Looking at how well the Learning Disability and Autism Programme is doing

The NHS England and NHS Improvement Learning Disability and Autism Programme works to improve the health of people with a learning disability, people who are autistic or both, and to support them to live well at home.

The things that the Learning Disability and Autism programme want to do are written in the NHS Long Term Plan.

This document is to show how well the Learning Disability and Autism Programme is doing at the things we promised in the NHS Long Term Plan.

It gives the important data from different services to show how well the NHS is carrying out its plans.

Reducing how many people are in hospital

- Where this document talks about people in hospital with a learning disability, it means people who have a learning disability only and people who have both a learning disability and are autistic.
- Where this document talks about autistic people in hospital, it means people who are autistic but do not have a learning disability.
- Where this document talks about hospital we mean: mental health hospitals, mental health wards in a general hospital or a hospital for people with a learning disability and autistic people.

Understanding how many adults with a learning disability and autistic adults are in mental health hospitals in each Transforming Care Partnership (TCP)

Transforming Care Partnerships (TCPs) are made up of:

- Clinical Commissioning Groups (the organisations that plan and pay for most NHS services)
- Specialised commissioners (a team within NHS England that plan and pay for specialist services)
- Provider Collaboratives (a Provider Collaborative is a group of hospitals working together to improve how services are provided for people with a learning disability, autistic people or both).
- Local authorities (sometimes called councils).

Transforming Care Partnerships work with people and their families and carers to plan and carry out local plans.

There are 44 TCPs in England.

By March 2024, no more than 30 adults with a learning disability and autistic adults out of every 1 million adults should be in hospital.

We know that 8 TCPs have already met this target.

Another 10 TCPs have met the target of 37 adults out of every 1 million adults which was the target for March 2020.

Looking at people who have gone into hospital and people who have moved back to the community (from March 2015 to September 2020)

There are 835 fewer people in hospital now than in March 2015. That is 29% fewer people.

In March 2015, 2,895 people with a learning disability and autistic people were in mental health hospital. 2,040 of those people are not in hospital now.

Many people have been admitted to hospital, and discharged again since March 2015. Over 9,300 people have been in hospital at some point between March 2015 and September 2020.

765 of the people in hospital in September 2020 had been in hospital continuously since March 2015. Nearly 360 of these people were in hospital on a **restricted section** of the Mental Health Act. This is when you have been to court and the judge thinks you are a risk to the public. The judge and two doctors agree that you are unwell and need to be in hospital instead of prison.

Looking at autistic people who are in mental health hospital and people with a learning disability who are in mental health hospital

Adults

Between March 2015 and September 2020, the number of autistic adults who were in hospital went up.

The reason for this increase is partly because there were fewer reports than there should have been about autistic adults before March 2017.

The number of adults in hospital who have a learning disability has gone down.

Children and young people under 18

Around 170 out of 205 children and young people in hospital in September 2020 were autistic.

Looking at the different types of ward that adults with a learning disability and autistic adults are staying on in mental health hospitals

The number of adults staying in most types of ward has gone down.

The number of adults staying in acute admission beds in general mental health hospitals has gone up. This is partly because earlier on in the Transforming Care programme, not everyone who was staying in hospital got recorded.

Looking at the numbers of adults with a learning disability and autistic adults staying in wards with different levels of security

The number of adults staying in all types of secure ward went down between March 2015 and September 2020.

Psychiatric intensive care units (PICUs) are services that provide care and treatment for adults with mental health needs who need the most support. In PICUs there are usually more staff and people usually only stay for a short time.

The number of adult patients in psychiatric intensive care units (PICUs) went up between 2015 and 2020. We think this is partly because the recording of people in PICUs has got better.

The increase in the number of autistic adults in non-secure mental health hospitals is partly because recording of information about autistic adults has got better.

Looking at the number of people who are in mental health hospital on a restricted section of the Mental Health Act

Someone might go to hospital under a restricted section of the Mental Health Act.

565 people who were in hospital in September 2020 were reported as on a restricted section of the Mental Health Act. This is more than 1 in 4 people.

Learning Disability Mortality Review (LeDeR)

The Learning Disability Mortality Review (LeDeR) programme helps us learn from the deaths of people with a learning disability. It does this by:

- reviewing the deaths of people with a learning disability
- supporting local areas across England to do reviews
- putting learning from reviews into action

There is information about how many reviews have been done for every clinical commissioning group (the NHS organisation that plans and pays for services in each area).

The information published about the reviews includes:

- how many deaths have been reported in each clinical commissioning group (CCG)
- how many deaths are being reviewed at the time

- how many reviews have been finished
- and how many reviews have not yet been given to a person to do the review

At the end of September 2020, the LeDeR programme had been told about 9,200 people with a learning disability who had died. All reviews should be completed within 6 months of a death being reported. Of the 7,240 reviews that should have been completed 5,235 had been done. 2,005 reviews still needed to be completed.

Annual Health Checks (AHC)

GP practices are encouraged to have an up to date learning disability register. This is so that they know about everyone aged 14 and over who has a learning disability, so they can make sure they have a health check (AHC) every year and get the right care.

As part of their Annual Health Check, people should have a health action plan.

NHS Digital publish data on the number of AHCs that have happened every three months in each GP Practice. This is not easy read.

https://digital.nhs.uk/data-and-information/publications/statistical/learning-disabilities-health-check-scheme

Just under 160,000 people had an AHC from April 2019 to March 2020. This is 6,736 higher than the year before.

Helpful links

The Learning Disability Improvement Standards for NHS trusts

NHS Improvement has developed new standards to help NHS trusts measure how well they are doing with making sure people with a learning disability and autistic people get the care they need:

Plain English learning disability improvement standards

Easy read learning disability improvement standards

Learning disability services statistics, NHS Digital

Assuring Transformation is the name of a data set collected by NHS Digital. It is used by NHS England and NHS Improvement to check that people with a learning disability and autistic people are getting the right care in hospital.

Statistics on people with a learning disability and autistic people from Assuring Transformation are published each month by NHS Digital. This includes easy read reports.

https://digital.nhs.uk/data-and-information/publications/statistical/learning-disability-services-statistics