

| | Reviewers' comments | Group response | Editorial response |
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| Is the layout easy to read? | | | |
| | Very good.....clear and unfussy | √ | √ |
| | Should add on to say that it should be for schools, any professionals working with FASD children and anyone working with families. | Agree | Added to page 2 |
| | Yes. Looks good. A lot of information but people need to get all the information because no one else gives this kind of information. | √ | √ |
| | The layout is excellent. Very clear and easy to read. The headings help with this. Page 2 clearly states what this is about which I really like. Very well written. The wee symbols are good. It lets folk see that it is based on good information but probably not for everyone then you can ignore them if you don't understand. | √ | √ |
| | I think it looks good. | √ | Changed at editorial |
| | Very easy to read. Well set out. Page 2 is really helpful. Explains well why there hasn't been the support. The final sentence is a must! It's good you | √ | √ |

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| | <p>give the website for the full guideline if people want to look into it further.</p> <p>Page 4 is helpful. Good and right amount of information.</p> <p>Boxes help to split information up and really draw your attention to crucial things. You get lost in a lot of information but the way this is set out means that doesn't happen!</p> | | <p>√</p> |
| | <p>Yes – the language clear and good balance of written and graphical content. It conforms to SIGN's accepted house style. Presentation is appropriate to those accessing it – on this occasion parents, carers and families not children themselves and feel they could contribute to section on education, movement from teenager to adulthood. Definition and the inclusion of symbols for recommendations is particularly useful due to complexities of the condition and strong recommendations are given to empower patient, carer and families. The statement that it's a first UK guideline on FASD makes a strong argument for the need for it.</p> <p>Very long section on assessment shows the need for and variety of methods used leading to it being a prolonged process.</p> <p>Excellent there are blank areas for people's comments/experiences to be highlighted.</p> <p>Standard support bodies and further information at end and usual section on</p> | <p>√</p> <p>√</p> <p>These will be added after consultation</p> | <p>√</p> <p>√</p> |

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| | the work of SIGN. | √ | √ |
| | Yes. It has a really good layout so you're not overwhelmed with the amount of information. | √ | |
| | <p>The booklet is well presented - the type is easy to read. However, there are a number of spelling and/or grammatical mistakes:</p> <p>Page 7 - it says "Academic acheivement" - it should be achievement.</p> <p>Page 18 - the whole bubble entitled "Psychologist" is poorly written. At the very least the word "specialise" should be changed to "specialises"</p> <p>Page 23 - the top section is badly written, with too many semi-colons</p> <p>Page 27 - in the paragraph "Your family's need..." the word "which" should be replaced by "what"</p> <p>OSHAY's FASD - the word guild, I believe, should be replaced by "Guide", and in the last part of the paragraph the word "we" should be replaced by "and"</p> <p>I was also concerned with the reference to "your child's named person" on Page 14 - I was not aware that this scheme was now in place - it was thrown out by the Supreme Court.</p> | <p>√</p> <p>Improve section and removed named person as Scottish government has not withdrawn this.</p> | <p>√</p> <p>Moved to list of terms on page 46</p> <p>Removed</p> |

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| | <p>Yes. Different coloured boxes was confusing - the recommendation boxes have different icons as explained at the beginning, so we know these differences are significant, but some other text boxes are blue and some are green with no explanation.</p> <p>Should the strapline across the front cover say “A booklet for parents, carers and families of children and young people exposed prenatally to alcohol”? Doesn’t the current wording apply to nearly everyone if there is a child or young person in your family?</p> <p>Can the font sizes of the text in the circles be made consistent? Also, I disliked the box which reads “Actual physical (age 18)” I think the phrase needs to be “actual physical age” and then age 18 repeated on the following line.</p> | <p>Text boxes giving information should be blue with ‘I’ symbol for consistency with other SIGN booklets.</p> <p>Agree but simplify language</p> <p>Agree but have ‘actual physical age’ in larger font</p> | <p>√</p> <p>√</p> <p>Changed at editorial</p> |
| | <p>It might be useful to include in the title of the booklet reference to the SIGN guideline. A sub-title e.g. FASD: the assessment process</p> <p>The format (layout) of the document is easy to read, however it could be considered to be a little clinical in it's format and in this way may not appeal to the target audience. The use of more colour and images might help to</p> | <p>Altered strapline</p> <p>Final booklet will have more colour and language edited by PLC.</p> | <p>√</p> <p>√</p> |

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| | <p>make it feel less clinical.</p> | | |
| | <p>In general the layout is easy to read except on pages where there is a lot of text not broken up, without headings or bullets points - an example would be p. 12 but there are others where it would be helpful to assist the reader with headings and bullets etc.</p> <p>Contents page - feeling that the first item should be "What is this booklet about?" rather than "Who is this booklet for?"</p> <p>Need to make the headings in the content page consistent with the headings on the actual pages. Example: P.11 heading is different from the one on the Contents page. Same on p.22 "What happens..." versus "What will happen". Content page headings need to be the same as the actual pages.</p> <p>Where there are several pages under 1 heading, please add the word continued after the heading at the top of each page. Example pp. 11-15</p> <p>Need to break up text either into bullet points or here p. 12 headings would help signpost the reader and help with access as follows: Support for you and your child, GIRFEC, Health services, How to register concerns. (some suggestions)</p> | <p>Agree – remove 2nd box as a result of other feedback</p> <p>House style</p> <p>Agree</p> <p>Add sub-headings into contents page</p> <p>If we remove the second part this would make it less reading.</p> | <p>√</p> <p>√</p> <p>√</p> <p>√</p> <p>√</p> |

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| | <p>p.15 - Section on Assessment - the case study at the beginning could be better presented. It is not introduced as such - needs to have something saying what it is. Adding names (fictitious ones) helps identifying with the case.</p> <p>Group felt strongly that para 2 was overly negative and while it is important to be honest about potential future problems, it was not appropriate at the beginning of the section on Assessment.</p> | <p>Agree, needs to stand out using quotation.</p> <p>Service users on group felt this was important to highlight</p> | <p>√</p> <p>√</p> |
| | Yes | √ | √ |
| | <p>Yes the layout is good, although I noticed only one little thing.</p> <p>Page 25 bullet point three. Should this read Your family's need to access multiple health services, who might know WHAT each other.</p> | Yes | √ |
| | This is an excellent, and very readable document. | √ | |
| | yes there is a good layout | √ | |
| | <p>not always, parents who start to look into this for the first time are probably highly stressed due to challenges in daily life with their child....</p> <p>plus not every body is that well educated and may need simpler terms</p> | <p>Aim to make simpler without</p> | Agree – simplified text at editorial |

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| | <p>for me I needed 4 chapters at the time</p> <p>What is it, what are the symptoms/ behaviours</p> <p>Where do I get a diagnosis</p> <p>What can I do in daily life</p> <p>Where do I get help afterwards</p> | <p>losing information. Final publication will have been edited by PLC.</p> <p>Re-structure to make more useful.</p> | <p>√</p> <p>√</p> |
| Are the images and diagrams appropriate and meaningful? | | | |
| | Absolutely | √ | √ |
| | <p>Front Cover</p> <p><i>Comments from parents and carers</i></p> <ul style="list-style-type: none"> • The front cover is very busy and feels like it is too much to look at all at once. • Like the ages <p><i>Person with FASD</i></p> <ul style="list-style-type: none"> • The paints are good and it shows what my brain feels like. • The ages are good as well to show people what the condition is like. | <p>The young person explained when we met how this image reflects how her brain feels. Other reviewers have found the image acceptable.</p> | √ |
| | Kinship carers discussed the diagram of 10 assessment areas and thought this was informative. They could relate to this. They agreed that it would be useful to have real examples attached to each one here to make it helpful | Include information from page 21 | √ |

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| | for people. | (consultation draft) in diagram. | |
| | Yes, very simple. | √ | √ |
| | Yes. Page 5 one is really good. Page 29 ones are good too. Maybe a few others could go in? | Difficult to illustrate and illustrations need to be meaningful | √ |
| | Cover challenges readership to find out its meaning and participation in the process the booklet describes. Useful blank boxes to assist. Very useful diagram on 10 areas of assessment (p5). Appropriate semi-graphical summaries with bullets (p6, p7) plus checklist for behavioural and thinking difficulties with inserted definitions of autism and ADHD. This is confirmed later and is employed by the writer in drawing together the professionals who are part of the multidisciplinary team (p18, p19). P29 has good graphics. | √ | √ |
| | Not that many but the ones that are there are appropriate. Maybe a photo of facial features? | A few people have commented that this would be helpful, However the group don't want to emphasise facial features as the majority of children don't have them. | √ |

