Care Quality Commission

Care for autistic people and people with a learning disability

Health inequalities for autistic people and people with a learning disability is still an unacceptable issue.

The latest Learning from Lives and Deaths – people with a learning disability and autistic people (LeDeR) report, published in November 2023, highlighted that life expectancy for these groups of people remains lower than for the general population. The report again shows that people from all ethnic minority backgrounds are at an increased risk of premature death.

While the report shows evidence of an increase in life expectancy for women with a learning disability, they are still dying 23 years earlier than women in the general population. In addition, the number of deaths of people with a learning disability who live in the most deprived areas of the country are 3 times more than those living in the least deprived areas.

The LeDeR report goes on to say that 42% of deaths of people with a learning disability were rated as avoidable, compared with 22% for the general population. This is reflected in information we receive through our regulatory work, such as people dying of avoidable constipation and choking. For example, a person with a learning disability who was admitted to hospital with constipation died in hospital 48 hours later with an impacted bowel.

Annual health checks with a GP

Anyone aged 14 and over who is on their GP's register of people with a learning disability is entitled to an annual health check once a year so they can talk to a doctor or nurse about their health, and any problems can be found and treated early.

This also enables people with a learning disability to receive reasonable adjustments, such as having longer appointments, bringing a carer with them, or having an appointment at the beginning or end of the day, if they find it hard to be in a busy waiting room.

Data published by NHS England suggests that in 2022/23, 80% of people aged 14 and over who were on the register of people with a learning disability received a health check. This was a significant increase compared with the previous year, and a huge improvement compared with 2018/19 when the data suggests just 59% of registered people received a health check.

However, these figures may only show a fraction of the picture, as not all GP surgeries maintain an up-to-date register. A report by the Women and Equalities Committee notes that, although an estimated 1.3 million people have a learning disability in England, only around a quarter of these were recorded on the register of people with a learning disability. This means that many people with a learning disability are missing out on the proactive care and treatment they are entitled to.

The report goes on to say that reducing the current waiting time for a diagnosis of autism is crucial to tackling health inequalities for autistic people (see below).

Through our regulatory work, we have seen examples where autistic people and people with a learning disability have not been supported to attend routine medical screening, such as breast screening, either by their social care service, or by their GP as part of their annual health check. We heard of an example where, following the identification of changes in a person's breast, a service didn't facilitate a visit to the GP in a timely way. The person was subsequently found to have breast cancer.

Our Expert Advisory Group has explored the challenges and barriers for people when accessing their GP, the inequalities related to primary care and the access to, availability and quality of annual health checks. The group includes people with lived experience and key stakeholders representing people with a learning disability and autistic people. They told us the key issues were related to:

- communication
- making reasonable adjustments for them
- lack of a person-centred approach
- the environment in waiting rooms
- lack of consideration of people's other protected characteristics.

They also spoke about the importance of continuity and choice, staff training and co-production to make sure people's individual needs were understood and met. The Expert Advisory Group then supported us to develop a set of questions they felt were important for CQC to ask during our assessments of primary care services.

These questions are feeding into our priority area of work to help tackle inequalities in health and to reduce early mortality. The project relates to the Learning from Lives and Deaths (LeDeR) programme, which was established in 2017 to investigate and reduce the unacceptably high levels of early mortality for autistic people and people with a learning disability.

To help inform our regulatory activity, we are exploring issues such as:

- the barriers and inequalities faced by autistic people and people with a learning disability in accessing primary care
- the quality and consistency of annual health checks and action plans with a GP for autistic people and people with a learning disability
- the provision of reasonable adjustments.

