

# Autism in under 19s: recognition, referral and diagnosis

Clinical guideline

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This guideline is the basis of QS51.

## Introduction

This guideline covers the recognition, referral and diagnosis of autism in children and young people from birth up to 19 years.

'The term autism describes qualitative differences and impairments in reciprocal social interaction and social communication, combined with restricted interests and rigid and repetitive behaviours. Autism spectrum disorders are diagnosed in children, young people and adults if these behaviours meet the criteria defined in the International Statistical Classification of Diseases and Related Health Problems (ICD-10) and the Diagnostic and Statistical Manual of Mental Disorders DSM-IV Fourth Edition (DSM-IV) and have a significant impact on function. The over-arching category term used in ICD-10 and DSM-IV is pervasive developmental disorder (PDD), a term now used synonymously with autism spectrum disorder (excluding Rett's syndrome); it is a behaviourally defined group of disorders, which is heterogeneous in both cause and manifestation.

The guideline development group recognised that individuals and groups prefer a variety of terms, including autism spectrum disorder, autistic spectrum condition, autistic spectrum difference and neuro-diversity. For clarity and consistency, in this guideline the term 'autism' is used throughout, in keeping with the use of 'autism' in recent Department of Health<sup>[1]</sup>, National Audit Office and Public Accounts Committee documents. However in this guideline 'autism' refers to 'autism spectrum disorders'.

Autism is a lifelong disorder that has a great impact on the child or young person and their family or carers. When autism is diagnosed, families and carers and the child or young person themselves can experience a variety of emotions, shock and concern about the implications for the future. They may also have a profound sense of relief that others agree with their observations and concerns. Diagnosis and the assessment of needs can offer an understanding of why a child or young person is different from their peers and can open doors to support and services in education, health services and social care, and a route into voluntary organisations and contact with other children and families with similar experiences. All of these can improve the lives of the child or young person and their family.

The core autism behaviours are typically present in early childhood, but features are not always apparent until the circumstances of the child or young person change, for example when the child

goes to nursery or primary school or moves to secondary school. Autism is strongly associated with a number of coexisting conditions. Recent studies have shown that approximately 70% of people with autism also meet diagnostic criteria for at least one other (often unrecognised) psychiatric disorder that is further impairing their psychosocial functioning. Intellectual disability (intelligence quotient [IQ] below 70) occurs in approximately 50% of young people with autism.

Autism was once thought to be an uncommon developmental disorder, but recent studies have reported increased prevalence and the condition is now thought to occur in at least 1% of children. This rising prevalence has increased demand for diagnostic services for children and young people of all ages in the health service.

Health services have a key role in recognising and diagnosing autism. Levels of understanding of autism among healthcare and other relevant professionals and availability of services differ greatly from one area to another. In addition, children and young people with certain coexisting conditions such as intellectual disability are less likely to be diagnosed with autism, leading to inequalities in healthcare and service provision.

Coordination between health agencies and other key services such as education, social care and the voluntary sector is important. Multi-agency staff should also work in partnership with the child or young person with autism and their family or carers.

This guideline does not cover management of autism but aims to improve recognition, referral and diagnosis, and the experience of children, young people and those who care for them. NICE is developing guidance on managing autism in children and young people (see [www.nice.org.uk](http://www.nice.org.uk)).

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<sup>[1]</sup> [Department of Health](#) (2010) Fulfilling and rewarding lives: the strategy for adults with autism in England.

## Patient-centred care

This guideline offers best practice advice on the recognition, referral and diagnosis of children and young people with autism.

Treatment and care should take into account the needs and preferences of children, young people and those who care for them. Children and young people with autism and their families and carers should have the opportunity to make informed decisions about their care and treatment in partnership with their healthcare professionals. If children and young people do not have the capacity to make decisions, healthcare professionals should follow the [Department of Health's advice on consent](#) and the [code of practice that accompanies the Mental Capacity Act](#). In Wales, healthcare professionals should follow [advice on consent from the Welsh Government](#).

If the child or young person is under 16, healthcare professionals should follow the guidelines in the Department of Health's '[Seeking consent: working with children](#)'.

Good communication between healthcare professionals and children and young people is essential. It should be supported by evidence-based written information tailored to the needs of the child or young person and their parents or carers. The information patients are given about recognition, referral and diagnosis of autism should be culturally appropriate. It should also be accessible to people with additional needs such as physical, sensory or intellectual disabilities, and to people who do not speak or read English.

Families and carers should be given the information and support they need.

Care of young people in transition between paediatric and adult services should be planned and managed according to the best practice guidance described in the Department of Health's '[Transition: getting it right for young people](#)'.

Adult and paediatric healthcare teams should work jointly to provide assessment and services to young people with autism. There should be clarity about who is the lead clinician to ensure continuity of care.

## Key priorities for implementation

The following recommendations have been identified as priorities for implementation.

### Local pathway for recognition, referral and diagnostic assessment of possible autism

- A local autism multi-agency strategy group should be set up, with managerial, commissioner and clinical representation from child health and mental health services, education, social care, parent and carer service users, and the voluntary sector.
- The local autism strategy group should appoint a lead professional to be responsible for the local autism pathway for recognition, referral and diagnosis of children and young people. The aims of the group should include:
  - improving early recognition of autism by raising awareness of the signs and symptoms of autism through multi-agency training (see tables 1–3 in appendix C)
  - making sure the relevant professionals (healthcare, social care, education and voluntary sector) are aware of the local autism pathway and how to access diagnostic services
  - supporting the smooth transition to adult services for young people going through the diagnostic pathway
  - ensuring data collection and audit of the pathway takes place.
- In each area a multidisciplinary group (the autism team) should be set up. The core membership should include a:
  - paediatrician and/or child and adolescent psychiatrist
  - speech and language therapist
  - clinical and/or educational psychologist.
- The autism team should either include or have regular access to the following professionals if they are not already in the team:
  - paediatrician or paediatric neurologist
  - child and adolescent psychiatrist
  - educational psychologist

- clinical psychologist
- occupational therapist.
- Consider including in the autism team (or arranging access for the team to) other relevant professionals who may be able to contribute to the autism diagnostic assessment. For example, a specialist health visitor or nurse, specialist teacher or social worker.
- Provide a single point of referral for access to the autism team.

