

# NATIONAL INSTITUTE FOR HEALTH AND CLINICAL EXCELLENCE

## SCOPE

### 1 **Guideline title**

Autistic spectrum conditions: diagnosis and management of autistic spectrum conditions in adults

#### 1.1 ***Short title***

Autistic spectrum conditions in adults

### 2 **The remit**

The Department of Health has asked NICE: 'To produce a clinical guideline on the management of autistic spectrum disorders in adults'<sup>1</sup>.

### 3 **Clinical need for the guideline**

#### 3.1 ***Epidemiology***

- a) Autistic spectrum conditions are lifelong neurological conditions. The way that they are expressed in individual people will differ at different stages of their lives, in response to interventions, and if they have coexisting conditions such as learning or language difficulties. A recent study conducted by Leicester University shows that the prevalence for all autistic spectrum conditions in adults in England is approximately 1%. In the past 30 years there has been a 25-fold increase in the prevalence of autistic spectrum conditions. This is probably a result of widening diagnostic categories, including the relatively recent subgroup of Asperger's syndrome, and the growth of services, better awareness, and improved

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<sup>1</sup> We are using the term 'autistic spectrum conditions' rather than 'autistic spectrum disorders' because this is the terminology more recently used in the Department of Health's Autism Strategy, and is preferred by many (but not all) adults on the autistic spectrum.

detection. This increase has had a significant impact on referrals to diagnostic services.

- b) People with autistic spectrum conditions commonly experience difficulty with cognitive and behavioural flexibility, altered sensory sensitivity (which can have both advantages and disadvantages), sensory processing difficulties, stereotyped mannerisms, emotional regulation difficulties, and a narrow and often highly focused range of interests and activities.
- c) These features may be along a continuum from mild to severe. For a diagnosis of autistic spectrum conditions 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.
- d) The two major diagnostic classification systems (DSM-IV and ICD-10) use similar but not identical criteria to diagnose autistic spectrum conditions. In the guideline we use ICD-10. Where we have included disorders not clearly specified in ICD-10 we have used the relevant DSM-IV criteria.
- e) Both DSM-IV and ICD-10 use the term pervasive developmental disorder, which encompasses autism, Asperger's syndrome and atypical autism (or pervasive developmental disorder not otherwise specified). For the purposes of this clinical guideline the term autistic spectrum conditions is used instead of pervasive developmental disorder because it is more widely understood.
- f) The June 2009 National Audit Office report 'Supporting people with autism through adulthood' reported that a significant proportion of adults with autism across the whole autistic spectrum are excluded both socially and economically. Their conditions are often overlooked by health, education and social care professionals, which creates barriers to accessing the support and services they need to live independently. In addition, people with autistic spectrum conditions are more likely to have coexisting

mental health and medical health problems, other developmental conditions and adaptive impairments. 'Diagnostic overshadowing' means there may be a tendency to overlook symptoms of autistic spectrum conditions in these groups and attribute them to being part of an intellectual disability. While this is an important issue, the signs and symptoms of autism can also lead to the misdiagnosis of co-occurring disorders.

### **3.2 Current practice**

- a) There is wide variation in rates of identification and referral for diagnostic assessment, waiting times for diagnosis, models of multi-professional working, assessment criteria, diagnostic practice, biomedical investigation and genetic counselling for adults with features of autistic spectrum conditions. These factors contribute to delays in reaching a diagnosis and subsequent access to appropriate services.
- b) When the diagnostic assessment process works well, professionals and carers communicate right from the start and the adults with autism are involved in the decisions relating to their care. This lays the foundation for a long-term understanding between adults with autism, carers and the professionals supporting their needs. However, many adults or their carers who suspect they have an autistic spectrum condition have had difficulties accessing a diagnostic assessment, particularly if they are not in contact with a specialist service for the assessment or treatment of another disorder. Even if they have managed to obtain a diagnosis they may receive no follow-up support because of the absence of appropriate services or of an agreed care pathway.
- c) The use of biomedical investigations to rule out other conditions, and thresholds for referral for genetic counselling vary markedly. Opinion also varies on the value of biomedical investigations in the diagnostic assessment of autistic and coexisting conditions.

- d) People with other existing conditions featuring intellectual, physical or sensory disability and/or mental health problems may not be recognised as having symptoms of an autistic spectrum condition. Some adults may be misdiagnosed as having personality disorders, eating disorders, or depression and their autistic spectrum condition may be overlooked.
- e) Some of the behaviours that define autistic spectrum conditions may also feature in other disabilities (such as learning disabilities), or be the result of other conditions (such as epilepsy). People may be wrongly diagnosed as having a mental illness when they have features of an autistic spectrum condition, or they may be misdiagnosed with autism when they have another condition. Misdiagnosis can lead to delays in receiving the necessary care and support.
- f) The process and content of information-sharing varies widely, for instance in the provision of information and support for the person and their family while awaiting diagnosis and immediately after.
- g) Current awareness and understanding of autism in adults among front-line health, education and social care professionals leaves room for improvement. In line with the Department of Health's Autism Strategy, a better understanding of the condition may enable better service delivery.
- h) Current treatment and management for autistic spectrum conditions is often focused on children and adolescence. Transition from child and adolescent mental health services to adult services can often be challenging and requires significant collaboration between several government organisations.
- i) Due to the qualitative impairments in communication and social interaction skills, adults with autistic spectrum conditions often have difficulty in engaging in long-term employment or other

purposeful/meaningful activity, especially if the person has a learning disability.

