Complete Summary

GUIDELINE TITLE

Assessment, diagnosis and clinical interventions for children and young people with autism spectrum disorders. A national clinical guideline.

BIBLIOGRAPHIC SOURCE(S)

Scottish Intercollegiate Guidelines Network (SIGN). Assessment, diagnosis and clinical interventions for children and young people with autism spectrum disorders. A national clinical guideline. Edinburgh (Scotland): Scottish Intercollegiate Guidelines Network (SIGN); 2007 Jul. 65 p. (SIGN publication; no. 98). [232 references]

GUIDELINE STATUS

This is the current release of the guideline.

This guideline was issued in 2007 and will be considered for review in three years. Any amendments to the guideline in the interim period will be noted on Scottish Intercollegiate Guidelines Network (SIGN) Web site.

COMPLETE SUMMARY CONTENT

SCOPE

DISEASE/CONDITION(S)

Autism spectrum disorders (ASDs) including autism, atypical autism and Asperger's syndrome

GUIDELINE CATEGORY

Diagnosis
Evaluation
Management
Treatment

CLINICAL SPECIALTY

Family Practice
Ophthalmology
Pediatrics
Psychiatry
Psychology

INTENDED USERS

Allied Health Personnel
Dietitians
Health Care Providers
Nurses
Occupational Therapists
Physicians
Psychologists/Non-physician Behavioral Health Clinicians
Public Health Departments
Social Workers
Speech-Language Pathologists

GUIDELINE OBJECTIVE(S)

To provide evidence-based recommendations on the assessment, diagnosis and clinical interventions for children and young people with autism spectrum disorders (ASD)

TARGET POPULATION

Children and young people with autism spectrum disorders (ASD)

INTERVENTIONS AND PRACTICES CONSIDERED

Diagnosis/Evaluation

1. Clinical assessment according to diagnostic criteria from the International Classification of Diseases of the World Health Organisation, 10th edition (ICD-10) and the Diagnostic and Statistical Manual, 4th edition (DSM-IV)
2. Surveillance
3. Identification of children of high risk (use of structured instrument)
4. Timing of diagnosis
5. Autism spectrum disorder-specific diagnostic history from parent/carer
6. Direct observation and assessment of social, and communication skills and behaviour
7. Evaluation of speech, language and communication skills
8. Assessment of intellectual, neuropsychological and adaptive functioning

9. Biomedical investigations
    - Examination of physical status, with particular attention to neurological and dysmorphic features
    - Karyotyping and Fragile X DNA analysis
    - Examination of audiological status
    - Other investigations to rule out recognised aetiologies of autism spectrum disorders (ASD) (e.g., tuberous sclerosis)
10. Assessment of comorbid conditions

Management/Treatment

1. Support for early communication skills
2. Interventions for social communication and interaction
3. Intensive behavioural programmes
4. Behavioural interventions
5. Pharmacologic therapy
    - Risperidone
    - Methylphenidate
    - Melatonin
6. Service provision
    - Training of healthcare personnel
    - Provision of information for parents/carers
    - Education and skills interventions for parents of pre-school children with ASD

MAJOR OUTCOMES CONSIDERED

- Accuracy of diagnostic tests
- Communication and social functioning
- Symptom relief
- Quality of life
- Adverse effects of treatment

METHODOLOGY

METHODS USED TO COLLECT/SELECT EVIDENCE

Hand-searches of Published Literature (Primary Sources)
Hand-searches of Published Literature (Secondary Sources)
Searches of Electronic Databases

DESCRIPTION OF METHODS USED TO COLLECT/SELECT THE EVIDENCE

A systematic review of the literature was carried out using a search strategy devised by a Scottish Intercollegiate Guidelines Network (SIGN) Information Officer. Databases searched include Medline, Embase, Cinahl, PsychINFO, and the Cochrane Library. For most searches, the year range covered was 1996-2006. Internet searches were carried out on various websites including the New Zealand Guidelines Programme, NeLH Guidelines Finder, and the US National Guidelines Clearinghouse. The Medline version of the main search strategies can be found on the SIGN website, in the section covering supplementary guideline material. The

main searches were supplemented by material identified by individual members of the development group.

