SIGN

Scottish Intercollegiate Guidelines Network

NHS Quality Improvement Scotland

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Assessment, diagnosis and clinical interventions for children and young people with autism spectrum disorders

A national clinical guideline

The guideline can be used in association with the suite of ASD specific resources developed by NHS Education for Scotland

July 2007

KEY TO EVIDENCE STATEMENTS AND GRADES OF RECOMMENDATIONS

LEVELS OF EVIDENCE

1++	High quality meta-analyses, systematic reviews of RCTs, or RCTs with a very low risk of bias
1+	Well conducted meta-analyses, systematic reviews, or RCTs with a low risk of bias
1-	Meta-analyses, systematic reviews, 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, eg case reports, case series
4	Expert opinion

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, 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.

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1 Introduction

1.1 THE NEED FOR A GUIDELINE

In 2001, the Public Health Institute of Scotland (PHIS) Autistic Spectrum Disorders Needs Assessment Report recommended that a SIGN guideline should be developed to improve the assessment and management of autism spectrum disorders (ASD) in Scotland.[1] The 2003 National Autism Plan for Children (NAPC) for England and Wales highlighted the need for a systematic approach to ASD assessment, diagnosis and intervention.[2]

The PHIS report reviewed ASD prevalence studies and estimated that there were 7,714 children under 19 in Scotland with ASD. The figure was based on a previously published ASD prevalence rate of 70.3 per 10,000 in pre-school children.[1, 3]

In a more recent study, the total prevalence of ASD in 9-10 year olds was 116.1 per 10,000 in the Thames region of London in 2006. [4]

ASD occurs more commonly in boys than girls, at a ratio of approximately 4:1, although this varies across the spectrum.[5] There is no evidence of an association between ASD and social class[6, 7] or ethnicity.[7, 8]

Early diagnosis and appropriate intervention, specialised education, and structured support may help a child to maximise his or her potential. There are significant disparities in multiagency ASD provision in Scotland.[9] Variation in referrals from primary care may be related to the problems that some primary care professionals can have in recognising the key symptoms of ASD. Referral rates may also be influenced by parental education and social class.[10] There is variation in referral pathways and service provision and in the range of healthcare and other professionals involved.

1.2 REMIT OF THE GUIDELINE

The guideline applies to children and young people up to the age of 18, which may include the period of transition from childhood to adult services. Sometimes the evidence and any consequent recommendations are age specific.

This guideline focuses on assessment, diagnosis and clinical interventions for ASD. It considers the evidence for joint working and consultation with children and young people, and with parents and carers. It also considers the evidence for how multidisciplinary and multiagency working can best address the needs of individuals with ASD at all levels of provision (primary, secondary and tertiary care).

The guideline does not examine the broad range of educational and social opportunities offered to children and young people with ASD, which may add value to their lives and promote social inclusion. Educational interventions which may influence clinical outcomes have been considered (*see section 3*).

The guideline does not review epidemiology, including that relating to the possible increase in the prevalence of ASD, and the use of the measles, mumps and rubella (MMR) vaccine. Summaries of the issues and the evidence around ASD and MMR have been published elsewhere, for example: www.mmrthefacts.nhs.uk/ or www.healthscotland.com/immunisation/mmr/mmrdiscussionpack.cfm and www.mrc.ac.uk/pdf-autism-report.pdf

The management of ASD involves a wide range of professionals. A number of different pathways of care, all involving a variety of specialists, exist across Scotland. This guideline will be of interest to healthcare professionals and others involved in the care of children with ASD, including; child and adolescent psychiatrists, clinical and educational psychologists, commissioners of health, educational and social children's services, dietitians, general practitioners (GPs), health visitors, nurses, occupational therapists, ophthalmologists, paediatricians, parent/carer groups, primary care mental health workers, psychotherapists, physiotherapists, social workers, speech and language therapists and teachers. The guideline will also be of interest to children and young people with ASD and their families.

1.3 AIM AND ETHOS OF THE GUIDELINE

The aim of this guideline is to provide the evidence base and recommendations to inform clinical service provision, in particular, assessment and clinical intervention. The guideline development group hopes that the concept of "ASD-friendly" services is a constant throughout this guideline. The involvement of parents and family and the young person affected by ASD is important to the success of any intervention. Healthcare professionals should be given adequate time for discussion with children, young people and parents and there should be continuity of care across services.

It is recognised that many assessments and interventions will be undertaken with partners in education, supported within the new framework of the Additional Support for Learning (Education) Scotland Act (2004), and with partners in social services (see www.opsi.gov.uk/legislation/scotland/acts2004/20040004.htm).

1.4 CHALLENGES IN REVIEWING THE EVIDENCE

Accurate diagnosis of ASD can be difficult, but when reviewing the literature for this guideline, it has only been possible to interpret and generalise from studies where the approach to diagnosis has been clearly stated. When considering the literature it was evident that studies of children and young people with ASD varied in terms of how the diagnosis had been made. This made it difficult to compare or combine the results of studies, as it was not always clear which, if any, definition of ASD had been used, or whether populations with similar characteristics were being studied.

When reviewing the literature the guideline development group considered the assessment process, classification system and diagnostic instrument to be important in the accurate diagnosis of ASD (*see annex 1 for further details*). Recommendations derived from studies that did not clearly describe how participants were diagnosed were downgraded according to the SIGN grading system.

Some interventions may be evaluated through methods not currently defined within the SIGN grading system. In recognition of this, meta-analyses of well conducted single case designs carried out over at least two cycles have been classed as level 2 evidence.

Recommendations have been made where evidence is available. There was often a lack of evidence for investigations and interventions that are in everyday use. Research in these areas should be a priority (*see section 9.4, recommendations for research*).

1.5 STATEMENT OF INTENT

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 and their carer where appropriate, covering the diagnostic and treatment choices available. However, it is 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.

1.6 REVIEW AND UPDATING

This guideline was issued in 2007 and will be considered for review in three years. Any updates to the guideline in the interim period will be noted on the SIGN website: **www.sign.ac.uk**

2 Definitions and concepts

2.1 DEFINITIONS

The term autism spectrum disorders has been used throughout this guideline to cover conditions termed autism, atypical autism and Asperger's syndrome (see annex 2). These are complex developmental disorders, behaviourally defined, that include a range of possible developmental impairments in reciprocal social interaction and communication, and also a stereotyped, repetitive or limited, behavioural repertoire. ASD may occur in association with any level of general intellectual/ learning ability, and manifestations range from subtle problems of understanding and impaired social function to severe disabilities.[1]

Impairments in each of the areas relevant to ASD diagnoses occur along a continuum from minimal to severe and categorical diagnoses inevitably involve defining a cut off. Diagnostic classification in itself should not be the basis for decisions about provision within education, or needs for social care and support.[2]

2.2 DIAGNOSTIC CRITERIA

There are two major diagnostic classification systems in current use, the International Classification of Diseases, version 10 (ICD-10)[11] and the Diagnostic and Statistical Manual of Mental Disorders 4th edition (DSM-IV).[12] They have similar symptom criteria for diagnosis, based on a triad of impairments, with the behaviours being discrepant from the individual's mental age:[13, 14]

- **social** – impaired, deviant and delayed or atypical social development, especially interpersonal development
- **language and communication** – impaired and deviant language and communication, verbal and non-verbal. Impairment in pragmatic aspects of language
- **thought and behaviour** – rigidity of thought and behaviour and impoverished social imagination. Ritualistic behaviour, reliance on routines, impairment of imaginative play.

A comparison of the two systems is given in annex 2.

ICD-10 (available in complementary clinical and research forms) is the most commonly used ASD classification system in the UK, although many research studies use DSM-IV or other criteria. For this reason and to minimise complexity, where differences of terminology occur between ICD-10 and DSM-IV, this guideline has used that within ICD-10.

The diagnostic criteria for ASD continue to develop as more research is done and understanding improves, and they are likely to change with future revisions. For example, for a diagnosis of Asperger's syndrome, both systems require no clinically significant general delay in language (speech of words and phrases by specified times) and no clinically significant general delay in cognitive development. DSM-IV also employs an explicit hierarchy, so that Asperger's syndrome can only be diagnosed if criteria for autism are not met. This is not specified in the same way within ICD-10.

Wider usage of diagnostic terms may be influenced by other factors and may not always reflect the definitions in classification systems. For example, the name Asperger's syndrome may be used for some individuals who speak well later, but did in fact have early language delay.

There is limited evidence on the reliability and validity of the existing classification systems, ICD-10 and DSM-IV. Several studies have explored the discriminatory validity of Asperger's syndrome and autism, but no studies have looked at predictive validity.

Three studies all found that the use of DSM-IV and ICD-10 criteria for autism improve the reliability of the diagnostic process.[15-17] The studies consistently found that:

- using either DSM-IV or ICD-10 increases the reliability of the diagnostic process. The effect is even greater when inexperienced practitioners are making the diagnosis
- the current criteria for Asperger's syndrome and autism have poor discriminant validity.

2+

C **All professionals involved in diagnosing ASD in children and young people should consider using either ICD-10 or DSM-IV.**

3 Recognition, assessment and diagnosis

3.1 RECOGNITION IN PRIMARY CARE

3.1.1 INTRODUCTION

The early detection of children requiring assessment for health problems and developmental disorders is desirable and is the aim of child health screening and surveillance programmes. These programmes are reviewed regularly by the Royal College of Paediatrics and Child Health. The most recent review entitled Health for all Children,[18] and commonly referred to as Hall 4, has led to a significant change in the provision of child health surveillance and screening in Scotland.[19]

Hall 4 states that every child and parent should have access to a universal or core programme of preventative pre-school care, but that formal screening should be confined to the evidence based programmes agreed by the UK National Screening Committee.[18] Hall 4 does not recommend formal universal screening for speech and language delay, global developmental delay or autism, but states that staff should elicit and respond to parental concerns as part of child health surveillance. The report emphasises the need for an efficient preliminary assessment, or triage process, to determine which children may need referral for fuller assessment and/or intervention.

3.1.2 SCREENING

Screening has been defined by the UK National Screening Committee as "a public health service in which members of a defined population, who do not necessarily perceive they are at risk of, or are already affected by a disease or its complications, are asked a question or offered a test, to identify those individuals who are more likely to be helped than harmed by further tests or treatment to reduce the risk of a disease or its complications".[20]

Any screening test must have a known specificity (analogous to the risk of false positives) and sensitivity (analogous to the risk of false negatives) within the population to which it is being applied. The UK National Screening Committee[20] and a systematic review[21] have not identified any research into ASD screening instruments that meet the rigorous criteria for a robust population screening test. 2+

Population screening for ASD is not recommended. False positive or false negative results from inappropriate use of screening tests may delay correct diagnosis. The decision about the need for referral and further assessment should be made on clinical grounds.

C **Population screening for ASD is not recommended.**

3.1.3 SURVEILLANCE

Child health surveillance takes a broad clinical approach involving partnership between parents, children and health professionals. Child health surveillance can contribute to the early recognition and diagnosis of ASD.[22] Surveillance for ASD should follow general developmental surveillance and should be considered by all professionals working with children and young people.

Responding to concerns raised by parents has a role in surveillance, and healthcare professionals should be aware that parental concerns about the absence of normal developmental features are as important as the presence of abnormal features.[22-27] 3

The recognition of children requiring further assessment for ASD requires a high level of vigilance for features indicative of abnormal development, both at any specific age and as they emerge over a period of time. Two structured instruments are of potential use to help identify young children with possible ASD during child health surveillance.

The Checklist for Autism in Toddlers (CHAT) was designed to identify 18 month old children at risk of ASD. It has been tested in a general population setting and was found to have acceptable specificity, but the sensitivity was too low for it to be used in total population screening.[28, 29]

4

The modified CHAT (M-CHAT) is a parent report version of the CHAT designed to be used as part of clinician led child health surveillance, with 18-24 month old children.[30]

A preliminary study suggests the M-CHAT is useful but final data on the psychometric properties from the ongoing follow up study are awaited.

These instruments can provide a useful structure for considering relevant clinical features during surveillance by healthcare professionals. Surveillance remains dependent on the use of clinical knowledge and skills to identify unusual patterns of development. Not all children with ASD will be identified during child health surveillance, and parents should be encouraged to return for further assessment, if they remain concerned about the development of their child.

Features which should alert healthcare professionals to the possibility of ASD are shown in Tables 1, 2 and 3.

D **As part of the core programme 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 behaviour**
- **CHAT or 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.**

Table 1 General developmental warnings of possible ASD in pre-school children[31]

Warning signs
▪ delay or absence of spoken language
▪ looks through people; not aware of others
▪ not responsive to other people's facial expression/feelings
▪ lack of pretend play; little or no imagination
▪ does not show typical interest in or play near peers purposefully
▪ lack of turn-taking
▪ unable to share pleasure
▪ qualitative impairment in non-verbal communication
▪ does not point at an object to direct another person to look at it
▪ lack of gaze monitoring
▪ lack of initiation of activity or social play
▪ unusual or repetitive hand and finger mannerisms
▪ unusual reactions, or lack of reaction, to sensory stimuli

Table 2 Warnings of possible ASD in school-age children[2]

Warning signs
Communication impairments
▪ abnormalities in language development including muteness ▪ odd or inappropriate prosody ▪ persistent echolalia ▪ reference to self as 'you', 'she' or 'he' beyond three years ▪ unusual vocabulary for child's age/social group ▪ limited use of language for communication and/or tendency to talk freely only about specific topics
Social impairments
▪ inability to join in play of other children or inappropriate attempts at joint play (may manifest as aggressive or disruptive behaviour) ▪ lack of awareness of classroom 'norms' (criticising teachers, overt unwillingness to co-operate in classroom activities, inability to appreciate or follow current trends) ▪ easily overwhelmed by social and other stimulation ▪ failure to relate normally to adults (too intense/no relationship) ▪ showing extreme reactions to invasion of personal space and resistance to being hurried
Impairments of interests, activities and/or behaviours
▪ lack of flexible cooperative imaginative play/creativity ▪ difficulty in organising self in relation to unstructured space (eg hugging the perimeter of playgrounds, halls) ▪ inability to cope with change or unstructured situations, even ones that other children enjoy (school trips, teachers being away etc)
Other factors
▪ unusual profile of skills/deficits ▪ any other evidence of odd behaviours including unusual responses to sensory stimuli

*Table 3 Additional warnings of possible ASD in adolescents**

NB difficulties are likely to be more subtle in older individuals or those without learning disability.

Warning signs
General picture
▪ long standing difficulties in social behaviours, communication and coping with change, which are more obvious at times of transition (eg change of school, leaving school) ▪ significant discrepancy between academic ability and 'social' intelligence , most difficulties in unstructured social situations, eg in school or work breaks ▪ socially 'naïve', lack common sense, not as independent as peers
Language, non-verbal skills and social communication
▪ problems with communication, even if wide vocabulary and normal use of grammar. May be unduly quiet, may talk at others rather than hold a to and fro conversation, or may provide excessive information on topics of own interest ▪ unable to adapt style of communication to social situations eg may sound like 'a little professor' (overly formal), or be inappropriately familiar ▪ may have speech peculiarities including 'flat', unmodulated speech, repetitiveness, use of stereotyped phrases ▪ may take things literally and fail to understand sarcasm or metaphor ▪ unusual use and timing of non-verbal interaction (eg eye contact, gesture and facial expression)
Social problems
▪ difficulty making and maintaining peer friendships, though may find it easier with adults or younger children ▪ can appear unaware or uninterested in peer group 'norms', may alienate by behaviours which transgress 'unwritten rules' ▪ may lack awareness of personal space, or be intolerant of intrusions on own space
Rigidity in thinking and behaviour
▪ preference for highly specific, narrow interests or hobbies, or may enjoy collecting, numbering or listing ▪ strong preferences for familiar routines, may have repetitive behaviours or intrusive rituals ▪ problems using imagination eg in writing, future planning ▪ may have unusual reactions to sensory stimuli eg sounds, tastes, smell, touch, hot or cold.

** developed by the guideline group based on their knowledge of the evidence base and their clinical experience*

3.1.4 SCREENING OF HIGH RISK GROUPS

The screening of children and young people thought to be at high risk (defined as secondary screening) may be applied, for example, to children referred to services because of developmental delay, emotional and behavioural problems, certain genetic syndromes or to siblings[32] of children and young people with a diagnosis of ASD.

Secondary screening is dependent on an awareness that a child is at higher risk of ASD, and the application of sound clinical knowledge and skills. Several structured instruments for use in secondary screening have been examined in a number of studies using relatively small cohorts.[30, 33-38] With all these instruments, the findings of the studies have not been replicated outwith the study settings. 2+

The use of these instruments can be considered as a supplement to the clinical assessment of at-risk children, and may improve the reliability of the process used to screen for ASD, see annex 4. A single specific instrument cannot be recommended as each one is designed for use within a limited age group, and often focuses on one particular ASD eg Asperger's syndrome.

☑ The assessment of children and young people with developmental delay, emotional and behavioural problems, or genetic syndromes should include surveillance for ASD as part of routine practice.

☑ Healthcare professionals should consider informing families that there is a substantial increased risk of ASD in siblings of affected children.

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.**

3.1.5 TIMING OF DIAGNOSIS

In children under two years old typical ASD behaviours may not be evident. Absence of such behaviours should not rule out the possibility of diagnosis.[22] 4

The evidence regarding the minimum age at which ASD can be reliably diagnosed is not clear. Findings suggest that:

- the diagnosis of autism is always more reliable and stable than the diagnosis of other autism spectrum disorders, regardless of age, and can be reliably diagnosed between the ages of 2-3 years by experienced healthcare professionals.[39, 40] 3
- in children later identified as having ASD, features reported when they were under two years may have been non-specific.[41]

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

☑ Regardless of the findings of any earlier assessments, referral for further diagnosis of an ASD assessment should be considered at any age.

Suggested criteria for alerting features for ASD in older children are given in Tables 2 and 3.

3.2 METHODS OF ASSESSMENT

3.2.1 INITIAL ASSESSMENT

The initial presentation can be to a wide range of professionals in primary care, education or social services. Important information can be gathered at this stage that may suggest the need for specialist assessment. Those involved in carrying out the initial assessment should be aware of the core features of ASD as well as of the wide range of different possible presentations, depending on the child's level of communication and intellect, personality, gender differences, family and educational supports.

Key areas to explore at this stage include:

- the nature of the problem: are the presenting features of the type represented by the diagnostic criteria for ASD?
- the severity of the problem (dysfunction and/or distress in a number of contexts including individual, family, educational or workplace, or severity in one such context).

☑ If, on the basis of initial assessment, it is suspected that a child or young person may have ASD, they should be referred for specialist assessment.

3.2.2 SPECIALIST ASSESSMENT

The aim of specialist assessment is to gather and record information that enables diagnosis and to formulate a multiagency management plan, leading to the development of an appropriate programme of supportive intervention. Such an assessment is necessarily comprehensive and may take place over a period of time.[2]

A diagnosis of ASD may be seen as a life long 'label'. For this reason, it is of equal importance that clinicians diagnose, and not diagnose, accurately. Specialist healthcare professionals must ensure that they are sufficiently informed and experienced to confidently diagnose in the majority of cases and that they collaborate, where possible, with relevant multiagency colleagues, so as to achieve diagnostic consensus. Healthcare professionals should also have a low threshold of referral to more specialised colleagues in cases of diagnostic disagreement or subtle presentation.

The process of assessment and diagnosis aims to review functioning in relevant domains, make diagnoses as appropriate and facilitate seamless, multiagency intervention. It should acknowledge that other conditions (for example, specific language impairment in a three year-old, or first onset depression in a 13 year-old) may present in a superficially similar way to ASD and also that there is significant potential for comorbidity.

Although the research evidence is limited, there is support for the use of multidisciplinary or multiagency teams. [42-45]

☑ The use of different professional groups in the assessment process is recommended as it may identify different aspects of ASD and aid accurate diagnosis.

☑ Specialist assessment should involve a history-taking element, a clinical observation/ assessment element, and the obtaining of wider contextual and functional information.

☑ Specialist assessment should be available for any children and young people who need it. Specialist teams should assess if their service is being used equitably. Apparent inequalities should be investigated and addressed.

☑ The appropriateness of an assessment of mental health needs should be considered for all children and young people with ASD.

3.2.3 COMPONENTS OF SPECIALIST ASSESSMENT

History taking (Parent/carer interview)

This is an important component of any ASD assessment. Without it, evidence of ASD-like behaviour cannot be put into context. Use of ASD-specific history-taking instruments can be useful in this process, although healthcare professionals should be mindful of a global perspective on the circumstances of a child or young person, taking into consideration the possibility of comorbidities and the possible differential diagnoses.

