Appendix B: Stakeholder consultation comments table

2021 surveillance of CG170 Autism spectrum disorder in under 19s: support and management (2013)

Consultation dates: 26th October to 6th November 2020

1. Do you agree with the proposal to not to update the guideline?

Stakeholder	Overall response	Comments	NICE response
ABA - Access4All		I see that you have rejected in your review for CG170 the evidence from the recent NIHR study of early ABA (EIBI) (https://www.journalslibrary.nihr.ac.uk/hta/hta24350#/full-report) This systematic review *did* find some evidence that early ABA helps autistic children more than the UK's Treatment as Usual - in key areas such as cognitive ability and adaptive behaviour. You dismiss the evidence as minimal, but in fact IQ gains of 10 points after 1 year and 14 points after 2 years matter a great deal to those of us hoping our beloved children might have a degree of independence in adult life. The adaptive behaviour gains are also significant, occurring in vital areas such as play skills, communication skills and daily living skills. These are huge gains for our children, not insignificant. You also talk of the cost-effectiveness of EIBI being out of line with NHS	Thank you for your comments about the NIHR study Interventions based on early intensive applied behaviour analysis for autistic children: a systematic review and cost-effectiveness analysis. The study was not rejected: we identified this study and fully considered the impacts of the findings, page 98 on the surveillance proposal provides these details. The authors of the study note that the review found limited evidence that early intensive applied behaviour analysis-based interventions may improve cognitive ability and adaptive behaviour, but the long-term impact of the interventions remains unknown. They also noted: 'Autism symptom severity was not measured in most included studies and the results were too limited to be conclusive, with no clear evidence that early intensive applied behaviour analysis-based interventions had any effect.' In

		QALY ratios, yet as per chart 26 on page 80 we see that there are reasonable levels at which early ABA *does* indeed meet NHS criteria for cost-versus-quality-of-life thresholds. Given all the above gains for our autistic children pre school, and the fact that they can be achieved at prices that meet criteria, one can't help but assume that – whatever the questions asked and wherever the research leads – NICE's answer on ABA is always a firm "no". You're letting kids down with such intransigence, which may be due in no small part to the fact that you have zero ABA-qualified or even pro-ABA bods on your panels for review, and in fact many folk from competitor interventions (SALT, OT) plus avowedly anti ABA groups of higher functioning autistic adults, such as the National Autistic Taskforce, and no pro ABA groups such as my own 7000-strong parent campaign ABA - Access4All. This is the opposite of good science, is in fact the literal meaning of the word 'prejudice'. You are leaving autistic kids high and dry without some high quality early intervention, greatly affecting their future quality of life (and the UK's £30bn spend on care in adulthood for autism).	assessing impact on recommendations we noted the study suggested ABA was probably not cost-effective. We note that the study reports that IQ in the ABA group improved by a mean difference of 12 points at 1 year compared to the treatment as usual group based on an individual patient data meta-analysis of 5 studies (n=161). It is encouraging that increases in IQ were reported by the study, however, as reported by the study authors on p.84 'Interpreting the meaningfulness of these observed effects in terms of their impact on the everyday lives of autistic children and parents is not straightforward…it should be noted that the outcome measures included were considered by the stakeholders in our Advisory Group to be limited in terms of both their ability to reflect benefits and their relevance to practice.' They also conclude 'the existing evidence cannot provide service providers with clear guidance on the value of implementing early intensive ABA-based interventions alongside, or in place of, current practice.' (page 91). The study reports that only two studies reported data on autism symptom severity, both favouring treatment as usual over ABA. Meta-analysis suggested this effect was not statistically significant. You refer to Chart 26 on page 80 of the report. This chart describes the effects on cost effectiveness of early ABA if costs of ABA and treatment as usual are varied in relation to the long-term effects of both treatments under 2 possible conditions: 1. optimistic estimates of the long term effects of ABA i.e. they are as good as they can be as observed in the study data; and 2. pessimistic – where the long-terms effects of ABA are as poor as they can be as observed in the study data. The optimistic analysis does report "if effect sizes could be obtained either at lower intensity or with lower staff-to-child ratios, then it is plausible that early intensive ABA-based

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			interventions could be cost-effective.” However, this analysis does not consider the huge variability in the cost and outcome data used in the economic model. The results of the analysis that does account for this variability are described on page 74 of the study, and the results presented in table 22 and it is also shown graphically in figure 23 (page 75 of the study). This concludes that taking into account public sector and NHS costs and the variability of the cost and outcomes data used in the economic model, the cost per quality adjusted life year (QALY) gained by ABA, compared with treatment as usual, is between £46,768 and £189,122, outside NHS cost effective thresholds of £20,000 to £30,000 per QALY. We would like to highlight that the recommendations do not say ‘do not use ABA’. Recommendations 1.3.1 to consider a specific social-communication intervention and 1.4.9 which describes the attributes of effective psychosocial interventions for behaviour that challenges potentially accommodate the use of ABA-based interventions. Additionally challenging behaviour and learning disabilities (NICE guideline NG11), also accommodates ABA-based therapies (see, for example, recommendation 1.7.5) but also makes a research recommendation to answer the following question: *are interventions based on the science and practice of applied behaviour analysis or antipsychotic medication, or a combination of these, effective in reducing the frequency and severity of behaviour that challenges shown by adults with a learning disability?* This acknowledges that further research is needed. This research recommendation is not answered by the NIHR systematic review and is therefore still valid. NICE cannot explicitly recommend an update to consider an intervention if evidence for its effectiveness or cost-effectiveness, compared to other treatments is equivocal.

			With respect to your comments about having no ABA experts on panels. We strongly dispute the claim that panels are prejudiced and NICE's processes unscientific. The panel members for the development of CG170, all of whom completed and signed declaration of interest documents, contain a diverse mix of patient experts and professionals. Their names can be seen here. The guideline was also subject to consultation with stakeholders, as were subsequent surveillance reviews like this one.
Evelina Children's Hospital, London	Update needed- I don't agree with proposal not to update	The sleep section of this guideline is out of date. As this comorbidity affects 80% of children and young people with ASD it should be more prominent and detailed. Since the original guidelines a medication has been licensed by MHRA specifically for use in children with ASD and sleep problems refractory to behavioural measures. There are many peer reviewed publications supporting this work and the sleep management section of this proposal needs updating accordingly.	Thank you for your comments about the MHRA licensing of medication for sleep disorder in autistic children. We proposed adding 'consider melatonin' to recommendation 1.7.7 as described in question 3 of this consultation. Your response to this question agreeing with this proposal is noted as are your comments about a more detailed pathway to support the use of melatonin. During this surveillance review we did not find any evidence that suggested that recommendations 1.7.4 to 1.7.8 that address sleep disorder needed amending apart from being more specific about what medication could be used.
False Allegations Support Organisation	No		Thank you for your response.
UK Society for Behaviour Analysis	Overall	The UK-SBA is disappointed that the guidance will not be informed by the NIHR Systematic Review of EIBI (early intensive behavioural intervention), July 2020. The study acknowledged the gains that can be made for autistic children in the areas of cognition and adaptive behaviour, findings which align with the conclusions of an earlier Cochrane study into EIBI by Reichow et al. (2018).	Thank you for your comments about the NIHR systematic review of early intensive behaviour interventions (EIBI) and for sharing the Reichow Cochrane review and Dr Chiesa's comments. In the surveillance proposal we noted that that while outcomes on the Vineland Adaptive Behaviour Scale showed no clear evidence of benefit, the intervention appeared to improve cognitive function at 1 year and at 2 years. However, the authors noted that: 'Autism

		Dr Mecca Chiesa, who was a member of the review team, made the following comments: The report states there is no evidence that ABA-based interventions improve challenging behaviour (which lies at the root of many poor outcomes for autistic children and higher costs to the state – e.g. school exclusions, ATU placements etc). The Advisory Group should have examined the extensive research on Challenging Behaviour and ABA-based interventions. It has a long history in the field dating back to the early 1980s. Currently, the UK is seeing increasing uptake of ABA services in adult NHS intensive support services for challenging behaviour, and also in some CAMHS children/adolescent services. NICE guidance NG11 references behaviour analysts and the just-released QS101 refers to the need for every community to have a 'specialist behavioural support team'. The NHS and many of the care groups in which it funds placements for autistic and/or learning disabled clients are employing PBS^ (Positive Behaviour Support) services, also an ABA-based intervention. There is no logic to the NHS adopting ABA for challenging behaviour at every age except pre school. It makes economic and social sense to tackle challenging behaviour earlier than when a crisis point is reached in the teens or adult life. That the review does not include mention of at least some of the important studies (see links below) demonstrating ABA's effectiveness in reducing and helping to redirect challenging behaviours is most unfortunate and misleading.	symptom severity was not measured in most included studies and the results were too limited to be conclusive, with no clear evidence that early intensive applied behaviour analysis-based interventions had any effect.' We also noted the study suggested ABA was probably not cost-effective allowing for the variability of the model data. We note that there was some effect on IQ and adaptive behaviour, but the study authors themselves note that 'the existing evidence cannot provide service providers with clear guidance on the value of implementing early intensive ABA-based interventions alongside, or in place of, current practice.' (p. 91). The following responses address Dr Chiesa's comments; it should be noted that this is a surveillance review that seeks to find out if the guidance is up to date, and we did not have an advisory committee(surveillance review process and methods are described in the NICE methods manual). We did, however, consult with topic experts and patient groups during the initial stages to gather intelligence about practice and recent and ongoing research. Dr Ciesa says: 'the report states that there is no evidence that ABA-based interventions improve challenging behaviour.' We are not sure what report is being referred to as no such statement is made in the surveillance proposal. The surveillance proposal does paraphrase the authors of the NIHR systematic review when it says: 'Data on language, behaviour that challenges, and adverse events were also lacking' from studies that were included in the meta-analyses. The NIHR systematic review authors say (p. 171) 'only one study reported autism symptom severity and behaviour that challenges and only one reported on parental stress.' We did not find any evidence that adult NHS intensive support services and CAMHS were increasing uptake of ABA services. We would be grateful if you have evidence from national policy or

		https://impact.ref.ac.uk/casestudies/CaseStudy.aspx?Id=4679 https://www.hee.nhs.uk/sites/default/files/documents/The%20key%20messages%20about%20Positive%20Behaviour%20Support_0.pdf https://www.researchgate.net/profile/Gary_Lavigna/publication/229006911_The_efficacy_of_positive_behavioural_support_with_the_most_challenging_behaviour_The_evidence_and_its_implications/links/53dfc1050cf2aede4b492e9c/The-efficacy-of-positive-behavioural-support-with-the-most-challenging-behaviour-The-evidence-and-its-implications.pdf	published evidence from systematic reviews, randomised controlled trials or diagnostic studies you could share with us about this. Challenging behaviour and learning disabilities (NG11) recommendation 1.1.5 recommends if initial assessment and management have not been effective health and social care provider organisations should ensure that teams providing care have access to specialist assessment, support and intervention services. These should provide advice, from a range of staff including behavioural analysts. This term will encompass those practicing ABA-based interventions and NG11 considered evidence from ABA-based interventions (for example, PBA) as CG170 does. As with CG170 it did not find sufficient evidence to make recommendations that specifically recommend named interventions based on an ABA approach, rather it makes recommendations that may encompass some ABA-based interventions, for example recommendation 1.7.5 which recommends consider personalised interventions for children, young people and adults that are based on behavioural principles and a functional assessment of behaviour. This is why NG11 makes a research recommendation to answer the following question: *are interventions based on the science and practice of applied behaviour analysis or antipsychotic medication, or a combination of these, effective in reducing the frequency and severity of behaviour that challenges shown by adults with a learning disability?* This acknowledges that further research is needed. This research recommendation is not answered by the NIHR systematic review and is therefore still valid. Learning disability: behaviour that challenges (QS101) does include Statement 8 that says: 'people with a learning disability and behaviour that challenges have access to specialist behavioural

			support in the community.' This accommodates ABA practitioners, but it does not specifically recommend ABA. Thanks to Dr Chiesa for comments about ABA use in pre-school children and for sharing 3 papers about this issue. The first paper is a brief research impact summary about managing challenging behaviour in people with Intellectual and Developmental Disabilities (IDD) and forms part of the University of Kent's Research Excellence Framework (REF) submission in 2014. The indicative sample of papers it references predate this surveillance review search start date of 27 January 2016 and are therefore out of scope. These studies would have been considered during development of the guideline. The second paper is called The key messages about Positive Behaviour Support and is an information sheet produced by Health Education England about Positive behaviour support (PBS). It is out of scope for this surveillance review because we can only consider national policy, guidelines, ongoing research or published evidence from systematic reviews, randomised controlled trials or diagnostic studies. The papers it references predate the 27 January 2016 start date for searches for this review. The third paper supplied by LaVigna and Willis is a literature review about the use of PBS in people with challenging behaviours. It was published in 2012 and predates the 27 January 2016 the start date for searches for this review.
Flynn Pharma Limited	The research recommendations for managing sleep problems in children with	In July 2018, the European Medicines Agency recommended granting a Paediatric Use Marketing Authorisation for Slenyto®, paediatric-appropriate prolonged-release melatonin mini tablets. The approval was based on a paediatric investigational plan (PIP) containing a	Thank you for your comments about Slentyo and we note your response to question 3 which are responded to below. We proposed amending recommendation 1.7.7 to include melatonin as a named pharmacological intervention pending the outcome of this

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	autism (2.3) are no longer current and should be updated along with section 1.7.7 to reflect the availability of a licensed paediatric- and condition (ASD)-appropriate formulation of melatonin.	Phase III study demonstrating short- and long-term efficacy and safety. The registration-seeking study followed the research recommendations cited in 2.3 and provided evidence of significant improvements, over baseline, in total sleep time, sleep initiation (latency) and maintenance, child behaviours (externalising), caregivers' quality of life and resolution of their own sleep disturbance. Gringras, P. et al. Efficacy and Safety of Pediatric Prolonged-Release Melatonin for Insomnia in Children with Autism Spectrum Disorder. J Am Acad Child Adolesc Psychiatry. 2017;56(11):948-957 Maras A, et al. Long-Term Efficacy and Safety of Pediatric Prolonged-Release Melatonin for Insomnia in Children with Autism Spectrum Disorder. Jnl Child and Adolesc Psychpharmacol. 2018; doi 10.1089:1-12 11	consultation. Removal of research recommendation 2.3 is also dependent on the outcome of this stakeholder consultation. Thank you for supplying the Gringras and Maras papers. These were identified during the current surveillance review, are described on p. 131 and form part of the rationale for the proposal to amend recommendation 1.7.7.
Autistic UK	No, we do not agree	Recommendation to update the introduction to remove functioning labels and allusion to a linear scale: Introduction (p. 5) – states differences in the severity of autism. While co-occurring conditions may have additional impact, autism isn't a linear scale. This doesn't account for environment, demands, executive dysfunction, physical health at the time, and the fluctuating nature of how well an Autistic person is able to 'cope' with a world which doesn't cate for Autistic experience. Recommendation regarding qualifying gender diagnostic disparity in guidance: Introduction (p. 6) – Stating that autism is more frequently diagnosed in boys without qualifying why means that this is used as a gatekeeping	Thank you for your comments. The introduction does not form part of the recommendations. Surveillance reviews do not assess or propose changes to sections within a guideline that are not recommendations (please see the NICE methods manual for details). The term 'function' is used within the recommendations in relation to assessment and adaptive skills, but we disagree that this acts to label people or is in any way used pejoratively. We also disagree that the guideline suggests autism can be conceptualised as being linear. The introduction notes: The way in which autism is expressed will differ across different ages and therefore for any individual may change over time as they mature, in response to environmental demands, in response to interventions, and in the context of coexisting conditions.'

		tool to refuse access to diagnostic services for girls/women/trans community. A North Wales psychologist stated at the North Wales Integrated Autism Service Launch that they were seeing nearly equal rates of diagnosis between women and men. This is due to their acknowledgment of masking etc. Recommendation regarding psychosocial interventions: P. 12 – Including techniques to expand interactive play isn't allowing the child to play how they want. Who are the trained professionals? This suggestion goes against the UNCRC Article 31 which states that children and young people have the right to have fun in the way they want, and that they also have the right to rest. This is whether or not they are disabled. This includes participating in growing Autistic culture. Autistic children need the right people to socialise with – often other Autistic children – and rather than interventions to make an Autistic child appear less Autistic, professionals should provide opportunities for the child to talk (in whichever way they communicate) about their intense interests, what matters to them etc. alongside being taught about social differences, safety, consent, and wellbeing. Milton D.E.M., Heasman B., Sheppard E. (2020) Double Empathy. In: Volkmar F. (eds) Encyclopedia of Autism Spectrum Disorders. Springer, New York, NY. [Online] https://doi.org/10.1007/978-1-4614-6435-8_102273-2 (Accessed 04/11/20)	Thank you for your comments about gender diagnostic disparity. The guidelines exist to reduce health inequalities and we found no evidence that disparities are caused by, or cause, gatekeeping behaviours in health and social care or other professionals who may work with autistic people. We acknowledge the issue and the lack of evidence in the area of diagnosis in girls and women and make research recommendation 1 in diagnosis in children (CG128) which says: 'If training improves earlier recognition and referral, this could be of particular benefit to at-risk groups for which there is evidence that autism is currently under-diagnosed, such as girls.' Thank you for your comments about psychosocial interventions. You refer to recommendation 1.3.1 which recommends consider a specific social-communication intervention for the core features of autism in children and young people that includes play-based strategies. This is based on evidence from meta-analyses for small to moderate effects of caregiver- or preschool-teacher-mediated and peer-mediated social communication interventions for pre-school children and on peer–child joint engagement for older children (8-9 years). The 'trained professional' (if this applies) is anyone trained to deliver these interventions, for example, a teacher. This is to ensure consistent delivery of the core components for maximum benefit. All of the recommendations in CG170 should be implemented in line with the principles set out in the patient-centred care section which says: 'Treatment and care should take into account individual needs and preferences. Patients should have the opportunity to make informed decisions about their care and treatment, in partnership with their healthcare professionals.' It should also be noted that the recommendations are not mandatory, and the guideline does not override the responsibility to make decisions appropriate to the