NUMBER OF SOURCE DOCUMENTS

Not stated

METHODS USED TO ASSESS THE QUALITY AND STRENGTH OF THE EVIDENCE

Weighting According to a Rating Scheme (Scheme Given)

RATING SCHEME FOR THE STRENGTH OF THE EVIDENCE

Levels of Evidence

1++: High quality meta-analyses, systematic reviews of randomised controlled trials (RCTs), or RCTs with a very low risk of bias

1+: Well-conducted meta-analyses, systematic reviews of RCTs, or RCTs with a low risk of bias

1-: Meta-analyses, systematic reviews of RCTs, or RCTs with a high risk of bias

2++: High quality systematic reviews of case control or cohort studies
High quality case control or cohort studies with a very low risk of confounding or bias and a high probability that the relationship is causal

2+: Well-conducted case control or cohort studies with a low risk of confounding or bias and a moderate probability that the relationship is causal

2-: Case control or cohort studies with a high risk of confounding or bias and a significant risk that the relationship is not causal

3: Non-analytic studies (e.g. case reports, case series)

4: Expert opinion

METHODS USED TO ANALYZE THE EVIDENCE

Systematic Review with Evidence Tables

DESCRIPTION OF THE METHODS USED TO ANALYZE THE EVIDENCE

Once papers have been selected as potential sources of evidence, the methodology used in each study is assessed to ensure its validity. The result of this assessment will affect the level of evidence allocated to the paper, which will in turn influence the grade of recommendation that it supports.

The methodological assessment is based on a number of key questions that focus on those aspects of the study design that research has shown to have a significant influence on the validity of the results reported and conclusions drawn. These key questions differ between study types, and a range of checklists is used to bring a degree of consistency to the assessment process. Scottish Intercollegiate Guidelines Network (SIGN) has based its assessments on the MERGE (Method for Evaluating Research and Guideline Evidence) checklists developed by the New South Wales Department of Health, which have been subjected to wide consultation and evaluation. These checklists were subjected to detailed evaluation and adaptation to meet SIGN's requirements for a balance between methodological rigor and practicality of use.

The assessment process inevitably involves a degree of subjective judgment. The extent to which a study meets a particular criterion (e.g., an acceptable level of loss to follow up) and, more importantly, the likely impact of this on the reported results from the study will depend on the clinical context. To minimize any potential bias resulting from this, each study must be evaluated independently by at least two group members. Any differences in assessment should then be discussed by the full group. Where differences cannot be resolved, an independent reviewer or an experienced member of SIGN Executive staff will arbitrate to reach an agreed quality assessment

Evidence Tables

Evidence tables are compiled by SIGN executive staff based on the quality assessments of individual studies provided by guideline development group members. The tables summarise all the validated studies identified from the systematic literature review relating to each key question. They are presented in a standard format to make it easier to compare results across studies, and will present separately the evidence for each outcome measure used in the published studies. These evidence tables form an essential part of the guideline development record and ensure that the basis of the guideline development group's recommendations is transparent.

Criteria for Assessing the Reporting of the Diagnosis of Autism Spectrum Disorder (ASD) in the Literature

When reviewing the literature the guideline development group found that the definitions of ASD used for diagnosis varied considerably when reported and were often not reported at all. To allow for consistency within the guideline the group agreed that three elements – assessment process, classification system and diagnostic instrument - were important in the accurate diagnosis of ASD. If a paper did not record diagnosis in this way it was downgraded.

