

Comments	Group response	Editorial response
Is the layout easy to read?		
<p>As with my comments on the booklet for adults - "I found the constant changes of colour annoying. People with ASD require it to be clear not pretty. You don't need the coloured boxes. Just use the symbols and make them different colours to make them easier to read."</p> <p>I still think the symbols would be easier to follow if different colours.</p>	<p>√</p> <p>User testing would be required.</p> <p>We carried out user testing of the different colours after the consultation but the majority of people preferred the green symbols.</p>	<p>√</p> <p>√</p>
<p>Easy to read layout for all booklets, nicely broken down using diagrams and good use of speech bubbles to get across real life views. Some pages seem slightly empty, text could fill the page better or more diagrams/bubbles could be used.</p>	<p>√</p>	<p>√</p>
<p>Yes</p>	<p>√</p>	<p>√</p>
<p>The booklet is presented very well, easy to follow and to understand.</p>	<p>√</p>	<p>√</p>
<p>I like that it is clear from the start what the booklet covers. The booklet looks very professional and better than other information seen.</p>	<p>Thank you.</p>	<p>√</p>
<p>Yes</p>	<p>√</p>	<p>√</p>
<p>Very well written and presented. Yes.</p>	<p>√</p>	<p>√</p>
<p>A bit cluttered in places but it looks good. What's the signs about? I'm not sure they are needed. We want to know what can help so should it not be the</p>	<p>Ok, we carried out user testing with another patient</p>	<p>√</p>

<p>interventions that you have researched and work?</p>	<p>version for a different audience who understood and liked symbols. Further user testing required.</p> <p>User testing presented the symbols to people. They understood them and found them helpful.</p>	<p>√</p>
<p>Are the images and diagrams appropriate and meaningful?</p>		
<p>Yes, they work well in this context.</p>	<p>√</p>	<p>√</p>
<p>Again, good use of images- many images are repeated between booklets and make sense in the context.</p>	<p>√</p>	<p>√</p>
<p>Yes. A bit of visual cue for finding their way around. The speech bubble quotes work well.</p>		<p>√</p>
<p>Yes</p>	<p>√</p>	<p>√</p>
<p>Yes. They help to break up the text and I would say they are suitable for this type of leaflet.</p>	<p>√</p>	
<p>I've just read the draft parent/carer guide. There is a good mix of narrative and images. As a parent of a child newly diagnosed in March, it is my opinion that this leaflet is written in a very narrow traditional and stereotypical view of autism. It makes a nod to the fact that girls often present differently but does not provide a thorough enough level of detail to help parents of girls who may be wondering</p>	<p>Parents helped us to develop this. Add box in giving information on girls.</p>	<p>√</p>

<p>about a diagnosis but not seeing a traditional presentation which is what most Professionals only recognise and is why girls diagnosis remains statistically significantly less. This is unfair and discriminatory. How about the addition of a section devoted to girls presentation. This might help parents who are struggling to work out what is wrong, but when read autism leaflets like this, they don't recognise their child. And professionals need this same distinction and better understanding too. Too many people stick to a stereotypical view and fail to spot symptoms in girls which leads to later diagnosis and later interventions. Not good. Please support and recognise girls appropriately in this leaflet. Dr Tony Atwood provides some excellent material explaining girls excellently. They are not any less valid than the stereotypical presentation. > Also CBT Is Suggested , however It is recognised as being pretty ineffective in most autism cases. So that puzzles me?</p>	<p>Recommended in guideline.</p>	<p>√</p>
<p>I think so. not really sure how you could illustrate this. I think the images break it up as sometimes leaflet have too much text.</p>	<p>√</p>	<p>√</p>
<p>Do you think that the language and tone is appropriate?</p>		
<p>Yes (out of the 3 booklets) it works best of all in this leaflet.</p>	<p>√</p>	
<p>Some of the language needs to be clarified or put in context to make it more meaningful: What does "recommendations based on research evidence" actually mean? How can they be ranked by strength? Dr Damian Milton's research paper published in 2014 entitled " So What Exactly are Autism Interventions Intervening With?" explains the problem with all research</p>	<p>This was tested with users in a research project. Suggests further user testing is required by SIGN if not understood by a wider audience. User testing indicated that people do understand what this means and they want this information.</p>	<p>√</p>

<p>evidence.</p> <p>http://www.bild.org.uk/EasysiteWeb/getresource.axd?AssetID=6239&type=full&se rvicetype=Attachment</p> <p>The guideline recommends ABA more highly than using a timetable to help ASD children. This is confusing for a parent and carer looking at interventions to help their child. There is controversy on social media about ABA , it is not generally available and I understand there are only a handful of certified therapists in Scotland. http://smallbutkindamighty.com/2015/06/16/aba-and-autism-the-thorny-problem-of-control-and-consent/. In contrast, using a timetable is probably the easiest understood, most widely used, established, powerful and effective intervention, which benefits many children of different neurologies without confusion or controversy. Timetables should be the most highly recommended.</p>	<p>We agree that using timetables is easily understood which is why we used this. Add in that parents can use routine.</p>	<p>√</p>
<p>The tone is missing any anger at injustice, which will be there for many of us in our pre-diagnosis lives if we were diagnosed any later than infants school age. A welcoming approach, positive about the future, of course matters to not making the whole autism scene and services daunting for the person. But a key service, whose absence undermines the effectiveness of other services and leaves the person feeling crushed stressed and uncared for, is the principle of undoing every mistake and injustice which the person suffered in their life before diagnosis, or is still suffering at the time of diagnosis. Some word on where to turn to pursue that, is a vital part of the whole situation the reader is in.</p> <p>YP and P+C will both impact the lives of children who are subject to school uniforms. To be subject to a uniform in conflict with the child's own sensory issues is wrong, all spectrumite children need to know they do not have to take that. At the NAS's conference in Aberdeen on 27 Mar 2015, Luke Beardon cited a case of a man he had met through the NAS, so I cited all his audience of c200 as child protection witnesses to it when I emailed notice of it to every education authority in Britain. He had been unable to pass exams and caused a failed school</p>	<p>Can we use this as a quote to put this message across? Reviewer agreed.</p>	<p>√</p>

