4-year surveillance 2016 – Autism spectrum disorder in under 19s: support and management (2013) NICE guideline CG170

Appendix A.2: summary of new evidence

Experience of care and the organisation and delivery of care

General principles of care

Access to health and social care services

170 – 01 **What services and treatments are effective in providing a positive experience of care for children and young people with autism and their families and carers?**

Recommendations derived from this question

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.

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 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
- 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.

Surveillance decision

No new information was identified at any surveillance review.

This review question should not be updated.

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170 – 02 What are the key problems associated with the experience of care for children and young people with autism and their families and carers?

Recommendations derived from this question

No recommendations made in the guideline.

Surveillance decision

This review question should not be updated.

4-year surveillance summary
A study[1] included 16 families following an Autism Spectrum Disorders (ASD) diagnosis. Parents reported difficulties accessing early intervention services at the intensity viewed necessary for optimal child outcomes.

Topic expert feedback
No topic expert feedback was relevant to this evidence.

Impact statement
New evidence comes from a very small study which is unlikely to be enough evidence to develop new recommendations.

This topic will be evaluated again at the next surveillance review.

New evidence is unlikely to change guideline recommendations.

170 – 03 For children and young people with autism, and their families and carers, what would help improve the experience of care?

Recommendations derived from this question

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.

Surveillance decision

This review question should not be updated.

4-year surveillance summary
A study[2] (n=176 families) reported that parents of young children with ASD felt that the accessibility, continuity and flexibility of services were the most important determinants of quality but continuity and accessibility were also perceived as being the least realised. Parents were more satisfied with the validity of information and the flexibility of services than with their continuity and accessibility.

Topic expert feedback
No topic expert feedback was relevant to this evidence.

Impact statement
The evidence is generally consistent with current recommendations which suggest ensuring full access to health and social care services.

New evidence is unlikely to change guideline recommendations.

Experience of care and the organisation and delivery of care

General principles of care

Knowledge and competence of health and social care professionals

Information and involvement in decision-making

Interventions for life skills

170 – 04 What information and day-to-day support is effective in supporting children and young people with autism and their families and carers:

Subquestion

- in the post-diagnosis period (including genetic advice and advice about investigation for possible causes of autism including regression)
- when treatment and care is provided (including case coordination or case management)
- at intervention/management plan reviews
- during periods of crisis
- at key transitions (for example, school transitions and transition to adult services)?

Recommendations derived from this question

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:
    - 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.

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.

1.5.1 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.

Surveillance decision

This review question should not be updated.

4-year surveillance summary

A study[3] included parents (n= 143) of young people (aged 2 to 18 years) with ASD. Parents reported that the most frequent service needs were information on services, family support, and respite care. They also reported a positive view on funding and quality of professional support available.

Topic expert feedback

No topic expert feedback was relevant to this evidence.

Impact statement

The evidence is generally consistent with current recommendations which suggest providing 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.

New evidence is unlikely to change guideline recommendations.

Experience of care and the organisation and delivery of care

General principles of care

Information and involvement in decision-making

170 – 05 What information and day-to-day support do children and young people with autism and their families and carers want:

Subquestion

- in the post-diagnosis period
- when treatment and care is provided
- at intervention/management plan reviews
- during periods of crisis
- at key transitions (for example, school transitions and transition to adult services)?

Recommendations derived from this question

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

1.1.11 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.

Surveillance decision

No new information was identified at any surveillance review.

This review question should not be updated.

Experience of care and the organisation and delivery of care

General principles of care

Organisation and delivery of services

170 – 06 **What are the essential elements that allow integration across services/agencies for the optimal organisation and delivery of care to children and young people with autism and their families and carers?**

Recommendations derived from this question

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 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
- 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.

Surveillance decision

No new information was identified at any surveillance review.

This review question should not be updated.

Experience of care and the organisation and delivery of care

General principles of care

Organisation and delivery of services

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

170 – 07 What alterations need to be made to routine and acute healthcare for children and young people with autism to ensure access for those with autism?

Subquestion

For children and young people with autism, and their families and carers, is the experience of care and the organisation and delivery of care different for:

- looked-after children
- immigrant groups
- children with regression in skills?

Recommendations derived from this question

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.