A. Components of diagnostic assessment
1. *A recognised **process** of obtaining information in necessary domains, usually by multidisciplinary or multiagency personnel* 2. *Mapping of the resulting information into a recognised **classification system** such as DSM–IV or ICD–10 (see section 2.2)*

3. *Assessment using a recognised and published* ***diagnostic instrument***	
B. Components of a reliable diagnosis	
Increasing accuracy and reliability	Use of a process, ***and*** a diagnostic classification system, ***and*** an instrument (i.e. 1, 2, ***and*** 3, from A)
	1. Use of a process ***and*** a diagnostic classification system OR 2. Use of an instrument ***and*** a diagnostic classification system
	The use of a process, a diagnostic classification system ***or*** an instrument, used ***singly***
	Diagnosis simply stated
Note: Each component of the assessment should be explicitly stated in the study/report under consideration	

Additional information can be found in the companion document titled "SIGN 50: A Guideline Developers' Handbook." (Edinburgh [UK]: Scottish Intercollegiate Guidelines Network. [SIGN publication; no. 50]), available from the SIGN Web site.

METHODS USED TO FORMULATE THE RECOMMENDATIONS

Expert Consensus

DESCRIPTION OF METHODS USED TO FORMULATE THE RECOMMENDATIONS

Synthesizing the Evidence

Guideline recommendations are graded to differentiate between those based on strong evidence and those based on weak evidence. This judgment is made on the basis of an (objective) assessment of the design and quality of each study and a (perhaps more subjective) judgment on the consistency, clinical relevance and external validity of the whole body of evidence. The aim is to produce a recommendation that is evidence-based, but which is relevant to the way in which health care is delivered in Scotland and is therefore implementable.

It is important to emphasize that the grading does not relate to the importance of the recommendation, but to the strength of the supporting evidence and, in particular, to the predictive power of the study designs from which that data was obtained. Thus, the grading assigned to a recommendation indicates to users the likelihood that, if that recommendation is implemented, the predicted outcome will be achieved.

Considered Judgment

It is rare for the evidence to show clearly and unambiguously what course of action should be recommended for any given question. Consequently, it is not always clear to those who were not involved in the decision making process how guideline developers were able to arrive at their recommendations, given the evidence they had to base them on. In order to address this problem, SIGN has introduced the concept of considered judgment.

Under the heading of considered judgment, guideline development groups summarize their view of the total body of evidence covered by each evidence table. This summary view is expected to cover the following aspects:

- Quantity, quality, and consistency of evidence
- Generalisability of study findings
- Directness of application to the target population for the guideline
- Clinical impact (i.e., the extent of the impact on the target patient population, and the resources needed to treat them.)
- Implementability (i.e., how practical it would be for the NHS in Scotland to implement the recommendation.)

Guideline development groups are provided with a pro forma in which to record the main points from their considered judgment. Once they have considered these issues, the group is asked to summarize their view of the evidence and assign a level of evidence to it, before going on to derive a graded recommendation.

Additional detail about SIGN's process for formulating guideline recommendations is provided in Section 6 of the companion document titled "SIGN 50: A Guideline Developers' Handbook." (Edinburgh [UK]: Scottish Intercollegiate Guidelines Network. [SIGN publication; no. 50], available from the SIGN Web site.

RATING SCHEME FOR THE STRENGTH OF THE RECOMMENDATIONS

Grades of Recommendation

Note: The grade of recommendation relates to the strength of the evidence on which the recommendation is based. It does not reflect the clinical importance of the recommendation.

A: At least one meta-analysis, systematic review of randomized controlled trials (RCTs), or RCT rated as 1++ and directly applicable to the target population; *or*

A body of evidence consisting principally of studies rated as 1+, directly applicable to the target population, and demonstrating overall consistency of results

B: A body of evidence including studies rated as 2++, directly applicable to the target population, and demonstrating overall consistency of results; *or*

Extrapolated evidence from studies rated as 1++ or 1+

C: A body of evidence including studies rated as 2+, directly applicable to the target population and demonstrating overall consistency of results; *or*

Extrapolated evidence from studies rated as 2++

D: Evidence level 3 or 4; *or*

Extrapolated evidence from studies rated as 2+

Good Practice Points: Recommended best practice based on the clinical experience of the guideline development group

COST ANALYSIS

A formal cost analysis was not performed and published cost analyses were not reviewed.