		Concerns regarding the use of antipsychotics: P. 14 – Suggesting the use of off-licence antipsychotics to assist with ‘behaviours which challenge’ is concerning for the reasons set out in our response to the adult guide. *Autistic UK response to adult guideline consultation: We are concerned with the use of the term ‘challenging behaviour’ and this point which states that assessment of challenging behaviour should be integrated into autism assessment. There is no legal single definition for the term ‘challenging behaviour’ (or indeed, ‘behaviours which challenge’) and its application is subjective. The individual shouldn’t be assessed based solely on behaviourism, rather the environment should be assessed to ensure it’s conducive to a good quality of life for the Autistic. I.e. there should be less focus on the Autistic’s behaviour, and more on those around them. There is also no consistency with the language which surrounds ‘challenging behaviour’ and the term has different meanings in different settings. Someone in a care home stating that someone has ‘challenging behaviour’ because they get upset while going to the park could result in someone else assuming the term* equates to violence and lead to inappropriate medical *intervention or denial of access to services leading to further health inequalities. It also leads to issues within the justice system if someone has been noted as having ‘challenging behaviour’. Why are NICE assuming*	circumstances of the individual, in consultation with them and their families and carers or guardian. as stated in the CG170 overview ‘Your responsibility section’. We disagree that recommendation 1.3.1 contravenes Article 31 of the United Nations Convention on the Rights of the Child. Thank you for sharing the Chapter by Milton in the encyclopaedia of autism spectrum disorders. This is out of scope for this surveillance review as our inclusion criteria are national policy, guidelines, ongoing research or published evidence from systematic reviews, randomised controlled trials or diagnostic studies. Thank you for your comments about the use of antipsychotics. We have copied your comments from the stakeholder consultation of the adult guideline (CG142) regarding behaviour that challenges (italics) into this document to help with the response about the use of antipsychotics. Your comment about the legal definition of challenging behaviour is responded to in autism in adults (CG142) consultation. We note your comments about the subjectivity of the term ‘challenging behaviour’ and the risk of inappropriate medical interventions. Recommendation 1.4.10 recommends antipsychotic medication for managing behaviour that challenges when psychosocial or other interventions are insufficient or could not be delivered because of the severity of the behaviour. This recommendation makes clear that antipsychotics should only be used when non-pharmacological interventions do not work or cannot practically be delivered because of the severity of behaviour. It also recommends monitoring and to stop treatment if there is no improvement at 6 weeks This is based on several meta-analyses of a

		Autistics will display 'challenging behaviour'? What will the outcomes of these subjective terms and assessments achieve? More useful would be recording strengths and weaknesses, likes and dislikes etc. Recommendation to add items to 1.3.2: 1.3.2 – MMS/CDM (ClO2) needs to be added to the list of 'not to use' pharmacological and dietary interventions. Comment regarding behaviourist strategies: 1.4.9 – Targeting behaviour isn't a solution. This, with your glossary definition of 'challenging behaviour', suggests that you recommend preventing stimming. All of the recommendations are reminiscent of ABA. Recommendation regarding qualifying outcomes linked to quality of life: 1.4.9 – Outcomes linked to quality of life need to specify that this is quality of life for the Autistic person. Many interventions aimed at Autistic children are designed to make parent/carer lives easier, not that of the Autistic. Recommendation regarding changing point regarding consistency: 1.4.9 – Consistency is not always appropriate depending on the context. When the Autistic person's anxiety is high demands need to be 'turned down' using a low arousal approach rather than expecting the same	number of randomised controlled trials that concluded antipsychotics showed benefit for a number of outcomes for people with challenging behaviours including irritability, lethargy and social withdrawal, stereotypic behaviour, hyperactivity and noncompliance, and inappropriate speech (see appendix 13 p.111). The guideline committee noted there was also evidence for potential harm with 2 types of antipsychotics and therefore made this a 'consider' recommendation (see page 436 full guideline). The committee also recognised that antipsychotics were often used for the management of behaviour that challenges without review of the underlying causes of that behaviour and recommended in 1.4.10 that a functional analysis of behaviour should be a core component of treatment. This analysis, along with a consideration of any coexisting mental or physical disorders and the wider social and physical environment, should help determine whether an antipsychotic should be used. It should also be noted that risperidone is licensed 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 subaverage intellectual functioning or mental retardation. Risperidone is therefore potentially licensed for use with some groups of autistic children. Thank you for your comments about chlorine dioxide, also known as 'Miracle mineral solution' or MMS. Recommendation 1.3.2 recommends to not use the following interventions for the management of core features of autism: antipsychotics, antidepressants, anticonvulsants, exclusion diets. This is based on evidence from randomised controlled trials that the harms of these interventions outweigh the benefits. MMS is not a pharmacological intervention and is therefore out of scope for CG170.

		input/output constantly across all settings. It is inappropriate to expect the same application of 'therapies' at home and at school, particularly as the same is not expected of non-Autistic children. This leads to burnout. Replacing the word 'consistent' with 'appropriate' removes burden from the Autistic, though this should be qualified with the addition of when consistency (staff members, not removing favoured items as punishment/operant tactics etc.) is required with the onus on the professional/parent/carer. Comment regarding consent and how this isn't followed: 1.4.12 – This doesn't translate into practice. Consent is not obtained from the Autistic person and has resulted in deaths (reference Oliver McGowan). Comment regarding the use of the term 'intervention': More generally, the term intervention suggests something that happens to the Autistic person to make them change, not changing what's going on around the Autistic person to accommodate neurological differences. Recommendation regarding CBT in guidance: 1.7.2 – It has been stated by many in the community that CBT doesn't work for Autistic people. This is verified in studies which use Autistic reporting as their data point. There are also no autism specific CBT therapists trained, so Autistic people get standard CBT rather than what is in the guidelines. As	Thank you for your comments about 1.4.9 which recommends that behavioural interventions for autistic people should focus on outcomes linked to quality of life. The recommendation applies to the person receiving the psychosocial intervention i.e. the autistic person, therefore the 'quality of life' referred to is that of the autistic person. Thank you for your comments about recommendation 1.4.9 behaviourist strategies. CG170 does not make any recommendations about preventing self-stimulatory behaviour, also known as 'stimming.' Applied behaviour analysis (ABA) involves a systematic study of the factors that may be causing behaviours or limiting skill acquisition, detailed assessment of the behaviour and assessment of potential rewards and maintaining factors in order to design interventions top effect change. Evidence about ABA-based interventions were considered during guideline development and this surveillance review, and the recommendations do accommodate some ABA techniques. Thank you for your comments about use of the word 'consistent' as used in recommendation 1.4.9 which recommends psychosocial interventions for behaviour that challenges should include consistent application in all areas of the child or young person's environment (for example, at home and at school). This is based on guidelines committee experience due to limited evidence about the effectiveness of psychosocial interventions. Consistent in this recommendation means implemented in the same way in different

		Autistics report no increase in quality of life, we would suggest removal of this recommendation until there are specific autism trained CBT therapists.	settings so as to avoid a situation where a child only receives an intervention in school and no intervention or only part of an intervention at home. This does not preclude varying the intensity of an intervention or using interventions adapted to the setting, as recommended by recommendation 1.4.6 which says: when choosing an intervention for behaviour that challenges take into account the environment. Thank you for your comment about 1.4.12 and consent. The guidelines are quite clear about obtaining consent and this is an implementation issue. Footnote 2 which is linked to from recommendation 1.4.10 (consider antipsychotic medication) says: '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.' Thank you for your comments about use of the word 'intervention.' Use of this word is in line with the NICE glossary of terms. Recommendation 1.1.9 makes recommendations about making adjustments to the social and physical environment and processes of care. All guideline recommendations should be applied in the context of patient-centred care. Thank you for your comments about CBT and recommendation 1.7.2 which recommends considering CBT for children and young people with autism and anxiety who have the verbal and cognitive ability to engage with the intervention. We did not find any evidence during this surveillance review that CBT does not work with autistic children for the treatment of anxiety.

Fair Treatment for the Women of Wales (FTWW)	No	The guideline needs updating to more fully accommodate the needs of girls and young women. For example, page 6 states that autism is more commonly diagnosed in boys without going into any detail about why girls may be less commonly diagnosed. This lack of detail erroneously reinforces the misconception that girls 'will only rarely be autistic', thereby perpetuating the failure to diagnose and invest in appropriate support. Page 14 of the guideline is another example of the problematic nature of subjective diagnostic criteria, with anti-psychotic medications being offered to those young people who present with 'behaviour that challenges'. For girls / young women, societal norms and gender stereotypes tend to see their behaviours judged more harshly, even by medical professionals. There is considerable evidence to demonstrate the impact of unconscious bias on females' and BAME individuals' healthcare experiences and this is unlikely to differ with the diagnosis, support, and management of autism. NICE has a responsibility to reflect these concerns and ameliorate them by updating its guideline accordingly. Failure to do so may see girls / young women / people of black and ethnic minorities over-medicated with very powerful anti-psychotic medication, harking back to the historical institutionalising of marginalised peoples, including women with menstrual disorders.	Thank you for your comments about girls and young women. It should be noted the section you refer to is from the guideline introduction and is not included in the surveillance review. The purpose of the surveillance review is to ensure the recommendations are current as described in the NICE methods manual, chapter 13. We acknowledge underdiagnosis in girls is an issue and diagnosis in children and young people (CG128) research recommendation 1 Training professionals to recognise signs and symptoms of autism attempts to stimulate research in this area. We did not find any evidence of why this is the case, nor did we find any tools that can adequately address this issue during this surveillance review, although we did find some evidence that suggested high quality diagnostic assessment may reduce this inequality (Loomes R, et al (2017)) . We will highlight this issue to the National Institute for Health Research (NIHR) as an area of potential health inequality where research is needed. Thank you for your comments about subjective diagnostic criteria. We found 7 studies about the use of antipsychotics and none mentioned inappropriate use as a result of gender stereotyping by health and social care professionals. Thank you for your comments about unconscious bias against black and minority ethnic groups, girls and women. Findings from the surveillance review about women and girls are outlined above. Topic experts raised the issue that take up of specialist services among black and minority ethnic groups was low, but we found no evidence about pathways or interventions to address this which would necessitate changing recommendations. All of the recommendations in CG170 where the subject of an equality impact assessment which

			included consideration of black and minority ethnic groups and other groups with protected characteristics.
Nottinghamshire Healthcare NHS Foundation Trust (Theresa Foster, Clinical Lead, CAMHS ID Team)	No	More information and support for parents needed	Thank you for your comments. Information and support for parent was included in the scope of the surveillance review and we did not identify anything that indicated recommendations needed changing.
University Hospitals Dorset NHS Foundation Trust		Please see below regarding changes as a result of COVID	Thank you for your response. We have addressed your comments about changes resulting from the COVID-19 pandemic below in the question 6 section.
Triple P UK Ltd	No	It is proposed a review is undertaken to identify the impact and outcomes of parenting programmes in supporting children with ASD and their families. The evidence base on parenting programmes including families of children with ASD has expanded considerably since the last update of evidence for this guideline (Sept 2016), including a number of RCTs, systematic reviews and meta-analyses. Please see reference list from page 13. A review of evidence related to parenting programmes for families of children with ASD warrants further attention and consideration of inclusion in this guideline. The role and importance of parenting programmes in support and management has not been specified in NICE guidelines for ASD, but has for other child learning difficulties/disorders. For example:	Thank you for your comments and for sharing the list of studies about parenting programmes. We have commented briefly on each of the shared studies immediately below. With respect to your comments about the highlighted NICE guidelines that include recommendations about parent training programmes it should be noted that management of autism in under 19s (CG170) has recommendation 1.2.3 which recommends 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, or are involved in the delivery of an intervention. Additionally, recommendation 1.4.9 about interventions for behaviour that challenges recommends agreement among parents, carers and professionals in all settings about how to implement the intervention.

		Antisocial behaviour and conduct disorders in children and young people: recognition and management: Psychosocial interventions: parent training programmes (1.5.1-1.5.10) Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges: Early intervention for children and their parents or carers (1.7.1-1.7.2) Mental health problems in people with learning disabilities: prevention, assessment and management: Specific psychological interventions (1.9.8-1.9.9). Attention deficit hyperactivity disorder: diagnosis and management: Identification and referral (1.2.4); Supporting families and carers (1.4.11). A review of the literature on parenting programmes for families of children with ASD will update the evidence base, enhance equity in the provision of support for children with learning difficulties/disorders, and identify the availability and effectiveness of parenting programmes to increase access and reach to support families of children with ASD. 1. Bischof, N. L., Rapee, R. M., Hudry, K., & Bayer, J. K. (2018). Acceptability and caregiver-reported outcomes for young children with autism spectrum disorder whose parents attended a preventative population-based intervention for anxiety: A pilot study. *Autism Research*, *11*(8), 1166-1174. doi:10.1002/aur.1963 2. DaWalt, L. S., DaWalt, L. S., Greenberg, J. S., Greenberg, J. S., Mailick, M. R., & Mailick, M. R.	You reference recommendations in 4 other NICE guidelines and although some are related, for example Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges, they have different scopes and make recommendations based on different although, occasionally overlapping, evidence bases comprising of studies with mostly non-autistic populations. It would be inappropriate to extrapolate from data about largely non-autistic groups to make recommendations about autistic populations. Recommendation 1.7 Interventions for coexisting problems in NICE guideline CG170 makes cross referrals to several related pieces of guidance. Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenge (NICE guideline NG11) is included in the NICE autism pathway which is linked to from the overview page of the guideline. Thank you for providing the studies. The inclusion criteria for this review are systematic reviews, randomised controlled trials and diagnostic studies published in the period between 27 January 2016 and 1 November 2019. Inclusion criteria are based on details from the abstracts of studies, not their full-text. Pilot studies and feasibility studies are out of scope. Our response to each reference is as follows: 1. Bischof et al was identified during the surveillance review search, but was out of scope because it is a pilot study. 2. De Walt et al was identified during surveillance and excluded due to lack of study data being described in the abstract. 3. Flynn et al post-dates our search cut-off date and was therefore not identified. This is a feasibility RCT that reports on preliminary outcomes of recruitment, retention, intervention adherence, and

		(2018). Transitioning together: A multi-family group psychoeducation program for adolescents with ASD and their parents. *Journal of Autism and Developmental Disorders, 48*(1), 251-263. doi:10.1007/s10803-017-3307-x 3. Flynn, S., Hastings, R. P., Burke, C., Howes, S., Lunsky, Y., Weiss, J. A., & Bailey, T. (2020). Online mindfulness stress intervention for family carers of children and adults with intellectual disabilities: Feasibility randomized controlled trial. *Mindfulness, 11*(9), 2161-2175. doi:10.1007/s12671-020-01436-0 4. Gobrial, E., & Raghavan, R. (2018). Calm child programme: Parental programme for anxiety in children and young people with autism spectrum disorder and intellectual disabilities. *Journal of Intellectual Disabilities, 22*(4), 315-327. doi:10.1177/1744629517704536 5. Grahame, V., Brett, D., Dixon, L. *et al.* Managing Repetitive Behaviours in Young Children with Autism Spectrum Disorder (ASD): Pilot Randomised Controlled Trial of a New Parent Group Intervention. *Journal of Autism and Developmental Disorders, 45*, 3168–3182 (2015). doi:10.1007/s10803-015-2474-x 6. Hemdi, A. & Daley, D. (2019). Are parenting interventions effective in improving parental functioning in parents of children with ASD?: a	acceptability of the intervention from 60 family carers of people with intellectual disabilities (autism is not mentioned) and as such is out of scope for this surveillance. 4.Gobrial et al. is out of scope for this surveillance review because it is not a randomised controlled trial, systematic review or diagnostic study. 5. Grahame et al. was published in 2015 and is outside the search date for this surveillance review. 6. Hemdi et al. is a meta-analysis (n=11 studies) that reports medium effects on parents' stress levels of parent training interventions. It also reports that parents feel more competent post-training, This study meets our inclusion criteria, however it was not identified in the search because it is not indexed by Medline. We will add this to the evidence summary. We have looked at the study outcomes and concluded that they support recommendation 1.2.3 which recommends when the needs of families and carers have been identified, offer information, advice, training and support. 7. Hinton et al. reports the results of a randomised controlled trial of a telemedicine intervention with parents and carers (n=98) of children with a range of developmental, intellectual and physical disabilities. The abstract does not mention autism and therefore this was not retrieved during surveillance. The study concludes that while parenting practices are improved no impact on children's behaviour was detected. Therefore, this supports recommendation 1.2.3 which recommends offering training to parents. 8. Hohlfeld et al. is a systematic review of 25 studies, 8 of which include children with autism. This was not identified by the search because it does not mention autism in the title or abstract. It concludes that parent training programmes resulted in a statistically significant increase in parental self-efficacy levels relative to

		meta-analysis. *International Journal of Academic and Scientific Research*. 7. Hinton, S., Sheffield, J., Sanders, M. R., & Sofronoff, K. (2017). A randomized controlled trial of a telehealth parenting intervention: A mixed-disability trial. *Research in Developmental Disabilities*, *65*, 74-85. doi:10.1016/j.ridd.2017.04.005 8. Hohlfeld, A. S. J., Harty, M., & Engel, M. E. (2018). Parents of children with disabilities: A systematic review of parenting interventions and self-efficacy. *African Journal of Disability*, *7*. doi:10.4102/ajod.v7i0.437 9. Johnson, C. R., Foldes, E., DeMand, A., & Brooks, M. M. (2015). Behavioral parent training to address feeding problems in children with autism spectrum disorder: A pilot trial. *Journal of Developmental and Physical Disabilities*, *27*(5), 591-607. doi:10.1007/s10882-015-9437-1 10. Kasperzack, D., Schrott, B., Mingebach, T., Becker, K., Burghardt, R., & Kamp-Becker, I. (2019). Effectiveness of the stepping stones triple P group parenting program in reducing comorbid behavioral problems in children with autism. *Autism: The International Journal of Research and Practice*, *24*(2), 136236131986606-436. doi:10.1177/1362361319866063 11. Lunsky, Y., P. Hastings, R., Weiss, J. A., M. Palucka, A., Hutton, S., & White, K. (2017). Comparative	baseline, particularly in parents of children younger than 5 years. It does not report results for autistic children separately therefore it is difficult to assess impact. Generally, it supports recommendation 1.2.3 to offer parental training. 9. The Johnson et al. study predates the search period for this surveillance review and is therefore out of scope. 10. Kasperzack at al. is a cohort study which is out of scope for this surveillance review which only consdered randomised controlled trials, systematic reviews and diagnostic studies. 11. Lunsky et al. was identified during this surveillance review and excluded because it does not provide adequate data in the abstract. 12. Mazzucchelli et al. reports the results of a pre-test, post-test feasibility study which is an out of scope study type for this surveillance review. 13. The Navroodi quasi-experimental study which is out of scope for this surveillance review. 14. The Rollins et al. study was identified during this surveillance review and was excluded because the abstract does not provide enough data. 15. The Ruane et al. study is a systematic review of the effects of the Triple P Stepping Stones parent training programs on child behaviour problems and parenting outcomes in families of children with developmental disabilities. It was not retrieved by the search because it does not mention autism in the abstract, title, or index terms. It does not report results for autistic children or report the proportions of autistic children included in the meta-analyses therefore it is difficult to assess the impact of the study on CG170. Generally, it reports positive results for the Stepping Stone intervention on child behaviour in mixed groups of unknown

