

ASD parent/carer booklet – user testing feedback

| Comment | Suggestion/Action | Editorial response |
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| General comments | | |
| I think it looks appealing. I think you've covered a lot of information in the book. And I think it goes in to detail you know about assessing your child and your child's profile | √ | √ |
| I like the fact that there is a lot of white space, pretty clear. Very clearly laid out. Like the bullet points. do like it's a bitesize way. I like that the information sign is in blue | √ | √ |
| The booklet is laid out quite nicely. I like the bullet points. Autism is hereditary so anything that helps to read about it is good. Easy to read chunks is good. | √ | √ |
| Really nicely laid out. Easy to read and find what you are looking for. Plenty of white space. Chunk size bits. Bullet points. Easier on the eye. Colour coded is a good idea. | √ | √ |
| Like the way it is laid out. Like broken down into boxes. Can flick back and forward through. Quite helpful. | √ | √ |
| I like the fact it is in an easy- read format. Can dip in and out of. | √ | √ |
| I like how the boxes are laid out with bullet points and different colours. Makes it easier to read. Overall, it is absolutely wonderful | √ | √ |
| Well laid out. Like how they're boxed in different colours and not just all together. | √ | √ |
| very descriptive, neatly explains things in bullet points without being too onerous. Obviously evidence based which is absolutely critical. Especially when there is such vast amount of info on line that people access that isn't robust | √ | √ |
| Lots if information in it. Like the different colour boxes. Draws attention and not too much on the page. Bitesize chunks. The photograph on the front cover is good as it is | √ | √ |
| I think it's quite straightforward and clear | √ | √ |
| Quite clear. Simple. Easy to read. Not big words | √ | √ |
| Yeah. Think qualify early on in booklet why the term autism is being used. And ASD, and mentioning Asperger's even though it's being phased out soon, variation across country. Autism is increasingly common used term. Strong you've focused on that. | √ | √ |
| Language is absolutely fine. Not too much issues. But anyone with any reading, writing, learning difficulties might | √ | √ |

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| need assistance. But this is where the health professionals come in. Nothing jumps out at me though that people won't understand. Can see stayed away from medical terms. Cant' see how you'd improve on it. | | |
| Think it explains the guideline in a nice lay language which is really good, I'm not a native speaker and I don't have any problems in terms of difficult language. Easy to read language. | √ | √ |
| Like helpful language. Collaborative and holistic. Especially definition of occupational therapist – not using “treat” but using “help”. I like the fact it just refers to autism only. Like it doesn't say “disorder” | √ | √ |
| It works. A lot of people should write in easy read | √ | √ |
| Yes, think fine. Clear. Not confusing, not lots of heavy jargon. Nice simple, straightforward, to point. | √ | √ |
| Overall good that is explains everything and is clear in black and white | √ | √ |
| I would like something like this when my son first got diagnosed, would answer my questions about his behaviors and what parents would expect to go through | √ | √ |
| I'd go about it in a very different way. Hard when translation of clinical guidelines and when agreed to be in line with that | The patient versions aim to be a translation of the guidelines | √ |
| Excellent. Really well done to everyone involved in the process | Thanks | √ |
| I wish I had had this. I was desperate for something like this I didn't know what I was doing. I didn't have a clue where to start and what to ask. Difficult to ask for something if you don't know what to ask for. This gives you help in what to ask for. E.g. occupational therapy. You can pick things that are relevant to your own situation. Very, very impressed. You have taken a difficult subject and explained it very very well. Good job on this one. | Thanks | √ |
| Nice. A5 size. Colourful. Images of family. Like the contents, I can just look at that area. If I need something specific. Like the signposting provided. | √ | √ |
| Looks so well produced and well presented, so professionally done– there are key booklets I would recommend as so clear to understand and clear to use. | √ | √ |
| I like the headings. It covers everything. It tells about difficulties and the thinking. I would pick it up as it looks like a fact sheet. Get to get some facts and get to know a bit about autism. It is the kind of thing you should be handed when you're going through diagnosis. I was not given anything I had to go and seek information. It was not explained what would happen. Nobody is sure of the diagnosis process, you're not told, this is what happens, this is how it's going to be, this is the reason why it's going to take so long. If you had this take away and digest it might make it easier. This will help. Parents can be quite vulnerable, important there is leaflet with all the facts, reassurance, can go away with something in their hand that shows that there is help and they are being helped. | √ | √ |
| Like the sections, easy to read that way. The colours as well. Excellent booklet. Really good. Have own difficulties in | Thanks | √ |

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| reading but easy to read. Giving you info without going too in-depth. Giving you enough info. Helpful. Certainly something I wish I'd had. | | |
| I think it looks appealing. I think you've covered a lot of information in the book. And I think it goes in to detail about assessing your child and your child's profile and basically what they're looking for | √ | √ |
| Like the way it is laid out. Like broken down into boxes. Can flick back and forward through. Quite helpful. | √ | √ |
| I like the fact it is in an easy- read format. Can dip in and out of. | √ | √ |
| I like how the boxes are laid out with bullet points and different colours. Makes it easier to read. Overall, it is absolutely wonderful. Only thing is it might be a bit overwhelming. Lots of info but I personally wished I had this. I wish I had had this booklet as it sets out a process and plan | √ | √ |
| I like the different colours for the recommendation in the booklet. | √ | √ |
| I like the fact that there is a lot of white space, pretty clear. Very clearly laid out. Like the bullet points. Like it's a bitesize way. I like that the information sign is in blue as information signs are usually in blue. | √ | √ |
| The booklet is laid out quite nicely. I like the bullet points. Autism is hereditary so anything that helps to read about it is good. Easy to read chunks is good. | √ | √ |
| Really nicely laid out. Easy to read and find what you are looking for. Plenty of white space. Chunk size bits. Bullet points. Easier on the eye. Colour coded is a good idea. Visually easy and accessible. Absorb at own pace. | √ | √ |
| Lots if information in it. Like the different colour boxes. Draws attention and not too much on the page. Bitesize chunks. The photograph on the front cover is good as it is positive, smiley picture on front. Child just playing with parent as any child would do. | √ | √ |
| Well laid out. Like how they're boxed in different colours and not just all together. | √ | √ |
| Very descriptive, neatly explains things in bullet points without being too onerous. Obviously evidence based which is absolutely critical. Especially when there is such vast amount of info on line that people access that isn't robust | √ | √ |
| Contents | | |
| It is straightforward which I think works, because going through diagnosis, it's a very busy time | √ | √ |
| SIGN guidelines are based on clinical evidence and so this is the right content, and the booklet also signposts parents to other support organisations if they need something else. | | |

