COMMENTS RECEIVED FROM EXTERNAL REFEREES AND OTHERS

Assessment, diagnosis and management of autism spectrum disorders

All reviewers submitted declarations of interests which were viewed by the guideline development group prior to the addressing comments.

Section	Reviewer's comments	Development group response
	I have read the draft SIGN guideline on autism and am impressed by its thoroughness and agree with its recommendations. It is very well written and represents an excellent outcome of what must have been a huge amount of work. I have no specific comments to add. Thank you for showing these to me at the draft stage. They will be invaluable in service development.	*Thank you*
	Well done to the group A very readable and succinct document and in many ways more 'user' friendly that the NICE guideline. Minor comments - really pleased you got the melatonin rec in	*Thank you*
	Thank you for asking me to comment on this impressive document. An update was needed and this does a good job.	*Thank you*
	The review was very well written, especially the introduction and the clinical recommendations. I was impressed to see the sections on adult services and the serious attempts to consider the needs of adults. I also thought the discussion of diagnosis in females was fair, measured and thought it goes beyond the rather meager data (for example, it doesn't mention the many studies that have reported no sex differences, even with quite large samples), I do believe the suggestions and comments made will be very helpful for clinicians and researchers.	*Thank you*
	I was struck by the variability in what was considered different levels of evidence for different kinds of research. I don't believe the variability is at all specific to SIGN, and I am probably biased, but the standards for psychopharmacological interventions seemed so much lower than standards for diagnosis, for example. Very small RCTs with rather questionable measures of outcome were sometimes rated 1++ for psychopharmacology whereas studies with thousands of participants in other areas of research were not considered adequate. I think we all, not just the SIGN committee, need to ask ourselves what it means that we have virtually no research that is considered adequate in some areas of ASD research (including diagnosis). It may be that the standards for double-blind studies are simply not appropriate. My analogy is whether we would expect people to compare the use of a tool such as a sphygmomanometer to measure blood pressure to a clinical estimate of blood pressure when there is no alternative tool that does quite the same thing.	*The 1++ ratings in the pharmacology sections relate to the quality of the systematic reviews of the RCTs, rather than RCTs. It is noted in the evidence statements that the RCTs are small or of poor quality. Recommendations are worded as conditional rather than strong to reflect the evidence base.*
	The conclusions and what is considered evidence is also variable even within sections. For example, no data are presented for the Childhood Autism Rating	

	Scale, which is used very commonly in the U.S. or the Social Responsiveness Scale, also used very commonly in the U.S. and for research. The amount of data available for the DISCO and 3dI is very limited. I do agree with the conclusion that a diagnosis should never be based on a single instrument or really even a combination of instruments without clinical judgment, but am worried that to dismiss all the research as of "poor quality" – I believe (if this is the same as NICE) because the clinical judgments were not made independent of observations during the ADOS or information from the ADI-R (when algorithms were not available) seems unfortunate to me.	*The KQ in the selective update focused on whether a combination of both ADOS and ADI-R was more effective than a single tool rather than detailing individual instruments, as ADOS and ADI-R are complementary.* *The studies are appraised based on the criteria in the SIGN methodology.*
	Overall, I hope these suggestions are helpful. I realize they come out of context and I am being more direct than I probably would be if part of the committee, as an outsider. As a matter of fact, I'm on a similar panel for the State of New York for early intervention guidelines including screening, assessment and treatments and I don't believe our committee has done nearly as competent a job as this panel. I hope this is helpful.	*Thank you*
	This is generally speaking very well done. I'm well aware of how difficult these things are to do and appreciate all the hard work that has gone into this. So take any comments/suggestions for what they are worth particularly given that I'm outside the U.K. and some things may be a bit more country specific.	*Thank you*
	The draft is well organized and the progression makes good sense. The discussion of levels of evidence, etc. is straightforward. I agree with the comments about off label use early on although this speak to the issue of evidence based treatments and evidence based practice – an issue that might well be discussed early on in some detail. There are some studies that simply will never ever be based on placebo controlled randomized trial (imagine that for jumping out of an airplane with or without a parachute!). And of course there is also the problems of treatments that are emerging (you do, to some extent, take care of this in your discussion of levels of treatment). An inherent difficulty, of course, is that new studies appear these days with great regularity so more or less instantly things can change.	*Noted, thank you*
	As a person likely on the autism spectrum and with a son diagnosed with Aspergers, I care about people waiting too long for an autism diagnosis.	*It is not within SIGN's remit to comment on timescales but these comments have been passed on to the Scottish Strategy for Autism Governance Group.*
	This is an excellent guideline, and I welcome the emphasis on breadth of assessment, across a range of different settings where possible, using the skills and experience of the multi-agency team, rather than focussing on one or other information gathering tool. Considerable research still requires to be carried out, much of which will be outwith Scotland, but there requires to be a commitment by SG to funding for interventions shown to be effective by that research.	*Noted, thank you.*
	I welcome the guideline group's work in updating and extending the scope of the guideline. I anticipate many challenges to implementing intervention recommendations which could potentially be delivered by a range of organisations or professionals, in	*Noted, thank you.*

	community settings.	
	As a person on the autism spectrum, I care about people waiting too long for an autism diagnosis. I'm now 28 and I still don't have a diagnosis. I lack a lot of support because I can't prove I have autism. Do you have any idea what it feels like in the workplace when you say you have a condition but can't prove it just because you don't have a piece of paper? No one should have to go through what I do, not everyone is as strong as I am to cope with it. I worry a lot of people are suffering greatly because they are not receiving the support they require.	*It is not within SIGN's remit to comment on timescales but these comments have been passed on to the Scottish Strategy for Autism Governance Group.*
	As a person with Aspergers syndrome, luckily well supported and have a full time as a senior manager, I absolutely understand that the time individuals have to wait for first assessment and diagnosis is far too long. When people are in crisis it is too late.	*It is not within SIGN's remit to comment on timescales but these comments have been passed on to the Scottish Strategy for Autism Governance Group.*
	I was surprised and disappointed at the complete lack of representation from the National Autism Organisations, either as part of the Guideline Development Group or as invited Specialist Reviewers. The phrase 'National Autism Organisations' incorporate organisations that are Scotland wide as well as UK wide (the National Autistic Society, Scottish Autism and Autism Initiatives). Between them, these organisations support thousands of individuals and families either through direct services or through informal supports. They are also frequently at the cutting edge of service and autism knowledge development. Their lack of involvement is clearly a missed opportunity for knowledge exchange as well as promoting shared ownership of the final guideline Given their involvement in and commitment to the National Autism Strategy as well as their extensive and lengthy experience with individuals and families across Scotland the guideline would inevitably have been enhanced by their inclusion. Was there any reason for their exclusion? This updated guideline will be of assistance to those providing diagnostic services across the age span. The Intervention section has been significantly enhanced since SIGN 98 and provides information to support services (both existing and those in development). Congratulations to everyone involved on all their hard work!	*The following organisations were contacted to nominate lay representatives or peer reviewers and highlight issues of concern to patients. These issues were discussed at the start of the process to feed into the key question setting:* • *ARC Scotland* • *Autism Initiatives UK Scotland* • *BAAGS (Border Autism and asperger's Group Support)* • *Contact a family* • *NAS* • *PASDA* • *Scottish Autism* • *Fife Action on Autism* • *Lothian Autistic Society* • *SIGN Patient Network.* *NAS, Scottish Autism and Autism Initiatives have also provided comments via the open consultation.* *Jean MacLellan is a representative of Autism Network Scotland.* *Noted, thank you.*
	Too much "SUGAR SWEET CANDY COATED" waste of public money in talking about Autism and no practical help re housing, shit smearing, nappies for Autistic`s, head banging, etc.	*Behaviour that challenges is addressed within the context of this evidence-based guideline.*
	We are happy to be consulted on any aspect of the document relating to music therapy at our office, or by email: info@bamt.org	*Noted, thank you.*
	You are clearly accepting the evidence that EIBI is more effective than treatment as usual, which is a first in the UK for official guidance, I think. This has to be really good news for everyone affected by autism in Scotland. Intensive behavioural interventions are now widely available across much of the developed world, particularly North America – and in a growing number of outstanding ABA school in England Wales and	*We hope that you are not reading too much into our comments. While the guideline accepts that the evidence base for EIBI has improved since the last guideline, we haven't recommended it because there remain areas that need further research. We believe this is in line with other recent reviews, including NICE. We have*

	Ireland. Here in Scotland however, there are no ABA-based schools or units or clinics, no local authority funded home ABA programmes (now my son's programme has ended) and no university departments specialising in behaviour analysis. So a very great deal of change must take place, including attitudinal and cultural change, for Scottish children to benefit from these same opportunities. You need to look at recommendations which would start to see Scottish children being able to benefit from these new technologies in a meaningful and evidence-based way. This document makes an excellent start. However difficult this is to deliver in practice in the short term, it must surely mean getting it right - the use of behaviour analysts, appropriate intensity and a very great deal of staff training.	*endeavoured to demonstrate the wider potential of this area of science and in particular to draw people's attention to a common error (using the term 'ABA' when referring to EIBI) which we believe causes much confusion, potentially to the detriment of evidence-based services for individuals with ASD. In order to emphasise this distinction more clearly, we have added further detail to section 6.3.1.*
	As a parent to ASD son. It took me approximately 18 months to persuade psychiatrist to refer for assessment. From then it took 9 months from referral to assessment. When we had social work intervention approximately 9 months later, they came out wholly unaware he was diagnosed. An entire respite request went in, months later and SW still questioned where diagnosis was made. Communication problems. Professionals with no autism awareness. Mainstream high schools are struggling for him to feel safe to attend. He is very clever, but currently only manages an 8 hour week. And his anxiety on this attendance is still extreme.	*It is not within SIGN's remit to comment on timescales but these comments have been passed on to the Scottish Strategy for Autism Governance Group.*
	Related articles: Stoa School Survey; Edinburgh Community Enterprise Stoa School Business plan and Lottery Application: admin@stoaschool.org ABA4ALL Publication: Recommendations to Government: For Professionals: On Treating Autistic Spectrum Disorders and Other Developmental Delays.	*Outwith remit of an evidence-based clinical guideline*
	Having been asked to comment on the draft guideline, I find nothing to disagree with. I know of no evidence which has not been considered and the overall product appears to be an excellent piece of work.	*Noted, thank you.*
	A very valuable update on recent learning and practice. Thank you for asking me to participate in the peer review.	*Noted, thank you.*
	Good document, better than NICE, but don't short change our kids on ABA delivered by amateurs.	*See comments in section 6.3.1*
	I may have missed something in the document, but aware of need for consideration of risk assessment as part of evaluation/assessment.	*Added to GPP in section 4.2.2*
	Personally, we have found as parents of a child diagnosed with Aspergers, that a minimum degree of professional intervention has been the key to his development into a reasonably well-functioning independently-living adult who has graduated from university thanks to the support of staff and help with computer equipment.	*Noted.*

	I commend you on the focus on behavioural interventions. Please note the holistic definition of the term ‘behaviour’ in behaviour analysis (www.behavior.org). In behaviour analysis, the term 'Behaviour' is viewed holistically as something that is contextualised within environmental contingencies. This is not the everyday meaning of the term behaviour. For a behaviour analyst the term ‘behaviour’ covers the phenomenological cascade of changes that simultaneously encapsulates two differing perspectives, what others see, ie, public behaviours, and at the same time what the individual ‘sees’, ie, private behaviours, such as emotions and cognitions (Moore, 2003). BCBAs are not regulated by HCPC simply because HCPC does no longer accept applications for new professions. A team of behaviour analysts (Dr Martin BCBA-D, Prof Dillenburger BCBA-D and Dr Hughes BCBA-D) met with HCPC in January of 2012 and prepared an application for aspirant profession. Shortly after this meeting HCPC decided not to accept any new aspirate profession applications. The UK Society for Behaviour Analysis (UK-SBA; President Dr Mecca Chiesa) is working on this, however with non-acceptance of new applications the HCPC requirement is simply not tenable in the new SIGN guidelines. It’s a ‘closed shop’! Therefore, this sentence should be changed to “They should be overseen by professionals trained to international standards in Applied Behaviour Analysis (ie, Board Certified Behaviour Analysts; BCBA), who are regulated by a professional body such as the Behaviour Analyst Certification Board (BACB). This is a very important distinction. I speak from personal experience: I am a HCPC registered clinical psychologist, also registered in the Division of Clinical Psychologists of the British Psychological Society since 2003. In 2006, I sat the BACB exam and became a Board Certified Behaviour Analyst-Doctoral; BCBA-D. Therefore, I know first-hand the difference between the two qualifications. As a Clinical Psychologist I studied one module on behaviour modification in 1980, however, this was not even the ‘tip of the iceberg’, compared to the amount of additional study I had to undertake to become a BCBA-D. Since I became a BCBA-D, I developed and teach on the MScABA at QUB (approved course by BACB) and therefore I am very familiar with the amount of study (270 hours of specific curriculum) and practice (1500 hours of supervised practice) that is a necessary pre-requisite prior to a student becoming eligible to sit the BCBA exam (a very rigorous 4 hour exam that has an annual pass rate of only about 60%; see http://bacb.com/wpcontent/uploads/2015/08/2014-ACS-pass-rate-BCBA-alpha-final.pdf). There is no way that someone who is “trained in the psychological theory and in child development” comes anywhere close the level of knowledge required to become a BCBA. This low training expectation would simply not qualify anyone to deliver ABA based interventions with professional integrity and fidelity. Therefore, I urge that SIGN adopt the NICE Guideline 11 model that clearly identifies behaviour analysts (ie, BCBA) as part of the multidisciplinary team.	*SIGN is similarly concerned with maintaining high professional standards, but cannot comment on matters concerning professional registration. In response to this and other comments, a sentence has been added to section 5 that emphasises the need for professionals to ensure they have the appropriate training and that they maintain fidelity to the approaches they implement.* *See comments in section 6.3.1*

	An improvement on the original SIGN 98 guideline, but in need of considerable changes to make this revision fit-for purpose. A major issue is the questionable compatibility of the evidence-base with DSM 5 and RDoC.	*The evidence review is a retrospective process and can only use the trials available. RDoC may be addressed in future revisions for the guideline.* *It is noted in the guideline that evidence has come from trials using DSM IV and ICD 10.*
	Art Therapy has been part of service delivery to people with autism since 1970's (In Lothian). Generally art therapy intervention with this client group work is well documented in case studies in own professional journal and in published art therapy literature. Would like to see art therapy being recognised in category for non-pharmalogical interventions for adults. My personal experience of working with this client group for 11 years leads me to believe that there is much for people with autism to utilise in the relationship and in the tools we provide.	*An additional search of interventions was carried out after peer review. Art therapy was included but no trials of sufficient quality were identified for inclusion in this evidence-based guideline.*
	The guideline covers everything I would have expected, however throughout there is reference to looking after the care givers. I personally don't feel supported. I feel everything is a battle, on top of fighting for everything, from DLA to social work support, I also have to be an autism expert. It's exhausting and it's a life sentence. Other warning signs in pre-school children would be Lack of empathy. Clumsiness. Lashing out/ biting.	*We are sorry to hear of these difficulties. We cannot extend the remit of the guideline to how to support caregivers, as it is focussing on clinical aspects of care.* *Potentially lack of empathy could be a warning sign, as could lashing out or biting, perhaps less so clumsiness. However there are various potential routes into such presentations not specific to ASD.*
	This submission has been drafted in consultation with Scottish Autism and Autism Initiatives, both of whom support our recommendations. We'd also like to note that throughout the response, where we say autism, we are talking about all conditions on the autism spectrum.	*Noted*
	On each point where I had no specific comments and was broadly in agreement with the body of the text I have said "no comments". Final comment is a big thank you for all the hard work from the development group!	*Noted* *Thank you*
	There are not enough resources in mainstream schools to sufficiently support children on the Aspergers / high functioning end of the scale through their sensory and social difficulties. Those working are quiet are the worst affected. The support required is set by the same people who will have to find that resource and as such, many children who would benefit from early intervention are falling through the net. What manager will say a child needs support with social interaction if they know they have no staff to do this. Certainly not any that are career driven. Parents have to be more and more assertive in order to get the support their children deserve. Government policy is not being carried out on the ground. It's heartbreaking.	*This is outwith the remit of the guideline but comments have been passed to the Scottish Strategy for Autism Governance Group.*
	Broadly I think the guideline is a well researched and useful tool to inform autism provision. I would find it more useful however if recommendations (especially the key ones) were referred to within other sections of the guideline (specifically in training and auditing of current practice). This would make for a more cohesive document and help services with the practicalities of implementing the guidelines.	*Key recommendations are highlighted at the front of the document for local boards to consider for implementation, including training and audit.*

	I am impressed by the update. I cannot help but wonder how big an impact the ICD 11 might have on some of the earlier suggestions - and whether, dependent on its publication, and earlier SIGN review will become inevitable? One other small point is that I was disappointed to note that Educational Psychology does not merit an explicit mention. As the guideline panel will know, the debate about the appropriateness or otherwise of our involvement in the diagnostic and assessment process continues to rage on in the profession nationally. I continue to strongly believe that our contextual/environmental/ecological approach to assessment adds much to the process. Notwithstanding that debate, however, we are a profession involved in ASD research and intervention. Even some of the academic search facilities like PsycINFO (etc) may have yielded some research results around interventions not included here. Thank you for the opportunity to peer review - a privilege to be asked.	*This can only be considered when new evidence is available. It is noted that ICD 11 is due for publication soon.* *Educational Psychologist has been added to section 4.2.3* *PsychINFO was used for the systematic literature search.*
	There are one or two points where clarity is lacking with respect to recommendations. On the first page there are two references to R – one 'strong' one 'conditional', yet they appear indistinguishable. On pages 5 & 6 and R appears in a shaded box. The meaning of that symbol is not apparently given in the document.	*Recommendations changed to R symbols.*
	It would be helpful if psychological support for parents was offered about six months after diagnosis. It was offered to us immediately after diagnosis [of their child, aged 3] but at that point we felt overwhelmed. Once we had time to think we felt grief and needed to adjust to coping with a future for our child which was different from the one we had envisioned. Having a professional getting in touch at that point and offering psychological support, rather than parents having to seek help themselves, would have helped. Can this be fed into the guideline?	*The GPP in section 11 has been amended to include support.* *The timing of the support is personal preference and therefore it is difficult to state an optimal time for intervention.*
	Autism guidelines have a long problematic history--it is likely they have been harmful rather than beneficial to autistics and have impeded the progress of research and practice. My view is that we should learn from this and do better. There are all too familiar major problems with standards (of science and ethics both) in this draft, in areas I know well. In these areas, SIGN seems like a major step back from NICE, rather than the steps forward and improvements which are needed. Unfortunately I did not have time to look in a detailed way at all sections of this guideline, or at all the references. But where I did look I too often found errors and poor standards. This can only be harmful. Because the standards here are so low, crucial issues are not addressed at all, for instance trial registration and publication bias. In non-autism areas, inadequate poor-quality guidelines are often identified as such, limiting their influence on research and practice. This has not happened in autism, where low standards have been aggressively demanded and imposed, including	*SIGN work with the research available, assess it for quality and take the quality into account when making recommendations.*

	through the misuse of very bad guidelines, which continues long after they are out of date.	
1.1	In England, the National Institute of Health and Care Excellence (NICE) specifies that there should be a maximum wait of three months from referral to first appointment. This should be included in the SIGN guidance to help ensure that people in Scotland are not waiting too long to access a diagnostic assessment.	*It is not within SIGN's remit to comment on timescales but these comments have been passed on to the Scottish Strategy for Autism Governance Group.*
	NICE recommendation is 3 months from referral to diagnosis.	*It is not within SIGN's remit to comment on timescales but these comments have been passed on to the Scottish Strategy for Autism Governance Group.*
	Assessment and Diagnosis process is taking too long. Parents and ASD children are struggling. And waiting means crucial months without adequate support.	*It is not within SIGN's remit to comment on timescales but these comments have been passed on to the Scottish Strategy for Autism Governance Group.*
	Terminology sometimes uses ASD and sometimes autism. No specific discussion of this so would it be preferable to stick to ASD throughout? It is asserted that 'autism is a lifelong condition' - many would dispute that it is always lifelong in a clinically evident way. Para 2 sentence 3: Depending on the severity of autistic difficulties, ASD may not be evident. Given importance of co-morbidities in influencing presentation, would altering wording to mention that eg 'severity of autistic difficulties and any associated co-morbidities' be helpful? No mention of ASL legislation in section 1 now - seems a pity to omit - is the view that GIRFEC replaces it?	*Terminology has been changed where appropriate but when citing studies that have defined their patient group according to ICD-10 or DSM IV, as patients with autism, we have retained the term autism.* *The point of the sentence is that ASD is prevalent in adulthood as well as childhood. The term 'condition' is discussed in section 3.* *A sentence on comorbidities has been added.* *The focus of the guideline is clinical so we have kept to citing GIRFEC.*
	BAMT endorses the need and value of this guideline.	*Noted, thank you.*
	prev rates—'at least' 1% in children if based on our study as we did not screen all mainstream schools — most districts are nearer 2% now and thus 3+referred for assessment 'lifetime' –what about recent evidence about some no longer meeting criteria?	*We are citing directly from the studies which state 0.7% and 0.94-0.99* *In this section we are stressing that this is not just a childhood condition and there is a need for recognition in adults too.*
	I welcome the opportunity to comment on this draft. I am very supportive of the work and aims of SIGN in general, and in particular the need to make evidence-based recommendations on all types of interventions available to help those with autism, their families and carers. I hope that you will find my comments helpful.	*Noted, thank you.*
	In England, the National Institute of Health and Care Excellence (NICE) specifies that there should be a maximum wait of three months from referral to first appointment. This should be included in the SIGN guidance to help ensure that people in Scotland are not waiting too long to access a diagnostic assessment. The waiting time for an autism assessment appointment should start from the time of initial referral and not the time from a mental health assessment in areas where this additional step is in place (such as for referral to the Regional Autism Spectrum Diagnostic Consultancy service in Edinburgh, serving Lothian and surrounding health	*It is not within SIGN's remit to comment on timescales but these comments have been passed on to the Scottish Strategy for Autism Governance Group.*

	boards). In addition, support services are needed for people who struggle to request an assessment, for example due to difficulty explaining issues. Self referral options would help overcome this problem.	
	Relevant and useful scene setting.	*Thank you.*
	Whilst I welcome the need for evidence update with regards ASD, SIGN has not consulted with the full range of relevant professions. The British Association of Art Therapists (BAAT) has a history of involvement in working with both children and adults who have a diagnosis of autism, in which an emerging body of evidence (for the most part theory generated) incorporating single case study research is available. The Arts therapies are included in the ASD strategic action plan for Wales (Welsh assembly government, April 2008). Section 12 (p.28) lists Arts therapies as one of those being regulated by the HCPC and represented on the Welsh assembly advisory committee. Chapter 5 the basis for intervention from theory to practice. Case studies of art therapy with individual autistic children demonstrate the use of the model and the outcomes, art therapy works as an integral part of overall management and treatment approaches to autism. 'Art therapy with children on the autistic spectrum, beyond words', K, Evans and J, Dubowski, Jessica Kingsley, London, 2001 The Autism Treatment Survey was developed to identify strategies used in education of children with autism spectrum disorders in Georgia. Respondents of the web-based survey included a representative sample of 185 teachers across the state, reporting on 226 children with ASD in grades preschool - 12th. 11.79% used art therapy, music therapy amongst others. Autism treatment survey: Services received by children with autism spectrum disorders in public school classrooms. Journal of autism and developmental disorders, May 2008, vol./is.38/5(961 -71), 0162-3257. ASD strategic action plan for Wales (Welsh assembly government, April 2008). Section 23 Arts therapies are identified as a key intervention for ASD assessment (p. 52, 53) and education (p. 54), and as a core therapeutic intervention (p.57 and 59). Section 23 (p.30) states that arts therapies provide an accessible and appropriate form of psychotherapy for those with ASD. And that services should be provided through Tiers 1 - 4 (p.24). Article 13 of the United Nations convention on the rights of the child (September 1990) states that: "the child shall have the right to freedom of expression; that this right shall include freedom to seek, receive and impart information and ideas of all kinds either orally, in writing or in print, in the form of art, or through any other media of the child's choice". Outcome studies show long term and individual art therapy is effective in promoting cognitive and emotional development, enabling relationships and	*An additional search of interventions was carried out after peer review. Art therapy was included but no trials of sufficient quality were identified to be included in this evidence-based guideline.*

	lessening destructive behaviours, referenced in the below: • 'Shaping experience and sharing meaning: art therapy for children with autism', Evans, K. (1998) • 'Art Therapy with Children on the Autistic Spectrum: Beyond Words', Evans, K & Dubowski, J (2001) • 'Shaping vitality affects: enriching communication', in D. Sandle (ed.). Development and diversity: New applications in art therapy. London: Free association (1998) • Annihilation anxiety and fantasy in the art of children with Asperger's Syndrome and others on the autistic spectrum, Henley, D. 2001 • 'The world is attacked by great big snowflakes: art therapy with an autistic boy, American Journal of Art Therapy, Kornreich, T. and Schimmel, B. 1991 • 'Psychodynamic Art Therapy Practice with People on the Autistic Spectrum'. (ed) Dolphin. M; Byers A; Goldsmith A; Jones R. Routledge (2014). The book is the result of a decade of work by a group of experienced art therapists. The book provides an overview of the theoretical context and the subsequent chapters give varied accounts of practitioners' experiences giving accounts of art therapy with either adults or children with autism.	
	I am not sure how the penultimate paragraph relates to this section - could be moved down to section 4.	*This has been clarified with an additional sentence.*
	I think that the last paragraph should specify that the evidence is for children's services only. I guess that this is sort of implicit in that the last guidelines were only for children - however, I still think it would be helpful to point this out. Otherwise, the information is relevant and to the best of my knowledge accurate. But I did find the first paragraph quite wordy and hard to follow. It was quite off-putting; the very first paragraph of the whole document. My heart sank at the thought of a further 64 pages. Whereas in fact the rest of the document (and indeed section) was much easier to follow. I think maybe even trying to make the sentences a little shorter in this very first paragraph might make a difference to first impressions?	*First paragraph has been reduced.*
	The NAS welcomes the revision of SIGN98 and its extension to cover adults. However, further work must be undertaken to ensure adults are adequately included to help make sure that they can get the help and support they need from clinicians and other professionals). The NICE guideline Autism: recognition, referral, diagnosis and management of adults on the autism spectrum for England and Wales offers some good practice which could be adapted so that these guidelines can genuinely include the needs of adults with autism. While SIGN has referenced some of the NICE recommendations, it hasn't included them as good practice for professionals in Scotland. We believe that SIGN should look again at including recommendations and good practice identified by NICE to ensure that adults on the spectrum in particular are able to receive a more positive experience. For example, in section 4.1.5 on identifying adults for assessment, the only good practice advice is to avoid assessment for those with an eating disorder. We think that it would be more	

	helpful for professionals and more widely applicable to give a greater prompt to them on who to identify for further assessment here.	*We have added some text and restructured the diagnosis section for clarity. We have not identified any evidence for older adults.*
	There should also be much greater clarity where recommendations are to be applied to all ages, including adults and older adults. If this isn't clear, there is a risk that incorrect assumptions are made and that adults with autism are not sufficiently supported.	
	In addition, while we acknowledge the limits of SIGN's remit, we feel that there is not a clear enough sense in this guideline of a pathway from identification of autism to the development of a personalised package of support. The guidelines set out some information on diagnosis and then some information on interventions. However, the NAS would like to see references to a clearer assessment of need post diagnosis and development of support that can meet those needs. Moreover, the guidelines should set out the purpose of any interventions and the person-centred outcomes they are trying to achieve for individuals.	*This is outside the remit of the clinical guideline but we hope the recommendations in the guideline will inform pathways and individual support packages.*
	We are also concerned that the SIGN guidelines are much less clear than the NICE guidelines at ruling out specific interventions for the management of autism. For example, the recommendations in the NICE adult guidelines clearly state that certain interventions should not be used. This can be most easily seen in the summary of recommendations [NICE, Autism: recognition, referral, diagnosis and management of adults on the autism spectrum, 9.2.1.11 – 9.4.1.9, p p350-57]. We are concerned to ensure that interventions that could potentially harm people with autism are clearly ruled out in clinical guidelines. We know that people on the spectrum are sometimes inappropriately prescribed medication to 'treat' challenging behaviour, at the expense of identifying the underlying causes of behaviour and putting in the right support in place as a response. We also hear of families being persuaded to spend thousands of pounds on 'treatment' for their child on the spectrum, which has no research base, may harm the individual (eg chelation) and may distract from the family finding the right type of support that can actually be helpful. It is irresponsible for SIGN not to make it much clearer for all audiences, which interventions are/should not be used.	*SIGN recommendations are evidence-based. Where there is evidence of harm we have included recommendations not to use that therapy.*
	The second paragraph of section 1 should also highlight the low adult identification rate and that in the context of adults on the autism spectrum that the majority will be unidentified though highly likely to be requiring services or support. Many adults struggle to access diagnostic services. Identification rates for children and young people are reflected in data sets for example on additional learning support in schools. These have shown significant improvement over the years since the Additional Support For Learning (Scotland) Act was passed. Scottish Government policy focusing on early years intervention across agencies has also provided greater observation of young children against development goals, leading to more children being identified and referred at an early age. However, most adults will not have benefited from this identification, but there is no reason to assume significantly different prevalence rates. Some	*The introduction covers reasons for low identification in adults.*

	measures have been taken to record autism within the learning disability dataset eSay, based on those identified as receiving social care support from local authorities. This identification is well below expected prevalence of autism even within the learning disability community.	
	Could recognising gender differences be a part of the 'need for guideline' section especially since this was not part of last version section 1.1? Clinically, this is an increasing issue in CAHMS as we see referral for assessment following treatment resistance for females in the service. It may also help drive research in this regard.	*The group did not consider it necessary to highlight in the introduction. Gender is discussed in section 4.1.6 and in the key recommendations.*
	‘A study in Glasgow...11.1 per year per 10,000 children’ More readable if expressed as % as per the preceding 2 sentences (and easier to read)	*% added*
	“Early diagnosis and appropriate intervention, specialised educational programmes, and structured support may help a person with ASD maximise his or her potential.” This unsourced statement can be read as meaningless (anything “may” happen). But it seems likely to encourage unhelpful biases, which may affect autistics who were not diagnosed early, did not receive autism-specific interventions or programs, etc. See your own ref 6, for evidence that most older autistics are not diagnosed as such, ergo we know little about autistic adult outcomes at a population-based level. This evidence is very preliminary but for now it suggests caution in making assumptions about autistic potential. In addition, evidence from population-based studies (Russell et al., 2012; Kim et al., 2011) at least raises the possibility that some autistics who are not diagnosed early may be better off than some who are. Further, a recent large 18-country clinic-based study found better abilities in later-diagnosed versus earlier-diagnosed autistics (Salomone et al., 2015). While these and similar findings are open to various interpretations, they also suggest that caution is in order. Russell, G., Golding, J., Norwich, B., Emond, A., Ford, T., & Steer, C. (2012). Social and behavioural outcomes in children diagnosed with autism spectrum disorders: a longitudinal cohort study. Journal of Child Psychology and Psychiatry, 53(7), 735-744. Kim, Y. S., Leventhal, B. L., Koh, Y. J., Fombonne, E., Laska, E., Lim, E. C., ... & Grinker, R. R. (2011). Prevalence of autism spectrum disorders in a total population sample. American Journal of Psychiatry, 168(9), 904-912. Salomone, E., Charman, T., McConachie, H., & Warreyn, P. (2015). Child's verbal ability and gender are associated with age at diagnosis in a sample of young children with ASD in Europe. Child: Care, Health and Development.	*Prognosis has now been updated.* *‘early’ has been removed from the sentence.*
1.1.1	Where possible we have indicated evidence we are aware of. We acknowledge that this is likely to have already been considered by SIGN in its review.	*Noted*

