

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) The prevalence in children and young people of 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 three main areas of functioning affected in people with ASD are:
 - Social communication (understanding verbal and non-verbal language).

- Social interaction (understanding other people's feelings and managing one's own).
 - Social imagination (understanding and predicting other people's intentions and behaviours and imagining situations outside one's own routine).
- c) Other features commonly found are lack of cognitive and behavioural flexibility; altered sensory sensitivity; stereotyped mannerisms; 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 or no 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, developmental disorders and adaptive impairments. Children with a diagnosed intellectual disability have been identified as a specific group where ASD is likely to be under-diagnosed.

3.2 Current practice

- a) There is wide variation in rates of 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 to agree on a diagnosis and plan for future management. 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 which can have a variable time frame requiring 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 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. Children's social circumstances (for instance, 'looked after' children) may also affect how quickly features of ASD are recognised.
- f) The behaviours that define ASD may also feature in other communication disorders and learning disabilities, as well as other childhood experiences such as acute trauma, long-term illness,

depression and maltreatment. As a consequence, children may be misdiagnosed with autism when they actually need different kinds of support and services.

- g) The process and content of information-sharing varies widely, for instance in the provision of information and support for the family immediately after diagnosis.
- h) Clinical guidance 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] 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 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 planning for 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 and including the age of 18 years).
- b) Specific subgroups of children in whom ASD is known to be less likely to be recognised: Children diagnosed with an intellectual disability.

4.1.2 Groups that will not be covered

- a) Adults (age 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) The guideline will also be relevant to, but will not cover the practice of, those working in educational and social services and the voluntary sector.

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) When to refer for diagnostic assessment.
- c) Following referral, the process of diagnostic assessment, including:
 - the purpose, accuracy and diagnostic value of methods of assessing ASD
 - diagnostic threshold
 - identification of any coexisting conditions.
- d) The clinical evidence for, and cost effectiveness of, biomedical investigations, including genetic tests to inform genetic counselling.
 - genetic assessments (for example, karyotype, fragile-X syndrome, comparative genomic hybridisation [CGH] array)
 - neuroimaging and electroencephalogram
 - metabolic tests
 - gastrointestinal function.
- e) Ongoing information and support for children, young people and parents/carers during the process of referral, assessment and diagnosis of ASD.
- f) The guideline development group will take reasonable steps to identify ineffective diagnostic interventions and approaches. If robust and credible recommendations for changing the approach to recognition and diagnosis to make more efficient use of resources can be made, they will be clearly stated. If the resources released are substantial, consideration will be given to listing such recommendations in the 'Key priorities for implementation' section of the guideline.

4.3.2 Clinical issues that will not be covered

- a) Population screening or surveillance.

- b) What should be undertaken as part of routine paediatric or mental health assessment.
- c) Models of service delivery.
- d) Interventions and ongoing management of ASD.
- e) 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.

4.5 *Economic aspects*

Developers will take into account both clinical and cost effectiveness when making recommendations involving a choice between alternative interventions. 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 consultation draft of the scope. The consultation dates are 9 June to 7 July 2009.

4.6.2 Timing

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

5 Related NICE guidance

5.1 Published guidance

- 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

5.2 Guidance under development

NICE is currently developing the following related guidance (details available from the NICE website):

- When to suspect child maltreatment. NICE clinical guideline (publication expected July 2009).

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).