1.1.9 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.

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).

Surveillance decision

No new information was identified at any surveillance review.

This review question should not be updated.

170 – 08 What are the effective ways of monitoring progress in children and young people with autism?

Recommendations derived from this question

No recommendations made in the guideline.

Surveillance decision

No new information was identified at any surveillance review.

This review question should not be updated.

Interventions aimed at improving the impact on the family

Families and carers

170 – 09 For children and young people with autism, what are the benefits of psychosocial, pharmacological or biomedical interventions for improving the impact on the family* when compared with alternative management strategies?

* Subgroup analyses will examine and compare treatment effects on the impact for the family when the interventions are specifically aimed at improving the impact on the family (direct outcomes) and when the primary target of the intervention was another outcome but effects on the family are examined (indirect outcomes) on coexisting problems or disorders are examined (indirect outcomes).

Subquestions

For children and young people with autism, and their families and carers, is the engagement with or effectiveness of interventions aimed at improving the impact on the family different for:

- looked after children?
- immigrant groups?
- children with regression in skills?

For children and young people with autism is the effectiveness of interventions aimed at improving the impact on the family moderated by:

- the nature and severity of the condition?
- the presence of coexisting conditions (including, mental and behaviour, neurodevelopmental, medical or genetic, and functional, problems and disorders)?
- age?
- gender?
- the presence of sensory differences?
- IQ?
- language level?
- family/carer contextual factors (for example, socioeconomic status, parental education, parental mental health, sibling with special education needs)?

For children and young people with autism is the effectiveness of interventions aimed at improving the impact on the family mediated by:

- the intensity of the intervention?
- the duration of the intervention?
- the length of follow-up?
- programme components?

Recommendations derived from this question

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.

1.2.1 Offer all families (including siblings) and carers verbal and written information about their right to:

- 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.

Surveillance decision

This review question should not be updated.

4-year surveillance summary

A randomised controlled trial (RCT)[4] (n=122 mothers of young children with ASD [mean age 34 months]) found that mothers in a brief cognitive behavioural intervention problem-solving education (PSE) group had significantly less parental stress compared to mothers under usual care. The risk reduction in clinically significant depressive symptoms did not reach statistical significance but there was a statistically significant reduction in mean depressive symptoms in PSE mothers compared to mothers under usual care.

Topic expert feedback

No topic expert feedback was relevant to this evidence.

Impact statement

The new evidence supports current recommendations which suggest offering support when the needs of families and carers have been identified.

New evidence is unlikely to change guideline recommendations.

Interventions aimed at the core features of autism

Specific interventions for the core features of autism

Psychosocial interventions

Pharmacological and dietary interventions

170 – 10 For children and young people with autism, what are the benefits of psychosocial, pharmacological or biomedical interventions for the core features of autism (overall autistic behaviours, impaired reciprocal social communication and interaction, and restricted interests and rigid and repetitive behaviours)* when compared with alternative management strategies?

* Subgroup analyses will examine and compare treatment effects on core autism features when the interventions are specifically aimed at these features (direct outcomes) and when the primary target of the intervention was another outcome but effects on core autism features are examined (indirect outcomes).

Subquestions

For children and young people with autism, and their families and carers, is the engagement with or effectiveness of interventions aimed at the core features of autism different for:

- looked after children?
- immigrant groups?
- children with regression in skills?

For children and young people with autism is the effectiveness of interventions aimed at the core features of autism moderated by (1.3.1):

- the nature and severity of the condition?
- the presence of coexisting conditions (including, mental and behaviour, neurodevelopmental, medical or genetic, and functional, problems and disorders)?
- age?
- gender?
- the presence of sensory differences?
- IQ?
- language level?
- family/carer contextual factors (for example, socioeconomic status, parental education, parental mental health, sibling with special education needs)?

For children and young people with autism is the effectiveness of interventions aimed at the core features of autism mediated by:

- the intensity of the intervention?
- the duration of the intervention?
- the length of follow-up?
- programme components?

Recommendations derived from this question

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.

1.3.1 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
- 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.

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).

1.6.1 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.

Surveillance decision

This review question should not be updated.

Psychosocial interventions

4-year surveillance summary
There were 10 new studies on different psychosocial interventions.