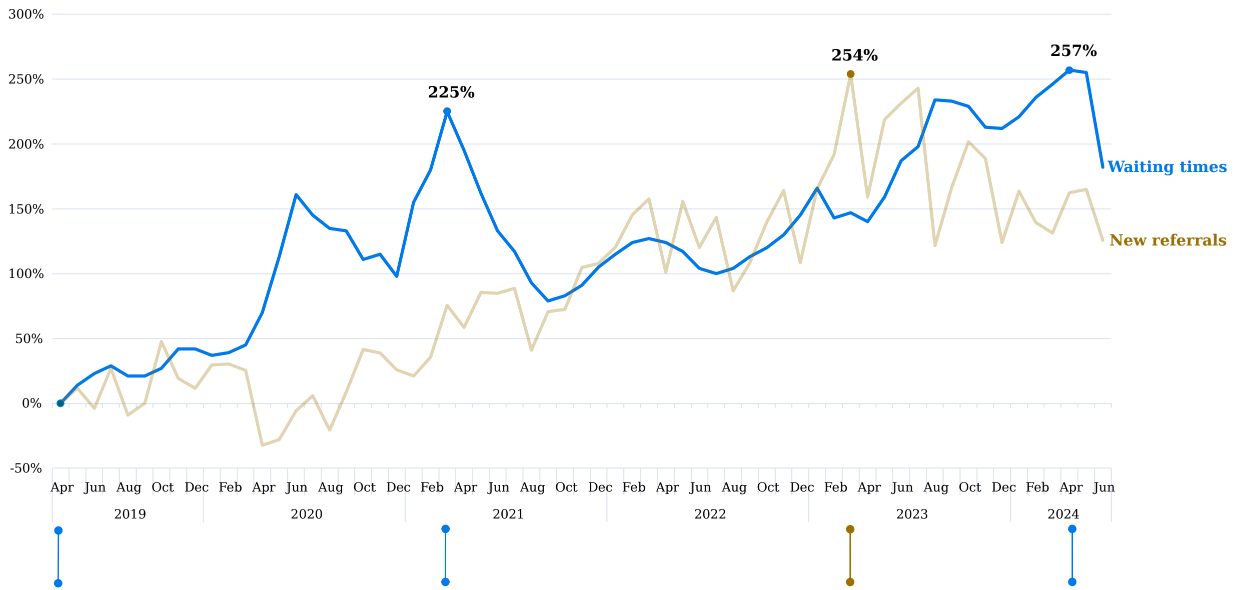
Health services are required to make reasonable adjustments to ensure that they can meet the health needs of people with a disability, including learning disabilities. This can include making information easier to read, using texts or making telephone calls to remind people to attend appointments, and allowing more time for consultations. In September 2023, the Reasonable Adjustment Digital Flag Information Standard was published. This aims to clearly identify everyone who may need reasonable adjustments during annual health checks and other contact and processes. We look forward to reviewing the impact of the digital flag on reducing health inequalities, which became mandatory from April 2024.

Diagnosing autism

NICE guidelines recommend that people who have been referred for a possible diagnosis of autism should have an assessment started within 3 months of their referral.

NHS England data shows that average waiting times against this recommendation have been increasing over recent years, reaching their highest level at 328 days in April 2024. Increases in average waits up to April 2024 come despite a broad trend of decreasing numbers of new referrals over the past year. As at June 2024, there were over 9,000 new referrals a month, compared with just over 14,300 in March 2023 (figure 20). While the data for June 2024 also shows a reduction in median waiting times, more data is required to see whether this is sustained.

Figure 20: Average waiting time from referral for a diagnosis of suspected autism to first appointment and number of new referrals – percentage change relative to April 2019



In April 2019 there were just over **4,000** new referrals, and the median waiting times was **92 days.**

In March 2021 waiting times reached a pandemic peak of **299 days.**

In March 2023 new referrals reached a peak of just over **14,300**. This was **254% higher** than they had been in April 2019.

In April 2024 waiting times were at thei highest recorded value (**328 days**), **257% higher** than in April 2019. In June 2024 waiting times decreased to **259 days**

Source: Mental Health Services Data Set (MHSDS)

Average waiting times are even longer for children and young people – at 356 days in April 2024 compared with 238 days for adults. This may be because the number of referrals for young people is considerably higher than for adults, at nearly 7,000 in April 2024 compared with just under 4,000.

Worryingly, since 2019, the proportion of open referrals without any appointment has been increasing, reaching 81% in June 2024, compared with 44% in April 2019. This means that many people are being referred and not being seen.

NHS Long Term Plan commitments

In last year's report, we described how our Mental Health Act reviews showed that autistic people and people with a learning disability continue to be placed in a mental health hospital inappropriately when they should be receiving care in the community.

Inappropriate hospital placements can cause considerable harm, especially if a person is in long-term segregation. Mainstream psychiatric inpatient care environments are usually bright and noisy and unsuitable for neurodiverse people. Inappropriate inpatient environments can also pose a higher risk to upholding people's human rights.