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| | <p>The images and diagrams are good.</p> <p>I think it would be good to have a few more diagrams showing the development of the foetus, and possible effects of alcohol at different stages.</p> | <p>√</p> <p>Diagram of fetus supplied by Jen Shields to be incorporated</p> | <p>√</p> <p>Simplified diagram to be included</p> |
| | <p>There are few diagrams or images. Perhaps an image of the typical sentinel facial features would be helpful.</p> | <p>See above.</p> | <p>√</p> |
| | <p>As mentioned above the use of more colour may help to make the booklet more appealing to the target audience. The use of the current colour pallet may make it difficult for some readers who are colour blind or have difficulties with blue and green.</p> <p>The images are fit for purpose, however basic, and therefore may not engage/draw in the reader as higher quality images could.</p> | <p>We have adhered to RNIB guidelines and have provided a contrast between text and backgrounds ie blue on white/green on white.</p> <p>Image of developing fetus to be added</p> | <p>√</p> <p>√</p> |
| | <p>The group particularly liked the front page. However they are querying the age p.1 of YP up to the age of 18 in the light of the Act providing continuing care to 21 and beyond for after care to 26??? Should this be clarified</p> | | <p>√</p> |

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| | <p>somewhere?</p> <p>Proportion of text to visuals - more images and diagrams are needed for balance - though the existing diagrams are good. More visuals will aid accessibility for readers especially those who may have literacy issues.</p> <p>Specific question on the nature of the blank boxes on pp. 9 and 10? What is to go in here?</p> | <p>Up to age 18</p> <p>Agree - difficult topic to describe by visuals. An easy read version would be more helpful but SIGN does not have capacity at this time to produce this.</p> <p>People's experience as explained in information</p> | <p>√</p> <p>√</p> |
| | <p>Yes - generally okay</p> | <p>√</p> | <p>√</p> |
| | <p>Yes</p> | <p>√</p> | <p>√</p> |
| | <p>Yes although the circles for autism and ADHD seem to suggest these are the most important- is this misleading</p> | <p>The circles were intended to be definitions but group now</p> | <p>Add some other bubbles</p> |

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| | there should be the same emphasis on secondary MH problems- self-harm, suicidal tendencies, BPD etc | suggest including overlapping circles to inform people that ASD/ADHD can co-occur with FASD. These are specifically mentioned in guideline. | |
| | I like the front cover not sure about the green dots with thumbs up like page 5 /17 18 21 29 30 33/ 34 is confusing since it headlines: what services are available. but lists strategies for daily life? | To be decided after editorial as these do not work for this guideline Changed to what can help | √ √ |
| Do you think that the language and tone is appropriate? | | | |
| | I personally would prefer us to use the spelling Foetal (as opposed to the American "Fetal") but I guess that's just a personal thing! I also prefer to use the term "FASDs" to highlight that there are a number of conditions on the spectrum as opposed to saying a child "has FASD" which is not true, either grammatically or medically. However I again know that this is just me! | Booklet adopts language from SIGN guideline. Guideline wording is FASD. | √ √ |

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| | Overall though I believe the wording is OK and the tone is excellent. | √ | √ |
| | Yes. Explains things well. | √ | √ |
| | It is very sensitively written which is what you need for this. The language is excellent, probably a very difficult thing to get just right. I read it and understood everything. | √ | √ |
| | Very. It's not patronising and sentences are simple. Page 15 - First two sentences are straight and to the point. Good message. | Thank you | √ |
| | Given the range of information being shared and its complexity reasonably so. It concentrates on sharing factual information and keeps points relatively brief (p12 and p13) for example and some emotional inclusion is therefore sacrificed (see other parent/carer booklets for personal experience). | We spoke to parents and families as part of consultation exercise and their stories/quotes will feature in final publication. | √ |
| | The language and tone are, on the whole, appropriate. | √ | √ |
| | Mostly, although there are some instances of over aggressive insistence on what the team should do. Also, too much repetition and uncomfortable emphasis on "if your concerns are not being taken seriously". The concept of formal complaint to the Health Boards is well established across the entire service, but to highlight it here seems to imply that complaints are particularly appropriate in this context, whereas the underlying issue is lack of clinician awareness and | Another group member also commented on use of this here. Unlikely to get through editorial process. | Agree, this has been removed. |

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| | <p>confidence with FASD, rather than competence or malpractice.</p> | | |
| | <p>Some of the language, tense and tone is at times ambiguous and could be confusing to a reader who has little or no knowledge of FASD or is unfamiliar with the content of the SIGN 156 guidelines.</p> <p>- Clearer reference needs to be made to the SIGN 156 guidelines.</p> <p>- With reference to the three types of recommendations (p3): from the parents point of view, it is unclear how the use of these within the document will help parents who are seeking a diagnosis for their child.</p> <p>- Throughout the document the language and tone makes it sound as if FASD is a new and developing issue / condition that has only recently been discovered. This is clearly not the case. It might be helpful to include reference to the historical context of alcohol in pregnancy, the discovery of the link between the unborn child and alcohol exposure and the developments in the medical community over recent years to acknowledge these issues and recognition of FASD.</p> | <p>Agree there needs to be clearer reference to SIGN 156 – see MN’s comments below. Making these suggested changes will make it clearer.</p> <p>Final publication will only have one style of recommendation and GPP.</p> <p>Add in sentence to say it has been known for many years that alcohol causes difficulties.</p> | <p>2 symbols available – one for recommendations based on evidence and another for GPP</p> <p>√ Not sure adding timeline/history is that helpful.</p> |

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| | <p>1. Too negative in placesAlthough the group acknowledge this is not a light hearted subject, carers and CYP are "stuck with the situation and therefore it does not help to be all gloom and doom!"</p> <p>Comment:</p> <p>" It is already scary for anyone reading this booklet because their child already has FASD it is too late so why make them feel any more guilty - it is not prevention tool."</p> <p>2. inconsistent levels of formality and register as it lurches wildly between formal and direct - examples on p.4 and use of more medicalised words p. 18 under physio - use of torso instead of trunk. A great deal of the text has a</p> | <p>Agree</p> <p>Group members felt very strongly about including the CMO's recommendation</p> <p>Agree – make more consistent</p> <p>Agree – make more consistent</p> | <p>√</p> <p>√</p> <p>Tried to address at editorial</p> |

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| | <p>tone more suitable for professionals than lay people.</p> <p>We would strongly recommend therefore that this booklet is passed by the Plain Language Commission (Clear English Standard) BEFORE publication. It needs to be accessible and easily read by a variety of audiences. https://www.clearest.co.uk/</p> <p>p.25 Who is the audience for this booklet? Is it also the patient - referred to here? It is not suitable for children and young people so we wonder why the use of the word patient?</p> <p>P.27 Wording far too direct and needs to be softened. Ref half way through 2nd para. "Adults need to be ready to change!!!"</p> | <p>All of SIGN's booklets are edited by PLC.</p> <p>Cannot see the word 'patient'. We have listed 'parents'.</p> <p>Reworded</p> | <p>√</p> <p>√</p> <p>√</p> |
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| | <p>The whole tone of the booklet is highly misleading and the content is an inaccurate interpretation of the SIGN guidelines. It perpetuates the myth that FASD is a recognised diagnosis which it is not. The SIGN guidelines do make this clear but unfortunately the associated materials have failed to recognise this. FAS affects only a small minority of children with FASD, and it is only for those with FAS that a diagnosis can be made. You should be making it clear that no 'diagnosis' will be made for the vast majority of the children affected by alcohol during pregnancy.</p> | <p>Make this clearer – refer to being described as having FASD rather than diagnosis of FASD.</p> | √ |
| | Yes | √ | √ |
| | Yes although ambiguous at times and based on many assumptions | ? | √ |
| | <p>I think if you are brand new to this subject it may be a bit overwhelming and I spotted a lot of things being mentioned that look fab on paper but don't mean much more plain English would be handy</p> | <p>This will be edited by PLC.</p> | <p>Addressed at editorial</p> |
| How useful is the content? | | | |
| | <p>Really, really useful and I only wish that Wales and England would follow the lead you are setting in Scotland in producing this type of document.</p> | √ | √ |

