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# **SASC Guidance on the Assessment and Identification of Autism / Autism Spectrum Conditions**

# **May 2022**

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## **Introduction**

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### **A note on language**

This paper uses **‘identity-first’ language**, i.e. an ‘autistic person' rather than a ‘person with autism’. However, we acknowledge that there are different preferences about the use of this terminology. For some, autism is a core part of their identity and they see themselves as autistic, rather than ‘someone with autism'. Other individuals prefer the term ‘with autism'. See also the sections below discussing The Autistic Voice, P.6 and Labels and Terminology, P.8.

This SASC[[1]](#footnote-1) guidance offers up to date sources of information on autism for specialist teacher-assessors. It is designed to increase awareness of the needs of autistic children, young people and adults. During an assessment for a suspected specific learning difficulty, where carers/parents/teachers of children, or adults themselves, raise the issue of autism, there is a responsibility to highlight the best local pathway to potential diagnosis. There is also a need to be aware of the needs of individuals who already have an autism diagnosis (and are seeking assessment of other issues) and apply effective strategies when working with them. It is important that all specialist assessors anticipate the potential communication and environmental needs of anyone referred to them.

### **The role of specialist teacher-assessors.**

It is now commonly recognised that, in autism, there is frequent co-occurrence and overlap with a range of other neuro-developmental conditions e.g. dyslexia, developmental coordination disorder (DCD)/dyspraxia etc. (Gillberg 2010).

Autistic children, young people and adults can present with specific literacy difficulties (Brimo et al 2021). Autistic children seem to have a higher incidence of ‘dyslexic-like’ difficulties compared to a more typical population, so may be referred for an assessment and meet criteria for the identification of specific literacy or other learning difficulties (SpLDs).

The association between dyslexia and autism is complex. Further research is needed in this area to understand patterns of co-occurrence across developmental conditions. Where there is co-occurrence, the style of literacy difficulty may not always reflect that found amongst a more typical ‘dyslexic’ profile, as some discrete skills can be enhanced in autism, such as effective word reading/decoding (hyperlexia) which may, in some individuals, be accompanied by comprehension difficulties (Ostrolenk, 2017). There is wide variability at group level. It may also be that co-occurring conditions result in protective factors. For example, an autistic person with strong visual skills may be able to use this attribute to manage aspects of any dyslexic difficulties. Conversely, co-occurrence can add in further risk factors for learning, and the accumulation of these factors can lead an individual to develop compensatory strategies and surface behaviours. This may mask complex and multiple underlying cognitive mechanisms and add to cognitive load and anxiety.

SASC does not advocate that specialist teacher- assessors, working with individuals, **screen for** or **diagnose** autism. While current training for specialist teacher-assessors covers autism awareness, it does not encompass identification and diagnosis. Professional boundaries and ethical issues need to be carefully adhered to. Diagnosis is a complex process and requires specialist training and qualification, relevant training and experience in both autism and the co-occurring condition/s, and a high level of expertise within a multidisciplinary ‘team approach’.

Specialist teacher-assessors, as part of their assessment practice, *can* document (where permission is given) relevant developmental characteristics and experiences, noting their impact on the learning or work context of the individual concerned. There may also be some contexts where specialist assessors are able to contribute insights on co-occurring issues such as dyslexia ***within*** a multidisciplinary team context.

## **Overview of Autism / Autism Spectrum Conditions**

This section provides a brief overview of autism, and how the concept of ‘the spectrum’ evolved, with references for further reading if specialist assessors are interested in extending their knowledge. It is important to be aware that conceptualisations of autism will continue to change over time and professionals need to stay informed of updates and use them appropriately.

Autism was first formally described by early clinicians (Kanner/Asperger) in the 1940s (Rosen et al, 2021) but there are anecdotal case studies predating this work, suggesting similar patterns have always been present. Kanner’s work led to the first list of common behaviours. Later on, there was an emergence of formal diagnostic criteria which adopted a categorical approach and led to the identification of specific subgroups such as childhood autism and Asperger’s Syndrome, which then influenced diagnostic criteria in the *International Classification of Diseases for Mortality and Morbidity Statistics* (ICD) and the *Diagnostic and Statistical Manual of Mental Disorders* (DSM) (Ouseley and Cermak, 2014).

Since that time there have been many changes in terminology and a broadening out, in both of the international diagnostic systems, ICD and DSM, of what we understand by autism. There has been a move away from subgroups to a wider spectrum model. Silberman (2015) captures the shifts over time, offering further insight into how the concept of an autism spectrum has evolved, with attention to changing models of diagnosis.

A useful summary of changes over time can also be found in Happe & Frith (2020) who identified seven major changes in how autism is thought of, operationalised and recognised, i.e.