The 2019 NHS Long Term Plan included several commitments relating to autistic people or people with a learning disability when they are an inpatient. To assess the progress on these commitments, we reviewed NHS England's Learning Disability Services Monthly Statistics from the Assuring Transformation dataset published in June 2024. We found the following from our review of the commitments and targets:

1. **NHS Long Term Plan commitment: Reduce the number of autistic people and people with a learning disability in mental health inpatient facilities to less than half of 2015 levels by March 2023/24**. In March 2015, there were 2,905 autistic people and/or people with a learning disability as inpatients. By March 2024, the target's deadline, there were 2,155 inpatients. This is only a 26% decrease on the March 2015 figure and as such, this commitment has **not** been met.
2. **NHS Long Term Plan commitment: By March 2023/24, for every 1 million adults, there will be no more than 30 people with a learning disability and/or autism cared for in an inpatient unit.** We found that, in March 2024, the rate of adult inpatients who are autistic or have a learning disability was around 43 per million. As such, this commitment has **not** been met. This rate also varies considerably by integrated care board area – ranging from 75 inpatients per million adults to 21 inpatients.

3. **NHS Long Term Plan commitment: Reduce the proportion of children and young people who are autistic or who have a learning disability in inpatient facilities to no more than 12 to 15 per million.** As at March 2024, of the 2,155 inpatients who are autistic and/or have a learning disability, 245 were under the age of 18, meaning there were 21 children and young people who were autistic or had a learning disability in inpatient facilities for every 1 million children under the age of 18. As such, this commitment also has **not** been met.

People with a learning disability in mental health hospital settings

NHS England data for June 2024 shows that among autistic people and people with a learning disability who are inpatients in a mental health hospital:

- more than half (53%, 1,080 people) had a total length of stay in hospital of more than 2 years
- nearly 1 in 6 (17%, 340 people) had a total length of stay in hospital of more than 10 years; the majority (71%) of these inpatients were subject to Part III of the Mental Health Act.

As at June 2024, less than a quarter (23%) of autistic people and people with a learning disability who were inpatients had a planned discharge date. Where a discharge had been planned, it was recorded that the relevant local authority was aware that an inpatient was to be transferred or discharged to their area in only 62% of cases. This lack of comprehensive joined-up planning and communication may inhibit the ability of services to arrange suitable care and support for people in the community.

At the end of March 2024 (last available data), there were 220 autistic people or people with a learning disability whose discharge from hospital was recorded as delayed. The following were the most commonly recorded reasons for these delays:

- more than half (56%) involved a lack of suitable housing
- a third (33%) involved delays while awaiting a place in a residential home
- a quarter (24%) involved a lack of social care support.

Our report Out of sight – who cares? and previous Independent Care (Education) and Treatment Reviews (IC(E)TR) looked at the care given to autistic people and people with a learning disability who were in long-term segregation. The report that followed from Baroness Hollins focused on autistic people and people with a learning disability who are detained in mental health and specialist learning disability hospitals. As a result of one of the report's recommendations, the previous government has asked us to take the lead on IC(E)TRs for the next 2 years, funded by the government's grant in aid initiative.

In the first year, we will be working alongside NHS England. We re-started the programme in May 2024 when there were 96 autistic people and people with a learning disability in long-term segregation. We are engaging with integrated care boards to prioritise those people for IC(E)TRs.

We want to highlight good practice that we can share with system partners to enable positive commissioning practice to shape the market. This will help ensure that the right support is available at the right time for people – especially support in the community. We will report on this activity throughout the 2-year programme, including its impact on people's quality of life and how each person has experienced the IC(E)TR process.

In all services, we expect care to be person-centred and providers to promote a culture that supports recovery, builds trust, and protects the safety and wellbeing of all people using services. Where we find this is not happening, we will continue to take action to make sure that people are safe.

Quality of mental health care for autistic people

Our analysis of comments received through Give feedback on care showed that many autistic people are struggling to get the mental health care they need.

People described issues in feeling they were refused access to mental health care, including referrals not being made and feeling that they were referred to services that did not support all their needs.

Some autistic people who sought care for their mental health found it difficult to make appointments, particularly at their GP practices. Autistic people sometimes reported that GP practices did not make reasonable adjustments to support them in booking their appointments, which led to them not being able to access their GP for support. This could lead to their mental health getting worse:

> “I asked if I could make appointments outside of this time and over the phone and they outright refused, so I now don't make appointments for things I need to.”

> “My wife is also experiencing psychological harm as she is unable to get the mental health treatment she requires. My wife is (undiagnosed) autistic and she finds the GP surgery very unaccessible [sic].”

