



## Autism

The management and support of children and young people on the autism spectrum

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## Introduction

This guidance has been developed by the National Institute for Health and Care Excellence (NICE) in collaboration with the Social Care Institute for Excellence (SCIE).



The term autism describes qualitative differences and impairments in reciprocal social interaction and social communication, combined with restricted interests and rigid and repetitive behaviours, often with a lifelong impact. 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 their family or carer, and lead to social vulnerability.

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.

Autism spectrum disorders are diagnosed in children, young people and adults if these behaviours meet the criteria defined in the International Statistical Classification of Diseases and Related Health Problems (ICD-10) and the Diagnostic and Statistical Manual of Mental Disorders Fourth Edition (DSM-IV) and have a significant impact on function. Both these diagnostic classification systems 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.

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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.

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 at least a third 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 individual 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 are interventions that can help some of the core features of autism, some of the symptoms, behaviours and problems commonly associated with autism, and support families and carers. 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 with autism (across the full range of intellectual ability) from birth until their 19th birthday, 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).

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Good communication between healthcare professionals and children and young people with autism and their families and carers is essential. It should be supported by evidence-based written information tailored to the person's needs. Support and care, and the information people are given about it, should be culturally appropriate. It should also be accessible to people with additional needs such as physical, sensory or learning disabilities, and to people who do not speak or read English.

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 and managing medicines and devices](#) 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.

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## 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 for England](#) – 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 the patient is under 16, their family or carers should also be given information and support to help the child or young person to make decisions about their treatment. Healthcare professionals should follow the [Department of Health's advice on consent](#). If someone does not have capacity to make decisions, healthcare professionals should follow 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 a young person is moving between paediatric and adult services, care should be planned and managed according to the best practice guidance 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. Diagnosis and management should be reviewed throughout the transition process, and there should be clarity about who is the lead clinician to ensure continuity of care.

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## Key priorities for implementation

The following recommendations have been identified as priorities for implementation.

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

- Ensure that all children and young people with autism have full access to health and social care services, including mental health services, regardless of their intellectual ability or any coexisting diagnosis.

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

- Health and social care professionals working with children and young people with autism in any setting should receive training in autism awareness and 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
    - ◇ 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 on them
  - 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

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- 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 and ensure a consistent approach is used across all settings
  - skills for communicating with a child or young person with autism.

### ***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. Minimise any negative impact by:
  - providing visual supports, for example, words, pictures or symbols that are meaningful for the child or young person
  - making reasonable adjustments or adaptations to the amount of personal space given
  - considering individual sensory sensitivities to lighting, noise levels and the colour of walls and furnishings.
- Make adjustments or adaptations to the 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 who may need a general anaesthetic in hospital (for example, for dental treatment).

### ***Psychosocial interventions***

- Consider a specific social-communication intervention for the core features of autism in children and young people that includes play-based strategies with parents, carers and teachers to increase joint attention, engagement and reciprocal communication in the child or young person. Strategies should:
  - be adjusted to the child or young person's developmental level
  - aim to increase the parents', carers', teachers' or peers' understanding of, and sensitivity and responsiveness to, the child or young person's patterns of communication and interaction
  - include techniques of therapist modelling and video-interaction feedback



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- include techniques to expand the child or young person's communication, interactive play and social routines.

The intervention should be delivered by a trained professional. For pre-school children consider parent, carer or teacher mediation. For school-aged children consider peer mediation.

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

- Assess factors that may increase the risk of behaviour that challenges in routine assessment and care planning in children and young people with autism, including:
  - impairments in communication that may result in difficulty understanding situations or in expressing needs and wishes
  - 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, such as lighting and noise levels
  - the social environment, including home, school and leisure activities
  - changes to routines or personal circumstances
  - developmental change, including puberty
  - exploitation or abuse by others
  - inadvertent reinforcement of behaviour that challenges
  - the absence of predictability and structure.

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

- 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 assessment of behaviour) as a first-line treatment.

