**The aim of this factsheet is to tell you more about the process of screening and diagnosis for adults who believe they may be autistic.**

**Disability Services**

# What is autism?

Autism is a lifelong developmental disability that affects the way a person communicates with and relates to people and the world around them. For students at university level, the most common diagnosis is ‘Level 1 Autism Spectrum Disorder’, which used to be known as Asperger Syndrome. People with this diagnosis are usually of average or above average intelligence but may have challenges navigating a non-autistic world, and they may experience high levels of stress and anxiety as a result.

Autism affects people in different ways, but everyone with a diagnosis of autism shares a difference in making sense of the world. Several traits are common to most autistic people, including:

* **Differences in communicating** – autistic people are often fluent and articulate in their speech, but may find it difficult to make conversation and small talk with non-autistic people, and may seem to lack interest in what someone else is saying, perhaps due to sensory distraction or differences in processing information. They may be quite literal in their understanding of spoken language or find metaphors and sarcasm harder to understand. Autistic people may also find it difficult to understand non-verbal signals and facial expressions when interacting with non-autistic people. However, they may have no difficulty interacting with other autistic or neurodivergent people.
* **Differences in social relationships** - many autistic people want to be sociable, and may be very good at socialising with other autistic people, but they might find it harder to understand the social rules that non-autistic people take for granted. This can lead to difficulties in some social settings, which can be stressful or tiring. Group environments can be particularly challenging. Some autistic people may find it harder to make or keep friends, although this is not true of all autistic people, many of whom have good friendships and relationships, often based on shared interests.
* **Differences in imaginative thought and flexible thinking** – autistic people often think in different and unique ways, which can be a significant asset, but they may find it hard to think in abstract and neurotypical ways and they may find it more difficult to manage change. Changes to timetables and routines can cause stress and anxiety. They may also find it hard to guess what someone else is thinking, and sometimes they may feel that they get stuck in ‘thought loops’, especially around negative thoughts.
* **Differences in sensory processing** – many autistic people experience differences with sensory processing and may become overwhelmed by too much sensory information. For example, they may feel uncomfortable in a large lecture room, filled with chatting students, with harsh fluorescent strip lighting. They may find it harder to process their body’s signals, such as feeling hungry, or feeling too hot or cold. Too much sensory information can prevent some autistic people from processing what they are being taught and can lead to spikes in anxiety and overload which is tiring and stressful and might lead to meltdown or shutdown.

These are the main features of autism, but the characteristics will vary greatly. Each autistic person experiences their autism in their own individual way, and will have their own individual requirements, preferences and aspirations.

# How can I find out if I am autistic?

## Step 1: Screening tools and checklists

There are several online screening tools which you can use to gauge whether you may have characteristics associated with autism. These are **not** diagnostic tests, but they can help in deciding whether to pursue a diagnostic assessment, and they are often used by diagnostic assessment services. The tools are:

* The full (50 question) adult Autism Quotient screening tool: <https://psychology-tools.com/autism-spectrum-quotient>
* The combined Empathizing and Systemizing Quotient screening tool: <https://openpsychometrics.org/tests/EQSQ.php>

These tools will take you through the questions and automatically calculate a score. They will explain the score you get, and what this might mean. Please be aware that these tools are quite old, and they tend to work better for male people, so don’t worry if your scores don’t indicate autism – they can be wrong.

You should also work through the Inclusive Autism Traits Checklist available at <https://autisticality.com/2016/03/21/inclusive-autistic-traits/>

## Step 2: Referral

**For students registered with a Leeds GP (including Leeds Student Medical Practice)**

If you are registered with a GP in Leeds, you can self-refer to the Leeds Autism Diagnostic Service, which is the NHS autism assessment service in the Leeds area. To do this, you will need to complete the self-referral form found on the LADS website: <https://www.leedsandyorkpft.nhs.uk/our-services/autism-diagnostic-service-lads/>. There is likely to be a wait of some weeks for your initial appointment. LADS will give you an indication of waiting times once you have been referred and accepted for assessment. Further information about LADS and their diagnostic pathway is available from the link given above.

**For students registered with a GP out of the Leeds area**

If you are registered with a GP outside the Leeds area, you will need to follow the referral process for your local health authority. For most areas, the standard process is to visit your GP to ask for a referral for an autism assessment. It is usually best to book a double appointment with your GP, so you have more time to talk, and to take with you the results of the screening tools mentioned above, and the Inclusive Autism Traits checklist.