### Autism diagnostic assessment for children and young people

- A case coordinator in the autism team should be identified for every child or young person who is to have an autism diagnostic assessment.
- Include in every autism diagnostic assessment:
  - detailed questions about parent's or carer's concerns and, if appropriate, the child's or young person's concerns
  - details of the child's or young person's experiences of home life, education and social care
  - a developmental history, focusing on developmental and behavioural features consistent with ICD-10 or DSM-IV criteria (consider using an autism-specific tool to gather this information)
  - assessment (through interaction with and observation of the child or young person) of social and communication skills and behaviours, focusing on features consistent with ICD-10 or DSM-IV criteria (consider using an autism-specific tool to gather this information)
  - a medical history, including prenatal, perinatal and family history, and past and current health conditions
  - a physical examination
  - consideration of the differential diagnosis (see recommendation 1.5.7)
  - systematic assessment for conditions that may coexist with autism (see recommendation 1.5.15)



- development of a profile of the child's or young person's strengths, skills, impairments and needs that can be used to create a needs-based management plan, taking into account family and educational context
- communication of assessment findings to the parent or carer and, if appropriate, the child or young person.
- Consider the following differential diagnoses for autism and whether specific assessments are needed to help interpret the autism history and observations:
  - Neurodevelopmental disorders:
    - ◇ specific language delay or disorder
    - ◇ intellectual disability or global developmental delay
    - ◇ developmental coordination disorder (DCD).
  - Mental and behavioural disorders:
    - ◇ attention deficit hyperactivity disorder (ADHD)
    - ◇ mood disorder
    - ◇ anxiety disorder
    - ◇ attachment disorders
    - ◇ oppositional defiant disorder (ODD)
    - ◇ conduct disorder
    - ◇ obsessive compulsive disorder (OCD)
    - ◇ psychosis.
  - Conditions in which there is developmental regression:
    - ◇ Rett syndrome
    - ◇ epileptic encephalopathy.
  - Other conditions:
    - ◇ severe hearing impairment

- ◇ severe visual impairment
- ◇ maltreatment
- ◇ selective mutism.

### **Communicating the results from the autism diagnostic assessment**

- With parental or carer consent and, if appropriate, the consent of the child or young person, make the profile available to professionals in education (for example, through a school visit by a member of the autism team) and, if appropriate, social care. This is so it can contribute to the child or young person's individual education plan and needs-based management plan.

## 1 Guidance

The following guidance is based on the best available evidence. The [full guideline](#) gives details of the methods and the evidence used to develop the guidance.

### 1.1 *Local pathway for recognition, referral and diagnostic assessment of possible autism*

- 1.1.1 A local autism multi-agency strategy group should be set up, with managerial, commissioner and clinical representation from child health and mental health services, education, social care, parent and carer service users, and the voluntary sector.
- 1.1.2 The local autism strategy group should appoint a lead professional to be responsible for the local autism pathway for recognition, referral and diagnosis of children and young people. The aims of the group should include:
- improving early recognition of autism by raising awareness of the signs and symptoms of autism through multi-agency training (see tables 1–3 in appendix C)
  - making sure the relevant professionals (healthcare, social care, education and voluntary sector) are aware of the local autism pathway and how to access diagnostic services
  - supporting the smooth transition to adult services for young people going through the diagnostic pathway
  - ensuring data collection and audit of the pathway takes place.
- 1.1.3 In each area a multidisciplinary group (the autism team) should be set up. The core membership should include a:
- paediatrician and/or child and adolescent psychiatrist
  - speech and language therapist
  - clinical and/or educational psychologist.
- 1.1.4 The autism team should either include or have regular access to the following professionals if they are not already in the team:

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

1.1.5 Consider including in the autism team (or arranging access for the team to) other relevant professionals who may be able to contribute to the autism diagnostic assessment. For example, a specialist health visitor or nurse, specialist teacher or social worker.

1.1.6 The autism team should have the skills and competencies to:

- carry out an autism diagnostic assessment
- communicate with children and young people with suspected or known autism, and with their parents and carers, and sensitively share the diagnosis with them.

1.1.7 Autism team members should:

- provide advice to professionals about whether to refer children and young people for autism diagnostic assessments
- decide on the assessment needs of those referred or when referral to another service will be needed
- carry out the autism diagnostic assessment
- share the outcome of the autism diagnostic assessment with parents and carers, and with children and young people if appropriate
- with parent or carer consent and, if appropriate, the consent of the child or young person, share information from the autism diagnostic assessment directly with relevant services, for example through a school visit by an autism team member
- offer information to children, young people and parents and carers about appropriate services and support.

1.1.8 Provide a single point of referral for access to the autism team.

- 1.1.9 The autism team should either have the skills (or have access to professionals that have the skills) needed to carry out an autism diagnostic assessment, for children and young people with special circumstances including:
- coexisting conditions such as severe visual and hearing impairments, motor disorders including cerebral palsy, severe intellectual disability, complex language disorders or complex mental health disorders
  - looked-after children and young people.

1.1.10 If young people present at the time of transition to adult services, the autism team should consider carrying out the autism diagnostic assessment jointly with the adult autism team, regardless of the young person's intellectual ability.

## 1.2 *Recognising children and young people with possible autism*

1.2.1 Consider the possibility of autism if there are concerns about development or behaviour, but be aware that there may be other explanations for individual signs and symptoms.

1.2.2 Always take parents' or carers' concerns and, if appropriate, the child's or young person's concerns, about behaviour or development seriously, even if these are not shared by others.

1.2.3 When considering the possibility of autism and whether to refer a child or young person to the autism team, be critical about your professional competence and seek advice from a colleague if in doubt about the next step.

