

Autism spectrum disorders: recognition, referral and diagnosis in children and young people

NICE guideline

Draft for consultation, January 2011

If you wish to comment on this version of the guideline, please be aware that all the supporting information and evidence is contained in the full version.

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Introduction

This guideline covers the recognition, referral and diagnosis of autism spectrum disorders (ASD) in children and young people from birth up to 18 years. Autism is the classical disorder in the autism spectrum. ASD is a lifelong disorder that usually has a great impact on the child, young person and their family. A diagnosis of ASD can bring a sense of relief to some young people, families and carers who may have always known there was something wrong. Diagnosis offers an understanding of why a child or young person is different from their peers, and some relief from what can be an intense sense of isolation from the world experienced by the child, their family and carers. It can also help them to get support from education, health services and voluntary organisations, and to make contact with other children and families with similar life experiences. All this can improve the life experience of the child or young person and their family.

The term ASD describes abnormal social interaction and communication behaviours, combined with unusual, rigid or repetitive behaviours. The term ASD is used throughout this guideline instead of the term pervasive developmental disorder (PDD), the term used in both the International Classification of Diseases 10th Revision (ICD-10) and the Diagnostic and Statistical Manual 4th Edition (DSM-IV). The terms PDD and ASD are regarded as conveying the same meaning.

The core ASD behaviours are typically present in early childhood although features may not always become apparent until the circumstances of the child or young person change, for example when the child goes to nursery or school or (less commonly) moves to secondary school. ASD is strongly associated with a number of coexisting conditions. Recent studies have shown that approximately 70% of individuals with ASD also meet diagnostic criteria for at least one other (often unrecognised) psychiatric disorder that is further impairing their psychosocial functioning. Intellectual disability (IQ below 70) co-occurs in approximately 50% of young people with ASD.

ASD was once thought to be an uncommon rare developmental disorder, but recent studies have reported increased measured prevalence rates and the condition is now thought to occur in at least 1% of the child population. 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 ASD. Levels of understanding of autism among healthcare and other relevant professionals and availability of services differ greatly from one area to another. In addition there are reported inequalities in recognising ASD in those with intellectual disability.

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

This guideline does not cover interventions for ASD but aims to improve recognition, referral and diagnosis, and the experience of children, young people and those who care for them.

Patient-centred care

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

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 ASD 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 (available from www.dh.gov.uk/consent) and the code of practice that accompanies the Mental Capacity Act (summary available from www.publicguardian.gov.uk). In Wales, healthcare professionals should follow advice on consent from the Welsh Assembly Government (available from www.wales.nhs.uk/consent).

If the child or young person is under 16, healthcare professionals should follow the guidelines in 'Seeking consent: working with children' (available from www.dh.gov.uk/consent).

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 ASD 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 also 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 'Transition: getting it right for young people' (available from www.dh.gov.uk).

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Adult and paediatric healthcare teams should work jointly to provide assessment and services to young people with ASD. 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.

A local pathway for recognition, referral and diagnostic assessment of possible ASD

- There should be a local ASD strategy group with representation from child health and mental health services, education, social care, parent and carer service users and the voluntary sector. [1.1.1]
- The local ASD strategy group should appoint a lead professional who is responsible for the local ASD pathway for recognition, referral and diagnosis of children and young people. The aims of the group should include:
 - improving early recognition of ASD by raising awareness of the signs and symptoms of ASD through training (see tables 1.1–1.3)
 - making sure the relevant professionals (healthcare, social care and education) are aware of the local ASD pathway and how to access diagnostic services
 - supporting the smooth transition to adult services for young people going through the diagnostic pathway. [1.1.2]
- There should be a multidisciplinary ASD team (the ASD team) which may include a:
 - paediatrician
 - child and adolescent psychiatrist
 - speech and language therapist
 - clinical or educational psychologist
 - occupational therapist. [1.1.3]
- Access to the ASD team should be through a single point of entry. [1.1.5]

The ASD diagnostic assessment for children and young people

- A case coordinator should be appointed from the ASD team for every child or young person who is to have an ASD diagnostic assessment. [1.5.2]