## Step 3: Diagnostic Assessment

**For students registered with a Leeds GP**

Below is a diagram and an overview of the diagnostic process offered by the Leeds Autism Diagnostic service. This process can vary according to your individual circumstances, and further information can be found on the [LADS website](https://www.leedsandyorkpft.nhs.uk/our-services/autism-diagnostic-service-lads/).



If you are referred to the Leeds Autism Diagnostic Service, your diagnostic assessment will take place in two or three stages. You will be sent some forms and questionnaires to complete (your Disability Coordinator can help you with these if required). Your parents will also be asked to provide some information, either in person, or by completing a questionnaire. If you do not want your parents to be involved, or if they cannot be involved, please let your Disability Coordinator know.

Your forms and questionnaires will be reviewed by the diagnostic team who will invite you to an initial assessment, provided there is enough information in your forms to indicate that an assessment is appropriate. If LADS has sufficient information about you and your background, along with your developmental history, they may be able to carry out additional interviews and test at this first appointment. This means that you may be given a diagnosis at your first appointment, around 13 weeks after referral.

If it is not possible to gather all the relevant information at the initial appointment you will be invited back to a Clinical Decisions meeting with the senior diagnosticians. They will ask you some more questions and undertake some more observations before giving you a diagnostic decision. There may be a longer wait for the Clinical Decisions meeting, which means that the assessment process may take many months or longer.

LADS most commonly use the ADOS diagnostic tool when assessing adults. You can find out more about diagnostic tools on the [National Autistic Society website](https://www.autism.org.uk/advice-and-guidance/topics/diagnosis/diagnostic-tools).

If you are given a diagnosis of autism, you will be invited back to LADS for a follow up meeting where you can find out more about autism and receive information about local services.

## For students registered with a GP outside the Leeds area

Diagnostic pathways vary across the country, but generally involve an initial information gathering appointment, and a clinical decisions appointment. Parents are often asked to contribute to the process, but not always.

## Private Assessment

If you feel you cannot wait for an assessment on the NHS, you may be able to find a private diagnostic service. This costs around £1000-£2500, but you will be seen quickly. It is important to ensure that you find someone who is qualified to carry out diagnostic assessments; for autism, this should be a registered Psychiatrist or registered Clinical Psychologist. You can find a list of questions to ask providers as an appendix to this document.

## I have managed this long without a diagnosis – why should I get one now?

Diagnosis is always a personal choice. As an adult, you can choose whether you want to be assessed for autism, and there is no right or wrong answer. It is very common for people to get to university age (and older) before finding out they are autistic. It is never too late to be diagnosed.

The benefits of diagnosis are that it might answer questions you've always had about yourself and explain things you have experienced in the past. It also means you can access funding, for example at University, for additional support. Autism is recognised as a disability in terms of the law, which means you would be protected by the Equality Act 2010 when it comes to things like applying for jobs.

The disadvantages are that some people feel they will be 'labelled' and will be treated differently as a result. They might worry that they will have to tell people about their diagnosis and that it might affect their future (in fact, this is quite rare – there are only a few circumstances where autistic people are legally obliged to tell someone about their diagnosis).

So the choice about whether or not to pursue a diagnosis is yours. You might want to talk to your family or friends to help you make the decision. You can also talk to your Disability Coordinator for further information and advice.

## Resources for further reading – please note that the University of Leeds is not responsible for external content

## Websites and forums

* Thinking Person’s Guide to Autism: <http://www.thinkingautismguide.com/>
* Information about diagnosis: <http://www.autism.org.uk/about/diagnosis.aspx>
* Autism/Aspergers communities: <http://www.wrongplanet.net/> and <http://www.aspiescentral.com/forum.php>
* A website created by and for university students on the autism spectrum: <http://www.users.dircon.co.uk/~cns/>
* Leeds University Union Neurodivergent Society: a student-run society for neurodivergent students, whether diagnosed or not: https://www.facebook.com/groups/luuneurodiversitysociety

## Books

* *Very late diagnosis of Asperger Syndrome: How seeking a diagnosis in adulthood can change your life*, Philip Wylie <http://www.amazon.co.uk/dp/1849054339>
* *I Think I Might Be Autistic: A Guide to Autism Spectrum Disorder Diagnosis and Self-Discovery for Adults*, Cynthia Kim <http://www.amazon.co.uk/dp/0989597113>
* *Nerdy, Shy and Socially Inappropriate: A User Guide to an Asperger Life*, Cynthia Kim <https://www.amazon.co.uk/Nerdy-Shy-Socially-Inappropriate-Asperger/dp/1849057575>

