

## Guidance to support families who have, or are considering paying for a private Autism or Attention Deficit Hyperactivity Disorder (ADHD) assessment

*These guidelines have been created by Buckinghamshire CAMHS neurodevelopmental and ADHD Clinic Team alongside some parents who have accessed private assessments.*

The following information is aimed to provide caregivers and professionals with information regarding best-practice standards for an assessment or diagnosis of Attention Deficit Hyperactivity Disorder (ADHD) and/or Autism. If a child or young person has been given a diagnosis of ADHD and/or Autism by a private practitioner (i.e. from a non-NHS service), their written diagnostic report should meet the same standards as a diagnosis provided by NHS assessment services. 'Gold standards' are determined through an assessment's compliance with the guidelines put forth by the National Institute for Health and Care Excellence (NICE).

### Why do I need to know about this?

Due to long waiting lists for autism and ADHD assessments in Buckinghamshire CAMHS, families are understandably exploring private assessments. We recognise that this is a huge financial decision for families, as well as the stress and time needed to navigate the different options and providers available to them. We are also aware that there are several private providers available with some not meeting NICE guidelines. We want to support families as best we can, to provide them with the knowledge and confidence to ensure that their private assessment is good and that it is then accepted by NHS services, for example being accepted onto the ADHD clinic waiting list for medication. We are unable to directly recommend a private provider.

### What are the NICE guidelines?

They consist of **recommendations on how to best identify, refer, diagnose, treat and manage patients** based on the best evidence available. NICE

guidelines are put together by experts, people using services, carers and the public.

You can access these guidelines via <https://www.nice.org.uk/guidance/ng87> and <https://www.nice.org.uk/Guidance/CG128>

## Attention Deficit Hyperactivity Disorder (ADHD) assessments

The NICE guidelines say:

- A diagnosis of ADHD should only be made by a specialist psychiatrist, paediatrician or other appropriately qualified healthcare professional with training and expertise in the diagnosis of ADHD
- The assessment should include discussion about behaviour and symptoms in the different parts and settings of the person's everyday life
- The assessment should include details of the child's development (pregnancy, birth, milestones and mental health)
- The child's behaviours must have been observed by the professional doing the assessment.
- A diagnosis of ADHD should not just be made using questionnaires or other's observations. However, questionnaires such as the Conners' rating scales and the Strengths and Difficulties Questionnaire (SDQ) are still important. Observations (for example, at school) are useful too, but not essential.
- The diagnosis of ADHD must meet the diagnostic criteria set out in either the DSM-5 or ICD-11 manuals
- There must be evidence that the ADHD causes at least moderate psychological, social and/or educational or occupational difficulties in multiple settings (for example, at home and school).
- The behaviours must be noticeable in 2 or more important settings including social, familial, educational and/or occupational settings.

**If the assessment meets the above criteria, and the child is diagnosed with ADHD, then Buckinghamshire CAMHS will accept this, and the child will not need to be re-assessed by the NHS. Please let us know, so that your child can be removed from the Buckinghamshire CAMHS neurodevelopmental assessment waiting list.**

### **What if my child is already on ADHD medication?**

If you do seek a private ADHD assessment and start medication for ADHD, the responsibility for ongoing prescribing and monitoring remains with the private provider until the child is seen and accepted by the NHS. The NHS will not continue medication which has been started by a non-NHS provider if this is felt to be unsafe or not follow prescribing guidelines. The ADHD clinic will not take over prescribing for sleeping medication. Once accepted onto the ADHD clinic waiting list there will be a wait before your child will be seen in clinic. We do not expedite children who are already on medication.

Before we can accept a young person to the Buckinghamshire CAMHS ADHD clinic waiting list, and if already taking ADHD medication we also require the following information:

- 1) Physical health observations (Heart rate, Blood pressure, Weight and Height)- before starting medication and the most recent recordings.
- 2) Documentation of the last private review, which must be no more than 6 months old at the point of referral into the ADHD clinic.
- 3) Documentation that young person is stable on ADHD medication. We are unable to accept referrals when a young person is still titrating (not yet stable) on medication.

### **What is a Shared Care Agreement with GP?**

This means that GPs will prescribe medication if this has been started by a specialist and the child is on a stable dose. If accepted, families will be able to source medication from the NHS and avoid paying private medication fees. There is no obligation for GPs to agree to a Shared Care Agreement (both with the NHS and with private providers) and it is worth checking with your GP. The responsibility for reviews remains with the specialist.

