

Who I am Matters – CQC report into the experiences of being in hospital for people with a learning disability and autistic people

The Care Quality Commission (CQC) has published a report today, *Who I am matters*, which assesses the experience of being in an acute hospital for people with a learning disability and autistic people. A summary of the key findings from the report is outlined below. If you have any questions about this briefing, please contact senior policy advisor Ella Fuller (ella.fuller@nhsproviders.org).

Key points

- CQC found that people with a learning disability and autistic people are often not being given the quality of care and treatment they have a right to expect when they go to hospital.
- Specific challenges include hospitals lacking effective systems for identifying people, particularly autistic people who do not have a learning disability. This means 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 regulator also highlighted the negative impact of hospital environments, and staff lacking the skills, knowledge and understanding to provide people with the individualised care and treatment they need. CQC conclude 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.
- Further common themes highlighted throughout the report include an over reliance on families to ensure people got the right care and support, people not always being fully involved in their care, and not always being communicated with in a way that met their individual needs.
- The regulator did see "pockets of excellence and of great people doing great things" and the report sets out a range of examples of good practice from the eight hospitals it visited for other trusts to learn from.
- CQC stress that a joined-up and strategic approach to making sure that people's needs are met, both at a hospital and system-wide level, is needed. The regulator concludes that the lack of a strategic approach to care suggests that leadership and oversight need to be explored further.

Background

CQC has undertaken a review of how acute hospitals support people with a learning disability and autistic people, and their experiences of physical health care in hospitals. This was one of several recommendations made following a multi-agency review into the death of [Oliver McGowan](#), which highlighted failures in his care, that his death was potentially avoidable, and that what happened to Oliver could happen to people in other services.

During February and March 2022, CQC collected evidence of people's experiences from eight hospital trusts. CQC intends for this review to help start a conversation about the quality of care in acute hospitals, and contribute to the wider conversation around care for people with a learning disability and autistic people as raised in its report [Out of sight: who cares?](#) Our briefing of that report can [be found here](#) and progress on the report's recommendations can be found [here](#).

CQC states that this latest review has shone a light on what it as an organisation needs to do better. CQC states it is using the findings of this review to inform the development of its new single assessment framework, to ensure that it will be asking the right questions to get to the heart of people's experiences and make sure much-needed improvements are accelerated.

Access to care

Barriers to accessing care

Experience of accessing care varied both between hospitals and within the same hospital. People had positive experiences when the right adjustments were made at the right time to enable them to access the right care. Staff in a couple of hospitals also worked with people to make departmental signs more accessible: signs were placed closer together and wording was changed, for example describing haematology services as 'bloods'.

CQC found that people's experiences were unacceptably difficult when adjustments were not made and they were left feeling ignored and not respected. CQC found people could face issues from the first point of contact. For example appointment letters were not always written in accessible formats and people could struggle with telephone and online forms to book appointments.

The staff people met on arrival also had an influence on their experiences of accessing care. Experiences were negative where reception staff were not routinely made aware of adjustments a

person may need and staff did not receive information that would help them interact with a person in a way that met their needs.

Meeting people's needs: reasonable adjustments

Health and social care providers have a legal responsibility to make reasonable changes to meet people's needs. Some good examples and efforts to achieve this outlined in the report include:

- **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.
- **Tailored appointments** – people were offered longer appointments and multiple procedures were carried out at the same time to reduce the number of hospital visits for people. 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, while others carried out assessments and consultations in people's own cars.
- **Adaptations by staff to minimise distress** – CQC found staff working to reduce change that would be unsettling or distressing, for example minimising the number of different members of staff who needed to see a person, or thinking innovatively about how different types of anaesthetic could be used.

However, CQC found reasonable adjustments were not applied consistently, and that people, their families and carers experienced varied levels of support and adjustments. The report highlights the various impacts of this included diagnostic tests not being carried out as they should have been, and people not being seen quickly enough. This could lead to poor experiences of care, sub-optimal care and patient safety risks.

The report highlights that previous poor experiences may put autistic people off seeking help sooner, and therefore present to services more unwell and in more distress. CQC also highlight that staff should be aware that when they're unwell, an autistic person may find it difficult to describe their pain or symptoms, or may communicate this in a different way to a non-autistic person. People and staff told CQC that identifying and meeting their needs could be more challenging when care was unplanned.

Specialist skills and knowledge

Most hospitals visited by CQC had specialist staff who could support people with a learning disability and autistic people while in hospital. People had better experiences of care when specialist teams

were involved as they made reasonable adjustments, ensured people's needs were met and supported non-specialist staff. They also reviewed people's needs and shared this information across teams and wards.

