

# **Autism: the management and support of children and young people on the autism spectrum**

## **NICE guideline**

**Draft for consultation, March 2013**

If you wish to comment on this version of the guideline, please be aware that all the supporting information and evidence is contained in the full version.

## Contents

Autism: the management and support of children and young people on the autism spectrum.....	1
NICE guideline .....	1
Draft for consultation, March 2013 .....	1
Contents .....	2
Introduction .....	4
Patient-centred care.....	6
Strength of recommendations .....	8
Interventions that must (or must not) be used .....	8
Interventions that should (or should not) be used – a ‘strong’ recommendation.....	8
Interventions that could be used.....	8
Key priorities for implementation.....	10
1 Recommendations.....	14
1.1 General principles of care .....	14
1.2 Families and carers .....	19
1.3 Interventions for the core features of autism.....	20
1.4 Interventions for behaviour that challenges .....	21
1.5 Interventions for life skills.....	26
1.6 Interventions for autism that should not be used in any context .....	26
1.7 Interventions for speech and language problems associated with autism.....	26
1.8 Interventions for sleep problems associated with autism .....	26
1.9 Interventions for coexisting mental health and medical problems.....	27
1.10 Transition to adult services .....	28
2 Research recommendations .....	30
2.1 Case management for children (aged 6-11 years) with autism.....	30
2.2 Managing behaviour that challenges in children and young people with autism .....	30
2.3 Managing sleep problems in children with autism.....	32

Autism: the management and support of children and young people on the autistic spectrum: NICE guideline DRAFT (March 2013) Page 2 of 40

2.4	Treating comorbid anxiety in children and young people with autism	32
2.5	Sensory sensitivities in children with autism .....	34
3	Other information .....	35
3.1	Scope and how this guideline was developed .....	35
3.2	Related NICE guidance .....	36
4	The Guideline Development Group, National Collaborating Centre and NICE project team.....	37
4.1	Guideline Development Group.....	37
4.2	National Collaborating Centre for Mental Health.....	39
4.3	NICE project team .....	39

## Introduction

Autism is a neurodevelopmental disorder, which in most people with the condition has a lifelong impact. Its core features include impaired social interaction, impaired communication, and restricted and repetitive interests and activities. In addition to these features, children and young people with autism frequently experience a range of cognitive, learning, language, medical, emotional and behavioural problems, including: a need for routine; difficulty in understanding other people, including their intentions, feelings and perspectives; sleeping and eating disturbances; and mental health problems such as anxiety, depression, problems with attention, self-injurious behaviour and other challenging, sometimes aggressive behaviour. These features may substantially impact on the quality of life of the individual and lead to a social vulnerability, especially in the most able group.

The clinical picture of autism is variable because of differences in the severity of autism itself, the presence of coexisting conditions and levels of cognitive ability, from profound intellectual disability in some people to average or above average intelligence quotient [IQ] in others.

Both the major diagnostic classification systems (International Classification of Diseases – 10th revision and Diagnostic and Statistical Manual of Mental Disorder – 4th edition) use the term 'pervasive developmental disorder', which encompasses autism, Asperger's syndrome and atypical autism (or 'pervasive developmental disorder not otherwise specified'). For a diagnosis of autism to be made, there must be impairments present and an impact on the person's adaptive function. Both classification systems are undergoing revision and have announced that the term 'autism spectrum disorder' will be used in future editions. For this guideline we will use the term 'autism' to include all autism spectrum disorders.

Although autism was once thought to be an uncommon developmental disorder, recent studies have reported prevalence rates of at least 1% in children and young people. Autism is diagnosed more frequently in boys.

## DRAFT FOR CONSULTATION

The core autism behaviours are typically present in early childhood, although some features may not manifest until a change of situation, for example, the start of nursery or school or, less commonly, the transition to secondary school. Regression or stasis of language and social behaviour is reported for 20–30% of children with autism. This usually, but not exclusively, occurs between the ages of 1 and 2 years, and the reasons for regression and stasis are unknown.

The way in which autism is expressed will differ across different ages and therefore for any person may change over time as they mature, in response to environmental demands, in response to interventions, and in the context of coexisting conditions.

Around 70% of people with autism also meet diagnostic criteria for at least one other (often unrecognised) psychiatric disorder that further impairs psychosocial functioning, for example, attention deficit hyperactivity disorder (ADHD) or anxiety disorders. Intellectual disability (IQ below 70) coexists in approximately 50% of children and young people with autism.

There are many claims of a 'cure' for autism, all of which are without foundation. However, there is a range of interventions which can help some of the core features of autism and some of the symptoms, behaviours and problems commonly associated with autism and to support families. There is also evidence for treatment strategies to reduce behaviour that challenges. This guideline will summarise the different ways that health and social care professionals can provide support, treatment and help for children and young people with autism, and their families and carers, from the early years through to their transition into young adult life.

This guideline covers children and young people from birth until their 19th birthday with autism (across the full range of intellectual ability) and their parents and carers. It should be used alongside [Autism: recognition, referral and diagnosis of children and young people on the autism spectrum](#) (NICE clinical guideline 128) and [Autism: recognition, referral, diagnosis and management of adults on the autism spectrum](#) (NICE clinical guideline 142).