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| | <p>Indeed it would be good if Wales and England would follow your lead in creating clinical pathways and raising awareness, amongst professionals as well as the public, in the way you are.</p> | | |
| | <p><i>Page 2</i></p> <p>Very good, captures the perspective.</p> <p><i>Page 4</i></p> <p>Clear information</p> <ul style="list-style-type: none"> • This needs to say no alcohol should be consumed at all and that it should not depend on the stage in pregnancy. • Important to show somewhere that it is not always about how much you drink, it could just be a single drink that you have which causes FASD. • Sentence at the end of paragraph 3 should come out. <p><i>Page 6</i></p> <ul style="list-style-type: none"> • The 3 out of 100 should be changed to 3.2% instead. • It is very hard to get a diagnosis and you don't get any support without one. • Some people are worried about a stigma of a FASD diagnosis. • FASD children are more easily led than other children and are at a high risk of drug and alcohol problems. | <p>√</p> <p>Reworded</p> <p>Disagree, not everyone will understand percentages. We have highlighted the need to get assessment as early as possible to get the right</p> | <p>√</p> <p>√</p> <p>√</p> <p>√</p> <p>√</p> |

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| | <ul style="list-style-type: none"> Information in green box is good. | <p>support. Issue of being easily led highlighted</p> | |
| | <p>The group welcomed this information. They found it useful and identified with the content. They found the information on assessment helpful as they didn't know how they could go about getting children assessed. They also agreed that the information on management strategies was essential for this booklet and discussed their own experiences in relation to these 8 strategies. They were keen to raise awareness of these strategies with teachers and others working with their children. They are keen to see this booklet being distributed to teachers, social workers and others involved with their children.</p> | <p>We will notify local authorities of publication to ensure teachers, etc are aware of this.</p> | <p>√</p> <p>√</p> |

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| | <p>Page 1 – the information given is useful and clear.</p> <p>Page 2 – helpful for people to understand the situation</p> <p>Page 4 – it tells is how it is and very straightforward</p> <p>Page 7 – Some kinship carers suspected their children may have FASD due to birth mother’s history of alcohol. They welcomed the information on pages 7 and 8.</p> <p>Page 9 – kinship carers shared their own experiences for use in the booklet if helpful.</p> <p>Page 11 – The older the get the more noticeable things become. The kinship carers knew the birth mother’s had a history of alcohol so they have been able to flag this up. They felt it was important to let professionals know this early on as it’s overlooked. They thought the booklet could emphasise this that parents, kinship carers need to share this information. Perhaps have statement in bold.</p> <p>Page 12 - Discussion took place around GIRFEC – they felt the first box was important to make people aware of this although there was some frustrations and confusion re the named person. They didn’t think head teachers knew children well enough. Useful quotes/advice from people re making an appointment with teachers each year to discuss what works for your child and what doesn’t.</p> <p>They talked about the low awareness among teachers of difficulties. They talked about changes that teachers could make to help children who have been exposed prenatally to alcohol.</p> | <p>√</p> <p>√</p> <p>√</p> <p>√</p> <p>√</p> <p>Place more emphasis on sharing information about alcohol history including section on this/</p> <p>Removed named person as no longer relevant</p> <p>Include quotes about talking to teachers</p> | <p>√</p> <p>√</p> <p>√</p> <p>√</p> <p>Quote changed</p> <p>New section on information sharing.</p> <p>√</p> |
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| | <p>“Take them to another area to calm down”</p> <p>Wobble boards</p> <p>Toys in a basket</p> <p>Sensory board – can make one with child to make it special</p> <p>Music - “X listens to music or whale sounds to calm down”.</p> <p>Always think younger, don’t expect too much of them</p> <p>Remind yourself it’s not all negative. “X is very caring, sympathetic, he does care about other people”</p> <p>Speak to class teacher each year about your child. Don’t be afraid to speak up for your child.</p> <p>13 – 21 – information on assessment was found to be helpful. Information on page 21 would be more helpful at the beginning and linked to real life examples.</p> <p>Page 29 – highlight listening to music as something that can help, avoiding busy places and loud noises</p> <p>Page 30 – better to withdraw privileges rather than punishing.</p> <p>Page 32 – This should be continuation of ‘What can help?’. Heading isn’t useful but all the information is helpful.</p> <p>Pages 33 and 34 - The group felt there was a lot of information under the 8 magic keys but felt it was needed to give people as much information as possible. They could relate to this content. “If you’re going on holiday tell</p> | <p>Improve section on what can help. Use quotes from parents/kinship carers to get message over – include tips that we know work for FASD children</p> <p>Agree – bring this information in at beginning.</p> <p>Agree</p> | <p>√</p> <p>Include this quote on page 27</p> <p>√</p> <p>√</p> <p>√</p> |
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| | <p>them where they're going and what it will be like. It's good to show them pictures so they know what to expect".</p> <p>Page 35 – It can be overwhelming for children with these difficulties to move into adulthood. Need to remember that they will think younger and they still need help. Perhaps highlight this here.</p> | <p>Ok</p> <p>Quote re thinking younger to be included alongside this information in 'what can help' section.</p> | <p>√</p> |
| | <p>Extremely useful. Just telling people what to do or how to get help can make such a difference. We didn't know who to turn to. We weren't getting help from school and GP wasn't interested. So if others got this leaflet they can take your advice and ask them to look at it so they know they should be helping. It can help to get a diagnosis. There's no support out there mind you.....</p> | <p>√</p> | <p>√</p> |
| | <p>My only doubt is that there are two references to not getting what you want, and on followed by instructions on how to complain.</p> <p>Of course I know that Scotland is full of rubbish GPs and not enough services, but I do worry that these references collude with that idea and male the tone more negative than it needs to be?</p> <p>Do other patient versions include advice on complaining?</p> | <p>Agree – not SIGN's remit to offer advice on how to complain.</p> | <p>√ Removed</p> |

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| | <p>Very. It really does tell people what to expect with assessment and diagnosis. It arms people so they can show them this and say they need a referral. There's no support afterwards though. We had to fight to get a diagnosis for Jade. We knew her mum took drugs and alcohol when she was pregnant so we were able to tell the medical people. Page 21 is helpful. 22 and 23 lets people know what will happen. Maybe other practical stuff though needed – that's what really helps.</p> | <p>√</p> <p>We have been working with families to gather helpful advice/practical tips which will feature in final publication.</p> | <p>√</p> |
| | <p>Adoption UK are now the organisation who will be Scottish Government Funded and offering a helpline for FASD. Add to booklet.</p> | <p>Agree</p> | <p>√</p> |
| | <p>The content is quite useful, but very repetitive.</p> <p>It mentions the help that should be available - my experience is that it is extremely hard to get to the assessment stage at all, let alone what to do after that. Management plan?</p> <p>Much more should be done with the educational system (teacher training etc) as most schools have no idea how to help these children learn.</p> | <p>Agree – restructuring should help</p> <p>One of the things families members said to us was to make people aware they can make appointment with</p> | <p>√</p> <p>√</p> |

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| | <p>Because my child does not have a diagnosis of FASD but exhibits many of the characteristics we have "gone down the Autism route" as the general public have some vague understanding of that . When my child behaves differently in public it is easier to say "Autism" and you get a knowing nod. Mentioning FASD would elicit a blank look.</p> | <p>teacher to tell them how to work with their child. Include quote.</p> <p>It is anticipated that the SIGN guideline will improve this situation.</p> | <p>√</p> |
| | <p>Partly useful because it really only covers assessment. So the assessment information is really helpful but people don't get the support they need. The information on what can help is useful and more of this would help. I know you are doing work on this asking for input so would welcome that.</p> | <p>√</p> | <p>√</p> |
| | <p>Contents.</p> <p>I am critical of some of the headings. Also some of the main headings could usefully have, beneath them ,subheadings. Once the text is finalised it would be worth looking at the contents page again</p> <p>Page 1</p> <p>I 'd make changes to the second last paragraph taking in information given in the introductory paragraph on page 2.</p> <p>But first, After " Foster parents and legal guardians" I'd add " The booklets may also be useful to teachers and others whose work</p> | <p>Agree</p> <p>Reworded</p> | <p>√</p> <p>√</p> |

