

# NATIONAL INSTITUTE FOR HEALTH AND CLINICAL EXCELLENCE

## Clinical Guideline: Autism Spectrum Disorders: recognition, referral and diagnosis in children and adolescents

Stakeholder Scoping Workshop

7 April 2009

The stakeholder scoping workshop is held in addition to the formal consultation on the scope which is taking place from 9 June 2009 until 7 July 2009.

The objectives of the scoping workshop were to:

- obtain feedback on the key clinical issues included in the first draft of the scope
- identify which patient or population subgroups should be specified
- seek views on the composition of the guideline development group (GDG)
- encourage applications for GDG membership.

The scoping group (technical team, NICE and GDG chair) presented a summary of the proposed scope, the timetable for guideline development, the guideline development process, the nature of stakeholder input into the guideline, the processes for recruitment to the GDG and a suggested constituency for this group. The stakeholder representatives were then divided into 5 groups which included a facilitator and a scribe and each group had a structured discussion around the key issues.

### **Guideline title:**

There was broad consensus in the meeting that the term 'young people' was more appropriate than 'adolescent'. The participants asked for some clarification of the conditions that were to be included under the heading 'autism spectrum disorders' as these terms are used differently in different policy documents. There was also some discussion and disagreement in the meeting about using the term "disorder" to describe the autism spectrum. It was suggested that the word 'condition' may be more appropriate, or that the specific meaning of "disorder" be clarified in the scope.

### **Population:**

There was discussion of the upper age cut-off since child and mental health services cover young people up to 19 years and transitional arrangements to adult services are important. The Scottish Intercollegiate Guideline Network (SIGN) guideline on autism and ASD chose a cut-off

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of 18 years which was seen as appropriate by many groups to ensure clarity of guidance across the NHS.

#### **Key clinical issues**

There was general agreement in the meeting that the clinical issues that had been included in the draft scope were of high importance and that there were no major omissions. The focus of the discussions was therefore mostly on the detail within each area of the guideline rather than proposals for additional content.

#### **Points raised during discussions**

The existing guideline on ASD produced by the Scottish Intercollegiate Guideline Network (SIGN) was identified by many participants as a valuable and well thought out document. The audience for the NICE guideline needs to be clarified because it may be used by professionals working with children outside the NHS who may have different needs, including those working in education and social care settings. It was suggested that the scope specifically refer to these groups. However, there was a suggestion that the guideline should not cast its net too wide and risk losing its focus on initial recognition, referral and diagnosis.

Some participants took issue with the use of the phrase 'signs and symptoms' of ASD. It was suggested that non medical audiences would find 'features' or 'clues' easier to understand.

Participants suggested that the features of ASD depend on the age of the child or young person and on the nature of the disorder. The features can change over time, and a child can go in and out of a disordered phase of autistic spectrum condition.

It was acknowledged that some features are harder to recognize than others and harder to diagnose as ASD, so a diagnosis may be provisional. Also, there was broad agreement that recognition and diagnosis does not occur at one point in time but is an on-going process, especially where the features may be harder to recognise or differentiate from other conditions.

Comorbidities were also discussed. It was suggested that it was important to distinguish between:

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- a. Those conditions that pre-dispose to ASD (e.g. genetic disorders such as Fragile X syndrome; TS)
- b. When a diagnosis of ASD is made, what other conditions are to be considered;
- c. How developmental disorders might impact on how the child/young person is screened/assessed for ASD.

It was suggested that the guideline produce warning signs or red flags to trigger further assessment.

A number of participants felt that the needs of children and young people and their families for support during this period should be considered in the guideline and that the child's and families' experience of ASD should be a key part of any assessment.

There was some discussion in the groups about whether the guideline could cover models of service, especially around multi-agency working to reach a confirmed diagnosis. Some participants thought that the guideline should propose different models of service that work well rather than a "one size fits all" diagnostic pathway.

Participants advised that diagnosis needs to be linked to the common assessment framework, with family assessment. It would be helpful if the guideline could consider how information is collected and shared efficiently so that the process is not seen as "starting again" at every appointment.

Since there is no definitive biomedical test for ASD, it was suggested in the groups that the guideline consider a broader approach to diagnosis, taking into consideration the social and developmental context of the child or young person and listening to the views of the child/young person, as well as their parents and carers who may not see ASD as a medical condition requiring professional support.

Participants also thought it would be helpful if the guideline considered the needs of professionals involved in caring for autistic children specifically frontline staff such as GPs, social workers and teachers.

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#### Equalities issues

The following groups of people were identified for particular attention in the guideline: girls, children and young people with learning disabilities, looked after children, children and young people with sensory impairment, children and young people from ethnic minorities and first generation immigrants, children from socially disadvantaged households, and young people not in education, employment or training

#### Suggested extensions to the scope

The following additional questions were proposed:

What is the impact on family members on a diagnosis of ASD?

What support do families require during and immediately after a diagnosis of ASD?

What is the evidence on a multi-disciplinary approach to assessment?

#### GDG membership

The stakeholders were asked for feedback on the following GDG constituency:

General practitioner	Health visitor	Community paediatricians
SENCO/ Educational	Child and adolescent	Psychiatrist with special interest
Psychologist	psychiatrist	in learning difficulties
Clinical psychologist	Speech therapist	

Patient/ parent representation from at least two parents, who may also have links with national organisations representing families of children with ASD and / or families fostering children with ASD;

Stakeholders suggested adding more representation from a wider range of parents/ carers, the education sector, a nurse specialist, a representative from social care, a specialist health visitor for 0 to 5 year olds, a child psychiatrist for 0 to 2 year olds and a representative from the Welsh Assembly Government.