- A Theory of Mind intervention was reported by a systematic review[5] (22 RCTs, n=695 children and adults). The systematic review reported positive effects on emotional recognition and joint attention behaviours within adult-child interaction in children and adults with ASD without reporting results specifically in children.

- A comprehensive psychosocial intervention was reported by an RCT[6] (n=60 children with high-functioning ASD, ages 7 to 12 years). This RCT reported significantly better encoding of sad facial expressions in children with high-functioning ASD who were in the comprehensive psychosocial intervention group.
- Interventions targeting parents were reported by 4 studies. One RCT[7] (n=152 pre-school children with autism) reported no significant but clinically meaningful symptom improvement in children receiving a parent-mediated, communication-focused therapy. Another RCT[8] (n=53 children with autism and significant language delay, aged 2 to 6 years) reported that children with autism and significant language delay had significant improvements in frequency of utterances and adaptive communication skills who were receiving a pivotal response treatment parent training group intervention. Another RCT[9] (n=86 toddlers with ASD, aged 22 to 36 months) reported that toddlers with ASD showed significant effects on joint engagement when randomised to a parent-training group (joint attention, symbolic play, engagement and regulation [JASPER]). A systematic review[10] (17 RCTs, n=919 children with ASD) reported significant results in positive change in patterns of parent-child interaction, improvement in child language comprehension, and reduction in the severity of children's autism characteristics in children with ASD receiving parent-mediated early interventions.
- Interventions targeting social skills/social communication were reported by a systematic review[11] (5 RCTs, n=196 participants with ASD, aged 5 to 21 years) which reported significant improvements in overall social competence and friendship quality in the social skills groups but no differences in relation to emotional recognition or social communication.
- Other interventions were reported in 2 studies. An RCT[12] (n=116 participants with ASD, aged 6 to 16 years) reported significant improvements in the therapeutic horseback riding group on measures of irritability (primary outcome), hyperactivity, social cognition and social communication in children and young people with ASD. A systematic review[13] (10 RCTs, n=165 children with ASD) reported that music therapy for children with ASD had an effect on social interaction, non-verbal communicative skills within the therapy context, verbal communicative skills, initiating behaviour, and social-emotional reciprocity. There was no significant difference in non-verbal communicative skills outside of the therapy context.
- An RCT[14] (n=27 children with pervasive developmental disorders) reported that children receiving additional language instruction made significantly more gains in language skills than those who were assigned to treatment as usual group.

Topic expert feedback

Topic experts highlighted the following relevant studies:

- An RCT[15] (n=54 children with autism, aged under 6 years) concluded that an iPad™ intervention targeting social communication skills in children with autism did not have an observable impact on real-world communication skills.
- An RCT[16] (n=228 high-functioning ASD participants, ages 8 to 19 years) concluded that a group-based social skills training (SOSTA-FRA) in children and adolescents with high-functioning ASD showed post intervention efficacy with regard to parent-rated social responsiveness.
- An RCT[17] (n=128 children with autism or pervasive developmental disorder not otherwise specified, ages 2 years 8 months to 5 years 11 months) found positive changes in parent-child interaction with the Play and Language for Autistic Youngsters Project Home Consultation model in combination with usual community services in young children with ASD.
- A 2-year follow-up study[18] of an RCT (n=39 with ASD, 6 years old) testing the effectiveness of the Early Start Denver Model (ESDM) which found that gains from early intensive intervention were maintained at follow-up.
- An RCT[19] (n=112 families of a child with ASD and who met criteria for being low-resourced) concluded that there were improvements in joint engagement, joint

attention and symbolic play with short-term community caregiver interventions for preschool children with ASD from low resourced families.

- A study[20] (sample size was not reported in abstract) found that parent synchrony and child initiations were mediator mechanisms by which the parent-mediated communication-focused treatment in children with autism (PACT) influenced changes in child behaviour through the targeted parent behaviour.
- A systematic review and meta-analysis[21] (26 studies, n=1738 participants with ASD, mean age 3.3 years) concluded that early interventions improved spoken languages outcomes for children with ASD.
- An RCT[22] (n=30, ages 8 to 14 years) concluded that a theatre-based intervention improved social competence outcomes in children with ASD.