Autism: the management and support of children and young people on the autistic spectrum: NICE guideline DRAFT (March 2013) Page 5 of 40

No antipsychotic medication has a UK marketing authorisation specifically for children with autism. The prescriber should follow relevant professional guidance, taking full responsibility for the decision. The patient (or those with authority to give consent on their behalf) should provide informed consent, which should be documented. See the General Medical Council's [Good practice in prescribing medicines – guidance for doctors](#) for further information. Where recommendations have been made for the use of drugs outside their licensed indications ('off-label use'), these drugs are marked with a footnote in the recommendations.

## Patient-centred care

This guideline offers best practice advice on the care of children and young people with autism.

Patients and healthcare professionals have rights and responsibilities as set out in the [NHS Constitution](#) – all NICE guidance is written to reflect these. Treatment and care should take into account individual needs and preferences. Patients should have the opportunity to make informed decisions about their care and treatment, in partnership with their healthcare professionals. If someone does not have the capacity to make decisions, healthcare professionals should follow the [Department of Health's advice on consent](#), the [code of practice that accompanies the Mental Capacity Act](#) and the supplementary [code of practice on deprivation of liberty safeguards](#). In Wales, healthcare professionals should follow [advice on consent from the Welsh Government](#).

If the patient is under 16, healthcare professionals should follow the guidelines in the Department of Health's [Seeking consent: working with children](#). Families and carers should also be given the information and support they need to help the child or young person in making decisions about their treatment.

If a young person is moving between paediatric and adult services, care should be planned and managed according to the best practice guidance

## DRAFT FOR CONSULTATION

described in the Department of Health's [Transition: getting it right for young people](#).

Adult and paediatric healthcare teams should work jointly to provide assessment and services to young people with autism and there should be clarity about who is the lead clinician to ensure continuity of care.

## **Strength of recommendations**

Some recommendations can be made with more certainty than others. The Guideline Development Group makes a recommendation based on the trade-off between the benefits and harms of an intervention, taking into account the quality of the underpinning evidence. For some interventions, the Guideline Development Group is confident that, given the information it has looked at, most patients would choose the intervention. The wording used in the recommendations in this guideline denotes the certainty with which the recommendation is made (the strength of the recommendation).

For all recommendations, NICE expects that there is discussion with the patient about the risks and benefits of the interventions, and their values and preferences. This discussion aims to help them to reach a fully informed decision (see also 'Patient-centred care').

### ***Interventions that must (or must not) be used***

We usually use 'must' or 'must not' only if there is a legal duty to apply the recommendation. Occasionally we use 'must' (or 'must not') if the consequences of not following the recommendation could be extremely serious or potentially life threatening.

### ***Interventions that should (or should not) be used – a 'strong' recommendation***

We use 'offer' (and similar words such as 'refer' or 'advise') when we are confident that, for the vast majority of patients, an intervention will do more good than harm, and be cost effective. We use similar forms of words (for example, 'Do not offer...') when we are confident that an intervention will not be of benefit for most patients.

### ***Interventions that could be used***

We use 'consider' when we are confident that an intervention will do more good than harm for most patients, and be cost effective, but other options may be similarly cost effective. The choice of intervention, and whether or not to



have the intervention at all, is more likely to depend on the patient's values and preferences than for a strong recommendation, and so the healthcare professional should spend more time considering and discussing the options with the patient.

## Key priorities for implementation

The following recommendations have been identified as priorities for implementation.

### General principles of care

- All children and young people with autism should have unrestricted access to health and social care services, including mental health services, regardless of their intellectual ability or any coexisting diagnosis.  
[recommendation 1.1.1]
  
- Health and social care professionals working with children and young people with autism in any setting should receive training in autism awareness and basic skills in managing autism, which should include:
  - the nature and course of autism
  - the nature and course of behaviour that challenges in children and young people with autism
  - recognition of common coexisting conditions, including mental health problems (such as anxiety and depression), physical health problems (such as epilepsy), sleep problems and other neurodevelopmental conditions (such as attention deficit hyperactivity disorder [ADHD])
  - the importance of key transition points, such as changing schools or health or social care services
  - the child or young person's experience of autism and its impact
  - the impact of autism on the family (including siblings) or carers
  - the impact of the social and physical environment on the child or young person
  - how to assess risk (including self-harm, harm to others, self-neglect, breakdown of family or residential support, exploitation or abuse by others) and develop a risk management plan
  - the changing needs that arise with puberty (including the child or young person's understanding of intimate relationships and

related problems that may occur, for example, misunderstanding the behaviour of others)

- how to provide individualised care and support.

[recommendation 1.1.8]

### **Making adjustments to the social and physical environment and processes of care**

- Take into account the physical environment in which children and young people with autism are supported and cared for and minimise any negative impact by making reasonable adjustments or adaptations to the:
  - amount of personal space given
  - setting, using visual supports (for example, words, pictures or symbols)
  - colour of walls and furnishings
  - lighting
  - noise levels
  - processes of health or social care (for example, arranging appointments at the beginning or end of the day to minimise waiting time, or providing single rooms for children and young people admitted to hospital).