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- Include the following elements in every ASD diagnostic assessment:
 - detailed enquiry about parent or carer concerns and if appropriate the child or young person's concerns
 - a medical history including prenatal, perinatal and family history and current health
 - The child's or young person's experiences of social care and education
 - a developmental history focussing on developmental and behavioural features consistent with ICD-10 or DSM-IV criteria (consider using an ASD-specific tool to gather this information)
 - assessment through interaction with and observation of the child or young person of their social and communicative skills and behaviours focussing on features consistent with ICD-10 or DSM-IV criteria (consider using an ASD-specific diagnostic tool to gather this information). [1.5.4]

- Consider the following differential diagnoses for ASD and if an alternative diagnosis is suspected carry out an appropriate assessment, including referral to other appropriate services:
 - neurodevelopmental disorders:
 - ◇ specific language delay or disorder
 - ◇ intellectual disability or global developmental delay
 - ◇ developmental coordination disorder (DCD)
 - neuropsychiatric disorders:
 - ◇ attention deficit hyperactivity disorder (ADHD)
 - ◇ mood disorder
 - ◇ anxiety disorder
 - ◇ attachment disorders
 - ◇ oppositional defiant disorder (ODD)
 - ◇ conduct disorder
 - ◇ obsessive-compulsive disorder (OCD)
 - conditions in which there is developmental regression:
 - ◇ Rett's syndrome
 - ◇ epileptic encephalopathy (EE)

- other conditions:
 - ◇ severe hearing impairment
 - ◇ severe visual impairment (blind)
 - ◇ maltreatment
 - ◇ selective mutism. [1.5.7]

After the ASD diagnostic assessment

- Construct a profile for every child or young person who has had an ASD diagnostic assessment, including their strengths, skills, impairments and needs to create a needs-based management plan. This should cover learning, communication, self-care and other adaptive skills, behaviour and emotional health, taking account of the family context and needs.[1.6.4]

Communicating with parents and professionals about the results from the ASD diagnostic assessment

- After assessment and diagnosis of ASD, make sure the profile is made available to professionals in education and, and if appropriate, social care, so it can contribute to the child's or young person's individual education plan and other aspects of the needs-based management plan, through for example, a school visit by a member of the ASD team. [1.8.9]

1 Guidance

The following guidance is based on the best available evidence. The full guideline ([\[hyperlink to be added for final publication\]](#)) gives details of the methods and the evidence used to develop the guidance.

1.1 *A local pathway for recognition, referral and diagnostic assessment of possible ASD*

- 1.1.1 There should be a local ASD strategy group with 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 ASD strategy group should appoint a lead professional who is responsible for the local ASD pathway for recognition, referral and diagnosis of children and young people. The aims of the group should include:
- improving early recognition of ASD by raising awareness of the signs and symptoms of ASD through training (see tables 1.1–1.3)
 - making sure the relevant professionals (healthcare, social care and education) are aware of the local ASD pathway and how to access diagnostic services
 - supporting the smooth transition to adult services for young people going through the diagnostic pathway.
- 1.1.3 There should be a multidisciplinary ASD team (the ASD team) which may include a:
- paediatrician
 - child and adolescent psychiatrist
 - speech and language therapist
 - clinical or educational psychologist
 - occupational therapist.

1.1.4 The ASD team should:

- provide advice to professionals about referring for ASD assessments
- decide on the assessment needs of those referred
- be skilled in communicating with children and young people with suspected or known ASD and with their parents and carers
- develop the profile (see 1.6.4) and management plan for each child or young person
- with parent or carer consent, share information from the ASD diagnostic assessment directly with relevant services, for example a school visit by an ASD team member
- give information to families and carers about appropriate services and support (see 1.9.1).

1.1.5 Access to the ASD team should be through a single point of entry.

1.1.6 The ASD team should either have the skills needed to carry out an ASD diagnostic assessment or have access to professionals that do, for assessing:

- children and young people of all ages taking into account the cultural setting or language background **and**
- children and young people with co-existing conditions such as deafness, blindness, motor disorders including cerebral palsy, intellectual disability, language disorders or additional mental health disorders.