<p>outcome, and lost life chances, unjustly, directly from a painful sensitivity to the knees, making them feel "on fire" from fabric pressure. This man's sensory issue makes him need to wear shorts, but he was forced by school dress code to wear long trousers, including under exam stress. It destroyed his schooling, unjustly, because he could not focus on work and exams with his body being tormented medically unsuitably.</p> <p>I happen to have a sensory issue favouring shorts too, and recognition of it as an adult worker by all the employment support systems. How have I this as an adult, ever since 2009, without it applying to school age children the same? Obviously it does apply to them, and they are medically harmed and harmed in their educational chances by anyone who says it does not apply to them and who omits it from their entitled needs at school.</p>		√
<p>Yes</p>	√	√
<p>No. I am not convinced by terminology such as switching between ASD and autism on page 3, although it becomes more consistent later on.</p>	<p>We had to do this as parents and young people did not like the term ASD but professionals use this term to help with the classification. Autism was the preferred term. We have tried to illustrate this on page 3 which us why it then becomes consistent as this is the term we use throughout the booklet. We will aim to improve this and clarify further.</p>	√

Under "observation" use of terms such as intervention and instrument are not friendly nor accessible terms for families	Change to 'tool'.	√
Yes	√	
Fine	√	
Yes, please clarify jargon on p. 16 Disco, Adi-R, 3di	Write in full with abbreviation in brackets.	√
I'd use sensory preferences or difficulties, not sensory behaviours on p. 22?	Use sensory difficulties	√
Yes, easy to follow and written in a sensitive tone. You won't please everyone!	√	√
How useful is the content?		
Very informative and neither overly positive or overly alarming.	√	√
Generally it would be more useful for parents and carers to understand the child if there was less focus on the diagnostic criteria and symptoms (relating to difficulties in social interaction, restrictive repetitive behaviour and use of imagination and play). Why are these the deficits/issues in themselves that need interventions, when are these acceptable differences in a person's way of being? Focus more on why these characteristics occur and only once they are understood can a parent/carer truly feel empowered and informed in how they wish to help an autistic child. Parents/carers need to understand an autistic child's experiences and what is driving their behaviour before they can really feel empowered to help.	The guideline focuses on diagnostic criteria and interventions so it was important to the parents we spoke to to highlight the signs and symptoms. We hope that by giving parents/carers a lay translation of the clinical guideline they will be empowered as they will be more aware of the diagnostic criteria and interventions recommended.	√

<p>The document could do more to promote the acceptance of neurological differences as psychologically this would help the parent / carer in their interaction with the child as well as the child's self-esteem. A large amount of an autistic persons issues are down to living in the majority neuro-typical society. Things have moved forward for LH individuals, are moving in the right direction for dyslexics and now its time to start moving forward with autism as a neurological difference? It should also be acknowledged up front that adverse autistic behaviour (outbursts, avoidance, controlling) is typically because a child is scared, anxious or angry. There seems to be an increasing amount of knowledge supporting this.</p> <p>It is unclear in the document what aspects of autism are being considered a disability, as opposed to a difference, or is the difference the disability?</p> <p>It would be useful to explain that autism is a brain difference which can impact any of the 8 senses and motor processes and therefore the way a child experiences the world.</p> <p>More information is needed about what drives autistic behaviour and impacts the levels of functioning:</p> <p>Functioning is impacted by the level of anxiety, sensory and motor processing issues and cognitive abilities and the level can vary at any point in time depending on what is happening in the wider environment. It is very important to understand how these impact the individual child so parents can make adaptations and have</p>	<p>Mention behaviour perceived to be challenging and give examples. State that this can apply to all ages.</p> <p>Add another box in to page 3.</p> <p>Outwith the remit of this booklet – see above on the purpose.</p> <p>See above. The purpose of this booklet is to explain the recommendations and give details on assessment processes and interventions. We signpost to other organisations who can help people get the information such as that suggested. For example NAS is better placed to address all of these. Our document is</p>	<p>√</p> <p>√</p> <p>√</p> <p>√</p>
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<ul style="list-style-type: none"> - placing indirect demands - hands on learning in context (so more literal and less abstract) - keeping language literal and consistent - spending time talking about different feelings, emotions and perspectives - spending time drawing attention the fact that different people have different likes/dislikes and strengths and weaknesses. <p>The document could usefully state autistic behaviours such as stimming and needing lots of down-time are usual and almost always important as it helps an autistic self-regulate. This will also help people understand the function of autistic behaviours and help acceptance.</p> <p>Explain more how girls present differently to boys. There is a lack of knowledge amongst parents/ carers and still a lot of stereotyping.</p>	<p>quote with permission.</p> <p>Ok, alter slightly. Include box about girls.</p>	<p>√</p>
<p>Initial concerns pages are very relevant and well placed at the front of the booklet.</p> <p>Good use of examples.</p> <p>Good use of images to complement recommendations- done best in this booklet.</p> <p>Clear explanations with points of view from carers.</p>	<p>√</p> <p>√</p> <p>√</p> <p>√</p>	<p>√</p> <p>√</p> <p>√</p> <p>√</p>
<p>YP and P+C The content includes links to books by autistic child authors. Doubtless they were promoted to you by families who had read them and felt useful empathy with their own child's experience. You put this in the draft in good faith, because not enough awareness has been spread that there is a child cruelty involved in sharing these links. Self-interested big organisations have just preferred the game of easy good publicity from child authors, and for it face the consequence of being seen to blame for neglect of the sufferings of other</p>	<p>Recommended to us by young people and families who had read them.</p>	<p>√</p>

