

Autism Spectrum Disorder

Diagnostic Assessment in Children

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Aim

The aim of this leaflet is to explain the diagnostic assessment of children referred for possible autism spectrum disorder.

What is autism?

Autism is a lifelong developmental disability. It is sometimes referred to as autism spectrum disorder or ASD. The word 'spectrum' is used as children with autism may not all present in the same way. Some are able to live independently with minimal difficulties. Others may require lifetime specialist input. However, they share three key areas of difficulties:

- Social communication
- Social interaction
- Social imagination

These difficulties must be present:

- across different environments
- for at least 6 months and
- before the age of 8 years

Around 700,000 people in the UK have autism. Children with autism may also have other co-existing conditions such as learning impairment, mood disorder, attention deficit hyperactivity disorder (ADHD) or underlying medical conditions.

The cause of ASD is not fully understood. There may be a combination of genetic and environmental factors.

Your child's rights before diagnosis

You do not need an autism diagnosis to apply for benefits and support for your child. Getting benefits and support should be based on your child's need rather than diagnosis.

Your child may be entitled to:

- community care
- extra help at school
- benefits

As a parent/carer, you may also be able to claim Carer's Allowance.

Professionals that may be involved in the diagnostic assessment

Community paediatrician

Your child's Special Educational Needs Co-ordinator (SENCo), GP or another healthcare professional usually need to refer your child to a community paediatrician. Community paediatricians are experts in child health and development, especially developmental disabilities. They are usually involved in the initial assessment of autism and signposting to support services.

Speech and language therapists

Speech and language therapists (SALT) assess speech and communication abilities. They may provide a social communication summary report if your child is under SALT. Some children may require further observation or assessment known as the Autism Diagnostic Observation Schedule (ADOS).

Clinical psychologist

Clinical Psychologists may be involved to provide direct assessment to children and young people with co-morbid mental health concerns, attachment difficulties, developmental trauma and/or significant adverse early life experiences (including Looked After Children).

The diagnostic assessment

Currently, there is an arrangement within Lincolnshire for the diagnostic assessment of children with suspected autism. You can expect the following to happen during and after your child's autism assessment.

The community paediatrician, SALT and clinical psychologist are likely to assess your child separately. The findings are usually brought together by the community paediatrician to inform the diagnosis. Hence, you may need to attend more than one appointment. It may be some time between appointments.

The assessment may include:

- reports from all settings (e.g. school, nursery)
- autism specific developmental and family history
- Social communication assessment (e.g. ADOS)

- observations in more than one setting
- cognitive communication, behaviour and mental health assessments
- MIM (an observational assessment of parent-child attachment)
- adaptive functioning assessment (Vineland)
- needs and strengths assessment of family members
- full physical examination
- tests and assessments for other conditions when appropriate.

The team should explain the reason for each test or assessment. You should be given plenty of time to ask questions. If you don't understand something, don't be afraid to ask for a more detailed explanation.

Waiting time

If your child's referral reaches threshold for acceptance, your child will be placed on the waiting list for autism assessment. We aim to get your child seen by a team member **within 18 weeks** once on the waiting list.

If Autism Diagnostic Observation (ADOS) assessment is required, your child will be referred to SALT. At present, the waiting list for ADOS is a minimum of **12 months**. Once ADOS is completed, your child will be seen by the community paediatrician. You will be informed whether your child meets the diagnostic criteria for autism spectrum disorder based on the reports and assessments done. A written report will be sent by post to you after the appointment.

Private diagnosis is an option if you wish to reduce the waiting time. The cost and follow up service of private assessment can vary. For details of independent diagnosticians, please contact the Autism Helpline 0808 800 4104 or refer to <http://www.autism.org.uk/>

After diagnosis

The majority of children are discharged after the final appointment when a diagnosis is given and you are signposted to local services. If your child has a co-existing condition requiring ongoing support from us, further follow up will be provided.

If you don't agree with the diagnosis

You may be told that your child is not on the autism spectrum or your child may be given a diagnosis with which you disagree.

You may wish to seek a second opinion. You can either:

- return to the GP explaining your situation and ask them to refer your child elsewhere, or
- pay for a private assessment (diagnosis given by private practitioners is not endorsed by community paediatrics but your child's school may endorse it).

Remember that the second assessment may reach the same conclusion as the first assessment.

To give feedback on this leaflet, contact:

**Community Paediatrics, Lincoln County Hospital, Greetwell Road, Lincoln,
LN2 5QY**

Tel: 01522 707156

For further related information: <http://www.autism.org.uk/>

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www.accessable.co.uk/united-lincolnshire-hospitals-nhs-trust

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