Quick reference guide

Issue date: September 2011

Autism

Recognition, referral and diagnosis of children and young people on the autism spectrum
About this booklet
This is a quick reference guide that summarises the recommendations NICE has made to the NHS in 'Autism: recognition, referral and diagnosis of children and young people on the autism spectrum' (NICE clinical guideline 128).

Who should read this booklet?
This quick reference guide is for GPs, paediatricians, psychiatrists, psychologists, speech and language therapists, occupational therapists and other staff who care for children and young people with possible autism.

Who wrote the guideline?
The guideline was developed by the National Collaborating Centre for Women’s and Children’s Health, which is linked with the Royal College of Obstetricians and Gynaecologists. The Collaborating Centre worked with a group of healthcare professionals, patients and carers, and technical staff, who reviewed the evidence and drafted the recommendations. The recommendations were finalised after public consultation.

For more information on how NICE clinical guidelines are developed, go to www.nice.org.uk

Where can I get more information about the guideline?
The NICE website has the recommendations in full, reviews of the evidence they are based on, a summary of the guideline for patients and carers, and tools to support implementation (see page 22 for more details).
Introduction

The term autism describes qualitative differences and impairments in reciprocal social interaction and social communication, combined with restricted interests and rigid and repetitive behaviours. In this guideline, ‘autism’ is used to refer to ‘autism spectrum disorder’ or ‘pervasive developmental disorder’.

Autism is a lifelong condition that has a great impact on children, young people and their families or carers. Diagnosis and needs assessment 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, social care and a route into voluntary organisations and contact with other children and families with similar experiences. All this can improve the lives of children, young people and their families.

The rising prevalence of autism has increased demand for diagnostic services in the NHS. This guideline covers the recognition, referral and diagnosis of autism in children and young people from birth up to 19 years.

Patient-centred care

Treatment and care should take into account children and young people’s individual needs and preferences, and those of their parents and carers. Good communication is essential, supported by evidence-based information, to allow parents and carers, and children and young people when appropriate, to reach informed decisions about their care. Follow advice on seeking consent from the Department of Health or Welsh Government if needed. If caring for young people in transition between paediatric and adult services refer to ‘Transition: getting it right for young people’ (available from www.dh.gov.uk).
Key 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 on pages 14–19)
  - 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:
  - 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)
Autism

Key priorities for implementation

- 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 page 11)
- systematic assessment for conditions that may coexist with autism (see page 11)
- 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 (see page 12).

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.
Service organisation

Strategy group

- 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
  - 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 on pages 14–19)
  - making sure the relevant professionals are aware of the local autism pathway and how to access diagnostic services
  - supporting the smooth transition to adult services for young people
  - ensuring data collection and audit of the pathway takes place.

The autism team

- 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.
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.

Autism team members should:
- provide advice to professionals about whether to refer children or young people for autism diagnostic assessments
- decide on the assessment needs of those referred or when referral to another service is needed
- carry out the autism diagnostic assessment
- share the outcome of the autism diagnostic assessment with parents and carers, and children and young people if appropriate
- with parent or carer consent (and the consent of the child or young person if appropriate) 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, parents and carers about appropriate services and support.

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

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 or mental health disorders
- looked-after children and young people.

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.
Recognising possible autism

**Concerns about development or behaviour**
- 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.
- 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.

**Signs and symptoms**
Use tables 1–3 on pages 14–19 to help identify the signs and symptoms of possible autism. 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.

**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's coping mechanisms 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.
- 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.
- 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
  - a previous assessment that concluded that there was no autism, if new information becomes available.
- Ask about the child or young person's use and understanding of their first language.
- 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.
- 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.
- 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 these tools may support a decision to refer but can also be for reasons other than autism
  - a negative score does not rule out autism.

Discuss developmental or behavioural concerns 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.
**Autism**

**Referral**

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

**Concern about signs or symptoms but no regression**
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 on pages 14–19). 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 table 4 on page 20)
- the likelihood of an alternative diagnosis.

