



**Surveillance report 2016 –
Autism spectrum disorder
in under 19s: recognition,
referral and diagnosis
(2011) NICE guideline CG128
and Autism spectrum
disorder in under 19s:
support and management
(2013) NICE guideline
CG170**

Surveillance report

Published: 22 September 2016

© NICE 2023. All rights reserved. Subject to Notice of rights (<https://www.nice.org.uk/terms-and-conditions#notice-of-rights>).

www.nice.org.uk

Contents

| | |
|--|----|
| Surveillance decision | 3 |
| Reason for the decision..... | 3 |
| Commentary on selected new evidence..... | 7 |
| Autism diagnostic assessment for children and young people | 7 |
| Specific interventions for the core features of autism – psychosocial interventions..... | 11 |
| Research recommendation 2.2 Managing behaviour that challenges in children and young people with autism..... | 17 |
| How we made the decision | 20 |
| New evidence..... | 20 |
| Views of topic experts | 21 |
| Views of stakeholders | 21 |
| NICE Surveillance programme project team..... | 22 |

Surveillance decision

We will plan an update of the following sections of the guideline on autism spectrum disorder in under 19s: recognition, referral and diagnosis (NICE guideline CG128):

- Referring children and young people to the autism team.
- Autism diagnostic assessment for children and young people.

We will not update the guideline on autism spectrum disorder in under 19s: support and management (NICE guideline CG170).

Reason for the decision

Autism spectrum disorder in under 19s: recognition, referral and diagnosis (NICE guideline CG128)

We found 259 new studies through surveillance of this guideline.

New evidence that could affect recommendations was identified. Topic experts, including those who helped to develop the guideline, advised us about whether the following sections of the guideline should be updated:

Referring children and young people to the autism team

Risk factors

- Do the following risk factors increase the likelihood of a diagnosis of autism and assist in the decision to refer for a formal autism diagnostic assessment?
 - Small for gestational age.
 - Prenatal use of selective serotonin reuptake inhibitors (SSRIs).
 - Fertility treatments.

Through surveillance, a vast amount of evidence was identified evaluating different risk

factors. Most of the studies reported an odds ratio of more than 1.25 for the risk factors, which was considered as clinically important by the guideline committee during the development of NICE guideline CG128. Topic experts recommended that this review question should be updated and that any update should be limited to consider a small number of relevant risk factors.

Decision: This review question should be updated.

Conditions with an increased risk of autism

- Do neurodevelopmental disorders (such as attention deficit hyperactivity disorder [ADHD] and intellectual disability [ID]) increase the likelihood of a diagnosis of autism and assist in the decision to refer for a formal autism diagnostic assessment?

Topic experts also raised the issue of delays in diagnosis of autism spectrum disorders (ASD) of 3–4 years because of an earlier diagnosis of neurodevelopmental disorders such as ADHD. The panel agreed that it was important for clinicians to not exclude a diagnosis of ASD in a patient with a diagnosis of ADHD. Topic experts recommended updating the conditions with an increased risk of autism to include neurodevelopmental disorders and gave examples such as ADHD and ID.

Decision: This review question should be updated.

Autism diagnostic assessment for children and young people

- How should information be integrated to arrive at diagnosis?
 - What is the agreement of an autism diagnosis across different diagnostic tools?

At the 4-year surveillance review it was considered that there was variable evidence showing agreement across the different tools. During guideline development, the guideline committee did not consider any evidence comparing agreement between diagnostic tools due to the low quality of evidence relating to accuracy. Due to heterogeneity between studies identified through the surveillance review, it was felt unlikely that there was sufficient evidence to make any recommendations in this area.

The cumulative evidence identified through the surveillance showed that a diagnosis of ASD is less common with the Diagnostic and Standard Manual version 5 (DSM-5) than with version IV (DSM-IV) or the text revision version (DSM-IV-TR). The current guidance refers

to DSM-IV as one of the diagnostic assessments. However, the DSM-IV was updated in 2013 and the new version (DSM-5) supersedes DSM-IV. Therefore, this evidence may have an impact on recommendations 1.5.5, 1.5.10, and 1.5.13, which refer to the DSM-IV criteria. Topic experts agreed that the terminology used in the guideline needed to be updated to reflect DSM-5 as it is being used in practice.

Decision: This review question should not be updated but the panel recommended that the terminology in the guideline should be amended to reflect the updated DSM-5 (recommendations 1.5.5, 1.5.10 and 1.5.13).