- 1.1.7 If young people present at the time of transition to adult services, the ASD team should consider carrying out the diagnostic assessment jointly with the adult ASD diagnostic team, regardless of the young persons' intellectual ability.

1.2 *Recognising children and young people with possible ASD*

- 1.2.1 Consider the possibility of ASD when 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 parental concerns about behaviour or development seriously, even if these are not shared by others.
- 1.2.3 When considering the possibility of ASD and whether to refer a child or young person to the ASD team, be self-critical about your professional competence and seek advice from a colleague if in doubt about the next step.
- 1.2.4 Use tables 1.1–1.3 to help identify the signs and symptoms of possible ASD.

Table 1.1 Preschool children (or equivalent mental age)

<p>Social interaction and communication behaviours</p> <ul style="list-style-type: none">• Delay in language development (babble or words)• Lack of meeting eye gaze• Lack of response to name despite normal hearing• Relative lack of responsive social smiling• Limited responsiveness to other people's facial expression or feelings• Rejection of cuddles• Relative lack of social interest in others• Lack of joint attention shown by lack of:<ul style="list-style-type: none">– gaze switching– following a point– using pointing at or showing objects to share interest• Lack of gestures and facial expression to communicate (although may place adult's hand on objects)• Relative lack of sharing enjoyment• Lack of imitation of others' actions• Lack of imagination and variety of pretend play• Lack of initiation of social play with others• Abnormal-sounding vocalisations• language present:<ul style="list-style-type: none">– odd or flat intonation– frequent repetition of set words and phrases ('echolalia')– reference to self as 'you' or 'she/he' beyond 3 years• limited and/or infrequent use of language for communication, for example use of single words although can speak in sentences <p>Unusual and/or rigid/repetitive behaviours</p> <ul style="list-style-type: none">• Unusual repetitive hand, finger and body mannerisms• Highly repetitive and/or stereotyped play, for example opening and closing doors, spinning• Over or under reactivity to sensory stimuli, for example textures, sounds, smells• Extremes of emotional reactivity to change and/or new situations, insistence on things being 'the same'• Over-focused and/or unusual interests• Excessive reaction to certain properties of food and/or extreme food fads• Unusually negative response to the requests of others (demand avoidant behaviour)
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Table 1.2 Primary school children (aged 5–11 years or equivalent mental age)

<p>Social interaction and communication behaviours</p> <ul style="list-style-type: none">• Delay in language development (babble or words)• Lack of meeting eye gaze• Lack of response to name despite normal hearing• Relative lack of responsive social smiling• Limited or unusual response to other people's facial expression and/or happiness or distress• Relative lack of social interest in others• Lack of joint attention shown by lack of:<ul style="list-style-type: none">– gaze switching– following a point– using pointing at or showing objects to share interest• Relative lack of or poorly integrated eye gaze, gestures, facial expressions and body orientation in social communication• Lack of greeting and farewell behaviours• Limited or excessive talking, as shown in talking at others rather than a to-and-fro conversation and providing excessive information on topics of own interest• Frequent repetition of set words and phrases• Lack of flexible imaginative play and/or creativity although film scenes may be re-enacted• Relative lack of interest in children of his or her own age• Lack of ability to share in the play and/or ideas of other children, or inappropriate attempts at joint play that may manifest as aggressive or disruptive behaviour• Unusually negative response to the requests of others (demand avoidant behaviour)• Lack of awareness of expected behaviour• Lack of enjoyment of situations that most children like, for example school trips <p>Unusual and/or rigid/repetitive behaviours</p> <ul style="list-style-type: none">• Over or under reactivity to sensory stimuli, for example textures, sounds, smells• Excessive reaction to certain properties of food and/or extreme food fads• Unusual repetitive hand, finger and body mannerisms• Over-focused and/or unusual interests• Strong preferences for familiar routines and things being 'just right'• Rigid expectation that other children should adhere to rules of play• Extremes of emotional reactivity excessive for the circumstances, for example in response to change or being hurried <p>Other factors that may support a concern about ASD</p> <ul style="list-style-type: none">• Unusual profile of skills and/or deficits (for example, social, and/or motor skills poorly developed, while particular areas of knowledge, reading or vocabulary skills are advanced for chronological and/or mental age)