1.2.4 To help identify the signs and symptoms of possible autism, use tables 1–3 (see appendix C). Do not rule out autism if the exact features described in the tables are not evident; they should be used for guidance, but do not include all possible manifestations of autism.

1.2.5 When considering the possibility of autism, be aware that:

- signs and symptoms should be seen in the context of the child's or young person's overall development

- signs and symptoms will not always have been recognised by parents, carers, children or young people themselves or by other professionals
- when older children or young people present for the first time with possible autism, signs or symptoms may have previously been masked by the child or young person's coping mechanisms and/or a supportive environment
- it is necessary to take account of cultural variation, but do not assume that language delay is accounted for because English is not the family's first language or by early hearing difficulties
- autism may be missed in children or young people with an intellectual disability
- autism may be missed in children or young people who are verbally able
- autism may be under-diagnosed in girls
- important information about early development may not be readily available for some children and young people, for example looked-after children and those in the criminal justice system
- signs and symptoms may not be accounted for by disruptive home experiences or parental or carer mental or physical illness.

1.2.6 When considering the possibility of autism, ask about the child or young person's use and understanding of their first language.

1.2.7 Do not rule out autism because of:

- good eye contact, smiling and showing affection to family members
- reported pretend play or normal language milestones
- difficulties appearing to resolve after a needs-based intervention (such as a supportive structured learning environment)
- a previous assessment that concluded that there was no autism, if new information becomes available.

1.2.8 Discuss developmental or behavioural concerns about a child or young person with parents or carers, and the child or young person themselves if appropriate. Discuss sensitively the possible causes, which may include autism, emphasising

that there may be many explanations for the child's or young person's behaviour.

1.2.9 Be aware that if parents or carers or the child or young person themselves have not suspected a developmental or behavioural condition, raising the possibility may cause distress, and that:

- it may take time for them to come to terms with the concern
- they may not share the concern.

1.2.10 Take time to listen to parents or carers and, if appropriate, the child or young person, to discuss concerns and agree any actions to follow including referral.

### 1.3 *Referring children and young people to the autism team*

1.3.1 Refer children younger than 3 years to the autism team if there is regression in language or social skills.

1.3.2 Refer first to a paediatrician or paediatric neurologist (who can refer to the autism team if necessary) children and young people:

- older than 3 years with regression in language
- of any age with regression in motor skills.

1.3.3 Consider referring children and young people to the autism team if you are concerned about possible autism on the basis of reported or observed signs and/or symptoms (see tables 1–3 in appendix C). Take account of:

- the severity and duration of the signs and/or symptoms
- the extent to which the signs and/or symptoms are present across different settings (for example, home and school)
- the impact of the signs and/or symptoms on the child or young person and on their family
- the level of parental or carer concern and, if appropriate, the concerns of the child or young person

- factors associated with an increased prevalence of autism (see box 1)
- the likelihood of an alternative diagnosis.

**Box 1 Factors associated with an increased prevalence of autism**

- A sibling with autism
- Birth defects associated with central nervous system malformation and/or dysfunction, including cerebral palsy
- Gestational age less than 35 weeks
- Parental schizophrenia-like psychosis or affective disorder
- Maternal use of sodium valproate in pregnancy
- Intellectual disability
- Neonatal encephalopathy or epileptic encephalopathy, including infantile spasms
- Chromosomal disorders such as Down's syndrome
- Genetic disorders such as fragile X
- Muscular dystrophy
- Neurofibromatosis
- Tuberous sclerosis

1.3.4 If you have concerns about development or behaviour but are not sure whether the signs and/or symptoms suggest autism, consider:

- consulting a member of the autism team who can provide advice to help you decide if a referral to the autism team is necessary
- referring to another service. That service can then refer to the autism team if necessary.

1.3.5 Be aware that tools to identify children and young people with an increased likelihood of autism may be useful in gathering information about signs and



symptoms of autism in a structured way but are not essential and should not be used to make or rule out a diagnosis of autism. Also be aware that:

- a positive score on tools to identify an increased likelihood of autism may support a decision to refer but can also be for reasons other than autism
- a negative score does not rule out autism.

1.3.6 When referring children and young people to the autism team, include in the referral letter the following information:

- reported information from parents, carers and professionals about signs and/or symptoms of concern
- your own observations of the signs and/or symptoms.

1.3.7 When referring children and young people to the autism team, include in the referral letter the following information, if available:

- antenatal and perinatal history
- developmental milestones
- factors associated with an increased prevalence of autism (see box 1)
- relevant medical history and investigations
- information from previous assessments.

1.3.8 Explain to parents or carers and, if appropriate, the child or young person, what will happen on referral to the autism team or another service.

1.3.9 If you do not think concerns are sufficient to prompt a referral, consider a period of watchful waiting. If you remain concerned about autism, reconsider your referral decision.

1.3.10 If the parents or carers or if appropriate, the child or young person, prefer not to be referred to the autism team, consider a period of watchful waiting. If you remain concerned about autism, reconsider referral.

- 1.3.11 If a concern about possible autism has been raised but there are no signs, symptoms or other reasons to suspect autism, use professional judgment to decide what to do next.

## 1.4 *After referral to the autism team*

- 1.4.1 When a child or young person is referred to the autism team, at least one member of the autism team should consider whether to carry out:

- an autism diagnostic assessment **and/or**
- an alternative assessment.

- 1.4.2 Carry out an autism diagnostic assessment if there is regression in language or social skills in a child younger than 3 years.

- 1.4.3 Refer first to a paediatrician or paediatric neurologist (if this has not already happened) children or young people:

- older than 3 years with regression in language
- of any age with regression in motor skills.

The paediatrician or paediatric neurologist can refer back to the autism team if necessary.

- 1.4.4 When deciding whether to carry out an autism diagnostic assessment, take account of the following (unless the child is under 3 years and has regression in language or social skills – see recommendation 1.4.2):

- the severity and duration of the signs and/or symptoms
- the extent to which the signs and/or symptoms are present across different settings (for example, home and school)
- the impact of the signs and/or symptoms on the child or young person and on their family or carer
- the level of parental or carer concern, and if appropriate the concerns of the child or young person

- factors associated with an increased prevalence of autism (see box 1)
- the likelihood of an alternative diagnosis.