	Acknowledge frontline - parents and children.	*This section describes the remit of the update.*
	Appropriate.	*Thank you*
	Consider changing 'This guideline updates SIGN 98 to reflect the most recent evidence.' to 'This guideline updates SIGN 98 to reflect evidence published between 2006 and 2014.'	*Changed*
1.2.1	I am supportive of the idea of extending the guideline from children and young people to include adults and older adults, so creating a comprehensive guideline for ASD.	*Noted*
	SIGN 98 referred to clinical intervention as does 1.2.3. Would it be advisable to stick to that terminology rather than using 'management' (as 'management' can include a very wide notion going beyond what would be considered 'clinical').	*Changed where appropriate throughout the document.*
	Towards enough autism specialists and professionals potentially involved to have significantly more autism awareness.	*It is hoped that implementation of the guideline will improve awareness.*
1.2.2	Comment related to this, re 1.3.1 Patient Version. This will need updating in line with the final revised document. For example, the original, in 'Behavioural / Psychological Interventions' includes 'The Lovaas programme should not be presented as an interventions that will lead to normal functioning'. This has been removed and updated in this consultation draft, so the patient version will need to change too.	*New patient versions will be produced to reflect the updated guideline.*
	Psychiatrists. Psychologists. CAMHS team. GP's. School teachers. PSA's.	*This is covered by 'multiagency colleagues'.*
	Appropriate.	*Thank you.*
	Given the new Children and Young People (Scotland) Act should it not be made clear that education and social work are key members of target users of the guideline.	*This is covered by 'multiagency colleagues'. The focus is of the guideline is clinical care.*
1.2.3	Reduce wait times for assessment and diagnosis. Get support in place to help ASD children reach their full potential.	*Implementation of the guideline should help to support this.*
	Sections 1.3.2 and 1.3.3. not appropriate here - most of this should be in sections 8 and 9. In the section on additional advice in relation to medications to be used within NHS Scotland (from SMC etc – would it be worth spelling out that this advice needs to be considered by prescribers , alongside their various clinical concerns and considerations about off label use. If there needs to be a section specifically on licensing, should there be a comment on the relatively limited range of medications with marketing authorisation which are actually available for children and adolescents?	*This is standard format for SIGN guidelines.* *This is discussed in sections 1.3.2 and 8 of the guideline.*
	Welcome acknowledgement of importance of involvement of parents, carers and those affected by ASD.	*Noted, thank you.*
	Is there a role for making part of the ethos of the guideline a recognition that given the spectrum ASD is a condition rather that disorder as is done in a later section?	*Think it is sufficient to leave this in section 3 rather than having repetition.*

General	In England, the National Institute of Health and Care Excellence (NICE) specifies that there should be a maximum wait of three months from referral to first appointment. This should be included in the SIGN guidance to help ensure that people in Scotland are not waiting too long to access a diagnostic assessment.	*It is not within SIGN's remit to comment on timescales but these comments have been passed on to the Scottish Strategy for Autism Governance Group.*
	We would like to suggest the inclusion of: 2.3 Non Pharmacological Interventions for Adults As for children in 2.2 above.	*Added following a second round of votes for priorities amongst the group members on the adult key questions.*
	This should be included in the SIGN guidance to help ensure that people in Scotland are not waiting too long to access a diagnostic assessment.	*It is not within SIGN's remit to comment on timescales but these comments have been passed on to the Scottish Strategy for Autism Governance Group.*
	I got confused with the difference between a strong and conditional recommendation - on page 3 they both appear to be down as "R" in grey type face. There are then the recommendations not updated from SIGN 95, A-D in white typeface on grey background. This section (2.1) starts off with an R and D in white type face which I think is a typo? Followed by two "R"s in grey type face.	*The A-D gradings have been removed, replaced with 'R'.*
	Following on from our opening concern, the focus of the guidelines should present, wherever possible, a balanced approach to the needs of both children and adults. We do acknowledge the stark difference in the amount of research on interventions for children and adults. However, the key recommendations section does not draw attention to interventions for adults. Therefore, a section of key recommendations from sections 9 and 10 on nonpharmacological interventions for adults and employment support respectively, should be included. Please see our comments on these sections for further details.	*Added*
2.1	Autistic , Low Functioning Autistic, Verbal Autistic, Non Verbal Autistic.	*These are the key recommendations.* *The groups listed were included in the literature review and evidence is discussed in other sections of the guideline.*
	2nd recommendation. 'language development' I prefer the phrase 'language and communication' as aspects of speech disorder(s) are not part of the autism presentation per se (though they can obviously co-occur)...	*Amended*
	Increased access is needed, as well as a national waiting time of 3 months. Consideration should be given to adult assessment and those who do not have contact with anyone who could provide reliable information about their childhood, or for those who wish to maintain privacy in relation to their health by not involving family members.	*It is not within SIGN's remit to comment on timescales but these comments have been passed on to the Scottish Strategy for Autism Governance Group.* *This is discussed in other sections. 2.1 is key recommendations.*
	Rather a confusing order of the recommendations, and mix of different kinds of recommendation - is there any way of harmonising it as important points for clinicians get rather lost. Could be an easier read if put the surveillance then assessment then diagnosis When there is only a 'should consider' recommendation for using a classification system at all, presumably the idea is that	*Symbols for recommendations have been made more consistent. These are the key recommendations and further explanation is provided in the relevant sections.*

	if used it should be recorded? I was unsure why this is a separate key recommendation - could they be combined?	
	Clear structure for assessment. Commitment to access within good timeframes.	*It is not within SIGN’s remit to comment on timescales.*
	Excellent.	*Thank you*
	I understand that (high-functioning) Aspergers no longer falls under DSM 5. Is this true?	*This is discussed in section 3.2*
	Consider: All professionals involved in diagnosing ASD in children, young people or adults should consider using the current version of either ICD or DSM. The classification system used for diagnosis should be recorded in the patient’s notes. This guideline and its recommendations are essentially based on a review of research carried out using DSM-IV Tr criteria. This earlier DSM system differs significantly from DSM 5 both in its criteria and in the population that it identifies. DSM IV Tr was replaced by DSM 5 at Easter 2014. DSM 5 criteria are also likely to differ significantly from the coming ICD 11 revision which is due to be introduced in 2018. Both will also differ from the RDoC criteria which are to be the basis for all future NIMH-funded research. These differences are highly significant not least for the extent to which the evidence-base covered by this review is likely to be consistent with current and future diagnostic practice in Scotland. As this difficulty is already known, it would be sensible to expand at least a little on these matters. Otherwise, I fear that we are consigning this guideline to obsolescence even before it has even been released.□ D: Evidence level 3 or 4; or Extrapolated evidence from studies rated as 2+ As part of the core programme of child health surveillance, healthcare professionals can contribute to the early identification of children requiring further assessment for ASD, and other developmental disorders. Clinical assessment should incorporate a high level of vigilance for features suggestive of ASD, in the domains of social interaction and play, speech and language development and behaviour. Ref.25 identified communication at 2y and both speech and behavioural concerns at 3.5y child health surveillance checks as helpful and conclude that “..if routine surveillance ceases, then an alternative method of early detection checks as helpful and conclude that “..if routine surveillance ceases, then an alternative method of early detection should be put in place.” GPP: Good Practice Point. The assessment of children and young people with developmental delay, emotional and behavioural problems, or genetic syndromes should include surveillance for ASD as part of routine practice. □If, as stated on p8, the assessment of children and young people with developmental delay, emotional and behavioural problems, or genetic syndromes should include surveillance for ASD as a useful part of routine practice, it also seems to follow from the significant co-morbidities across these diagnoses that the assessment of children and young people with ASD should also routinely include surveillance for developmental delay, emotional and	*We have followed the available evidence and classification systems. ICD-11 and RDoC are not available for SIGN to comment upon and we are unable to predict what the new ICD criteria will say.* *Professionally we have to use the current criteria that are in use and that was why the recommendation is worded this way.* *The guideline development group believe that the level of information provided by the guideline on these points is sufficient, in terms of the evidence base*

	behavioural problems, or genetic syndromes. Given the changes in criteria with the introduction of DSM 5 and particularly with the previous preclusion of ADHD co-morbidity from ASD on DSM-IV Tr criteria, there is a particular need to include clear guidance on those with comorbidity - the largest clinical group previously excluded from all DSM-based autism research studies. Consider: Clinicians should consider that females with ASD may present with a different symptom profile and level of impairment than males with ASD. There is increasing evidence of differences in some aspects of presentation, however the evidence is inconsistent on this (a number of studies have failed to find gender differences, if matching on IQ or MA, when comparing ABC, VABS, ADI-R, CARS or ICD-10 symptomology) specific implication at this time are limited, How this information cited should be considered and any clinical practice implications should be made clear. The removal of Rett's syndrome from this diagnostic category takes out a small subgroup with a poor prognosis and changes the pattern of presentation overall. Of the papers cited, Paper 44 is on a TEDS sample using the DAWBA, and suggests that girls with similar presentation to boys may often be missed or misdiagnosed where there are no behavioural or other co-morbid problems; Paper 45 is essentially a plea for more research, and not relevant here; Paper 46 is a meta analysis of 22 studies that reported similar presentations in both sexes except for increased rates of restricted, repetitive and stereotyped behaviour in preschool boys. Unfortunately this difference was only found in one of the five studies they cited (Hartley & Sikora 2009). Consider: A diagnostic assessment, alongside a profile of the individual's strengths and weaknesses, using a multidisciplinary team which has the skills and experience to undertake the assessments should be considered as the optimum approach for individuals suspected of having autism spectrum disorder. There is a danger that direct referral to community autism teams for ASD diagnostic assessment might lead to a failure to assess possible co-morbidities - sensory impairment, epilepsy.... Consider including here that diagnostic assessment should routinely include, in addition to diagnostic history and ADOS assessment, surveillance for developmental delay, emotional and behavioural problems, ADHD, and genetic syndromes, and profile the significant co-morbidities seen in this population. GPP: Good Practice Point: Specialist assessment should involve a history-taking element, a clinical observation/assessment element, and the obtaining of wider contextual and functional information. .As for previous point .	
	Agree with recommendations and best practice.	*Noted, thank you.*
	How can an NHS clinical child psychologist in England as part of a local CAMHS team diagnose a-typical autism & PDA(Pathological Demand Avoidance Syndrome) yet most Scottish CAHMS refuse to acknowledge its existence thus local school counties take lead from them on its non existence making things worse for our PDA diagnosed children by using standard ASD strategies! It might not be in the DSMV	*SIGN has focussed on information available in the evidence base. Clinical opinion on recently promulgated diagnostic variants may or may not be valid. Only when such knowledge enters the evidence base with sufficient reliability and validity in terms of positive or negative findings, can SIGN refer to it.*

	etc but it needs more recognition and acceptance and is accepted as part of the spectrum by a lot of high ranking autism professionals as well as NAS!	
	This summary of key recommendations should highlight an additional recommendation on the maximum time in which people should expect a diagnostic assessment to take place. NICE recommends a maximum of 3 months between referral and first appointment. The Quality Diagnostic Standard recommends a maximum time of 119 days from referral to sharing the diagnosis. The SIGN guidelines should reflect one of these key recommendations and set out an expected waiting time for diagnosis.	*It is not within SIGN's remit to comment on timescales but these comments have been passed on to the Scottish Strategy for Autism Governance Group.*
	Given that ASD can become evident at different developmental stages the important role of education in the recognition of ASD does not seem to have been made evident in this section.	*This section is for key recommendations. Further advice and evidence is in section 4*
	I think it is important to recognise the crucial role core professionals can take in the assessment and diagnostic process. In context and in tandem with all relevant and appropriate gathered information, I question the necessity for a Specialist to also observe the child/young person. In my clinical experience, the shared observations of those who know the child, and who spend time with them in differing settings is far more informative/valuable than a one-off clinical observation (in any context) by a member of the Specialist team.	*Recommending specialist observation of a child is not intended to undermine the value of any multiagency colleagues' observations or additional information. All is of equal potential value. This information would be gathered within the history taking and wider contextual information gathering. SIGN have emphasised the importance of specialist observation to ensure this important aspect of assessment is specifically accommodated by the assessing team and not omitted.*
	good on the females bit	*Noted, thank you*
2.1/2.2	(Addressing 2, 2.1, and 2.2 together): This key section is confusing in its format, priorities, order, standards, omissions—none of this is explained. The first "R" recommendation symbol is wrongly formatted, as though it an "old SIGN" recommendation, just much further down the alphabet. Two of the recommendations are based on outdated information and outdated grading indicating poor quality evidence (B and D), and 3 are not recommendations, but "good practice points" based on "clinical experience" only. These are thrown together as "key" without any apparent rationale. The message seems to be that evidence (whether good, bad, old, new) matters little, or not at all, when it comes to "key recommendations" for autistics.	*Old symbols removed* *The basis of the key recommendations is to prioritise which actions would make the most positive impact for people with ASD, rather than focusing on only those recommendations which are underpinned by strong evidence.*
2.2	Stem Cells, GcMAF, Homeopathy, Diet intervention such as Gluten Free, Dairy Free etc, Testing for gut problems and Sensitivities.	*No evidence is available for Stem Cells and GcMAF. Nutritional interventions are covered in section 6.4*
	Wondered if it would be appropriate to incorporate adults with intellectual disabilities and their carers into this section too? Given that there is a co-morbidity of around 40%.	*Due to resource restrictions on the remit it was agreed to focus on adults with ASD. Some evidence from NICE 142 is extrapolated from adults with intellectual disabilities, due to lack of evidence in adults with ASD.* *Adults with ASD and learning disability should be considered as the focus for the*

		next update of the guideline.
	'Behavioural interventions should be considered to address a wide range of specific behaviours in children and young people with ASD, both to reduce symptom frequency and severity and to increase the development of adaptive skills'. I think this is a good evidence-based recommendation which would benefit this population. However, looking at the recommendations you make in sections 6.3.1 and 6.3.2, I think that these should not be separated, but need to be combined to make sense in practical terms for service delivery. See my later comments. This might affect the wording for the key recommendation here, given the strength of your recommendation in 6.2.1. I would suggest: 'Behavioural interventions should be used to address a wide range of specific behaviours…'	*The guideline group consider that it is clearer to keep these recommendations separate.*
	As first-line. But access to psychiatrist / psychotherapist assessment to ensure medicines can be considered if circumstances indicate.	*Agreed. This is reflected in the guideline. Section 2.2 focuses on key recommendations.*
	I like what you say about ABA, but you then undercut it all by failing to mention that this is a proper discipline and needs BCBAs to implement it properly. It is no use either saying that only HCPC staff can oversee it, as you may know the HCPC is closed for any new professions. So there is no chance for behaviour analysts to become ratified. Which leaves my boy and others in an anomalous position: you agree ABA can work well, you give it an R rating, but then you effectively say it must be delivered by non-professionals. I don't think this is fair. I don't take my son to a chiropodist for a filling. This is a serious professional discipline and I wonder if SIGN has been lent on for cost reasons?	*We're sorry that you feel you and your son are in an anomalous position. SIGN are not involved in matters of professional registration. Our position is that programmes delivering ABA at high intensity (EIBI) require further research before we can consider it cost effective to recommend them widely. While EIBI is not currently deemed cost effective, we are recommending that ABA nonetheless informs practice. We have to leave it to services, professionals and families to work together to ensure the appropriate standards are adhered to.* *See response below.*
	I commend the team on the clear focus on the importance of involving parents, particularly with regard to their young children. There should be more emphasis, however, on the need to offer good quality behavioural parent training to ensure that parent mediated intervention programmes are of high treatment fidelity and based on evidence (Lamb, 2010). Our research has shown that parents are often better informed than professionals about evidence-based interventions, particularly those based on applied behaviour analysis (K. Dillenburger, Keenan, Doherty, Byrne, & Gallagher, 2010). An increasing number of parents now train formally in this science, e.g., our Open learning course (based on www.bacb.acm/rbt) attracts over 80 students per year, many of them parents. Many parents now train to become fully Board Certified Behaviour Analysts (www.bacb.com), (Barbera, 2007), which means that unless professional also hold this Masters level qualification, they will not be able to keep up. Functional assessment vs functional analysis I commend the team on a clear focus on assessment of adaptive functioning. However, there is a big difference between functional assessment and functional analysis (Schlinger & Normand, 2013). These procedures and concepts were developed by behaviour analysts (Hanley, Iwata, & McCord, 2003) and approved international training in	*SIGN cannot comment on matters of professional regulation. We would like to emphasise the clear separating line that we chose to draw between intensive developmental and behaviour programmes, and ABA as a wider and more fundamental science which informs training in a number of clinical and educational professions. Delivering EIBI may require additional professional qualifications, as suggested, but as we do not recommend this approach we feel it's reasonable not to comment on the training needs associated with it.* *In response to this and other reviewers' comments on this section, we have further emphasised the distinction between ABA and EIBI more clearly, as we feel it is crucial to understanding our decisions in this guideline update (see 6.3.1).* *The 2 references Moore, 2003 on private behaviours; and a pre-/post- study by Eikeseth, Klintwall, Hayward and Gale, 2015 on parent stress) are interesting papers but do not meet the quality criteria for inclusion in the SIGN review.*

	behaviour analysis includes them in training (see BCBA Tasklist, www.bacb.com). There are no other professional training courses that include comprehensive theoretical and practical training in functional analysis (Dillenburger et al., 2014). B Behavioural interventions should be considered to address a wide range of specific behaviours in children and young people with ASD, both to reduce symptom frequency and severity and to increase the development of adaptive skills. I commend you on the focus on behavioural interventions. Please note the holistic definition of the term 'behaviour' in behaviour analysis (www.behavior.org). In behaviour analysis, the term 'Behaviour' is viewed holistically as something that is contextualised within environmental contingencies. This is not the everyday meaning of the term behaviour. For a behaviour analyst the term 'behaviour' covers the phenomenological cascade of changes that simultaneously encapsulates two differing perspectives, what others see, ie, public behaviours, and at the same time what the individual 'sees', ie, private behaviours, such as emotions and cognitions (Moore, 2003). Page 22 should include new study on parent stress (Eikeseth & Gale, 2015) which shows that parent stress is reduced by participating in early and intensive behavioural intervention particularly maternal stress. Page 22: Applied behaviour analysis-based approaches are dependent on the skill and training of the personnel delivering them. There can be no debate about the accuracy of this fact and therefore staff in charge of these programmes need to be trained to internationally approved standards (www.bacb.com). Internationally, BCBAs are recognised as the professionals to oversee, design and supervise evidence-based interventions for autism, eg, increasing numbers of States in USA have full health cover under the condition that BCBA supervise the programmes. Increasing number of States have licensing laws for BCBAs. "They should be overseen by professionals trained in the psychological theory and in child development, who are regulated by a professional body such as the Health and Care Professions Council. There is a big problem with this recommendation: BCBAs are not regulated by HCPC simply because HCPC does no longer accept applications for new professions. A team of behaviour analysts (Dr Martin BCBA-D, Prof Dillenburger BCBA-D and Dr Hughes BCBA-D) met with HCPC in January of 2012 and prepared an application for aspirant profession. Shortly after this meeting HCPC decided not to accept any new aspirate profession applications. The UK Society for Behaviour Analsyis (UK-SBA; President Dr Mecca Chiesa) is working on this, however with non-acceptance of new applications the HCPC requirement is simply not tenable in the new SIGN guidelines. It's a 'closed shop'! Therefore, this sentence should be changed to "They should be overseen by professionals trained to international standards in Applied Behaviour Analysis (ie Board Certified Behaviour Analysts; BCBA), who are regulated by a professional body such as the Behaviour Analyst Certification Board (BACB). This is a very important distinction. I speak from personal experience: I am a HCPC registered clinical psychologist, also registered in the Division of Clinical	*The NICE guideline on behaviour that challenges is a very welcome addition to our evidence base as clinicians, and we're sure it will be widely studied by professionals supporting both adults and children. However, our guideline update is restricted to evidence concerning ASD specifically, so most if not all of the evidence informing NICE gl11 would not have been appropriate for our guideline.* *Our guideline group is as concerned as anyone about the standards that underpin service delivery in Scotland. ABA is not the only intervention that requires careful attention to treatment integrity and professional training. The guidelines group have therefore agreed that it would be worth highlighting these important concerns. We have added the following new sentence at the end of section 5 (Principles of intervention), with the intention that it will cover pharmacological and non-pharmacological interventions for children, young people and adults: "Where evidence-based interventions are available, they should be delivered by personnel with the appropriate skills and training, closely adhering to the protocols used in the original research."* *[this also covers comments on p6, p23 and p25]*