[recommendation 1.1.9]

### **Interventions for the core features of autism**

- Consider a social-communication intervention for the management of the core features of autism in children and young people. For pre-school children consider delivering the intervention with parent, carer or teacher mediation. For school-aged children consider delivering the intervention with peer mediation. [recommendation 1.3.1]

### **Interventions for behaviour that challenges**

- Include the potential for behaviour that challenges in routine assessment and care planning in children and young people with autism. Assess factors that may increase this risk, including:

- coexisting physical disorders, such as pain or gastrointestinal disorders
- coexisting mental health problems (such as anxiety or depression) and other neurodevelopmental conditions (such as ADHD)
- the physical environment, including sensory factors such as lighting and noise levels
- the social environment, including home, school and leisure activities
- changes to routines or personal circumstances
- impairments in communication that may result in difficulty understanding situations or in expressing needs and wishes
- developmental change, including puberty
- exploitation or abuse by others
- inadvertent reinforcement of behaviour that challenges.

[recommendation 1.4.1]

- If no coexisting mental health or behavioural problem, physical disorder or environmental problem has been identified as triggering or maintaining the behaviour that challenges, offer the child or young person a psychosocial intervention (informed by a functional behavioural analysis) as a first-line treatment. [recommendation 1.4.7]
- Consider antipsychotic medication<sup>1</sup> for managing behaviour that challenges in children and young people with autism when psychosocial or other interventions are insufficient or could not be delivered because of the

---

<sup>1</sup> At the time of consultation (April 2013), no antipsychotic medication had a UK marketing authorisation for use in children for this indication. The prescriber should follow relevant professional guidance, taking full responsibility for the decision. Informed consent should be obtained and documented. See the General Medical Council's [Good practice in prescribing medicines – guidance for doctors](#) for further information.

severity of the behaviour. Antipsychotic medication should be initially prescribed and monitored by a specialist who should:

- identify the target behaviour
- decide on an appropriate measure to monitor effectiveness, including frequency and severity of the behaviour and a measure of global impact
- review the effectiveness and any side effects of the medication after 3–4 weeks
- stop treatment if there is no indication of a clinically important response at 6 weeks.

[recommendation 1.4.10]

### **Families and carers**

- Offer families (including siblings) and carers an assessment of their own needs, including whether they have:
  - personal, social and emotional support
  - practical support in their caring role, including short breaks and emergency plans
  - a plan for future care for the child or young person, including transition to adult services.

[recommendation 1.2.2]

### **Transition to adult services**

- For young people aged 16 or older whose needs are complex or severe, use the care programme approach (CPA) in England, or care and treatment plans in Wales, as an aid to transfer between services. Involve the young person in the planning and, where appropriate, their parents or carers. Provide information about adult services to the young person, including their right to a social care assessment at age 18.

[recommendation 1.10.2]

# 1 Recommendations

The following guidance is based on the best available evidence. The full guideline [\[hyperlink to be added for final publication\]](#) gives details of the methods and the evidence used to develop the guidance.

## 1.1 *General principles of care*

### **Access to health and social care services**

1.1.1 All children and young people with autism should have unrestricted access to health and social care services, including mental health services, regardless of their intellectual ability or any coexisting diagnosis.

### **Organisation and delivery of services**

1.1.2 The overall configuration and development of local services for children and young people with autism should be coordinated by a local autism multi-agency strategy group (for people with autism of all ages) in line with [Autism: recognition, referral and diagnosis of children and young people on the autism spectrum](#) (NICE clinical guideline 128) and [Autism: recognition, referral, diagnosis and management of adults on the autism spectrum](#) (NICE clinical guideline 142).

1.1.3 The assessment, management and coordination of care for children and young people with autism should be provided through local specialist community-based multidisciplinary teams ('local autism teams') in line with [Autism: recognition, referral and diagnosis of children and young people on the autism spectrum](#) (NICE clinical guideline 128) and [Autism: recognition, referral, diagnosis and management of adults on the autism spectrum](#) (NICE clinical guideline 142).

1.1.4 Local autism teams should ensure that every child or young person diagnosed with autism has a case coordinator or key worker to

manage and coordinate treatment, care, support and transition to adult care in line with [Autism: recognition, referral and diagnosis of children and young people on the autism spectrum](#) (NICE clinical guideline 128).

1.1.5 Local autism teams should have the skills (or access to skills) to provide or organise the interventions and care recommended in this guideline for children and young people with autism who have particular needs, including those:

- with coexisting conditions such as severe visual and hearing impairments; other medical problems including epilepsy or sleep and elimination problems; motor disorders including cerebral palsy; intellectual disability; severe communication impairment (including lack of spoken language) or complex language disorders; or complex mental health disorders
- who are looked after by a local authority
- from immigrant groups
- with regression in skills.

1.1.6 Local autism teams should have a key role in the delivery and coordination of:

- specialist care and interventions for children and young people with autism, including those living in specialist residential accommodation
- advice, training and support for other health and social care professionals and staff (including in residential and community settings) who may be involved in the care of children and young people with autism
- assessing and managing behaviour that challenges
- assessing and managing coexisting conditions in autism
- reassessing needs throughout childhood and adolescence, taking particular account of transition to adult services

- supporting access to leisure and enjoyable activities
- supporting access to and maintaining contact with educational, housing and employment services
- providing support for families (including siblings) and carers, including offering short breaks and other respite care
- producing local protocols for:
  - information sharing, communication and collaborative working among healthcare, education and social care services, including arrangements for transition to adult services
  - shared care arrangements with primary care providers and ensuring that clear lines of communication between primary and secondary care are maintained.