<p>children: neglect both of preventing them and of the survivors.</p> <p>There are wronged child authors. There are child authors whose chance to complete their writings and to make it was destroyed, by blundering exercises of power by adults. This is a child abuse. It is obviously cruelty and torture violating the human right to personal expression. It is compounded and continued, into adult life, by there not being general and wide recognition that this injustice exists, and parity of acknowledgement as child authors between the wronged and the ones who were allowed to succeed.</p> <p>The books you list in YP show that child authorship has a correlation with Asperger's. Child cruelty, and abuse survivor cruelty to a vulnerable group of adults, are both perpetrated every time that successful child authors are publicised and recommended but wronged child authors' existence is not mentioned.</p> <p>You issue these booklets with a responsibility that their users and distributors are not perpetrating these wrongs by using and distributing the booklets, as well as yourselves in producing them. The only way to meet this responsibility is - to mention wronged child authors in the booklets, in YP and P+C. Mention that we exist, that it is a horribly cruel issue that has happened and a life damage that must be averted for all the children who the booklets seek to help.</p> <p>It happened to me by school homework pressure: I am a survivor of abusive homework that gave me a stress collapse of near-death desperation at age 14 - exactly the same age as Luke Jackson's success. The resulting child psychiatry was also responsible for it, by how life-controlling and autocratically it behaved during my time out of school. This actually included by a doctor who was himself a successful author, and literary name in Wales where this happened: Harri Pritchard-Jones. I believe that homework is the cause of a missing generation of</p>		
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<p>child authors, where no non-famous children seemed to emerge as them after Lindsay Brown in 1978 until the autism ones started in 2001. It correlates exactly with when authoritarian conservative gung-ho certainties were most in vogue as the approach to schooling. But let us not assume that this is the only cause. In all eras there might be another heartbreaking cause of wronged child authorship, which is when the child wants to write something that is against their parents' religion.</p> <p>I am key evidence for all wronged child authors who were left with no evidence of their own. For I had the small luck that a traceable public record of my child authorship was created by 2 newspaper stories, about the now discredited greedy idea of "giftedness", both written to praise the same school as would destroy it. South Wales Echo 20 Aug 1980 and Western Mail 19 Jan 1982. You can see from the dates that I belong to the generation who had no childhood Asperger recognition, but today there is still no certainty that no autistic kids are being missed from recognition when adults have other greedy ideas for them, or are spared from homework pressure. This is an evidenced danger to the children who, and whose families, your booklets are aimed at, so it is a danger the booklets need to reflect for that reason as well as for the impact done to the past survivors.</p> <p>Stella Macdonald, Scotland's first local autism coordinator and a prominent autism charity worker in the 00s, knew me and used her contacts and top level work in autism to try to spread word of the child authors issue. In 2003 I told the autism cross-party group about it, minuted. ANS's website has twice carried contributions from me about it. How despite these efforts had word of it not spread enough to be on your radar? That only adds to the proof that it needs writing about wherever you mention any successful child author or promote their book. It is not widely enough known for inaction, without it the promotion of any child author success will do the child cruelty described. To be allowed their child author chance is another of the school adjustments that readers need telling that autistic children</p>		
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<p>are entitled to: not to be swamped out of it by homework, and to be heard without fear of discipline any time they feel pressured with homework. Tony Attwood is a reference on that issue.</p> <p>While the wronged have suffered the further wrong of going unrecognised, Luke Jackson has been made the most lauded child author in history. Yet the injustice actually includes that the forces who gave him his chance did not give him the achievement of unaided child authorship at all. It is in open public record, it just does not get emphasised, that he too never produced an unaided book as a child. Of course he should have had the chance if he wished it, same as I should have. Freaks Geeks + Asperger Syndrome, the book you list in YP and P+C, his mother Jacqui told the Times on 16 Aug 2002 was more her work. Luke denied, on a now defunct forum site in 2004, that the report was accurate in its quote that Jacqui did 6 hours' work to every half hour Luke did. But the fact was repeated in several profiles of them, that Luke only produced unformed unordered writings which took Jacqui's intervention of editing and formatting to make into a book, in the case of both the books credited to him at child age. Their first short book, A User Guide To the GFCF Diet, contained several chapters credited to Jacqui despite bending the book's PR by crediting only Luke as its author on the front cover.</p>		
<p>Useful content for typical autism. I feel strongly that the leaflet should give a bit more information on atypical autism and mention Pathological Demand Avoidance. PDA is now recognised as part of the autism spectrum and awareness of PDA is very poor. There are many people who are given a diagnosis of ASC for their children who spend years trying all the strategies for typical autism, which causes a great amount of distress to the child and everyone else involved. It is imperative to offer this information and "signpost" to prevent this, as it causes escalation of resulting anxiety and extreme behaviours.</p>	<p>The guideline does not give any more specific information in relation to atypical autism.</p>	<p>√</p>
<p>Very comprehensive but mixed up at times. For instance behaviour point is repeated on page 30 and 32.</p> <p>Sleep signs of apnoea/obstructive sleep apnoea/snoring- why are these picked</p>	<p>Error – remove from page 32.</p> <p>Whilst accepting the</p>	<p>√</p>