CQC also found individual members of staff who have personal experience of interacting with people with a learning disability and autistic people were exceptionally skilled at looking after this group of individuals' needs and were passionate about making a difference. However, most of the hospitals CQC visited did not have a joined-up way of identifying these staff members and using their valuable skills and experience.

CQC also found that people did not always know that specialist support was available or how to get in touch with the specialist practitioner or team. Additionally, issues around staffing and availability made accessing specialist support more difficult: heavy workloads meant staff were unable to be involved in the care of all individuals. Specialist staff in one hospital described their frustration at only being able to offer a service between 9am and 5pm.

CQC concludes that access to specialist support is too variable, and 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

Identifying and meeting communication needs

Since 2016, health and care providers have been legally required to meet the Accessible Information Standard (AIS). However, during the review period CQC found limited evidence of hospitals identifying, recording, flagging and sharing information. CQC also found the quality of communication and information sharing varied both between and within services. The report highlights issues around access to, and the contents of, GP records. Hospital systems to identify those with additional needs were also not always effective, which created the risk that staff may not recognise or be able to meet people's needs. People told CQC they were more likely to have a positive hospital experience and be meaningfully included in their care when their communication needs were met by providers.

Communicating with people and their carers

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. However, CQC also heard about poor experiences of staff not meeting people and their families' needs, or where they felt communication could have been improved. Issues around communication increased with the person's level of need.

Many of the findings reflect conclusions from CQC's [2020 NHS adult inpatient survey](#), which found 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.

There was variation in the awareness of staff about communication aids such as easy read documents, picture exchange communication (PECs) and photo journeys. In several hospitals not all staff knew which aids were available, where to find them and how to use them. Some staff spoke positively about being able to request information in an easy read format. However, people told us that there was a lack of easy read resources on wards in some hospitals. CQC concludes that meeting individual needs through easy read formats is not suitable for all and there should 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 for staff about a person with a learning disability or an autistic person. CQC noted that people spoke positively about how hospital passports could give staff information about their individual needs and help them to deliver person-centred care. Across the eight hospitals that CQC visited it found that if a person did not have a hospital passport already, the hospital would suggest it or start one for them, and the specialist practitioner or team would help to create new passports and update existing ones.

However, CQC found these were not used consistently and staff were sometimes not aware that a person had a hospital passport or they did not have the time to read it. The quality of these passports were at times an issue, with some either not completed correctly, being out of date or missing key information. Staff were not always clear who was responsible for completing and updating hospital passports, which increased the risk of important information being inaccurate, such as medicines.

Similarly, CQC heard that electronic flags on hospitals' computer systems were not always effective in helping staff to identify and support people.

CQC found some hospitals were using electronic flagging more effectively than others. CQC concludes that electronic flagging should be 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

Impact of staff attitudes and behaviour

People's experiences of care and treatment when in hospital varied considerably. Where people said they had better experiences of care, staff were caring and responsive, and took the time to listen and engage with them. Positive experiences left people feeling respected and treated as individuals. However, this was not always the case, and a negative staff attitude was associated with poorer standards of care. The report highlights that while all hospitals 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 CQC visited used various ways to identify people's needs as well as any required reasonable adjustments. CQC found evidence that staff had made reasonable adjustments to the hospital environment, as well as delivered sensory and therapeutic interventions.

Most staff recognised that quieter environments, such as single rooms, could be more calming and make being in hospital less distressing. Staff would try to accommodate this where possible, but limited space or high demand meant it was difficult to do. Concern had been expressed about the isolating effects of single rooms and felt that there was a risk that staff may not be able to keep people in their line of sight. Families also told CQC that even when hospitals were aware of people's individual needs, these were not always met.

The importance of listening

The report found that staff were not always well informed or had the skills and knowledge to manage all the needs of people with a learning disability and autistic people. Families said that that staff tended to focus on a person's diagnosis and treatment and did not consider everyday tasks. CQC found an over reliance on people's family and carers to ensure that their individual needs 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. Reliance on families and carers was often linked to the availability of staff. 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 CQC heard that funding for paid care workers stopped when the person was admitted to hospital. The report highlights one hospital had arrangements to part-fund care providers so patients were supported by staff who were familiar to them.

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. Good examples include instances where staff engaged with people and supported them to make decisions. Staff also adapted their language and made sure that people understood what would happen before going ahead with a decision or procedure.