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

- 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 severity of the behaviour. Antipsychotic medication should be initially prescribed and monitored by a paediatrician or psychiatrist 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.

## ***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.

## ***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, and their parents or carers, including their right to a social care assessment at age 18.

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<sup>1</sup> At the time of publication (August 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 and managing medicines and devices](#) for further information.

# 1 Recommendations

The following guidance is based on the best available evidence. The [full guideline](#) gives details of the methods and the evidence used to develop the guidance.

This guidance is part of a series of clinical guidelines on autism. It should be read 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).

The wording used in the recommendations in this guideline (for example, words such as 'offer' and 'consider') denotes the certainty with which the recommendation is made (the strength of the recommendation). See [About this guideline](#) for details.

## 1.1 *General principles of care*

### Access to health and social care services

1.1.1 Ensure that all children and young people with autism have full 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 (including health, mental health, learning disability, education and social care 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 in children and young people](#) (covering identification and diagnosis) (NICE clinical guideline 128) and [Autism in adults](#) (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') which should include professionals from health, mental health, learning disability, education and social care services in line

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with [Autism in children and young people](#) (covering identification and diagnosis) (NICE clinical guideline 128) and [Autism in adults](#) (NICE clinical guideline 142).

1.1.4 Local autism teams should ensure that every child or young person diagnosed with autism has a case manager or key worker to manage and coordinate treatment, care, support and transition to adult care in line with [Autism in children and young people](#) (covering identification and diagnosis) (NICE clinical guideline 128).

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

- looked-after children and young people
- those from immigrant groups
- those with regression in skills
- 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
  - mental health problems.

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
- advice and interventions to promote functional adaptive skills including communication and daily living skills
- assessing and managing behaviour that challenges

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- assessing and managing coexisting conditions
  - 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 Refer 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 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:

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- mental health problems such as anxiety and depression
  - physical health problems such as epilepsy
  - sleep problems
  - 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 on them
  - 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 and ensure a consistent approach is used across all settings
  - skills for communicating with a child or young person with autism.

## **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. Minimise any negative impact by:

- providing visual supports, for example, words, pictures or symbols that are meaningful for the child or young person
- making reasonable adjustments or adaptations to the amount of personal space given
- considering individual sensory sensitivities to lighting, noise levels and the colour of walls and furnishings.

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- 1.1.10 Make adjustments or adaptations to the 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 who may need a general anaesthetic in hospital (for example, for dental treatment).

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

- 1.1.11 Provide children and young people with autism, and their families and carers, with information about autism and its management and the 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.
- 1.1.12 Make arrangements to support children and young people with autism and their family and carers during times of increased need, including major life changes such as puberty, starting or changing schools, or the birth of a sibling.
- 1.1.13 Explore with children and young people with autism, and their families and carers, whether they want to be involved in shared decision-making and continue to explore these issues at regular intervals. 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 their right to:

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- short breaks and other respite care
  - 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 or 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 *Specific interventions for the core features of autism***

#### **Psychosocial interventions**

1.3.1 Consider a specific social-communication intervention for the core features of autism in children and young people that includes play-based strategies with parents, carers and teachers to increase joint attention, engagement and reciprocal communication in the child or young person. Strategies should:

- be adjusted to the child or young person's developmental level
- aim to increase the parents', carers', teachers' or peers' understanding of, and sensitivity and responsiveness to, the child or young person's patterns of communication and interaction



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- include techniques of therapist modelling and video-interaction feedback
  - include techniques to expand the child or young person's communication, interactive play and social routines.

The intervention should be delivered by a trained professional. For pre-school children consider parent, carer or teacher mediation. For school-aged children consider peer mediation.

## Pharmacological and dietary interventions

1.3.2 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 Assess factors that may increase the risk of behaviour that challenges in routine assessment and care planning in children and young people with autism, including:

- impairments in communication that may result in difficulty understanding situations or in expressing needs and wishes
- 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, such as lighting and noise levels
- the social environment, including home, school and leisure activities
- changes to routines or personal circumstances
- developmental change, including puberty

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- exploitation or abuse by others
  - inadvertent reinforcement of behaviour that challenges
  - the absence of predictability and structure.