<p>out?- these are not common clinical presentations in children with ASD so should just fall within the category of "normal medical conditions" that all children may have and need to be dealt with in the normal way. I can envisage families asking me questions about being referred to a sleep clinic because of this point. Instead I think this bit should emphasise the sleep initiation and continuation in more practical detail rather than bringing this up.</p>	<p>importance of not becoming alarmist when coping with sleep problems, it is important that children with autism have the same care, and we avoid dismissing their need to have assessment of possible obstructive sleep apnoea if they have characteristic symptoms, but we could tone down the recommendation in the parent booklet to the following: Children with Autism may present with medical/physical causes of poor sleep just like other children and these should be considered</p>	<p>√</p>
<p>The part on "will my child's condition change?" should in fact be something more positive along the lines of "just as all children grow and develop, so do children with autism, instead of leaping into negatives, albeit these can be then discussed following initial statement.</p> <p>I am concerned that this leaflet is overly complex and full of negatives rather that</p>	<p>Remove</p> <p>Parents were involved in the</p>	<p>√</p> <p>√</p>

phrasing in a way which allows families to recognise their child but also see hope in what is known to help them.	development process.	
Good	√	√
Fairly	√	√
Very useful.	√	√
I think you have done a really good job but I don't like some of the language used. It sometimes puts blame on the child and I know that's not your intentions but it does come across this way. The signs you have listed are helpful but should probably say that your child might not have all of these as that could be quite scary.	Add sentence in to say that your child might not have all of these.	√
Does the content help patients and carers understand what the latest evidence supports around: diagnosis, treatment and self-care?		
Very much so.	√	
<p>(see relevant comments above.)</p> <p>P30 states that it is recommended that children with "autism should have access to support staff trained in ABA based technologies" .</p> <ul style="list-style-type: none"> - Which autistic children and for what aspects of their learning? - Support staff need to be trained in the science of ABA too? - Will this be supervised, monitored, regulated, by whom and how? - There are only a few certified therapist in Scotland so who will provide the training and practice supervision? - As ABA is a controversial therapy, there should first be an effective channel to escalate any concerns/make complaints. <p>Parents and carers need to understand why is ABA being strongly recommended now, in light of the above and following:</p> <p>1. There is an increasing amount of independent evidence questioning ABA effectiveness and its risks to a persons well-being, eg:</p>	<p>Guideline does not give specific details of ABA. There is one conditional recommendation on this.</p>	<p>√</p> <p>Therefore cannot say much in patient version.</p>

<p>http://smallbutkindamighty.com/2015/06/16/aba-and-autism-the-thorny-problem-of-control-and-consent/</p> <p>2. ABA is not validly supported by research: eg</p> <p>Dr Damian Milton's research paper published in 2014 entitled " So What Exactly are Autism Interventions Intervening With?"</p> <p>http://www.bild.org.uk/EasysiteWeb/getresource.axd?AssetID=6239&type=full&se rvicetype=Attachment</p> <p>3. ABA seems to be evidence based only in that it collects data documenting the increase or decrease in an observable behaviour.</p> <p>4. Therapists are modifying behaviour without understanding how autism drives it. eg:</p> <p>The US Guideline on ABA as a treatment for autism states that "examples of severe problem behaviours requiring focused intervention include....stereotypic motor or vocal behaviour, noncompliance and disruptive behaviour....." The document does not address self-regulation, sensory or anxiety issues impacting vocal stereotypic motor, non-compliance or disruptive behaviour.</p> <p>http://bacb.com/wp-content/uploads/2015/07/ABA_Guidelines_for_ASD.pdf (I am not aware of a UK equivalent.)</p> <p>5. At a high level the science of ABA is that people learn through the environment and uses positive reinforcements and aversives to modify behaviour. There is a real risk of an aversive being akin to a punishment.</p> <p>Other than at the highest level, can anyone truly understand the detail of ABA with its jargon, complex scientific analysis in published papers and huge amount of published papers? How can there ever be consensus on how it is used? An ABA Competency Framework published in England in 2011, sets out detailed "guidelines" about using aversives, amongst other things. http://uk-sba.org/wp-content/uploads/2016/01/UK-ABA-Autism-Education-Competence-Framework.pdf. How in practice can staff be trained, comply and be monitored? Staff often have to make a quick decisions in a therapy session in the heat of a moment.</p>		
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<p>Generally I believe the impact of an autistic persons sensory and anxiety issues and how these can be helped are underplayed in the guideline document.</p> <p>I look forward to future guidelines reflecting more our increased understanding of autism and how it drives behaviour, including:</p> <ul style="list-style-type: none"> - a most important intervention for any child being the way a parent/carers interacts with them, a way of being and the amount of joint attention and engagement and how this can be achieved - recent research into autism understanding and implications for interventions eg Intensive Interaction (Caldwell), Motor disruption and movement in autism a http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3713342/ (and Waldon). 		
<p>Best evidence explanation- perhaps as it is being targeted to someone concerned about wellbeing. Could use some explanations such as page 32 on are there other medicines that can help could be replicated on adult booklet. Much clearer reference to evidence throughout and why what is advised is advised.</p>	Ok	√
<p>Again, it does for typical autism but no evidence for PDA, no mention of traits, treatments, strategies or self care. It does mention CBT for anxiety but not an age this is appropriate from. The advice and strategies used for PDA are extremely different to those mentioned and again would give someone the wrong advice and send them off on a very damaging journey in the wrong direction.</p>	The content here reflects what is in the clinical guideline.	The decision on intervention will be made by parent/carers if appropriate and in partnership with HCP.
<p>SIGN Parents and Carers</p> <p>Publications listed are quite old. Autism Network Scotland could recommend others if useful?</p> <p>Not sure about Do-to Learn site being listed? Autism Toolbox more specific Scottish resource. Enquire, Scottish Strategy for Autism, Autism Network Scotland etc.</p> <p>ANS could send links to other website recommendations if wish to make these?</p> <p>Where can I find out more section (Parents)</p> <p>Consider order of info. Although alphabetical maybe some have a higher priority</p>	<p>Yes please, thank you.</p> <p>Ok</p> <p>Yes please, thank you.</p> <p>We have asked how people prefer it -</p>	<p>√</p> <p>√</p> <p>√</p> <p>√</p>