	Psychologists of the British Psychological Society since 2003. In 2006, I sat the BACB exam and became a Board Certified Behaviour Analyst-Doctoral; BCBA-D. Therefore, I know firsthand the difference between the two qualifications. As a Clinical Psychologist I studied one module on behaviour modification in 1980, however, this was not even the 'tip of the iceberg', compared to the amount of additional study I had to undertake to become a BCBA-D. Since I became a BCBA-D, I developed and teach on the MScABA at QUB (approved course by BACB) and therefore I am very familiar with the amount of study (270 hours of specific curriculum) and practice (1500 hours of supervised practice) that is a necessary pre-requisite prior to students becoming eligible to sit the BCBA exam (a very rigorous 4 hour exam that has an annual pass rate of only about 60%; see http://bacb.com/wpcontent/uploads/2015/08/2014-ACS-pass-rate-BCBA-alpha-final.pdf). There is no way that someone who is "trained in the psychological theory and in child development" comes anywhere close the level of knowledge required to become a BCBA. This low training expectation would simply not qualify anyone to deliver ABA based interventions with professional integrity and fidelity. Therefore, I urge that SIGN adopt the NICE Guideline 11 model that clearly identifies behaviour analysts (ie, BCBA) as part of the multidisciplinary team.	
	Good Practice Point Parent mediated intervention programmes should be considered for children and young people of all ages who are affected by ASD, as they may help families interact with their child, promote development and increase parental satisfaction, empowerment and mental health. Parent mediated interventions should be implemented with the same intensity, and with assessment and treatment fidelity to ensure replication of the approach being advocated. Behavioural interventions should be considered to address a wide range of specific behaviours in children and young people with ASD, both to reduce symptom frequency and severity and to increase the development of adaptive skills. As before, interventions should adopt the same assessment and intervention approach as is used in the literature in order to ensure fidelity and to allow outcomes to be evaluated and compared.	*See response above. A sentence has been added to section 5: "Where evidence-based interventions are available, they should be delivered by personnel with the appropriate skills and training, closely adhering to the protocols used in the original research."*
	Agree.	*Thank you*
3.1	Helpful to acknowledge the importance of terminology given the population of individuals who prefer the term 'Condition' as opposed to a 'disorder'.	*Noted.*
	Page 6 The effect is even greater when inexperienced practitioners are making the diagnosis Should this not be: The effect is even greater when experienced practitioners are making the diagnosis. Under Professional Resource section should include links to BACB training and Autism Guidelines (http://bacb.com/asd-practice-guidelines/)	*Noted, but we do not think the text needs to be amended.* *Resources provided in the information section are more generic than the suggested link.*
	See Autism from NAS.	*The group would prefer to retain the definition in the draft, which is aimed at healthcare professionals. There will be separate versions for young people, adults*

		and carers.
	Do you even want to get into DSM-5 (it has caused rather a mess in the U.S. and you may just want to ignore it as you've done).	*The guideline development group recognise the concern. On balance, we believe it is helpful to explain the direction of travel re categorisation of autism presentation, given the likelihood of future research being conducted according to DSM-5 classification.* *The group took the decision not to comment on the controversy surrounding the introduction of DSM-5 and instead focused on the need for professionals to use the most up to date version of the diagnostic criteria.*
	Para 1, sentence 1. I would include sensory atypicalities or behaviours here too (pace DSM-5	*Added*
	Para 2 'Some affected individuals who experience no functional impairment advocate that it is inappropriate to describe them as having a disorder and autism spectrum condition is a more appropriate term.' Should this be '**consider that** autism spectrum condition is a more appropriate term.'?	*Changed*
	Excellent.	*Thank you*
	To be honest, this is not the clearest definition I have ever seen. I think it might be helpful to make the sentences a little shorter - and also maybe to spell a few things out. It is fine as a professional to state eg "behaviourally defined" - but the guideline is written for family and people with autism as well. I think it might also be helpful to put in a little bit about learning disability here. It does mention cognitive impairment - but I think it would be helpful to put very simply in layman's language - some people with autism have global cognitive impairment (referred to in the UK as a learning disability) and some people with autism have normal intelligence. Clinically this is something that seems to confuse people a lot of the time. Eg Mr X can't have autism because he has/hasn't got a learning disability. Also, in terms of evidence supporting this document it is a huge mix of children, young adults, adults with and without learning disabilities. This is usually but not always made clear in accompanying text. I think that a really clear definition at the beginning would help the reader bear in mind how the guidelines relate to the people that they support/are working with.	*This document is aimed at healthcare professionals. There will be separate versions for young people, adults and carers which use plain English.*
	The recognition of autism spectrum condition being a more appropriate term is good change from the previous version.	*Noted, thank you.*
	Throughout, autism "severity" is not clearly defined or described. This may lead to unhelpful biases, including that strong autistic abilities, which contribute to autism "severity," are dysfunctional. An individual may have a very weak ("mild") autistic phenotype, severe difficulties, and a poor outcome. An individual may have a very strong ("severe") autistic phenotype, few or no difficulties, outstanding achievements and/or an excellent outcome. "Some affected individuals who experience no	*Guideline recommendations are a guide for practice and it is hoped that people will be offered the support they need as an individual.*

	functional impairment advocate that it is inappropriate to describe them as having a disorder and autism spectrum condition is a more appropriate term." This statement is unsourced and unhelpful. It is unclear how SIGN established that these "affected individuals" experience no functional impairment (however this is defined). It is unclear how SIGN established that individuals who do experience functional impairment want autism to be defined as a disorder, if that is the point here. Generally, do the assumptions here represent how SIGN wants autistics to be treated in research and practice? I hope not. Research does, however, suggest that defining autism as a "disorder" can create and sustain unhelpful biases which may harm autistic individuals and impede the progress of research (e.g., Baron-Cohen, 2005; Gernsbacher et al., 2006). Researchers, clinicians, and guideline writers should work to reduce—not increase—biases which make autistic lives more difficult. Baron-Cohen, S. (2005). Enhanced attention to detail and hyper-systemizing in autism. Commentary on Milne, E., Swettenham, J., & Campbell, R. Motion perception in autism: a review. Current Psychology of Cognition, 23, 59-64. Gernsbacher, M. A., Dawson, M., & Mottron, L. (2006). Autism: Common, heritable, but not harmful. Behavioral and Brain Sciences, 29(04), 413-414.	*Sentence amended*
3.2	This is a useful and current description of the diagnostic classification systems and will provide some clarity on what the differences actually are between ICD-10 and DSM-5 and how that relates to the diagnostic process.	*Noted, thank you*
	The shift to a 2 dimensional approach in DSM5 and the increasing evidence for that is likely to be important in any future revision of the UK system. Should this come first? Re ICD 10 the use of 'pervasive developmental disorder' was as a concept applying across several clinical groups, and involving a triad of impairments. ICD10 then has a description of categories within the broad PDD group, which have some differences in the nature and onset of impairments and in whether there is LD(including childhood autism and Asperger syndrome). My perspective is that emerging evidence then led many UK clinicians to adopt a broader concept of autism spectrum disorder and to acknowledge change over time in many individuals, so that the categories were not viewed as useful (even if clinicians at various times and for various reasons might refer to the separate categories of autism, high functioning autism, aspergers etc). These ideas and 'ASD' usage pervaded the last version of the guideline, and are in general use in Scotland for children and adolescents. In the previous guideline version there was acknowledgement that preferred usages by patients or others might include terms like Aspergers, but that this was not inconsistent with using ASD. In DSM5 Asperger syndrome is no longer separate, and this has been very contentious in US, because of how	*The group recognise the issue but on balance did not feel it was necessary to change the text.*

	the term was previously used and seen as a way of advocating for needs of individuals who might be viewed as more 'able'. Should this be mentioned? Unless guideline is recommending use of ICD there will be people using DSM5, and risk of confusions - it seems important to indicate there might be different usages. Concerns and diagnostic practices may be different for adults (others will be better placed to comment), but the clinical issue when diagnosing is to look for the underlying impairments, whatever the clinical presentation. Does this need some emphasis?	
	Agree fully with recommendation to use ICD10 or DSM5.	*Noted, thank you*
	Consider evidence for diagnosis of adults, other than that necessitating disclosure to a family member.	*In general the wording of the recommendations do not suggest that disclosure to a family member is necessary-only that information is obtained from a range of sources wherever possible e.g.* *'Specialist assessment should involve a history-taking element, a clinical observation/assessment element, and the obtaining of wider contextual and functional information.* *Healthcare professionals involved in specialist assessment should take an ASD-specific developmental history and should directly observe and assess the individual's social and communication skills and behaviour.* *Information about individual's functioning outside the clinic setting, should routinely be obtained from as many available sources as is feasible.*
	DSM5 has changed domain b with stereotyped language and hypo/hyper sensitivities	*Added*
	See Autism from NAS.	*This section is focussed on the diagnostic manuals DSM-5 and ICD-10, for use by healthcare professionals.*
	Valuable update of current position.	*Noted, thank you*
	It would be helpful to include a clear indication of the differences between DSM-IV Tr and DSM 5 to make the reader aware of the key changes in the population, and the likely relevance of pre-DSM 5 research: ASD and ADHD is now an allowed diagnosis; Rett syndrome and CDD have been removed; Early history is not as strongly emphasised making adult diagnosis easier; A part (but not all) of the group previously diagnosed as having Asperger syndrome are included in those diagnosed with ASD As NIMH is moving to the use of RDoC criteria and will no longer be funding DSM-based research, this is an important change which will affect the evidence-base.	*The group do not agree that early history is not as strongly recognised.* *The future evidence base will be covered in future revisions of the guideline.*
	Agree with text and recommendations	*Noted, thank you*
	The "R" here is formatted incorrectly, causing confusing with the "old SIGN" system. See point 2,	*Changed*

	2.1., 2.2 (Key Recommendations) above.	
	The population screening bit is a tad complicated as an issue. I understand that both in the UK and US groups have come out to say this given the great limitations of the screening instruments with high false positive rates. On the other hand there is clearly a strong sense that for many young children there is more potential for major change – the data on this aren't perhaps as strong there yet but the potential for loss is so great I'd wonder about this.	*SIGN is discussing screening in the UK context, although we recognise that this is different from the position that has been adopted in the US.* *Until further, robust evidence is available it is not recommended.*
4.1.1	Should there be something about recognition of adults presenting to primary care?	*New sentence added.*
	Useful to state that reintroduction of Hall 4 (reference?) means there is again a routine surveillance opportunity. Guideline will be very relevant to whoever is doing the checks.	*This is not a reintroduction. It was made universal rather than targeted surveillance. Reference added.*
	This section is all about children. This becomes evident as the document progresses. But for clarity I think it would be helpful to state this right at the start so that the reader knows how best to interpret the evidence. I don't work with children. I probably should know - but I have no clue what Hall 4 is.	*Reference to sect 4.1.5 identifying adults for assessment added.* *Hall 4 is referenced for further information.*
4.1.2	Once again, I think it would be worth clarifying that the evidence in this section is really about children. Even a statement such as there is no evidence looking at population screening in adults? I don't see how population screening would be feasible in adults. But the recommendation "C" from the old SIGN guideline is for a child guideline, whereas this is for children and adults; so I think that this justifies an explanatory comment.	*Reference to sect 4.1.5 identifying adults for assessment added.*
	As I'm sure the panel is aware, the American Academy of Pediatrics is very supportive of screening as are American advocacy organizations even though the U.S. Public Health Service recently did not recommend it. I felt the discussion in this document was fair, but believe it would be appropriate, given the recent literature on baby siblings, to include some reference to the need for more intense assessment of siblings if parents are concerned, even if it is primarily to help familial stress. In addition, I wondered if part of the statement about surveillance could be included in the recommendation that states there should not be population screening, because the need for surveillance (particularly given recent findings of significant effects of even low intensity parent-mediated treatments with very young children at risk) seems clear, at least to me.	*We have referred to siblings of children and young people with a diagnosis of ASD as being at particular high risk when we discuss secondary screening.* *We think it is sufficient to keep the two sections as they are, with surveillance placed immediately after screening.*
4.1.3	Does the recommendation that instruments used for information gathering not be used to determine if a referral for further assessment not contradict 4.1.4 which states that surveillance for asd be routine practice. Surely anything that flags up possible asd for further assessment should be considered.	*Surveillance may be something that needs to be progressed or may not. It is recommended as something to be alert to and bear in mind.*
	3rd para Sometimes I try to find alternative wording for normal/abnormal (though I know this is essentially a medical/health guideline). 'typical/atypical' does not work here but something else might...	*Point understood, but we prefer to keep original text.*

	Agree on regression issue and also on identification in adults.	*Noted, thank you*
	Risk also includes family history of ASD, prems and certain neurological disorders---asd relatives appears later 4.1.4	*These are covered in annex 3*
	"Opportunistic surveillance" smacks a little too much of Big Brother. It may head to paranoia!	*Child health reviews are optional.*
	Agree no comment.	*Noted, thank you*
	"Regression" is not clearly defined throughout this guideline. There is contradictory information about what "regression" means in autism and its consequences. "Intellectual disability" is not defined throughout, even though it is frequently mentioned. There is no indication of how intellectual disability should be identified in autism—what instrument(s) at what age with what thresholds.	*Definition added.* *Intellectual disability is the new term for learning disability in DSM5.*
4.1.4	GPP. Healthcare professionals should consider informing families that there is a substantial increased risk of ASD in siblings of affected children. The recurrence literature does not seem to have been reviewed. I usually cite ~10% and Sandin (2014, JAMA), Gronborg et al (2013, JAMA Pediatrics) and Constantino (2010, Am J Psychiatry)	*This is based on evidence from NICE which is included in Annex 3*
4.1.5	Useful.	*Noted thank you*
	The conclusion that the Autism Spectrum Quotient- 10 is a strong instrument seems questionable to me (the citation listed is NICE, not a research publication). I strongly support encouraging clinicians to ask individuals who can describe their own symptoms to do so, but there is actually quite a lot of evidence that this is not always meaningful in the same way as informant reports about social communication symptoms. I believe the specificity statistics cited are between ASD and typical individuals, which is not appropriate. I was very surprised by the inclusion of this as a recommended tool without better data. I believe the previous version of this instrument had very questionable specificity but there was never adequate testing of it, as appealing an instrument as it is.	*We are not saying it is a strong instrument. It is recommended as an option to help identify adults to refer for assessment. As well as specificity, this is based on its practical application (availability and ease of use).*
	'A study conducted in a gender clinic in London reported that among the 92 participants the prevalence of autistic traits consistent with a clinical diagnosis for an autism spectrum disorder based on the Autism Spectrum Quotient (AQ) was 5.5% (3 male to female and 2 female to male)' If this is not a diagnosis of ASD (it does not sound like one) I would re-phrase/tone down....	*Amended*
	Autism-Spectrum Quotient should read: Autism Spectrum Quotient.	*Changed*
	At present there is no mention of 'surveillance' in adults. Given current increasing awareness - would this be worthwhile? The guideline talks about ASD being diagnosable any age, so surveillance is relevant at any age too. Encouraging ASD awareness in services where adults with ASD might be encountered would parallel previous work with children and	*Adults are mentioned in the first sentence of 4.1.3 on surveillance.* *GPP added*

	adolescents. Adults with ED - depends where the 'adult with ED' is encountered. Might be helpful to indicate this. If in ED psychiatric service, 'ED' might be quite a limited category - mainly anorexia. Huke et al SR 2013 had many issues. Problems with case finding instruments, and, of the 2 studies not from same community sample one was small study of Inpatients with anorexia (highly selected subsample) and the other compared adults with ED with published norms on self report scale. High risk of inaccurate diagnosis not just due to effects of starvation on cognition. Also due to inappropriate approach to diagnosis of ASD focusing on current state only, without adequate focus on developmental history. Could this be incorporated into good practice point? If in services of other kinds, eg primary care, might encounter variety of eating issues in ASD, and need for careful assessment to distinguish their nature. Bolte et al 2002 and Karlsson 2013. Given NICE recommendations of looking for core ASD features whatever the population - should there be some kind of recommendation about considering ASD in adults in all mental health services.	*There is insufficient evidence to make any definitive statement in relation to where the adult with ED is encountered. As was noted, there were a number of limitations with the existing research that made more definitive conclusions difficult to support.* *GPP removed* *There was not consistent evidence to support such a recommendation.*
	This was interesting (and I agree with interpretation of data) - but it would be helpful to have a single explanatory sentence at the beginning. E.g. it is not sensible to undertake a population screen in adults, but should are there certain populations at higher risk that we should be targeting screening or raising awareness in?? Just to put the section in context.	*The need for opportunistic surveillance for adults is noted at the start of section 4.1.3 and there is not a consistent evidence base to indicate which other populations should be considered to be high risk in terms of the areas we were looking at.* *GPP added.*
	This section on adult identification should include more detailed best practice recommendations as in the NICE guideline [NICE, Autism: recognition, referral, diagnosis and management of adults on the autism spectrum, p93 ff. Clinicians are often operating without guidance is an issue. Therefore, rather than only referencing the NICE guidance on what should prompt assessment, these should be SIGN recommendations as well. It would be more widely applicable to give a greater prompt to professionals on who to identify for further assessment here. The NAS would also recommend that SIGN avoid using the term ‘warning signs’ both here and as the heading for Annex 2. We would suggest using indicators or a similarly neutral term. On whether assessment of patients with eating disorders should be avoided, we believe that this potentially needs to be looked at again to ensure that treatment for an eating disorder can be adapted in light of a person’s autism or suspected autism. In some cases, it may be the case that assessment could be considered, but with clinicians’ awareness of the potential impact on cognition. We also welcome that this is an area highlighted for further research under 13.2.	*Indicators from NICE are provided in Annex 2.* *An additional GPP has been added.* *Agree, changed* *GPP on eating disorders removed.*
	In this section I wondered about the high rates of co-morbidity with the range of anxiety disorders from childhood to adulthood and especially symptom overlap with OCD/SAD/GAD. Although, little research in the area see the following references: Simonoff, Emily et al. 2008, Psychiatric Disorders in Children With Autism Spectrum Disorders: Prevalence, Co-morbidity, and Associated Factors in a Population-	*Agree, wording of GPP in section 4.1.4 changed to incorporate.*

	Derived Sample, Journal of the American Academy of Child & Adolescent Psychiatry , Volume 47 , Issue 8 , 921 – 929 Cath D, C, Ran N, Smit J, H, van Balkom A, J, L, M, Comijs H, C, Symptom Overlap between Autism Spectrum Disorder, Generalized Social Anxiety Disorder and Obsessive-Compulsive Disorder in Adults: A Preliminary Case- Controlled Study. Psychopathology 2008; 41:101-110.	
	I agree with the crucial point about starvation effects on cognition.	*This is discussed in the text but the GPP has been removed, as per earlier comment.*
4.1.6	Provides information and some much needed clarity to the differences in presentation between genders. Should be helpful in improving the referral/ diagnostic pathway for females.	*Noted, thank you*
	Bullet 3 - less females - fewer females.	*Changed*
	Consider people who are transgender or have a non binary gender identity. They may not fit a typically gendered picture of anticipated traits.	*No evidence was identified.*
	Appropriate	*Noted, thank you*
	Interesting, and I hadn't come across this before. I think a balanced, reasonable recommendation. Reference 47 is incomplete - just initials, no names.	*Reference amended*
	‘Females with ASD may have better coping skills than males with ASD which may lead to fewer females being given a diagnosis, even when they have equivalently high levels of autistic traits to males who do receive a diagnosis’ The best evidence for this is the Ginny Russell ALSPAC paper: 2010 in Social Psychiatry and Epidemiology	*The study cited directly answers the key question asked, is more recent and is of similar quality to Russell.*
	Somewhere I would add a caveat about the preliminary nature of the putative sex differences in symptom profile as most studies suffer from clinical/referral bias sampling issues...	*Added.*
	The NAS very much welcomes the very helpful references to how autism can present differently in women and girls. In 2012, we reported how it can be harder for women and girls to access a diagnosis, particularly those who have Asperger syndrome or high functioning autism. Indeed, we found that just one-fifth of females were diagnosed with Asperger syndrome or high-functioning autism by the age of 11 [NAS, 2012, The way we are: autism in 2012, p.11]. However, we also think that somewhere in the guideline, there should be a wider recognition that anyone on the spectrum, particularly undiagnosed adults may have developed coping mechanisms, which mask their difficulties. A clear message to professionals also needs to be that every individual should be approached in a person centred way and clinicians should avoid stereotyping based on gender.	*We agree re masking symptoms but this is anecdotal, not published evidence.* *The recommendation in section 4.1.5 has been changed to highlight under diagnosis of ASD in adults.*
	Good addition to the guideline	*Noted, thank you*
	I think there could be more here about the extreme peer imitation/copying we see in girls with ASD, especially at the adolescent stage, where there often seems a clear motivation to 'fit in' that is not often observable in boys.	*Imitation is noted in the second bullet point in this section, and additional wording has been added to the first bullet point.*

	Parts of this section and its related "key recommendation" seem overstated, versus the ongoing uncertainties in the literature. This is a rapidly developing field with recent findings (e.g., Reinhardt et al., 2015; Howe et al., 2015) which suggest things may be more complicated. Also, the high profile discussion about autism in females has promoted unfortunate stereotypes ("autism in pink"), some of them extreme (females are interested in make-up and fashion, not in science and engineering). This is very concerning. Reinhardt, V. P., Wetherby, A. M., Schatschneider, C., & Lord, C. (2015). Examination of Sex Differences in a Large Sample of Young Children with Autism Spectrum Disorder and Typical Development. Journal of autism and developmental disorders, 45(3), 697-706. Howe, Y. J., O'Rourke, J. A., Yatchmink, Y., Viscidi, E. W., Jones, R. N., & Morrow, E. M. (2015). Female Autism Phenotypes Investigated at Different Levels of Language and Developmental Abilities. Journal of autism and developmental disorders, 1-13.	*We are citing directly from the research.*
4.1.7	In England, the National Institute of Health and Care Excellence (NICE) specifies that there should be a maximum wait of three months from referral to first appointment. This should be included in the SIGN guidance to help ensure that people in Scotland are not waiting too long to access a diagnostic assessment.	*It is not within SIGN's remit to comment on timescales but these comments have been passed on to the Scottish Strategy for Autism Governance Group.*
	This may just be American terminology, but I wondered if a statement about continuing re-evaluations, at least within preschool years, would be an appropriate addition to the statement (top of p. 11) about referral for further diagnosis.	*It was not part of the selective update to look at the efficacy of re-evaluations.*
	'In children under two years old typical ASD behaviours may not be evident. Absence of such behaviours should not rule out the possibility of diagnosis.[25]' I know what you are trying to say here and why but it needs re-phrasing...	*Sentence removed.*
	First bullet point. The better article is Lord et al (2006) AGP	*The update of the guideline did not extend back to 2006. This section is from SIGN 98. SIGN resources were not directed to reviewing additional evidence that did not change the message already given.*
	Music therapy may be of value in differential diagnosis of autism for very young (preschool) children, especially children displaying absence of normal language/communication features. See Wigram, T. 1992. 'Differential Diagnosis of Autism and Other Types of Disability.' In: Australian Journal of Music Therapy, Vol. 3, 1992, p. 16-26. See also the MTDA assessment tool developed by Oldfield.	*This is outwith the date range for the literature review of the guideline and would not provide enough substantial evidence to support a recommendation.*

	I wonder if the document would read better if this were put earlier in the section. There is a sort of progression from children to adults across section 4, and then this jumps back to pre-schoolers.	*Agree, section has been moved.*
4.1.8	Using the NICE guideline as a reference is appropriate here, but locally we are finding it impossible to get IQ assessments carried out, as our Educational Psychologists have moved away from them. Is this similar to other parts of Scotland?	*It is not the intention that IQ is assessed prior to the administration of AQ. Paragraph has been reworded.*
	Am not aware that any of these tools have been validated against DSM 5 diagnosis, and presumably normative data enthuse measures will be altered to reflect the differences as his becomes available.	*DSM5 is too recent for validation with the tools. We have to work with the evidence currently available.*
	The recommendation could specify that it excludes people with learning disabilities?	*Wording of recommendation amended.*
	As per 4.1.5 remove hyphen.	*Amended*
	Given the range of instruments available, I was not sure how only a few have been discussed in this section - was it only free instruments that were considered? Does this need further clarification?	*Only those with supporting evidence were discussed. It is stated that 'No other studies of instruments for this group were of sufficient quality to inform a recommendation.'*
	is a good rec as evidence does not justify 'should'	*It is a recommendation, based on low quality evidence and expert opinion from another guideline. It is therefore worded as 'may be considered' to reflect that it is conditional, due to the paucity of supporting evidence.*
	Recommendation I know that NICE recommends this but they ought not to have as the study it is based on should have been graded as 'low quality' and hence would not count - the most obvious flaw is the lack of diagnostic confirmation but there are others....!	*The recommendation is based not just on the evidence but due to the ease of use and availability of the test. The recommendation is based on low quality evidence and expert opinion, which is reflected in the wording, 'may be considered'.*
	As a practical matter there are many approaches to diagnosis and picking any one is a bit tricky but I understand why you recommend the ones you do	*Noted, thank you*
4.2.1	The list of the wide range of professionals should also include employment support services and the criminal justice system. Many adults with autism may have contact with these services.	*We prefer not to include an exhaustive list.*
4.2.2	BAMT supports this recommendation strongly. Music therapists have the skills to contribute usefully to identifying ad differentiating different aspects of ASD (and closely related difficulties e.g. language disorder, AD(H)D) and so aid accurate diagnosis.	*Noted*
	Necessary.	*Noted*
	Excellent.	*Noted, thank you.*
	Depression (and other psychiatric conditions) is fiendishly difficult to diagnose around the age of 13 years: is it just teenage angst?	*The guideline development group does not agree with this statement. Depression is diagnosable in adolescence.*
	Acknowledge that this is covered later on, but as somebody working with adults with LD, one of the most important initial steps is to gather information on the level of learning disability. Before even starting to carry out an ASD assessment. Otherwise features might "score" for ASD (such as need for routine and predictability) when in fact they are in keeping with the	*The guideline states, 'Those involved in carrying out the initial assessment should be aware of the core features of ASD as well as of the wide range of different possible presentations, depending on the individual's level of communication and intellect, personality, gender differences,*

	person's overall level of development. We don't do/request an IQ test prior to assessment - but personally if the person was not already well known to the LD team, I would carry out a Vineland's to get some sort of baseline. I wouldn't suggest that everybody has a Vineland's before assessment... But it is such a large part of an LD autism assessment that I think that it warrants mention right at the beginning. I guess that it goes without saying in children's services that you take their developmental age into account. However, I think that this does need stating for adult LD services as it is so fundamental to a good assessment.	*family and educational supports.* *There are many factors that require to be considered when interpreting the individual presentation. The decision of which are essential will vary across cases.*
	Diagnosis helps people take control of their lives, unlocking barriers to essential support and services, and often explaining years of feeling different. Crucially, it can help unlock the possibility of getting the right support to help autistic people live a fulfilling life. 61% of people who responded to an NAS survey said they felt relieved to get a diagnosis. 58% said that it led to getting new or more support [Bancroft (2012) The way we are: autism in 2012 (NAS: London)]. Being left without support can mean that people face social exclusion and anxiety, which can have negative effects on individuals' mental health. Research shows that 70% of children on the spectrum also have a mental health problem. While not all of these are attributable to not getting a diagnosis, getting a timely diagnosis and appropriate support, as a result, will reduce these numbers. Indeed, the National Audit Office in England concluded that "A diagnosis can also prevent people with autism being misdiagnosed with mental illness, such as schizophrenia or depression, or coming into inappropriate contact with the criminal justice system. Both these scenarios can have severe impacts on people's lives, as well as incurring high costs, for example through ongoing use of inappropriate medication or unnecessary confinement in secure accommodation." [NAO, 2011, Supporting people with autism through adulthood, para 3.7. NAO: London] We are therefore very concerned that there is no mention timeframes in which people should expect a diagnostic assessment to take place. A recent study found that almost three quarters of children (74%) and over half of adults (59%) were waiting longer than the recommended maximum time of 119 days from referral to sharing the diagnosis [Autism ACHIEVE Alliance, August 2014, Autism Spectrum Disorders: Waiting for assessment]. The SIGN guidelines should also reference this recommended maximum time, promoted by the Quality Diagnostic Standard. It should also be noted that NICE recommends a 3 month maximum waiting time from referral to initial appointment. In order to emphasise the importance of timely diagnosis to professionals, the guidelines should also include relevant references to evidence of the respective impact of timely or untimely diagnosis. It should also be clarified whether the reference to 'a multi-agency management plan' is a general term used to cover a Child's Plan, a school based support plan (e.g. Co-ordinated Support Plan or Individual Education Plan in school), or adult social care plan, rather than an additional plan. Also, further to the very welcome inclusion of the good	*The aim of special assessment is to gather and record information that enables diagnosis and to formulate a multi-management plan (eg co-ordinated support plan, IEP, adult care plan etc).* *It is outwith the remit of the guideline to make a recommendation on timing of diagnosis.* *The focus here is on clinical assessment and the profile of associated neurocognitive difficulties, rather than referral for assessment of suitable interventions. For children & young people and in keeping with the Children and Young People 2014 Act, services should be co-ordinated by the*

	practice point considering assessment of mental health needs, it would also be helpful to include here referral for social care assessment and support for learning in school.	*Named Person to develop a multi-agency plan to ensure the appropriate supports and services are in place eg social care, support for learning in school etc.*
4.2.3	See also the MTDA assessment tool (Oldfield, A. Interactive Music Therapy in Child and Family Psychiatry. London: Jessica Kingsley Publishers 2006). Music therapy may offer assessment opportunities at age below 2 years, as it need not depend on verbal competence being achieved. And Oldfield, A. 'Music therapy with children on the autistic spectrum: approaches derived from clinical practice and research.' Available online at: http://europepmc.org/abstract/eth/398246 See also Wigram and Gold 2006. 'Music therapy in the assessment and treatment of autistic spectrum disorder: clinical application and research evidence'.	*This is outside the remit of this update.*
	Thorough.	*Noted, thank you.*
	ADI-R I think you should refer to the Kim Lord preschool ADI work: Kim & Lord (2011) JADD and Kim et al (2013) JADD	*This paper is covered in the Falkmer systematic review which is cited.*
	The Cars has been updated (Cars 2 I think it is called) and the little I've seen of it makes it look good. At any rate you should update.	*The Childhood Autism Rating Scale is referred to in 4.2.3 and we have indicated that it has been updated to CARS-2.*
	Significant life events including severe illness that might have affected brain function also risk factors such as prems could go here at the end of this section NICE recommended no single instrument alone.	*This is covered by 'significant life events' and history of the individual's prenatal, perinatal and developmental history.*
	NICE also recommends the Adult Asperger Assessment (AAA), a semi-structured interview instrument that was developed for use with adults and integrates information from screening tools, viz., AQ and EQ. DSM-IV should this be replaced by DSM-5 as per the rest of the document? Good practice point: this is especially the case in adults when developmental information is not readily available.	*AAA requires a lifelong presentation to be present as a pre-requisite to an ASD diagnosis, therefore childhood information is still required.* *GPP added.* *ASD specific developmental history should be taken, however, in adults, the developmental history is not always available. Every effort should be made to ascertain it. This could be sought from a parent, sibling, cousin or any person who knew the individual well as a child. Diagnostic assessment should always be undertaken even in the absence of an informant for early developmental history.* *DSM-IV replaced with DSM-5*
	Although the link to vaccines has been discredited, a history of these should be taken into account – particularly those administered as a cocktail - so that possible onset of autism can be detected even in the years preceding three.	*The link to vaccines has been discredited so should not be included.*
	I am not aware that the ADI-R, ADOS-G, 3di, CARS or DISCO have yet been validated against DSM 5 diagnosis, and presumably normative data enthuse measures will be altered to reflect the differences as	*It is too soon for validation against DSM-5. Future studies will be reflected in future updates of the guideline.*

	this becomes available.	
	History taking - childhood history is not always possible in adults, some of whom have no appropriate informants. DSM V specifically allows for this - and has been a huge improvement on ICD-10 which stated that there had to be a childhood history in order to make a diagnosis. We have had people with learning disabilities coming through the system blatantly autistic and having gone without a diagnosis purely on the grounds that it was not possible to elicit a childhood history. (ie diagnostic letters eliciting ASD features but at the end stating that they did not reach diagnostic criteria because there was no childhood history). Would it be possible to put this in the guideline somewhere? eg in some cases childhood history may not be available. If it is not possible to get a good childhood history then all other information should be taken into account, but the individual should not be denied an appropriate diagnosis.	*GPP added*
	We note the reference to older people in this section and recognise that the diagnosis of older people can be more difficult. This may be because there may be no one available to help give a developmental history (NAS, 2013, Getting on? Growing older with autism, p.11), or because such input may seem quite irrelevant to the older adult seeking assessment. Information on developmental history is highly desirable as part of an assessment, but not essential. Lack of such information on developmental history should not, in itself, be a reason to refuse diagnosis. Various other factors make it more complex to diagnose older people with autism. Firstly, older adults may have developed an additional mental health problem because of a lack of support or a lack of understanding of why they feel ‘different’. Secondly, older people are more likely to have adapted their behaviour in response to life experiences. For example, they may have developed sophisticated coping mechanisms which disguise their autism (NAS, 2013, Getting on? Growing older with autism, p.11). In such circumstances, diagnosis may require more experienced expert clinicians. Therefore, the guidelines should acknowledge that the diagnostic process can be more difficult in older adults, but that this should not be a barrier to assessment. The guidelines should specifically state that the lack of information on developmental history should not be a reason to refuse diagnostic assessment of an older person. We do acknowledge the point made in the second paragraph of section 4.2.2 which encourages a low referral rate to more specialised colleagues. However, given the challenges outlined above, the guidelines should also advise that, professionals may need to seek support from more experienced clinicians with specialist knowledge, skills and training in order to assist with a diagnosis for an older person.	*GPP added to state diagnostic assessment should still be undertaken in the absence of developmental history.*
	This is an important update and I am in agreement with recommendation.	*Noted, thank you.*
4.3	Excellent.	*Noted, thank you.*
	Good addition.	*Noted, thank you.*