A clinical history should include:

- a description of the current problems experienced by the parent/carer, the child/young person and other individuals (eg teachers, nursery staff). The focus should be on eliciting features consistent with the triad of impairments described in section 2.2
- a history of the child/young person's pre-natal, perinatal and developmental history (including social and emotional factors) up to the patient's age at assessment. This should include a detailed enquiry into evidence of any problems at home, school or in other social relationships
- a family history including evidence of any ASD, speech and language difficulties, psychiatric disorders, learning disability, epilepsy or developmental neurological problems
- a description of who is in the family (eg use of a genogram) and any history of family problems (eg parental separation/divorce) which might be affecting the child or young person's behaviour.

A framework for an ASD-specific developmental history is important and a version is available in the NAPC.[2] In an older or more able individual, there may be successful compensation for disabilities, and problems may only be evident within a detailed developmental history.[46]

ASD-specific diagnostic instruments may be used to supplement the process of clinical history taking. There are two theoretical approaches to the diagnostic classification of ASD – the categorical and the dimensional. Categorical systems (such as ICD and DSM) have led to the development of such instruments as the **Autism Diagnostic Interview – revised** (ADI-R).[47, 48] The dimensional concept has led to the development of the **Diagnostic Interview for Social and Communication Disorders** (DISCO)[49] and the **Developmental**, **Dimensional and Diagnostic Interview** (3di).[50]

The **Autism Diagnostic Interview – revised** (ADI-R) has been shown to be a reliable diagnostic instrument.[47, 48] It should be used with caution in children with a developmental level below the age of two years. It has also been shown to be a valid instrument for diagnosing autism in children of pre-school age.[51] 2+

The 3di and DISCO allow structured data collection in relation to ASD and other conditions.

The published data on the 3di suggests that it is a reliable and valid ASD diagnostic interview schedule when compared to the ADI-R.[50] 2+

The published data on DISCO suggest that it has adequate inter-rater reliability for ICD-10 categories.[49, 52] 3

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)

The experience of interacting with a child or young person, in order to elicit clinical evidence of ASD that is compatible with ICD-10 or DSM-IV, is a significant professional task, which cannot be undertaken without a substantial amount of clinical experience. Such skills are not exclusive to disciplines. The crucial ingredients are training and experience.

Assessments of children and young people for ASD cannot be rushed. It may not be possible to obtain sufficient evidence in one session and the child/young person may require observation in different settings, eg at school (especially in unstructured activity such as break-time) as well as the clinic.[2] 4

ASD-specific diagnostic instruments may be used to supplement the process of clinical observation, as part of the diagnostic assessment.

The **Childhood Autism Rating Scale** (CARS) is an older instrument which encompasses history and observation of spontaneous behaviours relevant to autism.[53, 54]

The **Autism Diagnostic Observation Schedule–Generic** (ADOS-G),[55] has been shown to be a reliable diagnostic instrument and can be used to supplement clinical history. It provides standard contexts to elicit relevant social and communicative behaviours, rather than relying on what is spontaneously manifested by a child or young person. ADOS-G has an excellent diagnostic validity for autism versus non-ASD conditions, if controlled for expressive language level.[55] A study of an earlier version (the ADOS) found that it was also a very specific diagnostic instrument.[48] 2+

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

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

Contextual and functional information

Helpful information about a child or young person's functioning should be available from pre-school or school provision, and additional input can be sought from any other educational or social care professionals involved. Frameworks for information gathering to guide education professionals are available.

This type of information increases understanding as to how a child functions in groups, in unstructured settings, and when performing real life tasks. It may point clinicians towards difficulties that are not evident in one to one observations, or in more structured assessment contexts.

☑ Information about children's and young people's functioning outside the clinic setting, should routinely be obtained from as many available sources as is feasible.

3.3 INDIVIDUAL PROFILING

Children and young people with ASD vary considerably in their individual strengths and difficulties. More detailed assessment of communication, neuropsychological functioning, motor and sensory skills, and adaptive functioning may be helpful.

By definition, all children and young people with ASD have an impairment in communication which ranges from profound comprehension problems and lack of speech to subtle pragmatic or functional use of language difficulties, such as failure to understand sarcasm or use of metaphor. A wide range of speech and language and communication assessments are available[56-58] but there is limited evidence to support the use of one assessment tool over another *(see annex 3 for communication, speech and language assessments)*. 3

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.**

☑ Practitioners should note that an individual's level of comprehension may be at a lower developmental level than that suggested by their expressive language skills.

Children and young people with ASD will have a range of impairments in intellectual, neuropsychological and adaptive skills. A wide range of assessments were included in the search strategy *(see annex 3)*. These are useful for individual profiling but are not diagnostic instruments.[59-64] Some impairments, such as "theory of mind"[62-64] and executive function[60] are not specific to autism, although they may be more severe in children and young people with ASD. The degree of impairment is also influenced by levels of speech and language, communication and verbal mental age. 3

Insights from these assessments may promote understanding by care-givers, therapists, education and social work staff in optimally supporting the child and young person with ASD to reach their potential.

"Theory of mind" is not a diagnostic marker for autism but relates to communication and linguistic development. It may be of value as part of an assessment to inform intervention. Verbal mental age should be taken into account to avoid over interpreting deficits in "theory of mind".

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

There was insufficient evidence to make recommendations about occupational therapy or physiotherapy assessments.

☑ Occupational therapy and physiotherapy assessments should be considered where relevant.

3.4 BIOMEDICAL INVESTIGATIONS

There is a range of potential biomedical investigations that may be appropriate for a child or young person with suspected ASD. These are carried out to aid diagnosis through establishing aetiology, to exclude treatable conditions, to identify comorbid conditions and to establish baseline information prior to starting treatment. The evidence does not support the use of routine magnetic resonance imaging (MRI) brain imaging.[71-73] Whilst epilepsy is common in children with ASD,[74] there is no indication for an electroencephalogram (EEG) in the absence of other clinical criteria.[75]

A fifth to a third of pre-school children with ASD have a history of regression in acquired language skills during their second year of life. A total loss of acquired language skills is associated with a high probability of autistic conditions when this occurs in children under the age of three.[76] When children undergo language regression over the age of three, they are more likely to experience seizures and the differential diagnosis should include consideration of an acquired epileptic dysphasia/Landau Kleffner dysphasia.[76] Other conditions such as Rett disorder may appear superficially similar to ASD[77] and other neurodegenerative conditions such as mitochondriopathies may need to be considered and investigated.[78] 3

Around 10% of children with ASD have an identifiable cause[65] such as tuberous sclerosis and genetic investigations may be helpful.[66-69] Clinical examination for dysmorphic features and the presence of a learning disability may aid in the decision to investigate further.[66,70] For these reasons, medical paediatric history and examination may indicate that further biomedical investigations are warranted. [70] 3

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** *(eg tuberous sclerosis, see annex 3)*.

There is considerable interest in the role of the immune system and the influence of bowel function in children and young people with ASD. An extensive search was carried out for research in this area, using the terms listed in annex 3. In addition a variety of additional investigations for children and young people diagnosed with ASD were considered (included within the list of investigations given in annex 3). The guideline development group found no research evidence of an acceptable level in support of the clinical use of these investigations, and it is not possible at present to make a recommendation.

3.5 CONDITIONS ASSOCIATED WITH ASD

Children with ASD can experience the full range of developmental, medical and mental health problems that are experienced by children who do not have ASD. It is as crucial to their development as to any other child's that all comorbid conditions are appropriately assessed and managed. Clinicians should not assume that any problems are inevitable aspects of an ASD, as many comorbid conditions benefit from careful assessment and management.

Equally, children with ASD that has not been recognised may initially present to clinical services with a separate problem, eg epilepsy, a sleep disorder, or school refusal.[79]

A case control study found no evidence that children with autism were more likely than children without autism to have had defined gastrointestinal disorders at any time before their diagnosis.[80] Parent-reported gastrointestinal symptoms, in particular frequent vomiting and constipation, were more common post-diagnosis in one study. Parents also reported higher rates of food selectivity.[81] 2+

Children and young people with ASD have higher rates of epilepsy[65, 82-84] visual impairment[65, 84] and hearing impairment.[84, 85] As these associations have been described in the main in children and young people with learning disabilities, the extent of the specific association across the ASD spectrum is uncertain. 2+

There are some clinical conditions which seem to occur more frequently in children and young people with ASD, regardless of intellectual ability. Children with ASD experience higher rates of mental ill health and behaviour problems.[86, 87] In particular, there is evidence that anxiety and depression[88-92] and attention deficit and hyperkinetic disorders (ADHD)[93, 94] are more common. 2+

Parent-reported sleep problems are more frequent in children and young people with ASD.[95-98] 2+

There is also evidence that neuromotor problems, such as clumsiness[99] and tics[94,100] are commonly experienced by children and young people with ASD. 2-

Children and young people with ASD display the same attachment behaviours as children who do not have ASD. However, children and young people with ASD are more likely to be insecurely attached, affecting their responsiveness in contact with care-givers.[101] 2+

☑ Healthcare professionals should recognise that children and young people with ASD may also have medical problems or emotional difficulties/disorders and should have access to the same range of therapeutic interventions as any other child.

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.**

3.6 PROGNOSTIC INDICATORS IN CHILDHOOD

Only the evidence for prognostic indicators in childhood was reviewed.

In one small study, early joint attention and imitation skills were found to be predictive of pre-school language levels.[102] High IQ and language skills at an early age were also found to predict better eventual outcome in communication and social competence domains,[103-107] although social impairments and repetitive behaviours[103] may persist. 2+

Improvements in adaptive behaviour and decline in atypical features have been reported for adolescents with ASD and a high IQ, with poorer outcomes evident in social impairment and social skills for young people with learning disability.[108, 109] 3

Around a quarter of young children with ASD are reported to have had regression of skills. Early language regression before three years of age, in children referred for paediatric neurology assessment,[76] or those referred for ASD assessment[110] has a high probability of being associated with an ASD diagnosis. The majority of children with ASD who are reported to regress have not had normal skills prior to the loss, and most are reported to subsequently regain the lost skills.[111] Regression does not appear to be associated with worse prognosis during pre-school years.[41,110] 2+

There have been no adequate studies of later childhood or adolescent onset regression and it is not clear whether the phenomena are clinically the same.

4 Principles of intervention

Following a diagnosis of ASD, children and young people, parents and carers, and professionals want effective interventions to be available and need information to help make decisions about what form these could take.

There are many different interventions and treatments for ASD in everyday use, some of which are not evidence based.[112]

In 2001, the Medical Research Council (MRC) review of autism research stressed the need for scientifically robust evaluations of interventions and treatments *(see annex 3)*, with a particularly urgent need to evaluate biomedical interventions.[3]

If interventions and treatments are not supported by systematic reviews or RCTs (level 1 evidence) they may not appear in the guideline. The interventions that were included in the literature searches completed for this guideline are listed in annex 3.

Following a baseline assessment, the potential balance of risks and benefits from any treatment or intervention needs to be considered for each individual child, and discussed as appropriate with them and their parents/carers, so that they can make an informed decision. Children and young people, their parents/carers and clinicians, should, as far as possible, plan how they intend to evaluate the benefits from any intervention. This will help them to make a decision about whether or not to continue after any trial period.

All children and young people are entitled to benefit from their education and have positive wider life experiences. ASD symptoms can constitute a significant barrier and psychoeducational interventions for ASD are employed in this context. Parents, educationalists, health professionals, social workers and the voluntary sector may employ pragmatic, eclectic, individualised interventions to optimise a child's functioning, by promoting development of skills, or adapting the environment to compensate when skills are not present.[113] Many of these approaches are based on theoretical principles germane to ASD. Some are derived from generic considerations such as visual support to communication, or behavioural approaches to reduce challenging behaviour. Others are derived from more autism specific considerations such as the difficulty in 'mentalising' experienced in ASD, whereby the individual experiences difficulties understanding the motivations and perspectives of others.[100] Where appropriate, the guideline comments on these interventions as good practice points, recognising that many are in use in everyday practice in the UK and have widespread practitioner support.

5 Non-pharmacological interventions

5.1 PARENT MEDIATED INTERVENTIONS

Parent mediated intervention programmes are used to both advance the development and communication of an affected child and to offer practical advice and support to parents (*see section 7.2.2 for further details*).[114-117]

A Cochrane review of parent mediated early intervention for young children (aged 1-6 years) with ASD was only able to identify a few small studies, which could not be directly compared. This review concluded that there are insufficient reliable studies from which to draw general conclusions.[118] 1++

A pilot randomised controlled trial (RCT) described an increase in reciprocal social interaction in young children but no effect on adaptive behaviour, when parent training was added to standard care.[119] 1+

A non-randomised controlled trial of a training course for parents of pre-school children with ASD using the Hannen more than words programme showed benefit in vocabulary development and parents' use of facilitative strategies.[120] 3

☑ Parent mediated intervention programmes should be considered for children and young people of all ages who are affected by ASD, as they may help families interact with their child, promote development and increase parental satisfaction, empowerment and mental health.

5.2 COMMUNICATION INTERVENTIONS

5.2.1 SUPPORT FOR EARLY COMMUNICATION SKILLS

Many children and young people with autism have little or no speech. Those who do have speech have difficulties in using language effectively (pragmatic language impairment). The manner in which this is manifest is influenced by the child's acquisition of language. Many of the strategies implemented to support communication are designed and managed by speech and language therapists, working in combination with a wide range of professionals and in partnership with parents. Parent led interventions incorporate features such as working on joint attention and communicative intent (*see section 5.1*). Alternative/augmentative communication is employed in day to day educational support.[113]

Interventions which offer visual support to communication found increases in spontaneous imitation and social communicative behaviour suggesting a focus for future research.[121, 122] The evidence for interventions supporting communication was heterogeneous with a small number of studies looking at different aspects, eg intelligibility,[123] reading and writing as a visual support to communication.[122, 124] 3

An RCT showed that clinician mediated early intervention supported the development of joint attention and symbolic play.[125] 1++

A randomised comparison of two interventions for pre-school children with ASD provided preliminary evidence that the effects seen on initiating joint attention depended on the child's existing level of ability.[126] 1+

D **Interventions to support communication in ASD are indicated, such as the use of visual augmentation, eg in the form of pictures of objects.**

☑ Interventions to support communication in children and young people with ASD should be informed by effective assessment.

5.2.2 INTERVENTIONS FOR SOCIAL COMMUNICATION AND INTERACTION

A number of studies were identified that assessed the efficacy of interventions to directly support social communication and interaction, eg visual timetabling, operationalising through short stories or the use of speech bubbles or cartoons. The number of participants in each study was very small and the study populations were heterogeneous, making it difficult to generalise from their findings.[127-136] 1-3

Although it is difficult to synthesise the evidence as it relates to many different facets, the interventions are linked to theories about underlying core deficits in ASD. They fall into a number of areas, eg offering additional support to verbal social initiations, eg tactile prompting, or visual reinforcement, to help children with autism acquire an alternative to a theory of mind. Studies also looked at peer training, to support the social interaction and communication of the child with ASD and "buddy" programmes that aim to elicit more appropriate social skills in students with autism, in comparison to a passive proximity approach.

The evidence does not clarify which of these approaches is the most effective but many of them are currently in everyday educational use for children with ASD.

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.**

☑ Adapting the communicative, social and physical environments of children and young people with ASD may be of benefit (options include providing visual prompts, reducing requirements for complex social interactions, using routine, timetabling and prompting and minimising sensory irritations).

5.3 BEHAVIOURAL/PSYCHOLOGICAL INTERVENTIONS

Behavioural and other psychological interventions for ASD may be divided into three main groups:

- intensive behavioural programmes aimed at improving overall functioning and altering outcome
- interventions which aim to address specific behavioural difficulties associated with ASD, such as sleep disturbance, or to increase positive behaviours such as initiating social contact with peers
- a range of other behavioural/psychological interventions which do not fall readily into the other two groups *(see section 5.5)*.

5.3.1 INTENSIVE BEHAVIOURAL PROGRAMMES

Most intensive behavioural programmes for ASD are based on the principles of behaviour modification using applied behavioural analysis (ABA). These programmes are intensive, usually involving 20 to 40 hours of intervention per week. Their focus is primarily on early intervention with pre-school children, and they are often parent mediated, with support from helpers and professional consultants. The best known of the intensive ABA interventions is the Lovaas programme. [137, 138]

The Lovaas programme was the only intensive behavioural intervention examined by a systematic review.[139] The review confined itself to the question of whether this intensive behavioural intervention for pre-school children with ASD could achieve normalisation (interpreted as the capacity to follow a normal academic curriculum in a mainstream school). All studies included in this review were marked by considerable methodological flaws and there was also a concern that many had enrolled high functioning children with autism, making it difficult to generalise from the conclusions. The review concluded that a causal relationship cannot be established between a particular programme of intensive behavioural intervention and the achievement of 'normal functioning'. 1++

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

A comprehensive literature search, based on the terms in annex 3 did not find any good quality evidence for other intensive behavioural interventions.

5.3.2 INTERVENTIONS FOR SPECIFIC BEHAVIOURS

The possibility that specific skills deficits or sensory problems are contributing to particular behaviour patterns should be investigated prior to initiating any interventions.

One systematic review examined 251 studies of focal treatments for children and young people with ASD. Although the studies varied considerably in their quality, the review concluded that focal behavioural interventions consistently result in positive behavioural outcomes across a wide range of target areas.[140] These include aberrant behaviours (eg self-injury, aggression), language skills, daily living skills, community living skills (eg public transportation and shopping skills), academic skills and social skills. 2++

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

☑ Healthcare professionals should be aware that some aberrant behaviours may be due to an underlying lack of skills and also may represent a child's strategy for coping with their individual difficulties and circumstances.

5.3.3 AUDITORY INTEGRATION TRAINING

Auditory integration training (AIT) is offered to children with ASD on the premise that they experience "discomfort" when listening to certain sound frequencies. In AIT the subject listens to modulated music tapes through headphones for specified time periods. Two systematic reviews of the intervention were identified.[141, 142] Two thirds of the studies showed no benefit. An RCT showed no benefit conferred by AIT compared to listening to unmodulated music. [143] 1++

A **Auditory integration training is not recommended.**

5.3.4 MUSIC THERAPIES

Two well conducted systematic reviews were identified.[144,145] Due to the methodological limitations of the studies included in the systematic reviews, the limited number of studies and the lack of clinically relevant outcomes, there is insufficient evidence to make a recommendation about the use of music therapy in ASD. 1++

5.3.5 SLEEP PROBLEMS

By the age of one year most children are able to sleep through the night. If after this time a child is regularly unable to sleep, or has a period of good sleep which is disrupted, then this constitutes a sleep disorder. Sleep disturbance is reported to be a common problem for children and young people with ASD. The benefits of therapy to improve sleep problems have only been assessed in a small study of children with autism and fragile X syndrome, where it was shown to have a benefit.[146]

☑ Behavioural therapy should be considered for children and young people with autism who experience sleep disturbance.

5.3.6 OCCUPATIONAL THERAPY

The available studies were insufficient to support an evidence based recommendation about occupational therapy for ASD, including the use of particular interventions such as sensory integration.

☑ Children and young people affected by ASD may benefit from occupational therapy for generic indications, such as providing advice and support in adapting environments, activities and routines in daily life.

5.3.7 FACILITATED COMMUNICATION

Facilitated communication is defined by the American Psychological Society as "a process by which a facilitator supports the hand or arm of a communicatively impaired individual while using a keyboard or typing device."

Two systematic reviews of facilitated communication conclude that there is no evidence to validate claims that the person with autism is being helped to communicate, although there is extensive evidence of communications that are generated by the 'facilitator'.[147, 148] Given the ethical implications of these findings in relation to the integrity and dignity of children and young people with autism, the American Psychological Association has passed a resolution against the use of facilitated communication for people with ASD on ethical grounds. [149] 1++

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

5.4 BIOMEDICAL AND NUTRITIONAL INTERVENTIONS

Research into biomedical interventions, including diets and nutritional supplements, has been identified as a key priority for members of the National Autistic Society.[150] The list of potential biomedical interventions searched for in this guideline in given in annex 3.

A well conducted Cochrane systematic review was unable to identify an evidence base for or against casein and gluten exclusion diets.[151] Results of a subsequent, preliminary double blind clinical trial suggest that exclusion diets appear to have no significant benefits for children with ASD, although the authors acknowledge limitations.[152] There is insufficient evidence on the use of casein and gluten exclusion diets for children and young people with ASD and therefore no recommendation can be made. 1++ 1+

As with all children and young people, nutritional interventions may be required for children and young people with ASD who also have significant food selectivity and dysfunctional feeding behaviour (*see section 8.4.3 for details of how to contact the British Dietetic Association*).

