

<b>Is the layout easy to read?</b>		
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.	Others have not had any issues with the colours. This was developed with adults with ASD who advised these are ok.	√
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.	We plan to work on the layout so some pages are not empty or too cluttered in some pages.	√
Yes.	√	√
<p>On the whole presentation and layout are easy to read, however, some pages are too cluttered for a person on the spectrum sensitive to visual overload.</p> <p>Page 4. Too much on page suggest moving yellow circle from top of page 4 to the bottom of page 5.</p> <p>Regarding content most good but have some reservations I suggest the paper by Dr. Ava-Ruth Baker, MB ChB Dip Health Sci ( Mental Health) A medical doctor who is herself on the spectrum and specialises with diagnosis and support for adults and children in her practice " Autism Spectrum Consultancy" P.O. Box 19864. Christchurch 8241, New Zealand.</p> <p>Her papers are available are online at <a href="https://www.avaruthbaker.com">https:// www.avaruthbaker.com</a></p>	<p>Agree.</p> <p>Agree</p> <p>SIGN has carried out a systematic review of the evidence which is a very robust process to help them to reach recommendations.</p>	√
<p>The black text in the yellow bubbles is difficult to read as the letters are uneven and appear to move around. There is uneven layout in the coloured speech bubbles. I found the space at the top of the letters varied, which I found distracting.</p> <p>Overall, the pages with text to the left and the coloured bubbles to</p>	Improve this and use another colour	

<p>the right was too much on one page for me to take in easily.</p> <p>.</p> <p>In the information section, it would be helpful if the format was consistent, eg page 27 the phone number, website and email addresses are listed in a different order. Email is sometimes highlighted in bold, but not consistently. This makes it confusing to follow.</p>	<p>Adults we worked with asked for real examples using quotes but we will split this information over more pages to make it easier to read.</p> <p>We will ensure consistency in final draft.</p>	<p>√</p> <p>√</p>
<p>Very easy. The diagrams break it up.</p>	<p>√</p>	<p>√</p>
<p>Had a brief glance and noted one problem that I think should be addressed. Modern practice is to print documents in low contrast (mainly to save ink and cost). However, you may come across people like me who assists with the care of two people with Asperger's Syndrome. As an older person with eye problems, I cannot easily read a booklet in low contrast. pdf files are particularly poor in this regard unless care is taken to ensure that the right contrast is achieved.</p>	<p>Ensure high contrast for final publications.</p>	<p>√</p>
<p><b>Are the images and diagrams appropriate and meaningful?</b></p>		
<p>The cover is good. The images on page 1 made me think of toilets and that was disconcerting.</p>	<p>When we engaged with adults during the development of this, we had head and shoulders but adults didn't think this was helpful and suggested full bodies showing male and female.</p>	<p>√</p>
<p>All images seem appropriate, a good way of breaking up the text.</p>	<p>√</p>	<p>√</p>

Yes.	√	√
All images were appropriate and meaningful. None were there as titivation . Sparse enough to be effective and on the whole well placed,. Exception re visual overload p 4	√  Agree	√
I found the symbols used for recommendations difficult to relate to and kept having to flick back to the page where they are explained. It would be helpful if a key of these symbols is repeated when they are used.  I do not understand why the pencil and H symbols are used on page 15. Overall, I do not like the images, they are overly simplistic and not very representative. It took me a moment to figure out what the bottle of pills was.	We will include the key to symbols on pages where they are used in final draft or symbol and words to improve understanding.  Improve graphics.	√
See above.	√	√
Very easy to read.	√	√
<b>Do you think that the language and tone is appropriate?</b>		
For most it is fine but I have an issue with page 21 - it is not “challenging behaviour” it is “behaviour perceived to be challenging”. It is perjorative in the first form as it puts the responsibility onto the person with ASD.	Clinical members of the group have advised that the correct term is behaviour that challenges.	√
Tone appropriate generally.  Page 19 top line of purple box "behavioural interventions" seems to be crammed into one word and is difficult to read.	Agree	√
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	Turn MF's comment into quote with his permission to get this over.	√