METHOD OF GUIDELINE VALIDATION

External Peer Review
Internal Peer Review

DESCRIPTION OF METHOD OF GUIDELINE VALIDATION

The national open meeting is the main consultative phase of Scottish Intercollegiate Guidelines Network (SIGN) guideline development.

Peer Review

All SIGN guidelines are reviewed in draft form by independent expert referees, who are asked to comment primarily on the comprehensiveness and accuracy of interpretation of the evidence base supporting the recommendations in the guideline. A number of general practitioners (GPs) and other primary care practitioners also provide comments on the guideline from the primary care perspective, concentrating particularly on the clarity of the recommendations and their assessment of the usefulness of the guideline as a working tool for the primary care team. The draft is also sent to a lay reviewer in order to obtain comments from the patient's perspective. The comments received from peer reviewers and others are carefully tabulated and discussed with the chairman and with the guideline development group. Each point must be addressed and any changes to the guideline as a result noted or, if no change is made, the reasons for this recorded.

As a final quality control check prior to publication, the guideline and the summary of peer reviewers' comments are reviewed by the SIGN Editorial Group for that guideline to ensure that each point has been addressed adequately and that any risk of bias in the guideline development process as a whole has been minimised. Each member of the guideline development group is then asked formally to approve the final guideline for publication.

RECOMMENDATIONS

MAJOR RECOMMENDATIONS

Note from the Scottish Intercollegiate Guidelines Network (SIGN) and National Guideline Clearinghouse (NGC)*: In addition to these evidence-based recommendations, the guideline development group also identifies points of best clinical practice in the full-text guideline document.*

The grades of recommendations (A–D) and levels of evidence (1++, 1+, 1-, 2++, 2+, 2-, 3, 4) are defined at the end of the "Major Recommendations" field.

Diagnostic Criteria

C- All professionals involved in diagnosing Autism Spectrum Disorders (ASD) in children and young people should consider using either International Classification of Diseases (ICD)-10 or Diagnostic and Statistical Manual of Mental Disorders (DSM)-IV.

Recognition, Assessment, and Diagnosis

Recognition in Primary Care

Screening

C - Population screening for ASD is not recommended.

Surveillance

D - As part of the core program of child health surveillance, healthcare professionals can contribute to the early identification of children requiring further assessment for ASD, and other developmental disorders:

- Clinical assessment should incorporate a high level of vigilance for features suggestive of ASD, in the domains of social interaction and play, speech and language development and behavior
- The Checklist for Autism in Toddlers (CHAT) or modified CHAT (M-CHAT) can be used in young children to identify clinical features indicative of an increased risk of ASD but should not be used to rule out ASD

Screening of High Risk Groups

C - The use of an appropriate structured instrument may be a useful supplement to the clinical process to identify children and young people at high risk of ASD.

Timing of Diagnosis

D - ASD should be part of the differential diagnosis for very young (preschool) children displaying absence of normal developmental features, as typical ASD behaviors may not be obvious in this age group.

Methods of Assessment

Components of Specialist Assessment

History Taking (Parent/Carer Interview)

D - Healthcare professionals involved in specialist assessment should take an ASD specific diagnostic history

C - ASD specific history taking instruments may be considered as a means of improving the reliability of ASD diagnosis

Clinical Observation/Assessment (Child/Young Person Assessment/Interview)

D - Healthcare professionals should directly observe and assess the child or young person's social and communication skills and behavior.

C - Healthcare professionals should consider using ASD-specific observational instruments, as a means of improving the reliability of ASD diagnosis.

Individual Profiling

D - All children and young people with ASD should have a comprehensive evaluation of their speech and language and communication skills, which should inform intervention.

D - Children and young people with ASD should be considered for assessment of intellectual, neuropsychological and adaptive functioning.

