

Experiences of being in hospital for people with a learning disability and autistic people

Published: 3 November 2022

Page last updated: 4 November 2022

Who I am matters

Contents

- [Foreword from Paula McGowan OBE](#)
- [Foreword from Debbie Ivanova](#)
- [Fiona's story](#)
- [Key messages](#)
- [Background](#)
- [Access to care](#)
- [Communication](#)

- Care and treatment in hospital
 - Other equality characteristics and quality of care
 - Workforce skills and development
 - Conclusion
-

Foreword from Paula McGowan OBE

The NHS Constitution has 6 values, which says by living these values, we can ensure the best possible care for patients:

1. Working together for patients
2. Respect and dignity
3. Commitment to quality of care
4. Compassion
5. Improving lives
6. Everyone counts

The overriding evidence from this report has told us that these important values do not always exist for people with a learning disability and autistic people.

Please allow me to tell you a true story that happened a few days ago. I took my little dog to the vet because he had injured his front paw. Ted was in pain and was being very difficult for the vet to treat. He was scared, it was bright, it was noisy, he did not know the vet or the nurse, he was getting agitated and began to bark and whimper. I observed the vet talk softly, quietly and soothingly to Ted. I observed her standing back, giving Ted time and space, she was building his trust. She turned to me as Ted's carer and asked what worked best for Ted. I told her that the environment was too noisy for him. She immediately moved Ted to a quieter room, dimming down the light. She continued to reassure Ted, using a soft tone that was relaxed. Ted relaxed and his paw was treated effectively, he had a positive outcome.

I could not help comparing the experience of my teenage son Oliver's time in hospital, leading to his avoidable death, to that of my dog. I could not help reflecting on the experiences of neurodiverse people and their experiences in acute hospital settings throughout this report. I was very uncomfortable knowing that my dog had received far better care than most neurodiverse people had when in hospital. How have we allowed this to happen? Where is the outcry? Where is the shame?

I could have written this foreword before this report was written, because the same stories from autistic people and those who have a learning disability have been told repeatedly. We already know that due to inequality of health care, women die a shocking 26 years earlier than their peer's do, with men faring not much better.

I do not believe that any clinician goes into the caring profession wanting to cause harm or distress to their patients, I believe they want to be able to care and support their patients to the best of their ability.

Sadly, the truth is that huge numbers of staff simply do not have the knowledge or skills in caring and treating neurodiverse patients. They do not have knowledge in understanding exactly what neurodiversity is and how it affects the individual person. There is unconscious bias and at times prejudice, this leads to diagnostic overshadowing, which often leads to catastrophic outcomes for these communities. Staff do not have skills to make reasonable adjustments; many do not understand why these adjustments must be made. Neurodiverse people have told us that staff do not have the skills to communicate with them, they are not skilled in adapting their language to meet their individual needs, and they do not understand perceived challenging behaviour as a person trying to communicate their needs.

This report tells us that we must address a culture that does not treat neurodiverse people equally, fairly or respectfully. It also tells us there is too much reliance on specialist colleagues to support neurodiverse people; there are few of them, and they generally work weekdays only.

It is now time for change. We need leaders and decision makers to take ownership of these outrageous failings to neurodiverse people. They must apply the NHS principles that guides the NHS constitutions to these communities. It is time that decision makers take account and are held accountable when things go wrong and implement the lessons identified in this report. The Oliver McGowan Mandatory Training in Learning Disability and Autism will aim to ensure that health and social care staff receive training to provide a more effective service to neurodiverse people.

Foreword from Debbie Ivanova

As Paula has described, the findings of this report are not new. For too long we have been hearing that people with a learning disability and autistic people are not getting the care they need, when they need it. Our report is not only a reminder of this, but shines a light on the impact these failings have on people and their families.

This impact can be profound. We've heard how not listening to and not meeting the needs of people with a learning disability and autistic people can be distressing, both for the individuals and for their families and carers. These poor experiences affect people's health outcomes and potentially lead to an early death. They can also cause people trauma.

We know that better communication, real involvement and appropriate adjustments are all key to improving people's experiences of care when in hospital. During our time spent in hospitals looking at how care and treatment was delivered, we saw pockets of excellent work. However, nowhere did we see this happening in a way which was joined up or consistent.

Too often it is down to specialist staff or individual members of staff going the extra mile. Relying on these individual members of staff is not sustainable and can create a single point of failure, where knowledge and skills rest with one person. Organisations must ensure all of their staff are provided with training and opportunities to develop and share the skills they need to make sure they are providing care and treatment that meets people's needs.

As an organisation, we are determined to improve the care for people with a learning disability and autistic people. We intend to use the findings of this report as a catalyst to drive improvement. As well as embedding learning from our review into our new assessment framework, we will be continuing to bring people together to understand how to make those changes now.

It is almost 6 years since Oliver died and any further delays cannot be justified. Now is the time for action and I encourage all health and care leaders to use the learning from our report to drive improvement – to recognise and respect each person's humanity and individuality and respond differently.

Fiona's story

"My name is Fiona, I live alone and I have a mild learning disability and epilepsy. I recently had to go to the hospital because I broke my finger while running up the stairs. I didn't know it was broken for three days because I was scared to admit I'd done it.

I was very nervous and scared but I was in pain so went to A&E. I had an X-ray and was told it was broken and that I would need to come back to see a doctor. The whole experience in A&E was nerve wracking because it was during lockdown and so I wasn't allowed anyone with me.

I saw a doctor five days later who said it would need operating on. Coming to the operation they wouldn't let anyone with me then either, even though I had medical issues. I was told not to have anything to eat or drink the night before, but nobody had told me why. I took this too literally, which meant I couldn't go to the loo the next day to give a urine sample. I spent two hours trying to go, but still no one would explain why I needed to give a urine sample. It took them two hours to realise that I didn't understand why I had to provide a urine sample – it was in case I was pregnant, which would be a problem for the operation.

It was just so irritating. Everything got pushed out of proportion. Nothing went disastrously wrong, it was just that communication wasn't there in a way that was understandable for both parties."

Key messages

People have a right to expect:

- access to the care they need, when they need it and that appropriate reasonable adjustments are made to meet people's individual needs. This starts from the first point of contact with a hospital. This is not just good practice – it is a legal requirement.
- staff communicate with them in a way that meets their needs and involves them in decisions about their care
- they are fully involved in their care and treatment
- the care and treatment they receive meets all their needs, including making reasonable adjustments where necessary and taking into account any equality characteristics such as age, race and sexual orientation
- their experiences of care are not dependent on whether or not they have access to specialist teams and practitioners.

However:

- People told us they found it difficult to access care because reasonable adjustments weren't always made. Providers need to make sure they are making appropriate reasonable adjustments to meet people's individual needs.
- There is no 'one-size-fits-all' solution for communication. Providers need to make sure that staff have the tools and skills to enable them to communicate effectively to meet people's individual needs.
- People are not being fully involved in their care and treatment. In many cases, this is because there is not enough listening, communication and involvement. Providers need to make sure that staff have enough time and skills to listen to people and their families so they understand and can meet people's individual needs.

- Equality characteristics, such as age, race and sexual orientation, risked being overshadowed by a person's learning disability or autism because staff lacked knowledge and understanding about inequalities. Providers need to ensure that staff have appropriate training and knowledge so they can meet all of a person's individual needs.
 - Specialist practitioners and teams cannot hold sole responsibility for improving people's experiences of care. Providers must make sure that all staff have up-to-date training and the right skills to care for people with a learning disability and autistic people.
-

Background

For too long, people with a learning disability and autistic people have faced huge inequalities when accessing and receiving health care. There have been a number of initiatives over the years to try and improve people's experiences, but these changes have been far too slow. When people do not get care and support that meets their individual needs it can lead to harm and premature death that can be avoided. Equity for people with a learning disability and autistic people is therefore a critical patient safety issue.

The multi-agency review into [the death of Oliver McGowan](#) highlighted failures in his care that could have been prevented, and that what happened to Oliver could happen to people in other services. The review made several recommendations for change. These included a recommendation that CQC should review how acute hospitals support people with a learning disability and autistic people, and that we look at people's experiences of care in hospitals.

In response, we carried out a review focusing on what people experience when they need physical health care and treatment in hospital. This was part of our work to transform the way we regulate services for people with a learning disability and autistic people. We looked specifically at:

- [Access to care](#)
- [Communication](#)
- [Care and treatment in hospital](#)

- Other equality characteristics and quality of care
- Workforce skills and development.

What is a learning disability?

