National Institute for Health and Clinical Excellence

Autism in Children and Young People
Guideline Consultation Comments Table
29 March 2013-10 May 2013

NCCMH no.	Type	Stakeholder	Order No	Document	Section No	Page No	External Comments Please insert each new comment in a new row.	Developer's Response Please respond to each comment
1	SH	Treating Autism	20	Full	General		The Guideline does not place sufficient emphasis on the importance of ensuring that medical issues in children and young people with autism are thoroughly investigated and treated. Diagnosis of physical problems is more difficult in communication-impaired individuals, who may express pain or discomfort through behaviours such as aggression or self-harming. It is vital that pain is recognised and the cause identified and treated, in order to prevent needless suffering and inappropriate intervention, such as psychotropic medication. The Guideline should stress that priority must be given to the education of health professionals in the presentation of challenging behaviour as a possible manifestation of pain and discomfort caused by underlying medical problems.	Thank you for your comment. The Guideline Development Group agrees that it is very important that physical problems and pain are recognised and this can be difficult in autism. Pain is highlighted in section 1.4.1 of the NICE Guideline and is second on the list and we have covered pain and other factors that may contribute to behaviour that challenges in section 1.4 of the NICE Guideline. The Guidelines is 95% about comorbidities, behaviour that challenges, and so on; we cannot therefore take even more focus off autism.
2	SH	Treating Autism	21	Full	General		The sections on causation do not reflect the most significant current research. Hallmayer et al. (2011) a large, rigorous, and statistically sound study has been excluded while studies that are not even moderately powerful but support the genetic hypothesis of ASD are included. The failure to highlight Hallmayer et al. has perhaps skewed the rest of the literature review, particularly where subjective assessment of study validity is applied, most specifically in regard to treatment options. Our concern is compounded by the	Thank you for your comment. The Guideline Development Group have reviewed the introduction and made some revisions (for example, adding a reference to Hallmayer and the text 'but the possibility of an increase in ASD cannot be ruled out'). However, it should be noted that the introduction is not supposed to serve as a formal literature review, but rather a general introduction based on the Guideline Development Groups viewpoint and knowledge

							prevalence studies—especially those that have been excluded which show that a true increase is very likely. The underlying assumptions of this work, that ASD is genetic and homogenous in origin and lifelong and is not showing a true increase, leave little room for Excellence in Health care for those individuals who may have the sort of ASD that results from environmental triggers and may respond well to appropriate treatments.	of the literature.
3	SH	Treating Autism	22	Full	General		The criteria used by NICE to rate the quality of interventions should be revised in future to reflect the clinical complexity and heterogeneity of autism and the fact that in evaluating effects of randomised controlled trials, beneficial effects in a small subset of children can easily be obscured by the lack of effect in the majority. More adequately designed intervention trials should be recommended by Autism Guidelines, that would take into consideration heterogeneity of the underlying pathology and that attempt to elucidate different subtypes of autism based on imaging and clinical biomarkers, as well as suitability of specific interventions for each of those subtypes.	Thank you for your comment. The Guideline Development Group acknowledges that there are different viewpoints regarding how to rate the quality of interventions. Italso acknowledges that more can be done to determine if subgroups of participants respond differently to interventions. However, the Guideline Development Group does not believe this is an inherent limitation of the RCT framework as subgroups can be specified a priori and tested. The group reviewed the research recommendations and are satisfied with the suggested research designs.
4	SH	ABA Autism Education Ltd	2	Full	General	General	THE GUIDELINES IGNORE COMPREHENSIVE GUIDELINES FROM OTHER COUNTRIES SUCH AS THE USA THAT CLEARLY STATE THE EMPIRICAL EVIDENCE FOR THE USE OF ABA IN THE TREATMENT OF PERSONS WITH AUTISM (copy is attached) http://www.nationalautismcenter.org/pdf/NAC%20Standards%20Report.pdf	Thank you for your comment. The Guideline Development Group searched systematically for all available and relevant evidence. The Guideline Development Group reviewed the best available evidence rather than existing guidelines.
5	SH	ABA Autism Education Ltd	1	Full	General	General	THERE IS A METHDOLOGICAL FLAW IN THE GUILDELINES IN THAT THE ONLY STUDIES ABOUT THE EFFECTIVENESS OF ABA ARE GROUP STUDIES – THERE IS A WEALTH OF PEER REVIEWED LITERATURE SPANNING OVER 60 YEARS THAT DEMONSTRATES THE	Thank you for your comment. The Guideline Development Group acknowledges there are different views with regard to what constitutes the best available evidence when evaluating the effectiveness of

							EFFECTIVENESS OF ABA ACROSS A WIDE RANGE OF BEHAVIOURS IN THE FORM OF SINGLE SUBJECT DESIGNS – IT IS VITAL THAT THIS IS TAKEN INTO ACCOUNT e.g see Journal of Applied Behavior Analysis - http://seab.envmed.rochester.edu/jaba/jabaindx.asp	interventions, but the Guideline Development Group does not believe there are currently good methods for combining randomised and non-randomised evidence to answer questions about intervention effectiveness. Therefore, for a particular question, where there was RCT evidence, the Guideline Development Group focused on that evidence and did not search for non-randomised evidence. This method was set out in the review protocol before beginning the review, and it would not have been appropriate to change this approach after having reviewed the evidence. Regarding SCEDs, there are also considerable difficulties reviewing this type of research, particularly for the purpose of developing national clinical guidelines. For example, findings from single cases are difficult to generalise to a wider population and there is a significant risk of publication bias which further limits the reliability of findings from SCEDs. Furthermore, the Guideline Development Group notes that even proponents of SCEDs recognise that, at least in the area of ABA research for autism "…large multi-site randomized clinical trials are needed to narrow the confidence intervals for effect sizes, support comprehensive outcome assessments, identify potential mediators and moderators, and pinpoint active ingredients (eg, optimal amount of treatment)." (Smith, Eikeseth, Sallows, The Journal of Pediatrics, 155 (1), 151-152. A similar conclusion was reached by an AHRQ funded review that included both randomised and non-randomised research: "Some behavioral and educational interventions that

								vary widely in terms of scope, target, and intensity have demonstrated effects, but the lack of consistent data limits our understanding of whether these interventions are linked to specific clinically meaningful changes in functioning. The needs for continuing improvements in methodologic rigor in the field and for larger multisite studies of existing interventions are substantial. Better characterization of children in these studies to target treatment plans is imperative." (AHRQ Publication No. 11-EHC029-EF.)
6	SH	ABA Autism Education Ltd	3	Full	General	General	THE NICE GUIDELINES NOTE THAT CARERS EXPECT AND SEEK ABA TRAINING – THIS INFORMATION IS IMPORTANT IN LIGHT OF RECENT CASES OF ABUSE BY CARERS OF PERSONS WITH DISABILITIES AT WINTERBOURNE CAREHOME IN BRISTOL – PERSONS CARING FOR OTHERS NEED TO BE THOROUGHLY TRAINED IN THE PRINCIPLES ABA AND MONITORED AND FOLLOWED UP IN TERMS OF THE QUALITY OF SUPPORT AND CARE THEY PROVIDE	Thank you for your comment. Recommendation 1.1.8 in the NICE Guideline is that any health and social care professionals working in any situation with children and young people with autism should have training in basic skills in managing autism.
7	SH	ABA Autism Education Ltd	4	Full	General	General	THE ABA STUIDES THAT WERE CONSIDERED IN THE GUIDELINES MAINLY USED 'THE LOVAAS APPROACH' WHICH FIRSTLY IS A COMPLETE MISNOMER BECAUSE ABA IS ABA AND THE NAME OF A PERSON WHO USES THE PRINCIPLES HAS NO RELATIONSHIP TO ABA. THE FIELD IS COMPLEX INTERMS OF STRUCTURE OF DELIVERY AND IS CONSIDERED TO HAVE SEVERAL 'SUB' APPROACHES INCLUDING POSITIVE BEHAVIOURAL SUPPORT, VERBAL BEHAVIOUR AND OTHERS - ALTHOUGHT ALL ARE TECHINCALLY ABA – THE NICE GUILDEINES NEED TO UNDERSTAND AND EXPLAIN THIS COMPLEXITY IN THE FIELD OF ABA SO THAT PRACTITIONERS CAN EXPLAIN TO PARENTS AND	Thank you for your comment. In its analysis of studies the developers have used the description of the method of intervention used by the study authors.

							HELP THEM NAVIGATE THE SYSTEM	
8	SH	ABA Autism Education Ltd	6	Full	General	General	THE COST OF ABA FOR PARENTS IS PROHIBITIVE THERE IS A REAL NEED IS TO HAVE ABA PROGRAMMES START IN SCHOOLS AND NURSERYS FOR CHILDREN IDENTIFIED AS BEING AT RISK FOR DIAGNOSIS FROM AS EARLY AS POSSIBLE E.G. 2 YEARS RIGHT UP TO ABA FOR ADULTS IN POST 19 EDUCATION AND GROUP OR RESIDENTIAL CARE.	Thank you for your comment. In the review of evidence, the Guideline Development Group found no evidence to support ABA, and therefore could not make a recommendation about ABA. In addition, this Guideline does not cover causation. Although education is outside of the scope of this guideline, the role of the Local Autism Team and of the Strategy Group is to ensure full collaboration with education providers, as well as with health and social care. This is laid out in the recommendations 1.1.2, 1.1.3, 1.1.6, 1.1.11 and 1.8.2 in the NICE Guideline.
9	SH	ABA Autism Education Ltd	7	Full	General	General	THE PRINCIPLES OF ABA ARE NOT THE SAME THE PROCEDURES AND TACTICS OF ABA – THE NICE GUIDELINES DEMONSTRATE LACK OF UNDERSTANDING OF WHAT ABA IS – ITS HISTORY, ITS ATTITUDES, ITS PRINCIPLES ITS PROCEDURES, ITS RESEARCH, ITS ETHICS ETC ETC ARE NOT MADE CLEAR	Thank you for your comment. Sections 2.13 and 5.2.1 in the Full Guideline have been amplified to include a description of ABA approaches
10	SH	ABA Autism Education Ltd	8	Full	General	General	THE FIELD OF ABA IS UNREGULATED IN THE UK AND IT NEEDS TO BE REGULATED AS SOON AS POSSIBLE AS PARENTS ARE VULNERABLE TO UNQULIFIED PERSONS CONDUCTING BEHAVOUR CHANGE PROGRAMMES FOR THEIR CHILDREN AND NOT ADHERING TO THE PRINCIPLES AND ETHICS OF THE SCIENCE OF ABA – PRACTITIONERS NEED TO KNOW HOW TO ADVISE PARENTS WHAT TO LOOK OUT FOR IN TERMS OF PROVISION OF ABA CONSULTANCY, SUPERVISION AND THERAPISTS.	Thank you for your comment. NICE's remit does not include the regulation of professionals. Although the guideline does not include the regulation of professionals, the Guideline Development Group has tried to stress the importance of training and skills for health and social care professionals. Please see recommendation 1.1.8 in the NICE guideline in particular, which is about the knowledge and competence of health and social care professionals.
11	SH	ABA Autism Education Ltd	9	Full	General	General	ABA IS COMPLETELY MISUNDERSTOOD AS A RIGID, ON THE TABLE, DISCRETE TRIAL, ROBOT	Thank you for your comment. The Guideline Development Group has noted your strong

							MAKING SYSTEM – THIS IS NOT AT ALL THE CASE. ABA IS THE APPLICATION OF THE PRINCIPLES OF BEHAVIOUR TO CHANGE SOCIALLY SIGNIFICANT BEHAVIOUR – THE APPLICATION, THE ANALYSIS, THE DATA DRIVEN APPROACH AND THE DIFFERENCE IT CAN MAKE TO CHILDREN'S LIVES AND THE LIVES OF THEIR PARENTS SHOULD NOT BE DISMISSED WITH BIASED MIS CHARACTERIZATIONS – WHAT ABA IS SHOULD BE CAREFULLY DESRIBED SO THAT QUALITY SERVICES CAN BE ACCESSED.	feelings about ABA and has made changes to section 2.13 in the Full Guideline.
12	SH	Ambitious about Autism	1	Full	General	General	Ambitious about Autism would welcome more explicit information about how the draft NICE guidelines will inform the SEN landscape emerging as a result of the Children and Families Bill. In particular, it would be helpful to practitioners and parents if the guidelines explained how they will inform a young person's Education, Health and Care Plan (EHCP) Are the guidelines intended to inform the educational outcomes for young people with autism which are often dependent on health support. Government have been clear that EHCPs will have an 'education spine' but do NICE expect the contribution of health practitioners to EHCPs to be informed by this set of guidelines? Equally, there are many young people with autism withou a Statement, or in the future a EHCP, who have health needs which will impact on the educational attainment and progress and therefore we would recommend: - the SEN Tribunal should 'have regard' to these	Thank you for your comment. The Guideline Development Group has added a further reference to the children and families bill and to the education, health and care plan to section 2.13 in the Full Guideline on Multi Professional and Multiagency Collaboration. Although education is outside of the scope of this guideline, the role of the Local Autism Team and of the Strategy Group is to ensure full collaboration with education providers, as well as with health and social care. This is laid out in the recommendations 1.1.2, 1.1.3, 1.1.6, 1.1.11 and 1.8.2 in the NICE Guideline.

							guidelines - a commitment to following the guidelines forms part the local offer - adding reference to EHCPs into the guidelines and saying health and social care should be provided as part of a holistic package of care across all services as set out in the SEN reforms (if this is the intention) - that references to multi-agency assessments in the guidelines include mention of the need for assessments to be delivered in a single coherent process for families coordinated across education, health and care services.	
13	SH	Ambitious about Autism	2	Full	General	General	Ambitious about Autism believes the guidelines should include a commitment to the social model of disability under 'Patient-centred care' and highlight the need for independent advocacy to support young people to make decisions about their care**.** The transition section, should be explicit that transition planning should be multi-agency and link to the young person's plans to continue their education, enter employment, or live as independently as possible.	Thank you for your comment. The Guideline Development Group has added an explicit reference to the social model of disability in section 2.13 of the Full Guideline. The Guideline Development Group would like to direct your attention to section 1.8 Transition to adult services in the NICE Guideline, in particular recommendation 1.8.4 about multi-agency working, and recommendation 1.8.2 about carrying out a comprehensive assessment which includes, amongst other areas, education and occupation.
14	SH	Ambitious about Autism	3	Full	General	General	It would be helpful to parents and young people if the guidelines can make clear what families do the to seek redress if the guidance is not followed.	Thank you for your comment. Guideline recommendations are not mandatory, they are guidelines based upon the best evidence available. They do not replace clinical judgement; but they do help to guideline clinicians, families and children with autism. If the guidelines are not followed it is expected that health and social care professionals are able to justify this clearly and in a way that children and their families can understand.

15	SH	Autism Parents for ABA (APA)	1	Full	General	General	We the undersigned* are a group of 219 autism parents (plus a handful of grandparents) who believe that, although many of the conclusions reached in the report are very sensible, NICE has significantly underplayed the valuable role which ABA can play as an intervention for autism. We have all experienced very good results from ABA with our own children, in particular in the areas of speech/language and the management of challenging behaviours. Many of us have, in addition, experienced poor outcomes from the SALT and other "eclectic" provisions offered to us to manage the key deficits of our children's autism. Both challenging behaviours and speech are currently falling somewhere between health and education, and consequently we are experiencing confused and sub-optimal outcomes.	Thank you for your comment. The Guideline Development Group is pleased to have included chapter 4 with qualitative comments from individuals about a wide variety of care and interventions. The aim of the guideline is to improve the services for children and young people with autism and their families. The Guideline Development Group appreciates that individuals may benefit from ABA, however, in the review of evidence, the Guideline Development Group found no evidence to support ABA and there for cannot made a recommendation about it.
16	SH	Autism Parents for ABA (APA)	5	Full	General	General	We are worried that the panel involved in your process was SALT-heavy and ABA-light. Why, when in the US, Scandinavia and Canada it is the standard intervention for autism, does an ABA professional not even make it onto the core drafting group over here? In the US, a majority of states have mandated that ABA be covered under health/medical insurance policies as a treatment for autism. Here, it barely even makes it into the NICE guidance. Is the UK failing to move with the times on autism? We would respectfully also ask you to look again at some of the research on ABA, particularly at some of the Single Case Experimental Design studies. We believe	Thank you for your comments. NICE has an open and transparent process for recruiting Guideline Development Group members. Stakeholders are also invited to comment on proposed Guideline Development Group composition during the scoping stage of guideline development. NICE clinical guidelines are based on the best quality evidence and are developed according to rigorous and robust methodologies. The developers were unable to identify high quality evidence of effectiveness of the ABA approach in managing children and young people with autism.

							your system of evaluating research may be poorly suited to autism, which is a far from homogenous condition and muddied further by a wide variety of co-morbidities. We would refer you to Professor Richard Hastings' recent blog entry and the research by Professor KarolaDillenburger for further discussion of these points (see below). We would also query why the SALT and OT offered to our children does not seem subject to the same high standards of evidence as ABA, yet both are routinely and no-doubt expensively used within the NHS as interventions for autism?	The Guideline Development Group acknowledges there are different views with regard to what constitutes the best available evidence when evaluating the effectiveness of interventions, but they do not believe there are currently good methods for combining randomised and non-randomised evidence to answer questions about intervention effectiveness. Therefore, for a particular question, where there was RCT evidence, the Guideline Development Group focused on that evidence and did not search for non-randomised evidence. This method was set out in the review protocol before beginning the review, and it would not be appropriate to change this approach after having reviewed the evidence. Regarding SCEDs, there are also considerable difficulties reviewing this type of research, particularly for the purpose of developing national clinical guidelines. For example, findings from single cases are difficult to generalise to a wider population and there is a significant risk of publication bias which further limits the reliability of findings from SCEDs. Furthermore, The Guideline Development Group note that even proponents of SCEDs recognise that, at least in the area of ABA research for autism "…large multi-site randomized clinical trials are needed to narrow the confidence intervals for effect sizes, support comprehensive outcome assessments, identify potential mediators and moderators, and pinpoint active ingredients (eg, optimal amount of treatment)." (Smith, Eikeseth, Sallows, The Journal of Pediatrics, 155 (1), 151-152. A similar conclusion was reached by an AHRQ

								funded review that included both randomised and non-randomised research: “Some behavioral and educational interventions that vary widely in terms of scope, target, and intensity have demonstrated effects, but the lack of consistent data limits our understanding of whether these interventions are linked to specific clinically meaningful changes in functioning. The needs for continuing improvements in methodologic rigor in the field and for larger multisite studies of existing interventions are substantial. Better characterization of children in these studies to target treatment plans is imperative.” (AHRQ Publication No. 11-EHC029-EF.) This clinical guideline is not for the purpose of outlining the roles of professionals such as speech and language therapists and occupational therapists, but is focussed on evaluating evidence for particular interventions to inform health and social care professionals.
17	SH	Autism Parents for ABA (APA)	6	Full	General	General	Please don't dismiss us. ABA works, and if we use it more widely, for instance in mainstream schools, costs need be no higher than for existing interventions. Your own report acknowledges that the costs of sorting out challenging behaviours early will be more than balanced out later on, when these are no longer cute kids we are all dealing with, but grown men. ...*"Without ABA, my beautiful boy would now be heading towards 16 stone and 6ft 5, still non-verbal and punching me in the face when thwarted. Our family would be wrecked and his only hope would be medication and sending him away to some godforsaken institution. That would have broken all our hearts. Please look again at the ABA*	Thank you for your comment. NICE Clinical Guidelines are based on the best quality evidence and are developed according to rigorous and robust methodologies. The developers were unable to identify high quality evidence of effectiveness of the ABA approach in managing children and young people with autism. However, the Guideline Development Group are particularly conscious of the problems posed by behaviour that challenges. Chapter 6 of the Full Guideline examines all the high quality evidence for pharmacological, psychological and biomedical interventions aimed at behaviour that

							profession for other families". Anon, a mum from APA *..." Basically, since we started an ABA therapy program at home 15 months ago, my 8 year old son J's life and our life as a family has been transformed. Before we began the program, J's aggressive behavior was become scary to a point where his school refused to take him on a trip. At home he used to break furniture, hit out and shout.Although he still requires interventions, he is now transformed into a kind and gentle boy. However, putting ABA/VB program in place at school as well as home would accelerate J's progress both academically and socially. Unfortunately, in UK ABA is a postcode lottery." APA mum* "*... [We] worked with our grandson, who initially was not speaking or even recognising his name, for two and a half years, using ABA with the support of the Child Psychologist. Apart from a few speech therapy GROUP sessions, nothing was offered on the NHS. He had his fifth birthday last week, and has been at a normal school since last September, with a statement - he speaks beautifully with a great vocabulary, and just loves life. We cannot thank ABA enough for their early intervention methods."* APA Grandparents *List of 219 email addresses available from janemccready@live.co.uk	challenges and a number of recommendations have been made in light of the evidence (6.7.1.1 to 6.7.1.13). In addition, due to the weight of the problems associated with behaviour that challenges, the Guideline Development Group also took the view that it was necessary to support a research recommendation with a focus on parent training to reduce behaviour that challenges (please see research recommendation 2.2 in the NICE Guideline.) The Guideline Development Group are particularly conscious of the problems posed by challenging behaviour. The reason for this guideline is to ensure that the NHS and social care provide evidence based interventions in a timely manner.
18	SH	Autism Parents for ABA (APA)	7	Full	General	General	**Research Links or References** Does ABA work for children with autism? (7 essays, including "What's wrong with the draft NICE guidance?", plus "The most significant, and original, data on the outcomes of early intervention in autism?", "15 Criticisms of ABA and some responses")	Thank you for your comment and the references. The Guideline Development Group acknowledges there are different views with regard to what constitutes the best available evidence when evaluating the effectiveness of

							- Professor Richard Hastings, Bangor University, 2012/2013 http://profhastings.blogspot.co.uk/2012/12/autism-and-evidence-4-does-aba-workfor.html Keenan,M. &Dillenburger, K., (2011). If all you have is a hammer …RCTs and hegemony in science. Research in Autism Spectrum Disorders, 5, 1-13. http://www.sciencedirect.com/science/article/pii/S1750946710000218 The Emperor's New Clothes: Eclecticism in autism treatment, Dillenburger, K. (2011) http://www.sciencedirect.com/science/article/pii/S175094671100002X ABA endorsed in major US study: National Autism Center, 2009. The National Autism Center's National Standards Report [cited 08/23/2012] www.nationalautismcenter.org/pdf/NAC%20Standards%20Report.pdf Eldevik, S., Hastings, R. P., Jahr, E., & Hughes, J. C. (2012). Outcomes of behavioral intervention for children with Autism in mainstream pre-school settings. Journal of Autism and Developmental Disorders, 42, 210-220.	interventions, but does not believe there are currently good methods for combining randomised and non-randomised evidence to answer questions about interventions. Therefore, for a particular question, where there was RCT evidence, the Guideline Development Group focused on that evidence and did not search for non-randomised evidence. This method was set out in the review protocol before beginning the review, and the guideline development group do not believe it would be appropriate to change this approach after rhaving reviewed the evidence. Regarding SCEDs, there are also considerable difficulties reviewing this type of research, particularly for the purpose of developing national clinical guidelines. For example, findings from single cases are difficult to generalise to a wider population and there is a significant risk of publication bias which further limits the reliability of findings from SCEDs. Furthermore, the Guideline Development Group note that even proponents of SCEDs recognise that, at least in the area of ABA research for autism "…large multi-site randomized clinical trials are needed to narrow the confidence intervals for effect sizes, support comprehensive outcome assessments, identify potential mediators and moderators, and pinpoint active ingredients (eg,optimal amount of treatment)." (Smith, Eikeseth, Sallows, The Journal of Pediatrics, 155 (1), 151-152. A similar conclusion was reached by an AHRQ funded review that included both randomised and non-randomised research: "Some behavioral and educational interventions that

								vary widely in terms of scope, target, and intensity have demonstrated effects, but the lack of consistent data limits our understanding of whether these interventions are linked to specific clinically meaningful changes in functioning. The needs for continuing improvements in methodologic rigor in the field and for larger multisite studies of existing interventions are substantial. Better characterization of children in these studies to target treatment plans is imperative." (AHRQ Publication No. 11-EHC029-EF.)
19	SH	Autism Parents for ABA(APA)	8	Full	General	General	**ABA mandated in law by majority of US states : http://www.natlawreview.com/article/ state-legislation-affordable-care-act-aca-andautism-new-laws-bring-waves-change US State by state list of the 32 states whereautism treatment is mandatorily covered by health insurance, most of which name ABA specifically as a treatment for autism: http://www.ncsl.org/issues-research/health/ autism-and-insurance-coverage-statelaws. AspxGrindle, C. F., Kovshoff, H., Hastings, R. P., & Remington, B. (2009). Parents' experiences of home-based Applied Behavior Analysis programs for young children with autism. Journal of Autism and Developmental Disorders, 39, 42-56. Grindle, C. F., Hastings, R. P., Saville, M., Hughes, J. C., Huxley, K., Kovshoff, H., Griffith, G. M., Walker-Jones, E., Devonshire, K., & Remington, B. (2012). Outcomes of a behavioral education model for children with autism in a mainstream school setting. Behavior Modification, 36, 298-319. How Verbal Behaviour**	Thank you for these references.

							(ABA) Approach helps develop speech: http://www.amazon.com/The-Verbal-Behavior-Approach-Disorders/dp/1843108526/aref=sr_1_1?ie=UTF8&qid=1358195509&sr=8-1&keywords=the+verbal+behavior+approach How SALT and ABA are collaborating in the US http://www.asatonline.org/resources/clinician/speechpath.htm	
20	SH	Bangor University	3	Full	general	general	There is some mention in the draft guideline that interventions for autism are complex. However, there is no reference to the MRC complex interventions guidelines (nor to similar frameworks). These frameworks emphasise that different study designs and methods may be appropriate at different stages of the evidence development process. There are several problems for this guidance created by this issue: 1. The research question being addressed by a particular study was not considered when reviewing evidence nor when making recommendations. Thus, was a study testing efficacy, effectiveness, or translation into practice? Was a study at the stage of developing initial evidence for an intervention? 2. Interventions have been reviewed and sometimes recommended without reference to the full process that they would need to be subject to in order to be considered evidence-based. For example, the recent RCT of the Denver Early Start Model is an efficacy RCT. Given that purpose, it would be premature to recommend its use in practice (i.e., in the absence of data on implementation). Similarly, a RCT of horse riding therapy is reviewed in some detail but whether this intervention has a sensible theoretical basis is unknown.	Thank you for your comment. The Guideline Development Group accept that there are different views regarding the appropriateness of the approach used when evaluating complex interventions. The Guideline Development Group was well aware of these issues, and discussed them during the early stages of development. The approach used was agreed before reviewing the evidence, and therefore it would not have been appropriate to change this approach after having reviewed the evidence.

21	SH	Bangor University	4	Full	general	general	The search and inclusion criteria for studies to be included in the review process are currently ambiguous in a number of ways: 1. For Chapter 5, the focus is on intervention addressing the core features of autism. Actually, the inclusion criteria were about studies that included a MEASURE of autism symptoms as an outcome variable, there did not seem to be an evaluation of whether interventions were theoretically designed to affect autism symptoms directly. This is an important distinction. 2. The search criteria include meta-analyses but meta-analyses of interventions have not been included in drawing recommendations. For example, there are several meta-analyses of intensive behavioural intervention and a Cochrane review. Is it the case that meta-analyses were only included if they focused on RCT designs only? 3. There is no mention of whether mega-analyses (or individual participant data meta-analyses) would be included as evidence. Bangor University researchers have published what may be the only mega-analysis focused on autism interventions, and certainly a rare example of one where individual data were returned by authors for 100% of the studies identified through systematic review methods. The sample size of individual children analysed was also in excess of 400 children [Eldevik, S. Hastings, R. P., Hughes, J. C., Jahr, E., Eikeseth, S., & Cross, S. (2010). Using individual participant data to extend the evidence base for Intensive Behavioral Intervention for children with autism. *American Journal on Intellectual and Developmental*	Thank you for your comments. 1. The Guideline Development Group has made some changes to the headings to clarify this issue. A large number of studies included in the guideline did not report what their direct or critical outcomes were, therefore the Guideline Development Group had to determine what they were based on using the study aims. The Group believes the direct and indirect outcomes reflect what the studies hoped to achieve. 2. The Guideline Development Group used meta-analyses (of any design type) as a check that our search had picked up all available RCTs. If a meta-analysis included an RCT not picked up by our electronic database search, the Guideline Development Group assessed the RCT for eligibility and extracted data were relevant. 3. The Guideline Development Group did not specifically exclude individual patient meta-analyses, but only used them as a check for additional RCTs.

							Disabilities, **115**, 381-405.]	
22	SH	Bangor University	5	Full	general	general	Studies with N<400 children/young people are downgraded in terms of the quality of evidence that they provide. This is unethical. Research studies (especially controlled trials) that were externally funded are likely to have received a statistical review including a sample size calculation. One element of this approach is to ensure that only the sample size needed to demonstrate the effect is recruited (and indeed funded through a grant). Setting an arbitrary N of 400 ignores the complexity and cost of many autism interventions and disadvantages this disabled group.	Thank you for your comment. Under the GRADE system, downgrading for imprecision reflects the uncertainty associated with evidence from relatively small numbers of participants. The N<400 rule of thumb is across all studies in the meta-analysis (not an individual study) and is calculated using the assumption that a small effect would be clinically meaningful. Nevertheless, even with low quality evidence, strong recommendations can be generated in the right circumstances. Therefore, the Guideline Development Group does not agree with the assertion that this approach is unethical.
23	SH	Bangor University	6	Full	general	general	The whole guideline document is inappropriately focused on autism as a medical disorder. There is at least one other perspective – more of a social model. This influences many autism interventions such that the outcomes of interest may be more often broader measures of functioning since interventions are designed to have a positive quality of life impact. Most interventions (and most researchers) are not trying to cure autism or its “co-morbidities” but to make a positive difference to children with autism and their families and carers. This point is important because the process of selecting evidence is biased towards studies that take a broadly medical (rather than a social-educational) perspective on autism.	Thank you for your comment. The Guideline Development Group has added a sentence in section 2.13 of the Full Guideline referencing the ICF and social model. The introduction confirms that at present there is no medical cure for autism, and there are many other statements in the introduction that refer to the importance of functional and systemic outcomes. Evidence relating to social-educational interventions was systematically reviewed in the development of the guideline and there are recommendations relating to these. The guideline was developed in collaboration with the Social Care Institute for Excellence.
24	SH	Bangor University	7	Full	general	general	Missing evidence – qualitative studies and RCTs are included in the evidence reviews as suitable data. There is also recognition that in the absence of RCT evidence, other research approaches might be included. However, it is not clear whether this has been done. There are currently two key problems that	Thank you for your comment. The Guideline Development Group acknowledges there are different views with regard to what constitutes the best available evidence when evaluating the effectiveness of interventions, but does not believe there are currently good methods for

							need to be addressed: 1. Single case experimental designs (SCEDs) are a recognised methodology internationally and at a much higher level of evidence than qualitative studies. SCEDs include experimental control by using designs such as reversal designs and multiple baseline designs. Much of the evidence for social-educational focused interventions in autism uses SCED methods. Thus, a whole tranche of evidence is missed in the current draft guideline. This leads to errors such as statements that there are no "treatments" for repetitive behaviours in autism – there are very likely to be some in the SCED literature. The GDG just didn't look for these data. Because SCED methodologies are used primarily to generate evidence in developmental disabilities (especially autism, and learning disability) it does seem like discrimination against these disabled people to NOT include SCED evidence in NICE reviews. 2. In the absence of RCT evidence, the GDG have still made recommendations for practice but the evidence used to make these recommendations is unclear. Surely, the GDG should have carried out systematic reviews of non-RCT evidence to inform their recommendations and in the interests of transparency explained this process and allowed other people to critically evaluate the evidence used to make recommendations.	combining randomised and non-randomised evidence to answer questions about intervention effectiveness. Therefore, for a particular question, where there was RCT evidence, we focused on that evidence and did not search for non-randomised evidence. This method was set out in the review protocol before beginning the review, and it would not have been appropriate to change this approach after having reviewed the evidence. Regarding SCEDs, there are also considerable difficulties reviewing this type of research, particularly for the purpose of developing national clinical guidelines. For example, findings from single cases are difficult to generalise to a wider population and there is a significant risk of publication bias which further limits the reliability of findings from SCEDs. Furthermore, the guideline development group notes that even proponents of SCEDs recognise that, at least in the area of ABA research for autism "…large multi-site randomized clinical trials are needed to narrow the confidence intervals for effect sizes, support comprehensive outcome assessments, identify potential mediators and moderators, and pinpoint active ingredients (e.g. optimal amount of treatment)." (Smith, Eikeseth, Sallows, The Journal of Paediatrics, 155 (1), 151-152. A similar conclusion was reached by an AHRQ funded review that included both randomised and non-randomised research: "Some behavioral and educational interventions that vary widely in terms of scope, target, and intensity have demonstrated effects, but the lack

								of consistent data limits our understanding of whether these interventions are linked to specific clinically meaningful changes in functioning. The needs for continuing improvements in methodologic rigor in the field and for larger multisite studies of existing interventions are substantial. Better characterization of children in these studies to target treatment plans is imperative." (AHRQ Publication No. 11-EHC029-EF.) The Guideline Development Group strongly rejects the suggestion that excluding SCED methodologies is discrimination against people with developmental disabilities.
25	SH	Bangor University	8	Full	general	general	Qualitative research studies do not appear to have been evaluated for quality despite recommendations being based on the evidence from these studies.	Thank you for your comment. All qualitative studies were evaluated for quality based on criteria set out in the NICE Guidelines Manual 2012. Completed quality checklists can be found in Appendix 14.
26	SH	Bangor University	9	Full	general	general	There are inaccuracies throughout the guideline in relation to behavioural interventions for autism. First, there is no clear definition of what a "behavioural" intervention is. Second, there is an underlying mis-understanding of Applied Behavioural Analysis (ABA). ABA is an applied science and not an intervention approach. The whole document needs a thorough edit before publication by someone who is an ABA expert and can tighten up on the terminology used. For example, the GDG tentatively recommend the LEAP intervention model. They are also clear that many interventions (including the Early Start Denver Model) use ABA methods. PECS is also discussed positively, and PECS is an ABA-based intervention of course. In fact, our reading of the LEAP evaluation	Thank you for your comment. Sections 2.13 and 5.2.1 of the Full Guideline have been expanded with further descriptions of current intervention approaches many of which use ABA principles. The Guideline Development Group, in their review of existing evidence, did not find any evidence to support ABA and there for cannot made a recommendation about ABA. The guideline does address behaviour that challenges, and does so in a thoughtful and practical way. Please see the recommendations in section 1.4 of the NICE Guideline, Interventions for behaviour that challenges.

							paper that the GDG liked so much is that it is also a behavioural intervention. Granted, discrete trial teaching methods are not the core of the approach, but all of the core elements of the intervention described by the study authors are ABA teaching technologies. There is also evaluation research from the Bangor University team where a variety of behavioural methods were used together as an educational approach in the early years and in a mainstream setting (like the LEAP model) [see Grindle, C., Hastings, R. P., Saville, M., Hughes, J. C., Kovshoff, H., & Huxley, K. (2009). Integrating evidence-based behavioural teaching methods into education for children with autism. *Educational and Child Psychology,* **26**(4), 65-81. And Grindle, C. F., Hastings, R. P., Saville, M., Hughes, J. C., Huxley, K., Kovshoff, H., Griffith, G. M., Walker-Jones, E., Devonshire, K., & Remington, B. (2012). Outcomes of a behavioral education model for children with autism in a mainstream school setting. *Behavior Modification*, **36**, 298-319.] This might be helpful in supporting the recommendation to consider the LEAP model. It would be good to see the guideline include a specific section that draws together the guideline development group's perspective on behavioural methods. It is important to point out how many interventions that don't even call themselves "ABA" or behavioural actually rely almost exclusively or in large part on ABA teaching technologies. The guideline group could help a rapprochement and future collaboration between autism professionals/experts to the benefit of children with autism and their families. A final point on the behavioural aspects is that it is encouraging to see recommendations about the use of functional analysis and behavioural interventions based on functional analysis when dealing with	The Guideline Development Group have considered your comments and do not believe any further changes need to be made. They also reviewed the guideline in light of your comments regarding competency, and came to the view that this is adequately covered in the recommendations, including in recommendation 1.1.8 in the NICE Guideline, about knowledge and competence of health and social care professionals.

							challenging behaviours. The language used could do with a thorough edit though. For example, experts in behaviour analysis might reserve the term “functional analysis” for experimental functional analysis, which is a technique requiring considerable expertise and also ethical review. The term “functional assessment” may be what is meant. A small group of experts in ABA and Positive Behaviour Support would be able to take on an editing task. In addition, the guideline probably should clarify the competencies that may be needed to carry out some interventions (the example of experimental functional analysis is an example). The guideline could helpfully recommend referral to expert challenging behaviour teams or to a clearly (behaviourally) trained challenging behaviour expert within a multi-disciplinary team.	Thank you for this correction. The Guideline Development Group now referrs to ‘functional assessment of behaviour‘ to avoid misinterpretation.
27	SH	Bangor University	10	Full	general	general	There is a danger that this guideline will be mis-used. It is currently clearly only potentially appropriate for medical professionals and has not been written with social care in mind (despite comments to the contrary) and certainly not with education in mind. This does seem limiting when the new children and families bill in England is likely to lead to the new Education Health and Care plans. Thus, children with autism are mainly going to be supported through a joint plan that is led via local authorities (and thus, with much more of an education focus). There are two options here that need to be considered: 1. Ideally, re-vamp the guideline to be directly useful to education as a lead service supporting children with autism. This would mean considerably revising the way that the	Thank you for your comment. While this guideline does not cover educational aspects of the management of autism directly because it was outside the scope of the guideline, the guidance is, however, a collaboration with the Social Care Institute for Excellence and has foregrounded the involvement of social care services and education in the multidisciplinary Local Autism Teams and Strategy Group. The role of the Local Autism Team and of the Strategy Group is to ensure full collaboration with education providers, as well as with health and social care. This is laid out in the recommendations 1.1.2, 1.1.3, 1.1.6, 1.1.11 and 1.8.2 in the NICE Guideline.

