



Barnet, Enfield and Haringey  
Mental Health NHS Trust

Camden and Islington  
NHS Foundation Trust

# The Learning Disabilities/ Autistic Spectrum Disorder Keyworker Service

For children with Learning Disabilities  
and/or who are Autistic



## Who is the Keyworker Service for?

**The Learning Disability/Autistic Spectrum Disorder (LD/ASD) Keyworker Service forms part of the North Central London commitment to ensure that children/young people with Learning Disabilities and/or who are Autistic, with behaviours of concern and complex mental health needs, will have increased access to enhanced support and care, including intensive support/crisis services.**

Initially, keyworker support will be provided to children and young people with a learning disability and/or who are autistic who are inpatients in, or at risk of being admitted to, a mental health hospital. Keyworker support will then be extended to the most vulnerable children with a learning disability and/or who are autistic, including people who face multiple vulnerabilities such as looked after and adopted children, and children and young people in transition between services.

Keyworkers will make sure that these children, young people and families get the right support at the right time. They will make sure that local systems are responsive to fully

meeting the young people's needs in a joined-up way, and that whenever it is possible to provide care and treatment in the community with the right support.

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

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

## What do we mean by behaviours of concern and Mental Health needs?

**An autistic child or young person with/without a learning disability, is one with behavioural difficulties and a diagnosed mental health condition that is deteriorating, due to the immediate network of support and accessible services being unable to meet their needs.**

Behaviours of concern can be defined as *"behaviours of such an intensity, frequency, or duration that the physical safety of the person or others is likely to be placed in serious jeopardy, or behaviour which is likely to seriously limit use of, or result in the person being denied access to, ordinary community facilities"*

(Emmerson 2001)

These are children and young people who may exhibit significant self-injurious behaviour or who may

have an extreme form of 'demand avoidance' and who have become isolated at home. It is likely these children/young people will have been flagged by schools and families, and strategies have been put in place to treat them and support them, but that these are now no longer sufficient.

Mental health conditions can include anxiety, depression and obsessive-compulsive disorder, suicidal ideation, and self-harm.



## What will Keyworkers do?

Children and young people and their families will be assigned a Keyworker, whose role will be to work closely with the network to develop safer and less-restrictive evidence-based approaches that have the potential to improve the quality of life for children/young people and their families.

Support from our Keyworkers for families can last for up to 12 months while children are in crisis and have a high level of need. This support will continue until the newly established package of support is fully functional and things are starting to improve.

## Who can access the Service?

**Any young person up to the age of 18 years with a diagnosis of Learning Disability and/or who is Autistic, at risk of hospital admission, planning to be discharged into the community, and who is on the Local Dynamic Support Register.**

## Which areas will the Service cover?

**The Keyworker Service is available in all 5 Boroughs of the NCL, Barnet, Enfield, Camden, Islington and Haringey. In the North NCL (Barnet, Enfield, and Haringey), the service will be provided by Barnet Enfield and Haringey (BEH) Mental Health Trust in partnership with other providers in the Integrated Care System (ICS).**

The Integrated Care System is a partnership of organisations that come together to plan and deliver joined up health and care services and to improve the lives of children and young people.

In the South NCL (Camden & Islington), the Keyworker Service is delivered by the Whittington Health NHS Trust.

## Who can refer?

Referrals can be made by any professionals/services working with a child/young person.

A professional who knows your family can refer to the LD/ASD Keyworker Service because:

- Your child/young person has a diagnosis of a learning disability and/or who is autistic, with mental health needs and/or behaviours of concern.
- Your child is between the ages of 0-18 years old.
- Your child/young person's care/behaviour is becoming increasingly difficult to manage, there is an increased risk of family breakdown and/or your child/young person's behaviour is at point of crisis.
- Your child/young person is on the risk register and it is believed your family will benefit from accessing the service.

