

Autism spectrum disorder in under 19s: recognition, referral and diagnosis

NICE guideline

Draft for consultation, October 2017

This guideline covers recognising and diagnosing autism spectrum disorder in children and young people from birth up to 19 years. It also covers referral. It aims to improve the experience of children, young people and those who care for them.

Who is it for?

- Healthcare professionals
- Children and young people who have or may have autism spectrum disorder, and their families and carers

This guideline will update NICE guideline CG128 (published September 2011).

We have reviewed the evidence and updated [box 1](#) in recommendation 1.3.3 on factors associated with an increased prevalence of autism, which is marked as **[2017]**. You are invited to comment on the content of box 1.

We have not updated recommendations shaded in grey, and cannot accept comments on them. In some cases, we have made minor wording changes for clarification.

See [update information](#) for a full explanation of what is being updated.

This version of the guideline contains:

- the recommendations
- a rationale and impact section that explains why the committee updated box 1 and how this might affect practice
- the guideline context

- recommendations for research.

Information about how the guideline was developed is on the [guideline's page](#) on the NICE website This includes the evidence reviews, the scope, and details of the committee and any declarations of interest.

Full details of the evidence and the committee's discussion on the 2017 update are in [evidence review A: Factors and neurodevelopmental disorders that increase the likelihood of a diagnosis of autism spectrum disorder](#). Evidence for the 2011 recommendations is in the [full version](#) of the 2011 guideline.

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1 Recommendations

People have the right to be involved in discussions and make informed decisions about their care, as described in [your care](#).

[Making decisions using NICE guidelines](#) explains how we use words to show the strength (or certainty) of our recommendations, and has information about prescribing medicines (including off-label use), professional guidelines, standards and laws (including on consent and mental capacity), and safeguarding.

2 **1.1 Local pathway for recognition, referral and diagnostic** 3 **assessment of possible autism**

4 1.1.1 A local autism multi-agency strategy group should be set up, with
5 managerial, commissioner and clinical representation from child health
6 and mental health services, education, social care, parent and carer
7 service users, and the voluntary sector. **[2011]**

8 1.1.2 The local autism strategy group should appoint a lead professional to be
9 responsible for the local autism pathway for recognition, referral and
10 diagnosis of children and young people. The aims of the group should
11 include:

- 12 • improving early recognition of autism by raising awareness of the signs
13 and symptoms of autism through multi-agency training (see tables 1 to
14 3 in the [appendix](#))
- 15 • making sure the relevant professionals (healthcare, social care,
16 education and voluntary sector) are aware of the local autism pathway
17 and how to access diagnostic services
- 18 • supporting the smooth transition to adult services for young people
19 going through the diagnostic pathway
- 20 • ensuring data collection and audit of the pathway takes place. **[2011]**

21 1.1.3 In each area a multidisciplinary group (the autism team) should be set up.
22 The core membership should include a:

- 1 • paediatrician and/or child and adolescent psychiatrist
- 2 • speech and language therapist
- 3 • clinical and/or educational psychologist. **[2011]**

4 1.1.4 The autism team should either include or have regular access to the
5 following professionals if they are not already in the team:

- 6 • paediatrician or paediatric neurologist
- 7 • child and adolescent psychiatrist
- 8 • educational psychologist
- 9 • clinical psychologist
- 10 • occupational therapist. **[2011]**

11 1.1.5 Consider including in the autism team (or arranging access for the team
12 to) other relevant professionals who may be able to contribute to the
13 autism diagnostic assessment. For example, a specialist health visitor or
14 nurse, specialist teacher or social worker. **[2011]**

15 1.1.6 The autism team should have the skills and competencies to:

- 16 • carry out an autism diagnostic assessment
- 17 • communicate with children and young people with suspected or known
18 autism, and with their parents and carers, and sensitively share the
19 diagnosis with them. **[2011]**

20 1.1.7 Autism team members should:

- 21 • provide advice to professionals about whether to refer children and
22 young people for autism diagnostic assessments
- 23 • decide on the assessment needs of those referred or when referral to
24 another service will be needed
- 25 • carry out the autism diagnostic assessment
- 26 • share the outcome of the autism diagnostic assessment with parents
27 and carers, and with children and young people if appropriate
- 28 • with parent or carer consent and, if appropriate, the consent of the child
29 or young person, share information from the autism diagnostic

1 assessment directly with relevant services, for example through a
2 school visit by an autism team member
3 • offer information to children, young people and parents and carers
4 about appropriate services and support. **[2011]**

5 1.1.8 Provide a single point of referral for access to the autism team. **[2011]**

6 1.1.9 The autism team should either have the skills (or have access to
7 professionals that have the skills) needed to carry out an autism
8 diagnostic assessment, for children and young people with special
9 circumstances including:

- 10 • coexisting conditions such as severe visual and hearing impairments,
11 motor disorders including cerebral palsy, severe intellectual disability,
12 complex language disorders or complex mental health disorders
13 • looked-after children and young people. **[2011]**

