

What is the NHS Learning Disabilities and Autism Programme?

The Learning Disabilities and Autism Programme (formally Transforming Care), can improve the lives of children, young people or children and adults with autism and/or learning disability with behaviour that challenges and/or mental health issues. It is about improved support in your community.

This is to try to prevent you having to go to a mental health hospital or residential unit which may be far away from where you live.

Principles of the NHS Learning Disabilities and Autism Programme

There are 9 principles of Learning Disabilities and Autism Programme (formally transforming care).

- I have an interesting life that I enjoy
- My care and support is well planned
- I have choice and control about my care and support
- I live in the community with the support I need
- I have choice about where I live and who I live with
- I get good care from health services
- I get help from specialists in the community when I need it
- I get help to stay out of trouble with the police if I need it
- If I have to go into hospital because my health needs cannot be met in the community, it is high quality and I don't stay there longer than I need to

Why do we have the Learning Disabilities and Autism Programme?

- Learning Disabilities and Autism Programme (formerly transforming care) came about when people with learning disabilities were being treated very badly at a place called Winterbourne View Hospital.
- A review took place and a report called "Building The Right Support" explained how the NHS and Local Authority had to work together to make sure children, young people and adults with learning disabilities and/or Autism could get the support they needed nearer to home.

It can improve the lives of children, young people, and adults with learning disabilities and/or Autism who have complex behaviours, which may include a Mental health diagnosis.

How can the Learning Disabilities and Autism Programme help me?

- By developing good quality services with our wider partners including the voluntary sector in the community so you don't have to go into hospital or into an out of area residential unit
- If you do need to go into hospital, that you receive the best care, you don't stay there longer than you have to and if possible, you go into hospital close to your home and that you have support to resettle back into your local community

If you think that this applies to you or your child, please contact local health commissioners

If you think that this applies to you or your child, please contact the Children Young People's and Learning Disabilities and Autism team in the NHS Integrated Care Board nhsnw1.cypldateam@nhs.net

Dynamic Support Register

A **Dynamic Support Register (DSR)** is a list of people with a learning disability and autistic people who need support because they are at risk of going into a mental health hospital. We also include children and young people who are under the age of 18 when they are at risk of requiring a residential placement if they do not receive the right care and treatment in the community. A group of professionals from health, social care and education (if appropriate) meet regularly to ensure that there are plans in place to reduce the risk of admission. Inclusion on the DSR is optional and consent is required from the individual or their parent, depending on their age. Referrals to the DSR can be made by professionals working with the child or young person or self-referral

There are three Dynamic Support Registers in Westminster / Kensington and Chelsea:

Register	Contact
Children and young people (up to 18 yrs old)	nhsnw1.cypldateam@nhs.net
Autistic adults	
Adults with a learning disability including those who are also autistic	

The new [Dynamic Support Register and Care \(Education\) and Treatment Review policy and guidance](#) was published by NHS England in January 2023 and was coproduced by people with a learning disability and autistic people.

Care Education and Treatment Reviews

Where children or young people who are autistic or have a learning disability are at risk of an admission to an inpatient mental health unit, a Care Education and Treatment Review (CETR) may be called by the individual, their family or a professional. When a CETR is arranged the family and professionals all get together to review the needs and requirements of the young person and decide on the best next steps by working together. A clinical expert and a family member who has had similar experiences from another area will be present to help planning with fresh

eyes. If a young person is no longer in education, the meeting is known as a Care and Treatment Review.

The following tools have been developed by NHS England to help plan and understand the process:

NHS England has developed a [toolkit](#) to help understand and plan the process

ASD/LD Keyworker Team

The North West London ASD/LD Keyworker team is a programme designed to prioritise children and young people who are under 25 years old living with a learning disability (LD) and/or autism (ASD) and who have other complex behaviour or mental health needs that could increase their risk of hospitalisation or residential placement.

The service has been developed as a response to the NHS England long term plan commitment. It is funded by NHS England and is separate to other services a child or young person may receive.

The aim of the service is to reduce the risk of admission, support families during inpatient admission, to help avoid longer than needed stays, to reduce the risk of re-admission and to support return to the community.

Keyworkers are central to ensuring that children, young people, and their families can access the support they need in a coordinated way.

A core role for Keyworkers is to facilitate the co-production of this personalised approach.

What can a Keyworker do?

Keyworkers collaborate with other agencies and organisations working across systems to ensure the best possible outcomes for children and young people.

Key Workers will make sure that these children, young people and families get the right support at the right time.

A Keyworker will work with children and young people and their families and carers to make sure families are fully involved in their plans, feel listened to and informed and they have the support they need at the right time, in a co-ordinated way.

Key working should help families experience a reduction in stress and uncertainty and an increase in stability.

What support can a keyworker bring?

Types of support that Keyworkers can offer include:

- Help to identify what skills the young person would like to learn and develop
- Identifying the support they may need in accessing the community

- Helping young people learn about self-advocacy skills
- Support to think about preparation for adulthood
- Problem solving/thinking about risks
- Ongoing positive planning, thinking about risk enablement.
- Offering support in meetings and ensuring their views are heard
- Helping develop self-confidence and resilience.

Who Can Have a Keyworker?

Criteria for a Keyworker is:

A diagnosis of a learning disability, autism or both.

0-25 years of age

Potential risk of inpatient admission or are currently in hospital.

The child/young person is on the Dynamic Support Register (DSR). Priority referrals are with those rated Red & Amber.

Who is involved in the Keyworker team?

There are currently eight Keyworkers and a team leader working across North West London. They are employed by London Borough Hounslow on behalf of NHS North West London Integrated Care Board (ICB).

Positive Behaviour Support Consultancy (PBSC) work alongside Keyworkers to improve quality of life outcomes and also add a behaviour science perspective to support some of the children and young people known to the Keyworker team.

Mental Health Admission

- A mental health admission is when a young person needs to spend time in a specialist hospital setting, when risks to themselves or other people are too high to remain in their own community. This is usually because they are experiencing an episode of crisis.
- Sometimes this is needed to reduce the risk and understand the causes, but research shows people with a learning disability and/or autism, can find these environments difficult and challenging to be in.
- Keyworkers can help support planning for discharge from hospital as soon as possible. They help think about what support and plans need to be in place around the child or young person to enable them to stay safe and reconnect with their community. They can support other professionals with their assessments and plans and be involved in transitional planning.
- This can include developing transitional plans that the young person understands.

How to access the Keyworker service

If you think that your child or young person might be at risk of admission, or is already in a mental health setting, your Social Worker, Mental Health Care Co-

ordinator or any professional working with you can refer to the Keyworker service via the Dynamic Support Register (Dynamic Support Register)

Contact

If you would like any further information about the keyworker service, please contact us via email asdlldkeyworker@hounslow.gov.uk

Annual Health Checks

All people with a learning disability aged 14 and above can access an annual health check. This is usually with the GP or practice nurse.

The annual health check is important because it can help identify any health problems before they get worse, and help adults and young people to receive the care that they need. The Health Check also includes a health action plan which will give information on how to stay healthy and make recommendations for any referrals if they are needed.

It is important to check that those at age 14 or above are on the GP learning disabilities register to ensure that they can access their health check and make sure that reasonable adjustments are made to support access to appropriate health care

NHS England are working to make sure that more people are receiving a health check. If you think you or someone you know should have an annual health check, you can contact your GP surgery to arrange one.

More information on annual health checks is available from [Mencap](#)