1.4.5 If there is insufficient information to decide whether an autism diagnostic assessment is needed, gather any available information from healthcare professionals. With consent from parents or carers and, if appropriate, the child or young person, seek information from schools or other agencies.

1.4.6 If there is uncertainty about whether an autism diagnostic assessment is needed after information has been gathered, offer a consultation to gather information directly from the child or young person and their family or carers.

1.4.7 Once it has been decided to carry out an autism diagnostic assessment, with consent from parents or carers (and the child or young person if appropriate):

- seek a report from the pre-school or school if one has not already been made available
- gather any additional health or social care information, including results from hearing and vision assessments.

1.4.8 Avoid repeated information gathering and assessments by efficient communication between professionals and agencies.

## 1.5 *Autism diagnostic assessment for children and young people*

1.5.1 Start the autism diagnostic assessment within 3 months of the referral to the autism team.

1.5.2 A case coordinator in the autism team should be identified for every child or young person who is to have an autism diagnostic assessment.

1.5.3 The autism case coordinator should:

- act as a single point of contact for the parents or carers and, if appropriate, the child or young person being assessed, through whom they can communicate with the rest of the autism team
- keep parents or carers and, if appropriate, the child or young person, up-to-date about the likely time and sequence of assessments

- arrange the provision of information and support for parents, carers, children and young people as directed by the autism team
- gather information relevant to the autism diagnostic assessment (see recommendation 1.4.7).

1.5.4 Discuss with the parents or carers and, if appropriate, the child or young person, how information should be shared throughout the autism diagnostic assessment, including communicating the outcome of the assessment. Take into account, for example, the child or young person's age and ability to understand.

1.5.5 Include in every autism diagnostic assessment:

- detailed questions about parent's or carer's concerns and, if appropriate, the child's or young person's concerns
- details of the child's or young person's experiences of home life, education and social care
- a developmental history, focusing on developmental and behavioural features consistent with ICD-10 or DSM-IV criteria (consider using an autism-specific tool to gather this information)
- assessment (through interaction with and observation of the child or young person) of social and communication skills and behaviours, focusing on features consistent with ICD-10 or DSM-IV criteria (consider using an autism-specific tool to gather this information)
- a medical history, including prenatal, perinatal and family history, and past and current health conditions
- a physical examination
- consideration of the differential diagnosis (see recommendation 1.5.7)
- systematic assessment for conditions that may coexist with autism (see recommendation 1.5.15)
- development of a profile of the child's or young person's strengths, skills, impairments and needs that can be used to create a needs-based management plan, taking into account family and educational context.

- communication of assessment findings to the parent or carer and, if appropriate, the child or young person.

1.5.6 Perform a general physical examination and look specifically for:

- skin stigmata of neurofibromatosis or tuberous sclerosis using a Wood's light
- signs of injury, for example self-harm<sup>[2]</sup> or child maltreatment<sup>[3]</sup>
- congenital anomalies and dysmorphic features including macrocephaly or microcephaly.

1.5.7 Consider the following differential diagnoses for autism and whether specific assessments are needed to help interpret the autism history and observations:

- Neurodevelopmental disorders:
  - specific language delay or disorder
  - intellectual disability or global developmental delay
  - developmental coordination disorder (DCD).
- Mental and behavioural disorders:
  - attention deficit hyperactivity disorder (ADHD)
  - mood disorder
  - anxiety disorder
  - attachment disorders
  - oppositional defiant disorder (ODD)
  - conduct disorder
  - obsessive compulsive disorder (OCD)
  - psychosis.
- Conditions in which there is developmental regression:
  - Rett syndrome

- epileptic encephalopathy.

- Other conditions:

- severe hearing impairment

- severe visual impairment

- maltreatment

- selective mutism.

1.5.8 Consider which assessments are needed to construct a profile for each child or young person, for example:

- intellectual ability and learning style
- academic skills
- speech, language and communication
- fine and gross motor skills
- adaptive behaviour (including self-help skills)
- mental and emotional health (including self-esteem)
- physical health and nutrition
- sensory sensitivities
- behaviour likely to affect day-to-day functioning and social participation
- socialisation skills.

1.5.9 If there are discrepancies during the autism diagnostic assessment between reported signs or symptoms and the findings of the autism observation in the clinical setting, consider:

- gathering additional information from other sources **and/or**
- carrying out further autism-specific observations in different settings, such as the school, nursery, other social setting or at home.

- 1.5.10 Use information from all sources, together with clinical judgment, to diagnose autism based on ICD-10 or DSM-IV criteria.
- 1.5.11 Do not rely on any autism-specific diagnostic tool alone to diagnose autism.
- 1.5.12 Be aware that in some children and young people there may be uncertainty about the diagnosis of autism, particularly in:
- children younger than 24 months
  - children or young people with a developmental age of less than 18 months
  - children or young people for whom there is a lack of available information about their early life (for example some looked-after or adopted children)
  - older teenagers
  - children or young people with a complex coexisting mental health disorder (for example ADHD, conduct disorder, a possible attachment disorder), sensory impairment (for example severe hearing or visual impairment), or a motor disorder such as cerebral palsy.
- 1.5.13 Be aware that some children and young people will have features of behaviour that are seen in the autism spectrum but do not reach the ICD-10 or DSM-IV diagnostic criteria for definitive diagnosis. Based on their profile, consider referring to appropriate services.
- 1.5.14 If the outcome of the autism diagnostic assessment clearly indicates that the child or young person does not have autism, consider referring them to appropriate services based on their profile.
- 1.5.15 Consider whether the child or young person may have any of the following as a coexisting condition, and if suspected carry out appropriate assessments and referrals:
- Mental and behaviour problems and disorders:
    - ADHD
    - anxiety disorders and phobias

- mood disorders
  - oppositional defiant behaviour
  - tics or Tourette syndrome
  - OCD
  - self-injurious behaviour.
- Neurodevelopmental problems and disorders:
    - global delay or intellectual disability
    - motor coordination problems or DCD
    - academic learning problems, for example in literacy or numeracy
    - speech and language disorder.
- Medical or genetic problems and disorders:
    - epilepsy and epileptic encephalopathy
    - chromosome disorders
    - genetic abnormalities, including fragile X
    - tuberous sclerosis
    - muscular dystrophy
    - neurofibromatosis.
- Functional problems and disorders:
    - feeding problems, including restricted diets
    - urinary incontinence or enuresis
    - constipation, altered bowel habit, faecal incontinence or encopresis
    - sleep disturbances
    - vision or hearing impairment.