1. From a narrow definition to wider diagnostic criteria.
2. From a rare to a relatively common condition.
3. From something affecting children to a lifelong condition.
4. From something discrete and distinct to a dimensional view.
5. From one thing to many ‘autisms’ and a compound or ‘fractionable’ condition.
6. From a focus on ‘pure’ autism to recognition that complexity and comorbidity is the norm.
7. From conceptualising autism purely as a developmental disorder, to recognising a neurodiversity perspective, operationalised in participatory research models.

General definitions of autism and how it affects children, young people and adults can be found on the National Autistic Society (NAS) website. The NAS was founded in 1962 and is a charity for autistic people and their families. It has a vision to transform lives, changes attitudes and create a society that works for autistic people. The NAS offers many services, such as running specialist schools and adult support services, and is active in areas such as training, campaigning and research. See <https://www.autism.org.uk/>

In the devolved nations there are similar organisations that people may wish to refer to. For example, Scottish Autism, Autism Cymru and Autism NI:

[Scottish Autism - Autism Awareness Charity & Services for Children & Adults in Scotland](https://www.scottishautism.org/)

[Home - Awtistiaeth Cymru | Autism Wales | National Autism Team](https://autismwales.org/en/)

<https://www.autismni.org/>

In addition, the NHS provide valuable guidance, information and definitions:

<https://www.nhs.uk/conditions/autism/>

<https://www.nhsinform.scot/illnesses-and-conditions/brain-nerves-and-spinal-cord/autism-spectrum-disorder-asd>

## **Models of Autism**

### **Triad of Impairments**

The Triad of Impairments model (see below) developed by Wing and Gould (1979) became a key framework which has shaped diagnostic systems and influenced a range of psychological theories and interventions over time. It led to the emergence of a spectrum model and a shift away from the identification of defined sub-groups, to a focus on a range of dimensions and a personalised approach.

In this model of autism there is a **triad of impairments** in:

* **Social interaction:-**

Finding it hard to understand patterns of social organisation, to interact flexibly and recognize how people are feeling.

* **Social Communication (verbal and non-verbal)**:-

Finding it hard to communicate reciprocally in different contexts, taking into account the needs of the listener.

* **Social Imagination:-**

Finding it hard to imagine what others are thinking and having limited capacity to imagine different scenarios based on previous experience to plan and problem-solve new scenarios.

The 3 core elements of the Triad are associated with **rigid, repetitive patterns of behaviour and routines.** These can be simple or complex in nature, and include sensory issues and rumination as well as stereotyped movements or special skills and interests.

### **Dyad Model**

The Diagnostic and Statistical Manual of Mental Disorders (DSM-5, American Psychiatric Association, 2013) *combined* issues of social communication and interaction, as many clinicians feel they are tightly interwoven. This newer model has combined the triad model areas and now provides **two** key areas of focus:

* **Persistent deficits in social communication and social interaction.**
* **Restricted, repetitive patterns of behaviour, interests, or activities.**

There is also more emphasis on sensory issues and non-verbal communication, which is also the approach taken in the ICD-11 (ICD-11, World Health Organization, January 2022)

See references below to international classification systems.

### **Areas of Difference**

More recently, formal diagnostic criteria have been informed by definitions of autism that focus on differences rather than deficits. There is an attempt to avoid deficit-focused language and listen to the ‘autistic voice’. One example is the description used by the Autism Education Trust (AET) which is a not-for-profit organisation currently led by two national autism charities, the National Autistic Society (NAS) and Ambitious about Autism (AaA). It was established and supported by the Department for Education. The AET offers education professionals training, practical tools and resources to support children and young people with autism aged 0 to 25 years. It provides professional standards, competency and progression frameworks to allow organisations and individuals to audit and enhance their skills. Ithas, in more recent years, introduced a useful model for autism that describes 3 key areas of difference. The AET define autism as a *different* way of being, rather than as a *deficient* or *disordered* way of being. The AET refer to three key areas of difference in:

1. **Social Understanding and Communication**

Autistic people have differences in the way they communicate, understand and use language. They engage in social life from a different perspective (Milton, 2011). This leads to differences in how the person interacts and develops relationships.

1. **Sensory Processing and Integration**

Sensory differences can include hyper (high) or hypo (low) sensitivity in relation to the eight senses of **sight, hearing, touch, taste and smell, interoception** (internal sensations), **balance** (vestibular) and **body awareness**(proprioception). These differences will vary from person to person and can fluctuate in their responsiveness depending on a number of different factors, for example the time of day or the environment.

1. **Flexible Thinking, Information Processing and Understanding**

Autistic people have differences in their attention, interests and how they learn. This can include being very focused on particular interests. They have a different way of being flexible, so often feel safer and more comfortable with routines and structure as this lessens uncertainty.

Further information is available on the following AET link.

[What is autism? – Autism Education Trust](https://www.autismeducationtrust.org.uk/what-is-autism/)

### **The Autistic Voice**

The autistic voice is often captured in qualitative research summarising the experiences of autistic people, or in high quality online resources/narratives. Autistic people may talk about how their autism itself is not a problem, but the neurotypical world plus their autism can create mental health and other problems.