	Plenty of evidence that adaptive skills are lower than cognitive in ASD which is important for current function and future outcome and therapeutic targets	*This should be picked up under functional information.*
4.3.1	Theory of mind and the other cognitive theories could also be included within the Service provision/training section as essential for the understanding and provision of appropriate support.	*This is outside the remit of the selective update.*
	Appropriate.	*Noted, thank you*
	A significant subgroup of those with ASD will lack expressive language, perhaps the term non-verbal communication skills should be inserted here to indicate this.	*New sentence added:* *'Receptive and expressive language skills are generally equally impaired.'*
	Maybe point out (you do implicitly) more explicitly that this is NOT just tests of receptive or expressive vocabulary (a common mistake here in the US made by schools). As an aside I don't know enough about how your system works in terms of what testing is done in schools.	*We agree and have mentioned the wide range of difficulties within communication but are not able to recommend on the basis of the evidence one assessment instrument over another.*
	The second good practice point - I agree - is it worth mentioning that this may be a feature of autism? Certainly in LD, complex use of language but not actually knowing what they are saying??	*This is interesting but because of the remit and focus of the updated guidance it was an area that we were unable to consider the evidence for so can't include or comment on.*
	In this section, the importance of non-verbal communication, both use of and understanding of body language and the impact this has on social interactions is not covered.	*Note, but this section was not included in the remit of the selective update.*
	The term "verbal mental age" fosters unhelpful biases, and age equivalents are often limited and problematic in how they are used. Instead, use the less biased, more useful "verbal abilities."	*Changed.*
4.3.2	I'm not sure if neuropsychological is the appropriate term here. In this context, it appears to be referring more to psychometric and adaptive functioning assessment. Neuro-psychological and cognitive assessment is not just about developmental level.	*The sentence has been changed to note that it is useful to help establish a profile of strengths and difficulties.*
	Do you think those with asd are insecurely attached or demonstrate attachment differently?	*This is outwith the remit of the selective update.*
	Refer to previous comment re Educational Psychology not generally undertaking assessments for individual profiling.	*This is for a local discussion on implementation.*
	See comments above in section 4.2.2, some of which I think should be repeated here ("I acknowledge that this is covered later on, but as somebody working with adults with LD, one of the most important initial steps is to gather information on the level of learning disability. Before even starting to carry out an ASD assessment. Otherwise features might "score" for ASD (such as need for routine and predictability) when in fact they are in keeping with the person's overall level of development. We don't do/request an IQ test prior to assessment - but personally if the person was not already well known to the LD team, I would carry out a Vineland's to get some sort of baseline. I wouldn't suggest that everybody has a Vineland's before assessment... But it is such a large part of an LD autism assessment that I think that it warrants mention	*Wording in first paragraph amended to cover intellectual disability.*

	right at the beginning. I guess that it goes without saying in children's services that you take their developmental age into account. However, I think that this does need stating for adult LD services as it is so fundamental to a good assessment.	
	Standardised assessments only go some way to picking up strengths and weakness of neurotypical presentations and therefore may miss cognitive strengths or weaknesses (eg visual thinking/monoprocessing) in people with ASD.	*This is acknowledged in the first paragraph of this section.*
	I am not entirely convinced by the argument presented about discrete cognitive assessment necessarily being the only pathway to assist educators and others to appropriately target support. School cognitive and formative assessments are often more appropriate tools for understanding need and targeting support, as it is done from a contextual basis of understanding educative and curricular demands. I do appreciate the wording - 'should be considered for'.	*This is within the context of a clinical healthcare guideline and does not cover tools which may be used in education. The guideline states: Insights from these assessments **may** help to increase understanding and support.*
	In contrast with its importance, this section seems cursory, muddled, and poorly referenced. As mentioned above, there is nothing about how or when intellectual disability should be identified in autism. There is no mention that autistics may show very uneven ability profiles within IQ test batteries, or that different tests of intelligence, while giving equivalent results in typical individuals, may yield very different results in autistics.	*The first paragraph has been slightly reworded to cover what skills should be expected within the context of the individual's ability.*
4.3.3	Appropriate comment.	*Noted, thank you.*
	DSM-5 includes 'sensory interests'	*Noted, but the guideline development group think 'sensory behaviours' is adequate.*
	Occupational therapy and physiotherapy assessments should be considered where relevant. Behaviour analyst assessments should be added to this to be considered where relevant (see NICE, Behaviour Analysts are part of the team).	*This section is on sensory and motor skills so it would not be appropriate to include behaviour assessments here.* *ASD assessment is essentially about establishing the presence or absence of described behavioural signs and symptoms so is covered in other sections.*
	There is extensive evidence for atypical perception in autism, which is not mentioned here. In contrast, the popular view—reflected in DSM-5, and terms like "sensory behaviours"—that autistic senses don't work properly is highly questionable.	*We are citing DSM-5 because it is an internationally recognised classification.*
4.4	Gut problems and food sensitivity.	*This section is taken from SIGN 98 and not included in the literature review for the selective update. It was considered unlikely that there was new evidence that would radically change what is included here.*
	The statement in 4.4 that children with ASD are more likely to be insecurely attached is not correct. There are a number of studies before and after the meta-analysis cited that clarify what is different about the behavior of children with autism in classic attachment paradigms and what is not that reflect a much more complicated perspective.	*This section is taken from SIGN 98 and new evidence has not been reviewed. When agreeing the remit of the update, priority was given to areas where it was considered evidence has changed. The group were not aware of new evidence in this area.*
	I think the evidence for depression (especially in CYP) is more variable/weaker. I really don't want to push our own work but i was surprised amongst the references you had not used the Simonoff et al (2008) JAACAP paper which is the only epidemiological sample on	*This section is taken from SIGN 98 and new evidence has not been reviewed. We cannot include a study without conducting a full systematic search of the literature. This area was not prioritised for update as it was*

	MH...	*not considered likely that there was new evidence that radically changed what is stated in SIGN 98.*
	'Children and young people with ASD have higher rates of epilepsy' Higher than? Perhaps you can say 'elevated'	*Changed*
	In the next paragraph but one, there is an old citation that indicates that children with autism do not have more gastrointestinal problems than other children, but there is newer evidence that is not addressed. I think this is issue is not resolved, but it is definitely less clear-cut than presented here.	*This section is taken from SIGN 98 and new evidence has not been reviewed. When agreeing the remit of the update, priority was given to areas where it was considered evidence has changed. The group were not aware of new evidence in this area.*
	Para 1 sentence 2 is confusing. Are there 2 separate point - clinicians should not assume that their symptoms are inevitable aspects of ASD, and then that features raising query of ASD can occur in other disorders? eg Pooni et al 2012 identified adolescents with eating disorders with high rates repetitive behaviours but not ASD (on 3di). Usual worry is that ASD is missed, but it may be overdiagnosed too	*Separated into two sentences to clarify.*
	Heavily weighted towards children, no adult studies/information.	*This section is taken from SIGN 98. It is noted that these conditions can also apply to adults.*
	A more full statement than previously and very welcome. Locally this is a concern given that we have very little access to Paediatricians, CAMHS, other clinicians as part of the diagnostic process. At times the only healthcare professional on the specialist team is a Speech and Language Therapist.	*Noted. This is a local implementation issue.*
	Para. 5 children with ASD who have not...	*Prefer to keep sentence as it is.*
	I would order these issues to reflect their prevalence in the ASD population and order of importance - sleep is the most common, ADHD would be next and epilepsy third.	*Reordered*
	This section is all about children. I realised once I started to look into this that this was probably because there isn't the evidence in adults. However, I did find a couple of papers looking at the prevalence of mental health problems; Journal of Autism and Developmental Disorders December 2014, Volume 44, Issue 12, pp 3063-3071 Psychiatric Comorbidity and Medication Use in Adults with Autism Spectrum Disorder Tara R. Buck, Joseph Viskochil, Megan Farley, Hilary Coon, William M. McMahon, Jubel Morgan, Deborah A. Bilder 10.1007/s10803-014-2170-2 This was the only prevalence study I could find in adults - didn't say if some had LD. It found increased rates – based on the PAS-AD, which I find in clinical practice overestimates psychiatric illness compared with the original research in which it was found to have very high specificity and sensitivity. But it was at least a genuine population study. Many of the other studies looked at specific populations with ASD - such as people referred to psychiatric services, who unsurprisingly have higher psychiatric morbidity.	*This section is taken from SIGN 98. It is noted that these conditions can also apply to adults.*

	Journal of Autism and Developmental Disorders October 2008, Volume 38, Issue 9, pp 1676-1688 The Prevalence and Incidence of Mental Ill-Health in Adults with Autism and Intellectual Disabilities Craig A. Melville, Sally-Ann Cooper , Jill Morrison, Elita Smiley, Linda Allan, Alison Jackson,Janet Finlayson, Dipali Mantry 10.1007/s10803-008-0549-7 This was another population prevalence study, but only in people with learning disability. It did not show an association between mental illness and autism in this population. I do acknowledge the lack of evidence - but children grow up. Indeed are growing up and hitting adult psychiatric services. So I think it would be helpful to put a little more about adults - even if to acknowledge the lack of evidence and highlight the need for more research.	
	There is not enough emphasis on the importance of follow up appointments to provide the opportunity for parents to describe any changes in the condition and to allow follow up or investigations for co-morbid conditions. I have asked for routine follow ups to be told this is not possible. I have approached my GP each time and had to pursue this myself, causing undue stress.	*This is touched on in section 11.1.1 but it is difficult to go into more detail without a supporting evidence base.*
4.5	Scopes, Blood tests	*It is stated in the guideline that medical investigation should not be performed routinely.*
	Interested to know if your genetics service has agreed to fund ALL females having MECP2 testing—likely to prove expensive! And do you think the evidence good for average and above IQ? If schaefer quoted—many may follow that rather than your recs?	*A new GPP has been added advising discussion with the genetics service on who gets further testing.*
	The citations for the genetic studies range greatly in quality. There are many other papers about these topics of higher quality than the first two citations. These numbers are changing almost on a daily basis. Estimates of proportions of the population of children with ASD who have known genetic disorders are also highly dependent on ascertainment, an issue that is often not addressed in genetic studies. Given how fast estimates change these days, I wonder if the panel wants to state estimates as possible lower limits?	*The Schaefer paper provides an overview of what is a complex and fast developing area. It is the only paper that is included in the Effective Healthcare Programme Technical Brief Number 23 – Genetic testing for developmental disabilities, intellectual disability and autism spectrum disorder – Agency for Healthcare Research and Quality, published June 2015.*
	The genetics bit is, of course, rather controversial. The American College of Genetics is now recommending much more testing as I understand it. Perhaps point out the relevance of genetic testing for family issues (parents and new children and sibs)?	*American College of Genetics cites Schaefer, as we do. An additional GPP has been included advising seeking advice from local genetics services.* *The decision to offer genetic investigation is a clinical one in consultation with the family, with appropriate discussion of the likelihood of the results informing aetiology. This is too wide to discuss further in the guideline.*
	Should there be mention of seeking advice from expert medical colleague and / or clinical geneticist? The recommendation starts by saying 'where clinically relevant', which requires the assessor to make a judgement. Depending on who is doing ASD assessment, knowledge may vary considerably.	*GPP added.*

	Concerned re recommendation for FRAX testing only to be routine in males, and only carried out in females if indicators present, as typical phenotypic features often not apparent in young children.	*Karyotyping has been largely superseded by chromosomal microarray as in Table 1 on page 17 so this has been changed.*
	Excellent addition. Again, this will represent a significant change in direction for our local service, with additional pressures coming to bear on already very limited services. There will be significant training issues for members of our local specialist team in recognising 'where clinically relevant'.	*A new GPP has been added suggesting advice is sought from the local genetics service.*
	Thank you for being clear on how ridiculous some of the biomed stuff is, we need these things stated clearly!	*Noted*
	Although I would agree with Schaefer and Mendelsohn's approach, and the increasing numbers of anomalies being reported using CGH, I wonder if this should be given so much emphasis here given the preceding paragraphs and the limited evidence to date that this will substantively affect management other than a case-by-case basis.	*The guideline group considers the correct balance between excessive and insufficient detail in this rapidly-developing area has been achieved.*
	I think I would add as a good practice point - discuss or refer to local genetics services? Not sure what the rest of Scotland is like, but the Glasgow service have been extremely helpful with adults with possible underlying genetic conditions. We can phone and discuss whether referral is appropriate, then they assess and decide what genetic tests are appropriate. I think that for adult services (who especially in general adult services are unlikely to see many genetic conditions) this might provide a better service than the diagnostic service trying to investigate themselves. Other problem of course is that most ASD diagnostic services do not provide ongoing care and follow up. It might be better for them therefore to signpost host services rather than carry out all of these investigations themselves? (This is probably completely different where a paediatrician is making a diagnosis of ASD - but I think that these comments are fair for adult services.)	*Agree, added.*
	Should the recommendation make it clear who is responsible for making biomedical investigation referrals?	*The team should be responsible for making the biomedical investigation referral.*
4.6	In my view, not updating (and extending) this section is inexplicable, it is an error. The question of prognosis is hugely influential in autism research and practice, and many important papers relevant to this crucial issue have been published during the time of this update.	*This section has now been updated with a new search and a more recent well conducted systematic review has been added.*
	Early joint attention and imitation skills - A better study is Anderson et al (2007; JCCP)	*A new search has been conducted on prognosis which identified new systematic reviews which have been added to sects 4.4 and 4.6, but no strong quality studies which contradicted the evidence already supporting the statement on joint attention and imitation skills.*
	I take a bit of exception here. The problem is that there are several things that go into 'regression' – firstly it is all parent report (with some video evidence at times). Secondly sometimes it is stagnation rather than regression (child has some sounds and parents think a word or two then not much more), sometimes parents do report regression but when you get into it child already had delays in landmarks. Clear cut	*A further search was conducted for regression but no good quality evidence was identified.*

	regression seems very common and certainly after a clearly normal period of development (as in CDD) the outcome is poor. I'd put at least a sentence in here on this.	
General	This is a helpful and pragmatic introduction to interventions, which does not dismiss the impact of individualised approaches and straightforward good practice that has an insufficient evidence base. The complete intervention section (Chapter 6) is a welcome expansion from SIGN 98 and provides some clarity as well as useful and practical information for parents and professionals.	*Noted, thank you.*
	This section is a very helpful one, in acknowledging the two aspects of helpful intervention - promoting skills development, and adapting the environment to support individuals whose skills are insufficient in the situation they are in.	*Thank you*
	For the better wellbeing of the child/adult.	*The focus of the guideline is to improve the wellbeing of the child/adult.*
	'Others are derived from more autism specific considerations such as the difficulty in 'mentalising' experienced in ASD, whereby the individual experiences difficulties understanding the motivations and perspectives of others.[82]' Note sure 82 is the right reference for this...?	*Reference removed.*
	Excellent summary.	*Noted, thank you.*
	In England, the National Institute of Health and Care Excellence (NICE) specifies that there should be a maximum wait of three months from referral to first appointment. This should be included in the SIGN guidance to help ensure that people in Scotland are not waiting too long to access a diagnostic assessment.	*See similar comments in sections 1.1, 2, 2.1 and 4.1.7*
	It may be helpful for readers to insert a brief paragraph about the difficulty of conducting RCT-level research with problems that require individualised interventions. Meta-analysis is possible of smaller-N studies and there are a number of good papers on the child intervention literature in ASD published during the Guideline timeframe. The only such paper cited here is Roth, Gillis, Di Gennaro Reed (2014). I was also a little surprised at the number of reasonable-quality studies within the timeframe used for search that did not seem to have been used in this section. This may be my problem not the guideline groups and these may have been co sided and rejected for good reason, however I should like to know why I was unable to find citation to the following: Aldred, C., Green, J., Emsley, R., & McConachie, H.(2012) Mediation of treatment effect in a communication intervention for pre-school children with autism. Journal of Autism and Developmental Disorders, 42(3), 447-454. Dawson, G., Rogers, S., Munson, J., Smith, M., Winter, J., Greenson, J., Donaldson, A., & Varley, J. (2010) Randomized, Controlled Trial of an Intervention for Toddlers With Autism: The Early Start Denver Model. Pediatrics, 125(1), e17-e23. Dawson, G., Jones, E.J., Merkle, K., Venema, K., Lowy, R., Faja, S., Kamara, D., Murias, M., Greenson,	*Most of these papers refer to KQ8 for which systematic reviews, NICE and the AHRQ guideline were used, rather than individual studies.*

J., Winter, J., Smith, M., Rogers, S.J., & Webb, S.J. (2012) Early behavioral intervention is associated with normalized brain activity in young children with autism. Journal of the American Academy of Child and Adolescent Psychiatry, 51(11), 1150-1159.

Drahota, A., Wood, J.J., Sze, K.M., & Van Dyke, M. (2011) Effects of cognitive behavioural therapy on daily living skills in children with high-functioning autism and concurrent anxiety disorders. Journal of Autism and Developmental Disorders, 41(3), 257-265.

Fava, L., Strauss, K., Valeri, G., D'Elia, L., Arima, S., & Vicari, S. (2011) The Effectiveness of a Cross-Setting Complementary Staff- and Parent-Mediated Early Intensive Behavioral Intervention for Young Children with ASD. Research in Autism Spectrum Disorders, 5(4), 1479-1492.

Goods, K.S., Ishijima, E., Chang, Y-C., & Kasari, C. (2013) Preschool Based JASPER Intervention in Minimally Verbal Children with Autism: Pilot RCT. Journal of Autism and Developmental Disorders, 43(5), 1050-1056.

Ingersoll, B. (2012) Brief report: effect of a focused imitation intervention on social functioning in children with autism. Journal of Autism and Developmental Disorders, 42(8), 1768-1773.

Ingersoll, B. (2010) Brief report: Pilot randomized controlled trial of reciprocal imitation training for teaching elicited and spontaneous imitation to children with autism. Journal of Autism and Developmental Disorders, 40(9), 1154-1160.

Kasari, C., Gulsrud, A.C., Wong, C., Kwon, S., & Locke, J. (2010) Randomized controlled caregiver mediated joint engagement intervention for toddlers with autism. Journal of Autism and Developmental Disorders, 40(9), 1045-1056.

Keen, D., Couzens, D., Muspratt, S., & Rogers, S. (2010) The effects of a parent-focused intervention for children with a recent diagnosis of autism spectrum disorder on parenting stress and competence. Research in Autism Spectrum Disorders, 4(2), 229-241. Kenworthy, L., Anthony, L.G., Naiman, D.Q., Cannon, L., Wills, M.C., Luong-Tran, C., Werner, M.A., Alexander, K.C., Strang, J., Bal, E., Sokoloff, J.L., & Wallace, G.L. (2014) Randomized controlled effectiveness trial of executive function intervention for children on the autism spectrum. Journal of Child Psychology and Psychiatry executive function intervention for children on the autism spectrum. Journal of Child Psychology and Psychiatry, 55(4), 374-383.

Koenig, K., White, S.W., Pachler, M., Lau, M., Lewis, M., Klin, A., & Scahill, L.(2010) Promoting social skill development in children with pervasive developmental disorders: a feasibility and efficacy study. Journal of Autism and Developmental Disorders, 40(10), 1209-1218.

Landa, R.J., Holman, K.C., O'Neill, A.H., & Stuart, E.A. (2011) Intervention targeting development of socially synchronous engagement in toddlers with autism spectrum disorder: a randomized controlled trial.

	Journal of Child Psychology and Psychiatry, 52(1), 13-21. Landa, R.J., & Kalb, L.G. (2012) Long-term outcomes of toddlers with autism spectrum disorders exposed to short term intervention. Pediatrics, 130(Suppl 2), S186-190. McNally Keehn, R.H., Lincoln, A.J., Brown, M.Z., & Chavira, D.A. (2013) The Coping Cat program for children with anxiety and autism spectrum disorder: A pilot randomized controlled trial. Journal of Autism and Developmental Disorders, 43(1), 57-67. Peters-Scheffer N, Didden R, Mulders M, et al. (2013) Effectiveness of low intensity behavioral treatment for children with autism spectrum disorder and intellectual disability. Research in Autism Spectrum Disorders, 7(9), 1012-1025. Reaven, J., Blakeley-Smith, A., Culhane- Shelburne, K., & Hepburn, S. (2010) Group cognitive behaviour therapy for children with high-functioning autism spectrum disorders and anxiety: a randomized trial. Journal of Child Psychology and Psychiatry, 53(4), 410-419. Roberts, J., Williams, K., Carter, M., Evans, D., Parmenter, T., Silove, N., Clark, T., & Warren, A. (2011) A Randomised Controlled Trial of Two Early Intervention Programs for Young Children with Autism: Centre-Based with Parent Program and Home-Based. Research in Autism Spectrum Disorders, 5(4), 1553-1566. Schreibman, L., & Stahmer, A.C. (2014) A Randomized Trial Comparison of the Effects of Verbal and Pictorial Naturalistic Communication Strategies on Spoken Language for Young Children with Autism. Journal of Autism and Developmental Disorders, 44(5), 1244-1251. Storch, E.A., Arnold, E.B., Lewin, A.B., Nadeau, J.M., Jones, A.M., De Nadai, A.S., Jane Mutch P., Selles, R.R., Ung, D., & Murphy, T.K. (2013) The effect of cognitive- behavioural therapy versus treatment as usual for anxiety in children with autism spectrum disorders: A randomized, controlled trial. Journal of the American Academy of Child & Adolescent Psychiatry, 52(2), 132-142. Ung, D., Selles, R., Small, B.J., & Storch, E.A. (2015) A Systematic Review and Meta-Analysis of Cognitive-Behavioural Therapy for Anxiety in Youth with High-Functioning Autism Spectrum Disorders. Child Psychiatry & Human Development, 46(4), 533-547. Strauss, K., Vicari, S., Valeri, G., D'Elia, L., Arima, S., & Fava, L. (2012) Parent inclusion in Early Intensive Behavioral Intervention: the influence of parental stress, parent treatment fidelity and parent-mediated generalization of behaviour targets on child outcomes. Research in Developmental Disabilities, 33(2), 688-703. Sung, M., Ooi, Y.P., Goh, T.J., Pathy, P., Fung, D.S., Ang, R.P., Chua, A., & Lam, C.M. (2011) Effects of cognitive behavioural therapy on anxiety in children with autism spectrum disorders: a randomized controlled trial. Child Psychiatry and Human	

	Development, 42(6), 634-649. Williams, B.T., Gray, K.M., & Tonge, B.J. (2012) Teaching Emotion Recognition Skills to Young Children with Autism: A Randomised Controlled Trial of an Emotion Training Programme. Journal of Child Psychology and Psychiatry, 53(12), 1268-1276. Wood, J.J., Drahota, A., Sze, K., Har, K., Chiu, A., & Langer, D.A. (2009a) Cognitive Behavioural Therapy for Anxiety in Children with Autism Spectrum Disorders: A Randomized, Controlled Trial. Journal of Child Psychology and Psychiatry, 50(3), 224-234. Wood, J.J., Drahota, A., Sze, K., Van Dyke, M., Decker, K., Fujii, C., Bahng, C., Renno, P., Hwang, W-C., & Spiker, M. (2009b) Brief Report: Effects of Cognitive Behavioral Therapy on Parent- Reported Autism Symptoms in School-Age Children with High-Functioning Autism. Journal of Autism and Developmental Disorders, 39(11), 1608-1612.	
	We recommend that the guidelines do not use the word 'treatment' in relation to autism. 'Interventions' is a neutral general term which covers both pharmacological and non-pharmacological interventions. Greater emphasis in the guidelines is needed on ensuring appropriate person centred and non-pharmacological intervention and approaches to support. This relates to both children and adults. We are also concerned that the guidelines do not sufficiently highlight risks associated with the use of drugs in uncontrolled settings when there may be unpredictable or atypical responses from some individuals.	*Wording changed to interventions.* *The risks associated with the use of drugs in uncontrolled setting is highlighted. It is noted in the guideline that there are requirements to be clear about the outcome, offering drugs short-term, noting that they do not address the core difficulties of ASD and the need to only use them without appropriate expertise.*
	As a general comment it appears that the importance of the environment and environmental adaptations is an area for further consideration as opposed to the focus on skill development. There are many books written by people with ASD (Dona Williams/Temple Grandin to name a few) and clinicians/practitioners working with people with ASD.	*Noted, but this is outside the remit of the evidence-based guideline.*
	This section is very weak, all the more so considering the longstanding problem of poor quality autism intervention research, and of standards being lowered for autistics to accommodate this poor quality literature, and generally of standards being far lower for autistics in intervention research (and practice, and guidelines) than would be acceptable for anyone else. This section does not convey basic information about fair test of interventions. It does not convey the basic principle that interventions should be fairly tested before they are widely promoted and disseminated, nor that this has rarely happened in autism, even - or especially -with the most fanfared, expensive, lobbied-for interventions. This section (and the guideline as a whole) provides no avenues or resources for individuals who want to inform themselves about fair tests of interventions, and about basic standards in intervention research, and who want to become literate in clinical trials (possibly one of the most important skills for anyone concerned about the wellbeing of autistics).	*We have to work with the evidence that is available The recommendations are conditional which reflects weaknesses in the evidence base.* *British Association of Childhood Disability is aware of a piece of work being undertaken with the James Lind Alliance and Autistica identifying research priorities in autism spectrum disorder between researchers and the affected communities that should be reporting quite soon.*