Autism spectrum disorder in under 19s: support and management (NICE guideline CG170)

We found 51 new studies through surveillance of this guideline.

This included new evidence that supports current recommendations on:

- General principles of care (access to health and social care services, knowledge and competence of health and social care professionals, information and involvement in decision-making).
- Families and carers.
- Specific interventions for the core features of autism.
- Interventions for behaviour that challenges.
- Interventions for life skills.
- Interventions aimed at improving the impact on the family.
- Interventions for autism that should not be used.
- Interventions for coexisting problems.
- Transition to adult services.

We asked topic experts whether this new evidence would affect current recommendations on autism spectrum disorder in under 19s. Generally, the topic experts thought that an update was not needed. A topic expert suggested expanding the wording of recommendation 1.3.1 to include other psychosocial strategies to use with older children

and young people with autism. However, it was considered that new evidence from this surveillance review was unlikely to impact on the guideline, which already recommends other psychological strategies. There were new studies evaluating the combination of risperidone with other medications in the treatment of irritability but most of these medications were not licensed for children or for the treatment of autism, behaviour that challenges or for coexisting problems. Furthermore, this new evidence was reported by small studies, which are unlikely to be enough evidence to recommend the use of these unlicensed medications in combination with risperidone.

We did not find any new evidence on:

- General principles of care (organisation and delivery of services, making adjustments to the social and physical environment and processes of care).

None of the new evidence considered in surveillance of this guideline was thought to have an effect on current recommendations.

Overall decision

After considering all the new evidence and views of topic experts, we decided not to update NICE guideline CG170 and that a partial update of NICE guideline CG128 was necessary.

No equalities issues were identified during the surveillance process.

See [how we made the decision](#) for further information.

Commentary on selected new evidence

With advice from topic experts we selected 4 studies for further commentary.

Autism diagnostic assessment for children and young people

We selected the systematic review and meta-analysis by [Kulage et al. \(2014\)](#) for a full commentary because it adds useful new data to the evidence base reviewed for NICE guideline CG128, which could impact on current recommendations on autism diagnostic assessment.

What the guideline recommends

NICE guideline CG128 recommends that the following should be included in every autism diagnostic assessment:

- detailed questions about parent's or carer's concerns and, if appropriate, the child's or young person's concerns
- details of the child's or young person's experiences of home life, education and social care
- a developmental history, focusing on developmental and behavioural features consistent with the International Classification of Diseases version 10 (ICD-10) or the Diagnostic and Standard Manual version (DSM-IV) criteria (consider using an autism-specific tool to gather this information)
- assessment (through interaction with and observation of the child or young person) of social and communication skills and behaviours, focusing on features consistent with ICD-10 or DSM-IV criteria (consider using an autism-specific tool to gather this information)
- a medical history, including prenatal, perinatal and family history, and past and current health conditions
- a physical examination

- consideration of the differential diagnosis (see [recommendation 1.5.7](#))
- systematic assessment for conditions that may coexist with autism (see [recommendation 1.5.15](#))
- development of a profile of the child's or young person's strengths, skills, impairments and needs that can be used to create a needs-based management plan, taking into account family and educational context
- communication of assessment findings to the parent or carer and, if appropriate, the child or young person.

NICE guideline CG128 also recommends:

- That information from all sources, together with clinical judgment, should be used to diagnose autism based on ICD-10 or DSM-IV criteria.
- That healthcare professionals should be aware that some children and young people will have features of behaviour that are seen in the autism spectrum but do not reach the ICD-10 or DSM-IV diagnostic criteria for definitive diagnosis. Based on their profile, there should be consideration of referral to appropriate services.

Methods

Kulage et al. (2014) reported a systematic review and meta-analysis of 14 prospective and retrospective studies (n=16,548) assessing the impact of changes introduced through the Diagnostic and Standard Manual version 5 (DSM-5) on diagnosis of ASD. The authors conducted 2 meta-analyses:

- The first meta-analysis included all studies and examined whether the frequency of people diagnosed with ASD differed when using DSM-IV-TR criteria compared with DSM-5. Sensitivity analyses were done by age, country, study design and study quality to address heterogeneity.
- The second meta-analysis examined differences in autistic spectrum disorder (ASD) subgroup diagnoses (autistic disorder [AD], Asperger's disorder, and pervasive developmental disorder-not otherwise specified [PDD-NOS]) between DSM-IV-TR and DSM-5.

