**EMBARGOED UNTIL 00:01 ON THURSDAY 3 NOVEMBER 2022**

**NOT FOR ONWARD CIRUCLATION**

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

Today we have published a report on the experiences of being in hospital for people with a learning disability and autistic people. Our report ‘Who I am Matters’ is a stark reminder that people with a learning disability and autistic people are still not getting the care they need, when they need it and shines a light on the impact these failings have on people and their families.

During February and March 2022, CQC visited 8 hospitals in England. We found that although there were pockets of good practice, 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.

Our report looked at: **Access to care, Communication, Care and treatment in hospital, Protected characteristics and equality of care and Workforce skills and development.**

**Key findings include:**

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:**

**Access to care**

* People told us they found it difficult to access care because there were no reasonable adjustments made. Providers need to make sure they are making appropriate reasonable adjustments to meet people’s individual needs.

**Communication**

* 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.

**Care and treatment in hospital**

* 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.

**Other equality characteristics and quality of care**

* 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.

**Workforce skills and development**

* 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.

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 still too slow. As well as being a key equality issue, this is a critical patient safety issue.

**CQC’s Director for people with a learning disability and autistic people, Debbie Ivanova said:**

“For too long people with a learning disability and autistic people have not been getting the care they need, when they need it.

“This is not only distressing for the individuals and for their families and carers but can also significantly affect people’s health outcomes.

“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.

“We are determined to improve the care for people with a learning disability and autistic people. 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."