The [definition of a learning disability from Mencap](#) is “a reduced intellectual ability and difficulty with everyday activities, which affects a person for their whole life.” Approximately 1.5 million people in the UK have a learning disability. 1.3 million people have a learning disability in England, with approximately 300,000 of these being children.

[Information from the NHS](#) explains that a person with a learning disability might have some difficulty:

- understanding complicated information
- learning some skills
- looking after themselves or living alone.

[Mencap describes the different types of learning disability](#), which can be mild, moderate, severe or profound. The level of support someone needs depends on the individual. For example, someone with a mild learning disability may only need support with things like getting a job. However, someone with a severe or profound learning disability may need fulltime care and support with every aspect of their life – they may also have physical disabilities.

What is autism?

Autism is a lifelong developmental disability that affects how people communicate and interact with the world. There are an [estimated 700,000 autistic adults and children in England](#) – approximately 1% of the population. Although autism is not a learning disability, Mencap estimates that [around half of autistic people may also have a learning disability](#).

Autism is sometimes referred to as a spectrum, or autism spectrum disorder (ASD). It affects people in different ways, but three common features include the way a person:

- interacts with others in a social situation
- is able to communicate with others
- experiences the world around them.

Care and support for people with a learning disability and autistic people

Mencap highlights the [health inequalities for people with a learning disability](#), as they have poorer health than others and are more likely to experience a number of health conditions. Similarly, research from the [University of Cambridge published in October 2020](#) suggests that [autistic people are more likely to have chronic physical health conditions](#).

As highlighted in the 2018 [Learning Disabilities Mortality Review \(LeDeR\) Programme report](#), not getting care and support that meets people's individual needs can lead to avoidable harm and premature, avoidable death. The [2020 annual LeDeR report](#) highlighted that this risk increases for people with a learning disability from Black or minority ethnic groups.

What does the law say?

Under the [Equality Act 2010](#), disabled people have the right to be treated equally and to be protected from discrimination. This means taking reasonable steps to make sure disabled people are not treated less favourably, and have parity of access, experience and outcomes, as non-disabled people.

Reasonable adjustments may be required to ensure equal access, experience and outcomes in health and care. This includes, for example, the use of communication aids or sensory tools, where providers make specific adjustments to support a person to communicate their wishes and help plan their care. Making reasonable adjustments for people with a learning disability and autistic people is also essential to protect and fulfil their human rights.

As part of our regulatory role, we assess the quality of care and treatment provided, including whether information has been made accessible and reasonable adjustments have been made. Key regulations that we use when assessing care for people with a learning disability and autistic people include:

- **Regulation 9: Person-centred care** - For people with a learning disability or autistic people this could mean finding a quiet space to speak to the person or allowing a visit before an appointment to allow a person to be familiarised with their surroundings, to reduce anxiety.
- **Regulation 10: Dignity and respect** - This might mean for the person, staff including them in conversations, looking at the person when speaking to them or not ignoring the person and only speaking to care staff.
- **Regulation 11: Need for consent** - This could mean explaining things in a language or way that makes it easier for the person to understand. If a person is not able to consent to care and treatment that is offered, any decisions made must be in a person's **best interests**, and for over 16's, in line with the **Mental Capacity Act**. This may involve having the right people involved in the person's care to consult with, including professionals and a person's family or friends.

What we did

To plan this review, we set up an expert advisory group comprising people with lived experiences, their families and carers and other stakeholders. The role of the group was to help us gather evidence on our visits to hospitals by speaking with people and observing care and the environment.

We wanted to get a more in-depth understanding of people's experiences when they went to hospital. During December 2021 and January 2022, we spoke with 8 people who have lived experiences of learning disability and autism as well as their families and carers, including paid carers. They helped us to test the questions we wanted to ask during our visits to hospitals with our expert advisory group.

During February and March 2022, we collected evidence of people's experiences from 8 hospital trusts:

- Cambridge University Hospitals NHS Foundation Trust
- East Cheshire NHS Trust
- Isle of Wight NHS Trust
- Kettering General Hospital NHS Foundation Trust
- Kingston Hospital NHS Foundation Trust
- Leeds Teaching Hospitals NHS Trust
- South Warwickshire NHS Foundation Trust
- Royal Cornwall Hospitals NHS Trust

When we visited the hospitals, there were still restrictions because of the pandemic and some hospitals were experiencing an increase in COVID-19 related admissions. This restricted the movement of our reviewers on site, as well as our ability to speak to people with lived experiences who were receiving care on wards for COVID-positive people.

We therefore spoke with people with a learning disability and autistic people, their family, friends, carers, paid care workers, and staff by using virtual and on-site activity. This included interviews with people, focus groups, observations and an in-depth review of the care of 16 people. Although we spoke with staff, our focus was on what they thought about people's experiences.

Throughout this report, we present some experiences of people with a learning disability, autistic people and their carers. We also include quotes from people who responded to our 2020 survey of adult inpatients in NHS hospitals. This is to bring to life what we found and show what this means in practice for people.

It is important to note that our review is a commentary on what people told us about their experiences of care in acute hospitals, at a specific point time. It is intended to help start a conversation about the quality of care in acute hospitals, and add to the wider conversation around care for people with a learning disability and autistic people as raised in our report [Out of sight: who cares?](#)

Access to care

Key message: People have a right to expect access to the care they need, when they need it. However, people told us they found it difficult to access care because hospitals had not made reasonable adjustments. Providers need to make sure they are making appropriate reasonable adjustments to meet people's individual needs. This is not just good practice – it is a legal requirement. This starts from the first point of contact with a hospital.

Barriers to accessing care

Developed by disabled people in the 1970s and 1980s, [the social model of disability](#) says that people are disabled by barriers in society, not by their impairment or difference. These barriers can be physical, such as buildings without accessible toilets or can be caused by people's attitudes, which [Scope explains as assuming disabled people can't do certain things](#).

Under the Equality Act 2010, people have a legal right to expect services to make changes to remove barriers like these. However, throughout our review we found that people with a learning disability and autistic people continue to face barriers when accessing health care and treatment.

Overall, people's experiences of accessing care and treatment varied both between hospitals and within the same hospital. Where people had positive experiences, we heard that the right adjustments were made at the right time, to enable them to access the right care. When adjustments were not made, people's experiences were unacceptably difficult. They were left feeling like they were ignored, not treated with dignity and that their needs were not respected.

People could face issues from the first point of contact. For example, we found that appointment letters were not always written in accessible formats and that people could struggle with having to use the telephone and online forms to book appointments.

People's experiences were also influenced by the staff that they met on arriving at hospital. For example, the reception staff at one hospital were not routinely made aware of any adjustments that a person may need and they did not receive any information that would help them interact with a person in a way that met their needs. In another instance, we heard that security staff had stopped carers accompanying people into hospital because of COVID restrictions. This could lead to negative experiences when people arrived at the hospital.

Jessica's story

When I went in for surgery in September, we'd previously agreed that I could have a support worker who would be with me during admission, when I had the anaesthetic and during recovery, when I came back on the ward and to stay until I was settled back on the ward. But I did have a bit of a stress when I arrived at the ward doors at 7am on the day of the surgery as I was told my support worker couldn't be there even though it'd previously been agreed with the learning disabilities team and the ward manager. So, that was a major stress when I'd just got there, but the ward manager arrived a few minutes later and she sorted it out. But it threw me that what I had planned at first didn't happen.

In some hospitals, we heard about difficulties with the directional signs, which could make it harder for people to find their way around. At one hospital, staff told us they had feedback from people who use services that signs were too far apart and that they used medical words that were difficult to understand.

In a couple of other hospitals, staff told us how they had worked with people who use services to make the departmental signs more accessible. Suggested amends included placing signs closer together and changing wording, for example describing services such as 'haematology' as 'bloods'.

Meeting people's needs: reasonable adjustments

Reasonable adjustments are not an optional extra. Health and social care providers have a legal responsibility to make reasonable changes to meet people's needs. People told us about some good examples of staff making adjustments to support people to access care. These included:

- **Familiarisation visits** – people were able to visit the hospital before their appointment or stay as an inpatient to introduce them to the environment and staff and to minimise their anxiety. This meant that people were less anxious when they came to hospital for their appointment or treatment.
- **Tailored appointments** – for example, offering longer appointments and carrying out multiple procedures at the same time to reduce the number of hospital visits. This meant people who may need to see a number of different clinicians at hospital could see them all in one visit so they didn't have to manage repeated trips. Some hospitals also ran bespoke clinics for adults with additional needs.
- **Adaptations to the physical environment and reduced waiting times** – some hospitals enabled people to use quieter entrances, or moved people quickly through busy departments, for example the emergency department. Others carried out assessments and consultations in people's own cars. This meant that for these people, their experience of going to hospital was not further complicated by undue pressure. For example, one person told us:

“When I had my sigmoidoscopy I was very anxious and was sitting in the car park in meltdown not wanting to go inside the hospital. The nurse came to the car and was really patient and calm, she told me to take it easy and reassured me that it'll be alright and I would be well supported. I talked to her and the preparation team and they built a relationship with me – it was great.”