1.4.2 Develop a care plan with the child or young person and their families or carers that outlines the steps needed to address the factors that may provoke behaviour that challenges, including:

- treatment, for example, for coexisting physical, mental health and behavioural problems
- support, for example, for families or carers
- necessary adjustments, for example, by increasing structure and minimising unpredictability.

### **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 and assess for any new factors that could provoke the behaviour.

1.4.4 Offer the following to address factors that may trigger or maintain behaviour that challenges:

- 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
  - making adjustments or adaptations to the physical surroundings (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, take into account the following when choosing an intervention for behaviour that challenges:

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- 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 child or young person and the family or carers
  - 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 assessment of behaviour) as a first-line treatment.
- 1.4.8 The functional assessment should identify:
- 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
- consistent application in all areas of the child or young person's environment (for example, at home and at school)
- agreement among parents, carers and professionals in all settings about how to implement the intervention.

## 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 paediatrician or psychiatrist 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.

1.4.11 If antipsychotic medication is prescribed:

- start with a low dose
- use the minimum effective dose needed
- regularly review the benefits of the antipsychotic medication and any adverse events.

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<sup>2</sup> At the time of publication (August 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 and managing medicines and devices](#) for further information.

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 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***

1.6.1 Do not use neurofeedback to manage speech and language problems in children and young people with autism.

1.6.2 Do not use auditory integration training to manage speech and language problems in children and young people with autism.

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

1.6.4 Do not use the following interventions to manage autism in any context in children and young people:

- secretin
- chelation

- hyperbaric oxygen therapy.

## **1.7 Interventions for coexisting problems**

1.7.1 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:

- [Attention deficit hyperactivity disorder \(ADHD\)](#) (NICE clinical guideline 72)
- [Conduct disorders in children and young people](#) (NICE clinical guideline 158)
- [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).

1.7.2 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.

1.7.3 Consider adapting the method of delivery of CBT for children and young people with autism and anxiety to include:

- emotion recognition training
- greater use of written and visual information and structured worksheets
- a more cognitively 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

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- maintaining attention by offering regular breaks
  - incorporating the child or young person's special interests into therapy if possible.

## Interventions for sleep problems

1.7.4 If a child or young person with autism develops a sleep problem offer an assessment that identifies:

- what the sleep problem is (for example, delay in falling asleep, frequent waking, unusual behaviours, breathing problems or sleepiness during the day)
- day and night sleep patterns, and any change to those patterns
- whether bedtime is regular
- what the sleep environment is like, for example:
  - the level of background noise
  - use of a blackout blind
  - a television or computer in the bedroom
  - whether the child shares the room with someone
- presence of comorbidities especially those that feature hyperactivity or other behavioural problems
- levels of activity and exercise during the day
- possible physical illness or discomfort (for example, reflux, ear or toothache, constipation or eczema)
- effects of any medication
- any other individual factors thought to enhance or disturb sleep, such as emotional relationships or problems at school
- the impact of sleep and behavioural problems on parents or carers and other family members.

1.7.5 If the child or young person with autism snores loudly, chokes or appears to stop breathing while sleeping, refer to a specialist to check for obstructive sleep apnoea.

1.7.6 Develop a sleep plan (this will often be a specific sleep behavioural intervention) with the parents or carers to help address the identified sleep problems and to establish a

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regular night-time sleep pattern. Ask the parents or carers to record the child or young person's sleep and wakefulness throughout the day and night over a 2-week period. Use this information to modify the sleep plan if necessary and review the plan regularly until a regular sleep pattern is established.

1.7.7 Do not use a pharmacological intervention to aid sleep unless:

- sleep problems persist despite following the sleep plan
- sleep problems are having a negative impact on the child or young person and their family or carers.