1.1.7 Consider referring children and young people with autism to a regional or national autism service if there is a lack of:

- local skills and competencies needed to provide interventions and care for a child or young person with a complex coexisting condition, such as a severe sensory or motor impairment or mental health problem, **or**
- response to the therapeutic interventions provided by the local autism team.

### **Knowledge and competence of health and social care professionals**

1.1.8 Health and social care professionals working with children and young people with autism in any setting should receive training in autism awareness and basic skills in managing autism, which should include:

- the nature and course of autism
- the nature and course of behaviour that challenges in children and young people with autism
- recognition of common coexisting conditions, including mental health problems (such as anxiety and depression), physical



health problems (such as epilepsy), sleep problems and other neurodevelopmental conditions (such as attention deficit hyperactivity disorder [ADHD])

- the importance of key transition points, such as changing schools or health or social care services
- the child or young person's experience of autism and its impact
- the impact of autism on the family (including siblings) or carers
- the impact of the social and physical environment on the child or young person
- how to assess risk (including self-harm, harm to others, self-neglect, breakdown of family or residential support, exploitation or abuse by others) and develop a risk management plan
- the changing needs that arise with puberty (including the child or young person's understanding of intimate relationships and related problems that may occur, for example, misunderstanding the behaviour of others)
- how to provide individualised care and support.

### **Making adjustments to the social and physical environment and processes of care**

1.1.9 Take into account the physical environment in which children and young people with autism are supported and cared for and minimise any negative impact by making reasonable adjustments or adaptations to the:

- amount of personal space given
- setting, using visual supports (for example, words, pictures or symbols)
- colour of walls and furnishings
- lighting
- noise levels
- processes of health or social care (for example, arranging appointments at the beginning or end of the day to minimise

waiting time, or providing single rooms for children and young people admitted to hospital).

### **Information and involvement in decision-making**

1.1.10 Provide children and young people with autism, and their families and carers, with information about support available on an ongoing basis, suitable for the child or young person's needs and developmental level. This may include:

- contact details for local and national organisations that can provide:
  - support and an opportunity to meet other people, including families or carers, with experience of autism
  - information on courses about autism
  - advice on welfare benefits, rights and entitlements
  - information about educational and social support and leisure activities
- information about services and treatments available
- information to help prepare for the future, for example, transition to adult services.

- 1.1.11 Work with children and young people with autism and their family and carers to anticipate major life changes (such as puberty, starting or changing schools, or the birth of a sibling) and make arrangements for personal and social support during times of increased need.
- 1.1.12 Explore with children and young people with autism, and their families and carers, their interest in being involved in shared decision-making. If children and young people express interest, offer a collaborative approach to treatment and care that takes their preferences into account.

## **1.2 *Families and carers***

- 1.2.1 Offer all families (including siblings) and carers verbal and written information about:
- autism and its management
  - local and national support groups specifically for families and carers
  - their right to short breaks and other respite care and to a formal carer's assessment of their own physical and mental health needs, and how to access these.
- 1.2.2 Offer families (including siblings) and carers an assessment of their own needs, including whether they have:
- personal, social and emotional support
  - practical support in their caring role, including short breaks and emergency plans
  - a plan for future care for the child or young person, including transition to adult services.
- 1.2.3 When the needs of families and carers have been identified, discuss help available locally and, taking into account their

preferences, offer information, advice, training and support, especially if they:

- need help with the personal, social or emotional care of the child or young person, including age-related needs such as self-care, relationships and sexuality
- are involved in the delivery of an intervention for the child or young person in collaboration with health and social care professionals.

### **1.3 *Interventions for the core features of autism***

#### **Psychosocial interventions**

1.3.1 Consider a social-communication intervention for the management of the core features of autism in children and young people. For pre-school children consider delivering the intervention with parent, carer or teacher mediation. For school-aged children consider delivering the intervention with peer mediation.

1.3.2 A social-communication intervention should include training for parents, carers and teachers in strategies for increasing joint attention and reciprocal communication, using techniques such as video-feedback methods. Such strategies should:

- be appropriate for the child or young person's developmental level and sensitive and responsive to their patterns of communication and interaction
- include techniques of modelling and feedback
- include techniques to expand communication, interactive play and social routines.

## **Pharmacological and dietary interventions**

1.3.3 Do not use the following interventions for the management of core features of autism in children and young people:

- antipsychotics
- antidepressants
- anticonvulsants
- exclusion diets (such as gluten- or casein-free diets).

## **1.4 *Interventions for behaviour that challenges***

### **Anticipating and preventing behaviour that challenges**

1.4.1 Include the potential for behaviour that challenges in routine assessment and care planning in children and young people with autism. Assess factors that may increase this risk, including:

- coexisting physical disorders, such as pain or gastrointestinal disorders
- coexisting mental health problems (such as anxiety or depression) and other neurodevelopmental conditions (such as ADHD)
- the physical environment, including sensory factors such as lighting and noise levels
- the social environment, including home, school and leisure activities
- changes to routines or personal circumstances
- impairments in communication that may result in difficulty understanding situations or in expressing needs and wishes
- developmental change, including puberty
- exploitation or abuse by others
- inadvertent reinforcement of behaviour that challenges.