<p>Scottish Autism info – only really mentions advice line not the full range of services. Should maybe be similar to NAS info blurb?</p> <p>Should Autism Initiatives be mentioned (realise only adult services but still for future opportunities)</p>	<p>alphabetically suits people.</p> <p>Yes, we have included.</p>	<p>√</p>
<p>I am concerned that the layout is not clear enough with too much "noise". I think it should simplify around the core challenges of how to develop interaction, help behaviour (esp sleep and eating) and developing an understanding of how their child thinks differently.</p>	<p>We have provided a lay translation of our guideline which is the purpose of this document. Improve layout – less busy pages.</p>	<p>√</p>
<p>Very pleased to see ABA training and techniques mentioned (page 30). But <u>please</u> make sure the training is provided by proper ABA professionals and is not watered down.</p>	<p>It will be local health boards that provide training. SIGN has no control over this.</p>	<p>√</p>
<p>Should we include the material on the raised chance of having further children with ASD if you already have an affected child?</p>	<p>Agree.</p>	<p>√</p>
<p>Not sure</p> <p>On one hand I would say yes, to parents who are new to this is fair enough summary.</p> <p>On the other hand I would say that professionals need more practical experiences with ABA and compare it to services currently offered by NHS.</p>	<p>√</p>	<p>√</p>
<p>yes, you are very clear that it is based on the evidence and the ticks are good to show that its come from clinical opinion.</p>	<p>√</p>	<p>√</p>
<p>It does. The signs aren't needed. I don't think other parents would want this either. Just want to know what can help my child. I don't really care if its a strong recommendation or not. Maybe some will want this, I don't know but I don't.</p>	<p>Further user testing could help decide if parents of children with ASD want</p>	<p>√</p>

	<p>this/need this.</p> <p>User testing indicated that parents/carers found this information helpful and useful.</p>	√
<p>If possible, it would be good to allow the booklet to be photocopied for use outside NHS Scotland, e.g. in schools, social work, and by individuals.</p>	<p>Final booklet will state this.</p>	√
<p>Space between “for” and “?”</p>	√	√
<p>Good to have this. It sets out the path for people.</p>	√	√
<p>This is really clear.</p>	√	√
<p>This page is very helpful. You’ve said at very beginning that its based on a guideline but this page gives people that bit more information. You’re saying it twice which is good sometimes people don’t get it first time so good to say it hee too.</p>	√	√
<p>The p3 quote that "autism is not a terminal illness" is not appropriate, because it is not an illness at all! A person with ASD may be more likely to feel sensory overload, anxiety, distress, not validated, misunderstood or not accepted and any of these can result in illness.</p>	<p>Remove this quote as it is unhelpful.</p>	√
<p>Should we explain that DSM5 does not make the distinction of Aspergers and atypical autism. I would take these diagrams out because ICD 10 is likely to go to ICD 11 before we update the guideline again?? And families could get confused. Maybe we should say that we are moving away from all these subcategories , using ASD for all CYP adults affected and then describing how individuals are with respect to their language and cognitive development. I think we should emphasis at the beginning the ASD diagnosis and maybe abandon autism or at</p>	<p>Autism was the term preferred by parents/carers we spoke to. NAS also carried out a survey with parents and carers which also</p>	√

<p>least firmly say its shorthand for ASD.</p> <p>After discussion with KG</p> <p>page 3, I would swap Asperger's syndrome and autism around to give more prominence to autism especially as Asperger's syndrome is probably going to be abandoned ultimately when ICD-11 comes in.</p> <p>On page 4 where you say some individuals with autism also have difficulties with language development and a learning disability or both, can you also put "they may have unusual responses to sensory input or aspects of their environment".</p>	<p>highlighted that people did not want to use the term ASD. We will state in the document that this is the preferred term.</p> <p>Ok</p> <p>Ok</p>	<p>√</p> <p>√</p>
<p>I agree (with the above comment by AO'H). Work to be done on page 3.</p>	<p>√</p>	<p>√</p>
<p>There is a formatting issue on page 11. In the green box, second bullet point should continue and not produce the third bullet point.</p>	<p>√</p>	<p>√</p>
<p>P6 include difficult to engage, negative or avoidant of social demands?</p> <p>The P8 point about being aggressive when joining in with children's play is extreme. We are more likely to see a child who appears "bossy" or "overly controlling/directive".</p> <p>P8 include 'difficult in understanding others feelings and perspectives. (Think</p>	<p>Group feel what we have is better.</p> <p>It is more than being bossy, aggressive would be correct term but thoughts from people at user testing will influence this decision.</p> <p>Feelings are not the</p>	<p>√</p> <p>No-one brought this up at user testing.</p>

<p>others have the same thoughts.)?)</p> <p>p10 include organisational skills appear poor?</p> <p>P10/11 all these points equally apply to school age children. It may be misleading for parents to think otherwise.</p>	<p>same as thoughts. Wait until after user testing to decide on wording for this.</p> <p>Change to respond differently to other peoples facial expressions or feelings or not respond at all</p> <p>Agree</p> <p>Ok, cross reference</p>	
<p>P+C p9 says "not like the sound, taste, smell or touch of certain things" ! That includes certain clothes, hence, logically inescapably, it includes school uniforms. p36 says "It is important that everyone who is working with your child has the knowledge and skills to be able to deal with autism." This is breached by any school and teacher who coerces a child to wear clothes the child finds incompatible with their sensory issues, or who exposes a child without practically effective protection to a peer group who will coerce this by ribaldry and bullying. So the child's medical right for this not to happen must be mentioned. The child has it even it clashes with their parents' religion, too. It would be medical neglect and physical assault on the wellbeing of children's bodies to choose not to mention it.</p>	<p>Covered on page 10 and 30.</p>	<p>√</p>
<p>The signs were very helpful and also reassuring to parents, as many don't know if they are imagining things or not. Also the quotes are reassuring, especially the ones on page 5.</p> <p>The information on page 12 was helpful. I have 2 boys and a girl with autism, so it</p>	<p>Good to hear that quotes are useful.</p>	<p>√</p>