The quality of included studies was evaluated with the Quality Appraisal of Reliability

Studies (QAREL), which has 11 items evaluating 7 principles of the reliability of diagnostic tests: 1) appropriateness of subjects, 2) appropriateness of examiners, 3) blinding of examiners, 4) order effects of examination, 5) suitability of the time interval between repeated measures, 6) appropriate test and application, and 7) statistical analysis of inter- or intra-rater agreement.

Results

Fourteen studies were included. Eleven studies used the 2011 DSM-5 draft criteria and 3 studies used the 2010 DSM-5 draft criteria without substantial differences in the study findings. There was a reduction in diagnosis of the following using the full DSM-5 criteria compared to the DSM-IV-TR criteria, specifically:

- ASD (range 7.3% to 68.4%)
- AD (range 0% to 40%)
- Asperger's disorder (range 16.6% to 100%)
- PDD-NOS (range 50% to 97.5%).

The first meta-analysis included the subgroup of participants diagnosed with ASD using the DSM-IV-TR criteria (n=7517 participants, 14 studies). When DSM-5 criteria were applied, the pooled reduction in ASD diagnosis was 31% (95% confidence interval [CI] 20 to 44, $p < 0.001$). However, heterogeneity between and within studies was high ($Q = 945$, $p < 0.001$, $I^2 = 98.6$) and sensitivity analyses were done to identify responsible variables:

Age

- Age ≤ 3 years (47.8%, 95% CI 44.3 to 51.3; 1 study)
- Age ≤ 18 years (25.6%, 95% CI 14.1 to 41.8; 7 studies)
- Ages 4 to 18 years (53.8%, 95% CI 35.0 to 71.6; 1 study)
- Age ≥ 4 years (22.7%, 95% CI 10.5 to 42.4; 3 studies)
- All ages (48.1%, 95% CI 30.9 to 65.8; 2 studies)

There were significant differences between age subgroups ($p < 0.001$).

Country

- United States (33.4%, 95% CI 23.5 to 45.0; 8 studies)
- International (28.3%, 95% CI 13.3 to 50.5; 6 studies).

Study design

- Prospective (33.7%, 95% CI 26.8 to 41.4; 6 studies)
- Retrospective (28.5%, 95% CI 15.2 to 47.1; 8 studies).

Study quality

- Met <half quality criteria (28.5%, 95% CI 15.2 to 47.1; 8 studies)
- Met \geq half quality criteria (34.2%, 95% CI 14.5 to 61.4; 5 studies).

The second meta-analysis included 7 studies with participants meeting the DSM-IV-TR criteria for the ASD subgroups (n=1,227 participants with AD, n=80 with Asperger's disorder, and n=630 with PDD-NOS). When DSM-5 criteria were applied, the pooled reduction was significant for the following:

- AD diagnosis: 22% (95% CI 16 to 29, $p < 0.001$, heterogeneity: $Q = 27.7$, $p < 0.001$, $I^2 = 78.4$)
- PDD-NOS diagnosis: 70% (95% CI 25 to 97, $p = 0.01$, heterogeneity: $Q = 39.4$, $p < 0.001$, $I^2 = 87.3$).

A non-significant pooled reduction in diagnosis using DSM-5 was observed for the following:

- Asperger's disorder diagnosis: 70% (95% CI 17 to 96, $p = 0.38$, heterogeneity: $Q = 18.3$, $p < 0.001$, $I^2 = 83.6$).

Strengths and limitations

Strengths

The main strength was that the authors used the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines for their report. At least half QAREL items

were met by 5 studies.

Limitations

A limitation was that the population of included studies only partially matched the population looked at in NICE guideline CG128 because 3 studies included children and adults and 2 studies included only adults. This systematic review does not report on how many people who do not have a diagnosis at present would be now included by DSM-5. The authors concluded that this systematic review was underpowered to detect the true impact of DSM-5 for Asperger's disorder (only 4 studies with small samples).

The main weaknesses of the included studies in this systematic review were the lack of reporting about raters' blinding to the results of the DSM-IV-TR and the lack of appropriate statistical measures of agreement such as inter- or intra-rater reliability.

Impact on guideline

This systematic review and meta-analysis provides a comparison between DSM-IV-TR and DSM-5 criteria.