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| <p>Is it initial concerns that it might be autism? Or initial observations you might be able to see –they're not issues or concerns. Is it concerns or is it features or observations or aspects.</p> | <p>Change to 'Worried your child may have autism?' This will ensure consistency of question and answer format of booklet.</p> | <p>✓</p> |
| <p>I'd say 'what would help' rather than 'what can help'</p> | <p>Agree</p> | <p>✓</p> |
| <p>'What can help' - is 'what' the right word? Or is just 'help' better? What might mean people think there is a cure. From reading "who can help" might be better. The booklet should make sure not to raise expectations.</p> | <p>Change 'can' to 'would' as suggested by another user. Our booklets take the form of question and answer format so we now have the question 'what would help?' rather than having 'Help'.</p> | <p>✓</p> |
| <p>May be a bit to say what you would do next if you are a parent. If you had concerns. It's maybe in already – "if you had concerns what would you do next".</p> | <p>Agree - add question and answer in.</p> | <p>✓</p> |
| <p>Don't like all these question marks. I'd like them rephrased consistently.</p> | <p>Question and answer formats makes information easier to understand for a lay audience. We need to consider all levels of ability when producing</p> | <p>✓</p> |

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| | this information. | |
| Could potentially be colour coded but very clear. | Aim for consistent colours across all our booklets. | √ |
| Signposting very important so maybe “if you haven’t found what you need in this document, here is some further sources of support or information” | Agree - add sentence in . | √ |
| Perhaps there should be a bit about if you are not happy or professional not taking you seriously | SIGN guideline doesnt cover this. | √ |
| If there was a quicker easier reference to something that isn’t medical info eg a charity, I don’t know how you would differentiate it to say that it’s not just a medical condition like say diabetes. | We have offered a description of ASD to help people understand this and have tried to avoid any medical terms. | √ |
| You could put in that assessment is an individual thing. That the length of time of an assessment will vary and that it is an individual thing | Add bullet 'Explain to you that the length of time your child waits to go for the assessment will vary'. | √ |
| Like how it is categorised and includes others such as siblings, teenagers. Think you have the main ones there. Lots of helpful information. Otherwise you could go on | √ | √ |
| Very useful. Good. Gives different books that may be relevant and true. Good because these things have been properly checked | √ | √ |
| This is great. Internet bombards you with information. Guidelines of where to look are a great idea. I would have loved something like this to know where to start | √ | √ |
| Good to have something official to point you in the right direction. Rather than just googling. Really need to tell people to be critical about who they go to for advice | √ | √ |

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| Brilliant, website, phone numbers, books, as some people want to do their own thing for research. Variety there is good. | √ | √ |
| I would love if I had had this booklet years ago. I do not know all the organisations listed but brilliant to have everything on a couple of pages | Glad you think it's helpful. | √ |
| The fact that these are recommended, because you get a lot of sites out there that are just not helpful. It's good that you've got these ones that are recommended by the NHS. | √ | √ |
| Good to get proper guided info. Better than Googling or Facebook. Especially as well the books. Some people read every book, I haven't. All really good info. Covers everything. | √ | √ |
| Front cover | | |
| I'd maybe put the print for the 'booklet for parents and carers maybe a little bit bigger | Increase font size slightly | Agree. Can do |
| Font for parents and carers is a bit little. | As above | √ |
| Might want to say "parents, families and carers". Big factor. Affects everyone | Agree - add 'families' | √ |
| Autism affects the whole lifespan so is it for parents of adults? Not clear from the front. "parents and carers of children and young adults" might make it clearer. | Agree - add 'parents, carers and families of children and young people'. | √ |
| It might say that it is a booklet that relates to the early stages of the journey. A bit stark. Bland. | | √ |
| I don't know if you've got to link it in as to why, who's produced the booklet like that on the front. You know to say that it is in connection with – I know it says SIGN Scottish guidelines there but – you maybe have to say that it's SIGN guidelines for autistic spectrum or whatever, down at the bottom | The use of 'SIGN Scottish guidelines' on front cover was agreed after previous user testing as part of a research study. We would prefer to keep all SIGN's booklets consistent but will add this | √ |

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| | information in under 'What is this booklet about?' | |
| Maybe it should say that it is about 'information' for parents and carers. Something to say that it has helpful info for parents and carers. | Add sentence inside front cover thanking parents and carers who contributed to the booklet which illustrated that it will be helpful since parents/carers have been involved. | ✓ |
| Photos are difficult. I am the parent of a girl with autism – sometimes when you see picture of boy you think oh typical. But Like how the photo does not show disability as can affect all different on the spectrum. | Differing views, keep | ✓ |
| My only reaction to the photograph is that a boy with his father is stereotypical. Gender equality, autism in females is overlooked. Reinforces that it is only a male condition. | Differing views but would rather keep. People like how we have not shown someone with disability. | ✓ |
| Good to see a father on the front and not just the mother which is good | Good. | ✓ |
| I like the fact it just refers to autism only. Like it doesn't say "disorder" | Differing views, keep | ✓ |

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| <p>Autism is a spectrum. Some people might think seeing autism might mean it is more specific not covering a wider range. Confusion about asperger's falling in to same category. Once you read further it's clear but people knew to it might think there is a separate one for asperger's.</p> | <p>We have taken advice from NAS and clinicians invovled with group and suggest autism as title but with explanation inside.</p> | <p>√</p> |
| <p style="text-align: center;">Who is this booklet for?</p> | | |
| <p>Definitely helpful having this page in the book. Good for me to remember that that's the one for me, a good check, one to file and away and not one for us to look through</p> | <p>Glad it's useful.</p> | <p>√</p> |
| <p>Good aimed at people who are just going through the process. Helpful. Shows applies to people at start as well as diagnosis. Simple. Clear. Gives clear idea of where things should be going in process. Good to have this knowledge. I didn't know the path at the time, it was vague. Great to have process clearly laid out.</p> | <p>√</p> | <p>√</p> |
| <p>I prefer the term 'going through diagnosis' rather than 'may have autism'</p> | <p>Agree</p> | <p>√</p> |
| <p>Put something to explain that parent may be unsure whether child has autism. Not just for parents whose child is autistic. So they pick it up too. E.g "parents and carers who are maybe going through the process "</p> | <p>It is difficult to capture everything on the front cover as this would become very messy if we added everything that has been suggested. Other users found this clear. Add 'may be going through diagnosis' under 'Who is this booklet for' which will clarify.</p> | <p>√</p> |

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| Yeah. But what age are young people? Up to age 25 or age 18 or 16? This is key for services and diagnostic. | this is clarified later but add in up to the age of 18. | √ |
| Page 1 should say – what are the next steps. | Covered on contents page but add sentence in on page 5 to tell people to go to GP or HV with concerns. | √ |
| I wondered about the term autism in "may have autism" as there are so many variations of diagnosis | This is clarified later | √ |
| Yes. Might not need repetition of the wording ‘Who is this booklet for’ on page 1. Could just start with“parents and carers” | Majority at user testing found this page helpful and we aim to be consistent across all our patient versions of guidelines. | √ |
| There is no need to repeat the words ‘who is this booklet for, at the beginning | see above | √ |
| I don't think you need this as it is already on the front. It clutters it a bit. I would instantly gloss right past that. The fact it says autism and parents and carers already implies it is for me. Personally think page is a waste of paper | Users at previous user testing of another booklet found this page helpful. Majority of parents as ASD user testing also found helpful. We aim to be consistent across all our booklets. | This covers the information people wanted on front cover. |
| What is this booklet about? | | |