		effects of mindfulness and support and information group interventions for parents of adults with autism spectrum disorder and other developmental disabilities. *Journal of Autism and Developmental Disorders*, *47*(6), 1769-1779. doi:10.1007/s10803-017-3099-z 12. Mazzucchelli, T. G., Jenkins, M., & Sofronoff, K. (2018). Building bridges triple P: Pilot study of a behavioural family intervention for adolescents with autism spectrum disorder. *Research in Developmental Disabilities*, *76*, 46-55. doi:10.1016/j.ridd.2018.02.018 13. Navroodi, S. O. S., Nicknam, M., Ahmadi, A., Roodbarde, F. P., & Azami, S. (2018). Examining the effectiveness of group positive parenting training on increasing hope and life satisfaction in mothers of children with autism. *Iranian Journal of Psychiatry*, *13*(2), 129-135. 14. Rollins, P. R., John, S., Jones, A., & De Froy, A. (2019). Pathways early ASD intervention as a moderator of parenting stress on parenting behaviors: A randomized control trial. *Journal of Autism and Developmental Disorders*, *49*(10), 4280-4293. doi:10.1007/s10803-019-04144-4 15. Ruane, A., & Carr, A. (2019). Systematic review and Meta-analysis of Stepping Stones Triple P for parents of children with disabilities. *Family Process*, *58*(1), 232-246. doi:10.1111/famp.12352	composition. Data for the effects of this programme on autistic children would need to be seen in order to assess the impact of this intervention on recommendations. 16. The Ruane et al. randomised controlled trial reports results from 84 children with developmental disabilities and behaviour problems. Again, it does not report results for autistic children in the abstract but only for mixed-disability groups and it is therefore difficult to assess the impact on recommendations and for this reason was not retrieved by the search. It reports generally positive results but these are not enough to impact recommendations. 17. The Rutherford et al. study was identified during this surveillance review. The study was excluded because it does not report any data in its abstract. 18. The Schrott et al. study was identified during this surveillance review. The study was excluded because it does not report any data in its abstract. 19. The Sohmaran, et al. study reports the effects of psychological interventions on the parents of children with developmental disabilities from a meta-analysis of 11 studies. This does not report any results for the parents of autistic children, so was not identified by the search, and its impact is therefore difficult to assess. This study is also beginning to move away from the scope of CG170 which is about the management of autism in children. While training for parents is accommodated by the guideline psychological treatments for parents are not in scope and are covered by other guidelines. 20. The Tarver et al. study was identified during this surveillance review. It does not report in its abstract the sources that were searched to inform it and therefore it did not meet inclusion criteria for being a systematic review and was not included in the

		16. Ruane, A., Carr, A., Moffat, V., Finn, T., Murphy, A., O'Brien, O., . . . O'Dwyer, R. (2019). A randomised controlled trial of the Group Stepping Stones Triple P training programme for parents of children with developmental disabilities. *Clinical Child Psychology and Psychiatry*, *24*(4), 728-753. doi:10.1177/1359104519827622 17. Rutherford, M., Singh-Roy, A., Rush, R., McCartney, D., O'Hare, A., & Forsyth, K. (2019). Parent focused interventions for older children or adults with ASD and parent wellbeing outcomes: A systematic review with meta-analysis. *Research in Autism Spectrum Disorders*, *68*, 101450. doi:10.1016/j.rasd.2019.101450 18. Schrott, B., Kasperzack, D., Weber, L. *et al.* (2019). Effectiveness of the Stepping Stones Triple P Group Parenting Program as an Additional Intervention in the Treatment of Autism Spectrum Disorders: Effects on Parenting Variables. *Journal of Autism and Developmental Disorders*, *49*, 913–923. https://doi-org.libraryproxy.griffith.edu.au/10.1007/s10803-018-3764-x 19. Sohmaran, C., & Shorey, S. (2019). Psychological interventions in reducing stress, depression and anxiety among parents of children and adolescents with developmental disabilities: A systematic review and meta-analysis. *Journal of*	surveillance review We have checked the full text: it reports improvements in parent-reported child disruptive behaviour, hyperactivity and parent stress following behavioural parent interventions compared with controls This supports recommendation 1.4.9 which recommends offering a psychosocial intervention for behaviour that challenges which involves parents in design and implementation. 21. The Williams et al. study is a feasibility study and does not report any effectiveness data and is therefore not in scope for this surveillance review. 22. The Zand study is a pilot study, does not report effectiveness data and is therefore out of scope for this surveillance review.

		Advanced Nursing, *75*(12), 3316-3330. doi:10.1111/jan.14166 20. Tarver, J., Palmer, M., Webb, S., Scott, S., Slonims, V., Simonoff, E., & Charman, T. (2019). Child and parent outcomes following parent interventions for child emotional and behavioral problems in autism spectrum disorders: A systematic review and meta-analysis. *Autism: The International Journal of Research and Practice*, *23*(7), 136236131983004-1644. doi:10.1177/1362361319830042 21. Williams, M. E., Hastings, R. P., & Hutchings, J. (2020). The incredible years autism spectrum and language delays parent program: A pragmatic, feasibility randomized controlled trial. *Autism Research*, *13*(6), 1011-1022. doi:10.1002/aur.2265 22. Zand, D. H., Bultas, M. W., McMillin, S. E., Halloran, D., White, T., McNamara, D., & Pierce, K. J. (2018). A pilot of a brief positive parenting program on children newly diagnosed with autism spectrum disorder. *Family Process*, *57*(4), 901-914. doi:10.1111/famp.12334	
Royal College of Nursing	No	Updates are required due to new evidence and to promote best practice considering the most recent research results	Thank you for your comments. However, in the absence of references, we are not able to consider the evidence you refer to. If you are aware of new evidence that meets the inclusion criteria for the surveillance review which are published systematic reviews,

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			randomised controlled trials or diagnostic studies that have not already been considered, we would be grateful if you could share these with us. We can also consider information about ongoing research and updated or new national policy that is directly relevant to the topic.
British Association of Social Workers (BASW) – England	Not sure	100% of BASW England members respondents stated 'not sure'.	Thank you for comments.
The Challenging Behaviour Foundation	No	All the guidelines were published before Building the Right Support (NHSE et al 2015) set out new approaches including dynamic risk registers, CTRs/CETRs and other processes and structures which have changed the landscape to some extent. Recent years have also seen much more work added to the evidence base (see details here of 2018 Transforming Care evidence seminar re children https://www.challengingbehaviour.org.uk/driving-change/evidenceseminar.html) and other national reviews (e.g. Lenehan review, Children's Commissioners reviews, CQC reviews) which should all be incorporated into a review of the guideline.	Thank you for your comments. Thank you for your comments. Although the guidelines were published before 2015 all have undergone subsequent surveillance reviews to check they remain up-to-date, the latest in 2016 This resulted in a partial update to CG170 (please see summary of 2016 surveillance for CG128 and CG170 and CG142). CTRs and CETRs with children help to improve care for people whose behaviour is seen as challenging and/or improve care for people with mental health conditions. .Management of autism in under 19s contains recommendations 1.4.5 and 1.4.6 about reviewing support for behaviour that challenges. Section 1.3 in autism in adults Identifying the correct interventions and monitoring their use contains recommendations about monitoring and reviewing interventions. Recommendation 1.3.5 in section 1.3 recommends that there should be regular reviews of interventions to ensure their appropriateness. Thank you for sharing the Transforming Care evidence seminar: Children and young people with learning disabilities whose behaviours challenge. We are aware of transforming care and that it

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			aims to reduce hospitalisations and enable autistic people and those with learning disabilities to live in the community closer to family and friends. The seminar aimed to identify evidence from key decision makers of use to those commissioning, designing and delivering services to children and young people with learning disabilities or autism whose behaviours challenge. The document provides an overview of what was discussed but does not provide links to evidence that we can consider in relation to the recommendations. We note the comment 'NICE need to think about their criteria for what is considered as robust evidence and the implications of gaps in NICE guidelines for prioritisation of interventions and treatments by NHS England.' The 3 guidelines considered for this review all include research recommendations that acknowledge gaps in the evidence and they are an attempt to stimulate research. With the exception of new evidence for melatonin we did not find any evidence that suggests any of the research recommendations should be stood down because they have been answered. As part of the 2020 surveillance review, in addition to published evidence from the literature we also considered the latest national level policy, for example the UK government's Autism self-assessment framework which reviews progress in implementing the autism strategy in England. We also considered the views of topic experts and patient groups (see page 16 of surveillance review for an overview). None of this evidence indicated that recommendations were out of step with current policy.
National Autistic Society		As mentioned in our 2019 surveillance questionnaire, to better align with ICD-11 and DSM-V in the language it uses	Thank you for your comments about ICD-11 and DSM-V. We can confirm that we will track ICD-11 and assess its impact post-

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		around neuro-developmental conditions, rather than to conflate them with mental health disorders. This would help clinical practice and tackle persisting confusion among medical professionals. Additional information should be added on interventions on feeding/eating/drinking problems and demand avoidant behaviour. It is important that the guideline refers to the most recent work being undertaken by NHS England, NHS Wales and NHS Improvement, including the *Transforming Care* programme. This will ensure that the guideline aligns with NHS messaging and advice.	adoption, January 2022. In December 2017 we updated the guideline recommendation to refer to DSM-V. Thank you for your comments on feeding/eating/drinking problems and demand avoidant behaviour. We identified one small trial (n=38) that reported some improvement in diet variety and amount consumed with an intervention called 'Managing Eating Aversions and Limited variety' (MEAL) Plan (see section on improving dietary variety in surveillance proposal) but it was not sufficient evidence to impact recommendations because of its small size. Thank you for your comments about the Transforming Care programme. We are aware of transforming care and that it aims to reduce hospitalisations and enable autistic people and those with learning disabilities to live in the community closer to family and friends. We would need to see evidence evaluating outcomes from transforming care projects before we could refer to them or assess their impact. If you can share published evidence from these projects with us that would be helpful.
Royal College of Psychiatrists	No	The original guidance contained very few actual recommendations regarding treating ASD symptomatology. There was more on treatment of co-occurring conditions and meeting needs. Lots of recommendations for further research were originally included. These all need updating as to whether they occurred and the results summarised. New recommendations for further research in the same or new areas would be important to guide research funding and strategies at a national level.	Thank you for your comments about ASD symptomatology. The research recommendations that were made during CG170 development can be seen on the research recommendations page We did not find any evidence to stand these research recommendations down, with the possible exception of melatonin for sleep disorders, which we have consulted on. Thank you for your comments about recommendations about ASD symptomatology and comorbidity. We did not find any evidence

		Recommendations need updating on new research findings for the treatment of ASD symptomatology or comorbidities (mental health/behaviour) and physical health as well as clear social care/education recommendations regarding meeting needs. Also, the guidance needs cross referencing with the other NICE guidance for assessment and treatment of mental health conditions and behaviours to reference the reasonable adjustments that should be made to the other guidance (they don't give examples)- longevity of treatment, humour, imagery, micro-dosing, language used, setting, pace of treatments etc. Also referencing stomp-stamp regarding medications in ASD/ID and use of inpatient facilities (transforming care, CETRs). More could be included on recommended workforce to meet the needs- types of clinician and skill sets required. Training required.	that suggested recommendations needed adding or amending. With respect to your comments on cross-referencing, recommendation 1.7.1 cross refers to related guidelines on mental health and developmental conditions including Depression in children and young people (NICE clinical guideline 28). Recommendations 1.1.9 and 1.1.10 in the general principles of care section make recommendations about reasonable adjustments. Recommendation 1.1.10 recommends that adjustments or adaptations should be made to the processes of health or social care. It might also be helpful to know that NICE are developing Disabled children and young people up to 25 with severe complex needs: integrated service delivery and organisation across health, social care and education due to publish in January 2022. We identified STOMP-STAMP as part of this surveillance (see Other intelligence on drug treatments for children and young people with autism section in surveillance proposal). The STAMP initiative aims to prevent overmedication in children with learning disabilities. We assessed it as being supportive of recommendations 1.4.10 to 1.4.13 about drug treatments for autism and that it has the potential to increase the implementation of the guideline on managing autism in children and young people, therefore an update to the guideline is not necessary. CETRs with children help to improve care for people whose behaviour is seen as challenging and/or improve care for people with mental health conditions. NICE guideline CG170 contains recommendations 1.4.5 and 1.4.6 about reviewing support for behaviour that challenges. Thank you for your comments about training for clinicians, however NICE no longer make recommendations on training of staff. Please note, however that Diagnosis of autism in children (CG128) makes

			research recommendation 1 'training professionals' that addresses this and tried to stimulate research in this area. We plan to raise this issue with NIHR when we highlight underdiagnosis in girls as an area for research.
Help for Psychology		The research base has not changed sufficiently and Jan 2022 would be a better time for a thorough review.	Thank you for your comments. Guidelines are generally reviewed every 5 years unless an event (for example, an ongoing study directly relevant to a guideline, a drug safety update or a substantial change in policy or legislation) is brought to our attention that may impact the guidance (further details can be seen in the NICE methods manual chapter 13 Ensuring that published guidelines are current and accurate. further details can be seen in the NICE methods manual chapter 13 Ensuring that published guidelines are current and accurate). We then track these events and asses their impact on recommendations as soon as we can after the evidence is published. . For example, we plan to review the impact of ICD-11 when it is published in January 2022 . This will not be a full surveillance review. We are also aware from contacts in NHS England that the Re-ASCed (A Realist Evaluation of Autism ServiCe Delivery) study which is investigating what factors speed up autism diagnosis and what factors slow it down, is due to complete in 2022. We will monitor this study and asses its impact on the NICE autism guidelines on publication.
Cheshire and Wirral Partnership NHS FT	No. The guidelines could be improved by taking a broader and more holistic view of the child	- There is a need for greater integration with CG128 and with services focused on education / SEND / exclusion and school refusal services and offending services.	Thank you for your comments about integration with CG128. While there is an obvious overlap between these guidelines they have very different scopes. The scope can be seen here for CG170 and here for CG128. CG170 makes recommendation 1.1.2 which recommends the assessment, management and coordination of care for children and young people with autism should be provided

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	or young person and better integration with agendas and strategies of partner agencies.	- The guidelines could be improved with a stronger focus on employment outcomes. - Language isn't very neuro-diverse eg,"patient", "young people with autism" rather than "autistic young people". - More explicitly state diagnosis of autism shouldn't exclude access from health and social care services - There needs to be a review of the function of the specialist autism teams as described in the guidance to ensure it fits with the NHS long term plan aspirations and strategic direction towards needs led services. Whilst we would be very keen to see increased support for autistic children and young people, given the comorbidity and thresholds for diagnosis, it would be more appropriate to develop child development teams or neurodevelopmental teams (for CYP with ADHD and Autism) that reflect the SEND agenda, otherwise there would be an increase in push for diagnosis of autism and potential over diagnosis as the diagnosis would buy support from this proposed team. Instead, there should be support for Children and Young People who have atypical neurodevelopment with a focus on profile, needs and strengths and developing peer support groups for young people and families. - There is no specific intervention given for anxiety which can be very debilitating. There should be more focus on management of anxiety in that age	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. NICE are also developing Disabled children and young people up to 25 with severe complex needs: integrated service delivery and organisation across health, social care and education due to publish in January 2022. Thank you for your comments about employment outcomes. NICE guideline CG142 focuses on autistic people aged 18 and over and makes recommendations about employment, for example, recommendation 1,4.12 recommends for adults who are having difficulty obtaining or maintaining employment, consider an individual supported employment programme. There is overlap between CG170 and CG142 with respect to the ages covered. Thank you for your comments about neurodiverse language. We will discuss with our editorial colleagues about amending 'people with autism' to 'autistic people.' Thank you for your comments about exclusion from health and social care services. Autistic people should not be excluded from health and social care services and the guideline exists to reduce, ideally remove, health inequalities like the one you describe. We will add making decisions about your care to the recommendations pages of CG128, CG142 and CG170. Thank you for your comments about the function of specialist autism teams. and the NHS Long-term plan. We identified that the Long-term plan includes initiatives about testing and implementing ways to reduce waiting times for specialist autism diagnostic services (NHS Long Term Plan page 52, 3.33) and this is highlighted in the surveillance proposal - implementation issues. We assessed the guidelines as being in line with these initiatives. Additionally,

		group (16-18). Existing guidelines talk about management of challenging behaviour with meds and FAB but not anxiety which often leads to depression. Anxiety is not covered in other co-morbidities.	contacts at NHS England who are also stakeholders for this consultation highlighted to us their work addressing the initiatives in the long-term plan, and we plan to assess the impact of this work on recommendations once published. This includes the Re-ASCed (A Realist Evaluation of Autism ServiCe Delivery) study which is investigating what factors speed up autism diagnosis and what factors slow it down, and is due to complete in 2022. We will monitor this study and asses its impact on the NICE autism guidelines on publication. Thank you for your comments about interventions for anxiety in 16-18 year old young people. Recommendations 1.7.2 and 1.7.3 are about cognitive behavioural therapy (CBT) and adaptations to CBT for anxiety in people with autism. Additionally recommendation 1.1.8 highlights the need to recognise anxiety, which is described as a common coexisting condition. During surveillance we identified a number of studies about psychosocial and pharmacological interventions to reduce anxiety. Results were assessed as supporting current recommendations or are too inconclusive to impact them. We plan to follow the progress of the 'ADIE to prevent development of anxiety disorders in autism' study to assess its impact on publication. NICE has also produced Social anxiety disorder (NICE guideline CG159) which covers children and young people.