Impact statement

The new evidence reported improvements in core features of autism using different psychosocial interventions: Theory of Mind, comprehensive psychosocial interventions, parent training, social skills interventions (age 5 to 21), therapeutic horseback riding, music therapy, additional language instruction, and theatre-based interventions. Although these interventions were not specific social-communication interventions, they targeted the core features of autism suggested by the guideline: joint attention, engagement and reciprocal communication. Therefore, new evidence supports the benefit of interventions targeting the core features of autism: joint attention, engagement and reciprocal communication.

New evidence is unlikely to change guideline recommendations.

Pharmacological interventions

4-year surveillance summary

A systematic review[23] (9 RCTs, n=320 children and adults with ASD) evaluated treatment with selective serotonin reuptake inhibitors compared to placebo but studies including children were unsuitable for meta-analysis. One large, high-quality study in children showed no evidence of a positive effect of citalopram.

A pilot RCT[24] (n=60 children with autism, mean age 4.5 years) evaluated a combined treatment with bumetanide and applied behaviour analysis (ABA) compared with ABA only in children with autism. The combined treatment group showed lower scores in 2 outcomes measures: the Autism Behaviour Checklist (ABC) and the Clinical Global Impressions (CGI) compared with the ABA only group. Lower scores on ABC and CGI mean lower overall autistic behaviours.

Topic expert feedback

It was highlighted that selective serotonin reuptake inhibitors are not licensed for autism. Citalopram is not recommended for use in people under 18 years. It was also highlighted that bumetanide is not licensed for use in autism and it is used as a diuretic (loop diuretic) but not recommended for children under 12 years. None of these medications are recommended in the British National Formulary (BNF) for children for autism.

Impact statement

The new evidence reported no effects with citalopram and a positive effect with bumetanide together with applied behaviour analysis on overall autistic behaviours. Current recommendations suggest not using antidepressants for the management of core features of autism in children and young people. Bumetanide is not licensed to prescribe in children and young people with autism.

New evidence is unlikely to change guideline recommendations.

Biomedical interventions

4-year surveillance summary

There were 7 new studies reporting on biomedical interventions.

A randomised crossover trial reported in 2 publications[25,26] (n=20 male children with autism) found improvement in autistic behaviours in the treatment group under anodal transcranial direct current stimulation (tDCS) compared with a placebo group.

A systematic review[27] (1 RCT, n=49 children with ASD) reported that the included RCT in children with ASD did not provide evidence that multiple rounds of oral dimercaptosuccinic acid (a chelation agent) had an effect on ASD symptoms.

An RCT[28] (n=30 children with autism) reported that the L-Carnitine group showed significant improvement in the childhood autism rating scale (CARS) compared with the placebo group.

Three RCTs reported findings on omega-3 fatty acid supplementation. An RCT[29] (n=48 children with autism, 3 to 10 years old) reported that omega-3 fatty acid supplementation did not improve core symptoms of autism in children compared with placebo. Another RCT[30] (n=57 children with ASD, 5 to 8 years) found that there was no statistical significant difference between the omega-3 fatty acid group and the placebo group in the reduction of hyperactivity. The other RCT[31] (n= 38 children with ASD, 2 to 5 years old) found that the omega-3 fatty acid group had worsening scores on the Behaviour Assessment System for Children (BASC-2) compared to the placebo group.

Topic expert feedback
Topic experts highlighted the following studies:

A randomised clinical crossover trial[32] (n=31 children with autism) concluded that an oxytocin nasal spray was well tolerated and led to significant improvements caregiver-rated social responsiveness in young children with autism.

An RCT[33] (n=50 children with ASD, mean age 5.3 years) concluded that the clinician rated Clinical Global Impressions-Improvement (CGI-I) score was significantly lower in the methyl B12 group compared to the placebo group.

Impact statement
New evidence reported improvements on autistic behaviours using anodal transcranial direct current stimulation, L-Carnitine, and methyl B12. There was no evidence of an effect with multiple rounds of oral dimercaptosuccinic acid (a chelation agent) and omega-3 fatty acid supplementation. The guideline currently states that secretin, chelation and hyperbaric oxygen therapy should not be used but anodal transcranial direct current stimulation, L-Carnitine, and methyl B12 are not listed. However, evidence for these interventions comes from 3 small trials which is unlikely to be enough evidence to develop new recommendations.