- 1.5.16 Be aware that in children and young people with communication difficulties it may be difficult to recognise functional problems or mental health problems.

## 1.6 *After the autism diagnostic assessment*

- 1.6.1 If there is uncertainty after the autism diagnostic assessment about the diagnosis, consider keeping the child or young person under review, taking into account any new information.

- 1.6.2 If any of the following apply after assessment, consider obtaining a second opinion (including referral to a specialised tertiary autism team if necessary):

- continued uncertainty about the diagnosis
- disagreement about the diagnosis within the autism team
- disagreement with parents or carers or, if appropriate, the child or young person, about the diagnosis
- a lack of local access to particular skills and competencies needed to reach a diagnosis in a child or young person who has a complex coexisting condition, such as a severe sensory or motor impairment or mental health problem
- a lack of response as expected to any therapeutic interventions provided to the child or young person.

- 1.6.3 During the autism diagnostic assessment, consider any potential risk of harm to, and from, the child or young person and take appropriate action.

## 1.7 *Medical investigations*

- 1.7.1 Do not routinely perform any medical investigations as part of an autism diagnostic assessment, but consider the following in individual circumstances and based on physical examination, clinical judgment and the child or young person's profile:

- genetic tests, as recommended by your regional genetics centre, if there are specific dysmorphic features, congenital anomalies and/or evidence of intellectual disability
- electroencephalography if there is suspicion of epilepsy<sup>[4]</sup>.

## 1.8 *Communicating the results from the autism diagnostic assessment*

- 1.8.1 After the autism diagnostic assessment discuss the findings, including the profile, sensitively, in person and without delay with the parents or carers and, if appropriate, the child or young person. Explain the basis of conclusions even if the diagnosis of autism was not reached.
- 1.8.2 Use recognised good practice when sharing a diagnosis with parents, carers, children and young people.
- 1.8.3 For children and young people with a diagnosis of autism, discuss and share information with parents or carers and, if appropriate, the child or young person, to explain:
- what autism is
  - how autism is likely to affect the child or young person's development and function.
- 1.8.4 Provide parents or carers and, if appropriate, the child or young person, with a written report of the autism diagnostic assessment. This should explain the findings of the assessment and the reasons for the conclusions drawn.
- 1.8.5 Share information, including the written report of the diagnostic assessment, with the GP.
- 1.8.6 With parental or carer consent and, if appropriate, the consent of the child or young person, share information with key professionals involved in the child's or young person's care, including those in education and social care.
- 1.8.7 With parental or carer consent and, if appropriate, the consent of the child or young person, make the profile available to professionals in education (for example, through a school visit by a member of the autism team) and, if appropriate, social care. This is so it can contribute to the child or young person's individual education plan and needs-based management plan.
- 1.8.8 For children and young people with a diagnosis of autism, offer a follow-up appointment with an appropriate member of the autism team within 6 weeks of the end of the autism assessment for further discussion (for example about the

conclusions of the assessment and the implications for the child or young person).

1.8.9 For children and young people with a diagnosis of autism, discuss with parents or carers the risk of autism occurring in siblings and future children.

## 1.9 *Information and support for families and carers*

1.9.1 Provide individual information on support available locally for parents, carers, children and young people with autism, according to the family's needs. This may include:

- contact details for:
  - local and national support organisations (who may provide, for example, an opportunity to meet other families with experience of autism, or information about specific courses for parents and carers and/or young people)
  - organisations that can provide advice on welfare benefits
  - organisations that can provide information on educational support and social care
- information to help prepare for the future, for example transition to adult services.

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<sup>[2]</sup> See '[Self-harm: the short-term physical and psychological management and secondary prevention of self-harm in primary and secondary care](#)' (NICE clinical guideline 16).

<sup>[3]</sup> See '[When to suspect child maltreatment](#)' (NICE clinical guideline 89).

<sup>[4]</sup> See '[The epilepsies: the diagnosis and management of the epilepsies in adults and children in primary and secondary care](#)' (NICE clinical guideline 20).

## 2 Notes on the scope of the guidance

NICE guidelines are developed in accordance with a [scope](#) that defines what the guideline will and will not cover.

This guideline covers the signs and symptoms that should prompt professionals working with children, young people, and their parents or carers to consider autism; information requirements from other agencies; components of diagnostic assessment after referral; appropriate information and day-to-day support for children, young people and their parents or carers during referral, assessment and diagnosis; and ineffective diagnostic interventions and approaches.

It does not cover population screening or surveillance; routine paediatric or mental health assessment not specific to autism; the role and competencies of different professions in the recognition and diagnosis of autism; specific models for diagnostic services; interventions and ongoing management of autism, including specific therapeutic interventions during diagnosis; or reassessment and review of diagnosis.

### How this guideline was developed

NICE commissioned the National Collaborating Centre for Women's and Children's Health to develop this guideline. The Centre established a Guideline Development Group (see appendix A), which reviewed the evidence and developed the recommendations. An independent Guideline Review Panel oversaw the development of the guideline (see appendix B).

There is more information about [how NICE clinical guidelines are developed](#) on the NICE website. A booklet, 'How NICE clinical guidelines are developed: an overview for stakeholders, the public and the NHS' is [available](#).

### **3 Implementation**

NICE has developed [tools](#) to help organisations implement this guidance.