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| | <p>brings them into contact with children and young persons affected by FASD." Continuing. "All information is based on the recent national clinical guideline on children and young persons exposed to alcohol before they were born.. It is produced by the Scottish Intercollegiate Guidelines Network(SIGN) and is available on our website". [Add link]</p> <p>Page 2</p> <p>Introductory paragraph in bold now much shorter as follows." This booklet explains that clinical guideline. It is about "</p> <p>At the foot of the page the last sentence to read. " The professionals involved with your child should be following the clinical guideline.""</p> <p>Page 3</p> <p>I d delete the third paragraph as repetitive.</p> <p>First line of the second paragraph to read. " The clinical guideline, published in early 2019, is based..."</p> <p>Page 4</p> <p>Insert a new paragraph immediately after the introductory paragraph in bold:- "What do we mean by "exposed to alcohol"</p> | <p>Reworded</p> <p>Reworded</p> <p>Agree</p> <p>Improve this whole section</p> <p>Feedback when testing with users of the information was that this page was clear. Reviewer agreed when we met again.</p> | <p>√</p> <p>√</p> <p>√</p> <p>√</p> <p>√</p> |
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| | <p>At the end of the third line in what is presently the first paragraph delete " it " and substitute " substances in the alcohol "</p> <p>[note. In page 3 "You" =. the reader. In page 4, at the last line of the second paragraph the "you " in "you take" refers to the mother of the baby. A preferable construction there would be " is consumed " That is instead of " you take. '</p> <p>Page 5</p> <p>I suggested in the contents page that there might be an occasional subheading. "Getting technical" here is such a subheading, making it plain that this is something more complicated than what has gone before.</p> <p>Q I approve of the idea of the graphic I'm not happy with it: –</p> <p>Would not are better heading be " There are 10 areas of brain function which might be affected "</p> | <p>Reworded</p> <p>This sentence now removed after speaking with family members.</p> <p>Use more subheadings</p> <p>Group wish to keep image but we will add more text to explain areas of assessment.</p> <p>The group deliberately didn't refer to 10 brain domains but instead areas of assessment. After discussions with kinship carers</p> | <p>√</p> <p>√</p> <p>√</p> <p>√</p> <p>√</p> <p>Have tried to amend at editorial</p> |
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| | <p>We are not consistent. At 10 o'clock we have the medical description first followed by the translation into non-medical terms . More thought needs to be given to each of these 10 functions with the commonplace name first in each case then (In smaller print) the medical terminology.</p> <p>In the second line of the passage at the foot of the page delete" the ". And add the link at the end.</p> <p>Page 6</p> <p>Amend the first paragraph of the recommendation. Delete the present last paragraph.</p> <p>The first paragraph to read "There is a higher risk of FASD being detected in certain groups of people. For example:"</p> | <p>information in 2nd column of table on p21 would be more helpful here and move paragraph under image on p5 above. Discuss</p> <p>Make consistent</p> <p>√</p> <p>Alter wording to 'present'</p> | <p>√</p> <p>√</p> <p>√</p> |
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| | <p>The last paragraph to read " It is important that organisations and professionals working with these groups are aware of this problem."</p> <p>Somewhere we should have a bold sentence along the following lines . After the Green box on this page might be an appropriate place.</p> <p>"If someone you are in touch with on behalf of of your child does not seem to know about the condition ask us for another copy of this booklet for them."</p> <p>Page 7</p> <p>Substitute for the present two-lane introductory paragraph a new one as follows</p> <p>"There is a range of physical and psychological signs which indicate a child or young person may be affected by the FASD. The physical signs are sometimes called the sentinel features. The majority of children affected do not show any sentinel features however. In these cases, often when a child was premature, born with a smaller than usual head or is seen not to be thriving, the signs could include: " (Here taken the last three bullet points.)</p> <p>The contents of the blue box need major adjustment. I'd head it "Sentinel features " and confine it to the second third fourth fifth and seventh bullet points</p> <p>Page 8</p> <p>I'd expand the bold heading to read. " What are the behavioural and thinking difficulties you might notice"</p> | <p>Agree</p> <p>Ok.</p> <p>Make reference to how people can get more copies</p> <p>We want to keep simple. Include two boxes – physical difficulties and behavioural and thinking difficulties</p> | <p>√</p> <p>√</p> <p>√</p> <p>√</p> |
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| | <p>I'd delete, as 2V, the point. " difficulties with the daily living "– Or make that more specific</p> <p>Page 9</p> <p>In the third line of the introductory paragraph we repeat "your child's difficulties." Substitute "these"</p> <p>I think the quotation given here is too strong for this stage of the booklet</p> <p>Page 10</p> <p>Lines 2 /3 would be stronger if there is a full stop after "concerns" and a new sentence begun. " Take</p> <p>Second last line to begin " If you feel...</p> <p>Last line needs more explanation. Suggest something along these lines</p> <p>" ...a referral to a specialised department in a hospital. For example...."</p> | <p>Improve pages 7 and 8.</p> <p>No change</p> <p>Agree –use range</p> <p>Agree</p> <p>This hasn't come from the guideline</p> | <p>√</p> <p>√</p> <p>√</p> <p>√</p> <p>√</p> |
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| | <p>Page 11</p> <p>The introductory paragraph in bold to be expanded to read:</p> <p>They make their own judgements based on two key factors. Namely the amount and the timing of the baby being exposed to alcohol.</p> <p>In the third line of the first paragraph delete the word "when"– Substitute "the period over which".</p> <p>Conclude the Second paragraph of the first recommendation at the word "highlighted." Insert "An early assessment may be advised.But.... "</p> <p>Amend and add to the fourth line of that recommendations sorted reads as follows:-</p> <p>"apparent as more advanced skills fail to develop in which case, having noted the risk, the recommendation may be for"... an assessment at a later date.</p> <p>Pages 12, 13</p> | <p>and is unlikely to get approval at editorial stage – remove.</p> <p>Disagree – no change</p> <p>Disagree – need to ensure we use plan language.</p> <p>Change first recommendation to blue box as this doesn't reflect any recommendation</p> <p>This has been extensively revised to take</p> | <p>√</p> <p>√</p> <p>√</p> <p>√</p> |
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| | <p>It seems to me that page 13 should be ahead of page 12 but I'll comment on them in their present numbering</p> <p>Page 12</p> <p>The heading is not suitable.</p> <p>Adding "named person" after "this" In the fourth line makes for clearer reading</p> <p>Page 13</p> <p>I am not clear why some of the boxes have a green border and others have a blue on? Is it significant. ?</p> <p>Broadly the contents of these boxes is clear. I'd add a heading on subheading. " The assessment process" and in the first line of the first box delete the word " process " substituting. "takes place"</p> <p>Page 14</p> <p>Find room here for " The assessment is carried out by a team not an individual."</p> | <p>account of other comments</p> <p>Disagree</p> <p>These should be blue with 'I' to be consistent with SIGN's other booklets.</p> <p>Referral pathway added</p> <p>Agree need to say assessment is carried out by</p> | <p>√</p> <p>√</p> <p>√</p> <p>√</p> <p>√</p> |
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| | <p>I'd make the last bullet point a concluding sentence rather than bullet point" " They may take measurements and a photo of your child's face ."</p> <p>Page 15.</p> <p>Expand the first sentence of the introductory paragraph in bold print to read as follows</p> <p>"Ideally children should have an assessment as soon as possible after the suspicion arises that they may be affected by FASD . "</p> <p>[. in the next paragraph I am not happy with the words "to do well" but I'm struggling to find something better. I feel that we should stress the positives even though they are few. Maybe this paragraph could be introduced with something like this: –</p> <p>"If the advice given as a result of the assessment is followed there can be benefits in the short-term and in the long term. In the short-term??? [[Help }}</p> <p>In the longer term you need to prepare yourself for future problems which</p> | <p>team</p> <p>Agree</p> <p>'Suspicion arises' unlikely to be approved by plain language – alternative wording needed.</p> <p>Change to 'still achieve things in life'</p> <p>Too much detail</p> | <p>√</p> <p>√</p> <p>√</p> <p>√</p> |
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| | <p>may include. . . . “</p> <p>In the last line of this paragraph I'd delete. "and" substituting "leading in some cases to"</p> <p>Page 16</p> <p>I don't think what's in these boxes are recommendations. They are useful points and should be made but exactly how to tie them in with what went before then what comes after I'm not sure.</p> <p>Pages 17, 18</p> <p>I intend to run off copies of these pages and put minor suggested improvements onto these in handwriting.</p> | <p>Agree</p> <p>These are the recommendations from sections 3.6.1/3.7 of guideline but checked with PM for guideline</p> <p>See MN edits</p> | <p>√</p> <p>√</p> <p>√</p> <p>√</p> |
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| | <p>Page 19</p> <p>Second line of the first paragraph after “about” take in. "your and"</p> <p>Again I'm not sure if what's in the green box is a recommendation but again it's good material but I suggest can be improved. Delete “with your permission" Adding at the end “It is recommended that you give your permission for such appointments to be made. “</p> <p>Page 21</p> <p>This is another page which could be headed. " Getting technical”</p> <p>Page 22</p> <p>At the end of the first line take in "your child’s “ ; Second line presumably ' assessment '. in the singular.</p> <p>First recommendation. Question. What is the status of the feature– the small</p> | <p>Agree</p> <p>Second part of 3.7</p> <p>Move part of this to beginning in light of kinship carers' feedback. Include a heading.</p> <p>Agree</p> <p>Guideline group advised not to list small head as</p> | <p>√</p> <p>√</p> <p>√</p> |
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| | <p>head. There should be no diversion between what we say here and at page 7 – or elsewhere.</p> <p>Second recommendation. I don't like. "receive a descriptor of " Instead "be diagnosed with"</p> <p>"the team" Instead of"healthcare professionals" in the next line. "as well as measuring growth" looks wrong in this context. As does"family tree" Substitute " health history."</p> <p>Page 23</p> <p>Again we are using medical jargon in the third line of the first recommendation. "use the descriptor . " Is " flag your child up as being...". any better?</p> <p>In the second recommendation. We have already used " sentinel features " Why detail these again.? So, I'd substitute "sentinel ' for " following " adding at the end of this first sentence "who would not normally be called upon to be a member of an assessment team."</p> | <p>this isn't needed to make a diagnosis</p> <p>Change to 'described as having FASD'.</p> <p>Stop sentence after 'health issues'.</p> <p>Replace 'descriptor'</p> <p>Remove bullet points</p> | <p>√</p> <p>√</p> <p>√</p> <p>√</p> <p>√</p> |
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| | <p>Page 24.</p> <p>Bullet point 2 first line . Full stop at the end of the first line . Insert 'of it ' between 'implications' and 'for.' Delete line 2.</p> <p>Page 24</p> <p>Bullet point 4 line 2. Insert, after 'plan' 'written, so far as possible, in everyday language.</p> <p>Bullet point 7. line 1/2. Delete healthcare professional'. 'Insert the team member' . lines 2/3 'later ' instead of 'following diagnosis.'</p> <p>Page 25.</p> <p>Needs a (sub)heading maybe " How Best to Cope." and an introductory paragraph. Such as 'You should be prepared to talk with the team (or selected members of it) about the following.....</p> <p>Page 26</p> <p>Bullet point 4 'referrals' needs explanation.</p> <p>Last line, first box. Insert after 'should' 'ask for it if you do not receive'</p> | <p>Now combined with information from box on page 26.</p> <p>See above</p> <p>Agree</p> <p>See MN comments re combining with page 24.</p> | <p>√</p> <p>√</p> <p>√</p> <p>√</p> <p>√</p> |
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| | <p>Second box. Make it clearer what the recommendation is</p> <p>page 27.</p> <p>Text between boxes,line 5. Delete'adults' instead 'all in the household'</p> <p>Page 29</p> <p>Simple changes. Most readers will know what slanting boards and wobble cushions are but for those who will not an explanation?</p> <p>[I cannot be alone in bristling at the worst of examples of calling <i>one</i> child <i>they</i>. Although the emphasis must be on 'your child' most of the time now and then, such as here why not 'children' in place of 'your child' in the heading.</p> <p>Page 30</p> <p>Based on what I have learned about ADHD there must be many more examples of what doesn't work - which would be appreciated.</p> <p>Page 32</p> | <p>Move to section on moving into adulthood</p> <p>Reworded</p> <p>Agree.</p> <p>Keeps it personal</p> <p>This wasn't possible</p> | <p>√</p> <p>√</p> <p>√</p> <p>√</p> <p>√</p> |
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| | <p>line 3 of first paragraph 'are ' is wrong. Should be 'is.'</p> <p>Page 33</p> <p>Again the heading is inappropriate - a subheading is needed. Maybe another reference to 'getting technical again' which avoids the need to elaborate on the occasional unfamiliar term.</p> <p>Page 35</p> <p>Again - is there any harm in talking about teenagers, in the plural. in the heading</p> <p>Lines1/2 in the green box Was it intended here to replace 'transitioning to interdependent living situations' with ' moving out from the family home. ' I hope so. The former is dreadful.</p> | <p>Agree</p> <p>Agree –strategies to be combined with 'what can help?' sections</p> <p>Our booklets talk about 'my teenager/my child' as we always write in second person for this audience.</p> <p>√</p> <p>√</p> <p>√</p> <p>√</p> <p>Add sentence in on where to get a hold of this</p> | <p>√</p> <p>√</p> <p>√</p> <p>Changed at editorial</p> |
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| | <p>Could we consider using some of the space which currently awaits quotes or other insertions in the draft to create a new page, even two with the particular theme of - information useful when people in authority of some kind, have to deal with children with FASD? As I understand it there is a likelihood, , of a FASD youngster will have serious difficulties when coming into contact with the police or coming up against some other authority figure who will want and can expect to be obeyed . My suggestion is that these pages in our booklet be actually or subtly directed to such people with even a box suggesting these two pages "could be shown to or photocopied and handed to....." such people.</p> | booklet | √ |
| | <p>Please change “All information is based on a national guideline on Children and young people exposed to alcohol before they were born.” Surely all the information in this patient version is based on SIGN guideline 156? In turn, parts of SIGN 156 was based on the Canadian guideline, but not all of it. New evidence-based content is included in SIGN which is not in the Canadian document.</p> <p>If this change is made, then the following line is accurate, however as it stands “The full guideline is available on our website” is ambiguous as the only guideline you have referred to in the previous sentence is the Canadian guideline which is not available on the SIGN website.</p> | Agree | √ |