1.4.2 Develop a care plan that identifies factors that may provoke behaviour that challenges and outline the steps needed to address them, including:

- treatment (for example, for coexisting physical, mental health and behavioural problems)
- support (for example, for families)
- necessary adjustments (for example, environmental changes).

### **Assessment and initial intervention for behaviour that challenges**

1.4.3 If a child or young person's behaviour becomes challenging, reassess factors identified in the care plan (see recommendation 1.4.2), and assess for any new factors that could provoke the behaviour.

1.4.4 Address factors that may trigger or maintain behaviour that challenges by offering:

- treatment for physical disorders, or coexisting mental health and behavioural problems
- interventions aimed at changing the environment, such as:
  - providing advice to families and carers
  - changes to the physical environment (see recommendation 1.1.9).

1.4.5 If behaviour remains challenging despite attempts to address the underlying possible causes, consult senior colleagues and undertake a multidisciplinary review.

1.4.6 At the multidisciplinary review, consider the following when choosing an intervention for behaviour that challenges:

- the nature, severity and impact of the behaviour
- the child or young person's physical and communication needs and capabilities

- the environment
- the support and training that families, carers or staff may need to implement the intervention effectively
- the preferences of the family or carers and the child or young person with autism
- the child or young person's experience of, and response to, previous interventions.

### **Psychosocial interventions for behaviour that challenges**

1.4.7 If no coexisting mental health or behavioural problem, physical disorder or environmental problem has been identified as triggering or maintaining the behaviour that challenges, offer the child or young person a psychosocial intervention (informed by a functional behavioural analysis) as a first-line treatment.

1.4.8 The functional behavioural analysis should inform the choice of intervention by identifying:

- factors that appear to trigger the behaviour
- patterns of behaviour
- the needs that the child or young person is attempting to meet by performing the behaviour
- the consequences of the behaviour (that is, the reinforcement received as a result of the behaviour).

1.4.9 Psychosocial interventions for behaviour that challenges should include:

- clearly identified target behaviour
- a focus on outcomes that are linked to quality of life
- assessment and modification of environmental factors that may contribute to initiating or maintaining the behaviour
- a clearly defined intervention strategy that takes into account the developmental level and coexisting problems of the child or young person
- a specified timescale to meet intervention goals (to promote modification of intervention strategies that do not lead to change within a specified time)
- a systematic measure of the target behaviour taken before and after the intervention to ascertain whether the agreed outcomes are being met.

### **Pharmacological interventions for behaviour that challenges**

1.4.10 Consider antipsychotic medication<sup>2</sup> for managing behaviour that challenges in children and young people with autism when psychosocial or other interventions are insufficient or could not be delivered because of the severity of the behaviour. Antipsychotic medication should be initially prescribed and monitored by a specialist who should:

- identify the target behaviour

---

<sup>2</sup> At the time of consultation (April 2013), no antipsychotic medication had a UK marketing authorisation for use in children for this indication. The prescriber should follow relevant professional guidance, taking full responsibility for the decision. Informed consent should be obtained and documented. See the General Medical Council's [Good practice in prescribing medicines – guidance for doctors](#) for further information.



- decide on an appropriate measure to monitor effectiveness, including frequency and severity of the behaviour and a measure of global impact
- review the effectiveness and any side effects of the medication after 3–4 weeks
- stop treatment if there is no indication of a clinically important response at 6 weeks.

1.4.11 If antipsychotic medication is prescribed, start with a low dose, use the minimum effective dose needed and regularly review the benefits of the antipsychotic medication and any adverse events.

1.4.12 When choosing antipsychotic medication, take into account side effects, acquisition costs, the child or young person's preference (or that of their parent or carer where appropriate) and response to previous treatment with an antipsychotic.

1.4.13 When prescribing is transferred to primary or community care, the specialist initiating the prescription should give clear guidance to the practitioner who will be responsible for continued prescribing about:

- the selection of target behaviours
- monitoring of beneficial and side effects
- the potential for minimally effective dosing
- the proposed duration of treatment
- plans for stopping treatment.

## **1.5 *Interventions for life skills***

- 1.5.1 Offer children and young people with autism support in developing coping strategies and accessing community services, including developing skills to access public transport, employment and leisure facilities.

## **1.6 *Interventions for autism that should not be used in any context***

- 1.6.1 Do not use the following interventions for children and young people with autism in any context:

- secretin
- chelation
- hyperbaric oxygen therapy.

## **1.7 *Interventions for speech and language problems associated with autism***

- 1.7.1 Consult a speech and language expert in the autism team when managing receptive and expressive language problems in children and young people with autism (including when they are non-verbal).
- 1.7.2 Do not use neurofeedback to manage speech and language problems in children and young people with autism.
- 1.7.3 Do not use auditory integration training to manage speech and language problems in children and young people with autism.

## **1.8 *Interventions for sleep problems associated with autism***

- 1.8.1 Consult a sleep expert in the autism team when managing sleep problems in children and young people with autism.

- 1.8.2 Do not use omega-3 fatty acids to manage sleep problems in children and young people with autism.