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| <p>I think that's quite good because it's showing you know, if you've got no understanding of the SIGN guidelines at all, you know, the work behind this is actually showing that there is strong evidence to support you know that speech and language is one of the main areas that had to be you know assessed when I child you know is going through, either before assessment or after assessment, so I would say that's fine and it draws your eye to as well, you don't miss out anything</p> | <p>√</p> | <p>√</p> |
| <p>SIGN guidelines are based on clinical evidence and so this is the right content, and the booklet also signposts parents to other support organisations if they need something else.</p> | <p>√</p> | <p>√</p> |
| <p>I don't know what this booklet is about. I'm not sure what it's trying to achieve. Suggest would be helpful for new parents to have line that says "this booklet is there to help you with the next steps and understand" if that's the purpose of it? So is the booklet for diagnosis – to show what the professionals look for, not a booklet for parents to help understand their child's autism, not a booklet to show how to help their children. Wouldn't read this and know how to help my child. Would read it and expect all these specialist to treat my child's autism. Needs to be more meaningful.</p> | <p>The purpose is stated on this page. It gives information on recommendations from the clinical guideline. It is very clear and in bold that it gives you information about the care your child can expect.</p> | <p>√</p> |
| <p>Would everyone know what a clinical guideline means? Basically something that clinicians have to follow. Explain this here. "a guideline produced for specialist involved in ASD" to make it more meaningful.</p> | <p>This is covered at end, add link to specific ASD guideline on previous page.</p> | <p>√</p> |

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| Link to page 51 should say page 52 | Correct this | ✓ |
| Yes. Having the symbols is great. Huge amount of help. Maybe a bit bigger | other user testing has not flagged this up. | ✓ |
| Strong recommendation based on good quality research – not sure why ‘good’ is there quality I thought would have been enough. Yup, just that good quality – don’t think – well ,the two words mean the same so quality might be enough. Yup, just that good quality – don’t think – well ,the two words mean the same so quality might be enough. | Majority at user testing found helpful | ✓ |
| Clear but I do not know who SIGN is and if I can trust their opinion. If you had a body of parents and carers who have given their double thumbs up, thumbs up, tick, dubious cause that’s what the doctors say but not work in real life, that would hold more weight for me personally. Still a bit of an anonymous body of health professionals, not clear if they have hands on life experience | Add thank you in to parents and carers who contributed to the booklet. | ✓ |
| I like the different colours for the recommendation in the booklet. | ✓ | ✓ |
| Yeah it’s a good use of the signs you’ve used – ‘strong’, so anybody at a glance could tell, well you had enough evidence and research to uphold that recommendation, and for the not enough evidence symbol, you know it might be, there’s not enough research evidence at the minute it’s maybe something that could change in the future. I think those are fine. | ✓ | ✓ |
| Clear explanation. But confused about different levels of recommendations. More to take in. Rather than just basic understanding of what autism is. Different levels are just another thing to take in. At that point want clear and simple as possible. If I took time to read it it would make more sense. | ✓ | ✓ |
| From what I know now. It’s clear. But meaningless and misleading to give that information to parents. Disagree strongly with ABA therapy. Personal experience and reading. Appalling. ABA is multi million pound industry and always going | ✓ | ✓ |

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| <p>to get a strong recommendation. Grown for 50 years in American – have to make and sell research but none is good for supporting autism as an intervention. Good quality evidence – in previous SIGN guideline it wasn't good quality. Disagree strongly with research supporting ABA. Highly dangerous, confusing recommendations as there is not enough research due to lack of funding for non ABA therapies. That will never get to more than just a tick even. Would say ABA not good quality evidence.</p> | | |
| <p>Symbols clear. Really helpful having the key. Question mark is quite powerful. Think about e.g. if printed in black and white photocopy, question mark symbol is powerful</p> | √ | √ |
| <p>Very clear. Upset parents may not take it in. But does need to be there. Someone can go back over booklet and this will help to take it in if they bypass it. Think key is simple and straightforward. I understand that, but do parents want to know this? The difference between strong, research, clinical, evidence based, do they need to know that, do they want to know that? I would just leave key in. Why have both key and wording on all the pages. Too many words to look at. The key might be good later on when reflecting back but not at beginning. Can flick back to key rather than words on each page.</p> | √ | √ |
| <p>Having the symbols is great. Huge amount of help. Maybe a bit bigger. A lay person might not get the difference between research evidence and good quality research evidence and clinical experience. Some of the titling is medically minded. Might not see some of the titles. Maybe worth having the key regularly though the booklet then not have to have the title on each box. As a parent, does this mean anything to me, whether it is research or clinical evidence? I am interested in any rec and evidence. As parents, not need it as much as HCP, but double thumbs up does imply even stronger. Does tick enough or have to have wording alongside? Visual priority. The stuff with the question mark should come at the end. It is hierarchal information.</p> | √ | √ |
| <p>A tick to me says Yes definitely. But it is less clear here. Perhaps there should be three thumbs, then two thumbs and one thumb to mark the level of recommendation. To me a tick should mean strongly recommended. The tick doesn't fit in there. To the lay person, what is the difference between research evidence and good quality research evidence? How do you differentiate? Surely all research should be good quality. Otherwise why would you use that</p> | √ | √ |

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| <p>recommendation? Might be good to say why you differentiate. Perhaps a link or reference to find out about the different types of trials could be included if people want to find out more.</p> | | |
| <p>I understand the key but do not know if this would sway me in accepting the information in the booklet. I kind of glossed over this page.</p> | √ | √ |
| <p>Yeah I think that is clear and to have the visuals along the booklet explain that if something is a question mark it's because they don't have enough evidence</p> | √ | √ |
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| Definitions page 3 | | |
| <p>The wording of page 3 is the term 'Atypical autism' still used. I know that Aspersers is not in use. I thought that ASD is the preferred term</p> | <p>Chair of ASD guideline group has advised us to use the following: Healthcare professionals and researchers use the term autism spectrum disorders (ASD) to describe and diagnose a group of similar conditions. Over the years, there have been different words used to describe ASD, including autism, atypical</p> | √ |

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| | <p>autism and Asperser's syndrome. It is now thought that it is more helpful, both for diagnosis and research, to include all of these presentations within a single spectrum concept. It might be helpful to be aware of this when reading information about autism. Autism spectrum disorder (ASD) is now the most commonly given name for diagnosis.</p> | |
| <p>Atypical autism which concerns me - my son is between atypical and aspergers. Highly functioning so will be under aspergers although at the time he was diagnosed aspergers option wasn't there. Just given diagnosis of ASD. Is this the up to date booklet? This is the info I was telling the clinician and none of them were convinced – just ASD – but I see this clearly written in up to date booklet of a guideline I presume the clinician should know that these separate conditions exist. He shouldn't be under this umbrella. Aspergers syndrome is no longer used. The information does not match the reality. Called high-functioning autism. So seeing Asperger's syndrome here in up to date copy of guideline, how to professionals make that assumption that Asperger's no longer exists. It is confusing.</p> | <p>see above</p> | <p>v</p> |