## 4 Research recommendations

The Guideline Development Group has made the following recommendations for research, based on its review of evidence, to improve NICE guidance and patient care in the future.

### 4.1 *Training professionals*

Does training professionals to recognise signs and symptoms of autism lead to earlier assessment of needs and earlier diagnosis (and by implication reduce morbidity/improve health outcomes) among children and young people with suspected autism compared with no training?

#### **Why this is important**

Successful training of healthcare professionals in the Netherlands has been shown to improve their ability, confidence and skills in identifying children or young people who need an autism diagnostic assessment. A fully trained workforce can identify the number of children or young people with autism and provide accurate information both for planning individual care and at a strategic level for planning appropriate service provision.

If training improves earlier recognition and referral, this could be of particular benefit to at-risk groups for which there is evidence that autism is currently under-diagnosed, such as girls, and children and young people:

- with parents of lower educational attainment
- with English as an additional language
- with sensory impairments
- with intellectual disability.

Before extending training to a wider population, it is important to better understand its effectiveness in terms of age, number of children and young people at referral, and time between parents' concerns and autism diagnosis.

### 4.2 *Gathering information in schools or nurseries*

Does routine additional information from educational settings (such as nursery or school) improve accuracy in diagnosing autism among children or young people up to the age of 19 compared with signs and symptoms alone?

### **Why this is important**

Autism is primarily characterised by difficulties in social reciprocity, social communication and social understanding, along with rigid and repetitive ways of thinking and behaving. Diagnostic accuracy may be improved by interpreting information about how the child or young person presents in social settings away from the home and immediate family.

Nurseries or schools are the most obvious settings from which such information may be collected. However, the degree to which information from teachers and schools helps in accurate diagnosis has not been well tested.

### **4.3 *Additional assessments***

Do additional assessments (for IQ, language ability and motor ability) improve accuracy in diagnosing autism among preschool children (younger than 5 years) compared with signs and symptoms alone?

### **Why this is important**

Current NHS practice varies widely with regard to the proportion of children having an autism diagnostic assessment who also routinely undergo assessments of IQ, language and motor abilities.

As a consequence we do not know whether such assessments aid more accurate diagnosis of autism. This is particularly important if a differential or coexisting diagnostic decision is called for and/or if there may be specific management implications.

Studies may prove valuable to parents in terms of explaining some of the child's behaviours, leading to more targeted and informed support for the child, parents and the wider family.

### **4.4 *Comparative genomic hybridisation array***

What is the effectiveness and acceptability of comparative genomic hybridisation (CGH) array compared with current genetic testing in children and young people with identified autism?

### **Why this is important**

Recent scientific advances have led to the detection of genetic abnormalities that may partly or wholly explain why a child or young person has autism. As the tests become increasingly

sophisticated (for example using methods such as CGH array that detect more subtle variations), more genetic abnormalities are being identified, although their causal role in autism is not always clear. Improved detection of genetic causes of autism could increase the precision of genetic counselling for parents of a child or young person with autism and also for the wider family. At present, the yield of abnormal genetic results using CGH array is known to be higher in those with dysmorphic features and/or intellectual disability, but this may extend to the wider autism population with increasing test sophistication. Before extending CGH array testing to a wider population, it is important to have a better understanding of its diagnostic yield. It is also essential to identify any negative consequences that may result from routine testing.



## 5 Other versions of this guideline

### 5.1 *Full guideline*

The full guideline, [Autism spectrum disorders: recognition, referral and diagnosis in children and young people](#), contains details of the methods and evidence used to develop the guideline. It is published by the National Collaborating Centre for Women's and Children's Health.

### 5.2 *Information for the public*

NICE has produced [information for the public](#) explaining this guideline.

We encourage NHS and voluntary sector organisations to use text from this information in their own materials about the recognition, referral and diagnosis of autism.

## 6 Related NICE guidance

### Published

- [Looked-after children and young people](#). NICE public health guidance 28 (2010).
- [When to suspect child maltreatment](#). NICE clinical guideline 89 (2009).
- [Attention deficit hyperactivity disorder](#). NICE clinical guideline 72 (2008).
- [Depression in children and young people](#). NICE clinical guideline 28 (2005).
- [The epilepsies](#). NICE clinical guideline 20 (2004).
- [Self-harm](#). NICE clinical guideline 16 (2004).

### Under development

NICE is developing the following guidance (details available from [www.nice.org.uk](http://www.nice.org.uk)):

- Autism: recognition, referral, diagnosis and management of adults on the autism spectrum. NICE clinical guideline. Publication date to be confirmed.
- Autism: the management and support of children and young people on the autism spectrum. NICE clinical guideline. Publication date to be confirmed.

## 7 Updating the guideline

NICE clinical guidelines are updated so that recommendations take into account important new information. New evidence is checked 3 years after publication, and healthcare professionals and patients are asked for their views; we use this information to decide whether all or part of a guideline needs updating. If important new evidence is published at other times, we may decide to do a more rapid update of some recommendations. Please see our website for information about updating the guideline.

## **Appendix A: The Guideline Development Group, National Collaborating Centre and NICE project team**

### *Guideline Development Group*

**Susan Anderson** Parent and carer member

**Carol Bagnall** Specialist Health Visitor, NHS Heywood, Middleton and Rochdale Primary Care Trust

**Gillian Baird (Chair)** Consultant Paediatrician, Guy's and St Thomas' NHS Foundation Trust, London

**Tony Charman** Chair in Autism Education Department of Psychology and Human Development, Institute of Education, London

**Diana Howlett** Consultant Community Paediatrician, Weston Area Health Trust, Weston-super-Mare

**Anne Marie McKigney** Consultant Child Psychologist, Aneurin Bevan Health Board Wales

**Ann Le Couteur** Professor of Child and Adolescent Psychiatry, Institute of Health and Society, Newcastle University

**Jamie Nicholls** GP, Essex

**Sharon Richman** Consultant Community Paediatrician, Ealing Child Development Centre, London

**Lorraine Scott** Head of Learning and Support and Assessment Educational Officer, Middletown Centre for Autism, County Armagh