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| | <p>I'm not sure this sentence is even needed here as it is repeated on page 3.</p> <p>Just as we have a definition for the use of the word “parent”, could we also add a statement about the meaning of the word “child”? At the top there is the sentence about children and young people up to the age of 18, but for the rest of the document it just refers to “child”.</p> <p>Page 2</p> <p>I have a difficulty with the sentence “It is only recently that the condition has been recognised due to a number of reasons including the following...” The ambiguity is about what is meant by “recognised”. FAS was first described and defined in 1973, so it’s not accurate to suggest that it’s a new phenomenon that no-one had heard of before. I think it is alluding to the fact that HCPs are generally unaware of the condition or what the diagnostic criteria are. However, if we intend this then saying “only recently has the condition been recognised...” it implies that the previous barriers about lack of awareness and confusion about diagnosis have now been resolved – which is also not true. It’s an ongoing struggle, which this guideline is attempting to tackle.</p> <p>Maybe something like “Despite having been described in research for decades, the condition remains poorly understood due to a number of reasons....” would be better.</p> <p><u>Bullet points</u> – second bullet point “Lack of a recognised referral process for</p> | <p>Agree</p> <p>Reworded</p> <p>Agree</p> | <p>√</p> <p>√</p> <p>Changes made at editorial</p> <p>Changes made at editorial</p> |
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| | <p>assessment by professionals”</p> <p>Third bullet point –Multiple overlapping methods for diagnosing FASD but little training available for professionals in the use of any or guidance about how to choose an optimal method.</p> <p>Page 5</p> <p>I don’t feel that this graphic should be under the “what is FASD” section. I understand why you have done so, but as it has the heading “areas of assessment” it is very clearly defined as the set of domains of function that are assessed as part of the diagnostic workup. From the parent/carer’s point of view it is not a list of possible ways in which a child who is affected by PAE could be impaired. I think you could easily come up with a list of consequences which map to these assessments – ie speech production problems, difficulties in understanding and processing language, difficulties in focusing on a task, difficulties in planning and organising daily activities....</p> <p>These would be a better description of “What is FASD” at this stage, also, the same list of 10 areas of assessment are included on page 21 where it is more appropriate to have them, within the “How are children and young people assessed?” section, so we can avoid duplication by making this section focused on some possible ways individuals affected by PAE might present. There are also inconsistencies between the names of some areas of assessment on pages 5 and 21.</p> <p>Page 6</p> <p><u>Paragraph 1</u> – “...high levels of alcohol related illnesses and hospital admissions...” to avoid any confusion, could this be revised to “illnesses and hospital admissions which are related to alcohol”. As it is, I interpret it as</p> | <p>Agree</p> <p>Agree – family members/kinship carers informed us that this would be helpful.</p> <p>Kinship carers informed us that they would find it helpful to have this information at the beginning and linked to real life examples.</p> | <p>√</p> <p>√</p> |
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| | <p>“alcohol related illnesses and [unrelatedly] high levels of hospital admissions”.</p> <p>“Scotland has a reputation for binge drinking and has high levels of alcohol related illnesses and hospital admissions so this number is likely to be higher.” I don’t feel that the prevalence of binge drinking/alcohol related illnesses are a reason why the true prevalence of FASD is higher than the figure quoted. You can have high levels of a risk factor in a population and have a high reported prevalence. In our case, there is a reported figure of 3 per 100 which may or may not reflect the true prevalence. The reason we may suspect it is an underestimate is the method used to estimate this – ie, because there were no empirical studies of FASD prevalence in the UK, a derivation from the national level of alcohol consumption during pregnancy was made and weighted with a quotient of the mean number of women who consumed alcohol during pregnancy per 1 case of FASD (Lange et al 2017).</p> <p>It is the <u>indirectness</u> of this estimation which causes concern, not the actual size of the number. If the reported indirect prevalence had been 20 per 100, there would be the same concern about imprecision. I strongly think we need to avoid saying something akin to “because we know a lot of people drink a lot in Scotland, this estimate of 3 per 100 must be an underestimate”.</p> | <p>Take this sentence out</p> | <p>√</p> |
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| | <p>CAMHS – first use of abbreviation, spell this out here.</p> | | |
| | <p>More direct reference to the SIGN 156 guidelines and research that has been carried out both in the UK (Scotland) and further afield.</p> <p>- Reference needs to be added to include adoptive families (children) and acknowledge the limitations that may exist for this group around being able to provide history to pre-birth alcohol exposure.</p> <p>- p8, reference to behaviours of FASD being 'similar' to ASD and ADHD. We would suggest this needs re-wording so it reflects that fact that FASD often comorbidifies with these other conditions, and some of the behaviours are common between conditions.</p> <p>- p9, the quotations need to be introduced and put in context. A response may also possible be helpful.</p> <p>Quote to add "I had concerns about FASD, but ruled it out due to no facial</p> | <p>Agree</p> <p>Sentence to read information to be shared if people have it.</p> <p>√</p> <p>Will be in appropriate place in final draft. Unable to provide a response to quotes.</p> <p>Add quote</p> | <p>√</p> <p>√</p> <p>√</p> <p>√</p> |