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| <p>The term ' a child with autism' is often the choice of parents to describe their children, although some older children prefer to be referred to as autistic. The booklet should say that the term ' a child with autism' will be used in the booklet, there is differences of opinion. Asperger's - They're not diagnosing kids with Asperger's anymore (well in Perth and Kinross) but you still see that as a separate entity? So perhaps some acknowledgement that it will still be widely come across, and that some people still refer to it as that, but that they won't be diagnosed with that anymore. This is quite important.</p> | <p>Keep 'autism' as 'child with autism' is only used in the quotes. 'Autism' will apply to the terms in the recommendations too.</p> | <p>v</p> |
| <p>Aspergers syndrome is no longer used in this country and hasn't been used in 3 years, so if this is a new document why are you making reference to historical terms to someone who is looking to be diagnosed. Should be looking to future rather than historically. Booklet is not for adults who may have been diagnosed with old name. Actually the way autism is diagnosed now is one spectrum – Aspergers syndrome doesn't exist – they are being diagnosed as high functioning which is not referenced here. Many people would also argue it is not a disorder it is a condition. My query would be a lot about the information here. My research and my knowledge to date disagrees with this page and that would put me off the rest of the booklet as I feel it is outdated pieces of information that isn't going to teach my anything new. This wording is quite outdated. Not phrases that have been used in the diagnostic paperwork we have been given so already none of this is familiar to me</p> | <p>Iain McClure chair of ASD guideline group has advised and made amendments to this. We want to include the terms that people still use.</p> | <p>v</p> |
| <p>don't know how it is now – but we got our diagnosis a few years ago now and they said the aspergers part wasn't involved anymore, more just the ASD diagnosis, but important to point out the difference</p> | <p>As above</p> | <p>v</p> |
| <p>ASC is a medical term and not a personal preference. Both my daughter and husband were diagnosed with this. Not a minority group. This is an inaccuracy. I think this is really patronizing. Would not hook me in to the rest of the information in terms of respecting the information</p> | <p>Reword ASC box. E.g "ASD can occur with any level of intellectual or learning ability signs. Signs range from subtle problems of understanding and impaired social</p> | <p>Will try to simplify</p> |

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| | function, to severe disabilities. Some people also prefer the term autism spectrum condition (ASC) rather than a disorder" although first half of sentence still complicated. | |
| I think the box with ASC has a lot of big words and lot of difficult language. Most people will have some knowledge but some of the words maybe way it could be make less complex. | as above | √ |
| Yes. See you've said about people preferring the term with autism –piece of research last year with people with autism and they preferred to be described as not 'having autism', but 'being autistic'. Having autism seemed like a disease. Autistic is active description rather than having autism which is passive like I have a headache. But I see that's not what you've found. But lots of people don't like this and how they're described. Worth putting a point of note, that there's no right or wrong way it's just to be aware that the person might self-define as they get older. No singular definition. | Additional sentence "we use the term autism.... We are aware that everyone has difference preferences and identities" or similar | √ |
| Think autism community prefers "autistic", also the NAS survey last year also showed preference for "autistic" | Agree but parents we spoke to at the time of development told us they preferred autism. Add sentence to acknowledge that people will have different | √ |

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| | preferences. | |
| "three main areas of difficulty" needs explained/outlined on this page or referred to page 4 | Reword to make clearer. Refer to main areas of difficulty rather than three. | ✓ |
| Not a medical condition at all. Actually just an identification of a person type. Needs to take a different approach than a medical condition e.g like cancer. | outwith remit | Disagree with reviewer's comments. |
| I do not know if page 4 would help. It should say that autism is a lifelong condition and that an autistic child will be an autistic adult there should also be something to say that autism is hereditary. Booklet says no known cause which I think is wrong. Genetic links – it runs in families, to miss that out seems a bit negligent and inaccurate. | Booklet does refer to having higher risk of brothers/sister having autism. Make this stand out as vital information. | ✓ |
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| Quotes | | |

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| <p>Really like parents' comments. Really helpful. Especially that every person is different. Really helpful to hear what other parents' experiences have been. Having quotes</p> | <p>✓</p> | <p>✓</p> |
| <p>Good to hear these quotes</p> | <p>✓</p> | <p>✓</p> |
| <p>I like the quotes from other families. Helps to show that the booklet is designed to be user-friendly like the quotes from other families. Helps to show that the booklet is designed to be user-friendly</p> | <p>✓</p> | <p>✓</p> |
| <p>The quotes are really helpful and people can identify. Different people have different opinions.</p> | <p>✓</p> | <p>✓</p> |

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| <p>Pg 5. I would love to have one or two boxes in the booklet from nursery staff to say how children would behave in the nursery. To highlight the signs that show autism. How they are compared with other children. What signs do nursery staff notice, good experience in knowing the signs. Also quotes from healthcare professionals.</p> | <p>The idea of having quotes from parents is to personalise the information and use the parent/carer experience to complement the evidence. Parents are experts in this condition as many have told us so we think it's better to have quotes from them instead of professionals as the guideline has been written by professionals.</p> | <p>✓</p> |
| <p>Maybe there should be there should be a few more quotes with medical staff. Maybe there should be more quotes about how you get through the medical process. More about working as a team with GP, more about how you can do it, - more practical quotes to say you can do it, or e.g waiting list was long but I got through it....</p> | <p>We have mentioned that length of time will vary. See above re quotes from professionals.</p> | <p>✓</p> |
| <p>Quotes about going to the health professionals, approaching the professionals, those kind of quotes might be nice e.g "I went to my GP and...." It would be nice to have heard something from children. , I know this booklet is for parents. There should be something from young adults. Include quotes about how to approach a healthcare professional. A few more positive quotes would be nice. There is a depressing feel to the booklet.</p> | <p>We have quotes from young people in the booklet for them. We want this one to be different from there one so we</p> | <p>✓</p> |

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| | don't want to use the same quotes. | |
| Personal quotes are really useful. Parents can feel alone. Lovely to have quotes from real parents and people who have gone through it. | √ | √ |
| Good because people reading it might be feeling like that, good to know others are having those experiences or felt that way. Anything that personalises the info is useful. | √ | √ |
| Really good. All relevant comments. Good to know – you do feel isolated – not until you start going to stuff that you're not. So having this as your first contact with something is nice to know. | Really good. All relevant comments. Good to know – you do feel isolated – not until you start going to stuff that you're not. So having this as your first contact with something is nice to know. | Really good. All relevant comments. Good to know – you do feel isolated – not until you start going to stuff that you're not. So having this as your first contact with something is nice to |

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| | | know. |
| It wouldn't matter if these names were made up or not, but that's two boys, maybe a girl's name. I know it's more common in boys but there are girls out there. Just put a girl's name in there. | Agree add more quotes about girls | √ |
| The quotes are in relation to boys – specifying gender can be divisive. Maybe “my child” or more quotes or more photos to show girls. Would like more quotes about girls | Agree add quotes in about girls | √ |
| As long as they are not sticking to general issues, or stereotypical things, such as they didn't play or didn't speak. Stimming is a particular of the spectrum. More useful to put in ... Something along the lines of interaction with other children – didn't play with other kids is just one part of the spectrum. Important quotes, but just something extra. | General issues covered in signs of autism pages. | √ |
| Parent of child with and without autism sounds awkward. The quotes are all “parent of a child with autism” you could alternate it to from a parent of an autistic child and a parent of a child with autism. | The parent felt it was very important to let people know that she had children with and without autism. Personal preference. | √ |
| On page 3 I really do not like the quote that autism isn't something to be ashamed of. No need for this quote. Saying it's positive but double edged. Trigger. | Move quote to later in booklet | √ |
| I wondered – even for confidentiality if you just changed the names – that personal link, connection, not just a computer generated thing. ‘Helen, parent of child with autism’, not real names but would make it more personal. | Agree - add names to make more personal | √ |
| Check children's names – could be identifiable. Also page 16. Change to alias or "my son" etc | Change to alias names or "my child" "my son" "my daughter" | √ |