The Scottish Government has a *Different Minds One Scotland* campaign which covers these perspectives:

[Lived Experiences from autistic people living in Scotland | Different Minds](https://differentminds.scot/lived-experiences/)

The link below originates from Birmingham Open Media (BOM) which is a community group/centre for art, technology and science, dedicated to ‘creative innovation with purpose’. They open up the debate about autism and how it is portrayed and offer guidance to anyone identifying with an autistic profile.

[Am I Autistic? | BOM](https://bom.org.uk/am-i-autistic/)

## **Current Research Areas**

### **Gender Differences**

The way that autism manifests in individuals can vary greatly, despite commonalities in developmental characteristics. There has been increasing work in recent times on gender differences in autism, with an awareness that girls and women are more likely to be overlooked, often due to their use of ‘masking’ strategies (Mandy 2019). It is also argued that an historical ‘male dominated’ focus in the development of diagnostic systems has shaped practice. The following two links are useful for exploring reasons for gender differences as regards identification. The first is published by the National Association for Special Educational Needs (NASEN), a charitable membership organisation that exists to support and champion those working with, and for, children and young people with SEND and learning differences. The second is from the NAS website.

<https://nasen.org.uk/resources/girls-and-autism-flying-under-radar>

[autistic women and girls (autism.org.uk)](https://www.autism.org.uk/advice-and-guidance/what-is-autism/autistic-women-and-girls)

Milner et al (2019) discuss five themes in a project exploring insights into female presentation and experience of autism spectrum disorder: fitting in with the norm, potential obstacles for autistic women and girls, negative aspects of autism, the perspective of others, and positive aspects of having autism.

For further insight into living with autism as a female, the following BBC video of the experiences of the McGuinness family, may be useful.

[BBC One – Paddy and Christine McGuinness: Our Family and Autism](https://www.bbc.co.uk/programmes/m00122vl)

### **Mental Health**

Anxiety disorders are very common amongst people on the autism spectrum. Roughly 40% of individuals identified with autism have symptoms of at least one anxiety disorder at any time, compared with up to 15% in the general population (NAS 2021). Understandably, this can lead to sadness or depression – one reason why a mixture of anxiety and depression is common. See:

[Lived Experiences from autistic people living in Scotland | Different Minds](https://differentminds.scot/lived-experiences/)

[Mental health (autism.org.uk)](https://www.autism.org.uk/advice-and-guidance/topics/mental-health)

Although autism is not a mental health condition or a mental illness, people on the autism spectrum are more vulnerable to develop mental health problems. Research indicates that 70 per cent of children with autism develop mental health problems, while 16–35 per cent of adults with autism have a co-occurring psychiatric disorder.

[autism-guide-web-version.pdf (mind.org.uk)](https://www.mind.org.uk/media-a/4400/autism-guide-web-version.pdf)

**Autistica UK** have some action briefings which summarise current issues, research, and research needs, related to mental health issues in autism.

<https://www.autistica.org.uk/downloads/files/Autistica-Action-Briefing-Adult-Mental-Health.pdf>

<https://www.autistica.org.uk/downloads/files/Autistica-Action-Briefing-Children-and-Young-Peoples-Mental-Health.pdf>

## **Labels and Terminology**

Neurodiversity discourse has enabled people to talk positively about autism and view it as a natural way of being, rather than a pathology (Brownlow & O’Dell, 2009). Difficulties are presented as differences / alternatives rather than skills that are ‘lacking, deficient or impaired’. Personal strengths and skills are also identified as ways to build up a framework for support.

In August 2021 the British Psychological Society published guidance entitled:-

*Working with autism. Best-practice guidelines for psychologists.*

[New best-practice guidelines for working with autistic people | BPS](https://www.bps.org.uk/news-and-policy/new-best-practice-guidelines-working-autistic-people)

Within this document there is much useful material. Key areas to reflect on are the shifting focus on the concept of neurodiversity and whether to use ‘person-first’ language. ‘Neurodiversity’ is seen as describing a continuum of behaviours and differences in people’s skills, abilities and understanding. (BPS guidelines 2021).

The terminology used to describe autism continues to be debated. Terms used may include *autism*, *autism spectrum disorder* and *autism spectrum condition*. Some individuals can object to being referred to as ‘disordered’ and view autism as a different way of being. Others can feel that autism seriously challenges their lives and wish to retain the term ‘disorder’ so that their needs are recognised. Some children, young people and adults with high level needs require long term intensive care and support and cannot always express their views around this debate.