If a pharmacological intervention is used to aid sleep it should:

- only be used following consultation with a specialist paediatrician or psychiatrist with expertise in the management of autism or paediatric sleep medicine
- be used in conjunction with non-pharmacological interventions
- be regularly reviewed to evaluate the ongoing need for a pharmacological intervention and to ensure that the benefits continue to outweigh the side effects and risks.

1.7.8 If the sleep problems continue to impact on the child or young person or their parents or carers, consider:

- referral to a paediatric sleep specialist **and**
- short breaks and other respite care for one night or more. Short breaks may need to be repeated regularly to ensure that parents or carers are adequately supported. Agree the frequency of breaks with them and record this in the care plan.

## **1.8 *Transition to adult services***

1.8.1 Local autism teams should ensure that young people with autism who are receiving treatment and care from child and adolescent mental health services (CAMHS) or child health services are reassessed at around 14 years to establish the need for continuing treatment into adulthood.



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- 1.8.2 If continuing 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.
- 1.8.3 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.
- 1.8.4 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.
- 1.8.5 The assessment should make best use of existing documentation about personal, educational, occupational, social and communication functioning, and should include assessment of any coexisting conditions, especially depression, anxiety, ADHD, obsessive-compulsive disorder (OCD) and global delay or intellectual disability in line with [Autism in adults](#) (NICE clinical guideline 142).
- 1.8.6 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.
- 1.8.7 Involve the young person in the planning and, where appropriate, their parents or carers.
- 1.8.8 Provide information about adult services to the young person, and their parents or carers, including their right to a social care assessment at age 18.
- 1.8.9 During transition to adult services, consider a formal meeting involving health and social care and other relevant professionals from child and adult services.

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## 2 Research recommendations

### 2.1 *A key worker approach for children and young people with autism and their families*

What is the value of a key worker approach (defined by protocol and delivered in addition to usual care) for children and young people with autism in terms of parental satisfaction, functioning and stress and child psychopathology?

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

Autism is well characterised as a chronic disorder with lifelong disability in some individuals, yet the current health management structure is usually organised around single episodes of care. 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.

A key worker approach for children and young people with autism and their families 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 common in children and young people with autism but many are referred only when the behaviour has become severely impairing, they pose a threat to

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themselves or others, or everyday life has broken down. By this time, behavioural interventions may be difficult or impossible and antipsychotic medication is used despite it being symptomatic in its benefits, having long-term adverse effects and behavioural problems typically recurring after use.

A group-based parent training intervention (such as educating parents to identify triggers and patterns of reinforcement) should be evaluated using an RCT. Primary outcomes should be short- and medium-term reduction in behaviour that challenges. Secondary outcomes should include parental and sibling stress, quality of life and the child or young person's adaptive function. The medium-term use of medication should also be assessed. Cost effectiveness should encompass a wide range of services, such as additional educational support and social services, and health service use by families.

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

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

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

Sleep problems are common in children and young people with autism and have a significant negative impact on them and their parents. However, studies of melatonin have used different groups and preparations of melatonin precluding meta-analysis.

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

It should report primary and secondary outcomes followed 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**

Early trials of CBT for anxiety in children and young people with autism have been promising but have methodological shortcomings. Furthermore, the common pharmacological approaches have not been evaluated in this population.

A parallel-arm RCT should compare pharmacological and psychosocial interventions with placebo in children and young people with autism and an anxiety disorder. Pharmacological treatment should be with a selective serotonin reuptake inhibitor (SSRI) and dosing should follow research in typically developing children but with the option of evaluating outcomes at lower doses. The SSRI should be blinded with an identical placebo and an 'attention' or other psychosocial control group. The psychosocial intervention should be manualised and based on cognitive behavioural approaches shown to be effective in previous trials. The sample should cover the full age and intellectual range of children and young people and the size powered to deliver precise effect size estimates for both active arms.