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| There is some confusion with the quotes e.g. he sounded different - What is different? Don't really understand that or find it helpful for me. Can't identify with that experience. Would be important to have a broad statement of what can happen. | Keep as this is how the parent told us it was for them. Others haven't commented on this. | ✓ |
| What's stimming? I wasn't sure if it was a spelling mistake or ...you could put stimming then brackets to explain what it is. I've never heard of it but others might have. | Offer explanation | ✓ |
| Would not understand what 'stimming' is if I was new at this. If it said repetitive, or set routines I would understand it a bit more | Offer explanation | ✓ |
| Specific pages | | |
| Where do parents raise concerns? | Add sentence in to say contact GP or HV. | ✓ |
| I am confused about what ages of children apply to the signs in the booklet. There is a jumping around for different ages of children. Not clear if signs apply to both, uncertainty about what signs apply when and how. School aged daughter does not have any signs listed but does have some of the later ones. Need to be very clear and specific, even if repeating yourself. | Add sentence from page 12 "not all children" to bottom of each page. Page 12 then redesigned | ✓ |
| At page 9 it refers to children with unusual skills. Most autistic children will not have unusual skills, rather they are obsessed with things. This is not a special gift. Most children will not have an unusual skill, only a handful. This needs to be clear | Change to be exceptionally talented in music or maths. | ✓ |
| Use of the word "teenagers" in heading is not consistent with other terms throughout booklet e.g. page 12 – young people, young women, 25, young people. Again on page 46 and 47. | use consistent language - young people throughout | ✓ |
| Typo. Remove "a" from top right sentence "...with a different signs to boys and young men" | change | ✓ |
| Should there be a green box around the rec to be consistent with the booklet | This is our other style of presenting | ✓ |

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| | recommendations. | |
| Not sure who the questionnaire is for - who fills it out and who is with/sent to | Clarify - state that the professional will help parents to complete questionnaire. | ✓ |
| There are lots of 'mays' in here. This is uncertain. Who will fill in the questionnaire, child, parent, teacher, HCP? This would be nice to know. | clarify | ✓ |
| would say as regards wording of recommendation that referral sometimes comes from an educational setting not a healthcare setting | Agree - change to professionals | ✓ |
| Use wording - 'autism assessment' not just 'assessment'. | could use consistent language in all 3 boxes "autism assessment" or "assessment" | ✓ |
| Dislike the term "special questionnaire" Suggest e.g. "a particular type of questionnaire that you and your child will fill in together", or something similar | change wording | Agree |
| Bottom box seems to be a repetition of top box, both thumbs up, what's the difference, bottom box is just a sub point, it should be a bullet point in the top box [children under 3 who show regression] | Is a different recommendation | ✓ |
| Order would be: based on research evidence, based on clinical experience, based on anecdotal evidence | outwith remit | Anecdotal evidence not covered |
| Information box page 14 | | |
| Not sure what the 'disadvantages' of further assessment is. Personally don't think there are any. Can only help the child. | Remove 'disadvantages' | ✓ |
| What kind of disadvantages are there with assessment? The advantages will outweigh any disadvantage. This is confusing. What are the disadvantages? This would make me worry/a bit wary. Not only confusing it's making me worry. | Remove 'disadvantages' | ✓ |

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| Not sure about what the disadvantages of assessment are. Unless there could be information on disadvantages, but not clear. Seems to add element of concern. | Remove 'disadvantages' | ✓ |
| Wonder why 'what you would do at a specialist' is not in a box too. | Typo - "what happens at a specialist assessment". Subheading clearer | ✓ |
| What happens at a specialist? What does this mean? is this referral or assessment? Need to explain, and if specialists are different in top box from bottom box. | Typo as above | ✓ |
| Re the wording – what happens at a specialist, this should instead be – what happens at assessment. | Typo as above | ✓ |
| Children under 3 showing regression. Should check this hasn't been caused by virus (SANS) as it causes autistic traits. I'd put that in. | outwith remit | ✓ |
| Is this before, during or after the assessment. Or what should happen when you have got to the end of assessment. The book needs to be a good road map for people. This should be said in booklet. Should booklet say what professionals should do at the assessment? Will help autistic parents reading this book. Put it in to context. "by the end of assessment..." or "before assessment.." | Add sentence in to information box on page 14 'before your child has an autism assessment'. | ✓ |
| I am not clear about what professionals you are referring to. Who are you talking about? Who gives you the copy of the referral letter? S&L, GP? | Aim to clarify by saying 'professionals making the referral should do the following before the autism assessment' | ✓ |
| Something to say that professionals are non-judgmental might be included. Should be shown throughout the booklet. "as well as supporting the parents through this process" something that states this. Extra bullet point, | Extra bullet point - offer you and your family support | ✓ |

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| | This is a box telling people what information they should receive from professionals. | √ |
| Should be "listen to you" as point one. Would be reassuring. | | |
| Box should include a point about how long the process might take – timeframe | Agree | √ |
| I quite like the blue for information, the green for guidelines, I'm not sure what that other colour is, should that not be blue too? I'm not sure. | Use colours consistently | √ |
| The information box on page 14. There should be information included on how to handle professionals who do not do what is in the information box. | This information is not in the guideline | √ |
| Specific pages | | |
| Is there anywhere you can go to to get more information about DISCO. Even a brief ...like on the back a webpage link to give you more information about this. Haven't heard of that one. | We have said that the professionals involved in child's assessment can tell parents about them. Also state that the organisations listed on pages 42 to 44 can give information on these tools. | √ |
| refers to different type of interviews I have not heard about before. Feel a bit vague about this. | State that people can ask professionals for more information or sources of further support can give details. | √ |

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| Query these acronyms, but realise might mean something to parents/carers familiar with autism. | Say that they are history taking tools and people can ask if unsure. Provide space to write questions. | ✓ |
| Perhaps you could explain some of the clinical language in diagnosis such as the ADOS, just to explain that a bit more. | Provide definition in circle which explains it better. | ✓ |
| Read a lot on autism but have never heard about interviews and have not been involved in interviews although my child has had autism for five years. | Use the various terms people will hear. We talk about interviews but need to also refer to history taking tools. | ✓ |
| Educational psychologist is not explained. Other occupations are explained in circles | Add definition circle for educational psychologist | ✓ |
| Incomplete. Day to day chores and motor and key success marker of booklet – what is part of autism? Parents need help with managing child sensory issues. | outwith remit | ✓ |
| Re the wording at the top of the page, my son no speech. I would prefer the wording ‘ can range from no speech’ rather than ‘very little’ speech. | Change to "no speech"? | ✓ |
| I think that when talking about communication difficulties it might also be worth highlighting that communication is not just the spoken word and language. Some children do not speak. People automatically think of speech when they see communication. Is there scope to add this. I was focusing on lack of speech and thought fixing this would improve things. But communication is so much more than speech – those two examples there don’t show this. Saying e.g ‘Social communication’ is probably more important. A guide like this might have helped me in my early days | Suggest adding sentence or change wording in brown box to include non verbal communication. 'social interactions, facial expressions, and | ✓ |