The use of ‘person-first’ language is also debated, i.e., a ‘person with autism’ versus an ‘autistic person.’ In a 2015 NAS study, autistic adults and their families preferred the term ‘autistic’ while professionals tended to prefer the term ‘on the autism spectrum’ (Kenny et al., 2016). Kenny found that for some, autism is a core part of their identity and they see themselves as autistic, rather than ‘someone with autism’. Other individuals who do not see autism as central to their identity prefer the term ‘with autism’. It is important to clarify what language the individual would prefer, or if this is not possible, to seek guidance from their parents, families or carers. Given there are different preferences, documents and links referred to in this paper may reflect varied language-use in relation to the term ‘autism’.

See also: <https://www.ed.ac.uk/salvesen-research/about-neurodiversity>

## **Diagnostic pathways**

### **Issues in the use of screening tools**

There are many instruments available to rate behaviours associated with autism, or screen for autism, which are sometimes used by clinicians prior to or as part of a formal diagnostic process. **The use of these tools is not recommended as part of a 1:1 SpLD assessment.** Great caution and sensitivity should be applied by the assessor when reporting on **social and communication difficulties and/or sensory issues** (which may impact on choice of learning strategies) in a child’s profile. The use of social and communication checklists to inform the background information gathered *may* be helpful but ASD diagnostic checklists are **not** recommended. Such screeners are prone to bias, error and subjectivity and should only be used when:

* An individual has the appropriate **autism** **diagnostic training and qualification**, and can interpret the screening tools in the context of a thorough understanding of the developmental condition(s) being investigated,

**And**

* There is an opportunity, where necessary, to discuss outcomes with a supervisor, team, colleague or mentor.

SpLD assessors, therefore, should not attempt to screen for or diagnose autism. An exception is where specialist teachers/SENCOs/psychologists/other clinicians are working together as part of an agreed diagnostic pathway, and in multi-disciplinary teams. In this scenario, the team may have locally agreed protocols for the use of screening materials, and, under supervision and in a team context, a specialist teacher with relevant experience may be asked to use such materials.

All specialist assessors however, have a responsibility to report on any relevant factors that have arisen during their assessment. They should adopt an information-gathering approach and consider onward referral for further investigation where it is felt appropriate and consent is given. A template referral letter is provided for this purpose – see **Appendix 1.** While, in any referral, it is important to name the issue (e.g. autism) that is the subject of that referral, it is vital that the use of this terminology is discussed carefully with the parent/carer/individual being assessed, as appropriate. Their permission for such referral should be sought and it should be stressed that the chief purpose of the referral is to investigate the presenting issues in more detail. An autism ‘diagnosis’ may or may not be the outcome of that referral. If more than one presenting issue appears to need further investigation, the referral letter can of course be adapted accordingly.

### **Identifying relevant concerns**

The 2021 National Autism Strategy does highlight the need for early identification and increased awareness of autism in education. The strategy highlights that 1.8% of all pupils in England now have an autism diagnosis. The Strategy also highlights that less than 5 in 10 staff in schools were confident about supporting autistic students in schools. This information was part of the All-Party Parliamentary group for Autism (APPGA) ‘*Autism Act 10 Years On*’ report cited in the Autism Strategy. It is also noted that autistic students struggle to get support through SEND systems more generally and ‘early enough’.

Observations made during an assessment may highlight rigidity of approach to task, social interaction /communication issues, need for routines or sensory needs. It is also important to share information relating to any specific learning difficulties identified, as such needs will always be taken into account within a specialist autism assessment. Parents may raise the issue of autism and then it is then helpful to share details of local and or national guidelines for assessment and intervention. Encouraging individuals, parents and carers to talk to their GP, their school SENCO, or, in further and higher education, the learning, wellbeing or disability support teams, would always be a good starting point for a specialist assessor, as pathways do vary according to where individuals live.

### **Understanding pathways for identification and diagnosis**

The National Autistic Society offers advice for teachers who suspect autism/an ASC, as outlined in the links below. They stress it is important to first talk to the school and specifically the SENCO, who may have insight and can refer into local autism diagnostic pathways. Parents are advised to book an appointment with their child’s GP if they wish to go through the NHS. They can request that the GP refers their child to an autism diagnostic service that can arrange to carry out a formal diagnostic assessment which is multidisciplinary and carried out by clinicians with specialist skills and training. Some parents may choose to contact a private autism diagnostic service directly due to long waiting lists for assessment, but this can be costly.

<https://www.autism.org.uk/advice-and-guidance/professional-practice/teachers-diagnosis>

[Autism and diagnosis: advice for teachers](https://www.autism.org.uk/advice-and-guidance/professional-practice/teachers-diagnosis)

The NAS also offer parents and carers advice on what to do if they wish to explore a diagnostic assessment.