**Insufficient concern to refer immediately, or referral declined**
- If you do not think concerns are sufficient to prompt a referral, consider a period of watchful waiting.
- If the parents or carers (or when relevant the child or young person) prefer not to be referred to the autism team, consider a period of watchful waiting.

**Concerns raised, but no signs, symptoms or other reasons to suspect autism**
- Use professional judgment to decide what to do next.

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 or
- referring to another service. That service can then refer to the autism team if necessary.

**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.**

**Referral letter to the autism team**
Include:
- reported information from parents, carers and professionals about signs and/or symptoms of concern
- your own observations of the signs and/or symptoms.

Include if available:
- antenatal and perinatal history
- developmental milestones
- factors associated with an increased prevalence of autism (see table 4 on page 20)
- relevant medical history and investigations
- information from previous assessments.
Deciding on assessment

When a child or young person is referred, at least one member of the autism team should consider whether to carry out:
- an autism diagnostic assessment and/or
- an alternative assessment.
Avoid repeated information gathering and assessments by efficient communication between professionals and agencies.

Children and young people:
- older than 3 years with regression in language
- of any age with regression in motor skills.

Regression in language or social skills in a child younger than 3 years.

All other children who have been referred to the autism team, including those referred back from a paediatrician or paediatric neurologist.

When deciding whether to carry out an autism diagnostic assessment, 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
- 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 table 4 on page 20)
- the likelihood of an alternative diagnosis (see table 5 on page 20).

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 the child or young person if appropriate), seek information from schools or other agencies.

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

General principles
- A case coordinator in the autism team should be identified for every child or young person who is to have an autism diagnostic assessment.
- 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
  - keep parents or carers, and if appropriate the child or young person, up to date about the likely time and sequence of assessments
  - arrange information and support for parents, carers, children and young people
  - gather information relevant to the autism diagnostic assessment.
- Start the autism diagnostic assessment within 3 months of the referral.
- 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. Take into account, for example, the child or young person's age and ability to understand.
- 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.

Consider which assessments are needed
Consider which assessments will be needed to construct a profile, 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.

The autism diagnostic assessment
- Include in every autism diagnostic assessment:
  - detailed questions about parent's or carer's concerns (and if appropriate the child 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
  - consideration of differential diagnoses and systematic assessment for conditions that may coexist with autism (see pages 20–21)
  - 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 (see page 12).
- 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 or child maltreatment (see 'Related NICE guidance' on page 22)
  - congenital anomalies and dysmorphic features including macrocephaly or microcephaly.
- Consider differential diagnoses for autism and whether specific assessments are needed to help interpret the autism history and observations (see table 5 on page 20).
- Consider whether the child or young person may have a coexisting condition (see table 6 on page 21), and if suspected carry out appropriate assessments and referrals.
- 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 (see 'Related NICE guidance' on page 22).
**Diagnosis**

If there are discrepancies 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.

**Diagnosis**
- Use information from all sources, together with clinical judgment, to diagnose autism based on ICD-10 or DSM-IV criteria.
- Do not rely on any autism-specific diagnostic tool alone to diagnose autism.
- 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).
- Be aware that in children and young people with communication difficulties it may be difficult to recognise functional problems or mental health problems.
- Consider any potential risk of harm to, and from, the child or young person and take appropriate action.
- 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.

**Communicating the results from the autism diagnostic assessment**
- 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.
- Use recognised good practice when sharing a diagnosis with parents, carers, children and young people.
- 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.
- Share information, including the written report of the diagnostic assessment, with the GP.
- With parental or carer consent (and the consent of the child or young person if appropriate), share the profile with key professionals involved in the child's or young person's care, including those in education and social care.
- 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.
**Diagnosis not autism**
- If the child or young person clearly does not have autism, consider referring them to appropriate services based on their profile.