14 1.1.10 If young people present at the time of transition to adult services, the
15 autism team should consider carrying out the autism diagnostic
16 assessment jointly with the adult autism team, regardless of the young
17 person's intellectual ability. **[2011]**

18 **1.2 *Recognising children and young people with possible*** 19 ***autism***

20 1.2.1 Consider the possibility of autism if there are concerns about development
21 or behaviour, but be aware that there may be other explanations for
22 individual signs and symptoms. **[2011]**

23 1.2.2 Always take parents' or carers' concerns and, if appropriate, the child's or
24 young person's concerns, about behaviour or development seriously,
25 even if these are not shared by others. **[2011]**

26 1.2.3 When considering the possibility of autism and whether to refer a child or
27 young person to the autism team, be critical about your professional
28 competence and seek advice from a colleague if in doubt about the next
29 step. **[2011]**

1 1.2.4 To help identify the signs and symptoms of possible autism, use tables 1
2 to 3 (see the [appendix](#)). Do not rule out autism if the exact features
3 described in the tables are not evident; they should be used for guidance,
4 but do not include all possible manifestations of autism. **[2011]**

5 1.2.5 When considering the possibility of autism, be aware that:

- 6 • signs and symptoms should be seen in the context of the child's or
7 young person's overall development
- 8 • signs and symptoms will not always have been recognised by parents,
9 carers, children or young people themselves or by other professionals
- 10 • when older children or young people present for the first time with
11 possible autism, signs or symptoms may have previously been masked
12 by the child or young person's coping mechanisms and/or a supportive
13 environment
- 14 • it is necessary to take account of cultural variation, but do not assume
15 that language delay is accounted for because English is not the family's
16 first language or by early hearing difficulties
- 17 • autism may be missed in children or young people with an intellectual
18 disability
- 19 • autism may be missed in children or young people who are verbally
20 able
- 21 • autism may be under-diagnosed in girls
- 22 • important information about early development may not be readily
23 available for some children and young people, for example looked-after
24 children and those in the criminal justice system
- 25 • signs and symptoms may not be accounted for by disruptive home
26 experiences or parental or carer mental or physical illness. **[2011]**

27 1.2.6 When considering the possibility of autism, ask about the child or young
28 person's use and understanding of their first language. **[2011]**

29 1.2.7 Do not rule out autism because of:

- 30 • good eye contact, smiling and showing affection to family members

- 1 • reported pretend play or normal language milestones
- 2 • difficulties appearing to resolve after a needs-based intervention (such
- 3 as a supportive structured learning environment)
- 4 • a previous assessment that concluded that there was no autism, if new
- 5 information becomes available. **[2011]**

6 1.2.8 Discuss developmental or behavioural concerns about a child or young
7 person with parents or carers, and the child or young person themselves if
8 appropriate. Discuss sensitively the possible causes, which may include
9 autism, emphasising that there may be many explanations for the child's
10 or young person's behaviour. **[2011]**

11 1.2.9 Be aware that if parents or carers or the child or young person themselves
12 have not suspected a developmental or behavioural condition, raising the
13 possibility may cause distress, and that:

- 14 • it may take time for them to come to terms with the concern
- 15 • they may not share the concern. **[2011]**

16 1.2.10 Take time to listen to parents or carers and, if appropriate, the child or
17 young person, to discuss concerns and agree any actions to follow
18 including referral. **[2011]**

19 **1.3 Referring children and young people to the autism team**

20 1.3.1 Refer children younger than 3 years to the autism team if there is
21 regression in language or social skills. **[2011]**

22 1.3.2 Refer first to a paediatrician or paediatric neurologist (who can refer to the
23 autism team if necessary) children and young people:

- 24 • older than 3 years with regression in language
- 25 • of any age with regression in motor skills. **[2011]**

26 1.3.3 Consider referring children and young people to the autism team if you
27 are concerned about possible autism on the basis of reported or observed

1 signs and/or symptoms (see tables 1 to 3 in the [appendix](#)). Take account
2 of:

- 3 • the severity and duration of the signs and/or symptoms
- 4 • the extent to which the signs and/or symptoms are present across
- 5 different settings (for example, home and school)
- 6 • the impact of the signs and/or symptoms on the child or young person
- 7 and on their family
- 8 • the level of parental or carer concern and, if appropriate, the concerns
- 9 of the child or young person
- 10 • factors associated with an increased prevalence of autism (see box 1)
- 11 • the likelihood of an alternative diagnosis. **[2011]**

Box 1 Factors associated with an increased prevalence of autism [2017]

- 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.
- Attention deficit hyperactivity disorder.
- 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.