We also saw some good examples of staff working to reduce change to avoid unsettling or distressing people with a learning disability and autistic people. For example, minimising the number of different members of staff who needed to see the person.

Other good practice we found included staff thinking innovatively about how different types of anaesthetic could be used to minimise distress caused to people when undergoing procedures.

However, reasonable adjustments were not always made consistently. People, their family and carers experienced varied levels of support and adjustments. For example, we heard that diagnostic tests were not always carried out as they should be for some people with a learning disability as staff did not consider their physical disabilities. In one instance, hoists were not available at the time of a scan. This meant the person had to have a scan in her wheelchair when it should have been performed lying down.

Our findings resonate with the 2021 LeDeR annual report, [Learning from Lives and Deaths – People with a Learning Disability and autistic people \(LeDeR\) annual report](#). This identified a lack of reasonable adjustments in hospital inpatient care as a theme, including problems with access to specialist equipment.

This lack of support and reasonable adjustments also risked people not being seen quickly enough, or risked their condition deteriorating and requiring more interventions that would not have been necessary originally. In these situations, people not only have a poor experience, but are at risk of sub-optimal clinical care, patient safety risks.

People and staff also told us that identifying and meeting their needs could be more challenging when care was unplanned (such as an emergency attendance).

Jessica's story

Emergency admissions were a lot more problematic... Even just getting in, there were issues, because they'd brought in a new code system for admissions through A&E. They gave every patient a code, so you'd get a number if you'd broken your leg, for example. I'd dislodged my feeding tube... [but] there was no code for this on the system, so they logged me in as 'lack of appetite'... Because of that, I had to wait six hours for triage. When I did eventually see the doctor, she said "I thought I'd just be telling you to go home and phone your GP tomorrow; I didn't realise it was an emergency, or that you're autistic. If I'd have known that, I'd have called you in, ideally within an hour of your arrival, not six hours, because I wouldn't want you to deteriorate before endoscopy closes. So there might have been a chance for you to get sorted within the day rather than you having to stay in."

Previous poor experiences may put autistic people off seeking help sooner. This means that when they do go to hospital, their condition may be worse or they may be more distressed. This may make it more difficult for autistic people to explain themselves or process information. Staff should be aware that when they're unwell, an autistic person may find it difficult to describe their pain or symptoms. They may communicate this in a different way to a non-autistic person, for example smiling despite being in pain.

Fiona's story

I was running up the stairs, fell down onto my hand and broke one finger. This was on a Sunday and I didn't go to A&E until the next Tuesday. I was very nervous, very scared. I was in pain so went to A&E. I stood outside for about half an hour while everyone else was being seen. When I went in, they signed me up and they said "what's your name? What's your problem?" Fortunately, I had a [hidden disabilities] sunflower round my neck, and I showed them my wrist, which had a medical bracelet on it that lists which conditions I have, and in case I have a seizure.

I was told I needed an X-ray for my hand. When I had my X-ray, the person there told me to stand on a dot and how to place my hand to get the X-ray (saying, "twist your hand there, and here") and she said, "why aren't you in agony?" and I said, "I am in agony!" I said, "it's probably because I've been like it for four days and I've not been complaining because I've been too scared". She said "everyone's surprised that you're not saying you're in agony". I said "well I am slightly drugged-up. I'm also nervous". I then got very excited over the fact that she said it was broken, because it was a relief rather than it being a problem at that point.

Importance of specialist skills and knowledge

Most of the hospitals we visited had specialist staff, often referred to as learning disability liaison nurses or teams, who could support people with a learning disability and autistic people while in hospital. For example, they made reasonable adjustments and ensured people's needs were met while receiving health care and treatment. They also worked to support non-specialist staff to work with people with a learning disability and autistic people.

Specialist practitioners or teams were often involved in reviewing a person's needs, and then sharing this information across teams and wards. People told us that their experiences of care were better when these specialist practitioners or teams were involved. For example, one person told us:

"The learning disability team have been amazing and, together with the GP, agreed a care plan so that everyone knows what needs to happen if Gita is admitted."

This is also supported by the [2021 LeDeR annual report](#), which found that the input of learning disability liaison nurses throughout the hospital stay was highly valued.

However, people did not always know that specialist support was available or they did not know how to get in touch with the specialist practitioner or team. For example, one parent told us that although they felt the specialist team was really supportive, they had only become aware of the team by chance as someone at school had told them there was a team who could help.

Issues around staffing and availability could also create difficulties for people when accessing specialist support. Some specialist staff told us that because of the size of their workloads, they were unable to be involved in the care of all people with a learning disability or autistic people. This could mean that people with multiple needs received support, while people who had 'less complex' needs did not. This had a negative impact on autistic people in particular, who were less likely to receive a visit from a member of the team. Specialist staff in one hospital told us about their frustrations at only being able to offer a service between 9am and 5pm.

Staff who have personal experience of interacting with people with a learning disability and autistic people could also have a positive impact on their experiences. Often, these individual members of staff were exceptionally skilled at looking after the needs of people with a learning disability and autistic people, and were passionate about making a difference for this group of people. At one trust, some of these members of staff had been identified as link workers, which was noted next to their names on the staff picture board.

While we saw staff with these skills and experience in many organisations, most of the hospitals we visited did not have a joined-up way of identifying them and using their valuable skills and experience. This meant that people's experiences were influenced by whether these staff were on duty and if they were involved in their care.

What Jessica thinks

I have generally found that the staff who are best at making adaptations, or at least trying to appreciate the different needs of someone with autism or a learning disability, are not necessarily those who've had the official training but are those who have a family member or a loved one with different or additional needs. Quite often, even people who've attended training... are less well informed than those who say, "my little brother" or "my uncle", or whoever is autistic, or has low IQ, "even though he's different to you, I can see similarities. What can I do for you?" I think good practice comes down to experience and the ability to ask questions in a way that doesn't feel awkward rather than from statistics and theories.

Access to specialist support is too variable. For example, at one hospital the mother of a young woman told us that she was only listened to because of the involvement of the specialist team, and sometimes she had to ring them up herself to get help.

Whether and how people are able to get the support they need often varies depending on what time of day they arrive and who they are seen by, and can even vary depending on which part of the hospital they are accessing. Providers need to do more to make sure that – regardless of when people arrive and who sees them – people receive the right care and support that meets their needs.

Communication

Key message: Good communication is key to making sure that people are involved in their care, and people have a right to expect that communication is tailored to their needs. There is no one-size-fits-all solution and providers need to make sure that staff have the tools and skills to enable them to communicate effectively to meet people's individual needs.

Importance of identifying and meeting communication needs

Since 2016, health and care providers have been legally required to meet the [Accessible Information Standard](#). This standard sets out a specific, consistent approach to identifying, recording, flagging, sharing and meeting the information and communication support needs of people who use services, carers and parents of people with a disability, impairment or sensory loss. Applying this standard helps health and care providers meet their existing legal duties to make reasonable adjustments under the Equality Act 2010. We [check how providers are applying the standard](#) as part of our regulatory activity.

During our review, we found limited evidence about how hospitals were identifying, recording, flagging and sharing information. Our findings are supported by [research from Healthwatch](#), published in February 2022, which raised concerns about how well NHS trusts are meeting the standard.

People told us that when their communication needs were met, they were more likely to have a positive experience of hospital, and be meaningfully included in their care. The quality of communication and information sharing varied both between and within the services we visited. This started from the first point of contact with the hospital and the systems to identify people with a learning disability and autistic people.

In most hospitals we visited, staff told us that GP records and referrals could provide information about a person's learning disability or autism diagnosis and/or their additional needs, including communication needs. However, access to GP records was not always possible and these records did not always include information about a person's additional needs. In addition, while hospitals had systems to flag if someone had additional needs, these were not always effective.

These gaps created the risk that staff may not recognise or be able to meet people's communication needs. This includes understanding that people with a learning disability and autistic people may communicate their distress through their actions. We heard that without this knowledge staff may not be able to recognise and make adjustments to meet their needs, such as providing quiet spaces for people who are agitated and distressed. Often, their immediate response may be to call security staff to restrain a person. In other instances, it meant that people, their family and carers had to repeat information about their needs, which staff should already have access to from care plans and other records.