- j) There are variations in practice of diagnosis and appropriate referral for adults with autistic spectrum conditions. Adults at the higher end of the autistic spectrum often may not get a diagnosis because of beliefs that, for example, if a person is in a settled relationship or can talk fluently they cannot have an autistic spectrum condition. This may lead to inappropriate crisis admissions to services as a result of mental health problems, physical illness, homelessness or coming into contact with the criminal justice system.
- k) People with autistic spectrum conditions are at risk of exclusion and inequalities in service provision, particularly people from black or minority ethnic groups, older people, women and people with gender identity problems.
- l) The Department of Health published 'Fulfilling and rewarding lives: the strategy for adults with autism in England' (2009) on designing services to improve care and support from all public services. The National Audit Office is currently undertaking a study, 'Supporting people with autism through adulthood', focusing particularly on the transition from adolescence to adulthood.
- m) 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 2007). 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 autistic spectrum conditions. The Autistic Spectrum Disorder (ASD) Strategic Action Plan for Wales (2009) focused on diagnosis, access to services, community support,

employment and housing. This NICE guideline, along with the NICE guideline on autistic spectrum disorders in children and young people that is currently in development, will provide guidance for the NHS in England.

## **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) Adults (18 or older), with suspected or diagnosed high functioning (for example, above average cognitive functioning) or low functioning (for example, profound communication problems) autistic spectrum conditions.
- b) People with autistic spectrum conditions across the range of diagnostic groups, including atypical autism, Asperger's syndrome, pervasive developmental disorder and Rett's syndrome.
- c) Consideration will be given to the specific needs of:
  - people with coexisting conditions (such as dyslexia, dyspraxia, sensory sensitivity, depression, ADHD, OCD, personality disorders, eating disorders and anxiety disorders)
  - women
  - older people
  - people from black or minority ethnic groups

- transgender people.

#### **4.1.2 Groups that will not be covered**

- a) Children from birth up to 18 years old.

#### **4.2 *Healthcare setting***

- a) Primary, secondary, tertiary, health and social care and healthcare settings (including prisons and forensic services).
- b) Other settings in which NHS services are funded or provided, or where NHS professionals are working in multi-agency teams.
- c) The guideline will also comment on and include recommendations about the interface with other services, such as social services, education services and the voluntary sector.

#### **4.3 *Clinical management***

##### **4.3.1 Key clinical issues that will be covered**

- a) Signs and symptoms that should prompt health, education and social care professionals working with adults and/or their carers to consider the presence of an autistic spectrum condition. These will include signs and symptoms that should trigger referral for specialist assessment.
- b) Validity, specificity and reliability of the components of diagnostic assessment after referral, including:
  - structure for assessment, including strengths and skills
  - diagnostic thresholds
  - assessment tools, including imaging, genetic and biomedical techniques
  - assessment of risk
  - the impact of coexisting developmental, mental and physical conditions on the assessment.

- c) Psychosocial interventions, including: applied behavioural analysis, cognitive behavioural therapies, social groups, befriending schemes, mentoring and supported employment programmes.
- d) Pharmacological interventions, including: anticonvulsants, antidepressants, and antipsychotics for the treatment of symptoms that may arise from coexisting conditions.
- e) Physical interventions, such as diet.
- f) Information and day-to-day support (such as a telephone helpline or advocates) for adults with a suspected autistic spectrum condition, and their families and carers, during the process of referral, assessment, diagnosis and the delivery of any interventions.
- g) The organisation and delivery of care, and care pathways for the components of treatment and management (including transition planning), based on an ethos of multi-professional working.

#### **4.3.2 Clinical issues that will not be covered**

- a) Coexisting conditions if an autistic spectrum condition is not a primary diagnosis.

#### **4.4 Main outcomes**

- a) Diagnostic accuracy and the identification of coexisting conditions.
- b) Health-related quality of life.
- c) Functioning in social/occupational/educational settings.
- d) Outcomes for coexisting conditions, such as depression, anxiety and substance misuse.
- e) Continuity of care.



## **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 quality-adjusted life year (QALY), but a different unit of effectiveness may be used depending on the availability of appropriate clinical and utility data for adults with autistic spectrum conditions. Costs considered will be from an NHS and personal social services (PSS) perspective in the main analyses. In addition, further analyses may be conducted that will consider wider social costs associated with the care of adults with autistic spectrum conditions. Such costs may include for example special education and training costs, voluntary sector respite care costs and costs of housing services. 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 July 2010.

## **5          *Related NICE guidance***

### **5.1      *Guidance under development***

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

- Autism spectrum disorders in children and young people. NICE clinical guideline. Publication expected September 2011.

## **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](http://www.nice.org.uk/GuidelinesManual)). Information on the progress of the guideline will also be available from the NICE website ([www.nice.org.uk](http://www.nice.org.uk)).