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| | body language" See quotes | |
| People automatically assume that 'communication' is talking but so much more e.g facial expressions. Some people might not pick up on this. Perhaps you could include examples. "communication skills including non verbal" can' think of how you'd word it. Not just talking. See quotes for suggestion | see above | ✓ |
| On page 21 a recommendation is made about children who may have a range of skills or difficulties with intellectual reasoning. I am not sure what intellectual reasoning means as it is not a child's thinking style. Not sure how meaningful this information is. Not sure what psychological wellbeing means | Just say thinking and learning, change psychological wellbeing to emotional and mental health | ✓ |
| At page 22, under sensory information, you could give examples of this as it is a major day-to-day issue. Some people don't understand, e.g sounds, bright lights, smells like walking passed a coffee shop. | add quotes in to give examples. | ✓ |
| I don't understand the quote about early intervention. I would still have that quote but not sure about the meltdown part. Think it depends on the child. I wouldn't give reassurance about the meltdown changing as time goes on | This is a quote directly from a parent. We want to have a range of quotes with difference terms/langauge. | ✓ |
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| Not enough evidence box on page 31 | | |

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| <p>Nutritionally deficient they can prescribe deficiency supplements like iron, so not necessarily to treat autism symptoms, just to benefit the child, not just because autistic. Just get the message across that can't prescribe other supplements.</p> | <p>Reworded and term "treat" and "autism symptoms" changed</p> | <p>✓</p> |
| <p>I think that's quite good the symbol about the special diets. If I was to go with the recommendations that some people my said my son just wouldn't eat, so I quite like that it makes it clear that there is no special diet that is proven.</p> | <p>✓</p> | <p>✓</p> |
| <p>Language – to treat autism symptoms. For me, “your doctor can't prescribe nutritional supplements or special diets to treat autism”. Not “autism symptoms”. Query the wording. To treat autism there is no nutritional supplements. Remove 'symptoms'</p> | <p>as above, See suggestions in comments</p> | <p>✓</p> |
| <p>I do not like the word 'treat' as it may suggest a false hope and there is no way to treat it.</p> | <p>as above</p> | <p>✓</p> |
| <p>Bit confused about supplements and treating autism symptoms. I can see it is a grey area with no definite support. The answer written here is nutritional supplement but the question mentions both diet and nutritional supplements. Needs to be clearer. I agree that a doctor cannot prescribe nutritional supplements but this does not mean that doctors can treat autism. The research doesn't show enough definite evidence – is this evidence for diet or supplements? I agree with it but it's not a complete sentence.</p> | <p>Alter sentence to make clearer.</p> | <p>✓</p> |
| <p>Treatment of autism symptoms is an unpleasant phrase. There are no autism symptoms. Suggest 'to treat behavior symptoms associated with autism'. Just the wording.</p> | <p>as above</p> | <p>✓</p> |
| <p>I don't like the font for “are special diets helpful” is that a title? It doesn't stand out to me.</p> | <p>Put headings in bold</p> | <p>✓</p> |
| <p>Think heading 'are special diets helpful' should be inside the box. Not sure why outside the box</p> | <p>This is a subheading and should be outside the box.</p> | <p>✓</p> |

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| Add phrase no “research” evidence | Add not enough 'research' | ✓ |
| It is unclear as to what you are saying about diets. Showing no benefit? No research? Need to give something a bit more concrete. This is unclear | See above | ✓ |
| Specific pages | | |
| There should be a little more background on anti-psychotic medicines so that parents are not scared by this term. A lot of people see the word “anti psychotic” and are not sure why these are being used if their child is not psychotic. | Agree - add definition | ✓ |
| What do you mean by ‘behaviours which challenge’ Not clear are you talking about aggressive behaviours or stimming, and who is it challenging? Parents? Child? This is a bit vague | Add in definition | ✓ |
| Should there be a box around the rec for consistency | Other style of presentation but improve the look. | ✓ |
| First recommendation, not clear who the education and developing skills is offered by. Need to state who can help. | State who this is offered by | ✓ |
| On page 40 there is reference to a quote from a ‘parent of children with and without autism’. I did not understand this. Does that mean they have one child with and one child without? Personal reason? As opposed to reason that would benefit other parents – in quote they are not comparing. | Yes, they wanted people to know that they had one with and one without autism to make sure people knew they weren't just commenting from experience with or without. | ✓ |
| Where can I find out more? Pages 42 - 51 | | |

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| I like the alternative. It is more compact. But no real preference for one or the other. | Preference is for original format but lines need to be consistent. Add lines where missing. | ✓ |
| I like the alternative. There is more information in one glance. Rather than flicking back and forth. But a lot more info on original. Not sure it would be worth it. If all the info was still on it would only be 4 big boxes, so wouldn't see the advantage. | See above | ✓ |
| Prefer original. | See above | ✓ |
| Prefer alternative. Break up of lines in between. I see original has line, but to me visually it breaks it up more. Like the main bits and websites are in the colour. Good. Eyes drawn immediately. There is lines there [original] but the two columns – still prefer alternative | See above | ✓ |
| Prefer original. Better spaced out. Not lots of things together. | see above | ✓ |
| There are pros and cons for each. Someone who likes the bigger picture might go to full booklet. But someone who just wanted to find something quick might prefer alternative page. Idea is to have as much info as possible. You can put them all together like the alternative and use the blank pages at the end to put as a summary, and still have the full info on the earlier pages. | See above | ✓ |
| Not sure about the blocks. Maybe just me, thinks why is that in one block and that in the other. | See above | ✓ |
| Alternative format (gluacoma): You see very clearly who to speak to in this one. But I do like how much information it has in the original. But this does away with my original point about boxes. | see above | ✓ |
| Alternative version from gluacoma: Good so you can see what the whole is. Better if on one page so you can compare and contrast what's relevant to you. More information in original, don't want to lose information if putting on shorter page. Autistic people have difficulty in delving into stuff to find out what is relevant to them. Two versions of the information might be possible. A summary page of what is available without detail. Then full info. | See above | ✓ |
| Prefer original format | See above | ✓ |