<p>was good to have the information about girls being different.</p> <p>My main concern is whether clinical staff will use the booklet and make people aware of it.</p>	<p>√</p> <p>This is a challenge for all patient versions. We notify boards and patient groups when they are published and there has always been good uptake of ASD booklets in the past which is encouraging.</p>	<p>√</p>
<p>The tone of page 6 is consistently negative and is the first section describing a child/adult with autism.."your child may..." then becomes a long list of "Not"s which is depressing. Later sections are better with a mix of phrases.</p>	<p>Alter these but some we feel need to start with ,not, to ensure that people who are less educated or perhaps have ASD themselves can easily understand. We are aiming to put this across in the best way possible and whilst ensuring we are inclusive.</p>	<p>√</p>
<p>Page 7, Communication problems, second bullet point change "used" to "use".</p> <p>Page 14, last paragraph, add a comma after "assessment".</p>	<p>Agree</p> <p>√</p>	<p>√</p>
<p>There is a minor problem on page 12 when you refer to girls and young women just take out the 'a' so it reads "may present with different signs to boys and young men" rather than 'a' different signs, and you have repeated that actually in the box to the left of it where you have said "girls with autism may have different signs to</p>	<p>The one to the right is the recommendation so we need to keep this</p>	<p>√</p>

<p>boys with autism” so I don’t think you need to put both in.</p>	<p>in. The other is for information but if we take the one to the left out the text does not make sense. Keep both in.</p>	
<p>Page 18, second recommendation box. No hyphen in “mental-health”</p>	<p>Agree</p>	<p>√</p>
<p>On page 17 in the last box when it talks about getting information about a child and their day to day life. I think we should put in with their parent’s permission. So if we could put “they will do this following your permission, by contacting other people who can provide relevant information (for example your child’s teacher or social worker).”</p>	<p>Agree</p>	<p>√</p>
<p>What does difficulties with "intelligence" on p21 mean? (An autistic brain can have difference strengths and weakness than a neuro-typical brain.) Poor performance in IQ tests? Low perception or social functioning? Slow verbal processing speed (but may have very quick perceptual processing speed)? Written or verbal language comprehension issues? Poor motor functioning? Low functioning due to anxieties or sensory issues? We know that IQ does not relate to verbal ability, but verbal ability can impact results of some intelligence tests.</p> <p>p21/p22 because of the frequency of sensory and motor issues impacting someone with ASD why would this not be addressed by OT at the time of diagnosis as a matter of course? Sensory issues can result in a wide range of challenging behaviour, that may not be appropriate to address by only behavioural interventions. Challenging behaviour from sensory issues can affect eating, dressing, where a child is comfortable to visit, whether a child can sit still, focus for a length of time, see/hear at the same time, frequency of melt-downs (sensory overload).</p>	<p>Change to thinking and learning.</p> <p>There was insufficient evidence to make a recommendation on the use of Sensory integration therapy so group made good practice point that children may benefit from OTs who will support in adapting environments,</p>	<p>√</p> <p>√</p>

<p>Pg 26 states that a child's autism gets worse or improves (with or without interventions)? In what way and how is this measured? Is this to do with better strategies, self-regulation, Observable symptoms, behaviour, anxiety levels? This will by nature be a key area of interest for parents/carers and so it would be helpful to clarify this point.</p> <p>P27 quote about melt-downs is inappropriate as melt-downs occur when a child has had sensory or anxiety overload. It is the underlying cause that needed the intervention.</p> <p>P28 states that some programmes educate the parent/carer. Parent/carers are the most important person for helping any child, and they can only feel empowered to do this if they understand the child's autism and what drives their behaviour. As a result all programmes should involve educating parent/carers, especially as so much more has become understood in recent years about autism.</p>	<p>routines etc.</p> <p>Removed after discussion.</p> <p>We wanted to capture the thoughts of a range of parents. This is a direct quote and the parent we spoke to felt very strongly about that people know how to deal with this.</p> <p>We are reflecting what the evidence says.</p>	<p>√</p> <p>√</p> <p>√</p>
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<p>Page 22 – Recommendation – Health professionals should (know?) whether your child should be offered...generic testing, investigations to rule out specific cause of autism.</p> <p>- Could be more explanation of why & that there is no one cause</p> <p>Pg26 – In some cases your child’s autism may get worse or improve...outlook may be better - concern over language used here</p>	<p>Guideline doesn’t say.</p> <p>Remove</p>	<p>√</p> <p>√</p>
<p>The part on "will my child's condition change?" should in fact be something more positive along the lines of "just as all children grow and develop, so do children with autism, instead of leaping into negatives, albeit these can be then discussed following initial statement.</p>	<p>Remove.</p>	<p>√</p>
<p>Page 21, comments in circles about “Occupational therapist” and “Physiotherapist” – use consistency with formatting – one of the dashes is black, the other is orange.</p> <p>Page 26, Recommendation box – medical care for medical problems but also pastoral/social care for emotional difficulties.</p>	<p>Improve</p> <p>This is wording from guideline.</p>	<p>√</p> <p>√</p>
<p>On page 24 when you mention ‘agency and multidisciplinary team should do the following’, can you also put in “consider the process of interagency working attributable to the getting it right for every child (GIRFEC) approach now enshrined in the Children and Young People (Scotland) Act 2014.” This is on page 1 of the guidelines and I think we need to get it in somewhere.</p> <p>On page 25 when we put the bullet points ‘children and young people with autism are also more likely to have epilepsy, sight problems, hearing problems’, I think we should also insert intellectual disability.</p>	<p>Agree</p> <p>Agree</p>	<p>√</p> <p>√</p>
<p>P. 23 - Would it be possible to recommend counselling for parents who need to come in terms with diagnoses?</p>	<p>This is not a recommendation in the guideline so we cannot include this.</p> <p>Remove last</p>	<p>√</p>

