

NATIONAL INSTITUTE FOR HEALTH AND CLINICAL EXCELLENCE

SCOPE

1 Guideline title

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

1.1 Short title

Autism spectrum disorders in children and young people

2 The remit

The Department of Health has asked NICE: 'to develop a clinical guideline in relation to the initial recognition, referral and diagnosis of autism spectrum disorders in children and adolescents'.

3 Clinical need for the guideline

3.1 Epidemiology

- a) Autism spectrum disorders are lifelong neurological conditions. The way they are expressed in individual people will differ at different stages of their lives and in response to interventions. The number of identified cases of children and young people with all disorders in the autism spectrum (which includes autism, Asperger's syndrome and atypical autism) has risen in the past decade. The prevalence for all autism spectrum disorders (ASDs) ranges from 60 per 10,000 to more than 100 per 10,000 in the UK. The prevalence for autism is reported to range from 20 to 40 per 10,000. These numbers have had a significant impact on referrals to diagnostic services.

- b) The main areas of functioning affected in people with ASD as defined by the Diagnostic and Statistical Manual of Mental Disorders (DSM IVC) are:
- qualitative impairments in social interaction
 - qualitative impairments in communication
 - restricted, repetitive and stereotyped patterns of behaviour, interests and activities.
- c) Other features commonly found are a lack of cognitive and behavioural flexibility; altered sensory sensitivity; sensory processing difficulties, stereotyped mannerisms; emotional dysregulation, and a limited range of interests and activities.
- d) These features may be along a continuum from minimal to severe. The presence of features of the autism spectrum may have minimal impact on a person's ability to function in the world, and 'condition' is a more appropriate term than 'disorder'. For a diagnosis of ASD to be made there must be both the presence of impairments (as defined by the World Health Organization) and an impact on the person's functioning.
- e) The two major diagnostic classification systems (DSM IV and ICD10) use similar but not identical criteria. They both use the term pervasive developmental disorder (PDD), which encompasses autism, Asperger's syndrome and atypical autism (or PDD-NOS [not otherwise specified]). For the purposes of this clinical guideline the term ASD is used instead of PDD because it is more widely understood.
- f) Children and young people with ASD are more likely to have associated mental health and medical health problems, other developmental disorders and adaptive impairments. 'Diagnostic overshadowing' means there may be a tendency to overlook symptoms of ASD in these groups and attribute them to being part of an intellectual disability. Children with a diagnosed intellectual

disability have been identified as a specific group in which ASD may be under-diagnosed.

3.2 Current practice

- a) There is wide variation in rates of identification and referral for diagnostic assessment, waiting times for diagnosis, models of multiprofessional working, assessment criteria, diagnostic practice, and biomedical investigation and genetic counselling for children and young people with features of ASD. These factors contribute to delays in reaching a diagnosis and subsequent access to appropriate services.
- b) Healthcare professionals usually make the diagnosis of ASD in a child or young person. By working jointly with social care and educational professionals in a range of environments, healthcare professionals share information regarding the diagnosis and agree on a plan for future support and/or interventions for each child or young person. When the process works well, professionals and carers communicate right from the start, laying the foundation for a long-term understanding between children, carers and the professionals supporting their needs. However, practice varies and in some parts of the country waiting lists for multiprofessional specialist assessment are longer than 2 years.
- c) Diagnosis is a process that can have a variable time frame involving different competencies amongst the professionals involved. However, flexibility in approach to diagnosis is not always a feature of current diagnostic assessment in the NHS.
- d) The current use of biomedical investigations to rule out other conditions and thresholds for genetic counselling referral varies markedly. Opinion also varies on the value of biomedical investigations in the diagnostic assessment of autism and coexisting conditions.

- e) Children and young people with other existing conditions featuring intellectual, physical or sensory disability and/or mental health problems may not be recognised as having symptoms of ASD, and there may be overlaps between a developmental disorder and a coexisting condition. Children's social circumstances (for instance, 'looked after' children) may also affect how quickly features of ASD are recognised.
- f) Some of the behaviours that define ASD may also feature in other communication disorders and learning disabilities (such as childhood attachment disorders), as well as being the result of other conditions (such as epilepsy or acquired brain injury) or childhood experiences (such as trauma or maltreatment). Children and young people may be wrongly diagnosed as having a mental illness when they have features of ASD, or, conversely, they may be misdiagnosed with autism when they have another condition. Misdiagnosis can lead to delays in children and young people receiving the care and support that they need.
- g) The process and content of information-sharing varies widely, for instance in the provision of information and support for the family while awaiting diagnosis and immediately after.
- h) Clinical guidance for diagnosis has been published for the NHS in Scotland: 'Assessment, diagnosis and clinical interventions for children and young people with autism spectrum disorders' (Scottish Intercollegiate Guidelines Network [SIGN 98] 2007). The National Service Framework for Children, Young People and Maternity Services (2004) included an 'Autism exemplar', which described the 'patient journey' of a 3-year-old boy with ASD and built on guidance in the National Autism Plan for Children (NAP-C). The Autistic Spectrum Disorder Strategic Action Plan for Wales (2008) focused on the role of strategic health plans to develop services and interagency cooperation between health and education for children and young people with ASD. The

Department of Health published the consultation document 'A better future' (2009) on designing services to improve support for adults with autistic spectrum conditions. The National Audit Office is currently undertaking a study, 'Supporting people with autism through adulthood' focusing particularly on the transition from adolescence to adulthood.