DSM-5 was published after the development of NICE guideline CG128. Therefore, NICE guideline CG128 refers to DSM-IV criteria in [recommendation 1.5.5](#), [recommendation 1.5.10](#) and [recommendation 1.5.13](#). The introduction of the new DSM-5 criteria may have an impact on NICE guideline CG128 because the new criteria seem to be much more strict and therefore fewer people would meet ASD diagnosis.

Specific interventions for the core features of autism – psychosocial interventions

Two studies were selected for this area (Geretsegger 2014; Oono 2013).

What the guideline recommends

NICE guideline CG170 recommends that a specific social-communication intervention should be considered 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 preschool children consider parent, carer or teacher mediation. For school-aged children consider peer mediation.

We selected the Cochrane review by [Geretsegger et al. \(2014\)](#) for a full commentary because it provides evidence on music therapy for children with ASD. Music therapy is an emerging intervention that was not considered in NICE guideline CG170 because there was lack of evidence during guideline development.

Methods

Geretsegger et al. (2014) conducted a Cochrane review of 9 randomised controlled trials and 1 'counterbalanced' trial (n=165 children, 10 studies) assessing the effects of music therapy compared to placebo therapy or standard care for people with autism spectrum disorder. Music therapy interventions were delivered by professional music therapists through regular sessions including free and structured improvisation, playing music, singing songs, and listening (one-to-one and family-based settings). The duration of music therapy interventions ranged from 1 or 2 weeks (daily basis) to 7 months (weekly basis). Participants had a diagnosis of pervasive developmental disorder as defined by ICD-10 or DSM-IV or DSM-IV-TR. The primary outcomes were social interaction, non-verbal and verbal communicative skills, initiating behaviour, social-emotional reciprocity and adverse effects. Secondary outcomes included social adaptation skills.

Results

Participants were children between 2 and 9 years old. Children received a diagnosis of

ASD with a standardised tool including the Childhood Autism Rating Scale (CARS), the Autism Diagnostic Interview Revised (ADI-R), or the Social Responsiveness Scale (SRS). Outcome measures included non-generalised outcomes (changes in child's non-generalised behaviour in the same setting of the intervention) and generalised outcomes (changes observed in other settings).

- There was a greater effect on non-generalised social interaction skills following music therapy (standardised mean difference [SMD] 1.06, 95% CI 0.02 to 2.10, $p=0.046$; 1 study, $n=10$).
- There was a greater effect on generalised social interaction skills following music therapy (SMD 0.71, 95% CI 0.18 to 1.25, $p=0.0092$; 3 studies, $n=57$).
- There was a greater effect on non-generalised communicative skills (non-verbal) following music therapy (SMD 0.57, 95% CI 0.29 to 0.85, $p=0.000068$; 3 studies, $n=30$).
- Generalised communicative skills (non-verbal) were not significantly higher after music therapy compared to control therapy (SMD 0.48, 95% CI -0.02 to 0.98, $p=0.060$; 3 studies, $n=57$).
- There was a greater effect on non-generalised communicative skills (verbal) following music therapy (SMD 0.33, 95% CI 0.16 to 0.50, $p=0.00015$; 4 studies, $n=92$).
- Generalised communicative skills (verbal) were not significantly higher after music therapy compared to control therapy (SMD 0.30, 95% CI -0.28 to 0.89, $p=0.31$; 2 studies, $n=47$).
- There was a greater effect on non-generalised initiating behaviour following music therapy (SMD 0.73, 95% CI 0.36 to 1.11, $p=0.00011$; 3 studies, $n=22$).
- There was a greater effect on non-generalised social-emotion reciprocity following music therapy (SMD 2.28, 95% CI 0.73 to 3.83, $p=0.0039$; 1 study, $n=10$).
- There was a greater effect on non-generalised social adaptation following music therapy (SMD 1.15, 95% CI 0.69 to 1.61, $p<0.00001$; 3 studies, $n=22$).
- There was a greater effect on generalised social adaptation following music therapy (SMD 0.24, 95% CI 0.02 to 0.46, $p=0.029$; 1 study, $n=4$).
- None of the studies reported adverse effects.

Strengths and limitations

Strengths

The main strength was that the study used the Cochrane methodology and had low risk of bias. The authors judged that more than 75% of studies had low risk of attrition bias, reporting bias and other bias. If heterogeneity was present, it was not significant apart from a combined meta-analysis of non-generalised and generalised outcomes.