PDA Society	Yes	Specifically on the question of PDA. We would hope that this remains under review as further evidence is published. We agree that the PDA profile is identifiable in an assessment that follows the current Guidance It wouldn’t be appropriate for NICE to be referring to PDA as a ‘diagnosis’ currently. There is increasing evidence pointing to the need for differentiation of management strategies according to the group of characteristics seen in the ASD assessment which may be termed a ‘PDA profile’. These implications for management should be fully reported. It is hoped that additional clarity can be provided following the review in January 2022	Thank you for your comments. The guidelines are reviewed approximately every 5 years unless we identify or are alerted to new events that may trigger an exceptional review. If this happens we will undertake a review as soon as we can. An ‘event’ may be a large study, significant policy change, new guidelines or a safety alert (see the NICE methods manual Chapter 13 Ensuring that published guidelines are current and accurate for more details). The January 2022 review you refer to in your comments is referred to on p.68 of the surveillance report and it says: “we will consider how to update the references to ICD-11 and consider the effects on the wording of recommendations in line with its planned adoption in January 2022.” During preparation of the guideline, the developers acknowledged that PDA is not a recognised disorder in the sense that is not included in the ICD or DSM, and developed specific advice on how to differentiate between alternative diagnoses with similar features, available in appendix K of the full guideline. The appendix describes PDA as a particular subgroup of autism that it is characterised by a refusal to comply (demand avoidance) and such oppositional behaviour can be described as ODD. Recommendation 1.5.7 in ‘Autism spectrum disorder in under 19s: recognition, referral and diagnosis’ recommends considering ODD as a potential differential diagnosis and whether specific assessments are needed to interpret the autism history and observations.

Royal College of Paediatrics and Child Health	Yes	Regarding the first page of this proposal, should it read 'existing' rather than 'exiting'. A thorough review appears to have been conducted and areas for further consultation identified. Section 1.4.5: As input from certain health professionals does not immediately come to mind for gathering further information, it may be helpful to give examples of health professionals such as audiologists or those professionals who work in the hearing clinics. Behavioural concerns of many of these children is first spotted in an audiology clinic and these professionals would be able to provide invaluable information.	Thank you for your comments about the typo, this will be corrected. Thank you for your suggestion concerning recommendation 1.4.5. This recommendation was based on guideline development group consensus that a coordinated system for collecting information would speed up decision-making. There was no evidence found that highlighted specific healthcare professionals as being more key than others, with respect to gathering information.
Autistica, the UK's autism research charity	No. The decision not to update this guidance is an understandable but serious mistake.	We can understand why NICE has come to the conclusion not to update the guidance. In many areas, the applicable evidence base on how to effectively deliver healthcare for autistic people is limited. To those unfamiliar with the field, the progress of good-quality, relevant evidence will appear underwhelming. However, we are <u>not</u> confident that the surveillance proposal's conclusions accurately reflect the evidence base and policy context. We strongly recommend that NICE urgently discusses this surveillance proposal in detail with NHS England's Autism Team. Our reading of the surveillance proposal suggests that NICE were missing vital information about recent developments when drawing their conclusion.	Thank you for your comments. The surveillance review's conclusions were based on an assessment of evidence identified via contact with topic experts and patient groups including yourselves, Autistica and detailed systematic searches. We disagree the conclusions do not accurately reflect the evidence base and policy context. We greatly appreciate your ongoing engagement with this surveillance process, and during the initial stages of the surveillance review you responded to our questionnaire and submitted a large number of reports produced by Autistica. We considered these reports fully and none impacted recommendations. Many of the reports confirmed information we had seen elsewhere, for example in the NHS long term plan and some were out of scope for this surveillance process, because for example, they were news items which are not eligible as an evidence type. For this surveillance review the following types of evidence are eligible for inclusion: published systematic reviews of experimental, observational and

		Consultation issues The surprisingly short timeframes for this consultation have made it practically impossible to review NICE's surveillance report proposals in detail. The surveillance report itself is 172 pages long, cover 3 separate clinical guidelines, cites 201 academic publications and relies on considerable understanding of NICE's processes. We have had sight of this material for just over a week, in the middle of a pandemic – when our resources are stretched and we need to focus on informing other time-sensitive policy decisions – and while key parts of our policy and research teams are seconded to support NHS England. Unfortunately, this means our feedback cannot be comprehensive. The points we make below focus on some the more obvious anomalies that we could see while scanning through the surveillance report. It also means that we will be provided a single response, rather than separate responses concerning each guideline. *We would welcome clarification from NICE on why two weeks was considered adequate time to properly review and feedback on work that has taken well over a year to compile.* Concerns with the surveillance review Without replicating the surveillance review or having considerably more time and resource to examine the review's methodology, we cannot conclusively know how comprehensively NICE has accounted for the available	qualitative research; randomised controlled trials, diagnostic studies; new and updated national policy, guidelines and ongoing studies We had contact with representatives of NHS England and NHS Improvement (NHSE&I) early in the process, prior to, and during this consultation. Their comments have informed the surveillance decision to use a living surveillance model to monitor the progress of relevant work and assess the impact of findings on the autism guidelines on an ongoing basis. Thank you for your comments about the consultation timescale. The timescale for consultation was 2 weeks as per the standard NICE surveillance process (please see with 'Developing NICE guidelines: the manual', section 13 on Ensuring that published guidelines are current and accurate'). In addition to this we sent an email to all stakeholders 5 days before the consultation opened in order to give advanced notice of the consultation. You are able to contact us if you feel you are unable to respond within the specified timescale. We understand current circumstances with the COVID-19 pandemic can cause issues and we will feed your comments back to colleagues in the NICE programme management team. The work has taken longer than normal to complete due to delays caused by staff redeployment to Covid-19 rapid guidelines projects from March to October 2020 when non-COVID-19 work was suspended. With regards to your concerns with the surveillance review, the methodology for this review, including search sources, inclusion criteria, and details of topic experts and patient groups consulted is described on pages 4-11 of the surveillance proposal document and at the start of appendix A in the same document. Information about how evidence was interpreted, and conclusions drawn from it is provided in a 'surveillance proposal' that summarises findings at the end of each section in the surveillance proposal document. Further

		evidence; let alone the validity of its decisions over which evidence to utilise or dismiss. However, as a scientific funder that continually follows, assesses, and strategically intervenes to improve this evidence base there are pieces of research that we would have expected to see in the surveillance report. Their apparent absence is a cause of serious concern. In particular: The World Health Organization's (WHO) International Classification of Functioning, Disability and Health (ICF) core sets – A fundamental weakness of CG170, CG142, and current post-diagnostic support pathways for autistic people, is how skewed they are by historical biases in our understanding of autistic people's support needs. For example, CG170 says a lot about addressing "behaviour that challenges", a controversial issue with a confused and unreliable evidence base on the effectiveness of (relatively prolific) interventions. In contrast, those guidelines make few practical points about identifying, preventing or treating some of the most common causes of distress for autistic people, such as anxiety, uncertainty and sensory difficulties. These are the increasing focus of autism-specific intervention studies. For example: link.springer.com/article/10.1007/s10803-020-04442-2 trialsjournal.biomedcentral.com/articles/10.1186/s13063-019-3479-0	information about the surveillance process is contained in ensuring that published guidelines are current and accurate, Chapter 13 of the NICE guidelines manual. Thank you for your comments about post-diagnostic support pathways, historical biases and CG170's focus on behaviour that challenges; how this terminology is problematic; common causes of distress; and for sharing the 3 articles which you note are a sample of the evidence base about management of autism-specific features. The Hallet paper is a feasibility study and is out of scope for this surveillance review which only included systematic reviews, randomised controlled trials and diagnostic studies as stated in the surveillance proposal. The Rodgers paper is a protocol for a feasibility study and so does not report any results nor meet inclusion criteria – if a full RCT is planned following the outcomes of this study then this may be considered as a trial to track as relevant on-going research. The MacLennan paper is a non-interventional study that finds a correlation between autism traits, sensory hyporeactivity and phobias, which is also out of scope. Thank you for sharing the 5 papers from the WHO's ICF core sets. CG170 and CG142 are guided by the scope, the research questions that are derived by the expert committee and subsequent public consultation including surveillance review consultations such as this one. Our searches identified a qualitative study (the Mahdi studies you have shared) about the application of the WHO's ICF that concluded "the study findings support the need to understand the living experiences of individuals with Autism Spectrum Disorder (ASD) from a broader perspective, taking into account many areas of an individual's functioning and environment. The ICF can serve as foundation for exploring these living experiences." We excluded it because it is out of scope for this surveillance review which only

		onlinelibrary.wiley.com/doi/full/10.1002/aur.2259 Please note this is just a sample of ongoing research we happen to be aware of. We have not been able to review the literature in the time available. The ICF core sets are the result of an international research programme to identify (through a literature review), and then agreeing clinical, community and scientific consensus on, the major causes of ability or disability among autistic people (relative to their age). That programme has published 5 papers during the period considered by the surveillance review. We cannot see any evidence that those publications were identified and considered by the surveillance review. CG170 and CG142 should arguably be structured around the core sets, as a reflection of autistic people's needs. Instead, many of the most common and impactful causes of ability or disability for autistic people – the issues that are or should be the focus of intervention – are effectively absent from NICE's autism guidance. www.ncbi.nlm.nih.gov/pmc/articles/PMC6376609/ www.ncbi.nlm.nih.gov/pmc/articles/PMC5900830/ www.ncbi.nlm.nih.gov/pmc/articles/PMC5948258/ www.ncbi.nlm.nih.gov/pmc/articles/PMC5064728/ www.ncbi.nlm.nih.gov/pmc/articles/PMC6680328/ There are other relevant ongoing studies that we are aware of not cited in the surveillance review that we could list. We have focused on the three above because we	considered systematic reviews, randomised controlled trials and diagnostic studies. The 5 papers you have shared describe the consensus development of the ICF and are not interventional effectiveness studies reported in a systematic review, randomised controlled trial or diagnostic study. Of the other studies you have shared about the ICF the Bolte study describes its development; the first Schipper study is a survey. The Schipper study uses a systematic review approach for developing an instrument but does not provide any data on its validity as a diagnostic tool. These studies provide useful information about the context within which the guideline sits but they do not directly impact recommendations and they do not meet the inclusion criteria for this surveillance review. We will add the ICF core sets to our issues log for the autism guidelines in order to flag that evidence for the use of these core sets should be explicitly looked for when the guidance are next reviewed. Thank you for comments about the policy context. We disagree that the surveillance review authors have misunderstood the policy context. We identified the autism self-assessment framework which highlighted in chapter 5 of its executive summary that although all local authorities reported having an autism pathway, only 17% rated themselves as meeting requirements for the 3-month waiting time limit recommended in the NICE guideline on diagnosis of autism in children and young people (recommendation 1.5.1). Topic experts and patient expert groups highlighted implementation issues around diagnosis, joined up services and the competencies of healthcare staff in dealing with autistic people. We also met with representatives of NHSE&I who also highlighted that there are issues around implementing some of the recommendations.

		understand they are of considerable relevance to the work NHS England are leading to improve (and clarify) diagnostic and post-diagnostic support pathways for autistic people. Misunderstanding of the policy context *"Overall, the government reports and policies do not contradict any recommendations in NICE's autism guidelines. They do not suggest a need to update the guidelines."* This statement contradicts our understanding, as close stakeholders, of NHS England's workstream to improve the diagnosis and post-diagnostic support pathways for autistic people, as specified in the NHS Long Term Plan. Unless, NICE has directly and recently engaged with the NHS England Autism Team about that workstream, this assumption is flawed and unjustified. In fact, we suspect that NICE's expertise could be invaluable for realising goals set out in paragraph 3.33 (page 52) of the Long Term Plan. We note that the surveillance report does not mention the Long Term Plan commitment to: *"jointly develop packages to support children with autism or other neurodevelopmental disorders including attention deficit hyperactivity disorder (ADHD) and their families, throughout the diagnostic process."*	We also identified initiatives about diagnosis and testing and about management of autism in the NHS long-term plan, including section 3.33 which the surveillance review quotes and references on p. 19. Additionally, we identified the review of the 2014 Autism Strategy the outcomes of which will inform the aims of the NHS Long-term plan. The issues we identified are problems with implementing the recommendations due to lack of capacity, staff training and service organisation. We did not find evidence to suggest the current NICE guidelines, Therefore, we assessed current recommendations as being consistent with policy. We have recently engaged with the autism team at NHSE&I and will continue to do so. Discussions with them have informed the surveillance decision to use a living surveillance model to monitor the progress of relevant work and assess the impact of findings on the autism guidelines on an ongoing basis. You note in the Long term plan section 3.33's commitment to *"jointly develop packages to support children with autism…throughout the diagnostic process"* may require considerable work to guide intervention choice and that NICE has a role to play in this. NICE can make recommendations about choice of diagnostic tools and interventions only if the evidence is available on which to base them. If there is published evidence about screening tools or approaches that enable more effective and efficient intervention choices, from systematic reviews, randomised controlled trials or diagnostic studies, we would be grateful if you could share this with us.

		Delivering this commitment is likely to involve considerably more work in guiding intervention decisions that it may first appear. NICE should play an active role in this work. To be clear: we strongly recommend that NICE urgently discusses the risks of not updating CG142, CG170 and CG128 with NHS England's Autism Team. We are concerned that critical context was missing for the surveillance proposal.	With respect to section 3.33 in the NHS long term plan it also says: "Over the next three years, autism diagnosis will be included alongside work with children and young people's mental health services to test and implement the most effective ways to reduce waiting times for specialist services. This will be a step towards achieving timely diagnostic assessments in line with best practice guidelines." It also recommends that each child with autism, learning disability or both with the most complex care needs "will have a keyworker." Recommendations 1.5.1 and 1.5.2 which respectively recommend a maximum wating time of 3 months for an autism diagnostic assessment and recommend a case coordinator for every child having an autism assessment, are consistent with these aims. These recommendations are based on guideline development committee consensus and are informed by their experience and knowledge of examples of good practice in the UK.
Takeda UK Ltd	No		Thank you for your response
Healthwatch Calderdale	Agree		Thank you for your response.
Autism Rights Group Highland	No. The guideline should be changed. To inform those changes we recommend using the Independent Guide to Quality	Many conceptual issues which contribute to negative views of autism and which may lead to poor support, for example: • Concept of autism is professional-centred and medical. It does not reflect how autistic people characterise their own condition. This is essential for offering relevant care and support.	Thank you for your comments and for highlighting the Independent Guide to Quality Care for Autistic People by the National Autistic taskforce. This document was identified during our searches for policies and reports. It was concluded that recommendations in the autism guidelines under review did not contradict the conclusions and recommendations in the report, but that the report covered wider aspects of daily living that are out of the scope of the guidelines which are predominantly about diagnosis and

	Care for Autistic People 2019 by the *National Autistic Taskforce*: https://nationalautistictaskforce.org.uk/wp-content/uploads/RC791_NAT_Guide_to_Quality_Online.pdf	• 'Culturally' appropriate. Autistic communities have a distinct culture. Awareness of that is important. • Focusing on 'triggers' can hide causes. • Pg. 11 Autism is not in need of 'management', people are in need of support. The sort of thing that might be managed are, say, sensory environments, unpredictable behaviour of others, etc • Characterising help and support as 'interventions' is problematic • Concept of 'severity' is problematic • Misconception of social difficulties. See Milton, D. (2012). On the ontological status of autism: The 'double empathy problem'. Disability & Society, 27(6) https://kar.kent.ac.uk/62639/ • 1.4.8 With anger look to causes not 'management'. Autism does not cause anger. • 1.4.7 - 1.4.9: Functional analysis and reinforcement of desired behaviour is widely opposed by autistic adults who have experienced it. Current guideline unintentionally recommends what many autistic people consider abuse. • Transition to adulthood – importance of linking people to the wider community of autistic people should be mentioned.	management of autism. Thank you for your bulleted comments, we have responded to these below: • Autism concept as profession centred. The guideline is aimed at autistic people, families and carers and health and social care professionals as described on the 'who is it for?' section of the overview page and the language reflects this. We will amend 'people with autism' to 'autistic people' • In reference to 'culturally appropriate', without further details, we are unclear about how the guidance is not sensitive to this. It might be helpful to know that NICE have produced patient experience in adult NHS services (NICE guideline CG138) and are currently developing disabled children and young people up to 25 with severe complex needs due to publish in January 2022. • 'Triggers'. The guidance does not focus exclusively on triggers. Recommendation 1.4.8 recommends a number of factors a functional assessment should aim to identify and although it includes 'factors that appear to trigger the behaviour' it also includes consideration of the needs of the child, patterns of behaviour and its consequences. • The guidance is called Autism spectrum disorder in under 19s: support and management – and recommendations encompass both of these concepts. We do not agree that the use of the term 'intervention' is problematic, as the use of this word is in line with the NICE glossary of terms which describes an intervention as 'In medical terms this could be a drug treatment, surgical procedure, diagnostic test or psychological therapy. Examples of public health interventions could include action to help someone to be physically active or to eat a healthier diet. Examples of

			social care interventions could include safeguarding or support for carers.' - the concept of 'severity' in relation to identifying possible autism was used by the CG170 guidelines committee to reflect the fact that autism spectrum disorder can encompass a range of behaviours that manifest in various combinations, levels and intensity of presentation. The committee recognised that consideration should always be given to the child or young person as a whole, (see full guideline p.32). Without further information as to why this term is considered problematic, we are unable to consider making any changes. - Thank you for highlighting the term 'social difficulties' and the 2 papers. CG170 does not use the term social difficulties in its recommendations. - Recommendation 1.4.8 does not say or imply that autism causes anger, nor is 'anger' used anywhere within the recommendations. - Recommendations 1.4.7 – 1.4.9. We did not find any evidence to suggest that the recommendations in these guidelines may be considered 'abuse' by autistic people. The patient-centred care section in NICE guideline CG170 says:' Treatment and care should take into account individual needs and preferences. Patients should have the opportunity to make informed decisions about their care and treatment, in partnership with their healthcare professionals.' Person-centred care is about shared decision making with people, not about forcing people to engage in behaviours, and all of the recommendations should be applied in this context. NICE are currently

			developing shared decision making due to publish in January 2022. • Transition to adulthood. Recommendation 1.1.11 about involvement of autistic people in decision making recommends that children and young people with autism, and their families and carers, should have information about autism that may include support and an opportunity to meet other people, including families or carers, with experience of autism.
Nottinghamshire Healthcare NHS Foundation Trust (Yvette Ronan, Clinical Psychologist, CAMHS ID Team)	No	More information and support for parents needed	Thank you for your comment the guidelines, do highlight that autism team members should offer information to parents and carers about appropriate services and support (recommendation 1.1.7) and has a section on information and support for families and carers (recommendation 1.9.1).
Lead of NHSE funded study: Realist evaluation of autism diagnostic service delivery for children with possible autism	Fine	Few teams in our survey in above study have keyworker- whether this should stay as an ideal, or whether its not pratcial in current resources is a moot point	Thank you for your comments about key workers and the Realist Evaluation of Autism ServiCe Delivery (RE-ASCeD study you are leading on. We plan to monitor and assess the impact of this study when it publishes.