This topic will be evaluated again at the next surveillance review.

New evidence is unlikely to change guideline recommendations.

Interventions aimed at the core features of autism

Interventions for autism that should not be used

170 – 11 For children and young people with autism, what are the potential harms associated with psychosocial, pharmacological or biomedical interventions?

Recommendations derived from this question

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.

Surveillance decision

This review question should not be updated.

4-year surveillance summary
There were 2 studies reporting adverse events of psychosocial and biomedical interventions.

Psychosocial interventions

- A systematic review[11] (5 RCTs, n=196 participants with ASD, aged 5 to 21 years) found that no adverse events were reported following a social skills intervention.

Biomedical interventions

- An RCT[30] (n=57 children with ASD, 5 to 8 years) on omega-3 fatty acids reported that adverse events were rare and not associated with omega-3 fatty acids without data in the abstract.

Topic expert feedback
No topic expert feedback was relevant to this evidence.

Impact statement
Adverse events were not reported for social skills interventions. Therefore, this evidence is not likely to change current recommendations. The guideline already recommends that omega-3 fatty acids should not be used.

New evidence is unlikely to change guideline recommendations.

Interventions aimed at behaviour that challenges

Interventions for behaviour that challenges

Anticipating and preventing behaviour that challenges

Assessment and initial intervention for behaviour that challenges

Psychosocial interventions for behaviour that challenges

Pharmacological interventions for behaviour that challenges

170 – 12 For children and young people with autism, what are the benefits of psychosocial, pharmacological or biomedical interventions for anticipating, preventing or managing behaviour that challenges or poses a risk*, when compared with alternative management strategies?

* Subgroup analyses will examine and compare treatment effects on behaviour that challenges when the interventions are specifically aimed at these behaviours (direct outcomes) and when the primary target of the intervention was another outcome but effects on behaviour that challenges are examined (indirect outcomes).

Subquestions

For children and young people with autism, and their families and carers, is the engagement with or effectiveness of interventions aimed at reducing behaviour that challenges or poses a risk different for:

- looked after children?
- immigrant groups?
- children with regression in skills?

For children and young people with autism is the effectiveness of interventions aimed at reducing behaviour that challenges or poses a risk moderated by:

- the nature and severity of the condition?
- the presence of coexisting conditions (including, mental and behaviour, neurodevelopmental, medical or genetic, and functional, problems and disorders)?
- age?
- gender?
- the presence of sensory differences?
- IQ?
- language level?
- family/carer contextual factors (for example, socioeconomic status, parental education, parental mental health, sibling with special education needs)?

For children and young people with autism is the effectiveness of interventions aimed at reducing behaviour that challenges or poses a risk mediated by:

- the intensity of the intervention?
- the duration of the intervention?
- the length of follow-up?
- programme components?

Recommendations derived from this question

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.

1.4.1 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
- 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.

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:

- 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.

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.

1.4.10 Consider antipsychotic medication** 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.

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.

** 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.

Surveillance decision

This review question should not be updated.

Psychosocial interventions

4-year surveillance summary

An RCT[34] (n=180 children with ASD and disruptive behaviours, aged 3 to 7 years) compared parent training (specific strategies to manage disruptive behaviour) with parent education (information about autism but no behaviour management strategies). There were significantly greater declines in the Aberrant Behaviour Checklist-Irritability subscale and in the Home Situations Questionnaire-Autism Spectrum Disorder in the parent training group compared to the parent education group.

Topic expert feedback

A topic expert suggested that the summarised above[34] relates to research recommendation RR-02 because the RCT compares the efficacy of parent training (equipping parents with skills) with more broad parent education interventions.

Impact statement

The evidence is generally consistent with current recommendations which suggest offering the child or young person a psychosocial intervention (informed by a functional assessment of behaviour) as a first-line treatment.

New evidence is unlikely to change guideline recommendations.

Pharmacological interventions

4-year surveillance summary

There were 10 new studies on antipsychotics alone or in combination with other interventions. All of these studies, apart from Handen et al. (2013)[35], used the Aberrant Behaviour Checklist (ABC) which is a measured of behaviour that challenges and it was considered a critical outcome measure by the Guideline Committee during the development of the guideline.

