

Autism and ADHD Services (All Age) in Northamptonshire – Frequently Asked Questions (FAQ)

This FAQ is designed for everyone, as it is publicly accessible. While it is primarily aimed at professionals in primary care, schools, social care and other frontline services to promote consistent messaging and understanding, it also serves an important role for patients and the wider public.

By providing clear, reliable information, this FAQ helps:

- Patients make better-informed choices to support their care and wellbeing. You do not need an assessment for most areas of support, but you do require a diagnosis to be prescribed ADHD medication.
- Professionals reduce the volume of queries, complaints, and Freedom of Information (FOI) requests
- Limit the need for MP engagement on recurring issues

We encourage all users—whether professionals or members of the public—to refer to this FAQ as a trusted source of guidance.



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1. Is a formal diagnosis necessary to access support for Autism or ADHD?

While having a diagnosis can be helpful to identify and validate the difficulties people may face, it's not always required for accessing support for autism or ADHD. Support should be tailored to an individual and made available based on a person's difficulties and challenges, even without a formal diagnosis.

Here's why a diagnosis isn't always necessary for support:

- Focus on Needs: Support is based on the individual's specific needs, not just a diagnosis.
- **Varied Support Options:** Support can come from various sources, including professionals, charities, local authorities, and family/friends.
- Education: Education settings can offer many different types of support and can help to access more specialist support without a diagnosis. A diagnosis is not needed for an Education, Health and Care Plan. EHCPs are based on assessed needs, not diagnosis. Evidence from school and professionals can be sufficient.
- **Social Care:** Social care assessments can be requested to identify support needs, and don't require a diagnosis.
- **Benefits:** Some benefits are awarded based on individuals' needs and how they impact daily living, including Disability Living Allowance, and Personal Independent Payment.
- Impact of assessment: A diagnostic assessment can offer understanding of neurodiverse presentation and validation for individuals, but it's not essential for accessing support (such as reasonable adjustments in school or the work place).

In summary: While an assessment can be beneficial for understanding neurodiverse presentations, it's not a requirement for receiving assistance tailored to individual needs. Individuals can access support through various avenues, even before or without a formal assessment. The exception to this is if you require ADHD medication.

2. Why are the waiting times so long for Autism and ADHD assessments?

As a population we are getting better at understanding what neurodiversity looks like and are better able to identify where a referral for assessment might be helpful. This is one reason why there has been a rapid increase in need for assessment in the UK and in many parts of the world.

In Northamptonshire, as elsewhere nationally and internationally, this surge in demand has outpaced the capacity of NHS services, leading to long waiting lists.

We are working hard to increase the number of assessments being offered and delivering the most efficient pathways possible to reduce waiting times, as well as provide help for families while they wait.



When prescribing medication, the service needs to be specialist-led and this is a highly skilled specialist who requires many years of training. This is why it can be a challenge to support the prescribing of certain controlled drugs or prescription medications, whose manufacture, possession, and use are heavily regulated by government laws due to their potential for abuse or harm.

We are aiming to reduce the waiting time over the next few years. The waiting time nationally for completing ASD/ADHD assessments can range from 1 year with some parts of the UK reporting waits as long as 13 years.

3. What support is available without the need of a diagnosis or while I wait?

Local Support Services:

All Ages		
Enfold - Your local autism information hub	a charity providing services to the Autistic Community in Northamptonshire	
CHAT Health	the local free confidential and 24/7 crisis support text messaging service (Text 07480635531) or call 0800 448 0828	
Shout	the UK's free, confidential and 24/7 mental health text service for crisis support (Text 85248)	
Northamptonshire Carers Association	support to informal carers in Northamptonshire	
Sport4Fitness CIC I Home I Everyone Can Achieve - Fernie Fields Sports Club, Fernie Field, Moulton, Northampton, UK - England - Northamptonshire SEN	dedicated to making sport, physical activity, and wellbeing accessible to all in Northamptonshire	
Sea of Support - S.O.S Facebook	neurodiversity support group in Kettering	
AuDHD Community Embraced Facebook	neurodiversity support group in Corby	
Home Northampton TRACK Consultancy	Café and employment opportunities for autistic people	
Children and Young People		
SENDIASS SEND Information Advice Support Service North Northamptonshire Council West Northants SENDIASS	Information, advice, and support for families of children with Special Education Needs and Disabilities (SEND).	
West Northants SEND IASS		
Specialist Support Service (North Northamptonshire	The SEND Support Service offers advice and support to children, young people, families,	
 SEND Support Service North Northamptonshire Council 	carers and a range of educational establishments for children with a wide range of special	