Biomedical Investigations

D - Where clinically relevant, the need for the following should be reviewed for all children and young people with ASD:

- Examination of physical status, with particular attention to neurological and dysmorphic features
- Karyotyping and Fragile X DNA analysis
- Examination of audiological status
- Investigations to rule out recognised aetiologies of ASD (e.g., tuberous sclerosis, see Annex 3 in the original guideline document)

Conditions Associated with ASD

C - Healthcare professionals should be aware of the need to routinely check for comorbid problems in children and young people with ASD. Where necessary, detailed assessment should be carried out to accurately identify and manage comorbid problems.

Non-Pharmacological Interventions

Communication Interventions

Support for Early Communication Skills

D - Interventions to support communication in ASD are indicated, such as the use of visual augmentation (e.g., in the form of pictures of objects).

Interventions for Social Communication and Interaction

D - Interventions to support social communication should be considered for children and young people with ASD, with the most appropriate intervention being assessed on an individual basis.

Behavior/Psychological Interventions

Intensive Behavioral Programmes

A - The Lovaas programme should not be presented as an intervention that will lead to normal functioning.

Interventions for Specific Behaviors

B - Behavioral interventions should be considered to address a wide range of specific behaviors in children and young people with ASD, both to reduce symptom frequency and severity and to increase the development of adaptive skills.

Auditory Integration Training

A - Auditory integration training is not recommended.

Facilitated Communication

A - Facilitated communication should not be used as a means to communicate with children and young people with ASD.

Pharmacological Interventions

Risperidone

B - Risperidone is useful for short term treatment of significant aggression, tantrums or self injury in children with autism

B - Weight should be monitored regularly in children and young people who are taking risperidone.

Methylphenidate

B - Methylphenidate may be considered for treatment of attention difficulties/hyperactivity in children or young people with ASD.

Secretin

A - Secretin is not recommended for use in children and young people with ASD.

Melatonin

D - Melatonin may be considered for treatment of sleep problems which have persisted despite behavioral interventions.

Service Provision

ASD Training

D - All professions and service providers working in the ASD field should review their training arrangements to ensure staff has up-to-date knowledge and adequate skill levels.

Training and Support for Parents

Information Provision

D - Professionals should offer parents good quality written information and an opportunity to ask questions when disclosing information about their child with ASD

D - Parents should be provided with information in an accessible and absorbable form.

Meeting Support Needs

B - Education and skills interventions for parents of pre-school children with ASD should be offered.

Definitions:

Grades of Recommendation

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D: Evidence level 3 or 4; *or*

Extrapolated evidence from studies rated as 2+

Good Practice Points: Recommended best practice based on the clinical experience of the guideline development group

Levels of Evidence

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3: Non-analytic studies (e.g. case reports, case series)

4: Expert opinion

CLINICAL ALGORITHM(S)

None provided

EVIDENCE SUPPORTING THE RECOMMENDATIONS

TYPE OF EVIDENCE SUPPORTING THE RECOMMENDATIONS

The type of supporting evidence is identified and graded for each recommendation (see "Major Recommendations").

BENEFITS/HARMS OF IMPLEMENTING THE GUIDELINE RECOMMENDATIONS

POTENTIAL BENEFITS

Appropriate early diagnosis and management of children and young people with autism spectrum disorders may help a child to maximize his or her potential.

POTENTIAL HARMS

- Adverse effects associated with risperidone include tiredness/sedation early in treatment and increased appetite and weight gain
- Methylphenidate adverse effects may include difficulty falling asleep, appetite decrease, irritability and emotional outbursts.
- Melatonin is not a licensed medication, which limits the information that is available about effectiveness and safety

QUALIFYING STATEMENTS

QUALIFYING STATEMENTS

This guideline is not intended to be construed or to serve as a standard of care. Standards of care are determined on the basis of all clinical data available for an individual case and are subject to change as scientific knowledge and technology advance and patterns of care evolve. Adherence to guideline recommendations will not ensure a successful outcome in every case, nor should they be construed as including all proper methods of care or excluding other acceptable methods of care aimed at the same results. The ultimate judgement must be made by the appropriate healthcare professional(s) responsible for clinical decisions regarding a particular clinical procedure or treatment plan. This judgement should only be arrived at following discussion of the options with the patient, covering the diagnostic and treatment choices available. It is, however, advised that significant departures from the national guideline or any local guidelines derived from it should be fully documented in the patient's case notes at the time the relevant decision is taken.