A Cochrane systematic review of combined vitamin B6 and magnesium treatment for children and young people with ASD found insufficiently robust studies to meet the criteria set for the review and therefore no recommendation can be made.[153] 1++

☑ Gastrointestinal symptoms in children and young people with ASD should be managed in the same way as in children and young people without ASD.

☑ Advice on diet and food intake should be sought for children and young people with ASD who display significant food selectivity and dysfunctional feeding behaviour, or who are on restricted diets that may be adversely impacting on growth, or producing physical symptoms of recognised nutritional deficiencies or intolerances.

5.5 INTERVENTIONS FOR SPECIFIC GROUPS OF CHILDREN AND YOUNG PEOPLE

There was little evidence to inform the question of whether or not any specific dietary/non-pharmaceutical interventions are more appropriate for children with specific forms of ASD, or particular types of comorbidity.

Cognitive behaviour therapy (CBT) has been shown to be feasible in children with ASD who have a verbal IQ of at least 69.[154] However, this systematic review was unable to draw reliable conclusions about the effectiveness, or potential harm, of CBT in this group. 1++

☑ Professionals should be aware that some interventions require a level of verbal and cognitive development which precludes their employment with some groups of children and young people with ASD.

6 Pharmacological interventions

6.1 GENERAL PRINCIPLES

Any pharmacological treatment considered for children and young people with ASD should not be viewed in isolation but seen as a possible component of a multistranded package of care.

There are no controlled long term studies demonstrating that pharmacological interventions affect the core difficulties or outcomes in children and young people with ASD. There is no evidence directly comparing pharmacological and non-pharmacological approaches.

Pharmacological treatment may be considered when appropriate, for treatment of comorbid psychiatric or neurodevelopmental conditions in ASD. Pharmacological treatment may also be considered as a short to medium term intervention for specific severe symptoms occurring in children and young people with ASD. Treatment for other comorbid medical conditions, eg epilepsy, which may be required for children and young people with ASD, is not further discussed in this guideline (see SIGN guideline 81 diagnosis and management of epilepsies in children and young people).[155]

Only medications available in the UK are discussed. No pharmacological treatments have ASD as a licensing indication, and there are few drugs specifically licensed for use in children and adolescents.

An assessment of the need for pharmacological intervention should include an appraisal of the child's environment (school and home) and daily routines (eg sleep, daily activities, meals etc). Changes in these areas may be worth attempting before using medication, and are likely to complement the effects of medication, if it is appropriate for this to be prescribed. It is possible that treatment of comorbid difficulties with medication may enhance the ability of children and young people to benefit from other approaches. There have as yet been no systematic studies of combining other interventions and medication.

6.1.1 FRAMEWORK FOR USE OF MEDICATION

The potential balance of risks and benefits from any pharmacological treatment needs to be considered for each individual child, and discussed as appropriate with them and their parents/carers, so that they can make an informed decision.

If a trial of pharmacological treatment is agreed, there should be careful pre-treatment assessment of the child's overall symptoms and functioning, and definition of the 'target symptoms', ie those expected to respond to the drug, as far as possible. There should be agreement about how symptoms and any emergent side effects of treatment will be measured, as well as the monitoring arrangements and expected duration of any trial of medication. Children and young people, their parents/carers and clinicians, should, as far as possible, plan how they intend to make a decision about whether or not to continue with medication, after any trial period.

☑ Pharmacological treatment of children with ASD should only be undertaken by doctors with appropriate training and access to pharmacy or other support as required.

6.2 RISPERIDONE

Risperidone in low doses (up to 2 mg daily in children weighing up to 45 kg and up to 3.5 mg daily in those weighing over 45kg)[156] may be helpful in reducing severe irritability and aggression in children or young people who have autistic disorder and significant aggression, tantrums or self injury. Effects persisted at six months, but not after medication was discontinued.[157] Scores on repetitive/stereotyped behaviours were reduced but there was no effect on core social deficits.[158] Similar findings were reported in a separate though less robust trial.[159] In both these trials the majority of patients had learning disability. Adverse effects (most commonly tiredness/sedation early in treatment and increased appetite and weight gain) occurred more often with risperidone.[159, 160] A small blinded discontinuation trial in a group with ASD where two thirds were of normal intellectual ability indicated a possible effect of risperidone on severe aggression, tantrums and self injurious behaviour.[161] 1+

Weight gain may be a significant problem at daily doses of 2 mg and lower.[156, 162, 163] There is no evidence that any specific variables predict weight gain.[164]

Liver function tests do not appear to be significantly affected by up to 12 months treatment with risperidone.[163-165]

In young children (under 10 years) with ASD, raised prolactin levels without obvious clinical effects, have been associated with short term (three months) risperidone treatment.[166-168] Levels fell by 24 weeks in the only study where measurement was repeated.[166] No data are available for older children or adolescents. The implications of raised prolactin levels are unknown.

B
- **Risperidone is useful for short term treatment of significant aggression, tantrums or self injury in children with autism**
- **Weight should be monitored regularly in children and young people who are taking risperidone.**

☑ Doctors should inform young people and parents that prolactin levels may rise in association with risperidone treatment and that the implications of this are unknown.

6.3 METHYLPHENIDATE

There is evidence that methylphenidate reduces hyperactivity in children up to 14 years with ASD and comorbid ADHD (with a mean IQ in the learning disability range).[160] This finding is supported by clinical experience/expert opinion about the use of stimulant medication in children with ASD and attentional/hyperactivity problems (see SIGN guideline 52 on attention deficit and hyperkinetic disorders in children and young people).[171] Adverse effects (difficulty falling asleep, appetite decrease, irritability and emotional outbursts) were more common in children receiving methylphenidate compared to those on placebo.[160] In one study from a specialist paediatric clinic, response to methylphenidate and level of side effects were not significantly different in children with ADHD and ASD compared with children with ADHD alone.[169] The use of a test dose is worthwhile to assess whether methylphenidate will be tolerated.[160, 170] 1+ 4

There is no evidence about the use of other stimulant medication for these problems in children and young people with ASD. If methylphenidate is not tolerated use of other medication could be considered with reference to SIGN guideline 52 on attention deficit and hyperkinetic disorders in children and young people.[171]

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

☑
- Use of a test dose to assess if methylphenidate is tolerated could be considered in children prior to any longer trial.
- Side effects should be carefully monitored *(see SIGN guideline 52 on attention deficit and hyperkinetic disorders in children and young people)*.[171]

6.4 FLUOXETINE

A single RCT indicated statistically significant but small clinical benefit from fluoxetine on repetitive behaviours in children and young people with ASD. Side effects were similar to placebo.[172] 1+

A case series of young children with ASD treated with fluoxetine found parent reported response correlated with associated features including parent reported family history of affective disorder.[173] 3

There is insufficient evidence to make a recommendation about the use of fluoxetine.

6.5 NALTREXONE

All studies related to children less than eight years of age and naltrexone did not improve symptoms of ASD.[174-177] 1+

6.6 SECRETIN

Secretin (human or porcine) as a single dose, or in multiple doses, for up to six months does not improve ASD symptoms, and no subgroup of children who benefit has been consistently identified.[178-187] 1++

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

6.7 MELATONIN

Melatonin is not licensed as a medication in the UK, although it is in clinical use to treat sleep problems in children and young people with ASD or other developmental difficulties.

In typically developing children there is some evidence that melatonin improves sleep difficulties which have persisted after behavioural treatment.[188-190]

For developmentally disabled children (only a very few of whom had ASD), there is evidence that melatonin is tolerated but it is not clear if it is of any benefit.[191, 192] 3

One small RCT including limited diagnostic and clinical information suggested that melatonin improves sleep in children with autism.[193] 1+

An uncontrolled study indicated melatonin was tolerated in children and young people with Asperger's syndrome.[194] 3

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

☑ Obtain an adequate baseline sleep diary before any trial of melatonin.

- Continue sleep hygiene measures (bedtime and wake up routine, avoidance of day time sleep) and a sleep diary, during any medication trial.
- Ensure patient and family are fully informed that melatonin is not a licensed medication, which limits the information that is available about effectiveness and safety.

6.8 OTHER TREATMENTS

There is insufficient good quality evidence to make recommendations on the use of the following drugs, amantadine, (a single small RCT indicated possible benefit on investigator, but not parent rated, measure of hyperactivity[195]), cyproheptadine as an adjunct to haloperidol (high risk of side effects)[196] or divalproex sodium.[197, 198]

For the following drugs single RCT evidence does not indicate benefit: clomipramine (high rate of side effects),[199] lamotrigine (in children under 11),[200] vancomycin (outcome measured two to eight months after course of treatment in children with regressive autism).[201]

Observational studies only have been completed for aripiprazole, citalopram, fluvoxamine, guanfacine, olanzapine, quetiapine, sertraline or venlafaxine.

Sertraline is licensed for treatment of obsessive compulsive disorder (OCD) in children and adolescents, and its use may be relevant in children or young people with ASD who have comorbid OCD. The diagnosis may be difficult as compulsive behaviours are common in ASD. Some children do have evidence of more typical OCD features with repetitive thoughts or behaviours which appear to them as senseless and are, at least to some extent, resisted. The possibility of benefit at a low dose of sertraline and worsening at a higher dose was indicated in a single very small descriptive study of anxiety symptoms in children with ASD.[202]

7 Service provision

7.1 ASD TRAINING

Despite the increasing awareness of, and interest in, the nature of ASD, there are considerable gaps in training for professionals working with children and young people with ASD. This results in a lack of knowledge, skills and expertise across all general and specialist professional groups.[203-209]

The small body of evidence on training in ASD points to improvement in attitudes of mainstream teachers towards the inclusion of children with ASD in their classes,[203, 208, 210] increased levels of confidence of parents in relation to service provision[1] and in benefits in knowledge for medical staff from evidence based educational intervention.[211] 4

The PHIS Autistic Spectrum Disorders Needs Assessment Report viewed improved training as vital to many of its proposals, and recommended that there should be a review of training provision in Scotland.[1] Consequently, an extensive audit of existing training and training needs was undertaken, leading to the publication of the National Training Framework for Autistic Spectrum Disorders.[9]

The framework highlighted major gaps in training at every level and across every sector. For most practitioners there was no pre-service training and the majority of training that was undertaken was introductory only, even for those whose work was mainly in the ASD field. Subsequent work resulted in the creation of a web-based learning resource for primary care practitioners www.nes.scot.nhs.uk/asd

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

7.2 TRAINING AND SUPPORT FOR PARENTS

7.2.1 INFORMATION PROVISION

A limited amount of evidence was identified where either outcomes were not described in terms of parent satisfaction,[212] there was no information on the diagnostic tool used to define the children,[213] or the number of participants in the study was not clear. [214]The principles that emerged were that parents felt more satisfied if at the time of disclosure they were given good quality written information, with an opportunity to ask questions[213] and that parents value a multidisciplinary diagnostic assessment.[214] 4

D
- **Professionals should offer parents good quality written information and an opportunity to ask questions when disclosing information about their child with ASD**
- **Parents should be provided with information in an accessible and absorbable form.**

☑ The information provided should relate to the child or young person's particular ASD presentation.

7.2.2 MEETING SUPPORT NEEDS

Families with children with autism often experience high stress levels as a consequence of their care giving responsibilities, the child's cognitive impairment and the need for long term support.[215-218] 4

Education and skills interventions have been shown to lead to significant improvements in the self reported mental health of parents of pre-school children.[116] 1+

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

☑ Education and skills interventions should be offered to parents of all children and young people diagnosed with ASD.

Informal social supports are important to absorb family stress.[219, 220] It is important to consider the needs of siblings of children and young people with ASD. Supporting parents through provision of training in communication with their children[215] is discussed in section 5.1.

☑ Professionals should assess the family context and informal support systems that are available and consider supplementing these as appropriate.

7.2.3 SUPPORT DURING TRANSITION

Transitions, at all stages from pre-school to adulthood, are recognised as posing challenges for children and young people with ASD. However, available evidence is very limited. A single study was identified in which telephone interviews with parents were used to capture their perceptions of transition and the support needed. [221] Parents reported that increased social work contact with families during periods of transition was valued.

Professionals should be aware that difficulties with transition may arise because the high level of support being provided prior to a transition was unrecognised. Reassessing support needs and planning ahead prior to a transition may allow appropriate new support to be put in place.

Although individual support needs will vary, some basic aspects may be generally applicable. For example, a survey of supervisors of adults with ASD employed within a supported work environment, indicated the support strategies used were based on principles largely applicable to all young people, including clear guidance, mentoring and regular reviews.[222] 4

In the Scottish legal context, 'parental responsibility' ends when a young person reaches the age of 16. If parents wish to continue to be involved in decisions about their child's medical treatment, ie to be in a position to give consent or take decisions on behalf of their children beyond age 16, they can do so only by acquiring the relevant authority under the Adults with Incapacity legislation.

☑ Families and services should plan ahead to reduce the impact of transitions.

☑ Social work contact with families should be instituted or extended during periods of transition.

☑ Families should be advised of relevant legislation under the Adults with Incapacity Act (Scotland).

7.3 TIMING OF INTERVENTIONS

No evidence to guide service provision was identified regarding the optimum timing of interventions. No robust evidence was found to support the benefits of early intervention or to suggest that late intervention may not be worthwhile. Some types of intervention are more appropriate at different developmental stages (*see sections 5 and 6*).

☑ Interventions should commence as soon as possible after concerns are identified.

7.4 MODELS OF SERVICE PROVISION

No evidence was identified to indicate whether a particular model of service provision was more effective in improving outcomes for children and young people with ASD. There appears to be a consensus in the literature that the involvement of a range of professionals is important and that the competencies of those professionals are more important than their professions as such. There appears to be agreement on the need for multiagency involvement. This is particularly relevant given the situation with regard to legal responsibilities, where for example, additional support for learning (ASL) provision is an educational responsibility and disability assessment is the responsibility of social services.

There is a danger that a piecemeal approach is taken to the delivery of services to individuals over the course of their lifetime. As a result, particularly in regard to periods of transition, there should be multiagency life long planning.

In response to the PHIS assessment report,[1] the Scottish Executive has published an implementation report[223] which includes a quality diagnostic service standard for children and adults with autistic spectrum disorders. This is available at www.scotland.gov.uk/Publications/2006/02/28094616/11

8 Information for discussion with children, young people, parents and carers

This section reflects the issues likely to be of most concern to children, young people and their parents and carers. These points are provided for use by health professionals when discussing ASD with children, young people and their parents and carers and in guiding the production of locally produced information materials.

8.1 PROVIDING INFORMATION AND SUPPORT

Provision of information should always be viewed as a two way process. The concerns and questions which children, young people and their parents/carers wish to raise should be identified during assessment, and be responded to as far as possible. There is evidence to suggest that parents are more satisfied if they are given good quality information and have the opportunity to ask questions. [213, 224]

8.1.1 AT THE TIME OF DIAGNOSIS

Information on the diagnostic process and the roles of children, young people and parents should be explained along with information on the roles of the various professions involved. Parents need to have their early concerns acknowledged and to receive support in the management of their child.[213, 225-227]

It is essential that parents of children diagnosed with ASD, and children and young people themselves, receive clear, accurate and appropriate written and verbal information about the condition including short and long term consequences. The information should be appropriate to the child's age, ability level and cultural background and should be provided at a pace that suits the circumstances.

Where feasible and appropriate childcare should be made available for a short time during disclosure of the diagnosis. This would allow parents to focus fully on the information being given and allow for questions.

Consideration should be given to how the diagnosis should be shared. This may require seeing children, young people and parents separately, sequentially or simultaneously. For young people their own engagement and understanding of the diagnosis will be important in negotiating appropriate supports.

It is recognised that this is a particularly stressful period for children, young people and their parents and links forged with local professionals at this time can be helpful following diagnosis.

Surveys of parents reported the importance placed on the quality of the communication skills of the professionals disclosing the diagnosis.[213, 225-227]A negative experience could affect parental satisfaction and cause added stress. Healthcare professionals should be aware that the absence of clearly defined terminology and uncertainty of diagnosis is difficult for parents. This can be challenging when young people have a mixture of difficulties. Where a diagnosis can be clearly made the use of straightforward terminology in communication to parents is important. When the diagnosis is uncertain (ie borderline according to current diagnostic criteria) then healthcare professionals should explain this situation to parents. In all circumstances healthcare professionals should work with the family to identify how services can meet the needs of the child.

Children, young people and their parents should have the opportunity to ask questions following the diagnosis. It has previously been recommended that follow-up arrangements should be offered once there has been time to reflect on the implications of the diagnosis.[1]

Professionals should recognise that children, young people and their parents may have a significant adjustment reaction to the diagnosis and for some this adjustment period may be prolonged and difficult.

ASD affects all aspects of the child's and the family's life and the importance of social supports and family networks were noted.[215, 219, 220, 226, 228] Families are required to take on multiple roles when their child is diagnosed including at times, the roles of co-therapist, and advocate. Supporting family involvement in these roles is crucial and will impact on the success of any intervention.

A number of studies comment on the issue of encouraging families to participate in any decisions related to their child and the importance of feeling that their opinions are valued.[213, 225-227]

☑ Families require high quality verbal and written information at time of diagnosis. This should include a written report of the outcome of the various assessments and the final diagnosis.

The sample checklist in section 8.3 suggests the type of information required.

☑ Professionals involved in diagnostic disclosure and information giving should receive ongoing education and training.

☑ Children, young people and their parents should routinely receive written information. This may include copies of the letters sent to the various professionals who have been asked to assess their child.

☑ Children, young people and their parents should be encouraged to continue to learn about ASD and useful interventions and support.

8.2 FEEDBACK FROM FOCUS GROUPS

Young people with ASD may themselves make use of this guideline, and it was felt important to obtain as much input from them as possible, in addition to the information provided via parents and professionals, during the work of the guideline development group. Focus group sessions involving an independent facilitator and young people were held in two centres, in different regions of Scotland.

In keeping with the goal of 'ASD friendly services', the aim of the focus groups was to hear how young people themselves understood or heard of their diagnoses, to explore what they had found helpful and to ask for their ideas about information about ASD which should be provided.

The young people who took part were a selected sample without learning disability, who knew about their diagnoses of ASD, were of late primary or secondary school age, and were attending specialist educational provision (relevant permission having been obtained). In one centre four young people were seen individually by the independent facilitator, and in the other eight young people met with the facilitator in two small groups. The young people were asked about their diagnosis and how they had been told about it, what was better or worse for them once they knew, what they found helped them, and what they thought others should be told about ASD.

Young people referred to difficult experiences prior to diagnosis, and in their previous schools, including bullying. Most young people wanted to be told the truth and spoke of things being better once they knew what was wrong. The young people thought others should understand and not make fun of them, and often said things were easier when they where in a school where ASD was understood. They thought it was important to know that they were not 'mad' or 'stupid'. The kind of difficulties which they would want others to know about, or be told, included that they needed space, got confused, might lose their patience, found it hard to concentrate, and needed a quiet place to go. Some had read relevant books about ASD and found them helpful, and there were also comments that it would be easier to speak to someone with ASD.

Young people able to contribute to these focus groups were obviously a selected sample but their perspectives emphasise the importance of young people being involved in discussion about diagnosis at some appropriate stage, and being able to contribute to the information others receive about their individual difficulties.

8.3 CHECKLIST FOR PROVISION OF SERVICES AND INFORMATION

This section explains what information parents/carers, and the child or young person as appropriate, can reasonably expect to be provided at the key stages of the patient journey and how assessment and intervention should usually be organised (*see sections 3.2 to 3.6 for more discussion of the evidence base*).

The checklist was designed by members of the guideline development group based on their clinical experience and their understanding of the evidence base.