- An RCT[36] (n=85 participants with autistic disorder and serious behavioral problems, 6 to 17 years old) reported no significant differences between aripiprazole and placebo in preventing relapse of irritability symptoms in children and young people with autistic disorder and serious behavioural problems.
- An RCT[35] (n=124 children with ASD and serious behaviour problems, aged 4 to 13 years) reported that risperidone together with parent training reduced inappropriate behaviour and increased compliance to parental requests in children with ASD and serious behaviour problems. Behaviours were assessed with a Structured Observational Analog Procedure (SOAP) which is an analogue measure of parent-child interactions.
- An RCT[37] (n=34 children and adolescents with autism) reported that children and adolescents with autism taking buspirone added to risperidone had less irritability compared with participants in the risperidone and placebo group.
- An RCT[38] (n=40 children with autism) reported that children with autism taking celecoxib added to risperidone showed greater improvement in irritability compared with children in the risperidone plus placebo group.
- An RCT[39] (n=40 children with autism, aged 4 to12 years) reported that children with autism taking galantamine added to risperidone showed greater improvement in irritability compared with the risperidone plus placebo group.
- Two RCTs reported that children and adolescents with ASD (n=40)[40] and autistic disorders (n=40)[41] taking N-acetylcysteine added to risperidone showed reduced irritability compared with the risperidone plus placebo group.
- A pilot RCT[42] (n=44 children with autistic disorder, aged 4 to 12 years) reported that children with autistic disorders taking pioglitazone added to risperidone showed reduction in irritability compared with the placebo group.
- An RCT[43] (n=49 children with autistic disorder, 5 to 12 years old) reported that children with autistic disorders taking riluzole added to risperidone showed

improvements in irritability compared with the risperidone plus placebo group.

An RCT[44] (n=62 children with ASD accompanied by hyperactivity, impulsiveness, and distractibility, mean age 8.5 years [SD 2.25]) found that children taking extended-release guanfacine showed a greater decline in scores on the Aberrant Behavior Checklist-hyperactivity subscale and better improvement on the Clinical Global Impression-Improvement scale compared with the placebo group.

Topic expert feedback
It was highlighted that:

- Aripiprazole only license for use in young people is ‘for the treatment of schizophrenia in adults and in adolescents aged 15 years and older.’
- Buspirone is not recommended for people younger than 18 years.
- Celecoxib and galantamine are not licensed for children.
- Galantamine is only license for dementia in adults. Not licensed for children.
- Guanfacine was recently licensed for ADHD in children and adolescents age 6 to 17 years. ESNM can be seen here.
- N-acetylcysteine is used in paracetamol overdose.
- Pioglitazone is licensed for type 2 diabetes in adults. The Summary of Product Characteristics (SPC) says ‘The safety and efficacy of pioglitazone in children and adolescents under 18 years of age have not been established. No data are available.’
- Riluzole used in adults to delay mechanical ventilation. The SPC says ‘not recommended for use in paediatric population, due to a lack of data on the safety and efficacy.’
- Risperidone is only license in children for conduct disorder. SPC says: ‘indicated for the short-term symptomatic treatment (up to 6 weeks) of persistent aggression in conduct disorder in children from the age of 5 years and adolescents with sub average intellectual functioning or mental retardation diagnosed according to DSM-IV criteria, in whom the severity of aggressive or other disruptive behaviours require pharmacologic treatment. Pharmacological treatment should be an integral part of a more comprehensive treatment programme, including psychosocial and educational intervention. It is recommended that risperidone be prescribed by a specialist in child neurology and child and adolescent psychiatry or physicians well familiar with the treatment of conduct disorder of children and adolescents.’

It was also confirmed that there are not changes in the footnote about antipsychotic medications which is included in the guidance recommendations online. This was checked on the 5th of April 2016.