<https://www.autism.org.uk/advice-and-guidance/topics/diagnosis/diagnostic-assessment/parents-and-carers>

[parents (autism.org.uk)](https://www.autism.org.uk/advice-and-guidance/topics/diagnosis/diagnostic-assessment/parents-and-carers)

### **Adult Referrals**

The NAS also offer advice for adults who think they have autism – see link below. Some diagnostic teams accept self-referrals but in most cases a GP referral is required or the individual may be referred by another health professional who is already involved. Most adults see either a psychiatrist, clinical psychologist, or a team made up of professionals from different disciplines:

<https://www.autism.org.uk/advice-and-guidance/topics/diagnosis/diagnostic-assessment/adults>

### **Higher Education (H.E.) settings**

Autism&Uni is a project that was originally funded by the European Union as a research initiative to support young people on the autism spectrum to help them navigate the transition from school into Higher Education (HE). Dr Marc Fabri, at Leeds Beckett University, has led this project in recent years. Good practice guidelines for professionals and online toolkits are provided.

[» Best Practice Guides – The Autism&Uni project (autism-uni.org)](https://www.autism-uni.org/bestpractice/)

Marc Fabri also provides 5 top tips to support students in higher education on the NAS website.

[Top 5 autism tips: autistic students at university](https://www.autism.org.uk/advice-and-guidance/professional-practice/tips-students-university)

The NAS also offer specific online training focusing on the needs of students in H.E.

[Autism and SPELL in higher education](https://www.autism.org.uk/what-we-do/professional-development/training-and-conferences/spell-higher-education)

### **Steps for all children, young people and adults**

Specialist assessors are advised to follow the advice given above *and* the steps below.

1. If concerns are raised by parents/carers or adults being assessed around autism, knowing the pathways for your area is helpful to ensure you provide accurate advice.
2. Where concerns are raised, signpost the individual concerned to a GP, or specialist autism diagnostic team, and refer to the advice and support systems on the National Autistic Society website [Contact us (autism.org.uk)](https://www.autism.org.uk/what-we-do/contact-us). With children and young people, encourage individuals to talk to SENCOs in school, learning support teams in further education, and disability and wellbeing student support services in higher education establishments, as relevant. You can also suggest parents search ‘local offer’ and the name of their education authority. The local offer details the services available for children and young people with special education needs and disabilities.
3. If you are aware that local pathways would accept referrals from specialist assessors use a template letter (see Appendix 1) and share relevant reports, with consent. Your observations may provide valuable background and support the important notion of multi-disciplinary collaboration. Increased collaboration between health and education staff to improve delays in identification and intervention has recently been highlighted as a priority in the National Autism Strategy (GOV.UK 2021).
4. Take care when signposting services, to ensure that those individuals and services you refer individuals to, have the required specialist training and experience and are registered with appropriate regulatory bodies.
5. Take careful note of the fact that parents may be on a journey of understanding their child’s needs and there is a need for sensitivity when talking to them about wider concerns. They may already be exploring and understanding issues relevant to a potential specific literacy difficulty. Some parents, or indeed young adults, may not be ready to access a formal autism diagnostic assessment, even if some traits are presenting. In some cases it may not be required or desired. Timing is crucial if these discussions are to take place and they are often best carried out by a professional who knows them well and by those who understand the diagnostic process.
6. Young adults who are seeking a diagnosis may choose to contact individual psychologists, or other specialist trained professionals who are working privately, to carry out a diagnostic process. If you are referring individuals to a private psychologist it is important to identify professionals who have had highly specialist training in autism diagnosis. For example, training such as DISCO, ADI-R, 3Di and ADOS[[2]](#footnote-2). They need to be following the NICE guidance <https://www.nice.org.uk/guidance/cg142>
7. The cost of a private diagnosis will not be accessible to all and some individuals will need to work with their GP to explore options. The National Autistic Society states that adults are most likely to be referred to an assessment centre or local Clinical Commissioning Group, with private diagnosis an option too.
8. The Covid-19 pandemic has had a significant impact on waiting lists for a diagnosis of autism, both NHS and privately funded, due to lockdown restrictions Significant issues with delays in acquiring a diagnosis were already being highlighted by a BMA briefing (2019)[[3]](#footnote-3) prior to the pandemic and have now become more marked. It is important to ensure that, in the light of this, individuals and families are not given the impression that they can quickly get a diagnosis. Some skilled and experienced clinicians will give an ‘individual’ clinician diagnosis as an interim measure and assess needs, which may be sufficient in some contexts, whilst an individual is on a waiting list for a more in-depth multi-disciplinary diagnosis fulfilling NICE guidelines. This kind of interim assessment can be referred to as a ‘working’ or ‘indicative’ diagnosis. It allows for interventions to be implemented and matched to a needs assessment based on the recommendations of the clinician. However, the Disabled Student Allowance (DSA) system still requires that a GP or consultant authorises an autism diagnosis and confirms its substantial impact on day-to-day life, and this may require a more detailed diagnostic process to have occurred, involving medical clinicians. The new National Autism Strategy[[4]](#footnote-4) (GOV.UK 2021) discussed later in this document, indicates a welcome future commitment to speeding up diagnosis.

