

What does the terminology mean?

Autistic Spectrum Disorder (ASD) - This is the umbrella term used for all the diagnoses found on the autistic spectrum. The characteristics of children with an ASD vary from one child to another but are generally seen in three main areas, called the autistic triad. These are: difficulty with social interaction; difficulty with language and communication skills; presence of repetitive and stereotyped behaviours.

Autism - This diagnosis is given to children when they have difficulties in all three areas of the triad. Children with this diagnosis will have had some delay in the onset of their language skills although their language skills at the time of diagnosis may be fine.

Asperger Syndrome - This diagnosis is given to children when they have difficulties in all three areas of the triad, but they have had no delay in the onset of language.

Atypical Autism / Pervasive Developmental Disorder – Not Otherwise Specified - These diagnoses are given to children who have had difficulties in just two of the three areas of the autistic triad.

Social Communication Disorders Clinic

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Autistic Spectrum Disorders: Accessing Assessment

This information booklet provides basic information for parents who are concerned that their child may have an autistic spectrum disorder. It provides guidance on the process of getting your child a diagnostic assessment.



What are the benefits of getting a diagnosis?

It can be a difficult decision to pursue a diagnosis of autism or Asperger Syndrome for your child.

There are sometimes concerns that, if a diagnosis is given, the child may become defined by their diagnostic label or their skills and abilities may be underestimated due to others' perception of the diagnosis.

For many, however, a formal diagnosis can:

- bring a sense of relief (both for the child and the family)
- helps the individual, families, professionals and others to better understand and manage the child's needs and behaviour
- help to open doors to get access to support and services that may be beneficial to a child with ASD.

Because ASDs present differently from person to person, making a diagnosis can be difficult. High Functioning Autism and Asperger Syndrome are often diagnosed later than autism, due to the ability of more able children to develop coping strategies that can mask their true difficulties.

Getting an initial assessment

If you are concerned that your child may have an ASD, your first step must be to visit your GP.

When you visit your GP, it can help to take along a list of behaviours and characteristics that make you suspect your child has an ASD. These can act as useful prompts during your appointment.

Once your GP is convinced of your child's difficulties, s/he should refer you for a specialist assessment, which will occur locally to you.

If you have difficulties in getting your GP to agree to make the referral, you may wish to keep a record of the difficulties that you are having. You could also ask your child's school to write a letter of support or, if your GP is part of a group practice, ask to see one of the other doctors.

Who will diagnose my child?

There are a number of different health professionals who may be involved in diagnosing an ASD in children. Most frequently these would be psychiatrists, clinical psychologists or paediatricians. These professionals can help establish what is causing your child's difficulties and provide help and support for both parents and the child following a diagnosis being given.

Your child's GP is described by the NHS as a tier 1 service. Tier 2 services would include Child Development centres and your local community paediatrician. Your local Child and Adolescent Mental Health Service (CAMHS) can be either tier 2 or tier 3 NHS service.

Getting a second opinion

If your child has had an initial assessment, but you are concerned that the conclusions do not match your own views there are several steps that you can take in order to get a second opinion.

1. A first step would be to talk to the professionals that carried out the initial assessment. It might be helpful to ask them to explain how and why they came to the conclusions.
2. If, following this discussion, you still do not agree with the professionals then you can ask them to refer you for a second opinion. This could be provided either by another member of their team or by a Tier 4 NHS service (national specialist services) such as the Social Communication Disorders Clinic at Great Ormond Street Hospital.
3. If your local team is unwilling to make the referral, or you feel uncomfortable in asking them, then you can go back to your GP and ask for a second opinion from a national specialist service.
4. Once the Tier 4 service has received the referral they will contact the tier 2 / 3 service and ask them to support this request. It is important that your local paediatric or Child Mental Health services are involved in the longer term.