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| Prefers original - but some sections aren't lined off - make sure all consistently formatted | See above | ✓ |
| Quite like alternative style | See above | ✓ |
| Prefer original booklet. Broken down into sections. Clear. Not just list. | See above | ✓ |
| Second version too much. Too many lines. Difficult to find exactly what looking for. Initial version with colouring and headings is preferable. Easier to read. Lots of info on original. | all as above | ✓ |
| I would include details of carer centres. They are a great support and are local. I would put in something about a carers centre because then they know there is something out there just for them as well. They are a great support and also practical help with short breaks. There are local ones so will be some form of carers centre nationally | Touched on this on page 37. Add more to sentence at top of page 42. Add Carers Trust information in to this section. | ✓ |
| Perhaps include a line or reference to asking professionals if they can direct parents to local support groups. "please ask your health care professional for local groups" Everyone cannot be listed in the booklet. | Agree - add sentence in. | ✓ |
| The only other info I think would be useful is your local info. Obviously can't because different for eg Aberdeen and Glasgow. But maybe down to paediatrician to let you know this | Agree - add sentence in. | ✓ |
| Might be useful place to list national network of carers' organisations. Could then find local branch. | List Carers trust | ✓ |
| A bit more about ongoing support. Where to find that. You come to the end of diagnosis and appointments and left to go out in the world without knowing where to go from here. So a bit about – know its not the remit but even to signpost – if you have any questions you can - link to the 'further info' page like NAS. Even a link to say – overleaf there are some support organisations if you have any questions, just to bridge the end of the booklet to the next section. Just to link it, seems to be it stops. [the support and the booklet] | See above | ✓ |
| A sentence might be added to say that if you do not understand anything, ask your healthcare professional. Just 'they will support and help you as well as a person.' | Agree | ✓ |

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| Isolation is associated with diagnosis. Booklet should makes link to support organisations. Carers centres, local support groups, very valuable support. Encourage to access what third sector support might be out there | Agree | √ |
| What support is there for parents. | As above | √ |
| | | |
| I would keep the ‘i’ symbol if it is about information. Like blue colour. | Agree | √ |
| There could be a font change. It’s good and clear and readable but a lot of pages. | We have an agreed font for house style | √ |
| I would have a tick box next to them. Can then mark which info you have read. | See comment below. Differing views | √ |
| Important to say don’t need them all because people might see it as a list and need to get and read them all. Might be quite prescriptive. | Add in to sentence above "Some resources will be more relevant to you than others. | √ |
| It needs to be at the beginning of the booklet | Disagree. The purpose of patient versions of guidelines is to give people access to the recommendations from guidelines and we then signpost to other organisations. | √ |
| Maybe if the phone numbers were on bold. Black but bold – like page 52. Would make stand out more | Ok, phone numbers in bold to stand out | √ |

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| <p>Last point. Should include “you and your child (if appropriate)”</p> | <p>Disagree, we want to describe what each organisation does so this is helpful for everyone looking at it. It might be a grandmother looking at it for example.</p> | <p>✓</p> |
| <p>It might even tell people to call a local library to get books for you as well as you to source them.</p> | <p>Agree but we have to choose which information we want included carefully otherwise document will be huge which might then put people off.</p> | <p>✓</p> |
| <p>Worth putting in NAS main general enquiry as well as help hotline.</p> | <p>Add this</p> | <p>✓</p> |
| <p>Do the list of organisations in relevance order, not alphabetical order. Enquire is more important than the British Dietetic Association. Diet has not been proven as an effective measure.</p> | <p>Different people will prioritise differently?</p> | <p>✓</p> |
| <p>Some of the publications are very old and tend to be boy-based, from 5 -6 years ago. There may be more up-to-date publications as well.</p> | <p>Agree these are old but we sought advice from parents at time of development who informed us that these are still relevant.</p> | <p>✓</p> |

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| <p>Quite a few of the 'useful publications' are a bit older and there are other books about autism. 2003, 2005, 2004. Not familiar with them, might be good, but need more up to date ones, and more practical information.</p> | <p>The ones we have listed were recommended to us by parents who told us they were still relevant despite them being older. We are open to other suggestions. Noone came back to us with suggestions.</p> | <p>Assume no one gave suggestions</p> |
| <p>Some of the references look to be old and out-of-date. 2004. What strikes me is that none of these were in the last 10 years. 1986. Lots more personal accounts have been published during the past two years. Especially by women. Certainly some more recent ones.</p> | <p>See above</p> | <p>✓</p> |
| <p>There are books that are 20 years old. I want names I will recognise.</p> | <p>See above</p> | <p>✓</p> |
| <p>Check for up-to-date further information</p> | <p>We have asked ANS to look at this for us.</p> | <p>✓</p> |
| <p>Newer publications potentially better. Some are out of date.</p> | <p>all as above</p> | <p>✓</p> |
| <p>There are east coast organisations in the booklet that I am not familiar with. Put in West coast ones as well or just keep it national.</p> | <p>Keep these as national</p> | <p>✓</p> |
| <p>Parents struggle with 'how do you tell your child they have autism'. You could include details of books on this but I'm not sure where you'd find this information.</p> | <p>Suggestions welcome</p> | <p>✓</p> |
| <p>A Blue Bottle Mystery is a good book for young kids. It's a fiction book about a boy with Asperger's.</p> | <p>Thank you for suggestion</p> | <p>✓</p> |
| <p>Lots of Facebook pages give support and there are forums, and this might be worth mentioning.</p> | <p>User testing revealed some websites and forums are not</p> | <p>✓</p> |

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| | trusted. Majority liked our list of recommended "official" recommendations. Facebook outwith this | |
| I would recommend facebook support groups. Support networks should be championed a bit more | as above | ✓ |
| The Autism parenting community on Facebook is massive and full of good, factual, reliable information and is where most parents I know turn for information. If you were to use a diagram that they used, here, then I think there would be a unity and trust built it. A lot of the graphics that we share are accurate, they're based on real life experience. | as above | ✓ |
| How are SIGN guidelines produced? | | |
| I think that's easy to understand | ✓ | ✓ |
| Quite straight-forward. I'd use it as an information page telling me how you've got your evidence. Makes you think it is proper and you can trust it | ✓ | ✓ |
| Clear enough. Reassuring to see the process that you go through to reach end product. | ✓ | ✓ |
| The information about SIGN ratifies then quality of the content of the document. Whether you're familiar with SIGN or not, reassurance there is quality control. | ✓ | ✓ |
| I think signs are clear. The way you progress. Publish for everyone. Very glad that guidelines include opinions of parents as well as carers | ✓ | ✓ |
| Maybe say that you've asked parents of children who have autism | Add sentence at beginning or end around public consultation and parents | ✓ |
| There should be a reference to parents on page 52, not just patients and carers. | This is standard text explaining how all guidelines | ✓ |

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| | are produced, not just ASD. Parents would fall into the carer category. | |
| Does it talk about public consultation? Public consultation is important. IT shows you are actually asking/talking to people and not just letting everyone know about the guideline. The quotes show that you have spoken to people. Something clearer to show you do this. | As above | SIGN will consider including this in the diagram for the next patient version we produce. |
| You should maybe say at beginning how parents and carers were involved in it's production. Might make the booklet more accessible | As above | We will work on this diagram to include this information . |
| Really dislike ...you're really teaching parents about how to bring up a child. You wouldn't give neurotypicals a booklet about how to bring up your child. This almost gives bad message unless very clear very early in the booklet to explain what it is about, it's about looking at the areas that impact your child and their functioning. Then I agree with the research being specific about how to help them with this. Context. It really is that autism is a 'thing' that we can help you with which I don't like. Not clear. Almost implies you're going to get help for the autism. Find this a bit overwhelming. | Don't understand comment | Don't understand reviewer's comment |
| Would be interesting to have inside front cover rather than back. | previous user testing results showed back | ✓ |
| Some symbols don't make sense to me. Three crosses and a question mark do not make sense to me. Rest are fine. Would suggest another symbol. | previous user testing results | ✓ |

