

## Info-sheet on Private Diagnoses for ASD/C and ADHD

*(based on the NICE Guidelines 2017; 2018)*

The following information sheet is aimed to provide caregivers and professionals with basic information regarding best-practice standards for a diagnosis of Attention Deficit Hyperactivity Disorder (ADHD) and/or Autism Spectrum Disorder (ASD). If a child or young person has been given a diagnosis of ADHD and/ or ASD 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?**

If a person's private diagnosis of ADHD and/or ASD cannot be evidenced to have met the same standards as an NHS diagnosis, it may be more difficult for them to access certain treatment options. For example, if a private diagnosis of ADHD does not meet (or cannot be evidenced to have met) NICE guidance for assessment, it may be more difficult for them to access ADHD medication through the NHS. This also applies to families with young people who are already on medication and have obtained diagnoses and assessment reports from non-UK practitioners.

This information sheet can also be used as a guide for families who are considering obtaining a private neurodevelopmental assessment of ADHD and/or ASD. We have included a summary of questions/ things to look out for in pursuing a private diagnosis of ADHD and/or ASD.

**Please be aware** that the information in this document applies only to situations where families are looking to pursue/ have received a private diagnosis. The information in this document should not be used by any agency as a barrier for young people/ children to access support for their needs in school.

# NICE

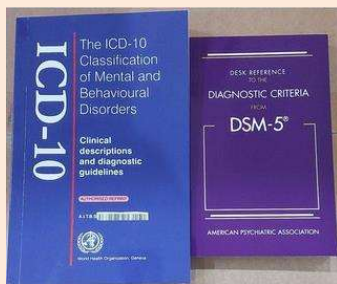
National Institute  
for Health and  
Care Excellence

## What are the NICE guidelines?

These are national recommendations for health and care in England. They are based upon the best available evidence and are put together by experts, people using services, carers and the public. Although they are the recommended guidelines for health and care that services are meant to work towards, we recognise that many services across the UK may not meet these guidelines due to various constraints (e.g. monetary resources).

## What manuals are used for diagnoses?

In the UK, diagnoses of ADHD and ASD are made in accordance with one of two globally used diagnostic manuals:



1. International Classification of Diseases (ICD)
2. Diagnostic and Statistical Manual of Mental Disorders (DSM)

*\*the numbers attached after the manual (e.g. ICD-10) indicate which version it is, currently the most recent manuals are the ICD-11 and DSM-5*

In the UK, the ICD is the most commonly used diagnostic manual.

**Kindly note**, for the purposes of this document we will be using the acronym 'ASD' as both the DSM-5 and ICD-11 (latest versions of the manuals) use the term 'Autism Spectrum Disorder' for diagnosis of this condition. However, we would like to recognise and acknowledge that most people in the Autism community prefer use of the title 'Autism Spectrum Condition' and relate to Autism as part of their identity as opposed to a disorder.

### NICE Guidelines: Autism Spectrum Disorder (ASD)

The NICE guidelines provide recommendations for what to consider when deciding whether or not to carry out an ASD assessment for a child/ young person. This includes:



- the severity and duration of signs and/or symptoms,
- the extent to which the signs and/or symptoms are present across different settings (i.e. home and school),
- the impact of the signs and/or symptoms on the child or young person and on their family or carer,
- the level of parent/ carer concern and, where possible, the concerns of the child or young person,
- the factors associated with an increased prevalence of autism
- the likelihood of an alternative diagnosis (NICE, 2017).

The NICE guidelines also provide standard recommendations for an assessment of ASD. Most relevant of which are that the assessment should be:



- made by a team of qualified professionals with the appropriate and specific training and expertise in diagnosing ASD. This includes the skills needed to carry out an assessment of children and young people with special circumstances (i.e. coexisting conditions, looked-after children and young people), **and**



- based on a full picture of the life of the person being assessed; encompassing:
  - their parent/ carer(s)'s concerns and, if appropriate, the child/ young person's concerns,
  - the young person's experiences of home life, education and social care,
  - the young person's social and communication skills and behaviours,
  - a consideration of alternative/ differential diagnoses and systematic assessment for co-existing conditions,
  - developmental, medical and family history, **and**



- does not rely on any *single* autism-specific diagnostic tool to diagnose autism (NICE, 2017).

## **NICE Guidelines: Attention Deficit Hyperactivity Disorder (ADHD)**

The NICE guidelines provide standard recommendations for a diagnosis of ADHD. Most relevant of which are that the diagnosis **must** be:



- made by a qualified professional with the appropriate and specific training and expertise in diagnosing ADHD, **and**
- based on a full picture of the life of the person being assessed; encompassing the person's:



- behaviour in more than one domain in their life (ie: school and home),
- impacts of concerning behaviour and,
- developmental, medical and family history, **and**



- based on evidence obtained from a range of sources, including (but not limited to) questionnaires completed by parents/carers and teachers, verbal observations of behaviour from parents/carers and teachers, and clinician observations of the individual (NICE, 2018).