12

13 1.3.4 If you have concerns about development or behaviour but are not sure
14 whether the signs and/or symptoms suggest autism, consider:

- 1
- consulting a member of the autism team who can provide advice to
- 2 help you decide if a referral to the autism team is necessary
- referring to another service. That service can then refer to the autism
- 3 team if necessary. **[2011]**
- 4

5 1.3.5 Be aware that tools to identify children and young people with an

6 increased likelihood of autism may be useful in gathering information

7 about signs and symptoms of autism in a structured way but are not

8 essential and should not be used to make or rule out a diagnosis of

9 autism. Also be aware that:

- a positive score on tools to identify an increased likelihood of autism
- 11 may support a decision to refer but can also be for reasons other than
- 12 autism
- a negative score does not rule out autism. **[2011]**
- 13

14 1.3.6 When referring children and young people to the autism team, include in

15 the referral letter the following information:

- reported information from parents, carers and professionals about signs
- 17 and/or symptoms of concern
- your own observations of the signs and/or symptoms. **[2011]**
- 18

19 1.3.7 When referring children and young people to the autism team, include in

20 the referral letter the following information, if available:

- antenatal and perinatal history
- 22
- developmental milestones
- 23
- factors associated with an increased prevalence of autism (see [box 1](#) in
- 24 recommendation 1.3.3)
- relevant medical history and investigations
- 25
- information from previous assessments. **[2011]**
- 26

27 1.3.8 Explain to parents or carers and, if appropriate, the child or young person,

28 what will happen on referral to the autism team or another service. **[2011]**

- 1 1.3.9 If you do not think concerns are sufficient to prompt a referral, consider a
2 period of watchful waiting. If you remain concerned about autism,
3 reconsider your referral decision. **[2011]**
- 4 1.3.10 If the parents or carers or if appropriate, the child or young person, prefer
5 not to be referred to the autism team, consider a period of watchful
6 waiting. If you remain concerned about autism, reconsider referral. **[2011]**
- 7 1.3.11 If a concern about possible autism has been raised but there are no signs,
8 symptoms or other reasons to suspect autism, use professional judgment
9 to decide what to do next. **[2011]**

To find out why the committee updated box 1 in recommendation 1.3.3 on factors associated with an increased prevalence of autism, and how this might affect practice, see [rationale and impact](#).

10

11 **1.4 After referral to the autism team**

12 1.4.1 When a child or young person is referred to the autism team, at least one
13 member of the autism team should consider whether to carry out:

- 14
- an autism diagnostic assessment and/or
 - 15 • an alternative assessment. **[2011]**

16 1.4.2 Carry out an autism diagnostic assessment if there is regression in
17 language or social skills in a child younger than 3 years. **[2011]**

18 1.4.3 Refer first to a paediatrician or paediatric neurologist (if this has not
19 already happened) children or young people:

- 20
- older than 3 years with regression in language
 - 21 • of any age with regression in motor skills.

22 The paediatrician or paediatric neurologist can refer back to the autism
23 team if necessary. **[2011]**

1 1.4.4 When deciding whether to carry out an autism diagnostic assessment,
2 take account of the following (unless the child is under 3 years and has
3 regression in language or social skills – see recommendation 1.4.2):

- 4 • the severity and duration of the signs and/or symptoms
- 5 • the extent to which the signs and/or symptoms are present across
6 different settings (for example, home and school)
- 7 • the impact of the signs and/or symptoms on the child or young person
8 and on their family or carer
- 9 • the level of parental or carer concern, and if appropriate the concerns
10 of the child or young person
- 11 • factors associated with an increased prevalence of autism (see [box 1](#) in
12 recommendation 1.3.3)
- 13 • the likelihood of an alternative diagnosis. **[2011]**

14 1.4.5 If there is insufficient information to decide whether an autism diagnostic
15 assessment is needed, gather any available information from healthcare
16 professionals. With consent from parents or carers and, if appropriate, the
17 child or young person, seek information from schools or other agencies.
18 **[2011]**

19 1.4.6 If there is uncertainty about whether an autism diagnostic assessment is
20 needed after information has been gathered, offer a consultation to gather
21 information directly from the child or young person and their family or
22 carers. **[2011]**

23 1.4.7 Once it has been decided to carry out an autism diagnostic assessment,
24 with consent from parents or carers (and the child or young person if
25 appropriate):

- 26 • seek a report from the preschool or school if one has not already been
27 made available
- 28 • gather any additional health or social care information, including results
29 from hearing and vision assessments. **[2011]**

1 1.4.8 Avoid repeated information gathering and assessments by efficient
2 communication between professionals and agencies. **[2011]**

3 **1.5 *Autism diagnostic assessment for children and young***
4 ***people***

5 1.5.1 Start the autism diagnostic assessment within 3 months of the referral to
6 the autism team. **[2011]**

7 1.5.2 A case coordinator in the autism team should be identified for every child
8 or young person who is to have an autism diagnostic assessment. **[2011]**

9 1.5.3 The autism case coordinator should:

- 10
- 11 • act as a single point of contact for the parents or carers and, if
 - 12 appropriate, the child or young person being assessed, through whom
 - 13 they can communicate with the rest of the autism team
 - 14 • keep parents or carers and, if appropriate, the child or young person,
 - 15 up-to-date about the likely time and sequence of assessments
 - 16 • arrange the provision of information and support for parents, carers,
 - 17 children and young people as directed by the autism team
 - 18 • gather information relevant to the autism diagnostic assessment (see
- 19 [recommendation 1.4.7](#)). **[2011]**

20 1.5.4 Discuss with the parents or carers and, if appropriate, the child or young
21 person, how information should be shared throughout the autism
22 diagnostic assessment, including communicating the outcome of the
23 assessment. Take into account, for example, the child or young person's
age and ability to understand. **[2011]**

24 1.5.5 Include in every autism diagnostic assessment:

- 25 • detailed questions about parent's or carer's concerns and, if
- 26 appropriate, the child's or young person's concerns
- 27 • details of the child's or young person's experiences of home life,
- 28 education and social care

- 1 • a developmental history, focusing on developmental and behavioural
- 2 features consistent with ICD-10 or DSM-5 criteria (consider using an
- 3 autism-specific tool to gather this information)
- 4 • assessment (through interaction with and observation of the child or
- 5 young person) of social and communication skills and behaviours,
- 6 focusing on features consistent with ICD-10 or DSM-5 criteria (consider
- 7 using an autism-specific tool to gather this information)
- 8 • a medical history, including prenatal, perinatal and family history, and
- 9 past and current health conditions
- 10 • a physical examination
- 11 • consideration of the differential diagnosis (see recommendation 1.5.7)
- 12 • systematic assessment for conditions that may coexist with autism (see
- 13 recommendation 1.5.15)
- 14 • development of a profile of the child's or young person's strengths,
- 15 skills, impairments and needs that can be used to create a needs-
- 16 based management plan, taking into account family and educational
- 17 context
- 18 • communication of assessment findings to the parent or carer and, if
- 19 appropriate, the child or young person. **[2011, amended 2017]**

20 1.5.6 Perform a general physical examination and look specifically for:

- 21 • skin stigmata of neurofibromatosis or tuberous sclerosis using a
- 22 Wood's light
- 23 • signs of injury, for example self-harm¹ or child maltreatment²
- 24 • congenital anomalies and dysmorphic features including macrocephaly
- 25 or microcephaly. **[2011]**

26 1.5.7 Consider the following differential diagnoses for autism and whether

27 specific assessments are needed to help interpret the autism history and

28 observations:

¹ See the NICE guideline on [self-harm in over 8s: short-term management and prevention of recurrence](#).

² See the NICE guideline on [child maltreatment: when to suspect maltreatment in under 18s](#).

1 their profile, consider referring to appropriate services. **[2011, amended**
2 **2017]**

3 1.5.14 If the outcome of the autism diagnostic assessment clearly indicates that
4 the child or young person does not have autism, consider referring them
5 to appropriate services based on their profile. **[2011]**

6 1.5.15 Consider whether the child or young person may have any of the following
7 as a coexisting condition, and if suspected carry out appropriate
8 assessments and referrals:

9 • Mental and behaviour problems and disorders:

- 10 – ADHD
- 11 – anxiety disorders and phobias
- 12 – mood disorders
- 13 – oppositional defiant behaviour
- 14 – tics or Tourette syndrome
- 15 – OCD
- 16 – self-injurious behaviour.

17 • Neurodevelopmental problems and disorders:

- 18 – global delay or intellectual disability
- 19 – motor coordination problems or DCD
- 20 – academic learning problems, for example in literacy or numeracy
- 21 – speech and language disorder.

22 • Medical or genetic problems and disorders:

- 23 – epilepsy and epileptic encephalopathy
- 24 – chromosome disorders
- 25 – genetic abnormalities, including fragile X
- 26 – tuberous sclerosis
- 27 – muscular dystrophy
- 28 – neurofibromatosis.

29 • Functional problems and disorders:

- 30 – feeding problems, including restricted diets
- 31 – urinary incontinence or enuresis

- 1 – constipation, altered bowel habit, faecal incontinence or encopresis
2 – sleep disturbances
3 – vision or hearing impairment. **[2011]**

4 1.5.16 Be aware that in children and young people with communication
5 difficulties it may be difficult to recognise functional problems or mental
6 health problems. **[2011]**

7 **1.6** *After the autism diagnostic assessment*

8 1.6.1 If there is uncertainty after the autism diagnostic assessment about the
9 diagnosis, consider keeping the child or young person under review,
10 taking into account any new information. **[2011]**

11 1.6.2 If any of the following apply after assessment, consider obtaining a
12 second opinion (including referral to a specialised tertiary autism team if
13 necessary):

- 14 • continued uncertainty about the diagnosis
15 • disagreement about the diagnosis within the autism team
16 • disagreement with parents or carers or, if appropriate, the child or
17 young person, about the diagnosis
18 • a lack of local access to particular skills and competencies needed to
19 reach a diagnosis in a child or young person who has a complex
20 coexisting condition, such as a severe sensory or motor impairment or
21 mental health problem
22 • a lack of response as expected to any therapeutic interventions
23 provided to the child or young person. **[2011]**