Communicating with people and their carers

A key element of the [Accessible Information Standard](#) is making sure that people have access to the information they receive, and that they can understand it, as well as making sure they receive support to communicate if they need it. People with a learning disability and autistic people may also need more time to process this information.

Through our [2020 NHS adult inpatient survey](#), we heard that people experienced better care when staff explained things clearly and reassured them. Staff speaking with people as an equal also helped them to feel respected.

People who were well known to staff or a particular ward tended to have a better experience. Wards and clinics that saw many autistic people and people with a learning disability were also better at providing support. At one hospital, a support worker told us that staff on the medical ward, where a number of people with a learning disability were admitted, were willing to learn and appeared to have a better understanding of the needs of people with a learning disability.

However, people and carers also told us about poor experiences of staff not meeting their needs or where they felt communication could have been improved. For example, at one hospital a person told us that staff spoke too quickly and did not give them time to absorb and understand what they were saying.

These findings again reflect what we heard in the 2020 adult inpatient survey, where respondents described staff talking to them in a rude or negative way. People with a learning disability and autistic people also described being treated like children. As a result, people told us that they didn't feel respected.

Fiona's story

I needed surgery for my broken finger... On the day of the operation, they wouldn't let anyone stay with me... So I was pretty distressed around the idea of them being able to understand me as well as me understanding them. I went in at 7:30am like they said. I think I was first in the queue. They'd told me "don't have anything to eat or drink the night before. You can have a little bit of water with your medication." I took this too literally, as it turned out; I didn't have enough water in my system to go to the loo. I spent two hours in the waiting room trying to go to the loo. And nobody would explain why [they needed me to give a sample of urine] – they didn't tell me until the end. It was in case I was pregnant, which would be a problem for the operation. But I was like, I haven't had sex, so how can I be pregnant? It took them two hours to understand that I didn't understand why I had to provide a urine sample. It was just so irritating... communication wasn't there... If my mum or support worker had been there, they could've said "look, just wait and allow her time to allow it to just happen instead of making her try and go", it might have been easier. It happened about three hours later.

Issues around communication increased with the person's level of need. This ranged from staff not adjusting to meet a person's needs, to them not knowing how to interact with a person at all.

Another parent described the difficulty for staff in communicating with their daughter who is autistic, as well as having [global developmental delay](#) and a learning disability, and does not communicate verbally:

"...more could be done with the nursing staff ... to [help them] understand what it means having a child with special educational needs... and can't understand instructions such as 'stay still', 'stay on the bed', and 'don't lick the floor'... at times, staff almost look a bit frightened because they don't know how to approach it. Maya is also non-verbal, so at times staff have said, 'oh, should we ask her if she wants this?' And you sort of say, well Maya is non-verbal..."

There was variation in the awareness of staff about communication aids, such as picture exchange communication (PECs) and photo journeys, and how easily staff could access these.

Communication boxes contain a range of tools to help staff communicate with people. In one hospital that we visited, the contents of the boxes varied and not all the wards had them. At another hospital, we heard that staff were using their own money to stock them.

In several hospitals, not all staff knew what communication aids were available or where to find them. Some staff did not know how to use some types of communication aids, for example those that people brought in from home. In these instances, it was not clear that staff knew who would be able to help them. If staff do not have the right tools, or don't know how to use them, they will be less likely to communicate with people in the way they need. As a result, people will not be able to be involved in their care and the quality of care they receive will suffer.

Some staff spoke positively about being able to request information in an easy read format. At one hospital, staff told us that easy read literature was available online, which people could access directly or staff could do so on their behalf. At another hospital, the staff intranet provided information material about common conditions in an easy read format, along with links to useful materials from specialist organisations. The specialist learning disabilities practitioner also sometimes sent the appropriate relevant information to people in advance of their appointment.

However, in some hospitals people told us that there was a lack of easy read resources on wards. We heard this was often because of the trust's measures to address infection prevention and control. For example, one parent told us that she and others often found that when they visited their loved ones in hospital, they had not filled in the menu choice forms because they were not in an accessible format and their loved one didn't know how to fill it out.

Several hospitals told us about working with people who use services to develop accessible information. However, relying on easy read formats as an answer to meeting individual needs is not suitable for all. For some people who have a learning disability, a document of any kind does not make information more accessible. There needs to be a range of resources available to meet the needs of people with more complex communication needs.

Hospital passports and electronic flagging

[Hospital passports](#) provide important information that staff need to know about a person with a learning disability or an autistic person. This information includes details about people's likes and dislikes, communication needs, pre-existing health conditions and medication needs.

People spoke positively about how hospital passports could give staff information about their individual needs and help them to deliver person-centred care. For example, at one hospital a parent told us that her daughter's hospital passport meant that she did not have to explain so often that her daughter did not speak, which was upsetting for her. In another hospital, we heard how the use of hospital passports prompted staff to think more about how distressing it can be for some people when coming into hospital.

Across the 8 hospitals we visited, we heard that if a person did not have a hospital passport already, the hospital would suggest it or start one for them. In several hospitals, the specialist practitioner or team would help to create new passports and update existing ones.

However, hospital passports were not used consistently. Staff were sometimes not aware that a person had a hospital passport, or they did not have the time to read it. We also heard that staff would rely on families and carers to relay this information if they were present, even if this was captured in their passports.

One parent we spoke with told us her daughter had recently been given a hospital passport, which they had completed with lots of information about their daughter and how to help her when she is in hospital. While they were optimistic that the passport would work, they were still concerned about staff being too busy and not having enough time to read it.

At another hospital, carers told us that hospital passports were continually ignored. This could lead to staff missing important information about a person. For example, in one instance, a person who spoke Polish as their first language had a hospital passport that included simple phrases for staff to use written in Polish. However, because staff had not checked their hospital passport, they had not requested a Polish interpreter, and just spoke to the person in simple phrases in English.

There were also issues around the quality of hospital passports, with some either not completed correctly, being out of date or missing key information. One hospital used an electronic hospital passport scheme, but there were concerns that the information was not up-to-date as the passports were sometimes printed out on paper and revisions made on the paper copy. This was a risk to a person's care and support when their needs changed. It was also unclear which staff had access to the electronic version. For example, some staff in the emergency department were not even aware of this system.

Staff were not always clear who was responsible for completing and updating hospital passports, which increased the risk of inaccurate important information such as medicines. In some instances, staff asked a person's carer or family member for information to update the hospital passport. Staff at one hospital told us they were waiting for a person's relative to complete their hospital passport, but they were unable to because of the visiting restrictions due to the pandemic. This risked not being able to meet the person's needs.

Similarly, we heard that electronic flags on hospitals' computer systems were not always effective in helping staff to identify and support people with a learning disability and autistic people. All hospitals we visited had the option to add a flag on people's records, but this was used in different ways. In some hospitals, the flags were used generically and only noted that a person had additional needs – not specifically that they had a learning disability or were autistic. In some cases, the flag would just point staff to other records. While some hospitals had a flagging alert for people with a learning disability, these did not flag if a person was autistic.

The use of electronic flags also relied on staff having access to the computer systems, so there was the risk that some staff may not see it. For example, in one hospital we heard that not all staff had access to the electronic system and as a result relied on other staff telling them if a person had a learning disability or was autistic. Several hospitals used multiple electronic systems, which also affected the ability of staff to access this information, although we heard of some hospitals making changes to address this.

Not having access to information or sharing it with all staff – clinical and non-clinical – can have a significant impact on people who use services, as illustrated in the following story from Jessica.

Jessica's story

[During my stay in hospital] I went to the toilet one night and I overheard one of the nurses saying that they were frustrated because a side room had been allocated for me, but by the time the porters had transferred me to the ward, bed managers had placed a medical patient in there. So, then I ended up in a bay for a couple of nights, which was really not appropriate. It's not just clinical staff who need to be aware of these issues, it's bed managers as well.

We found some examples where hospitals were using electronic flagging more effectively. For example, at one hospital we were told that the flag prompts staff to assess people who have a care plan. This plan then stays with them during their stay and is available for future admissions. The flag also initiates a referral to the integrated discharge team. At another hospital, when people were being discharged staff would add details about what had worked well for a person during their stay, which was helpful if they return to hospital. However, this was not done routinely.