	educational needs and/or autism, aged 0 to 19 years
Inclusion and Intervention Service (West Northamptonshire, formerly known as Specialist Support Service) Inclusion and Intervention Support Team (IIST) West Northamptonshire Council	Support children with Special Educational Needs and Disabilities (SEND) aged 0 to 19 across West Northamptonshire, with 2 distinct offers – Early Years and School Age - both of which provide a family offer
iDiscover NHFT	iDiscover is a community of children, young people, families, and carers in Northamptonshire offering free courses, workshops, and resources to help you grow.
iDiscover toolkit NHFT	Offers a range of helpful tools and resources for children, young people, and their families
Drop-in Cafés The Reach Collaborative	4-hour drop-in service delivered weekly at 8 places across the county.
The Reach Collaborative Youth Counselling in Northamptonshire – for more information contact 01536 518339	The REACH collaborative provides services for children, young people and their families to have free access to evidence-based early intervention services that improve their mental health, emotional wellbeing and resilience. REACH also offers a range of other services to support CYP and their families, such as drop-in cafes, Re:Start, LGBTQ+ support groups, social groups, and Happy Heads - more details are available on the website.
Northamptonshire Parent Carer Voices	supporting families of children and young people with special educational needs and disabilities.
WNVP West Northants Voices in Partnership	parent carer forum for parents of children and young people with special educational needs and disabilities in the west of Northamptonshire
SENDsational Families CIC - Empowering Parents and Carers	champions mental, emotional, physical and spiritual health and wellbeing of adults raising children with special educational needs and disabilities (SEND), with or without a formal diagnosis.
SENDS 4 Dad	support for dads and male carers who have a child or adult with special educational needs and/or a disability
Northants SEND Mummas Facebook	peer support group for mothers and female carers of SEND children.
Spectrum Club (Northamptonshire) Facebook	autism support group for parents of autistic children across Northamptonshire



Brackley & District SEND Support Group Facebook	the Brackley and District SEND Support Group is a supportive parent-led online community that meets twice each month for coffee or tea and a chat.	
Information About Your Local Family Hubs	North Northamptonshire single point of contact for families with children 0-19 or up to 25 years old if they have special educational needs and disabilities (SEND) and the staff will be able to give you information, advice and support.	
Family Hub locations West Northamptonshire Council	Towcester is open and two more will be opening soon.	
Speak to your SENCO via your child's education setting, they may access support such as Mental Health in Schools teams or Educational Psychology		
Adults only		
Recovery College NHFT	offers a range of different courses to help adults and others to understand health conditions and help with recovery.	

National Online Resources:

Support

Northamptonshire Mind | Mental Health

ADHD UK Discovery Platform	self-management strategies and tools.
Home Autistica Autism research and campaigning Autistica	National Autistic Research
National Autistic Society	advice, guidance and services
Home - Neurodiversity UK	community of Neurodiversity UK
ADHD Foundation The Neurodiversity Charity	

supporting mental health needs in

Northamptonshire

While there is currently no dedicated health funding for pre-assessment support, your GP, school, or support service may still offer helpful guidance.

4. What assessment routes are available?

There are three main routes:

a. Standard NHS Referral

- Request a referral via your GP to local NHS services e.g. Northampton General Hospital (NGH) or Northamptonshire Health Foundation Trust (NHFT).
- NHS assessments take a **holistic approach**, considering physical and mental health, social context, presentation in more than one setting, and co-occurring conditions.



• All locally commissioned NHS services will offer medication prescribing where it is appropriate for the treatment of a patient.

For children's services, more than 500 extra neurodevelopmental assessments for autism and/or ADHD are being offered to young people in Northamptonshire as part of a drive to help reduce waiting lists in 2025/26. For more information, please refer to the following link: Extra autism and ADHD assessments offered to help cut waiting lists in Northamptonshire | Our latest updates | NHFT

b. Right to Choose (RtC)

Please be aware that where medication is advised following a diagnosis not made by NHFT (for example, ADHD diagnosed via a private or non-NHFT provider), it is **not standard practice** for a GP to prescribe the recommended medication.