**Autism diagnosed**
- Offer a follow-up appointment with an appropriate member of the autism team within 6 weeks of the end of the autism diagnostic assessment for further discussion (for example, about the conclusions of the assessment and the implications for the child or young person).
- 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.
- Discuss with parents or carers the risk of autism occurring in siblings and future children.
- Provide individual information on support available locally for parents, carers, children and young people, according to the family's needs. This may include:
  - contact details for:
    - local and national support organisations
    - 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.

**Diagnosis uncertain**
- Consider keeping the child or young person under review, taking into account any new information.
- 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
  - a lack of response as expected to any therapeutic interventions provided to the child or young person.
### Tables 1–3 Signs and symptoms of possible autism

#### Using this table
These signs and symptoms 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)

<table>
<thead>
<tr>
<th>Social interaction and reciprocal communication behaviours</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Spoken language</strong></td>
<td></td>
</tr>
<tr>
<td>• Language delay (in babble or words, for example less than ten words by the age of 2 years)</td>
<td></td>
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<tr>
<td>• Regression in or loss of use of speech</td>
<td></td>
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<tr>
<td>• Spoken language (if present) may include unusual:</td>
<td></td>
</tr>
<tr>
<td>– non-speech like vocalisations</td>
<td></td>
</tr>
<tr>
<td>– odd or flat intonation</td>
<td></td>
</tr>
<tr>
<td>– frequent repetition of set words and phrases ('echolalia')</td>
<td></td>
</tr>
<tr>
<td>– reference to self by name or ‘you’ or ‘she/he’ beyond 3 years</td>
<td></td>
</tr>
<tr>
<td>• Reduced and/or infrequent use of language for communication, for example use of single words although able to speak in sentences</td>
<td></td>
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<tr>
<td><strong>Responding to others</strong></td>
<td></td>
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<tr>
<td>• Absent or delayed response to name being called, despite normal hearing</td>
<td></td>
</tr>
<tr>
<td>• Reduced or absent responsive social smiling</td>
<td></td>
</tr>
<tr>
<td>• Reduced or absent responsiveness to other people’s facial expressions or feelings</td>
<td></td>
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<tr>
<td>• Unusually negative response to the requests of others (demand avoidant behaviour)</td>
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</tr>
<tr>
<td>• Rejection of cuddles initiated by parent or carer, although may initiate cuddles themselves</td>
<td></td>
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<tr>
<td><strong>Interacting with others</strong></td>
<td></td>
</tr>
<tr>
<td>• Reduced or absent awareness of personal space, or unusually intolerant of people entering their personal space</td>
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<tr>
<td>• 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</td>
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<tr>
<td>• Reduced or absent imitation of others’ actions</td>
<td></td>
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<tr>
<td>• Reduced or absent initiation of social play with others, plays alone</td>
<td></td>
</tr>
<tr>
<td>• Reduced or absent enjoyment of situations that most children like, for example, birthday parties</td>
<td></td>
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<tr>
<td>• Reduced or absent sharing of enjoyment</td>
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</tbody>
</table>

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

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
Using this table
These signs and symptoms 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 2 Signs and symptoms of possible autism in primary school children (aged 5–11 years or equivalent mental age)