3. THIS QUESTION RELATES ONLY TO AUTISM SPECTRUM DISORDER IN UNDER 19S: SUPPORT AND MANAGEMENT (CG170)

Do you think it is appropriate for autism spectrum disorder in under 19s recommendation 1.7.7 to be amended to include the following: 'If medication is needed to aid sleep, consider melatonin'? If not, why?

Stakeholder	Overall response	Comments	NICE response

Evelina Children's Hospital, London		Yes- and there should be more detail to support this and suggest pathways- see answer to question 1 above	Thank you for your response agreeing with the proposal to add 'consider melatonin' and to question 1. During this surveillance review we did not find any evidence that suggested that recommendations 1.7.4 to 1.7.8 that address sleep disorder needed amending apart from being more specific about what medication could be used.
Flynn Pharma Limited		It is Flynn's view that it is entirely appropriate that melatonin should be considered for the treatment of insomnia in children with ASD. Given the prevalence, and the known negative correlates with child and caregiver well-being, investigating and treating insomnia should be at the forefront of therapeutic interventions for children with ASD. Children with ASD can, however, present special challenges for drug administration and may present with unusual feeding difficulties, restrictive diets, dysphagia and tactile sensitivities/defensiveness. Until now, there were no licensed insomnia medications for this population thus necessitating off-label use of medicines or use of wholly unlicensed preparations. CG170 (2013) did not make recommendations for the management of insomnia in ASD children because of the absence of evidence. However, since then	Thank you for your response to this question agreeing with the proposal to add 'consider melatonin' to recommendation 1.7.7.

		(in September 2018), on the basis of robust evidence of long-term (2 years) efficacy and safety, paediatric prolonged-release melatonin (PRM) was licensed by EMA for the management of insomnia in children (2-18 years) with ASD and/ or SMS where sleep hygiene measures have been insufficient. PRM is formulated to be both condition-(ASD) and paediatric-(2-18 years) appropriate and the minitablets (1mg and 5mg) are 3mm in diameter, flavourless and odourless.	
2gether NHS Foundation Trust (now Gloucestershire Health and Care NHS Foundation Trust)		Our team support this statement, adding 'consider melatonin trial if sleep hygiene has been ineffective'	Thank you for your response agreeing with the proposal to add 'consider melatonin' to recommendation 1.7.7.
Child Oriented Mental Health intervention Centre (COMIC) – a collaborative research team between University of York and Leeds and York Partnership NHS Foundation Trust		Yes I do as there is clear evidence to show that it works, both in RCTs and systematic reviews. Melatonin should however only be considered after behaviour management/parental advice has been tried first. There should also be clarity to a trial of withdrawing melatonin once sleep is established.	Thank you for your response. Recommendation 1.7.6 states that a sleep plan should be developed which will often be a sleep specific behavioural intervention. Recommendation 1.7.7 currently states that medication should not be used unless the sleep plan has not improved the situation, as such, medication would not be commenced without other interventions being put in place first. The recommendation also states that any pharmacological intervention should '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'; as such we think that the current recommendations cover your concern regarding when melatonin should be stopped.

Autistic UK		We agree that it is appropriate to add melatonin into the guide as a consideration with the following caveat: It is essential that all other avenues have been explored prior to melatonin being considered. Clinicians also need to consider sleeplessness as a form of communication – anxiety, PTSD, trying to 'unpick' apprehensions from the day, etc. Usage also needs to be carefully monitored to ensure it is not overused or misused. It may be worth for clinicians to consider having regular prescribing breaks to review its need and efficacy.	Thank you for your comment. We agree that caution should be used when recommending the use of a specific medication and this is reflected in recommendation 1.7.7. 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. Recommendation 1.7.4 also highlights the need for a thorough sleep assessment: 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.
University Hospitals Dorset NHS Foundation Trust		It is appropriate for recommendation 1.7.7 to be amended as proposed.	Thank you for your response agreeing with the proposal to add ‘consider melatonin’ to recommendation 1.7.7.
Royal College of Nursing		Yes, I do. There is evidence to suggest this practice is efficient in treating insomnia in young people. BNF for Children entry on melatonin states that this is licensed for use to treat insomnia in children aged between 2 to 17 years of age, when sleep hygiene measures alone have proven to be ineffective.	Thank you for your response agreeing with the proposal to add ‘consider melatonin’ to recommendation 1.7.7.
National Autistic Society		Yes, we think it is appropriate for autism spectrum disorder in under 19s recommendation 1.7.7. to be amended to include the consideration of melatonin. The consideration	Thank you for your response agreeing with the proposal to add ‘consider melatonin’ to recommendation 1.7.7.

		and recommendation of melatonin has already been happening on a large scale for under 19s for whom melatonin would be an appropriate medication, and one preparation of melatonin is medically licenced. However, we believe that melatonin is unlikely to be effective on its own and should be recommended in combination with other sleep hygiene and/or behavioural interventions, including those already listed in recommendation 1.7.7.	With regards to your comment that melatonin is unlikely to be effective on its own and should be recommended in combination with other sleep hygiene and/or behavioural interventions, this is addressed in recommendation 1.7.7, which says 'If a pharmacological intervention is used to aid sleep it should: … be used in conjunction with non-pharmacological interventions', this would include other sleep hygiene and/or behavioural interventions.
Royal College of Psychiatrists		Yes. Perhaps go further- use of liquids, slenyto (micro tablet), long acting vs short acting. Regarding tolerance of taking meds in CYP with ASD.	Thank you for your comment. Recommendations made will only include generic medication rather than brand specific or type specific formats. This allows specialist clinicians to make a decision as to the type of medication used based on the individual and their needs.
Help for Psychology		I would agree with this	Thank you for your response agreeing with the proposal to add 'consider melatonin' to recommendation 1.7.7.
Cheshire and Wirral Partnership NHS FT		Yes – it currently seems to be impossible for some families to obtain a prescription for melatonin. A number of sleep services are now available locally, but none of these services include a medic / prescribing nurse and as such there are no available options if medication is needed – i.e. if behavioural and therapeutic approaches have not been effective. It is also an issue for children who have used melatonin who then transition as it is extremely difficult to get melatonin prescribed in adulthood, thus adding to the stress of transition.	Thank you for your response agreeing with the proposal to add 'consider melatonin' to recommendation 1.7.7 and for your comments on difficulties with obtaining a prescription for melatonin. The recommendation states that medication should only be used following consultation with a specialist paediatrician or psychiatrist with expertise in the management of autism or paediatric sleep medicine. The use of melatonin for autism spectrum disorders is specifically mentioned in the Children's BNF; however only 'learning disabilities' is mentioned in the adult's BNF. The searches for melatonin in this

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			review were restricted to children as those over 19 years old are out of scope for guideline CG170. As such we have only found evidence for children. Transition to adult services is included in CG170. Section 1.8 of guideline CG170 covers transition to adult services and includes the following recommendations: • 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.
Royal College of Paediatrics and Child Health		Yes – melatonin is now widely used to good effect.	Thank you for your response agreeing with the proposal to add 'consider melatonin' to recommendation 1.7.7
Sussex Partnership Foundation Trust		Yes	Thank you for your response.
Lead of NHSE funded study: Realist evaluation of autism		Would add only after demonstrated instution of sleep hygiene and this is not working-a lot of families say do sleep hygiene but often not doing this in practice. Big	Thank you for your comment.

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diagnostic service delivery for children with possible autism		resource impliactions too if this becomes routine for any child with autism	There is already content within section 1.7 of the recommendations to reflect this: • Recommendation 1.7.6 states that a sleep plan should be developed which will often be a sleep specific behavioural intervention. • Recommendation 1.7.7 currently states that medication should not be used unless the sleep plan has not improved sleep quality and or duration. The amendment to include melatonin would be as a 'consider' recommendation and will not detract from the existing recommendations regarding sleep hygiene as they are clear that any pharmacological intervention should be undertaken only if other options have failed. Please see : 'Making decisions using NICE guidelines which describes how wording is used within recommendations.

4. Do you have any comments on areas excluded from the scope of the guideline?

Stakeholder	**Overall response**	**Comments**	**NICE response**
False Allegations Support Organisation		Our voluntary group, again takes up the slack and are making ourselves available to anyone in this position. However, FASO are limited in what their volunteers from all walks of life can do. Professional should be available and neds to be in place.	It might be helpful to know that NICE have produced quality standards that provide metrics against which service performance can be benchmarked. There is an autism quality standard (QS51) based on the guidelines which includes, for example, quality statement 4, which says: 'People with autism are offered a named key worker to coordinate the care and support detailed in their personalised plan.' Information about how to use quality statements can be found at this link.

UK Society for Behaviour Analysis	1.4.7 1.3.1	The UK-SBA believes that, with two key amendments, CG170 could more clearly convey which approaches would meet the needs of young people with autism, and which professions are best suited to providing specialist support. Point 1.4.7 recommends that interventions be informed by "functional assessment", a procedure which has its origins in behaviour analysis, and has been tested and refined through 40 years of applied behaviour analytic research. We therefore respectfully request that, under the general heading of "psychosocial interventions", the guidance makes specific reference to applied behaviour analysis. Point 1.3.1 recommends that interventions should be delivered by a "trained professional". There is however, no mention of what constitutes appropriate training. We respectfully request the guidelines be amended to reflect the fact that, by virtue of the training and assessment they must undergo to be deemed competent to practise, behaviour analysts would qualify as "trained professionals". This would be consistent with NG11, in which the profession of behaviour analyst is specifically referenced. These amendments would go a long way toward protecting autistic children and young people, and will increase the likelihood that they receive effective, scientifically validated interventions from professionals qualified to deliver them.	Thank you for your comments. Thank you for your comments about recommendation 1.4.7. The recommendation says if an autistic child presents with behaviour that challenges, offer them a psychosocial intervention (informed by a functional assessment of behaviour) as a first-line treatment. This is based on guideline committee expertise in the absence of "conclusive evidence for the use of psychosocial interventions for behaviour that challenges…The committee considered the need for an assessment of behaviour that challenges itself and of any underlying communication impairments or unrecognised physical or mental disorders…(and therefore they)…proposed that a functional analysis of the behaviour should be the basis for the development of any psychosocial intervention." While the recommendation accommodates applied behaviour analysis (ABA) therapies that produce the outcomes described, we did not find sufficient evidence at this timepoint to suggest ABA should be explicitly recommended. It should be noted that CG170 did consider evidence from ABA-based interventions and we did find some evidence during this surveillance review about ABA-based interventions (see surveillance report, p.97). However, the evidence for its effectiveness is largely equivocal and therefore it is not enough for us to recommend it explicitly although recommendations do accommodate its use where it is appropriate. Thank you for your comments about recommendation 1.3.1. which as you state says that interventions should be delivered by a trained professional. Use of the word 'professional' means someone whose training is endorsed, monitored and validated by a recognised professional body. As the guideline is aimed at health, social care, medical practitioners and teachers it encompasses all of those professions.

Autistic UK		Comment in agreement with findings on p. 9: P. 9 Surveillance – We agree that there is insufficient implementation of the guidance for those Autistic people who do not have a learning disability. Recommend adding information pertaining to suicide: P. 20 Surveillance – As with the adult guidance, this guideline does not reference suicide. As with adults, Autistic young people have an increased risk in suicide attempts, therefore your guidelines should be updated to at least include a cross reference to mental health guidelines. Chen, M., et al. (2017) Risk of Suicide Attempts Among Adolescents and Young Adults With Autism Spectrum Disorder: A Nationwide Longitudinal Follow-Up Study in The Journal of Clinical Psychology, Vol. 79 No. 9 [Online] https://www.psychiatrist.com/JCP/article/Pages/autism-spectrum-disorder-and-suicide-attempts.aspx (Accessed 04/11/2020)	Thank you for your comments about implementation and about adding risk of suicide and cross-referring to mental health guidelines. Recommendation 1.1.8 does recommend that health and social care professionals should have training to recognise common comorbidities like depression and anxiety. Recommendation 1.7.1 about comorbidities cross refers to Depression in children and young people (NICE guideline CG28 [now replaced by NICE guideline NG134]) which does include recommendations concerning treatment for those at risk of suicide. Thank you for sharing the paper by Chen et al. We did identify this paper during the surveillance review but it was excluded as it is not a systematic review, randomised controlled trial or diagnostic study, so did not meet the inclusion criteria for the surveillance review (these are described in the Evidence considered in surveillance section of the surveillance proposal).
Fair Treatment for the Women of Wales (FTWW)		The experiences and needs of autistic females and other marginalised communities are not adequately represented in the existing guideline. The surveillance document refers to the under-diagnosis of females and the importance of reducing associated suicide rates. However, the proposal to not update the existing guideline does not address these	Thank you for your comments about the experiences and needs of autistic females, sex and gender considerations and the needs of other marginalised groups. We identified new evidence that does indicate an underdiagnosis in girls and women. However, no evidence for gender-specific diagnostic criteria were identified, and new evidence suggests that high-quality diagnostic assessment may reduce this disparity. CG128

		issues and may in fact perpetuate the gender gap in diagnosis and management of autistic individuals.	research recommendation 1 Training professionals to recognise signs and symptoms of autism includes addressing underdiagnosis in girls acknowledges this issue and we will highlight this to the National Institute for Health Research (NIHR) as an area where research is needed (see surveillance proposal p. 11). Without evidence of effectiveness of gender specific diagnostic and management interventions we are unable to amend recommendations. However the guidance does address this issue: for example, diagnosis of autism in children (CG128) recommendation 1.2.5 recommends 'clinicians should be aware that autism may be underdiagnosed in girls'. Autism in adults (CG142) recommendation 1.8.3 recommends that local autism strategy groups should develop pathways specifically for women. It might be helpful to note that NICE has produced guidance on preventing suicide in community and custodial settings (NG105) aimed at commissioners in the NHS and local authorities and others working in health and social care and organisations in the public, private, voluntary and community sectors. With respect to your comments about marginalised groups, each of the guidelines has to undergo an equalities impact assessment to ensure they do not act to exclude particular groups; for example, looked-after children, people who are homeless, people who misuse drugs and people in prison. Identifying such groups is an aspect of NICE's compliance with both general public law requirements to act fairly and reasonably, and human rights obligations. The equality impact assessments can be seen for each of the guidelines can be reached from the following links: Diagnosis and management of autism in under 19s

			Autism spectrum disorder in adults Autism spectrum disorder in under 19s: support and management
Nottinghamshire Healthcare NHS Foundation Trust (	More guidance required	We frequently work with young people with a diagnosis of ASD and their parents. One area which is reported by parents is the little support following post diagnosis of Autism. Parents report being given leaflets with information of groups which they can contact, but have found this not to be helpful. It is often seen as a relief when a child receives a diagnosis for parents after many years of struggling with behavioural issues and the child's presentation being different to others. However understandably it can feel like a bereavement and post diagnosis would be an adequate time to support the family with this journey. Existing services which are providing support such as CAMHS ID, Small Steps and Family Services are often only involved when there is a problem. The Autism team discussed in the NICE guidance is ideal to support with referral, assessment and diagnosis and I see that there is discussion around support to families and carers, but it may also be the perfect opportunity to provide robust post diagnostic support for new diagnoses.	Thank you for your comments about support for parents following diagnosis of autism and how challenging this can sometimes be for some parents. As you note there are recommendations about families and carers in both CG128 and CG170. CG128 recommendation 1.8.3 recommends for children and young people with a diagnosis of autism, to share information with parents or carers and, if appropriate, the child or young person, to explain what autism is and how autism is likely to affect the child or young person's development and function. We did not find any new evidence that suggested recommendations in CG128 or CG170 should be amended. We are aware of issues about service delivery implementation which are discussed in the surveillance report section 'Autism service capacity and implementing the guidelines' but these are issues with implementing the recommendations and are not considered as impacting recommendation content.
University Hospitals Dorset NHS Foundation Trust	In agreement	No additional comments	Thank you for your response.