Primary outcome measures should be reduction in anxiety symptoms by parent report. Secondary outcomes may include self- and teacher-report, blinded measures such as heart rate and skin conductance, patient satisfaction, changes in adaptive function, quality of life and disruptive behaviour. Adverse effects should be evaluated and an economic evaluation included.

## **2.5 *Teacher-, parent- and peer-mediated psychosocial interventions in pre-school children with autism***

Are comprehensive early interventions that combine multiple elements and are delivered by parents and teachers (for example, the Learning Experiences – an Alternative Program for Preschoolers and their Parents [LEAP] model) effective in managing the core symptoms of autism and coexisting difficulties (such as adaptive behaviour and developmental skills) in pre-school children?

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## Why this is important

Many children with autism are diagnosed in the pre-school period when service provision is advice and support to parents and professionals in nursery or early years educational settings. There is evidence from one moderate-sized trial that adequately supervised comprehensive programmes can help manage the core symptoms of autism and coexisting difficulties. However, the quality of the trial was low.

The research programme should be in 4 stages:

1. Develop a manualised programme suitable to UK public service settings (health services, early years education, and so on).
2. Test its feasibility and acceptability in pilot trials with blinded assessment of outcome.
3. Formally evaluate the outcomes on core symptoms of autism and coexisting difficulties in a large-scale trial, including health economic analysis.
4. Conduct a series of smaller trials to determine the elements, length and intensity required to ensure effectiveness of the programme, as well as longer-term outcomes.

## 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 publication of the guideline (August 2013). Further information is available on the [NICE website](#).

- [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 in children and young people](#). NICE clinical guideline 128 (2011).
- [Constipation in children and young people](#). NICE clinical guideline 99 (2010).
- [Medicines adherence](#). NICE clinical guidance 76 (2009).
- [Attention deficit hyperactivity disorder \(ADHD\)](#). NICE clinical guideline 72 (2008).
- [Obsessive-compulsive disorder \(OCD\) and body dysmorphic disorder \(BDD\)](#). NICE clinical guideline 31 (2005).
- [Depression in children and young people](#). NICE clinical guideline 28 (2005).
- [Post-traumatic stress disorder \(PTSD\)](#). NICE clinical guideline 26 (2005).

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## About this guideline

NICE clinical guidelines are recommendations about the treatment and care of people with specific diseases and conditions in the NHS in England and Wales.

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

This guideline was developed by the National Collaborating Centre for Mental Health, which is based at the Royal College of Psychiatrists. The Collaborating Centre worked with a Guideline Development Group, comprising healthcare professionals (including consultants, GPs and nurses), patients and carers, and technical staff, which reviewed the evidence and drafted the recommendations. The recommendations were finalised after public consultation.

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

### ***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.

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## **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.

## ***Other versions of this guideline***

The full guideline, 'Autism: the management and support of children and young people on the autism spectrum', contains details of the methods and evidence used to develop the guideline. It is published by the National Collaborating Centre for Mental Health.

The recommendations from this guideline have been incorporated into a [NICE Pathway](#).

We have produced [information for the public](#) about this guideline.

## ***Implementation***

[Implementation tools and resources](#) to help you put the guideline into practice are also available.

## ***Your responsibility***

This guidance represents the view of NICE, which was arrived at after careful consideration of the evidence available. Healthcare professionals are expected to take it fully into account when exercising their clinical judgement. However, the guidance does not override the individual responsibility of healthcare professionals to make decisions appropriate to the circumstances of the individual patient, in consultation with the patient and/or guardian or carer, and informed by the summaries of product characteristics of any drugs.

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Implementation of this guidance is the responsibility of local commissioners and/or providers. Commissioners and providers are reminded that it is their responsibility to implement the guidance, in their local context, in light of their duties to have due regard to the need to eliminate unlawful discrimination, advance equality of opportunity and foster good relations. Nothing in this guidance should be interpreted in a way that would be inconsistent with compliance with those duties.

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