<table>
<thead>
<tr>
<th>Social interaction and reciprocal communication behaviours</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Spoken language</strong></td>
</tr>
<tr>
<td><em>Spoken language may be unusual in several ways:</em></td>
</tr>
<tr>
<td>– very limited use</td>
</tr>
<tr>
<td>– monotonous tone</td>
</tr>
<tr>
<td>– repetitive speech, frequent use of stereotyped (learnt) phrases, content dominated by excessive information on topics of own interest</td>
</tr>
<tr>
<td>– talking ‘at’ others rather than sharing a two-way conversation</td>
</tr>
<tr>
<td>– responses to others can seem rude or inappropriate</td>
</tr>
<tr>
<td><strong>Responding to others</strong></td>
</tr>
<tr>
<td><em>Reduced or absent response to other people’s facial expression or feelings</em></td>
</tr>
<tr>
<td><em>Reduced or delayed response to name being called, despite normal hearing</em></td>
</tr>
<tr>
<td><em>Subtle difficulties in understanding other’s intentions; may take things literally and misunderstand sarcasm or metaphor</em></td>
</tr>
<tr>
<td><em>Unusually negative response to the requests of others (demand avoidant behaviour)</em></td>
</tr>
<tr>
<td><strong>Interacting with others</strong></td>
</tr>
<tr>
<td><em>Reduced or absent awareness of personal space, or unusually intolerant of people entering their personal space</em></td>
</tr>
<tr>
<td><em>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</em></td>
</tr>
<tr>
<td><em>Reduced or absent greeting and farewell behaviours</em></td>
</tr>
<tr>
<td><em>Reduced or absent awareness of socially expected behaviour</em></td>
</tr>
<tr>
<td><em>Reduced or absent ability to share in the social play or ideas of others, plays alone</em></td>
</tr>
<tr>
<td><em>Unable to adapt style of communication to social situations, for example may be overly formal or inappropriately familiar</em></td>
</tr>
<tr>
<td><em>Reduced or absent enjoyment of situations that most children like</em></td>
</tr>
<tr>
<td><strong>Eye contact, pointing and other gestures</strong></td>
</tr>
<tr>
<td><em>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</em></td>
</tr>
<tr>
<td><em>Reduced or absent social use of eye contact, assuming adequate vision</em></td>
</tr>
<tr>
<td><em>Reduced or absent joint attention shown by lack of:</em></td>
</tr>
<tr>
<td>– gaze switching</td>
</tr>
<tr>
<td>– following a point (looking where the other person points to – may look at hand)</td>
</tr>
<tr>
<td>– using pointing at or showing objects to share interest</td>
</tr>
</tbody>
</table>

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

<table>
<thead>
<tr>
<th><strong>Ideas and imagination</strong></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Reduced or absent flexible imaginative play or creativity, although scenes seen on visual media (for example, television) may be re-enacted</td>
<td></td>
</tr>
<tr>
<td>Makes comments without awareness of social niceties or hierarchies</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th><strong>Unusual or restricted interests and/or rigid and repetitive behaviours</strong></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Repetitive ‘stereotypical’ movements such as hand flapping, body rocking while standing, spinning, finger flicking</td>
<td></td>
</tr>
<tr>
<td>Play repetitive and oriented towards objects rather than people</td>
<td></td>
</tr>
<tr>
<td>Over-focused or unusual interests</td>
<td></td>
</tr>
<tr>
<td>Rigid expectation that other children should adhere to rules of play</td>
<td></td>
</tr>
<tr>
<td>Excessive insistence on following own agenda</td>
<td></td>
</tr>
<tr>
<td>Extremes of emotional reactivity that are excessive for the circumstances</td>
<td></td>
</tr>
<tr>
<td>Strong preferences for familiar routines and things being ‘just right’</td>
<td></td>
</tr>
<tr>
<td>Dislike of change, which often leads to anxiety or other forms of distress (including aggression)</td>
<td></td>
</tr>
<tr>
<td>Over or under reaction to sensory stimuli, for example textures, sounds, smells</td>
<td></td>
</tr>
<tr>
<td>Excessive reaction to taste, smell, texture or appearance of food or extreme food fads</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th><strong>Other factors that may support a concern about autism</strong></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>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)</td>
<td></td>
</tr>
<tr>
<td>Social and emotional development more immature than other areas of development, excessive trusting (naivety), lack of common sense, less independent than peers</td>
<td></td>
</tr>
</tbody>
</table>
### Using this table

These signs and symptoms 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>
<thead>
<tr>
<th>Table 3 Signs and symptoms of possible autism in secondary school children (older than 11 years or equivalent mental age)</th>
</tr>
</thead>
</table>