<p>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>Fine, except you may wish to re-read the final sentence on page 19. Grammatically it does not flow and I suspect it contains an error.</p> <p><i>“As they are commonly used to try to help a wide range of different behaviours, you health-care professional should consider them would benefit from support to help change aspects of your behaviour.”</i></p>	<p>Some text has been lost here. We will correct this.</p>	<p>√</p>
<p>The language is not patronising and not too sophisticated ( in that it isn't academic or technical ) and there is sufficient and succinct explanation of terminology included within the flow of the language.</p>	<p>√</p>	<p>√</p>
<p>Overall the language is easy to follow, but then suddenly terms such as diagnostic instrument are used. Why not state questionnaire or tool for assessment and diagnosis.</p> <p>Instrument is very abstract and not used in everyday language for this purpose.</p> <p>Page 18 CBT is used, but not explained as cognitive behavioural therapy until a page later.</p> <p>I do not understand what <i>“anti psychotic medication”</i> means.</p>	<p>Agree. Tool the preferred term by group.</p> <p>Agree. Move quote or bring in definition earlier.</p>	<p>√</p> <p>√</p>

<p>The term “<i>challenging behaviour</i>” is unpleasant. I sometimes show stressed behaviour, but I prefer not to have the term challenging behaviour used. The behaviour may challenge services, but the individual may not term the behaviour as inappropriate. People with autism may have significant challenges fitting in and conforming to what is termed “normal” but why is someone’s anxiety or reaction to sensory overload termed as challenging behaviour?</p> <p>Withdrawal and isolation are also autistic responses, these are not mentioned.</p>	<p>Include definition</p> <p>Use the term behaviour that challenges – see above re clinical group’s advice.</p> <p>Include these.</p>	<p>√</p> <p>√</p>
<p>It is just right. Not too simple.</p>	<p>√</p>	<p>√</p>
<p><b>How useful is the content?</b></p>		
<p>Good use of external links at the end.</p> <p>Real life examples throughout are beneficial</p>	<p>√</p>	<p>√</p>
<p>Fine.</p>	<p>√</p>	
<p>Content is useful but more could be given regarding the " insider" perspective for both practitioners and those seeking diagnosis.</p> <p>I do appreciate that quotes from individuals are used to illustrate points... works really well.</p> <p>Sensory issues, communication issues in social environments, and executive function issues need to be emphasised as they are the areas we autistics struggle with in everyday life. These areas are usually largely overlooked in most diagnostic assessment tools.</p> <p>Once again I refer to Dr. Ava- Ruth Baker's papers available at</p>	<p>Our content is based on the clinical guideline.</p> <p>√</p> <p>We have mentioned these where appropriate. This patient version is a translation of the clinical guideline.</p>	<p>√</p> <p>√</p>

www.avaruthbaker.com under heading of Articles.		
The content is very useful and relevant. The information at the end is very helpful. I do not understand why NAS is listed twice and Scottish Autism only listed once. I find the Scottish Autism website very helpful.	Remove NAS from website section as full details given above.	√
Very informative.	√	√
Really helps.	√	√
I have a more general comment, which is that while I appreciate that this is for healthcare practitioners (who have in my personal experience have distinguished themselves in the past by not reading the guidelines on the NES website even when the site is drawn to their attention), I think it is important to also have a leaflet addressed to potential employers. This is a health care issues as one of the case studies on the NES website shows – unemployment and lack of constructive activity leads to depression and other problems.	We do not have resources to develop a separate leaflet but we could add a sentence in at the beginning stating that this will be useful for employers to help them understand and support people with autism in the workplace.	√
<b>Does the content help patients and carers understand what the latest evidence supports around: diagnosis, treatment and self-care?</b>		
It is a good outline with useful links to encourage further enquiry if required.	√	√
Very clear recommendations in boxes	√	√
Yes.	√	√
Content does point patients and carers to organisations etc that	√	√