**Emily Siminoff** Professor of Child and Adolescent Psychiatry, Institute of Psychiatry, London

**Zoe Thompson** Parent and carer member

**Penny Williams** Principal Speech and Language Therapist for Autism, Mary Sheridan Centre for Child Health, London

## *National Collaborating Centre for Women's and Children's Health*

Shona Burman-Roy Senior Research Fellow

Hannah Rose Douglas Associate Director

Huajie Jin Research Assistant (until November 2010)

Monica Lackhanpaul Clinical Co-Director Children's Health (until September 2009)

Sarah Latreille Research Assistant (until December 2009)

Juliet Kenny Project Manager (from March 2010)

Hugh McGuire Research Fellow

Gemma Malin Senior Research Fellow (until April 2010)

Stephen Murphy Clinical Co-Director Children's Health (from September 2009)

Manveet Patel Project Manager (until March 2010)

### *NICE project team*

Christine Carson Programme Director

Ben Doak Guideline Commissioning Manager

Elaine Clydesdale Guideline Coordinator

Ruaraidh Hill Technical Lead

Prashanth Kandaswamy Health Economist

Korin Knight-Mossop Editor

## **Appendix B: The Guideline Review Panel**

The Guideline Review Panel is an independent panel that oversees the development of the guideline and takes responsibility for monitoring adherence to NICE guideline development processes. In particular, the panel ensures that stakeholder comments have been adequately considered and responded to. The panel includes members from the following perspectives: primary care, secondary care, lay, public health and industry.

**John Hyslop (Chair)** Royal Cornwall Hospital NHS Trust

**Kieran Murphy** Johnson & Johnson Medical Ltd

**Ash Paul** Bedfordshire Primary Care Trust

**Sarah Fishburn** Lay representative

## Appendix C: Signs and symptoms of possible autism

### *Using tables 1–3*

The signs and symptoms in tables 1–3 are a combination of delay in expected features of development and the presence of unusual features, and are intended to alert professionals to the possibility of autism in a child or young person about whom concerns have been raised. They are not intended to be used alone, but to help professionals recognise a pattern of impairments in reciprocal social and communication skills, together with unusual restricted and repetitive behaviours.

*Table 1 Signs and symptoms of possible autism in preschool children (or equivalent mental age).*



## **Social interaction and reciprocal communication behaviours**

### *Spoken language*

- Language delay (in babble or words, for example less than ten words by the age of 2 years)
- Regression in or loss of use of speech
- Spoken language (if present) may include unusual:
  - non-speech like vocalisations
  - odd or flat intonation
  - frequent repetition of set words and phrases ('echolalia')
  - reference to self by name or 'you' or 'she/he' beyond 3 years
- Reduced and/or infrequent use of language for communication, for example use of single words although able to speak in sentences

### *Responding to others*

- Absent or delayed response to name being called, despite normal hearing
- Reduced or absent responsive social smiling
- Reduced or absent responsiveness to other people's facial expressions or feelings
- Unusually negative response to the requests of others (demand avoidant behaviour)
- Rejection of cuddles initiated by parent or carer, although may initiate cuddles themselves

### *Interacting with others*

- Reduced or absent awareness of personal space, or unusually intolerant of people entering their personal space
- Reduced or absent social interest in others, including children of his/her own age – may reject others; if interested in others, may approach others inappropriately, seeming to be aggressive or disruptive
- Reduced or absent imitation of others' actions
- Reduced or absent initiation of social play with others, plays alone

- Reduced or absent enjoyment of situations that most children like, for example, birthday parties
- Reduced or absent sharing of enjoyment

*Eye contact, pointing and other gestures*

- Reduced or absent use of gestures and facial expressions to communicate (although may place adult's hand on objects)
- Reduced and poorly integrated gestures, facial expressions, body orientation, eye contact (looking at people's eyes when speaking) and speech used in social communication
- Reduced or absent social use of eye contact, assuming adequate vision
- Reduced or absent joint attention shown by lack of:
  - gaze switching
  - following a point (looking where the other person points to – may look at hand)
  - using pointing at or showing objects to share interest

*Ideas and imagination*

- Reduced or absent imagination and variety of pretend play

*Unusual or restricted interests and/or rigid and repetitive behaviours*

- Repetitive 'stereotypical' movements such as hand flapping, body rocking while standing, spinning, finger flicking
- Repetitive or stereotyped play, for example opening and closing doors
- Over-focused or unusual interests
- Excessive insistence on following own agenda
- Extremes of emotional reactivity to change or new situations, insistence on things being 'the same'
- Over or under reaction to sensory stimuli, for example textures, sounds, smells
- Excessive reaction to taste, smell, texture or appearance of food or extreme food fads

*Table 2 Signs and symptoms of possible autism in primary school children (aged 5–11 years or equivalent mental age).*

## **Social interaction and reciprocal communication behaviours**

### *Spoken language*

- Spoken language may be unusual in several ways:
  - very limited use
  - monotonous tone
  - repetitive speech, frequent use of stereotyped (learnt) phrases, content dominated by excessive information on topics of own interest
  - talking 'at' others rather than sharing a two-way conversation
  - responses to others can seem rude or inappropriate

### *Responding to others*

- Reduced or absent response to other people's facial expression or feelings
- Reduced or delayed response to name being called, despite normal hearing
- Subtle difficulties in understanding other's intentions; may take things literally and misunderstand sarcasm or metaphor
- Unusually negative response to the requests of others (demand avoidant behaviour)

### *Interacting with others*

- Reduced or absent awareness of personal space, or unusually intolerant of people entering their personal space
- Reduced or absent social interest in people, including children of his/her own age – may reject others; if interested in others, may approach others inappropriately, seeming to be aggressive or disruptive
- Reduced or absent greeting and farewell behaviours
- Reduced or absent awareness of socially expected behaviour
- Reduced or absent ability to share in the social play or ideas of others, plays alone
- Unable to adapt style of communication to social situations, for example may be overly formal or inappropriately familiar