Limitations

A limitation of this systematic review was the small sample size of the included studies (6 studies with 10 or fewer participants and 4 studies with 50 or fewer participants). Sample size limitation was partially compensated by most of the studies using crossover designs. The authors judged that half or more of the studies had unclear risk of selection bias, detection bias and performance bias.

Impact on guideline

This systematic review and meta-analysis provides evidence that music therapy may have positive effects on social interaction and communication skills in children with ASD. Two of the 10 included studies in this systematic review were also considered during guideline development under art-based interventions. However, there are no specific recommendations in NICE guideline CG170 for the use of art-based interventions for the treatment of autism. Guideline committee members commented during this surveillance review that there was not a clear opinion about music therapy in the current guideline. It was concluded that the evidence from this Cochrane review was not enough to update NICE guideline CG170 in this area because the evidence was from studies with small sample sizes and unclear risk of relevant bias.

We selected the Cochrane review by [Oono et al. \(2013\)](#) for a full commentary because it provides evidence that children with ASD may make gains in language skills following parent-mediated interventions and topic experts felt that this evidence is very applicable to [recommendation 1.3.1](#).

Methods

Oono et al. (2013) conducted a Cochrane review of 17 randomised controlled trials (n=919)

assessing the effectiveness of parent-mediated early interventions in terms of the benefits for both children and their parents. Control groups included no treatment, treatment as usual, waiting list, alternative child-centred intervention not mediated by parents or an alternative parent-mediated intervention different to the intervention under study. Parent-mediated early interventions were delivered by professionals (including group or individual training) to improve the management of their children's ASD-related difficulties in areas such as communication, social development, learning and behaviours. The duration of the interventions ranged from 1 week to 2 years. Participants were children with ASD (aged between 17 months to 6 years with varied levels of functioning). The primary outcomes were child communication and social development (including language development [comprehension and expression], social communication skills and skills in interaction with parent) and parents' level of stress. Sensitivity analyses were done including studies with low and unclear risk of bias in 4 domains: sequence generation, allocation concealment, blinding of outcome, and attrition.

Results

Meta-analyses included 10 studies that evaluated interventions focusing on parent interaction style in facilitating children's communication compared to 'treatment as usual'. The rest of the studies could not be compared directly because they were different in their theoretical basis, interventions, and outcome measures.

Significant improvements were observed in the following parent-mediated intervention groups:

- Language development (comprehension [parent report]) (mean difference [MD] 36.26, 95% CI 1.31 to 71.20, $p=0.042$; 3 studies, $n=204$).
- Autism severity (SMD -0.30, 95% CI -0.52 to -0.08, $p=0.0081$; 6 studies, $n=316$).
- Shared or joint interaction (coding of parent-child interactions) (SMD 0.41, 95% CI 0.14 to 0.68, $p=0.0032$; 3 studies, $n=215$).
- Parent synchrony (coding of parent-child interactions) (SMD 0.90, 95% CI 0.56 to 1.23, $p<0.00001$; 3 studies, $n=244$).

For the following outcomes, no significant differences were observed between parent-mediated interventions and control groups:

- Language development (comprehension [direct or independent assessment]) (SMD 0.29, 95% CI -0.20 to 0.78, $p=0.25$; 2 studies, $n=200$).
- Language expression (direct or independent assessment) (SMD 0.14, 95% CI -0.16 to 0.45, $p=0.36$; 3 studies, $n=264$).
- Language expression (parent report) (MD 29.44, 95% CI -14.99 to 73.86, $p=0.19$; 3 studies, $n=204$).
- Joint language (direct or independent assessment) (SMD 0.45, 95% CI -0.05 to 0.95, $p=0.077$; 2 studies, $n=64$).
- Child communication (parent or teacher report) (MD 5.31, 95% CI -6.77 to 17.39, $p=0.39$; 3 studies, $n=228$).
- Child initiations (coding of parent-child interactions) (SMD 0.38, 95% CI -0.07 to 0.82, $p=0.095$; 4 studies, $n=268$).
- Parent stress (SMD -0.17, 95% CI -0.70 to 0.36, $p=0.52$; 2 studies, $n=55$).

Regarding social communication skills, meta-analysis was not performed for this outcome and studies reported mixed results (no differences using a directly observed assessment measure, improvements with more intensive treatment, and significant improvements on teacher-reported social and language skills).

Strengths and limitations

Strengths

The main strength was that the study used the Cochrane methodology and had low risk of bias. The authors judged that between 50% and 75% of the included studies had low risk of selection bias (randomisation), detection bias, attrition bias and reporting bias. Eleven meta-analyses were performed including the primary outcomes without heterogeneity in 5 studies and non-significant heterogeneity in 4 studies.