Triple P UK Ltd		The role and importance of parenting programmes in support and management has not been specified in NICE guidelines for ASD, but has for other child learning difficulties/disorders. For example: Antisocial behaviour and conduct disorders in children and young people: recognition and management: Psychosocial interventions: parent training programmes (1.5.1-1.5.10) Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges: Early intervention for children and their parents or carers (1.7.1-1.7.2) Mental health problems in people with learning disabilities: prevention, assessment and management: Specific psychological interventions (1.9.8-1.9.9). Attention deficit hyperactivity disorder: diagnosis and management: Identification and referral (1.2.4); Supporting families and carers (1.4.11). In line with other child learning difficulties and disorders, a review of parenting programmes should be undertaken for cohorts of families of children with ASD to identify the impact parenting programmes can have on enhancing support and management. This will improve the equity of information and support mechanisms available for children with ASD and their families. The evidence base on parenting programmes for families of children with ASD has expanded considerably since the last update of evidence for this guideline (Sept 2016) and	Thank you for your comments about the role of parenting programmes. Management of autism in under 19s (CG170) has recommendation 1.2.3 which recommends 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, or are involved in the delivery of an intervention. Additionally, recommendation 1.4.9 about interventions for behaviour that challenges recommends agreement among parents, carers and professionals in all settings about how to implement the intervention. You reference recommendations in 4 other NICE guidelines and although some are related, for example Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges, they have different scopes and make recommendations based on different evidence bases. It would not be appropriate to make recommendations for autistic people by extrapolating from evidence from largely non-autistic populations. During this surveillance review we did identify evidence for effectiveness of parent interventions (see parent-mediated interventions section in the surveillance proposal) and it was assessed as being consistent with current recommendations. We also plan to monitor the progress of several ongoing studies to assess their impact on recommendations when they publish, which are also outlined in the parent-mediated interventions section in the surveillance proposal.

		warrants further attention. It is suggested a review of the evidence base is undertaken to identify the impact and outcomes of parenting programmes in supporting children with ASD and their families. A preliminary literature review of articles published since Sept 2016 has identified over 20 additional studies reporting on parenting programmes for parents of children with ASD (either exclusively or as part of a broader cohort of parents of children with disabilities). This includes a number of RCTs and systematic reviews and meta-analyses. Findings indicate parents of children with ASD that participate in a parenting programme report significant improvements in parenting style, self-efficacy, confidence, stress, depression, and problem-solving. Clinically and statistically significant reductions in child maladaptive behaviours (both teacher- and parent-reported), as well as improvement in social interactions for adolescents, have also been found. These studies also demonstrate high levels of participant engagement and satisfaction. Please see reference list from page 13. It is suggested that health service provider responsibility and ownership in coordinating parenting programmes is clearly articulated in the ASD support and management guidelines, similar to how this is outlined in the guidelines for ADHD: Diagnosis and management: Service organisation (1.1.3).	Thank you again for supplying the references - we have responded to each of these in the responses to your comments in relation to question 1.
Royal College of Nursing	Yes	In line with the Equality Act {2010), young people should be given equal opportunities to access services and this	Thank you for your comments. CG170 recommendations underwent an equality impact assessment (EIA) to ensure compliance with the

		does not always happen due to a lack of appropriate resources.	Act, as did diagnosis in children (CG128). The links to the EIAS are below: Diagnosis and management of autism in under 19s Autism spectrum disorder in under 19s: support and management
The Challenging Behaviour Foundation	Although the guidance includes the need to monitor and review medication within the initial 6-week period, there is a need for more information about the process for **monitoring and reviewing the use of medication in the longer term**.	The inappropriate and overmedication of people with Autism is a serious issue. We recommend that the guidance includes links to the NHS project Stopping over medication of people with a learning disability, autism or both (**STOMP**), which can be found here: https://www.england.nhs.uk/learning-disabilities/improving-health/stomp/ As part of STOMP, the Challenging Behaviour Foundation created a medication pathway which can be found here: https://medication.challengingbehaviour.org.uk/	Thank you for your comment about medication monitoring. CG170 recommendation 1.4.10 recommends reviewing the effectiveness and any side effects of antipsychotic medication after 3–4 weeks and stop treatment if there is no indication of a clinically important response at 6 weeks. Thank you for your comment about STOMP-STAMP. We identified STOMP-STAMP as part of this surveillance (see Other intelligence on drug treatments for children and young people with autism section in surveillance proposal). We assessed it as being supportive of current recommendations on drug treatments for autism and that it has the potential to increase the implementation of the guideline on managing autism in children and young people, therefore an update to the guideline is not necessary. Thank you for sharing the pathway with us which is aimed at families and carers of people with autism. We recommend you submit this to the NICE endorsement team for it to be considered as a NICE implementation tool. More information can be found on the NICE endorsement page.
National Autistic Society	There should be a greater focus in the guideline on mental health and	As we referred to in our 2019 surveillance questionnaire, mental health is consistently a leading concern of parents of autistic children. Research suggests that 71% autistic children have a mental health problem. This is often	Thank you for your comments. As you note the National Autistic Society along with several other topic experts and patient organisations noted that autistic people are frequently admitted for inpatient psychiatric care. Thank you for sharing your research.

	mental well-being, including the development of self-identity. More detail is needed on the forms and adaptations of psychosocial intervention that could be used. The guideline should explicitly reflect the work being done by NHS England and NHS Wales. 1.1.8 needs to include support/interventions for specific cognitive difficulties which commonly co-exist, such as executive functioning impairments.	because of a lack of (timely) support. Meanwhile, our research into the *Transforming Care* programme has found that an increasing number of autistic children are ending up in inpatient mental health hospitals. Improved guidance on how to adapt mental health interventions would assist clinical professionals in tailoring therapies and avoid many mental health problems developing further. We believe that the guideline would benefit from reflecting the work of NHS England and NHS Wales. Currently, there is ongoing work around diagnosis, post-diagnosis and mental health. NICE should link up with teams in NHS England and NHS Wales to ensure that all guidelines and practice reflect each other.	Unfortunately, the link did not work but I think you are referring to Beyond Transforming Care What needs to change? (December 2018). This reports that data from the NHS Digital Assuring Transformation dataset that has indicated an increase in the number of autistic people receiving mental health inpatient care between 2015 and 2018. During this surveillance review we identified two initiatives from the NHS long-term plan (see surveillance proposal document p. 22) that were relevant to inpatient care, but they did not indicate that NICE recommendations no longer represent best practice, but rather that services have not been able to achieve recommended best practice. The recommendations in the autism guidelines apply to secondary settings, including inpatient settings and should be applied to them. For example, CG170 recommendation 1.1.9 recommends practitioners consider the physical environment in which autistic children and young people are supported and cared for and minimise any negative impact by making adjustments. The guidelines also include recommendations about training of health and social care professionals, for example, recommendation 1.1.2 in diagnosis in children (CG128) recommends an autism strategy group should be appointed which has responsibility for raising awareness of the signs and symptoms of autism through multi-agency training. Similarly recommendation 1.1.6 in management of autism in children (CG170) recommends that autism teams provide training and support for other health and social care professionals and staff who may be involved in the care of autistic children. Thank you for your comments about NHS England NHS Wales. We have been in touch with NHS England who have highlighted ongoing work, for example, the Realist Evaluation of Autism ServiCe Delivery (RE-ASCeD) study, which was also highlighted by patient

	1.7 needs to include the development of executive functioning skills.		groups during the initial surveillance. We plan to monitor and assess the impact of this study when it publishes. The SHAPE study published post-stakeholder consultation. SHAPE is a 2-stage exploratory mixed methods study that investigated the experiences of service users and staff and the outcomes associated with implementing specialist autism teams (SATs). The study directly addresses CG142 research recommendation 2.2 which asks 'What structure and organisation of specialist autism teams are associated with improvements in care for people with autism?.' The study reports that only 16% of Local Authorities have SATs for autistic adults without learning disabilities. There is evidence that SATS combining diagnosis and post-diagnostic care improve mental health outcomes and there was a strong association with improved mental health with increasing multidisciplinary skills mix, which was also associated with increasing costs. The authors recommend that further robust comparative research comparing SATs with diagnosis-only centres is needed, therefore research recommendation 2.2 remains valid. The authors note that while some senior practitioners involved in SATs thought NICE's vision for SATs needed modifying, the modifications highlighted were more applicable to SAT service specifications than the NICE guideline recommendations themselves. It was also reported that sustainability may be improved by focussing SAT services on low intensity interventions and mainstream staff skilling. The findings of the SHAPE study therefore support recommendations 1.1.13 and 1.1.14 which recommend that SATs are established in each area, describe the professional composition of SATs, and recommend that SATs provide both diagnostic and care services. As the study findings do not have an impact on

			current recommendations and was published after the date for included studies considered in this surveillance review, we will ensure that the study and the impact of any further published research on SATs is considered in future surveillance reviews of the NICE autism guidelines. NHS England have also responded as stakeholders to this consultation and we have considered their responses fully. Thank you for your comments about recommendation 1.1.7 and 1.1.8 and support for specific cognitive difficulties particularly executive functioning impairments. We did not identify any evidence specific to executive functioning impairments during this surveillance review that suggested recommendations needed amending. CG170 recommendation 1.7.1 cross refers to Attention deficit hyperactivity disorder (ADHD) (NICE guideline CG72).
Royal College of Psychiatrists	Yes	Needs cross reference to other nice guidance e.g., challenging behaviour. Also how to modify assessments and treatments for other mental health disorders- link to those guidances.	Thank you for your comments. Recommendation 1.7.1 about coexisiting conditions makes several cross-referrals. Challenging behaviour and learning disabilities (NICE guideline NG11) is included in the NICE autism pathway.
Cheshire and Wirral Partnership NHS FT	Emphasis on the importance of the profile of strengths and needs (including aspects such as central coherence,	Given the heterogeneity of the population, there is a need to ensure that support and management is individually matched to unique profiles. This is needed to ensure more targeted and cost-effective intervention planning. There is a need for autism guidelines to be fully integrated (ideally co-created) with other agencies. Successful integration of policies at the highest level would serve to	Thank you for your comments about the importance of the profile of strengths and needs during assessment. Recommendation 1.5.5 in diagnosis in children (CG128) recommends every diagnostic assessment should include 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. CG170 also makes recommendation

	executive functioning and emotional regulation) obtained during assessment (improve links to CG128). More explicit links to the national autism policies of other agencies on training and implementation of services (e.g. NAS, Autistica, education (including SEND and NEET), employment, offending services, etc) There is no specific intervention given for anxiety which can be very debilitating. There should be more focus on	enable the necessary improvements in training and at the point of service delivery; ultimately transforming the experience for autistic individuals and their families.	1.1.11 which recommends shared decision making and recommends make information about services and treatments available. Thank you for your comments about explicit links to national autism policies from other organisations about training and implementation. If you have any policies that you can recommend that contain recommendations about implementing NICE autism recommendations in services we recommend you share them with the NICE endorsement team for consideration as implementation tools. More information can be found on the NICE endorsement page. Thank you for your comments about anxiety. CG170 acknowledges anxiety as a coexisting condition in several recommendations and recommendation 1.7.2 recommends the use of CBT and adaptations of CBT for this condition in recommendation 1.7.3. NICE has also produced guidance for managing anxiety including social anxiety disorder (NICE guideline CG159). Thank you for your comments about the heterogeneity of the population and the need for individual matched interventions. The guideline makes outcome based recommendations that accommodate the broad presentation of autism. For example recommendation 1.3.1 recommends a specific social intervention for the core features of autism that is adjusted to a child's development level. Thank you for your comments about integrating co-authoring. The guideline was originally developed by NICE in collaboration with the Social Care Institute of Excellence (SCIE). The guideline development group who wrote the recommendations included representation from lay members and patient groups, and draft recommendations were subject to stakeholder consultation. The

	management of anxiety in that age group (16-18). Existing guidelines talk about management of challenging behaviour with meds and FAB but not anxiety which often leads to depression. Anxiety is not covered in other co-morbidities		guideline development group member list and stakeholder comments for CG170 are accessible from the NICE website.
PDA Society	The next review should have additional focus on settings, and how to ensure the best setting for the individual.	The need for consideration of environment is included in current guidance, but we hope there will be substantially more relating to community and inpatient care following the recent published reports.	Thank you for your comments. The recommendations in CG170 apply to primary, secondary and tertiary health and social care. This is covered in the scope of the guideline. If new evidence emerges about inpatient and community settings we will consider this at the next surveillance review or as it emerges if it is included in ongoing studies that we plan to track as described in the 'ongoing research' section of the surveillance document.
Autistica, the UK's autism research charity	Yes. We cannot develop a substantive response to this	We cannot develop a substantive response to this question in the time available.	Thank you for your comments about the timescale of the consultation. We allowed 2 weeks for the consultation and sent out notification that the consultation would begin 1 week before the start date. This is the standard amount of time given for consultation

	question in the time available, however, we are concerned about the scope and structure of the existing guidance.	However, as per our earlier comments, we are concerned that the guidance does not reflect the range (and relative frequency of) the many difference causes of ability and disability among autistic children (as described in work like the ICF core sets for autism). As a result, CG170 fails to guide (and potentially discourages) public service providers and commissioners in intervening to support those issues. NICE should be playing a leading role in ensuring those needs are recognised by public services and that there is clarity over the evidenced interventions available to meet them. Within many issues, there may not be interventions with robust evidence of feasibility, acceptability and effectiveness/efficacy available; however, recognising and signalling that lack would be immensely valuable in dissuading bad practice and in stimulating research on those topics.	on a surveillance review proposal (please see with 'Developing NICE guidelines: the manual', section 13 on Ensuring that published guidelines are current and accurate'); however if you had contacted us to say this was an issue we could have allowed more time for you to respond. Thank you for your comments about the range of frequency of the many different causes of ability and disability. We thank you for drawing to our attention to the ICF core sets, but we did not find any relevant evidence that met the inclusion criteria and would impact recommendations (i.e. from systematic reviews, randomised controlled trials or diagnostic studies). NICE's role is to produce evidence-based recommendations and we cannot do that if the evidence is not available. We signal lack of evidence by making research recommendations. For CG170 they can be seen on the research recommendations page. We will add the ICF core sets to our issues log for autism in order to flag that evidence for the use of these core sets should be explicitly looked for when the autism guidance is next reviewed.
Nottinghamshire Healthcare NHS Foundation Trust (	More guidance required.	We frequently work with young people with a diagnosis of ASD and their parents. One area which is reported by parents is the little support following post diagnosis of Autism. Parents report being given leaflets with information of groups which they can contact, but have found this not to be helpful. It is often seen as a relief when a child receives a diagnosis for parents after many years of struggling with behavioural issues and the child's presentation being different to others. However understandably it can feel like a	Thank you for your comments about support for parents following diagnosis of autism and how challenging this can sometimes be for some parents. As you note there are recommendations about families and carers in both CG128 and CG170. CG128 recommendation 1.8.3 recommends for children and young people with a diagnosis of autism, to share information with parents or carers and, if appropriate, the child or young person, to explain what autism is and how autism is likely to affect the child or young person's development and function.

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		bereavement and post diagnosis would be an adequate time to support the family with this journey. Existing services which are providing support such as CAMHS ID, Small Steps and Family Services are often only involved when there is a problem. The Autism team discussed in the NICE guidance is ideal to support with referral, assessment and diagnosis and I see that there is discussion around support to families and carers, but it may also be the perfect opportunity to provide robust post diagnostic support for new diagnoses.	We did not find any new evidence that suggested recommendations in CG128 or CG170 should be amended. We are aware of issues about service delivery implementation which are discussed in the surveillance report section 'Autism service capacity and implementing the guidelines' but these are issues with implementing the recommendations and are not considered as impacting recommendation content. We note your comments about the involvement of CAMHS involvement only if there is a problem. The recommendations in both CG128 and CG170 recommend multidisciplinary working both strategically and operationally. For example, CG170 recommendation 1.1.3 recommends 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. We appreciate that recommendations are not always followed making this an implementation issue. We are aware of these implementation issues and unfortunately we cannot directly influence them. However, we plan to monitor the review of the 2014 Autism Strategy, the outputs of which will inform the NHS Long-term plan objectives for autism services, and asses its impact on recommendations when it publishes.

5. Do you have any comments on equalities issues?			
Stakeholder	**Overall response**	**Comments**	**NICE response**
False Allegations Support Organisation		Those accused of rape/ sex offences/child protection issue are treated differently and assumed to be guilty -therefore robust checks on identifying those who are Autistic is paramount. (as for all mental health patients arising from false allegations.	Thank you for your comments. The guideline is aimed at health and social care practitioners including those working with people who may come into contact with the justice system. NICE has also published Mental health of adults in contact with the criminal justice system (NICE guideline NG66) which covers assessing, diagnosing and managing mental health problems in adults who are in contact with the criminal justice system.
Child Oriented Mental Health intervention Centre (COMIC) – a collaborative research team between University of York and Leeds and York Partnership NHS Foundation Trust	Yes	We have just completed an RCT (NIHR funded) of Lego based therapy in schools for children with ASD. This shows statistically significant improvements in social skills and cost effectiveness. We are submitting the report in December 2020 to the NIHR.	Thank you for sharing this information. Your comments refer to An evaluation of LEGO-based therapy in school for children with autism. We identified this ongoing research during surveillance. We will track it to publication and assess its impact on CG170 recommendations when it publishes results.
Fair Treatment for the Women of Wales (FTWW)		The guideline needs updating to take much more account of protected characteristics listed in the Equality Act 2010, most particularly: sex, gender reassignment, race, and disability (which would include the sensory and mental health issues which are often associated with autism).	Thank you for your comments about protected characteristics and the Equality Act 2010. The recommendations in all 3 autism guidelines underwent equality impact assessments. NICE uses this approach to consider not just equality in relation to groups sharing the characteristics protected by the Equality Act (2010) but also health inequalities arising from

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		It is worth noting that the Equality Act enshrines protected characteristics as 'aspects of a person's identity that make them who they are'. This has significant implications for NICE's recommendations for treatment which include social and behavioural skills. Further, under Equality Law and the Public Services Equality Duty, there is a requirement that reasonable adjustments are made to accommodate the needs of those in possession of protected characteristics. Some aspects of the NICE recommendations suggest the opposite: that neurodiverse people should learn skills that make them more 'socially acceptable' Geographical considerations need to be factored into an updated guideline, including the limited access to specialist services and personnel in Wales, both those directly dealing with autism, and those providing support for health issues associated with it, such as eating disorder clinics.	socioeconomic factors or associated with the shared circumstances, behaviours or conditions of particular groups (for example, looked-after children, people who are homeless, people who misuse drugs and people in prison). Identifying such groups is an aspect of NICE's compliance with both general public law requirements to act fairly and reasonably, and human rights obligations. The equality impact assessments for each of the guidelines can be reached from the following links: Diagnosis and management of autism in under 19s Autism spectrum disorder in adults Autism spectrum disorder in under 19s: support and management Thank you for your comments about the Equality Act and highlighting that it enshrines the 'aspects of a person's identity that makes them who they are.' We disagree that recommendations about social and behavioural skills act to try and make neurodiverse people more socially acceptable. The recommendations are clear that an autistic person's preferences and wishes must be taken into account: the guideline recommendations about management of autism in adults and children (CG142 and CG170) both include sections on person-centred care and the recommendations should be applied in the context set out in these sections. Specifically, CG142 (adults) person-centred care section says: 'Support and care should take into account peoples' needs and preferences. People with autism should have the opportunity to make informed decisions about their care, in partnership with their healthcare professionals.' CG170 (management in children) patient-centred care section says:' Treatment and care should take into account individual needs and preferences. Patients should have the opportunity to make informed

			decisions about their care and treatment, in partnership with their healthcare professionals. If the patient is under 16, their family or carers should also be given information and support to help the child or young person to make decisions about their treatment.' Additionally all of NICE's autism guidelines contain a 'your responsibility' section which says 'when exercising their judgement, professionals and practitioners are expected to take this guideline fully into account, alongside the individual needs, preferences and values of their patients or the people using their service.' Thank you for your comments about geographical issues. We identified evidence from government policy and from topic experts that included lack of service capacity that applied to both Wales and England. We also identified sections of the NHS Long-term plan designed to address these issues and we plan to monitor them and assess their impact (see surveillance report p.18). These plans apply to Wales and England. NICE has a remit to produce national recommendations for the NHS in Wales and England in order to reduce health inequalities. These are designed to reduce regional inequalities in both countries.
Triple P UK Ltd	Yes	The role and importance of parenting programmes in support and management has not been specified in NICE guidelines for ASD, but has for other child learning difficulties/disorders. For example: - Antisocial behaviour and conduct disorders in children and young people: recognition and management - psychosocial interventions: parent training programmes (1.5.1-1.5.10)	Thank you for your comments about the role of parenting programmes. Management of autism in under 19s (CG170) has recommendation 1.2.3 which recommends 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, or are involved in the delivery of an intervention. Additionally, recommendation 1.4.9 about interventions for behaviour that