24 1.6.3 During the autism diagnostic assessment, consider any potential risk of
25 harm to, and from, the child or young person and take appropriate action.
26 **[2011]**

27 **1.7** *Medical investigations*

28 1.7.1 Do not routinely perform any medical investigations as part of an autism
29 diagnostic assessment, but consider the following in individual

1 circumstances and based on physical examination, clinical judgment and
2 the child or young person's profile:

- 3 • genetic tests, as recommended by your regional genetics centre, if
4 there are specific dysmorphic features, congenital anomalies and/or
5 evidence of intellectual disability
- 6 • electroencephalography if there is suspicion of epilepsy³. **[2011]**

7 **1.8** ***Communicating the results from the autism diagnostic*** 8 ***assessment***

9 1.8.1 After the autism diagnostic assessment discuss the findings, including the
10 profile, sensitively, in person and without delay with the parents or carers
11 and, if appropriate, the child or young person. Explain the basis of
12 conclusions even if the diagnosis of autism was not reached. **[2011]**

13 1.8.2 Use recognised good practice when sharing a diagnosis with parents,
14 carers, children and young people. **[2011]**

15 1.8.3 For children and young people with a diagnosis of autism, discuss and
16 share information with parents or carers and, if appropriate, the child or
17 young person, to explain:

- 18 • what autism is
- 19 • how autism is likely to affect the child or young person's development
20 and function. **[2011]**

21 1.8.4 Provide parents or carers and, if appropriate, the child or young person,
22 with a written report of the autism diagnostic assessment. This should
23 explain the findings of the assessment and the reasons for the
24 conclusions drawn. **[2011]**

25 1.8.5 Share information, including the written report of the diagnostic
26 assessment, with the GP. **[2011]**

³ See the NICE guideline on [epilepsies: diagnosis and management](#).

1 1.8.6 With parental or carer consent and, if appropriate, the consent of the child
2 or young person, share information with key professionals involved in the
3 child's or young person's care, including those in education and social
4 care. **[2011]**

5 1.8.7 With parental or carer consent and, if appropriate, the consent of the child
6 or young person, make the profile available to professionals in education
7 (for example, through a school visit by a member of the autism team) and,
8 if appropriate, social care. This is so it can contribute to the child or young
9 person's individual education plan and needs-based management plan.
10 **[2011]**

11 1.8.8 For children and young people with a diagnosis of autism, offer a follow-
12 up appointment with an appropriate member of the autism team within
13 6 weeks of the end of the autism assessment for further discussion (for
14 example about the conclusions of the assessment and the implications for
15 the child or young person). **[2011]**

16 1.8.9 For children and young people with a diagnosis of autism, discuss with
17 parents or carers the risk of autism occurring in siblings and future
18 children. **[2011]**

19 **1.9 Information and support for families and carers**

20 1.9.1 Provide individual information on support available locally for parents,
21 carers, children and young people with autism, according to the family's
22 needs. This may include:

- 23 • contact details for:
 - 24 – local and national support organisations (who may provide, for
 - 25 example, an opportunity to meet other families with experience of
 - 26 autism, or information about specific courses for parents and carers
 - 27 and/or young people)
 - 28 – organisations that can provide advice on welfare benefits
 - 29 – organisations that can provide information on educational support
 - 30 and social care

- 1 • information to help prepare for the future, for example transition to adult
2 services. [2011]

3 **Recommendations for research**

4 The guideline committee has made the following recommendations for research

5 ***1 Training professionals***

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

10 **Why this is important**

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

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

- 20 • with parents of lower educational attainment
21 • with English as an additional language
22 • with sensory impairments
23 • with intellectual disability.

24 Before extending training to a wider population, it is important to better understand
25 its effectiveness in terms of age, number of children and young people at referral,
26 and time between parents' concerns and autism diagnosis. [2011]

1 **2 *Gathering information in schools or nurseries***

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

5 **Why this is important**

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

11 Nurseries or schools are the most obvious settings from which such information may
12 be collected. However, the degree to which information from teachers and schools
13 helps in accurate diagnosis has not been well tested. **[2011]**

14 **3 *Additional assessments***

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

18 **Why this is important**

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

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

26 Studies may prove valuable to parents in terms of explaining some of the child's
27 behaviours, leading to more targeted and informed support for the child, parents and
28 the wider family. **[2011]**