## How do I refer?

Currently all referrals to the service come through the Dynamic Support Register for the borough in which the young person resides. If you would like to discuss a referral you can contact the team via email on: **[beh-tr.ldasdkeyworkerservice@nhs.net](mailto:beh-tr.ldasdkeyworkerservice@nhs.net)**



## What is a Dynamic Support Register?

**NHS England requires all local authorities to hold a Dynamic Support Register.**

The Dynamic Support Register (DSR), identifies children/young people with Learning Disabilities and/or who are Autistic, with an elevated risk of admission (or home placement breakdown).

Needs are classified using a colour coded system, red, amber and green to indicate the level of risk severity of each case. Those with the most complex needs are red and those with the less high-risk needs are green.

Any professional who knows the family can refer the child/young person via the DSR.

Multi Agency professionals meet to review young people on the DSR for the purposes of care planning and ensuring their needs are met.

The meetings take place on a fortnightly basis.

DSR is not a disability register, which is usually held by local authorities. A Disability Register is a voluntary register of children and young people from birth to 18 years of age who live in the borough and have a disability or special educational needs.

## Who does not qualify for the Service?

A child/young person does NOT meet the criteria to access this service, if there is NO diagnosis of a learning disability and/or autism,

or your child is NOT on the DSR, and the concerns identified are being effectively addressed by other existing support services.





## What are the difficulties experienced by children and young people with learning disabilities and/or who are autistic?

**Children/young people with learning disabilities and/or who are autistic, are pre-disposed to challenges arising from biological and psychosocial vulnerabilities.**

Biological vulnerabilities include the increased likelihood of experiencing the impactful consequences of syndromes, physical health issues (e.g., pain), epilepsy/seizures and sensory impairments.

Psychosocial vulnerabilities include a lack of communication skills, negative life events, family stress, mental health issues, lack of meaningful activity, impoverished social networks, institutionalised accommodation, and/or socio-economic disadvantage.

Autistic children/young people with learning disabilities, can often face exclusionary assumptions and attitudes from professionals and society more widely, as well as falling within the gaps in commissioning of services. This can result in being unable to access the right health, care, and educational support at the right time. This can lead to unmet health, social care, and educational needs, which cause stress on children/young people and their families and can result in a family placement breakdown or inpatient admission.



## Role and responsibilities of the LD/ASD Keyworker Service?

### The Keyworker service aims to:

- Reduce/prevent the number of children/young people admitted to hospital.
- Support children/young people and their families in the home, to apply therapeutic and clinical interventions to help them manage at home and in the community, with the aim of decreasing the need for the child/young person to be admitted to hospital.
- Work closely with the child/young person and their families to identify the appropriate support and agree to the right pace and intensity of their involvement, as well as to agree specific goals and outcomes.
- Link in with other local support services to provide additional resources for the child/young person and their families that includes respite care in the form of short breaks or social prescribing support.
- The Keyworker is to hold existing services to account around timely and appropriate delivery, ensuring recognition of need for reasonable adjustments and capable environments?

### The Keyworker will:

- Work with the family and the team around the child/young person to identify the appropriate support and to ensure provider/collaborative planning with the child/young person and their family.
- Support the child/young person and their family through discharge from hospital, back into the community.
- Ensure the voice/s of the child/young person and their family is being heard and that they are invited to be part of any planning and decision making around the child/young person's plan of care.
- Support the family to navigate the appropriate systems of care to access support from relevant services.
- In the event that a young person does require hospital admission, the service will provide intensive support prior to, and following discharge, working in partnership with other local agencies to help the child/young person and their family, adjust to life back in the community.
- The Keyworker will work in partnership with Care Coordinators (sharing some tasks at a time of crisis) to boost and empower Care Coordination, but not replace them. Their roles are vital but temporary, until the crisis has been de-escalated after which, the various teams are expected to continue the provision of the package on their own.
- Adopt a co-production approach (involving parents, and children/young people with lived experience of learning disabilities and/or who are autistic, to co-design the service.





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