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| | <p>features. It was only after understanding the condition better that I was able to feel confident to ask for an FASD assessment".</p> | | √ |
| | <p>The group felt that the most important information they would like to see in the booklet should cover:</p> <ol style="list-style-type: none"> 1. Signs of FASD 2. History of parent 3. What helps - including home, community, statutory and voluntary. NB: There are very few organisations mentioned in the section p. 36 onwards. 4. Difference between with sentinel features or no features and what this means for diagnosis and support. The 2 categories are outlined but insufficient information around the implications. p.22 <p>In general too much information and a good deal of repetition in places around pp.11-27 where assessments are described. It may be off-putting for carer to have this level of complexity and detail. They could be signposted to more resources for those who are interested.</p> <p>pp.15-22 much of this repeats information in pp.11-15. is there a way this can be streamlined?</p> | <p>Re-structuring should help with repetition</p> | <p>Revised</p> <p>Covered in page 25</p> <p>√</p> <p>√</p> |

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| | <p>Welcomed the addition of the SIGN Guideline information p.40 on wards in the interests of transparency.</p> | √ | |
| | <p>Firstly I welcome the booklet, it has been a long time coming.</p> <p>Comments are as follows: The booklet is very repetitive, several sections contain the same information and for parents / carers who are already under incredible stress this repetition may be overwhelming. It also makes the booklet longer than it needs to be another put off for extremely busy parents/ carers.</p> <p>Page 2: I find the statement that until recently there has been low awareness that exposure to alcohol during pregnancy..... etc, both patronising and untrue. Canada, USA and Australia have been developing assessment processes and services for those exposed to FASD for many, many years. As Scotland has a longstanding relationship with alcohol misuse it is incredulous to make this statement. Booklets for parents MUST be honest.</p> <p>Page 3: Referring parents/carers to pages 36-39 for resources that provide support is to say the least misleading, only two organisations provide support and only one in Scotland. FASD Scotland relies on primarily on its co-ordinator to provide the much needed support for Parents and children throughout Scotland, but this is an impossible task as parents in different parts of the country may need support at the same time, its difficult to be in more than one place at a time. The Government need to address this matter and provide adequate funding and resources to ensure appropriate support across the country.</p> <p>Page 12: As a grandparent who has for the past 7 years tried to access assessment processes and resources suitable for my grandchildren this section is almost a work of fiction. Particularly when the carers have to educate all of the professionals involved regarding the condition, this includes Education,</p> | <p>√</p> <p>Amended this section</p> <p>Adoption UK added in light of government funding for FASD hub.</p> <p>This will start to</p> | <p>See above</p> <p>√</p> <p>√</p> |