<p>offer support and some treatments... e.g. melatonin , CBT.etc</p> <p>As I'm not a British citizen I'm not aware of what is available in the UK.</p> <p>A major point for me is that I do not consider that " I have autism" I am autistic it is the existential nature of my being. I, like many autistics, object to the use of " having ASD" it is not like having the measles, or a heart attack or for that matter diabetes... it is truly existential.</p>	<p>We discussed the use of the terms with adults and referred to a survey carried out by NAS on preferences for terms. Adults agreed that we should use the term autism to keep our information simple but we do say that it covers ASD. Very difficult to use a term that everyone agrees with.</p>	
<p>The booklet does not refer to the waiting time or that some areas do not have a pathway for diagnosis. For example, in Orkney there is currently no pathway for adult assessment and diagnosis of autism.</p> <p>It also does not reflect that the assessment process in itself can be stressful and the individual may need support during this time.</p> <p>There is no mention of local support groups and who the peer support from others with autism can help during the assessment process and waiting time.</p>	<p>Out with remit.</p> <p>Include a sentence on page 10 to reflect this and sign post people to local groups.</p>	<p>√</p> <p>Page 12</p>
<p>I would say so.</p>	<p>√</p>	<p>√</p>
<p>I assume the “shutterstock” watermark will be removed from the final publication.</p>	<p>Yes</p>	<p>√</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 draft will include a statement re this.</p>	<p>√</p>
<p>'Information' should have a lowercase 'i'</p>	<p>√</p>	<p>√</p>
<p>Page 0 "Kate's story" use of "mad bad and dangerous to Know..." doesn't seem very appropriate and spelling and grammar problems, but difficult as this is a direct quote.</p> <p>Kate's story use of explaining services aren't available and "I end up costing the NHS huge amounts of money" although relevant to the leaflet, and you don't want to screen what she is saying is maybe not appropriate to be the first thing patients read when opening the leaflet and is quite negative and could discourage from reading further, which is not what we want to do.</p>	<p>Agree it is difficult to change this as this is a direct quote submitted to us for use in this booklet. People have liked this.</p>	<p>√</p>
<p>Grammatical errors to be corrected:</p> <p><i>"I was being looked after by NHS mental health teams, but nobody raised the possibility of autism. There were endless group sessions, group hugs and mental exercises which made me worse.</i></p> <p><i>An OT at Jobcentre Plus recognised the signs and my desperation, and arranged for me to see an NHS clinician within a fortnight. I don't know how she did it given the waiting lists, but I am here today because she succeeded. I was diagnosed at 47 and it stopped me killing myself. I went from mad, bad and dangerous to know, and became an integrated human being. Not overnight, of course, and I still have autism, all the things that made life so hard before, as well as a couple of the most common comorbid. It took me 5 years of thinking and reading before I asked for a place on the post diagnostic course.</i></p> <p><i>My support now is from the autistic community. I need 1:1 autism-professional interventions every couple of months to stop issues</i></p>	<p>This is a patient story in their own words. We do not want to change this.</p>	<p>√</p>



<p><i>turning into crises. They aren't available, and so I end up costing the NHS huge amounts of money in emergency support. The diagnosis has made a huge difference and, as I learn more about autism and myself, life keeps getting better!"</i></p>		
<p>Story is good.</p>	<p>√</p>	<p>√</p>
<p>P1 is a bit confusing. The symbols with the “?” in, state may have autism, Does that mean may have autism but not yet formally [formally] diagnosed?  The booklet does not refer to people who wish to remain self diagnosed.</p>	<p>Yes.  ?</p>	<p>√  Can access booklet through a healthcare professional or from SIGN website.</p>
<p>Could page 3 fit on the bottom of page 2?</p>	<p>Yes, but when we met to discuss this booklet with adults with autism they wanted this information on two pages as too much to take in.</p>	<p>√</p>
<p>Page 4. Too much on page suggest moving yellow circle from top of page 4 to the bottom of page 5.</p>	<p>Agree move yellow circle (top of page 6) to bottom of page 5. We plan to alter layout so pages may change.</p>	<p>√</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 thern 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 least firmly say</p>	<p>Adults and parents told us they did not like the term ASD and preferred to use the term autism which is why it is written in this way. We still need to get over that it covers ASD.  Anne O'Hare has reworded</p>	<p>√</p>

<p>its shorthand for ASD.</p>	<p>this section.</p>	
<p>A comma is needed after 'below'. There isn't consistency in capitalisation. For example, Asperger's syndrome is written twice with a lower case 's' and once with a capital 'S'.</p> <p>Definitions cause some difficulty. For example, definition of Asperger's syndrome is "where a person has all three main areas of difficulty..." but the box below gives four areas of difficulty.</p> <p>Page 4 black box. Space needed after full stop between "difficulties.These.."</p>	<p>Final proofreading will correct these.</p> <p>Improve this page.</p>	<p>√</p> <p>√</p>
<p>Comma needed after "for example", both here (on page 5) and elsewhere in the document.</p> <p>Comment in yellow box (Kate). Correct to "<i>I am overwhelmed by my senses. Supermarkets are dreadful: the noise, the lights, the smell.</i>"</p> <p>Page 6: Text in circle at the top is smaller and askew, which some people may find difficult to read.</p> <p>Page 8: Additional difficulties/signs, 3<sup>rd</sup> point – misplace comma between "<i>university,college</i>"</p>	<p>√</p> <p>This is (written) in the person's own words.</p> <p>We plan to split the information up on this page – see above. This will improve the information in circle too.</p> <p>√</p>	<p>√</p> <p>√</p> <p>Need to make text horizontal</p>