Limitations

A limitation was the variation in outcomes measures which limited the number of studies included in the meta-analyses. The authors judged that there was high risk of allocation concealment and performance bias in most of the included studies.

Impact on guideline

This systematic review and meta-analysis provides evidence that children with ASD may make gains in language skills following parent-mediated interventions. Four of the 17 included studies in this systematic review were also considered during guideline development under behavioural interventions. They also commented about the limitations and low quality of evidence from this systematic review. It was concluded that the evidence from this Cochrane review was not enough to update NICE guideline CG170 in this area because the evidence had high risk of allocation concealment and performance bias.

Research recommendation 2.2 Managing behaviour that challenges in children and young people with autism

We selected the randomised controlled trial by [Bearss et al. \(2015\)](#) for a full commentary because it partially addresses research recommendation 2.2 in the guideline.

What the guideline recommends

The research recommendation suggests an evaluation of a group-based parent training intervention for parents or carers of children and young people with autism in reducing early and emerging behaviour that challenges in the short- and medium-term compared with treatment as usual. The guideline committee considered that a randomised controlled trial design should be used assessing short- and medium-term reduction in behaviour that challenges, parental and sibling stress, quality of life and the child or young person's adaptive function, medium-term use of medication, and cost effectiveness of a wide range of services, such as additional educational support and social services, and health service use by families.

Methods

Bearss et al. (2015) conducted a 24-week randomised controlled trial (n=180) assessing whether parent training was superior to parent education for reducing behavioural problems in children with ASD confirmed by DSM-IV-TR (aged 3 years to 6 years 11 months). Exclusion criteria were children in whom there would be treatment changes, children with receptive language <18 months, not enrolled in a school programme, living in

a household without an English-speaking caregiver, with a diagnosis of Rett disorder or childhood disintegrative disorder, presence of a known serious medical condition, a current psychiatric disorder requiring alternative treatment, or children whose parents participated in a structured parent training programme in the past 2 years previous to this randomised controlled trial (RCT). The study was conducted in 6 sites in the United States. Parent training was delivered individually in 11 core sessions over 16 weeks covering the identification of children's behaviours, strategies to manage behaviours, and maintenance of improvements. Parent education was delivered in 12 sessions over 24 weeks covering information on ASD without any instruction on behaviour management. The primary outcomes were the parent-rated Aberrant Behaviour Checklist-Irritability subscale (ABC-I) and the parent-rated Home Situations Questionnaire – Autism Spectrum Disorder (HSQ-ASD). It was pre-specified that 25% reduction of both ABC-I and HSQ-ASD indicated clinically meaningful improvement. The secondary outcomes were the Improvement item of the Clinical Global Impression scale (CGI-I), adaptive functioning and parent-child interactions (measured using the Standardised Observational Analogue Procedure [SOAP]). Adverse events were assessed by an independent evaluator. Outcomes were measured at baseline, week 12 and week 24.

Results

Effect sizes were calculated by taking the difference in the least squares means at week 24 and dividing by the pooled standard deviation at baseline.

The 24-week parent training programme led to a greater reduction in disruptive behaviour on parent-reported outcomes compared with parent education but this reduction was not clinically meaningful:

- The ABC-I decreased 47.7% (from 23.7 to 12.4) in the parent training group and 31.8% (from 23.9 to 16.3) in the parent education group (least squares mean difference -3.9 , 95% CI -6.2 to -1.7 , $p < 0.001$, effect size=0.62).
- The HSQ-ASD decreased 55.0% (from 4.0 at baseline to 1.8 by week 24) in the parent training group and 34.2% (from 3.8 to 2.5) in the parent education group (least squares mean difference -0.7 , 95% CI -1.1 to -0.3 , $p < 0.001$, effect size=0.45).

The 24-week parent training programme led to a greater overall improvement compared with parent education rated by an independent clinician blinded to treatment assignment:

- The CGI-I was rated much improved or very much improved by 68.5% of participants in the parent training group compared with 39.6% of participants allocated to the parent education group ($p < 0.001$). The number needed to treat was 4.
- The most frequent adverse events were cough and rhinitis (around 50% in each group) and diarrhoea (around 30% in each group). No significant differences were found in adverse events between parent training and parent education groups.