Across all sectors, people perceived a lack of knowledge about autism among staff had implications for how they believed they were treated in relation to their mental health. A few people described positive experiences of staff taking account of their autism in the care they provided. For example, one person told us:

> “Nurse practitioners are skilful, warming and understanding. I have had amazing experiences with [2 doctors] who have both been absolutely amazing with my mental health, autism and ADHD.”

However, many autistic people reported a lack of understanding around autism and mental health, which could influence staff attitudes and create further barriers to access support. This included autistic traits being mistaken for symptoms of mental ill health, or staff not understanding that autism is not a mental health condition.

> "During the assessment I exhibited autistic behaviours; these were mistaken for a mental health crisis and I was detained under a section 5(2)."

> "The practice appears chaotic in its administration and there appears to be a total lack of knowledge on autism, it is not a mental health condition."

In particular, we heard that staff lacked knowledge around treating mental health issues in autistic young people, which people felt could be improved through better training:

> "If professionals could have a little more knowledge on autism? I feel like this would be beneficial in delivering treatment that may help me more."

> "I believe it would have made my mental health appointments a lot easier if I felt like people could understand or at least empathise with my struggles and the barriers around accessing support."

Autistic people said this lack of understanding could make their mental health worse, and reinforces the need for better knowledge among staff around both autism and mental health to ensure autistic people get effective mental health support:

> "I said I needed to leave to get some space (I am an autistic individual and can have meltdowns and overwhelm) and I asked them to do what needs to be done. I was then

> told in that intense moment of upset that if I left, I would be discharged, and that is what happened, despite me explaining I felt worse and I felt like I was a danger to myself and feeling hopeless.”

Restrictive practice in services for autistic people and people with a learning disability

Our cross-sector policy position on restrictive practice makes clear that in all services we expect care to be person-centred and that providers promote a culture that supports recovery, builds trust, and protects and promotes the safety, wellbeing and human rights of all people using services.

Where we find this is not happening, we will take regulatory action to make sure that people are safe.

Through our inspections and the information we receive, we know that people with a learning disability and autistic people are too often subject to various forms of restrictive practice, including the inappropriate use of chemical restraint and extreme restraint in the form of intubation.

This can happen when there is a lack of suitable skilled and trained staff to support people who are distressed. It has led to multiple examples of abuse and inappropriate and illegal restrictive practices being used.

We have also seen examples of closed cultures forming because staff do not speak up – either because they are part of the culture, they don't recognise that what they are doing is restrictive, or because they are worried about repercussions.

Last year, during an inspection of a residential care home providing personal care and support to autistic people and people with a learning disability we found that staff used blanket restrictive practices without ensuring safeguards were in place to protect people's rights. For example, staff used verbal, authoritative commands to instruct people what to do and what not to do. Staff did not recognise this as a restrictive intervention and the provider did not have a monitoring system to evaluate whether they met ethical and legal standards.

Where we have found disproportionate restrictive practice and unlawful deprivations of liberty, we have taken enforcement action and shared our concerns with local authority commissioners and safeguarding teams to make sure people are protected from harm. We continue to monitor these services to check that they have made improvements and complied with the requirements to enable them to meet the regulations.

Our concerns about excessive restrictive practices in services for autistic people and people with a learning disability are reinforced by our experimental analysis for this report of provider information returns submitted by care homes to CQC between April 2021 and April 2024. The analysis found that:

- On average, around 15% to 20% more residents had restraint or restriction in their care plan in care homes where over half of residents had been recorded as autistic or having a learning disability compared with care homes where no residents were recorded as being autistic or having a learning disability.

- In care homes where over half of residents were recorded as autistic or having a learning disability, the incidence of restraint was on average nearly 12 times higher than in care homes where nobody was recorded as being autistic or having a learning disability. This amounts to a yearly average of approximately 2 incidents of restraint for every 3 residents in care homes where over half of residents are recorded as autistic or having a learning disability.

Many services are working hard to ensure their staff are trained in line with regulatory requirements in supporting people with a learning disability and autistic people. However, there are still services providing care and support from staff who have not been trained.

Following a consultation last year, some services have been waiting for the Oliver McGowan Code of Practice to be published before securing training for staff.

The Code of Practice will greatly help to improve the understanding of the requirements on health and social care staff to support people with a learning disability and autistic people.

It is not acceptable that staff who have not received training, which is mandated in regulations, continue to provide services to people. Our focus is on how providers and leaders are assured that their staff have the skills they need to deliver care and support to people in a way that meets their needs. We know that where staff are trained to meet the needs of autistic people and people with a learning disability, quality of life and outcomes are improved.