## **Diverse Routes to a Diagnosis – examples and case studies**

**Year 2 Child** – Parent raises concerns about social and communication difficulties and eating issues with family GP, who refers child to local autism multi-disciplinary specialist diagnostic service based within a Child Development clinic at a local hospital. Paediatrician works in collaboration with speech and language therapist, occupational therapist and a specialist clinical psychologist to formulate a diagnosis.

**Year 9 child** – Parent speaks to school SENCO as student is school-refusing, is socially isolated and has many routines. There is a family history of Obsessive Compulsive Disorder (OCD). The SENCO speaks to a specialist teacher from the autism outreach service who observes and works with the student and then refers the student to the Child and Adolescent Mental Health Service (CAMHS), where there is a diagnostic pathway for older students. A psychiatrist works in collaboration with a specialist clinical psychologist and mental health nurse to make a diagnosis of autism.

**17-year-old** – No issues in school but mental health issues have led to student accessing counselling support and sessions with a NHS psychiatrist for low mood, self-harm and anxiety. The psychiatrist raises the possibility of an autism assessment after completing some screening questionnaires. The family decides to fund a private referral to a specialist centre run by a national autism charity as there are long waiting lists for NHS diagnostic services. Student is seen by 2 psychologists trained in diagnostic practice who confirm autism.

**21-year-old student** – A student makes a self-referral to a private autism diagnostic service run by a team of psychologists and mental health professionals. The student was previously diagnosed with dyslexia and dyspraxia whilst at school and received some additional support in school and university. Reasons for referral were related to problems transitioning into employment, conflict with peer group, rigid routines impacting on day-to-day functioning and development of motor and vocal tics. The team formulate a diagnosis of autism.

The journey to a diagnosis can be complex – view Amy’s story from the Ambitious about Autism (AaA) website. AaA are a charity who promote the voices of autistic children and young people and offer a range of support services and advice.

[Getting my autism diagnosis | Ambitious about Autism](https://www.ambitiousaboutautism.org.uk/about-us/media-centre/blog/getting-my-autism-diagnosis)

**Case studies showing different diagnostic routes**

In the links below clinical case scenarios have been put together as accompanying tools to improve professional’s knowledge of how the NICE guideline for children, young people and adults can be implemented. These illustrate the complexity and unique differences that may present.

[Clinical case scenarios (Children YP) (nice.org.uk)](https://www.nice.org.uk/guidance/cg128/resources/clinical-case-scenarios-pdf-183180493)

[Clinical case scenarios (Adults) (nice.org.uk)](https://www.nice.org.uk/guidance/cg142/resources/autism-in-adults-clinical-case-scenarios-pdf-pdf-186542317)

## **Diagnostic Practice**

If a child, young person or adult is referred for an autism assessment there are various diagnostic tools and frameworks used. The clinical team will need to assess an individual against a set of criteria found in international classification systems. The process can be lengthy and may involve assessment over time. Interventions may be implemented and reviewed as part of the process.

### **The National Institute for Health and Care Excellence (NICE) and other guidelines**

There are ‘gold standard’ guidelines for the diagnosis of autism (e.g., NICE, 2016, 2017; SIGN, 2016, Welsh Gov 2021). Multi- disciplinary teams are required to ensure the correct skills and training are present to carry out a comprehensive autism diagnostic assessment.

This will include:

* Taking a detailed developmental history from an informant using validated specialist instruments (DISCO, ADI etc.).
* Carrying out skilled observations of social, communication and behaviour patterns consistent with DSM 5 and ICD criteria.
* Integrating assessments of any health, physical or mental health conditions that may coexist.
* Carrying out psychological assessments, speech and language assessments and assessment of social skills.
* Gaining the views of the child, young person or adult.

In the case of children and young people, core members of the assessment team should include a paediatrician and/or child and adolescent psychiatrist, speech and language therapist and a clinical or educational psychologist. Other professionals who may contribute might include occupational therapists, specialist health visitors, a specialist nurse, specialist teachers, or social workers who are embedded in autism diagnostic teams.

NICE guidelines stress the need to gain a profile of the child or young person’s strengths skills, difficulties and needs that can be used to create a needs-based management plan, taking into account family and educational context. The most effective assessments will address cognitive, physical, social, emotional, language, behavioural and neurological issues and this requires a wide team of skills and training

Adult diagnosis may be carried out by a smaller team but should still follow the model of collaborative assessment with more than one clinician wherever possible. Those engaged in the process need to have specialist training.

National Institute for Health and Care Excellence (NICE) guidelines:

Under 19s: <https://www.nice.org.uk/guidance/cg128>

Adults : <https://www.nice.org.uk/guidance/cg142>

Scotland: <https://www.sign.ac.uk/assets/sign145.pdf>

Wales: [Code of Practice on the Delivery of Autism Services - Supporting Guidance (gov.wales)](https://gov.wales/sites/default/files/publications/2021-08/code-of-practice-on-the-delivery-of-autism-services-supporting-guidance.pdf)

NICE have produced a Quick Guide of ‘what to expect‘ for young people and their families if referred for an autism assessment and diagnosis.