							guideline is described (i.e., should not be as a medical model approach), and the nature of the evidence included. 2. Include very clear statements that the guideline is not devise to be relevant to questions about the education of children with autism and an explicit health warning that it should not be used by education authorities and schools as a source of guidance about autism interventions.	
28	SH	BetsiCadwaladr University Health Board	1	Full	general	general	The Guideline in general is welcomed and clearly describes the diagnosis, clinical features, prevalence, causes, impact etc.	Thank you for your comment.
29	SH	BetsiCadwaladr University Health Board	2	Full	general	general	Document mentions “care”, “support”, and “management” which are all important, however, it would be appropriate to mention treatment and intervention as well	Thank you for your comment. The Guideline Development Group reviewed the guideline and think there’s a good balance between the recommendations on care, support and management, and the recommendations on treatment and intervention. Unfortunately, the Guideline Development Group found little evidence to support specific interventions and the Guideline therefore reflects this.
30	SH	BetsiCadwaladr University Health Board	3	Full	general	general	The omission of Single Case Experimental Design studies in evidence evaluation is considered short sighted; It appears that the selection process for reviewing the evidence is fundamentally flawed: in that it allows an evaluation of a horse-riding intervention whilst completely ignoring the vast Single Case Experimental Design studies. It has been remarked that this is tantamount to discrimination, in that much of the research within the learning disability population is necessarily SCED in nature.	Thank you for your comment. The Guideline Development Group acknowledges there are different views with regard to what constitutes the best available evidence when evaluating the effectiveness of interventions, but the Guideline Development Group does not believe there are currently good methods for combining randomised and non-randomised evidence to answer questions about interventions. Therefore, for a particular question, where there was RCT evidence, the Guideline Development Group focused on that evidence and did not search for non-randomised evidence. In practice, this meant that for all questions other than those reviewed in Chapter 4, only RCT evidence was reviewed. This method was set

								out in the review protocol before beginning the review, and the Guideline Development Group does not believe it would be appropriate to change this approach having reviewed the evidence. Furthermore, the Guideline Development Group notes that even proponents of SCEDs recognise that, at least in the area of ABA research for autism "…large multi-site randomized clinical trials are needed to narrow the confidence intervals for effect sizes, support comprehensive outcome assessments, identify potential mediators and moderators, and pinpoint active ingredients (eg,optimal amount of treatment)." (Smith, Eikeseth, Sallows, The Journal of Pediatrics, 155 (1), 151-152. A similar conclusion was reached by an AHRQ funded review that included both randomised and non-randomised research: "Some behavioral and educational interventions that vary widely in terms of scope, target, and intensity have demonstrated effects, but the lack of consistent data limits our understanding of whether these interventions are linked to specific clinically meaningful changes in functioning. The needs for continuing improvements in methodologic rigor in the field and for larger multisite studies of existing interventions are substantial. Better characterization of children in these studies to target treatment plans is imperative." (AHRQ Publication No. 11-EHC029-EF.) The Guideline Development Group strongly rejects the suggestion that excluding Single Case Experimental Design studies methodologies is discrimination against people

								with developmental disabilities.
31	SH	BetsiCadwaladr University Health Board	8	Full	general	general	It is suggested that the process for inclusion/exclusion of studies is fundamentally flawed: to include and evaluate studies on Lego therapy and horse-riding does not do the NICE process justice: it is possible to add weight to the process by including studies evaluated by using meta-analysis and Individual Participant Data Meta-Analysis processes.	Thank you for your comment. The Guideline Development Group acknowledges there are different views with regard to what constitutes the best available evidence when evaluating the effectiveness of interventions, but the Guideline Development Group does not believe there are currently good methods for combining randomised and non-randomised evidence to answer questions about interventions. Therefore, for a particular question, where there was RCT evidence, the Guideline Development Group focused on that evidence and did not search for non-randomised evidence. In practice, this meant that for all questions other than those reviewed in Chapter 4, only RCT evidence was reviewed. This method was set out in the review protocol before beginning the review, and the Guideline Development Group does not believe it would be appropriate to change this approach having reviewed the evidence. Furthermore, the Guideline Development Group notes that even proponents of SCEDs recognise that, at least in the area of ABA research for autism "…large multi-site randomized clinical trials are needed to narrow the confidence intervals for effect sizes, support comprehensive outcome assessments, identify potential mediators and moderators, and pinpoint active ingredients (eg,optimal amount of treatment)." (Smith, Eikeseth, Sallows, The Journal of Pediatrics, 155 (1), 151-152. A similar conclusion was reached by an AHRQ

								funded review that included both randomised and non-randomised research: “Some behavioral and educational interventions that vary widely in terms of scope, target, and intensity have demonstrated effects, but the lack of consistent data limits our understanding of whether these interventions are linked to specific clinically meaningful changes in functioning. The needs for continuing improvements in methodologic rigor in the field and for larger multisite studies of existing interventions are substantial. Better characterization of children in these studies to target treatment plans is imperative.” (AHRQ Publication No. 11-EHC029-EF.) The Guideline Development Group strongly rejects the suggestion that excluding Single Case Experimental Design studies methodologies is discrimination against people with developmental disabilities.
32	SH	BetsiCadwaladr University Health Board	9	Full	general	general	The current presentation of Autism is that of a medical disorder. It is suggested that it would be helpful to change this. Autism is not a curable condition; applying treatments to core symptoms will not enable the subject to recover. It is suggested that treatments/interventions that are applied to common difficulties experienced by children and young people with autism could be evaluated, rather than core symptoms per se. Thus, teaching children with Autism adaptive skills could be evaluated.	Thank you for your comment. The Guideline Development Group has added a sentence in section 2.13 of the Full Guideline referencing the ICF and social model. There are many other statements in the introduction that refer to the importance of functional outcomes. The outcome’ adaptive skills’ was indeed searched for and appears in section 7.2 of the Full Guideline.
33	SH	British Association for Music Therapy (BAMT)	1	Full	General	General	The evidence for music therapy reviewed in this document is considerably limited by the emphasis put on considerations such as sample size. Much useful literature has had to be excluded, and that which has been included has frequently been ‘downgraded’ because of e.g. small sample sizes. We would encourage the committee to consider wider issues	Thank you for your comment. The Guideline Development Group acknowledges that there are different viewpoints about what constitutes the best available evidence when evaluating the effectiveness of interventions. However, the Guideline Development Group set out in the review protocol before beginning the review that

							relating to the quality of studies. The website www.ResearchAutism.net have provided a perspective on this challenging issue and offer guidance for parents and professionals which allows informed scrutiny and decision making around choice of intervention. We consider the current NICE Guidelines in development could offer more help to commissioners/providers as well as parents, carers and professionals who are struggling with difficult choices in the real world, linked to social and economic means as well as the uneven availability of services.	very small RCTs would be excluded as the potential for misleading results is very high. It should be noted though, that under the GRADE approach, downgrading the quality of evidence does not preclude making recommendations if the reason for doing so can be justified.
34	SH	British Medical Association	1	Full	General	General	Overall, the guidelines are comprehensive but there is still room for improvement in making the care of autistic children a less frustrating passage for the child, the parents and indeed the professionals involved.	Thank you for your comment.
35	SH	British Medical Association	2	Full	General	General	Anecdotally, parents have commented to GPs that there are problems accessing CAMHS and a long wait for appointments. Sometimes it seems that a crisis has to develop before things get moving and there is an impression that some professionals do not quite know how to deal with autistic children. There is a need for more NHS-led parenting skills programmes as often parents will try and access these privately because of frustration with the wait for NHS programmes.	Thank you for your comment. Similar findings regarding long wait times were recorded in the experience of care review. The Guideline Development Group agrees and has suggested future research is done that includes teaching skills to parents to help cope with behaviour that challenges, please see the research recommendations in section 2.2 of the NICE Guideline.
36	SH	British Medical Association	3	Full	General	General	We are concerned about the difficulty of transferring from child to adult care as we believe that this transition is significant. Consistency of care is very important with this group of patients as bad experiences can reverberate for years. Transition may not need to be costly but it does need careful thought out future planning with clear and well communicated goals. Co-ordination with parents, teachers and social workers must be robust and open. A named and familiar key worker (who can smooth the rocky patches) is often mentioned by patients' parents as being helpful.	Thank you for your comment. The need for a key working/case coordinator approach is in recommendation 1.1.4 in the NICE Guideline and appears in both the Autism diagnosis in children and young people: Recognition, referral and diagnosis of children and young people on the autism spectrum guideline (NICE CG 128) and the Autism: recognition, referral, diagnosis and management of adults on the autism spectrum (NICE CG142) guideline. The coordination of transition care will be a major task for local commissioning. The autism team

								has a key role in transition to adult services (please see recommendation 1.1.6 in the NICE Guideline.)
37	SH	British Medical Association	4	Full	General	General	Whilst the guidelines recognise the importance of sensory appropriate environments, we believe that this needs to be more widely disseminated. Furthermore, awareness of autistic behaviour and the possible triggers for this should be part of educational intelligence.	Thank you for your comment. Although education is outside of the scope of this guideline, the role of the Local Autism Team and of the Strategy Group is to ensure full collaboration with education providers, as well as with health and social care. The Guideline Development Group reviewed the guideline in light of your comment, and would like to draw your attention to recommendation 1.1.9, about making adjustment to the social and physical environment and processes of care.
38	SH	British Psychological Society	1	Full	General	General	The Society welcomes the development of these guidelines and the wide and full assessment of the current evidence base. While we have some comments to make, we support the proposed guidelines subject to these amendments as a very positive step forward for children, young people and their families. The focus on transition is also very much supported.	Thank you for your comments.
39	SH	British Psychological Society	2	Full	General	General	The document mentions “care”, “support”, and “management” which are all important, however, we would also recommend the inclusion treatment and intervention.	Thank you for your comment.
40	SH	British Psychological Society	3	Full	General	General	The Society understands the review methodology excludes Single Case Experimental Design but would highlight the fact that this means that a significant body of literature in the field of ASD has not been considered.	Thank you for your comment. The Guideline Development Group acknowledges there are different views with regard to what constitutes the best available evidence when evaluating the effectiveness of interventions, but the Guideline Development Group does not believe there are currently good methods for combining randomised and non-randomised evidence to answer questions about interventions. Therefore, for a particular question, where there was RCT evidence, the Guideline Development

								Group focused on that evidence and did not search for non-randomised evidence. This method was set out in the review protocol before beginning the review, and the Guideline Development Group does not believe it would be appropriate to change this approach having reviewed the evidence. Furthermore, the Guideline Development Group notes that even proponents of SCEDs recognise that, at least in the area of ABA research for autism "…large multi-site randomized clinical trials are needed to narrow the confidence intervals for effect sizes, support comprehensive outcome assessments, identify potential mediators and moderators, and pinpoint active ingredients (e.g. optimal amount of treatment)." (Smith, Eikeseth, Sallows, The Journal of Pediatrics, 155 (1), 151-152. A similar conclusion was reached by an AHRQ funded review that included both randomised and non-randomised research: "Some behavioral and educational interventions that vary widely in terms of scope, target, and intensity have demonstrated effects, but the lack of consistent data limits our understanding of whether these interventions are linked to specific clinically meaningful changes in functioning. The needs for continuing improvements in methodologic rigor in the field and for larger multisite studies of existing interventions are substantial. Better characterization of children in these studies to target treatment plans is imperative." (AHRQ Publication No. 11-EHC029-EF.)
41	SH	College of	2	Full	Gener	Gener	It is to be applauded that the evidences for (or lack of	Thank you for this suggestion, however the

		Mental Health Pharmacy			al	al	evidence for) various biomedical and nutritional interventions are presented. However there appears to be no data presented (or no statement about a lack of evidence) about antifungal treatment in autism, which some families do try.	Guideline Development Group focused on biomedical interventions for which there was RCT evidence; thus not all treatments that have been tried are listed
42	SH	College of Occupational Therapists	3	Full	Outcome Tables	General	In the outcome tables it is not clear if the items listed as indirect/direct outcomes are the outcomes the studies achieved or hoped to achieve.	Thank you for your comment. A large number of studies included in the guideline did not report what their direct or critical outcomes were, therefore the Guideline Development Group had to determine what they were based on the study aims. The Guideline Development Group believes the direct and indirect outcomes reflect what the studies hoped to achieve.
43	SH	Department of Health	1	Full	General	General	Thank you for the opportunity to comment on the draft for the above clinical guideline. I wish to confirm that the Department of Health has no substantive comments to make, regarding this consultation**.**	Thank you for your comments.
44	SH	Hampshire Autistic Society	1	Full	General	General	I would like to give my support to the content of the Guidelines and feel that there is an opportunity to strengthen the document by incorporating linkages within the Guidelines to the Autism Adult Strategy - (which incorporates transition from the age of 14) and the integration of the Single Assessment and EHC planning processes into the Guidelines (SEN Reform Bill). These two connected strands are not weaved into the Guidelines and recommendations and as such the potential for parallel service delivery rather than joined up is heightened. I believe that the Voluntary sector has a significant role to play in supporting the delivery of support and services to children (and adults) with autism and connecting the strands of service delivery – and making sense of such to the user! This needs to be	Thank you for your comment. The Guideline Development Group reviewed the guideline in light of your comment. However, the guideline already recommends that the local autism multi-agency strategy group is for people with autism of all ages, in recommendation 1.1.2 in the NICE Guideline.

							reflected in the commentary. I am happy to support the integration of these comments into the Guidelines, if you feel that this is appropriate.	
45	SH	National Autistic Society	1	Full	General	General	The Children and Families Bill will be introducing major changes to the SEN system, with core provisions placing a strong stress on the integration of education, health and social care. While the NAS understand that NICE guidelines are primarily for health and social care professionals, the near total omission of education professionals and schools from the guidance is a major cause for concern. The introduction of education, health and care plans, integrated assessments and joint commissioning arrangements will necessitate much greater linkages between education and health and social care than seems to be recognised in the guidance. There is a risk that the valuable work that has gone into producing the guidance will be wasted if it is not more effectively shared and developed with education professionals. With all of the changes occurring the NAS believes it is vital that some context is given to this guideline, at least for the purposes of ensuring that health and social care professionals are better informed about the SEN system. In addition, NICE could commit to reviewing the guideline in a few years to ensure that the recommendations in this document are workable within the new SEN framework.	Thank you for your comment. Whilst the Guideline Development Group agrees this is an important issue, it is outside the scope of this document and would be inappropriate for NICE guidelines to interpret the Children and Families Bill, or related guidance. NICE has a process that reviews whether NICE guidelines need to be updated.
46	SH	Neonatal and Paediatric Pharmacists Group (NPPG)	1	Full	General	General	Neonatal and Paediatric Pharmacists group have no comment.	Thank you for your comment.
47	SH	Optical	1	FULL	Gener	Gener	On behalf of the Optical Confederation, we would like	Thank you for your comments. The Guideline

		Confederation			al	al	to thank you for inviting us to comment on the draft clinical guideline 'Autism - management of autism in children and young people'. We are content with the draft guideline and are happy to support it. We trust this guideline will be read by health and social care professionals alongside CGs 128 and 142, which include recommendations that all health and social care professionals who provide care and support for adults with autism and their families, partners and carers should take into account communication needs arising from sight problems; and that if there is suspicion of visual impairment on an individual basis, and using information from the comprehensive assessment and physical examination, and clinical judgement, consider further investigations, including...sight test. We would like to remain part of any future consultations on this guideline and any other autism guidance	Development Group has added in further references to the two other autism guidelines (Autism: recognition, referral, diagnosis and management of adults on the autism spectrum [CG142] and Autism diagnosis in children and young people: Recognition, referral and diagnosis of children and young people on the autism spectrum [CG128]) to make it clear to readers that this guideline needs to be read in tandem with them.
48	SH	QUEEN'S UNIVERSITY BELFAST	10	Full	Gener al	genera l	NICE proposed guidelines are full of misinterpretation of ABA eg again they do not include single system research designs, or recent international systematic reviews of EIBI. In fact, there are no proper, internationally endorsed recommendations on EIBI. See USA mandating ABA coverage in nearly all States, ABA-based interventions now recognized as Medically necessary. http://stimcity.org/2012/07/06/senate-hearing/ These guidelines should consult with a Board Certified Behaviour Analyst Professional bodies to ensure that they are not misrepresenting ABA. NICE Team should include and consult with the Association for Professional Behavior Analysts	Thank you for your comment. The Guideline Development Group (GDG) acknowledge there are different views with regard to what constitutes the best available evidence when evaluating the effectiveness of interventions, but they do not believe there are currently good methods for combining randomised and non-randomised evidence to answer questions about intervention effectiveness. Therefore, for a particular question, where there was RCT evidence, the GDG focused on that evidence and did not search for non-randomised evidence. This method was set out in the review protocol before beginning the review, and it would not be appropriate to change this approach after having reviewed the evidence.

							(ggreen3@cox.net) or the European Association for Behaviour Analysts (Professor Erik Arntzen<erik.arntzen@hiak.no) before going into print. They should consider the recommendations from the National Autism Project (NAP) http://www.nationalautismcenter.org/pdf/NAC%20Standards%20Report.pdf (BTW, these are constantly updated to ensure latest research evidence is included). NAP are also in the process of developing specific guidelines for different professionals (light years ahead of these new NICE guidelines) e.g., Recommending FBA without a deep understanding of behavior analysis is perilous thing to do. “Nothing about us without us”. ABA is not ONE intervention for ASD. If this is not corrected, this wrong interpretation will continue ad infinitum. The ethic of people writing clearly outside their area of expertise is questionable. Most professional bodies have ethics requirements that state that professionals should not write outside their area of expertise. Therefore the panel requires a BCBA to be included or at least to proof read and review the document. See also cost-benefit analysis for EIBI which shows that up to $1 million can be saved across a single lifetime with good effective early intervention. See below additional evidence and comments (under 1 Full document, General comments)	Regarding single-case experimental designs (SCEDs), there are also considerable difficulties reviewing this type of research, particularly for the purpose of developing national clinical guidelines. For example, findings from single cases are difficult to generalise to a wider population and there is a significant risk of publication bias which further limits the reliability of findings from SCEDs. Furthermore, The GDG note that even proponents of SCEDs recognise that, at least in the area of ABA research for autism “…large multi-site randomized clinical trials are needed to narrow the confidence intervals for effect sizes, support comprehensive outcome assessments, identify potential mediators and moderators, and pinpoint active ingredients (eg, optimal amount of treatment).” (Smith, Eikeseth, Sallows, The Journal of Pediatrics, 155 (1), 151-152. A similar conclusion was reached by an AHRQ funded review that included both randomised and non-randomised research: “Some behavioral and educational interventions that vary widely in terms of scope, target, and intensity have demonstrated effects, but the lack of consistent data limits our understanding of whether these interventions are linked to specific clinically meaningful changes in functioning. The needs for continuing improvements in methodologic rigor in the field and for larger multisite studies of existing interventions are substantial. Better characterization of children in these studies to target treatment plans is imperative.” (AHRQ Publication No. 11-EHC029-EF.)

								Regarding ABA, the National Autism Project acknowledges that treatments can be classified in many ways. The GDG agree with this, but had to decide on an approach used, and set this out before examining the evidence (please see sections 2.13 and 5.2.1 of the Full Guideline). Stakeholders from many organisations, including those with a special interest in ABA, have responded, and having considered all comments carefully the GDG do not believe there is any justification for changing the approach to reviewing the evidence. The Guideline Development Group have decided to use the term functional assessment of behaviour to avoid any misinterpretation. The Guideline Development Group made this decision because while agreeing that only people competent to undertake an assessment or intervention should do so, they disagree with the suggestion that a functional assessment of behaviour can only be done by people trained in ABA. On the contrary, psychologists and other healthcare professionals are able to undertake behavioural assessments and do so as a routine part of their job. Nevertheless, the Guideline Development Group do agree that ABA is very much more than an assessment, even a very sophisticated one. ABA is a complex interventions, as defined by the MRC. However, as the guideline is not recommending ABA, competence in this is not a requirement for this or any other part of the guideline.
49	SH	QUEEN'S UNIVERSITY	8	Full	general	General	The inclusion/exclusion criteria of studies have not taken into account the fact that single-subject research	Thank you for your comment. As described above, the Guideline Development Group

		BELFAST					designs provide sufficient control and allow us to make safe claims about the independent variable (i.e., in this case the intervention or educational package used). This type of research studies should be considered as a crucial factor for the design of the present guidelines (together with RCTs). Additionally, the number of the participants included in each study should not pose an exclusion criterion, as replication increases the credibility, generalizability and transferability of outcomes resulting from single-subject research designs with less than 10 participants.	acknowledges there are different views with regard to what constitutes the best available evidence when evaluating the effectiveness of interventions, but there are considerable difficulties reviewing single-case experimental designs, particularly for the purpose of developing national clinical guidelines.
50	SH	Royal College of Nursing	1	Full	General	General	The Royal College of Nursing welcomes proposals to develop this guideline. It is timely.	Thank you for your comment.
51	SH	Royal Manchester Childrens Hospital	15	FULL	General	General	Routine service user and their carers evaluation needed for access to healthcare and transition	Thank you for your comment.
52	SH	Royal Manchester Childrens Hospital	16	FULL	General	General	All healthcare staff trained in autism	Thank you for your comment.
53	SH	Royal Manchester Childrens Hospital	17	FULL	General	General	Use of other methods of communication e.g pictorial communication tools e.g www.widgit.com	Thank you for your comment.
54	SH	Step by Step School	1	Full	General	General	We would like to thank NICE, all members of the GDG and everyone else that is involved in this guideline. It is a very comprehensive piece of work that contains many important recommendations, with the potential to make meaningful quality of life improvements for c120,000+ children with autism and their families	Thank you for your comments.
55	SH	Step by Step School	23	Full	General	General	We note on page 143 that a high proportion of parents and carers feel that regular behavioural therapy is an important need, which is currently often unmet. It is therefore disappointing that the GDG does not appear to be recommending broader use of behavioural therapies especially in young children with autism.	Thank you for your comment and references. Unfortunately, family and carers reported a large number of unmet needs across the studies in the experience of care chapter and it was not possible for the Guideline Development Group

							It might be that some of the available evidence has not been considered by the GDG. In particular, we would highlight the following and would like to understand if/why these papers may have been excluded from the evidence base for this guideline :- - Lovaas 1987; Journal of Consulting and Clinical Psychology 55 p3-9 - Sallows 2005; American Journal of Mental Retardation 110 (6), p 417-438 - Eikeseth 2007; Behaviour Modification 26(1), p264-278 - Eldevik 2010; American Journal on Intellectual and Development Disabilities; Sept 2010 Vol 115, No 5 pp391-405 - Grindle 2012; Behaviour Modification May 2012; 36(3):298-319 - Reichow B ; Cochrane Database Syst Rev ; 2012 Oct 17	to make recommendations about all. As described in Appendix 12d, Lovass 1987 and Eikeseth 2007: Excluded due to non-randomised group assignment. Sallows: Excluded as the planned comparison of intensive versus non-intensive behavioural treatment was not carried out. Instead, data from the two groups were combined and a pre- to post-comparison made. The lack of a control group in this post-hoc design meant that efficacy data could not be extracted. Eldevik 2010: Excluded as it was based on individual data across a number of study designs. Grindle 2012: Excluded as non-RCT. Reichow 2012: Excluded as systematic review with no new useable data and any meta-analysis results not appropriate to extract.
56	SH	Step by Step School	24	Full	General	-	We note the comments “very serious imprecision” when referring to existing behavioural studies, for example DAWSON 2010 on page 195 and CARR 2006 on page 381. We would ask GDG to consider whether any organisation in the world would have sufficient resources to conduct the equivalent of the DAWSON study in 400 subjects (we guess this would cost over £25m). If the GDG agrees that this is unlikely to happen due to financial constraints, then we ask the GDG to recommend a way forward to do this kind of research appropriately, even if a different methodology is needed which does not currently meet NICE evidence standards. It does not seem acceptable to us to require a level of evidence that can	Thank you for raising this issue. Under the GRADE approach, rating down for imprecision is done on the basis of all studies included in the analysis (not individual studies, unless there is only one study). Nevertheless, unlike some other approaches, under the GRADE approach quality of the evidence and strength of recommendations is separated. Therefore, even in the face of very low quality evidence, it may be appropriate to make recommendations.

							almost never be achieved in practice, as this would potentially mean that an effective intervention would never be recommended in UK	
57	SH	SWYPFT	1	Full	General	General	This is a comprehensive document with a significant amount of information. It will be important to distil this information into its main messages when published for the use of services and service users. It provides particularly useful service user feedback, especially in relation to CAMHS and the difficulties that service users experience in accessing advice and support. In a similar vein, it raises significant issues in relation the NHS service capacity, staff training, and integrated commissioning to ensure collaborative working between health, social, and educational services	Thank you for your positive comments. You will be able to find the information and key messages distilled in the NICE Pathway (for clinicians) and the Information for the Public (for service user and carers).
58	SH	The UK Society for Behaviour Analysis (UK-SBA)	1	Full	General	General	The UK Society for Behaviour Analysis (UK-SBA) welcomes the opportunity to comment on the draft for consultation: *Autism: the management and support of children and young people on the autism spectrum (March 2013)*. The UK-SBA was open for membership in March this year and therefore has not had the opportunity until now to contribute to this process although many of our members will have contributed through their own organisations. The UK-SBA is a non-profit membership organisation committed to advancing the science and effective and ethical practice of Behaviour Analysis, with the aim of broadening public awareness of the discipline, and promoting and disseminating relevant research studies. That this has been a complex task for all involved in preparing the Guideline is evident and the following comments made with a view to complementing what has already been achieved.	Thank you for your comments.

59	SH	The UK Society for Behaviour Analysis (UK-SBA)	2	Full	General	General	**1) Medical model** The guidelines are clear that the context of the guidance is Health and Social care (P 11 lines 26 – 25). The UK-SBA appreciates that the process that NICE uses for the development of clinical guidance is well established, comprehensive and meticulous and we recognise the limitations that the GDC members were working within. In other medical areas this may not be a concern but in autism intervention it poses specific difficulties. <u>Health or education?</u> For instance, it is stated (P 28 line 30) that "guidance does not directly concern education services". However, the guidance goes on to say that "the information in this guidance is relevant to all settings and all professionals" (P 28 line 31), and the entire section 2.10 (P 22 & 23) *Services for People with Autism, previous guidelines and the National Context* quite correctly acknowledges the historical collaboration between health and education, the importance of multi-agency and multi professional working and the role that education plays in providing services for children with autism. Throughout the guidance are many studies based in educational settings and descriptions of the experiences of individuals, carers and professionals within the education system. It is important that these are included but it potentially leads to a lack of clarity in relation to the boundaries between health and	Thank you for your comment. The Guideline Development Group believes that the medical model for intervention is sometimes appropriate (e.g. certain mental health disorders, constipation etc.) The importance of functional outcomes is emphasised throughout and a reference to the social model of disability is now included in section 2.13 of the Full Guideline. NICE is specifically enjoined to make recommendations to health and social care professionals to work closely with education. The Guideline Development Group were acutely aware of the huge importance of education and the educational environment, hence the inclusion of the sentence you refer to in your comment. Although education is outside of the scope of this guideline, the role of the Local Autism Team and of the Strategy Group is to ensure full collaboration with education providers, as well as with health and social care. This is laid out in the recommendations 1.1.2, 1.1.3, 1.1.6, 1.1.11 and 1.8.2 in the NICE Guideline.

							education. Furthermore, in the absence of an equivalent set of guidelines within education, NICE guidelines will be used by educationalists and commissioners of services within education. Indeed many of the professionals consulted (P 11 lines 26 – 35) including Speech and Language Therapists and Occupational Therapists work directly in education settings and there is a risk that educations providers may use the guidelines as an excuse to no longer fund services which fall outside the remit of the current guidance. <u>What constitutes evidence?</u> This is of particular concern because the GRADE process which although extremely rigorous and well suited to certain medical interventions does not include evidence based practice which in other contexts (such as education) or other fields (such as psycho-social interventions) would meet criteria. The guideline clearly states that interventions for autism are complex in nature (e.g. P 29 line 42).Section 2.15 *Evaluating the evidence of the effectiveness of intervention for children and young people with autism*P 29 & 30 acknowledges the difficulties of conducting research into interventions with autism. It would seem appropriate therefore that the Medical Research Council guidelines surrounding the development of evidence for complex interventions and other similar frameworks be included in the NICE review process. Of particular relevance is the exclusion of single case experimental design (SCED) methodology; relevant	The Guideline Development Group acknowledges there are different views with regard to what constitutes the best available evidence when evaluating the effectiveness of interventions, but we do not believe there are currently good methods for combining randomised and non-randomised evidence to answer questions about intervention effectiveness. Therefore, for a particular question, where there was RCT evidence, we focused on that evidence and did not search for non-randomised evidence. We set this method

							because the recommendations do call for the use of functional analysis and behavioural interventions based on functional analysis when dealing with challenging behaviours. Those interventions often focus on teaching skills to reduce problem behaviours and a large body of research to evaluate such interventions uses SCED approaches. The guidelines state for example that there are no interventions for repetitive behaviours (P 180 line 15) – this is not correct. There are studies of such interventions but they are not included because they are SCED. This is not just true of research into autism but also, for example, challenging behaviour in adults with learning disabilities. Several other evidence review bodies (including the What Works Clearing House) throughout the world have recognised that SCED evidence is of value and have established methods and criteria for reviewing SCED evidence. The National Standards Project (NSP) in the US is amongst the largest and most comprehensive reviews of autism intervention undertaken to date and includes SCED's. The NSP also helped to inform the New Zealand Technical Review of Published Research on ABA interventions for people with Autism Spectrum Disorder which was commissioned by the New Zealand Ministry of Education and Ministry of Health (Mudford, 2009). This review provides numerous examples of behaviour analytically evaluated strategies (mostly SCEDs) that have strong evidence of efficacy. http://www.nationalautismcenter.org/pdf/NAC%20Standards%20Report.pdf The current exclusion of SCED evidence is likely to be	out in the review protocol before beginning the review, and it would not be appropriate to change this approach after having reviewed the evidence. Nevertheless, having reviewed the MRC guidelines for evaluating complex interventions, it's not clear that studies using SCED methodology would necessarily be appropriate as the basis for recommendations. Also, there are also considerable difficulties reviewing this type of research, particularly for the purpose of developing national clinical guidelines. For example, findings from single cases are difficult to generalise to a wider population and there is a significant risk of publication bias which further limits the reliability of findings from SCEDs. Furthermore, the Guideline Development Group notes that even proponents of SCEDs recognise that, at least in the area of ABA research for autism "…large multi-site randomized clinical trials are needed to narrow the confidence intervals for effect sizes, support comprehensive outcome assessments, identify potential mediators and moderators, and pinpoint active ingredients (eg,optimal amount of treatment)." (Smith, Eikeseth, Sallows, The Journal of Pediatrics, 155 (1), 151-152. A similar conclusion was reached by an AHRQ funded review that included both randomised and non-randomised research: "Some behavioral and educational interventions that vary widely in terms of scope, target, and intensity have demonstrated effects, but the lack of consistent data limits our understanding of

							detrimental to people with disabilities. One might even argue that it is potentially discriminatory - since SCED evaluation methods have been primarily (though not exclusively) applied to interventions used with people with disabilities and not to (or less so with) other groups. There is also a question about why meta-analyses were not included in the evidence discussed in the draft guidance since meta-analyses should have been identified as potentially to include as a part of the review process (if you look at the inclusion criteria for the performed literature searches). The UK-SBA recommends that the following study is reviewed: Eldevik S, Hastings RP, Hughes JC, Jahr E, Eikeseth S, Cross S. Meta-analysis of early intensive behavioral intervention for children, *Journal of Clinical Child & AdolescentPsychology,* 2009; *38*: 439-450. We further recommend the following study, a mega analysis which includes over 400 children. Although not a RCT it seems inconsistent that such a large sample paper using an established methodology like mega-analysis is not use to inform the guideline somehow: Eldevik S, Hastings RP, Hughes JC, Jahr E, Eikeseth S, Cross S. Using participant data to extend the evidence base for intensive behavioural intervention for children with autism. *American Journal on*	whether these interventions are linked to specific clinically meaningful changes in functioning. The needs for continuing improvements in methodologic rigor in the field and for larger multisite studies of existing interventions are substantial. Better characterization of children in these studies to target treatment plans is imperative." (AHRQ Publication No. 11-EHC029-EF.) It should be noted though, that under the GRADE approach, downgrading the quality of evidence does not preclude making recommendations if the reason for doing so can be justified. The Guideline Development Group does not agree that exclusion of SCEDs would be 'detrimental to people with disabilities'. The Guideline Development Group has taken an inclusive approach in which the best available evidence reporting on the outcomes of interest in all children and young people with autism have been included. Where reported, all data pertaining to characteristics protected under Equalities legislation have been extracted and presented to the Guideline Development Group.

							Intellectual and Developmental Disabilities, 2010; 115:381–405. The UKSBA is of the view that a comprehensive guidance that covers both health and education is the better outcome but recognises that this is probably beyond the scope of the current guidance and, given that limitation, we request greater clarity on how the guidance might be used and in particular ways in which it should not be used. We request a review of the research included (perhaps there can be a section of research that does not satisfy the GRADE criteria but is otherwise included?) This would not be entirely inconsistent as expert opinion and qualitative studies have been used as the basis for certain recommendations.	
60	SH	The UK Society for Behaviour Analysis (UK-SBA)	3	Full	General	General	**2) Behavioural interventions** <u>Functional analysis/assessment</u> It is encouraging to see recommendations about the use of functional analysis and behavioural interventions based on functional analysis when dealing with challenging behaviours and the UK-SBA welcomes this. However we are concerned that the language used is misleading and could lead to an inappropriate use of the recommendations. This is not a difficult issue to resolve and we suggest that a group of experts in Behaviour Analysis (ABA and Positive Behaviour Support) be invited to address this. For	Thank you for your comment. We have decided to use the term functional assessment of behaviour to avoid any misinterpretation.

							example, experts in behaviour analysis might reserve the term “functional analysis” for experimental functional analysis, which is a technique requiring considerable expertise and also ethical review. The term “functional assessment” may be what is meant. In addition, the guideline should clarify the competencies that may be needed to carry out some interventions (the example of experimental functional analysis is an example). The guideline could helpfully recommend referral to expert challenging behaviour teams or to a clearly (behaviourally) trained challenging behaviour expert within a multi-disciplinary team. A Board Certified Behaviour Analyst for example has completed at a minimum a Master’s degree in Behaviour Analysis or other natural science, education, human services, engineering, medicine or a field related to behaviour analysis and approved by the Behaviour Analyst Certification Board (BACB), undertaken 1500 hours of clinical supervision, passed the BACB examination and has to undergo a recertification process every three years which includes 36 hours of continued professional development. <u>The role of behavioural intervention in teaching functional skills</u> Behavioural approaches are not just concerned with behaviour management. A core component of Behaviour Analysis is the teaching of functional skills. In this respect the UK-SBA also requests greater clarity on the outcomes covered in the guidance. We fully understand the context within which the guidance is written and hence the scope being the “*management and support of children and young people on the*	The Guideline Development Group has emphasised functional outcomes following ICF principles but have not described who should do this except in broad terms or where the evidence suggests differently. Expertise in autism is a key principle for all who work with children and young people with autism.

							autism spectrum". Yet throughout the guidance a broader set of outcomes is recommended such as those included on P 25 line 27: "*support to develop the skills needed for independent living (or what is realistic and appropriate), and autonomy of choice and decision-making whenever this can be achieved (Wittemeyer et al, 2011)*", and the outcomes listed throughout chapter 3 e.g. P 75, lines 9-11 & 34; 111 lines 6,16 and 24; P 178 lines 2-4. It is not clear throughout the guidance how such skills development is to be achieved and by whom. It would be helpful to acknowledge the role that behaviour analysts can play in providing such support. There is also extensive literature on the acquisition of specific learning targets but again these have not been included as they are often reported as SCEDs. <u>Accuracy in the representation of ABA</u> The lack of clarity in the language used around behavioural interventions is not just in relation to understanding challenging behaviour. There could be more consistency in how behavioural approaches are described throughout the text of the guideline. Throughout the guidance there is an oversight that many interventions described are based on ABA or incorporate elements of ABA for example LEAP, PECS and the Early Denver Start Model. Some interventions do not refer to ABA but actually rely almost exclusively or in large part on ABA teaching technologies. In addition there are category errors in which ABA is grouped alongside ABA based interventions appearing to be an "alternative" or is grouped with techniques which do not have the same scientific basis. For	This comment highlights that nearly all interventions and educational approaches for any child involve some ABA principles. The decision was made to divide intervention/treatment aims in a way that would be most accessible to the reader. The study methodology described by the authors was used in classification.

							example on P 86, there is a category error in the table in which ABA is grouped with music therapy, support group, parent training, speech and language therapy, service dog, social skills group, Touch therapy, and EIBI. The UK-SBA welcomes this evaluation as an opportunity to agree an accepted definition of behaviour analysis: http://uk-sba.org/behaviour-analysis/ and to include a section that draws together perspectives on behavioural methods. The UK-SBA recommends that the GDG considers evaluation research from the UK where a variety of behavioural methods were used together as an educational approach in the early years and in a mainstream setting (like the LEAP model) [seeGrindle, C., Hastings, R. P., Saville, M., Hughes, J. C., Kovshoff, H., & Huxley, K. (2009). Integrating evidence-based behavioural teaching methods into education for children with autism. *Educational and Child Psychology,* **26**(4), 65-81. And Grindle, C. F., Hastings, R. P., Saville, M., Hughes, J. C., Huxley, K., Kovshoff, H., Griffith, G. M., Walker-Jones, E., Devonshire, K., & Remington, B. (2012).Outcomes of a behavioral education model for children with autism in a mainstream school setting. *Behavior Modification*, **36**, 298-319.] <u>Parental perception of ABA</u> The UK-SBA acknowledges that the Guidelines attempt to present a balanced view and point out that there are mixed parent responses about ABA. That is fair and we support the case for a balanced view. However we do not think that this has been achieved.	The Guideline Development Group spent a great deal of time looking at the way studies were grouped and are satisfied that they are as close to the evidence as possible. Although there may be some similarities between aspects of ABA and aspects of other interventions such as LEAP or PECS, the Guideline Development Group did not view these as derivative of ABA or a part of ABA.

							The comments chosen in the guidance appear to be more heavily weighted towards highlighting the pitfalls of engagement in EIBI rather than the benefits. Many of the statements made in relation to parents experiences as subjective and emotive: p. 114 line 24 for example "*Your home is never your own as there are always people trooping through it and in the most intimate way in that they come into the bedrooms* ". In contrast the statements that appear to support ABA tend to be objective and less emotive such as Carers *are critical of lack of access to ABA*; P 113 (lines 42-45). There are plenty of examples of qualitative studies which report subjective comments in support of ABA. (seeGrindle, C. F., Kovshoff, H., Hastings, R. P., & Remington, B. (2009). Parents' experiences of home-based Applied Behavior Analysis programs for young children with autism. *Journal of Autism and Developmental Disorders,* 39, 42-56. ''*I had heard from edpsychs [Educational Psychologists] about how EIBI has such a negative impact on family life, but actually for me EIBI is what keeps me going"* The guidance raises the issue that EIBI may be stressful for parents (p. 114 line 6)., but there is now considerable research evidence (and not just from qualitative interview studies either) to suggest that there are no reported additional increases in stress for parents or siblings through engagement in IBI compared to parents receiving other interventions (e.g., Remington et al, 2007) and in some cases parents even report decreased levels (e.g., Smith et al., 2000). The guidance also mentions interview data regarding negative impacts on family relationships including for	The qualitative evidence was thematically coded by two members of the technical team. These themes have since been reviewed and the Guideline Development Group believed that the quotes used are reflective of the evidence that met the criteria to be included in the review.

							siblings, P 114 (line 13) but Cebula (2012) showed that siblings in IBI families experienced neither significant drawbacks nor benefits in terms of their psychological adjustment, the quality of their relationship with the child with autism, and their self-concept compared to control siblings at any point during, or after intervention use.	
61	SH	University of Ulster	1	Full	general	general	Applied Behaviour Analysis is incorrectly portrayed in the document. There is no evidence of having consulted with professionals trained in Applied Behaviour Analysis, or with professional organisations in Behaviour Analysis. Furthermore, there is no inclusion of findings from Single-Case Research Designs as a legitimate scientific practice; RCTs are not the only way to assess the effectiveness of an intervention. The misunderstanding of ABA throughout the document and its relation to RCTs has been discussed at length by Keenan, M. &Dillenburger, K. (2011). When all you have is a hammer …: RCTs and hegemony in science. Research in Autism Spectrum Disorders, 5, 1-13.	Thank you for your comment. The Guideline Development Group has carefully reviewed the text in light of these comments. Several members of the Guideline Development Group are familiar with ABA, and has added further description of ABA in sections 2.13 and 5.2.1 of the Full Guideline. The Guideline Development Group acknowledges there are different views with regard to what constitutes the best available evidence when evaluating the effectiveness of interventions, but the Guideline Development Group does not believe there are currently good methods for combining randomised and non-randomised evidence to answer questions about interventions. Therefore, for a particular question, where there was RCT evidence, the Guideline Development Group focused on that evidence and did not search for non-randomised evidence. This method was set out in the review protocol before beginning the review, and the Guideline Development Group does not believe it would be appropriate to change this approach having reviewed the evidence. Furthermore, the Guideline Development Group notes that even proponents of SCEDs recognise that, at least in the area of ABA research for autism "…large multi-site randomized clinical trials are needed to narrow the confidence

								intervals for effect sizes, support comprehensive outcome assessments, identify potential mediators and moderators, and pinpoint active ingredients (eg,optimal amount of treatment)." (Smith, Eikeseth, Sallows, The Journal of Pediatrics, 155 (1), 151-152. A similar conclusion was reached by an AHRQ funded review that included both randomised and non-randomised research: "Some behavioral and educational interventions that vary widely in terms of scope, target, and intensity have demonstrated effects, but the lack of consistent data limits our understanding of whether these interventions are linked to specific clinically meaningful changes in functioning. The needs for continuing improvements in methodologic rigor in the field and for larger multisite studies of existing interventions are substantial. Better characterization of children in these studies to target treatment plans is imperative." (AHRQ Publication No. 11-EHC029-EF.)
62	SH	ABA Autism Education Ltd	5	Full	General	General	THE NICE GUIDELINES IGNORE THE ADVICE FROM THE BEHAVIOR ANALYST CERTIFICATION BOARD IN THE USA FOR THE TREATMENT OF ASD BY ABA PROFESSIONALS see www.bacb.com (copy foguildeines attached to this email) http://www.bacb.com/Downloadfiles/ABA_Guidelines_for_ASD.pdf	Thank you for your comment and for providing a link to the BACB guideline. Having reviewed this document, it is clear that the advice given is based on expert opinion and does not follow any commonly accepted standards for guideline development (for example, http://annals.org/article.aspx?articleid=1103747). NICE guidelines do follow these standards and are based on a rigorous and transparent process (please see the Guidelines Manual 2012: www.nice.org.uk).
63	SH	College of Occupational Therapists	1	Full	General	N/A	The page numbers do not match up with the table of contents.	Thank you for your comment, the page numbering has been amended in the Full Guideline.