Table 1.3 Secondary school children (over 11 years or equivalent mental age)

<p>Social interaction and communication behaviours</p> <ul style="list-style-type: none">• Long-standing difficulties in social behaviours and social communication• Poorly integrated gestures, facial expressions, body orientation and odd and/or limited eye contact used in social communication• Lack of awareness of personal space, or intolerant of intrusions in own space• Speech peculiarities such as flat or odd tone or pitch• Repetitive speech, use of stereotyped (learnt) phrases• Poor greeting and farewell behaviours• Unable to adapt style of communication to social situations, for example may be overly formal or inappropriately familiar• May take things literally and fail to understand sarcasm or metaphor• Makes comments without awareness of social niceties and/or hierarchies• Lack of 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• History of a lack of flexible imaginative play• May appear unaware or uninterested in what other young people his or her age are interested in• Social and emotional development more immature than other areas of development, excessive trusting (naivety), lack of common sense, less independent than peers• Problems losing at games, turn taking and understanding 'changing the rules'• Poor response to the requests of others and to the perceived expectations (demand avoidant behaviour)• Lack of awareness of expected behaviour <p>Unusual and/or rigid/repetitive behaviours</p> <ul style="list-style-type: none">• Highly repetitive behaviours and/or rituals that impact negatively on the young person's daily activities• Excessive and unusual reaction to certain sensory stimuli• Excessive reaction to certain properties of food and/or extreme food fads• Unusual repetitive hand, finger and body mannerisms• A strong adherence to rules or fairness that leads to argument• Preference for highly specific interests or hobbies• Disproportionate emotional distress at what seems trivial to others, for example change in routine <p>Other factors that may support a concern about ASD</p> <p>Unusual profile of skills and deficits (for example, social and/or motor skills poorly developed, while particular areas of knowledge, reading or vocabulary skills are advanced for chronological and/or mental age)</p>
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1.2.5 Do not rule out ASD because the exact behaviours described in tables 1.1–1.3 are not evident. The features described should be used for guidance, but do not include all possible manifestations of ASD.

1.2.6 When considering the possibility of ASD, be aware that:

- signs and symptoms should be seen in the context of the child's overall development
- signs and symptoms will not always have been recognised by parents or by other professionals
- when secondary school children present with possible ASD, signs or symptoms may have been masked by the child's coping mechanisms and/or a supportive environment
- you should not assume language delay is accounted for because English is not the family's first language because language delay could be a pointer to ASD
- ASD may be missed in children with an intellectual disability
- the signs and symptoms of ASD may be more subtle in girls
- important information about early development may not be readily available for some children and young people in whom ASD is suspected, for example looked after children and those in the criminal justice system.

1.2.7 Do not rule out ASD because of any of the following:

- a child's or young person's difficulties appear to resolve after a needs-based intervention (such as a supportive structured learning environment)
- reported normal or advanced pre-school development
- good eye contact, smiling and showing affection to family members.

- 1.2.8 When considering the possibility of ASD, do not rule in or out the possibility of ASD because of a conclusion from a previous diagnostic assessment.
- 1.2.9 When considering the possibility of ASD, ask about the child's use and understanding of their first language.
- 1.2.10 Discuss developmental or behavioural concerns about a child or young person with parents or carers and the young person themselves where appropriate. Discuss sensitively the possible causes, which may include ASD, emphasising that there may be many explanations for the child's or young person's behaviour.
- 1.2.11 Be aware that if parents or carers 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 to start with.
- 1.2.12 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 ASD team*

- 1.3.1 Refer children and young people urgently to the ASD team if there is regression of language or social skills together with any signs and symptoms of ASD (see tables 1.1–1.3).
- 1.3.2 If you have concerns about development or behaviour but you are not sure whether the signs and/or symptoms suggest ASD, consider consulting a member of the ASD team or referring to another appropriate service. These services can then refer to the ASD team if necessary.

1.3.3 Consider referring to the ASD team if you are concerned about possible ASD on the basis of reported or observed signs or symptoms (see tables 1.1–1.3). Take account of the following:

- 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
- the presence of risk factors for ASD (see table 1.4)
- the likelihood of an alternative diagnosis.