The [NHS Long Term Plan](#) set out the commitment that by 2023/24, there will be a new 'digital flag' available in patient records to make sure that staff know if a person has a learning disability or is autistic. At the time of writing this report, NHS England and NHS Improvement are developing the final '[digital reasonable adjustment flags](#)'. While this is a welcome improvement, the findings of our review have highlighted the limitations around electronic flagging. As a result, it is important that it is seen as one of a number of tools, and not a solution, for identifying and meeting the needs of people with a learning disability and autistic people.

Care and treatment in hospital

Key message: People have a right to expect to be fully involved in their care and treatment. In many cases this is still not happening because there is not enough listening, communication and involvement. Providers need to make sure that staff have the time and skills listen to people and their families so they understand and can meet people's individual needs.

Impact of staff attitudes and behaviour

Where people said they had better experiences of care, staff were caring and responsive, and took the time to listen and engage with them. However, this wasn't always the case and people's experiences of care and treatment when in hospital varied greatly.

People and their friends, family and carers who had positive experiences described hospital staff as 'kind', 'helpful', 'thoughtful' and going 'above and beyond'. Positive experiences like this left people feeling respected and treated like individuals.

At one hospital, a person with a learning disability told us that staff encouraged him to maintain his independence by encouraging him to walk using a frame. At another hospital, a carer described the hospital staff as 'brilliant', particularly the specialist nurse who had made sure they had a carer's pass and that their relative had a hospital passport. In response they said they had given staff "a hero card with Heroes chocolates for the heroes".

These experiences echoed the responses we received through the 2020 adult inpatient survey, which highlighted that positive staff attitudes could be associated with good standards of care.

Equally, a negative staff attitude was associated with poorer standards of care. For example, at one hospital, we witnessed a person's parent becoming extremely distressed by the behaviour of the doctors in the palliative care team. The person had lived in the same care setting for 30 years, but the doctors were discussing discharging them to a hospice, which was an unfamiliar setting. None of the doctors tried to talk with the person directly and did not notice that his mum was distressed by the conversation.

While all the hospitals we visited had pockets of good and poor practice, none put people with a learning disability and autistic people consistently at the centre of their care experience.

Assessing and meeting people's needs

The hospitals we visited used various ways to identify people's needs, including medical and general care needs, as well as any required reasonable adjustments. For example, they used different ways to assess pain.

However, not all staff were good at assessing pain for people who did not communicate verbally or express pain in usual ways. For example, the mother of a person with a learning disability and suspected autism told us that staff did not understand her daughter's needs as she cannot indicate which bit of her hurts. She said her late husband said 'vets do a better job' in relation to people who cannot point and explain how they are feeling.

Jessica's story

When nurses do their NEWS (National Early Warning Score) chart, which measures things like blood pressure, pulse and temperature, one of the questions they're meant to ask on that chart is about pain levels. I do not modulate and express pain in a neuro-typical way; when I'm in pain I don't cry or scream, I just go quieter and quieter and stiller and stiller.

I also cannot describe pain on a 0 to 10 numerical scale, my brain just doesn't compute that. However, I can rate pain in colours. I have my own colour charts in my hospital pack, which goes from green to signify being perfectly comfortable, through yellow, orange then red and up to black which is absolute agony. Even though I can't do a number, I can point to somewhere on the colour chart and the nurses can easily translate that into a number for me.

Sometimes the nurses won't ask about my pain at all or sometimes when they do ask and I try to show on my colour chart they say, "oh no, just tell me the number". But it's more worrying when they see me sat there quiet and still and think I'm fine and relaxed. Better practice would be staff [being aware] that if I'm quiet and still there's something wrong. When I'm fine I just do not sit still! But by just not asking those questions, they make assumptions.

Other systems to identify needs included staff carrying out assessments and reviews, observing people, speaking with people or their families and carers, and using written information such as GP notes, hospital passports and electronic records ([see the section on communication](#)).

Families told us that even when hospitals were aware of people's individual needs, these were not always met.

We heard specifically about problems getting hold of the right equipment, such as hoists and compatible slings. This could have a negative impact on people and cause them distress. For example, one person was allocated a bed on a ward, but staff were unable to get him into the bed because no hoist was available. The person was so uncomfortable he kept trying to get into the bed and could not understand why he could not lie down. He was extremely distressed, which he showed by biting his hand, and was in tears by the time staff were able to put him in the bed.

Where we saw good practice, we found evidence that staff had made reasonable adjustments to the hospital environment, as well as sensory and therapeutic interventions, to put people at the centre of their care. For example, in one hospital the paediatric ward would try to accommodate autistic children and children with a learning disability in a quieter bay with direct access to the garden when possible to offer a more familiar environment.

Most staff recognised that quieter environments, such as single rooms, could be more calming for people and make being in hospital less distressing. Single rooms also gave people more privacy and could be tailored to meet their needs, for example by adjusting lighting or allowing them to have personal items. For example, in one instance, a person with a learning disability was being violent towards staff. They thought this could be due to overstimulation in a 6 bay area and because activities were not tailored to their needs. In response, they moved the person to a side room and involved a play therapist.

Staff told us that they would try to place people with a learning disability and autistic people in a single room or a smaller unit. However, we heard that this was not always possible because of limited space or high demand.

As part of our review, we spoke with the mother of a young person with a learning disability, who was also thought to be autistic. The mum explained how, during one visit to the hospital, she had to hold her daughter for 6 hours because there was no safe bed or chair for her to use. Because of this, the consultant agreed for her child to go home to recover from a prolonged seizure, but this was not ideal as it meant there would be no medical support for them. However, not having appropriate equipment in hospital meant this was the lesser of the two unfavourable situations.

We heard that the hospital environment itself could be traumatic for people and staff need to be mindful of this. Furthermore, traumatic experiences in hospital can cause future visits to be more distressing than they may otherwise be. Having to stay in these busy and noisy environments could cause people distress, and lead to issues with their sleep.

In some hospitals, staff told us that they aimed to create more side rooms or quiet areas during refurbishments. However, not all people preferred to be in a private or quiet area. For example, one autistic person who had a learning disability was allowed to walk around and chat to other patients, which helped them to avoid stress. In another instance, a person was in a single room as he needed aerosol generating procedures, but he was moved as soon as this was completed as he was afraid of being on his own.

There were also concerns about the isolating effects of single rooms. This includes the risk that staff may not be able to keep people in their line of sight. In one instance, the family of a person with a learning disability told us they were happy that their relative was not put in a side room as they thought "he would be forgotten if he was placed in one".

During our visits, we heard examples of where staff had taken steps to address people's sensory needs. This included using items like headphones, fiddle toys, music and scent diffusers to calm people and keep them comfortable.

Therapeutic interventions were available in some instances, especially for children. For example, we heard that play therapists used sensory materials and distraction techniques to keep children and young people calm during procedures or interventions.

We also heard other examples of how staff helped people with sensory issues when having clinical tests and procedures. This included dressing a person in the necessary gowns and stockings after being sedated, working with people to de-sensitise them to pieces of equipment, removing surgical drains and tubes before waking a person up from sedation, and minimising the use of a ventilation mask. We also heard of staff taking different approaches such as helping the person understand what would happen, slowly introducing new things, demonstrating procedures on themselves first, and giving people different options.

Some hospitals had sensory rooms and children's play areas to meet people's needs. For example, at one hospital, staff used the sensory room to do a blood test for a person with a learning disability. The clinician taking blood asked the person what music they would like to hear during the appointment, and when we met the person they were tapping their foot to music. Their two carers were impressed with how smoothly the appointment had gone as they told us the person usually found hospital appointments very distressing.

The importance of listening

Staff were not always well informed or lacked the skills and knowledge about how to manage all the needs of people with a learning disability and autistic people. Families told us that staff tended to focus on a person's diagnosis and treatment and did not consider everyday tasks such as eating, drinking, going to the toilet, positioning and regular medicines, which can be complex and time-critical for some people.

At one hospital, the parent of a person with a profound learning disability and physical disabilities told us how staff in the emergency department took no account of their relative's needs in relation to eating, drinking and going to the toilet. Staff assumed food and drink could be consumed quickly and easily, and failed to recognise that a trip to the toilet could take 30 minutes and risked the person being absent when called. In another instance, a mother told us that she had to explain her child's needs every time they were moved to another ward, which caused significant stress and anxiety.

Families also told us that they were worried about the safety of other patients and how hospitals meet the needs of people without a good support network. They told us that they felt their relatives' needs were only met because they communicated them and advocated for them. For example, one mother told us how staff routinely offered food and drink to her child who had been tube fed from a very young age. She told us that if she had not been there to explain, he would not have been able to tell staff himself.