64	SH	Betsi Cadwaladr University Health Board	6	Full	1.1.8	16	We welcome the recommendation that “Health and social care professionals working with children and young people with autism in any setting should receive training in autism awareness and basic skills in managing autism” and suggest that this training should include training in appropriate interventions and treatment, rather than simply assessment, recognition, care and support.	Thank you for your comments. The Guideline Development Group would like to direct your attention to the final paragraph of recommendation 1.3.1 in the NICE Guideline, which states the following: “The intervention should be delivered by a trained professional”.
65	SH	Ambitious about Autism	4	Full	1.1.19		Section 1.1.19 should include the need to make reasonable adjustments to support communication with the young person.	Thank you for your comment, however as there is no 1.1.19 in the Full Guideline the Guideline Development Group is unfortunately unable to find which the section referred to.
66	SH	The UK Society for Behaviour Analysis (UK-SBA)	6	Full	1.2.1 & 3.3.3	11 & 34	P 11 lines 4 -7 and P 34 line 29: A broad range of professionals within health services has been consulted. This is to be commended; however, given the inclusion of recommendations re behavioural approaches the UKSBA thinks that the inclusion of behaviour analysts to represent the profession of behaviour analysis is important, and this omission that has led to some errors and inaccuracies.	Thank you for your comment. The Guideline Development Group covered all the relevant areas of the scope and were appointed to do so and selected as such. The NCCMH is satisfied that all relevant expertise were included. Furthermore, stakeholder consultation provides broader expertise which the Guideline Development Group feels has added considerably to the Guideline. Thank you for contributing to this valuable part of the process.
67	SH	Royal College of Nursing	3	Full	1.2.3	11; 42	‘the *treatment of autism’*	Thank you.
68	SH	Royal College of Nursing	4	Full	1.2.3	12; 1	‘psychological and psychosocial interventions in combination with pharmacological interventions in the *treatment of autism’*	Thank you.
69	SH	Royal College of Nursing	5	Full	1.2.3	12; 6	‘integrate the above to provide best-practice advice on the care of individuals throughout the *course* of their *treatment* ‘	Thank you.
70	SH	British Academy of Childhood Disability (BACD).	2	Full	1.8	26	Sleep disorders in children and young people with autism are a crucial problem for many families that may have profound effects on the functioning of the family. Melatonin can be extremely helpful and, whilst the evidence base is not robust, it ought to be considered	Thank you for this suggestion. Interventions (including melatonin) for sleep problems are reviewed in section 7.8 of the Full Guideline. The Guideline Development Group decided that a research recommendation for a trial involving the use of melatonin was warranted based on

							in children and young people with autism who have sleep disorders (and so deserves mention at this point in the guideline). Although the evidence base for the benefit of melatonin in autism may not be robust, this could still be recommended on the consensus of the guideline development group. This was the approach taken with the NICE guideline for melatonin in Chronic Fatigue Syndrome/Myalgic Encephalomyelitis CG53) as indicated in these sections of the full guideline: *1.6.3.3 Melatonin may be considered for children and young people with CFS/ME who have sleep difficulties, but only under specialist supervision because it is not licensed in the UK* This was agreed as a symptomatic treatment despite a lack of robust research evidence (in reference to melatonin and other pharmacological treatments in CFS), as was explained in the following section: *6.4.2.1* *The view of the GDG was that symptomatic treatment should be provided on the basis of general principles of symptom management, except where it was inappropriate for people with CFS/ME.*	the evidence reviewed – please see section 2.3 of the NICE Guideline.
71	SH	British Psychological Society	6	Full	2 & general	14	The consultation document repeatedly refers to autism in the singular - as 'a' disorder. Even when addressing terminology explicitly (2.3) it refers in the singular to autistic spectrum disorder, or autistic spectrum condition. Although technically accurate, since everybody diagnosed with autism by definition has similar functional abnormalities or disturbances, referring to autism in this way gives the impression that autism is a unitary medical condition, despite acknowledging its heterogeneous aetiology and	Thank you for your comment. The Guideline Development Group is following the suggestion made by the BPS to use the phrasing from the Autism diagnosis in children and young people: Recognition, referral and diagnosis of children and young people on the autism spectrum guideline (CG 128) which describes the choice of terminology used in the guideline. The Guideline Development Group notes that DSM-5 refers to autism spectrum disorder in the

							presentation. We would therefore strongly recommend that the document utilise the term “disorders” to more accuracy reflect this.	singular.
72	SH	British Psychological Society	7	Full	2 & general	14	The consultation document repeatedly refers to ‘symptoms’ as symptoms *of autism*, when strictly speaking autism (as a term denoting a cluster of behavioural characteristics) is itself a sign and/or symptom of a (usually unknown) underlying cause. Other signs and symptoms of underlying cause(s) are referred to as ‘coexisting’ conditions, implying that autism is a distinct disease entity. The overall impression given is that autism is a unitary medical condition, albeit one with unknown origins and differing widely in presentation. Although this causal model is *possible*, there are alternative models. Kanner (1943) for example, notes a number of abnormalities with feeding, motor function and sensory responses, but attributes them to an underlying disturbance of affective contact, using the causal model in vogue at the time. By contrast, Wing & Gould (1979) list a number of ‘organic conditions’ associated with autistic characteristics in their Camberwell study, and Gillberg& Coleman (1992) devote six chapters of *The Biology of the Autistic Syndromes* to a wide range of disease entities (including chromosomal abnormalities, metabolic disorders and viral and bacterial infections) documented as associated with a diagnosis of autism. None of these authors could say for sure that the associated disease entities caused the autism but the implication that they could have done is clear. As Rutter&Schopler (1988) comment: “The last issue concerns the question of etiological heterogeneity within the field of autism syndromes. We have already noted that there is undoubted heterogeneity. The very fact that the clinical picture of autism can arise from diseases as diverse as congenital rubella, tuberous sclerosis, encephalopathy, infantile spasms with hypsarrhythmia, cerebral	Thank you for this suggestion. In accordance with the Autism diagnosis in children and young people: Recognition, referral and diagnosis of children and young people on the autism spectrum guideline (CG128), this guideline describes the core features that make up the autism spectrum of disorders/conditions and the associated/co-morbid /co-existing conditions that are commonly found. Treatments focus on improving functionality within an ICF framework taking into account developmental processes and changes with age as well as diagnosed conditions. Section 2.3 Terminology used in the guideline has been altered as suggested.

							lipoidosis and neurofibromatosis makes that clear." The introduction to NICE CG128, Autism diagnosis in children and young people: Recognition, referral and diagnosis of children and young people on the autism spectrum provides a much clearer definition of autism. It says; "The term autism describes qualitative differences and impairments in reciprocal social interaction and social communication, combined with restricted interests and rigid and repetitive behaviours. Autism spectrum disorders are diagnosed in children, young people and adults if these behaviours meet the criteria defined in the International Statistical Classification of Diseases and Related Health Problems (ICD-10) and the Diagnostic and Statistical Manual of Mental Disorders DSM-IV Fourth Edition (DSM-IV) and have a significant impact on function. The over-arching category term used in ICD-10 and DSM-IV is pervasive developmental disorder (PDD), a term now used synonymously with autism spectrum disorder (excluding Rett's syndrome); it is a behaviourally defined group of disorders, which is heterogeneous in both cause and manifestation. The guideline development group recognised that individuals and groups prefer a variety of terms, including autism spectrum disorder, autistic spectrum condition, autistic spectrum difference and neuro-diversity. For clarity and consistency, in this guideline the term 'autism' is used throughout, in keeping with the use of 'autism' in recent Department of Health[1], National Audit Office and Public Accounts Committee documents. However in this guideline 'autism' refers to 'autism spectrum disorders." Recommendation: Insert the opening paragraph (quoted above) from the introduction to CG128 at the beginning of section 2.3 Terminology used in the guideline. References	

							Gillberg, C. & Coleman, M. (1992) The Biology of the Autistic Syndromes (2nd edition), Mac Keith Press. Kanner L. (1943) Autistic disturbances of affective contact, Nervous Child, 2, 217-250. Rutter, M. &Schopler, E. (1988). Concepts and diagnostic issues in E. Schopler& G.B. Mesibov (eds.) Diagnosis and assessment in autism. Springer. Wing, L. & Gould, J. (1979). Severe impairments of social interaction and associated abnormalities in children: Epidemiology and classification, Journal of Autism and Childhood Schizophrenia, 9, 11-29.	
73	SH	Autism Treatment Trust	1	Full	2.1	14	Line 22 statement: "*findings of high concordance rates of autism in identical twins indicated a genetic cause*". Statement is not in accordance with most recent twin study that has higher validity than earlier works. Hallmayer et al. (2011), found that the concordance rates of autism in monozygotic twins are much lower than previously thought, concluding that genetic factors *"are of substantially lower magnitude than estimates from prior twin studies of autism"*and that "*susceptibility to ASD has moderate genetic heritability and a substantial shared twin environmental component".* This line 22 should therefore be changed, in order to fully reflect current knowledge, into: **"*findings of concordance rates of autism in identical twins indicate dual environmental and genetic causalities.*"** Line 24 statement "*it is now evident that autism involves atypical brain development with many different genetic mechanisms probably being involved*" There is no clear evidence that substantiate this statement. Despite numerous claims made that autism is genetic in origin, the three largest genome-wide association studies performed on more than 3000	Thank you for your comment. The Guideline Development Group reviewed the guideline in light of your comments and feel satisfied that to assert a genetic cause, alongside environmental factors, is an accurate reflection of the evidence as it stands.

							individuals in total have failed to detect any specific gene association with any consistency across the studies (Wang et al., 2009; Weiss et al., 2009; Pinto et al., 2010). These studies instead have identified a small number of ASD individuals with novel genetic changes called Copy Number Variation or CNV. However, as Pinto et al. states, "*the population attributable risk ... is estimated to be 3.3%*". This says, in effect, that 96.7% of ASD cannot be attributed to these genetic changes. This is consistent with the conclusions reached from the Autism Genome Project, a genome-wide association study that analysed a total of 2705 (Anney et al. 2012): no common genetic variations were found associated with ASD. Furthermore, multi-genome analysis work by Saxena et al. 2012, demonstrates a predisposition to aberrant immune response in response to an immune environmental factor, such as an infection. There are numerous studies implicating a range of environmental factors in the etiology of autism: these are microbial, immunological and toxicological in nature. For example, investigations of methylation patterns in monozygotic twins discordant for autism spectrum disorder further have implicated large contribution of environmentally driven epigenetic factors in autism (Wong et al. 2013). The statement in line 24 should be changed to: ***"it is now evident that autism involves atypical brain development with many different environmental and genetic mechanisms probably being involved".*** AnneyR ,Klei L , Pinto et al. (2012) Individual common variants exert weak effects on the risk for autism	

							spectrum disorder. Hum Mol Genet. Nov 1;21(21):4781-92. Hallmayer, J., Cleveland, S., Torres, A., et al. (2011) Genetic heritability and shared environmental factors among twin pairs with autism. Archives of general psychiatry, 68: (11): 1095. Pinto, D., Pagnamenta, A.T., Klei, L., et al. (2010) Functional impact of global rare copy number variation in autism spectrum disorders. Nature, 466: (7304): 368-372. Saxena, V., Ramdas, S., Ochoa, C.R., et al. (2012) Structural, Genetic, and Functional Signatures of Disordered Neuro-Immunological Development in Autism Spectrum Disorder. PloS one, 7: (12): e48835 Wang, K., Zhang, H., Ma, D., et al. (2009) Common genetic variants on 5p14.1 associate with autism spectrum disorders. Nature, 459: (7246): 528-533. Weiss, L.A., Arking, D.E., Daly, M.J., et al. (2009) A genome-wide linkage and association scan reveals novel loci for autism. Nature, 461: (7265): 802-808. Wong CC, MeaburnEL , Ronald A et al. (2013) Methylomic analysis of monozygotic twins discordant for autism spectrum disorder and related behavioural traits. Mol Psychiatry. Apr 23. doi: 10.1038/mp.2013.41.	
74	SH	British Psychological Society	4	Full	2.1	14	Strictly speaking, autism was not first described in 1943 by Kanner, but by EugenBleuler, referring to a characteristic of schizophrenia. Bleuler's*Dementia praecox oderGruppe der Schizophrenien*(1911) *and his Lehrbuch der Psychiatrie*(1916) were widely read. Kanner qualified as a doctor in Berlin in 1921, so would have been familiar with his work. Although Asperger's description of 'autistic psychopathy' was independent of Kanner's, he explicitly derives his description from Bleuler (Asperger, 1944). References Asperger, H (1944). Autistic psychopathy in childhood, (tr. Frith), in Autism and Asperger's Syndrome, U. Frith, (ed.), Cambridge: Cambridge University Press, (1991).	Thank you for your comment. This has been amended in section 2.1, History, of the Full Guideline to: "Childhood Autism was first described as a specific condition in 1943 by Leo Kanner in the USA (Kanner, 1943) and was independently described in Austria in 1944 by Hans Asperger"

							Bleuler, PE (1911). Dementia praecox oderGruppe der Schizophrenien. F. Deuticke, Leipzig/Wien. Bleuler, PE (1916) Lehrbuch der Psychiatrie. J. Springer, Berlin	
75	SH	British Psychological Society	5	Full	2.1	14	Bleuler, Kanner and Asperger each use 'autism' as a *descriptive* term for particular behavioural characteristics, although Kanner and Asperger each proposed that they had identified a distinct personality disorder in children that hadn't been described previously. Section 2.1 conflates autism as a descriptive term with the construct of autism as a distinct disorder. **Recommendation:** **Section 2.1 be amended to read 'Childhood autism was first described in 1943…'**	Thank you for your comment. This has been .amendedin section 2.1, History, of the Full Guideline to: "Childhhod Autism was first described as a specific condition in 1943 by Leo Kanner in the USA (Kanner, 1943) and was independently described in Austria in 1944 by Hans Asperger"..
76	SH	Treating Autism	1	Full	2.1	14	Line 22 statement: "*findings of high concordance rates of autism in identical twins indicated a genetic cause*". GDG members should be aware by now that these findings have been challenged by the largest and most detailed autism twin study to date, Hallmayer et al. (2011), which found that the concordance rates of autism in monozygotic twins are much lower than previously thought, concluding that genetic factors *"are of substantially lower magnitude than estimates from prior twin studies of autism"*and that "*susceptibility to ASD has moderate genetic heritability and a substantial shared twin environmental component".* This line 22 should therefore be changed, in order to fully reflect current knowledge, into: "*findings of concordance rates of autism in identical twins indicate a substantial environmental component with moderate genetic heritability.*" Line 24 statement "*it is now evident that autism involves atypical brain development with many different genetic mechanisms probably being involved*" is both misinformed and misleading, as there is no	Thank you for your comment. This has been amended accordingly. Regarding your comment about line 22, section 2.1 of the Full Guildeline, we have amended this to: "Findings of high concordance rates of autism in identical twins in comparison with non-identical twins indicated a strong genetic influence in autism (Folstein & Rutter, 1977)", similar to your suggestion. Regarding your comment about line 24, section 2.1 of the Full Guildeline, we have amended this to: "It is now evident that autism involves atypical brain development with many different genetic, epigenetic and environmental mechanisms probably being involved (Levy et al., 2009; Hallmayer et al., 2011; Anney et al., 2012)", in line with your helpful suggestion.

							such evidence with regards to 'genetic mechanisms' for the vast majority of affected individuals. The three largest genome-wide association studies performed on more than 3000 individuals in total have failed to detect any specific gene association with any consistency across the studies (Wang et al., 2009; Weiss et al., 2009; Pinto et al., 2010). These studies identify a small number of ASD individuals with novel genetic changes called Copy Number Variation or CNV. However, as Pinto et al. states, "*the population attributable risk ... is estimated to be 3.3%*". This says, in effect, that 96.7% of ASD cannot be attributed to these genetic changes. Even if CNVs are implicated in a small percentage of cases, they could be merely reflective of environmental insults on the genome or act as predisposing risk factors rather than causative ones. This likelihood is perfectly illustrated by results of a multi-genome analysis study (Saxena et al. 2012), indicating links between genetic factors that predispose individuals to aberrant immune response to infections and risk of developing autism, where "*the genetic background by itself would not be enough via this view to cause a deranged developmental process which would rather only occur in the presence of relevant infections*." Furthermore the Autism Genome Project, a genome-wide association study (Anney et al. 2012) that analysed a total of 2705 families in two stages, found that no common genetic variations were significantly associated with ASD. Results of investigations into methylation patterns in monozygotic twins discordant for autism spectrum disorder further implicates large contribution of environmentally driven epigenetic factors in autism (Wong et al. 2013). Therefore, in order to accurately reflect the up-to-date	

							scientific knowledge, the statement in line 24 should be changed to: *"it is now evident that autism involves atypical brain development with many different environmental and genetic mechanisms probably being involved".* AnneyR ,Klei L , Pinto et al. (2012) Individual common variants exert weak effects on the risk for autism spectrum disorder. Hum Mol Genet. Nov 1;21(21):4781-92. Hallmayer, J., Cleveland, S., Torres, A., et al. (2011) Genetic heritability and shared environmental factors among twin pairs with autism. Archives of general psychiatry, 68: (11): 1095. Pinto, D., Pagnamenta, A.T., Klei, L., et al. (2010) Functional impact of global rare copy number variation in autism spectrum disorders. Nature, 466: (7304): 368-372. Saxena, V., Ramdas, S., Ochoa, C.R., et al. (2012) Structural, Genetic, and Functional Signatures of Disordered Neuro-Immunological Development in Autism Spectrum Disorder. PloS one, 7: (12): e48835 Wang, K., Zhang, H., Ma, D., et al. (2009) Common genetic variants on 5p14.1 associate with autism spectrum disorders. Nature, 459: (7246): 528-533. Weiss, L.A., Arking, D.E., Daly, M.J., et al. (2009) A genome-wide linkage and association scan reveals novel loci for autism. Nature, 461: (7265): 802-808. Wong CC, MeaburnEL , Ronald A et al. (2013) Methylomic analysis of monozygotic twins discordant for autism spectrum disorder and related behavioural traits. Mol Psychiatry. Apr 23. doi: 10.1038/mp.2013.41.	
77	SH	Royal College of Nursing	6	Full	2	14; 2	'This guideline is about the *management and support* of children and young people with autism and their parents and carers. It covers children from birth to 19 years old'	Thank you for your comment. The Guideline Development Group has amended the sentence structure.
78	SH	British	1	Full	4		This Chapter includes 100 references indicating that	Thank you for your comment. The Guideline

		Academy of Childhood Disability (BACD).					the families of children and young people with autism are often not receiving the support that they need and have to fight for services. Repeatedly families request more training to help manage their child with autism. Therefore in this guideline on managing autism, the guideline development group should consider making a consensus recommendation on referring parents to training programmes. The NICE guideline on ADHD (CG72) recommends providing parent training from a consensus perspective, even though there was no robust evidence to support this approach (a single research study involving 32 people). If such a recommendation is also made in this autism guideline then it needs to appear in the NICE version of the guideline since it is likely that some (most?) commissioners will refer to this version rather than the full guideline.	Development Group felt there was insufficient evidence on group training for parents in autism, however recommendation 1.2.1 in the NICE Guideline specifically recommends giving information about support groups for families/carers. The Guideline Development Group has also added a research recommendation on parent training in section 2.5 of the NICE Guideline.
79	SH	Autism Treatment Trust	2	Full	2.5	18	Line 26 states: *"The factors affecting the rising measured prevalence are not fully known but include changing diagnostic criteria, new ascertainment methods, dependence on existing registers of special needs as well as diagnostic substitution."* This statement does not reflect the current consensus on trends of autism prevalence rate. A number of reviews and study papers have concluded that change of diagnosis criteria, earlier age of diagnosis and increased awareness, do not alone explain the current rates of autism across the western world. It does not explain the age distribution either with more diagnosed children of a younger age than older ASD children. The statement should be read instead ***"The factors affecting the rising measured prevalence are not fully known but include changing diagnostic criteria, new ascertainment methods, dependence on existing registers of special needs as well as***	Thank you for your comment. The Guideline Development Group has added ' However, the possibility of an increase in ASD cannot be ruled out' to section 2.5 of the Full Guideline.

							diagnostic substitution; a true increase in number of ASD cases cannot be ruled out*."* This is a more accurate statement, which is still relatively conservative in the light of current evidence. Zahorodny, W., Shenouda, J., Howell, S., et al. (2012) Increasing autism prevalence in metropolitan New Jersey. Autism, 2012 Dec 17. Centers for Disease Control and Prevention CDC (2012) Prevalence of autism spectrum disorders--Autism and Developmental Disabilities Monitoring Network. MMWR SurveillSumm, 61: (3): 1-19. Blaxill, M. F. 2004, "What's going on? The question of time trends in autism.",*Publ.HealthRepts.*, vol. 119, pp. 536-551. Barbaresi, W. J., Katusic, S. K., Colligan, R. C., Weaver, A. L., & Jacobsen, S. J. 2005, "The incidence of autism in Olmsted County, Minnesota, 1976-1997: results from a population-based study", *Arch.Pediatr.Adolesc.Med.*, vol. 159, no. 1, pp. 37-44. Hertz-Picciotto I, Delwiche L. 2009. The rise in autism and the role of age at diagnosis. *Epidemiology,* Vol20,1:84-90.	
80	SH	Treating Autism	2	Full	2.5	18	It is stated that: *"The factors affecting the rising measured prevalence are not fully known but include changing diagnostic criteria, new ascertainment methods, dependence on existing registers of special needs as well as diagnostic substitution."* This statement is misleading as it fails to clarify that true increase cannot be ruled out – no data published to date can be used to completely rule out true increase in autism prevalence due to environmental factors and the significance of this cannot be overstated. Contrary	Thank you for your comment. The Guideline Development Group has added ' However, the possibility of an increase in ASD cannot be ruled out' to section 2.5 of the Full Guideline.

							to the implications of the above quotation, publications of last several years show that moderate and severe cases of autism are also on the increase, and are not accounted for fully with diagnostic substitution, showing that at least a part of the increase in rate is likely real. The Zahorodny et al. (2012) study could not detect any possible explanation for the observed recent increase in autism prevalence, despite the most rigorous investigation of available data, and concluded that "*the possibility of an increase in ASD prevalence due to changing risk cannot be ruled out".* The possibility that the increase in prevalence is real and due to environmental factors is especially pertinent in the light of findings by Hallmayer et al. (2011) (see comment no.1). Considering the enormous implications of a true increase in the rates of autism, NICE should acknowledge this possibility clearly, by following the working assumption of the National Institute of Mental Health: "*As diagnostic changes and ascertainment fail to explain the majority of the increase in autism prevalence, it seems* ***prudent*** *[our emphasis] to assume that there are indeed more children affected and continue an aggressive search for causes while striving to improve detection, treatments, and services. Our working assumption is that there are both more children affected and more detected*." (quote) Zahorodny, W., Shenouda, J., Howell, S., et al. (2012) Increasing autism prevalence in metropolitan New Jersey. Autism, 2012 Dec 17. Centers for Disease Control and Prevention CDC (2012) Prevalence of autism spectrum disorders--Autism and Developmental Disabilities Monitoring Network. MMWR SurveillSumm, 61: (3): 1-19.	
81	SH	Autism Treatment Trust	3	Full	2.6	18	Statement in line 22 "*There is evidence of a substantial genetic basis with strong heritability*" is factually incorrect and should be changed to "***There is***	Thank you for your comment. Current research continues to evolve and to reflect that, the Guideline Development Group has amended the

							evidence of a substantial environmental component with moderate genetic heritability", in order to reflect the current scientific evidence. See comment number 1. Line 39 statement "*To date, however, no firm links to specific environmental factors have been established*" As commented above.	opening to section 2.5 of the Full Guideline to: 'It is now evident that autism involves atypical brain development with many different genetic, epigenetic and environmental mechanisms probably being involved.'
82	SH	Step by Step School	25	Full	2.6	18	The text states that no firm link to environmental factors has been established. Based on recent published studies, it would seem that two potential ones have been found (i) antidepressant use during pregnancy (ii) valproate use during pregnancy	Thank you for your comment. Current research continues to evolve and to reflect that, the Guideline Development Group has amended section 2.5 of the Full Guideline to: 'It is now evident that autism involves atypical brain development with many different genetic, epigenetic and environmental mechanisms probably being involved.'
83	SH	Treating Autism	3	Full	2.6	18	Statement in line 22 "*There is evidence of a substantial genetic basis with strong heritability*" is factually incorrect and should be changed to "*There is evidence of a substantial environmental component with moderate genetic heritability*", in order to reflect the current scientific evidence. For full explanation and references see our comment number 1. Again it should be mentioned in this paragraph (lines 20-29) that findings of rare copy number variants in a small minority of individuals with autism are possibly a consequence of environmental insults on the genome and have not been proven as causative but may reflect increased vulnerability to environmental insults (as per Saxena et al. 2010 findings – full reference available in our comment number 1). Line 39 statement "*To date, however, no firm links to specific environmental factors have been established*"	Thank you for your comment. Current research continues to evolve and to reflect that, the Guideline Development Group has amended section 2.5 of the Full Guideline to: 'It is now evident that autism involves atypical brain development with many different genetic, epigenetic and environmental mechanisms probably being involved.'

							is again misleading in the context of very limited and scattered genetic findings being assigned greater importance than warranted in the previous paragraph.	
84	SH	Autism Treatment Trust	4	Full	2.7	20	Common co-existent conditions have not been comprehensively listed. Missing comorbidities include: Gastro-intestinal problems (reflux, inflammation, food sensitivities, microbial overgrowth), immune problems (infections, eczema, allergies, asthma). These conditions impact on functioning and cause or increase 'behaviour that challenges' (Kohane et al., 2012, Schieve et al. 2012, Jyonouchi 2010, Tracey and Wallace 2001). Jyonouchi, H. (2010) *Autism spectrum disorders and allergy: observation from a pediatric allergy/immunology clinic*. Expert Review of Clinical Immunology, 6: (3): 397-411. Kohane, I.S., McMurry, A., Weber, G., et al. (2012*) The Co-Morbidity Burden of Children and Young Adults with Autism Spectrum Disorders*. PloS one, 7: (4): e33224. Schieve, L.A., Gonzalez, V., Boulet, S.L., et al. (2012) *Concurrent medical conditions and health care use and needs among children with learning and behavioral developmental disabilities, National Health Interview Survey*, 2006–2010. Research in developmental disabilities, 33: (2): 467-476. Tracy J.M., Wallace R. (2001) *Presentations of physical illness in people with developmental disability: the example of gastro-oesophageal reflux.* Med J Aust. Jul 16;175 (2):109-11	Thank you for your comment. The Guideline Development Group has added the following to the end of section 2.7 of the Full Guideline: "'These and other common medical problems can further impair psychosocial functioning and cause or increase behaviour that challenges (Kohane et al., 2012). Mortality rates are higher in autism than in the general population, in association with comorbid medical health issues (Gillberg et al., 2010).'
85	SH	Autism Treatment Trust	5	Full	2.7	20	To add: Mortality rates are higher in autism than in the general population, in association with untreated medical medical health issues (Pickett et al., 2006; Gillberg et al., 2010; Bilder et al., 2012; Woolfenden et al., 2012, Tyler et al., 2011, Jaffe and Timell, 2003). Bilder, D., Botts, E.L., Smith, K.R., et al. (2012) *Excess*	Thank you for your comment. The Guideline Development Group has amended the end of section 2.7 of the Full Guideline: 'Mortality rates are higher in autism than in the general population, in association with comorbid medical health issues'.

							Mortality and Causes of Death in Autism Spectrum Disorders: A Follow up of the 1980s Utah/UCLA Autism Epidemiologic Study. Journal of Autism and Developmental Disorders, Sep 25: 1-9. Gillberg, C., Billstedt, E., Sundh, V., et al. (2010) *Mortality in autism: a prospective longitudinal community-based study. Journal of Autism and Developmental Disorders*, 40: (3): 352-357. Jaffe, J.S. and Timell, A.M. (2003*) Prevalence of low bone density in institutionalized men with developmental disabilities.* Journal of Clinical Densitometry, 6: (2): 143-147. Pickett, J.A., Paculdo, D.R., Shavelle, R.M., et al. (2006) 1998-2002 *Update on "Causes of death in autism".* Journal of Autism and Developmental Disorders, 36:(2): 287. Tyler, C.V., Schramm, S.C., Karafa, M., et al. (2011) *Chronic disease risks in young adults with autism spectrum disorder: forewarned is forearmed.* American journal on intellectual and developmental disabilities, 116: (5): 371-380. Woolfenden, S., Sarkozy, V., Ridley, G., et al. (2012) A systematic review of two outcomes in autism spectrum disorder–epilepsy and mortality. Developmental Medicine & Child Neurology, 54: (4): 306-312.	
86	SH	Treating Autism	4	Full	2.7	20	A number of commonly co-existent conditions are mentioned; however, many have been left out including reflux, eczema, allergies, asthma, ear and respiratory infections, migraines, and severe headaches. Any and all of these conditions could 'further impair psychosocial functioning' and cause or increase 'behaviour that challenges' (Kohane et al., 2012, Schieve et al. 2012, Jyonouchi 2010, Tracey and Wallace 2001). Further to this, appropriate treatment of any co-existent conditions could improve psychosocial functioning and decrease behaviour that challenges. Jyonouchi, H. (2010) *Autism spectrum disorders and*	Thank you for your comment. The Guideline Development Group has added to section 2.7 of the Full Guideline the following: "these and other common medical problems can further impair psychosocial functioning and cause or increase behaviour that challenges".

							allergy: observation from a pediatric allergy/immunology clinic. Expert Review of Clinical Immunology, 6: (3): 397-411. Kohane, I.S., McMurry, A., Weber, G., et al. (2012*) The Co-Morbidity Burden of Children and Young Adults with Autism Spectrum Disorders*. PloS one, 7: (4): e33224. Schieve, L.A., Gonzalez, V., Boulet, S.L., et al. (2012) *Concurrent medical conditions and health care use and needs among children with learning and behavioral developmental disabilities, National Health Interview Survey*, 2006–2010. Research in developmental disabilities, 33: (2): 467-476. Tracy J.M., Wallace R. (2001) *Presentations of physical illness in people with developmental disability: the example of gastro-oesophageal reflux.* Med J Aust. Jul 16;175 (2):109-11	
87	SH	Treating Autism	5	Full	2.7	20	It should be mentioned in this section that mortality rates appear to be much higher in autism, and could be as much as three to ten times higher than in the general population. These deaths tend to be the result of medical comorbidities, such as epilepsy, gastrointestinal conditions and respiratory disorders (Pickett et al., 2006; Gillberg et al., 2010; Bilder et al., 2012; Woolfenden et al., 2012). Without appropriate intervention, individuals with autism appear to be at significant risk for developing diabetes, coronary heart disease, and cancer, as well as severe osteoporosis (Tyler et al., 2011, Jaffe and Timell, 2003). Bilder, D., Botts, E.L., Smith, K.R., et al. (2012) *Excess Mortality and Causes of Death in Autism Spectrum Disorders: A Follow up of the 1980s Utah/UCLA Autism Epidemiologic Study*. Journal of Autism and Developmental Disorders, Sep 25: 1-9. Gillberg, C., Billstedt, E., Sundh, V., et al. (2010) *Mortality in autism: a prospective longitudinal community-based study. Journal of Autism and*	Thank you for your comment. The Guideline Development Group has amended the end of section 2.7 of the Full Guideline: 'Mortality rates are higher in autism than in the general population, in association with comorbid medical health issues'. .

							Developmental Disorders, 40: (3): 352-357. Jaffe, J.S. and Timell, A.M. (2003*) Prevalence of low bone density in institutionalized men with developmental disabilities.* Journal of Clinical Densitometry, 6: (2): 143-147. Pickett, J.A., Paculdo, D.R., Shavelle, R.M., et al. (2006) 1998-2002 *Update on "Causes of death in autism".* Journal of Autism and Developmental Disorders, 36:(2): 287. Tyler, C.V., Schramm, S.C., Karafa, M., et al. (2011) *Chronic disease risks in young adults with autism spectrum disorder: forewarned is forearmed.* American journal on intellectual and developmental disabilities, 116: (5): 371-380. Woolfenden, S., Sarkozy, V., Ridley, G., et al. (2012) A systematic review of two outcomes in autism spectrum disorder–epilepsy and mortality. Developmental Medicine & Child Neurology, 54: (4): 306-312.	
88	SH	Association for Family Therapy and Systemic Practice	3	FULL	2.9 2.9 2.16	21 22 30	The full guidelines evidence the impact of autism on family members, including high stress levels, poor physical health, negative economic impact	Thank you for your comment.
89	SH	Royal College of Nursing	7	Full	2.9	22; 25	'*appropriate intervention and supportive social and economic conditions* can have a significant impact on outcomes and functioning for individuals across the spectrum, and on the extent to which their families can adapt and flourish.'	Thank you for your comment.
90	SH	Bangor University	1	Full	2.10	23	Line 23 – is the AET an organisation covering England and Wales or just England?	Thank you for your comment. AET covers England only.
91	SH	Bangor University	2	Full	2.10	23	The Welsh Government has an ASD strategic action plan, but this is not mentioned at all in this section. It should be mentioned because the guideline is meant to be for England and Wales.	Thank you for your helpful comment. The Welsh Government's ASD strategic action plan has been referenced in the full guideline.
92	SH	Royal College of Nursing	8	Full	2.11	24; 1	'THE NEED FOR A GUIDELINE ON THE *MANAGEMENT AND SUPPORT* FOR CHILDREN AND YOUNG PEOPLE WITH AUTISM AND THEIR	Thank you for your comment.

							FAMILIES'	
93	SH	Royal College of Nursing	10	Full	2.11	24; 12	'This shortfall relates not only to *autism-specific interventions,* but also to medical and healthcare more generally'	Thank you for your comment.
94	SH	Royal College of Nursing	11	Full	2.11	24; 33	*Management and support* for children, young people and their families and carers needs a life-span approach	Thank you for your comment.
95	SH	Royal College of Nursing	9	Full	2.11	24; 5	'*lifelong management and care*'	Thank you for your comment.
96	SH	Royal Manchester Childrens Hospital	1	FULL	2.12	25	Transition plans to include hospital settings	Thank you for your comment. The Guideline Development Group has added 'young people looked after by hospital services for co-existing conditions need good transition plans to adult care' to section 2.12 of the Full Guideline.
97	SH	Sheffield Children's Hospital NHS Trust	1	FULL	1.8.1	26	Research indicates that sleep difficulties in children and young people with Autism are most effectively treated using melatonin (which has to be prescribed by a paediatrician) and behavioural methods together. Sleep difficulties need treating immediately otherwise development is compromised (and the sleep difficulty may become intractable). Therefore the guideline could read: Treat sleep problems in a timely manner. Consult a clinical psychologist and paediatrician. Consider prescribing oral melatonin to be given in conjunction with psycho-education and/or behavioural treatments.	Thank you for your comment. The Guideline Development Group has written a new section in the NICE guidelines on sleep problems outlining a hierarchical approach from primary care to specialist. The use of melatonin in autism was examined carefully and the Guidelines Development Group was of the opinion that there was not enough evidence for a specific recommendation.
98	SH	Royal Manchester Childrens Hospital	2	FULL	2.12	26	Same with transition with Children's - adult	Thank you for your comment. The Guideline Development Group has added 'young people looked after by hospital services for co-existing conditions need good transition plans to adult care' to section 2.12 of the Full Guideline.
99	SH	The UK Society for Behaviour Analysis (UK-SBA)	7	Full	2.13 & 4.1	27 & 28 59	P 27 & 28 also P 59 lines 23-25: The UK-SBA welcomes this entire section on conceptual frameworks but is disappointed that it falls short of what could be included. A description on what constitutes a behavioural approach for instance (see	Thank you for your comment. Sections 2.13 and 5.2.1 of the Full Guideline have now been expanded,

							above) could be helpful here and in particular the focus on what is important to the individual and his or her family (rather than “treating” autism as a whole.)	
100	SH	Treating Autism	6	Full	2.13	28	While adaptations to improve ‘goodness of fit’ are a welcome recommendation, the term ‘neurodiversity’ is often used to downplay or outright reject the severity of the disabilities and medical problems suffered by most people on the severe end of the autism spectrum. As well, adaptations must never serve instead of treatment, but must be provided as part of the treatment continuum, with the goal being their redundancy upon effective treatment outcomes. The above is especially true in light of the enormous social and economic costs of autism (section 2.16 Full document), which impact the family and wider society. Furthermore, if left untreated, the symptoms of autism in many sufferers will result in ‘loss of productivity’ in adulthood, preventing them from finding employment and contributing to society, regardless of quality and level of costly support or ‘goodness of fit’ adaptations provided. It is highly inappropriate for a NICE publication, funded by taxpayer money, to recommend ‘accepting autism‘ instead of placing ameliorating and/or reducing symptoms of autism as the highest priority.	Thank you for your comment. The Guideline Development Group agrees with the important aims of improved functionality of the individual and the reduction of unwanted behaviours that impact negatively on function using both specific treatments and environmental modifications in the treatment continuum. The guideline does address direct interventions for core features of autism, (recommendations 1.3 in the NICE Guideline), coexisting problems (recommendations 1.7 in the NICE Guideline) and behaviour that challenges (recommendations 1.4 in the NICE Guideline). The guideline does also suggest that adjustments to the environment should be made. The Guideline Development Group do not think that these are mutually exclusive.
101	SH	Peach	3	Full	2.14	28	Behaviour Analysts have been missed from the list of professionals on line 41-42	Thank you for your comment. The list of professionals is exampled not exhaustive
102	SH	Royal Manchester Childrens Hospital	3	FULL	2.14	28	Not just emergency care but routine health care too e.g in Hospital	Thank you for your comment, the Guideline Development Group has now included hospital care as you have suggested.
103	SH	The UK Society for Behaviour Analysis (UK-	8	Full	2.13	28 & 29	P 28 lines 41-44 and 29 lines 1-2 “behavioural psychologists” /need for “behavioural input” is mentioned but Behaviour Analysts are not included in the suggested “experts” although SLTs and OT’s are.	Thank you for your comment. The list of professionals is exampled not exhaustive.

		SBA)						
104	SH	Peach	1	Full	2.15	General	I understand that it is not in the NICE remit to consider single case experimental designs, but this is missing out on a wealth of scientifically valid data for interventions which can have a significant positive impact on the quality of life and long term outcome of many individuals with autism.	Thank you for your suggestion, but there are considerable difficulties reviewing this type of research, particularly for the purpose of developing national clinical guidelines. For example, findings from single cases are difficult to generalise to a wider population and there is a significant risk of publication bias which further limits the reliability of findings from SCEDs. Furthermore, the Guideline Development Group notes that even proponents of SCEDs recognise that, at least in the area of ABA research for autism "…large multi-site randomized clinical trials are needed to narrow the confidence intervals for effect sizes, support comprehensive outcome assessments, identify potential mediators and moderators, and pinpoint active ingredients (e.g, optimal amount of treatment)." (Smith, Eikeseth, Sallows, The Journal of Pediatrics, 155 (1), 151-152. A similar conclusion was reached by an AHRQ funded review that included both randomised and non-randomised research: "Some behavioural and educational interventions that vary widely in terms of scope, target, and intensity have demonstrated effects, but the lack of consistent data limits our understanding of whether these interventions are linked to specific clinically meaningful changes in functioning. The needs for continuing improvements in methodologic rigor in the field and for larger multisite studies of existing interventions are substantial. Better characterization of children in these studies to target treatment plans is imperative." (AHRQ Publication No. 11-EHC029-EF.)
10	SH	Autism	6	Full	2.15	29	Indeed, gold-standard methodology for the testing of	Thank you for your comment. The Guideline

5		Treatment Trust					the effectiveness of health treatments is a RCT. This approach has however been criticised for being reductionist and non-representative of complex clinical practice, particularly in the areas of social development where complex treatment interventions are studied (Robson 2002). In contrast to an efficacy trial of a specific drug, many treatments applied in mental health practices are multi-layered. As stated, there are treatment effects from the intervention protocol itself, effects of the environment, and because the main agent of delivery is interpersonal, diverse issues of the treatment process are likely to be important as well as variable. Furthermore, the impact of placebo (non-drug or non-process) related variance in drug trials is apparently increasing (Fava et al, 2003). This factor may be particularly relevant in autism. Involving autistic children in a study can be perceived by parents as some form of support that could in turn constitute in itself an “emotional therapy” to the child and his/her family. It is likely that this placebo effect has been a confounding factor that has significantly affected the interpretation of prior RCT studies in autism (Sandler and Bodfish 2002). The conclusions should therefore be instead that suitable adapted methodology of testing of efficacy of intervention should be employed, instead of systematically refuting any published report that does not conform to a RCT design. Of note, the guidelines must reflect on the report of Optimal Outcomes made recently by Fein et al., 2013. Fein, D., Barton, M., Eigsti, I.M., et al. (2013) *Optimal outcome in individuals with a history of autism*. Journal of Child Psychology and Psychiatry, 54: (2): 195-205.	Development Group accepts that there are different views with regard to what constitutes the best available evidence when evaluating the effectiveness of interventions. However, on balance, the Group believes that the benefits of using a randomised design outweigh the problems when compared to other study designs. Furthermore, the methodology was agreed by the Guideline Development Group before the start of the review process, and it would not be appropriate to use a different method after reviewing the evidence.