Table 1.4 Risk factors for ASD

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| <ul style="list-style-type: none">• Intellectual disability• A sibling with ASD• Birth defects associated with central nervous system malformation and/or dysfunction including cerebral palsy• Gestational age less than 35 weeks• Maternal use of sodium valproate in pregnancy• Neonatal encephalopathy or epileptic encephalopathy including infantile spasms• Chromosomal disorders such as Down's syndrome• Genetic disorders such as fragile X• Duchenne muscular dystrophy• Neurofibromatosis• Tuberous sclerosis |
|---|

1.3.4 Be aware that:

- ASD-specific screening tools may be useful in gathering information about signs and symptoms of ASD in a structured way but are not essential and should not be used to make or rule out a diagnosis of ASD:
 - a positive score on a screening instrument may support a decision to refer but can also be positive for reasons other than ASD
 - a negative score does not rule out ASD.

- 1.3.5 When referring to the ASD team, provide in a written report all relevant and available information, including:
- reported information from parents, carers and professionals about signs and/or symptoms of concern
 - your own observations of the signs and/or symptoms
 - antenatal and perinatal history
 - developmental milestones
 - known risk factors for ASD (see table 1.4)
 - relevant medical history and investigations.
- 1.3.6 Explain to parents what will happen after referral.
- 1.3.7 Watch and wait if you do not think concerns are sufficient to prompt a referral. If you remain concerned about ASD, reconsider your referral decision.
- 1.3.8 If the parents or carers prefer not to be referred to the ASD team, consider a period of watchful waiting. If you remain concerned about ASD, reconsider referral.
- 1.3.9 If a concern about possible ASD has been raised but there are no signs or symptoms or other reasons to suspect ASD, use professional judgment to decide on management.

1.4 *After referral to the ASD team*

- 1.4.1 When a child or young person is referred to the ASD team, at least one member of the ASD team should consider without delay whether to proceed to:
- an ASD diagnostic assessment **and/or**
 - an alternative assessment.

1.4.2 Carry out an ASD diagnostic assessment without delay if there is regression of language or social skills together with any signs and symptoms of ASD (see tables 1.1–1.3).

1.4.3 In the absence of regression, decide whether to carry out an ASD diagnostic assessment taking into account the following:

- 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
- the presence of risk factors (see table 1.4)
- the likelihood of an alternative diagnosis.

1.4.4 If there is insufficient information to decide whether an ASD diagnostic assessment is needed, consider:

- offering the child or young person a consultation with a relevant healthcare professional(s)
- gathering necessary information from other healthcare professionals (for example, hearing test results for a pre-school child)
- with parental or carer consent, obtaining information from schools or other agencies.

1.5 *The ASD diagnostic assessment for children and young people*

1.5.1 Once it is decided to carry out an ASD diagnostic assessment, this should start without delay and within 3 months of the initial referral to the ASD team.

1.5.2 A case coordinator should be appointed from the ASD team for every child or young person who is to have an ASD diagnostic assessment.

1.5.3 The ASD case coordinator should:

- act as a single point of contact for the parents or carers and for the child or young person undergoing an ASD diagnostic assessment, and for relevant professionals
- make sure that parents, carers, children and young people have appropriate information and access to appropriate support during diagnostic assessment
- explain to parents and carers the likely time and sequence of assessments.

1.5.4 Include the following elements in every ASD diagnostic assessment:

- detailed enquiry about parent or carer concerns and if appropriate the child or young person's concerns
- a medical history including prenatal, perinatal and family history and current health
- The child's or young person's experiences of social care and education
- a developmental history focussing on developmental and behavioural features consistent with ICD-10 or DSM-IV criteria (consider using an ASD-specific tool to gather this information)
- assessment through interaction with and observation of the child or young person of their social and communicative skills and

behaviours focussing on features consistent with ICD-10 or DSM-IV criteria (consider using an ASD-specific diagnostic tool to gather this information).