<p>p. 26- Please send me any research and evidence showing that autism may improve without being managed! I would be very interested in numbers & percentages supporting this statement. Email - suzie@zuniautism.uk</p>	<p>paragraph on page 26 as this is not supported by evidence.</p>	<p>√</p>
<p>What can help?</p>		
<p>P27 refers to "an autism treatment". Treatment is defined as "medical care given to a patient for an illness or injury". What is meant by this in the context of autism? What should parent and carers be looking to treat? Observable autistic behaviours? Or underlying issues: effective communication, anxiety, sensory, motor? What is the knowledge and guidance about the importance of addressing the underlying issues (sensory, anxiety, etc) before higher level social and executive functioning skills can effectively be addressed?</p> <p>P27 quote about melt-downs is inappropriate as melt-downs occur when a child has had sensory or anxiety overload. It is the underlying cause that needed the intervention.</p> <p>P28 states that some programmes educate the parent/carer. Parent/carers are the most important person for helping any child, and they can only feel empowered to do this if they understand the child's autism and what drives their behaviour. As a result all programmes should involve educating parent/carers, especially as so much more has become understood in recent years about autism.</p> <p>P29 states your child needs help "fitting in at school". Fitting in or coping? Is it not more of a two way process - a child needs help to cope and fit in with school</p>	<p>Remove 'treatment'</p> <p>√</p> <p>No others have commented on this.</p> <p>The aim of this patient version is to help empower parents by making them aware of interventions supported by evidence.</p> <p>Change to 'coping at school'.</p>	<p>√</p> <p>√</p> <p>√</p> <p>√</p>

<p>and the school to make reasonable adaptations to help?</p> <p>P30 states that it is recommended that children with "autism should have access to support staff trained in ABA based technologies" .</p> <ul style="list-style-type: none"> - Which autistic children and for what aspects of their learning? - Support staff need to be trained in the science of ABA too? - Will this be supervised, monitored, regulated, by whom and how? - There are only a few certified therapist in Scotland so who will provide the training and practice supervision? - As ABA is a controversial therapy, there should first be an effective channel to escalate any concerns/make complaints. <p>Parents and carers need to understand why is ABA being strongly recommended now, in light of the above and following:</p> <ol style="list-style-type: none"> 1. There is an increasing amount of independent evidence questioning ABA effectiveness and its risks to a persons well-being, eg: http://smallbutkindamighty.com/2015/06/16/aba-and-autism-the-thorny-problem-of-control-and-consent/ 2. ABA is not validly supported by research: eg Dr Damian Milton's research paper published in 2014 entitled " So What Exactly are Autism Interventions Intervening With?" http://www.bild.org.uk/EasysiteWeb/getresource.axd?AssetID=6239&type=full&servicetype=Attachment 3. ABA seems to be evidence based only in that it collects data documenting the increase or decrease in an observable behaviour. 4. Therapists are modifying behaviour without understanding how autism drives it. eg: The US Guideline on ABA as a treatment for autism states that "examples of severe problem behaviours requiring focused intervention include....stereotypic motor or vocal behaviour, noncompliance and disruptive behaviour....." The 	<p>Guideline doesn't give details.</p>	<p>√</p>
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<p>document does not address self-regulation, sensory or anxiety issues impacting vocal stereotypic motor, non-compliance or disruptive behaviour.</p> <p>http://bacb.com/wp-content/uploads/2015/07/ABA_Guidelines_for_ASD.pdf (I am not aware of a UK equivalent.)</p> <p>5. At a high level the science of ABA is that people learn through the environment and uses positive reinforcements and aversives to modify behaviour. There is a real risk of an aversive being akin to a punishment.</p> <p>Other than at the highest level, can anyone truly understand the detail of ABA with its jargon, complex scientific analysis in published papers and huge amount of published papers? How can there ever be consensus on how it is used? An ABA Competency Framework published in England in 2011, sets out detailed "guidelines" about using aversives, amongst other things. http://uk-sba.org/wp-content/uploads/2016/01/UK-ABA-Autism-Education-Competence-Framework.pdf. How in practice can staff be trained, comply and be monitored? Staff often have to make a quick decisions in a therapy session in the heat of a moment.</p> <p>Generally I believe the impact of an autistic persons sensory and anxiety issues and how these can be helped are underplayed in the guideline document.</p> <p>I look forward to future guidelines reflecting more our increased understanding of autism and how it drives behaviour, including:</p> <ul style="list-style-type: none"> - a most important intervention for any child being the way a parent/carer interacts with them, a way of being and the amount of joint attention and engagement and how this can be achieved - recent research into autism understanding and implications for interventions eg Intensive Interaction (Caldwell), Motor disruption and movement in autism a http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3713342/ <p>https://pure.strath.ac.uk/portal/files/30824008/Trevarthen_Delafield_Butt_FiIN2013.pdf (and Waldon).</p>		
<p>Page 33 – recommending behavioural therapy for sleep problems – how does that follow? Any behavioural intervention is a question against the child’s personal liberty, and not to happen lightly or without the child’s own decision involvement.</p>	<p>These are the recommendations in</p>	<p>√</p>