							Pellicano, E. (2012) *Do autistic symptoms persist across time? Evidence of substantial change in symptomatology over a 3-year period in cognitively able children with autism. American journal on intellectual and developmental disabilities*, 117: (2): 156-166. Ozonoff(2013) Editorial: *Recovery from autism spectrum disorder (ASD) and the science of hope.* J Child Psychology and Psychiatry, 54: (2). Broderick, A.A. (2009). *Autism, "recovery (to normalcy)," and the politics of hope*. Intellectual and Developmental Disabilities, 47, 263–281. Green, J. (2006), "The evolving randomised controlled trial in mental health; studying complexity and treatment process", *Advances in Psychiatric Treatment*, vol. 12, pp. 268-279. Sandler, A. D. &Bodfish, J. W. (2000), "Placebo effects in autism: lessons from secretin", *J.Dev.Behav.Pediatr.*, vol. 21, no. 5, pp. 347-350. Robson, C. (2002), *Real world research*Balckwell Publishing, Oxford. Fava, M., Evins, A. E., Dorer, D. J., &Schoenfeld, D. A. (2003), "The problem of the placebo response in clinical trials for psychiatric disorders: culprits, possible remedies, and a novel study design approach", *Psychother.Psychosom.*, vol. 72, no. 3, pp. 115-127	
106	SH	Treating Autism	7	Full	2.15	29	Points made regarding the evaluation of evidence of the effectiveness of intervention aside, a recent study confirms that some diagnosed children completely recover from autism, or reach an "optimal outcome" (Fein et al., 2013). The common thread of optimal	Thank you for your comment. The Guideline Development Group were aware of the Fein study, but does not believe it would be appropriate to cite in this section, which is about evaluating outcomes in research, not whether

							outcomes seems to be the intensity of the treatment approach and the involvement of parents. The heterogeneity of ASD may mean that more specific answers will be easier to find by looking more closely at children who have progressed significantly or have already reached an optimal outcome. Fein, D., Barton, M., Eigsti, I.M., et al. (2013) *Optimal outcome in individuals with a history of autism.* Journal of Child Psychology and Psychiatry, 54: (2): 195-205. Pellicano, E. (2012) *Do autistic symptoms persist across time? Evidence of substantial change in symptomatology over a 3-year period in cognitively able children with autism.* American journal on intellectual and developmental disabilities, 117: (2): 156-166.	children with autism recover. Please note that the course and outcome of autism and the improvements with age are specifically commented on in section 2.8 of the Full Guideline.
107	SH	Treating Autism	8	Full	2.16	30	In addition to economic cost of autism, the devastating impact of autism on mental and physical health of family members should merit a mention. The stress of caregiving or being brought up alongside siblings with autism 'exacts a significant psychophysiological toll' and negatively impacts health and psychosocial functioning. Aggressive and delinquent behaviour in particular is both very prevalent in autism and has a significant negative impact on families and society as a whole. De Andrés-García S, Moya-Albiol L , González-Bono E. (2012) *Salivary cortisol and immunoglobulin A: responses to stress as predictors of health complaints reported by caregivers of offspring with autistic spectrum disorder*. HormBehav. 2012 Sep;62(4):464-74. Fisman S, Wolf L, Ellison D (2010) *A longitudinal study of siblings of children with chronic disabilities*. Can J Psychiatry. 2000 May; 45(4):369-75. Geluk, C.A., Jansen, L., Vermeiren, R., et al. (2011*) Autistic symptoms in childhood arrestees: longitudinal*	Thank you for your comment. Please see section 2.9 of the Full Guideline which makes similar comment on the impact of autism on the family, which the Guideline Development Group regarded as immensely important.

							association with delinquent behavior. Journal of Child Psychology and Psychiatry, 53: (2): 160-167. Hodgetts, S., Nicholas, D. and Zwaigenbaum, L. (2013) *Home Sweet Home? Families' Experiences With Aggression in Children With Autism Spectrum Disorders*. Focus on Autism and Other Developmental Disabilities. January 18, 2013. Kanne, S.M. and Mazurek, M.O. (2011) *Aggression in children and adolescents with ASD: Prevalence and risk factors.* Journal of Autism and Developmental Disorders, 41: (7): 926-937. Lovell B (2012*) The psychosocial, endocrine and immune consequences of caring for a child with autism or ADHD.* Psychoneuroendocrinology. Apr;37(4):534-42.	
108	SH	The UK Society for Behaviour Analysis (UK-SBA)	9	Full	2.16	31	P 31 line 21 refers to long-term maintenance. Behaviour Analysis provides a methodology to target and monitor this at the level of the individual. "Generalisation" is not included. We would suggest that it is – and again is one of the core dimensions of Behaviour Analysis.	Thank you for your comment. Generalisation is important in autism and has now been added to section 5.2.1 of the Full Guideline, to paragraph 2.
109	SH	Treating Autism	9	Full	3.3	34	Line 4 statement "*During the consultation phase, members of the GDG were appointed by an open recruitment process*" is incorrect, as carer (lay) members of the group were not appointed according to the procedures laid out in the recruitment documentation, in that there was no shortlisting of applicants and the interviewing phase was not carried out for at least some of the applicants. At least some of the unsuccessful applicants were not informed of the outcomes or scoring results or criteria used in the rejection of their applications.	Thank you for your comment. The NICE Public Involvement Programme are responsible for the recruitment process for service user and carer vacancies and then passing applications to the National Collaborating Centre for Mental Health (NCCMH), who shortlist and select members of the Guideline Development Group. Service user and carer applications were processed as per the NICE Information for Applicants procedure. Service user and carer applications were shortlisted, unsuccessful applicants were informed via letter, and therefore interviews were not carried out for all applicants. The NICE Public Involvement Programme have r**eword**ed the recruitment paperwork to avoid any

								misinterpretation of the process in the future. If any unsuccessful applicant would like to know more about why they were not selected, please encourage them to contact the NCCMH, and we will explain our decision.
110	SH	Peach	4	Full	2.14	36	The National Standards Project by the National Autism Center could be included here.	Thank you for your comment. The Guideline Development Group has considered your suggestion, but took the view not to refer to specific national guidelines as they may become outdated.
111	SH	The UK Society for Behaviour Analysis (UK-SBA)	10	Full	3.5	36	P 36 line 9: The National Standards Project (NSP) is amongst the largest and most comprehensive reviews undertaken to date and we suggest should have been included http://www.nationalautismcenter.org/pdf/NAC%20Standards%20Report.pdf.	Thank you for your suggestion, but based on other consultation comments we've removed the list in section 3.5.1 on Methodology of the Full Guideline, as the appropriate document to cite is the NICE guidelines manual.
112	SH	British Association for Music Therapy (BAMT)	2	Full	3.9	57	The document states that stakeholders consulted included: 'Professional stakeholders' national organisations that represent the healthcare professionals who provide the services described in the guideline'. We presume this refers (in advance) to the current consultation exercise, since BAMT (the professional stakeholder for music therapy) was not consulted during the development of the guidelines, despite offering to provide expert advice to the committee.	Thank you for your comment. All registered stakeholders are consulted during the development of the scope and on the draft guideline.
113	SH	Treating Autism	10	Full	4.1	59	It is stated that '*the results of the qualitative analysis were instead presented by the National Autistic Society (NAS) to an expert advisory group of children and young people with autism recruited from a number of different settings to validate the conclusions of the analysis*.' Did the qualitative analysis include any representation of views of those who are moderately or severely affected by autism? Our profound concern is that once again views and opinions of those individuals who are more verbal and able to communicate are	Thank you for your comment. The groups consulted did vary in terms of the severity of their autism. The second and third groups required a higher level of support to answer the questions. In some cases the participant was given a choice of statements and asked to signal which they agreed with, so that vocal ability was not relied on (please see Appendix 18).

							taken as being representative of the whole spectrum and that the most disenfranchised people with ASD have been further marginalized.	
114	SH	The UK Society for Behaviour Analysis (UK-SBA)	12	Full	4.2.7 – 4.2.10	94, 114, 115, 143, 145,161,162	P 162: There is no recommendation in relation to Behavioural support/approaches/interventions despite p94: lines 5-9: Carers are critical of lack of access to ABA; P 113 (lines 42-45) -p 114 Mixed views about impact of home programmes on family life, but interesting point about parents and families learning about behaviour management in home setting; P 115 lines 9-12: involvement in ABA and other parent training helps equip parents with behaviour management strategies; P 143 lines 23-25 and 29-30: behavioural interventions come out as particularly popular; P 145 lines 24-28: ABA is very popular and leads to zero dissatisfaction; P 161 lines 1-2 Professionals trained in managing behavioural problems are seen as very important.	Thank you for your comment. The Guideline Development Group reviewed the guideline in light of your comments. Although it found insufficient evidence to be able to recommend ABA, it found found sufficient evidence to recommend behavioural interventions, specifically around behaviour that challenges.
115	SH	Association for Family Therapy and Systemic Practice	4	FULL	4.2.7	99	AFT welcomes the attention given to the needs of siblings. Systemic family therapists are uniquely placed through their clinical trainings and skills to intervene at the level of the family and to provide contexts for siblings of children with autism to voice their own experiences and needs. Research indicates the importance of this in reducing conflict and stress levels in families, and supporting relationships and well-being of all family members, including the child or young person with the diagnosis.	Thank you for your comment.
116	SH	Peach	5	Full	4.2.7	102	Peach have over 130 cases on its books at any one time and each and every family would testify that we routinely work very well within the multi-disciplinary team.	Thank you for your comment.
117	SH	The UK Society for Behaviour Analysis (UK-SBA)	11	Full	4.2.7	102	P 102: lines 38-39: The UK-SBA regrets carer reports that choice of ABA led to withdrawal of other professional support. We wholly endorse multi-professional cooperation and would welcome the opportunity afforded by this review to demonstrate that.	Thank you for your comment.

118	SH	British Association for Music Therapy (BAMT)	3	Full	4.2.7	112:6-12, 25-30 and 113:1-8	We welcome the attention given in the document to research on the experience of parents and carers. We notice the many reported comments showing parents'/ carers' positive views of music therapy, and also drawing attention to the very limited access that currently exists to music therapy services. While OT and SALT interventions are also often requested by parents, these interventions are much more widely available. We hope the committee will recognise that these positive responses to music therapy are very significant in relation to its comparatively small size as a profession, and that its history of active research and substantial qualitative research base is both impressive and articulates the ways in which music therapy benefits children and young people with autism.	Thank you for your comment. The Guideline Development Group are confident that any evidence on the use of music therapy with children and young people with autism will have been picked up by the extensive search strategy (Appendix 7). The high quality evidence that was found has been reviewed in Chapter 7, Section 7.3.3 of the Full Guideline.
119	SH	Association for Family Therapy and Systemic Practice	5	FULL	4.2.7	114	This highlights the stresses that emerge in families due to high levels of intervention. It also highlights a wish to benefit from home-based therapeutic interventions which include and involve other family members. Systemic family therapists are uniquely placed to support families in understanding and working through the stresses of intervention, and the impact of autism on the experiences and needs of all family members.	Thank you for your comment.
120	SH	Royal Manchester Childrens Hospital	4	FULL	4.2	118	All healthcare professionals not just GP	Thank you for your comment. This is a quote taken from Carbone 2010 in which it was identified that GPs specifically need to recognise carers as experts on their children.
121	SH	Royal Manchester Childrens Hospital	5	FULL	4.2	118	And acute/specialist/tertiary care (i.e. not just secondary care)	Thank you for your comment. This section is termed as *secondary* care as Dittrich 2011 identified secondary care specifically.
122	SH	Royal Manchester Childrens Hospital	6	FULL	4.2	118	And preparation (as well as need for predictable).	Thank you for your comment. This is a quote taken from Dittrich 2011 in which negative experiences were associated with a failure to appreciate the need for predictability specifically.

123	SH	Royal Manchester Childrens Hospital	7	FULL	4.2	118	Title should include acute/specialist/tertiary	Thank you for your comment. This section is termed as *secondary* care as Dittrich 2011 identified secondary care specifically.
124	SH	Royal Manchester Childrens Hospital	8	FULL	4.2	118	Include acute/specialist/tertiary & include transition from children's to adult services across all hospital services	Thank you for your comment. This is information taken from Beresford 2010, which looked at the transfer from community paediatrics to adult mental health, and not transition in general from children's to adult services across all hospital services.
125	SH	Association for Family Therapy and Systemic Practice	6	FULL	4.2.9	136	Many carers of children with autism require the services of a large number of professionals. Systemic family therapists are very well placed through clinical training and core skills to intervene to enhance positive relationships between the child with autism, their family members and involved professionals. They have the high-level skills necessary to move between different levels of the autistic child's support system, and to recognise the how different levels of the system influence and can effectively support each other.	Thank you for your comment. The list of commonly reported services is taken from Brown 2012, which does not include systematic family therapists.
126	SH	Association for Family Therapy and Systemic Practice	7	FULL	4.2.9	137	It is reported that 69% of parents felt their child's needs had not been met by the services provided. As well as providing an argument for greater provision of services, this also suggests that there is a need to respectfully engage carers around their hopes and fears for the future development of the child with autism. Systemic family therapists are ideally placed through their training and core skills to work with family members at the level of the beliefs that inform their views of the future for the child with autism.	Thank you for your comment. Systematic family therapists were not listed in the studies looked at for this section (Brown 2012, Makintosh 2012, Kogan 2008, Krauss 2003 and Montes 2009).
127	SH	Association for Family Therapy and Systemic Practice	8	FULL	4.2.9	142	A majority of carers in one survey were dissatisfied with the service they received from CAMHS and did not feel that the CAMHS clinicians had a sufficient understanding of autism. Conversely, feedback via ESQ-CHI in one multidisciplinary CAMHS (Special Needs) *MOSAIC CAMHS LB Camden* team which includes family therapists has, based upon routine parent/carer completion of ESQ-CHI, been	Thank you for your comment. The Guideline Development Group appreciated that not all carers are dissatisfied with CAMHS, and the results of any survey cannot be generalised to all services. What is important for the purposes of the guideline, is to determine if recommendations can be made to improve care that are based on the best available evidence.

							overwhelmingly positive. The following are sample quotes, following contact with the team's family therapists, from parental responses to the CHI-ESQ question: what was really good about your care? All the parents' children had diagnoses of autism: • Attentive listening, X questions/explores different areas of behaviour problems; very good with observing my child • The people here do not talk down to me and listen to what I have to say and do not judge us – thank you for the help you are giving me and my family • X listened and told me what to do. He contacted the school for me too. He tried to communicate with my son. He waited for the other kids to come home – he talked to them too. So he did extra. When he contacted the school they met together and now I'm going to get more help. My son is already changing and I'm really happy • Listening, problem-solving, talking and being able to express your feelings and to cry without being judged, able to be yourself. I am very grateful and glad that me and my son come here • Genuinely felt that my daughter was important and her views were very important • The care I received was professional and friendly. I was treated with a lot of respect and felt understood – I would leave the premises feeling happier and more confident that things will get better and that I'm doing a very good job looking after my family	
12	SH	Royal	9	FULL	4.2	147	Confirm that this is a concern in all healthcare settings	Thank you for your comment. The studies

8		Manchester Childrens Hospital					– acute/specialist/community	Kogan 2008 and Lai 2011 are specifically about access to primary care services, and not acute, specialist and community settings.
129	SH	British Association for Music Therapy (BAMT)	4	Full	4.2.9	147	Music therapy is referred to here under 'complementary and alternative therapies'. The association of music therapy here with (unregulated) alternative/ complementary treatments/ therapies suggests a lack of recognition of music therapy in the UK as an established clinical discipline recognised by the HCPC. We would request that music therapy is distinguished from complementary/ alternative therapies, as it is e.g. on the National Autistic Society website.	Thank you for your comment. This heading is an exact quote from the paper reviewed.
130	SH	Royal Manchester Childrens Hospital	10	FULL	4.2	149	Acute care and secondary care to be considered	Thank you for your comment. This section is termed as *secondary* care as Dittrich 2011 and Cassidy 2008 identified secondary care specifically.
131	SH	Royal Manchester Childrens Hospital	11	FULL	4.2	149	Include Acute care/specialist in involvement for support for family and carers.	Thank you for your comment. The themes raised in this section are a summary of themes that were taken from the quantitative analysis for service user and family and carer experience data, and therefore the Guideline Development Group is unable to insert additional themes that did not arise from this data.
132	SH	The UK Society for Behaviour Analysis (UK-SBA)	13	Full	4.2.10	162	P 162 lines 1-6: The UK-SBA welcomes this recommendation but suggests that it is re-worded to reflect a more person-centred response to the individual. There is a lot of guidance elsewhere that suggests that eliminating potential sources of sensory difficulties will reduce problem behaviours – but what may be aversive for some may be stimulating for others and any environmental changes have to be responsive to individual needs.	Thank you for your comment. The Guideline Development Group feels that this recommendation is adequately worded as it stands and supports being responsive to individual needs.
133	SH	The UK Society for Behaviour	14	Full	4.2.10	162	P 162 lines 11 & 12: The UK-SBA welcomes the recommendation that children be offered "evidence based interventions aimed at preparation and coping	Thank you for your comment. The standard term that the guideline uses is healthcare professional unless there are very good reasons

		Analysis (UK-SBA)					strategies to facilitate access to community services etc." but thinks that this could be more specific and in particular highlight the role of behaviour analyst in providing such services.	to specify – for example, prescribing of controlled drugs, some particular role within the NHS (e.g. the coordinating role and gatekeeping role of GPs), or some other statutory duty which rests with a particular professional group (e.g. social work roles). The Guideline Development Group is not concerned with professional roles per se, but with interventions and care being delivered by health care professionals with the relevant competencies and experience.
134	SH	The UK Society for Behaviour Analysis (UK-SBA)	15	Full	4.5	172	P 172 lines 1-3: We welcome the recommendation for training in autism and basic skills in autism and suggest that the guidelines take this a step further by referring to identified competencies in working with and supporting individuals with autism. The UK ABA Autism Education Framework for example outlines autism specific competencies that are relevant to anyone irrespective of their discipline. http://www.ambitiousaboutautism.org.uk/page/what_we_do/research/aba_competencies.cfm	Thank you for your comment. The Guideline Development Group's view was that a stronger evidence base would be required to underpin such a recommendation specifying competency, therefore the Guideline Development Group have chosen to continue with the current phrasing "understanding and basic skills".
135	SH	National Autistic Society	2	Full	4.6.1.1	174	The NAS welcomes the general principle that all children with autism should have unrestricted access to health and social care services regardless of intellectual ability or any co-existing diagnosis. However there is a vast gap between this principle and current reality on the ground. The NAS regularly hears from parents of children with Asperger syndrome and high functioning autism, in particular who are told that their son or daughter does not qualify for support from children with disabilities team, as their criteria excludes autism/Asperger syndrome. In areas where we have questioned the legality of excluding Asperger syndrome and/or autism from support from the children with disabilities team, we have been told that they can be supported by the	Thank you for your comment. The Guideline Development Group agrees that services for children and young people, and their carers and families, is very variable across different geographical areas and often within areas. This is one of the most important reasons for the guidelines to be commissioned and for a quality standard to be developed from this and other guidelines about autism, its diagnosis and management. It is clear from this guideline that the local arrangements for an autism strategy group and a local autism team make it very clear that children and young people and their families cannot be excluded from access to services in the way you describe. The guideline will help support families as the Commissioners will be using the guidelines and especially the quality

							safeguarding team in the local authority. However, this can mean that they are not able to access the same range of services as other children with disabilities (such as particular short breaks services) and it means that they are supported by professionals whose primary concern is safeguarding, which we believe is inappropriate. This is perhaps something to be addressed further in the forthcoming quality standard on autism in children. We would welcome a recommendation from NICE that the Care Quality Commission (CQC) undertake a review to look at equity of access to social care support and health for children with autism across the spectrum.	standard to commission services for autism. The guidelines and quality standard will be used by the CQC to evaluate services. Indeed, the quality standards are at the heart of the new health and social care act which clearly states that quality standards will be used to drive commissioning, reimbursement and regulation, the latter being the job of the CQC.
136	SH	BetsiCadwaladr University Health Board	4	Full	4.6.1.5	174	The Recommendation refers to children and young people with “particular needs” and then mentions “immigrant groups” We welcome this acknowledgement that the linguistic and cultural needs of children and young people warrant consideration within the framework of an Autism service. However, the Recommendation needs to make specific reference to children and young people who are Welsh speakers in Wales. Welsh speakers are not immigrants; they are indigenous. Welsh Government have recognised that children and young people are one of four vulnerable groups for whom identifying their linguistic needs is a matter of clinical priority In addition, Welsh and English have equal status in Wales, and public bodies are required to provide equitable services in both languages where necessary This needs to be made explicit in the guidelines. NB There may well be other considerations for other indigenous languages in other parts of the UK.	Thank you for your comment. The recommendation refers to particular groups where there is evidence that people from those groups do not access services with as much frequency as the general population. The Guideline Development Group takes your point, however, and have added a section to the introduction to the NICE guideline that makes it clear that support and care for children and young people with autism should be culturally appropriate and accessible to people with additional needs such as physical, sensory or learning disabilities, and to people who do not speak or read English.

137	SH	Royal Manchester Childrens Hospital	12	FULL	4.6	175	Include acute/specialist/tertiary care for training	Thank you for your comment. The Guideline Development Group believes this has been covered by 'advice, training and support for other health and social care professionals and staff'.
138	SH	Royal Manchester Childrens Hospital	13	FULL	4.6	175	How to communicate with children and young people and their families	Thank you for your comment. The Guideline Development Group believes that communicating with children and young people and their families is covered in the recommendations, under section 4.6.1.13 on Families and Carers of the Full Guideline.
139	SH	National Autistic Society	4	Full	4.6.1.6	175	The NAS welcomes the key role for multi-disciplinary autism teams in co-ordinating and delivering support for children and young people with autism. The NAS believes that the role of the local autism team should be expanded to include greater links to and training of educational professional and greater integration with CAMHS.	Thank you for your comment. The Guideline Development Group agrees that multi-disciplinary teams play an important role in co-ordinating and delivering support for children and young people with autism. The Guideline Development Group reviewed the guideline in light of your comments, and would like to refer you to the role of the Local Autism Team in recommendation 1.1.6 of the NICE Guideline, the second bullet point of which states: "Local autism team should have a key role in the delivery and coordination of: ...advice, training and support for other health and social care professionals and staff (including in residential and community settings) who may be involved in the care of children and young people with autism" Although education is outside of the scope of this guideline, the role of the Local Autism Team and of the Strategy Group is to ensure full collaboration with education providers, as well

								as with health and social care. This is laid out in recommendations 1.1.2, 1.1.3, 1.1.6, 1.1.11 and 1.8.2 in the NICE Guideline.
140	SH	National Autistic Society	3	Full	4.6.1.8	175	The NAS commends NICE and the GDG on the scope of the training that health and social professionals require. However the NAS believes the guidance must also highlight the need for training to apply to all professionals who work with children, including in education and child care settings. While we appreciate that the NICE Guidelines only apply to Health and Social Care professionals the complete omission of education professionals raises concerns about a lack of adequate integration and information sharing across services. The need for such integration is a key driver of the Government's reforms of the SEN system as set out in the Children and Families Bill. The NAS believes more work needs to be done to raise awareness and share learning from the guideline across services. Lack of understanding at school often leads to the inappropriate and inefficient use of mental health resources. For example, the NAS was told of the example of a secondary school which reduced TA support for children with autism and the saw schools referrals to CAMHS increase significantly due to increased bullying. Incidents such as this may have been prevented if there was more effective joint working and planning between schools and mental health services. It could be that a greater role could be found for the autism team to engage with education professionals. A lack of training and understanding across health and social care professionals currently causes significant problems. Parents regularly report that they feel that are often not believed when first reporting concerns about their child's development or post-diagnosis when	Thank you for your comment. Although it is outside of the scope, the Guideline Development Group have included education wherever this has been possible, primarily through LEAP and the strategy team, The guideline recommends that the local autism team works with other education, health and social care professions, and the Guideline Development Group would like to draw your attention to recommendation 1.1.3 in the NICE Guideline: "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" Regarding training, the Guideline Development Group have made the following recommendation in 1.1.8 of the NICE Guideline: "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".

							reporting specific health or behavioural problems. As a result of such experiences, some parents with autism report that they become reluctant to involve social services in their lives because they have become aware via other parents, of this lack of understanding. In extreme cases, we hear of parents being accused of fabricated and induced illness.	
141	SH	The UK Society for Behaviour Analysis (UK-SBA)	16	Full	4.6.1.8	175	P 175: lines 39-40: We welcome the recommendation that professionals should receive training in the nature and course of behaviour that challenges in children and young people with autism and the opportunity to work with NICE to implement this.	Thank you for your comment.
142	SH	Royal Manchester Childrens Hospital	14	FULL	4.6	176	And changes to pathway of patient journey in Hospital	Thank you for your comment, the Guideline Development Group is unclear which recommendation your comment is referring to which therefore makes it difficult to respond.
143	SH	Association for Family Therapy and Systemic Practice	9	FULL	4.6.1.11 4.6.1.12 4.6.1.13 4.6.1.14	177	This section highlights the need to work with children and young people with autism and their families and carers to: anticipate major life changes; be involved in decision-making; be provided with information and explanations about autism; and have their personal, social and emotional needs addressed. Systemic family therapists are ideally placed to engage with children with autism and their families in these areas.	Thank you for your comment.
144	SH	National Autistic Society	7	Full	4.6.1.16	178	The NAS welcomes the recommendation for offering training in life skills. However we feel there is a significant omission of skills training in schools. In particular we would add peer mentoring in schools, social skills training and adaptations to be made in school to support unstructured time. The lack of support for unstructured time in school leads to disproportionately high level of informal school exclusions of children with autism. In a survey conducted by the NAS, 32% of parents who responded told us they had to collect their child at lunchtime or before the end of the school day. As many as 19% reported this happening on more than one occasion.	Thank you for your comment. Thank you for drawing attention to this. The Guideline Development Group has noted your comments, but making recommendations to professionals in schools and colleges remains outside the scope of the guideline. Although education is outside of the scope of this guideline, the role of the Local Autism Team and of the Strategy Group is to ensure full collaboration with education providers, as well as with health and social care. This is laid out in the recommendations 1.1.2, 1.1.3, 1.1.6, 1.1.11

							In one case we have been told of a child who has been excluded from school at lunchtime since October 2012. Although the child is supported 1:1 throughout the rest of the day, the school refused to provide a structured activity at lunchtime and is not able to manage challenging behaviour during unstructured time. It is therefore vital that greater emphasis is placed in the guidelines on training education and other professionals to help children with autism cope better with unstructured time at school. This could be dealt with by advising health and social care professionals to work with schools on these issues.	and 1.8.2 in the NICE Guideline.
145	SH	National Autistic Society	10	Full	4.6.1.17	178	The recommendations on transition do not refer to the Autism Act statuary guidance provisions on mental health transition nor to education duties where someone has a statement. These should both be added to the guidelines.	Thank you for your comment. The NICE guideline refers readers to the latest policy documentation about transition in the 'patient-centred care' section.
146	SH	Royal College of Nursing	12	Full	5	179	*INTERVENTIONS* AIMED AT THE CORE FEATURES OF AUTISM	Thank you.
147	SH	The UK Society for Behaviour Analysis (UK-SBA)	4	Full	5.1 – 5.6	179 - 348	**Recommendations in Chapter 5** The UK-SBA fully supports the recommendations in Chapter 5 (section 5.6.1), commends the GDG on their inclusion, and is pleased to see that a number of behavioural studies/interventions were included in the review. As will be apparent from some of the comments above these recommendations are entirely compatible with using Behaviour Analytic principles (and indeed that they may be most effective when accompanied/built on behavioural principles) and the UK-SBA would welcome the opportunity to participate in any further work that develops these recommendations. For example, p 259 point 5.2.6 lines 30-36: all the interventions listed (e.g. parent-child join attention and	Thank you for your comments. Sections 2.13 and 5.2.1 of the Full Guideline have been expanded to include reference to ABA principles and practice. This section has been altered to indicate that some approaches have both a developmental and behavioural perspective Although there may be some apparent similarities between aspects of ABA and aspects of other interventions such as LEAP or PECS, the Guideline Development Group did not find evidence to support ABA and therefore has not made a specific recommendation about ABA. The interventions that are being recommended

							joint engagement etc.) are precisely what good ABA practice can enhance. That the recommendations are entirely compatible with a Behaviour Analytic approach may not be apparent from the early sections of Chapter 5 and we would welcome the opportunity to address some inaccuracies. For example P 179 line 25 correctly asserts that "some aspects of core deficits are developmental in nature" but the section goes on to suggest a dichotomy between those approaches that are developmentally based and others including those based on behavioural principles. This is inaccurate. Behavioural approaches are in fact developmentally informed. P 180 lines 16 – 18 states "*There are no psychosocial interventions with the child/young person or parents/carers that focus specifically on the understanding and management of repetitive, stereotyped or rigid behaviours*" is not accurate. The analysis of behaviour that is at the core of behaviour analytic approaches seeks to understand the function of all behaviour – not just that which challenges and this includes the behaviour listed above. The aim with any Behaviour Analytic approach would be to understand the function of these behaviours with the aim of teaching functionally equivalent replacement behaviours but only for those which present a danger to the individual or others (according to the definition of challenging behaviour, Emerson 2009) or is a barrier to learning for the individual or a barrier to his or her access to peers, social interaction or activities. The UK-SBA accordingly agrees with the recommendation outlined further down the page: lines 14 – 30 and suggest that this is entirely consistent with a behaviour analytic approach.	are those for which the Guideline Development Group has found the best evidence. The Guideline Development Group reviewed the guideline in light of your comments and is satisfied that the guideline accurately reflects the evidence.
14	SH	Contact a	1	Full	5.2.1	190	*Lines 9 – 19*	Thank you for your comment. The point being

8		Family					It says that these have not been evaluated. There has been one promising research study: Ref , Beresford, B., Stuttard, L., Clarke, S., Maddison, J. and Beecham, J. (2012) Managing Behaviour and Sleep Problems in Disabled Children: An investigation into the effectiveness and costs of parent-training interventions, http://php.york.ac.uk/inst/spru/pubs/2192/ The first element of this was a rapid systematic review of the evidence but the second element carried out evaluations of the effectiveness of parent-training interventions for parents of disabled children with sleep problems and parents of disabled children with behaviour problems. This was first published in 2012 but the reference in the full draft guidelines shows a date of 2010. Has GDG considered the evidence from second element of this study?	made in the introduction to this chapter was that even widely accessed parent-training programmes have not been well evaluated. The Guideline Development Group has corrected the date of the Beresford et al paper. The Guideline Development Group considered the study reported to be relevant to the qualitative review of the experience of care. The studies of parent-training interventions cannot be included due to non-randomised group allocation.
149	SH	QUEEN'S UNIVERSITY BELFAST	6	Full	5.2.1. Introduction 4 Psychosocial interventions to improve social and communication 5 outcomes	190 Lines 21-33	No mention of Applied Behaviour Analysis is made here, even if PECS is based on the science of Behaviour Analysis. Also, there is no mention of specific techniques based on Applied Behaviour Analysis that aim to improve social and communication skills, as these have been presented in the last decades in scientific journals such as The Analysis of Verbal Behavior and the Journal of Applied Behaviour Analysis.	Thank you for your comment. Sections 2.13 and 5.2.1 of the Full Guideline have been expanded to include reference to ABA principles and practice. Although there may be some similarities between aspects of ABA and aspects of other interventions such as LEAP or PECS, the Guideline Development Group did not view these as derivative of ABA or a part of ABA. In the review of evidence, the Guideline Development Group found no evidence to support ABA and there for cannot make a recommendation about it.

150	SH	Step by Step School	26	Full	5.2.1	190	This section does not seem to mention EIBI which is well established in UK. The Cochrane review found positive effects of EIBI with expressive language, receptive language and daily communication skills and therefore it seems an oversight not to mention at all	Thank you for your comment. Reference to EIBI has now been made in section 5.2.1 of the Full Guideline.
151	SH	The UK Society for Behaviour Analysis (UK-SBA)	17	Full	5.2.1	190	P 190, line 32-33: PECS is not a specific intervention, and its success, or otherwise, depends entirely on the competency of those using it to (ideally) facilitate the development of vocal verbal behaviour.	Thank you for your comment. The Guideline Development Group agrees and this comment has now been added to section 5.2.1 of the Full Guideline, to the penultimate paragraph of the Psychosocial interventions to improve social and communication outcomes sub section.
152	SH	QUEEN'S UNIVERSITY BELFAST	7	Full	5.2.1. Psychosocial interventions to ameliorate negative impacts of repetitive, stereotyped or rigid behaviours or sensory sensitivities.	191	No mention of Applied Behaviour Analysis is made here, as the scientific basis of effective interventions that aim to reduce the negative impact of repetitive, stereotyped or rigid behaviours or sensory sensitivities.	Thank you for your comment. Sections 2.13 and 5.2.1 of the Full Guideline have been expanded to include reference to ABA principles and practice.
153	SH	British Association for Music Therapy (BAMT)	5	Full	5.2.5	249	We note that Kim, Gold and Wigram (2008) 'The Effects of Improvisational Music Therapy on Joint Attention Behaviors in Autistic Children: A Randomized Controlled Study' (Journal of Autism and	Thank you for your comment. The criteria for inclusion in the review stated that any trial must have 10 or more participants in

							Developmental Disorders 38:1758-66) is not referred to. The trial (n=10) compared improvisational music therapy to play sessions and showed 'significantly more and lengthier events of eye contact and turn-taking in improvisational music therapy than play sessions.' The study is cited in the Cochrane Library (issue 1, 2010) which is included in the Guideline's list of sources for literature review (p.36). We wondered why this study has been excluded?	each arm of the trail. The Guideline Development Group set this method out in the review protocol before beginning the review, and does not believe it would be appropriate to change this approach after having reviewed the evidence.
154	SH	The UK Society for Behaviour Analysis (UK-SBA)	18	Full	5.2.5	249	Page 249, line 1: The Kasari (2006, 2008) studies are often cited as an example of a specific and successful intervention and contrasted with ABA., Joint attention training' is not an intervention, it is simply addressing one of the core deficits associated with autism and is, therefore, just a curriculum area, and ABA is also not an intervention, but the application of scientific principles to human learning.	Thank you for your comment. The Guideline Development Group has clarified social communication intervention.
155	SH	Autism Treatment Trust	7	Full	5.4.1	288	General point made on evaluation of treatment efficacy: Beside the RCT design being unsuitable to evaluate treatment efficacy (see above), there is yet a further complication, associated with the heterogeneity of ASD. The literature in autism does amply support the many physiological, immune and toxic factors that are associated with the condition. Autism is not a single condition but a complex heterogeneous group of syndromes. The majority of the published studies have used broad based behavioural diagnosis of autism as a study group. Until diagnosis is refined treatment evaluation studies are the only option. None the less, the biomedical movement offers many exciting possibilities for intervention that should be embraced more enthusiastically by the medical and scientific	Thank you for your comment. The Guideline Development Group agrees about the heterogeneity of autism and emphasise the importance of comorbidities. The Guideline Development Group acknowledges there are different views with regard to what constitutes the best available evidence when evaluating the effectiveness of interventions, but the Guideline Development Group does not believe there are currently good methods for combining randomised and non-randomised evidence to answer questions about interventions. Therefore, for a particular question, where there was RCT evidence, the Guideline Development Group focused on that evidence and did not search for non-randomised evidence. The Guideline Development Group set this method out in the review protocol before

							communities. Gillberg, C. and Coleman, M. 2000 &1992. The biology of the autistic syndromes. Cambridge University Press.	beginning the review, and does not believe it would be appropriate to change this approach after having reviewed the evidence.
156	SH	Treating Autism	11	Full	5.4.1	288	Since it is now widely accepted that autism is a highly heterogeneous condition, both in presentation and in underlying pathology, it must not be implied, as in line 14, that any single treatment trial, be it behavioural, pharmacological or biomedical, should be expected to show statistical significance across all subgroups. Since not one of the intervention trials reviewed in this guideline took heterogeneity of autism and underlying pathology into consideration, it would be unreasonable to expect any of the interventions to reach statistical significance across all subgroups. This must be stated clearly. This problem is now widely recognised, and illustrated by the recent decision of National Institute of Mental Health itself not to fund any research in future that relies solely on symptomatic diagnosis in cohort recruitment. Inadequately designed treatment trials that do not take account of subgroups, biomarkers or other helpful delineations should not be used by NICE to refute the efficacy of possible treatment modalities. Instead, NICE guidelines should reflect the Fein et al. (2013) and similar research that shows that 'optimal outcomes' are realistic objectives for individuals with ASD. The guidelines should also state that current and future research and treatment modalities must be improved to reflect the complexity and heterogeneity of ASD. Secondly, the criteria used by NICE to rate the quality of interventions must be revised to reflect the clinical complexity and heterogeneity of autism and the fact that in evaluating effects of randomised controlled trials, beneficial effects in a small subset of children may be obscured by the lack of effect in the majority. Anderson M., Zimmerman A.W, Akshoomoff N. et al. (2004) *Autism clinical trials: biological and medical*	Thank you for your comment. As acknowledged in section 2.15 of the Full Guideline, there are many difficulties evaluating the effectiveness of interventions. Having reviewed section 5.4.1 of the Full Guideline, the Guideline Development Group does not believe this section needs to be changed. As can be seen in the review protocol (section 5.1.1) the Guideline Development Group were interested in moderators of treatment effectiveness, but as you make clear, more research needs to be done before the evidence base is sufficient to make clinical practice recommendations for subgroups of children and young people with autism.

							issues in patient selection and treatment response. CNS Spectr. 2004 Jan;9(1):57-64. Bent S. Hendren R.L. (2010) *Improving the prediction of response to therapy in autism*. Neurotherapeutics. Jul;7(3):232-40.	
157	SH	British Association for Music Therapy (BAMT)	6	Full	5.5	348:36-41 (mis-numbered as p.380 in document)	"The GDG judged that socio-communication interventions should be recommend for children with autism and, where they are delivered, should include common core elements of being play-based and including training for the intervention administrator / mediator (care-giver, teacher or peer) on strategies for increasing reciprocal social communication and interaction". This (and section 5.6.1.2, p.350) describes everything music therapists working with children with ASD and their families do. Even if there is at present not enough hard RCT evidence to 'prove' that these interventions are effective, they are already occurring in many places in the UK and are described in the literature. They should not be completely ignored in such a long report that mentions many other interventions which are less widespread (e.g. horse riding).	Thank you for your comments. The guideline does not dictate which professional should deliver the social communication intervention but emphasises the core features/components of the intervention
158	SH	Royal College of Nursing	14	Full	6	349	*INTERVENTIONS* AIMED AT BEHAVIOUR THAT CHALLENGES	Thank you.
159	SH	The UK Society for Behaviour Analysis (UK-SBA)	5	Full	6.1 – 6.7	349 - 447	**Recommendations in Chapter 6** The UK-SBA broadly welcomes the recommendations in Chapter 6 section 6.7.1. Concern about some of the terminology used and the need for professional training for those conducting functional analyses (and adherence to ethical guidelines) has already been noted above. The UK-SBA would also like to offer its assistance in reviewing this section, in particular with a view to making it more rigorous for example suggesting ways in which the measures recommended can be made accountable and ensuring that decision	Thank you for your comment. Section 5.2.1 of the Full Guideline has now been expanded with more explicit reference to ABA.