On the whole, staff understood that consent and decision making should be underpinned by mental capacity assessments where appropriate. However, this was not always the case and CQC found a situation where an autistic person with a learning disability was not assessed because staff assumed that they understood with the help of their family.

In a few trusts, CQC found that people were not always involved in day-to-day decisions about their care, and involving people in discharge planning needed to be improved in particular. Some carers felt that hospitals wanted to discharge people too quickly or without enough information or understanding about what would happen after discharge.

Managing medicines

CQC found the quality of medicine review varied, and 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 CQC found that this did not always happen. 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.

CQC also checked what systems hospitals had for the use of sedation, rapid tranquilisation and chemical restraint. It found that most 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. Although some staff said other options would be considered first, CQC found examples where people had been given sedatives or anti-psychotic medicines to calm them, however, most hospitals had systems that triggered a review where medicines were used to restrain a person.

Other equality characteristics and quality of care

Protected equality characteristics

While most staff 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. Staff also noted that it could be difficult to get support from interpreting services at the time of important conversations, which meant that they often relied on family members to interpret. Families described how challenging this was especially when having to sign effectively while listening carefully and asking questions to staff about care. At the time of the CQC visits none of the trusts had a consistent or strategic approach to identifying people's protected characteristics.

The report does highlight how some hospitals supported people with protected characteristics, for example asking individuals about their preferred names and pronouns, developing autism strategies and inequalities strategies, and improving data collections to improve how they identify any unintended impacts on people with protected characteristics.

Equality of care and reasonable adjustments

CQC 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 such as sunflowers lanyards. However CQC notes that not everybody will have a formal diagnosis or be happy to share information about their additional needs. CQC also found that staff may not understand what the terms learning disability and autism mean.

Additional physical and/or medical needs

The impact of staff's lack of understanding was heightened when people had physical and medical needs in addition to their learning disability or autism. Across a number of trusts, CQC heard people who had swallowing difficulties experienced delays in receiving the soft food that they needed. CQC 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. In some instances, people's medical issues could be overshadowed by their learning disability or autism and as a result, there was a risk that staff could ignore or misinterpret people's medical needs. However, 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.

Workforce skills and development

Skills, knowledge and understanding of staff

Outside of the specialist teams, people's experience of care depended on the knowledge, skills and experience of individual members of staff. 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. While there was evidence across services of staff with experience supporting colleagues to develop their skills and knowledge, this was not consistent and their expertise was felt to be 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 seven 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 visited, a single member of staff was responsible for providing specialist expertise and advice, whereas other hospitals had specialist teams that ranged from two to 10 people. These teams were usually referred to as a learning disability liaison nurse or team, even if their remit was wider than this. One hospital had taken a more positive, holistic approach to caring for people with a learning disability and autistic people: 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. Aside from this hospital, the majority of hospital staff relied heavily on specialist practitioners and teams.

Specialist staff felt they were in extremely high demand and 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.

Training and information sharing

CQC heard good examples from specialist teams providing bespoke training for specific wards or units, and specialist teams playing a proactive part in learning from incidents. However, CQC was not assured that the learning from either positive or negative experiences were systematically shared across all staff and across all sites. Often information was disseminated in a more generalised way through newsletters, videos and frequently asked questions on hospital's intranets.

CQC was not assured that current training courses gave staff the skills, knowledge, or confidence to care for people with a learning disability and autistic people. Staff did receive training about how to support these groups of people as part of their induction, but there was a lack of ongoing training and skills development in this area across most hospitals. Access to training had also been affected by the pandemic, and some staff reported that current mandatory or e-learning packages were not providing the appropriate skills that staff needed and they wanted more training.

NHS Providers view

This welcome report draws much-needed attention to the importance of improving access to, and the quality of, care for people with a learning disability and autistic people. While the CQC found several examples of good practice from which others can learn, we share the regulator's concern that people's experiences are too variable.

There is more that trusts can do to improve the quality of care for all. That includes putting in place appropriate reasonable adjustments and making sure that patients, their carers and families are involved fully in decisions about their care. However, we need to do more to ensure that the full range of services which people with a learning disability and autistic people rely on are properly resourced and prioritised across the country.

It is all the more challenging to make the necessary improvements to care because staff and services are under increasing pressure across the health and care system, while striving to deliver high-quality care. There need to be enough staff in services with the right skills and experience in looking after people with a learning disability and autistic people. Greater capital investment is also crucial so patients get the care they need in environments that properly meet their needs.