<p>Page 10: I appreciate the quotes are only the opinions of people with autism, but it may come across as being presented as fact. What this person is saying is generally not true.</p> <p>Page 11: Should multiagency team be inside the brackets?</p> <p>Page 14, first line: “<i>healthcare</i>”</p> <p>Page 16, first paragraph. Some people may interpret this as saying they can bring a partner or family member only and not a friend, etc. Perhaps say "a person like a partner or family member..."</p> <p>It should probably also say you can have someone accompany you to the earlier clinical appointments.</p>	<p>We have included names of the individuals providing us with quotes for this reason. So people know that it is not SIGN that is saying this.</p> <p>Reword this.</p> <p>√</p> <p>Agree</p> <p>Agree. Add a statement in assessment section.</p>	<p>√</p> <p>√</p> <p>√</p> <p>√</p>
<p>I do not understand why the pencil and H symbols are used on page 15</p>	<p>Remove ‘H’.</p>	<p>√</p>
<p>I have an issue with page 21 - it is not “challenging behaviour” it is “behaviour perceived to be challenging”. It is perjorative in the first form as it puts the responsibility onto the person with ASD.</p>	<p>See above.</p>	<p>√</p>
<p>Page 19 top line of purple box "behavioural interventions" seems to be crammed into one word and is difficult to read.</p>	<p>Agree</p>	<p>√</p>
<p>Page 19</p> <p>Social skills programmes: “<i>healthcare</i>” one word? elsewhere in document as well.</p>	<p>√</p>	<p>√</p>

<p>Behavioural interventions: redundant comma after “<i>moment</i>” line 4.</p> <p>Page 20, 1<sup>st</sup> recommendation: define “<i>psychosocial therapy</i>”.</p>	<p>√</p> <p>Provide definition</p>	<p>√</p> <p>√</p>
<p>Page 18 CBT is used, but not explained as cognitive behavioural therapy until a page later.</p>	<p>Move quote under recommendation on page 20,</p>	<p>√</p>
<p>Information in title should start with lower case “I”.</p>	<p>Agree</p>	
<p>On pages 27 and 30 of the booklet there is a reference to <b>The National Autistic Society</b> 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 <b>The National Autistic Society Scotland</b> is mentioned also on p27 and 30 of the booklet reflects that the charity doesn’t refer to itself as ‘NAS’ anymore.</p> <p><b>The National Autistic Society Scotland</b></p> <p>Central Chambers, 1st Floor, 109 Hope Street, Glasgow G2 6LL Tel: 0141 221 8090 Website: <a href="http://www.autism.org.uk">www.autism.org.uk</a> Email: <a href="mailto:scotland@nas.org.uk">scotland@nas.org.uk</a></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</p>	<p>√</p> <p>Thanks.</p> <p>We will not include the addresses. Only website, email address and phone number. Including this makes the documents extremely large and patients have told us that its more helpful to</p>	<p>√</p> <p>√</p> <p>√</p>

<p>range of information on autism, and the charity operates a free helpline (0808 800 4104).</p> <p><b>The National Autistic Society</b></p> <p><a href="http://www.autism.org.uk">www.autism.org.uk</a></p> <p>The National Autistic Society website offers a range of information on autism and the support available for parents and carers.</p>	<p>include websites and email addresses.</p>	
<p>Page 27 and 28: delete the slash at the end of the first four website links.</p> <p>Page 30: delete the slash at the end of <a href="http://www.do2learn.com/">www.do2learn.com/</a></p>	<p>√</p> <p>Autism Network Scotland advised us to remove this website.</p>	<p>√</p> <p>√</p>
<p>In the information section, it would be helpful if the format was consistent, eg page 27 the phone number, website and email addresses are listed in a different order. Email is sometimes highlighted in bold, but not consistently. This makes it confusing to follow.</p> <p>The information at the end is very helpful. I do not understand why NAS is listed twice and Scottish Autism only listed once. I find the Scottish Autism website very helpful.</p>	<p>Ensure consistency.</p> <p>Remove.</p>	<p>√</p> <p>√</p>