1.5.5 Carry out a physical examination in:

- preschool children
- those with intellectual disability or a family history of intellectual disability
- those with dysmorphic features
- those in whom there is concern regarding physical maltreatment or neglect (see 'When to suspect child maltreatment' [NICE clinical guideline 89]) or self-injurious behaviour/self-harm (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])
- those with a history suggesting a neurological disorder including suspicion of epilepsy
- children or young people in whom you think it appropriate.

1.5.6 In the physical examination, look for:

- skin stigmata of neurofibromatosis or tuberous sclerosis using a Wood's light
- signs of injury, for example self-harm or child maltreatment (see NICE clinical guidelines 16 and 89 respectively).

- 1.5.7 Consider the following differential diagnoses for ASD and if an alternative diagnosis is suspected carry out an appropriate assessment, including referral to other appropriate services:
- neurodevelopmental disorders:
 - specific language delay or disorder
 - intellectual disability or global developmental delay
 - developmental coordination disorder (DCD)
 - neuropsychiatric disorders:
 - attention deficit hyperactivity disorder (ADHD)
 - mood disorder
 - anxiety disorder
 - attachment disorders
 - oppositional defiant disorder (ODD)
 - conduct disorder
 - obsessive-compulsive disorder (OCD)
 - conditions in which there is developmental regression:
 - Rett’s syndrome
 - epileptic encephalopathy (EE)
 - other conditions:
 - severe hearing impairment
 - severe visual impairment (blind)
 - maltreatment
 - selective mutism.
- 1.5.8 Avoid repeated information gathering and assessments by efficient communication between professionals and agencies.
- 1.5.9 Consider whether specific assessments are necessary to help the interpretation of the ASD history and observations, for example a cognitive or language assessment appropriate to the child or young persons’ age and ability.

- 1.5.10 Consider which assessments are required to profile each child's or young person's skills and impairments, 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
 - sensory sensitivities
 - behaviour likely to affect participation.
- 1.5.11 Use information from all sources, together with clinical judgment, to diagnose ASD based on ICD-10 or DSM-IV criteria.
- 1.5.12 Do not rely on any single ASD-specific diagnostic tool without other sources of information to diagnose ASD.
- 1.5.13 Be aware that in some children and young people there may be uncertainty about the diagnosis of ASD, particularly in those with:
- a chronological age of less than 24 months
 - a mental age of less than 18 months
 - a lack of available information about their early life (for example some looked-after or adopted children)
 - a complex comorbid mental health disorder (for example ADHD, conduct disorder, a possible attachment disorder) sensory impairment (for example blindness or deafness), or motor disorder such as cerebral palsy.

1.5.14 Consider whether the child or young person may have, or have symptoms of, any of the following coexisting conditions and if suspected, carry out appropriate assessments:

- Neuropsychiatric:
 - ADHD
 - anxiety disorders and phobias
 - mood disorders
 - oppositional defiant behaviour
 - tics and Tourette syndrome
 - obsessive compulsive disorder
 - self-injurious behaviour
- Neurodevelopmental:
 - global delay or intellectual disability
 - motor coordination
 - academic learning problems, for example literacy and numeracy
 - speech and language disorder
- Medical or genetic problems and disorders:
 - epilepsy and epileptic encephalopathy
 - chromosome disorders
 - genetic abnormalities including fragile X
 - tuberous sclerosis
 - Duchenne muscular dystrophy
 - neurofibromatosis
- Functional problems:
 - eating/feeding
 - urinary continence/eneuresis
 - bowels/encopresis
 - sleep
 - vision and hearing impairment.

- 1.5.15 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 ASD diagnostic assessment*

- 1.6.1 If after the ASD diagnostic assessment there is uncertainty about the diagnosis:

- consider keeping the child or young person under review
- carry out another ASD diagnostic assessment within 6 months
- take account of information arising from any needs-based interventions provided in the interim.

- 1.6.2 If during the ASD diagnostic assessment, there were discrepancies between reported signs or symptoms and the findings of the ASD observation in the clinic setting, consider:

- gathering additional information from other sources
- carrying out further ASD-specific observation(s) in a different setting such as the school or nursery.