<p>So clarify it. It to follow from a sleep issue?</p>	<p>the guideline.</p>	
<p>Pg 30 – Recommendation – Children with autism should have access to support from staff trained in ABA based technologies - require further clarification for context of applied behavioural analysis-based technologies. I think some parents and practitioners see this as an opportunity to prioritise specific ABA programmes rooted in the Lovaas approach.</p> <p>Pg34 – Healthcare professionals should consider prescribing antipsychotic medication to reduce irritability... This is a recommendation but maybe more info/explanation be given on this type of medication or a link within references?</p> <p>SIGN Guidelines – Quick Reference Guide</p> <p>We are aware that these have been published but still have comments below</p> <p>Page 3 – Intensive Behavioural and Developmental Programmes – require further clarification for context of applied behavioural analysis-based technologies</p> <p>(Language and tone appropriate) Pg 30 – need to understand that some behaviour only takes place because your child is using it to make up for their lack of skills</p> <p>– 'lack of skills' concern over language used is challenges better?</p>	<p>Guideline doesn't give specifics.</p> <p>Define antipsychotic</p> <p>Group members wish to have 'lack of skills' but we will see if people at user testing comment on this.</p> <p>Kept lack of skills as people did not have a problem with this.</p>	<p>√</p> <p>√</p> <p>√</p> <p>√</p>
<p>Page 27 – don't know if "<i>treatments for autism</i>" is the right expression</p> <p>Page 29, first recommendation box – change "<i>PECs</i>" to "<i>PECS</i>".</p> <p>Page 29, second recommendation box – I would close quote marks after "<i>in</i>" rather than "<i>school</i>"</p> <p>Page 32, 2nd paragraph of "<i>Are there any medicines that can help?</i>" - e.g. aggression</p>	<p>Agree – see above</p> <p>Agree</p> <p>We have changed text slightly.</p> <p>Change eg to 'such as' in 2nd paragraph.</p>	<p>√</p> <p>√</p> <p>√</p> <p>√</p>
<p>On page 31 I would take out the sentence "there continues to be very active</p>	<p>Agree</p>	<p>√</p>

<p>research into the role of some interventions such as diet and nutritional supplements for children and young people with autism” and instead put “the research into interventions such as diet and nutritional supplements for children and young people with autism has not shown that there are definite benefits and so your doctor cannot prescribe nutritional supplements to treat autism symptoms”.</p>		
<p><u>Page 31</u> - The content on "Special diets" is inadequate. There is no acknowledgement that children with ASD are more likely to be highly selective in their eating habits and more likely therefore to have inadequate diets that require significant support from Dietitians and psychologists. They will need this if they are to be able to know whether or not the diet is adequate and if not, to be able to influence it in an effective way.</p> <p>In addition, there no recognition that supplements play an important role in children with poorly balanced diets and that expert advice should be sought to ensure that the supplements chosen are appropriate.</p> <p>Finally, there needs to be a qualifying statement after the dismissive one about special diets, to say something like:</p> <p>"However, difficulties with attention, sleep and mood can be compounded by a poor diet, so it is important to have your child's diet assessed by a Dietitian, in case there are some nutritional deficiencies that need to be addressed". If this statement is not made, then the impression given is that the brain is not affected in any way by a poor diet. (I say this because while the evidence that dietary interventions for ASD is quite weak, evidence that nutritional deficiencies affect the brain is strong and so is evidence that a significant minority of children with ASD are profoundly selective and have extremely poor and inadequate diets)</p> <p>In summary, the section should be headed: "Nutrition & diet" and the "Are special diets helpful" bit merely an additional question under that heading. The best comparison is sleep which gets mentioned elsewhere as a difficulty. How can we acknowledge that sleep is often a problem but diet not when these are the 2 things parents of children with ASD most often struggle with?</p>	<p>Anne O’Hare has suggested alternative text for this. We can only include information which has come from the recommendation in the guideline.</p>	<p>Add text in about getting advice from dietician if child is having difficulty eating a healthy diet.</p>
<p>p27- I am very pleased that you encourage Early Intervention, yet I suggest you precisely clarify what this means in day-to-day practice.</p>	<p>We state in the 3rd sentence that</p>	

<p>times, socialising and group time, independent play, transitions - Please update this.</p> <p>P. 32 - copy of recommendation from p. 30</p>	<p>Remove from page 32</p>	<p>√</p>
<p>The "change" quote on p37 I would argue is a misquote in this section- I wonder if the parent who said it, in fact meant change between activities rather than change between services...sorry that is how I read it.</p>	<p>They meant change between services. This hasn't been a problem for any other reviewers.</p>	<p>√</p>
<p>Page 38, recommendation box – <i>Adults with Incapacity (Scotland) Act 2000...Children and Young People (Scotland) Act 2014</i></p> <p>New Scottish Government website is gov.scot but there is probably more relevant information from the mental welfare commission - www.mwscot.org.uk/the-law/adults-with-incapacity-act</p>	<p>Add www.scotland.gov.uk</p>	
<p>P36 - ... Services. - Interested public and professionals get autism awareness training, this is good but not enough. Knowing the fact about autism is the baseline. The next building blocks should be ABA awareness for all professionals and parents. Also please ensure only board certified professionals are allowed to claim that they do ABA. It is dangerous to be "doing" or claiming that someone does ABA without the appropriate training</p>	<p>Agree. This is why SIGN recommends that Local authorities and NHS boards should make sure that staff are suitably trained to work with children who have autism.</p>	<p>√</p>
<p>p. 41 - Information on the cause and effect - These do not need to be in as nobody knows the answers to these questions anyway</p>	<p>Remove bullet point on cause of autism</p>	<p>√</p>

	and how it will change in the future.	
<p>On pages 43 and 50 of the booklet there is a reference to The National Autistic Society and on page 22 of the booklet for young people there is a dead link.</p> <p>We have got some suggested copy below with up-to-date information that would be useful in all booklets where The National Autistic Society Scotland is mentioned (also on p27 and 30 of the booklet for adults) and reflects that the charity doesn't refer to itself as 'NAS' anymore.</p> <p>The National Autistic Society Scotland</p> <p>Central Chambers, 1st Floor, 109 Hope Street, Glasgow G2 6LL Tel: 0141 221 8090 Website: www.autism.org.uk Email: scotland@nas.org.uk</p> <p>The National Autistic Society Scotland works across Scotland to provide quality, personalised support and advice services for autistic people and their families and carers. It's website hosts a range of information on autism, and the charity operates a free helpline (0808 800 4104).</p> <p>The National Autistic Society</p> <p>www.autism.org.uk</p> <p>The National Autistic Society website offers a range of information on autism and the support available for parents and carers.</p>	<p>Update information on The National Autistic Society in all three booklets.</p>	<p>√</p>