

Understanding NICE guidance

Information for people who use NHS services

Diagnosing autism in children and young people

NICE 'clinical guidelines' advise the NHS on caring for people with specific conditions or diseases and the treatments they should receive.

This booklet is about recognising and diagnosing autism in the NHS in England and Wales. It explains guidance (advice) from NICE (the National Institute for Health and Clinical Excellence). It is mainly written for parents and carers of children and young people who may have autism but there is also information for young people themselves. It may also be useful for anyone with an interest in the condition.

The booklet is to help you understand the care that should be available in the NHS. It does not describe autism or how it is diagnosed in detail. A member of your healthcare team should discuss this with you. There are examples of questions you could ask throughout this booklet to help you with this. You can get more information from the organisations listed on page 11. Medical terms printed in **bold type** are explained on page 10.

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The advice in the NICE guideline covers:

- the signs of autism
- how autism should be diagnosed in children and young people.

It does not look at:

- how the NHS should support children and young people with autism after diagnosis. NICE is developing another guideline on this. Details are available at www.nice.org.uk

Care for children and young people who may have autism

In the NHS, patients and healthcare professionals have rights and responsibilities as set out in the NHS Constitution (www.dh.gov.uk/en/DH_113613). All NICE guidance is written to reflect these. Children and young people with possible autism and their parents and carers (if appropriate) have the right to be involved in discussions and make informed decisions about care with the healthcare team. Their choices are important and healthcare professionals should support these wherever possible. All children, young people and their parents and carers should be treated with dignity and respect.

To help children and young people, and their parents and carers if appropriate, to make decisions, healthcare professionals should explain autism and how it is diagnosed. They should cover possible benefits and risks related to the circumstances of the child or young person. Children and young people, and their parents and carers, should be given relevant information that is suitable for them and reflects any religious, ethnic, or cultural needs they have. It should also take into account whether they have any physical or learning disability, sight or hearing problem or language difficulties. They should have access to an interpreter or advocate (someone who helps people to put their views across) if needed.

When parents and carers are involved they should be able to discuss or review their child's care. As assessment and diagnosis progress, or circumstances change, it is possible for children and young people (or, if appropriate, their parents and carers) to change their mind about assessments and investigations.

Healthcare professionals should follow the Department of Health's advice on consent (www.dh.gov.uk/en/DH_103643) and the code of practice for the Mental Capacity Act. Information about the Act and consent issues is available from www.nhs.uk/CarersDirect/moneyandlegal/legal. In Wales healthcare professionals should follow advice on consent from the Welsh Government (www.wales.nhs.uk/consent).

If the child or young person is under 16, their parents or carers will need to agree to their assessments and investigations, unless it is clear that the child fully understands and can give their own consent.

Care of young people who are moving from services for children to adult services should be planned according to guidance from the Department of Health ('Transition: getting it right for young people' available from www.dh.gov.uk).

Autism

People with **autism** have difficulties with social situations, with to-and-fro communication, and often with their behaviour. This booklet uses the word autism, but there are other terms that different people prefer to use – for example, autism spectrum disorder, autistic spectrum condition, autistic spectrum difference and neuro-diversity.

If there is concern that a child or young person may have a problem with development or behaviour, healthcare professionals look for clues as to what the problem might be. The signs that might suggest autism include problems with speech (not speaking as well as would be expected, not speaking at all or unusual-sounding speech), not talking much, talking only about things they are interested in, or repeating specific words or phrases. They also look for problems understanding and responding to other people's facial expressions, body language or feelings. Other signs include disliking getting physically close to people, or not knowing how close they can get to other people. Children with autism may have little imagination. They have difficulties playing with other children and may prefer to be alone. They may react strongly to certain smells or sounds or to any change in their routine. Some children have unusual repetitive hand, finger or body movements.

These signs can alert healthcare and other professionals that a child or young person may have autism. However, a child may show different signs, or different signs at different ages, and some signs may have another explanation.

Information for parents and carers

Initial concerns

If you or a healthcare professional or teacher have concerns about your child's development or behaviour, you (and your child if appropriate) should be able to discuss these with your child's healthcare professional. They should ask about your child's development, behaviour and about how they talk with and relate to others. Any professional should do this sensitively, take any concerns you have seriously, and take time to listen to you and your child. You should be given time to consider the concerns, especially if you had not previously suspected a problem.