Checklist for provision of services and information

Before assessment	
Initial professional concerned should: (*eg health visitor, teacher, GP*)	▪ explain to child/young person and parent/carer that a child/ young person's behaviour shows various 'clinical clues' that may suggest the possibility of an autism spectrum disorder or a social interaction or social communication difficulty (see Tables 1,2 and 3) ▪ discuss the advantages and disadvantages of further assessment with the parent/carer (and young person, as appropriate) as they see it and check that they have agreement to organise this ▪ healthcare professionals should enquire about any other information which might represent evidence of comorbidity (eg ADHD, depression) or an alternative diagnosis (eg specific language impairment) as far as their expertise allows
Person making referral for further assessment should:	▪ include all relevant information regarding any concerns, the child/ young person's current situation and details of any professionals involved ▪ explain the patient/parent's understanding of the reason for referral ▪ consider providing patient/parent with a copy of the referral letter ▪ initiate general management/behaviour strategies and family support in the interim, if necessary by involving multiagency colleagues
The specialist team receiving the referral should:	▪ ensure child/ young person and parents receive information about the process which will follow referral, including likely timescale of any pre-assessment and assessment phases, and who will be involved ▪ if corresponding with professional colleagues to arrange assessments, consider copying correspondence to families ▪ inform the parent/carer that they are welcome to bring a supporter if they wish ▪ explain that, if any part of the assessment is to be video recorded, the team will obtain written consent of the patient and/or carer (as appropriate) to retain the recording

At assessment appointment(s)	
Specialist team should:	▪ check current understanding of child/ young person and parents/ carers, as appropriate, about the reasons for referral and their level of agreement with the concerns of the referring professional ▪ explain proposed assessments and agree with child/young person and parent/carer how these will be organised and which colleagues will be involved ▪ repeat explanations and revise arrangements as needed
At any feedback appointment(s)	
Specialist team should:	▪ allow sufficient time for explanation and discussion of the findings and be sensitive to the potential distress that may arise in the child/ young person and parent/carer and their possible needs to be seen separately ▪ find out what child/young person and family understand about diagnosis, and add information as appropriate (eg if a diagnosis of ASD has been made, a member of the team should explain the triad of impairments and how the referred patient's presentation fits into ICD-10/DSM-IV criteria) ▪ offer basic information based on current knowledge re causation, intervention and prognosis, any investigations indicated, and the probable next steps to provide appropriate multiagency supportive intervention, as appropriate ▪ provide information about what written feedback will be made available, and check with the child/ young person and parent/ carer (as appropriate) how it should be made available to relevant colleagues ▪ if any part of the assessment has been video recorded, obtain written consent of the parent/carer and patient (as appropriate) to retain the recording ▪ if the patient is considered unable to have the outcome of the assessment explained to them at feedback, discuss with parent/carer how this might be undertaken at a later date and the best timescale ▪ in cases of diagnostic uncertainty, discuss with the parent/carer how and when to best review/repeat the assessment, or options for further specialist assessment

Supportive intervention following diagnosis of ASD	

Multiagency/ multiprofessionals should: (*integrated and collaborative and in partnership with the family*)	▪ involve relevant multiagency colleagues (education, social work, voluntary sector, careers advisors, as appropriate)
	▪ tailor intervention to requirements of individual and family, working in partnership
	▪ provide further information as needed eg about the triad of impairments or any comorbidity
	▪ consider implementing specific therapeutic interventions/approaches including for any comorbidity
	▪ discuss potential educational approaches with the parent/carer and patient (as appropriate), including additional support for learning
	▪ have in place arrangements for liaising/sharing required information with education services
	▪ discuss wider family/sibling support, provision of respite, and role of social work assistance
	▪ provide information about :
	  ▪ entitlement to benefits
	  ▪ potential voluntary/community supports
	  ▪ available parent training opportunities
	  ▪ recommended sources of further information
	▪ organise for the family to have a named contact for ongoing assistance (consider implementing *National Autism Plan for Children's recommendation of a key worker*). [2]

8.4 SOURCES OF FURTHER INFORMATION

Useful sources of general information on autism spectrum disorders including contact details for local parent support groups across Scotland.

8.4.1 SUPPORT ORGANISATIONS

The Scottish Society for Autism
Hilton House
Alloa Business Park
Whins Rd
Alloa
FK10 3SA
Tel: 01259 720044
Email: autism@autism-in-scotland.org.uk
Website: www.autism-in-scotland.org.uk

National Autistic Society –Scotland
Central Chambers
109 Hope St
Glasgow
G2 6LL
Tel: 0141 221 8090
Email: autismhelpline@nas.org.uk
Website: www.autism.org.uk

NHS Education for Scotland
NES has developed, in conjunction with the University of Birmingham, a learning resource about ASD for primary care professionals, including GPs. This includes a web resource and downloadable leaflets, accessible from www.nes.scot.nhs.uk/asd

NES also has an information booklet for parents and carers of recently diagnosed children or young people. Professionals living in Scotland who are involved in diagnosing ASD have been given copies of this booklet to give to parents. Additional copies can be requested from the Scottish Autism Service Network by calling 0141 950 3072 or by emailing scottishautismnetwork@strath.ac.uk

Scottish Autism Service Network
The Scottish Autism Service Network is a professional network for autism in Scotland. The network will support networking and an information hub.
Tel: 0141 950 3072
E-mail: scottishautismnetwork@strath.ac.uk
Website: www.scottishautismnetwork.org.uk/

8.4.2 ADDITIONAL READING

This reading list is not meant to be comprehensive and some books may endorse treatments that are not recommended by the guideline.

The autistic spectrum. A guide for parents and professionals
L Wing. Constable. (1996)

A mind apart. Understanding children with autism and Asperger's syndrome
P Szatmari. Guilford Press. (2004)

Autistic spectrum disorders: Good practice guidance. Department of Education and Skills.
DfES Publications, Sudbury, Suffolk CO10 6ZQ
www.teachernet.gov.uk/wholeschool/sen/asds

Explaining the enigma
U Frith. Blackwell Publishing. (2003)

People with autism behaving badly. Helping people with ASD move on from behavioural and emotional challenges. J Clements. Jessica Kingsley Publishers (2005)

For parents of younger children

Autism: How to help your young child.
Leicestershire County Council and Fosse Health Trust (1998)

Autism in the early years. A practical guide.
V Cumine, J Leach and G Stevenson. David Fulton Publishers (2000)

Sleep Better! A Guide to Improving Sleep for Children with Special Needs.
VM Durand. Jessica Kinsley Publishers (1998)

Toilet training for individuals with autism & related disorders. A comprehensive guide for parents and teachers.
M Wheeler. Jessica Kingsley Publishers (1999)

Can't eat, won't eat; dietary difficulties and autistic spectrum disorders.
B Legge. Jessica Kingsley Publishers (2001)

Sensory perceptual issues in autism & Asperger syndrome.
O Bogdashina. Jessica Kingsley Publishers. (2003)

Books for siblings

Everybody is different. A book for young people who have brothers and sisters with autism.
F Bleach. The National Autistic Society. (2001)

Can I tell you about Asperger syndrome? J Welton. Jessica Kingsley Publishers (2003)

Personal accounts (autism)

George and Sam.
C Moore. Penguin Publishers (2004).

Through the eyes of aliens. A book about autistic people.
JL O'Neil. Jessica Kingsley Publishers. (1999)

Emergence labeled autistic
T Grandin. Warner Books. Arena Press (1986)

For parents of older children/adolescent age

Understanding and working with the spectrum of autism
W Lawson. Jessica Kingsley Publishers. (2001)

The Complete Guide to Asperger's Syndrome.
T Atwood. Jessica Kingsley Publishers. (2006)

Aperger syndrome. A practical guide for teachers.
V Cumine J Leach and G Stevenson. David Fulton Publishers (1998)

Asperger syndrome and adolescence. Helping preteens and teens get ready for the real world.
T Bolick. Fair Winds Press (2004)

A parent's guide to Asperger syndrome and high functioning autism
Ozonoff, Dawson and McPartland. Guildford Press (2002)

Autism and Asperger Syndrome: Preparing for adulthood. Second edition
Patricia Howlin. Routledge (2004)

Transitions

Transition toolkit. A framework for managing change and successful transition planning for children and young people with ASD.
K Broderick & T Mason-Williams. BILD publications (2005)

Succeeding in college with Asperger syndrome. A student guide.
J Harpur. M Lawlor and M Fitzgerald. Jessica Kingsley Publishers. (2004)

Personal accounts (Asperger's syndrome)

Martian in the playground.
C Sainsbury. Lucky Duck Publishing. (2000)

Pretending to be normal
L Holliday-Willey. Jessica Kingsley Publishers. (1999)

Eating an artichoke.
E Fling. Jessica Kingsley Publishing (2000)

Freaks, Geeks and Asperger Syndrome. A user guide to adolescence.
L Jackson, Jessica Kingsley Publishers. (2002)

8.4.3 WEBSITES

British Dietetic Association

Provides a range of fact sheets in relation to diet including diet and autism spectrum disorders.
www.bda.uk.com

Careers Scotland
Provides services, information and support to individuals at all ages and stages of planning a career.
www.careers-scotland.org.uk

Enquire
The Scottish advice service for Additional Support for Learning.
www.enquire.org.uk

www.autism.org.uk
The NAS website is extensive, comprehensive and easy to use. Includes information on parent training and support programmes, EarlyBird and Help!

www.asd-forum.org.uk
Asperger and ASD UK Online Forum. Well supported, well organised Internet support group with email discussion and bulletin boards for sharing information.

www.dwp.gov.uk/lifeevent/discare
Information on benefits and disability living allowance.

Skill Scotland
An information and advice service for young people and adults with any kind of disability in post-16 education training and employment.
www.skill.org.uk/scotland

HM Inspectorate for Education
Improving Scottish Education. Education for Pupils with Autism Spectrum Disorders 2006
www.hmie.gov.uk/documents/publication/epasd.pdf

9 Implementation, resource implications and audit

9.1 LOCAL IMPLEMENTATION

Implementation of national clinical guidelines is the responsibility of each 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.

9.2 RESOURCE IMPLICATIONS

Group members identified the following recommendations which may have resource implications for NHSScotland.

From section 3.2.3

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

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

The use of such instruments requires training for staff. At present the availability of such training courses is limited. Resources are required for trainers, attendance at courses and updates, training materials and equipment for ADOS-G (kit cost £1300, training pack £700).

From section 3.2.3

D **Health care professionals should directly observe and assess the child or young person's social and communication skills and behaviour.**

From section 3.4

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** *(eg tuberous sclerosis, see annex 3)*.

From section 3.5

C **Clinicians 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.**

Implementation of these recommendations is likely to require local services to look at the organisation of child and adolescent services to ensure that relevant investigations and assessments are undertaken for all children with ASD. In some areas this may lead to a requirement for additional sessions of some staff groups, such as those providing cognitive assessment, to avoid an effect on waiting times for patients with other conditions.

From section 3.3

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

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

From section 5.2

D **Interventions to support communication in ASD are indicated, such as the use of visual augmentation, eg in the form of pictures of objects.**

From section 5.2.2

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.**

From section 5.3.2

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

These recommendations may require additional sessions from speech and language therapists and clinical psychologists in some areas of Scotland. This may have a resultant effect on waiting times for patients with other conditions.

From section 7.1

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

Implementation of this recommendation is likely to require resources for trainers, attendance at courses and updates and training materials and equipment.

9.3 KEY POINTS FOR AUDIT

The following clinical indicators could be used to gauge the assessment and management of children and young people with ASD:

- referral routes for diagnosis of ASD, eg the number of children recommended for further assessment following child health surveillance, the use of CHAT or M-CHAT to identify clinical features indicative of an increased risk of ASD
- diagnostic criteria, and procedures used for diagnosis of ASD, eg the number of professionals using either ICD-10 or DSM-IV when making the diagnosis of ASD, the number of children having all appropriate diagnostic measures done eg the availability of information about children and young people's functioning from sources outside the clinic setting
- additional assessments of children and young people with diagnoses of ASD, eg the proportion of children and young people with ASD who have a comprehensive evaluation of their speech and language and communication skills, intellectual, neuropsychological and adaptive functioning, physical or other assessments if relevant
- treatment of sleep problems including baseline sleep diaries, use of behavioural therapy
- pharmacological treatment provision and monitoring - access to pharmacy support, weight monitoring if risperidone prescribed

- proportion of parents offered post-diagnosis training, proportion receiving social work support, nature of preparation for transitions
- information provision - type and timing of information provided for children, young people, families and relevant professionals
- training of staff - generic and ASD specific.

9.4 RECOMMENDATIONS FOR RESEARCH

Further research is required to address numerous areas where there is insufficient evidence to make a recommendation or to support existing clinical practice. The following areas have been identified as especially important:

Recognition, assessment and diagnosis

- Psychiatric comorbidity in children and adolescents with ASD
- Development/validation of ASD screening instruments that meet the rigorous criteria for a robust population screening test
- What is the minimum age at which ASD can be reliably diagnosed?
- Improved evidence on the reliability and validity of the existing classification systems, ICD-10 and DSM-IV
- Which parallel assessment tools (eg speech and language, communication, neuropsychological) to use and when
- Research into the role of biomedical investigations in identifying the aetiology of ASD.

Non-pharmacological interventions

- What is the efficacy of biomedical interventions, including diets and nutritional supplements?
- What is the efficacy of non-pharmacological interventions?
- Are there any specific dietary/non-pharmaceutical interventions that are more appropriate for children with specific forms of ASD, or particular types of comorbidity?
- What is the optimal timing of interventions? Are there benefits from early intervention?
- The role of occupational therapy and physiotherapy for children and young people with ASD, in particular at assessment
- The role of music therapy for children and young people with ASD
- The role of environmental adaptation.

Pharmacological interventions

- Melatonin use
- Further risperidone studies and systematic reviews/meta-analysis
- Long term effectiveness of medication, including potential synergistic effects with other interventions
- More research is needed on the use of fluoextine and other selective serotonin reuptake inhibitors.

Service provision

- Are particular models of service provision more effective in improving outcomes for children and young people with ASD?
- How are transitions, at all stages from pre-school to adulthood, best managed?
- The role of multidisciplinary or multiagency teams
- What comprises effective training in ASD for professionals?

10 Development of the guideline

10.1 INTRODUCTION

SIGN is a collaborative network of clinicians, other healthcare professionals and patient organisations and is part of NHS Quality Improvement Scotland. SIGN guidelines are developed by multidisciplinary groups of practising clinicians using a standard methodology based on a systematic review of the evidence. Further details about SIGN and the guideline development methodology are contained in "SIGN 50: A Guideline Developer's Handbook", available at **www.sign.ac.uk**

10.2 THE GUIDELINE DEVELOPMENT GROUP

Dr Iain McClure*(Chair)	*Consultant Child and Adolescent Psychiatrist, Murray Royal Hospital, Perth*
Mrs Jennifer Beattie	*Principal Teacher in Special Needs, Kenmay Academy, Aberdeenshire*
Mrs Sheila Boyd	*Occupational Therapist, Scottish Centre for Autism, Glasgow*
Ms Margo Cattanach	*Community Charge Nurse - Learning Disabilities, Larbert*
Dr Sally Cheseldine	*Consultant Clinical Psychologist, Child and Adolescent Mental Health Services, Edinburgh*
Mr Paul Dickinson	*Clinical Psychologist, NHS Highland, Inverness*
Mrs Penny Ellingham	*Social Worker, Royal Hospital for Sick Children, Edinburgh*
Dr David Fitzpatrick	*Clinical Paediatric Geneticist, MRC Human Genetics Unit, Edinburgh*
Mrs Bette Francis	*Vulnerable Adults Unit, Scottish Executive Health Department, Edinburgh*
Dr Anne Gilchrist*	*Consultant Adolescent Psychiatrist, Royal Cornhill Hospital, Aberdeen*
Dr Rob Henderson	*Specialist Registrar in Public Health Medicine, Highland NHS Board, Inverness*
Mrs Alison Leask*	*Project Manager, NHS Education for Scotland and Chair, Autism Argyll*
Dr Tommy MacKay	*Consultant Psychologist, Psychology Consultancy Services, Dunbartonshire*
Ms Marjory Macleod	*Senior Dietitian, Sighthill Health Centre, Edinburgh*
Mrs Roslyn McCaughey (Secretary)	*Senior Speech and Language Therapist, Renton Primary School, Renton*
Dr John March	*Research Scientist, Moredun Research Institute, Penicuik*
Dr Craig Melville*	*Senior Lecturer in Learning Disabilities Psychiatry, University of Glasgow, Gartnavel Royal Hospital*
Mrs Rona Membury	*Lay Representative, Inverness*
Dr Elise Merry	*Consultant Paediatrician, Armitstead Child Development Centre, Dundee*
Professor Anne O'Hare* (Vice-chair)	*Consultant Paediatrician, Royal Hospital for Sick Children, Edinburgh*
Dr Safia Qureshi	*SIGN Programme Director*
Ms Marion Rutherford	*Speech and Language Therapist, Royal Hospital for Sick Children, Edinburgh*
Ms Chris Simmonds	*Health Visitor, Aberdeen*
Dr Georgina Soulby	*Consultant Community Paediatrician - Children Services, Raigmore Hospital, Inverness*

Ms Janis Toy	*Residential Services Manager, Daldorch House School, East Ayrshire*
Ms Diane Waugh	*Lay Representative, Sense Scotland, Glasgow*
Ms Joanna Welsh	*SIGN Information Officer*

**member of the writing group*

10.2.1 ACKNOWLEDGEMENTS

The guideline development group is grateful to the following former members of the guideline development group and members of SIGN staff who have also contributed to the development of this guideline.

Dr Jaqueline Atkinson	*Senior Lecturer in Public Health and Public Policy, University of Glasgow*
Mr Robin Harbour	*SIGN Quality and Information Director*
Dr Roberta James	*SIGN Programme Manager*
Dr Ken Lawton	*General Practitioner, Great Western Road Medical Group, Aberdeen*
Ms Jean MacLellan	*Branch Head, Community Care Division Branch 4, Scottish Executive Health Department, Edinburgh*
Dr Julie Pennycook	*General Practitioner, Merrylee Medical Centre, Glasgow*

The membership of the guideline development group was confirmed following consultation with the member organisations of SIGN. All members of the guideline development group made declarations of interest and further details of these are available on request from the SIGN Executive. Guideline development and literature review expertise, support and facilitation were provided by the SIGN Executive.

10.3 SYSTEMATIC LITERATURE REVIEW

The evidence base for this guideline was synthesised in accordance with SIGN methodology. A systematic review of the literature was carried out using a search strategy devised by a 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.

Details of the search coverage, also see annex 3.	
Patient searches	
Databases covered:	Dates covered:
Caredata	1996 – April 2004
Cinahl	1996 – April 2004
Embase	1996 – April 2004
Medline	1996 – April 2004
Psychinfo	1996 – April 2004
Social Work Abstracts	1988 – April 2004
Guidelines	
GIN Website	Embase (1999-2004)
National Guidelines Clearinghouse	Medline (1999-2004)
NeLH Guidelines Finder	
NICE Website	
Systematic reviews	
Databases covered: Medline, Embase, Cinahl, PsycInfo, Cochrane	Dates covered: 1996-2006
RCTs	Dates covered:
Databases covered:	1996 - 2006
CINAHL	
CCTR	
Embase	
Medline	
Psychinfo	
Observational studies	
Databases covered: Medline, Embase, Cinahl, PsycInfo, Cochrane	Dates covered: 1996-2006
Diagnostic studies	
Databases covered: Medline, Embase, Cinahl, PsycInfo, Cochrane	Dates covered: 1996-2005

10.4 CONSULTATION AND PEER REVIEW

10.4.1 NATIONAL OPEN MEETING

A national open meeting is the main consultative phase of SIGN guideline development, at which the guideline development group presents its draft recommendations for the first time. The national open meeting for this guideline was held on 3 October 2005 and was attended by representatives of all the key specialties relevant to the guideline. The draft guideline was also available on the SIGN website for a limited period at this stage to allow those unable to attend the meeting to contribute to the development of the guideline.

10.4.2 SPECIALIST REVIEW

This guideline was sent in draft form to the following independent expert referees, who were asked to comment primarily on the comprehensiveness and accuracy of interpretation of the evidence base supporting the recommendations in the guideline. SIGN is very grateful to all of these experts for their contribution to the guideline.