	In much of the autism literature, and in many autism guidelines, the term "evidence-based" has been undermined by extremely low or non-existent standards of evidence. So invoking this (weakly-sourced) term does not help anyone make better decisions, and it may do the contrary. Suggested free resource on fair tests (there are many others): The James Lind Library http://www.jameslindlibrary.org	
6.1	Diet, Therapy after the diagnosis such as PTSD Therapy.	*Nutritional interventions are discussed in section 6.4. Psychosocial therapies are discussed in 6.3.*
	1st sentence. Ref 82 is the wrong reference here.	*Removed*
	I know this is summarising Helen's Cochrane review but I was surprised this section was so short (e.g. compared to the PECS section below) - given the amount of studies. Also since the review there have been further Kasari and Wetherby large RCTs (both in Pediatrics)	*This section was not subject to a full literature review in this update, but updated with the updated version of the Cochrane Review previously cited. Adding further references is outwith the remit of the selective update.*
	As evidence is all re children I was unsure why PMI 'should be considered for all children and young people'. Feasibility of PMI with adolescents would need demonstrating!	*There are interventions for adolescents, eg Peers programme.*
	Appropriate.	*Thank you*
	I commend the team on the clear focus on the importance of involving parents, particularly with regard to their young children. There should be more emphasis, however, on the need to offer good quality behavioural parent training to ensure that parent mediated intervention programmes are of high treatment fidelity and based on evidence (Lamb, 2010). Our research has shown that parents are often better informed than professionals about evidence-based interventions, particularly those based on applied behaviour analysis (K. Dillenburger, Keenan, Doherty, Byrne, & Gallagher, 2010). An increasing number of parents now train formally in this science, e.g., our Open learning course (based on www.bacb.acm/rbt) attracts over 80 students per year, many of them parents. Many parents now train to become fully Board Certified Behaviour Analysts (www.bacb.com), (Barbera, 2007), which means that unless professional also hold this Masters level qualification, they will not be able to keep up.	*Participants need appropriate skills and training according to the protocols used in the original research. A statement to this effect has been added to Section 5.* *Training for parent is covered in section 10.1*
	There is not enough emphasis on the importance of supporting parents throughout the child's lifetime. This is a lifelong disability, but following diagnosis there is not much support offered to the care giver. Ultimately it is the parent who will deliver any techniques learned or implement any training they receive. To do this they need to have their stress levels assessed and offered support. Early links with social work is essential to try and take away some of the burden of caring to allow the parent to become an autism specialist, and learn how to cope with their child's condition.	*Noted. Support for parents is covered in sections 10 and 11.*
	The 1++ level evidence which is high quality with low risk of bias is inconsistent with paragraph 2 of section 6.1 which states that a Cochrane review reported inconsistent and inconclusive results with risk of bias.	*The 1++ reflects how well the Cochrane review was conducted and therefore how reliable their conclusions are.* *Wording has been changed to make this*

		clearer.
	In the first paragraph, ref 82 is irrelevant; and ref 122 appears not to be from the literature, but from a service provider, obviously not a good source. The most important paper in this field, a large well-designed - by autism standards - multi-site RCT (Green et al., 2010), is not cited. Green, J., Charman, T., McConachie, H., Aldred, C., Slonims, V., Howlin, P., & PACT Consortium. (2010). Parent-mediated communication-focused treatment in children with autism (PACT): a randomised controlled trial. The Lancet, 375(9732), 2152-2160.	*Ref 82 removed. Reference 122 is from SIGN 98. It is providing background information rather than supporting a recommendation.* *The Green paper has been picked up in the additional search and is now included.*
6.2.1	PECS.	*PECS is covered in this section.*
	Welcome recommendation that interventions should be informed by effective assessment.	*Noted, thank you.*
	Picture Exchange Communication System. 'It is easy to implement as children do not need to master pre-requisite skills such as eye contact or gestures'. You omit to mention here other prerequisite skills without which, PECS is a non-starter. A child needs to understand the concept of picture-object correspondence, he or she needs to be able to observe and copy simple motor actions, and also needs to be able to co-operate and comply. My son had none of these skills (see my comments under 6.3 below), but it was possible to teach them with enough time and practice, using discrete trial teaching. This took many months, and it required an experienced ABA professional to first identify all the underlying deficits which prevented him from making progress, and then successfully address them. Today, many years later, my son still uses a similar system to communicate, but it is now an app on an iPod touch which has been customised to work very much like PECS. In summary, PECS may not be easy to implement, especially for the most severely affected individuals who most need it, and you may need a very highly skilled person to do it. A child who hasn't got the prerequisite skills for PECS may well be making little or no progress in other developmental areas. There may not be a high proportion of children with autism who fit in to this category, but I would expect everyone on the guideline development group to have come across them. Without specialist ABA help they are likely to have a very poor outcome, consume vast financial resources in terms of care over their lifetime, and live in conditions, perhaps in hospital, causing much distress to them and their family.	Changed to: "Individuals learning PECS do not need to master prerequisite skills such as eye contact or gestures [125] and PECS can be used with children with or without intellectual disability.[125, 126]" *A statement has been added to section 5 regarding training levels.*
	Excellent.	*Thank you*
	Sign isn't included as a support - see Goldstein 2002, JADD, volume 32, issue 5, pg 373 for a review of communication intervention for children with autism.	*Sign has been added:* '*Visual supports may be objects of reference, photographs, picture symbols, **signs** and gestures and may be displayed in a variety of ways, including using electronic technology.'*
	"Alternative/augmentative communication" often means text to speech devices, or generally the use of text (rather than speech) to communicate. There is no mention of text here, and reducing AAC to "visual supports" is inaccurate. No literature (only a book) is cited re "visual supports."	*We do say that visual supports may be displayed in a variety of ways and do not exclude "text".*

	The PECS section is very weak, based entirely on two papers, one of which involves only single case designs (ref 127) and was accepted so rapidly it is unlikely to have been properly peer reviewed (per Johnny Matson's editing practices in RDD, at that time). The other (ref 126) suggest very modest, very limited results from a small number of group designs. Note also that picture symbols are not how everyone communicates, because they are far too limited as well as difficult to use (as are isolated "signs" which may be taught to autistics by therapists who do not know sign language). That autistic children can learn PECS suggests their cognitive abilities are underestimated, but it's unclear why autistics should be required to work so hard to achieve such limited communication. This is not demanded of typical children. Under "Environmental visual supports" ref 128 is irrelevant, the rest of the references are collectively unimpressive and seem haphazard. Why cite such poor quality evidence? The recommendation on visual supports is very poorly supported by the provided evidence.	*The grading of the literature as "3" reflects this.* *This is the evidence that is available and the level 3 reflects its quality.* *Recommendation is conditional, not strong.*
	The recommendation that interventions to support communication in children and young people should be informed by effective assessment is very sensible, but not supported by any research presented. Perhaps something could be said earlier that leads up to it, even if clinical consensus is then cited?	*This is a good practice point, which signifies that it is the consensus of the guideline development group.*
6.2.2	PECS.	*PECS is discussed in 6.2.1*
	Above you labeled Helen's as Cochrane so I would do the same here...	*Amended*
	Recommendation refers only to 'communication' - focus is presumably intended to be use of communication socially (or similar).	*Changed to 'social communication'.*
	As above, welcome interventions being individualised.	*Noted*
	Appropriate.	*Noted*
	When reading this section I was thinking some of Whalen & Schreibman work on Joint Attention training was reviewed as there was a RCT conducted on this. See, Whalen & Schreibman (2003). Joint attention training for children with autism using behaviour modification procedures, Journal of Child Psychology and Psychiatry, Volume 44, Issue 3, pages 456–468. Connie Kasari, Stephanny Freeman & Tanya Paparella(2006). Joint attention and symbolic play in young children with autism: a randomized controlled intervention study. Journal of Child Psychology and Psychiatry Volume 47, Issue 6, pages 611–620, June 2006.	*This was outside the remit of the selective update.*
	This section is mixed in both quality and content, and includes very poor quality reviews (e.g., involving meta-analysis of small poor quality studies) as evidence.	*It reports the evidence that is available and flaws/quality of the evidence is noted.*
6.3	This is my background and experience, and why I wish to comment on this section: I have an 18 year old son with diagnoses of autism, severe learning disability, epilepsy and hyperacusis. Additionally he has	*It is helpful for the guideline group to hear about individual experiences and to learn about the impact that guidelines can have on individuals and families. However, the*

	persistent problems with both short term and long term memory. He also can also present with challenging behaviour. Nevertheless, as he enters early adulthood, I feel that he has reached his potential, and he leads a busy, physically active and very happy life, and has acquired many functional skills which enable him to be a useful member of his community. He is making saleable goods in sheltered workshops, so we achieved our long term goal that he would be capable of doing meaningful work. I attribute this success entirely due to the fact that he benefited from an ABA-based educational intervention. I am a qualified and experienced teacher, and I ran here in Scotland an ABA-based educational programme for my son, with a team of trained tutors for 16 years, from 1999 to 2015. The programme was professionally supervised by board certified behaviour analysts, professionals properly qualified and experienced in ABA. It was fully funded by my local authority, which eventually accepted the case that this was a cheaper and better alternative to his attending residential school. I presented figures to demonstrate that it would cost around 8 times as much money to send him to an autistic specialist residential school in Scotland. The original idea was for the programme to run for 2 or 3 years, by which time my son, we hoped, would be able to learn independently. But he had been regressing in many developmental areas before we began, and it quickly became clear that such were his needs, and his difficulties retaining even the most functional of skills, that there would be a serious regression if we stopped. So, we kept going. It was very successful longer term intervention. My son continued to make real progress, to maintain what he had learned, and gain new skills and independence by small steps, right up in to adulthood. My son attended local schools part time - mainstream nursery and primary school to start, and then later, special secondary school. He was accompanied at all times by trained ABA tutors at school (by agreement with head teachers and the local authority), he was taught one to one by them at home, and they took him out and about on community trips. Because of the severity of my son's needs, the ABA programme was individualised and tailored to meet his needs to a very high degree. It concentrated on practical functional skills and basic communication, generalisation and maintenance of skills and it never went anywhere near abstract concepts such as self-monitoring or theory of mind. He lost none of his diagnoses. But he made the most valuable and life enhancing progress. There were very many examples of good co-operation with this ABA programme from other professionals such as speech and language therapy, teaching staff, head teachers, educational psychology, clinical psychology, audiology, paediatricians, psychiatry, learning disability nursing service and social workers. Nevertheless I also met many professionals who did	*guideline recommendations must be based on objectively appraised evidence from generalised trials.* *We tried to make a clear distinction between ABA (which has widespread applications at low and high intensity) and intensive behavioural and developmental programmes which have erroneously become known as "ABA for Autism". It is possible that we weren't sufficiently clear however, so we have given this more emphasis. While you may not have come across any schools offering EIBI, this won't mean that ABA-based approaches weren't available. While the evidence suggests clear advantages of ABA techniques and principles across a wide range of intervention categories covered in the guideline, we concluded that the evidence for intensive behavioural and developmental programmes required further research, about cost effectiveness among other areas, before it can be recommended for children with ASD.* *Nonetheless, the guidelines group were encouraged by the many good practice examples and descriptions of multi-agency collaboration you describe. We were sorry you have met professionals who you feel haven't been supportive, but we note that this would not necessarily have been out of step with previous guidelines. This is a rapidly changing area of need.* *Ultimately, our focus is to ensure that all children can benefit from the kinds of outcome you describe.*

	not support ABA, and a familiar pattern emerged – they always refused my invitation to come and see it in action, tried to put obstacles in our way, and some of them even tried to intervene to end funding for the programme. Those professionals who did come to observe the teaching in action, without exception, liked what they saw, and often fed ideas in to the programme from their own professional specialism, much to my son's benefit. I would like other children to benefit in the future from ABA-based intervention, as my son did. I ran the home based programme myself as there was no realistic alternative, and I felt that he really needed this intervention. But I do not think that home programmes like this are the general solution to ABA provision in Scotland. Rather, Health, Education and Social services should provide ABA-based intervention, ideally nursery and school provision, for those who need it and can benefit. In the United States, ABA-based interventions for autism are regarded as medical interventions and paid for by health insurance. In England Wales and Ireland they have more often been regarded as educational interventions and paid for by Education services. I considered moving South of the border to try to get my son in to one of the excellent ABA schools there (many are OFSTED rated 'Outstanding' in every category). But financial concerns made this very difficult (I am not wealthy – my husband is a civil servant and I have not been in paid employment in recent years in order to run my son's programme on a daily basis). I was concerned that we might uproot the family but still not get a place at an ABA school. However I know two families who did leave Scotland for this reason and did get an ABA-based school education for their children.	
	Appropriate.	*Noted*
	There is no section 6.5 (range of other behavioural/psychological interventions which do not fall readily into the other two groups) included in the draft I downloaded from link as per bullet point 3 in this section.	*Reference to 6.5 removed.*
	Firstly the guideline states under section 6.3 - 'Behavioural and Psychological intervention' a reference to section 6.5 for further details - however there is not a section 6.5. If a section has been accidentally missed out then this might be the section that the next few points refer to i.e. family therapy or family support. There is not very much information about family intervention or comment on the enormous impact raising and supporting a child with ASD can have on the family and its individual members i.e. systemic impact on family life - and what supports would be indicated. There is a limited family therapy literature on this - there are several papers from the US that comment on Family Therapy to support parents of children with autism spectrum disorders.	*Reference to 6.5 removed.* *We recognise that it is difficult to manage. Later sections of the guideline highlight this but lack of evidence makes it difficult to provide substantial comment.*

6.3.1	3rd paragraph - ‘whilst such principles have been applied widely in community, hospital and educational settings for many years…..they are not typically provided at a high intensity.’ I assume you mean behavioural principles here, as it is mentioned in the context of EIBI? If that’s the case, I don’t think it is true that such principles have been applied widely at all - at any intensity. I went to look at a large number of specialist autistic schools and units, catering for more severely affected children (as my son is in this category) in Scotland’s central belt. I never saw at any time anything I recognised as teaching based on behavioural principles being used. That is what I was looking for, and if I had found it, my son might have gone there and I could have abandoned his ABA programme. Most of the time, nothing educational seemed to be happening, with challenging behaviour preventing meaningful activity, or children simply engaged in sensory-seeking behaviours. Staff quite often seemed to be afraid to place any demand on a child, in case it set off a bout of challenging behaviour. If you mean other principles here, and not behavioural principles, it needs to be re-worded. But then I don’t understand what it means. I am concerned that you think the knowledge and expertise required to do ABA-based teaching is already here in Scotland, waiting to be accessed – and I do not think that it is. Paragraphs 4,5,6,7. From my understanding of the research base, I broadly agree with your description and assessment of the evidence, and its limitations, here. This is the first official British guidance that I am aware of that has come to a clear and positive conclusion about the benefits of ABA-based interventions for autism. SIGN should be highly commended for leading the way here. As your specialist review panel now includes academics in this field, I will leave detailed comment on the research base to them. With the exception of references to intensity, upon which I would like to comment. Quoting directly from the paper you reference here 143 ‘A growing evidence base suggests that some children receiving early intensive behavioural and developmental interventions (e.g., many hours of intervention a week over the course of 1–2 years) show substantial improvements in cognitive and language skills over time compared with children receiving low-intensity interventions, community controls, and eclectic non-ABA based intervention approaches'. ‘Children receiving low-intensity interventions have not demonstrated the same substantial gains as seen in the early intensive intervention paradigms regarding cognitive and adaptive skills’. So I think that this paper supports the idea that	*Yes, we were referring to behavioural principles, or ‘ABA’ as distinct from (but underpinning) EIBIs.* *We agree that EIBI programmes have not been implemented widely in Scotland, but this does not mean that broader ABA principles are not informing practice across a range of clinical, educational and social care settings. The guidelines group was made up of a representative range of professions, covering a range of services and settings, and on balance we feel that our comments are fair. This does not mean that there isn’t work to do and significant improvements do need to be made, but we are not in a position to comment on service quality. In view of reviewers’ comments, we have formally stated that evidence-based treatments should be delivered by personnel with the appropriate skills and training (section 6.3), and we expect a high standard from clinicians and services in response to the guideline and recommendations. We also suggest a number of audits and further research that can contribute to driving service quality.* *The comments regarding intensity have been considered, and we agree that this paragraph was unclear. We did not want to imply that there are no benefits of additional intensity, but that the extra benefits that have been shown are unclear and inconsistent. Some papers do show benefit of high intensity over low – some for IQ, others for adaptive function, some find a weak link between intensity and outcome but not a statistically significant one.* *What we wanted to emphasise is that while we weren’t recommending universal EIBI, this should not be interpreted as meaning that ABA is ineffective – just that the higher intensities of EIBI are not yet unequivocally justified. Again, it is important to distinguish between EIBI at different intensities and ABA.* *We have clarified the overall structure of our summary so that our conclusions and the reasoning behind them are more obvious.* *The points about the availability of ABA professionals, ABA units and ABA schools cannot be addressed by the guideline group. However, in response to the reference to the lack of EIBI professionals, EIBI schools or EIBI units, we would not expect these to be available on a statutory basis given that previous guidelines have not recommended such an approach. This guideline has stated that we cannot recommend it either, but we very much hope that people do not make the erroneous assumption that we are*

	intensity is important. Similarly you say ‘It is not clear how much extra benefit is gained from increasing intensity’, but looking at the paper you reference here 150, no studies consisting of ABA-based interventions below 10 weekly hours and 45 weeks duration were considered for inclusion. So this represents the very lowest intensity considered by this paper, and that is still a lot of hours of intervention. Again this supports the idea that intensity is important. You cannot, I feel, use this paper to support the idea that, in fact, intensity does not matter. Paragraph 8 - I do not agree with the content of this paragraph, and I wish to make a number of points: 1. ‘In Scotland practitioners with comprehensive ABA skills are not widely available outside certain branches of clinical psychology..’ Are there any Scottish clinical psychologists with comprehensive ABA skills? I do not know that any examples exist. If they do, why are these professionals not practising and offering comprehensive ABA-based interventions to help people with autism? If they have some training in behaviour analysis but they are not actually using it, then surely they cannot have the necessary experience to be skilled in delivering it. There are no schools or units or clinics which use comprehensive ABA-based interventions for autism in Scotland. There are no publicly funded home based ABA programmes in Scotland either, now my son’s programme has ended. There are a very small number of privately funded programmes organised by families themselves, often with restricted hours wrapped around school attendance. When I started my son’s ABA programme in 1999, there were very few people in the UK qualified and experienced in ABA – and I got together with other families in Scotland to fly in such a person from the USA. Over time, board certified behaviour analysts (BCBA) began to appear South of the border and in Ireland, but for many years, there was no one in Scotland. Even now there are only 4 BCBAs in Scotland and one (lesser qualified) BCABA. See the international Behavior Analyst Certification Board register http://info.bacb.com/o.php?page=100155 2. ‘…but health, education and social care staff can access training to support children with communication difficulties which will involve ABA competencies, such as task analysis, shaping, fading or functional analysis…’ I have a number of worries about the training mentioned here. What training is this, and who is to provide it? What qualification, experience, knowledge and background do the trainers have? Who will prioritise and select the most functional and relevant achievable targets for an individual child? Who will give ongoing support and supervision and problem solve when a child gets stuck, leaps ahead, regresses or fails to make progress? Who will work to ensure learned skills are generalised and made functional in the child’s everyday life – without which, skills may be quickly lost?	*concluding that ABA is not effective. If in the future the evidence-base does justify a wider recommendation of EIBI, then we would hope to have at that point, clearer knowledge of which professionals should be involved in making treatment decisions and then in delivering and/or supervising delivery of the approach. Until such a recommendation is made it would be premature to comment on professional competences and professional regulation issues. We have made it clear that whatever programme a professional is delivering, whether medical or psychosocial, their professional body will expect them to have the appropriate training.* *In this light, we share your concern about service standards and competences. However, our role as a guideline group is to assess the evidence for what works and present this to a multi-agency audience. We appreciate your examples, which highlight the crucial nature of integrated working across agencies.* *We agree that the way an ABA programme is constructed needs to be carefully considered and not implemented in bits and pieces or “chunks”. However, it is not the case that the only way to provide ABA is via intensive and comprehensive programmes. We cannot recommend EIBI widely because the data doesn’t yet justify this, but in the meantime there are other forms of ABA which are not so comprehensive or intensive. It would not be appropriate to rule out all applications of ABA on the basis of conclusions about the most intensive variant (EIBI).* *Finally, we anticipate that it may take some time for services to look at these guidelines and consider their staff training and competence frameworks. Each agency (health, education, social care) will have different priorities, but we are now all operating under the same Autism strategy, with a national ASD competency framework to guide developments. The guidelines group hope that service users, services and professionals will find our guidance on the evidence base helpful to them in seeking high quality support for individuals with ASD.*

	ABA-based intervention for autism is not made up of a collection of discrete chunks, which can be applied competently in isolation from each other without a proper understanding and appreciation of the underlying principles. ABA's great strength is its potential for individualisation to a child's very particular needs, and you just can't do that with a superficial knowledge of a collection of techniques described in isolation like this. You need properly qualified and experienced BCBAs to assess children and have frequent direct contact with then, and deliver training to and supervise people working with them. 3.'Specific ABA programmes such as PECS may be supported locally by speech and language therapists, psychologist and others.' As I said before, PECS may not be easy to implement, particularly with the groups of children who need it most. I am concerned that many speech and language therapists (SALTS) and psychologists are not sufficiently well trained or experienced to do this with more severely affected children. Behaviour Analysis is a fast moving science. It has changed and expanded in scope and techniques a great deal from the early days of my son's programme back in 1999. We incorporated newer techniques when they came from the early days of my son's programme back in 1999. We incorporated newer techniques when they came onstream, such as the Verbal Behaviour teaching manding (requesting) as a priority, and Errorless Teaching, but these approaches would have benefited my son much earlier on had they been available. Behaviour analysis will continue to improve and develop, and you need to have properly qualified people – board certified behaviour analysts - who must necessarily update their skills with the obligation to continue professional development in order to keep their registration. It's not good enough to have someone trained in another branch of psychology trying to practice this science. 4. 'There is also a lack of research into long term follow-up on treatment effect' I agree that this is the case and that it should be said. But it should also be said about every other intervention in the draft document. It is odd to single out Intensive behavioural and developmental programmes for comment in this way – it implies other interventions have benefited from research in to long term follow up, when it is my understanding that they have not. 5. R 'All children with autism spectrum disorders should have access to support from staff trained in applied behaviour analysis-based technologies (eg Picture Exchange Communication System, discrete trial training, task analysis, prompting, fading, shaping) to build independence in adaptive, communication and social skills. This does not need to be high intensity'. This is a bold and positive statement, and SIGN should be congratulated for making it. Nevertheless I must address several problems. I'm worried here about the 'staff trained in applied behaviour analysis-based technologies'. Are these the people who have accessed training courses in separate ABA competencies, described in the	

	paragraph immediately above the R statement? ABA-based intervention for autism does not work like that. For example, discrete trial training. No one can go on a stand-alone course on this, and then go back and implement it to benefit children. It’s not as easy or straightforward as that. One able child may not need discrete trial training at all, but rather benefit straight away from Natural Environment Training (which is where you hope discrete trial training will ultimately lead). Then, even if discrete trial training is appropriate, it will look very different for different children. For example, a bright four year old who cannot read, but is making good progress; and an 18 year old with severe learning difficulties who can read well, but is continually confusing similar stimuli and making slow progress. (In the latter case, my own son, a specific discrete trial format was devised which involved matching large sets of non-identical pictures of 2 confused stimuli to written labels. The written word ‘stuck’ in his memory more easily than the spoken word, and this emerged as the most efficient way to teach new language and resolve confusions, and also maintain language long term). You need properly trained, qualified and experienced behaviour analysts to implement ABA-based technologies, if children are to benefit. It reads to me as if you would like to break ABA in to bite-sized chunks, which might fit in, here and there, with the standard eclectic provision for autism widely available already in Scotland. But that is not what the body of research supports, at all. The children in the research studies who made that measurable progress have each benefited from many ABA-based technologies over the duration of the intervention, some of which you have listed but others which you have not. ‘This does not need to be high intensity’. As explained earlier, I do not think that the existing research base supports the idea that intensity is not important. The jury may be out on the ‘optimum’ level of intensity, but in practice, the level of intensity required should be determined on an individual basis by a trained and experienced professional. This is consistent with GIRFEC. You are implying here that low intensity is just fine, and set no lower limit. This may be convenient and much easier and cheaper to implement, but it is not an evidence-based recommendation. This sentence should be omitted. Under Good practice points, I agree with the first sentence here. But I have comments on the next one: ‘They should be overseen by professionals trained in the psychological theory and in child development, who are regulated by a professional body such as the Health and Care Professions Council’. You say ‘professionals trained in the psychological theory’. Do you mean behaviour analysis here, as ‘the psychological theory’? If so, you should make it clear and say behaviour analysis. If not, then exactly what psychological theory do you mean?	