IMPLEMENTATION OF THE GUIDELINE

DESCRIPTION OF IMPLEMENTATION STRATEGY

Implementation of national clinical guidelines is the responsibility of each National Health Service (NHS) Board and is an essential part of clinical governance. It is acknowledged that every Board cannot implement every guideline immediately on publication, but mechanisms should be in place to ensure that the care provided is reviewed against the guideline recommendations and the reasons for any differences assessed and, where appropriate, addressed. These discussions should involve both clinical staff and management. Local arrangements may then be made to implement the national guideline in individual hospitals, units and practices, and to monitor compliance. This may be done by a variety of means including patient-specific reminders, continuing education and training, and clinical audit.

Key points for audit are identified in the original guideline document.

IMPLEMENTATION TOOLS

Audit Criteria/Indicators
Chart Documentation/Checklists/Forms
Quick Reference Guides/Physician Guides

For information about availability, see the "Availability of Companion Documents" and "Patient Resources" fields below.

INSTITUTE OF MEDICINE (IOM) NATIONAL HEALTHCARE QUALITY REPORT CATEGORIES

IOM CARE NEED

Living with Illness

IOM DOMAIN

Effectiveness
Patient-centeredness

IDENTIFYING INFORMATION AND AVAILABILITY

BIBLIOGRAPHIC SOURCE(S)

Scottish Intercollegiate Guidelines Network (SIGN). Assessment, diagnosis and clinical interventions for children and young people with autism spectrum disorders. A national clinical guideline. Edinburgh (Scotland): Scottish Intercollegiate Guidelines Network (SIGN); 2007 Jul. 65 p. (SIGN publication; no. 98). [232 references]

ADAPTATION

Not applicable: The guideline was not adapted from another source.

DATE RELEASED

2007 Jul

GUIDELINE DEVELOPER(S)

Scottish Intercollegiate Guidelines Network - National Government Agency [Non-U.S.]

SOURCE(S) OF FUNDING

Scottish Executive Health Department

GUIDELINE COMMITTEE

Not stated

COMPOSITION OF GROUP THAT AUTHORED THE GUIDELINE

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**Member of the writing group*

FINANCIAL DISCLOSURES/CONFLICTS OF INTEREST

Declarations of interests were made by all members of the guideline development group. Further details are available from the Scottish Intercollegiate Guidelines Network (SIGN) Executive.

GUIDELINE STATUS

This is the current release of the guideline.

This guideline was issued in 2007 and will be considered for review in three years. Any amendments to the guideline in the interim period will be noted on Scottish Intercollegiate Guidelines Network (SIGN) Web site.

GUIDELINE AVAILABILITY

Electronic copies: Available in Portable Document Format (PDF) from the Scottish Intercollegiate Guidelines Network (SIGN) Web site.

AVAILABILITY OF COMPANION DOCUMENTS

The following are available:

- Quick reference guide: Assessment, diagnosis and clinical interventions for children and young people with autism spectrum disorders. Scottish Intercollegiate Guidelines Network, 2007 Jun. 2 p. Available in Portable Document Format (PDF) from the Scottish Intercollegiate Guidelines Network (SIGN) Web site.
- SIGN 50: A guideline developer's handbook. Edinburgh (Scotland): Scottish Intercollegiate Guidelines Network. (SIGN publication; no. 50). Available from the SIGN Web site.
- Appraising the quality of clinical guidelines. The SIGN guide to the AGREE (Appraisal of Guidelines Research & Evaluation) guideline appraisal instrument. Edinburgh (Scotland): Scottish Intercollegiate Guidelines Network, 2001. Available from the SIGN Web site.

Also, chart documentation of suggested screening instruments in high risk groups is provided in Annex 4 of the original guideline document.

PATIENT RESOURCES

None available

NGC STATUS

This summary was completed by ECRI Institute on August 31, 2007.

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