Professor Gillian Baird	*Professor of Developmental Paediatrics, Guy's and St Thomas' Hospital NHS Trust, London*
Ms Sue Barnard	*Consultation and Involvement Officer for Children with Disabilities and their Families, Aberdeen*
Dr Alan Begg	*General Practitioner, Angus*
Dr Isabel Claire	*Clinical Psychologist, Autism Research Centre, Cambridge University*
Ms Joanna Daly	*Policy and Parlimentary Officer – Scotland, National Autistic Society*
Ms Amanda Di Candia	*Lay Reviewer, Aberdeen*
Professor Aline-Wendy Dunlop	*Professor of Childhood and Primary Studies, Lead Director, National Centre of Autism Studies, University of Strathclyde*
Dr Allison Ferguson	*Consultant Paediatrician and Lead Consultant for Yorkhill Community Autism Teams, Glasgow*
Mr John Forrester	*Training and Assessment Consultant, Jigsaw Centre, Aberdeen*
Professor David Goldberg	*Consultant Epidemiologist, Health Protection Scotland, Glasgow*
Professor Rita Jordan	*Professor in Autism Studies, The University of Birmingham*
Dr Deb Keen	*Associate Professor of Educational Psychology, The University of Queensland, Australia*
Professor Ann Le Couteur	*Professor of Child and Adolescent Psychiatry, Royal Victoria Infirmary, Newcastle upon Tyne*
Professor Catherine Lord	*Professor of Psychology and Psychiatry, University of Michigan Autism and Communicative Disorders Clinic, USA*
Mr John McDonald	*Chief Executive, The Scottish Society for Autism, Alloa*
Ms Fiona McGillivary	*Social Worker, Errol*
Mr Andy Moir	*Occupational Therapist, Borders Autism Team, Selkirk*
Mr Andrew Power	*Head of Prescribing Team, North Glasgow NHS Trust*
Ms Trish Reynolds	*Chair, Wick Caithness Autism Parent Support Group*
Mr David Rex	*Child Health Dietitian, Raigmore Hospital, Inverness*
Professor Sir Michael Rutter	*Professor of Developmental Psychopathology, Institute of Psychiatry, London*
Ms Val Sellars	*Speech and Language Therapist, Scottish Centre for Autism, Glasgow*
Professor David Skuse	*Professor of Psychiatry, Institute of Child Health, London*
Dr Vicky Slonims	*Prinicpal Speech and Language Therapist, Guy's and St Thomas' Hospital NHS Trust, London*
Mrs Laura Stewart	*Paediatric Dietitian, Royal Hospital for Sick Children, Edinburgh*
Dr Lorna Wing	*Consultant Psychiatrist, The Centre for Social and Communication Disorders, Kent*

10.4.3 SIGN EDITORIAL GROUP

As a final quality control check, the guideline was reviewed by an editorial group comprising members of SIGN Council to ensure that the specialist reviewers' comments were addressed adequately and that any risk of bias in the guideline development process as a whole has been minimised. The editorial group for this guideline was as follows:

Dr Keith Brown	*Member of SIGN Council*
Mr Robert Carachi	*Member of SIGN Council*
Professor Gordon Lowe	*Chair of SIGN; Co-Editor*
Ms Anne Mathew	*Member of SIGN Council*
Dr Moray Nairn	*Programme Manager, SIGN*
Dr Sara Twaddle	*Director of SIGN; Co-Editor*

Abbreviations

3di	Developmental, dimensional and diagnostic interview
ABA	Applied behavioural analysis
ADHD	Attention deficit and hyperkinetic disorders
ADI-R	Autism diagnostic interview – revised
ADOS-G	Autism diagnostic observation schedule–generic
AIT	Auditory integration training
ASL	Additional support for learning
ASD	Autism spectrum disorder
CARS	Childhood autism rating scale
CAST	Childhood Asperger syndrome test
CBT	Cognitive behaviour therapy
CHAT	Checklist for autism in toddlers
DISCO	Diagnostic interview for social and communication disorders
DNA	Deoxyribonucleic acid
DSM-IV	Diagnostic and statistical manual of mental disorders 4th edition
EEG	Electroencephalogram
GP	General practitioner
Hall 4	Health for all Children
ICD-10	International classification of diseases, version 10
IQ	Intelligence quotient
M-CHAT	Modified checklist for autism in toddlers
MMR	Measles, mumps and rubella
MRC	Medical Research Council
MRI	Magnetic resonance imaging
NAPC	National autism plan for children
OCD	Obsessive compulsive disorder
PHIS	Public Health Institute of Scotland
RCT	Randomised controlled trial
SIGN	Scottish Intercollegiate Guidelines Network

Annex 1

Criteria for assessing the reporting of the diagnosis of 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.

<table>
<tr><td colspan="2">A. Components of diagnostic assessment</td></tr>
<tr><td colspan="2">1. A recognised process of obtaining information in necessary domains, usually by multi-disciplinary 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</td></tr>
<tr><td colspan="2">B. Components of a reliable diagnosis</td></tr>
<tr><td rowspan="5">Increasing accuracy and reliability</td><td>Use of a process, and a diagnostic classification system, and an instrument (i.e. 1, 2, and 3, from A)</td></tr>
<tr><td>1. Use of a process and a diagnostic classification system
OR
2. Use of an instrument and a diagnostic classification system</td></tr>
<tr><td>The use of a process, a diagnostic classification system or an instrument, used singly</td></tr>
<tr><td>Diagnosis simply stated</td></tr>
<tr><td colspan="2">NB each component of the assessment should be explicitly stated in the study/report under consideration</td></tr>
</table>

Annex 2

Comparison of ICD-10[11] and DSM-IV[12] definitions of autism

ICD-10 research criteria	DSM-IV
F84.0 Childhood autism A. Presence of abnormal or impaired development before the age of three years, in at least one out of the following areas: (1) receptive or expressive language as used in social communication; (2) the development of selective social attachments or of reciprocal social interaction; (3) functional or symbolic play. B. Qualitative abnormalities in reciprocal social interaction, manifest in at least one of the following areas: (1) failure adequately to use eye-to-eye gaze, facial expression, body posture and gesture to regulate socialnteraction; (2) failure to develop (in a manner appropriate to mental age, and despite ample opportunities) peer relationships that involve a mutual sharing of interests, activities and emotions; (3) A lack of socio-emotional reciprocity as shown by an impaired or deviant response to other people's emotions; or lack of modulation of behaviour according to social context, or a weak integration of social, emotional and communicative behaviours. C. Qualitative abnormalities in communication, manifest in at least two of the following areas: (1) a delay in, or total lack of development of spoken language that is not accompanied by an attempt to compensate through the use of gesture or mime as alternative modes of communication (often preceded by a lack of communicative babbling); 2) relative failure to initiate or sustain conversational interchange (at whatever level of language skills are present) in which there is reciprocal to and from responsiveness to the communications of the other person;	**299.00 Autism** 1. A total of six (or more) items from (1), (2), and (3), with at least two from (1), and one each from (2) and (3): 1. qualitative impairment in social interaction, as manifested by at least two of the following: A. marked impairment in the use of multiple nonverbal behaviors such as eye-to-eye gaze, facial expression, body postures, and gestures to regulate social interaction B. failure to develop peer relationships appropriate to developmental level C. a lack of spontaneous seeking to share enjoyment, interests, or achievements with other people (e.g., by a lack of showing, bringing, or pointing out objects of interest) D. lack of social or emotional reciprocity 2. qualitative impairments in communication as manifested by at least one of the following: A. delay in, or total lack of, the development of spoken language (not accompanied by an attempt to compensate through alternative modes of communication such as gesture or mime) B. in individuals with adequate speech, marked impairment in the ability to initiate or sustain a conversation with others C. stereotyped and repetitive use of language or idiosyncratic language D. lack of varied, spontaneous make-believe play or social imitative play appropriate to developmental level 3. restricted repetitive and stereotyped patterns of behavior, interests, and activities, as manifested by at least one of the following:

(3) stereotyped and repetitive use of language or idiosyncratic use of words or phrases; (4) abnormalities in pitch, stress, rate, rhythm and intonation of speech; D. Restricted, repetitive, and stereotyped patterns of behaviour, interests and activities, manifest in at least two of the following areas: (1) an encompassing preoccupation with one or more stereotyped and restricted patterns of interest that are abnormal in content or focus; or one or more interests that are abnormal in their intensity and circumscribed nature although not abnormal in their content or focus. (2) apparently compulsive adherence to specific, non-functional, routines or rituals; (3) stereotyped and repetitive motor mannerisms that involve either hand or finger flapping or twisting, or complex whole body movements; (4) preoccupations with part-objects or non-functional elements of play materials (such as their odour, the feel of their surface, or the noise or vibration that they generate); (5) distress over changes in small, non-functional, details of the environment. E. The clinical picture is not attributable to the other varieties of pervasive developmental disorder; specific developmental disorder of receptive language (F80.2) with secondary socio-emotional problems; reactive attachment disorder (F94.1) or disinhibited attachment disorder (F94.2); mental retardation (F70-F72) with some associated emotional or behavioural disorder; schizophrenia (F20) of unusually early onset; and Rett's syndrome (F84.2).	A. encompassing preoccupation with one or more stereotyped and restricted patterns of interest that is abnormal either in intensity or focus B. apparently inflexible adherence to specific, nonfunctional routines or rituals C. stereotyped and repetitive motor mannerisms (e.g., hand or finger flapping or twisting, or complex whole-body movements) D. persistent preoccupation with parts of objects 1. Delays or abnormal functioning in at least one of the following areas, with onset prior to age 3 years: (1) social interaction, (2) language as used in social communication, or (3) symbolic or imaginative play. 2. The disturbance is not better accounted for by Rett's Disorder or Childhood Disintegrative Disorder. **299.80 Pervasive Developmental Disorder not otherwise specified (inclulding Atypical Autism)** This category should be used when there is a severe and pervasive impairment in the development of reciprocal social interaction associated with impairment in either verbal or nonverbal communication skills or with the presence of stereotyped behavior, interests, and activities, but the criteria are not met for a specific Pervasive Developmental Disorder, Schizophrenia, Schizotypal Personality Disorder, or Avoidant Personality Disorder. For example, this category includes "atypical autism" – presentations that do not meet the criteria for Autistic Disorder because of late age at onset, atypical symptomatology, or subthreshold symptomatology, or all of these.
F84.1 Atypical autism A. Presence of abnormal or impaired development at or after age three years (criteria as for autism except for age of manifestation). B. Qualitative abnormalities in reciprocal social interaction or in communication, or restricted, repetitive and stereotyped patterns of behaviour, interests and activities (criteria as for autism except that it is not necessary to meet the criteria in terms of number of areas of abnormality).	**299.80 Asperger's Disorder** 1. Qualitative impairment in social interaction, as manifested by at least two of the following: 1. marked impairment in the use of multiple nonverbal behaviors such as eye-to-eye gaze, facial expression, body postures, and gestures to regulate social interaction 2. failure to develop peer relationships appropriate to develpmental level

C. The disorder does not meet the diagnostic criteria for autism (F84.0).

Autism may be atypical in either age of onset (F84.11) or phenomenology (84.12), these two types being differentiated with a fifth character for research purposes. Syndromes that are atypical in both respects should be coded F84.12.

F84.10 Atypicality in age of onset

A. Does not meet criterion A for autism. That is, abnormal or impaired development is evident only at or after age three years.
B. Meets criteria B, C, D and E for autism (F84.0).

F84.11 Atypicality in symptomatology

A. Meets criterion A for autism (i.e. presence of abnormal or impaired development before the age of three years).
B. Qualitative abnormalities in reciprocal social interactions or in communication, or restricted, repetitive and stereotyped patterns of behaviour, interests and activities (criteria as for autism except that it is not necessary to meet the criteria in terms of number of areas of abnormality).
C. Meets criterion E for autism.
D. Does not meet the full criteria B, C and D for autism (F84.0).

F84.12 Atypicality in both age of onset and symptomatology

A. Does not meet criterion A for autism. That is abnormal or impaired development is evident only at or after the age of three years.
B. Qualitative abnormalities in reciprocal social interactions or in communication, or restricted, repetitive and stereotyped patterns of behaviour, interests and activities (criteria as for autism except that it is not necessary to meet the criteria in terms of number of areas of abnormality).
C. Meets criterion E for autism.
D. Does not meet the full criteria B, C and D for autism (F84.0).

3. a lack of spontaneous seeking to share enjoyment, interests, or achievements with other people (e.g., by a lack of showing, bringing, or pointing out objects of interest to other people)
4. lack of social or emotional reciprocity

1. Restricted repetitive and stereotyped patterns of behavior, interests, and activities, as manifested by at least one of the following:
   1. encompassing preoccupation with one or more stereotyped and restricted patterns of interest that is abnormal either in intensity or focus
   2. apparently inflexible adherence to specific, nonfunctional routines or rituals
   3. steroetyped and repetitive motor mannerisms (e.g., hand or finger flapping or twisting, or complex whole-body movements)
   4. persistent reoccupation with parts of objects
   3. The disturbance causes clinically significant impairment in social, occupational, or other important areas of functioning.
4. There is no clinically significant general delay in language (e.g., single words used by age 2 years, communiative phrases used by age 3 years).
5. There is no clinically significant delay in cognitive development or in the development of age-appropriate self-help skills, adaptive behavior (other than in social interaction), and curiosity about the environment in childhood.
6. Criteria are not met for another specific Pervasive Developmental Disorder or Schizophrenia.

Annex 3

The key questions used to develop the guideline

KQ No.	Question	Include/Exclude
1	Which methods, parental concerns and developmental features are of relevance to surveillance for ASD?	All questions relate to children. In this context the term "child" encompasses all individuals aged 0 – 18 years inclusive.
2	Can groups at high risk for a diagnosis of ASD be reliably identified for the purposes of screening?	
3	Is there a sensitive, specific, cost-effective method of screening for ASD?	
4	What is the minimum age at which ASD can be reliably diagnosed?	
5	Are there reliable, valid and useful methods of assessment for use in the diagnosis of ASD?	*(See list below)*
6	Are there reliable, valid and useful diagnostic interview/observation schedules for use in ASD assessments?	*(See list below)*
7	What evidence is there that, prior to and at the time of diagnosis, specific methods of support or providing information to parents have a positive impact on children and their families?	Genetic counselling
8	Is there any evidence that early assessment and diagnosis confers benefit to an individual or their family?	
9	Are there effective training interventions for professionals involved in the recognition, assessment, and diagnosis of ASD?	
10	What is the evidence to support the use of multiagency teams in assessment and support in ASD?	
11	Is there evidence for a reliable and valid diagnostic classification system/list of diagnostic criteria for use in the diagnosis of ASD?	*(See below)*
12	Which conditions occur in association/comorbidly with ASD, and can their presence be specifically excluded or confirmed?	*(See below)*
13	What range of psychological, biological, communication, or social investigations are indicated during the process of assessment and diagnosis of ASD, and when should they be carried out?	*(See below)*

14	Is there evidence that specific findings at the time of ASD diagnostic assessment can reliably predict prognosis?	
15	Which dietary/non-pharmaceutical interventions have been shown to improve outcome for children with ASD?	*(See list below)*
16	Which pharmaceutical medications have been shown to improve outcome for children with ASD?	*(See list below)*
17	Does timing, duration, and intensity of dietary/non-pharmaceutical interventions influence outcome in ASD?	*(See list below)*
18	Does timing, duration, and intensity of pharmaceutical interventions influence outcome in ASD?	*(See list below)*
19	Is early intervention more effective than late intervention in ASD?	
20	Is there evidence that any specific dietary/non-pharmaceutical interventions are more appropriate for children with particular forms of ASD, or particular types of comorbidity?	*(See list below)*
21	Is there evidence that any specific pharmaceutical interventions are more appropriate for children with particular forms of ASD, or particular types of comorbidity?	*(See list below)*
22	Is there evidence that particular models of service delivery are more effective than others in improving outcome in ASD?	ASD-specific service compared to general service. Inclusive educational setting compared to special educational setting. Multidisciplinary/agency service compared to single agency Home based compared to classroom based interventions Clinical integrated pathway compared to single service.
23	What evidence is there to support particular approaches to providing information to parents or carers of children who have, or may have, ASD?	
24	What evidence is there that identifies the general support needs of parents or carers following a diagnosis of ASD in a child?	Include genetic counselling
25	What are the support needs of ASD patients, their parents or carers during transitions, and how should they be monitored?	Include genetic counselling

Assessment methods for use with Question 5:
Activities of daily living (ADL)
Assessment of communication
Assessment of social functioning
Clinical history
Developmental history
Dietitian
Direct observation
Functional skills assessment
Multiagency assessment
Multi-disciplinary assessment
Neurocognitive assessment
Occupational therapist
Paediatrician
Peer interaction
Physical examination
Play-based assessment
Psychiatrist
Psychologist
Psychotherapist
Speech and language therapist

For use with Question 6:	
ASD specific instruments (screening and diagnostic):	
3di	Parent interview for autism
ACE	Pervasive developmental disorders – mental retardation (PDD-MR)
Asperger syndrome (and high-functioning autism) diagnostic interview (ASDI)	Prutting Pragmatic Profile Social communication questionnaire
Asperger syndrome screening questionnaire (ASSQ)	SCDC
Australian Scale for Asperger syndrome (ASAS)	SNAP
Autism behaviour checklist (ABC)	Social Response Scale (SRS)
Autism diagnostic observation schedule (ADOS) and ADOS-G	STAT
Autism screening questionnaire (ASQ)	TEACCH checklist
Autism spectrum quotient (AQ)	Wing autistic disorder interview checklist
Autistic diagnostic interview (ADI, and also ADI-R)	
Childhood Asperger syndrome test (CAST)	
Childhood autism rating scale (CARS)	
Child communication checklist (CCC)	
Diagnostic interview for social communication disorders (DISCO)	
ERNIE	
Gillam autism rating scale (GARS)	
Narrative assessment protocol	

For use with Question 11:	
Diagnostic and statistical manual of mental disorders – 3rd Edition (DSM-III)	
Diagnostic and statistical manual of mental disorders – 3rd Edition (Revised) (DSM-III-R)	
Diagnostic and statistical manual of mental disorders – 4th Edition (DSM-IV)	
Diagnostic and statistical manual of mental disorders – 4th Edition (Text Revision) (DSM-IV-TR)	
Gillberg's criteria (1989, 1991)	
International classification of diseases 8 (ICD 8)	
International classification of diseases 9 (ICD 9)	
International classification of diseases 10 (ICD-10)	
Szatmari's criteria (1989)	
For use with Question 12:	
Anxiety	Learning difficulties
Attention deficit hyperactivity disorder (ADHD)	Obsessive Compulsive Disorder (OCD)
Catatonia	Psychomotor disorders
Conduct disorder	Reactive attachment disorder
Constipation	Sensation disorders
Depression	Sleep disorders
Disruptive behaviour	Speech/Communication disorders
Dyslexia	Tics
Dyspraxia	Tourette syndrome
Epilepsy	Vision disorders
Gastrointestinal disorders	
Hearing disorders	
Immunology	

For use with Question 13: Physical examination
Auditory testing
Blood tests: calcium/phosphorus; creatinine; full blood count; lactic acid; lead; magnesium; phenylalanine; pyruvic acid; 24 hour urine–uric acid
Chromosomal investigations
CT Scan
Electroencephalogram (EEG)
Immunological testing
Karyotyping
PET Scan
Molecular genetics testing, including fragile X
Monitoring of growth and development
MRI scan
Sleep electroencephalogram
SPECT Scan
Test for inborn errors of metabolism – methylmalonic acidurea; mitochondrial cytopathies; mucopolysaccaridoses; ornithine transcarbamilase; phenylketonuria; purine and pyrimidine disorders; Smith's Lemli-Opitz syndrome; tyrosine hydroxylase deficiency; urinary indolylacryloylacine (IAG).
Visual testing

For use with Question 13: Communication, speech and language assessment	
A gesture test	Renfrew language scales
A visual perception/spatial assessment	Reynell developmental language scales
British picture vocabulary scale	School based assessment of motor and process skills
Central coherence	School function assessment
Child communication checklist	Sensory motor profile
Clinical evaluation of language fundamentals (CELF - pre-school 3-6.11 years, CELF–3UK 6-21 years)	Social use of language programme
Derbyshire language scheme	Symbolic play test
Functional skills assessment	Test of pretend play
Happe stories	Test of reception of grammar
Macarthur communication development inventory	The autistic continuum
Movement ABC test	The pragmatics profile of early communication skills in children
Play assessment	Theory of mind stories
Pre-school language scales-3 (UK)	Understanding ambiguity

For use with Question 13: Cognitive assessments		
Bailey	Kaufman	Psychoeducational profile revised (PEP-R)
BASII	Leiter	Ravens CPM
Emotion perception tests (eg FEEST)	McCarthy scales	Stanford-Binet
Frontal lobe/executive function tests (eg Tower of Hanoi, Wisconsin card sort)	Merrill-Palmer	Vineland adaptive behaviour scales
Griffith scales	Mullen scales	Wechsler tests – WPPSI, WISC WAIS