	Certainly I agree with training in child development. But more than this, to be a competent practitioner and deliver good ABA-based interventions, a behaviour analyst must have extensive up to date knowledge and practical experience in the field. The Behaviour Analysis Certification Board (BACB, http://bacb.com/) registration ensures that this is the case, or registration is lost, which is why I think you should stipulate board certified behaviour analysts here. '…who are regulated by a professional body such as the Health and Care Professions Council'. I agree with this – all such professions should be regulated, in order to protect patients and clients. It is my understanding that the United Kingdom Society for Behaviour Analysis (UK-SBA, http://uk-sba.org/) has been applying to the Health and Care Professions Council for a number of years. However, the HCPC are not accepting new applications, from behaviour analysts or indeed any other recently developed health and care professions. This presents a problem – the world moves on at a rapid pace, and new professions develop, whilst others disappear, and this arrangement seems not to take account of that. However that is the situation at present, and so regulation of behaviour analysts must pass to the BACB. I do not think those with autism should be denied effective intervention and suffer because the HCPC is not accepting new applications. The BACB can and does revoke or suspend certification for behaviour analysts, following investigation of complaints.	
	ABA should not be promoted. Parents requesting this should be given the full range of information, including the detrimental effects as described by adults who have been through ABA.	*The research that was considered by the group showed no evidence of detrimental effects. We are aware of anecdotal concerns that have been expressed, but these tend to be about very early programmes (such as the Lovaas model). Many of these reports actually referred to other work done by that team, such as their work with severely institutionalised individuals rather than their EIBI for pre-school children.* *The objective data shows a clear benefit from these methods over treatment as usual and we need to recommend that the approach receive further attention.* *We agree with you that parents should have access to the full range of information about all the approaches that they may come across, and this is advocated in section 11.*
	I like the emphasis on behavioral skills in practitioners and the comment that high intensity not necessary—all nicely written but is that considered part of core training for any psychologist? It surely should be, discrete trials functional analysis etc problem with PECS is usually in implementation—not taught properly and assumption made that it is just the other side of TEEACH!	*Agree, but the guideline cannot comment specifically about the training of any health professional.*
	ESDM (and Sally R) is always very clear it is behavioural and developmental (in fact she uses the term 'relationship based')	*Emphasis to the developmental nature has been added.*

	‘Only one systematic review concluded there was no impact.[149] This may be due to the inclusion of a study which compared high-intensity clinic-based ABA with high intensity parent-delivered ABA.’ I don't agree with this (it was not down to one study) - It simply set a higher threshold (as did NICE).	*It wasn’t their threshold that we have an issue with, but the validity of their conclusions. Spreckley and Boyd’s paper concludes that “there is currently inadequate evidence that ABI has better outcomes than standard care”. To reach this conclusion, they reviewed 4 studies providing 3 separate datasets (one was a follow-up providing longer-term outcomes). The review isn’t clear about how to differentiate EIBI from more generic ABI, describing ABA as an approach developed by Lovaas. Perhaps for this reason, they include studies with intensive programmes in their control groups (the four comparison groups received 5, 16, 29 or 31 hours a week), making it hard to see how they can draw conclusions about the outcomes of ABI compared to standard care. One included study in particular contaminated their conclusion given that it was comparing intensive clinic-directed ABI with intensive parent-directed ABI. This was pointed out in a recent Cochrane review (Reichow et al., 2012). The study showed that both parent and clinic-directed EIBI led to improvements, but the lack of difference between the two treatment groups clearly dilutes the positive outcomes produced by the other two studies contributing data to Spreckley and Boyd’s meta-analysis (see figure 2). Their data therefore doesn’t support conclusions comparing ABI with standard care.*
	GPP Why is this point made in this section and not elsewhere. Yes, obviously I know why but to naive (impartial?) it seems uneven...?	*A more general point has been added to section 5 so this GPP has been removed.*
	Agree it does NOT have to be of high intensity but SHOULD be of high quality (i.e. appropriate to child’s abilities).	*The guideline development group considers that emphasis is on quality in relation to all interventions.*
	There is a very nice review paper by Laura Schreibman that discusses naturalistic behavioral – developmental paradigms that might be helpful. As it reads, this section seems a bit out of date, given the number of recent modifications of more traditional ABA that are presently published. The reference to EIBI as being typically more than 30 hours a week is not accurate. Very few studies, even of the staunchest behaviorists, have actually managed to provide more than 15-20 hours a week. I found this section, including the first recommendation, hard to follow and quite out of date. The statement that access to support staff does not need to be high intensity may be true, but is not supported yet by literature. It is possible, given the recent effects of relatively low intensity parent-mediated treatments, that this is accurate, but there are no direct comparisons of lower and higher intensity yet to support this conclusion (which is acknowledged in a previous paragraph). If the panel wants to say this, it needs to be clear that this is based on their opinions.	*We have taken out some of the older studies and changed the description of intensity.*

	There is also a statement that precedes the recommendation that EIBI has no effect on parent stress, perceptions or other parent measures, based on a recent Cochrane Review. I'm surprised about the reliance on Cochrane Reviews, which have strengths but sometimes are out of date or miss major research points. The statement here (6.3.1) conflicts with statements later under service provision (10.1) that talk about the needs to address the stress of families of children with autism.	*The point we make is that EIBIs, despite being intensive, don't appear to increase the stress of parents.*
	The SIGN Guidelines conclude recognition, and therefore requires implementation, for an effective use of ABA intervention for children with ASD in Scotland. This warrants prioritisation within the GIRFEC guidelines and needs to replace TEACH methodology presently practised in Special Needs Schools. Despite conclusive evidence of the efficacy of Applied Behaviour Analysis in improving the outcome for ASD children, particularly those with low functioning learning, behavioural and communication difficulties, there is no practise nor professional ABA knowledge being implemented within the education structure of Scottish Special Needs Education. The Tailor Ed Foundation work with over 300 families across Edinburgh to support and advise families with ASD children by supporting, training and implementing a behaviour based approach. They are, however not included in the services provided by the education authority. They have provided "In Service" training workshops to school staff and other professionals, but may not work with children directly within school (despite other charities such as Barnardos being given access). Without such an experienced organisation or BACB qualified consultant, ABA provision will not be successfully introduced in Scotland. All ABA schools in England (including; Treehouse, TreeTops, Jigsaw, Rainbow, Snowflakes) are full to capacity and have excellent OFSTED reports. The Health Improvement Guidelines indicate that Scottish children should be afforded the same opportunity. The Stoa School Charity project aims to establish Scotland's first ABA school in 2016. It will cater for an initial cohort of 5 children and will fund their places until council provision of funding begins, at which point the school will expand accordingly and plans to provide the first residential facility within the Edinburgh locality for children who are low functioning ASD will commence. Education is protected in accordance with GIRFEC guidelines. The group of children who remain the biggest burden, not least financially, throughout life, (children who require 1:1 support) are those with low level ability ASD and related conditions. It needs to be recognised and practice ensured that investment in childhood will effect outcomes in adulthood. Education is protected in accordance with GIRFEC guidelines. Weak links between education and welfare services	*We have not recommended that ABA should replace the TEACCH methodology. Services are free to implement either or both approaches depending on their circumstances and needs.* *We tried in this draft guideline to differentiate between ABA, a broad-based scientific model with a wide range of applications (e.g. PECS, sleep programmes, interventions for behaviours that challenge etc.), and EIBI, a specific variant of ABA. We are concerned that the two often get confused, and we needed as a guideline to be clear that when we make a recommendation about one (eg EIBI), this should not be taken as referring to the others. Other parts of our guideline refer to several ABA-based programmes, and the growing tendency to confuse ABA and EIBI is detrimental to the development of evidence-based services in Scotland.* *It would appear that when this reviewer discusses 'ABA', it is a reference to EIBI. We have now added further clarification, emphasising the distinction between ABA and EIBI.* *More detailed studies on cost effectiveness are needed, and the Scottish Government has already commissioned work looking at the costs of ASD across the lifespan. This is a rapidly evolving field of scientific endeavour.* *The SIGN guideline is targeted at the clinical healthcare setting, so educational studies have not been reviewed. These comments are outwith the remit of the guideline.*

	related to children's educational welfare during overnight respite stays require attention; Low functioning children (not exclusively on the autism spectrum) need a systematic and consistent approach towards essential living skills such as; dressing, washing, drying, wiping, pouring, walking nicely, going round the shops, making requests, following instructions, accepting No etc. Without basic function skills the curriculum for excellence is meaningless to this group. At present teachers are under pressure to follow curriculum guidelines and create; RESPONSIBLE CITIZENS. EFFECTIVE CONTRIBUTORS. CONFIDENT INDIVIDUALS. SUCCESSFUL LEARNERS. If, as a society, we intend to honour this group of citizens, we must ensure they learn essential living skills and ABA has proven the most effective approach. Concrete recommendations: Edinburgh Education Authority To recognise the need for the appointment of a BACB applied behaviour analysis consultant and team of experts to introduce, train and support staff in learning. Prioritise Nurseries and early years intervention and teaching staff in special needs schools. Organise links encouraging joint training and collusion of staff in Education and Welfare; learning Applied Behaviour Analysis and the Verbal Behaviour approach and how to implement it to the benefit of the pupil/client recipient. Afford premises, through Edinburgh City Council for Stoa School and support funding of pupils. Appoint researcher to analyse efficacy of methods used and compare to TEACH methodology. Recognition that further financial investment in childhood education will benefit society as more independent adults evolve: The lifetime cost to society for someone with autism is estimated to be £4.7m with only 7% being spent on education. Improvements in educational provision could potentially result in major savings later in the costs of supporting adults with autism. ("Economic Consequences of Autism in the UK"; the Foundation for People with Learning Disabilities Nov 2007).	
	As mentioned before there is likely to be a training need amongst local service providers on these interventions.	*Yes, this has been discussed within the guideline group. It is important that services maintain staff competences in line with the evidence. Recommending general ABA skills rather than intensive and comprehensive EIBI competences will involve a more gradual learning curve and allows services to target their training to the needs of the individuals they are supporting.*
	As stated before, right summary, wrong professionals. Think you are wrong that no research has been done into lower intensity programmes, see Eldevik et Al. Submission to the SIGN review committee - from parent group ABA -Access4All Thank you for your new autism guideline and particularly for the section on page 22, where you recommend that all children with ASD can benefit from at least some ABA. But please ensure that, if you are	*We don't consider that no research has been done into lower intensities. In fact, we were saying that it can be effective even at lower intensities. What was unclear was how much benefit you get from each step up in intensity – this is very important when deciding how widespread an application might be.*

	delivering ABA or cascading ABA training down to your staff, you start the cascade from the right source and employ BCBAs. These are the proper professionals to oversee such training, they've studied to masters' level in the science and practice of behaviour analysis. The wrong professionals will mean poorer outcomes: it will have been a false economy for both our children and the public purse. [101 parents, plus a few professionals, here undersigned. We are not all from Scotland, but believe your guideline has a wider relevance and so hope you will note our comments as below]. These names are available on request.	*While it is correct that we recommend ABA skills, we do not recommend EIBI. We are unable to comment on the potential role of BCBAs, or on matters of professional regulation. The economic impact requires more rigorous research and discussion, and we have clarified this recommendation.*
	With Scotland and the wider UK there is no reference made by any service provider of behavioural interventions to Lovaas. Although instrumental in the initial development of what is now termed Applied Behaviour Analysis and Verbal Behaviour this term is no longer used. Please remove it as it is detrimental to the perceptions of ABA and other behavioural interventions....as soon as you mention it individuals assume 40 hours a week and a clinical therapy room where learners are drilled. This is NOT how ABA is delivered in 2015! There is no recommended minimum hours per week - figures such as 30 hours, 40 hours etc put a lot of parents off from investigating the intervention. Those who are running programmes, have success with much less input. There are a number of qualified Board Certified Behaviour Analysts (BCBAs) and Board Certified Assistant Behaviour Analysts (BCABAs) working within Scotland and the UK as a whole who deliver Applied Behaviour Analysis and Verbal Behaviour programmes. Details can be found on the register: http://info.bacb.com/o.php?page=100155&by=country. More recognition is required of these professionals. There is also a UK Society for Behaviour Analysis: http://uk-sba.org/behaviour-analysis/ which has been set up recently.	*The UCLA project was instrumental in leading the way in the development of intensive ABA programmes, and needs to be mentioned. However, while Lovaas needs to be referenced, it would be more consistent if his name wasn't attached to the programme acronym in the same way as we've referred to other programmes (e.g. LEAP and ESDM).* *We note the comments about recommended minimum hours, and do not wish to put any parents off from exploring the full range of options. On the other hand, we feel it is important to our review that we highlight the significant intensities involved in some of these programmes, as they have a strong bearing on their cost-effectiveness. We have added some detail concerning the wider range of programmes available nowadays. Our conclusion is that progress seems to be possible at lower intensities, and we hope that this is encouraging for parents.* *We try not to specify professional groups unless there is specific evidence for doing so in the papers we review.*
	There is mention in paragraph 1 of LEAP and ESDM, but not subsequently and the specific research is not referred to while EIBI is given far more emphasis. Should the Denver Early Start model not be discussed more here?	*It is included in some of the systematic reviews. While it would be interesting to look at individual models and their relative strengths/weaknesses, we did not feel this would add significantly to a section that was already quite long.*
	I think that the recommendation re EIBI is very good. It acknowledges the evidence base (NICE does not acknowledge meta-analyses which puts much of the literature on behaviour analysis at a disadvantage) and understands and makes the point that a number of interventions are ABA based. The issue re intensity however is less clear. I think that the recommendations need to be a bit more specific about the difference between EIBI which by definition is intensive (Early Intensive …) and the evidence base is the 30 hours + (which is acknowledged) and other ABA based interventions which may be effective but may not require the same level of intensity. Although EIBI has been shown to be effective with young children there is ample single case analysis that teaching functional skills (and this is the focus of ABA	*We agree that decisions about intensity and choice of strategy or technology will be down to individual clinicians. We cannot specify specific providers for such a wide range of potential applications of ABA across homes and educational, health, social care or voluntary settings.* *The statement on staff training has been moved to section 5 as it is relevant to more than just ABA-based interventions.*

	unlike SLT) improves quality of life outcomes and reduces the lifelong economic cost. The possibility of being able to support a young person in their own community also increases when functional skills are taught and this is a current priority post Winterbourne. The level of intensity should be based on a thorough assessment of an individual's needs (skills based assessment and functional analysis of CB/barriers to learning). I welcome the recommendation that staff need to be trained in ABA technologies … I think that this might be strengthened by adding "from a recognised provider" and list provider organisations as an appendix? Or signpost folks to the UK-SBA?	
	There is a lack of clarity as to what is being recommended within this section. It would be clearer if the references to interventions based on ABA were set in the context of these approaches being part of an eclectic approach. Indeed, NICE approaches this area by including a more general section on psycho-social interventions. We are concerned that this section could be used inappropriately to promote interventions based on ABA. The guidelines should more explicitly acknowledge the different effects of ABA-based interventions and the level of controversy around particular aspects of some of them. Specifically the guidelines state that 'No harms arising from EIBI have been reported.' While this may be the case in terms of evidence accepted as part of this review, this could easily be read as meaning that there have been no concerns raised, which is not the case. The NAS does not agree with the recommendation that all children on the autism spectrum should be able access support from ABA trained staff. Aspects of ABA can help some children. However, each child with autism has unique needs and abilities and many will benefit from a 'mixed menu' of different types of support. We also have concerns that where there is some evidence for a number of interventions based on ABA, as currently drafted the guidance goes too far in recommending its use above other interventions, which may be more helpful for the child.	*The guideline group does not agree that copying NICE's approach would help with the flow of the guideline. Organising interventions by outcomes would mean that the more comprehensive interventions (such as EIBI) would be discussed in many different sections, therefore lacking any overall coherence.* *We have attempted to be clear that the evidence for EIBI, which is only one of many forms of ABA-based intervention, is improving. This is in line with NICE and other significant recent reviews of the field. We do not recommend EIBI however, and in response to these comments about the lack of clarity, we have tried to make this clearer.* *We are aware of anecdotal concerns, including claims (many of them misattributed) of punishment being used in very early models, but punishment has not been tolerated in clinical services since the 1990s, whether in ABA or other programmes. The evidence of gains resulting from these programmes is significant both clinically and statistically, and this is what our judgements are based on. There is of course a longstanding concern about the delivery of behavioural support more generally, nowadays addressed by person-centred approaches and values-based services. We recognise this in the guideline where we say that these should be implemented using person-centred frameworks within organisational contexts that review and supervise practice.* *The guideline does not specify which ABA elements should be delivered to which individual, and leaves this question to the professionals, families and services supporting them. PECS will not benefit everyone but surely when it is appropriate it should be delivered by personnel with the right training. The benefits of ABA over no ABA are clear from the evidence that has been reviewed, by NICE, ourselves and others. What isn't clear is the intensity at which ABA programmes need to be*

		delivered. We are therefore not recommending EIBI across the board but we cannot use this to rule out ABA entirely, as this comment seems to be suggesting. Another issue that we have tried to clarify further following feedback from reviewers is the distinction that we draw between EIBI (comprehensive and intensive) and ABA, which includes skills as basic as task analysis, prompting, shaping and fading – basic support skills that we believe should be part of the basic training of all personnel supporting individuals with ASD. We left open the question of precisely which ABA skills would suit each different role occupied by those working with individuals and families, as we didn't want to be prescriptive. We recognise that this may have resulted in some lack of clarity but we obviously want to avoid being prescriptive - the task of matching interventions to individuals is complex and guidelines need to allow flexibility. *We hope that this clarifies our position and that we are at least broadly in agreement with NAS in our concerns about evidence-based services being provided by personnel with the appropriate skills and supervision, working in person-centred and values-based services.*
	It would be helpful to include more information in the evidence section about the conclusions relating to intensity and outcomes in EIBI from the meta-analytic studies that are cited. Currently, only one reference to a meta-analytic review is used to support the conclusion that intensity is not necessarily a key variable. Other reviews included analysis of predictors/moderators of outcome. For example, Eldevik et al 2010 found that "intensity" (measured as number of hours per week of intervention) was a significant predictor of outcome. The only study that I am aware of to directly manipulate intensity was actually Lovaas 1987 - a 40 hr/week model vs. a 10 hr/week model. Much better outcomes were found in the 40 hours group (in a non-randomised design). My point is that the short summary of evidence is OK although rather limited in scope. The issue is the translation of the evidence into a recommendation. I agree that we cannot say that high intensity is required to deliver positive outcomes, and clearly strong outcomes have been reported in some lower intensity interventions (e.g., 15-20 hrs/week). However, the recommendation is worded as if there is evidence to clearly show that higher intensity IS NOT needed. The recommendation is: "this does not need to be high intensity". I would suggest that this statement is simply deleted since it is clearly not evidence-based when presented in a section of the guideline about intensive behavioural and developmental programmes. 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 Behavioural Intervention for children with	*While our summary of evidence is short, it is longer than for any other intervention we reviewed, which is reasonable given that the number of studies deemed to be of sufficiently good quality was greater than most other areas of intervention that the guideline considered.* *Our initial judgement included discussion of a number of factors related to outcomes (age, IQ, intensity, duration) concluding that findings about all of these were equivocal or inconsistent. However, the discussion was not included in the final guideline document leading to some mismatch between the summary of evidence and conclusions.* *Our intention was not to say that higher intensity doesn't produce more benefit, but that it isn't clear how much more benefit is produced by each step up in intensity so we cannot judge how much each step up is worth? Hence we recommend further research into the impact (on costs and outcomes) of these manipulations.* *In particular, we felt it was important not to miss the fact that low intensity (non-EIBI) ABA is also beneficial – we may not recommend EIBI, but we shouldn't forget that ABA itself is still very valuable, and it would be irresponsible to allow people to assume that our review of EIBI is concluding that ABA is not warranted on any level. We have also clarified an earlier section differentiating EIBI from the more*

	autism. American Journal on Intellectual and Developmental Disabilities, 115, 381-405. Please also note that Eldevik et al 2010 is an individual participant data meta-analysis involving individual child level data analysis from 100% of studies included from the systematic search. It is a shame that these detailed data are not referenced in the guideline document. The other recommendation in this section also needs some editing. The recommendation states: "They should be overseen by professionals trained in the psychological theory and in child development, who are regulated by a professional body such as the Health and Care Professions Council." I have no problem with this expectation, and it is clearly important that key staff involved in the delivery of ABA-based interventions are regulated appropriately. At present, this recommendation could easily be perceived as lacking balance. Please could a phrase be added to be clear that competencies in ABA should be required alongside suitable professional qualifications. My suggested rewording is as follows: "They should be overseen by professionals trained in the psychological theory and in child development, who are regulated by a professional body such as the Health and Care Professions Council, and who have a recognised high level of competencies in ABA (such as accreditation as a Board Certified Behavior Analyst, or demonstrated consultant level competencies as defined in the UK ABA autism competencies framework)." The ABA competencies framework is downloadable from the following website: http://www.ambitiousaboutautism.org.uk/who-we-are/research **Supporting documents available on request*** On reflection I have complicated the issue of ABA competencies. The straightforward thing to do is to say ABA competencies are also needed as described in the UK ABA autism competencies framework. This refers to the behaviour analyst certification board criteria at higher levels and also has the advantage of clarifying competencies in autism and also professional behaviour. So it deals with the underlying issue that I imagine the SIGN committee were trying to address.	*general term 'ABA', which we felt needed more emphasis.* *Eldevik et al. (2010) was a very useful paper, but we have chosen to reference review papers rather than each individual trial.* *We have received a number of comments either requesting information about ABA competencies or asking us to signpost readers to the BCBA website. If we were recommending universal EIBI, then we would have needed to advise on competences, supervision and training options. An ABA competencies framework, especially an accepted UK framework will be very helpful for some services. Given the range of services being provided and the breadth of ABA itself we didn't want to be prescriptive about which providers or technologies should be prioritised by which services. Services managing behaviour that challenges can access frameworks and competencies for positive behavioural support; those prioritising communication needs should be able to look elsewhere – we would like this recommendation to be adopted in a flexible way that allows interventions to be matched to individual needs across a wide range of services many of whom will not require the level of accreditation that you refer to.*
	The information here is accurate and the recommendation appropriate but worry that the wording implies that having some training in some specific ABA technologies if sufficient. Whilst the guidance on supervision and training that is offered helps qualify this, I can't see how this will work in practice in Scotland. I would welcome guidance on how I can ensure that staff in my service are appropriately trained and supervised when implementing ABA technologies.	*We have left this deliberately open, in order to allow services the flexibility to match supports with support needs according to local strengths and resources.*
	This section is well-informed in relation to Behaviour Analysis in general and to research concerning the benefits of Behaviour Analysis in the field of ASD. It makes the subtle (but not often recognized) point that the variety of ways of referring to particular types of	*We have clarified our summary and the reasons for our conclusions in line with comments from reviewers that have highlighted a lack of clarity in our original document. We agree that decisions about*

	intervention programmes (e.g. Lovaas, ESDM etc see p.22) is underpinned by the fact that they “are best described as behavioural and developmental programmes (p.22). This is an important point to make in the public sphere where Lovaas, ESDM, LEAP etc. are often thought of as different “approaches to” or “interventions for” ASD. The clarification herein will be helpful to families and professionals dealing with ASD and will assist funders in decision making on the allocation of funding. Paragraph ending “This does not need to be high intensity”. The statement should be removed. Decisions concerning intensity are clinical and depend on the entering skills of the child/young person being assessed and provided with Behaviour Analytic services. Intensity varies across skills and across time and is a matter of judgment by a competent professional. The statement is inappropriate. The statement in the middle of the page that “Applied Behaviour Analysis approaches are dependent on the skill and training of the personnel delivering them” is accurate and well made. It is important to note in a public document that the success of ABA is dependent on skills and training. If or when services fail to bring about progress for their users, the statement encourages the seeking-out of further or more advanced training for staff rather than abandonment of what is internationally recognised as the treatment of choice for children and young people with ASD. Final statement: Text recommends persons implementing Applied Behaviour Analysis-based approaches “should be overseen by professionals trained in the psychological theory and in child development, who are regulated by a professional body such as the HCPC”. Given the possibility of error and potential for harm, the suggestion of oversight by trained professionals is entirely appropriate and is implicit in the statement noted above “ABA approaches are dependent on the skills and training of personnel delivering them”. The guidelines should specify that procedures should be designed and overseen by, specifically, professionals with certification as Board Certified Behaviour Analysts (BCBAs). BCBA is an internationally recognised professional certification guaranteeing that the holder has achieved the following: 1) A Masters degree in Behaviour Analysis consisting of 270 hours of classroom teaching (including 45 hours on Ethical and Professional Conduct) and successful completion of related assignments and/or examinations, 2) Between 750 and 1500 hours of supervised practice, supervised by a BCBA (hours vary depending on the type of experience accrued – fieldwork, practicum, intensive practicum)	*intervention and intensity will be down to individual clinicians and should be based on detailed and individualised assessment.* *There is growing consensus about the importance of EIBI and its potential value but we are not yet able to recommend it widely.* *The wording of the recommendation has been revised.* *The statement on training has been moved to section 5 as it applies to all interventions, not just ABA-based interventions*

	3) An examination consisting of 150 questions for which the Behaviour Analyst Certification Board allocates 4 hours to complete. BCBAs must, in addition, complete 36 hours of Board-approved continuing education in each certification cycle (currently three years, soon to reduce to two years). The Behavior Analyst Certification Board (BACB) is the regulatory body for Behaviour Analysts, setting education and training standards, and with a rigorous disciplinary procedure. The ultimate sentence in the recommendation on page 23 should therefore read: “They should be overseen by professionals credentialed as Board Certified Behaviour Analysts (BCBA)”. As with other sciences and scientific approaches (e.g. medicine), “getting it right” requires extensive training while “getting it wrong” is easily done without that training.	
	Many problems throughout this section, including the unsourced descriptions of the interventions. If “intensive” is defined as “30 or more hours per week” (the only provided definition), this does not include ESDM (15hrs/wk) or “intensive” ABA-based interventions in numerous papers. An ABA-based program providing a “maximum” of 15 hrs/wk is called “intensive” and “EIBI” in the literature, though intensities ranging from 10-20 hrs/wk are also called “non-intensive.” Actual hours per week received by autistics in these programs are very poorly reported across the whole literature, with few exceptions. While manuals exist (and sometimes are mentioned), not all “intensive” ABA-based interventions with results reported in the literature are manualised, contrary to the claims here. Of the 8 (the text says 9, but the provided references are 143-150, which is 8 references) cited systematic reviews claimed to be “well-conducted,” only NICE is of adequate quality, though it has obvious factual errors. The AHRQ systematic reviews (2 are cited, one updates the other) use a highly questionable novel system of standards which produces some haphazard results, and have important errors, particularly obvious in the update. The remaining 5 cited systematic reviews have even lower standards as well as major errors. E.g., ref 150 modifies an existing older standard such that both RCTs and blinding are radically redefined (non-RCTs are redefined as RCTs, and studies are considered double-blind because children are presumed unable to name the intervention they receive). This should never be taken seriously. Ref 148 was accepted within 5 days of being submitted, suggesting it was not conventionally peer reviewed. All the meta-analyses wrongly combine research designs and wrongly combine outcomes at high risk of bias. A study using aversive procedures is included (refs 146, 147, 150), which is unacceptable. There are unreported conflicts	*We had not defined a minimum intensity, but appreciate that newer models of EIBI are tending towards lower intensities, and our comments on typical intensity now reflect this.* *Referencing error amended.* *The systematic reviews included satisfy the criteria set out by the SIGN review process. We describe the quality of the trials cited in the reviews as low to moderate, and the reliability of the evidence is moderate for some outcomes and low for others. We appreciate that opinions will differ but hope that we have at least been clear about the basis for our decisions, so that our conclusions can be judged in the appropriate context.* *We do not believe that aversive procedures have any place in modern clinical practice. Studies proposing to use such methods would no longer receive ethical approval or pass peer review for publication. Conflicts of interest and other sources of potential bias were considered by most of the reviews we considered and we take account of these in our conclusions. There is clearly further research required and we say so. We do believe however that the progress that has been made in this field – in becoming more rigorous but also in moving towards more playful, developmental and less intensive programmes, should be recognised.* *We are unclear what is meant by “ABA-based lore”. If it refers to the statement towards the end of paragraph 4 where we state “Only one systematic review concluded there was no impact” this is because there was only one review of the ten we reviewed that concluded EIBI has no impact (Spreckley and Boyd). We suggest a*

	of interest. Re “No harms arising from EIBI have been reported” no attempt has been made to assess harms, thus none is reported. The claim re “only one systematic review” is ABA-based lore, it is the opinion of some individuals and has no place here, keeping in mind that most of the cited systematic reviews are unacceptable in numerous ways due to extremely low standards. Re intensity, the relevant measure is whether treatment intensity correlates with outcomes. This requires much better quality research than currently exists, and much better reporting. What evidence there is shows no correlation between treatment intensity and outcomes. But again the context is a very poor quality literature. The recommendation here and the “good practice” point are not well-founded and risk being harmful both to autistic individuals and to the progress of autism research.	*significant flaw in this review’s choice of control group. This is an objective opinion based on clear evidence reviewed by this group.* *We appreciate that it is difficult to make firm conclusions on the basis of low to moderate quality evidence. It might seem sensible to conclude nothing, and wait for ‘convincing proof’. However, this area has produced more controlled trials and randomised controlled trials, and in our opinion it is possible to draw some tentative conclusions. We have not recommended that EIBI should be widely implemented because the evidence is still not conclusive. But it would be going against the evidence to conclude that no ABA-based approaches should be implemented. We have tried to strike a balance in a complex area, and understand that we will not please everyone. We hope that the basis for our conclusions is at least clear and objective.*
6.3.2	Excellent.	*Thank you*
	Now that you have made recommendations under 6.3.1, I am not sure that the distinction you make between ‘intensive behavioural and developmental interventions’ and ‘behavioural interventions’ here is valid any longer. If a child or young person has access to support from staff properly trained in ABA-based technologies, as described in your recommendation from 6.3.1, then it would be most helpful if this was consistent and integrated with any additional focal or specific behavioural interventions which you mention here. It would be more efficient and make more sense to have all these behavioural interventions delivered by the same people. So I think you should consider combining 6.3.1 and 6.3.2.	*Title changed but the group prefer to keep the two sections separate.* *6.3.2 has been revised and moved to sect 6.3.9*
	I think there is a Sam Odom review that it much more recent....	*Unsure which review this is. The most recent review by Odom was published after our cut off date for literature searching. The section has been updated using NICE and AHRQ.*
	The section on behavioral interventions is well done. It is a shame that the OT stuff is so weak. (They are commonly used here by the schools).	*Thank you.* *There is a need for good quality OT research, which is noted in the Recommendations for research section.*
	Needs more emphasis that such behaviours can persist –debatable at what point you describe them as mental health hence we tended to stick to mental health and behavioural so important to step in early—this is an area where people assume it is just ‘part of autism’.	*The section has been rewritten and it is noted that further trials are needed with longer time periods for measuring sustainability of outcomes.*
	'Depending on context 'children' can mean up to age 18. Given that supporting evidence is said to be from preschool children, does there need to be some specification about age of children?	*Updated with Warren and NICE which covers a wider age group than just preschool.*
	To say that skill deficits and sensory processing should be investigated prior to a behavioural interventions seems to suggest they are something separate,	*Sentence amended.*