- 1.6.3 Consider obtaining a second opinion, including referral to a specialised tertiary ASD team if necessary, if after assessment there is:

- continued uncertainty about the diagnosis
- disagreement about the diagnosis within the ASD team
- disagreement with parents or carers about the diagnosis
- a lack of local access to particular skills and competencies required to reach a diagnosis in a child or young person who has a complex comorbidity, such as a severe sensory or motor impairment or mental health problem
- a failure to respond as expected to any therapeutic interventions being provided.

- 1.6.4 Construct a profile for every child or young person who has had an ASD diagnostic assessment, including their strengths, skills, impairments and needs to create a needs-based management plan. This should cover learning, communication, self-care and other adaptive skills, behaviour and emotional health, taking account of the family context and needs.
- 1.6.5 Assess the risk of harm to and from the child or young person arising from their condition.

1.7 *Medical investigations*

- 1.7.1 Do not routinely perform any medical investigations as part of an ASD diagnostic assessment but consider the following in individual circumstances and based on clinical judgment:
- electroencephalography (EEG) if there is suspicion of epilepsy (see 'The epilepsies: the diagnosis and management of the epilepsies in adults and children in primary and secondary care' [NICE clinical guideline 20])
 - genetic tests, as recommended by your regional genetics centre, when there are specific dysmorphic features and/or evidence of intellectual disability.

1.8 *Communicating with parents, carers and professionals about the results from the ASD diagnostic assessment*

- 1.8.1 After the ASD diagnostic assessment, discuss the findings in person with the parents or carers without delay. Explain the basis of conclusions even if the diagnosis is not yet certain.
- 1.8.2 When discussing the diagnosis with families, carers, children and young people, use generic guidelines for sharing and disclosing diagnosis to children and young people.
- 1.8.3 Discuss with the parents and/or carers how information should be shared with the child or young person. Take into account, for example, their age and ability to understand.
- 1.8.4 Provide information specific to the child or young person based on their profile.
- 1.8.5 When ASD is diagnosed, discuss with parents and/or carers the risk of ASD occurring in siblings and future children.
- 1.8.6 Provide a written report for the child or young person and parents and/or carers explaining the findings of the assessment and the basis for the conclusions drawn.
- 1.8.7 Share information from the diagnostic assessment with the GP and, with parental or carer consent (and if appropriate the consent of the child or young person), key professionals including those in education and social services.
- 1.8.8 Offer a follow-up appointment with an appropriate member of the ASD team within 6 weeks of the assessment for further discussion.

- 1.8.9 After assessment and diagnosis of ASD, make sure the profile is made available to professionals in education and, and if appropriate, social care, so it can contribute to the child's or young person's individual education plan and other aspects of the needs-based management plan, through for example, a school visit by a member of the ASD team.

1.9 *Information and support for families and carers*

- 1.9.1 Provide information on support available locally for children and young people with ASD on an individual basis 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 ASD, or information about specific courses for parents and carers and/or young people)
 - advice on available social benefits
 - education and social services
 - information to help prepare for the future for example, transition to adult services.

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. The scope of this guideline is available from <http://guidance.nice.org.uk/CG/Wave15/78/Scope/pdf/English>.

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

The guideline does not cover population screening or surveillance; the basic components of any routine paediatric or mental health assessment not specific to ASD; the role and competencies of different professions in the recognition and diagnosis of ASD; specific models for running a diagnostic service; interventions and ongoing management of ASD, including specific therapeutic interventions during diagnosis; and 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 (www.nice.org.uk/HowWeWork). A booklet, 'How NICE clinical guidelines are developed: an overview for stakeholders, the public and the NHS' (fourth edition, published 2009), is available from NICE publications (phone 0845 003 7783 or email publications@nice.org.uk and quote reference N1739).

3 Implementation

NICE has developed tools to help organisations implement this guidance (see www.nice.org.uk/guidance/CG191).

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

What is the effectiveness and cost effectiveness of training professionals in early recognition and identification of children and young people with ASD?

Why this is important

Earlier (and quicker) recognition would probably be more acceptable to children and young people and their parents and families. It could also reduce distress (although parents who have not recognised the problems themselves may find a diagnosis distressing). We do not have information on whether

earlier identification reduces morbidity or improves outcomes (on the basis that supports and interventions are put in place earlier). We have limited information on effectiveness of training.