							making in relation to interventions proposed is evidence based (at the level of the individual).	
160	SH	Royal College of Nursing	15	Full	6.2	357	Psychosocial *interventions* aimed at behaviour that challenges	Thank you.
161	SH	College of Occupational Therapists	2	Full	Table 9	363	Spelling typo "…assessed using th(e) Stanford…"	Thank you for your comment, this has been corrected.
162	SH	Royal College of Nursing	17	Full	6.3	377	Pharmacological *interventions* aimed at behaviour that challenges	Thank you.
163	SH	Autism Treatment Trust	8	Full	6	380	The evaluation of treatment protocols presented in the overall guidelines does not take into account of the true limitations of trials (as stated above) and tend to reject the conclusions of a given study, based on maladjusted criteria of evaluation. Consequently, the conclusions reached by NICE appeared as bias and as being reached with non-scientific motives.	Thank you for raising this issue. As described above, the Guideline Development Group accepts that there are different perspectives when it comes to evaluating the evidence. However, the Guideline Development Group set out the approach in the review protocol before beginning the review, and the GRADE approach means that the recommendations are based on transparent decisions. The Guideline Development Group rejects the assertion that these were reached using non-scientific motives.
164	SH	Treating Autism	12	Full	5.4.6	380	Page numbering is incorrect: page numbers skip from 337 to 380, and many pages are then numbered the same, as 380!	Thank you for your comment, the page numbering has now been corrected.
165	SH	Treating Autism	13	Full	6	380 *(see previous comment re incorrect page numbering in the*	The following comment refers to the whole of section 6 INTERVENTIONS AIMED AT BEHAVIOUR THAT CHALLENGES Much greater emphasis needs to be placed on the potential causative role of medical comorbidities in challenging behaviour, particularly of severely affected children and young people who are unable verbally to communicate pain. It needs to be clearly stated that there is a real danger of 'diagnostic overshadowing', in that medical problems may easily be overlooked and behaviours mistakenly assumed to be psychological in	Thank you for your comment. The Guideline Development Group considered your concern, and believe that the guideline has emphasised this already with the recommendation in section 1.4 in the NICE Guideline, Interventions for behaviour that challenges. The guideline clearly recognises that autism exists commonly with a number of other conditions, both psychological and physical. When behaviour becomes challenging, the guideline already recommends that other

						draft document)	origin. Medical problems that are common in individuals with autism and that should be screened for in such situations can include, amongst others: toothache, headache, gastrointestinal reflux, oesophagitis, tonsillitis/sore throat, chronic painful constipation (underlying cause will be relevant), chronic diarrhoea, ear infection, respiratory infection, urinary infection, glue-ear, allergy disorders, seizure disorders, arthritis, fractures, severe sleep disturbances. According to current NICE guidelines on constipation, symptoms of constipation can include, amongst others "***abdominal pain, distension or discomfort, poor appetite, lack of energy, an unhappy, angry or irritable mood and general malaise***. *… It has been suggested that some healthcare professionals underestimate the impact of constipation on the child or young person and their family. This may contribute to the poor clinical outcomes …*". Since these very symptoms are routinely dismissed by health care professionals as 'just part of autism', this Guideline must draw attention to this issue. The Buie et al. (2010) study makes it clear that in autism the underlying cause of constipation will be relevant. NICE guideline should educate health professionals that "*unhappy, angry or irritable mood and general malaise"* should never be dismissed as 'autism behaviours', and state clearly that medical professionals must be aware and informed of common behavioural manifestations of health problems in autism, including constipation. A paper by Tracy and Wallace (2001) draws attention to the importance of clinicians being informed on how developmental disability can profoundly affect the presentation of many relatively common medical conditions. Examples from clinical practice of	possible causes, apart from autism itself, should be considered. This is a standard approach through the guideline. The Guideline Development Group reviewed the guideline in light of your comments and feels that the guideline has the correct balance between treatment of autism and treatment and management of coexisting conditions. The guideline is obviously not able to detail all possible coexisting conditions, and has therefore given examples of those that are more likely to occur.

							behavioural presentations of physical illness are given, including many extreme behaviours such as screaming, biting, head banging, and aggression. Assessment of these patients often reveals medical conditions such as gastro-oesophageal reflux, fractures, infections and constipation, with the conclusion that many of those behaviours are often probably indicators of physical discomfort. Jyonouchi (2010) points out that care providers "*should be aware of the potential impact of allergic diseases on behavioralsymptoms and cognitive activity in ASD children*." In addition to stressing that behavioural and/or pharmacological interventions for behaviour that challenges can only be instigated once detailed medical investigations have been carried out and no physical cause has been identified, NICE guideline should include more specific recommendations to health professionals. **Basic recommendations should be made with regards to screening for common physical/medical problems that may be causing aberrant symptoms and behaviours in children and young people with autism.** Buie, T., Campbell, D.B., Fuchs, G.J., et al. (2010) *Evaluation, diagnosis, and treatment of gastrointestinal disorders in individuals with ASDs: a consensus report.* Pediatrics, 125: (Supplement 1): S1-S18. Furuta, G.T., Williams, K., Kooros, K., et al. (2012) *Management of Constipation in Children and Adolescents With Autism Spectrum Disorders*. Pediatrics, 130: (Supplement 2): S98-S105. Jyonouchi, H. (2010) *Autism spectrum disorders and allergy: observation from a pediatric allergy/immunology clinic.* Expert Review of Clinical	

							Immunology, 6: (3): 397-411 Tracy J.M., Wallace R. (2001) *Presentations of physical illness in people with developmental disability: the example of gastro-oesophageal reflux.* Med J Aust. Jul 16;175 (2):109-11	
166	SH	Royal College of Nursing	18	Full	6.4	404	Biomedical *interventions* aimed at behaviour that challenges	Thank you.
167	SH	College of Occupational Therapists	4	Full	6.4.2	409	Need to state how many complementary therapy studies were used at the beginning of the section to provide some context.	Thank you for your comment. The Guideline Development Group believes section 6.4.1 of the Full Guideline, Studies Considered, provides this context and it outlines the number of complementary studies that were included.
168	SH	Peach	2	Full	6.6	446	The term 'functional analysis' should be changed to 'functional assessment'. Functional analysis is a technical term for a specific technique that can only be run by qualified personnel e.g. behaviour analysts. It requires putting the individual into a situation where the challenging behaviour is likely to be exhibited. This has obvious ethical implications and so shouldn't be recommended as a general practise.	Thank you for your comment. The Guideline Development Group now uses the term functional assessment of behaviour to avoid misinterpretation
169	SH	Autism Treatment Trust	9	Full	6.6	446 and 447	Generally there is insufficient advice to guide practitioners to understand deviant behaviours as well as potential root causes of these behaviours. See further comment in the attached document submitted for Topic Engagement exercise on Quality Standard (attached document).	Thank you for your comment. The Guideline Development Group agrees that there is insufficient evidence to guide understanding of behaviour and its 'causes, although there is probably quite a lot of contradictory advice. However, the Guideline Development Group cannot consider documents submitted outside of this consultation process and developing the quality standards are not addressed as part of this guideline, therefore the Guideline Development Group cannot respond to it.
170	SH	Treating Autism	14	Full	6.6	446 and 447	With regards to the use of antipsychotics for behaviour that challenges: in addition to stating that '*a functional analysis of behaviour should be a core component of treatment*' it needs to be stressed clearly here again that care providers must be aware that common	Thank you for your comment. The Guideline Development Group agrees and it is emphasised in recommendation 1.4.1 in the NICE Guideline:

							medical problems can manifest in individuals with autism as behaviours that challenge. It also should be stressed that when pain is the underlying reason for the behaviour that challenges, antipsychotic may further worsen the pain and worsens the behaviour that challenges. Tracy J.M., Wallace R. (2001) *Presentations of physical illness in people with developmental disability: the example of gastro-oesophageal reflux.* Med J Aust. Jul 16;175 (2):109-11	"...Assess factors that may increase this risk, including: • Coexisting physical disorders, such as pain or gastrointestinal disorders • Coexisting mental health problems (such as anxiety or depression) and other neurodevelopmental conditions (such as ADHD)...
171	SH	Autism Parents for ABA (APA)	2	Full	6.6/6.7	446-451	On challenging behaviour, although we welcome the NICE guidance's recommending of ABA methods, eg functional behavioural analysis, there is no requirement to consult or utilise the expertise of professional Behaviour Analysts. This is an anomaly, given that in other sections you do recommend consulting the relevant experts, eg a sleep expert for sleep problems. It appears therefore as if you are recommending behaviour analysis-lite, delivered by well-meaning but wholly untrained staff? An ABA consultant will have trained at Masters level, have 270 hours of Behavior Analyst Certification Board (BACB) approved training, and will have conducted atleast 1500 hours of supervised practice before passing the BCBA (Board Certified Behaviour Analysis) examination. (See www.bacb.com for lists of certificants). Would they not be a good resource to tap into?	Thank you for your comment. In the review of evidence, the Guideline Development Group found no evidence to support ABA and there for cannot make a recommendation about it. The Guideline Development Group has made a general recommendation that when providing interventions for children and young people with autism, professionals should be competent to do this. However, the guideline does not recommend the use of ABA, and therefore it is inappropriate to recommend individuals trained in ABA to carry our interventions in this guideline.
172	SH	Royal College of Nursing	20	Full	7	448	*INTERVENTIONS* AIMED AT ASSOCIATED FEATURES OF AUTISM AND COEXISTING CONDITIONS	Thank you.
173	SH	National Autistic Society	5	Full	6.7.1.2	449	The Guidance recommends the development of "a care plan that identifies factors that may provoke behaviour that challenges and outline the steps	Thank you for your comment. The guideline does not recommend who should write the care plan, as NICE guidelines do not generally

							needed to address them” The guidelines are unclear on whether a care plan should be developed for every child with autism. Moreover it is unclear who would write the plan and be responsible for implementing it. There should be greater clarity on who will be offered care plans and who will be responsible for implementing them. If key workers are to be responsible for care plans they must be sufficiently trained in autism.	specify professional roles, because interventions and care should be delivered by health care professionals with the relevant competencies and experience. Protocols should be developed locally to cover these issues. The Guideline Development Group believes that the guideline already addressed the issue you raised regarding a care plan for every child or young person with autism, as the guideline recommends a case manager or key worker for every child or young person with autism – please see recommendation 1.1.4 in the NICE Guideline: “Local autism teams should ensure that every child or young person diagnosed with autism has a case manager or key worker.”
174	SH	The UK Society for Behaviour Analysis (UK-SBA)	19	Full	6.7.1	450	Page 450, line 2: The UK-SBA welcomes the recommendation of the use of a functional behaviour analysis but as noted above is concerned that one needs significant training and experience to be able to conduct such an assessment. To do otherwise is unethical and potentially dangerous.	Thank you for your comment. The Guideline Development Group has emphasised training in autism as essential for anyone working with a child, young person or their family who has autism. An important general principle is that professionals should not work beyond their skill level. Please see recommendation 1.1.8 in the NICE Guideline: “Health and social care professionals working with children and young people with autism in any setting should receive training in autism awareness and basic skills in managing autism...”
175	SH	National Autistic Society	6	Full	6.7.1.10	450	The NAS has concerns about the use of anti-psychotic medication for managing challenging behaviour. We believe the root causes of challenging behaviour can be masked by the use of such medication and impede understanding of the causes of such behaviour. We	Thank you for your comment. Hierarchical approach is outlined throughout section 1.4, Interventions for Behaviour that Challenges, of the NICE Guideline.

							are not convinced that the benefits of such medication outweigh the harms as the evidence from clinical trials is weak. There is a risk that such medications may be used instead of psycho-social interventions and become a first or second line treatment. The guidelines do state that anti-psychotic medications should be considered when psycho-social interventions have failed but we feel stronger safeguards are needed. The NAS believes the guidance should be much clearer on emphasising that for challenging behaviour anti-psychotics should not be used unless it can be demonstrated that they have a specific therapeutic purpose. We agree that this needs to be overseen by a specialist.	The guideline clearly states that antipsychotics should only be prescribed by a specialist and only after psychosocial and other interventions are insufficient (recommendation 1.4.10 in the NICE Guidelin). The use of antipsychotics in the context of behaviour that challenges is not for their specific antipsychotic actions; antipsychotics are used as a last resort after having tried other non- pharmacological interventions when behaviour that challenges in a wide range of different metal health conditions, including dementia, schizophrenia and psychosis, or in any other context. In none of these contexts are the antipsychotics being used for their antipsychotic properties, rather for their sedating and calming effects, and to reduce autonomic arousal.
176	SH	British Association for Music Therapy (BAMT)	7	Full	7.3.3	508:1	The studies reported in this section are not ‘arts-based’ but specifically ‘music therapy-based’ and relate to practice delivered by a qualified music therapist. We recommend the heading for this section is changed to reflect this e.g. ‘Music Therapy based interventions for speech and language as a direct outcome.’ Similarly throughout this section replace ‘arts based’ with ‘music therapy based.’	Thank you for your comment. Reporting of studies has followed the descriptions used by the relevant authors.
177	SH	Autism Parents for ABA (APA)	4	Full	7.3.9/7.3.10	546	Perhaps some SALTs will tell you - "ABA speech isn't real speech, it's not intrinsic but rote-learned". Now although some children at the higher end of the autistic spectrum will gain normal speech through ABA (or indeed SALT), we are very painfully aware that some of our children may only develop limited speech or language, and will certainly never rival Stephen Fry as conversationalists. But my gosh, life is easier for us autism parents (and the teachers, and the carers who will take	Thank you for your comment The Guideline Development Group reviewed the guideline in light of your comments and came to the view that the guideline accurately reflects the evidence as it stands, and did not think that the evidence supported recommendations for specific professions. The Guideline Development Group did not wish to recommend ABA or SALT, and although there are many professionals providing these interventions, the Guideline Development Group did not feel that they could recommend these interventions, nor

							over when we are dead) if a child has hundreds/thousands of words and phrases such as "toilet" or "juice" or "head hurts". We parents call it real, functional speech, even if it is not seen as fluent in academic terms. We believe you may be denying thousands of autistic children a voice, literally, if this guidance goes ahead as it stands. If there is no appetite for a wholesale revamp of autism SALT in this country, possibly for economic reasons, could NICE not perhaps recommend greater collaboration between SALTs and ABA professionals? Or even some ABA training modules for SALTs?	recommend how the professionals should interact. Obviously with the variation in clinical practice and in social care that currently exists in the field, it is important that the Guideline Development Group adheres as closely as possible to the evidence base to help the field, unify and reduce the variation.
178	SH	Autism Parents for ABA (APA)	3	Full	7.3.9/7.3/10	546	On speech, we feel that NICE has failed to recognise that much of the SALT provision in this country is simply not fit-for purpose in dealing with the particular social communication problems of autism – neither in terms of resourcing nor expertise. We do not blame the SALTs themselves as, in the absence of any other autism professionals on the scene, they are being thrown into the front line daily with no budget or extra training. Often they don't even get the budget to deliver therapy themselves directly, but just visit once a term and leave the poor teacher or LSA with a few ideas. Unsurprisingly, it doesn't work well. SALTs are great on speech *production* problems; less so on speech *motivation* problems. They are not trained, as are ABA professionals, in the need for differential motivation of children with autism. Put simply, for many children with autism, it may not be that they can't talk, but that they'll not see the point in talking. The social deficits of autism mean that children on the spectrum are quite happy to drag mummy or teacher to what they want, rather than use words. ABA uses the child's own particular interests to encourage words; it is called	Thank you for your comment which graphically illustrates the need for autism expertise in any professional working with children and young people with autism. To address this, the Guideline Development Group made recommendation 1.1.8 (NICE Guideline), regarding knowledge and competence of health and social care professionals.

							"mand" training,it is a simple yet effective technique – yet without it, we believe many of our children might never have spoken their first word.SALTs are also not made aware of the need first to teach autistic children basic skills of imitation, and they are not trained in the only proven technique which will turn echoed speech into functional (the "echoic to mand"transfer protocol). We would like to see many more autistic children benefiting from ABA based interventions - whether delivered at home, in ABA schools or in mainstream schools via LSAs trained in ABA. To illustrate the point starkly, several parents on the list have been signed off by the SALT service on the grounds: "sorry, if it's autism speech problems we can't help".	
179	SH	National Autistic Society	9	Full	7.3.10.1	546	We have some concern that the recommendation on providing speech and language therapy for those with receptive and expressive language difficulties may lead to overly narrow interpretations of when it should be used. These are not the only communication difficulties in autism. Social communication and interaction are both key features of the triad of impairments, and are equally as important as receptive and expressive language skills in terms of benefitting from Speech and Language Therapy input.	Thank you for your comment. We have addressed your concern by removing this recommendation, based on your comment. The local autism team is defined in the Autism diagnosis in children and young people: Recognition, referral and diagnosis of children and young people on the autism spectrum guideline (CG128), and states that speech and language therapists must be included, as it is a real need. Speech and language should be assessed on the basis of the evidence. The guideline recommends that certain interventions should not be used: please see the following recommendations in the NICE Guideline: 1.7.10 “Do not use neurofeedback to manage speech and language problems in children and young people with autism.”

								and 1.7.11 “Do not use auditory integration training to manage speech and language problems in children and young people with autism”. However, the Guideline Development Group did not find specific concrete evidence for specific interventions for speech and language therapy. So whilst the Guideline Development Group believed that speech and language must be assessed, it cannot specify what should be done in particular, just that it should be included.
180	SH	British Psychological Society	8	Full	7.5	561	The importance of the causal-model-in-use is highlighted by the way the sensory sensitivities associated with autism are construed in the literature. Although specific sensory processing abnormalities in individuals diagnosed with autism are well-documented (e.g. Milne et al., 2002; Plaisted et al., 2003), findings are often seen as contradictory or inconclusive (e.g. Rogers &Ozonoff, 2005) because individuals diagnosed with autism are - as a consequence of the diagnostic process - implicitly assumed to have the same underlying condition (Gerrard&Rugg, 2009). Although it acknowledges the heterogeneity of autism, the consultation document frames sensory sensitivities, not in terms of specific abnormalities in specific sensory modalities in specific *individuals*, but at the *group level.* It also frames sensory sensitivities in terms of hyper/hypo-sensitivities to sensory stimuli, or in terms of sensory integration, despite the questionable evidence base for both these theoretical models, to which the American Academy of Pediatrics has recently drawn attention. There is a substantial literature on sensory	Thank you for your helpful comment. Section 7.5.1 in the Full guideline has been updated with your suggested wording.

							abnormalities and autism, but section 7.5.1 refers only to an anecdotal account by Temple Grandin and a paper on developmental patterns, both over 20 years old, and fails to cite more recent and comprehensive review papers such as Rogers &Ozonoff (2005) or Marco et al. (2011). **Recommendation:** **That the first part of paragraph 7.5.1 be rewritten along the following lines;** **Sensory sensitivities associated with autism have most frequently been framed in terms of over or under sensitivity or poor sensory integration, both models reflecting theories about information processing and brain function current in the 1960s and 1970s. The evidence supporting these models has been called into question by recent developments in neuroscience, as has the efficacy of sensory therapies (American Academy of Pediatrics, 2012). Reviews of the literature suggest that sensory processing varies considerably between individuals with autism (Rogers &Ozonoff, 2005; Marco et al, 2011). Sensory sensitivities may be implicated in rigid behaviours and stereotypical and/or self-stimulatory behaviours such as spinning, hand flapping or rocking. Sensory difficulties can have a significant impact on the daily lives of children with autism, for example, extreme reactions to certain sights, sounds and textures, and their ability to adjust to new environments. Eating problems are also often associated with sensory problems. References** **American Academy of Pediatrics (2012). Policy statement: Sensory integration therapies for children with developmental and behavioral disorders, Pediatrics, 129, 1186 -1189.** **Gerrard, S. &Rugg, G. (2009). Sensory impairments and autism: A re-examination of causal modelling Journal of Autism and Developmental Disorders**	

							39, 1449-63. **Marco, E.J., Hinkley, L.B.N., Hill, S.S. &Nagarajan, S.S. (2011). Sensory processing in autism: A review of neurophysiologic findings, Pediatric Research** **69, 48-54.** **Milne, E., Swettenham, J., Hansen, P., Campbell, R., Jeffries, H. &Plaisted, K. (2002). High motion coherence thresholds in children with autism. Journal of Child Psychology and Psychiatry, 43, 255-263.** **Plaisted, K., Saksida, L., Alcántara, J. &Weisblatt, E. (2003). Towards an understanding of the mechanisms of weak central coherence effects: Experiments in visual configural learning and auditory perception. experiments in visual configural learning and auditory perception, Philosophical Transactions of the Royal Society of London B. 358, 375–386.** **Rogers, S. &Ozonoff, S. (2005). Annotation: What do we know about sensory dysfunction in autism? A critical review of the empirical evidence. Journal of Child Psychology and Psychiatry, 46, 1255-1268**	
181	SH	National Autistic Society	8	Full	5.9	571	We spoke to a number of parents and a range of professionals in developing our response. Key concerns were raised about the lack of recommendations for addressing sensory difficulties. The NAS believes more weight should be given to the steps needed to be taken to manage sensory difficulties. The lack of access to OTs and Sensory OTs in particular was cited by one parents group as the single biggest issue voiced by parents in relation to support for their children. Others have highlighted that OT input is important for addressing other difficulties such as fine and gross motor movements which may or may not result from sensory sensitivities. While the	Thank you for your comment. Occupational Therapists with autism expertise are recommended members of the autism team as in the Autism diagnosis in children and young people: Recognition, referral and diagnosis of children and young people on the autism spectrum guideline, NICE CG 128. The Guideline Development Group regarded sensory sensitivities to be a very important aspect of the experience of children and young people with autism. Nonetheless, there is a lack of evidence about what precisely to do about sensory sensitivities. The Guideline Development Group has made a research

							NAS understands a larger evidence base may be needed, we believe greater priority should be put on ensuring further research to assess the impact and benefit of Occupational Therapists.	recommendation on sensory sensitivities in section 7.5.10.1 of the Full Guideline.
182	SH	College of Occupational Therapists	5	Full	7.5.9	571	The discussion in this section is too brief and should recognise that there are case studies that demonstrate positive changes for participation and family life for children with sensory processing difficulties and autism through the use of environmental adaptations or sensory integration based therapeutic intervention.	Thank you for your comment. The Guideline Development Group acknowledges there are different views with regard to what constitutes the best available evidence when evaluating the effectiveness of interventions but the Guideline Development Group does not believe there are currently good methods for combining randomised and non-randomised evidence (including case studies) to answer questions about interventions. Therefore, for a particular question, where there was RCT evidence, the Guideline Development Group focused on that evidence and did not search for non-randomised evidence. The Guideline Development Group set this method out in the review protocol before beginning the review, and does not believe it would be appropriate to change this approach after having reviewed the evidence. Due to the lack of evidence relating to this important topic, the Guideline Development Group felt it was necessary for a research recommendation be made to address this issue, please see section 7.5.10.1 of the Full Guideline.
183	SH	Autism Treatment Trust	10	Full	7.7.1	581	The guidelines here need to recommend that health professionals should consider screening for medical problems, including allergies and gastrointestinal problems, in anxious or irritable individuals with ASD. Mazurek, M.O., Vasa, R.A., Kalb, L.G., et al. (2012)	Thank you for your comment. The Guideline Development Group agrees and have emphasised this in recommendation 1.4.1 in the NICE Guideline: ‘Assess factors that may increase the risk of

							Anxiety, Sensory Over-Responsivity, and Gastrointestinal Problems in Children with Autism Spectrum Disorders. Journal of Abnormal Child Psychology, Aug 1: 1-12. Chen, M.-H., Su, T.-P., Chen, Y.-S., et al. (2013) *Comorbidity of allergic and autoimmune diseases in patients with autism spectrum disorder: A nationwide population-based study.* Research in Autism Spectrum Disorders, 7: (2): 205-212. Klein, G.L., Ziering, R.W., Girsh, L.S., et al. (1985) *The allergic irritability syndrome: four case reports and a position statement from the Neuroallergy Committee of the American College of Allergy*. Annals of allergy, 55: (1): 22. Price, C.E., Rona, R.J. and Chinn, S. (1990) *Associations of excessive irritability with common illnesses and food intolerance*. Paediatric and perinatal epidemiology, 4: (2): 156-160.	behaviour that challenges in routine assessment and care planning in children and young people with autism, including:... • coexisting physical disorders, such as pain or gastrointestinal disorders • coexisting mental health problems such as anxiety or depression and other neurodevelopmental conditions such as ADHD...'
184	SH	Treating Autism	15	Full	7.7.1	581	Following the statement (line 22): *'Other issues commonly associated with autism such as sensory sensitivities, sleep, feeding and gastrointestinal problems and medical problems such as epilepsy may also impact on the child's mental health, perhaps contributing to heightened levels of anxiety and other behavioural symptoms*.' the Guideline here needs to recommend health professionals should consider screening for medical problems, including allergies and gastrointestinal problems, in anxious or irritable individuals with ASD. Mazurek, M.O., Vasa, R.A., Kalb, L.G., et al. (2012) *Anxiety, Sensory Over-Responsivity, and Gastrointestinal Problems in Children with Autism Spectrum Disorders*. Journal of Abnormal Child Psychology, Aug 1: 1-12. Chen, M.-H., Su, T.-P., Chen, Y.-S., et al. (2013) *Comorbidity of allergic and autoimmune diseases in patients with autism spectrum disorder: A nationwide*	Thank you for your comment. The Guideline Development Group agrees and have emphasised this in recommendation 1.4.1 of the NICE Guideline: 'Assess factors that may increase the risk of behaviour that challenges in routine assessment and care planning in children and young people with autism, including:... • coexisting physical disorders, such as pain or gastrointestinal disorders • coexisting mental health problems such as anxiety or depression and other neurodevelopmental conditions such as ADHD...'

							population-based study. Research in Autism Spectrum Disorders, 7: (2): 205-212. Klein, G.L., Ziering, R.W., Girsh, L.S., et al. (1985) *The allergic irritability syndrome: four case reports and a position statement from the Neuroallergy Committee of the American College of Allergy*. Annals of allergy, 55: (1): 22. Price, C.E., Rona, R.J. and Chinn, S. (1990) *Associations of excessive irritability with common illnesses and food intolerance*. Paediatric and perinatal epidemiology, 4: (2): 156-160.	
185	SH	Royal College of Nursing	21	Full	8	629	*INTERVENTIONS* AIMED AT IMPROVING THE IMPACT ON THE FAMILY	Thank you.
186	SH	Association for Family Therapy and Systemic Practice	10	FULL	8.1	633	This section summarises the fact that autism is both a life-long neurological condition and that autistic behaviours may have a significant influence on the interactions of family members and that the interactions of family members may significantly influence presenting autistic behaviours. As is stated, autistic behaviours influence parental stress levels just as parental stress levels influence autistic behaviour. This example of circular – rather than linear, unidirectional – communication fits with the core systemic concept of circular patterns of communication and provides a strong rationale for the establishment of designated family therapists in specialist multidisciplinary teams.	Thank you for your comment which supports the statement about interaction within families in Section 8.1.
187	SH	Royal College of Nursing	22	Full	8.2	634	Psychosocial *interventions* aimed at improving the impact of autism on the family	Thank you
188	SH	Royal College of Nursing	23	Full	8.3	644	Pharmacological *interventions* aimed at improving the impact of autism on the family	Thank you
189	SH	Royal College of Nursing	24	Full	8.4	645	Biomedical *interventions* aimed at improving the impact of autism on the family	Thank you
19	SH	The UK	20	Full	8.2.2	645	P 645 “Current Practice” on impact on families: cites	Thank you for your comment and offer of help.

0		Society for Behaviour Analysis (UK-SBA)					lack of access to evidence-based or specialised help. Few parents get parent training. This is an area where training for parents and families that incorporates some basic behavioural principles would be really helpful – as reflected in research recommendation 2.2 (page 30 of the executive summary) - which on p 31 talks about "e.g. educating parents about simple functional behaviour analysis to identify triggers and examine patterns of reinforcement", and the UK-SBA would be happy to provide guidance on how this might be achieved.	We will pass on your comment to the NICE implementation advisor..
191	SH	Royal College of Paediatrics and Child Health	7	Appendices	General	General	We know that many people struggle to access services like CAMHS, and in particular to get a diagnosis if they are referred to them. Too often anxiety and other mental ill health are attributed to the diagnosis of autism itself. Autism does not always mean anxiety disorder.	Thank you for your comment. The guideline does give fairly comprehensive guidance about which teams should provide or broker services for children and young people with autism and their families (see Section 1.1 of the NICE guideline). It also gives guidance on how to manage coexisting conditions, including mental health problems such as anxiety (see Section 1.7 of the NICE guideline).
192	SH	Autism Treatment Trust	12	NICE	General	General	*Please see comments submitted for Topic Engagement exercise on Quality Standard (attached document)*	Thank you for your comment. The Guideline Development Group cannot respond to comments made outside of this consultation process, and Quality Standards are not addressed as part of this guideline.
193	SH	British Association for Music Therapy (BAMT)	8	NICE	General	General	The committee appear to have decided not to mention professions by name in the main body of the guidelines (although the use of the term 'speech and language expert' on p.26 is anomalous – if 'speech and language therapist' is not the intended meaning, what is meant?) The absence of professional titles/trainings is not helpful for two reasons: 1) Service providers/commissioners are given no guidance on what kind/level of training is appropriate in the delivery of services for children and young people with autism, and;	Thank you for your comment. The standard term that the guideline uses is healthcare professional unless there are very good reasons to specific, such as prescribing of controlled drugs, some particular role within the NHS (e.g. the coordinating role and gatekeeping role of GPs), or some other statutory duty which rests with a particular professional group (e.g. social work roles). The Guideline Development Group is not concerned with professional roles per se, but with interventions and care being delivered by healthcare professionals with the relevant

							2) Services such as music therapy which are often provided by e.g. education services or charities (i.e. non-NHS provision) may as a result not be recognised among the services that are locally available and which are, or could be, contributing significantly to care and treatment of children and young people with autism.	competencies and experience. The term 'speech and language expert' has now been removed. The Guideline Development Group did consider training issues and made recommendations where it felt it was necessary. Regarding services such as music therapy, there was not sufficient evidence to warrant making a recommendation for these interventions.
194	SH	British Paediatric Mental Health Group	4	NICE	General	General	The glaring hole in the middle of this guidance is the complete absence of any mention of schools as important providers of support and intervention for CYP with autism. This seems bizarre and counter-productive. Any barriers to schools' inclusion in this guidance ought to be removed as a matter of urgency.	Thank you for drawing attention to this. The Guideline Development Group has noted your comments, but making recommendations to professionals in schools and colleges remains outside the scope of the guideline. Although education is outside of the scope of this guideline, the role of the Local Autism Team and of the Strategy Group is to ensure full collaboration with education providers, as well as with health and social care. This is laid out in the recommendations 1.1.2, 1.1.3, 1.1.6, 1.1.11 and 1.8.2 in the NICE Guideline.
195	SH	British Psychological Society	30	NICE	General	General	The Society recommends that the document includes more frequent references to education throughout the guidance. Where references are made to 'health and social care' the substitution of 'health, social care and education' professionals/services would be more representative of the services needed/used.	Thank you for drawing attention to this. The Guideline Development Group has noted your comments, but making recommendations to professionals in schools and colleges remains outside the scope of the guideline. Although education is outside of the scope of this guideline, the role of the Local Autism Team and of the Strategy Group is to ensure full collaboration with education providers, as well as with health and social care. This is laid out in the recommendations 1.1.2, 1.1.3, 1.1.6, 1.1.11 and 1.8.2 in the NICE Guideline.

196	SH	College of Mental Health Pharmacy	1	NICE	General	General	On pages 12 and 24 it is correctly stated that antipsychotic medication should be considered for managing behaviour that challenges. It is acknowledged that co-morbid conditions may require medication, for example see page 27 paragraph 1.9.1. With this in mind we suggest that under paragraph 1.1.10 'Information and involvement in decision making', it be stated that **'the young person, families or carers be offered the services of a specialist mental health pharmacist when medication is to be used**.' It is acknowledged in the Full version that it is a distressing time for the person with autism, their families and carers when diagnoses are made and how medication is handled. It is our experience that when patients and carers are given the opportunity to discuss medication issues with a specialist mental health pharmacist some anxieties are allayed and a better informed decision is reached on how medication is used.	Thank you for your comment. The Guideline Development Group felt that issues around prescribing antipsychotic medication were adequately covered in section 1.4 of the NICE guideline. Section 1.1.1 contains general principles of care and as such it would not be appropriate to raise the issue of medication here, which is only recommended for severe challenging behaviour or as a second-line treatment for challenging behaviour.
197	SH	Contact a Family	2	NICE	General	General	*The guidance needs to be strengthened to provide the vision for a much more integrated service with education and social care and between secondary and primary care health services.* *What is the GP practices role in providing support for children on the ASD spectrum and their families when they have been discharged from paediatric services.* There is often an assumption that when children diagnosed with autism are discharged from paediatric services they receive appropriate support from education and social care. Contact a Family regularly hear from families who have been discharged from paediatric services without information or support to help them cope with the consequences of looking after a child with autism. Chapter 4 in the full autism guidelines provides ample	Thank you for your comment. The guidance is quite clear that there should be an integrated approach including all disciplines in health and social care (see the local autism team and the strategy group). The guideline covers all parts of health and social care and gives guidance on transition from children's services to adult services. However, the important role for primary care in identifying children at an early stage who may have autism spectrum disorders is covered in the Autism: recognition, referral and diagnosis of children and young people on the autism spectrum guideline (NICE CG 128), and not in this guideline. The points you raise about variability in the

							evidence (100 research papers) to support this. It shows that families are not being provided with information and support, are having to fight for services and parent carers want support and interventions to assist them with the challenges they face including behaviour that challenges and sleep. Sleep and behaviour problems can have a huge impact on the whole families health and wellbeing. Challenging behaviour puts immense strain on the whole family. If the child does not sleep this often means the rest of the family does not sleep. Currently there is a postcode lottery regarding which parents receive information and training to support them with these leading to health inequalities. Many families are not aware such interventions exist and only find out later often when their child's challenging behaviour brings the family to crisis point. This lack of support can have long term consequences on health outcomes for the whole family. Also not providing early interventions leads to heavier uses of social services and specialist education services as well as increasing referrals to CAMHS later on when the family hits crisis point.	provision of information are dealt with in sections 1.1 and 1.2 of the NICE Guideline, which make recommendations on information for children, young people and to families and carers. Support for carers is specifically given in section 1.2 of the NICE Guideline. There is little evidence on the effective management of sleep in children and young people with autism but the Guideline Development Group gives guidance on the basis of the best evidence available in recommendations 1.7.4 to 1.7.9 in the NICE Guideline. There is also section 1.4 in the NIVE Guideline on Interventions for behaviour that challenges. The Guideline Development Group agrees that there is much variability in service provision for children and people with autism, hence the need for this suite of guidelines.
198	SH	Department for Education	1	NICE	General	General	I understand that the guideline is directed at health and social care professionals but I was surprised that, apart from occasional mentions of teachers and schools, there wasn't much emphasis on the importance of health and social care professionals working closely with teachers and schools. Given that most social-communication, behaviour and speech and language interventions are delivered in schools I would have thought the need for health and social care to work with education should be highlighted. Similarly there is a statutory transition planning process for children with "statements" of special educational needs – children would benefit if this process was linked in with any	Thank you for your comment. The Guideline Development Group agrees that effective provision of services should include an integrated approach with health, social care and education. The guideline does identify the need for an autism strategy team which should include education, as described in the previous two guidelines on Autism: recognition, referral and diagnosis of children and young people on the autism spectrum (NICE CG 128) and Autism: recognition, diagnosis and management of adults on the autism spectrum (NICE CG 142). However, the guideline was commissioned

							planning for transition to adult health and care services. While not in place yet and therefore this cannot be reflected in this guideline, it is worth noting that the current Children and Families Bill aims to reform the special educational needs system. SEN statements will be replaced by “Education, Health and Care plans” which, as the name suggest, are designed to closer working between the three agencies and to ensure more joined-up provision for children and young people.	before a more integrated and inclusive approach became possible with the health and education act, and so the Guideline Development Group was unable to make recommendations to education providers, Although education is outside of the scope of this guideline, the role of the Local Autism Team and of the Strategy Group is to ensure full collaboration with education providers, as well as with health and social care. This is laid out in the recommendations 1.1.2, 1.1.3, 1.1.6, 1.1.11 and 1.8.2 in the NICE Guideline.
199	SH	Nottinghamshire Healthcare NHS Trust	1	NICE	General	General	We see considerable numbers of patients who are autistic within the special needs dental service which often means we need to provide treatment to these patients under GA. I would just like you to note that this has not been mentioned in the document . We provide a cradle to grave service for this group of patients and thought it may be worth noting this somewhere in the document.	Thank you for your comment. Specialist dental services are very important and recommendation 1.1.10 in the NICE Guideline has been amended accordingly. Please also see section 2.13, Conceptual Frameworks for Intervention, in the Full Guideline.
200	SH	Royal College of Paediatrics and Child Health	1	NICE	General	General	We were disappointed that there is no mention or parent information, parent training programs and sleep interventions in the NICE guideline. There is also no mention of Melatonin to assist with children not responding to behavioural interventions on their own. Can we ask that the GDG consider adding information into the NICE guideline at least suggesting parents be given information, offered training and help with sleep. Reading the autism full guidelines there appears to be some consensus to support this.	Thank you for your comment. The section on interventions for sleep problems has been revised significantly based on stakeholder comments, and the available evidence – please see recommendations 1.7.4 to 1.7.9 in the NICE Guideline. In section 1.7.7,of the NICE Guideline, the Guideline Development Group felt a general recommendation for pharmacological interventions in certain circumstances could be made, but specific mention of melatonin was not warranted. The Guideline Development Group did support a research recommendation in section 2.3 of the NICE Guideline on Managing sleep problems.

								In section 1.1, General principles of care, there is a subsection about information, including for families (please see recommendations 1.1.11 to 1.1.13). There is a research recommendation in section 2.2 about parent training.
201	SH	Royal College of Paediatrics and Child Health	4	NICE	General	General	Multidisciplinary Autism Teams – there needs to be guidance on the level of resource which should be provided- there is a risk that as the specialist team is hopelessly limited and unable to cope with the referrals it closes its waiting list. Then, since the establishment of the specialist team has disempowered other relevant clinicians who previously provided some help, the autistic child and family now get no help at all. This has happened in some areas with regard to specialist diagnostic teams for autism.	Thank you for your comment. The Guideline Development Group is concerned about resources, and the lack of them. In a changing NHS and social care landscape it is not possible to estimate the level of resource for any particular size of CCG. It is the intention that a specialist team should empower others rather than the opposite.
202	SH	Royal College of Paediatrics and Child Health	5	NICE	General	General	What organisations should be responsible for providing the service? If this is not specified, then there is no obligation to provide. As now Paediatric services, CAMHS, Education and Social Services can all say the service should be provided by someone else. From experience, it is all but impossible to get an autistic spectrum child seen by a child psychiatrist.	Thank you for your comment. The Guideline Development Group has clearly recommended that a local autism team should either directly provide services or be directly responsible for ensuring such services as those specified in this guideline are provided by another local, regional or national service. The Guideline Development Group discussed at length the role of CAMHS and came to the view that the emphasis should be on the local autism team to either broker or provide care for children and young people with autism.
203	SH	Royal College of Paediatrics and Child Health	6	NICE	General	General	Right to education. Secondary schools, frequently cope with disruptive autistic students by agreeing with the parents that the young person will attend only half time otherwise he will be excluded. This drastically reduces access to education but parents are reluctant to stand up for the child's right to fulltime education because the only alternative is a unit for conduct disorders.	Thank you for your comment. The Guideline Development Group has recommended that the autism team has a key role in access to and liaising with education in recommendation 1.1.6 in the NICE Guideline.
204	SH	Royal College of Paediatrics	8	NICE	General	General	There should be much more emphasis on providing training programmes for parents and referring parents	Thank you for your comment. There is insufficient evidence to recommend provision of

		and Child Health					to such programmes. This approach is much stronger in the NICE guidelines on the management of ADHD and on Antisocial behaviour and conduct disorders. It is also important to refer parents to parent support groups.	training programs generally with the exception of the social communication intervention covered in recommendation 1.3.1 in the NICE Guideline. Information about offering families support is covered in recommendation 1.2.1 in the NICE Guideline.
205	SH	Royal College of Paediatrics and Child Health	33	NICE	General	General	We thought, the Guidelines were quite clear and liked the sections on co-operating and working together of Health and Local Authorities, as this is usually what holds the system up. It is very thorough but there is not enough Guidance on dual diagnosis with other conditions like Down's Syndrome, although it did mention ADHD we don't think that it went into enough detail.	Thank you for your comments. The Guideline Development Group covered all of the comorbidities and co-existing conditions that were specified in the scope. Unfortunately, there was very little evidence that would suggest that the management of these comorbidities and co-existing conditions should be managed in any way differently as a result of co existing autism than the way they would be managed alone. Coexisting Conditions are covered in sections 7 and 2.7 of the Full Guideline.
206	SH	The Disabilities Trust	1	NICE	General	General	The Disabilities Trust was founded over 30 years ago and today is one of the UK's leading national charities. Autism Spectrum Partners, which is part of the Trust is committed to providing an environment which encourages personal development, confidence and independence to people with autistic spectrum disorders and learning disabilities, while our person centred approach puts the individual at the heart of everything that we do. We offer individually tailored support to people in achieving their personal potential and to empower them to live their lives as independently as possible. Service users are encouraged to develop their social, vocational and recreational skills and ensure that they are fully involved in all decisions affecting their lives, allowing them to achieve their aspirations with and privacy, respect, choice and	Thank you for your comments.

							inclusion. We are confident that our skills and expertise in this area can help to further inform the recommendations included here for the management of children and young people with autism.	
207	SH	The Disabilities Trust	7	NICE	General	General	Whilst we recognise that a description of 'challenging behaviour,' may be in the full version of the NICE recommendations, we would like the Centre to be clear on what constitutes challenging behaviour. The Trust would prefer this recommendation to be broad enough to allow service professionals to use it as a guide but also clear enough so that it is not open to too much subjectivity. Our care professionals have witnessed others (outside of the service) label challenging behaviour where an individual licked her yogurt pot and it was used as a rationale for medicating her.	Thank you for your comment and for the example of bad practice, which the Guideline Development Group found slightly alarming. This is nevertheless bad practice, and no guideline would prevent this. As you will note from the guideline, the Guideline Development Group has used the phrase 'behaviour that challenges' rather than 'challenging behaviour'. In this context 'behaviour that challenges' refers to any behaviour that exceeds the capacity of those around and the environment to be able to contain that behaviour. This avoids making any reference to specific behaviours that may be deemed as challenging.
208	SH	Association for Family Therapy and Systemic Practice	1	NICE	General		This response is submitted by AFT, the Association for Family Therapy and Systemic Practice (www.aft.org.uk). AFT is committed to supporting developments in practice, research, training and delivery of high quality therapeutic services for children, young people and their families and other caring groups. It is the UK's leading organisation for professionals working systemically with individuals, couples, families and other networks of care across the lifespan. AFT's membership is multi-disciplinary and includes Family and Systemic Psychotherapists (aka family therapists), clinical psychologists, psychiatrists, GPs, nurses, social workers, teachers, occupational therapists, health visitors and others committed to	Thank you for your comment.

							developing their systemic practice skills and understandings	
209	SH	Autism Treatment Trust	11	NICE	Introduction		Statement “Regression or stasis of language and social behaviour is reported for 20–30% of children with autism”. Should be corrected to reflect more objectively current literature to 40-50% of children presenting with regressive autism. Robin L Hansen; Sally Ozonoff; Paula Krakowiak; Kathleen Angkustsiri; Carrie ... *Ambulatory Pediatrics;* 2008; 8, 1; Regression in Autism: Prevalence and Associated Factors in the CHARGE Study. ProQuest Nursing & Allied Health Source pg. 25 R Luyster, J Richler, S Risi, WL Hsu, 2005 Early regression in social communication in autism spectrum disorders: a CPEA Study Developmental Neuropsychology Vol 27 (3): 311-336.	Thank you for your comment. As more research has been done the 3 trajectory model of early onset, stasis or frank regression becomes clearer. The idea of regression is thus a continuum of alteration of trajectory and the precise prevalence unclear. The Guideline Development Group have changed this in the NICE Guideline introduction to: “Regression or stasis of language and social behaviour is reported for at least a third of children with autism.”
210	SH	British Academy of Childhood Disability (BACD).	3	NICE	General		There should be much more emphasis on providing training programmes for parents and referring parents to such programmes. This approach is much stronger in the NICE guidelines on the management of ADHD and on Antisocial behaviour and conduct disorders. It is also important to refer parents to parent support groups.	Thank you for your comment. There is insufficient evidence to recommend provision of training programs generally with the exception of the social communication intervention covered in recommendation 1.3.1 of the NICE Guideline. Information about offering families support is covered in recommendation 1.2.1 in the NICE Guideline.
211	SH	British Academy of Childhood Disability (BACD).	5	NICE	Intro		All those with autism suffer social vulnerability to different extents, not particularly the most able.	Thank you for your comment. This has been amended in the NICE Introduction.
212	SH	British Academy of Childhood Disability	4	NICE	Intro		Some parents are adamant that their child was different from birth, lacking any social interaction.	Thank you for your comment. The Guideline Development Group has added this to the Full Guideline, section 2.8 Onset and Course of Autism.