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		- Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges: Early intervention for children and their parents or carers (1.7.1-1.7.2) - Mental health problems in people with learning disabilities: prevention, assessment and management: Specific psychological interventions (1.9.8-1.9.9). - Attention deficit hyperactivity disorder: diagnosis and management: identification and referral (1.2.4); supporting families and carers (1.4.11). In line with other child learning difficulties and disorders, a review of parenting programmes should be undertaken for cohorts of families of children with ASD to identify the impact parenting programmes can have on enhancing support and management. This will improve the equity of information and support mechanisms available for children with ASD and their families. A preliminary literature review of articles published since the last update of evidence for this guideline (Sept 2016) has identified over 20 additional studies reporting on parenting programmes for parents of children with ASD (either exclusively or as part of a broader cohort of parents of children with disabilities), reporting positive outcomes for both parents and children. Please see reference list from page 13.	challenges recommends agreement among parents, carers and professionals in all settings about how to implement the intervention. You reference recommendations in 4 other NICE guidelines and although some are related, for example Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges, they have different scopes and make recommendations based on During this surveillance review we did identify evidence for effectiveness of parent interventions (see parent-mediated interventions section in the surveillance proposal) and it was assessed as being consistent with current recommendations. We also plan to monitor the progress of several ongoing studies to assess their impact on recommendations when they publish, which are also outlined in the parent-mediated interventions section in the surveillance proposal. Thank you again for supplying the references - we have responded to each of these in the responses to your comments in relation to question 1.
Royal College of Nursing	Yes	Consider communication barriers for people with both hearing impairments and learning disabilities.	Thank you for your comments. The 3 guidelines include recommendations about communicating with people with learning disabilities and hearing impairments. Diagnosis in children (CG128) makes several recommendations about coexisting conditions including recommendation 1.1.19 which

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			recommends that 'the autism team should either have the skills (or have access to professionals that have the skills) needed to carry out an autism diagnostic assessment, for children and young people with special circumstances including…'– the list includes learning (intellectual) disability and hearing or vision impairment. Autism in adults (CG142) recommendation 1.1.15 recommends 'all health and social care professionals providing care and support for adults with autism and their families, partners and carers should… take into account communication needs, including those arising from a learning disability, sight or hearing problems or language difficulties, and provide communication aids or independent interpreters.' Management of autism in under 19s (CG170) recommendation 1.1.5 recommends '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… severe visual and hearing impairments (and) intellectual disability.'
British Association of Social Workers (BASW) – England	Yes	Same comment as per CG142. These comments are: The BASW England capabilities statement and CPD pathway resources contain resources to support autistic people, social workers, social work organisations and educators. The full reference is below: BASW. (2020). *BASW Capabilities Statement and CPD Pathway Resources*. Accessed 04.11.2020. Available from: https://www.basw.co.uk/capabilities/autistic-adults/resources. In particular, this addresses issues around	Thank you for your comments and for sharing *BASW Capabilities Statement and CPD Pathway Resources*. The document describes what social workers need to know and be able to do to make positive changes in the lives of adults with learning disability. We would recommend that you submit this as a potential implementation tool for endorsement. Further details can be found on the NICE endorsement page. Thank you for your comments about gender-bias and sexism.

		people from Black and Minoritized communities commonly being excluded from timely diagnosis and intervention due to racial discrimination. This issue closely links to the gender-bias and inherent sexism which exists in the autistic diagnostic process – another area of discrimination which ought to be addressed. Furthermore, one BASW England member said: 'I could not find any discussion of equalities issues which is an omission. In particular I would have expected to see a recommendation that universal health services IAPT (Improved Access to Psychological Therapies) must make reasonable adjustments as per the Equality Act 2020 to ensure they are accessible to autistic people.	Diagnosis of autism in children (CG128) recommendation 1.2.5 recommends 'clinicians should be aware that autism may be underdiagnosed in girls' and autism in adults (CG142) recommendation 1.8.3 that local autism strategy groups should develop pathways specifically for women. We identified new evidence that does indicate an underdiagnosis in girls and women. However, no evidence for gender-specific diagnostic criteria were identified, and new evidence suggests that high-quality diagnostic assessment may reduce this disparity. CG128 research recommendation 1 Training professionals to recognise signs and symptoms of autism includes addressing underdiagnosis in girls acknowledges this issue and we will highlight this to the National Institute for Health Research (NIHR) as an area where research is needed. (see surveillance proposal p. 11). The recommendations in all 3 autism guidelines underwent equality impact assessments. NICE uses this approach to consider not just equality in relation to groups sharing the characteristics protected by the Equality Act (2010) but also health inequalities arising from socioeconomic factors or associated with the shared circumstances, behaviours or conditions of particular groups (for example, looked-after children, people who are homeless, people who misuse drugs and people in prison). Identifying such groups is an aspect of NICE's compliance with both general public law requirements to act fairly and reasonably, and human rights obligations. The equality impact assessments can be seen for each of the guidelines can be reached from the following links Diagnosis and management of autism in under 19s Autism spectrum disorder in adults

			Autism spectrum disorder in under 19s: support and management
National Autistic Society	Autistic people face an unacceptable and well-documented health inequality – evidence suggests that this results in an increased risk of premature mortality.	This health inequality is now enshrined in the Government's Mandate to NHS England and the NHS England Long Term Plan. The All Party Parliamentary Group on Autism last year published its Autism Act: 10 Years On report, which highlights the additional barriers that autistic people with other protected characteristics may face. We would be happy to discuss these further with you.	Thank you for your comments about increased premature mortality and for sharing The Autism Act, 10 Years On: A report from the All Party Parliamentary Group on Autism on understanding, services and support for autistic people and their families in England. This document concludes that whilst the Autism Act has led to welcome improvements in some areas of support, for example there has been an increasing recognition of autism among commissioners and the public, there is significant unmet need. These unmet needs stem from a low awareness of the duties that are included in the Autism Act. The report also highlights that allocation of funding has affected the ability to provide services. We are aware from topic experts, and this is also highlighted in the provided report, that there are service capacity issues and these are having an impact on implementing recommendations in NICE guidelines particularly around diagnosis and assessment. Topic experts also highlighted lack of staff training which is also described on p.23 of your report. The autism topics were referred to NICE by the Department of Health and Social Care in order to help reduce health inequalities in autistic people. We believe the implementation of NICE recommendations and also the NICE autism quality standard (QS51) will help to reduce these inequalities. We understand that the guidelines can only be implemented in the context of local and national priorities for funding and developing services. We have not

			identified any evidence that suggests the recommendations may be contributing to these issues. The findings of the government's Autism self-assessment framework which reviews progress in implementing the 2014 autism strategy in England are consistent with the issues highlighted by topic experts and patient groups. The government has started a review of the 2014 Autism Strategy to address these issues and we will monitor its progress and assess its impact on the guidelines covered by this surveillance review on publication.
Royal College of Psychiatrists		References to cultural sensitivities re: gender of a therapist and cultural issues.	Thank you for your comments. Management of autism in children (CG170) has recommendation 1.1.11 in the general principles of care which recommends when involving children and their carers in decision-making provide 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 accommodates cultural sensitivities. We did not find any evidence about the impact of clinician gender on a child's response to the clinician.
Cheshire and Wirral Partnership NHS FT	To be more explicit re MH services not excluding children or young people due to a diagnosis of Autism.		Thank you for your comment on ensuring mental health services do not exclude children or young people due to a diagnosis of Autism. Recommendation 1.1.1 in CG170 recommends: 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. We also plan to add a link to NICE's information on making decisions about your care which includes information about shared decision making.

PDA Society		There remains a very stereo-typical view of what 'autism looks like' and so being more specific about (or greater acknowledgment of) less typical autism, autism in girls / women, greater heterogeneity in gender and sexuality and the failure to even consider ASD in certain groups is essential. Evolution of more holistic or integrated assessments should help. In addition, the move by clinicians to less of a deficit model in terms of language used is also important (reflective of the neurodiversity movement	Thank you for your comments about greater acknowledgement of how autism may present in different ways in different groups of people, particularly in girls and women. Diagnosis of autism in children (CG128) recommendation 1.2.5 recommends 'clinicians should be aware that autism may be underdiagnosed in girls' and autism in adults (CG142) recommendation 1.8.3 that local autism strategy groups should develop pathways specifically for women. Although recommendation 1.2.8 (in CG128) does link to an appendix of possible signs and symptoms of autism, it does caution to 'not rule out autism if the exact features described in the tables are not evident; they should be used for guidance, but do not include all possible manifestations of autism.' We identified new evidence that does indicate an underdiagnosis in girls and women. However, no evidence for gender-specific diagnostic criteria were identified, and new evidence suggests that high-quality diagnostic assessment may reduce this disparity. CG128 research recommendation 1 Training professionals to recognise signs and symptoms of autism includes addressing underdiagnosis in girls1 Training professionals to recognise signs and symptoms of autism includes addressing underdiagnosis in girls and we will highlight this to the National Institute for Health Research (NIHR) as an area where research is needed. (see surveillance proposal p. 11). Thank you for your comments about a 'deficit model.' We found no evidence that suggested clinicians view autistic people as being 'deficient' or used a 'deficit model' when supporting autistic people.

Autistica, the UK's autism research charity	We cannot develop a substantive response to this question in the time available.		Thank you for your comments about the timescale of the consultation. We allowed 2 weeks for the consultation and sent out notification that the consultation would begin 1 week before the start date. This is the standard amount of time given for consultation on a surveillance review proposal (please see with 'Developing NICE guidelines: the manual', section 13 on Ensuring that published guidelines are current and accurate'); however if you had contacted us to say this was an issue we could have allowed more time for you to respond.

6. NICE acknowledges that services may be impacted by the current COVID-19 situation.

Please tell us if there are any particular issues we should be considering in relation to the Autism guidelines?

Stakeholder	Overall response	Comments	NICE response
False Allegations Support Organisation	Issues	Answer 6 - The availability of the local NHS mental health groups is not working and reject requests for support od autistic persons and are often signed off unnecessarily. Thy are easily rejecting requests – for mental health support and leaving persons to take their life. The Autistic person and their families need to have in place and recognise a competent, robust and ethical support system to support their needs, whilst being traumatised. NICE guidelines should make these requirements stricter and accountable for the MoJ The guidelines should encompass that the MoJ system be fit for purpose and identify individuals with Autism FASO	Thank you for your comments. We appreciate that this is a difficult time for service delivery. We plan to look at NICE mental health guidelines as a whole, in order to explore the implications of the long term plan and other system drivers including the impact of COVID-19 on our mental health portfolio. Diagnosis of autism in children (CG128) recommendations will apply to health and social care professionals who work with people who come into contact with the justice system. The guideline scope says: 'This is an NHS guideline. It will comment on the interface with other services, such as social services and the voluntary sector. But it will not include recommendations relating to services provided exclusively by these agencies, except relating to care provided in those settings by healthcare professionals funded by the NHS.'

		are the ones picking up the individuals and families to support them going through the justice system.	Therefore, we are unable make recommendations about Ministry of Justice services.
Autistic UK		Recommend adding information regarding the misuse of DNARs: Guidelines should be updated to state that encouraging Autistics to agree to a DNAR being added to their medical file during a global pandemic is unacceptable. Recommend adding sections regarding the difficulties Autistics have in accessing healthcare: Difficulties in accessing healthcare, particularly without support, affects many people in the Autistic community, regardless of whether or not they have a learning disability. We have been informed of some of our Autistic stakeholders being refused accompaniment and/or someone to advocate for them in medical settings during the pandemic due to it being deemed unnecessary due to the lack of a co-occurring learning disability. Guidance should be updated to add that all Autistics are entitled to receive support and/or advocacy from someone during appointments should they wish to have one. Consider the rise in excess deaths within the community and the reasons for this including co-occurring conditions: The rise in excess deaths within our community during the pandemic is of concern. Some of these pertain to co-occurring conditions such as asthma, heart defects/disease, and mental health conditions. The lack of an updated co-occurring conditions list is concerning as it is repeatedly mentioned in literature that excess deaths pertain to co-	Thank you for your comments about 'do not attempt resuscitation' instructions. This is outside the scope of these guidelines which are about the diagnosis and management of autism not about the management of COVID-19. We have not identified any evidence on the misuse of DNARs, but we will share you're your comments with colleagues in NICE's COVID-19 team. NICE have also produced making decisions about your care a guide for the public about using NICE guidelines to inform their care, which includes advice about shared decision making that says:' It is your right to be involved in making choices about your care'. Thank you for your comments about issues with accessing healthcare for autistic people and the importance of autistic people having the choice of being accompanied to healthcare appointments. While we appreciate that services have to mitigate risk by minimising numbers during the pandemic this should not act to exclude carers or advocates being refused access to healthcare facilities if that results in an autistic person attending a healthcare service unaccompanied when they do not feel comfortable doing so, or they are vulnerable. Diagnosis and management of autism in adults (CG142) recommendation 1.1.1 still applies. This recommends that all staff working with autistic adults should work in partnership with autistic adults and, where appropriate, with their families, partners and carers.

		occurring conditions rather than solely being because a person is Autistic, yet guidelines do not reflect this. As Autistics often present with pain/discomfort differently to non-Autistics, both due to communication and interoception differences, they also tend to seek medical advice later than non-Autistics. Therefore, some of our stakeholders who work in medical professions have reported that Autistics have worse prognoses than non-Autistic counterparts. However, our Autistic stakeholders also state that they are often dismissed without investigation for medical concerns because they don't 'look' as sick/in pain as non-Autistic counterparts. We recommend that medical co-occurring conditions such as CHD and asthma are added to the list of co-occurring conditions which, in turn, will assist in the earlier referral for diagnosis and treatment of said conditions. Bazian (2016). People with autism are 'dying younger,' warns study on NHS [Online] https://www.nhs.uk/news/neurology/people-with-autism-are-dying-younger-warns-study/ (Accessed 04/11/20) Calderon, J., Henson, B., & Ware, J. (2020). Congenital heart disease and autism: A possible link? In Harvard Health Publishing [Online] https://www.health.harvard.edu/blog/congenital-heart-disease-and-autism-a-possible-link-2020010218552 (Accessed 04/11/20)	Thank you for your comments about the rise in excess deaths within the autistic community and for sharing references about this. We are aware of this issue and reducing this inequality is the reason that the Department for Health and Social Care referred these topics to NICE. The study overview by the NHS Behind the headlines service you have shared entitled 'People with autism are 'dying younger,' warns study', highlights these issues. It draws on a Swedish study which reports the average age of death for people with autistic spectrum disorder is 53.87 years, compared with 70.2 years for people without. It notes suicide and epilepsy 'stand out' as causes. Autism in adults recommendation 1.2.10 recommends that during a comprehensive assessment, take into account and assess for possible differential diagnoses and coexisting disorders or conditions, such as mental health disorders like depression and anxiety, and neurological conditions including epilepsy. This study was conducted in a Swedish setting and its applicability to a UK setting in questionable, although it does seem to support the current recommendations about considering specific co-occurring conditions. The Croen et al. study you highlighted describes the frequency of several psychiatric and 'medical conditions' among a large, diverse, insured population of autistic adults in the United States. It reports that depression, anxiety, bipolar disorder, obsessive–compulsive disorder, schizophrenia, and suicide attempts are higher in autistic people than non-autistic people. The study published in April 2015 predates the search period for this surveillance review which is from January 2016, It also reports results from a sample of people (n=15.070) living in California and its applicability to a UK setting is open to question. However, the guidelines accommodate the co-

		Croen, L. A., Zerbo, O., Qian, Y., Massolo, M. L., Rich, S., Sidney, S., & Kripke, C. (2015). The health status of adults on the autism spectrum. In Autism : the international journal of research and practice, 19(7), 814–823. [Online] https://doi.org/10.1177/1362361315577517 (Accessed 04/11/20)	occurring conditions highlighted by this study and it is supportive of recommendations about coexisting conditions. Thank you for your comments about co-occurring conditions. The list of co-occurring conditions in diagnosis of autism in children (CG128) is based on guideline committee expertise and a review of studies of the prevalence of co-occurring conditions. The list of co-occurring conditions in autism in adults (CG142) is based mainly on guideline development committee expertise. The committee considered that attention should also be paid to coexisting physical health problems but noted that a number of co-occurring conditions will be outside the expertise of a specialist autism team. Given this, the guidelines committee highlighted the important role of the specialist team io seek advice from other healthcare professionals on the management of coexisting physical health problems. To that end CG142 recommendation 1.2.5 recommends a comprehensive assessment should be team-based and draw on a range of professions and skills. Most of the evidence identified in this surveillance review was consistent with the lists of coexisting conditions in current recommendations. Evidence for conditions not currently on the list (obesity, asthma, persistent crying as infants, and hypocholesterolaemia) tended to be from studies with methodological limitations and did not sufficiently establish links between autism and other coexisting conditions. It might be helpful to know that NICE has produced rapid covid-19 guidelines on managing acute myocardial injury (NICE rapid guideline NG171) and severe asthma (NG166) that place people at greater risk during the pandemic. The full list of COVID-19 guidelines can be reached at this link and they apply to autistic and non-autistic people.

