors listened and instead of dialysis they put me on a very special diet. No chocolate, no cheese, no nice things. It was hard, but it worked – for two years! Everybody was proud of me. So that made me proud of myself.

Eventually the hospital staff said it was time to get on the list for a transplant. I was so scared and worried. I felt sick with anxiety and they could see this. I was amazed by how they helped me though. They arranged for a visit to the hospital and the operating room, I met the nurses on the ward, and we went through exactly what would happen in surgery. They made me feel so comfortable. Three weeks later, I was rushed to hospital because my new kidney was ready.

On 24 August 2016 I had a successful kidney transplant and I recovered well. After surgery so many parts were sore and achy, and I had to use a wheelchair for a long time. But the team explained to me why I was feeling pain, which reassured me. Through everything they made reasonable adjustments so I got the care I needed.

That kidney transplant changed my life. I have loads of energy now and I can eat cheese and chocolate again! I often think about the donor and the amazing medical team who cared for me in hospital. I am so grateful.”

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“The team explained to me why I was feeling pain, which reassured me.”

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## Notes on research

### Survey of people with a learning disability

This survey was conducted by Mencap and was carried out between 10 March and 23 June 2017. The total sample size was 500 people with a learning disability. Participation was open to people with a learning disability who had previously been to hospital as a patient and were over the age of 16. The online version of the survey was hosted by Survey Monkey. There was also a paper version for those who preferred this way of completing the survey.

### Survey of healthcare professionals

All figures, unless otherwise stated, are from YouGov Plc. The total sample size was 506 adults who are UK public sector healthcare professionals. Fieldwork was undertaken 3 – 9 March 2017. The survey was carried out online.

### Freedom of Information requests to universities

Requests were submitted by Mencap under the Freedom of Information Act 2000 to all English universities identified as offering an undergraduate or postgraduate course in medicine, or an undergraduate course in nursing. 72 requests were sent to relevant universities on 17 February 2017 and by 31 May 2017, 63 responses had been returned – an 87.5% response rate.

### Freedom of Information requests to NHS trusts

Requests were submitted by Mencap under the Freedom of Information Act 2000 to all NHS Foundation Trusts in England identified as providing acute care. 157 requests were sent to relevant trusts on 16 February 2017 and by 31 May 2017, 118 responses had been returned – a 75.2% response rate.



## Find out more and join our campaign

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