		(BACD).						
213	SH	British Psychological Society	10	NICE	Intro		It is suggested that under the second bullet point the following principle should be included: All children and young people with autism should have a multi-disciplinary assessment of their special educational needs, with monitoring and reviews of their needs over time. They should be provided with the support and resources necessary to meet their needs in pre-school, school and college settings.	Thank you for your comment. Although education is outside of the scope of this guideline, the role of the Local Autism Team and of the Strategy Group is to ensure full collaboration with education providers, as well as with health and social care. This is laid out in the recommendations 1.1.2, 1.1.3, 1.1.6, 1.1.11 and 1.8.2 in the NICE Guideline.
214	SH	British Psychological Society	11	NICE	Intro		The Society believes that an important adjustment to the social environment appears to be missing here. The need for an enhanced adult/child ratio in response to the social communication deficits of autism and the inability of many such children to respond when addressed as a member of a group.	Thank you for your comment. The introduction to the NICE guideline has been amended. In addition, the Guideline Development Group has added wording to section 2.12 of the Full Guideline, Transition to Adult Life.
215	SH	British Psychological Society	9	NICE	Introduction		As in point 1 above, the NICE version gives the impression that autism is a distinct disorder, rather than a descriptive term for a cluster of behavioural impairments. Again, the introduction to NICE CG128 was clearer and more accurate. **Recommendation:** **That the first three paragraphs of the Introduction incorporate the introduction to CG128 as in the following;** **The term autism describes qualitative differences and impairments in reciprocal social interaction and social communication, combined with restricted interests and rigid and repetitive behaviours, often with a lifelong impact. In addition to these features, children and young people with autism frequently experience a range of cognitive, learning, language, medical, emotional and behavioural problems, including: a need for routine; difficulty in understanding other people, including their intentions, feelings and**	Thank you for your comment. We have followed your recommendation and amended the NICE guideline introduction accordingly.

							perspectives; sleeping and eating disturbances; and mental health problems such as anxiety, depression, problems with attention, self-injurious behaviour and other challenging, sometimes aggressive behaviour. These features may substantially impact on the quality of life of the individual and lead to a social vulnerability, especially in the most able group. **The clinical picture of autism is variable because of differences in severity, the presence of coexisting conditions and levels of cognitive ability, from profound intellectual disability in some people to average or above average intelligence quotient [IQ] in others.** **Autism spectrum disorders are diagnosed in children, young people and adults if these behaviours meet the criteria defined in the International Statistical Classification of Diseases and Related Health Problems (ICD-10) and the Diagnostic and Statistical Manual of Mental Disorders Fourth Edition (DSM-IV) and have a significant impact on function. Both these diagnostic classification systems use the term 'pervasive developmental disorder', which encompasses autism, Asperger's syndrome and atypical autism (or 'pervasive developmental disorder not otherwise specified'). For a diagnosis of autism to be made, there must be impairments present and an impact on the person's adaptive function. Both classification systems are undergoing revision and have announced that the term 'autism spectrum disorder' will be used in future editions. For this guideline we will use the term 'autism' to include all autism spectrum disorders.**	
216	SH	Carmarthenshire Education and Children's	14	NICE	GENERAL		Overall, the document makes some reference to educational settings, environment and intervention. However, it does not include education or education	Thank you for your comment. NICE can only make recommendations on areas of health and social care; it is outside of the scope of NICE

		Services					professionals with regards to delivery or receipt of training, development of appropriate interventions etc. Surely a multi-agency approach to meeting the child/young person's (who has ASD) needs, with health, social care and educational professionals all working together, would be a far more effective approach, given the length of time children spend in schools.	guidelines to make any recommendations on education. Although education is outside of the scope of this guideline, the role of the Local Autism Team and of the Strategy Group is to ensure full collaboration with education providers, as well as with health and social care. This is laid out in the recommendations 1.1.2, 1.1.3, 1.1.6, 1.1.11 and 1.8.2 in the NICE Guideline.
217	SH	Carmarthenshire Education and Children's Services	15	NICE	General		There are inerrant problems in the transition between children and adult services health – in general health and CAMHS. Many of the documents are dependent upon an effective transition for young people however, health services continue to be funding driven and so there are still problems in the 16, 17 and 18 age group. In addition because of the delays in diagnosis within children's services any potential referrals for 16 or 17 year olds presents a problem – if they are referred to children's services the delays in assessment results in a young person having to be re-referred to adult services to begin the assessment pathway again. It would be far more useful if young people aged 16 plus were able to be referred to adult services for an assessment/diagnosis in the first instance.	Thank you for your comment. A description of transition and the problems across services and some solutions are in the introduction section to 2.12 in the FullG.
218	SH	Carmarthenshire Education and Children's Services	16	NICE	General		How are the wishes, feelings and views of children and young people going to be gained most effectively and meaningfully throughout the process?	Thank you for your comment. The Guideline Development Group supports strongly the concept of 'children's voices' in planning and implementing services. The Guideline Development Group recognises that the new NHS structures are enjoined to seek user opinion including those of children and young people. All NICE guidelines relating to children and young people have a particular problem in that the voices of children and young people are not heard in the guideline. Each Guideline

								Development Group must find the best way of getting the voice of children and young people into the guideline, sometimes through parents and carers, as was done on this guideline, or by consulting organisations. This Guideline Development Group also did extra work with the National Autistic Society, done wholly with groups of children and young people, supported by their carers. It is difficult to get children and young people's views, and their families and carers' views, into the guideline, but this is covered by the guideline process.
219	SH	Carmarthenshire Education and Children's Services	3	NICE	Intro		Paragraph 2, 'General Principles of Care' again makes no reference of education professionals. Reference is later made to 'key transition points such as changing schools' so surely educational setting is paramount here. There is also reference to the social and physical environment, which would include education settings? (i.e. social and educational inclusion, the whole-school ethos, classroom, playground etc). Assessment of risk should also be applied to both mainstream and specialist settings, and knowledge of/appropriate interventions/methods of managing the behaviour exhibited by pupils with ASD should be incorporated into school behaviour policies, under the guidance of professionals who have specialist knowledge of ASD. This also links with the need for secondary schools to be aware of changing needs/behaviour at the onset of puberty. These issues may indicate a need for tripartite training (i.e. health, social care and education) for educational settings to meet the needs of children who are: - pre-school, school-aged, in FE and for those going through transition into HE/employment?	Thank you for your comment. NICE can only make recommendations on areas of health and social care; it is outside of the scope of NICE guidelines to make any recommendations on education. Although education is outside of the scope of this guideline, the role of the Local Autism Team and of the Strategy Group is to ensure full collaboration with education providers, as well as with health and social care. This is laid out in the recommendations 1.1.2, 1.1.3, 1.1.6, 1.1.11 and 1.8.2 in the NICE Guideline.
220	SH	Carmarthenshire Education and Children's	1	NICE	Intro		Why is ASD diagnosed most frequently in boys? Is this an inherent difficulty with the diagnostic criteria currently applied?	Thank you for your comment. Diagnosis is covered in the NICE CG128 on Autism diagnosis in children and young people:

		Services						recognition, referral and diagnosis of children and young people on the autism spectrum (2011).
221	SH	Carmarthenshire Education and Children's Services	2	NICE	Intro		Reference is made to pre-school/school in paragraph 1. However, paragraph 4 states that 'This guideline will summarise the different ways that health and social care professionals can provide support….'with no mention of education. As the vast majority of children spend a great proportion of their day in school, education should surely be included here?	Thank you for your comment. NICE can only make recommendations on areas of health and social care; it is outside of the scope of NICE guidelines to make any recommendations on education. Although education is outside of the scope of this guideline, the role of the Local Autism Team and of the Strategy Group is to ensure full collaboration with education providers, as well as with health and social care. This is laid out in the recommendations 1.1.2, 1.1.3, 1.1.6, 1.1.11 and 1.8.2 in the NICE Guideline.
222	SH	Carmarthenshire Education and Children's Services	4	NICE	Key priorities		Paragraph 2, 'Making adjustments' refers again to the physical environment, but no mention is made of the classroom, school or educational setting.	Thank you for your comment. NICE can only make recommendations on areas of health and social care; it is outside of the scope of NICE guidelines to make any recommendations on educational settings. Although education is outside of the scope of this guideline, the role of the Local Autism Team and of the Strategy Group is to ensure full collaboration with education providers, as well as with health and social care. This is laid out in the recommendations 1.1.2, 1.1.3, 1.1.6, 1.1.11 and 1.8.2 in the NICE Guideline.
223	SH	Carmarthenshire Education and Children's Services	5	NICE	Key priorities		'For school-aged children consider delivering the intervention with peer mediation' – who is it envisaged will deliver this intervention/training peers etc? Again, shouldn't the focus be on training/working with education staff as well as health and social care?	Thank you for your comment. The Guideline Development Group is not able to specify exact professional roles per se, but instead focus on interventions and care being delivered by health and social care professionals with the relevant competencies and experience.
224	SH	East and North Herts NHS Trust	1	NICE	introduction		" …ways that health and social care professionals can provide support, treatment…." Can we include education professionals	Thank you for your comment. NICE can only make recommendations on areas of health and social care; it is outside of the scope of NICE guidelines to make any recommendations on educational settings. Although education is

								outside of the scope of this guideline, the role of the Local Autism Team and of the Strategy Group is to ensure full collaboration with education providers, as well as with health and social care. This is laid out in the recommendations 1.1.2, 1.1.3, 1.1.6, 1.1.11 and 1.8.2 in the NICE Guideline.
225	SH	QUEEN'S UNIVERSITY BELFAST	9	NICE	Key priorities for implementation-General principles of care		Given that interventions based on Applied Behaviour Analysis should be encouraged for being evidence based (see examples of references below) health and social care professionals should receive education at Master's level on how to effectively put them in place and a bullet point mentioning this should be added in page 10 or 11 of this document. Additionally, in page 12 of the same document, a "functional behavioural analysis" is recommended but no training is provided to professionals on how to conduct it and there is neither a mention of the science of Behaviour Analysis where this paradigm comes from nor a mention on the necessary education that professionals should have before using it. -American Academy of Pediatrics. (2007). *Management of Children with Autism Spectrum Disorders, 120*, 1162-1182. -Haute Autorité de Santé-Recommended interventions for autism (2012): http://www.has-sante.fr/portail/upload/docs/application/pdf/2012-03/recommandations_autisme_ted_enfant_adolescent_interventions.pdf -New Zealand Guidelines Group. The effectiveness of applied behaviour analysis interventions for people with autism spectrum disorder. *Systematic Review.* Wellington; 2008. -Scottish Intercollegiate Guidelines Network (2007). Assessment, diagnosis and clinical interventions for children and young people with autism spectrum disorders: A national clinical guideline. -Surgeon General. (1999). Mental health: A report of	Thank you for your comment. The Guideline Development Group has replaced the term "functional analysis" with "Functional assessment of behaviour" to avoid misinterpretation.

							the Surgeon General. U.S. Public Health Service. Retrieved on 21/11/2012 from http://profiles.nlm.nih.gov/ps/retrieve/ResourceMetadata/NNBBJC.	
226	SH	QUEEN'S UNIVERSITY BELFAST	2	NICE	Key priorities for implementation-Interventions for behaviour that challenges		"inadvertent reinforcement of behaviour that challenges" is here mentioned as the last variable to take into account when considering intervention for challenging behaviours despite thousands of research articles showing how effective functional analysis can be in recognising sources of reinforcement for specific behaviours. Additionally, there is no mention of the education/training that professionals need in order to know the principles of learning (e.g., reinforcement), how to identify them and how to use them when putting an effective intervention in place. Master's level education in the science of Behaviour Analysis is required in order to be specialised in these procedures.	Thank you for your comment. There will always be different views about the listing of points but importantly, reinforcement is in the list. All psychologists are trained in functional assessment of behaviour
227	SH	QUEEN'S UNIVERSITY BELFAST	1	NICE	Key priorities for implementation-Interventions for the core features of autism		In this paragraph it is mentioned "Consider a social-communication intervention for the management of the core features of autism in children and young people. For pre-school children consider delivering the intervention with parent, carer or teacher mediation. For school-aged children consider delivering the intervention with peer mediation". However, research shows that for an intervention to be effective, it should be based on the science of Applied Behaviour Analysis, it should be intensive and have an early onset. No mention if these core features is made here.	Thank you for your comment. In the review of evidence, the Guideline Development Group found insufficient evidence to support ABA and therefore cannot make a recommendation about it. Recommendations are based on a very careful assessment of the evidence using the GRADE process. The components of the intervention recommended directly follow from the research evidence.
228	SH	Rotherham Doncaster and South Humber NHS Foundation Trust	1	NICE	General		Extremely welcome to have guidance on intervention and ongoing support for this client group. Focus on transition is also very much supported.	Thank you for your comments.
22	SH	Rotherham	2	NICE	Gener		The scope of the guidance seems to be mainly on	Thank you for your comment. The guideline

9		Doncaster and South Humber NHS Foundation Trust			al		healthcare/clinical interventions whilst it is known that educational and social supports are crucial possibly more important in the support of young people with ASD. It would be nice to see integrated guidelines as well as guidance to provide integrated care. Should the **team around the child**/young person be given more of a mention as well as CPA.	makes the local autism team and the strategy group central to coordinating, brokering and providing care. The CPA is for transfer between children's/young people's services and adults.
230	SH	Rotherham Doncaster and South Humber NHS Foundation Trust	3	NICE	General		The document is rather repetitive in places. Could this be addressed in the final edit? Especially pages 10/11 repeated word for word on pages 17/18	Thank you for your comment. Pages 10 to 13 of the NICE guideline contain the 10 key recommendations for implementation, prioritised from the rest of the recommendations which are on pages 14 onwards.
231	SH	Rotherham Doncaster and South Humber NHS Foundation Trust	4	NICE	General		The research recommendations are interesting, commended and serve to underline the lack of evidence base in this field and the need to develop one asap.	Thank you for your comments.
232	SH	Rotherham Doncaster and South Humber NHS Foundation Trust	11	NICE	General		**Social stories** are widely used with children and young people on the autism spectrum and marketed as an effective intervention. Is the reason this intervention not mentioned in the guideline, due to lack of evidence of efficacy? Surprised it did not get a mention.	Thank you for your comment. Social Stories are now mentioned in section 5.2.1 of the Full Guideline.
233	SH	Royal College of Paediatrics and Child Health	10	NICE	Intro, paragraph 1		Some parents are adamant that their child was different from birth, lacking any social interaction.	Thank you for your helpful comment. The Guideline Development Group has added wording to section 2.8 Onset and Course of Autism, in the Full Guideline in line with your comment.
234	SH	Royal College of Paediatrics and Child Health	9	NICE	Introduction, paragraph 1, final sentence		All those with autism suffer social vulnerability to different extents, not particularly the most able.	Thank you for your comment. The NICE introduction has now been amended.
23	SH	Royal College	1	NICE	Intro		All people with autism will have social integration	Thank you for your comment.

5		of Speech and Language Therapists					difficulties, although those with higher functioning may be able to recognise the impact of their difficulties more keenly.	
236	SH	Royal College of Speech and Language Therapists	2	NICE	Intro		The following sentence seems clumsy: 'However, there is a range of interventions which can help some of the core features of autism and some of the symptoms, behaviours and problems commonly associated with autism and to support families.". Strategies need to be continued throughout the person's life and funding needs to reflect this.	Thank you for your comment. The Guideline Development Group has restructured this sentence to '. However, there are interventions that can help some of the core features of autism, some of the symptoms, behaviours and problems commonly associated with autism, and support families and carers.'
237	SH	Step by Step School	2	NICE	intro		Towards the end of the first paragraph, we recommend adding the words "and family" after the word individual, given that the impact is often on both	Thank you for your comment. The Guideline Development Group has added 'and family or carer' as you have suggested.
238	SH	Step by Step School	3	NICE	intro		In the first paragraph, we find it hard to accept that the most able group is "more vunerable" than the least able group, as the least able group is sometimes non-verbal and/or with low IQ	Thank you for your comment, this clause has been removed.
239	SH	Step by Step School	4	NICE	intro		The last paragraph seems to have been drafted to avoid stating that autism prevalence has been increasing. Since autism was not identified until the 1940's it does not seem controversial to us that the prevalence has been increasing. By clearly stating prevalence is increasing, it alerts policy makers that additional resources are required to be able to implement this guideline. (This point has been mentioned in section 2.5 of the full guideline, but deserves mention in the NICE version too)	Thank you for your comment. The NICE Guideline introduction has been amended. The Guideline Development Group has also added to section 2.5 in the full guideline the following: "However, the possibility of an increase in ASD cannot be ruled out".
240	SH	Step by Step School	5	NICE	patient-centred care		We feel there is an opportunity in this section to mention the proposed integration of various assessments today into an integrated "Education, Health and Care Plan"	Thank you for your comment. The guideline is a collaboration between health and social care. The education and health legislation came after the guideline was commissioned.
241	SH	Step by Step School	21	NICE	1	-	We ask the GDG to consider making a recommendation for NHS to offer genetic testing (eg every 5 years). Genetic discoveries in autism are being made all the time, and it would likely be helpful for parents and siblings to be made aware (if they so chose) of any known genetic markers that may indicate a higher chance of having another child (or grandchild)	Thank you for your comment. As advised in the Autism diagnosis in children and young people: Recognition, referral and diagnosis of children and young people on the autism spectrum Guideline (CG 128), the genetic testing advised for autism without intellectual disability or dysmorphic features remains a matter for

							with autism in the family	regional genetic centres.
242	SH	Step by Step School	22	NICE	1	-	Many younger autistic children have difficulties with feeding / eating balanced diet comprising minimum required intake of all nutrients. We feel that GPs should explore what food intake the child is having, and if needed, make a referral to a dietician for specialist advice. This was in the scope document for this guideline 4.3.1e	Thank you. The Guideline Development Group agrees that the primary care physician should explore the child's food intake. The Guideline Development Group thinks that this is within the competence of general practitioners who can refer to dieticians if need be and to specialist feeding clinics if there are persistent problems. In the Autism: recognition, referral, diagnosis and management of adults on the autism spectrum guideline (CG 142), problems with feeding are directly covered under routine assessment and would form part of any care plan. The Guideline Development Group reviewed diet: exclusion diets should not be used as there is no evidence of them – please see recommendation 1.3.2 in the NICE Guideline. Apart from this, the Guideline Development Group did not find any specific evidence to guide the management of feeding problems and therefore cannot make a specific recommendation in this area.

243	SH	Association for Family Therapy and Systemic Practice	2	NICE	1.1.8 1.1.11 1.1.12 1.2.1 1.2.2 1.2.3	10 13 16 17 19 19 19 19-20	AFT welcomes the NICE guidelines, in particular the emphasis on the impact of autism on the family (including siblings) and carers, and the need to offer personal, social, emotional and practical support to family members. AFT further welcomes the attention given in the guideline to transition to adult services. AFT supports the establishment of specialist multidisciplinary CAMHS teams that include designated Systemic Family Therapists (also often referred to by their full accredited title, Family and Systemic Psychotherapists). Systemic Family Therapists are valued members of many generic CAMHS teams. It is especially important that Family and Systemic Psychotherapists have a presence within specialist CAMHS teams working with children with autism and their families and carers, offering significant added value to the work with children and families and to supporting involved professionals in effective multidisciplinary team working.	Thank you for your comments.
244	SH	British Academy of Childhood Disability (BACD).	7	NICE	1	10, second bullet	This training list should include communication skills.	Thank you for your comment; communication skills has been added to recommendation 1.1.8 in the NICE Guideline as the final bullet point
245	SH	Alder Hey Children's NHS Foundation Trust	1	NICE	1.1.1	14	All children with autism and comorbid mental health conditions, behavioural difficulties, have access to AHCNFT (Alder Hey Children's NHS Foundation Trust) CAMHS service regardless of intellectual ability (services are also provided with staff with expertise in learning difficulties) and co-morbid conditions.	Thank you for your comment.
246	SH	British Academy of Childhood Disability (BACD).	6	NICE	1.1.1	10, first bullet	Why not 'must' instead of 'should'?	Thank you for your comment. The use of the word 'must' has a very specific meaning in NICE guidelines, as explained at the front of the document:

								We usually use 'must' or 'must not' only if there is a legal duty to apply the recommendation. Occasionally we use 'must' (or 'must not') if the consequences of not following the recommendation could be extremely serious or potentially life threatening.
247	SH	British Psychological Society	12	NICE	1.1.1	14	The Society supports this recommendation and believes that CAMHS services will need to pay attention to this.	Thank you for your comment.
248	SH	East and North Herts NHS Trust	2	NICE	1.1.1	10	Include education professionals	Thank you for your comment. NICE can only make recommendations on areas of health and social care; it is outside of the scope of NICE guidelines to make any recommendations on education. Although education is outside of the scope of this guideline, the role of the Local Autism Team and of the Strategy Group is to ensure full collaboration with education providers, as well as with health and social care. This is laid out in the recommendations 1.1.2, 1.1.3, 1.1.6, 1.1.11 and 1.8.2 in the NICE Guideline.
249	SH	Rotherham Doncaster and South Humber NHS Foundation Trust	5	NICE	1.1.1	14	Absolutely – some CAMHS services will need to pay attention to this.	Thank you for your comment.
250	SH	Royal College of Paediatrics and Child Health	11	NICE	1.1.1, first bullet point	10	Why not 'must' instead of 'should'?	Thank you for your comment. The use of the word 'must' has a very specific meaning in NICE guidelines, as explained at the front of the document: *We usually use 'must' or 'must not' only if there is a legal duty to apply the recommendation. Occasionally we use 'must' (or 'must not') if the consequences of not following the recommendation could be extremely serious or*

								potentially life threatening.
251	SH	Royal College of Paediatrics and Child Health	12	NICE	1.1.1, second bullet point	10	This training list should include communication skills.	Thank you for your comment; communication skills has been added to recommendation 1.1.8 in the NICE Guideline, as the final bullet point.
252	SH	Alder Hey Children's NHS Foundation Trust	2	NICE	1.1.2	14	No on-going multi agency strategy group in the region. A time limited local multi agency strategy group was convened by the head Educational Psychologist from Liverpool Local authority earlier this year.	Thank you for your comment.
253	SH	British Psychological Society	14	NICE	1.1.2	14	We would also suggested adding the following bullet point: who have parents with mental health problems/ alcohol or drug dependency problems" as an additional group with very specific and greater needs.	Thank you for your comment, however we feel that this is not relevant to the overall configurations and development of local services being coordinated by a multi-agency strategy group.
254	SH	British Psychological Society	13	NICE	1.1.2	15	Reference is made to children and young people who have particular needs. We suggest that the reference to children who are looked after by a local authority should be made more inclusive and hence read: "who are looked after by local authority/ adopted/ living in alternative family placements such as with Special Guardians or in Kinship care/ who are currently remanded within secure children's homes, secure units and/or Youth Offending Institutes.	Thank you for your comment. The Guideline Development Group did consider this, but thought the list was too long and likely to end up missing some groups, and therefore decided therefore to use with the recognised term, Looked After Children.
256	SH	Step by Step School	11	NICE	1.1.2	14	We recommend that the guideline defines "local" to help with practical implementation. The NHS has now been restructured, and the definition of "local" may need to look differently vs the other two autism guidelines. For example, is "local" now referring to the territories of each Health and Well Being Board (c 130 in England)? Or perhaps CCG territories (200+ in England) ?	Thank you for your comment. The Guideline Development Group is grateful that you have raised this very important issue. The Guideline Development Group agrees with you that 'local' will change over time, which is why the Guideline Development Group would rather stay with the term 'local', than defining it in some other way.
257	SH	Step by Step School	12	NICE	1.1.2	14	We recommend a "national mechanism with teeth" to ensure that the local autism multi-agency strategy groups are put in place and functioning effectively. We propose that this is addressed via a quality standard	Thank you for your comment, however quality standards are outside of the scope of this guideline.

258	SH	Alder Hey Children's NHS Foundation Trust	3	NICE	1.1.3	14	No local specialist community-based multidisciplinary autism team available locally. No dedicated service for those without mental health problems, although some are reviewed periodically in community paediatric out- patient clinics. AHCNFT CAMHS contribute to (ideally tripartite – medical, psychological and speech therapy) assessment of autism. Management and intervention of mental health difficulties and behavioural difficulties is provided by AHCNFT CAMHS services.	Thank you for your comment. The Guideline Development Group understood you to be saying that there were no Local Autism Teams available in your areas, and that this is the case elsewhere as well. This is precisely why the Guideline Development Group wanted to echo the other two autism guidelines (Autism: recognition, referral, diagnosis and management of adults on the autism spectrum [CG 142] and Autism diagnosis in children and young people: Recognition, referral and diagnosis of children and young people on the autism spectrum [CG 128], saying that these teams should be available locally in all areas.
259	SH	Rotherham Doncaster and South Humber NHS Foundation Trust	6	NICE	1.1.3	14	Local autism teams. Is guidance needed on the core membership of such teams and the size in relation to local need/population size?	Thank you for your comment. The Guideline Development Group understood you to be saying that there were no Local Autism Teams available in your areas, and that this is the case elsewhere as well. This is precisely why the Guideline Development Group wanted to echo the other two autism guidelines (Autism: recognition, referral, diagnosis and management of adults on the autism spectrum (CG 142) and Autism diagnosis in children and young people: Recognition, referral and diagnosis of children and young people on the autism spectrum (CG 128), saying that these teams should be available locally in all areas. Key professionals who should be included in the team are outlined in Autism: recognition, referral, diagnosis and management of adults on the autism spectrum (CG 142)
260	SH	Alder Hey Children's NHS Foundation Trust	4	NICE	1.1.4	14	Those who are offered an intervention in AHCNFT CAMHS have an allocated case manager/care coordinator or partnership clinician who oversees and co-ordinated their care in a multi-disciplinary fashion	Thank you for your comment.

261	SH	Step by Step School	13	NICE	1.1.4	14	We welcome the recommendation to appoint case managers/coordinators for every child with autism. We recommend that the guideline specifies the type of person who could do this role (eg specialist nurse?) and the approximate case load expectations per person (eg 100 autistic children per case worker FTE). We estimate that implementing this recommendation might require for example appointing over 1000 specialist nurses FTEs, and so we recommend dedicated funding is allocated	Thank you for your comment. We cannot specify professional roles per se, but instead focus on interventions and care being delivered by health care professionals with the relevant competencies and experience.
262	SH	Alder Hey Children's NHS Foundation Trust	5	NICE	1.1.5	15	CAMHS services have access to skills for children presenting with particular needs through the AHCNFT CAMHS and/or liaison with Community and Hospital paediatricians. Speech therapy and dietician input is not available to children under AHCNFT CAMHS. Our CAMHS service caters for looked after children and for those children from immigrant groups.	Thank you for your comment.
263	SH	Carmarthenshire Education and Children's Services	6	NICE	1.1.5	15	Which professionals would be involved in a local autism team? Teams should include educational professionals such as the educational psychologist, or advisory teacher for ASD as well as health and social care colleagues.	Thank you for your comment. Recommendation 1.1.3 in the NICE Guideline details which professionals should be involved in the local specialist community-based multidisciplinary team, in line with the Autism diagnosis in children and young people: Recognition, referral and diagnosis of children and young people on the autism spectrum guideline (CG 128). We agree on the need for educational involvement. Explicit reference is made in recommendation 1.1.5 of the NICE Guideline, giving the autism team responsibility for access and liaison. Educational professionals are strongly recommended to be involved as members of the autism team as in the Autism diagnosis in children and young people: Recognition, referral and diagnosis of children and young people on the autism spectrum guideline (CG 128). and the Autism: recognition,

								referral, diagnosis and management of adults on the autism spectrum guideline (CG142).
264	SH	British Psychological Society	15	NICE	1.1.5 and 1.1.6	15	The Society welcomes the acknowledgement that "Local autism teams should have a key role in the delivery and coordination of: specialist care and interventions for children and young people with autism" and suggest that the guidelines should include "consider if appropriate, an early intervention package, based on the principles of Applied Behaviour Analysis, supervised by a competent behaviour analyst, and meditated through trained staff and supported by parents." Guidance is also needed on the core membership of such teams and the size in relation to local need/population size	Thank you for your comment. NICE does not dictate who should carry out interventions but sets out the core principles of the intervention and emphasises that the person or persons should be trained. Explicit reference is made in recommendation 1.1.5 in the NICE Guideline, giving the autism team responsibility for access and liaison. Educational professionals are strongly recommended to be involved as members of the autism team as in the Autism: recognition, referral, diagnosis and management of adults on the autism spectrum guideline (CG 142) and in the Autism diagnosis in children and young people: Recognition, referral and diagnosis of children and young people on the autism spectrum guideline (CG 128).
265	SH	BetsiCadwaladr University Health Board	5	NICE	1.1.6	15	We welcome the acknowledgement that "Local autism teams should have a key role in the delivery and coordination of: □ specialist care and interventions for children and young people with autism" and suggest that the guidelines should include " consider an early intervention package, based on the principles of Applied Behaviour Analysis, supervised by a competent behaviour analyst, and meditated through trained staff and supported by parents."	Thank you for your comment. NICE does not dictate who should carry out interventions but sets out the core principles of the intervention and emphasises that the person or persons should be trained. Explicit reference is made in recommendation 1.1.5 in the NICE Guideline, giving the autism team responsibility for access and liaison. Educational professionals are strongly recommended to be involved as members of the autism team as in the Autism: recognition, referral, diagnosis and management of adults on the autism spectrum guideline (CG 142) and in the Autism diagnosis in children and young people: Recognition, referral and diagnosis of children and young people on the autism spectrum guideline (CG 128).

266	SH	Carmarthenshire Education and Children's Services	7	NICE	1.1.6	15	Paragraph 2 mentions 'advice, training and support for other health and social care professional and staff', but there is no mention of education staff specifically i.e. teachers, support assistants, lunch-time supervisors etc., when we know that the greatest difficulty for children with an ASD is during unstructured times, such as break times in school.	Thank you for your comment. The Guideline Development Group agree that this is an important area, however NICE can only make recommendations on areas of health and social care, and it is outside of the scope of NICE guidelines to make any recommendations on education. Although education is outside of the scope of this guideline, the role of the Local Autism Team and of the Strategy Group is to ensure full collaboration with education providers, as well as with health and social care. This is laid out in the recommendations 1.1.2, 1.1.3, 1.1.6, 1.1.11 and 1.8.2 in the NICE Guideline.
267	SH	East and North Herts NHS Trust	3	NICE	1.1.6	15	Local autism teams should have a key role in the delivery and coordination of or access to the delivery and coordination of	Thank you.
268	SH	The Disabilities Trust	4	NICE	1.1.6	15 -16	The Trust is keen that local autism teams proactively help service users attain these goals. To do this we would ask that the recommendations of the guideline are less limiting in terms of what can be achieved. For example, whilst the guideline recommends that those with autism are supported with 'leisure and other enjoyable activities,' we would like an extra recommendation that would allow for the transition into a work placement and employment. We recognise that employment has been mentioned slightly lower down the page and also on page 26, but we would encourage the guideline to go further and explain how someone with autism would practically and emotionally be supported into work. This should also include establishing disability and autism awareness training for future potential employees to encourage those with autism to apply for roles. Further for the employee to recognise the benefits that hiring someone with a disability may also bring.	Thank you for your comment. This guideline should be read in conjunction with NICE CG 142, Autism: recognition, referral, diagnosis and management of adults on the autism spectrum, for an integrated service. It describes transition into work plus training for employers and the need for support for both.

269	SH	Alder Hey Children's NHS Foundation Trust	6	NICE	1.1.6	16	CAMHS services provides input into specialist schools for children with autism, either on an individual basis if the child is known to our service and also consultation to staff in school and residential care settings when the child in under CAMHS.	Thank you for your comment.
270	SH	British Academy of Childhood Disability (BACD).	13	NICE	1.1.7	16	Families should be informed about this national help and be able to request referral.	Thank you for your comment.
271	SH	Dimensions	2	NICE	1.1.7	16	We often encounter not a lack of skills locally, but a lack of capacity locally to take on new referrals for children and young people with autism. It would be good if it were made clear here that this should also result in a regional referral	Thank you for your comment. The Guideline Development Group has sympathy with the capacity problem but feel that recommendation 1.1.7 in the NICE Guideline covers any situation in which there is a 'local lack'.
272	SH	Royal College of Paediatrics and Child Health	18	NICE	1.1.7	16	Families should be informed about this national help and be able to request referral.	Thank you for your comment.
273	SH	Alder Hey Children's NHS Foundation Trust	7	NICE	1.1.8	16	CAMHS staff have basic awareness in the understanding and management of dealing with autism. Some have particular expertise and we have a Clincal Lead in ASD. A multidisciplinary team approach ensures skills are shared. Intervention is offered based on understanding and risk management principles and ability to provide individualised care and support.	Thank you for your comment.
274	SH	British Association for Music Therapy (BAMT)	9	NICE	1.1.8	16	'Knowledge and Competence of Health and Social Care Professionals'. We agree with the guideline's emphasis on the importance of training in autism awareness. We would point out that music therapists receive training in autism awareness as part of their pre-registration training, often to a high level and certainly more than 'basic'. They are therefore already well equipped to offer interventions for children and young people with autism.	Thank you for your comment.
27	SH	British	16	NICE	1.1.8.	16	The Society welcomes the recommendation that	Thank you for your comment. With regarding to

5		Psychological Society					"Health and social care professionals working with children and young people with autism in any setting should receive training in autism awareness and basic skills in managing autism" and suggests that this should include training in appropriate interventions and treatment, rather than simply assessment, recognition, care and support	training in the use of interventions, the Guideline Development Group made recommendations where they felt it was necessary, in the interventions section.
276	SH	Carmarthenshire Education and Children's Services	8	NICE	1.1.8	16	Should include educational professionals	Thank you for your comment. NICE can only make recommendations on areas of health and social care; it is outside of the scope of NICE guidelines to make any recommendations on education. Although education is outside of the scope of this guideline, the role of the Local Autism Team and of the Strategy Group is to ensure full collaboration with education providers, as well as with health and social care. This is laid out in the recommendations 1.1.2, 1.1.3, 1.1.6, 1.1.11 and 1.8.2 in the NICE Guideline.
277	SH	Dimensions	4	NICE	1.1.8	16	This list should include the importance of consistency of support across various settings (e.g. home, school, leisure, therapeutic sessions, etc.)	Thank you for your comment. In order to clarify this, the Guideline Development Group has amended the penultimate bullet of recommendation 1.1.8 in the NICE Guideline to: "how to provide individualised care and support and ensure a consistent approach is used across all settings"
278	SH	Royal College of Nursing	25	NICE	1.1.8	16	***Health and social care professionals*** *working with children and young people with autism in any setting should receive training in autism awareness and basic skills in managing autism, which should include:* What about training for those providing education for this young people?	Thank you for your comment. NICE can only make recommendations on areas of health and social care; it is outside of the scope of NICE guidelines to make any recommendations on education. Although education is outside of the scope of this guideline, the role of the Local Autism Team and of the Strategy Group is to ensure full collaboration with education providers, as well as with health and social care. This is laid out in the recommendations 1.1.2,

								1.1.3, 1.1.6, 1.1.11 and 1.8.2 in the NICE Guideline.
279	SH	British Academy of Childhood Disability (BACD).	14	NICE	1.1.8	16-17	As commented above (re page10) this training should include communication skills, especially so that the professional can discuss management with the child or young person with autism, rather than relying on the parents provide this communication.	Thank you for your helpful suggestion. The following bullet points has been added to recommendation 1.1.8 in the NICE Guideline: 'skills for communicating with a child or young person with autism'
280	SH	Royal College of Paediatrics and Child Health	19	NICE	1.1.8	16-17	As commented above (re page10) this training should include communication skills, especially so that the professional can discuss management with the child or young person with autism, rather than relying on the parents provide this communication.	Thank you for your helpful suggestion. The following bullet points has been added to recommendation 1.1.8 in the NICE Guideline: 'skills for communicating with a child or young person with autism'
281	SH	Royal College of Speech and Language Therapists	3	NICE	1.1.8	16-7	Professionals should have training on the full range of autism presentations as this affects their ability to be useful to families and other professionals.	Thank you for your comment. The Guideline Development Group thinks this is covered by the existing recommendation 1.1.8 in the NICE Guideline, as it explicitly states that training should cover the nature and course of autism in the first bullet point.
282	SH	QUEEN'S UNIVERSITY BELFAST	3	NICE	1.1.8. Knowledge and competence of health and social care professionals	17	It is here mentioned that health and care professionals should receive training in different topics but none of these includes training in Applied Behaviour Analysis (i.e., the science that underpins the intervention of choice for children with Autism)	Thank you for your comment. The Guideline Development Group emphasises the need for training in awareness and understanding of autism for all health and social care professionals working with children and young people with autism. In the review of evidence, the Guideline Development Group did not find enough evidence to support ABA and therefore cannot make a recommendation about it or about training professionals in it.
283	SH	Step by Step School	6	NICE	1.1.8	11 and 16	We recommend stating that these training recommendations also apply to HCPs such as dentists	Thank you for your comment. The Guideline Development Group believes that both of these

							and opticians	points are covered by using the term 'in any setting'.
284	SH	Royal College of Paediatrics and Child Health	13	NICE	1.1.9, , adjustments	11	This should be shared with DfE since space in schools is being restricted, especially in new builds.	Thank you for your comment, however NICE guidelines are unable to make recommendations for the DfE. Although education is outside of the scope of this guideline, the role of the Local Autism Team and of the Strategy Group is to ensure full collaboration with education providers, as well as with health and social care. This is laid out in the recommendations 1.1.2, 1.1.3, 1.1.6, 1.1.11 and 1.8.2 in the NICE Guideline.
285	SH	Step by Step School	7	NICE	1.1.9	11 and 17	With regards to "processes of care" – we recommend being explicit that higher staffing levels (eg nurses) may be required to care for certain patients with autism when in hospital	Thank you for your comment, however staffing levels is a matter for local implementation.
286	SH	British Academy of Childhood Disability (BACD).	8	NICE	1.1.9	11, adjustments	This should be shared with DfE since space in schools is being restricted, especially in new builds.	Thank you for your comment, however NICE guidelines are unable to make recommendations for the DfE. Although education is outside of the scope of this guideline, the role of the Local Autism Team and of the Strategy Group is to ensure full collaboration with education providers, as well as with health and social care. This is laid out in the recommendations 1.1.2, 1.1.3, 1.1.6, 1.1.11 and 1.8.2 in the NICE Guideline.
287	SH	Alder Hey Children's NHS Foundation Trust	8	NICE	1.1.9	17	CAMHS follows flexible approach to appointments with tailoring them to the need of children. We do home visits, visits in places the child might prefer and also the timing of appointments is flexible.	Thank you for your comment.
288	SH	British Psychological Society	17	NICE	1.1.9	17	We suggest that the second bullet be amended to suggest that individuals bring their own communication tools and those working with them use them to communicate with the child, and to enable the child to with them	Thank you for your comment. The Guideline Development Group considered your suggestion but decided not to change this recommendation which is about adapting the existing environment. This would not of course preclude children and young people from bringing their own communication tools.