#### 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 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

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

**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
### Table 4 Factors associated with an increased prevalence of autism (referred to from pages 9 and 10)

- 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

### Table 5 Possible differential diagnoses (referred to from page 11)

<table>
<thead>
<tr>
<th>Neurodevelopmental disorders</th>
<th>Mental and behavioural disorders</th>
<th>Conditions in which there is developmental regression</th>
<th>Other conditions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Specific language delay or disorder</td>
<td>Attention deficit hyperactivity disorder (ADHD)</td>
<td>Rett syndrome</td>
<td>Severe hearing impairment</td>
</tr>
<tr>
<td>Intellectual disability or global developmental delay</td>
<td>Mood disorder</td>
<td>Epileptic encephalopathy</td>
<td>Severe visual impairment</td>
</tr>
<tr>
<td>Developmental coordination disorder (DCD)</td>
<td>Anxiety disorder</td>
<td></td>
<td>Maltreatment</td>
</tr>
<tr>
<td></td>
<td>Attachment disorders</td>
<td></td>
<td>Selective mutism</td>
</tr>
<tr>
<td></td>
<td>Oppositional defiant disorder (ODD)</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Conduct disorder</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Obsessive compulsive disorder (OCD)</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Psychosis</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
### Table 6 Possible coexisting conditions (referred to from page 11)

<table>
<thead>
<tr>
<th>Mental and behavioural problems and disorders</th>
<th>Neurodevelopmental problems and disorders</th>
<th>Medical or genetic problems and disorders</th>
<th>Functional problems and disorders</th>
</tr>
</thead>
<tbody>
<tr>
<td>ADHD</td>
<td>Global delay or intellectual disability</td>
<td>Epilepsy and epileptic encephalopathy</td>
<td>Feeding problems, including restricted diets</td>
</tr>
<tr>
<td>Anxiety disorders and phobias</td>
<td>Motor coordination problems or DCD</td>
<td>Chromosome disorders</td>
<td>Urinary incontinence or enuresis</td>
</tr>
<tr>
<td>Mood disorders</td>
<td>Academic learning problems, for example in literacy or numeracy</td>
<td>Genetic abnormalities, including fragile X</td>
<td>Constipation, altered bowel habit, faecal incontinence or encopresis</td>
</tr>
<tr>
<td>Oppositional defiant behaviour</td>
<td>Speech and language disorder</td>
<td>Tuberous sclerosis</td>
<td>Sleep disturbances</td>
</tr>
<tr>
<td>Tics or Tourette syndrome</td>
<td></td>
<td>Muscular dystrophy</td>
<td>Vision or hearing impairment</td>
</tr>
<tr>
<td>OCD</td>
<td></td>
<td>Neurofibromatosis</td>
<td></td>
</tr>
<tr>
<td>Self-injurious behaviour</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Further information

Ordering information
You can download the following documents from www.nice.org.uk/guidance/CG128

- The NICE guideline – all the recommendations.
- A quick reference guide (this document) – a summary of the recommendations for healthcare professionals.
- ‘Understanding NICE guidance’ – a summary for patients and carers.
- The full guideline – all the recommendations, details of how they were developed, and reviews of the evidence they were based on.

For printed copies of the quick reference guide or ‘Understanding NICE guidance’, phone NICE publications on 0845 003 7783 or email publications@nice.org.uk and quote:

- N2662 (quick reference guide)
- N2663 (‘Understanding NICE guidance’).

Implementation tools
NICE has developed tools to help organisations implement this guidance (see www.nice.org.uk/guidance/CG128).

Related NICE guidance
For information about NICE guidance that has been issued or is in development, see www.nice.org.uk

Published


Under development
NICE is developing the following guidance (details available from 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).

Updating the guideline
This guideline will be updated as needed, and information about the progress of any update will be available at www.nice.org.uk/guidance/CG128