The professional should discuss with you how these signs are affecting your child and the rest of your family. They should also discuss your concerns, the possibility of a different cause of the signs, and whether there are any other factors that would make autism more likely (such as a brother or sister with autism). You can together decide whether your child should be referred for specialist assessment (see page 6). If the concerns are not strong and you prefer to wait for a while before referral, you and the professional can decide to review the situation after a period of time. The professional should explain what should happen after your child has been referred. They should also put all the information they have gathered so far into a letter for the specialist team.

If you think that your child's care does not match what is described in this booklet, please talk to a member of your healthcare team in the first instance.

Questions you might like to ask your healthcare team

- My child seems to be doing quite well for his/her age – why do you think he/she may have autism?
- Can you tell me more about the signs of autism?
- Could my child have a condition other than autism?
- Why have the signs of possible autism not been noticed until now?
- Why is it important for my child to be assessed for autism now?

If you have talked to your healthcare team, and you think that an assessment is suitable for your child but it is not available, you can contact your local patient advice and liaison service ('PALS') or NHS Direct Wales.

Specialist assessment

If your child is referred for assessment for possible autism, they will see someone from a team known as the autism team. After reading the referral letter, the autism team may gather more information (for example, from your child's school, if you agree). This will help them decide what to offer your child next – this may be an autism assessment, and/or an assessment for a different kind of condition if they think this would be helpful. If they think an autism assessment is appropriate, this should start within 3 months of the referral. One of the members of this team should be your child's case coordinator, who should be your point of contact. The case coordinator should explain the assessment to you and your child, and make sure you can get relevant information and support.

If there is not enough information to decide whether an autism assessment is appropriate, you and your child may be offered a consultation with someone from the autism team before deciding whether a full assessment is needed.

Who might see my child in the autism team?

The autism team may include the following professionals (see the glossary on page 10 for more information):

- **paediatrician**
- **child and adolescent psychiatrist**
- **clinical or educational psychologist**
- **speech and language therapist**
- **occupational therapist**
- **paediatric neurologist.**

Members of the autism team should be good at communicating with children and young people who may have autism.

What happens at an autism assessment?

The assessment should involve members of the autism team talking with you and talking with and observing your child, and finding out about:

- your concerns, and those of your child if appropriate
- how your child has been getting on at home, in nursery or school, or in care
- your child's past and present health, and that of the family
- your child's behaviour and development.

There should be someone available who is able to assess children and young people who have visual or hearing impairments, conditions like cerebral palsy, difficulties with language, mental health problems and intellectual disabilities.

Your child should be given a physical examination. There may also be other specific assessments that could help to provide more information, such as an assessment of how your child uses language.

It may be useful for your child to see different healthcare or educational professionals. These people should talk to each other and share information so that assessments are not repeated unnecessarily.

Questions you could ask about the assessment

- Can you tell me about what the members of the autism team do?
- Please give me more details about my child's assessment for autism.
- Will my child need any other kinds of assessments?
- Who will do the assessments? Where will they be carried out? Will my child need to go into hospital?
- How long will we have to wait to find out about the results and how will we be told about them?
- Why does my child need a physical examination?
- Will my child have to have a blood test?
- Will it be possible to say for definite if my child has autism?

After the assessment

The autism team should use all the information from the assessment, the information you have given them and any information from your child's school or healthcare professionals to help them come to a decision about whether your child has autism. They should write down and keep a record of the assessment and all the information gathered so far, taking into account your family and your family's needs. This record should include your child's strengths, skills, difficulties and needs, and what help your child may need in terms of learning, communication, day-to-day care, sensory issues and behavioural and emotional health. The autism team should share information from the assessment with your child's GP, and if you agree, with other professions such as your child's school or social services if appropriate, to help them offer you the support you need.

A member of the team should talk to you (and your child, if appropriate) about all of this, soon after the assessment, and give you a written report explaining the findings of the assessment.

NICE is developing another guideline that explains how children and young people with autism should be supported in the NHS. Details are available at www.nice.org.uk

If your child is diagnosed with autism

You should be offered another appointment with a member of the autism team within 6 weeks of the end of the assessment so you can talk more and ask any questions you may have. They should explain more about autism and how it might affect your child.

You should also be given information about the support you and your child can get in your local area. For example, you may be given contact details for support groups that can give you the opportunity to meet other families with experience of autism, and advice about where to find out about welfare benefits and other services that are available. Your child's healthcare professional should also talk to you about the possibility of siblings and future children having autism.

If the diagnosis is uncertain

Sometimes there can be uncertainties when diagnosing autism. The autism team may offer to see your child again or they may offer to refer your child to another team that can help, for example an autism team in specialist care.