1 **4 Comparative genomic hybridisation array**

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

5 **Why this is important**

6 Recent scientific advances have led to the detection of genetic abnormalities that
7 may partly or wholly explain why a child or young person has autism. As the tests
8 become increasingly sophisticated (for example using methods such as CGH array
9 that detect more subtle variations), more genetic abnormalities are being identified,
10 although their causal role in autism is not always clear. Improved detection of genetic
11 causes of autism could increase the precision of genetic counselling for parents of a
12 child or young person with autism and also for the wider family. At present, the yield
13 of abnormal genetic results using CGH array is known to be higher in those with
14 dysmorphic features and/or intellectual disability, but this may extend to the wider
15 autism population with increasing test sophistication. Before extending CGH array
16 testing to a wider population, it is important to have a better understanding of its
17 diagnostic yield. It is also essential to identify any negative consequences that may
18 result from routine testing. [2011]

19 **Rationale and impact**

20 ***Factors associated with an increased prevalence of autism***

21 **Why the committee updated box 1 in recommendation 1.3.3**

22 The evidence showed that children and young people with attention deficit
23 hyperactivity disorder (ADHD) are more likely to have autism spectrum disorder than
24 those without ADHD. Therefore ADHD was added to the list of factors associated
25 with an increased prevalence of autism.

26 **How the updated recommendation might affect practice**

27 Including ADHD as a factor associated with an increased prevalence of autism will
28 help to promote early diagnosis of autism spectrum disorder. It also allows for joint

1 assessment for both conditions in children and young people with signs or symptoms
2 that could be caused by either condition.

3 The committee agreed that this supports current practice and is unlikely to lead to a
4 substantial resource impact.

5 Full details of the evidence and the committee's discussion are in [evidence review A:
6 Factors and neurodevelopmental disorders that increase the likelihood of a diagnosis
7 of autism spectrum disorder](#).

8 **Putting this guideline into practice**

9 **[This section will be finalised after consultation]**

10 NICE has produced [tools and resources](#) to help you put this guideline into practice.

11 **[Optional paragraph if issues raised]** Some issues were highlighted that might need
12 specific thought when implementing the recommendations. These were raised during
13 the development of this guideline. They are:

- 14 • [add any issues specific to guideline here]
15

16 Putting recommendations into practice can take time. How long may vary from
17 guideline to guideline, and depends on how much change in practice or services is
18 needed. Implementing change is most effective when aligned with local priorities.

19 Changes recommended for clinical practice that can be done quickly – like changes
20 in prescribing practice – should be shared quickly. This is because healthcare
21 professionals should use guidelines to guide their work – as is required by
22 professional regulating bodies such as the General Medical and Nursing and
23 Midwifery Councils.

24 Changes should be implemented as soon as possible, unless there is a good reason
25 for not doing so (for example, if it would be better value for money if a package of
26 recommendations were all implemented at once).

1 Different organisations may need different approaches to implementation, depending
2 on their size and function. Sometimes individual practitioners may be able to respond
3 to recommendations to improve their practice more quickly than large organisations.

4 Here are some pointers to help organisations put NICE guidelines into practice:

5 1. **Raise awareness** through routine communication channels, such as email or
6 newsletters, regular meetings, internal staff briefings and other communications with
7 all relevant partner organisations. Identify things staff can include in their own
8 practice straight away.

9 2. **Identify a lead** with an interest in the topic to champion the guideline and motivate
10 others to support its use and make service changes, and to find out any significant
11 issues locally.

12 3. **Carry out a baseline assessment** against the recommendations to find out
13 whether there are gaps in current service provision.

14 4. **Think about what data you need to measure improvement** and plan how you
15 will collect it. You may want to work with other health and social care organisations
16 and specialist groups to compare current practice with the recommendations. This
17 may also help identify local issues that will slow or prevent implementation.

18 5. **Develop an action plan**, with the steps needed to put the guideline into practice,
19 and make sure it is ready as soon as possible. Big, complex changes may take
20 longer to implement, but some may be quick and easy to do. An action plan will help
21 in both cases.

22 6. **For very big changes** include milestones and a business case, which will set out
23 additional costs, savings and possible areas for disinvestment. A small project group
24 could develop the action plan. The group might include the guideline champion, a
25 senior organisational sponsor, staff involved in the associated services, finance and
26 information professionals.

27 7. **Implement the action plan** with oversight from the lead and the project group.
28 Big projects may also need project management support.

1 **8. Review and monitor** how well the guideline is being implemented through the
2 project group. Share progress with those involved in making improvements, as well
3 as relevant boards and local partners.

4 NICE provides a comprehensive programme of support and resources to maximise
5 uptake and use of evidence and guidance. See our [into practice](#) pages for more
6 information.

7 Also see Leng G, Moore V, Abraham S, editors (2014) Achieving high quality care –
8 practical experience from NICE. Chichester: Wiley.

9 **Context**

10 This guideline was updated in 2017 to include attention deficit hyperactivity disorder
11 (ADHD) in the list of factors that should be taken into account when considering a
12 referral for possible autism spectrum disorder and when considering whether to carry
13 out an autism spectrum disorder diagnostic assessment. This is because there is
14 evidence showing an increased prevalence of autism spectrum disorders in children
15 and young people with ADHD. In addition, it is important that clinicians do not
16 exclude or delay referral for possible autism spectrum disorder because of an earlier
17 diagnosis of ADHD.