[Assessment and diagnosis of autism: what to expect | Quick guides to social care topics | Social care | NICE Communities | About | NICE](https://www.nice.org.uk/about/nice-communities/social-care/quick-guides/assessment-and-diagnosis-of-autism-what-to-expect)

###  **International Classification Systems**

All of the above guidelines recommend the use of two internationally recognised systems:

1. International Classification of Diseases (ICD-11, World Health Organization, January 2022)
2. Diagnostic and Statistical Manual of Mental Disorders (DSM-5, American Psychiatric Association, 2013).

The formal DSM-5 Autism Diagnostic Criteria are as follows:

**A. Persistent deficits in social communication and social interaction across multiple contexts, as manifested by the following, currently or by history (examples are illustrative, not exhaustive, see text):**

* Deficits in social-emotional reciprocity, ranging, for example, from abnormal social approach and failure of normal back-and-forth conversation; to reduced sharing of interests, emotions, or affect; to failure to initiate or respond to social interactions.
* Deficits in nonverbal communicative behaviours used for social interaction, ranging, for example, from poorly integrated verbal and nonverbal communication; to abnormalities in eye contact and body language or deficits in understanding and use of gestures; to a total lack of facial expressions and nonverbal communication.
* Deficits in developing, maintaining, and understanding relationships, ranging, for example, from difficulties adjusting behaviour to suit various social contexts; to difficulties in sharing imaginative play or in making friends; to absence of interest in peers.

**B. Restricted, repetitive patterns of behaviour, interests, or activities, as manifested by at least two of the following, currently or by history (examples are illustrative, not exhaustive; see text):**

* Stereotyped or repetitive motor movements, use of objects, or speech (e.g., simple motor stereotypies, lining up toys or flipping objects, echolalia, idiosyncratic phrases).
* Insistence on sameness, inflexible adherence to routines, or ritualized patterns or verbal nonverbal behaviour (e.g., extreme distress at small changes, difficulties with transitions, rigid thinking patterns, greeting rituals, need to take same route or eat food every day).
* Highly restricted, fixated interests that are abnormal in intensity or focus (e.g., strong attachment to or preoccupation with unusual objects, excessively circumscribed or perseverative interest).
* Hyper- or hypo reactivity to sensory input or unusual interests in sensory aspects of the environment (e.g., apparent indifference to pain/temperature, adverse response to specific sounds or textures, excessive smelling or touching of objects, visual fascination with lights or movement).

**C. Symptoms must be present in the early developmental period (but may not become fully manifest until social demands exceed limited capacities or may be masked by learned strategies in later life).**

**D. Symptoms cause clinically significant impairment in social, occupational, or other important areas of current functioning.**

There are also specifiers to indicate whether the individual has an accompanying intellectual impairment, language impairment, neurodevelopmental, genetic or medical conditions.

The International Classification of Diseases (ICD 11) is scheduled to follow very similar descriptors and to use the wider spectrum model: see descriptor below from ICD11.

**6A02 Autism spectrum disorder**

‘*Autism spectrum disorder is characterised by persistent deficits in the ability to initiate and to sustain reciprocal social interaction and social communication, and by a range of restricted, repetitive, and inflexible patterns of behaviour, interests or activities that are clearly atypical or excessive for the individual’s age and sociocultural context. The onset of the disorder occurs during the developmental period, typically in early childhood, but symptoms may not become fully manifest until later, when social demands exceed limited capacities. Deficits are sufficiently severe to cause impairment in personal, family, social, educational, occupational or other important areas of functioning and are usually a pervasive feature of the individual’s functioning observable in all settings, although they may vary according to social, educational, or other context. Individuals along the spectrum exhibit a full range of intellectual functioning and language abilities.*’

Unlike the DSM-5, the ICD-11 does not stipulate that a person must have a certain number or combination of features to meet the threshold for autism. Instead, it lists various defining features and relies on the clinical judgement of skilled diagnostic teams. ICD 11 also has specific codes for autism with and without disorders of intellectual development, and indicates if it co-exists with or without impaired functional language, or an absence of functional language.

### **Good practice guidelines / National Autism Strategy (NAS)**

The new National Autism Strategy (GOV.UK 2021) was published in July 2021.

Local Authorities (LAs) and the National Health Service (NHS) are required to have regard to this strategy.**[[5]](#footnote-5)**

There are 6 key areas of focus:

* Improving understanding and acceptance of autism within society
* Improving autistic children and young people’s access to education, and supporting positive transitions into adulthood
* Supporting more autistic people into employment
* Tackling health and care inequalities for autistic people
* Building the right support in the community and supporting people in inpatient care
* Improving support within the criminal and youth justice systems

This strategy built on previousreviews and strategies to produce a combined children, young people and adult strategy as previous work had often not taken a lifelong perspective. It integrated reviews of the SEN COP (DES/DOH 2015), National Autistic Society research and also the rapid research carried out by the London School of Economics (Pais and Knapp, 2020) to improve understanding of autistic people’s experience during the Covid-19 pandemic.