### **What happens if a private diagnosis doesn't meet NICE guidelines?**

If a young person's private assessment is not compliant with NICE guidelines, then another diagnostic assessment may have to be completed if they wish to access an NHS service that requires an autism or ADHD diagnosis, for example starting ADHD medication. In these cases, a young person can be added to the NHS assessment waiting list but will not be expedited.

## Autism assessments

The NICE guidelines say:

- A diagnosis of Autism should only be made by a specialist psychiatrist, paediatrician or other appropriately qualified healthcare professional with training and expertise in the diagnosis of autism.
- The assessment should include discussion about behaviour and symptoms in the different parts and settings of the person's everyday life.
- The assessment should include details of the child's development (pregnancy, birth, milestones and mental health). Tools such as the ADI-R or the DISCO are helpful for this. Professionals must be trained to use these.
- The child's behaviours must have been observed by the professional doing the assessment. Tools such as the Autism Diagnostic Observation Scale (ADOS) or MIGDAS are recommended for this. Professionals must be trained to use these.
- A diagnosis of autism should not just be made using questionnaires or other's observations. However, some questionnaires such as the ASSQ, CAST, CAT-Q, and the Strengths and Difficulties Questionnaire (SDQ) or Revised Child Anxiety and Depression Scale (RCADS) are still important. Observations (for example, at school) are useful too, but not essential.
- The diagnosis of Autism must meet the diagnostic criteria set out in either the DSM-5 or ICD-11 manuals
- The behaviours must be noticeable in 2 or more important settings including social, familial, educational and/or occupational settings.
- The assessment must be completed by more than one professional with different professional backgrounds (a multi-disciplinary team, or MDT).

- Other causes for behaviour must be assessed for ruled out, for example, the behaviours being caused by a response to trauma, or due to a mental or physical health need.

**If the assessment meets the above criteria, and the child is diagnosed with autism, then Buckinghamshire CAMHS will accept this, and the child will not need to be re-assessed by the NHS. Please let us know, so that your child can be removed from the Buckinghamshire CAMHS neurodevelopmental assessment waiting list.**

**Things to look out for when seeking a private provider**

	<b>Essential</b>	<b>Avoid</b>
<b>Who is making the diagnosis?</b>	<p>The clinician should be a specialist with appropriate expertise in diagnosing autism and/ or ADHD. This clinician could be from a range of healthcare backgrounds - Paediatricians, Psychiatrists, Occupational Therapists, Speech and Language therapists, Clinical Psychologists, Specialist Nurses.</p> <p>Information about their experience and qualifications should be readily available to you.</p> <p>The Health and Care Professions Council (HCPC) register can be checked:</p> <p><a href="#">The Health and Care Professions Council (HCPC)</a> <a href="#">The HCPC</a></p> <p>The Nursing and Midwifery Council (NMC) can be checked:</p> <p><a href="#">Search the register - The Nursing and Midwifery Council</a></p> <p>The Royal College of Psychiatrists can be checked</p> <p><a href="#">Public members list</a></p>	<p>Non-qualified individuals</p> <p>Providers who cannot tell you about their training and experience</p>

	<p>Not all providers will be able to prescribe medication for ADHD following a diagnosis. Drug treatment is not indicated in all young people with ADHD and the decision to use ADHD medication must be based on a thorough assessment of the severity of the symptoms.</p>	
	<b>Essential</b>	<b>Avoid</b>
<p><b>What should an ADHD and/ or autism assessment include?</b></p>	<p>A comprehensive ADHD and/ or autism assessment should include a full early developmental history. This will include information about your child's early years and development to see when difficulties were first apparent.</p> <p>A direct observation of your child should take place.</p> <p>Rating scales, questionnaires or tools should help the assessment. There are several available which might include:</p> <p>ADHD: Conner's questionnaires, Young DIVA 5, QB test, SNAP-IV rating scale</p> <p>Autism: ADOS, DISCO, ADI-R, CAT-Q, ASSQ</p> <p>Other: Strengths and Difficulties Questionnaire, RCADS</p> <p>Assessment of child's overall mental health, family history, educational history, social history and</p>	<p>Developmental history not undertaken</p> <p>Child not seen by clinician</p> <p>No rating scales or observational data used.</p> <p>Focus just on ADHD and/or</p>