4.2 *Additional assessments*

What is the effectiveness and cost effectiveness of additional assessments (language, motor, psychiatric history or use of scales) in:

- diagnosing ASD
- differentiating ASD from other conditions
- identifying common comorbidities in children and young people with signs and symptoms of ASD?

Why this is important

Improved differential diagnosis (and identification of the common comorbidities) would improve acceptability and satisfaction for children and young people and their families and carers. Some of the comorbidities have proven treatments (for example, ADHD), so it may be possible to reduce morbidity.

4.3 *Biomedical investigations*

What are the effectiveness, cost effectiveness and acceptability to parents, carers, children and young people, of biomedical investigations (that is, EEG, brain imaging, genetic tests, metabolic tests or other blood or urine tests) for establishing aetiology, and/or of genetic counselling in children and young people with identified autism spectrum disorder?

Why this is important

The area of research focuses not on diagnosis of ASD but on aetiology or genetic counselling, which are part of the wider diagnostic assessment, along with profiling. As yet, few genetic tests have obvious treatment implications and the value of these tests in improving the welfare of children and young people or the family is not well understood. As more genetic findings emerge, they might prove valuable in terms of explaining the underlying cause of a child's ASD but we have no evidence that this would improve outcomes.

4.4 *Gathering information in schools or nurseries*

What are the effectiveness and cost effectiveness of gathering information in schools or nurseries on children referred to the ASD team to improve diagnostic certainty?

Why this is important

The Guideline Development Group considered that gathering information in schools and nurseries could improve the timing, effectiveness and quality of the diagnostic assessment, and the accuracy of diagnosis.

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, and is available from our website ([www.nice.org.uk/guidance/CG\[XX\]/Guidance](http://www.nice.org.uk/guidance/CG[XX]/Guidance)). **Note: these details will apply to the published full guideline.**

5.2 *Quick reference guide*

A quick reference guide for healthcare professionals is available from [www.nice.org.uk/guidance/CG\[XX\]/QuickRefGuide](http://www.nice.org.uk/guidance/CG[XX]/QuickRefGuide)

For printed copies, phone NICE publications on 0845 003 7783 or email publications@nice.org.uk (quote reference number N[XXXX]). **Note: these details will apply when the guideline is published.**

5.3 *'Understanding NICE guidance'*

A summary for patients and carers ('Understanding NICE guidance') is available from [www.nice.org.uk/guidance/CG\[XX\]/PublicInfo](http://www.nice.org.uk/guidance/CG[XX]/PublicInfo)

For printed copies, phone NICE publications on 0845 003 7783 or email publications@nice.org.uk (quote reference number N[XXXX]). **Note: these details will apply when the guideline is published.**

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

6 Related NICE guidance

Published

- Guidance on when to suspect maltreatment. NICE clinical guideline 89 (2009). Available from www.nice.org.uk/guidance/CG89
- Attention deficit hyperactivity disorder. NICE clinical guideline 72 (2008). Available from www.nice.org.uk/guidance/CG72
- Depression in children and young people. NICE clinical guideline 28 (2005). Available from www.nice.org.uk/guidance/CG28
- The epilepsies. NICE clinical guideline 20 (2004). Available from www.nice.org.uk/guidance/CG20
- Self-harm. NICE clinical guideline 16 (2004). Available from www.nice.org.uk/guidance/CG16

Under development

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

- Autistic spectrum conditions in adults. 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

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NICE project team

To be completed by NICE

[Name; style = Unnumbered bold heading]

Associate Director/Programme Director/Centre for Clinical Practice Director

[Delete as appropriate]

[Name; style = Unnumbered bold heading]

Guideline Commissioning Manager

[Name; style = Unnumbered bold heading]

Guideline Coordinator

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Technical Lead

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Health Economist

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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.

NICE to add

[Name; style = Unnumbered bold heading]

[job title and location; style = NICE normal]

Appendix C: The algorithm

Please see the full guideline for the ASD care pathway.