If your child does not have autism

Your healthcare professional may offer to refer you to other specialists (for example, child health services or child and adolescent mental health services, also known as CAMHS), if they think they may be able to help.

Information for young people who may have autism

People with autism can find it difficult to deal with social situations, to communicate with other people, and to use and understand language. They may also behave differently from other people and find it difficult to use their imagination.

How do people find out if I have autism?

You or your parents, teachers or other people who look after you may have concerns about you. For example, you may find it difficult to make friends with other people the same age as you, or you may have difficulties with talking easily to, or understanding, other people. If your parents or others who help to care for you think you may have autism, they may talk to you about seeing a team of specialists to find out more about your difficulties. This is called an assessment.

The team of specialists can include people who are experts in children's health and development, and other people who can help to understand how you think, behave or communicate.

What happens in the assessment?

People from the autism team should meet you and your family and talk with you all. They should ask you and your family about how you get on at school, your general health, and any worries or difficulties you may have.

You may need to see more than one person from the team and have different kinds of assessments. For example, someone may find out more about how you communicate, or how you learn things.

What happens after the assessment?

Someone from the team should talk to you and your family soon after the assessment to explain what they have found out. They should write this down for you and give you or your family a copy.

If the team thinks you do have autism, they should talk with you about what happens next and give you and your family some information about people you can talk to, to help you with your autism.

Sometimes, though, it's not possible to say for certain that someone has autism, so you may be asked back to see the team again in the future. Or, people who seem like they might have autism may have other medical conditions that need to be assessed separately. You may, for example, have been feeling depressed or anxious. You should be helped with these sorts of problems too, but you may need to see a different team of people for this. This should be explained to you.

Questions you might like to ask

- Can you tell me what happens in the assessment?
- Can I get more help at school?
- I don't think that I have a problem, so why does this matter?
- Will I still be able to do the things I like doing?

Glossary

Autism This booklet uses autism to refer to a group of similar conditions including autism, atypical autism and Asperger's syndrome.

Child and adolescent psychiatrist A doctor who specialises in children and young people's mental health.

Clinical psychologist Someone who can assess children's psychological functioning, emotional wellbeing and development, and provide help with behavioural, emotional and mental health problems.

Educational psychologist Someone who works to help people to overcome learning difficulties and problems with their emotions or behaviour, in schools or other places of education.

Occupational therapist Someone who helps people learn to carry out everyday tasks on their own.

Paediatrician A doctor who specialises in children's health.

Paediatric neurologist A doctor who specialises in children's nervous systems (which includes the brain, spinal cord and muscles).

Speech and language therapist Someone who helps people with speech, language and communication problems, to help them to communicate as well as possible.

More information

The organisations below can provide more information and support for families of children who may have autism. NICE is not responsible for the quality or accuracy of any information or advice provided by these organisations.

- National Autistic Society, 0808 800 4104
www.autism.org.uk
- Ambitious about Autism, 020 8815 5444
www.ambitiousaboutautism.org.uk
- Autism Education Trust, 020 7923 5754
www.autismeducationtrust.org.uk

NHS Choices (www.nhs.uk) may be a good place to find out more. Your local patient advice and liaison service (usually known as 'PALS') may be able to give you more information and support. You should also contact PALS if you are unhappy with the treatment you are offered, but you should talk about your care with a member of your healthcare team first. If your local PALS is not able to help you, they should refer you to your local independent complaints advocacy service. If you live in Wales you should speak to NHS Direct Wales for information on who to contact.

About NICE

NICE produces guidance (advice) for the NHS about preventing, diagnosing and treating medical conditions. The guidance is written by independent experts including healthcare professionals and people representing patients and carers. They consider the evidence on the condition and treatments, the views of patients and carers and the experiences of doctors, nurses and other healthcare professionals. Staff working in the NHS are expected to follow this guidance.

To find out more about NICE, its work and how it reaches decisions, see www.nice.org.uk/AboutGuidance

This booklet and other versions of the guideline aimed at healthcare professionals are available at www.nice.org.uk/guidance/CG128

You can order printed copies of this booklet from NICE publications (phone 0845 003 7783 or email publications@nice.org.uk and quote reference N2663). The NICE website has a screen reader service called Browsealoud, which allows you to listen to our guidance. Click on the Browsealoud logo on the NICE website to use this service.

We encourage NHS and voluntary organisations to use text from this booklet in their own information about autism in children and young people.