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| | <p>Health and Social Work Services all of the individuals who are meant to provide the support. Unless professionals believe the condition exists and have knowledge about it they don't have a chance to help the children or parents. Even those professionals who tried to understand and help didn't know how to. Girfec can record the difficulties and problems but without skilled professionals across Agencies and Departments the appropriate resources can't be identified never mind provided. Even if resources are made available they are not always appropriate or helpful to the child and parents because most professionals with the best will in the world provide what they think is needed, not what is actually needed. And, because of beaurocracy the resources cannot be flexibly used, if somethings not working it is sensible to adjust the resource but that's not always possible because the funds were committed for only one thing not something else that may help. This can be a total waste of money. This is not the same in all agencies or departments but that is only after 7 years of negotiation. Complaining to the health board is a waste of time it cannot conjure up professional's skilled and knowledgeable about this condition to undertake assessments.</p> <p>I can't state it clear enough there are no services for children with FASD. They may get some services provided by NHS professionals but it is not in relation to FASD, it can be ADHD, Autism or something else but in the end it is a FASD diagnosis that is required and without this the services the child needs cannot be provided because no one really understands or knows what their needs are. There are no community resources for FASD children, they are often unable to cope with mainstream community services and are therefore isolated from the community as is their parents.</p> <p>Page 25: It is a reality that parents/ carers have to educate the professionals but this needs to be addressed by the Government as soon as possible. You mention caregiver fatigue but state that they need to educate the professionals, carers are fatigued and it should not be their responsibility to educate professionals, when their attempts often fall on deaf ears. Sometimes during this process these very fatigued parents become the focus of professionals who don't understand the behaviour difficulties of</p> | <p>change now we have a guideline and government support for training relevant professionals.</p> <p>Add in sentence highlighting that support services will not be specific to FASD.</p> <p>Add information highlighting referral process.</p> <p>Deleted bullet point about parents educating. Government</p> | <p>√</p> <p>√</p> <p>√</p> |
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| | <p>those with FASD, and parents in addition to looking after their children in very difficult circumstances are the subject of child protection investigations. The outcome of which is usually unfounded and statements like “oh the family need some help” but even then it doesn’t always manifest. EDUCATION OF PROFESSIONALS IS URGENT ACROSS THE COUNTRY.</p> <p>WHAT CAN HELP?</p> <p>“You should talk to your child about FASD and help them to express their feelings” Our family was criticised heavily at a Girfec meeting for doing this as it was felt to be inappropriate by the “professionals”, despite all guidance not from this country stating children should be told.</p> <p>Page 30: “Having a good network of social support.....etc”. Many parents who care for children with FASD often don’t have this, the children’s behaviours and needs consume all of the time their carers have. The children’s obsessive behaviours often chase away friends. Friends also feel inadequate to help because they are not sure how to help. Children often become upset because any visitor to their home can have an unsettling over stimulating effect. Leaving the parent to deal with this after the “supports” have left making their caregivers and child’s life even more difficult. This is particularly the case for lone parent’s who may have more than one child with the condition. Advice is really helpful and we have received it from FASD Scotland but it is concrete physical resources that families need, particularly when they have more than one child.</p> <p>Pages 33/34: These pages are particularly helpful for parents who know their children are</p> | <p>support and funding is a positive step towards improving the situation. This is the role of guideline</p> <p>See above</p> <p>Parents on group felt this was important.</p> | <p>√</p> <p>√</p> <p>√</p> |
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| | | Reduce repetition by re-structuring. | |
| | <p>Just a brief summary of what I felt were the main issues for the child I worked with and then a description of the strategies I put in place so that her experience was a positive one.</p> <ul style="list-style-type: none"> • Processing difficulties (difficulty retaining instructions and following them) • Organisational difficulties (remembering where resources were etc, packing her bag) • Behavioural/Emotional difficulties (found managing emotions really challenging and was very sensitive but had extreme difficulty in verbalising what was wrong) • Vulnerabilities - the other children around didn't understand the needs therefore could often be involved in friendship issues due to the peers lacking understanding. • Working below 'expected' curricular level • Needed a lot of 1:1 support • Perfectionist - had to type everything on a laptop otherwise work would never be completed due to the child needing her handwriting to be perfect, this included artwork • Lacked social awareness • ADHD <p>Strategies:</p> <ul style="list-style-type: none"> • Organisation box to store everything in - bag, jacket, jotters etc which I would help to organise at the end of every week | <p>Group to agree on the inclusion of these tips on what can help together with information gathered from families. Group agreed on ones that had evidence of benefit which clinicians advised on.</p> | <p>√</p> |

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| | <ul style="list-style-type: none"> • Friendship support • regular contact with adoptive parents • Laptop to complete all work • Visual timetable • 1:1 support where possible • Wobble stool • Chunking of instructions/asking to repeat instructions back • Visual supports (now/next) • Passport to Success support sheet (list of strengths, things I find tricky and ways you can help me) • Building up positive relationship • Explaining I had read lots about the child's condition so they were aware that I had a good knowledge but also if there was anything further the child would like me to know then I was always happy to listen and take it on board. • Lots of preparation/pre warning if things were going to change • Routines • Eye contact/name said when asking to do something • Not asking child to speak aloud in group settings as they were very shy | | |
| | <p>Most importantly, you should be making it clear that FASD is not a diagnosis and in no part of the document is it correct to use the word 'diagnosis' in relation to FASD. This error is made on pages 1,2,6,15,22,24 and 25.</p> <p>It is very unhelpful and very poor clinical practice to suggest to parents that you can know that alcohol is the cause of their child's behavioural difficulties when this is simply not the case. And in Scotland, we do not use diagnoses which are not listed in the International Classification of Diseases. In my view it would be much more straightforward if you explained that alcohol is a toxin during prgnancy and you can be assessed to find out if a child so exposed has neurodevelopmental impairment. You can add that you can be sure the problems are due to alcohol only when the facial features are present.</p> | <p>Avoid using diagnosis in places and use 'may be described'</p> | <p>√ Changed to FASD can exist along with</p> |

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| | <p>The vast majority of children who were exposed to alcohol during pregnancy will not show any physical features (on page 7 you use the word 'difficulties' whereas you should say that most show no physical signs at all). There is no evidence that autism is associated with FASD and this is implied on p8.</p> | | |
| | <p>It lets you know what FASD is, how it is diagnosed and how to access help and support which is really useful.</p> | √ | √ |
| | <p>Quote on page 9 - I don't think seizures very common – perhaps not a good example.</p> <p>CAMHS – page 10 - Need to define this – abbreviation not appropriate Page 11 – Change to 'The amount and timing of the baby's exposure to alcohol are key'</p> | <p>Group to look at quotes gathered from meetings.</p> <p>Agree</p> | √ |
| | <p>Why 18? Especially with FASD where the problems may not be fully realised until transitions to adulthood and those over 18 are functioning at a much lower age level?</p> <p>There is only one short paragraph about transitions to adulthood but the complexities of negotiating the system as a carer of someone with a (non) diagnosis after 18 is very difficult as they are deemed an adult. Those who have experienced being in care are considered still a young person (adoption UK) until aged 25 but this is not recognised by professionals.</p> <p>p10 "if you feel you are not taken seriously you can ask for a referral"- this is odd - surely that is not the reason to ask for a referral- my GP asked for a referral because she was taking me seriously- although the referral was knocked back.</p> <p>re amounts of alcohol - this is not always possible for children in fostering or adoption.</p> | <p>See MN's comments.</p> <p>Include recommendation from page 26 of booklet.</p> <p>Reworded</p> | Reworded √ |
| | <p>When giving out advice on how to get a diagnosis or support afterwards you are on dodgy grounds because we were let down by basically everybody:</p> | With the support for Government | √ |

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| | <p>specialist paediatrician, school psychologist, speech therapist, teachers (don't get me started on GIRFEC!!) Enquire / CAMHS!!!!!!!!!!!!!! and social services treated us as bad parents and send the police round for good measure</p> <p>You have no working system in Scotland yet, where you can send people for a diagnosis or even support, because at the end of the day the majority of professionals know very little about FASD and most of them don't like it when a parent knows more about their child than they do..... and if the Council decides it has no money, then that's it: no actual support in school, no help or relief for stressed parents</p> | <p>and the clinical guideline this situation should improve in time.</p> <p>Add information on referral pathway.</p> | |
| <p>Does the content help patients and carers understand what the latest evidence supports around: assessment and diagnosis of children and young people affected by prenatal exposure to alcohol</p> | | | |
| | <p>It does.....although I think you underestimate the prevalence (research by Dr Cheryl McQuire, published in November 2018 suggests our rates might be anywhere between 6% and 17%)</p> <p>I recognise you said that 3% might be an underestimation in Scotland but I think that families would appreciate knowing that this is an extremely common condition.</p> | <p>Taking information from guideline</p> | <p>√</p> |
| | <p>What happens if there is Noone trained in FASD diagnosis in your local area? Parents are getting passed around, waiting 3 months for each appointment and then being informed there is no medic trained in FASD.</p> <p>Generally CAMHS are not trained in diagnosing FASD. CAMHS have a remit on mental health issues. CAMHS would generally see a child with poor mental health. This does not automatically become active for someone</p> | <p>This situation will improve in time with support from Government and</p> | <p>√</p> |

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| | <p>with FASD.</p> <p>Can we be more specific where for sure someone would be able to get a medic who is trained in FASD assessment/diagnosis. According to Patricia we have about 80 trained FASD diagnostician in Scotland and an estimated 5% of the population with this condition. We obviously have a mismatch and need to specify how for sure parents can get their child assessed/diagnosed. I am aware some medics have funded the child to attend Dr Mukherjee clinic in Surrey. Is this our fall back position? Alternatively, can families request a referral to Crosshouse or to a local authority who has FASD trained diagnosticians.</p> <p>Parents should not be left with the uncertainty when seeking an NHS medical assessment.</p> <p>Can you establish the various routes towards an assessment/diagnosis within the NHS senior management/staff.</p> | <p>the publication of the SIGN guideline</p> | |
| | <p>Yes. I wish we had this when we were in the dark about what was wrong. We knew there was something but we didn't know. It's good you have the physical difficulties and behavioural difficulties highlighted in boxes. The areas of assessment table is really helpful. The green boxes on page 11 are so to the point - really good and well written information. Page 12 is really helpful advice but lots of people struggle to get the support. We were very lucky in the end and our son's teacher pushed and pushed for a diagnosis. We have learned how to deal with it. There's a lack of support but you can</p> | <p>√</p> | <p>√</p> |