Investigations to be covered ***Supplementary investigations following diagnosis (to supplement KQs 13, 14 and 15):***	
Absolute CD4 cells Absolute CD8 cells Absolute CD16 NK cells Absolute CD19 B cells Albumin Blood toxic metals –lead, mercury, cadmium, aluminium C-reactive proteins Calcium/corrected calcium CD4/CD8 ratio Cholesterol Chromium Coeliac screen Copper Cytotron lymph count Essential fatty acids – red cells Ferritin Folate Functional blood B vitamins Globulin Glucose Hair mineral analysis HUFA – highly unsaturated fatty acids IgA IgE IgG IgM	Iron/iron saturation Liver function tests Magnesium Malabsorption Manganese Measles serology MMR antigens Nitric oxide Opioid peptides Organic acid profile –glycolysis, amino acid metabolites, fatty acid metabolites, yeast/fungal, bacterial, anaerobic bacterial, Krebs cycle, neurotransmitters, pyrimidines Phosphate Plasma sulphate Red cell lipid Red cell magnesium Routine haematology Selenium Serum vitamins, including B6, B12 Stool culture/parasitology/clostridia difficile toxin Total protein Triglycerides Urea and electrolytes Uric acid Urine kryptopyrroles Urine sulphate inorganic /organic Urine sulphite Zinc

Interventions to be covered ***Non-pharmacological interventions (re: KQs 15, 17 and 20):***		
Anger management programme; attachment; circle of friends	Homeopathy	Speech therapy
Behavioural interventions	Light and sound therapy	SPELL
British sign language	LOVAAS or ABA (applied behavioural analysis)	SPIRALS
Challenging behaviour interventions	Makaton	Talking mats
Child's talk	Movement programmes; physical exercise	TEACCH (Treatment and Education of Autistic and related Communication in Handicapped Children)
Cognitive behavioural therapy; desensitisation therapy; group therapy	Occupational therapy; art therapy; auditory integration therapy; music therapy; Tomatis method	Teaching methods; brain gym
Communication/language training; augmentive communication	Parent programmes	Theory of mind training
Communication intervention; computer interventions; virtual reality training	Peer mediated intervention	Total communication
DDAT (Dyslexia, Dyspraxia, Attention Deficit Treatment Centre)	Picture Exchange Communication System (PECS); sign communication; signed English	Verbal behaviour
Developmental skills	Portage	Visual language
Dolphins	Precision teaching	Visual therapies; colorimetric therapy; Irlen lenses/ glasses; orthoptics
EarlyBird	Psychotherapy; autogenic training	**and combinations of the above**
Facilitated communication	Psychodynamic psychotherapy	
Gentle teaching; growing minds; intensive interaction	Self awareness training	
Hanen Parent Programme	Sensory integration therapy	
Heavy metal chelation	Sexual health	
HELP	Social communication training	
Herbal/homeopathic interventions	Social interaction training	
Holding therapy	Social skills training; daily life therapy	
	Social stories	
	Sonrise OPTIONS	

Interventions to be covered **(a) Pharmacological therapy (Re: KQs 16, 18 and 21)**		
Antibiotics	Haloperidol	Psychostimulants; dexamphetamine; methylphenidate (Ritalin)
Anticonvulsants; carbamazepine, valproic acid (sodium valproate)	Laxatives	Secretin
Antidepressants; atomoxetine	Lithium	Selective Serotonin Reuptake Inhibitors (SSRIs); fluoextine; fluvoxamine; paroxetine; sertraline; venlafaxine
Antiemetic agents; chlorpromazine	Melatonin	Sertraline
Antifungal agents	Naltrexone	Steroids
Antimigraine agents; clonidine	Nystatin	Tricyclic antidepressants; amitriptyline; clomipramine; desipramine; imipramine
Antipsychotic agents; clozapine; olanzapine; quetiapine; risperidone; thioridazine	Opiate antagonists	
Antiviral agents; acyclovir	Pimozide	

Interventions to be covered **(b) Diet therapy (Re: KQs 15, 17 and 20)**	
Amino acids	Manganese
Dietary supplements; enzymeaid; evening primrose oil	Myelin based protein supplements; probiotics
Dimethylglycine	Omega 3 fatty acids; docosahexaeonic acid (DHA), eicosapentaenoic acid (EPA), short chain fatty acids
Eye-Q	Special diets; additive free, exclusion diets, casein free, gluten free, low salicylate, low sugar, molecular diet, orthomolecular diet, yeast free.
Fatty acids; essential fatty acids	Vitamins; vitamin B6, vitamin C/ascorbic acid
Highly unsaturated fatty acids (HUFA)	Zinc
Liquorice	
Magnesium	

Annex 4

Structured instruments for use in screening high risk groups

Instrument	Format	Description	Target Age Range
Pervasive Developmental Disorders Rating Scale[229]	Completed by a professional	Adequate reliability	1-18 years old
Modified-Checklist for Autism in Toddlers (**M-CHAT**) [30]	Parent questionnaire	Developed from the CHAT, accurately discriminates autism from other developmental disorders	18-30 months old
The Childhood Autism Rating Scale (**CARS**) [53]	Completed by professionals after taking a clinical history and observing the child		Over 2 years old
The Screening Tool for Autism in Two Year Olds (**STAT**) [34]	Completed by a professional after interacting with the child in a structured play context	High sensitivity, specificity and acceptable reliability	24-35 months old
Checklist for Autism in Toddlers (**CHAT**) [37]	Completed by a professional after a brief interview with parents and a semi-structured observation period with the child	Accurately discriminates autism from other developmental disorders	2-3 years old
The Social Communication Disorders Checklist[230]	Parent self report	Good reliability and validity	3-18 years old
Social Communication Questionnaire[36]	Parent or primary care giver report	Based on ADI-R, able to discriminate between children with a diagnosis of an ASD and children who do not have an ASD	Over 4 years old
Social Responsiveness Scale[231]	Parent or teacher report	Measures the severity of social impairment. Correlates with ADI-R scores	4-18 years old
Childhood Asperger Syndrome Test (**CAST**) [33, 232]	Parent questionnaire	Good sensitivity and specificity	5-11 years old

References

1. Public Health Institute of Scotland (PHIS). Autistic Spectrum Disorders: Needs Assessment Report. Glasgow: PHIS; 2001. [cited 29 March 2007]. Available from URL: http://www.phis.org.uk/pdf.pl?file=publications/Autistic%20Spectrum%20Disorders.pdf
2. Le Couteur A. National Initiative for Autism: Screening and Assessment (NIASA). National Autism Plan for Children (NAPC): Plan for the identification, assessment, diagnosis and access to early interventions for pre-school and primary school aged children with autism spectrum disorder (ASD). London: National Autistic Society; 2003. [cited 29 March 2007). Available from url: http://www.cafamily.org.uk/NAPFront.PDF
3. Medical Research Council (MRC). MRC Review of Autism Research: Epidemiology and Causes. London: MRC; 2001. [cited 2 Apr 2007]. Available from URL: http://www.mrc.ac.uk/Utilities/Documentrecord/index.htm?d=MRC002394
4. Baird G, Simonoff E, Pickles A, Chandler S, Loucas T, Meldrum D, et al. Prevalence of disorders of the autism spectrum in a population cohort of children in South Thames: the Special Needs and Autism Project (SNAP). Lancet 2006;368(9531):210-5.
5. Fombonne E. The epidemiology of autism: a review. Psychol Med 1999;29(4):769-86.
6. Stoto MA, Cleary SD, Foster VB. Epidemiologic Studies of MMR Vaccine and Autism. [Presented at Institute of Medicine Immunization Safety Review Committee Meeting: MMR Vaccine and Autism]. Washington DC; 2001. [cited 11 April 2007}. Available from URL: http://www.iom.edu/Object.File/Master/7/604/new_Stoto.pdf
7. Whitehouse W, Edwards A, Edwards M, Pandit S, Sungun-Paliwal SR, Powell JE. The increasing incidence of autistic spectrum disorders [abstract]. Eur J Paediatr Neurol 1999;3:A13-A4.
8. Bryson SE. Epidemiology of Autism: Overview and Issues Outstanding. In: Cohen DJ, Volkmar FR, eds. Handbook of Autism and Pervasive Developmental Disorders. 2nd ed. New York: Wiley; 1997: 41-6.
9. MacKay T, Dunlop A-W. The Development of a National Training Framework for Autistic Spectrum Disorders: A Study of Training for Professionals Working in the Field of ASD in Scotland. London: The National Autistic Society; 2004. [cited 2 Apr 2007]. Available from URL: http://www.nas.org.uk/nas/jsp/polopoly.jsp?d=368&a=5259
10. Baird G, Cass H, Slonims V. Diagnosis of autism. BMJ 2003;327(7413):488-93.
11. World Health Organization (WHO). The ICD-10 Classification of Mental and Behavioural Disorders: Diagnostic Criteria for Research. Geneva: WHO; 1993.
12. American Psychiatric Association (APA). Diagnostic and Statistical Manual of Mental Disorders DSM-IV. 4th ed. Arlington (Va): APA; 1994.
13. The Nature and Definition of Autism. In: Jordan, R. Autistic Spectrum Disorders: An Introductory Handbook for Practitioners. London: David Fulton Publishers Ltd; 1996: 7-28.
14. Wing L. The Autistic Spectrum. London: Constable and Robinson Ltd; 1996.
15. Volkmar FR, Klin A, Siegel B, Szatmari P, Lord C, Campbell M, et al. Field trial for autistic disorder in DSM-IV. Am J Psychiatry 1994;151(9):1361-7.
16. Klin A, Lang J, Cicchetti DV, Volkmar FR. Brief report: Interrater reliability of clinical diagnosis and DSM-IV criteria for autistic disorder: results of the DSM-IV autism field trial. J Autism Dev Disord 2000;30(2):163-7.
17. Volkmar FR, Cicchetti DV, Bregman J, Cohen DJ. Three diagnostic systems for autism: DSM-III, DSM-III-R, and ICD-10. J Autism Dev Disord 1992;22(4):483-92.
18. Hall DMB, Elliman D. Health for all Children. 4th ed. Oxford: Oxford University Press; 2003.
19. Scottish Executive. Health for all Children 4: Guidance on Implementation in Scotland. Edinburgh: Scottish Executive; 2005. [cited 2 Apr 2007]. Available from url: http://www.scotland.gov.uk/Publications/2005/04/15161325/13269
20. UK National Screening Committee. What is Screening? [cited 2 Apr 2007]. Available from url: http://www.nsc.nhs.uk/whatscreening/whatscreen_ind.htm
21. Mawle E, Griffiths P. Screening for autism in pre-school children in primary care: systematic review of English Language tools. Int J Nurs Stud 2006;43(5):623-36.
22. Tebruegge M, Nandini V, Ritchie J. Does routine child health surveillance contribute to the early detection of children with pervasive developmental disorders? An epidemiological study in Kent, U.K. BMC Pediatr 2004;4:4.
23. Rogers SJ, Hepburn SL, Stackhouse T, Wehner E. Imitation performance in toddlers with autism and those with other developmental disorders. J Child Psychol Psychiatry 2003;44(5):763-81.
24. De Giacomo A, Fombonne E. Parental recognition of developmental abnormalities in autism. Eur Child Adolesc Psychiatry 1998;7(3):131-6.
25. Rogers SJ, Hepburn S, Wehner E. Parent reports of sensory symptoms in toddlers with autism and those with other developmental disorders. J Autism Dev Disord 2003;33(6):631-42.
26. Dissanayake C, Crossley SA. Autistic children's responses to separation and reunion with their mothers. J Autism Dev Disord 1997;27(3):295-312.
27. Malhi P, Singhi P. Recognition of autism in young children. Stud Psychol (Bratisl) 2003;45(1):75-80.
28. Baron-Cohen S, Wheelwright S, Cox A, Baird G, Charman T, Swettenham J, et al. Early identification of autism by the CHecklist for Autism in Toddlers (CHAT). J R Soc Med 2000;93(10):521-5.
29. Baird G, Charman T, Baron-Cohen S, Cox A, Swettenham J, Wheelwright S, et al. A screening instrument for autism at 18 months of age: A 6-year follow- up study. J Am Acad Child Adolesc Psychiatry 2000;39(6):694-702.
30. Robins DL, Fein D, Barton ML, Green JA. The Modified Checklist for Autism in Toddlers: an initial study investigating the early detection of autism and pervasive developmental disorders. J Autism Dev Disord 2001;31(2):131-44.
31. New York State Department of Health, Early Intervention Program. Clinical Practice Guideline: Autism/Pervasive Developmental Disorders: Assessment and Intervention for Young Children (Age 0-3 years). [cited 2 Apr 2007]. Report of Recommendations available from URL: http://www.health.state.ny.us/community/infants_children/early_intervention/autism/index.htm#contents
32. Lauritsen MB, Pedersen CB, Mortensen PB. Effects of familial risk factors and place of birth on the risk of autism: A nationwide register-based study. J Child Psychol Psychiatry 2005;46(9):963-71.
33. Scott FJ, Baron-Cohen S, Bolton P, Brayne C. The CAST (Childhood Asperger Syndrome Test): preliminary development of a UK screen for mainstream primary-school-age children. Autism 2002;6(1):9-31.
34. Stone WL, Coonrod EE, Turner LM, Pozdol SL. Psychometric Properties of the STAT for Early Autism Screening. J Autism Dev Disord 2004;34(6):691-701.
35. Brereton AV, Tonge BJ, Mackinnon AJ, Einfeld SL. Screening young people for autism with the Development Behavior Checklist. J Am Acad Child Adolesc Psychiatry 2002;41(11):1369-75.
36. Berument SK, Rutter M, Lord C, Pickles A, Bailey A. Autism screening questionnaire: Diagnostic validity. Br J Psychiatry 1999;175:444-51.
37. Scambler D, Rogers SJ, Wehner EA. Can the Checklist for Autism in Toddlers differentiate young children with autism from those with developmental delays? J Am Acad Child Adolesc Psychiatry 2001;40(12):1457-63.
38. Siegel B. PDDST-II Pervasive Developmental Disorders Screening Test-II: Early Childhood Screener for Autistic Spectrum Disorders. San Antonio (TX): Harcourt Assessment; 2004.
39. Stone WL, Lee EB, Ashford L, Brissie J, Hepburn SL, Coonrod EE, et al. Can autism be diagnosed accurately in children under 3 years? J Child Psychol Psychiatry 1999;40(2):219-26.
40. Cox A, Klein K, Charman T, Baird G, Baron-Cohen S, Swettenham J, et al. Autism spectrum disorders at 20 and 42 months of age: Stability of clinical and ADI-R diagnosis. J Child Psychol Psychiatry 1999;40(5):719-32.
41. Werner E, Dawson G, Munson J, Osterling J. Variation in early developmental course in autism and its relation with behavioral outcome at 3-4 years of age. J Autism Dev Disord 2005;35(3):337-50.
42. Jordan R. Multidisciplinary work for children with autism. Educ Child Psychol 2001;18(2).

43. Prelock PA, Beatson J, Bitner B, Broder C, Ducker A. Interdisciplinary assessment of young children with autism spectrum disorder. Lang Speech Hear Serv Sch 2003;34(3):194-202.
44. Rafin C. A multidisciplinary approach to working with autistic children. Educ Child Psychol 2001;18(2):15-27.
45. Moore K, McConkey R, Sines D, Cassidy A. Improving diagnostic and assessment services for children with autistic spectrum disorders. Early Child Dev Care 1999;154:1-11.
46. Royal College of Psychiatrists. Psychiatric services for adolescents and adults with Asperger syndrome and other autistic-spectrum disorders. London: Royal College of Psychiatrists; 2006. (Council Report CR136). [cited 2 Apr 2007]. Available from URL: http://www.rcpsych.ac.uk/files/pdfversion/cr136new.pdf
47. Noterdaeme M, Mildenberger K, Sitter S, Amorosa H. Parent information and direct observation in the diagnosis of pervasive and specific developmental disorders. Autism 2002;6(2):159-68.
48. Noterdaeme M, Sitter S, Mildenberger K, Amorosa H. Diagnostic assessment of communicative and interactive behaviours in children with autism and receptive language disorder. Eur Child Adolesc Psychiatry 2000;9(4):295-300.
49. Leekam SR, Libby SJ, Wing L, Gould J, Taylor C. The Diagnostic Interview for Social and Communication Disorders: Algorithms for ICD-10 childhood autism and Wing and Gould autistic spectrum disorders. J Child Psychol Psychiatry 2002;43(3):327-42.
50. Skuse D, Warrington R, Bishop D, Chowdhury U, Lau J, Mandy W, et al. The developmental, dimensional and diagnostic interview (3di): a novel computerized assessment for autism spectrum disorders. J Am Acad Child Adolesc Psychiatry 2004;43(5):548-58.
51. Lord C, Rutter M, Le Couteur A. Autism Diagnostic Interview--Revised: A revised version of a diagnostic interview for caregivers of individuals with possible pervasive developmental disorders. J Autism Dev Disord 1994;24(5):659-85.
52. Wing L, Leekam SR, Libby SJ, Gould J, Larcombe M. The Diagnostic Interview for Social and Communication Disorders: Background, inter-rater reliability and clinical use. J Child Psychol Psychiatry 2002;43(3):307-25.
53. Schopler E, Reichler RJ, DeVellis RF, Daly K. Toward objective classification of childhood autism: Childhood Autism Rating Scale (CARS). J Autism Dev Disord 1980;10(1):91-103.
54. Rellini E, Tortolani D, Trillo S, Carbone S, Montecchi F. Childhood Autism Rating Scale (CARS) and Autism Behavior Checklist (ABC) Correspondence and Conflicts with DSM-IV Criteria in Diagnosis of Autism. J Autism Dev Disord 2004;34(6):703-8.
55. Lord C, Risi S, Lambrecht L, Cook EH, Jr., Leventhal BL, Dilavore PC, et al. The Autism Diagnostic Observation Schedule-Generic: A standard measure of social and communication deficits associated with the spectrum of autism. J Autism Dev Disord 2000;30(3):205-23.
56. Charman T, Drew A, Baird C, Baird G. Measuring early language development in preschool children with autism spectrum disorder using the MacArthur Communicative Development Inventory (Infant Form). J Child Lang 2003;30(1):213-36.
57. Cohen IL, Schmidt-Lackner S, Romanczyk R, Sudhalter V. The PDD Behavior Inventory: a rating scale for assessing response to intervention in children with pervasive developmental disorder. J Autism Dev Disord 2003;33(1):31-45.
58. Botting N, Conti-Ramsden G. Autism, primary pragmatic difficulties, and specific language impairment: can we distinguish them using psycholinguistic markers? Dev Med Child Neurol 2003;45(8):515-24.
59. Norbury CF, Nash M, Baird G, Bishop DVM. Using a parental checklist to identify diagnostic groups in children with communication impairment: a validation of the Children's Communication Checklist–2. Int J Lang Commun Disord 2004;39(3):345-64.
60. Gilotty L, Kenworthy L, Sirian L, Black DO, Wagner AE. Adaptive skills and executive function in autism spectrum disorders. Child Neuropsychol 2002;8(4):241-8.
61. Carter AS, Volkmar FR, Sparrow SS, Wang JJ, Lord C, Dawson G, et al. The Vineland Adaptive Behavior Scales: Supplementary norms for individuals with autism. J Autism Dev Disord 1998;28(4):287-302.
62. Dahlgren S, Sandberg AD, Hjelmquist E. The non-specificity of theory of mind deficits: Evidence from children with communicative disabilities. Eur J Cognit Psychol 2003;15(1):129-55.
63. Rajendran G, Mitchell P, Rickards H. How do individuals with Asperger syndrome respond to nonliteral language and inappropriate requests in computer-mediated communication? J Autism Dev Disord 2005;35(4):429-43.
64. Kaland N, Moller-Nielsen A, Smith L, Mortensen EL, Callesen K, Gottlieb D. The Strange Stories test–a replication study of children and adolescents with Asperger syndrome. Eur Child Adolesc Psychiatry 2005;14(2):73-82.
65. Fombonne E, Du Mazaubrun C, Cans C, Grandjean H. Autism and associated medical disorders in a French epidemiological survey. J Am Acad Child Adolesc Psychiatry 1997;36(11):1561-9.
66. Estecio M, Fett-Conte AC, Varella-Garcia M, Fridman C, Silva AE. Molecular and cytogenetic analyses on Brazilian youths with pervasive developmental disorders. J Autism Dev Disord 2002;32(1):35-41.
67. Reddy KS. Cytogenetic abnormalities and fragile-X syndrome in Autism Spectrum Disorder. BMC Med Genet 2005;6:3.
68. Nicolson R, Szatmari P. Genetic and neurodevelopmental influences in autistic disorder. Can J Psychiatry 2003;48(8):526-37.
69. Miles JH, Hillman RE. Value of a clinical morphology examination in autism. Am J Med Genet 2000;91(4):245-53.
70. Shevell MI, Majnemer A, Rosenbaum P, Abrahamowicz M. Etiologic yield of autistic spectrum disorders: a prospective study. J Child Neurol 2001;16(7):509-12.
71. Lahuis B, Kemner C, Van Engeland H. Magnetic resonance imaging studies on autism and childhood-onset schizophrenia in children and adolescents - A review. Acta Neuropsychiatrica 2003;15(3):140-7.
72. Brambilla P, Hardan A, Ucelli Di Nemi S, Perez J, Soares JC, Barale F. Brain anatomy and development in autism: Review of structural MRI studies. Brain Res Bull 2003;61(6):557-69.
73. Goldberg J, Szatmari P, Nahmias C. Imaging of autism: lessons from the past to guide studies in the future. Can J Psychiatry 1999;44(8):793-801.
74. Billstedt E, Gillberg C. Autism after adolescence: population-based 13- to 22-year follow-up study of 120 individuals with autism diagnosed in childhood. J Autism Dev Disord 2005;35(3):351-60.
75. Kagan-Kushnir T, Roberts SW, Snead OC, 3rd. Screening electroencephalograms in autism spectrum disorders: evidence-based guideline. J Child Neurol 2005;20(3):197-206.
76. Shinnar S, Rapin I, Arnold S, Tuchman RF, Shulman L, Ballaban-Gil K, et al. Language regression in childhood. Pediatr Neurol 2001;24(3):185-91.
77. Kerr A. Annotation: Rett syndrome: recent progress and implications for research and clinical practice. J Child Psychol Psychiatry 2002;43(3):277-87.
78. Oliveira G, Matoso E, Vicente A, Ribeiro P, Marques C, Ataide A, et al. Partial tetrasomy of chromosome 3q and mosaicism in a child with autism. J Autism Dev Disord 2003;33(2):177-85.
79. Clarke DF, Roberts W, Daraksan M, Dupuis A, McCabe J, Wood H, et al. The prevalence of autistic spectrum disorder in children surveyed in a tertiary care epilepsy clinic. Epilepsia 2005;46(12):1970-7.
80. Black C, Kaye JA, Jick H. Relation of childhood gastrointestinal disorders to autism: Nested case-control study using data from the UK general practice research database. Br Med J 2002;325(7361):419-21.
81. Valicenti-McDermott M, McVicar K, Rapin I, Wershil BK, Cohen H, Shinnar S. Frequency of Gastrointestinal Symptoms in Children with Autistic Spectrum Disorders and Association with Family History of Autoimmune Disease. J Dev Behav Pediatr 2006;27(Suppl2):S128-S37.
82. Danielsson S, Gillberg IC, Billstedt E, Gillberg C, Olsson I. Epilepsy in Young Adults with Autism: A Prospective Population-based Follow-up Study of 120 Individuals Diagnosed in Childhood. Epilepsia 2005;46(6):918-23.
83. Giovanardi Rossi P, Posar A, Parmeggiani A. Epilepsy in adolescents and young adults with autistic disorder. Brain Dev 2000;22(2):102-6.

