

Understanding Autism

Handout 1 - The autism spectrum and diagnosis



Around one in 100 people are on the autism spectrum

The figure of one in 100 comes from The National Autistic Society.

People of any gender can be autistic



Autism in girls and women is much more likely to have been missed or misdiagnosed.

There is now more awareness of how autism may present differently in females.

For example, girls (compared with boys) are more likely to:

- Copy the social behaviour of others and 'mask' the difficulties they have.
- Be a quiet pupil at school and go unnoticed.
- Have more typical interests and hobbies.

There are likely to be many undiagnosed autistic adults in the UK. The exact ratio of male to female is unknown and research is ongoing.

Autism is neurodevelopmental

It is a difference in the way the brain develops. Autism is lifelong and autistic children grow up to become autistic adults.

Research suggests that autism can be caused by a variety of factors that lead to the brain developing differently.

Genetic factors play a role, though no single 'autistic gene' has been identified.

These genetic factors can be passed from parents to children.

Some autistic people have a learning disability and some do not

Mencap estimates that around 50% of autistic people also have a learning disability.

However, people of all intellectual abilities can be autistic, and many autistic people have successful careers in a wide range of professions.

You may not realise that a person is autistic when you meet them.

Some people may not disclose that they are autistic, or may not have had a diagnosis.

Some autistic people carry an autism alert card. A person may use this to alert others when feeling overwhelmed and finding communication difficult.

The autism spectrum

There is no such thing as a typical autistic person.

As well as people having different intellectual abilities, issues such as sensory differences, communication differences and anxiety can have a greater or lesser impact on the lives of different autistic people.

It's therefore too simplistic to think of the autism spectrum as a simple scale with 'more able' people at one end, and 'less able' people at the other.

The spectrum model is an attempt to represent this diversity and complexity.



Uneven abilities

An autistic person may have 'uneven abilities' and excel at certain tasks whilst finding other, seemingly less complex, tasks very challenging.

For example, a person may be studying a subject at Masters level, but perhaps find it hard to plan an unfamiliar journey, make a telephone call to book a health appointment or organise paperwork at home.

Because of issues like sensory sensitivities, an autistic person may struggle significantly in some environments whilst managing very well in others.

Whilst some autistic people lead very independent lives, others, particularly many people with a learning disability, may need care and support to live their day to day life.



Autistic people who also have a learning disability

Some people with a learning disability are fairly independent, and perhaps just require support with complex aspects of daily living such as managing money and bills.

Other people with a learning disability may need a lot of support to enable them to stay safe and well, communicate their needs, make choices and take part in activities.

Autistic people who don't have a learning disability

Some autistic people who don't have a learning disability may also need support at times. High levels of anxiety, communication and sensory differences can affect people's ability to manage their day to day life.

Some autistic people can experience significant mental health difficulties.

Other terms you may hear people use

Asperger Syndrome was an official diagnosis until 2013, when it was replaced by 'Autism Spectrum Disorder'.

Many people diagnosed with Asperger Syndrome choose to continue to use the term. High Functioning Autism is not an official diagnosis, though some people use this term to describe people who do not have a learning disability.

How to ask for an adult autism diagnostic assessment

A person's GP can refer them for an autism diagnostic assessment. There are different diagnostic services for people who have a learning disability.



People who do not have a learning disability

A person's GP can refer them to the Neurodevelopmental Service which covers Surrey and North East Hampshire. It is a free NHS service.

Not all GPs have an up-to-date understanding of autism, and some may need persuading to make the referral.

Since the Autism Act 2009 more NHS diagnostic services exist, though waiting lists for an assessment can be long.

People who have a learning disability

Diagnostic assessments can be carried out by NHS Community Learning Disability Teams.

Later life diagnosis

Many people who do not have a learning disability are diagnosed in adult life. There is no age limit for diagnosis, and there are still many undiagnosed autistic adults.

Some adults seek an autism diagnosis assessment after their child has been diagnosed.

Some people may have other diagnoses, which they feel don't accurately explain their difficulties. They may feel that autism better describes their needs.

A diagnostic assessment can help to make sure that people receive the right ongoing support.

There is no simple 'test' for autism

A diagnostic assessment involves a meeting with an autism specialist, and a series of questionnaires. A parent or sibling, who has known the person since they were a child, often comes to the meeting.

This helps, as a person's autistic characteristics need to have been present from childhood.



The diagnostic criteria focus on the difficulties a person may experience. Common strengths of autistic people are explored in Handout 2 - Common strengths and passionate interests.

An brief overview of the diagnostic criteria

A person does not necessarily need to show all of the characteristics outlined below to be given a diagnosis of 'autism spectrum disorder'.