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| | showed back | |
| You could add that 'we analyse research papers' not just that 'we read research papers'. But I am just nitpicking here. But people with autism phenotype do pay attention to details like that | Previous user testing and other consultation exercise informed us that people liked this. | ✓ |
| I understand you need to put it in, but would prefer a link to go to a website for the information. It' just more information and clutter. | Need this page in. | ✓ |
| Missing information | | |
| A little bit text overload. The use of boxes is almost invalidated because of the number of boxes. But I do like using the boxes – stricter approach to when use boxes and why, what colours do we use and why, there could be different colours for different chapters. The different coloured boxes do not suggest there is a theme. Need for clarity. How to coloured boxes relate to each other. Especially the brown box – what is that? Next page has green box but no symbol. Does that mean there should be? Needs a theme for box usage. Brown and maroon as well. | Consistency in colours, boxes | ✓ |
| The tick list for professionals on page 24 is helpful. But not something as a reader you would ever tick – should be appropriate for each box. | Consistency for tick boxes and info box bullet points | ✓ |
| May be used for checking what to do, e.g when dealing with your GP. A little bit more proactive. Even at the end of each chapter. Pose a question – have you discussed? How did you feel? Little pointers to keep involved. Can be a practical usage guide as well. | If there is space, could put a box as on page 40 at the end of each chapter. | ✓ |
| Even having a couple of spare pages at the back of the booklet for people to take notes in a meeting or something like that. Certainly something like this would be handy to have when going to meetings. | As above, or more space at end | ✓ |
| Should explain what you should expect about meetings at school. And about IEPs. good to see what you're entitled to. | Th only information we can give is what | ✓ |

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| | we already have from guideline. | |
| There are different processes in different local authority areas. Booklet does not cover this. Booklet does explain some parts of the process but should say that this will differ depending on the local authority. | national guideline. | ✓ |
| Like to know how long process will be to reach diagnosis. | similar comments there re length of time will vary, add this in as bullet. We don't know for sure how long it will take. | ✓ |
| Because it follows the clinical guideline, there is the gap of the understanding of autism which is missing from this book. Focusing straight on getting assessed and getting help. Tone of all doom and gloom and bad. Could be an extra bit to be more comforting, understanding, positive, autism is a difference in the way brain processes etc | This is remit of guideline re assessment. | Organisations cover this type of information. |
| Know has to come from medical stance but makes it sounds like it's something that needs treating and I don't think that's right. | Hopefully this will now be improved since we have taken on board alot of comments from user testing and made changes. | ✓ |
| The language is out-of-date. If this is going out now I would address the definition terms. Shame not to change this now and next year when it's out, we can't change it. Language for the future, not the past | Chair of group to advise SIGN. | ✓ |
| not coming out that not parents fault. | Suggestions welcome, while being mindful of the purpose of patient versions of | Don't understand |

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| | guidelines. | |
| For autistic people a reading booklet, more visual would be a help | Add more visuals | |
| Parent with learning difficulties or different level of education might be quite wordy. | There were very many comments from user testing re easy to read, chunks, bitesize, clear etc. Could add more visuals if appropriate. Participant understood booklet, was commenting on others | √ |
| The balance of the booklet is wrong. It could be stronger about autistic children with talents, for example their attention to detail, and not just be negative. The booklet conveys negativity. There could be some more good points about autism. | translation of guideline | √ |
| I would emphasise a lot more the difference in girls with autism and that autism can be very hidden, and masked by high intelligence. Also, emphasise the positives in autism. Lining up toys is not a difficulty It is a slightly odd or different behavior which can be quite characteristic or particularly neat | RE hidden in girls - This is on page 12, and might be clearer when page redesigned. | √ |
| There is no evidence that the family has a part in this. There should be a lot more priority to families, not just what the doctors say | Purpose of document is to give parents/carer access to recommendations. | √ |

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| Subheadings might be useful – can affect your child medically, physically, emotionally etc, and then say for medical symptoms – for behavioural symptoms . etc? | ? | ? |
| The date should be on the front page of the booklet so that it shows it is the current version of the booklet. | Add date | ✓ |
| If there was more evidence of anecdotal evidence this would be more relevant to me, as well as parent input | outwith remit | SIGN does not use anecdotal evidence |
| There are no details on motor issues. Everyone who is autistic has motor issues. My concern is that it is incomplete re understanding your child’s profile. Sensory issues and impact on behaviour needs addressed. I expected to see evidence of how to help motor skills and anxiety. | outwith remit | ✓ |
| Is there anything said about multi-sensory support, as a child cannot change because to autism but the environment can be changed. 80% of people have this. One of most powerful support identifying triggers – you’ve made connection with OT which this relates to. | guideline only rec's OT not specifics | ✓ |
| The booklet should explain that lots of meetings have to take place and when eg at nursery and at school | We can't be too specific as guideline doesn't tell us how many meetings people will need to have. This varies between individuals. | ✓ |
| Sensory problems are a major thing but this is not even mentioned in the description of what is autism on page 3. If possible something right at the beginning of the booklet so mention this and that it impacts on behavior. There is mention on page 4 that children may have unusual responses to sensory input. Not sure clear enough. Can see snippets of it in there. Definitely needs to be clearer. | add this to table on page 4. | ✓ |
| There is nothing about gender dysphoria which is quite common and this needs to be mentioned at some point. All the icons show male and female. | outwith remit at moment | ✓ |

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| <p>Some of the recommendations do not happen. Where does this leave you as a parent? There should be something to say who can help if you do not get the recommended care as a parent.</p> | <p>We have added in that parents can speak to GP or HV.</p> | <p>✓</p> |
| <p>Statement saying eg each NHS area – there is someone to contact if you feel you’re not getting the right information or not getting listened to. Even if you just have a list of the areas in a box. I know they are recommendations but if parents think they’re not getting anywhere – where do you go?</p> | <p>As above</p> | <p>✓</p> |
| <p>Where do you go as a parent if your child is not in school or nursery? Who do you contact? The booklet could tell a parent to go to their GP or a health visitor. Even to let them know that it’s ok to contact or go to GP if you have these concerns</p> | <p>We had added in that parents can contact GP.</p> | <p>✓</p> |
| <p>There is a missing piece of information. Something called James Lind Alliance (JLA) looks at uncertainties for different health issues. Published a piece on autism earlier this year. Thought this might have come up in this meeting today. It is important to know how the Alliance reached their top ten recommendations on autism. Comes from parents patients and children with autism, voices. This is missing from the booklet although was only published recently this year so maybe before the guideline was produced. Know you can’t have everything in the booklet.</p> | <p>outwith remit?</p> | <p>Wish we had known about this – more to feed in to the guideline rather than booklet.</p> |