	whereas they should be done as part of the assessment and design of a behavioural intervention.	
	Recommendation at B, end of page. The statement should read "Behavioural interventions should address a wide range of ……" Delete "be considered to".	*Weaknesses in the evidence base do not support such a strongly worded recommendation.*
	The major cited paper here (ref 152) represents unacceptably low standards of science and ethics which have no place in this or any autism guideline. This dated (1996) review is of too poor quality to be considered "systematic." Neither included nor excluded studies are listed. All included studies are of very poor quality (single subject designs). Diagnostic standards are non-existent. A range of aversive procedures are included; which ones and how many is unclear due to the extremely poor reporting. More recent reviews updating this area are not an improvement. See above re the cited AHRQ (Warren et al., 2011) review.	*The Matson review has been removed and updated with AHRQ and NICE. AHRQ was critically appraised as a good quality systematic review.*
6.3.3	Appropriate.	*Thank you*
	This is an area, along with diagnosis, that I worry about making blanket statements about studies being of poor quality. I am sure that there are many reasons to criticize many of the studies, but it seems like it would be more scientifically valuable to allude to the limitations, particularly when, in other parts of the review, these are not discussed, rather than making statements such as this one. I also wonder about the statement of small clinical effects (for Social Stories), given that many well-respected medical interventions also have small effects (maybe it would be reasonable to include in the introduction a statement about how big effects have to be to be considered strong – the effects reported for several of the medications are much stronger, but the risks of harm from the medications are also stronger than any risk of harm from a Social Story).	*The section reports the conclusions of a meta-analysis and is consistent with other parts of the guideline, where study weaknesses are highlighted. Citing effect sizes supports the summary of the trials and is part of SIGN methodology.*
	The cited TEACCH systematic review (ref 153) uses the unacceptably low standards in ref 150 (same author), see above. Standards this low do not belong in this, or any, guideline.	*Under SIGN's appraisal criteria the systematic review scored as well conducted. The caveats with the quality of the studies included are documented in the study and the guideline.*
6.3.4	Lots of 'd=' without explanation of what this means.	*An explanation has been added here and to abbreviations.*
	Appropriate.	*Noted, thank you.*
	The NAS welcomes the recommendations on adapting CBT for children and young people and the further detail provided in section 7.5. However, 7.5 sits within the adults section, so it is unclear whether these adaptations are relevant to children as well. This should be clarified. We recommend that all staff working within CAMHS tiers 2, 3 and 4 must have basic training in autism, and have access to specialist advice. Specialist autism capacity should be made available within tiers 2, 3 and 4 of CAMHS. Autism-appropriate tier 4 services must be available at a regional level. To emphasise the importance of meeting mental health needs, the guidelines should reference that research	*Issues around staff competences are the remit of the NHS Education for Scotland competency framework, but these comments are noted.* *The high level of mental health co-morbidities experienced by children, young people and adults with ASD is described elsewhere in the guideline (see section 4.4).* *New sentence added: "Mental health difficulties are more prevalent among individuals with ASD than the typically developing population (see section 4.4), and there has been a number of reviews of*

	has found that 71% of children with autism develop mental health problems like depression, anxiety disorders, attention deficit hyperactivity disorder (ADHD) and OCD [Simonoff E. et al (2008), Psychiatric disorders in children with autism spectrum disorders: prevalence, co-morbidity, and associated factors in a population-derived sample, Journal of American Academy of Child and Adolescent Psychiatry 47: 4: 921-929]. This compares to a prevalence rate of around 10% in other children [Green, H., McGinnity, A., Meltzer, H., et al. (2005). Mental health of children and young people in Great Britain 2004. London: Palgrave].	*CBT for co-occurring mental health conditions in ASD"*
	To fit with previous sections, a reference to the ABA technologies involved in CBT would be helpful here.	*The guideline group think that the behavioural elements of CBT would be clear enough from the name and that discussion of the elements involved would require more space than warranted without necessarily clarifying the definition.*
	It may be pertinent to note that higher levels of anxiety in autism are consistently associated with higher intelligence, and that anxiety may be atypical in autism, making it difficult to assess, and making results from anxiety measures difficult to interpret.	*These are very interesting points which we hope will be the subject of a lot of careful further research, but at this stage there is little definitive we can say about them. In relation to the first point, we have noted that the research we reviewed only involved individuals with an IQ>70. In relation to the second, we have added the following sentence to the first paragraph:* *Despite some evidence of beneficial outcomes, important theoretical questions remain about whether "anxiety in ASD is a true co-morbidity or a manifestation of core ASD symptoms".*
	Last recommendation under 6.3.4 should read "conditions".	*Amended*
6.3.5	CHEARS who test for hyperacusis.	*CHEARS is a private organisation which is based in the south of England. We have searched for hyperacusis interventions but no evidence was identified.*
	Appropriate.	*Thank you*
	The levels of evidence (1++) does not appear to be in line with what is stated in the text.	*It is the Cochrane review which merits the 1++. Wording changed to make this clearer.*
	The paragraph on Auditory Integration Training is different than others. What 5 point scale is referred to on the Aberrant Behavior Checklist?	*Phrase removed.*
6.3.5/6	Given the paucity of evidence and the poor performing evidence where available, a GPP instructing against spending resources on these two 'approaches' would be appropriate. A public document which makes recommendations has a duty to the public purse to recommend against spending resources on procedures with little or no evidence in their favour. The 'therapies' or 'approaches' named in these sections are practiced widely in schools for children with ASD at considerable cost to the public purse. Given the dearth of any positive evidence of benefit, there should be a recommendation against spending further public funds on Auditory Integration Therapy, Sensory Integration Therapy, Occupational Therapy.	*Occupational therapy is one of the most frequently requested interventions for individuals with ASD and those receiving it report high levels of satisfaction with input provided (Goin-Kochel, et al 2009; Green et al 2006; Mandell et al, 2005) yet resources allocated for Occupational therapy appear to represent an extremely small component of overall costs in caring for individuals with ASD. Input is primarily and increasingly delivered in consultative or group formats. Occupational Therapists only accept referrals where there are clear functional deficits and barriers to occupational performance which clinical reasoning*

	Such a recommendation would free-up funds for training in and implementation of evidence-based practices.	*suggests their skill set is best placed to address. OT triage or initial assessment often results in advice for self-management and/or onward referral to more appropriate services, which may include further support for behaviour, social or leisure factors. It is accepted that evidence to support SIT and SBI in particular is limited, but this is partly due to significant constraints on research activity. Sensory Integration approaches are also now embedded in many interventions for autism such as the Early Start Denver Model (Dawson et al, 2010; and the Floortime model (Greenspan and Weider, 1997).*
6.3.6	OT for higher functioning kids but a waste of space for some.	*See response to comments in section 6.3.5/6.*
	Appropriate.	*Thank you*
	Thanks for being honest that there is little or no research to back up SIT: why then is the state paying for so much of it! Put the money instead into ABA, which works better.	*See response to comments in section 6.3.5/6.*
	The recommendation for OT does not seem to be based in the findings. On the basis of the results reported in the guidelines, there should be a recommendation to caution the use of SIT and SBI. A lot of money is spent on these interventions at the moment in spite of the very limited evidence to support these methods (cited in document). In fact there is evidence that they can increase problem behaviours (Lang et al., 2012).	*See response to comments in section 6.3.5/6.*
	Occupational therapy is not offered routinely in my experience and despite asking for input on several occasions I am still waiting.	*We are sorry to hear this. This is an issue for implementation and outwith the remit of the guideline.*
	The text makes no reference to research evidence of any kind (positive or otherwise). The Good Practice Point is therefore puzzling. Why would Occupational Therapy be considered good practice without the evidence (assuming there is some) being evaluated? The Good Practice Point should be deleted and instead a statement to the effect that paying for Occupational Therapy out of public funds cannot be justified at this time.	*See comments above and the National Autistic Society statement: each child with autism has unique needs and abilities and many well benefit from a 'mixed menu' of different types of support.*
	In addition to the lack of evidence supporting these approaches, as mentioned above the premise that autistic senses do not work properly is dubious and possibly misleading. The more accurate view, founded in a very large literature, is that autistic perception is atypical, which may produce advantages and disadvantages depending on available information and opportunities.	*Occupational therapists agree with the assertion that autistic sensory perception is atypical and may confer advantage in certain situations. Occupational Therapists will only provide intervention where an individual with ASD has demonstrable deficits in functional skills required for occupational performance. They may refer to sensory integration theory if difficulties in this sphere are highlighted as key barriers to participation by carers. However, the primary focus is always on improving occupational performance and an eclectic range of approaches, including behavioural theory are drawn on to achieve this. In practice in Scotland, Occupational therapists aim to work collaboratively and*

		consultatively with those who are key carers for individuals with ASD and this may include ABA therapists.
6.3.7	White noise therapy which stimulates the inner ear.	*We have searched for white noise but no evidence was identified.*
	6.3.7 Music Therapies. I would suggest the title of intervention is Music Therapy, since this is consistent with the HCPC regulated professional title.	*Changed*
	BAMT fully endorses this statement and is glad to see music therapies included in these guidelines. See also later comments about non-pharmacological interventions for adults with ASD.	*Noted, thank you.*
	Appropriate.	*Thank you*
	The autism literature also features numerous exceptional autistic musicians. Opportunities to develop musical abilities, rather than music used as therapy only, may be important and possibly worth mentioning as a non-intervention approach or avenue founded in the non-intervention literature.	*This is outside the remit of this evidence-based clinical guideline.*
6.3.8	Blue lights.	*No evidence on blue lights was identified.*
	Wondered if it would be more helpful to incorporate the fact that Melatonin is only available on license in adults over 55 in the summary point rather than simply as footer? Current research highlights a lack of evidence for SOME sleep hygiene practices, would it be better to drop this term and simply include the specific techniques which do have an evidence base? Or even to stipulate that there is inconclusive evidence for sleep hygiene practices alone, although they are more efficacious if implemented as part of a CBT for insomnia treatment plan.	*Melatonin is discussed in section 8.8* *The guideline development group think this section does what the comment requests.*
	Appropriate.	*Thank you*
	Sleep: there is a body of research showing evidence of ABA based interventions being effective with sleep problems (France & Hudson, 1990; Jin, Hanley, & Beaulieu, 2013; Piazza & Fisher, 1991).	*The studies are outwith the date range of the literature search/not of sufficient quality to be included as evidence.*
	Sleep management has been offered on several occasions but no one has actually followed through with obtaining an appointment for us.	*The guideline cannot comment on individual service delivery.*
	Again, to improve consistency of terminology in the document, does the reference to 'behavioural therapy' again relate to access to those skilled in ABA technologies?	*Behavioural approaches to sleep management are more general than ABA.*
	"Behavioural therapy should be tried before a pharmacological intervention". It is not clear from the text why this statement appears at the end of a paragraph and is not included in the best practice point that follows. Given the foregoing text in the guideline, it would be more appropriately placed in the best practice section.	*This is reporting on the conclusions of the NICE guideline. It is also included as a GPP.*
6.3.9	Thanks for the good sense on this utter nonsense.	*No action required.*
6.4	All diets should be specified to the individual GFCF, Alkaline diet etc.	*No evidence identified, but dietary problems should be followed up.*

	This section seems to conflict a bit with previous statements that children with autism do not have GI problems. Perhaps the earlier statement could include a reference to restricted eating, which is well documented in children with autism, and then this could follow up.	*The guideline development group do not agree that there are inconsistencies. Children with ASD should be treated as any other child with GI problems.*
	Nutritional interventions may also be required for children and young people with ASD and a co-morbid diagnosis of eating disorder as part of treatment programme which is adapted for ASD.	*This is covered by the term 'dysfunctional feeding behaviour' in the GPP.*
	As there appears to be no good quality evidence that routine use of exclusion diets or supplements is beneficial in ASD, do we need to make the first recommendation more robust? Agree that "Gastrointestinal symptoms ....without ASD." but suggest adding, "and routine use of exclusion diets or supplements is not recommended, unless indicated by individual assessment" or equivalent.	*There would need to be evidence showing lack of efficacy or harms before a recommendation could be made. Currently there is just a lack of evidence.*
	Appropriate.	*Noted, thank you.*
	Page 27 6.4 Feeding: there is a body of research showing evidence of ABA based interventions being effective with food selectivity and other feeding problems (Addison et al., 2012; Rivas et al., 2014; Volkert & Vaz, 2010).	*This section is about nutritional interventions, not management of behaviour around eating.*
	It would be helpful to specify who should be sought for advice on diet and food intake.	*Dietician added to GPP.*
General	Hyperbaric Oxygen Treatment (HBOT), Gc MAF, Homeopathy, MAF cream, supplement interventions	*A further search has been conducted but no evidence was identified for these interventions.*
	BAMT notes the non-inclusion of 'Music Therapies' for adults in Section 7, compared to its inclusion for children in Section 6.3.7. While we are not aware of further RCT trial evidence for music therapy with adults (as distinct from children), we are aware of music therapy being successfully used in the care of adults with ASD as a social skills and/or psychosocial intervention. We would urge SIGN to consider including Music Therapies in Section 7 by extension of its value acknowledged for children in Section 6.	*It is hoped that readers of the guideline will extrapolate from the child evidence on topics that are not covered in this adult section. This has been made clearer with the addition of a sentence at the end of the section 7 introduction ("There are gaps in the adult evidence-base when compared to the child sections, and we anticipate that readers will extrapolate carefully from the evidence about interventions for children and young people"). It would be inappropriate to have a section on music therapy when there has been no research on this topic - there are many unresearched topics and we cannot comment on them all.*
	Appropriate.	*Noted, thank you*
	Could something be put in about sensory integration somewhere in this section? This is increasingly used in LD, and although I am not sure how good the evidence, sensory integration based interventions seem to be really effective for some people. It might be worth asking a lead OT about evidence? But also putting up for discussion with the adult practitioners in the guideline group whether they also find this an effective intervention. The other thing that is routinely used in adult LD services (and is endorsed by NAS) is PBS. Although I couldn't find any evidence. And in fact what we actually do is get nursing and	*Sensory needs have been discussed in the child section, and we hoped that readers of the guideline would be able to extrapolate from that when there are areas missing from the adult evidence-base. We have made this clearer in the section 7 introduction ("There are gaps in the adult evidence-base when compared to the child sections, and we anticipate that readers will extrapolate carefully from the evidence about interventions for children and young people").* *We have not presented a synthesis of our advice or a 'typical programme', because*

	psychology involved, do behavioural applied analysis and put in a robust autism specific care plan with plenty of structure and routine, no overloading (sensory or otherwise) and limit over whelming verbal communication. And it seems to work for most people. This isn't really reflected in this section. (Not that this section wasn't helpful - it just doesn't seem to reflect what actually happens in adult LD services where we probably see the most enduring problems with extremely challenging behaviour).	*while these may be helpful we need to make judgements about each element of the evidence-base.* *The model described in the comment is usually associated with more enduring or extreme situations and especially behaviour that challenges, for which PBS would be very appropriate. This evidence base is not included because it isn't specifically an ASD evidence-base.*
	This section on non-pharmacological interventions recommended for adults is much less substantial that the previous section for children and young people. While we appreciate the evidence base is weaker, the NICE guidelines are much clearer on listing recommended interventions. The SIGN guidelines should follow this example and consider more fully recommending interventions highlighted by NICE. This section should also reference the Scottish Government document The Scottish Strategy for Autism: Menu of interventions. This section should also include a new subsection on assistive technology (in order to be very clear that it is different to facilitated communication. There is emerging evidence of the positive effects of this technology. Indeed, we welcome the inclusion of studies on the efficacy of computer-based interventions to improve communication.	*This section is lighter because the evidence-base is much weaker, but it is substantially improved since the last guideline and we anticipate that it will grow further with future updates. We cannot include topics or interventions which didn't come up in our literature search, and this includes assistive technology for cognition, whether it is used to support communication, planning or other important functions. The menu of interventions is a list of needs and while practitioners will find it very helpful, it doesn't constitute evidence of the kind that allows inclusion in a scientific guideline.* *However, we have added a sentence to the introduction to this section which clarifies our hope that readers can extrapolate from the evidence in the child section where it is necessary.*
	Generally in agreement with this section however again there is little mention of the role of sensory information processing and environmental adaptations that go beyond classroom/home adaptations, movement breaks and include autism friendly designs. Have book chapters been included in the review for evidence? e.g. Wilkes, K. (2005). The sensory world of the autistic spectrum: a greater understanding. London: The National Autistic Society	*We have strict criteria about the kind of evidence that we can review and include when making national recommendations about practice. There are gaps in the evidence-base as it applies to adults, and we hope that readers can extrapolate from the child evidence where this is the case. In order to clarify this we have added a new sentence at the end of the introduction to section 7.*
	The claimed poor outcomes for autistic adults are based on very limited biased samples, not including later-diagnosed or non-diagnosed adults (who may be the great majority; see your own ref 6), for example. Claims that autistic adults have extremely poor (and costly) outcomes, no matter how weakly founded, plausibly make autistic lives more difficult. Failing to recognize major limitations in the evidence on adult outcomes also impedes autism research. Successful autistic adults understandably may avoid any participation in autism research, not only because they are busy, or because they associate autism with very bad adult outcomes (ergo irrelevant to their own situation), but because they rightly fear discrimination. While we wait for good quality population-based studies of autistic adults, a more balanced view of autistic adult outcomes is suggested by literature in areas other than follow-up studies. Numerous autistic adults appear in this literature, along with information about their demographics, employment, education,	*This highlights some challenges that are very tricky to negotiate, and we recognise that our approach may not please everyone. This is a guideline focused on the needs of children, young people and adults who by definition experience impairments that warrant both diagnosis and intervention, and while we acknowledge that not all of those with an ASD need or want 'intervention' we have chosen to focus on the group that have needs for which a clinical guideline can identify and summarise a research evidence and from which we can draw recommendations. This may not apply or appeal to every person who identifies themselves as having an ASD, but we believe that it is nonetheless a clinically important endeavour.* *We await improvements in the research and in our understanding of the lives of*

	relationships, etc. This section needs a far better start to put the rest in perspective.	*individuals with ASD.*
7.1	Appropriate.	*Noted, thank you.*
7.2	The guidelines should offer a concise definition of what facilitated communication is, as well as clearly state that facilitated communication is not recommended, rather than only reference the NICE recommendation.	*A definition of facilitated communication is given in section 6.3.9.* *A recommendation not to use it has been added.*
7.3	Appropriate.	*Noted, thank you.*
7.4	Appropriate.	*Noted, thank you.*
	I thought the paragraph about "Conclusions must be made with caution…" was fair and thoughtful. I wondered if it might be moved up earlier in the document because it is relevant to the discussion of behavioural interventions for children as well. The discussion about interventions for adults seems more clinical and a bit less dogmatic than that for children and I was not sure why.	*Added to section 5*
	Behavioural interventions for adults "Conclusions must be made with caution given that it is a meta-analysis of single-case studies, and because the quality of many of the papers included in the review was low." This sentence should be reworded as it implies an assumption that single-case studies are automatically of low quality. Research methodology is a hotly discussed topic and well conducted single case/single system designs have been well recognized as valid high quality research methods (IES, 2010; Keenan & Dillenburger, 2011).	*The value of single-case methods and recent developments in the statistical treatment of single case data were discussed by the guidelines group in relation to a number of our considered judgements. We have described the quality of many of these reviewed studies as low as an issue separated from our description of them as single case studies. The improvements in single case statistical techniques are recent, and many single-case studies, while experimental, do not present the data required to permit review by these statistical methods. We look forward to continuing improvements in this area, and in particular to the fruits of newly developed methods (e.g. SCED) for grading the quality of single-case research.*
	I think that the whole of section 7.4 (adults) should be reviewed in light of the NICE guidelines on CB especially in relation to the evidence base for the use of functional analysis to understand problem behaviour.	*We recognise that there is a considerable evidence-base around supports and interventions for individuals who present behaviour that challenges, and we believe that NICE gl11 will be very helpful for practitioners working with ASD. However, that evidence-base is not specific to people with ASD and therefore it was not included in our guideline's literature review.* *A sentence signposting the NICE CB guideline has been added.*
	This section is puzzling to clinical and academic professionals (especially BCBAs) who practice with adults and are familiar with the extensive empirical literature on Behaviour Analytic interventions for adults with ASD and/or Learning Disability. As noted on page 29, the NICE GDG did recommend Behavioural Interventions for adults whose behaviour challenges (CB). They named Behaviour Analysts among the professionals to be consulted in cases of CB and did so on the basis of published research rather than expert consensus. The literature is awash with studies	*We preferred to separate the children and adult sections so that the adult evidence for clarity. A sentence on extrapolating from studies in children,* *'Where there are gaps in the adult evidence base, it may be possible to extrapolate carefully from the evidence about interventions for children and young people.'*

	evaluating experimental functional analysis of CB and the development of programmes for improving the lives of adults. For a very early example relating to these issues, see the following publication: Van Houten, R. & Axelrod, S. (Eds). (1993). Behavior Analysis and Treatment. NY: Plenum Press. See also the Journal of Applied Behavior Analysis – search for Challenging Behavior in that journal. To be a Behaviour Analyst, the idea that one may not extrapolate from studies with children to studies with adults is as alien as suggesting that gravitational forces stop working when one reaches the age of majority. As a science of behaviour, Behaviour-Analytic principles may be brought to bear equally for adults and children. The specific types of procedures invoked may differ for the two groupings. Nevertheless, the basic principles remain. Behaviour does not cease to be susceptible to reinforcement contingencies according to age. The age range covered by students of Behaviour Analysis at the University of Kent since 2006 is 3yrs – 72yrs. The students received the same training and were supervised to adapt that training to a variety of client groups – successfully in every case. This section should conclude with reference to the NICE GDG conclusions and a recommendation that Behaviour Analytic procedures such as Experimental Functional Analysis and replacement behaviour shaping be employed particularly in cases of CB.	*A sentence signposting the NICE challenging behaviour guideline has been added.*
7.5	Appropriate.	*Noted, thank you.*
	'NICE found only one study of CBT for adults with ASD' In cases like this should you cite the primary paper as well as NICE?	*It is SIGN methodology to cite the systematic review to emphasize that a thorough search had been conducted. Citing the individual study as well may be misleading as it would be a double reference to one source of evidence.*
	The discussion of ways to modify CBT was also very nice and much more clinically oriented than the discussions about interventions in children – why?	*It is based on a summary of clinical guidance, due to lack of evidence. The child section discusses individual studies.*
	In the second paragraph, beginning "The SIGN review identified…" there is a typo in the second sentence "was" should read "were."	*Amended*
	The discussion of harms in this section is also even more relevant to interventions with children and could be moved up to earlier.	*Harms were taken into account in the considered judgement for the children's interventions. Only one of the systematic reviews addressed harms and none were reported.*
	This section refers to involving a parent / carer in delivery of therapy, This will only be possible if the parent / carer is fully supported and assessed routinely for stress / depression. We need help to deal with the constant grief spurts we experience throughout our children's lives. Each time another milestone is not achieved.	*Many of the approaches we examine refer to the importance of involving family members and other carers. This we think recognises the fact that family stress and grief processes need to be taken into consideration alongside other needs.*
	The NAS welcomes the recommendations on adapting CBT and the inclusion of examples of how practitioners should go about this from the NICE guidelines.	*Noted, thank you.*

8.1	Paragraph 5. In line with the rest of the document, this really needs updating if not to contradict advice offered elsewhere. You should add 'the use of behavioural approaches should be tried' here, alongside trying changes to the child's environment or daily routines, before making a decision about using medication.	*The group consider that this is adequately covered and the section does not need to be changed.*
	General section on psychopharmacology for children and young people (from SIGN 98) said there was no evidence directly comparing pharmacological and non pharmacological treatment. From the draft guideline there has, since then, been a trial of melatonin vs other interventions for sleep problems (description of trial appears in separate sections on non pharmacological treatment and pharmacological).	*Text amended.*
	The NAS has concerns about the use of medication for managing challenging behaviour. We believe the root causes of challenging behaviour can be masked by the use of medication and impede understanding of the causes of such behaviour. We are not convinced that the benefits of such medication outweigh the harm. The use of medication must be considered very carefully and only when all other interventions/therapies have been attempted. It should be prescribed by medical professionals experienced in autism and mental health. We would also strongly suggest that further assessment is made regarding the use of Risperidone, related both to its side effects and clinical testing.	*The guideline group share these concerns and have amended text to say balance of risks and benefits needs to be very carefully considered.* *Sentence and recommendation added to sect 8.2 re monitoring.*
8.1.1	Comments should include discussion with patients and/or parents about the unlicensed/off label nature of any medicine and what this means.	*Reference to section 1.2.3 added to sect 8.1*
8.2	When discussing aripiprazole and risperidone, I think it is worth reinforcing they are unlicensed for ASD at the start of this paragraph. I appreciate there is a general statement at the introduction to section 8 but think it would be better to be reinforced when discussing evidence in some detail for individual medicines, and this reinforced in the summary recommendation.	*As no pharmaceutical therapies are licensed for ASD it would be too repetitive to have this statement in every section. It is given in the introduction and a reference to section 1.2.3 added.*
	The NAS has specific concerns about the use of anti-psychotic medication for managing challenging behaviour, including irritability. 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 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 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. In addition, it should be prescribed by medical professionals experienced in autism and mental health.	*Sentence from NICE and additional recommendation added.*