	<p>medical history is an important part of the assessment process. Characteristics of ADHD and autism should be present in the early developmental period. Understanding this helps to identify if any differences in behaviour may be occurring for other reasons, such as experiencing significant life events or having other health complications which may require further assessment.</p>	<p>autism characteristics</p> <p>Focus on current presentation only.</p>
	<b>Essential</b>	<b>Avoid</b>
<b>How is a diagnosis made?</b>	<p>A diagnosis of ADHD and/ or autism should meet either the DSM-5 criteria or the ICD-11 criteria. These are internationally recognised and used and can be found for free online.</p> <p>The impact of the ADHD symptoms should cause at least moderate impairment in multiple settings and these symptoms need to be present in 2 or more settings.</p>	<p>Diagnostic criteria not used in assessment process.</p> <p>Evidence of symptoms are not sought from other settings.</p>
<b>What to consider if medication is started</b>	<p>The clinician will undertake a baseline physical examination of any young person before commencing medication. This will include measurement of height, weight, pulse, blood pressure and heart sounds. A more thorough physical examination may be required in some young people, particularly if there is a medical or family history of serious cardiac disease, a history of sudden death in young family members, or abnormal findings on cardiac examination.</p>	<p>No baseline physical examination takes place.</p>
<b>Assessment report</b>	<p>All information gathered in the assessment should be available in the assessment report.</p>	<p>Limited report</p>

<b>Post diagnosis support</b>	<p>A good service provider should offer support and guidance throughout your journey.</p> <p>Access to support or resources.</p> <p>Insights into strengths and areas that may need support.</p> <p>An explanation of your rights under disability laws or policies.</p>	<p>Following diagnosis there is no further support or recommendations provided to families</p>
	<b>Essential</b>	<b>Avoid</b>
<b>Other things to consider</b>	<p>Clear costing is provided by the private provider.</p> <p>If the provider offers a joint Autism and ADHD assessment.</p> <p>A diagnosis of ADHD can be made by a single clinician with appropriate training and experience in ADHD assessments though it is good practice for that practitioner to be part of a Multi-Disciplinary Team (MDT)</p>	<p>Hidden and unclear fees</p>

**What support will be provided post diagnosis?**

While you don't need an ADHD or autism diagnosis to get support, it can help families, young people and educational settings to understand how this impacts daily life. It would be unlawful for a public body to refuse to provide care and support because there had been no diagnosis, and such support should always be needs led.

For support around education, we recommend contacting The Special Educational Needs and Disability Information, Advice and Support Service or SENDIAS.

<https://www.buckinghamshire.gov.uk/schools-and-learning/bucks-sendias-service/>

They provide free, confidential, impartial information, advice and support on all matters relating to special educational needs and disability for children and young people aged 0 to 25 and their parents/carers.

If your family is experiencing multiple or complex issues you need support with, the Buckinghamshire Family Support Service can work directly with families and/or young people. Such difficulties might include difficulties engaging with education, risk taking behaviours, poor family relationships, difficulty maintaining boundaries within the home, vulnerable to exploitation and substance misuse.

Following diagnosis parents have access to a specialist local organisation called Autism Early Support (AES). Although they are called Autism Early Support, they also support parents with

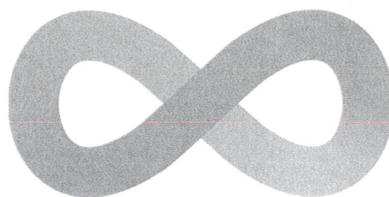
children who have both Autism and ADHD. It includes a series of interactive workshops and Family Support Groups that are designed to help parents/carers: -

<https://autismearlysupport.org.uk/programme-of-support-for-parents-carers/>

If a young person would still like to consider ADHD medication, they can opt in to the ADHD medication clinic waiting list. If the young person is over 17 years and 9 months old when requesting medication you will need to contact your GP.

A parent/ carer or young person can self-refer into Buckinghamshire CAMHS if there are concerns around mental health.

[Make a referral | Oxford Health CAMHS](#)



We hope that you find this guidance helpful. We would like to thank the parents who took their time with developing this guidance, based on their experience, to help you.

If you, or your young person would like to be part of future collaboration projects like this then please visit the participation page of the Buckinghamshire CAMHS website.

Thank You

Buckinghamshire Neuro Assessment and ADHD clinic Team

April 2025- Bucks Neuro Assessment and ADHD clinic Team



Oxford Health  
NHS Foundation Trust

Buckinghamshire  
CAMHS



Positive mental health for  
young people