The assessment focuses on:

- Social communication and interaction.
- Restricted, repetitive behaviours, interests or activities.

Social communication and interaction

This includes looking at:

- Difficulties a person may have with friendships and social relationships, sharing of interests and emotions, having two way conversations and adjusting how they behave in different social situations.
- A person's ability to interpret gesture, voice tone, and facial expressions.
- Differences in how a person uses eye contact.

Restricted, repetitive behaviours, interests or activities

This includes looking at:

- Behaviours like lining up objects, rocking and repeating phrases.
- Strong attachments with unusual objects.
- Deep and passionate interests in a narrow range of topics, which can at times be all consuming.
- Difficulties managing change, and moving from one activity to another, preferring things to be the same (e.g foods & journeys), and having very fixed routines.
- Whether a person is more or less sensitive in one or more of their senses, such as touch, taste, smell, sight and hearing.

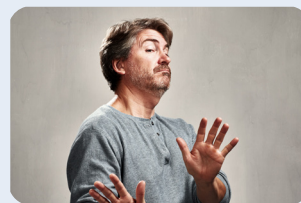
The diagnosis is given in the form of a diagnostic report

The report is checked by a Consultant Psychiatrist. Some people will be told they do not have an autism spectrum disorder, and some people may be referred for further support if they have more complex needs.

PDA (Pathological Demand Avoidance)

PDA is widely understood to be a profile on the autism spectrum. Whilst not a separate diagnosis the PDA profile can be identified during an autism diagnostic assessment.

People have a need for control which is often anxiety related, and are driven to avoid everyday demands and expectations (including things that they want to do or enjoy) to an extreme extent. Specialists can offer advice on helpful approaches to support.



A person who does not meet the criteria for an autism diagnosis, but has significant challenges with social communication and interaction, could potentially be given a diagnosis of Social Communication Disorder.

The autism diagnostic criteria have changed over the years

As our understanding of autism has developed, the diagnostic criteria have widened to become more accurate. Some autistic people diagnosed today would not have met the more narrow criteria in the past.

Recovery college courses

There are a range of courses available which are designed to help people improve their health and wellbeing.

Courses include the Autism Post Diagnostic Course.

For more information go to: www.sabp.nhs.uk and search for 'recovery college'. If you can't see the courses advertised email: Recovery.College@sabp.nhs.uk

Support after diagnosis

An autism diagnosis does not guarantee that a person will be eligible for social care or mental health services. A post diagnostic course is offered in Surrey and North East Hampshire. A person's diagnostic report should highlight the strengths they have as well as their difficulties.

The report will also identify the support a person needs in relation to social communication, and restricted, repetitive behaviour, interests or activities.

There are 3 potential levels of support:

- 1) requiring support
- 2) requiring substantial support
- 3) requiring very substantial support



Some autistic people will be eligible for Personal Independence Payments (PIP), though often people have to battle to get assessors to recognise the impact of their 'hidden difficulties' on their daily life.



I was diagnosed when I was 11 years old. It really helped because I got the extra help I needed at school, particularly with English, as I really struggled with comprehension.



Since my diagnosis people say I seem more autistic. The truth is I just spend less time pretending I'm not autistic these days !



I told my manager at work that I was autistic, and she said 'you don't look autistic' - I have no idea what autistic is supposed to look like !

I asked for a diagnostic assessment after my son was diagnosed. At first I thought 'he can't be autistic, he's just like me' !



I see my diagnosis as a signpost rather than a label. It helps me understand my strengths, and why certain things are a struggle. I'm not so hard on myself these days.



Getting the diagnosis was just the start. I've begun to analyse my life. Looking back I can now see myself as an autistic kid rather than a naughty kid.



You have to be careful about stereotypes. At school I was a really quiet pupil. My mum read a leaflet about Asperger Syndrome which said that children are often noisy and disruptive in class, so she thought I couldn't be autistic.



I don't have many sensory sensitivities, but my friend has lots. He does find communication much easier than me though, so we're just autistic in different ways. I guess that's why it's called a spectrum.



The term 'high functioning autism' isn't always helpful. Yes, I'm intelligent, but in some environments I get so easily overwhelmed I can barely function at all.



I plan my life carefully these days to make sure my needs for rest and recovery are factored in. My diagnostic report and the post diagnostic course really helped me to understand myself, and plan a lifestyle that suits my strengths and needs.



It all fell into place once I got my autism diagnosis. Previously my anxiety about busy places was treated as a phobia, but now we all understand that it's a sensory need, rather than a fear.