289	SH	Carmarthenshire Education and Children's Services	9	NICE	1.1.9	17	This should equally apply to schools	Thank you for your comment, it is outside of the scope of NICE guidelines to make any recommendations on education. Although education is outside of the scope of this guideline, the role of the Local Autism Team and of the Strategy Group is to ensure full collaboration with education providers, as well as with health and social care. This is laid out in the recommendations 1.1.2, 1.1.3, 1.1.6, 1.1.11 and 1.8.2 in the NICE Guideline.
290	SH	Dimensions	3	NICE	1.1.9	17	We believe that it should be mentioned here about the importance of consistency in layout of spaces (e.g. task specific areas), and the importance of clutter free environments.	Thank you for your comment. The Guideline Development Group considered your suggestion but decided not to change the recommendation because it was judged that the examples that had been provided about the physical space were sufficient.
291	SH	Royal College of Speech and Language Therapists	4	NICE	1.1.9	17-8	Sensory integration issues need to be assessed and addressed through occupational therapy input.	Thank you for your comment. NICE guidelines do not generally specify professional roles, because interventions and care should be delivered by health care professionals with the relevant competencies and experience.
292	SH	Royal College of Speech and Language Therapists	5	NICE	1.1.9	17-8	Visual supports need to be at a level that is meaningful to the child – objects of reference, photos, symbols, printed words. This may vary according to context and level of development.	Thank you for your comment. The Guideline Development Group considered the recommendation in light of your comment and added "that are meaningful for the child or young person". .
293	SH	Royal College of Speech and Language Therapists	6	NICE	1.1.9	17-8	Cultural issues need to be addressed and dealt with accordingly.	Thank you for your comment. The following has been added to the NICE guideline introduction to refer to cultural issues: "Good communication between healthcare professionals and children and young people with autism and their families and carers is essential. It should be supported by evidence-based written information tailored to the person's needs. Support and care, and the information people are given about it, should be culturally appropriate. It should also be accessible to

								people with additional needs such as physical, sensory or learning disabilities, and to people who do not speak or read English."
294	SH	British Academy of Childhood Disability (BACD).	15	NICE	1.1.10	18	Above all, families appreciate timely information and support.	Thank you for your comment
295	SH	Royal College of Nursing	26	NICE	1.1.20	18	*Provide information about adult services to the young person, including their right to a social care assessment at age 18.* This should include carers where appropriate, so suggest read: **Provide information about adult services to the young person and their cares where appropriate, including their right to a social care assessment at age 18.**	Thank you for your helpful comment; the Guideline Development Group has added "and their parents or carers" to this recommendation (1.8.3 in the NICE Guideline) in response to your comment.
296	SH	Carmarthenshire Education and Children's Services	10	NICE	1.1.10	18	Need again to link with education with regards to pre-school and transition. Should reflect multi-agency working, with health, social care and education professionals all involved.	Thank you for your comment. NICE can only make recommendations on areas of health and social care; it is outside of the scope of NICE guidelines to make any recommendations on education. Although education is outside of the scope of this guideline, the role of the Local Autism Team and of the Strategy Group is to ensure full collaboration with education providers, as well as with health and social care. This is laid out in the recommendations 1.1.2, 1.1.3, 1.1.6, 1.1.11 and 1.8.2 in the NICE Guideline.
297	SH	Royal College of Paediatrics and Child Health	20	NICE	1.1.10	18	Above all, families appreciate timely information and support.	Thank you for your comment
29	SH	Carmarthenshi	11	NICE	1.1.11	19	Need to link with what educational settings can provide	Thank you for your comment. NICE can only

8		re Education and Children's Services						make recommendations on areas of health and social care; it is outside of the scope of NICE guidelines to make any recommendations on education. Although education is outside of the scope of this guideline, the role of the Local Autism Team and of the Strategy Group is to ensure full collaboration with education providers, as well as with health and social care. This is laid out in the recommendations 1.1.2, 1.1.3, 1.1.6, 1.1.11 and 1.8.2 in the NICE Guideline.
299	SH	Alder Hey Children's NHS Foundation Trust	9	NICE	1.1.12	19	The CAPA approach and Care aims philosophy in CAMHS allows for shared decision making and a collaborative approach in working with children and families.	Thank you for your comment, it is encouraging to hear of such good practice.
300	SH	Carmarthenshire Education and Children's Services	12	NICE	1.2.1	19	Educational settings/schools/ educational psychologists can again play a role here too. Outreach can be provided from specialist provisions.	Thank you for your comment. Whilst the guideline does recommend that healthcare professional work closely with education services, NICE guidelines are unable to make specific recommendations for educational settings. Although education is outside of the scope of this guideline, the role of the Local Autism Team and of the Strategy Group is to ensure full collaboration with education providers, as well as with health and social care. This is laid out in the recommendations 1.1.2, 1.1.3, 1.1.6, 1.1.11 and 1.8.2 in the NICE Guideline.
301	SH	Contact a Family	3	NICE	1.2.1	19	***1.2.1 Families and carers*** Add *'parents or carers of children aged 3 and 11 years on the autism spectrum be offered a referral to a specialist parent-training/education programme as an early intervention.* The NICE guidelines for ADHD recommend parent	Thank you for your comment. With regards to autism, the guideline has a strong emphasis on working with whole families and their carers. There was insufficient evidence to make a specific recommendation on parent training, which is why the Guideline Development Group supported adding a research recommendation into the NICE Guideline, now in section 2.2, on managing

							training early on despite the full guidelines only referencing one research study of 32 people with ADHD. This was because the NICE Guidelines on Antisocial Behaviour and conduct disorders in children and young people guidelines found sufficient research evidence to support offering parent training programme to parents of children and young people aged between 3 and 11 years who have been identified as being at high risk of developing oppositional defiant disorder or conduct disorder. '*Parent training aims to improve parenting skills (Scott, 2008). As following chapters show, there are scores of randomised controlled trials (RCTs) suggesting that it is effective for children up to about 10 years old. Parenting interventions based on social learning theory address the parenting practices identified in research as contributing to conduct problems.* (ref 2.7.1,full NICE guidelines: Antisocial Behaviour and conduct disorders in children and young people guidelines) These guidelines recommend offering this training early on as a preventative measure when it is more effective. *Conduct disorder should offer good opportunities for prevention because it can be detected early reasonably well, early intervention is more effective than later, and there are a number of effective interventions*(Ref 2.9 full NICE guidelines: Antisocial Behaviour and conduct disorders in children and young people guidelines) As children with autism are at high risk of developing conduct disorders, the autism guidelines should include offering parents information and training interventions early on as a preventative intervention.	behaviour that challenges in children and young people with autism: "Is a group-based parent training intervention for parents or carers of children and young people with autism clinically and cost effective in reducing early and emerging behaviour that challenges in the short- and medium-term compared with treatment as usual?"

302	SH	Step by Step School	14	NICE	1.2.1	19	We recommend that the guideline is more specific about what rights families and carers have to access short breaks and respite care. Without guidance, this would likely vary across the country depending on capacity rather than need. If this is out of scope of the current guideline, it should be clearly stated in this guideline how this question is to be addressed in future	Thank you for your comment, it would not be appropriate for clinical guidelines to go into detail about specific legislation, rather to make recommendations that healthcare professionals ensure their rights and needs are met.
303	SH	Royal College of Speech and Language Therapists	7	NICE	1.2.2	19	Families should be offered ongoing support and advice to help them manage the care and extended education for their child including transition into adult care.	Thank you for your comment, the Guideline Development Group feel that is addressed within the recommendation.
304	SH	British Academy of Childhood Disability (BACD).	10	NICE	1	12, recommendation 1.4.7	Often there are multiple factors contributing to behaviour that challenges and so additional support may be required as well as offering a psychosocial intervention.	Thank you for your comment. The Guideline Development Group thinks this issue is covered by the other recommendations in this section.
305	SH	British Academy of Childhood Disability (BACD).	12	NICE	1	13, families and carers	Support for siblings is important but often not offered.	Thank you for your comment, the Guideline Development Group agrees that this is an important point.
306	SH	Royal College of Paediatrics and Child Health	17	NICE	1.2.2 families and carers	13	Support for siblings is important but often not offered.	Thank you for your comment, the Guideline Development Group agrees this is an important point.
307	SH	The Disabilities Trust	3	NICE	1.2.2	13	We require clarification on this point - is this recommendation aimed at service providers or just local authorities, or both? Whilst the Trust does and will continue to encourage family support, it is unclear how this level of support would be accessed or set up. Unfortunately we do not feel that this is a practical key priority, especially in the current climate. All service providers are constantly being asked to provide more care services for less funding from local authorities. If care budgets continue	Thank you for your comment. All recommendations are for health and social care professionals and the Guideline Development Group feels strongly that professionals should offer assessment of families' own needs. Please also see appendix 19 on local authority duties.

							to be cut so drastically - our priority has to be the service user and their care before we asses how the families are coping.	
308	SH	Step by Step School	10	NICE	1.2.2	13 and 19	We welcome this recommendation, but believe that it needs to be clear who has responsibility for offering families and carers these assessments. Should the responsible person be the case manager referred to elsewhere in the guideline or should it be the family GP or should it be Social Services? More specificity would increase the degree of implementation in practice	Thank you for your comment. The NICE guidelines are for all health and social care professionals engaged with families. Please also see appendix 19 on local authority duties.
309	SH	British Psychological Society	18	NICE	1.2.3	19	The Society believes that It would be helpful to acknowledge that, whilst there may not be proven evidence of many aspects of interventions designed to address autism, the families of such affected children may often be helped by interventions demonstrated to affect other contributory problems in parents or siblings such as anxiety (e.g. through CBT). This may better equip them to manage the challenges arising from daily life alongside autism	Thank you for your comment. Recommendation 1.2.2 in the NICE Guideline explicitly offers families an assessment of their own needs.
310	SH	Step by Step School	8	NICE	1.3.1	11 and 20	We believe the recommendation requires further detail to be practical. It is not clear who the GDG is recommending will provide this intervention (ie which role within the NHS eg SALT?) and whether the recommendation is for direct intervention to the child or only through a “train the trainer” approach. It is also not clear whether the GDG is recommending a single intervention of a few months or an ongoing intervention over years	Thank you for your comment. This recommendation results from a thorough analysis of research studies. The recommendation has been reworded to ‘consider a specific social communication intervention’. The title of this section has also been amended to ‘specific interventions for the core features of autism’.
311	SH	Royal College of Speech and Language Therapists	8	NICE	1.3.1	17-8	An experienced speech and language therapist needs to have input into the psychosocial interventions.	Thank you for your comment. This recommendation results from a thorough analysis of research studies. The recommendation has been reworded to make clear that the intervention should follow one of the specific manualised programs via a specifically trained person.
312	SH	Royal College of Speech and	9	NICE	1.3.1	17-8	School-aged children continue to require multiagency and parental support where they are more severely	Thank you for your comment. Recommendation 1.1.3 in the NICE Guideline highlights the need

		Language Therapists					affected and in specialist schooling. This continues throughout their lives.	for multiagency working at all times when working with children and young people with autism.
313	SH	Alder Hey Children's NHS Foundation Trust	10	NICE	1.3	20	No intervention is provided for core features except via education for children with comorbid SLD especially.	Thank you for your comment. After reviewing the evidence, the Guideline Development Group felt that the recommendations in section 1.3 of the NICE Guideline for a social-communication intervention were warranted.
314	SH	BetsiCadwaladr University Health Board	7	NICE	1.3	20	We would like to recommend that a new section is incorporated here: **Behavioural Interventions** – Interventions that teach the child and young person with autism adaptive skills - This section focuses on evidence-based interventions with young children with autism, such as Applied Behaviour Analysis, and teaches pre-learning, social, language, academic and play skills - Another paragraph in this section could focus on evidence-based interventions with older children and young people, focusing on adaptive and daily living skills. - A third aspect to this section could include the reference to challenging behaviour management, functional assessment. - The final aspect to this section needs to suggest that staff and parents need training on how to apply the strategies listed above.	Thank you for your comment.The Guideline Development Group reviewed the guideline in light of your comment and were satisfied that the recommendations reflect the current evidence, including not recommending ABA. Nevertheless, there are recommendations on managing behaviour that challenges – see section 1.4 of the NICE Guideline. Unfortunately there is insufficient evidence to recommend parent training programmes, which is why the Guideline Development Group have supported a research recommendation on this, now in section 2.2, on managing behaviour that challenges in children and young people with autism: "Is a group-based parent training intervention for parents or carers of children and young people with autism clinically and cost effective in reducing early and emerging behaviour that challenges in the short- and medium-term compared with treatment as usual?"
315	SH	British Academy of Childhood Disability (BACD).	16	NICE	1.3.1	20	Why only "consider" this support? Importance of early intervention should be stressed.	Thank you for your comment, the word 'consider' has a very specific meaning in NICE guidance, as described at the start of the document. A 'consider' recommendation is used when the evidence is not strong enough to use 'offer'.
316	SH	British Academy of	17	NICE	1.3.1	20	Could communication support be mentioned such as PECS, Makaton, electronic tablets?	Thank you for your comment. This recommendation results from a thorough

		Childhood Disability (BACD).						analysis of research studies, in which PECS and Makaton were not used. The Guideline Development Group has added an additional bullet point in recommendation 1.1.6 in the NICE Guideline, about advice and interventions to promote functional adaptive skills including communication and daily living skills. There is a research recommendation about PECS in chapter 7 of the Full Guideline, Interventions aimed at associated features of autism and coexisting conditions.
317	SH	British Association for Music Therapy (BAMT)	10	NICE	1.3.1	20	'Consider a social communication intervention for the management of the core features of autism…'. It is not clear from the guidelines what constitutes a social communication intervention and who is competent to deliver such an intervention, or how this relates to the level of clinical complexity involved. We would argue, in the light of the research evidence (Lim 2010 and Kim et al 2008 - see 5 above for ref.) that music therapy as delivered by a registered music therapist should be considered within this category. We ask the committee to clarify the scope of the term and recommend the appropriate kind and level of professional training/regulation/ supervision for those delivering the intervention.	Thank you for your comment. This recommendation results from a thorough analysis of research studies, in which music therapy was not included. The recommendation has been reworded to 'consider a specific social communication intervention'. The title of this section has also been amended to 'specific interventions for the core features of autism'.
318	SH	British Psychological Society	19	NICE	1.3.1	20	The Society would welcome the inclusion of more specific guidance on evidence based approaches or packages under Social-communication interventions	Thank you for your comment. The Guideline Development Group developed the recommendation based on the current evidence base. Further information may be developed during implementation.
319	SH	Carmarthenshire Education	13	NICE	1.3.1	20	Who would provide the training for social-communication interventions?	Thank you for your comment. Recommendation 1.1.6 in the NICE Guideline recommends that

		and Children's Services						the local autism team has a key role in the delivery and coordination of training and support, see bullet 2.
320	SH	QUEEN'S UNIVERSITY BELFAST	4	NICE	1.3 Interventions for the core features of autism	20	No mention of Applied Behaviour Analysis (i.e., the science that underpins the intervention of choice for children with Autism) as the basis for an effective intervention. The term "social-communication" intervention is here used in a vague way, thus does not clarify what exactly is recommended (i.e., does a scientific, evidence-based intervention exist and if this is the intervention based on ABA, then why isn't it mentioned here in a straightforward way?)	Thank you for your comment. ABA has now been discussed in sections 2.13 and 5.2.1 of the Full Guideline. In the review of evidence, the Guideline Development Group found no evidence to support ABA and therefore cannot make a recommendation about it.
321	SH	Rotherham Doncaster and South Humber NHS Foundation Trust	7	NICE	1.3.1	20	Social-communication interventions. No specific evidence based approach or package is mentioned. More specific guidance on this would be helpful.	Thank you for your comment. The Guideline Development Group developed the recommendation based on the current evidence base. Further information may be developed during implementation.
322	SH	Royal College of Paediatrics and Child Health	21	NICE	1.3.1	20	Why only "consider" this support? Importance of early intervention should be stressed.	Thank you for your comment, the word 'consider' has a very specific meaning in NICE guidance, as described at the start of the document. A 'consider' recommendation is used when the evidence is not strong enough to use 'offer'.
323	SH	Royal College of Paediatrics and Child Health	22	NICE	1.3.1	20	Could communication support be mentioned such as PECS, Makaton, electronic tablets?	Thank you for your comment. This recommendation results from a thorough analysis of research studies, in which PECS and Makaton were not used. The Guideline Development Group has added an additional bullet point in recommendation 1.1.6 in the NICE Guideline, about advice and interventions to promote functional adaptive skills including communication and daily living skills. There is a research recommendation about

								PECS in chapter 7 of the Full Guideline, Interventions aimed at associated features of autism and coexisting conditions.
324	SH	British Paediatric Mental Health Group	1	NICE	1.4	21-26	This section is very helpful, but more use of the word 'should' would help us to persuade commissioners to set up the necessary networks and teams!	Thank you for your comment. The Guideline Development Group takes your point, but 'should' is used to specifically denote greater certainty in relation to the evidence. The guideline uses 'consider' to denote less certainty.
325	SH	British Psychological Society	20	NICE	1.4.1 and 1.4.2	21	The Society welcomes the guidelines raising the issue of preventing behaviour that challenges, and routinely assessing for this. We believe that there should be some reference to the current work on developing NICE guidelines for Challenging Behaviour.	Thank you for your comment.Tthe forthcoming NICE guidelines have been added to the 'related NICE guidance' in section 3.2 of the NICE Guideline, Related NICE Guidance.
326	SH	Royal College of Speech and Language Therapists	10	NICE	1.4.1	21	A multidisciplinary team approach is extremely important when determining the risk in the case of behaviour that challenges.	Thank you for your comment, the Guideline Development Group agrees that a multidisciplinary team approach is important – recommendation 1.1.3 in the NICE Guideline sets out that this should be the case for all aspects of management for children and young people with autism.
327	SH	Royal College of Speech and Language Therapists	11	NICE	1.4.1	21	We suggest moving communication difficulties to the top of the list as all of these factors are compounded when the child is not able to communicate. A risk assessment should be carried out at home as well as in the school situation.	Thank you for your helpful comment. The Guideline Development Group has moved impairments in communication to the top of the list as you have suggested. The Guideline Development Group agrees that a risk assessment should consider all aspects of the child's environment as stated in the recommendation.
328	SH	QUEEN'S UNIVERSITY BELFAST	5	NICE	1.4 Interventions for behaviour that challen	21-24	Here, a very brief summary of a functional analysis is provided, as this has been described in the behaviour analytic literature. However, again there is no mention of the scientific area that underlie this paradigm (e.g., Behaviour Analysis as the science that studies human behaviour)	Thank you for your comment. The NICE version of the guideline is a summary of the recommendations, rather than a description of the evidence. Therefore, it would not be appropriate to include a summary of functional analysis in section 1.4.

					ges			
329	SH	British Academy of Childhood Disability (BACD).	9	NICE	1.4.1	11, behaviour that challenges	Should the professionals who ought to offer this support (and qualifications) be mentioned? Please include support for sleep disorders.	Thank you for your comment. All recommendations in NICE Guidelines in general apply to health and social care professionals. Guidelines do not usually specify which health and social care professional should be responsible for implementing those recommendations, except where there are legal constrains, such as in relation to the Mental Health Act or prescribing. Although guidelines recommend that people should be competent to carry out an intervention, it cannot describe what specific qualifications people should have as this is outside of the scope of the guideline. The section on sleep problems in Section 1.7 has been extensively revised given the feedback from stakeholders.
330	SH	Royal College of Paediatrics and Child Health	14	NICE	1.4.1, , behaviour that challenges	11	Should the professionals who ought to offer this support (and qualifications) be mentioned? Please include support for sleep disorders.	Thank you for your comment. All recommendations in NICE Guidelines in general apply to health and social care professionals. Guidelines do not usually specify which health and social care professional should be responsible for implementing those recommendations, except where there are legal constrains, such as in relation to the Mental Health Act or prescribing. Although guidelines recommend that people should be competent to carry out an intervention, it cannot describe what specific qualifications people should have as this is outside of the scope of the guideline. The section on sleep problems in Section 1.7

								has been extensively revised given the feedback from stakeholders.
331	SH	Dimensions	1	NICE	1.4.1	12	It might be useful at the top of the page in the list regarding items to consider in assessment to discuss predictability and structure more explicitly	Thank you for your helpful comment. The Guideline Development Group has modified recommendations 1.4.1 and 1.4.2 accordingly.
332	SH	Royal College of Paediatrics and Child Health	15	NICE	1.4.7	12	Often there are multiple factors contributing to behaviour that challenges and so additional support may be required as well as offering a psychosocial intervention.	Thank you for your comment, the Guideline Development Group believe this is the reason an assessment of these behaviours needs to be conducted as per recommendations 1.4.1 and 1.4.2 of the NICE Guideline.
333	SH	Step by Step School	9	NICE	1.4.7	12 and 23	We believe the recommendation needs to be further explained to be practical. In our view, many GPs will not understand the words “psychosocial intervention informed by a functional behaviour analysis” nor understand who in the NHS is able to provide this service. If this is to become a first line treatment it needs to be explained. We suggest additional sentences to (i) define what this intervention is in plain English (ii) define who can provide it in NHS. It should also be noted that if the child is non-verbal, has limited receptive language and has low IQ (which will more often than not be the case), “talking therapies” are unfortunately unlikely to be effective. Behavioural therapies are more likely to be needed. However, the guideline is not clear if ABA type therapy is considered by the GDG to be “psychosocial intervention informed by a functional behaviour analysis”. In the scope document of the guideline, ABA was specifically mentioned - see section 4.3.1a, but this term is almost non-existent in the guideline. This needs to be clarified as terminology will cause much confusion to parents and professionals alike. “Psychosocial intervention” is in our opinion too broad a term to be helpful to anyone in the NHS	Thank you for your comments. The Guideline Development Group has changed the phrase to functional assessment of behaviour. The Guideline Development Group have considered your comments and disagree that the rest of the wording will not be understood by GPs. NICE guidelines are always directed at health and social care professionals unless otherwise specified The scope serves to guide the Guideline Development Group to consider all the evidence regarding all the interventions included in the scope, but it does not prescribe recommendations in advance which necessarily will depend on the evidence.
334	SH	British Academy of Childhood	11	NICE	1.4.10	12-13	Some families will not want their child to be given psychotropic medication.	Thank you for your comment, this is understood and the guideline makes it clear that this should only be in exceptional circumstances. As

		Disability (BACD).						always, the wishes of the child and their families should be considered and a care plan developed in collaboration with them.
335	SH	Royal College of Paediatrics and Child Health	16	NICE	1.4.10	12-13	Some families will not want their child to be given psychotropic medication.	Thank you for your comment, this is understood and the guideline makes it clear that this should only be in exceptional circumstances. As always, the wishes of the child and their families should be considered and a care plan developed in collaboration with them.
336	SH	The Disabilities Trust	2	NICE	1.4.10	13	The Disabilities Trust welcomes the recommendation for the use of antipsychotic medicine. We agree that the use of this type of medicine can be used positively for the management of autism in some individuals. However we are concerned that there is no 'gold standard' or mention of what specific psycho-social interventions may work, and therefore the path to anti-psychotic medication may be different dependent on an individual professional. (please see example given on point 5 regarding for further information)	Thank you for your comment. Please see recommendation 1.4.9 in the NICE Guideline which identifies what a psychosocial intervention for challenging behaviour should look like.
337	SH	Royal College of Paediatrics and Child Health	2	NICE	1.33 and 1.6	Page 21 and 26	Treatments not to be followed are in two different places- suggest they should all be together. We would add 'Biomedical treatments' as these are marketed as such and tend to include chelation and 'allergy diets' not just restricted to the diets in the guideline.	Thank you for your comment. The interventions that are not recommended are in two separate sections because antipsychotics, antidepressants, anticonvulsants and exclusion diets are not recommended for the core features of autism (recommendation 1.3.2 in the NICE Guideline), while secretin, hyperbaric oxygen therapy and chelation are not recommended in any context (recommendation 1.6.1 in the NICE Guideline).
338	SH	Royal College of Paediatrics and Child Health	3	NICE	1.33 and 1.4.10	Page 21 and Page 24	1.33 states anti-psychotic medication should not be used. We feel that this should be qualified as there is a small a minority of adolescent or adult autistic individuals who also have severe learning disability who have been able to be maintained at home by such medication, usually Risperidone. These patients should be monitored by a psychiatrist.	Thank you for your comment. This section is about interventions specifically for the core impairments of autism. The use of antipsychotics for challenging behaviour is covered in section 1.4 of the NICE Guideline, where monitoring is also covered.

339	SH	The Disabilities Trust	5	NICE	1.4.2	22	The Trust strongly recommends that the guidance team re-think the wording for this guideline. A care plan should primarily be an enquiring approach with full involvement of the service user, their families or carer. Within point 1.4.2 there should be explicit mention of consultation and discussion with the service user at the moment this is not the case. The Trust is aware that involving someone with autism in their own care plan can be difficult due to their difficulties with social interaction and challenging behaviour. However we make a concentrated effort to have them at meetings or alternatively by finding any imaginative way possible to get their input. We also use advocates to elicit crucial information which will provide the service user with a good care plan and ultimately a better quality of life.	Thank you for your comment. The Guideline Development Group has amended the recommendation accordingly: 'Develop a care plan with the child or young person and their families or carers that outlines the steps needed to address the factors that may provoke behaviour that challenges, including:...'
340	SH	British Paediatric Mental Health Group	2	NICE	1.4.5	22	It is not clear what a multidisciplinary review means, who should be involved.	Thank you for your comment. The Guideline Development Group believes the term 'multidisciplinary review' (used, for example in recommendation 1.4.5 in the NICE Guideline) will be understood by healthcare professionals, and the term is used in other NICE guidelines without further explanation. Who should be involved will depend on the local context.
341	SH	British Psychological Society	21	NICE	1.4.4	22	The Society is concerned that it is unclear as to what coexisting behavioural problems would be. This should be termed behaviour that challenges. The second bullet point under 1.4.4 refers to providing advice to families and carers, but it is not clear what the advice is This section should include a recommendation to address some of the issues that we know can cause behaviour that challenges, without needing to do a formal functional assessment. For example, suggesting that at this stage the worker could ensure	Thank you for your comment. The Guideline Development Group reviewed the guideline in light of your suggestions, but decided not to make changes, as what is understood to be behavioural includes ADHD. The Guideline Development Group agrees the importance of addressing common causes of behaviour that challenges – these are exampled in recommendation 1.4.1 in the NICE Guideline.

							that the child has appropriate means of communication, has appropriate and enjoyable activities, and has opportunities to develop skills	
342	SH	British Academy of Childhood Disability (BACD).	18	NICE	1.4.5 and 1.4.6	22-23	Prevention and early intervention should be stressed to try to prevent, or at least ameliorate, later challenging behaviour.	Thank you for your comment, recommendation 1.4.1 in the NICE Guideline specifically addresses the prevention and early intervention of challenging behaviour.
343	SH	Royal College of Paediatrics and Child Health	23	NICE	1.4.5 and 1.4.6	22-23	Prevention and early intervention should be stressed to try to prevent, or at least ameliorate, later challenging behaviour.	Thank you for your comment, recommendation 1.4.1 in the NICE Guideline specifically addresses the prevention and early intervention of challenging behaviour.
344	SH	Royal College of Speech and Language Therapists	12	NICE	1.4.6	22-3	Implementation needs to be consistent across all contexts. Preferences of the family need to be listened to and care needs to be taken to ensure that the family are also implementing the interventions effectively. (This is where the use of strategies can break down and behaviours can become out of hand and residential care has to be considered.)	Thank you for your helpful comment. This is an important point and the Guideline Development Group has added the following bullet point to recommendation 1.1.8 to reflect this: 'how to provide individualised care and support and ensure a consistent approach is used across all settings' Two further bullet points have also been inserted in recommendation 1.4.9 in the NICE Guideline: • 'consistent application in all areas of the child or young person's environment (for example, at home and at school) • agreement among parents, carers and professionals in all settings about how to implement the intervention.'
345	SH	British Association for Music Therapy (BAMT)	11	NICE	1.4.7	23	'Offer the child or young person a psychosocial intervention (informed by a functional behavioural analysis) as a first-line treatment.' Again, it is not clear what constitutes a psychosocial intervention and who is competent to deliver such an intervention, or how	Thank you for your comment. Psychosocial interventions are a common and well understood phrase but the included principles are in recommendation 1.4.9 in the NICE Guideline.

							this relates to the level of clinical complexity involved. We argue that functional psychosocial benefits are often the principle aim and outcome of music therapy interventions, and that practitioners have the required level of training for effective inter-relational and interpersonal practice. We also note that, while the contribution of music therapy to functional outcomes is mentioned in the section: 'Arts-based interventions for speech and language as a direct outcome' there is no mention here of the psycho-social benefits of music therapy. We would ask the committee to clarify the scope of this term and recommend the appropriate kind and level of professional training/regulation/supervision required to deliver such an intervention effectively.	The evidence for music therapy was reviewed, please see sections 7.3.3 for direct outcomes and 5.2.5 for indirect outcomes in the Full Guideline. The use of the phrase 'Arts based therapy' was taken from a study on "reported patterns on alternative and complementary therapy on children with ASD".
346	SH	British Paediatric Mental Health Group	3	NICE	1.4.7	23	It is unclear what level of training the person delivering this intervention must have.	Thank you for your comment, all healthcare professionals should be competent and sufficiently trained in any interventions they are delivering. In addition, this guideline recommends that anyone working with children and young people with autism should be trained in the specifics of autism, see recommendation 1.1.8 in the NICE Guideline.
347	SH	Royal College of Speech and Language Therapists	13	NICE	1.4.7	23	Consistent application of the strategies discussed above must be in place before medication clouds issues surrounding behavioural difficulties. Functional behavioural analysis should be a separate recommendation.	Thank you for your comment which is an important point and the Guideline Development Group added the following bullet point to recommendation 1.4.9 in the NICE Guideline: : 'agreement among parents, carers and professionals in all settings about how to implement the intervention.'
348	SH	Alder Hey Children's NHS Foundation Trust	11	NICE	1.4.10	24	Antipsychotic medication when prescribed is initiated and monitored by the psychiatrists in the CAMHS team.	Thank you for your comment, as practice varies in each local area the wording of recommendation 1.4.10 is not that specific but ensures a specialist in this area carries out the prescribing.
34	SH	British	22	NICE	1.4.9	24	Regarding the second bullet point, the Society would	Thank you for your comment. The Guideline

9		Psychological Society					welcome clarification about how quality of life may be defined in this context and appropriate outcomes. We also recommend that The bullet points should be altered slightly by moving the third one “assessment and modification of environmental factors that may contribute to initiating or maintaining the behaviour”, and using it as an example of the current fourth point, so that that reads “a clearly defined intervention strategy assessment and modification of environmental factors that may contribute to initiating or maintaining the behaviour of the child or young person.”	Development Group does not think it would be appropriate to define quality of life or outcomes in a recommendation. Also, merging bullet points three and four would not in our opinion add clarity to the recommendation.
350	SH	Dimensions	6	NICE	1.4.10	24	Could it be suggested here that a psychosocial intervention is attempted before a user tries a pharmacological intervention? We’re not sure if the guidelines allow for a staged intervention approach in this way but ideally, one would recommend a non-pharmacological approach in the first instance.	Thank you for your comment. Recommendation 1.4.10 does state that pharmacological interventions should only be used ‘when psychosocial or other interventions are insufficient or could not be delivered because of the severity of the behaviour.’
351	SH	Dimensions	5	NICE	1.4.9	24	Although I understand this may have been omitted for various reasons, it would be useful here to explain specific types of interventions that have a strong evidence base demonstrating their effectiveness, such as early intensive behavioural intervention or ABA, for example.	Thank you for your comment. The Guideline Development Group felt that it was more appropriate to specify in recommendation 1.4.9 in the NICE Guideline what a psychosocial intervention should include rather than naming specific interventions or approaches.
352	SH	East and North Herts NHS Trust	4	NICE	1.4.10	24	A definition of a “specialist” would be helpful	Thank you for your comment. The recommendation has been amended to be more specific. It now refers to a paediatrician or psychiatrist.
353	SH	Rotherham Doncaster and South Humber NHS Foundation Trust	8	NICE	1.4.9	24	Commend the focus on outcomes that are linked to quality of life, specified timescale to meet intervention goals, & systematic measure of the target behaviour.	Thank you for your comment.
354	SH	Royal College of Speech and Language Therapists	14	NICE	1.4.9	24	A systematic method of disseminating the intervention goals and required modifications to all people concerned with the child is fundamental.	Thank you for your comment. The Guideline Development Group agreed but judged that dissemination could be determined at the local level.

355	SH	Royal College of Speech and Language Therapists	15	NICE	1.4.10	24-5	A specialist speech and language therapist should be involved in determining whether communication is functional for 1.4.1 and multidisciplinary consensus should be sought.	Thank you for your comment. The Guideline Development Group felt that assessment for behaviour that challenges would be conducted or organised by the local multidisciplinary autism team, which would include a speech and language therapist. Please note that no professional is mentioned specifically in recommendation 1.4.1 in the NICE guideline as it is expected that the precise organisation of the team would be determined at the local level.
356	SH	Alder Hey Children's NHS Foundation Trust	12	NICE	1.4.13	25	Transfer of medication prescribing of antipsychotics to primary care occurs when the child is 16 or has had a period of stability on the medication.	Thank you for your comment., the Guideline Development Group asserts that these measures should be undertaken during any transfer of medication prescribing.
357	SH	Step by Step School	15	NICE	1.5.1	26	While we agree with this recommendation, we do not see how GPs, etc can take on this responsibility. It could perhaps be something the case managers could be responsible for?	Thank you for your comment. Recommendation 1.5.1 does not specify that GPs should take on this responsibility.
358	SH	British Academy of Childhood Disability (BACD).	19	NICE	1.5.1	26	Employment competencies are defined for the typical population and so many young people with autism cannot find employment. There needs to be a fundamental review of how employment is structured for people with autism and other disabilities.	Thank you for your comment, support for people with autism in employment settings is explored in the Autism: recognition, referral, diagnosis and management of adults on the autism spectrum guideline (CG142).
359	SH	Royal College of Paediatrics and Child Health	24	NICE	1.5.1	26	Employment competencies are defined for the typical population and so many young people with autism cannot find employment. There needs to be a fundamental review of how employment is structured for people with autism and other disabilities.	Thank you for your comment, support for people with autism in employment settings is explored in the Autism: recognition, referral, diagnosis and management of adults on the autism spectrum guideline (CG142).
360	SH	British Psychological Society	23	NICE	1.6	26	Although there are good reasons why secretin, chelation or hyperbaric oxygen therapy should not be used to *manage autism* in children and young people, there might be circumstances where one of these interventions is clinically indicated e.g the use of chelation in a case of acute metal poisoning.	Thank you for your comment. The Guideline Development Group has reviewed recommendation 1.6.1 in the NICE Guideline and reworded it to: 'Do not use the following interventions to manage autism in any context in children and

							Recommendation: **The opening clause of section 1.6.1 be amended to read;** **'Do not, in any context, use the following interventions to manage autism in children and young people;'**	young people'.
361	SH	British Academy of Childhood Disability (BACD).	20	NICE	1.7	26	Lack of SLT support for children and young people with autism is a frequent reason to resort to Tribunals. Such support needs to be readily available, not just on a consultation basis.	Thank you for your comment. The speech and language therapist is a core member of the autism team, see the Autism diagnosis in children and young people: Recognition, referral and diagnosis of children and young people on the autism spectrum guideline (CG 128). The Guideline Development Group has added a bullet point to recommendation 1.1.6 in the NICE Guideline, explaining that local autism teams should have a key role in the delivery and coordination of: 'advice and interventions to promote functional adaptive skills including communication and daily living skills' Taken together, the Autism diagnosis in children and young people: Recognition, referral and diagnosis of children and young people on the autism spectrum guideline (CG 128), and this guideline regard speech and language therapy and the skills they provide to be an integral part of what the autism team does.
362	SH	Royal College of Paediatrics and Child Health	25	NICE	1.7	26	Lack of SLT support for children and young people with autism is a frequent reason to resort to Tribunals. Such support needs to be readily available, not just on a consultation basis.	Thank you for your comment The speech and language therapist is a core member of the autism team, see the Autism diagnosis in children and young people: Recognition, referral and diagnosis of children and young people on the autism spectrum guideline (NICE CG 128). The Guideline Development Group has added a bullet point to recommendation 1.1.6 in the NICE Guideline, explaining that local autism teams

								should have a key role in the delivery and coordination of: 'advice and interventions to promote functional adaptive skills including communication and daily living skills' Taken together, the Autism diagnosis in children and young people: Recognition, referral and diagnosis of children and young people on the autism spectrum guideline, and this guideline regard speech and language therapy and the skills they provide to be an integral part of what the autism team does.
363	SH	British Association for Music Therapy (BAMT)	12	NICE	1.7.1	26	'Consult a speech and language expert in the autism team when managing receptive and expressive language problems in children and young people with autism (including when they are non-verbal).' We would urge the committee to include mention here of non-verbal interventions such as music therapy in the assessment and treatment of language problems, especially in the case of pre-verbal and non-verbal children and young people. In our experience, wherever music therapists are available their expertise is appreciated by speech and language therapists and by carers. We believe this document offers an opportunity to recognize music therapists' expertise in working with autism as a valuable additional resource in assessment and treatment.	Thank you for your comment The speech and language therapist is a core member of the autism team see guideline NICE CG 128. The Guideline Development Group has added to 1.1.6 in the NICE Guideline, explaining that local autism teams should have a key role in the delivery and coordination of: 'advice and interventions to promote functional adaptive skills including communication and daily living skills' Music therapy was evaluated, however the Guideline Development Group felt that there was not sufficient evidence to warrant making a recommendation for these interventions. The evidence for music therapy has been reviewed in sections 7.3.3 (direct outcomes) and 5.2.5 (indirect outcomes) of the Full Guideline.
364	SH	Alder Hey Children's NHS Foundation	13	NICE	1.8	26	No sleep specialist available for sleep difficulties in children with autism.	Thank you for your comment. The Guideline Development Group has written a new section on sleep problems outlining a hierarchical approach from primary care to specialist –