84. Kielinen M, Rantala H, Timonen E, Linna SL, Moilanen I. Associated medical disorders and disabilities in children with autistic disorder: a population-based study. Autism 2004;8(1):49-60.
85. Rosenhall U, Nordin V, Sandstrom M, Ahlsen G, Gillberg C. Autism and hearing loss. J Autism Dev Disord 1999;29(5):349-57.
86. Brereton AV, Tonge BJ, Einfeld SL. Psychopathology in Children and Adolescents with Autism Compared to Young People with Intellectual Disability. J Autism Dev Disord 2006;36(7):863-70.
87. Bradley EA, Summers JA, Wood HL, Bryson SE. Comparing rates of psychiatric and behavior disorders in adolescents and young adults with severe intellectual disability with and without autism. J Autism Dev Disord 2004;34(2):151-61.
88. Evans DW, Canavera K, Kleinpeter FL, Maccubbin E, Taga K. The Fears, Phobias and Anxieties of Children with Autism Spectrum Disorders and Down Syndrome: Comparisons with Developmentally and Chronologically Age Matched Children. Child Psychiatry Hum Dev 2005;36(1):3-26.
89. Kim JA, Szatmari P, Bryson SE, Streiner DL, Wilson FJ. The prevalence of anxiety and mood problems among children with autism and Asperger syndrome. Autism 2000;4(2):117-32.
90. Muris P, Steerneman P, Merckelbach H, Holdrinet I, Meesters C. Comorbid anxiety symptoms in children with pervasive developmental disorders. J Anxiety Disord 1998;12(4):387-93.
91. Weisbrot DM, Gadow KD, DeVincent CJ, Pomeroy J. The presentation of anxiety in children with pervasive developmental disorders. J Child Adolesc Psychopharmacol 2005;15(3):477-96.
92. Gillott A, Furniss F, Walter A. Anxiety in high-functioning children with autism. Autism 2001;5(3):277-86.
93. Frazier JA, Biederman J, Bellordre CA, Garfield SB, Geller DA, Coffey BJ, et al. Should the diagnosis of attention-deficit/hyperactivity disorder be considered in children with pervasive developmental disorder? J Atten Disord 2001;4(4):203-11.
94. Sturm H, Fernell E, Gillberg C. Autism spectrum disorders in children with normal intellectual levels: associated impairments and subgroups. Dev Med Child Neurol 2004;46(7):444-7.
95. Honomichl RD, Goodlin-Jones BL, Burnham M, Gaylor E, Anders TF. Sleep patterns of children with pervasive developmental disorders. J Autism Dev Disord 2002;32(6):553-61.
96. Allik H, Larsson J-O, Smedje H. Sleep Patterns of School-Age Children with Asperger Syndrome or High-Functioning Autism. J Autism Dev Disord 2006;36(5):585-95.
97. Cotton S, Richdale A. Brief report: parental descriptions of sleep problems in children with autism, Down syndrome, and Prader-Willi syndrome. Res Dev Disabil 2006;27(2):151-61.
98. Couturier JL, Speechley KN, Steele M, Norman R, Stringer B, Nicolson R. Parental perception of sleep problems in children of normal intelligence with pervasive developmental disorders: prevalence, severity, and pattern. J Am Acad Child Adolesc Psychiatry 2005;44(8):815-22.
99. Noterdaeme M, Mildenberger K, Minow F, Amorosa H. Evaluation of neuromotor deficits in children with autism and children with a specific speech and language disorder. Eur Child Adolesc Psychiatry 2002;11(5):219-25.
100. Baron-Cohen S, O'Riordan M, Stone V, Jones R, Plaisted K. Recognition of faux pas by normally developing children and children with Asperger syndrome or high-functioning autism. J Autism Dev Disord 1999;29(5):407-18.
101. Rutgers AH, Bakermans-Kranenburg MJ, van Ijzendoorn MH, van Berckelaer-Onnes IA. Autism and attachment: A meta-analytic review. J Child Psychol Psychiatry 2004;45(6):1123-34.
102. Charman T, Baron-Cohen S, Swettenham J, Baird G, Drew A, Cox A. Predicting language outcome in infants with autism and pervasive developmental disorder. Int J Lang Commun Disord 2003;38(3):265-85.
103. Starr E, Szatmari P, Bryson S, Zwaigenbaum L. Stability and change among high-functioning children with pervasive developmental disorders: a 2-year outcome study. J Autism Dev Disord 2003;33(1):15-22.
104. Charman T, Taylor E, Drew A, Cockerill H, Brown JA, Baird G. Outcome at 7 years of children diagnosed with autism at age 2: Predictive validity of assessments conducted at 2 and 3 years of age and pattern of symptom change over time. J Child Psychol Psychiatry 2005;46(5):500-13.
105. Szatmari P, Bryson SE, Boyle MH, Streiner DL, Duku E. Predictors of outcome among high functioning children with autism and Asperger syndrome. J Child Psychol Psychiatry 2003;44(4):520-8.
106. Sigman M, McGovern CW. Improvement in cognitive and language skills from preschool to adolescence in autism. J Autism Dev Disord 2005;35(1):15-23.
107. Fisch GS, Simensen RJ, Schroer RJ. Longitudinal changes in cognitive and adaptive behavior scores in children and adolescents with the fragile X mutation or autism. J Autism Dev Disord 2002;32(2):107-14.
108. Coplan J, Jawad AF. Modeling clinical outcome of children with autistic spectrum disorders. Pediatrics 2005;116(1):117-22.
109. McGovern CW, Sigman M. Continuity and change from early childhood to adolescence in autism. J Child Psychol Psychiatry 2005;46(4):401-8.
110. Lord C, Shulman C, DiLavore P. Regression and word loss in autistic spectrum disorders. J Child Psychol Psychiatry 2004;45(5):936-55.
111. Goldberg WA, Osann K, Filipek PA, Laulhere T, Jarvis K, Modahl C, et al. Language and other regression: assessment and timing. J Autism Dev Disord 2003;33(6):607-16.
112. Francis K. Autism interventions: a critical update. Dev Med Child Neurol 2005;47(7):493-9.
113. Jordan R, Jones G, Murray D. Educational Interventions for Children with Autism: A Literature Review of Recent and Current Research. London: Department for Education and Skills; 1998. (Research Report No 77). [cited 2 Apr 2007]. Available from URL: http://www.dfes.gov.uk/research/programmeofresearch/projectinformation.cfm?projectid=12797&resultspage=1
114. Shields J. The NAS EarlyBird Programme: partnership with parents in early intervention. The National Autistic Society. Autism 2001;5(1):49-56.
115. Sussman F. More Than Words: Helping Parents Promote Communication and Social Skills in Children with Autism Spectrum Disorder. Toronto: Hanen Centre; 1999.
116. Tonge B, Brereton A, Kiomall M, MacKinnon A, King N, Rinehart N. Effects on Parental Mental Health of an Education and Skills Training Program for Parents of Young Children With Autism: A Randomized Controlled Trial. J Am Acad Child Adolesc Psychiatry 2006;45(5):561-9.
117. Sofronoff K, Leslie A, Brown W. Parent management training and Asperger syndrome: a randomized controlled trial to evaluate a parent based intervention. Autism 2004;8(3):301-17.
118. Diggle T, McConachie HR, Randle VRL. Parent-mediated early intervention for young children with autism spectrum disorder (Cochrane Review). In: The Cochrane Library, Issue 1, 2005. London: John Wiley & Sons Ltd.
119. Aldred C, Green J, Adams C. A new social communication intervention for children with autism: Pilot randomized controlled treatment study suggesting effectiveness. J Child Psychol Psychiatry 2004;45(8):1420-30.
120. McConachie H, Randle V, Hammal D, Le Couteur A. A controlled trial of a training course for parents of children with suspected autism spectrum disorder. J Pediatr 2005;147(3):335-40.
121. Charlop-Christy MH, Carpenter M, Le L, LeBlanc LA, Kellet K. Using the picture exchange communication system (PECS) with children with autism: assessment of PECS acquisition, speech, social-communicative behavior, and problem behavior. J Appl Behav Anal 2002;35(3):213-31.
122. Eikeseth S, Jahr E. The UCLA reading and writing program: an evaluation of the beginning stages. Res Dev Disabil 2001;22(4):289-307.
123. Koegel RL, Camarata S, Koegel LK, Ben-Tall A, Smith AE. Increasing speech intelligibility in children with autism. J Autism Dev Disord 1998;28(3):241-51.
124. Bebko JM, Perry A, Bryson S. Multiple method validation study of facilitated communication: II. Individual differences and subgroup results. J Autism Dev Disord 1996;26(1):19-42.
125. Kasari C, Freeman S, Paparella T. Joint attention and symbolic play in young children with autism: a randomized controlled intervention study. J Child Psychol Psychiatry 2006;47(6):611-20.
126. Yoder P, Stone WL. Randomized comparison of two communication interventions for preschoolers with autism spectrum disorders. J Consult Clin Psychol 2006;74(3):426-35.

127. Shabani DB, Katz RC, Wilder DA, Beauchamp K, Taylor CR, Fischer KJ. Increasing social initiations in children with autism: effects of a tactile prompt. J Appl Behav Anal 2002;35(1):79-83.
128. Thiemann KS, Goldstein H. Social stories, written text cues, and video feedback: effects on social communication of children with autism. J Appl Behav Anal 2001;34(4): 425-46.
129. Thiemann KS, Goldstein H. Effects of peer training and written text cueing on social communication of school-age children with pervasive developmental disorder. J Speech Lang Hear Res 2004;47(1):126-44.
130. Laushey KM, Heflin LJ. Enhancing social skills of kindergarten children with autism through the training of multiple peers as tutors. J Autism Dev Disord 2000;30(3):183-93.
131. Bolte S, Rudolf L, Poustka F. The cognitive structure of higher functioning autism and schizophrenia: a comparative study. Compr Psychiatry 2002;43(4):325-30.
132. Williams C, Wright B, Callaghan G, Coughlan B. Do children with autism learn to read more readily by computer assisted instruction or traditional book methods? A pilot study. Autism 2002;6(1):71-91.
133. Silver M, Oakes P. Evaluation of a new computer intervention to teach people with autism or Asperger syndrome to recognize and predict emotions in others. Autism 2001;5(3):299-316.
134. Roeyers H. The influence of nonhandicapped peers on the social interactions of children with a pervasive development disorder. J Autism Dev Disord 1996;26(3):303-20.
135. Wellman HM, Baron-Cohen S, Caswell R, Gomez JC, Swettenham J, Toye E, et al. Thought-bubbles help children with autism acquire an alternative to a theory of mind. Autism 2002;6(4):343-63.
136. Solomon M, Goodlin-Jones BL, Anders TF. A social adjustment enhancement intervention for high functioning autism, Asperger's syndrome, and pervasive developmental disorder NOS. J Autism Dev Disord 2004;34(6):649-68.
137. Lovaas OI. Behavioral treatment and normal educational and intellectual functioning in young autistic children. J Consult Clin Psychol 1987;55(1):3-9.
138. McEachin JJ, Smith T, Lovaas OI. Long-term outcome for children with autism who received early intensive behavioral treatment. Am J Ment Retard 1993;97(4):359-72.
139. Bassett K, Green CJ, Kazanjian A. Autism and Lovaas treatment: A systematic review of effectiveness evidence. Vancouver (BC): BC Office of Health Technology Assessment, Centre for Health Services and Policy Research (BCOHTA); 2000. [cited 2 Apr 2007]. Available from URL: http://www.chspr.ubc.ca/node/351
140. Matson JL, Benavidez DA, Compton LS, Paclawskyj T, Baglio C. Behavioral treatment of autistic persons: a review of research from 1980 to the present. Res Dev Disabil 1996;17(6):433-65.
141. Sinha Y, Silove N, Wheeler D, Williams K. Auditory integration training and other sound therapies for autism spectrum disorders (Cochrane Review). In: The Cochrane Library, Issue 1, 2004. London: John Wiley & Sons Ltd.
142. Tochel C. Sensory or auditory integration therapy for children with autistic spectrum disorders. In: Bazian Ltd (ed) STEER: Succninct and Timely Evaluated Evidence Reviews 2003; 3(17). Wessex Institute for Health Research and Development, University of Southampton and Bazian Ltd. [cited 2 Apr 2007]. Available from URL: http://www.wihrd.soton.ac.uk/projx/signpost/steers/STEER_2003(17).pdf
143. Bettison S. The long-term effects of auditory training on children with autism. J Autism Dev Disord 1996;26(3): 361-74.
144. Ball CM. Music therapy for children with autistic spectrum disorder. In: Bazian Ltd (ed) STEER: Succninct and Timely Evaluated Evidence Reviews 2004; 4(1). Wessex Institute for Health Research and Development, University of Southampton and Bazian Ltd. [cited 2 Apr 2007]. Available from URL: http://www.wihrd.soton.ac.uk/projx/signpost/steers/STEER_2004(1).pdf
145. Gold C, Wigram T, Elefant C. Music therapy for autistic spectrum disorder (Cochrane Review). In: The Cochrane Library, Issue 2, 2006. London: John Wiley & Sons Ltd.
146. Weiskop S, Richdale A, Matthews J. Behavioural treatment to reduce sleep problems in children with autism or fragile X syndrome. Dev Med Child Neurol 2005;47(2):94-104.
147. Mostert MP. Facilitated communication since 1995: a review of published studies. J Autism Dev Disord 2001;31(3):287-313.
148. Simpson RL, Myles BS. Effectiveness of facilitated communication with children and youth with autism. J Spec Educ 1995;28(4):424-39.
149. Jacobson JW, Mulick JA, Schwartz AA. A history of facilitated communication: Science, pseudoscience, and antiscience science working group on facilitated communication. Am Psychol 1995;50(9):750-65.
150. Charman C, Clare P. Mapping autism research: Identifying UK priorities for the future. London: The National Autistic Society; 2004.
151. Millward C, Ferriter M, Calver S, Connell-Jones G. Gluten- and casein-free diets for autistic spectrum disorder (Cochrane Review). In: The Cochrane Library, Issue 2, 2004. London: John Wiley & Sons Ltd.
152. Elder JH, Shankar M, Shuster J, Theriaque D, Burns S, Sherrill L. The gluten-free, casein-free diet in autism: results of a preliminary double blind clinical trial. J Autism Dev Disord 2006;36(3):413-20.
153. Nye C, Brice A. Combined vitamin B6-magnesium treatment in autism spectrum disorder (Cochrane Review). In: The Cochrane Library, Issue 4, 2004. London: John Wiley & Sons Ltd.
154. White AH. Cognitive behavioural therapy in children with autistic spectrum disorder. In: Bazian Ltd (ed) STEER: Succninct and Timely Evaluated Evidence Reviews 2004; 4(5). Wessex Institute for Health Research and Development, University of Southampton and Bazian Ltd. [cited 2 Apr 2007]. Available from URL: http://www.wihrd.soton.ac.uk/projx/signpost/steers/STEER_2004(5).pdf
155. Scottish Intercollegiate Guidelines Network (SIGN). Diagnosis and management of epilepsies in children and young people. Edinburgh: SIGN; 2005. (SIGN publication no. 81). [cited 2 Apr 2007]. Available from URL: http://www.sign.ac.uk
156. McCracken JT, McGough J, Shah B, Cronin P, Hong D, Aman MG, et al. Risperidone in children with autism and serious behavioral problems. N Engl J Med 2002;347(5):314-21.
157. Risperidone treatment of autistic disorder: longer-term benefits and blinded discontinuation after 6 months. Am J Psychiatry 2005;162(7):1361-9.
158. McDougle CJ, Scahill L, Aman MG, McCracken JT, Tierney E, Davies M, et al. Risperidone for the core symptom domains of autism: results from the study by the autism network of the research units on pediatric psychopharmacology. Am J Psychiatry 2005;162(6): 1142-8.
159. Nagaraj R, Singhi P, Malhi P. Risperidone in children with autism: randomized, placebo-controlled, double-blind study. J Child Neurol 2006;21(6):450-5.
160. Research Units on Pediatric Psychopharmacology Autism Network. Randomized, controlled, crossover trial of methylphenidate in pervasive developmental disorders with hyperactivity. Arch Gen Psychiatry 2005;62(11):1266-74.
161. Troost PW, Lahuis BE, Steenhuis MP, Ketelaars CE, Buitelaar JK, van Engeland H, et al. Long-term effects of risperidone in children with autism spectrum disorders: a placebo discontinuation study. J Am Acad Child Adolesc Psychiatry 2005;44(11):1137-44.
162. Martin A, Scahill L, Anderson GM, Aman M, Arnold LE, McCracken J, et al. Weight and leptin changes among risperidone-treated youths with autism: 6-month prospective data. Am J Psychiatry 2004;161(6):1125-7.
163. Hellings JA, Zarcone JR, Crandall K, Wallace D, Schroeder SR. Weight gain in a controlled study of risperidone in children, adolescents and adults with mental retardation and autism. J Child Adolesc Psychopharmacol 2001;11(3): 229-38.
164. Aman MG, Arnold LE, McDougle CJ, Vitiello B, Scahill L, Davies M, et al. Acute and long-term safety and tolerability of risperidone in children with autism. J Child Adolesc Psychopharmacol 2005;15(6):869-84.
165. Szigethy E, Wiznitzer M, Branicky LA, Maxwell K, Findling RL. Risperidone-induced hepatotoxicity in children and adolescents? A chart review study. J Child Adolesc Psychopharmacol 1999;9(2):93-8.
166. Gagliano A, Germano E, Pustorino G, Impallomeni C, D'Arrigo C, Calamoneri F, et al. Risperidone treatment of children with autistic disorder: effectiveness, tolerability, and pharmacokinetic implications. J Child Adolesc Psychopharmacol 2004;14(1):39-47.

