



A guide to Private Autism Diagnosis

Accessing a private adult autism assessment



Some people who think they may be autistic or are self-diagnosed and would like a formal diagnosis, may seek a private diagnosis. Private diagnosis usually costs anywhere between £750 and £2,500+.

If you're unable to afford this, or have no reason to seek a private diagnosis, you can request an autism assessment for free through the NHS, though you often need a referral from your GP.

However, in Leeds you can self-refer to the Autism Diagnostic Service (LADS): <u>https://</u> <u>www.leedsandyorkpft.nhs.uk/our-services/autism-diagnostic-service-lads/</u>. The waiting times for an NHS assessment are often long, sometimes years.

Private assessments are usually available much sooner and give you more choice and flexibility. You can usually self-refer.



If you're able to, bring someone close to you who can help explain your past experiences – a family member or close friend, preferably someone who knew you in early childhood. This can make the diagnosis process easier.

Sometimes, service providers such as the DWP and NHS services won't accept a private diagnosis and require an NHS one before they will agree to support you.

They may be more willing to accept a private diagnosis if it was carried out by an assessor who is also contracted to provide assessments for the NHS. It may also be worth staying on the waiting list for an NHS diagnosis, even if you get a private one.

If you are seeking a diagnosis in order to qualify for disability related adjustments in the workplace, it may be worth asking your employer for an occupational health assessment. This may help have your needs met at work while you wait for diagnosis.

How do I choose?

There are often lots of options available, especially as many assessments can take place online by video appointment.

Things to consider when choosing a private autism assessment provider:



• Are they reputable? Look for reviews and impartial information about the service. If possible, see if you can get recommendations from people you know and trust, i.e. good friends, or professionals you already know or work with. You could check for reviews on different websites (i.e. Trustpilot, Google, Facebook).

Bear in mind that sometimes people can leave fake reviews, so they may not always be accurate. A lot of reviews from a few different places should give you a good representation.

• What is your budget? Autism assessments vary in cost. Make sure you know what all the costs are up front, as well as what's included. Check if they can offer follow up appointments or support if you think this will be helpful.



- How many appointments will you need to attend? Some assessments take place over one longer appointment, some require a few or even several appointments.
- How accessible is the venue to you? If the appointments are face to face, what transport will you need? This is especially important if you need to travel there a few times. If you have other accessibility requirements such as wheelchair access, ensure the venue is suitable.
- If you want to bring a friend or family member with you to the assessment, check with the provider that they are able to accommodate this, and whether they can go into the assessment with you are required to wait in the waiting room etc.
- **Do you also want to be assessed for any co-occurring conditions such as ADHD or OCD?** Some specialists can offer these services as part of the same assessment. Some may also specialise in certain areas such as autism in women, who can be more difficult to diagnose.

- Do you have someone who knew you in childhood who can be interviewed or fill in a questionnaire? Usually, evidence that your autistic traits have been present since a young age is required to obtain a diagnosis. If you don't know anyone or are not comfortable including them in the process, some clinicians can find ways around this.
- How will you feel if you do not receive an autism diagnosis? Check what the process is if you do not agree with their decision. You may be able to appeal, or you may want to get a second opinion either through your GP or by paying for another private assessment elsewhere.

What assessment tools do they use?



Private clinicians are usually of a higher standard if they follow **NICE best practice guidelines**.

The diagnosis tools they use can vary. They assess you against a set of criteria for autism which is found in the DSM-5 and ICD-10 diagnostic manuals.

Some common diagnostic tools are:

- <u>Autism Diagnostic Observation Schedule (ADOS)</u>
- The Diagnostic Interview for Social and Communication Disorders (DISCO)
- Autism Diagnostic Interview Revised (ADI-R)



After your assessment, you should receive a detailed report of the assessment and any diagnosis made. You may also be informed of the result verbally on the day of your last appointment, or shortly after by telephone.

Contact us

This guide was produced by **Leeds Autism AIM**, part of The Advonet Group. We are a free service coled by and run for autistic adults (aged 18+) in the Leeds area.



If you need help to process information you have been given about the autism diagnostic process, we can support you by:

- Speaking to you by phone, via email, text chat or in person at our Autism Hub
- Sending you information that is easy to process about getting a diagnosis
- Passing on information about where to get a private autism diagnosis in your area



If you have any questions about this guide or about diagnostic services in Leeds, please contact us:

- Email us at leedsautismaim@advonet.org.uk
- Call The Advonet Group's office on 0113 244 0606 and ask for someone from the Leeds Autism AIM team
- Follow us on Facebook at @leedsautismaim
- Follow us on Twitter at @leedsautismaim

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