			The Calderon et al paper you have shared with us is a blog that gives an overview of a possible link between congenital heart disease and autism, but it is outside the inclusion criteria for this surveillance review, which only considered randomised controlled trials, systematic reviews and diagnostic studies. We did identify 7 systematic reviews and 2 observational studies that reported on risk factors related to cardiovascular and metabolic conditions during pregnancy (see surveillance proposal p.24). None of these studies reported odd ratios greater than 2.0 for increased risk, which was the threshold for inclusion in diagnosis of autism in children (CG128). .
Fair Treatment for the Women of Wales (FTWW)		Covid-related pauses on health services have restricted access to mental health support and psychological therapy for those underlying / co-existing conditions experienced by autistic individuals. Stress emanating from the uncertainty of the situation may have a pronounced impact on autistic individuals. Further, government guidance regarding handwashing, social distancing, masks etc will be exacerbating repetitive and restrictive behaviours and worsening some of the more distressing aspects of autistic people's lives and the lives of those close to them. For autistic females, the restrictions around maternity services, such as partners not being allowed into pregnancy	Thank you for your comments about mental health services. We plan to look at NICE mental health guidelines as a whole, in order to explore the implications of the long term plan and other system drivers including the impact of COVID-19 on our mental health portfolio. Thank you for your comments about stress and uncertainty for autistic individuals and the effect of government guidance. We appreciate the situation may be difficult for some autistic people, but we are unable to comment on the effects of government guidance. Thank you for your comments about maternity services. NHS staff have a duty to mitigate risk during COVID-19. However diagnosis and management of autism in adults (CG142) recommendation 1.1.1 still applies. This recommends that all staff working with autistic adults should work in partnership with them and, where appropriate,

			with their families, partners and carers. This partnership working still applies during COVID-19. NICE has also produced COVID-19 rapid guideline: arranging planned care in hospitals and diagnostic services (NG179) which applied to all adults and children and contains recommendations on shared decision making.
University Hospitals Dorset NHS Foundation Trust	Autism spectrum disorder in under 19s: support and management	Children with ASD are likely to present with increased behavioural difficulties associated with unexpected changes to routine (e.g. having to self-isolate). Support needs to be offered to families and young people about formalised approaches to managing unexpected change.	Thank you for your comments about behaviour difficulties. We will share your comments with colleagues in the NICE COVID-19 team. Recommendation 1.4.1 in CG170 acknowledges that changes to routine can cause behaviour that challenges and recommendation s 1.4.2 recommends developing a care plan with parents and carers that provides support to the child and parents and carers. We also plan to look at NICE mental health guidelines as a whole, in order to explore the implications of the long term plan and other system drivers including the impact of COVID-19 on our mental health portfolio.
Triple P UK Ltd	Yes, it is important to consider virtual mechanisms available to increase reach and access to support for children with ASD and their families.	It is suggested a review of evidence is undertaken to identify the availability and outcomes of virtual parenting programmes to meet the needs of children with ASD and their families. Virtual parenting programmes should be articulated in support and management guidelines to improve reach and equity in access to meet diverse circumstances, family needs or individual preferences (e.g., during COVID-19 restrictions; families that live in geographically isolated areas; work commitments preventing access to face-to-face care; a personal	Thank you for your comments about virtual parenting programmes; and for sharing the paper by Hinton et al. This reports the results of a randomised controlled trial of a telemedicine intervention with parents and carers (n=98) of children with a range of developmental, intellectual and physical disabilities. The abstract does not mention autism and therefore this was not retrieved during surveillance. The study concludes that while parenting practices are improved no impact on children's behaviour was detected. Therefore, this supports recommendation 1.2.3 which recommends offering training to parents.

		preference for support delivered virtually or with flexibility; difficulty in accessing or affording face-to-face care). Recent RCT evidence is available to indicate virtual parenting programmes for parents of children with developmental disabilities (including ASD) leads to improvements in parenting practices, parenting self-efficacy, and improvement in the parent-child relationship. This study also reports high levels of participation engagement and satisfaction. *[Hinton, S., Sheffield, J., Sanders, M. R., & Sofronoff, K. (2017). A randomized controlled trial of a telehealth parenting intervention: A mixed-disability trial. Research in Developmental Disabilities, 65, 74-85. doi:10.1016/j.ridd.2017.04.005]*	We will share these comments and the paper with colleagues in the NICE COVID-19 team.
Royal College of Nursing	Yes	Assessment and diagnosis appointment delayed. Lack of appropriate community support due to not having a formal diagnosis. Families struggling to cope with family members who lack input from specialised community services. Impact on family members' mental health due to not being able to cope without support. - In the recent RCN submission to the All Party Parliamentary Group for people with Special Educational Needs and Disabilities (SEND), expressed the need to have fully resourced specialist workforce to enable effective provision of nursing care to this group. The RCN cited the following:	Thank you for your comments about appropriate community support and the impact on family members mental health due to lack of support from specialised community services. We plan to look at NICE mental health guidelines as a whole, in order to explore the implications of the long term plan and other system drivers including the impact of COVID-19 on our mental health portfolio. We note your comments about the Royal College of Nursing's (RCN) submission to the Special Educational Needs and Disabilities (SEND) All Party Group about under investment in the specialist workforce supporting autistic people, nursing staffing levels and removal of bursaries for trainee nurses. CG170 recommendation 1.1.18 recommends 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 including recognition of key transition points, communication skills, the ability

		- there has been an under investment in the services and nursing specialist workforce to meet the needs of children and young people with SEND. Greater investment is required to sustain and develop a nursing workforce to achieve safe and effective care. To do this we need more nurses to lead and deliver better care for this group of children and young people in their communities. - there is a crisis in nursing staffing levels with almost half (44%) of current practicing nurses set to reach retirement age within 10 years. This outlook has been made more difficult by removing the bursaries that many trainee nurses rely on to support themselves while they are in training. We are also concerned that budgets for on-the-job training (continued professional development), which helps nurses acquire new skills and meet regulatory requirements are being cut.	to recognise coexisting conditions, and the impact that autism has on a child or young person.
British Association of Social Workers (BASW) – England	Yes	One England member said: 'Guidance on Personal Protective Equipment (PPE) and supporting people to desensitize to using PPE and seeing people in PPE Guidance of Covid-19 test for autistic people: e.g desensitisation through the rather unpleasant swab test, as well as support to adjust and accept social distancing'. Another member said: 'In terms of Autism services- need to be far more then diagnostic- What is needed is a locus to call people in to work in it otherwise people end up going to the wrong place and they either don't get seen, an	Thank you for your comments about PPE, swab tests and social distancing. NHS England have produced Managing capacity and demand within inpatient and community mental health, learning disability and autism services for all ages. This says: 'Providers should consider whether it is possible to reconfigure the inpatient estate to create 'cohorted' wards to reduce the risk of contagion. This will need to be considered in line with the specialist nature of service provision and the considerations for all services needs of each patient group and the requirement to make reasonable adjustments for people with a learning disability and those who are autistic.' It also makes recommendations about service planning within community settings.

		assessment or a service. Having a central point is key to enabling people to get access to the right support. The Autism Act doesn't cut it which is why areas can get away with having a diagnostic service only. The Autism strategy is delayed and unlikely to be published until December 2020'.	Thank you for your comments about autism services and having a central point of contact. Autism in adults (CG142) makes research recommendation 2.2 about the future structure of specialist teams. This acknowledges that the Department of Health's autism strategy (2010) proposes the introduction of a range of specialist services for autistic people built around specialist autism teams, However, there is little evidence to guide the establishment and development of these teams. It proposes a large-scale observational study, which should provide important information on the characteristics of teams associated with positive outcomes for autistic people in terms of access to services and effective coordination of care.
The Challenging Behaviour Foundation	As restrictions continue, the guidance should emphasise the need for reasonable adjustments to ensure barriers to provision of appropriate support are removed.	Emerging research into the impact of Covid 19 on autistic children, young people and adults and those with learning disabilities and their families shows there have been negative and some positive impacts of lockdown restrictions. Increased flexibility around meeting virtually rather than face to face has been beneficial to some individuals and the opportunity for flexibility at diagnosis and support should be carried forward. Research by the National Autistic Society has found the negative impact of Covid 19 has been felt most strongly by those with higher support needs, autistic women and non-binary people.	Thank you for sharing the National Autistic Society's report which was also shared with us by the National Autistic Society. The report is called Left stranded: The impact of coronavirus on autistic people and their families in the UK and describes the findings of a survey (n=4,232) of autistic people and their families. It reports that compared to the general public, autistic people were seven times more likely to be chronically lonely during June and July 2020 and six times more likely to have low life satisfaction. We are aware of the impact that the pandemic has had on people's mental health and on mental health services from a number of sources including stakeholders. We plan to look at NICE mental health guidelines as a whole, in order to explore the implications of the long term plan and other system drivers including the impact of COVID-19 on our mental health portfolio.

		https://www.autism.org.uk/what-we-do/news/coronavirus-report#:~:text=We%20found%20that%3A,**%20(comparisons%20using%20ONS%20data) An additional focus should be included in the guidelines to make sure appropriate support is in place for these groups of individuals, especially as Covid 19 restrictions are likely to continue for a long time.	Thank you for your comments about meeting virtually and the potential positive impacts of this for some people. We will share these comments with NICE's COVID-19 team.
National Autistic Society		Our Left Stranded report highlights the devastating impact on the mental health, wellbeing and education prospects on hundreds of thousands of autistic people and their families. 9 in 10 autistic people worried about their mental health during lockdown and 85% said their anxiety levels got worse. Autistic people were also 7 times more likely to be chronically lonely than the general population and 6 times more likely to have low life satisfaction (comparisons using ONS data).	Thank you for sharing this information about the report. The report is called Left stranded: The impact of coronavirus on autistic people and their families in the UK and describes the findings of a survey (n=4,232) of autistic people and their families. It reports that compared to the general public, autistic people were seven times more likely to be chronically lonely during June and July 2020 and six times more likely to have low life satisfaction. We are aware of the impact that the pandemic has had on people's mental health and on mental health services from a number of sources including stakeholders. We plan to look at NICE mental health guidelines as a whole, in order to explore the implications of the long term plan and other system drivers including the impact of COVID-19 on our mental health portfolio.
Royal College of Psychiatrists		Limitations/advantages to online treatments. – may actually be preferred. Delays due to need for face to face work not possible due to PPE/social distancing.	Thank you for your comments about online treatments and disruption and restriction of face-to-face work due to PPE. These service changes and their effect on intervention fidelity remain to be assessed. When evidence emerges for these areas we will assess them in relation to autism.

Cheshire and Wirral Partnership NHS FT		Inclusion of recommendations on virtual / online resources for autism support as research evidence emerges.	Thank you for your comments about virtual/online treatments. As new evidence emerges on the impact of online resources on intervention fidelity and effectiveness we will address this. We plan to look at NICE mental health guidelines as a whole, in order to explore the implications of the long term plan and other system drivers including the impact of COVID-19 on our mental health portfolio.
PDA Society		We were pleased that there was consideration of adaptations needed for those with ASD / LD as new laws were put in place. As Guidance isn't being correctly implemented in many areas anyhow, trying to identify the possibility of flexibility that could be adopted in times of crisis is probably meaningless	Thank you for your comments. We are aware that the pandemic has been difficult for services and that there are unfortunately issues with implementing guidance recommendations.
Royal College of Paediatrics and Child Health		Many children with autism are first referred to the audiology clinics as they 'appear not to hear well' but are found to have no hearing difficulties. In these clinics their behavioural difficulties are sometimes seen more easily because of the expectations from them in performing a hearing test. A fast-track referral system from these clinics may help in earlier referral and diagnosis of autism in such children and less stress in the parents with long waiting times. A key difficulty is implementation and service delivery, but this has been acknowledged and the review of the 2014 autism strategy is awaited.Additional comments:	Thank you for your comments about audiology clinics. Autism diagnosis in children (CG128) recommendation 1.1.2 recommends that the local autism strategy group should aim to: • improving early recognition of autism by raising awareness of the signs and symptoms of autism through multi-agency training • making sure the relevant professionals (healthcare, social care, education and voluntary sector) are aware of the local autism pathway and how to access diagnostic services This accommodates working with professionals working in audiology clinics. Thank you for your comments about the review of the 2014 autism strategy. We plan to assess the impact of the review on

		It is mentioned that buspirone is licensed for anxiety and this is not correct. The SmPC says the following in section 4.2 *Children:* *Placebo-controlled trials, in which 334 patients were treated with buspirone for up to six weeks, have not shown buspirone at doses recommended for adult to be an effective treatment for generalised anxiety disorder in patients less than 18 years.* *Plasma concentrations of buspirone and its active metabolite were higher in paediatric patients, compared to adults given equivalent doses. (See 5.2, Pharmacokinetic Properties.)*	recommendations in the NICE autism guidelines when it is published. Thank you for your comments about buspirone and anxiety. This is a typo in the surveillance review which reads *'Buspirone is licensed for the treatment of anxiety in children and its use is off label in the evidence described. The BNF for children and the electronic medicine compendium notes that the efficacy and safety of buspirone has not been determined in children.'* It should of course read: *Buspirone is NOT licensed for the treatment of anxiety in children and its use is off label in the evidence described…'* This will be corrected.
Autistica, the UK's autism research charity		Comments as per CG142 The evidence available on the impact of the pandemic on autistic adults has obviously been limited by the timeframes it has been around, as well as the impact of COVID-19 on the sectors ability to fund and run research projects. However, the evidence that is available strongly suggests that COVID-19 (and the necessary public health measures to contain it) will have a serious and disproportionate impact on autistic children's mental health. www.autistica.org.uk/downloads/files/Autistica-Action-Briefing-Impact-of-COVID-19-on-autistic-people.pdf The impact of poor mental health on autistic people will persist long beyond the end of the pandemic. Currently	Thank you for your comments about the impact of COVID-19 on autistic children's mental health, and for sharing the action briefing that describes how COVID-19 is acting to widen health inequalities. We also note its comment on the positive and negative impacts of digital mental health support and the need to know about effective delivery. We will share the latter comments with colleagues in NICE's COVID-19 team. Your comments about the impact of the pandemic persisting after it Thank you for your comment about the long-term impact of COVID-19 on the mental health of autistic people. We plan to look at NICE mental health guidelines as a whole, in order to explore the implications of the long term plan and other system drivers including the impact of COVID-19 on our mental health portfolio. We note your comment about Department of Health and Social Care (DHSC) commissioned research about the impact of COVID-19

		CG170 provides little guidance for clinicians and public services on how practically to identify and address those issues. For reference, the Department of Health and Social Care (DHSC) has commissioned ongoing research, led by the London School of Economics, about the impact of COVID-19 on autistic people. NICE should approach the DHSC for the findings of that research.	on autistic people. We will contact them for more information as suggested.
Takeda UK Ltd	Yes	There needs to be an evaluation on appropriate use and effectiveness of telepsychiatry in this patient cohort	Thank you for your comments. We are aware of the issues around the use of digital resources and telemedicine, particularly in relation to mental health and learning disability services.
Other comments			
Child Autism UK		Child Autism Comments Regarding Autism spectrum disorder in under 19s: support and management - surveillance consultation Since the last review in 2013, several significant papers have been released which show or reference the efficacy of ABA as a treatment for children with autism. I've made a table below of some key ones for your consideration and hope that you will reconsider reviewing this approach.	Thank you for your comments about ABA and for sharing the study abstracts. It should be noted that CG170 and CG128 (diagnosis in children) underwent a surveillance review in 2016 to check whether or not it was up to date. This found that CG128 needed to be partially updated in relation to recommendations on 'referring children and young people to the autism team' and 'autism diagnostic assessment for children and young people'; CG170 was found to be up to date. We identified an NIHR study about ABA: 'Interventions based on early intensive applied behaviour analysis for autistic children: a systematic review and cost-effectiveness analysis. And an overview is on page 98 on the surveillance proposal.' This is a systematic review and individual participant data meta-analysis to evaluate the clinical and cost effectiveness of an early intensive applied

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			behaviour analysis-based intervention (ABA) for autistic children. In the surveillance proposal we noted that that while outcomes on the Vineland Adaptive Behaviour Scale showed no clear evidence of benefit, the intervention appeared to improve cognitive function at 1 year and at 2 years. However, the authors noted that: 'Autism symptom severity was not measured in most included studies and the results were too limited to be conclusive, with no clear evidence that early intensive applied behaviour analysis-based interventions had any effect.' We also noted the study suggested ABA was not cost-effective. It should be noted that while evidence for ABA is too equivocal for NICE to recommend an update in this area, ABA is accommodated by recommendations 1.3.1 to consider a specific social-communication intervention and 1.4.9 which describes the attributes of effective psychosocial interventions for behaviour that challenges. ABA is a theoretical approach that underpins a number of interventions. Thank you for sharing the papers about ABA. The inclusion criteria for this surveillance review was systematic reviews, randomised controlled trials and diagnostic studies published 27 January 2016 to 1 November 2019. Estes A et al. (2015) predates the search period for this review. It was considered during 2016 surveillance and was assessed as supporting recommendations about managing the core features of autism. Haglund, N. *et al.* (2020) is an experimental study (n=104) that reports a naturalistic developmental behavioural intervention (NDBI) produces a statistically significant improvement in Swedish children's total ADOS score compared with treatment as usual. It also reports no difference between groups for the ADOS symptoms

			severity score. It should be noted this is not a randomised controlled trial, participants were offered a choice of interventions and were not blinded to them. This resulted in 67 people in the NDBI group compared with 27 in the treatment as usual group. The study is not an RCT and does not meet inclusion criteria. The results are likely to be biased due to lack of randomisation and blinding. Howard et al (2014) predates the search period for this review and is not an RCT so was not included in this surveillance review, nor the 2016 surveillance review. Stock R et al, (2013) predates the search period for this review. Dixon R et al (2019) reports the results of a randomised controlled trial (n=28) that compared traditional ABA, consisting of verbal behavior techniques, with comprehensive ABA and waitlist control. It reports that both ABA techniques improved intelligence scores compared to leaving children on a waiting list and comprehensive ABA improved intelligence scores more than traditional ABA, Due to the small sample size this is not considered sufficiently robust evidence to recommend updating the guideline to consider making explicit recommendations naming ABA. However, we are grateful to you for highlighting this study, which was not identified by the search strategy because it is not indexed by Medline or Embase. We will add this to the surveillance review. We will ensure that the cumulative evidence based on ABA is considered at the next surveillance review, when we hope there will be further well conducted and powered RCTs published in this area that will enable us to consider the impact of ABA on autistic people. Sinai-Gavrilov et al. (2020) was not identified in our search as it post-dates the search period for the review. It reports the results of a quasi-experimental study (n=52) that compared the Early start

			Denver model with a multidisciplinary intervention in preschool settings in Israel. The study reports an improvement with time for adaptive behaviour and language skills for ESDM compared with MDI although the latter started from a lower baseline. However, this is not an RCT, so does not meet our inclusion criteria. Keenan, M et al. (2015) predates the search period for this review.