- i) This guideline is needed to make services more child and family/supporter centred and to help reduce variation in professional practice by improving initial recognition of the features of ASD and the timing and process of diagnostic assessment to enable longer-term future care.

4 The guideline

The guideline development process is described in detail on the NICE website (see section 6, 'Further information').

This scope defines what the guideline will (and will not) examine, and what the guideline developers will consider. The scope is based on the referral from the Department of Health.

The areas that will be addressed by the guideline are described in the following sections:

4.1 *Population*

4.1.1 Groups that will be covered

- a) Children and young people from birth up to 18 years until their 19th birthday.
- b) Specific subgroups of children in whom ASD is known to be less likely to be recognised.
 - Children diagnosed with an intellectual disability, because the components of a core diagnosis may be different for children in this group.

4.1.2 Groups that will not be covered

- a) Adults (19 and older).

4.2 *Healthcare setting*

- a) Primary, secondary and tertiary care by healthcare professionals who have direct contact with, and make decisions concerning, the care of children and young people.
- b) This is an NHS guideline. It will comment on the interface with other services, such as social services and the voluntary sector. But it will not include recommendations relating to services provided exclusively by these agencies, except relating to care provided in those settings by healthcare professionals funded by the NHS. The guideline may include some recommendations for education services, either directly or indirectly, relating to collaborative working with NHS professionals.

4.3 *Clinical management*

4.3.1 Key clinical issues that will be covered

- a) Signs and symptoms (features of ASD) that should prompt professionals working with children and/or parents or carers to consider ASD in a child or young person. These will include signs and symptoms that should trigger referral for specialist assessment.
- b) Information requirements from other agencies.
- c) The components of diagnostic assessment after referral, including:
 - methods of assessing ASD
 - diagnostic thresholds for ASD
 - assessment of the most common coexisting conditions and differential diagnoses, including other developmental disorders,

speech and language disorders, intellectual disabilities, and mental health problems

- clinical evidence for and cost effectiveness of (which test should be done on whom and for what purpose):
 - biomedical investigations (including sequencing and number of tests)
 - genetic assessments (such as karotype, fragile x, comparative genomic hybridization [CGH] array)
 - neuroimaging (computed tomography [CT], magnetic resonance imaging [MRI], single photon emission computed tomography [SPECT], positron emission tomography [PET])
 - electroencephalograms [EEGs]
 - metabolic tests.
- d) The information and day-to-day support (such as a telephone helpline) appropriate for children, young people and parents/carers during the process of referral, assessment and diagnosis of ASD.
- e) Ineffective diagnostic interventions and approaches.

4.3.2 Clinical issues that will not be covered

- a) Population screening or surveillance.
- b) The basic components of any routine paediatric or mental health assessment not specific to ASD.
- c) The role and competencies of different professions in the recognition and diagnosis of ASD.
- d) Specific models for running a diagnostic service.
- e) Interventions and ongoing management of ASD, including specific therapeutic interventions during diagnosis.
- f) Reassessment and review of diagnosis.

4.4 Main outcomes

- a) Diagnostic accuracy of clinical and other features for the recognition of ASD.
- b) Diagnostic accuracy of biomedical investigations in ASD.
- c) Identification of coexisting conditions.
- d) Health-related quality of life, measured in quality-adjusted life years (QALYs) if possible.
- e) Children and young people's views and the views of their parents and carers of the process of referral, assessment and diagnosis, and their support and information needs.
- f) A clinical pathway that describes the components of an effective diagnostic service, based on an ethos of multiprofessional working.

4.5 Economic aspects

Developers will take into account both clinical and cost effectiveness when making recommendations involving a choice between alternative diagnostic and biomedical investigations. A review of the economic evidence will be conducted and analyses will be carried out as appropriate. The preferred unit of effectiveness is the QALY and the costs considered will usually only be from an NHS and personal social services (PSS) perspective. Further detail on the methods can be found in 'The guidelines manual' (see 'Further information').

4.6 Status

4.6.1 Scope

This is the final scope.

4.6.2 Timing

The development of the guideline recommendations will begin in September 2009.

5 Related NICE guidance

- When to suspect child maltreatment. NICE clinical guideline 89 (2009). Available from www.nice.org.uk/CG89
- Attention deficit hyperactivity disorder. NICE clinical guideline 72 (2008). Available from www.nice.org.uk/CG72
- Depression in children and young people. NICE clinical guideline 28 (2005). Available from www.nice.org.uk/CG28

6 Further information

Information on the guideline development process is provided in:

- ‘How NICE clinical guidelines are developed: an overview for stakeholders’, the public and the NHS’
- ‘The guidelines manual’.

These are available from the NICE website

(www.nice.org.uk/guidelinesmanual). Information on the progress of the guideline will also be available from the NICE website (www.nice.org.uk).