8.2.1	Unlicensed point as above.	*See comments above.*
	Evidence not relevant to NHS in Scotland. Does each ineffective medication need a separate section or could sections on medications for which no current evidence be combined?	*It is useful to include, for information. It is easier for readers to locate the section if it is within the SGAs section.*
8.5.2	This is where I was surprised the evidence was considered so strong.	*This is because it is rated as the quality of the Cochrane review rather than the studies in it. It has been reworded to clarify.*
8.7.2	The "love" hormone. Some evidence that this might work because it is produced during intimacy and seems to work in the bonding process between mother and baby.	*As stated, further studies are needed to determine efficacy.*
8.8	Melatonin – This is not recommended by SMC and is also only licensed as monotherapy for the short-term treatment of primary insomnia characterised by poor quality of sleep in patients who are aged 55 or over. This recommendation is contrary to the license and current SMC advice. SMC would not be able to assess for use in children until the product was licensed (and the company submitted). I don't think this background is clear enough in the section.	*Wording revised.*
	Don't agree that recommendation should include "and reduce night-time waking", as not clear that evidence backs any effects on this aspect of sleep difficulty, only sleep onset latency.	*Removed*
9.1	Given the emphasis in the guideline of ASD being lifelong it seems unhelpful to have such a separation and emphasis on separate listing of drugs for adolescents and adults. Principles of pharmacotherapy overlap in terms of consent, baseline measures, adequate assessment and monitoring, and prescriber skills. If division by age is felt necessary need to give age range for subjects when studies being used as evidence - definition of adult can be 16+.	*It was considered more accessible to have separate sections. Most of the adult evidence is extrapolated from child studies.*
	Perhaps a word about polypharmacy – it is a real risk for adults. Typically folks are on 3 or 4 things and it gets hard to sort out!	*This is common to any prescribing. 'Interactions with other medicines' has been added to the good practice point.*
9.2	Antipsychotic medication should be considered for addressing challenging behaviour in adults with ASD, either with a psychosocial intervention or on its own, when psychosocial or other interventions could not be delivered due to the severity of challenging behaviours. There is a body of research evidence of ABA based interventions being effective when based on properly conducted functional analysis (see Iwata, Dorsey, Slifer, Bauman, & Richman, 1994) (rather than functional assessment) even with severe challenging behaviours. Therefore this sentence should have a cautionary note, such as 'as a last resort'.	*We cannot add a comment such as 'as a last resort' because these findings came from NICE who did not feel it necessary to qualify in this way. This comment is asking a different question ie is ABA better at managing challenging behaviours than anti psychotics, which the evidence review for this guideline did not address.*
	As with my comments about children, I think it needs to be clearer that the medicines discussed (antipsychotics) are all unlicensed/off label for use in ASD.	*It is not unlicensed in this context. It is recommended for behaviour that challenges, not core symptoms of autism.*
	Similarly, there is a recommendation for adults to receive antipsychotic medication. I was again surprised that this did not have at least some disclaimers, even though I do concur that is sometimes necessary. I may have been inordinately affected by the recent press about risperidone (even though the	*The recommendations are based on NICE guidance and include caveats for review and stopping treatment.*

	difficulties preceded the clinical trials in autism and do not really cast doubt on those).	
	I think that I would reference the huge body of work by Deb and Unwin. They have looked extensively at the prescription of medicine for people with learning disabilities - they have not looked specifically at autism; but this work has influenced national and international guidelines. Characteristics and the trajectory of psychotropic medication use in general and antipsychotics in particular among adults with an intellectual disability who exhibit aggressive behaviour S. Deb, G. Unwin & T. Deb. Journal of Intellectual Disability Research doi: 10.1111/jir.12119 volume 59 part 1 pp 11–25 January 2015. This is just a general reference with lots of other useful references. Deb S., Kwok H., Bertelli M., Salvador-Carulla L., Bradley E., Torr J. et al. (2009) International guide to prescribing psychotropic medication for the management of problem behaviours in adults with intellectual disabilities. World Psychiatry 8, 181–6. This is a reference for guidelines for prescribing medication for the management of challenging behaviour. International guidelines drawn up following guidelines drawn up for the Royal college of psychiatrists. They make a number of recommendations, which I think are relevant for the SIGN guidelines. In particular, they have done a lot of work on the successful withdrawing of antipsychotic medication - the challenging behaviour does not always recur. Would you consider adding a recommendation that there should be long term review of antipsychotic medication, as it may be possible to reduce the dose or discontinue altogether??	*This has been addressed in the recommendation. It would be appropriate in any clinicians practice to keep a patient under review who was on medication and to reassess the benefits of those medications over time and withdraw if no longer needed or ineffective. This is reflected in the good practice point in 9.1*
9.3	The NAS has concerns about the use of anti-psychotic medication for managing challenging behaviour, including irritability. 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 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 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. In addition, it should be prescribed by medical professionals experienced in autism and mental health.	*We make it clear that medication should only be prescribed by a specialist.* *An additional recommendation has been added to the children's section that children treated with antipsychotics should be reviewed after three weeks and treatment stopped at six weeks if no benefit.*
9.6	There is mention of fluoxetine trial in adolescents in this section (no reference). Seems to conflict with what is said in 8.5.1.	*Fluoxetine is used to treat coexisting mental illness in adults and its prescribing could be different from adolescents.*
9.10.2	See above comments under 8.7.2. (The "love" hormone. Some evidence that this might work because it is produced during intimacy and seems to work in the bonding process between mother and baby.)	*As stated, further studies are needed to determine efficacy.*

9.11	The license is summarised to highlight that melatonin is only licensed for short term use in adults over 55 years, but it should also refer to primary insomnia to be clear that it is not licensed for ASD.	*Added*
	Re recommendation: Use of melatonin should follow consultation with a psychiatrist with expertise in the management of sleep medicine and / or ASD, and be in conjunction with behavioural interventions. We have previously discussed this as adult LD services for Glasgow (= 12 consultant LD psychiatrists). We agreed that we were not prepared to offer psychiatric input only to facilitate prescription of melatonin. I think it was mostly pragmatic - i.e. otherwise we would end up having large caseloads purely to review melatonin prescription, when arguably our time would be better spent elsewhere. But there was also a feeling from some of the older psychiatrists that we had not had training in sleep medicine, and why should we be seeing patients who do not have a psychiatric illness? Are we really the best placed, or would a GP (with access to medical history including epilepsy) be better placed to prescribe melatonin? In practice, I think that patients are referred in to the team, and they are sent on to psychiatry when nursing advice and intervention has not been successful. But if this is a recommendation in the SIGN guidelines, there is a real risk that GPs will subsequently send all of their patients on melatonin for ongoing psychiatric review - even if they had been well and stable for years, and no longer under CAMHS / LD_CAMHS or other specialist children's service. However, I don't feel strongly - as I think that it would probably be good practice for psychiatry or other specialist to at least initiate melatonin, even if they don't end up reviewing them for the next 50 years.	*Because the indication is unlicensed in adults under the age of 55 it is preferable for it to be initiated by a specialist.*
General	More activity based help such as outdoor sports and indoor sports for adults and children.	*A further search was conducted but no evidence identified.*
	Appropriate.	*Thank you*
	We acknowledge the limited remit of SIGN to recommend service provision. However, given that there is a section on service provision, this should be as robust as possible and apply to both children and adults. There is a particular deficit in terms of covering service provision for adults. This section should also reference the importance of referring for community care assessments. The guidelines should specifically reference that some people with autism will require access to services which understand and are able to meet the needs of people specifically related to their autism [Scottish Strategy for Autism, p7]. Given the acute barriers faced by people with autism when moving into work, these guidelines should include a new section 10.5 covering individual supported employment programmes for adults on the spectrum. There is evidence of their effectiveness. The NICE has a clear recommendation around the provision of individual supported employment programmes for adults on the spectrum [NICE, Autism:	*The evidence for this section has not been reviewed but further detail about service provision for adults has been added.* *This is outwith the remit of the guideline.*

	recognition, referral, diagnosis and management of adults on the autism spectrum, 7.9.4, p254].	
	In agreement with the outline of the section however no good practice points are made on how to co-ordinate training and who should deliver this. The Autism training framework points competencies and training needs but does not make recommendations on who is best placed to deliver this. How do we ensure quality training in Scotland?	*This is a discussion for an implementation meeting, rather than for inclusion in this evidence based clinical guideline.*
10.1	Welcome the involvement of parents with preschool children in interventions.	*Noted, thank you.*
	Excellent.	*Thank you*
	Again, support for the caregiver needs more emphasis and possibly a sign guideline of its own. I have battled with social work for 3 years to get some care support to help look after my son. Everything is a battle and basically getting out of bed each day is a battle, support us and we will be able to support our children.	*Noted, but without the evidence base it is difficult to include more detail in a clinical, evidence-based guideline.*
	Given the well-informed treatment of Behaviour-Analytic programmes noted earlier in the document (6.3.1) and the statement above concerning the extension of scientific principles from children to adults, the statement at B and the good practice point should read: B: Behaviour-Analytic awareness and training for parents of preschool children with ASD should be provided. Behaviour-Analytic interventions should be offered to parents of all children and young people with ASD.	*This suggestion is too specific for this section.*
10.2	Makes the important point that gaps in professional training can reduce effectiveness of delivery of interventions Is compliance with the Autism Training framework mandatory at all levels?	*Noted*
	Excellent.	*Thank you*
	You say in 6.3.1 'In Scotland practitioners with comprehensive ABA skills are not widely available..' and 'Applied behaviour analysis approaches are dependent on the skill and training of the personnel delivering them'. However, there is no reference to or recognition of the skills gap here in 10.2, and the training needed to address the shortage of people trained in behaviour analysis in Scotland. I can't find any reference to behaviour analysis or ABA in the Autism Training Framework. You need to highlight the very great need for specialist training of this type here.	*The evidence in this section has not been reviewed and is taken from SIGN 98.*
	The Autism Training Framework (NHS Education for Scotland) D: Not sure if I have read this correctly - are we saying this is specifically for autism practitioners and services or is it the case that all services should check ASD training is relevant for all their staff?	*The recommendation is intended that those working with individuals with ASD have appropriate training. Taken verbatim from SIGN 98.*
	We need proper ABA professionals training staff in ABA. Just one or two at the top, as if you don't start with the right application of the principles, it will all be too watered-down by the time it reaches the children and will be ineffective.	*This is covered by the recommendation which applies to the training needs of all healthcare professionals. Focussing on ABA is too specific.*

	See BACB guidelines, these should be included as pre-requisite requirements for anyone carrying out behavioural interventions. There are 4 different levels and clear supervisory structures. These are internationally recognized and should be adhered to. The foundations for Licensure for BCBAs were laid some time ago (Dorsey, Weinberg, Zane, & Guidi, 2009) and this is now rolled out across USA (http://bacb.com/licensure-regulation/).	*This is covered by the recommendation which applies to the training needs of all healthcare professionals. Focussing on ABA is too specific.*
	There should also be a good practice point on raising awareness and sharing learning from the guideline across services.	*This is for implementation meetings rather than inclusion in the guideline.*
	Given the acknowledged lack of comprehensively trained professionals in ABA technologies and recommendation that such professionals be available (section 6.3.1) I expected there to be reference to this training need within the training section.	*This is covered by the recommendation which applies to the training needs of all healthcare professionals. Focussing on ABA is too specific.*
	Given the well-informed treatment of Behaviour-Analytic programmes noted earlier in the document (6.3.1) and good practice recommendation that Applied Behaviour Analysis approaches should be implemented, training recommendations re ABA should be made in this section.	*This is covered by the recommendation which applies to the training needs of all healthcare professionals. Focussing on ABA is too specific.*
10.3	Issue of patient satisfaction with outcomes for children as well as parents Should diagnostic tool be included under support for professionals(11) Need to produce good quality written information perhaps also in other formats is fully endorsed As is opportunity to ask questions about disclosure of information Also recognise the need for full range and individualisation of ASD presentations.	*This is general clinical practice and outwith the remit of the guideline.*
	Should link back to the importance of parent training and the effectiveness of parent initiated interventions.	*This is about general support and information rather than specific training for parent-initiated interventions.*
	There could be a point relating to adults rather than only children.	*Amended*
10.4	What support mechanisms can be in place to enable this and. Would patient friendly summary of legislation usefully be included Section 11 The timescale of support could perhaps be staged Questions need to be answered immediately but will change obviously after diagnosis is absorbed and adjustment period must as described be flexible.	*Legislation is outwith the remit of the guideline. Timescale for support is difficult to determine.*
	Provision of link to the Scottish Transition Forum in the Resources section would be helpful (www.scottishtransitionsforum.org.uk)	*Added*
	Someone who has and is looking after the same child to explain the problems rather than it being someone's chore, and job to do.	*This is covered in GIRFEC.*
	Appropriate.	*Thank you*
	Possibly extend to add examples of changes and transitions that do not only relate to the most obvious, e.g. move from CAMHS to AMH services, but to include other ordinary transitions/changes as per The Autism Training Framework Key Area 3.	*This is covered in the Scottish Transitions Framework.*
	This is well done.	*Thank you*

11.1	Yes but plea for it to be simple and understandable as assessment evidence has potential for jargon Again endorse need for training of professionals in this Copying in to letters valuable but again care must be taken with language to ensure its value and alternative formats considered Fully agree with knowledge of condition being updated	*Noted*
	Do you want to slightly more explicitly mention information (and training) for professional staff involved in the individual's care. Most obviously for CYP teachers etc. but applies more generally (e.g. Pat's work on employment and some of the AS community initiatives in the USA)	*This is outside the remit of this clinical guideline.*
	The section on “at the time of diagnosis” is very thoughtful but stylistically very different than some of the previous sections, which are less thoughtful and include various amounts of literature citations and criticisms. I think most clinicians would find this section very useful.	*The evidence-based nature of the guideline requires other sections to include descriptions of the underpinning research and the reliability of its findings. This section is based on more qualitative approaches to provide good practice advice.*
	Proper Autism web sites AOA, Arnica, JABS all seem to be missing of any official merchandise.	*AOA and JABS are related to vaccines and Andrew Wakefield research, which has been discredited.* *Cannot find an Arnica site related to autism.*
	Excellent.	*Thank you*
	Information is an important and welcomed section. There should be full sharing of information. Well trained parents take lots of data on child behaviour changes and professionals don’t always appreciate this.	*Noted, thank you.*
	The guidelines should clearly state that information should be made accessible in accordance with both legal requirements and good practice.	*GPP added re consent to provide information.*
	Agree in general - in clinical experience there is perhaps some situations were either family or individual may benefit from support around diagnosis issues and adjusting to a diagnosis.	*Noted*
11.1.1	Difficult to provide a written report at point of confirming diagnosis, but as soon as possible after dx is confirmed. Agree about verbal information given at this time and also to provide literature and information on local services etc available.	*Would prefer to keep the good practice point as it is to encourage healthcare professionals to provide written information as soon as possible after diagnosis is confirmed.*
	Again, there will be training implications for our local team due to the lack of healthcare professionals involved in the diagnosis/identification of ASD. Locally the healthcare professionals are not the members of the team sharing the findings of the assessment process.	*This is an implementation issue within the local service.*
	I think that may be worth commenting on the process if the person is NOT given a diagnosis of ASD? For example, they should be given an alternative explanation of any symptom or functional impairment? And if the person has ongoing needs, they should be signposted to an alternative service?	*Agree, but this is outwith the remit of this guideline. Differential diagnosis and diagnostic uncertainty are included in the checklist for provision of information.*

	Note that this guideline provides almost no information with respect to prognosis (“short and long-term consequences”), beyond the biased, weakly-founded claims that most autistic adults have very bad outcomes. It is unclear what to do here, but dire predictions of bad autistic outcomes have major negative consequences. Is there room, somewhere, to explain that with few exceptions (e.g., where there is a diagnosed genetic syndrome with more reliable information about prognosis), prognosis in autism across any time span is largely unknown at an individual level. To put it in very direct language, autistics should not be written off. This is wrong at every level—science, ethics, basic human rights. Yet autistics are written off all the time, including in the literature, and in guidelines. Obviously this would adversely affect anyone’s outcome.	*A new search for prognosis and regression has been carried out. Two new systematic reviews have been added (sects 4.4 and 4.6), but otherwise no further evidence of sufficient quality was identified.*
	Good practice point: issue of involvement of carer/advocate/partner etc and need for Consent to include them in the information especially if they are very much involved in Moving things forward.	*GPP added*
11.2	List of sources of information seems comprehensive.	*Noted, thank you*
	The information on the NHS Inform web pages requires updating. The pages continue to have a focus on the Triad of Impairments and Asperger syndrome which has the potential to be confusing for parents and individuals on the spectrum (particularly with the new diagnostic criteria). I note that some of the pages were last updated in 2012 which means information on welfare benefits etc has been superseded. The resource Health Talk online (www.healthtalk.org) has an excellent suite of resources on autism which covers the age span and includes information for parents, individuals on the spectrum, siblings and grandparents. The resource uses short 'talking heads' video clips of people's experiences on numerous aspects of autism including thoughts on diagnosis. The format makes it readily accessible for a wide range of the population. Professional Resources: Whilst the ASD Learning Resource is excellent should the Guideline take the opportunity to promote other health based resources such as the RCGP online resource Autism in General Practice (www.rcgp.org.uk)? Local Support groups and telephone helplines. The NHS Inform support services link does not contain a great deal of information on local support groups although it may improve with time. I would suggest adding the National Autistic Society, Autism Services Directory as the content is considerably more comprehensive and it is easier to negotiate. A link can be found on the NAS home page or accessed using the link below. http://www.autism.org.uk/directory.aspx	*Comments passed on to NHS Inform and link to A to Z article removed.* *Added* *This is only available to RCGP members, and others on subscription. SIGN prefer to limit the resources cited to those that are open access.* *Added*

	Given the strong emphasis on behavioural interventions throughout this document, you should provide links to organisations offering information and training on ABA-based interventions. For example: • The ABA charity Child Autism UK (formerly known as Peach) http://www.childautism.org.uk • The United Kingdom Society for Behaviour Analysis http://uk-sba.org • The Behavior Analysis Certification Board http://bacb.com	*The organisations cited provide general information for patients and carers, rather than listing every organisation/healthcare profession with input into autism spectrum disorders. We have included a link to NHS Inform which provides a wider list of ASD organisations.*
	Helpful and relevant.	*Noted, thank you.*
	Please change the contact details from the UK office to the Scotland office: The National Autistic Society Scotland - The National Autistic Society Scotland works throughout Scotland for people affected by autism (including Asperger syndrome). The NAS Scotland provides a wide range of quality, personalised support services for people with autism and their families and carers. NAS Scotland Central Chambers, 1st Floor 109 Hope Street Glasgow G2 6LL Tel: 0141 221 8090 Email: scotland@nas.org.uk Web: www.autism.org.uk In addition, reference should be made to: The Scottish Strategy for Autism http://www.autismstrategyscotland.org.uk Autism in Pink - An EU-funded partnership between four European autism organisations which has been set up to carry out research into autism in women www.autisminpink.net Email autisminpink@nas.org.uk	*Amended* *The Strategy is cited elsewhere in the guideline.* *This is outside the remit of this section of the guideline.*
	Sources of further information should include UK-Society for Behaviour Analysis http://uk-sba.org For information on Behaviour Analysis, Training and professional Certification Child Autism UK www.childautism.org.uk UK charity providing Behaviour-Analytic services and/or advice to families with children with autism.	*The organisations cited provide general information for patients and carers which link to more specific services rather than listing every organisation/healthcare profession or local support group with input into autism spectrum disorders. We have included a link to NHS Inform which provides a wider list of ASD organisations*
	FINAL RESOURCE: (Learning Resource) should read Web Resource. Change options to optometrists. ADD? NHS Education Scotland e-learning module 'Practical Strategies for the Primary Care Practitioner'. http://www.knowledge.scot.nhs.uk/home/learning-and-cpd/learning-spaces/autism-spectrum-disorder.aspx ADD? NHS Education for Scotland (2014) The Pharmaceutical Care of people with learning	*Added*

	disabilities. [Online] Available from: http://www.nes.scot.nhs.uk/education-and-training/by-discipline/pharmacy/about-nespharmacy/educational-resources/resources-by-topic/clinical-governance/learning- disabilities.aspx (Accessed 03/08/15).	*This is a document which can be accessed via the general NES learning resource already included.*
11.3	Just a formatting consideration for the final document... could this checklist be formatted over two pages to allow for potential printing? It is a useful resource / checklist for services, particularly those in development.	*Yes*
	P45 multi-professional group should include Behaviour Analyst (see above and also NICE Guideline 11).	*The list is not that specific.*
	Excellent.	*Noted, thank you*
	Could add this to the row "At Assessment appointment" for the specialist team. - Ensure that any identify unmet needs are signposted to the appropriate services?	*Added*
	Mention of RISK? Issue of consent regarding adults especially 'high functioning' specialist team: inform individual if adult, the parent/carer that they are welcome...	*GPP on consent added but would prefer not to get into further detail.*
	This is a great idea – I wish we did more of this!	*Thank you*
12.1	Appropriate.	*Thank you*
	Minor points -The lettering R R √√ B etc is very confusing, it is not clear at all what these letters mean.	*These have been changed to 'R'.*
	No mention is made of integration of social and health care or GIRFEC responsibilities of different agencies.	*This is outwith the remit of the guideline.*
12.2	In England, the National Institute of Health and Care Excellence (NICE) specifies that there should be a maximum wait of three months from referral to first appointment. This should be included in the SIGN guidance to help ensure that people in Scotland are not waiting too long to access a diagnostic assessment.	*This is outside the remit of the guideline. See previous comments.*
	I think there are costs in implementing the strategy/guideline, but I would not be able to quantify them.	*There may be costs for implementing, but for a budgetary impact assessment SIGN's threshold is £5 million. It is not considered likely that implementation of any of the recommendations will reach this threshold.*
	Please invest in ABA: you will save money at the other end if kids learn non-aggression, personal care and communication in their early years.	*See previous comments on ABA (section 6.3.1)*
12.3	It would be useful if the already developed audit tool was available on the SIGN website following the launch of the guideline.	*Permission is being sought from the authors.*
	Excellent. Will the SIGN 98 audit tool be appended?	*Permission is being sought from the authors.*
	You should add to the 'key points' here, something which refers to your key recommendation 2.2. For example: • Do children have access to support from staff trained in ABA-based interventions? If so, what is the nature of training and qualification of staff; and at what intensity	*Audit point added.*

	is this being provided?	
	I know that this is a bit fussy, but these are not actually "audit" - more service evaluation and observational research to assist with the implementation of the guideline. May I suggest a few more based on experience: - are (adults) receiving an ICD-10 or DSM V diagnosis as per guidelines - are (adults) receiving appropriate support, follow-up and information following diagnosis - are people actually able to access an appropriate diagnostic service at all.	*Added* *The audit point for children and young people has been adapted to include adults.* *This is for service delivery, not based on a recommendation but may become apparent if audit of the first suggestion is carried out.*
	We are concerned that the suggested key points for auditing of current practice do not reference adults with autism, including older adults. The audit should also monitor how long people wait for a diagnostic assessment. We recommend that these key points should also include: - How long children, adults and older adults are waiting between referral and initial appointment for assessment - How many adults with autism are offered an assessment and at what age - Is there a transition pathway for support from children's services to support from adults - Is there a pathway from diagnosis to support from social care for adults - Are there referral pathways and interventions in place to support adults with autism to move into employment.	*Some audit points have been amended to include adults and new points added.* *Audit points should be based on recommendations or discussion in the guideline and waiting times are not covered.* *This is too vague to use as an audit tool.* *Added* *Outwith the guideline remit.*
	Is there a role for including auditing co-morbidity, psychological interventions offered and medications prescribed?	*Further audit points have been added.*
	Had hoped this section would refer back to the recommendations made and the audit of their implementation. It focuses heavily on diagnosis and recommendations relating to intervention appear to be neglected.	*Additional points added.*
	Given the emphasis placed on Behaviour Analysis in earlier sections it is worth including in the audit of services whether or not and to what extent Behaviour Analysis is in place either in the public or private sphere in Scotland. Please see comments above re page 25. The "approaches" commented on there should be part of the recommendation for audit of current practices. In particular, audit of their cost to the public purse should be recommended. Given the paucity of evidence of benefit, public funds may subsequently be appropriately re-directed to fund training in ABA which has, as the document notes, considerable evidence of benefit.	*See previous comments on Behaviour Analysis (section 6.3.1).*
	Needs question marks.	*Added*

12.4	The SMC advice on melatonin should also be included here, despite it being not recommended (SMC No 500/08). There has been a NICE MTA which superseded some SMC guidance, (NICE TA 98) but it was published in 2006, but does not appear to have been updated so far. In this SMC section, it may be worth highlighting that SMC only looks at newly licensed medicines and therefore medicines that don't have a license for ASD are out with SMC remit.	*Added* *This is covered in section 1.3.3*
13.1	We are confident that SIGN have considered all relevant publications. However, for reference and in case of need, we include here details of publications we are aware of that were considered by NICE National Clinical Guideline 170 in their review. Allgood N. Parents' perceptions of family-based group music therapy for children with autism spectrum disorders. Music Therapy Perspectives. 2005;23:92-99. Gattino GS, Riesgo RDS, Longo D, Leite JCL, Faccini LS. Effects of relational music therapy on communication of children with autism: a randomized controlled study. Nordic Journal of Music Therapy. 2011; 20:142-154. Kim, Jina, Wigram, Tony and Gold, Christian. "The Effects of Improvisational Music Therapy on Joint Attention Behaviors in Autistic Children: A Randomized Controlled Study" J Autism Dev Disord (2008) 38:1758–1766 Lim HA. Effect of "developmental speech and language training through music" on speech production in children with autism spectrum disorders. Journal of Music Therapy. 2010;47:2-26. We are also aware of evidence of parents noting the lack of available music therapy provision, reported here: Dymond SK, Gilson GL, Myran SP. Services for children with autism spectrum disorders. Journal of Disability Policy Studies. 2007;18:133-147. Serpentine EC, Tarnai B, Drager KDR, Finke EH. Decision making of parents of children with autism spectrum disorder concerning augmentative and alternative communication in Hungary. Communication Disorders Quarterly. 2011;32:221-231.	*SIGN have cited the 2014 Cochrane review rather than individual studies.*
	Appropriate.	*Noted, thank you.*
	Eldevik et al 2010 needs to be added.	*This paper is Eldevik S, Hastings RP, Hughes JC, Jahr E, Eikeseth S,Cross S. Using participant data to extend the evidence base for intensive behavioral intervention for children with autism. Am J Intellect Dev Disabil 2010;115(5):381-405* *It was not selected from the original search results because we used systematic reviews rather than individual studies.*
	Can the search terms be included as unclear how some interventions or assessment tools are included and others not.	*Additional search being conducted and terms will be listed in annex 1.* *Search strategies will be published as supporting material on the SIGN website.*

13.1.1	Appropriate.	*Noted, thank you.*
	Line 3 "early management of patients with head injury" does not outline patient issues or how qualitative information was included in the guideline. Could this be a typo?	*Amended*
	"A literature search for qualitative and quantitative studies that addressed patient issues of relevance to early management of patients with a head injury?" This text seems to have wrongly been copied from SIGN 110 on brain injury, see p. 45 of that document. It is irrelevant to autism and needs to be changed.	*Amended*
13.1.2	I think the last sentence shouldn't be included in the bullet points - I think it is a typo.	*Aiding implementation is one of the criteria for addressing cost effectiveness.*
13.1.12	Appropriate.	*Noted, thank you.*
13.2	Positive to note the research recommendations have a focus on topics which are more likely to have a practical impact on the individual/ families living with autism.	*Noted, thank you.*
	Funding of research monitoring the learning progress of pupils at Stoa School and comparisons with similar cohort learning through the TEACH system in special needs schools.	*The recommendations for research are based on the key questions used to produce the guideline. This is outwith the remit.*
	Helpful and focused.	*Noted, thank you.*
	I note the need identified for studies into the adaptation and/or development of identification and screening tools for children and adults with ASD who have an intellectual disability. As this is a significant proportion of the population, and various recommendations are made in the guideline based on this, the lack of adequate measures at present is a cause for concern.	*Noted*
	Clinical audit to identify core service delivery in treatment settings would be useful to establish base line data. Evaluation of art therapy as psychological therapy intervention with this client group.	*The audit points are to check if the recommendations in the guideline are being implemented. There are no recommendations on what constitutes core service delivery or art therapy.*
	It should be clarified that research should examine technology-based interventions looking to improve communication. We particularly welcome that the research should consider the preferences and abilities of the individual with autism, and whether the software can be customised to their needs.	*CBI is included in the recommendations for research.*
	I ask this question without providing any suggestions about where to seek the evidence (!) however I have been aware of research on the impact of digital interventions e.g. using iPad/online interaction/e-befriending services, etc. Is there insufficient data to include research findings on this subject here? Another area I feel that is missing from the guideline is regards parents who have ASD themselves. This is a burgeoning area of challenge requiring support from services, and as we continue to improve our diagnostic systems and processes, I feel Services need also to prepare for interventions and support for the parenting stage in the life of the person with ASD. I know the impact is massively under-researched, but I would be hopeful that a mention here would strike an anecdotal chord with many practitioners across the agencies	*Permission is being sought from the authors*

	(and with those parents themselves). Is it an area that could be flagged up?	
	Appropriate, although would it be helpful to add the audit tool for SIGN 98?	*Permission is being sought from the authors.*
	It misses out adults with a mild learning disability. Could put them in the "adult" box - but actually in terms of clinical presentation they fit much better with the adolescent box (which describes an adult with a mild LD down to a T). For the moderate or severe intellectual disability - it may be helpful to reiterate that all of the features are over and above what would be expected from the known level of cognitive impairment. I would expect somebody with a severe/profound LD to need rigid routines, repetitive activities and limited empathy - just more so and with a qualitative autistic flavour in somebody who also had autism. But I think that overall the boxes are very helpful.	*The guideline group do not think it is necessary to include a list for adults with mild learning disability, as clinicians will be able to pick up signs and symptoms from those listed for adolescents and adults.* *Agree. Added*
	In Annex 2 Warning signs for school aged children no mention is made of non-verbal difficulties as for pre-school children and these continue to warning signs at this developmental stage.	*Added*
14.3	p53 Dr Janine Robinson NHS Education for Scotland	*Amended*
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