## **Summary and Key Messages**

* Specialist teacher- assessors should not screen for or diagnose autism.
* The information gathered as part of a specialist assessment for specific learning difficulties can contribute important details to facilitate the screening and diagnosis process and should be shared with relevant specialist diagnostic services if appropriate consent is given.
* The specialist assessor can signpost parents, young people and adults to appropriate services if autism is raised by a family or individual during an assessment.
* Diagnosis of autism should be carried out by experienced multi-disciplinary diagnostic teams who have had specialist training. Private diagnosis is increasing but it is important to ensure referrals are made to suitably qualified and experienced clinicians.
* The new National Autism Strategy (Gov.UK 2021) sets out targets to improve the quality of the diagnostic process and increase autism awareness and promote good practice.
* It is important that special assessors have a good understanding of autism, the various models of autism and the most up to date policy and good practice guidelines.
* Specialist assessors may need to make adjustments to their assessment practice when working with a student who has already been diagnosed with autism.
* There is a higher incidence of ‘dyslexic like’ difficulties in autism than in the non-autistic population.
* Autistic individuals may also therefore meet the criteria for the identification of a specific literacy/learning difficulty.
* Specialist assessors need to be aware of the co-occurrence of the range of neurodevelopmental conditions found amongst the autistic population.
* Gender differences is a current key area of research and interest in the field of autism.
* There is useful advice around mental health issues and autism on the MIND and Young Mind’s websites
* Pathways to diagnosis are very variable but usually the first point of reference is the GP.
* With children and young people, it is useful to encourage discussion with the SENCO or learning/student support services in further or higher education settings. The SEND ‘Local Offer’ is a good source of information for local support services.
* There are specialist charities and organisations that can offer advice and information such as the NAS, AET, AaA etc.

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## **Appendix 1: Referral letter template**

Your name, qualifications and contact details

Date

To (Whom It May Concern, Name of GP if known)

CC: Parent(s)/ Carer(s)/Teacher and/or school as relevant

Re: Name of child/young person/student

DOB:

On (give date) X was referred to me (give reason as appropriate e.g., for an assessment to

investigate a suspected specific learning difficulty / because of concerns about progress at

school / college/ university.

A full developmental history was taken at the assessment. X’s parent(s)/carer(s)/teacher(s) contributed information about difficulties with social and communication characteristics at school, and the age at which they began.

Difficulties associated with social interaction, social communication, social imagination and routines, including sensory issues [delete as required] were described by X and parent(s)/carer(s)/teacher(s): (Briefly list/bullet point difficulties)

During my assessment X: (give examples of difficulties noted at assessment, e.g., social interaction, social communication, social imagination and routines including sensory issues etc.

Briefly list any other relevant results of assessment and relevant contextual information.

I am making this referral because it appears X would benefit from specialist screening for a potential multi-disciplinary autism diagnostic assessment to determine the most accurate diagnosis/diagnoses and provide recommendations for support.

In making this referral I am following the SASC Guidance on the assessment and identification of Autism Spectrum Conditions, which can be found via the

Downloads tab at www.sasc.org.uk.

Yours sincerely/faithfully

**NB to assessors using this template:**

In this referral letter the term autism has been used so that it is very clear what the referral might cover and the individual concerned is directed to the most appropriate pathway.

It is extremely important however, that there has been a prior discussion with the individual/parent/carer so that they understand the reasons for the use of this term in the referral letter and have given permission for this referral to be made. Despite the progress made in de-stigmatising autism, people can be extremely anxious and concerned about the implications of a diagnosis. On the other hand, there can be relief that someone has been listening to their concerns and helping them move forward to find out more about the issues that they would like explored. It could be helpful for specialist assessors to explain directly why they cannot themselves screen for or diagnose autism, why they have therefore avoided the use of such terminology in their assessment reports (except in documenting onward referral) but ***have*** used this terminology directly in the referral letter itself.

1. [www.sasc.org.uk](http://www.sasc.org.uk) [↑](#footnote-ref-1)
2. DISCO Diagnostic Interview for Social and Communication Disorders framework

 ADI-R Autism Diagnostic Interview Revised

 3Di Autism Diagnostic Interview

 ADOS Autism Diagnostic Observation Schedule. [↑](#footnote-ref-2)
3. [autism-briefing.pdf (bma.org.uk)](https://www.bma.org.uk/media/2056/autism-briefing.pdf) [↑](#footnote-ref-3)
4. <https://www.gov.uk/government/publications/national-strategy-for-autistic-children-young-people-and-adults-2021-to-2026> [↑](#footnote-ref-4)
5. <https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/1004528/the-national-strategy-for-autistic-children-young-people-and-adults-2021-to-2026.pdf> [↑](#footnote-ref-5)