167. Masi G, Cosenza A, Mucci M, Brovedani P. Open trial of risperidone in 24 young children with pervasive developmental disorders. J Am Acad Child Adolesc Psychiatry 2001;40(10):1206-14.
168. Masi G, Cosenza A, Mucci M, Brovedani P. A 3-year naturalistic study of 53 preschool children with pervasive developmental disorders treated with risperidone. J Clin Psychiatry 2003;64(9):1039-47.
169. Santosh PJ, Baird G, Pityaratstian N, Tavare E, Gringras P. Impact of comorbid autism spectrum disorders on stimulant response in children with attention deficit hyperactivity disorder: a retrospective and prospective effectiveness study. Child Care Health Dev 2006;32(5):575-83.
170. Di Martino A, Melis G, Cianchetti C, Zuddas A. Methylphenidate for pervasive developmental disorders: safety and efficacy of acute single dose test and ongoing therapy: an open-pilot study. J Child Adolesc Psychopharmacol 2004;14(2):207-18.
171. Scottish Intercollegiate Guidelines Network (SIGN). Attention deficit and hyperkinetic disorders in children and young people. Edinburgh: SIGN; 2001. (SIGN publication no. 52). [cited 2 Apr 2007]. Available from URL: http://www.sign.ac.uk
172. Hollander E, Phillips A, King BH, Guthrie D, Aman MG, Law P, et al. Impact of recent findings on study design of future autism clinical trials. CNS Spectr 2004;9(1):49-56.
173. DeLong GR, Ritch CR, Burch S. Fluoxetine response in children with autistic spectrum disorders: correlation with familial major affective disorder and intellectual achievement. Dev Med Child Neurol 2002;44(10):652-9.
174. Feldman HM, Kolmen BK, Gonzaga AM. Naltrexone and communication skills in young children with autism. J Am Acad Child Adolesc Psychiatry 1999;38(5):587-93.
175. Kolmen BK, Feldman HM, Handen BL, Janosky JE. Naltrexone in young autistic children: replication study and learning measures. J Am Acad Child Adolesc Psychiatry 1997;36(11):1570-8.
176. Willemsen-Swinkels SH, Buitelaar JK, van Berckelaer-Onnes IA, van Engeland H. Brief report: six months continuation treatment in naltrexone-responsive children with autism: an open-label case-control design. J Autism Dev Disord 1999;29(2):167-9.
177. Williams PG, Allard A, Sears L, Dalrymple N, Bloom AS. Brief report: case reports on naltrexone use in children with autism: controlled observations regarding benefits and practical issues of medication management. J Autism Dev Disord 2001;31(1):103-8.
178. Coniglio SJ, Lewis JD, Lang C, Burns TG, Subhani-Siddique R, Weintraub A, et al. A randomized, double-blind, placebo-controlled trial of single-dose intravenous secretin as treatment for children with autism. J Pediatr 2001;138(5):649-55.
179. Corbett B, Khan K, Czapansky-Beilman D, Brady N, Dropik P, Goldman DZ, et al. A double-blind, placebo-controlled crossover study investigating the effect of porcine secretin in children with autism. Clin Pediatr (Phila) 2001;40(6):327-31.
180. Dunn-Geier J, Ho HH, Auersperg E, Doyle D, Eaves L, Matsuba C, et al. Effect of secretin on children with autism: a randomized controlled trial. Dev Med Child Neurol 2000;42(12):796-802.
181. Molloy CA, Manning-Courtney P, Swayne S, Bean J, Brown JM, Murray DS, et al. Lack of benefit of intravenous synthetic human secretin in the treatment of autism. J Autism Dev Disord 2002;32(6):545-51.
182. Owley T, McMahon W, Cook EH, Laulhere T, South M, Mays LZ, et al. Multisite, double-blind, placebo-controlled trial of porcine secretin in autism. J Am Acad Child Adolesc Psychiatry 2001;40(11):1293-9.
183. Roberts W, Weaver L, Brian J, Bryson S, Emelianova S, Griffiths AM, et al. Repeated doses of porcine secretin in the treatment of autism: a randomized, placebo-controlled trial. Pediatrics 2001;107(5):E71.
184. Sandler AD, Sutton KA, DeWeese J, Girardi MA, Sheppard V, Bodfish JW. Lack of benefit of a single dose of synthetic human secretin in the treatment of autism and pervasive developmental disorder. N Engl J Med 1999;341(24):1801-6.
185. Sponheim E, Oftedal G, Helverschou SB. Multiple doses of secretin in the treatment of autism: a controlled study. Acta Paediatr 2002;91(5):540-5.
186. Unis AS, Munson JA, Rogers SJ, Goldson E, Osterling J, Gabriels R, et al. A randomized, double-blind, placebo-controlled trial of porcine versus synthetic secretin for reducing symptoms of autism. J Am Acad Child Adolesc Psychiatry 2002;41(11):1315-21.
187. Williams KW, Wray JJ, Wheeler DM. Intravenous secretin for autism spectrum disorder (Cochrane Review). In: The Cochrane Library, Issue 3, 2005. London: John Wiley & Sons Ltd.
188. Buscemi N, Vandermeer B, Pandya R, Hooton N, Tjosvold L, Hartling L et al. Melatonin for treatment of sleep disorders: Evidence Report/Technology Assessment No. 108. Rockville: Agency for Healthcare Research and Quality; 2004. [cited 2 Apr 2007]. Available from URL: http://www.ahrq.gov/downloads/pub/evidence/pdf/melatonin/melatonin.pdf
189. Smits MG, Nagtegaal EE, van der Heijden J, Coenen AM, Kerkhof GA. Melatonin for chronic sleep onset insomnia in children: a randomized placebo-controlled trial. J Child Neurol 2001;16(2):86-92.
190. Smits MG, van Stel HF, van der Heijden K, Meijer AM, Coenen AM, Kerkhof GA. Melatonin improves health status and sleep in children with idiopathic chronic sleep-onset insomnia: a randomized placebo-controlled trial. J Am Acad Child Adolesc Psychiatry 2003;42(11):1286-93.
191. Niederhofer H, Staffen W, Mair A, Pittschieler K. Brief report: melatonin facilitates sleep in individuals with mental retardation and insomnia. J Autism Dev Disord 2003;33(4):469-72.
192. Dodge NN, Wilson GA. Melatonin for treatment of sleep disorders in children with developmental disabilities. J Child Neurol 2001;16(8):581-4.
193. Garstang J, Wallis M. Randomized controlled trial of melatonin for children with autistic spectrum disorders and sleep problems. Child Care Health Dev 2006;32(5):585-9.
194. Paavonen EJ, Nieminen-von Wendt T, Vanhala R, Aronen ET, von Wendt L. Effectiveness of melatonin in the treatment of sleep disturbances in children with Asperger disorder. J Child Adolesc Psychopharmacol 2003;13(1):83-95.
195. King BH, Wright DM, Handen BL, Sikich L, Zimmerman AW, McMahon W, et al. Double-blind, placebo-controlled study of amantadine hydrochloride in the treatment of children with autistic disorder. J Am Acad Child Adolesc Psychiatry 2001;40(6):658-65.
196. Akhondzadeh S, Erfani S, Mohammadi MR, Tehrani-Doost M, Amini H, Gudarzi SS, et al. Cyproheptadine in the treatment of autistic disorder: a double-blind placebo-controlled trial. J Clin Pharm Ther 2004;29(2):145-50.
197. Hellings JA, Weckbaugh M, Nickel EJ, Cain SE, Zarcone JR, Reese RM, et al. A double-blind, placebo-controlled study of valproate for aggression in youth with pervasive developmental disorders. J Child Adolesc Psychopharmacol 2005;15(4):682-92.
198. Hollander E, Soorya L, Wasserman S, Esposito K, Chaplin W, Anagnostou E. Divalproex sodium vs. placebo in the treatment of repetitive behaviours in autism spectrum disorder. Int J Neuropsychopharmacol 2006;9(2):209-13.
199. Remington G, Sloman L, Konstantareas M, Parker K, Gow R. Clomipramine versus haloperidol in the treatment of autistic disorder: a double-blind, placebo-controlled, crossover study. J Clin Psychopharmacol 2001;21(4):440-4.
200. Belsito KM, Law PA, Kirk KS, Landa RJ, Zimmerman AW. Lamotrigine therapy for autistic disorder: a randomized, double-blind, placebo-controlled trial. J Autism Dev Disord 2001;31(2):175-81.
201. Sandler RH, Finegold SM, Bolte ER, Buchanan CP, Maxwell AP, Vaisanen ML, et al. Short-term benefit from oral vancomycin treatment of regressive-onset autism. J Child Neurol 2000;15(7):429-35.
202. Steingard RJ, Zimnitzky B, DeMaso DR, Bauman ML, Bucci JP. Sertraline treatment of transition-associated anxiety and agitation in children with autistic disorder. J Child Adolesc Psychopharmacol 1997;7(1):9-15.
203. Barnard J, Broach S, Potter D, Prior A. Autism in Scotland's Schools: Crisis or Challenge? London: The National Autistic Society; 2002. [cited 2 Apr 2007]. Available from URL: http://www.nas.org.uk/content/1/c4/29/27/aawrn_s02.pdf
204. Cascella PW, Colella CS. Knowledge of Autism Spectrum Disorders Among Connecticut School Speech-Language Pathologists. Focus Autism Other Dev Disabl 2004;19(4):245-52.

205. Doherty K, Fitzgerald M, Matthews P. Services for autism in Ireland. Irish J Psychol 2000;21(1-2):50-69.
206. Helps S, Newsom-Davis IC, Callias M. Autism: The teacher's view. Autism 1999;3(3):287-98.
207. Jordan R, Jones G. Educational Provision for Children with Autism in Scotland: Interchange No 46. Edinburgh: The Scottish Office Education and Industry Department; 1997. [cited 2 Apr 2007]. Available from URL: http://www.scotland.gov.uk/edru/Pdf/ers/interchange_46.pdf
208. McGregor E, Campbell E. The attitudes of teachers in Scotland to the integration of children with autism into mainstream schools. Autism 2001;5(2):189-207.
209. Shah K. What do medical students know about autism? Autism 2001;5(2):127-33.
210. Barnard J, Broach S, Potter D, Prior A. Autism in Schools: Crisis or Challenge? London: The National Autistic Society; 2002.
211. Kennedy T, Regehr G, Rosenfield J, Roberts SW, Lingard L. Exploring the gap between knowledge and behavior: a qualitative study of clinician action following an educational intervention. Acad Med 2004;79(5):386-93.
212. Bartolo PA. Communicating a diagnosis of developmental disability to parents: multiprofessional negotiation frameworks. Child Care Health Dev 2002;28(1):65-71.
213. Brogan CA, Knussen C. The disclosure of a diagnosis of an autistic spectrum disorder: Determinants of satisfaction in a sample of Scottish parents. Autism 2003;7(1):31-46.
214. Moore V, Titcomb J, Johnson C, Cronk E, Baker S, Thysson L, et al. Developing an autism assessment service II: Analysis of the first 81 cases seen. Child Psychol Psychiatr Rev 1998;3(3):121-7.
215. Rivers JW, Stoneman Z. Sibling relationships when a child has autism: marital stress and support coping. J Autism Dev Disord 2003;33(4):383-94.
216. Sharpley CF, Bitsika V, Efremidis B. Influence of gender, parental health, and perceived expertise of assistance upon stress, anxiety, and depression among parents of children with autism. J Intellect Dev Disabil 1997;22(1):19-28.
217. Weiss MJ. Harrdiness and social support as predictors of stress in mothers of typical children, children with autism, and children with mental retardation. Autism 2002;6(1):115-30.
218. Eisenhower AS, Baker BL, Blacher J. Preschool children with intellectual disability: syndrome specificity, behaviour problems, and maternal well-being. J Intellect Disabil Res 2005;49(Pt 9):657-71.
219. Hastings RP, Johnson E. Stress in UK families conducting intensive home-based behavioral intervention for their young child with autism. J Autism Dev Disord 2001;31(3):327-36.
220. Pakenham KI, Sofronoff K, Samios C. Finding meaning in parenting a child with Asperger syndrome: correlates of sense making and benefit finding. Res Dev Disabil 2004;25(3):245-64.
221. Newsome WS. Parental perceptions during periods of transition: implications for social workers serving families coping with autism. J Fam Soc Work 2000;5(2):17-31.
222. Hagner D, Cooney BF. "I Do That for Everybody": Supervising Employees With Autism. Focus Autism Other Dev Disabl 2005;20(2):91-7.
223. Public Health Institute of Scotland's Autistic Spectrum Disorder Needs Assessment Report: Scottish Executive Report on Implementation and Next Steps. Edinburgh: Scottish Executive; 2006. [cited 2 Apr 2007]. Available from URL: http://www.scotland.gov.uk/Publications/2006/02/28094616/0
224. Hasnat MJ, Graves P. Disclosure of developmental disability: A study of parent satisfaction and the determinants of satisfaction. J Paediatr Child Health 2000;36(1):32-5.
225. Howlin P, Moore A. Diagnosis in autism: A survey of over 1200 patients in the UK. Autism 1997;1(2):135-62.
226. Mansell W, Morris K. A survey of parents' reactions to the diagnosis of an autistic spectrum disorder by a local service: Access to information and use of services. Autism 2004;8(4):387-407.
227. Reed P, Osborne LA. Parents and Caregivers' perceptions of communication with professionals during the diagnosis of autism: Report by the South East Region Special Education Needs Partnership. London: University College London; 2002. [cited 12 April 2007]. Available from URL: http://www.sersen.uk.net/docs/Focus%20Group%20Research%20-%20Parents%20Perceptions1.doc
228. Symon JB. Parent education for autism: Issues in providing services at a distance. J Posit Behav Interv 2001;3(3):160-74.
229. Williams TO, Jr., Eaves RC. The reliability of test scores for the Pervasive Developmental Disorders Rating Scale. Psychol Sch 2002;39(6):605-11.
230. Skuse DH, Mandy WP, Scourfield J. Measuring autistic traits: heritability, reliability and validity of the Social and Communication Disorders Checklist. Br J Psychiatry 2005;187:568-72.
231. Constantino JN, Davis SA, Todd RD, Schindler MK, Gross MM, Brophy SL, et al. Validation of a Brief Quantitative Measure of Autistic Traits: Comparison of the Social Responsiveness Scale with the Autism Diagnostic Interview-Revised. J Autism Dev Disord 2003;33(4):427-33.
232. Williams J, Scott F, Stott C, Allison C, Bolton P, Baron-Cohen S, et al. The CAST (Childhood Asperger Syndrome Test): test accuracy. Autism 2005;9(1):45-68.

NON-PHARMACOLOGICAL INTERVENTIONS

PARENT-MEDIATED INTERVENTIONS

☑ Parent intervention programmes should be considered as they may help families interact with their child, promote development and increase parental satisfaction, empowerment and mental health.

COMMUNICATIONS INTERVENTIONS

D
- **Interventions to support communication are indicated, such as the use of visual augmentation, eg in the form of pictures of objects**
- **Interventions to support social communication should be considered, with the most appropriate intervention being assessed on an individual basis.**

☑ Adapting the communicative, social and physical environments of children and young people with ASD may be of benefit *(eg providing visual prompts, reducing requirements for complex social interactions, using routine, timetabling and prompting and minimising sensory irritations).*

BIOMEDICAL AND NUTRITIONAL INTEVENTIONS

☑ Gastrointestinal symptoms in children with ASD should be managed in the same way as in children without ASD.

☑ Advice on diet and food intake should be sought for children and young people with ASD who display significant food selectivity and dysfunctional feeding behaviour, or who are on restricted diets that may be adversely impacting on growth, or producing physical symptoms of recognised nutritional deficiencies or intolerances.

NON-PHARMACOLOGICAL INTERVENTIONS

BEHAVIOURAL/PSYCHOLOGICAL INTERVENTIONS

B **Behavioural interventions should be considered to address a wide range of specific behaviours, both to reduce symptom frequency and severity and to increase the development of adaptive skills.**

☑ Healthcare professionals should be aware that some aberrant behaviours may be due to an underlying lack of skills or may represent a child's strategy for coping with their individual difficulties and circumstances.

☑ Behavioural therapy should be considered for children and young people who experience sleep disturbance.

☑ Children and young people may benefit from occupational therapy, eg providing advice and support in adapting environments, activities and routines in daily life.

A
- **The Lovaas programme should not be presented as an intervention that will lead to normal functioning.**
- **Auditory integration training is not recommended.**
- **Facilitated communication should not be used as a means to communicate with children and young people with ASD.**

☑ Professionals should be aware that some interventions require a level of verbal and cognitive development which precludes their employment with some groups of children and young people with ASD.

PHARMACOLOGICAL INTERVENTIONS

The potential balance of risks and benefits from any pharmacological treatment needs to be considered for each individual child, and discussed as appropriate with them and their parents/carers, so that they can make an informed decision.

No pharmacological treatments have ASD as a licensing indication, and there are few drugs specifically licensed for use in children and adolescents. Pharmacological treatment may be considered when appropriate, for treatment of comorbid psychiatric or neurodevelopmental conditions in ASD or as a short to medium term intervention for specific severe aggression or other symptoms.

☑ Pharmacological treatment of children with ASD should only be undertaken by clinicians with appropriate training and access to pharmacy or other support as required.

RISPERIDONE

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

☑
- Use of a test dose to assess if methylphenidate is tolerated could be considered in children prior to any longer trial
- Side effects should be carefully monitored.

MELATONIN

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

ASSESSMENT, DIAGNOSIS AND CLINICAL INTERVENTIONS FOR CHILDREN AND YOUNG PEOPLE WITH AUTISM SPECTRUM DISORDERS

RECOGNITION, ASSESSMENT & DIAGNOSIS

RECOGNISING POSSIBLE ASD

C **Population screening for ASD is not recommended.**

D **As part of the core programme 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 behaviour**
- **CHAT or 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**

☑ The assessment of children and young people with developmental delay, emotional and behavioural problems, or genetic syndromes should include surveillance for ASD as part of routine practice.

☑ Healthcare professionals should consider informing families that there is a substantial increased risk of ASD in siblings of affected children.

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.**

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

☑ If on the basis of initial assessment, it is suspected that a child or young person may have ASD, they should be referred for specialist assessment.

☑ Regardless of the findings of any earlier assessments, referral for further diagnosis of an ASD assessment should be considered at any age.

☑
- The use of different professional groups in the assessment process is recommended as it may identify different aspects of ASD and aid accurate diagnosis
- Specialist assessment should involve a history-taking element, a clinical observation/assessment element, and the obtaining of wider contextual and functional information
- The appropriateness of an assessment of mental health needs should be considered for all children and young people with ASD.

SPECIALIST ASSESSMENT

HISTORY TAKING

D
- **Healthcare professionals 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

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

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

CONTEXTUAL AND FUNCTIONAL INFORMATION

☑ Information about children and young people's functioning outside the clinic setting, should routinely be obtained from as many available sources as is feasible.

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 in turn, inform intervention.**

☑ Practitioners should note that an individual's level of comprehension may be at a lower developmental level than that suggested by their expressive language skills.

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

☑ Occupational therapy and physiotherapy assessments should be considered where relevant.

BIOMEDICAL INVESTIGATIONS

D **Where clinically relevant, the need for the following should be reviewed for all children and young people with ASD:**
- **physical status, with particular attention to neurological and dysmorphic features**
- **karyotyping and Fragile X DNA analysis**
- **audiological status**
- **investigations to rule out recognised aetiologies of ASD** *(eg tuberous sclerosis)*

SPECIALIST ASSESSMENT (CONTD)

CONDITIONS ASSOCIATED WITH ASD

C Clinicians 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.

☑ Healthcare professionals should recognise that children and young people with ASD may also have medical problems or emotional difficulties/disorders and should have access to the same range of therapeutic interventions as any other child.

SERVICE PROVISION

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

☑ Social work contact with families should be instituted or extended during periods of transition.

INFORMATION AND SUPPORT

D
- **Professionals should offer parents good quality written information and an opportunity to ask questions when disclosing information about their child with ASD**
- **Parents should be provided with information in an accessible and absorbable form.**

☑ Children, young people and their parents should routinely receive written information. This may include copies of the letters sent to the various professionals who have been asked to assess their child.

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

☑ Education and skills interventions should be offered to parents of all children and young people diagnosed with ASD.

☑ Families should be advised of relevant legislation under the Adults with Incapacity Act (Scotland).