Impact statement
The new evidence reported improvements in irritability with different medications added to risperidone: buspirone, celecoxib, galantamine, N-acetylcysteine, pioglitazone, or riluzole. Other pharmacological interventions also had a positive effect on hyperactivity (extended-release guanfacine), behavioural problems (risperidone together with parent training), and irritability (high dose of risperidone). No effects were found with aripiprazole. Although these studies did not specify targeting behaviour that challenges in the abstract; irritability, hyperactivity and behavioural problems were among the outcome measures for studies on behaviour that challenges during guideline development. It was highlighted that most of the interventions are not currently licensed for children. Current recommendations suggest antipsychotics for behaviour that challenges. Therefore, new evidence supports current recommendation.

New evidence is unlikely to change guideline recommendations.

Interventions aimed at associated features of autism and coexisting conditions

Interventions for coexisting problems

Interventions for sleep problems

170 – 13	**For children and young people with autism, what are the benefits of psychosocial, pharmacological or biomedical interventions for coexisting problems or disorders (including adaptive behaviour, speech and language problems, IQ and academic skills, sensory sensitivities, motor skills, common coexisting mental health problems and common functional problems)* when compared with alternative management strategies?**

* Subgroup analyses will examine and compare treatment effects on coexisting problems or disorders when the interventions are specifically aimed at these features (direct outcomes) and when the primary target of the intervention was another outcome but effects on coexisting problems or disorders are examined (indirect outcomes).

Subquestions

For children and young people with autism, and their families and carers, is the engagement with or effectiveness of interventions aimed at coexisting problems or disorders different for:

- looked after children?
- immigrant groups?
- children with regression in skills?

For children and young people with autism is the effectiveness of interventions aimed at coexisting problems or disorders moderated by:

- the nature and severity of the condition?
- the presence of coexisting conditions (including, mental and behaviour, neurodevelopmental, medical or genetic, and functional, problems and disorders)?
- age?
- gender?
- the presence of sensory differences?
- IQ?
- language level?
- family/carer contextual factors (for example, socioeconomic status, parental education, parental mental health, sibling with special education needs)?

For children and young people with autism is the effectiveness of interventions aimed at coexisting problems or disorders mediated by:

- the intensity of the intervention?
- the duration of the intervention?
- the length of follow-up?
- programme components?

Recommendations derived from this question

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.

1.7.1 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
- maintaining attention by offering regular breaks
- incorporating the child or young person's special interests into therapy if possible.

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 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.

Surveillance decision

This review question should not be updated.

4-year surveillance summary

There were 5 studies reporting psychosocial and pharmacological interventions for coexisting problems and disorders in children and young people with autism.

Attention-deficit/hyperactivity disorder (ADHD)

An RCT[45] (n=128 children with ASD and ADHD, aged 5 to 14 years) reported that atomoxetine and parent training (alone and in combination) reduced ADHD symptoms compared with placebo.

Sensory difficulties

A randomised trial[46] (n=32 children with autism, aged 4 to 8 years) reported that children in the occupational therapy group scored significantly higher on Goal Attainment Scales and also scored significantly better on measures of caregiver assistance in self-care and socialisation than the usual care group.

Anxiety

Two RCTs (n=45 children with high-functioning ASD and anxiety, aged 7 to 11 years)[47] (n=33 adolescents with ASD and anxiety, aged 11 to 15 years)[48] and a pilot RCT (n=30 adolescents with ASD and anxiety symptoms)[49] reported that psychosocial interventions improved anxiety symptoms.

Topic expert feedback

No topic expert feedback was relevant to this evidence.

Impact statement

The evidence is generally consistent with current recommendations which suggest offering 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.

New evidence is unlikely to change guideline recommendations.

Transition to adult services

170 – 14 What are the essential elements that assist in the transition into adulthood services for young people with autism?

Recommendations derived from this question

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.

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.

Surveillance decision

This review question should not be updated.

4-year surveillance summary

A national survey[50] (sample size was not reported in abstract) reported that less than a quarter of youths with ASD received health care transition services. Only 14% of youths with ASD had a discussion with their paediatrician about transitioning to an adult provider, less than a quarter had a discussion about health insurance retention, and just under half discussed adult health care needs or were encouraged to take on appropriate responsibility.

A study[51] (n=39 families of young people with ASD) reported that youths with ASD and a comorbid psychiatric diagnosis and lower levels of adaptive behaviour received more services during the transition to adulthood. Greater unmet needs were reported for youth who were racial/ethnic minorities, who had more behaviour problems, and whose parents had greater anxiety.