Strengths and limitations

Strengths

The main strengths of this study were the low risk of selection bias and reporting bias as well as that this study was focused on children which make the results applicable to NICE guideline CG170.

Limitations

A limitation of this study was the high risk of performance bias and detection bias. Although some outcome assessors were blinded, this blinding was restricted to the secondary outcomes only as the parents could not be blinded for the parent-rated outcomes. These limitations have an impact on the applicability of the results to NICE guideline CG170.

Impact on guideline

This RCT partially addresses NICE guideline CG170 research [recommendation 2.2](#) because it did not measure parental and sibling stress and quality of life and it was individual not group based. Although adaptive skills were measured, this publication only shows baseline data but it is mentioned that these results will be presented in a separate report. There was not an assessment of medium-term use of medication or a cost-effectiveness analysis which was an additional criterion of the research recommendation.

How we made the decision

We check our guidelines regularly to ensure they remain up to date. We based the decision on surveillance 6 years after the publication of [autism spectrum disorder in under 19s: recognition, referral and diagnosis](#) (2011) NICE guideline CG128, and 4 years after the publication of [autism spectrum disorder in under 19s: support and management](#) (2013) NICE guideline CG170.

For details of the process and update decisions that are available, see [ensuring that published guidelines are current and accurate](#) in 'Developing NICE guidelines: the manual'.

Previous surveillance update decisions for [NICE guideline CG128](#) are on our website.

New evidence

Autism spectrum disorder in under 19s: recognition, referral and diagnosis (NICE guideline CG128)

We found 83 new studies in a search for diagnostic studies published between 1 January 2014 and 26 January 2016. We also considered 4 additional studies identified by members of the guideline committee who originally worked on this guideline. A further 3 studies were identified through post-publication communications.

Evidence identified in previous surveillance 4 years after publication of the guideline was also considered. This included 144 studies identified by search and 25 studies identified during the 2-year evidence update.

From all sources, 259 studies were considered to be relevant to the guideline.

We also checked for relevant ongoing research, which will be evaluated again at the next surveillance review of the guideline.

See [appendix A1](#): summary of new evidence from surveillance and references for all new evidence considered.

Autism spectrum disorder in under 19s: support and management (NICE guideline CG170)

We found 38 new studies in a search for randomised controlled trials and systematic reviews published between 1 January 2013 and 19 January 2016. We also considered 7 additional studies identified by members of the guideline committee who originally worked on this guideline. A further 6 studies were identified through post-publication communications.

From all sources, 51 studies were considered to be relevant to the guideline.

We also checked for relevant ongoing research, which will be evaluated again at the next surveillance review of the guideline.

See [appendix A2](#): summary of new evidence from surveillance and references for all new evidence considered.

Views of topic experts

We considered the views of topic experts, including those who helped to develop the guideline and other correspondence we have received since the publication of the guideline. This included a meeting with experts to discuss potential areas for update in NICE guideline CG128.

Views of stakeholders

Stakeholders commented on the decision not to update NICE guideline CG170. Overall, 11 stakeholders commented. See [appendix B](#) for stakeholders' comments and our responses.

Eleven stakeholders commented on the proposal not to update the guideline: 3 agreed with the decision and 9 disagreed with the decision. Consultees suggested new evidence which was related to specific review questions and recommendations. The relevant evidence was added to appendices A1 and A2 but was not felt to impact on guideline recommendations. Consultees felt that applied behavioural analysis (ABA) should be recommended by NICE as an intervention to manage autism in children and young people. However, it was noted that high quality evidence was not found for ABA during guideline

development or surveillance review. Most of the evidence for ABA comes from single-case experimental designs which have limitations like the restriction of generalisation to wider population and the high risk of publication bias. This area will be considered again at the next surveillance review of the guideline.

This surveillance review also proposed to remove 4 research recommendations from the NICE version of NICE guideline CG170 and the NICE research recommendations database. Six consultees answered the proposal. Four consultees disagreed and 2 agreed with this proposal. It was decided to retain these research recommendations based on the overwhelming feedback on their importance.

See [ensuring that published guidelines are current and accurate](#) in 'Developing NICE guidelines: the manual' for more details on our consultation processes.

NICE Surveillance programme project team

Sarah Willett

Associate Director

Philip Alderson

Consultant Clinical Adviser

Emma McFarlane

Technical Adviser

Yolanda Martinez

Technical Analyst

The NICE project team would like to thank the topic experts who participated in the surveillance process.