		Trust						please see recommendations 1.7.4 to 1.7.9 in the NICE Guideline.
365	SH	British Academy of Childhood Disability (BACD).	21	NICE	1.8	26	Sleep disorders in children and young people with autism are a crucial problem for many families that may have profound effects on the functioning of the family. Melatonin can be extremely helpful and, whilst the evidence base is not robust, it ought to be considered in children and young people with autism who have sleep disorders (and so deserves mention at this point in the guideline).	Thank you for your comment. The Guideline Development Group has written a new section on sleep problems outlining a hierarchical approach from primary care to specialist – please see recommendations 1.7.4 to 1.7.9 in the NICE Guideline. The use of melatonin in autism was examined carefully and the evidence to date does not reach the GRADE threshold for a specific recommendation.
366	SH	British Psychological Society	24	NICE	1.8	26	The Society is concerned that The advice appears to overlook the recent meta-analysis on Melatonin in autism that indicates its overall beneficial effect. Reference Rossignol, D.A and Frye, R.E. (2011). Melatonin in autism spectrum disorders: a systematic review and meta-analysis. Developmental Medical Child Neurology, 53(9):783-92.	Thank you for your comment. The Guideline Development Group has written a new section on sleep problems outlining a hierarchical approach from primary care to specialist – please see recommendations 1.7.4 to 1.7.9 in the NICE Guideline. The use of melatonin in autism was examined carefully and the evidence to date does not reach the GRADE threshold for a specific recommendation.
367	SH	Contact a Family	4	NICE	1.8	26	Add *Melatonin may be considered for children and young people on the autism spectrum, who have sleep difficulties, and do not respond to behavioural interventions on their own, but only under specialist supervision because it is not licensed in the UK* There is research to support this including two RCTs but the full guidelines said they were not of sufficient high quality to make a recommendation. One RCT(Gringas) was discounted as the study included children and young people with developmental disabilities as well as autism. By contrast the GDG developing NICE guidelines	Thank you for your comment. We have written a new section on sleep problems outlining a hierarchical approach from primary care to specialist – please see recommendations 1.7.4 to 1.7.9 in the NICE Guideline. The use of melatonin in autism was examined carefully and the evidence to date does not reach the GRADE threshold for a specific recommendation.

							for CFS/ME took the view that treatment of symptoms should be provided on the basis of **general principles of symptom management** rather than requiring research trials specific to the condition. *The view of the GDG was that symptomatic treatment should be provided on the basis of general principles of symptom management, except where it was inappropriate for people with CFS/ME.* (6.4.2.1, NICE guidelines: CFS/ME in adults and children) The CFS/ME guidelines make the recommendation that *Melatonin may be considered for children and young people with CFS/ME who have sleep difficulties, but only under specialist supervision because it is not licensed in the UK (1.6.3.3* NICE guidelines: CFS/ME in adults and children) There is much more research supporting use of melatonin in supporting the sleep for children and adolescents with developmental disabilities compared to that for children with CFS/ME. (Ref research review Sleep disorders in children and adolescents with learning disabilities and their management, Turk J**,** Advances in Mental Health and Learning Disabilities Volume 4 Issue 1 March 2010)	
368	SH	Flynn Pharma Ltd	1	NICE	1.8.1	26	There are a limited number of sleep experts working in the area of neurodevelopmental disorders in the UK, making routine access to expert advice for all patients aspirational. To reduce the impact of the limited number of sleep experts in the UK, access to algorithm	Thank you for your comment. The Guideline Development Group has written a new section on sleep problems outlining a hierarchical approach from primary care to specialist – please see recommendations 1.7.4 to 1.7.9 in

							based, practical guidance on the management and treatment of sleep disorders in patients with autism would be more likely to ensure all patients have equal access to the same quality and types of treatments, be they sleep hygiene or pharmacotherapy based.	the NICE Guideline. The use of melatonin in autism was examined carefully and the Guideline Development Group was of the opinion that there was not enough evidence for a specific recommendation.
369	SH	British Academy of Childhood Disability (BACD).	22	NICE	1.8.1	26	Before consulting a sleep expert an assessment should be made of the possible causes of sleep disturbance and steps taken to address any causes identified (e.g. pain). Support offered for sleep disturbance needs to be tailored to the home environment and parental goals and temperament. Prevention and early intervention should be stressed.	Thank you for your comment. The Guideline Development Group has written a new section on sleep problems outlining a hierarchical approach from primary care to specialist – please see recommendations 1.7.4 to 1.7.9 in the NICE Guideline. The use of melatonin in autism was examined carefully and the evidence to date does not reach the GRADE threshold for a specific recommendation.
370	SH	Flynn Pharma Ltd	2	NICE	1.8.1	26	Considerable variance in both clinical guidelines and prescribing practice exists across the UK when considering the management of sleep disorders in patients with neurodevelopmental disorders, resulting in post-code variations taking place. Whilst accepting the level 1a evidence base for the treatment of sleep disorders in patients with autism is limited, the overall dataset consistently indicates a beneficial role for melatonin pharmacotherapy to promote and sustain sleep in patients with autism. When pharmacotherapy is indicated, stronger advice relating to the evidence for both the use and type (immediate release or prolonged release) of melatonin should be developed to reduce the post-code variance that currently exists. This could usefully mirror or extend upon NICE Evidence Summary (ESUOM2) for Melatonin (Jan 2013).	Thank you for your comment. The Guideline Development Group has written a new section on sleep problems outlining a hierarchical approach from primary care to specialist – please see recommendations 1.7.4 to 1.7.9 in the NICE Guideline. The use of melatonin in autism was examined carefully and the evidence to date does not reach the GRADE threshold for a specific recommendation.
371	SH	Flynn Pharma Ltd	3	NICE	1.8.1	26	With regard to the use of melatonin, to promote good prescribing practice and to protect patient safety, the MHRA has issued recent guidance (Drug Procurement Advice, 2008); subsequently, a risk stratification hierarchy has been developed that can be applied to the prescribing and dispensing decisions for melatonin	Thank you for your comment. The Guideline Development Group has written a new section on sleep problems outlining a hierarchical approach from primary care to specialist – please see recommendations 1.7.4 to 1.7.9 in the NICE Guideline. The use of melatonin in

							products that should be used to meet individual patient's clinical needs while minimising risk to the patient (and prescriber). On safety (risk stratification) and cost grounds (Prescription Costs Analysis, data on file and ESUOM2), the use of the UK licensed product (Circadin®) is preferable, even when used off-label (in paediatrics or crushed for example) compared to the use of unlicensed melatonin preparations. This information regarding risk, safety and cost should be consistently communicated to prescribers, to encourage consistent prescribing practice across the UK.	autism was examined carefully and the evidence to date does not reach the GRADE threshold for a specific recommendation.
372	SH	Royal College of Paediatrics and Child Health	26	NICE	1.8	26	Sleep disorders in children and young people with autism are a crucial problem for many families that may have profound effects on the functioning of the family. Melatonin can be extremely helpful and, whilst the evidence base is not robust, it ought to be considered in children and young people with autism who have sleep disorders (and so deserves mention at this point in the guideline).	Thank you for your comment. The Guideline Development Group has written a new section on sleep problems outlining a hierarchical approach from primary care to specialist – please see recommendations 1.7.4 to 1.7.9 in the NICE Guideline. The use of melatonin in autism was examined carefully and the evidence to date does not reach the GRADE threshold for a specific recommendation.
373	SH	Royal College of Paediatrics and Child Health	27	NICE	1.8.1	26	Before consulting a sleep expert an assessment should be made of the possible causes of sleep disturbance and steps taken to address any causes identified (e.g. pain). Support offered for sleep disturbance needs to be tailored to the home environment and parental goals and temperament. Prevention and early intervention should be stressed.	Thank you for your comment. The Guideline Development Group has written a new section on sleep problems outlining a hierarchical approach from primary care to specialist – please see recommendations 1.7.4 to 1.7.9 in the NICE Guideline. The use of melatonin in autism was examined carefully and the evidence to date does not reach the GRADE threshold for a specific recommendation.
374	SH	Alder Hey Children's NHS Foundation Trust	14	NICE	1.9.2	27	CBT is offered in our CAMHS for children able to use the psychological work. Adapted CBT is used. Family work where families are supported either conjointly or in joint work is offered as an adjunct to CBT.	Thank you for your comment.
375	SH	British Academy of	23	NICE	1.9.1	27	Help for severe anxiety may also be required.	Thank you for your comment. This list is illustrative, not exhaustive.

		Childhood Disability (BACD).						
376	SH	British Psychological Society	25	NICE	1.9.1	27	The Society agrees that medication should not be first line/used in isolation.	Thank you for your comment.
377	SH	Rotherham Doncaster and South Humber NHS Foundation Trust	9	NICE	1.9	27	Sometimes it is helpful to combine psychosocial and pharmacological interventions from the off rather than saying first try this, then if that does not work try that ....certainly in the complex cases we see. However we agree that medication should not be firstline/used in isolation.	Thank you for your comment. In this section both psychosocial and pharmacological treatments are recommended.
378	SH	Royal College of Paediatrics and Child Health	28	NICE	1.9.1	27	Help for severe anxiety may also be required.	Thank you for your comment. This list is illustrative, not exhaustive.
379	SH	Royal College of Speech and Language Therapists	17	NICE	1.9.2	27	Some students who are not able to express themselves verbally are able to engage in CBT with appropriate alternative communication aids / strategies.	Thank you for your comment. None of the evidence underpinning this covered non-verbal children using communication aids
380	SH	Step by Step School	16	NICE	1.9.1	27	ADHD clinical guideline 72 does not mention children with autism. Are the GDG comfortable that the recommendations in guideline 72 are robust in children with autism? There seems to be some evidence that ADHD medications are less effective in children with autism and ADHD (for example see Archives of General Psychiatry 2005;62:1266-1274). Our suggestion would be to add a research recommendation to conduct RCTs in co-morbid children with ADHD + autism	Thank you for your comment. Evidence of whether ADHD with autism should be differently treated was searched for and the Guideline Development Group concluded that ADHD guidelines should be followed
381	SH	Rotherham Doncaster and South Humber NHS Foundation Trust	10	NICE	1.9.2/3	27 & 28	The recommendations on use of CBT with this group are most welcome as is the guidance on how to adapt it.	Thank you for your comment.
38	SH	British	26	NICE	1.9.2	27 +	The Society strongly welcomes the recommendations	Thank you for your comment.

2		Psychological Society			and 1.9.3	28	on use of CBT with this group together with the guidance on how to adapt it.	
383	SH	Alder Hey Children's NHS Foundation Trust	15	NICE	1.10.1	28	A transition policy is in place to support young people who need transfer to adult or other services. This is usually implemented around 15 years 7 months and at 17 years 7 months depending on the nature and severity of the mental disorder. Adult services do not accept young people with ASD until their 18th birthday and, for children who do not have coexisting SLD, a gap in service exists. A CQUIN related to transition to adult MH services involves an audit of unmet need with a view to future commissioning. There is an adult Aspergers service in the region which starts at 18.	Thank you very much; this is a very common experience.
384	SH	Alder Hey Children's NHS Foundation Trust	16	NICE	1.10.2	28	CPA is used in children and young people with autism with complex difficulties in the management of their care in our service and also in the transfer of care.	Thank you for your comment, it is encouraging to hear of such good practice.
385	SH	Royal College of Speech and Language Therapists	18	NICE	1.10.2	28	All young people regardless of the severity of their diagnosis require support at this time of enormous change as it is when they have most difficulties.	Thank you for your comment. The Guideline Development Group is in agreement.
396	SH	British Academy of Childhood Disability (BACD).	24	NICE	1.10.3	29	Should this process be 'must' rather than 'should'?	Thank you for your comment. The use of the word 'must' has a very specific meaning in NICE guidelines, as explained at the front of the document: *We usually use 'must' or 'must not' only if there is a legal duty to apply the recommendation. Occasionally we use 'must' (or 'must not') if the consequences of not following the recommendation could be extremely serious or potentially life threatening.*
387	SH	Royal College of Nursing	27	NICE	1.10.4	29	*During transition to adult services, consider a formal meeting involving health and social care and other*	Thank you for your comment. This is covered by 'other relevant professionals' to ensure no

							relevant professionals from child and adult services. **This should include education professionals, their involvement is important at this stage to enable seamless transition for the young people still in education.**	professional important in the child's life is excluded.
388	SH	Royal College of Paediatrics and Child Health	29	NICE	1.10.3	29	Should this process be 'must' rather than 'should'?	Thank you for your comment. The use of the word 'must' has a very specific meaning in NICE guidelines, as explained at the front of the document: *We usually use 'must' or 'must not' only if there is a legal duty to apply the recommendation. Occasionally we use 'must' (or 'must not') if the consequences of not following the recommendation could be extremely serious or potentially life threatening.*
389	SH	Royal College of Speech and Language Therapists	19	NICE	1.10.3	29	This list should include severe communication disorders involving the use of communication aids.	Thank you for your comment. This recommendation (now recommendation 1.8.2) is about doing a comprehensive assessment and transferring information and would clearly include information about all levels of severity.
390	SH	National Autistic Society	11	NICE	2	30	The NAS would also welcome further research on dietary issues, toileting and the use of Occupational Therapy.	Thank you for your comment. The Guideline Development Group considered altering the research recommendations and while they support the research you suggest, they decided to focus on the research recommendations they have already prioritized.
391	SH	Step by Step School	18	NICE	2	30	Given the scale of the research proposed in this guideline, we ask the GDG to recommend setting up a National Autism Research Steering Group to monitor the funding and delivery of these important research recommendations. Without an oversight body and public funding, these recommendations are unlikely to be followed-up	Thank you for your comment, however this would be outside the remit of a clinical guideline.
392	SH	Step by Step School	19	NICE	2	30	We ask the GDG to add a research recommendation to conduct a formal RCT on Early Intensive	Thank you for your comment. The Guideline Development Group has now included a

							Behavioural Intervention (EIBI) including parameters to assess cost effectiveness. The recent Cochrane review by Reichow 2012 in children <6 years (203 participants) found positive effects in favour of EIBI across a range of domains. An earlier review by Eldevik 2010 (309 children) found significant impacts of IBI. IBI is now a well established therapy in UK. The GDG appears to have concluded that the quality of RCT evidence published so far (eg DAWSON2010, CARR2006, SMITH2000,etc) is not yet of sufficient quality and that there is a lack of economic evidence from UK based trials (conclusion in full guideline 7.2.9 page 500). It would therefore be logically consistent for the GSG to make a research recommendation to address the evidence gaps in clinical effectiveness and cost effectiveness of EIBI in a UK setting	research recommendation on managing behaviour that challenges in children and young people in autism - please see section 2.2 of the NICE Guideline.
393	SH	Step by Step School	20	NICE	2	30	The valuable research recommendation on PECS seems to have been excluded from the NICE version, but appears in the full version in 7.3.10.4. Could this be an oversight?	Thank you for your comment. A number of research recommendations are made in the full guideline, however the NICE guideline only lists the top 5 prioritised by the Guideline Development Group, in accordance with NICE policy.
394	SH	British Psychological Society	28	NICE	2.1	30	The Society is concerned that the case management of autism is only discussed as a research recommendation from the age of 6yrs. In practice much important work can and should be done in the years before this.	Thank you for your comment. The Guideline Development Group have amended the guideline to specify case management, as opposed to case coordination, in order to be more specific. The Guideline Development Group recorded a lack of clear evidence re case management in the area of autism, where as there was a lot of evidence about its effect in other areas of mental health. The Guideline Development Group have made a recommendation of case management in recommendation 1.1.4 in the NICE Guideline: "Local autism teams should ensure that every child or young person diagnosed with autism

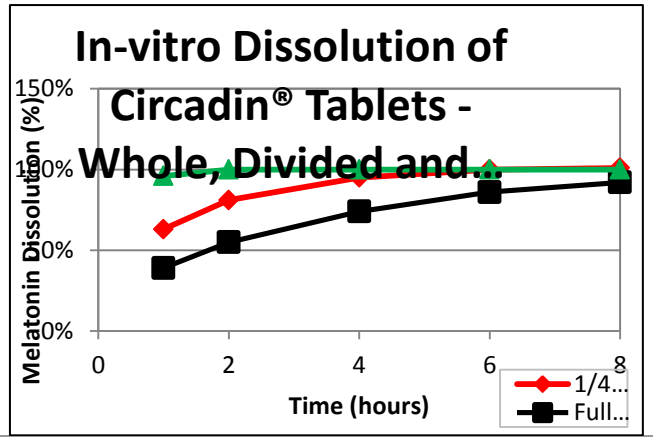
								has a case manager or key worker to manage and coordinate treatment, care, support and transition to adult care...". However, specific research into case management in autism is also necessary, which is why the NICE Guideline supports a research recommendation in Case Management in section 2.1. Thank you for drawing our attention to the age group that had been specified; this has now been amended to children and young people, without a specified age range.
395	SH	British Academy of Childhood Disability (BACD).	25	NICE	2	30	Research into early intervention and prevention is important.	Thank you for your comment. The guideline does not cover prevention, recognition, diagnosis or assessment as these are covered in other guidelines: Autism diagnosis in children and young people: recognition, referral and diagnosis of children and young people on the autism spectrum (CG128); and Autism: recognition, referral, diagnosis and management of adults on the autism spectrum (CG142).
396	SH	Royal College of Paediatrics and Child Health	30	NICE	2	30	Research into early intervention and prevention is important.	Thank you for your comment. The guideline does not cover prevention, recognition, diagnosis or assessment as these are covered in other guidelines: Autism diagnosis in children and young people: recognition, referral and diagnosis of children and young people on the autism spectrum (CG128); and Autism: recognition, referral, diagnosis and management of adults on the autism spectrum (CG142).
397	SH	Treating Autism	16	NICE	2.1	30	It is stated that "*Autism is well characterised as a chronic disorder with lifelong disability*" yet this information is, at best, incomplete, and at worst highly misleading. Fein et al. (2013) clearly establish that ASD is not a lifelong condition for everyone. The	Thank you for your comment. The improvement in many with autism is acknowledged in section 2.8- of the full guideline, Onset and Course of Autism.

							significance of this science is impossible to overstate and anyone with a professional or personal interest in ASD must be aware of the changing paradigm in understanding this disorder. The characterisation of ASD as lifelong has been a self-fulfilling one that has limited treatment options and decisions, and continues to do so. Secondly it must be stated that a significant percentage of autism is regressive in nature, in that previously typically-developing children suddenly regress into autism. Fein, D., Barton, M., Eigsti, I.M., et al. (2013) Optimal outcome in individuals with a history of autism. Journal of Child Psychology and Psychiatry, 54: (2): 195-205. Pellicano, E. (2012) *Do autistic symptoms persist across time? Evidence of substantial change in symptomatology over a 3-year period in cognitively able children with autism.* American journal on intellectual and developmental disabilities, 117: (2): 156-166. Barger, B.D., Campbell, J.M. and McDonough, J.D. (2012) *Prevalence and Onset of Regression within Autism Spectrum Disorders: A Meta-analytic Review*. Journal of Autism and Developmental Disorders, 1-12. Ekinci, O., Arman, A.R., Melek, I.,et al. (2012) *The phenomenology of autistic regression: subtypes and associated factors*. European child & adolescent psychiatry, 1-7.	The quoted sentence has been changed to state 'lifelong disability in some individuals'.
398	SH	Treating Autism	17	NICE	2.2	30 and 31	The main priority of research into the management of challenging behaviour should be to investigate the extent to which pain from medical issues may be a cause. It may be possible to design a case study in which subjects presenting with autism and challenging behaviour are screened for a wide range of painful medical conditions. The research objective would be to assess the extent to which challenging behaviour is symptomatic of pain due to medical issues.	Thank you for the comment. The Guideline Development Group agrees the importance of pain from medical issues and this is highlighted in the second bullet point of recommendation 1.4.1 in the NICE Guideline.

							For references see our comment no. 13	
399	SH	Royal College of Speech and Language Therapists	20	NICE	2.2	30-1	Communication is not mentioned as important in this section. There can be a reduction in behaviour in a student with severe challenging behaviour where they have been taught functional communication skills. Sadly, the communication skills of younger children do not develop sufficiently for them to meet their needs. Behaviour meets their needs more effectively.	Thank you for your comment, which the Guideline Development Group agrees with. Communication has now been mentioned in recommendation 1.4.1 in the NICE Guideline: 'Assess factors that may increase the risk of behaviour that challenges in routine assessment and care planning in children and young people with autism, including: • impairments in communication that may result in difficulty understanding situations or in expressing needs and wishes...'
400	SH	British Psychological Society	27	NICE	2	30ff	Randomised Controlled Trials (RCTs) and meta analyses are referred to in relation to the areas of recommended research. Although RCTs and meta-analyses are important, caution needs to be exercised in respect of disorders with a heterogeneous aetiology. It is highly likely that autistic spectrum disorders have different causes in different individuals, so treatments effective in one case might not be effective in others. RCTs can reveal sub-groups, but there is a risk, if patients with heterogeneous disorders are treated as a homogeneous group, of findings that cancel each other out at the group level being seen as inconclusive. For example, in Elder et al (2006) study of gluten-free casein-free (GFCF) diet, variation in individual urinary peptide levels was reported, but individual results were not published and the group-level results seen as inconclusive. Similarly, a meta-analysis of the effects of melatonin on the sleep of patients with autism could show no overall positive results at the group level even if the sleep of some individuals improved significantly. Recommendation: Insert at the beginning of section 2; 'Autistic spectrum disorders have a heterogenous aetiology and expression varies considerably between	Thank you for your comment. The methodology used in the development of this guideline prioritises the use of RCTs for comparisons between one treatment and another, whether the comparator is placebo, standard care or another active treatment. RCTs are always comparisons of the mean benefits of each condition. It is anticipated that the treatments which show a benefit *on average*, will be those most likely to be beneficial to the majority of children and young people with autism spectrum disorder. Those which show no benefits *on average* cannot be recommended.

							individuals. Caution should be exercised in interpreting research results at the group level.' Reference Elder, J.H., Shankar, M., Shuster, J., Theriaque, D., Burns, S. & Sherrill, L. (2006). The gluten-free, casein-free diet in autism: results of a preliminary double blind clinical trial, Journal of Autism and Developmental Disorders, 36, 413-20.	
401	SH	Treating Autism	18	NICE	2.2 and 2.4	31 and 32	Guidelines should consider recommending that large scale trials of low doses of beta blockers, and possibly other adrenergic agents, be carried out for aggression, anxiety and irritability in autism, as these have a long history of being used successfully for controlling those symptoms in general population, have relatively good to very good safety profiles, including in children, and have already been trialed on a small scale in adults with autism with promising results in ameliorating some of core autism symptoms and cognitive functioning in ASD. Bodner, K.E., Beversdorf, D.Q., Saklayen, S.S., et al. (2012) *Noradrenergic moderation of working memory impairments in adults with autism spectrum disorder.* Journal of the International Neuropsychological Society, 18: (3): 556. Narayanan, A., White, C.A., Saklayen, S., et al. (2010) *Effect of Propranolol on Functional Connectivity in Autism Spectrum Disorder—A Pilot Study. Brain imaging and behavior*, 4: (2): 189-197. Ratey, J.J., Bemporad, J., Sorgi, P., et al. (1987) *Brief report: open trial effects of beta-blockers on speech and social behaviors in 8 autistic adults*. Journal of Autism and Developmental Disorders, 17: (3): 439-446.	Thank you for your comment. The research recommendations in section 2 of the NICE Guideline are not fully worked up to full proposals, they are outlines only.
402	SH	British Academy of Childhood	26	NICE	2.3	32	The age range for sleep studies should be reduced to 2 years. Sleep difficulties have often developed by this age and early intervention is desirable.	Thank you for your comment. The Guideline Development Group thinks the age group mentioned is appropriate for a study. The

		Disability (BACD).					Standard release melatonin should be compared with a slow release formulation since he former might have a greater effect on sleep onset latency which could be very important for some families. Too much emphasis should be avoided on measuring sleep onset latency and total sleep time. Although assessing other consequences of disordered sleep are proposed, such as the parental stress index, more work needs to be carried out on which outcomes are most beneficial to, and desired by, parents. The cost benefit analysis of such a study should take into consideration the potential cost of parental job loss, family breakdown, the increased risk of abuse and the increased need for respite or residential care in families of children with autism and disordered sleep.	research recommendations in section 2 of the NICE Guideline are not fully worked up proposals.
403	SH	Flynn Pharma Ltd	4	NICE	2.3	32	A comprehensive paediatric investigational plan (PIP) including a randomised controlled trial has been developed and approved by EMA, and initiated by Neurim (MA holders for Circadin®). This PIP meets the requirements set-out in section 2.3, including a randomized, double-blind, placebo controlled, trial to investigate the efficacy and safety of melatonin to alleviate sleep disturbances in children with neurodevelopmental disabilities (including autism), with an open-label long-term (80 week) follow-up safety and tolerability study on patients completing the initial blinded phase; http://www.emea.europa.eu/docs/en_GB/document_library/PIP_decision/WC500130881.pdf).	Thank you for your comment. It will be important to be able to separate those with autism from others and that all start at the same baseline post sleep hygiene measures.
404	SH	Flynn Pharma Ltd	5	NICE	2.3	32	The description of the clinical work required suggests that patients are 'randomised to either slow-release melatonin or placebo'. This description implies that the nature of the on-set of action is delayed and is hence misleading; the correct terminology would be prolonged-release. This is not a semantic point; - 'prolonged release' means just that, release of the	Thank you for your comment. The Guideline Development Group has used the term 'prolonged release' as this is more factually accurate. The research recommendations in section 2 of the NICE Guideline are not fully worked up proposals.

							active over a period of time and without any initial delay. It is not 'delayed or slow-release' and nor is it something which is lacking a component of 'fast-release'. The reality for Circadin® is that melatonin release is initiated immediately, and by virtue of the formulation, this release continues over a number of hours. The specific release or *in vitro* dissolution characteristics of prolonged release melatonin tablets 2mg demonstrate that the product releases ~ 40% of its dose immediately and the remainder over a number of hours (Data on file, CIRC/LTR/12/0107, 2012). 	
405	SH	Royal College of Paediatrics and Child Health	31	NICE	2.3	32	The age range for sleep studies should be reduced to 2 years. Sleep difficulties have often developed by this age and early intervention is desirable. Standard release melatonin should be compared with a slow release formulation since he former might have a greater effect on sleep onset latency which could be very important for some families. Too much emphasis should be avoided on measuring sleep onset latency and total sleep time. Although assessing other consequences of disordered sleep are proposed, such as the parental stress index, more work needs to be carried out on which outcomes are	Thank you for your comment. The research recommendations in section 2 of the NICE Guideline are not fully worked up proposals. This comment highlights the importance of asking parents about what outcome matters to them.

							most beneficial to and desired by parents. The cost benefit analysis of such a study should take into consideration the potential cost of parental job loss, family breakdown, the increased risk of abuse and the increased need for respite or residential care in families of children with autism and disordered sleep.	
406	SH	Step by Step School	17	NICE	2.3	32	We welcome research on managing sleep problems in autism as this is a major health issue. We are not sure where the recommendation comes from to focus on the slow-release formulation of melatonin. Slow release melatonin may be more difficult to give young children if requires swallowing tablets with special coatings, etc. We would suggest a comparison between immediate release and slow release is carried out. We would also suggest studying 1.5mg vs 3mg. Separately, we think that a 3 month stage 1 is too long, and many parents would not participate with such a design. When sleep is a problem, a more urgent intervention is required and this reality should be reflected in the trial design to maximise recruitment	Thank you for your comment. The research recommendations in section 2 of the NICE Guideline are not fully worked up proposals but outlines. These and other comments will be important for whoever takes forward any proposal.
407	SH	Treating Autism	19	NICE	2.4	32	The Guideline should mention possible medical causes, including allergic disorders, well know to cause anxiety and irritability in general population. Considering the high prevalence of allergic disorders and general immune dysregulation in autism, this should be considered and ruled out on a case-by case basis when anxiety and/or irritability are present. Another medical disorder that may play a role in increased anxiety is autonomic dysfunction, also suspected to be prevalent in autism. This disorder should be considered and ruled out on a case by case basis when there is increased anxiety in autism. Chen, M.-H., Su, T.-P., Chen, Y.-S., et al. (2013) *Comorbidity of allergic and autoimmune diseases in patients with autism spectrum disorder: A nationwide*	Thank you for your comment. The guideline scope did not include the treatment of allergic disorder or immune dysregulation in autism. Nor did the scope cover autonomic dysregulation.

							population-based study. Research in Autism Spectrum Disorders, 7: (2): 205-212. Goodwin, R.D., Galea, S., Perzanowski, M., et al. (2012) *Impact of allergy treatment on the association between allergies and mood and anxiety in a population sample.* Clinical & Experimental Allergy, 42(12):1765-71.	
408	SH	The Disabilities Trust	6	NICE	2.4	33	Whilst The Trust acknowledges the effect of both pharmacological and psychosocial interventions for anxiety disorders in children and young people with autism, the focus seems to be very much on the use of medicinal procedures as a first resort rather than establishing good communication between, the service user, autism team and family or carers. We would strongly encourage that NICE highlight that pharmacological and psychosocial interventions for anxiety disorders should always try to be managed through a communicative route primarily rather than jumping to other interventions.	Thank you for your comment. The guideline does cover the evidence available for the treatment of anxiety and found some evidence for the use of psychological interventions. Beyond the evidence for the treatment of anxiety in children and young people with autism, the guideline must refer to the evidence for the treatment of anxiety in non-autistic groups as the next best evidence available. The guidelines on different forms of anxiety disorders are, therefore, referred to.
409	SH	British Academy of Childhood Disability (BACD).	27	NICE	2.5	34	Parents do not always agree that Sensory Integration intervention is labour intensive and can readily accommodate this therapy into home and school life. This approach needs to be supervised by an OT specialised in sensory integration for children with autism.	Thank you for your comment. The standard term that the guideline uses is healthcare professional unless there are very good reasons to specific – for example, prescribing of controlled drugs, some particular role within the NHS (e.g. the coordinating role and gate keeping role of GPs), or some other statutory duty which rests with a particular professional group (e.g. social work roles). The Guideline Development Group is not concerned with professional roles per se, but with interventions and care being delivered by health care professionals with the relevant competencies and experience.
410	SH	British Association for Music Therapy (BAMT)	13	NICE	2.5	34	We are pleased to see that the guidelines encourage further large and robust trials of treatments where existing research shows moderate effect sizes in spite of small cohort sizes/limited precision. In light of the	Thank you for your comment. Unfortunately only a restricted number of research recommendations (maximum of 5) can be made in the NICE guideline. Based on the evidence

							existing RCTs of music therapy interventions which, despite small cohort sizes, show significant effect sizes and demonstrate researchers' commitment to music therapy as a clinical intervention, we request that the Guidelines make a similar recommendation here for further large scale and robust RCT trials of music therapy (delivered by music therapists) as a social communication intervention, in order to strengthen the existing research base. We notice that a similar recommendation is being made here for research on sensory integration treatments (delivered by occupational therapists) that has struggled similarly with small cohort sizes in research trials.	reviewed in the meetings, the Guideline Development Group decided that the five that have been made in the NICE Guideline are the ones with the highest priority. The Guideline Development Group decided to replace the research recommendation on Sensory Sensitivities with a research recommendation on teacher-, parent- and peer-mediated psychosocial interventions in preschool children with autism.
411	SH	Royal College of Paediatrics and Child Health	32	NICE	2.5	34	Parents do not always agree that Sensory Integration intervention is labour intensive and can readily accommodate this therapy into home and school life. This approach needs to be supervised by an OT specialised in sensory integration for children with autism.	Thank you for your comment. The Guideline Development Group decided to replace the research recommendation on Sensory Sensitivities with a research recommendation on teacher-, parent- and peer-mediated psychosocial interventions in preschool children with autism. The research recommendation on Sensory Sensitivities is in the full guideline in a shorter format, in which the sentence you are referring to no longer appears.
412	SH	British Psychological Society	29	NICE	3.1	35	The Society recommends that the sentence towards the end of the page should read: "Secondary outcomes should include 'A REDUCTION IN' parental and sibling stress…"	Thank you for your comment. It is NICE style to denote the type of outcome to be measured only, and not state whether it should be improvement, reduction, etc, as in 'quality of life, adaptive function'.

These organisations were approached but did not respond:

Action Before Crisis
Action for ADHD - Northants
Action for Advocacy
Action for Aspergers

PLEASE NOTE: Comments received in the course of consultations carried out by the Institute are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that the Institute has received, and are not endorsed by the Institute, its officers or advisory committees.

Airedale NHS Trust
Allocate Software PLC
Associate Development Solutions Ltd
Association for Dance Movement Psychotherapy UK
Association for Psychoanalytic Psychotherapy in the NHS
Association of Anaesthetists of Great Britain and Ireland
Association of Child Psychotherapists, the
Association of Directors of Childrens Services
Association of Optometrists
Association of Paediatric Chartered Physiotherapists
Association of Professional Music Therapists
Association of Psychoanalytic Psychotherapy in the NHS
Autism Alliance UK
Autism Diagnostic Research Centre
Autism Education Trust
Autism in Mind
Autism NI - Northern Ireland's Autism Charity
Autism Outreach
Autism Rights Group Highland
Autism West Midlands
Barnsley Hospital NHS Foundation Trust
Bath Spa University
Belfast Health and Social Care Trust
Biolab
Birmingham & Brunel Consortium
Birmingham Community Healthcare Trust
Black Country Partnership Foundation Trust
Bradford District Care Trust
Break Charity
Breakspear Medical Group Ltd
Bridgewater CHC
Bright Futures Autism Limited
British Association for Adoption and Fostering
British Association for Community Child Health
British Association for Counselling and Psychotherapy
British Association of Art Therapists
British Association of Behavioural and Cognitive Psychotherapies
British Association of Dramatherapists

British Association of Music Therapy
British Association of Play Therapists
British Association of Prosthetists&Orthotists
British Association of Psychodrama and Sociodrama
British Association of Social Workers
British Confederation of Psychotherapists / Psychoanalytic Council
British Dietetic Association
British Medical Journal
British National Formulary
British Nuclear Cardiology Society
British Psychodrama Association
British Society of Neuroradiologists
British Society of Paediatric Gastroenterology Hepatology and Nutrition
Buckinghamshire County Council
Calderdale and Huddersfield NHS Trust
Cambridgeshire County Council
Camden Carers Centre
Camden Link
Camden Provider Services
Capsulation PPS
Capsulation PPS
Care Quality Commission (CQC)
Central & North West London NHS Foundation Trust
Central Lancashire Primary Care Trust
Central London Community Health Care NHS Trust
Centre for Excellence & Outcomes C4EO
Centre for Excellence in Outcomes
Cerebra
Challenging Behaviour Foundation
Children, Young People and Families NHS Network
Children's Commissioner for Wales
Children's Services Development Group
City and Hackney Teaching Primary Care Trust
Clarity Informatics Ltd
Cochrane Developmental, Psychosocial and Learning Problems
Coeliac UK
College of Optometrists
Contact

Critical Psychiatry Network
Croydon Health Services NHS Trust
Department for Communities and Local Government
Department of Health, Social Services and Public Safety - Northern Ireland
DO NOT USE (disbanded) Bradford and Airedale Primary Care Trust
DO NOT USE
Dorset Primary Care Trust
Drinksense
Ealing Hospital NHS Trust
Economic and Social Research Council
Elemental Nutrition
Empowerment Matters
Energy Therapy World-Wide Net
Epilepsy Action
Equalities National Council
ESPA Research
European Association for Behaviour Analysis
Fair Play for Children
Family Futures
Federation of Ophthalmic and Dispensing Opticians
Five Boroughs Partnership NHS Trust
Forum for Advancement in Psychological Intervention
Fostering Solutions
Foundation for People with Learning Disabilities
Gateshead Council
Gender Identity Research and Education Society
George Eliot Hospital NHS Trust
George Still Forum
Glencare
Great Western Hospitals NHS Foundation Trust
Greater Manchester West Mental Health NHS Foundation Trust
Halton& St. Helens Primary Care Trust
Hammersmith and Fulham Primary Care Trust
Harrow Local Involvement Network
Hartlepool Borough Council
Havencare
Health Protection Agency
Health Quality Improvement Partnership

Healthcare Improvement Scotland
Healthcare Inspectorate Wales
Hertfordshire Partnership NHS Trust
Hindu Council UK
Hockley Medical Practice
holistic family care
Humber NHS Foundation Trust
Hyperactive Children's Support Group
Independent Children's Homes Association
Independent Healthcare Advisory Services
Information Centre for Health and Social Care
International Autistic Research Organisation
JKP Analysts, LLC
Kent and Medway NHS and Social Care Partnership Trust
Kettering General Hospital
Lancashire Care NHS Foundation Trust
Leeds and York Partnership Foundation Trust
Leeds Community Healthcare NHS Trust
Leicestershire Partnership NHS Trust
Lilly UK
Liverpool Primary Care Trust
London Borough of Barking and Dagenham
Luton and Dunstable Hospital NHS Trust
Mears Group
Medicines and Healthcare products Regulatory Agency
Medicines for Children Research Network
Medway Community Centre
Mental Health Group - British Dietetic Association
Mental Health Providers Forum
Mild Professional Home Ltd
Mind
Mind Wise New Vision
Ministry of Defence
National Association for Gifted Children
National Attention Deficit Disorder Information and Support Service
National CAMHS Support Service
National Clinical Guideline Centre
National Collaborating Centre for Cancer

National Collaborating Centre for Mental Health
National Collaborating Centre for Women's and Children's Health
National Commissioning Group
National Deaf Child and Adolescent Unit
National Development Team for Inclusion
National Institute for Health Research Health Technology Assessment Programme
National Patient Safety Agency
National Public Health Service for Wales
National Treatment Agency for Substance Misuse
Netmums
NHS Bedford & Luton Cluster
NHS Clinical Knowledge Summaries
NHS Confederation
NHS Connecting for Health
NHS County Durham and Darlington
NHS Direct
NHS England
NHS Halton CCG
NHS Plus
NHS Warwickshire Primary Care Trust
NHS West Essex
NICE technical lead
Noblecare
Noblecare
Norfolk Community Health and Care NHS Trust
NORTH EAST LONDON FOUNDATION TRUST
North Essex Mental Health Partnership Trust
North Tees and Hartlepool NHS Foundation Trust
Northumberland, Tyne & Wear NHS Trust
Nottingham Children's hospital
Nottingham City Council
Nottingham University Hospitals NHS Trust
Office of the Children's Commissioner
Oxford Health NHS Foundation Trust
Parents' Education as Autism Therapists
Parents for the Early intervention of Autism
Parents Opening Doors
Parents Protecting Children UK

Parkwood Healthcare
PartneriaethPrifysgolAbertawe
Patient Assembly
Play Therapy UK
POhWER
PromoCon
Prospect PBS Training Ltd
Public Health Agency
Public Health Wales NHS Trust
Qbtech Ltd
RAF Families Federation
Rainbows Childrens Hospice
RASDN -HSC.Board/Public Health Agency
Research Autism
Respond
Rotherham Primary Care Trust
Roundhouse Care Ltd
Royal Berkshire NHS Foundation Trust
Royal College of Anaesthetists
Royal College of General Practitioners
Royal College of General Practitioners in Wales
Royal College of Midwives
Royal College of Obstetricians and Gynaecologists
Royal College of Paediatrics and Child Health ,Gastroenetrology, Hepatology and Nutrition
Royal College of Pathologists
Royal College of Physicians
Royal College of Psychiatrists
Royal College of Psychiatrists in Scotland
Royal College of Psychiatrists in Wales
Royal College of Radiologists
Royal College of Surgeons of England
Royal National Institute of Blind People
Royal Pharmaceutical Society
Royal Society of Medicine
Ruskin Mill Educational Trust
Safeguarding the Rights of Children with Autism
Salisbury Autistic Care LTD
SCHOOL AND PUBLIC HEALTH NURSES ASSOCIATION

Scottish Intercollegiate Guidelines Network
Sensory Integration Network
Sheffield Teaching Hospitals NHS Foundation Trust
Shire Pharmaceuticals Ltd
Social Care Association
Social Care Institute for Excellence
South Essex Partnership NHS Foundation Trust
South Essex Partnership University Foundation Trust
South London &Maudsley NHS Trust
South Staffordshire and Shropshire Healthcare NHS Foundation Trust
South Tyneside NHS Foundation Trust
South West London and St George's Mental Health NHS Trust
Southend-on-Sea Borough Council
Southern Health Foundation Trust
Speak Out Against Psychiatry
St Andrews Healthcare
St John's RC School
St Jude Medical UK Ltd.
St Mary's Hospital
Sunfield
Surrey and Border Partnership Trust
Sussex Partnership NHS Foundation Trust
Tavistock& Portman NHS Foundation Trust
Tees, Esk and Wear Valleys NHS Trust
The Challenging Behaviour Foundaton
The Children's Trust
The College of Social Work
The Fostering Foundation
The Fragile X Society
The Haemophilia Society
The Rotherham NHS Foundation Trust
The Sound Learning Centre
The University of Glamorgan
Tizard Centre
Tourettes Action UK
Tuberous Sclerosis Association
Turning Point
UK Young Autism Project

Unite - the Union
United Kingdom Council for Psychotherapy
University Centre for Excellence in Developmental Disabilities
University Hospitals Birmingham
University of Edinburgh
University of Nottingham
University of York
User Voice
Walsall Local Involvement Network
Warrington Primary Care Trust
WASP with asperger limited
Welsh Government
Welsh Local Government Association
Western Cheshire Primary Care Trust
Western Sussex Hospitals NHS Trust
Westminster Local Involvement Network
Whitstone Head Educational
Wigan Council
Wirral University Teaching Hospital NHS Foundation Trust
Women's Support Network
Worcestershire Acute Hospitals Trust
Worcestershire Health and Care NHS Trust
York Hospitals NHS Foundation Trust
YoungMinds