## **1.9 *Interventions for coexisting mental health and medical problems***

- 1.9.1 Offer psychosocial and pharmacological interventions for the management of coexisting mental health or medical problems in children and young people with autism in line with NICE guidance for children and young people, including:

- [Antisocial behaviour and conduct disorders in children and young people](#) (NICE clinical guideline 158)
- [Attention deficit hyperactivity disorder \(ADHD\)](#) (NICE clinical guideline 72)
- [Constipation in children and young people](#) (NICE clinical guideline 99).
- [Depression in children and young people](#) (NICE clinical guideline 28)
- [Epilepsy](#) (NICE clinical guideline 137)
- [Obsessive-compulsive disorder \(OCD\) and body dysmorphic disorder \(BDD\)](#) (NICE clinical guideline 31)
- [Post-traumatic stress disorder \(PTSD\)](#) (NICE clinical guideline 26).

- 1.9.2 Consider the following for children and young people with autism and anxiety who have the verbal and cognitive ability to engage in a cognitive behavioural therapy (CBT) intervention:

- group CBT adjusted to the needs of children and young people with autism
- individual CBT for children and young people who find group-based activities difficult.

1.9.3 Consider adaptations to the method of delivery of CBT for children and young people with autism and anxiety, such as:

- emotion recognition training
- greater use of written and visual information, structured worksheets and a more concrete and structured approach
- simplified cognitive activities (for example, multiple-choice worksheets)
- involving a parent or carer to support the implementation of the intervention, for example, involving them in therapy sessions
- maintaining attention by offering regular breaks
- incorporating the child or young person's special interests into therapy if possible.

## **1.10 *Transition to adult services***

1.10.1 Reassess young people with autism who are receiving treatment and care from child and adolescent mental health services (CAMHS) or paediatric services at around 14 years to establish the need for continuing treatment into adulthood. If treatment is necessary, make arrangements for a smooth transition to adult services and give information to the young person about the treatment and services they may need. The timing of transition may vary locally and individually but should usually be completed by the time the young person is 18 years. Variations should be agreed by both child and adult services.

1.10.2 For young people aged 16 or older whose needs are complex or severe, use the care programme approach (CPA) in England, or care and treatment plans in Wales, as an aid to transfer between services. Involve the young person in the planning and, where appropriate, their parents or carers. Provide information about adult services to the young person, including their right to a social care assessment at age 18.

- 1.10.3 As part of the preparation for the transition to adult services, health and social care professionals should carry out a comprehensive assessment of the young person with autism. The assessment should make best use of existing documentation about personal, educational, occupational and social functioning, and should include assessment of any coexisting conditions, especially depression, anxiety, ADHD, OCD and global delay or intellectual disability, in line with [Autism: recognition, referral, diagnosis and management of adults on the autism spectrum](#) (NICE clinical guideline 142).
- 1.10.4 During transition to adult services, consider a formal meeting involving health and social care and other relevant professionals from child and adult services.

## **2 Research recommendations**

### **2.1 *Case management for children (aged 6-11 years) with autism***

What is the value of case management (defined by protocol and delivered in addition to usual care) for children (aged 6–11 years) with autism in terms of parental satisfaction, functioning and stress and child psychopathology?

#### **Why is this important**

Autism is well characterised as a chronic disorder with lifelong disability, yet the current health management structure is usually organised around single episodes of care. There is a significant body of international research into the management of chronic conditions such as diabetes and asthma, but nothing on autism. Key to commonly accepted strategies in chronic illness is the provision of case management. The theory and practice of management of chronic illness, as well as widely expressed service-user opinion, indicate that a chronic care model for the organisation of autism services could be appropriate and cost effective.

Case management for children with autism should be formally evaluated in a randomised controlled trial (RCT) reporting short- and medium-term outcomes (including cost-effectiveness) with a follow-up of at least 6 months and again at 12 months. The outcomes (parental satisfaction, functioning and stress and child psychopathology) should be assessed by structured clinical interviews, parent- and self-reports using validated questionnaires and objective measures of behaviour. The study needs to be large enough to determine the presence of clinically important effects, and mediators and moderators (in particular the child or young person's age) should be investigated.

### **2.2 *Managing behaviour that challenges in children and young people with autism***

Is a group-based parent training intervention for parents or carers of children and young people with autism clinically and cost effective in reducing early

and emerging behaviour that challenges in the short- and medium-term compared with treatment as usual?

### **Why this is important**

Behaviour that challenges is a common and potentially very serious problem for children and young people with autism. It is not only an indicator of distress but often limits their participation in family life, education and community activities. Once behaviour that challenges has become established, it is unlikely to diminish without intervention. Presently, many children and young people are referred only when the behaviour has become severely impairing to themselves and/or others, when they represent a threat to themselves and others or when there is a breakdown in everyday life (often leading to high levels of educational support including residential schooling, long-term hospital admissions and social service support). At this point, behavioural interventions may be difficult or impossible to initiate and antipsychotic medication is used. However, antipsychotic medication is undesirable as a first-line intervention because it is symptomatic in its benefits, has significant long-term adverse effects and behaviour problems typically recur when it is stopped.