### **What happens if a private diagnosis is non-compliant with NICE guidelines?**

If a young person's private assessment is not compliant with NICE guidelines, another diagnostic assessment may have to be completed if they wish to access an NHS service that requires a formal ASD/ ADHD diagnosis. This includes diagnoses where there is no evidence of an appropriate assessment having been completed (i.e. where there is no diagnostic report, or the diagnostic report does not provide evidence for an assessment having been completed in accordance with NICE guidelines).

**For private ADHD diagnoses**, this can *sometimes* be avoided by supplementing the diagnosis with further information. For example, if the ADHD diagnosis was made based on only information obtained from parents, there is no information from school and the child/ young person is already on ADHD medication, this might happen:



- following a referral into your local CAMHS, a clinician may request for the child/young person to stop taking ADHD medication for a short period of time. Following this period, the young person's school will be asked to complete some forms to provide information on the young person's behaviour in their school environment.
- If there is sufficient evidence from school to support the ADHD diagnosis, the clinician may still be able to refer you to the appropriate service (i.e. psychiatric appointment for medication) even if the school information was not included in the original ADHD assessment.

The short adjustment period ensures that school will be able to make observations based on the young person's baseline behaviour without support from medication. School should be informed about this process so that they are aware that there may be a difference in the child's behaviour during this period.

If the young person is on stimulant medication (any brand of methylphenidate, dexamfetamine or lisdexamfetamine) there is no medical difficulty with stopping medication for the period recommended. Most young people do not have any medical issues with stopping stimulants over short periods of time. *(That being said, please do not stop your medication without advice from a prescribing clinician.)*



If the young person is on a non-stimulant (guanfacine or atomoxetine) it might not be appropriate to stop the medication, but we might discuss reducing the dose over the period of screening.

### **Summary: What to look out for when pursuing a private assessment**

This checklist provides a summary of things to look out for when considering/ pursuing a private ASD and/or ADHD assessment. Diagnoses compliant with NHS standards will allow you to tick all of the boxes and should be evidenced through a diagnostic report.

#### **ASD Assessment**

Is the assessment and diagnosis being made by a team of qualified professionals with appropriate training and expertise in diagnosing ASD

- (including/ with access to clinicians like: *specialist child and adolescent psychiatrist, paediatrician, psychologist with training and experience in working with autistic children and young people, speech and language therapist and/ or occupational therapist*)?

*\*The assessment team does not have to include all of the above clinicians.*

Is the diagnosis being made based on:

- a full assessment of the young person's mental, clinical and social presentation (including discussion with parent(s)/ carer(s) about behaviour and symptoms in the different domains of the young person's everyday life), **and**
- a full developmental (i.e. development through childhood), medical and psychiatric history, **and**
- (through interaction with, and observation of the young person and use of standardised measures – e.g. ADOS, BOSA) an assessment of the young person's social and communication skills and behaviours; with focus on features consistent with the ICD-11/ DSM-5 **and**
- observer (person aside diagnostician) reports and assessment of the person's mental state (including use of standardised measures/ questionnaires – e.g. Social Communication Questionnaire).

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Did the assessment also consider the following things besides ASD symptoms:

- Coexisting conditions.
- Family and educational context.

(If appropriate) has the diagnosis been made with consideration of other assessments that help contribute towards the young person's profile, like:

- general physical examination looking specifically for potential signs of *neurofibromatosis*, *tuberous sclerosis*, signs of injury (ie: self-harm, child maltreatment) and *congenital anomalies and dysmorphic features*.
- assessment of other neurodevelopmental conditions that may contribute towards similar symptomology/ traits that appear associated with autism (ie: specific language delay/ disorder, learning disability/ global developmental delay, developmental coordination disorder (DCD)/ dyspraxia).
- assessment of other mental/ emotional and behavioural disorders.
- assessment of conditions in which there is developmental regression.
- assessment of severe hearing/ visual impairment, maltreatment and selective mutism.

(If there are discrepancies) during the assessment between reported signs and findings in the clinical setting, was additional information from other sources and/ or further autism-specific observations in different settings carried out?

***\*end of ASD assessment checklist\****

## ADHD Assessment

Is the assessment and diagnosis being made by a specialist psychiatrist, paediatrician or qualified healthcare professional with appropriate training and expertise in diagnosing ADHD?

Is the diagnosis being made based on:

- a full assessment of the young person's mental, clinical and social presentation (including discussion about behaviour and symptoms in the different domains of the young person's everyday life), **and**
- a full developmental (ie: development through childhood) and psychiatric history, **and**
- observer (person aside diagnostician) reports and assessment of the person's mental state (including use of standardised measures/questionnaires – e.g. Conners, SNAP-IV).

Has the diagnosis been made after the young person's symptoms of hyperactivity/ impulsivity and/ or inattention have met **all** the below:

- the diagnostic criteria in the DSM-5 and ICD-11.
- cause **at least** moderate psychological, social and/ or educational impairment on interview and/ or direct observation in multiple settings.
- pervasive; occurring in **2 or more** important settings including social, familial, educational and/ or occupational settings.

Did the assessment also consider the following things besides ADHD symptoms:

- The young person's needs.
- Coexisting conditions.
- Social, familial and educational circumstances.
- Physical health.
- Assessment of parents' or carers' mental health.

***\*end of ADHD assessment checklist\****