There are **strict safety protocols** that must be followed before a GP can consider prescribing in these cases. This includes the establishment of a **formal, shared care arrangement** between the diagnosing provider and the GP. Such arrangements are essential to ensure the ongoing safety, monitoring, and support for the person being prescribed medication.

Do not assume your GP will prescribe, even if another provider suggests they should. GPs must act in the best interest of their patients, within the boundaries of clinical safety and governance, and this sometimes means declining to prescribe without the necessary safeguards in place.

This approach exists for **very important reasons of patient safety**—please speak to your GP directly about any questions you have regarding prescribing and diagnosis.

Process for Right to Choose

If you are registered with a GP in England under the NHS, you have a legal right to choose your mental healthcare provider and your mental healthcare team. This means you can select an alternative provider that that is NHS-approved in England. The chosen provider must have a contract with an NHS Integrated Care Board (ICB) or NHS England to deliver autism and/or ADHD assessments under Right to Choose/Patient Choice.

Right to Choose within mental health is relatively new. Not all patients, GPs, or clinicians may be aware of how it works, so it's important to know your options.

- You can find extensive information about Right to Choose via the NHS website: Your
 choices in the NHS. if a GP agrees that an ADHD or autism assessment is clinically
 appropriate, the individual has the right to choose a provider that offers this service under
 NHS funding.
- There is a legal right to choose any qualified provider with an NHS contract. You will need to identify the organisation that you would like to be referred to
- Your GP may make the referral using the provider's specific form. However, where there are data protection concerns, GPs may advise of an alternative approach. Please speak to your GP practice to gain further advice.



Important Note:

When choosing a right to choose provider, you may want to consider whether they offer the services that you need. For example, not all providers offer a prescribing service which means you may need to be referred back to an NHS provider.

GP surgeries are unable to guarantee that the practice can carry out any tests recommended by a provider. We also cannot guarantee that we will be able to prescribe NHS prescriptions based on the assessment you receive if we are unable to enter into the appropriate shared care prescribing agreement with the provider.

Please be advised we are unable to recommend any Right to Choose providers. Patients are advised to review whether the provider they are interested in holds a current contract with an ICB in England for the age group and pathway (e.g. autism, ADHD) they are interested in. Then they would need to discuss this with their GP, who would make the referral.

A patient can only be on a locally commissioned (e.g. NGH/NHFT) or Right to Choose Pathway, they cannot be on both.

ADHD UK provides information on organisations that have been awarded an NHS contract. Right to Choose - ADHD UK.

Another resource when considering providers can be found here <u>Public information :: West Yorkshire Health & Care Partnership</u>

c. Private Assessments

- Self-funded
- Costs range from £500 to £3,500+, depending on the type of assessment and provider.
- Private diagnoses may not be accepted for NHS prescribing or follow up care.

To enhance the likelihood of private assessments being accepted, research the following:

- Adherence to NICE Guidelines: The assessment must follow the National Institute for Health and Care Excellence (NICE) guidelines. This includes using recognised diagnostic tools (e.g., ADOS-2, ADI-R) and involving qualified professionals such as psychiatrists, psychologists, or speech and language therapists
- Provider Credentials: The clinician must be registered with an appropriate regulatory body (e.g., GMC for doctors). NHS services are more likely to accept diagnoses from reputable providers with a multidisciplinary approach
- Comprehensive Reports: A detailed diagnostic report that aligns with NHS standards increases the likelihood of acceptance. Some NHS services may even use these reports to initiate support or treatment

Limitations and Risks

• No Guarantee of Acceptance: NHS clinicians are not obligated to accept private diagnoses. They may disagree with the findings or require a confirmation assessment



- Medication Prescriptions: If you receive a private ADHD diagnosis, your NHS GP
 may refuse to prescribe medication unless the diagnosis is confirmed through NHS
 channels. This is due to legal and clinical responsibility for prescribing
- Waiting Lists: A private diagnosis does not allow you to skip NHS waiting lists for treatment. You may still need to wait for an NHS assessment to access funded care

If you want to be transferred back to NHSE following a diagnosis for prescribing purposes, then a new referral to an organisation will be needed. It will be at the discretion of the clinician whether they will accept a private diagnosis and prescribe or whether they want to repeat the diagnostic process.

- **Discuss with your GP** before booking a private assessment.
- Research providers thoroughly to ensure they meet NHS standards.
- **Keep documentation** of the assessment and share it with your GP for inclusion in your NHS records.