- Reduced or absent enjoyment of situations that most children like

*Eye contact, pointing and other gestures*

- Reduced and poorly integrated gestures, facial expressions and body orientation, eye contact (looking at people's eyes when speaking) and speech used in social communication
- Reduced or absent social use of eye contact, assuming adequate vision
- Reduced or absent joint attention shown by lack of:
  - gaze switching
  - following a point (looking where the other person points to – may look at hand)
  - using pointing at or showing objects to share interest

*Ideas and imagination*

- Reduced or absent flexible imaginative play or creativity, although scenes seen on visual media (for example, television) may be re-enacted
- Makes comments without awareness of social niceties or hierarchies

*Unusual or restricted interests and/or rigid and repetitive behaviours*

- Repetitive 'stereotypical' movements such as hand flapping, body rocking while standing, spinning, finger flicking
- Play repetitive and oriented towards objects rather than people
- Over-focused or unusual interests
- Rigid expectation that other children should adhere to rules of play
- Excessive insistence on following own agenda
- Extremes of emotional reactivity that are excessive for the circumstances
- Strong preferences for familiar routines and things being 'just right'
- Dislike of change, which often leads to anxiety or other forms of distress (including aggression)
- Over or under reaction to sensory stimuli, for example textures, sounds, smells

- Excessive reaction to taste, smell, texture or appearance of food or extreme food fads

*Other factors that may support a concern about autism*

- Unusual profile of skills or deficits (for example, social or motor coordination skills poorly developed, while particular areas of knowledge, reading or vocabulary skills are advanced for chronological or mental age)
- Social and emotional development more immature than other areas of development, excessive trusting (naivety), lack of common sense, less independent than peers

*Table 3 Signs and symptoms of possible autism in secondary school children (older than 11 years or equivalent mental age).*

## **Social interaction and reciprocal communication behaviours**

### *Spoken language*

- Spoken language may be unusual in several ways:
  - very limited use
  - monotonous tone
  - repetitive speech, frequent use of stereotyped (learnt) phrases, content dominated by excessive information on topics of own interest
  - talking 'at' others rather than sharing a two-way conversation
  - responses to others can seem rude or inappropriate

### *Interacting with others*

- Reduced or absent awareness of personal space, or unusually intolerant of people entering their personal space
- Long-standing difficulties in reciprocal social communication and interaction: few close friends or reciprocal relationships
- Reduced or absent understanding of friendship; often an unsuccessful desire to have friends (although may find it easier with adults or younger children)
- Social isolation and apparent preference for aloneness
- Reduced or absent greeting and farewell behaviours
- Lack of awareness and understanding of socially expected behaviour
- Problems losing at games, turn-taking and understanding 'changing the rules'
- May appear unaware or uninterested in what other young people his or her age are interested in
- Unable to adapt style of communication to social situations, for example may be overly formal or inappropriately familiar
- Subtle difficulties in understanding other's intentions; may take things literally and misunderstand sarcasm or metaphor



- Makes comments without awareness of social niceties or hierarchies
- Unusually negative response to the requests of others (demand avoidant behaviour)

*Eye contact, pointing and other gestures*

- Poorly integrated gestures, facial expressions, body orientation, eye contact (looking at people's eyes when speaking) assuming adequate vision, and spoken language used in social communication

*Ideas and imagination*

- History of a lack of flexible social imaginative play and creativity, although scenes seen on visual media (for example, television) may be re-enacted

*Unusual or restricted interests and/or rigid and repetitive behaviours*

- Repetitive 'stereotypical' movements such as hand flapping, body rocking while standing, spinning, finger flicking
- Preference for highly specific interests or hobbies
- A strong adherence to rules or fairness that leads to argument
- Highly repetitive behaviours or rituals that negatively affect the young person's daily activities
- Excessive emotional distress at what seems trivial to others, for example change in routine
- Dislike of change, which often leads to anxiety or other forms of distress including aggression
- Over or under reaction to sensory stimuli, for example textures, sounds, smells
- Excessive reaction to taste, smell, texture or appearance of food and/or extreme food fads

*Other factors that may support a concern about autism*

- Unusual profile of skills and deficits (for example, social or motor coordination skills poorly developed, while particular areas of knowledge, reading or vocabulary skills are advanced for chronological or mental age)
- Social and emotional development more immature than other areas of development, excessive trusting (naivety), lack of common sense, less independent than peers

## Appendix D: The algorithm

The algorithms are available on pages 26–32 of the [full guideline](#) and in the [NICE pathway](#).

## About this guideline

NICE clinical guidelines are recommendations about the treatment and care of people with specific diseases and conditions in the NHS in England and Wales.

The guideline was developed by the National Collaborating Centre for Women's and Children's Health. The Collaborating Centre worked with a group of healthcare professionals (including consultants, GPs and nurses), patients and carers, and technical staff, who reviewed the evidence and drafted the recommendations. The recommendations were finalised after public consultation.

The methods and processes for developing NICE clinical guidelines are described in [The guidelines manual](#).

The recommendations from this guideline have been incorporated into a [NICE pathway](#). We have produced [information for the public](#) explaining this guideline. Tools to help you put the guideline into practice and information about the evidence it is based on are also [available](#).

### Changes after publication

January 2012: minor maintenance

January 2013: minor maintenance

October 2013: minor maintenance

### Your responsibility

This guidance represents the view of NICE, which was arrived at after careful consideration of the evidence available. Healthcare professionals are expected to take it fully into account when exercising their clinical judgement. However, the guidance does not override the individual responsibility of healthcare professionals to make decisions appropriate to the circumstances of the individual patient, in consultation with the patient and/or guardian or carer, and informed by the summary of product characteristics of any drugs they are considering.

Implementation of this guidance is the responsibility of local commissioners and/or providers. Commissioners and providers are reminded that it is their responsibility to implement the guidance, in their local context, in light of their duties to avoid unlawful discrimination and to have

regard to promoting equality of opportunity. Nothing in this guidance should be interpreted in a way that would be inconsistent with compliance with those duties.

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