18 The term autism describes qualitative differences and impairments in reciprocal
19 social interaction and social communication, combined with restricted interests and
20 rigid and repetitive behaviours. Autism spectrum disorders are diagnosed in children,
21 young people and adults if these behaviours meet the criteria defined in the
22 International Statistical Classification of Diseases and Related Health Problems
23 (ICD-10) and the Diagnostic and Statistical Manual of Mental Disorders Fifth Edition
24 (DSM-5) and have a significant impact on function. The overarching category term
25 used in ICD-10 is pervasive developmental disorder (PDD), a term now used
26 synonymously with autism spectrum disorder (excluding Rett's syndrome); it is a
27 behaviourally defined group of disorders, which is heterogeneous in both cause and
28 manifestation.

29 DSM-5 refers to autism spectrum disorder (ASD) as a single condition with different
30 levels of symptom severity in 2 core domains: 1) deficits in social communication and

1 social interaction and 2) restricted repetitive behaviours (RRBs), interests, and
2 activities and sensory anomalies. Autism spectrum disorder encompasses the 4
3 separate disorders from the previous DSM-IV: autistic disorder (autism), Asperger's
4 disorder, childhood disintegrative disorder and pervasive developmental disorder not
5 otherwise specified. Because both components are required for diagnosis of autism
6 spectrum disorder, social (pragmatic) communication disorder is diagnosed if no
7 RRBs are present. Note that childhood disintegrative disorder is excluded from ASD
8 in DSM-5.

9 The guideline development group recognised that individuals and groups prefer a
10 variety of terms, including autism spectrum disorder, autistic spectrum condition,
11 autistic spectrum difference and neuro-diversity. For clarity and consistency, in this
12 guideline the term 'autism' is used throughout, in keeping with the use of 'autism' in
13 recent Department of Health⁴, National Audit Office and Public Accounts Committee
14 documents. However in this guideline 'autism' refers to 'autism spectrum disorders'.

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

25 The core autism behaviours are typically present in early childhood, but features are
26 not always apparent until the circumstances of the child or young person change, for
27 example when the child goes to nursery or primary school or moves to secondary
28 school. Autism is strongly associated with a number of coexisting conditions. Recent
29 studies have shown that approximately 70% of people with autism also meet
30 diagnostic criteria for at least one other (often unrecognised) psychiatric disorder that

⁴ Department of Health (2010) [Fulfilling and rewarding lives: the strategy for adults with autism in England](#).

1 is further impairing their psychosocial functioning. Intellectual disability (intelligence
2 quotient [IQ] below 70) occurs in approximately 50% of young people with autism.

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

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

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

16 This guideline aims to improve recognition, referral and diagnosis, and the
17 experience of children, young people and those who care for them. NICE has also
18 produced a guideline on [autism spectrum disorder in under 19s: support and](#)
19 [management](#).

20 ***More information***

To find out what NICE has said on topics related to this guideline, see our web
page on [autism](#).

21

22 **Update information**

23 **October 2017**

24 The evidence has been reviewed and box 1 on factors associated with an increased
25 prevalence of autism has been updated. This is marked as **[2017]**.

1 Where recommendations are shaded in grey and end **[2011]**, the evidence has not
 2 been reviewed since the original guideline.

3 Where recommendations are shaded in grey and end **[2011, amended 2017]**, the
 4 evidence has not been reviewed but changes have been made to the
 5 recommendation. These may be:

- 6 • changes to the meaning of the recommendation (for example, because of
 7 equalities duties or a change in the availability of medicines, or incorporated
 8 guidance has been updated)
- 9 • editorial changes to the original wording to clarify the action to be taken.

10 These changes are marked with yellow shading, and explanations of the reasons for
 11 the changes are given in 'Recommendations that have been deleted or changed' for
 12 information.

13 See also the [original NICE guideline and supporting documents](#).

14 ***Recommendations that have been deleted or changed***

15 **Amended recommendation wording (change to meaning)**

Recommendation in 2011 guideline	Recommendation in current guideline	Reason for change
1.5.5 Include in every autism diagnostic assessment: <ul style="list-style-type: none"> • detailed questions about parent's or carer's concerns and, if appropriate, the child's or young person's concerns • details of the child's or young person's experiences of home life, education and social care • a developmental history, focusing on developmental and behavioural features consistent with ICD-10 or DSM-IV criteria (consider using an autism-specific tool to gather this information) • assessment (through interaction with and 	1.5.5 Include in every autism diagnostic assessment: <ul style="list-style-type: none"> • 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-5 criteria (consider 	Updated to reflect the most recent version of DSM.