For advice on what to look for in a provider, you may wish to read the following advice:

Getting an autism diagnosis - Enfold

Private Diagnosis - For Adult ADHD | ADHD UK

ADHD Diagnosis Pathways (Children) - ADHD UK

5. Prescribing following an ADHD diagnosis

- If a patient has been seen by an NHS ADHD service and medication is recommended, this is normally started by the NHS service. Once the dose is stabilised, GPs can prescribe as part of a Shared Care Agreement.
- This enables the care and treatment you receive for ADHD to be shared between the NHS service and your GP. This will only occur when your ADHD medication is stable. For more information, please see the General Medical Council (GMC) practice advice Shared care - professional standards - GMC
- GPs are **not expected** to initiate or manage treatment without support from a specialist.
- They retain the **clinical right to decline** shared care if they feel it is unsafe or inappropriate.

We have Shared Care Agreements in place with **NHFT and NGH** based on national Regional Medicines Optimisation Committee (RMOC) templates. These allow for safe NHS prescribing when the patient is under ongoing specialist care.

If the provider only offers a **diagnosis without follow-up**, any request for your GP to prescribe would be considered a **transfer of care**, not shared care, and GPs would be advised to decline.

Right to Choose providers may have a contract that allows prescribing; where this is the case, monitoring and follow-up will be by the Right to Choose provider. It is best to check this before being referred. There are no agreed shared care arrangements with any RtC providers for ADHD medications in Northamptonshire and GPs are not expected to prescribe.



If someone is seen privately and medication is recommended, then prescribing would also be expected to be private.

6. Are there locally accredited private providers?

Currently, **no private providers in Northamptonshire** are locally accredited to deliver equivalent ADHD follow-up care to NHS providers. This means they are not eligible for Shared Care Agreements via the Northamptonshire Prescribing Advisory Group (NPAG). Therefore, they may assess and diagnose you, but there are no guarantees these providers will be able to prescribe medication. Please be advised that private activity may not be continued with the NHS. Please see section 7 below, What happens if a Right to Choose provider includes prescribing?

7. What happens if a Right to Choose provider includes prescribing?

If a provider holds an **NHS contract** and offers prescribing under RtC:

- They are responsible for the prescribing.
- The cost is reimbursed by the ICB.
- There is **no expectation** that the GP will take over prescribing unless an appropriate Shared Care Agreement is established.

If a provider is used **privately** (not via RtC), NHS prescribing **will not be available**, and the patient may need to continue privately.

8. What should I tell my GP if I want to use Right to Choose (RtC)?

- Where Right to Choose applies, RtC referrals can only be made by a GP.
- The individual will not get a list of assessment service providers and will need to look for suitable providers in their own time and can use supporting information to help them make a choice.
- Download the referral form from the RtC provider's website.
- Discuss with your GP and ask how to make the referral under the Right to Choose framework.

9. Will the provider consider my other health needs?

NHS assessments consider your health **holistically**, including other diagnoses, medications, and support needs.



When opting for a **Right to Choose or private providers**, patients will need to **check what service the provider delivers**. including considering any other co-occurring medical conditions if you have **complex health needs**.

10. Can I access NHS care if I've already started private treatment for autism or ADHD?

Yes. If you begin treatment privately, you can request to transfer to NHS care at any stage, provided the treatment is commissioned by the NHS. However, you may need to wait and be reassessed by an NHS clinician, and you won't receive preferential treatment due to having started privately. **Please be advised that you cannot remain on two waiting lists.**

Will the NHS cover costs for private assessments or treatments?

No. If you choose to pay privately for assessments or treatments that are not commissioned by the NHS, you are responsible for all associated costs—including monitoring, investigations, and management of complications. The NHS will only cover costs of services where the GP has made a referral.

Can I mix NHS and private care for autism or ADHD?

Not within the same episode of care. NHS and private care must be clearly separated. For example, you cannot have a private ADHD assessment and then expect NHS prescriptions or monitoring unless you meet NHS criteria and are reassessed by an NHS clinician.

Can my GP prescribe ADHD medication recommended by a private consultant?

Only if:

The medication is listed on the ICB formulary (a list of medicines, dressings, or other healthcare products that are approved for use within a specific Integrated Care System (ICS). It serves as a guide for prescribers, helping them choose cost-effective and clinically appropriate items for their patients) or normally funded by the NHS. This can only take place if there is an appropriate shared care agreement in place accepted by the GP.