Importance of observations

A care worker told us about the 29-year-old man she was supporting who had complex needs, including a learning disability and severe epilepsy. On one of our visits, the care worker told us that his care home was unable to support him 24/7 in hospital, which left her concerned about the quality of his care. She said that the ward he was on was very short staffed and she felt staff were out of their depth.

The care worker told us that the person she was supporting could not easily communicate, and had to be observed to understand how he was feeling. However, when she had arrived at the hospital, he was sweating a lot and nobody had noticed. The care worker was also not sure he had been given any intravenous (IV) fluids overnight as it was not recorded in his medical notes.

In addition, we heard the person was meant to be fed through his tube at 6.30am, but he had still not had it by the time the care worker arrived at 11.30am. All these factors could affect his seizures. She also told us that staff did not seem to understand how to clean and maintain his pump (part of the tube feeding system) and had seen them “flummoxed” by it.

We found an over-reliance on people’s family and carers to ensure that their individual needs, such as keeping clean, were met. Some hospitals had tried to address this, for example by introducing a carers’ policy that clearly defined responsibilities for carers and for nurses. This included “not expecting the carer to carry out nursing tasks, such as washing and dressing, unless agreed”.

Reliance on families and carers was often linked to the availability of staff. For example, in one hospital, a nurse told us that because of staff shortages they could not always provide one-to-one care for people with a learning disability or autistic people, instead having to rely on carers being present or rely on staff to check the person frequently. This reliance on families and carers was further compounded by complexities around how people’s care was funded when they went to hospital.

In some instances, we heard that funding for paid carer workers stopped when the person was admitted to hospital. In one hospital, staff told us that paid carer worker who wanted to continue to provide support were not able to because of a lack of funding. In another hospital, staff bemoaned the absence of care workers for particular patients. Issues around funding were not always in the trust’s control. However, one hospital had arrangements to part-fund care providers so that patients were supported by staff who were familiar to them.

When people had negative experiences, they were often caused by staff not listening to them and/or their families and carers. As illustrated by Maya's story, this could have potentially serious consequences.

Maya's story

My daughter, Maya, has Dravet syndrome, which is associated with severe epilepsy. She has a very clear emergency care plan that details the protocol staff must follow if she has a seizure. This includes that she cannot have phenytoin as it will prolong her seizure. So, whenever we're in an emergency situation in hospital, I'm shouting "no phenytoin" and I'm always listened to.

However, there was one time recently when Maya's seizure had been going on for 45 minutes, so they were getting ready to intubate her. It's always a bit panicked, with a lot going on, but this time the doctor ignored me and said, "Let's draw up the phenytoin". So, I repeated "no phenytoin" – she just looked at me and repeated, "Let's draw up phenytoin", and I literally put my hand over Maya's cannula and said, "I don't have time to explain this right now. Can you just pretend that she's allergic and then we'll talk about it afterwards. It's on her care plan." A nurse who knows Maya very well then stepped in and said to the team that they needed to use phenobarbital next.

After the seizure, I asked another doctor what would have happened if Maya had had phenytoin and they said the seizure just wouldn't have stopped. Doctors' training needs to be clear that if there is a care plan they need to read it.

Involvement in care planning and discharge

There was variation in how well people, their families and carers were involved in making decisions about their care. We saw some good examples where staff engaged well with people and supported them to make choices about treatment, medicines and food. However, in a few trusts we found that people were not always involved in day-to-day decisions about their care.

Where staff engaged people well, we heard that they adapted their language and made sure that people understood what would happen before going ahead with a decision or procedure. Radiographers at one hospital told us about the different approaches they would take. This included taking the time to introduce people to X-ray machines, letting people explore the machines, and staff drinking barium to show the person it is okay or adding chocolate milkshake mix to it.

Staff generally understood that consent and decision making should be underpinned by mental capacity assessments where appropriate. For example, at one hospital a woman with a learning disability and epilepsy needed a specific medicine to control her epilepsy that required her not to become pregnant as it would harm the foetus. She was assessed to have capacity if information was pitched at the right level for her to understand. Staff used a visual storyboard to explain that the epilepsy medicine she was taking could harm a baby if she were to become pregnant, and provide information about options for contraceptives. She chose to have a contraceptive implant and was then encouraged to mark the arm where she wanted the implant to be embedded.

However, we found that mental capacity assessments were not always carried out. For example, an autistic person with a learning disability was not assessed because staff assumed that they understood with the help of their family.

Involving people in discharge planning needed to be improved. For example, in some instances staff did not give enough information to people about when they would be discharged and while they were being discharged. People and their family or carers told us that they did not always have enough information or understanding about what would happen after discharge, as they still had questions about:

- self-care
- medicines
- managing pain
- tube feeding
- progress after their operation.

This meant there was a risk that people were discharged without discussing all the required considerations.

Some carers told us they felt that hospitals wanted to discharge people too quickly. For example, at one hospital a person with a learning disability who was also autistic told us that they and their family had felt rushed as the hospital had "insisted on discharge" before they felt ready to go home. The family took them back to the emergency department within a week as they were in pain.

This view is supported by the findings of our 2020 adult inpatient survey, which showed that respondents felt they did not receive enough information when they went home. People told us that there was a lack of information about medicines, exercise and medical equipment. There were also issues raised about incorrect information on discharge letters and not being told when they were expected to go home. They also told us about being discharged before they felt confident to go home and look after themselves.

Managing medicines

On admission to hospital, people's medicines should be reviewed to make sure that they are appropriate and are meeting their needs. This review should also include understanding people's routine for taking medicines. However, the quality of medicines reviews varied, and we found that pharmacy staff were not always aware that a person had a learning disability or was autistic.

In most cases, medicines were tailored to people's individual's needs and preferences, but people told us that this doesn't always happen. This was also supported by the findings from our 2020 adult inpatient survey in which people felt that staff often did not consider interactions between medicines and food, other medicines and existing conditions. This risks people being more likely to suffer the consequences of interactions between medicines, which is avoidable.

Jessica's story

When you have multiple health problems, you may see 6, 7 or 8 consultants each with their own speciality, all writing letters recommending a specific medicine or treatment plan. But it's the GP who has to weigh up, "Consultant A has told me this, Consultant B has told me that these two drugs interact, or cause these side effects, we need to keep safety first". My GP has known me since primary school and has been my named doctor for 11 years. He may not be a specialist but he's known me for years and has dealt with the interactions between the different things. He's weighed up the different medications and phoned up to change the dose. But many hospital consultants don't want to listen to what he has to say about working with me in a more holistic way...

People were generally able to self-administer their medicines if they had been assessed as able to do this, but this was not always recorded. In some cases, this was because electronic prescribing systems or trusts' policies did not allow medicines administered by families and carers to be recorded.

Poor records management and problems with getting the right medicines meant that not everyone either received the medicines they needed or did not receive them at the right time. Again, this was supported by the findings of our 2020 adult inpatient survey where people told us that staff sometimes delayed, or denied, access to their medicines from home. This means that these people could be at risk of having a poorer outcome because they are unable to take their regular medicines.

Having a routine for taking medicines was particularly important to autistic people, and some autistic people told us that they had negative experiences when they had not received their medicines at the usual times.

Jessica's story

I personally prefer to self-administer my medication. Routine is really important to me and I take them at the exact same time every day. I know what I need to take and when. I understand that I can't do intravenous and controlled drugs, but I'm perfectly capable of doing everything else.

On one admission to hospital, I asked for a self-administer form to sign out and to keep my meds with me, they said "you have a learning disability, of course you can't self-administer". I have autism, I don't have a learning disability; even if I did have a learning disability, that wouldn't necessarily mean I am not capable of administering my own meds safely. It has to be assessed on an individual basis.

Not taking my medicine could have an impact on my mental health and also on my body; I have some meds that have to be taken at exactly 12-hour intervals. If there's an emergency on the ward, I could be delayed by three hours in taking my meds and then my body's got to deal with that, never mind the emotional stress of that.

As part of our visits, we also checked what systems hospitals had for the use of sedation, rapid tranquilisation and chemical restraint ([see also the section on workforce and training](#)).

People with a learning disability and autistic people are more likely to be prescribed a psychotropic medicine. Psychotropic medicines affect how the brain works and include medicines for psychosis, depression, anxiety, sleep problems and epilepsy. Sometimes they are also given to people because staff do not understand that they are trying to communicate a need. The NHS is committed to reducing the use of these medicines through the [STOMP](#) (stopping over medication of people with a learning disability, autism or both) and [STAMP](#) (supporting treatment and appropriate medication in paediatrics) projects.