<p>observation of the child or young person) of social and communication skills and behaviours, focusing on features consistent with ICD-10 or DSM-5 criteria (consider using an autism-specific tool to gather this information)</p> <ul style="list-style-type: none"> • a medical history, including prenatal, perinatal and family history, and past and current health conditions • a physical examination • consideration of the differential diagnosis (see recommendation 1.5.7) • systematic assessment for conditions that may coexist with autism (see recommendation 1.5.15) • development of a profile of the child's or young person's strengths, skills, impairments and needs that can be used to create a needs-based management plan, taking into account family and educational context. • communication of assessment findings to the parent or carer and, if appropriate, the child or young person. 	<p>using an autism-specific tool to gather this information)</p> <ul style="list-style-type: none"> • 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-5 criteria (consider using an autism-specific tool to gather this information) • a medical history, including prenatal, perinatal and family history, and past and current health conditions • a physical examination • consideration of the differential diagnosis (see recommendation 1.5.7) • systematic assessment for conditions that may coexist with autism (see recommendation 1.5.15) • development of a profile of the child's or young person's strengths, skills, impairments and needs that can be used to create a needs-based management plan, taking into account family and educational context. • communication of assessment findings to the parent or carer and, if appropriate, the child or young person. [2011, amended 2017] 	
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1.5.10 Use information from all sources, together with clinical judgment, to diagnose autism based on ICD-10 or DSM-IV criteria.	1.5.10 Use information from all sources, together with clinical judgment, to diagnose autism based on ICD-10 or DSM-5 criteria. [2011, amended 2017]	Updated to reflect the most recent version of DSM.
1.5.13 Be aware that some children and young people will have features of behaviour that are seen in the autism spectrum but do not reach the ICD 10 or DSM-IV diagnostic criteria for definitive diagnosis. Based on their profile, consider referring to appropriate services.	1.5.13 Be aware that some children and young people will have features of behaviour that are seen in the autism spectrum but do not reach the ICD 10 or DSM-5 diagnostic criteria for definitive diagnosis. Based on their profile, consider referring to appropriate services. [2011, amended 2017]	Updated to reflect the most recent version of DSM.

- 1 **Changes to recommendation wording for clarification only (no change to**
- 2 **meaning)**

Recommendation numbers in current guideline	Comment
1.3.7, 1.4.4	'See box 1' has been amended to 'See box 1 in recommendation 1.3.3' for clarity. Yellow highlighting has not been applied to these changes.

3 ***Changes after publication***

4 **February 2016:** Corrected job role for committee member.

5 **Appendix: Signs and symptoms of possible autism**

6 ***Using tables 1 to 3***

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

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

Social interaction and reciprocal communication behaviours

Spoken language

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

Responding to others

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

Interacting with others

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

Eye contact, pointing and other gestures

- Reduced or absent use of gestures and facial expressions to communicate (although may place adult's hand on objects).

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

Ideas and imagination

- Reduced or absent imagination and variety of pretend play.

Unusual or restricted interests and/or rigid and repetitive behaviours

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

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

Social interaction and reciprocal communication behaviours

Spoken language

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

Responding to others

- Reduced or absent response to other people's facial expression or feelings.

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

Interacting with others

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

Eye contact, pointing and other gestures

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

Ideas and imagination

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

Unusual or restricted interests and/or rigid and repetitive behaviours

- Repetitive 'stereotypical' movements such as hand flapping, body rocking while standing, spinning, finger flicking.
- Play repetitive and oriented towards objects rather than people.
- Over-focused or unusual interests.
- Rigid expectation that other children should adhere to rules of play.
- Excessive insistence on following own agenda.

- Extremes of emotional reactivity that are excessive for the circumstances.
- Strong preferences for familiar routines and things being 'just right'.
- Dislike of change, which often leads to anxiety or other forms of distress (including aggression).
- Over or under reaction to sensory stimuli, for example textures, sounds, smells.
- Excessive reaction to taste, smell, texture or appearance of food or extreme food fads.

Other factors that may support a concern about autism

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

1

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

Social interaction and reciprocal communication behaviours

Spoken language

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

Interacting with others

- Reduced or absent awareness of personal space, or unusually intolerant of people entering their personal space.
- Long-standing difficulties in reciprocal social communication and interaction: few close friends or reciprocal relationships.
- Reduced or absent understanding of friendship; often an unsuccessful desire to have friends (although may find it easier with adults or younger children).
- Social isolation and apparent preference for aloneness.
- Reduced or absent greeting and farewell behaviours.
- Lack of awareness and understanding of socially expected behaviour.
- Problems losing at games, turn-taking and understanding 'changing the rules'.

- May appear unaware or uninterested in what other young people his or her age are interested in.
- Unable to adapt style of communication to social situations, for example may be overly formal or inappropriately familiar.
- Subtle difficulties in understanding other's intentions; may take things literally and misunderstand sarcasm or metaphor.
- Makes comments without awareness of social niceties or hierarchies.
- Unusually negative response to the requests of others (demand avoidant behaviour).

Eye contact, pointing and other gestures

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

Ideas and imagination

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

Unusual or restricted interests and/or rigid and repetitive behaviours

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

Other factors that may support a concern about autism

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

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