This question would be answered using an RCT design reporting short- and medium-term outcomes. The intervention should consider the main causes of behaviour that challenges that are likely to be amenable to a behavioural intervention, such as educating parents about simple functional behaviour analysis to identify triggers and examine patterns of reinforcement. The primary outcomes should be short- and medium-term reduction in behaviour that challenges; a priority will be to include or develop robust and ecologically valid blinded outcome measures. Secondary outcomes should include parental and sibling stress, quality of life and adaptive function of the child or young person. In addition, the use of medication in the medium term to manage behaviour that challenges should be assessed. Cost effectiveness should include use of a wide range of services, such as additional educational support and social services as well as the use of health services by other family members.

### **2.3 *Managing sleep problems in children with autism***

Is a sleep hygiene intervention or melatonin a clinically and cost effective treatment of sleep onset, night waking and reduced total sleep in children (aged 4–10 years) with autism?

#### **Why is this important?**

Sleep problems are common in autism and have a significant negative impact on parental coping as well as on the child. There is some evidence that sleep hygiene techniques and use of melatonin are effective in autism. However existing studies of melatonin have used different groups and different preparations of melatonin precluding meta-analysis.

The intervention being assessed should be formally evaluated in an RCT in 3 stages: (1) recording sleep onset, night waking and total sleep time over 3 months using a diary completed by parents and actigraphy; (2) random allocation to sleep hygiene treatment by booklet or by professional contact for those with a sleep problem; (3) after 3 months random allocation to slow-release melatonin or placebo for those with persistent sleep problems; after a further 3 months, those on placebo would be offered the active preparation.

It should report primary and secondary outcomes with a follow-up at 12 months for all participants. Primary outcomes should include increased total sleep time and decreased night waking. Secondary outcomes should include improved sleep onset, a change in Aberrant Behaviour Checklist measures of behaviour that challenges, and improvement in parental stress index and satisfaction and the child's cognitive function.

### **2.4 *Treating comorbid anxiety in children and young people with autism***

What is the comparative clinical and cost effectiveness of pharmacological and psychosocial interventions for anxiety disorders in children and young people with autism?



### **Why this is important**

Anxiety disorders are common in children and young people, including in those with autism. Early trials of CBT for anxiety in children and young people with autism have shown promising results but individual studies have methodological shortcomings. Furthermore, the common pharmacological approaches have not been evaluated, despite their demonstrated efficacy in otherwise typically developing children and their suggested effects in adults with anxiety and autism. In some regions, selective serotonin reuptake inhibitors (SSRIs) are being prescribed for this indication despite the absence of an evidence base or a licence. Having evidence-based alternative interventions would provide greater choice for children and young people and their parents or carers, and the possibility of offering an alternative intervention if the first is unsuccessful.

This question should be answered using a parallel-arm RCT design comparing pharmacological and psychosocial interventions with placebo in children and young people with autism and an anxiety disorder (generalised anxiety disorder, separation anxiety disorder, social anxiety, panic disorder and agoraphobia). Pharmacological treatment should be with an SSRI and the dosing protocol should follow that used in research in typically developing children but should have the option of evaluating outcome at a lower dose than that usually expected to be effective (because of the suggestion that children and young people with autism may respond to lower doses). The SSRI should be blinded with an identical placebo and the use of an 'attention' or other psychosocial control group. The psychosocial intervention should be manualised and based on the cognitive behavioural approach used in children and young people with and without autism that has been shown to be effective in previous trials. The sample size should be powered to deliver precise effect size estimates for medication and CBT arms. If possible the full age and intellectual range of children and young people should be included and there should be demonstrable impairment secondary to the anxiety disorder.

Primary outcome measures should be reduction in anxiety symptoms. It is likely that parent-reported measures will be most pragmatic but self- and

teacher-reported measures should also be considered as secondary outcomes, as well as blinded measures such as heart rate, heart rate variability and skin conductance. Additional secondary outcome measures should include patient satisfaction, changes in adaptive function and quality of life and disruptive behaviour. Adverse effects should be evaluated. An economic evaluation should be included.

## **2.5      *Sensory sensitivities in children with autism***

Does sensory integration therapy reduce sensory sensitivities in children (aged 5–10 years) with autism across a range of contexts?

### **Why is this important?**

First-hand accounts describe the considerable negative impact that sensory sensitivities can have on the daily lives of both affected individuals and their families or carers. A wide range of sensory-based interventions are used in the UK across health and education for people with autism. Currently sensory integration therapy is one of the most frequently requested interventions by parents of young children with autism and sensory processing difficulties. There is some limited evidence the sensory integration therapy can elicit improvements in sensory problems, however, the quality was low and there are no adequately powered RCTs or UK-funded research. Moreover the intervention itself is very labour intensive.

The intervention should be formally evaluated in an RCT. The intervention being assessed would be a manualised sensory integration treatment in children aged 5-10 years with a diagnosis of autism, who are in full-time education, and who have been identified, using a standardised measure, as having sensory sensitivities. It should be administered by an appropriately qualified professional (an occupational therapist) for a specified period of time using fidelity measures to ensure adherence to the programme. The intervention should be supported with a programme of activities in school to encourage generalisation of skills. It should be compared with a programme of school-based activities to meet the participants' sensory needs as identified

using the standardised measure. This intervention should be of the same intensity and have the same number of sessions as the primary intervention.