In general, hospitals had processes or policies for using these medicines to restrain or control behaviour that staff found challenging, although there was little evidence how well these worked in practice. The rapid tranquillisation policy at one hospital had a learning disability section, which had been developed in collaboration with a pharmacist with specialist knowledge of learning disabilities and mental health.

Although some staff said other options would be considered first, we found examples where people had been given sedatives or anti-psychotic medicines to calm them. For example, at one trust we found a person was prescribed a medicine to calm or sedate them if other interventions did not work.

Most hospitals had systems that triggered a review where medicines were used to restrain a person. For example, one hospital's electronic prescribing system had a built-in check for reviewing sedatives.

Other equality characteristics and quality of care

Key message: People have a right to expect care and treatment that meets all their needs. Equality characteristics, such as age, race and sexual orientation, risked being overshadowed by a person's learning disability or autism because staff lacked knowledge and understanding about inequalities. Providers need to ensure that staff have appropriate training and knowledge so they can meet all of a person's individual needs.

Protected equality characteristics

To respect individuality, people need to be cared for and treated with an approach that meets their individual needs. Not doing so carries a risk that these needs are not met.

Protected equality characteristics are personal characteristics that are protected from discrimination under the Equality Act 2010. There are 9 protected characteristics, however one (marriage and civil partnerships) only relates to equality in employment. The other eight also relate to equality when providing services, including health services.

- age
- disability
- gender reassignment
- pregnancy and maternity
- race
- religion or belief
- sex
- sexual orientation.

As part of our review, we wanted to understand the experiences of people with a learning disability and autistic people in relation to their protected equality characteristics. We looked at whether and how hospitals were meeting their needs to reduce the risk of them experiencing health inequalities.

We struggled to identify how staff were making sure they could meet every individual need for a person. While most staff we spoke with were aware of the need to provide equal care, they often struggled to describe what this meant in practice or how they would approach this.

Some hospitals we visited told us how they were supporting people with a learning disability and/or autistic people who identified as lesbian, gay, bisexual or transgender (LGBT). For example, in a couple of instances we heard that staff had asked an individual who identified as LGBT about their preferred names and pronouns, and these preferences were recorded on their notes or above the bed. However, at one hospital, a person told us that staff were not always using their preferred name and pronoun even when this was clearly noted in multiple places during their stay. Mistakes with preferred names and pronouns could lead to some people feeling disrespected.

We also heard about difficulties with interpreting services. Staff told us it could be difficult to get this support at the time of important conversations. This meant that they often relied on family members to interpret. For example, one parent whose son has complex needs described the challenge of accessing a British Sign Language (BSL) interpreter across hospitals, even for planned appointments, and having to make a 'fuss' before each appointment to secure one. They told us how having to take on the interpreter role themselves was challenging as it was difficult to sign effectively while listening carefully and asking questions to staff about his care.

Staff in some hospitals told us about their plans to improve care for autistic people and people with a learning disability to include other protected characteristics. This included developing autism strategies and inequalities strategies, and improving data collections to improve how they identify any unintended impacts on people with protected characteristics.

One trust had taken into consideration and supported a person's autism and their mental health condition to make sure all their needs were met. In this instance, doctors recognised that the person was not just struggling with food but had an eating disorder. In response, they were able to support the person by explaining that her eating disorder was harming her.

However, at the time of our visits none of the trusts we visited had a consistent or strategic approach to identifying people's protected characteristics. We heard how information about a person's protected characteristics, such as their religion or ethnicity, may be recorded on hospital passports and electronic records. Some staff also told us they would try to get to know people as quickly as possible so they could meet their needs. For example, one person told us about the positive impact of staff getting to know their loved one:

"The nurse at first admission was with Mo for a placement previously [and] fundamentally had an understanding of how Mo's needs relate to each other; that means I had a champion in hospital who did the right thing for Mo and would do the same for other people. Was only that day, but it made a positive [difference]..."

However, there was the risk that staff may not share this knowledge with others. This meant reasonable adjustments for people with a learning disability or autistic people may not take account of their additional characteristics because they weren't known.

Equality of care and reasonable adjustments

We saw some positive examples of how staff recognised the different ways that people may signal that they have additional needs, for example the use of visual identifiers like sunflowers lanyards. One hospital highlighted when reasonable adjustments were required by adding stickers to a person's notes and on the boards above their bed to highlight that they had additional needs.

While these visual identifiers were helpful, not everybody with a learning disability or who is autistic will have a formal diagnosis or be happy to share information about their additional needs. For example, one person told us how before being diagnosed as autistic in her 40s, she had been ignored and experienced significant health issues because she doesn't give the 'right facial clues' that go with symptoms. Another person told us:

"Being autistic is a disadvantage when using services, although a couple of times it has been useful. For example, once I was in a waiting room and asked the receptionist if she could turn the radio off because I was autistic and was finding it unbearable – that felt like a good time to say it. But more often than not I don't tell people I'm autistic unless they know from my medical records or I feel it's a safe situation to do so."

Even when staff are aware that a person has a learning disability or is autistic, we found they may not understand what these terms mean. For example, some staff we spoke with used the term 'people with a learning disability' to mean both people with a learning disability and autistic people.

Jessica's story

On the wards I'd already been on, they already knew I was autistic and I reiterated that anyway. Plus, I had my hospital passport with me. There was one night shift where the healthcare assistant said something to me which I felt really offended by, and so I acted defensively. She reacted by scoffing and saying that she was "only being sarcastic". And I said "oh sorry. I'm autistic and I don't always understand people's sense of humour, especially sarcasm." And then she went off saying "everyone's autistic nowadays. Just because you have a hospital passport doesn't mean you should get special treatment". She was actually shouting this to me, literally.

Additional physical and/or medical needs

The impact of this lack of understanding was again heightened when people had physical and medical needs in addition to their learning disability or autism. Across a number of trusts we heard that people with a learning disability who had swallowing difficulties experienced delays in receiving the soft food that they needed. At one hospital, the sister of a person with a learning disability told us that her brother had lost weight because his minced and moist meal was not available for the first two days of each of his four admissions.

We also found that people's epilepsy was not well-supported in hospital, despite estimates that one in five people with a learning disability will have epilepsy. For example, at one trust, staff did not understand the risk of epilepsy for a person in their care. They kept the curtain closed around the person's bed, even though the learning disability team had asked for it to be kept open, so staff could monitor them. The person's mother had raised their epilepsy risk with staff, but they did not listen to her, and curtains were kept closed.

In some cases, people's medical issues could be overshadowed by their learning disability or autism. At one hospital, we found that a person's learning disability or autism seemed to 'trump' other characteristics and was used to define their identity. As a result, there's a risk that staff could ignore or misinterpret people's medical needs.

For example, one person told us that they had a kidney problem and staff were always 'getting at' them because they weren't drinking enough. The person had told the staff that they wanted coffee as they don't like water or fizzy drinks, but staff told them they were too busy to get it for them. The person told us they were frustrated because they knew their kidney wasn't working properly because they weren't drinking enough, but no one would get them a drink they liked.

We heard that the services that regularly saw a large number of autistic people and people with a learning disability were better at considering all the needs of an individual person, and not just focusing on their learning disability or autism. This could mean that these staff developed skills that enabled them to meet all the person's needs, leading to better experiences.

Workforce skills and development

Key message: Specialist practitioners and teams improve people's experiences of care but they cannot have sole responsibility for this. People have a right to expect the same quality of care from all members of staff, not just specialist practitioners or teams. Providers must make sure that all staff have up-to-date training and the right skills to care for people with a learning disability and autistic people.

Skills, knowledge and understanding of staff

Having the skills, knowledge and understanding of people with a learning disability and autistic people had a direct influence on their experience of care. People consistently told us that they had better experiences of care when they were cared for by staff with the right skills and experience. For example, one parent told us that their experience of care started to improve once the specialist team was involved. They described how the specialist made sure a hospital passport was completed and they allocated a single room.

These members of staff, often specialist practitioners, were described as very knowledgeable and supportive, and were able to ensure appropriate care for people with a learning disability or autistic people.

Outside of the specialist teams, people's experience of care depended on the knowledge, skills and experience of individual members of staff. For example, those who worked regularly with people with a learning disability or autistic people, or who had personal experience with family members, were often exceptionally skilled in working in this area.