Topic expert feedback

No topic expert feedback was relevant to this evidence.

Impact statement

New evidence was found reporting issues related to transition services. Current recommendations suggest what should be covered during the transition to adult services including the engagement of the young people with autism and their parents and carers.

New evidence is unlikely to change guideline recommendations.

Research recommendations

Prioritised research recommendations

At 4-year and 8-year surveillance reviews of guidelines published after 2011, we assess progress made against prioritised research recommendations. We may then propose to remove research recommendations from the NICE version of the guideline and the NICE database for research recommendations. The research recommendations will remain in the full versions of the guideline. See NICE's research recommendations process and methods guide 2015 for more information.

These research recommendations were deemed priority areas for research by the Guideline Committee; therefore, at this 4-year surveillance review time point a decision **will** be taken on whether to retain the research recommendations or stand them down.

We applied the following approach:

- New evidence relevant to the research recommendation was found and an update of the related review question is planned.
  - The research recommendation will be removed from the NICE version of the guideline and the NICE research recommendations database. If needed, a new research recommendation may be made as part of the update process.
- New evidence relevant to the research recommendation was found but an update of the related review question is not planned because the new evidence is insufficient to trigger an update.
  - The research recommendation will be retained because there is evidence of research activity in this area.
- New evidence relevant to the research recommendation was found but an update of the related review question is not planned because evidence supports current recommendations.
  - The research recommendation will be removed from the NICE version of the guideline and the NICE research recommendations database because further research is unlikely to impact on the guideline.
- Ongoing research relevant to the research recommendation was found.
  - The research recommendation will be retained and evidence from the ongoing research will be considered when results are published.
- No new evidence relevant to the research recommendation was found and no ongoing studies were identified.
  - The research recommendation will be removed from the NICE version of guideline and the NICE research recommendations database because there is no evidence of research activity in this area.
- The research recommendation would be answered by a study design that was not included in the search (usually systematic reviews or randomised controlled trials).
  - The research recommendation will be retained in the NICE version of the guideline and the NICE research recommendations database.
- The new research recommendation was made during a recent update of the guideline.
  - The research recommendation will be retained in the NICE version of the guideline and the NICE research recommendations database.

RR – 01 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?

No new evidence relevant to the research recommendation was found and no ongoing studies were identified.

Surveillance decision

It was proposed to remove the research recommendation from the NICE version of the guideline and the NICE research recommendations database because there is no evidence of research activity in this area. We considered the views of stakeholders after consultation. Therefore it was decided to retain this research recommendation based on the feedback on its importance.

RR – 02 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?

New evidence relevant to the research recommendation was found but an update of the related review question is not planned because the new evidence is insufficient to trigger an update.

A topic expert suggested that the RCT[34] included in 170-12 (Psychosocial interventions) concerns to this RR. However, the RCT does not meet 2 RCT criteria recommended to answer this question regarding the evaluation of medium-term use of medication and a cost-effectiveness evaluation.

Surveillance decision

The research recommendation will be retained because there is evidence of research activity in this area.

RR – 03 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?

No new evidence relevant to the research recommendation was found and no ongoing studies were identified.

Surveillance decision

It was proposed to remove the research recommendation will be from the NICE version of the guideline and the NICE research recommendations database because there is no evidence of research activity in this area. We considered the views of stakeholders after consultation. Therefore it was decided to retain this research recommendation based on the feedback on its importance.

RR – 04 What is the comparative clinical and cost effectiveness of pharmacological and psychosocial interventions for anxiety disorders in children and young people with autism?

No new evidence relevant to the research recommendation was found and no ongoing studies were identified.

Surveillance decision

It was proposed to remove the research recommendation from the NICE version of the guideline and the NICE research recommendations database because there is no evidence of research activity in this area. We considered the views of stakeholders after consultation. Therefore it was decided to retain this research recommendation based on the feedback on its importance.

RR – 05 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?

No new evidence relevant to the research recommendation was found and no ongoing studies were identified.

Surveillance decision

It was proposed to remove the research recommendation from the NICE version of the guideline and the NICE research recommendations database because there is no evidence of research activity in this area. We considered the views of stakeholders after consultation. Therefore it was decided to retain this research recommendation based on the feedback on its importance.

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