There should be blinded assessment of the individuals' sensory sensitivity, pre- and post-intervention, using primary measures specified at the outset of the study and standardised assessment of parent-reported change in repetitive, stereotypical behaviours including motor mannerisms such as hand flapping or spinning. Secondary outcomes may include change in on-task behaviour as observed by a blinded assessor measuring amount of time taken on tasks in the classroom. The research will also need to include the systematic monitoring of any adverse effects during the course of the intervention and a health economic analysis. Investigators should also consider any ongoing support in order to maintain any observed gains after the initial treatment period.

### **3 Other information**

#### **3.1 *Scope and how this guideline was developed***

NICE guidelines are developed in accordance with a [scope](#) that defines what the guideline will and will not cover.

##### **How this guideline was developed**

NICE commissioned the National Collaborating Centre for Mental Health to develop this guideline. The Centre established a Guideline Development Group (see section 4), which reviewed the evidence and developed the recommendations.

The methods and processes for developing NICE clinical guidelines are described in [The guidelines manual](#).

### **3.2      *Related NICE guidance***

Details are correct at the time of consultation on the guideline (April 2013).

Further information is available on [the NICE website](#).

#### **Published**

##### ***General***

- [Medicines adherence](#). NICE clinical guidance 76 (2011).

##### ***Condition-specific***

- [Antisocial behaviour and conduct disorders in children and young people](#). NICE clinical guideline 158 (2013).
- [Autism in adults](#). NICE clinical guideline 142 (2012).
- [Epilepsy](#). NICE clinical guideline 137 (2012).
- [Autism diagnosis in children and young people](#). NICE clinical guideline 128. (2011).
- [Constipation in children and young people](#). NICE clinical guideline 99 (2010).
- [Attention deficit hyperactivity disorder \(ADHD\)](#). NICE clinical guideline 72 (2008)
- [Obsessive-compulsive disorder \(OCD\) and body dysmorphic disorder \(BDD\)](#). NICE clinical guideline 31 (2005)
- [Post-traumatic stress disorder \(PTSD\)](#). NICE clinical guideline 26 (2005)
- [Depression in children and young people](#). NICE clinical guideline 28 (2005)

## **4 The Guideline Development Group, National Collaborating Centre and NICE project team**

### **4.1 *Guideline Development Group***

#### **Gillian Baird (Chair)**

Consultant Paediatrician and Professor of Paediatric Neurodisability, Guy's and St Thomas' NHS Foundation trust and King's Health partners, London

#### **Tim Kendall (Facilitator)**

Medical Director and Consultant Psychiatrist, Sheffield Health and Social Care NHS Foundation Trust and Director, National Collaborating Centre for Mental Health

#### **Virginia Bovell**

Patient and carer member

#### **Carole Buckley**

General Practitioner, Bristol

#### **Tony Charman**

Chair in Clinical Child Psychology, King's College London

#### **Nick Gould**

Emeritus Professor of Social Work, University of Bath

#### **Jonathan Green**

Professor of Child and Adolescent Psychiatry, King's College London

Honorary consultant, Royal Manchester Children's Hospital

#### **Patricia Howlin**

Emeritus Professor of Clinical Child Psychology, King's College London

#### **Glenys Jones**

Lecturer in Autism, University of Birmingham

**Ann Le Couteur**

Professor of Child and Adolescent Psychiatry, Newcastle University

Honorary Child and Adolescent Consultant Psychiatrist, Northumberland Tyne and Wear NHS Foundation Trust

**Robin Mackenzie**

Patient and carer member, Medical Law and Ethics, University of Kent

**Barbara Parker**

Patient and carer member

**Emily Simonoff**

Academic lead, Child and Adolescent Mental Health, Institute of Psychiatry

**Stephen Simpson**

Community Learning Disability Nurse, South West Yorkshire Partnership NHS Foundation Trust

**Vicky Slonims**

Clinical Lead Speech and Language Therapist, Guy's and St Thomas' NHS Foundation Trust

Honorary Senior Lecturer, Kings College London

**Alison Stewart**

Manager, Speech and Language Therapy Service to Education, Central London Community Healthcare Trust

Honorary Lecturer City University

**Katy Strudwick**

Clinical Specialist Paediatric Occupational Therapist, St Thomas' Hospital

**Gabriel Whitlingum**

Consultant Paediatrician, Hampshire Hospitals Foundation Trust

## **4.2      *National Collaborating Centre for Mental Health***

### **Lucy Burt**

Research Assistant

### **Katherine Leggett**

Project Manager (until November 2012)

### **Ifigeneia Mavranouzouli**

Health Economist

### **Odette Megnin-Viggars**

Systematic Reviewer

### **Sabrina Naqvi**

Project Manager (from November 2012)

### **Sarah Stockton**

Senior Information Scientist

### **Clare Taylor**

Senior editor

## **4.3      *NICE project team***

### **Christine Carson**

Centre for Clinical Practice Director

### **Caroline Keir**

Guideline Commissioning Manager

### **Margaret Ghlaimi**

Guideline Coordinator

### **Nichole Taske**

Technical Lead

### **Jasdeep Hayre**

Health Economist

DRAFT FOR CONSULTATION

**Anna Poppa**

Editor