## Articles

(See also the shared drive at <https://goo.gl/cWKkUT> which is regularly updated with articles)

* *Inclusive autistic traits*, Jay Avery <https://goo.gl/kEuT3N>
* *Autism: Overload*, Shayne Holzman <https://goo.gl/68atfb>
* *Autism as an Adult, Susan Dunne* <https://goo.gl/qvjXDL>
* *Lesser-known things about Asperger’s Syndrome,* Robyn Steward <https://goo.gl/pT5XFJ>
* *What Does It Meant to Look Autistic?* M. Nicole R. Wildhood <https://goo.gl/WJcpxS>

**Blogs and Vlogs**

* Autistic Not Weird: <https://autisticnotweird.com/>
* The Autistic Advocate: <https://theautisticadvocate.com/>
* Aspergers from the Inside: blog at <https://aspergersfromtheinside.com/>, YouTube channel at <https://goo.gl/hSLLEw>
* Everyday Aspergers: <https://www.facebook.com/everydayaspergers/>
* Life with Aspergers: <http://life-with-aspergers.blogspot.co.uk/>
* Agony Autie: https://www.youtube.com/channel/UCN9fwImPnx16e8-eThlKCWQ
* Musings of an Aspie: <https://musingsofanaspie.com/>
* Neurowonderful: blog at <http://neurowonderful.tumblr.com/>, YouTube channel at <https://www.youtube.com/user/neurowonderful>
* Autisicality: <https://autisticality.com/>

## Social Media

If you use Twitter, you can follow the hashtag #ActuallyAutistic and use the hashtag #AskingAutistics to connect with other autistic people for advice, guidance and support. The following are some accounts by autistic people who explain their experiences of autism. Please note that the University of Leeds is not responsible for external content.

[Pete Wharmby](https://twitter.com/commaficionado)

[AutisticSciencePerson](https://twitter.com/AutSciPerson)

[NeurodivergentRebel](https://twitter.com/NeuroRebel)

[Thinking Person’s Guide to Autism](https://twitter.com/thinkingautism)

[AgonyAutie](https://twitter.com/AgonyAutie)

[TheAutisticAdvocate](https://twitter.com/KieranRose7)

[Autist Making Way](https://twitter.com/AutistMakingWay)

[Erin Ekins](https://twitter.com/QueerlyAutistic)

[Ann Memmott PGC](https://twitter.com/AnnMemmott)

[Autistictic](https://twitter.com/autistictic)

[Emily](https://twitter.com/ItsEmilyKaty)

**Appendix**

**Private assessment: questions to ask potential providers**

* **Who will carry out the assessment?**  An adult diagnosis of autism can only be formally confirmed by a Psychiatrist or a Clinical Psychologist.  Some providers also involve Speech & Language Therapists or Occupational Therapists (a multi-disciplinary team), and some use specialist nurses to undertake some of the information gathering, before making a decision on whether a psychiatrist or psychologist should complete the assessment.
* **Does the provider focus primarily on children, or do they have good experience of assessing adults?**  It is a good idea to find a provider who is experienced in assessing adults.  You could ask how many adult assessments they have done or ask how many years of experience their diagnosticians have in assessing adults.
* **Which diagnostic tool does the provider use?**  The common tools are ADOS and DISCO – DISCO is generally considered a better tool for assessing adults as it takes a broader, more holistic view of the individual and is based on discussion rather than undertaking tasks, which is more appropriate for adults.
* **How much developmental history does the provider require, and in what format?** Some providers request that a parent or close relative who knew the person being assessed when they were very young is present at the assessment.  Others capture information via a Relative’s Questionnaire, and some will assess without requiring parental involvement.
* **Does the provider issue a full report after the assessment, or simply a letter confirming the outcome?**  Although assessments which include a report can be more expensive, the report itself is often extremely helpful.
* **What format does the assessment take?** Is it over one session, or more?  How long do sessions usually last?  A DISCO assessment takes as long as required – perhaps 4-5 hours, whereas an ADOS assessment is usually quicker.  If it’s a long assessment, will there be an opportunity for a break?
* **How autism-friendly does the provider seem to be?**  Have they thought about the sensory environment of the assessment room (e.g. flexible lighting, minimal distractions, comfortable surroundings, as few people as possible present)?  Do they communicate effectively and flexibly?
* **Does the provider offer any post-diagnostic support included in the cost of assessment?**  This is not essential, but it’s worth asking to see if this type of support is included in the cost of the assessment.