Currently there are no shared care agreements in place between private providers and Northamptonshire.

What if the private consultant recommends a drug not funded by the NHS?

Your GP may seek advice from the ICB about an NHS-funded alternative. You can still choose to purchase the recommended drug privately, but the NHS will not cover any part of the cost.

What happens if I want to switch from private to NHS care mid-treatment?

You can do so if the treatment is commissioned by the NHS. However, the NHS will not reimburse any private costs already incurred. Any change of provider, the patient will start at the end of the waiting list and may lengthen the time waiting.



11. How Northamptonshire Integrated Care Board (ICB) Support People with Autism and ADHD in Northamptonshire

Northamptonshire Integrated Care Board **(NICB)** is the statutory NHS body responsible for planning and overseeing the delivery of health services across Northamptonshire. It was established on **1 July 2022**, replacing the former Clinical Commissioning Group (CCG), as part of a national move to more integrated health and care systems

We're here to make sure people with autism and ADHD get the care and support they need.

Here's how we're helping:

Helping You Get a Diagnosis

We work with local NHS services to provide **diagnostic assessments** for autism and ADHD. We know waiting can be difficult, so we're working hard to **reduce delays** and make the process smoother.

Bringing Services Together

We connect **GPs, schools, mental health teams, and community services** so that your care is **joined-up and easier to access**.

Listening to You

We've partnered with organisations like **Healthwatch Northamptonshire**, **Neurodiversity Peer Support Groups and Parent Groups** to hear directly from **you**, **your family**, **and carers**.
Your feedback helps us **improve services** and make them more responsive to your needs.

Supporting Mental Health

We understand that people with autism and ADHD may also need help with their mental health. That's why we're working to **improve access to services** and training, so you get the right support without having to repeat your story.

Improving Awareness and Access

We're working with national and regional colleagues to **raise awareness of the Right to Choose**, helping you understand your options for care.

We're also part of the **national ADHD taskforce**, the Midlands ADHD Community of Practice, and the National Clinical Reference Group which is focused on improving **access to services and patient safety**.

Making the Most of Resources

We're reviewing how services are funded to make sure we're using NHS money wisely—so we can **improve care and keep it sustainable** for the future.

Advocating for Better Services

We're actively investing to develop **joined-up neurodiversity services** to better meet the needs of people in Northamptonshire.

If you or someone you care for is affected by autism or ADHD, we're working to make sure you get **better**, **more joined-up care that meets your needs**.



12. If you wish to seek an assessment

If you wish to proceed on an assessment pathway:

- For Children and Young People: Start with the Nursery Health Visitor or the School Nurse. For Electively Home Educated, start with the GP
- **For Adults:** Start with your GP, who can guide you through NHS, Right to Choose, or private options.
- **Be cautious**: Not all services include medication or long-term support.
- Advocate for yourself: It's okay to ask questions and request clarification.

The GP can refer you to the Children's Referral Management Centre for the Autism and ADHD team to review medication.

For mental health concerns, you may wish to contact the following services:

CHAT Health	the local free confidential and 24/7 crisis support text messaging service (Text 07480635531) or call 0800 448 0828
Shout	the UK's free, confidential and 24/7 mental health text service for crisis support (Text 85248)

We appreciate your patience and your efforts to seek support. Your voice helps shape future services.

Thinking About a Diagnosis for Autism or ADHD?

If you're considering a formal diagnosis for autism or ADHD, especially as an adult, it's important to reflect on what you hope to gain from it. A diagnosis can offer clarity, validation, but it's not guaranteed, and the process can be lengthy and complex. There may not be any additional services to support at the end of the process. Pursuing a diagnostic pathway does not always result in a diagnosis, and it's helpful to manage expectations from the outset.

Before starting the diagnostic journey, you may find it useful to explore community support, peer networks, and self-help resources. These can often provide practical strategies and emotional support to help manage challenges day-to-day. For some, these resources may be enough without needing a formal diagnosis.

However, if you are seeking ADHD medication, a formal diagnosis is required before any prescriptions can be made. In these cases, following the diagnostic pathway is essential.

Taking time to consider your needs and options can help you make a more informed decision about whether a diagnostic assessment is the right step for you.