One parent described the impact of where staff had recognised her daughter's needs and amended her care:

"Maya had [dental] treatment in hospital rather than at the dentist. The staff have been fabulous. They tell Maya everything that's going on, let her feel all the instruments. They are very well arranged for treating people like Maya and it makes a huge difference in managing anxiety. Completely different from the care and treatment at the other hospital who didn't have an understanding of Maya's issues."

While we saw evidence of staff with experience supporting colleagues to develop their skills and knowledge, this was not consistent and we felt their expertise was an underused resource.

Availability and access to specialist teams

Specialist practitioners or teams were usually only available on weekdays during office hours (9am to 5pm), and most covered both children and adults. One hospital was looking to expand the service to 7 days a week, but in another hospital the future of these teams was uncertain as specialist staff were on fixed-term contracts.

In half of the hospitals we visited, a single member of staff was responsible for providing specialist expertise and advice. Other hospitals had specialist teams that ranged in size from 2 to 10 people. Where there were specialist individuals or teams, they were usually referred to as a learning disability liaison nurse or a learning disability team, even if their remit was wider than this.

In a few trusts, the remit of the learning disability liaison practitioner or team only focused on adults. Staff at one hospital told us that they did not consider having no similar dedicated team for children to be negatively affecting the quality of care. However, they told us that this is an area for improvement in the context of a rising number of children with additional support needs. Staff at another hospital told us they had recently recruited someone who would focus on supporting children.

One hospital had taken a more positive, holistic approach to caring for people with a learning disability and autistic people. While they didn't have any specialist resource, they had created an environment that promoted the responsibility of all staff to make reasonable adjustments. They also had clear processes and plans that guided staff to take the correct actions.

Apart from this hospital, we found that the majority of hospital staff relied heavily on specialist practitioners and teams. We felt that often, for example if a person was admitted at the weekend, staff would wait for the specialist practitioner or team to make reasonable adjustments or changes to their care, which could have an impact on their wellbeing and health outcomes.

All specialists told us they were in extremely high demand. As a result, they were not always able to be involved in the care of all people with a learning disability or autistic people who came into hospital. This could mean that people with multiple or higher needs received support, while people who were seen as 'less complex', particularly autistic people, did not.

Training and information sharing

Specialist teams were also well placed to provide specific training on learning disability and autism. We heard examples of teams providing bespoke training for specific wards or units, as well as specific groups of staff, which was well received.

We also found examples of specialist teams playing a proactive part in learning from incidents. In one example, the specialist practitioner identified a potential risk of over-medication for one person. In response, they acted as an advocate for the person at risk, engaging with medical staff about their concerns and producing an information guide to help staff make decisions when using this medicine. This led to reducing the use of the medicine and therefore a reduced risk to the person.

However, we could not be assured that lessons learned from either positive or negative experiences were systematically shared across all staff and across all sites at the hospitals we visited. Often, we heard of generalised ways of disseminating information. This included, for example, through screen savers, newsletters, videos, frequently asked questions on the intranet, and posters. As a result, there was little learning relating to people with a learning disability and autistic people.

Improving the understanding of learning disability and autism among health and social care staff is crucial in reducing health inequalities including avoidable harm. However, we were not assured that current training courses gave staff the skills, knowledge, or confidence to care for these groups of people.

Often, we heard that staff received training about how to support people with a learning disability or autistic people as part of their induction. But across nearly all hospitals visited, we found a lack of ongoing training and skills development in this area. In some instances, we heard that staff had not received any specific training, particularly around autism. Autistic people told us that not all staff recognised autism or understood the communication difficulties associated with it.

This was supported by feedback from our 2020 adult inpatient survey, which highlighted the impact of this lack of training, particularly for autistic people:

“... I would... like to educate the nursing staff that just because I am autistic does NOT automatically mean that I have a learning disability too and need easy read documents or be spoken down to. It was not from every member of staff but I do find this ignorance offensive.”

The lack of appropriate training also created the risk that staff may not be aware of appropriate interventions and de-escalation techniques to use when people became agitated, and could lead to the use of restraint. For example, at one hospital a person with a learning disability was restrained after being admitted to hospital at the weekend as the specialist team was not working. We heard that was not repeated once the specialist team became involved the following week.

Access to training for staff had also been affected by the pandemic. We were told the reasons for this included that staff were either sometimes unable to leave the ward because of staff shortages, training had moved online, or some training had been cancelled completely due to infection prevention and control, and social distancing. In some cases, training had still not restarted.

Jessica's view on training

Nurses at one hospital have told me that when they put on staff training – for nurses, healthcare assistants, doctors or any member of the healthcare teams outside of the Vulnerabilities Team – the attendance is really quite low, which is disheartening. Some people will be on shifts and can't make it. But if they're offering the training and yet they're not getting the take-up, then how are staff going to improve? It concerns me because I'm usually articulate and when I'm really stressed out or in pain I can usually still write things down, or I can type using my iPad. But if it's still a struggle for me, then what about someone who's non-verbal or communicates through Talking Mats? If nurses struggle to understand me – who is articulate even if I'm not always very verbal – what about those other people?

Staff told us that current mandatory or e-learning packages were not providing the appropriate skills that staff needed and that they wanted more training. Staff at one hospital suggested practical training would be beneficial. Suggestions included training around how a receptionist could ask someone if they had support needs, and how a nurse could prepare someone to have a cannula inserted if they do not like to be touched.

From 1 July 2022, a [new legal requirement introduced by the Health and Care Act 2022](#) requires all CQC registered providers to ensure their staff receive learning disability and autism training at a level appropriate to their role. This applies to all settings, including acute hospitals, and providers need to consider the training needs of staff who deliver care directly as well as administrative staff, for example reception and call-handlers.

To support this new legislative requirement, the government will be rolling out the [Oliver McGowan training package](#). Co-designed by autistic people, people with a learning disability, family, carers and subject matter experts, this training is intended to ensure that health and social care staff have the skills and knowledge to provide safe, compassionate, and informed care.

Conclusion

People with a learning disability and autistic people are still not being given the quality of care and treatment they have a right to expect when they go to hospital. It is clear from our findings and other multiple studies published previously that, nearly 6 years after Oliver McGowan's death, change and improvement is too slow. As well as being a key equality issue, this is a critical patient safety issue.

Through our review, we have seen pockets of excellence and of great people doing great things. However, we have continued to find that staff often lack the skills, knowledge and understanding to make sure they can provide people with the individualised care and treatment they need. Combined with a lack of effective systems for identifying people, particularly autistic people who do not have a learning disability, this means that hospitals are not always aware of an individual's needs, and so are unable to put in place the reasonable adjustments people have a right to expect. The impact of this cannot be underestimated.

Being in hospital and the noisy, bright environment, can in itself be a traumatic experience for people with a learning disability and autistic people. Some may communicate this trauma and distress through their behaviour. But without the right skills and knowledge, staff may not understand this or how to meet their needs. This can escalate into situations that staff are unable to manage, in turn leading to people being restrained and compounding their trauma.

To reduce health inequalities, it is vital to improve the understanding of learning disability and autism among health and social care staff. Too often, this lack of skills and knowledge means it is down to families and carers to ensure their loved ones' needs are met. Families and carers should not be used to absorb the impact of organisational challenges – they should be free to be families, friends and allies of people with a learning disability and autistic people, without having to shoulder additional responsibilities.

We know from the people we spoke with who have lived experience, that the factors needed to give people a positive care experience are not especially complex. Listening, taking time to understand people's needs and communicating with them in a way they can engage with can all help people feel like partners in their care. But it is not just about improving the skills and knowledge of individual members of staff.

Time and again, we found that there was no joined-up or strategic approach to making sure that people's needs were met, both at a hospital and system-wide level. While leadership or oversight was not a focus of this report, the lack of a strategic approach to care may indicate that this is an issue that needs to be explored further.

People need to be at the heart of these conversations. There needs to be meaningful engagement with people with a learning disability and autistic people at a local level to understand their experiences of acute care, and what improvements need to be made. Integrated care boards will have a key role in facilitating this engagement.

We heard isolated examples of how hospitals had worked with people with a learning disability and autistic people to improve services, but we did not see evidence that their involvement featured prominently or regularly. Hospitals are often missing opportunities to capture the expertise of people who use services to drive improvements. Opportunities to learn from both positive and negative experiences need be identified clearly and acted on to drive improvement.

This review has also shone a light on what we as an organisation need to do better. It is clear that we have not always been listening as well as we could to the voices of people who use services. We are already using the findings of this review in developing our new single assessment framework, to ensure that we will be asking the right questions to get to the heart of people's experiences and make sure that much-needed improvements are accelerated.

Print this document

© Care Quality Commission 2022