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| | just do what you can. | | |
| | Yes. Very helpful document. The boxes with bullets are so clear and nicely written. Page 26 green tick box good that you have revision of care plans is needed. page 27 learning about FASD is a a must so good that's in. Clear and straight to the point too. page 35 - recommendation highlights the need for adjustments to management plan and let's hope that happens! | √ | √ |
| | Yes. It benefits from exploration of range of behaviours and pre-knowledge of early indications which should prompt referral for child to be assessed and support put in place. It also points to what should happen after assessment and diagnosis, accepting that one size does not fit all (p27) | √ | √ |
| | Yes around the assessment process. | √ | √ |
| | <p>It is really good to get greater awareness of this issue as it is far more prevalent than people realise.</p> <p>However, it is really difficult to enter into the assessment process when dealing with a foster child, or someone who has been adopted. The details are often not available. Talking about the child's birth mother can, in some instances, be extremely upsetting for the child. My child (now nearly 18) blames me for their possible FASD even though I am not the birth mother. They don't want to hear anything critical of the birth mother.</p> <p>Assessment and diagnosis possibly - what comes next definitely not.</p> | √ | √ |

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| | <p>Yes, where it is aligned with the evidence or recommendations from SIGN 156. Some areas appear to be written from personal experience.</p> <p><u>Recommendation based on clinical experience</u> – I’m not clear where this has come from. There is no recommendation in the SIGN guideline to increase the awareness of healthcare professionals about the level of risk of FASD across defined population subgroups.</p> <p>Page 11</p> <p>Suggest reword first sentence to “It’s important to have as much information as possible about intake of any alcohol during pregnancy, the amount and stage of pregnancy when consumption occurred and, if there was a binge or social drinking pattern and when it was taken.”</p> <p>First Strong recommendation based on good-quality research evidence – again, I’m not sure on which guideline recommendation this statement is based. The “action” part of this statement which should reflect the recommendation is “children at risk should be highlighted” but this doesn’t match any SIGN recommendation.</p> | <p>Personal experience used for quotes and helpful advice – need to make this clear in final publication.</p> <p>GPP on page 23 of clinical guideline.</p> <p>These have come from section 2 of the guideline but this isn’t clear so we need to work on this so it’s clear where they have come from.</p> | <p>√</p> <p>√</p> |
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| | <p>Second Strong recommendation based on good-quality research – this recommendation doesn’t fully match the SIGN recommendation about referral. This version suggests that referral can happen when “you and your healthcare professional are concerned that there is a possibility that your child may have FASD...” whereas the guideline recommendation requires that “referral for consideration of PAE as a cause of possible neurodevelopmental disorder should be made...only when there is evidence of significant physical, developmental or behavioural concerns and probable PAE.” The scope of these two statements seem very different. In one case there is concern about the possibility of FASD, while in the other there is significant physical, developmental or behavioural concerns and probable PAE.</p> <p>Also, neither of these are strong recommendations based on good-quality research evidence. The second one doesn’t appear to be based on any evidence, and may be one of the areas where the Canadians used consensus.</p> <p>Page 12</p> <p>Again, I feel this is overstating what is included in the SIGN guideline. I understand the possible frustrations in accessing services across the country which are not established into consistent national pathways, however a SIGN publication is not the right platform to be telling individuals how to bypass existing structures. The SIGN patient version should explain the clinical recommendations from the full guideline in more simple</p> | <p>Make clearer to reflect guideline – group to advise</p> <p>Changed to two symbols reflect if it’s based on evidence or GPP</p> <p>Reviewers have suggested losing the second box.</p> | <p>√</p> <p>√</p> <p>√</p> |
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| | <p>language, rather than facilitate complaints procedures. This page contains “difficulty accessing services...”, “request the assistance of other services...” and “if your concerns are not being taken seriously...”, which are unlikely to pass through editorial review.</p> <p>Page 13</p> <p>Why are these boxes different colours? Does it signify anything?</p> <p>First box. Bullet point 3 – I feel this language is clumsy. You don’t generally inform people of their own wishes. Could this be rephrased to “Offer the chance to bring someone to the assessment...”?</p> <p>Second box – see revisions below</p> <p>You may not have all the information documents but you should take the following to the assessment appointment if you have it:</p> <ul style="list-style-type: none"> • birth records which gives information about date of birth, weight and length • Parent Personal held Child Health Records (PHCHR PCHR) or Red Book – this gives information about the child’s history of growth, weight and height • medical history such as illnesses, any surgery, vision or hearing problems • school reports and any issues that have been raised by teachers or the | <p>These should be blue with the ‘I’ symbol as per other booklets. KG to work with Graphics.</p> <p>Agree</p> | <p>√</p> <p>√</p> |
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| | <p>school</p> <ul style="list-style-type: none"> • photos of your child where you can see their face at different ages. <p>Page 15</p> <p>I can see how compelling this quotation is, but it is very long. I'm also concerned that it doesn't directly support the statement about early assessment. The statement suggests that it is important to have early assessment to prevent poor educational attainment, school exclusion, mental health issues, homelessness, substance abuse and criminality, but there is no evidence from the quotation that the girl suffered any of these effects as a result of not receiving an early assessment / diagnosis, so I'm left wondering what to conclude. Other than the final line "<i>knowing that she has FASD has helped her to live with it</i>" the quotation doesn't express why early assessment/diagnosis brings benefits.</p> <p>Page 17</p> <p>Speech and language therapist circle – "A professionals who works with people who have difficulties with speech or spoken/written communication and social interaction."</p> <p>Unclear whether you intended this to read "speech or spoken communication" as these seemed the same to me. SLTs are involved in both spoken and written language communication problems.</p> | <p>This was intended to demonstrate the differences. We could cut this down or we have many other examples now that we have collected as part of this consultation.</p> <p>√</p> <p>Amended</p> <p>√</p> | <p>√</p> <p>√</p> <p>√</p> |
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| | <p>Occupational therapist circle – “A professional who is trained to help assesses and helps how people to manage their daily physical activities related to fine motor skills (movement related to involving small muscles in the fingers, toes, lips or tongue). They also have skills in assessing sensory difficulties (how our senses are working and how well these senses come together so we can make sense of understand the world around us.)”</p> <p>Page 18</p> <p>Physiotherapist circle – “A person who assesses and offers helps people with related to our gross motor skills (large muscles movements in our legs, arms, torso or feet). A physiotherapist will also be able to assess balance and coordination.”</p> <p>Psychologist circle – “A professional who specialises in the understanding study of the human mind brain processes relating to our thoughts feelings and behaviours. How our brain and body work together to influence behaviour.”</p> <p>I’m not sure this is the best possible description of a psychologist. Does Jen have a view on this?</p> <p>Psychiatrist circle – “A medical doctor who specialises in diagnosing and treating difficulties people have with thinking, mental health related conditions. They are also interested in how thoughts, feelings and</p> | <p>Amended</p> <p>√</p> <p>Amended</p> <p>√</p> | <p>√</p> <p>√</p> <p>√</p> <p>√</p> <p>√</p> |
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| | <p>behaviours are connected. Although there is no single drug to treat FASD specific medication, a psychiatrist can assess suitability for medication to treat mental health related symptoms which are related to FASD.”</p> <p>Page 19</p> <p>Recommendation – “...(for example your child’s teacher or learning support teacher, Educational al Psychologist or social worker).”</p> <p>Educational psychologist circle – “A professional who helps children and young people who have with conditions which make it difficult for them to understand and be understood, and to join in with things in school and other activities. These problems can include a range of emotional and social problems or learning difficulties.”</p> <p>Page 20</p> <p>I believe the recommendation on this page has been arrived at through combination of various guideline recommendations, (medical assessment (section 3.2), sentinel features (section 3.3) and neurodevelopmental assessment (section 3.4). However, I’m not sure where the bullet point about “Gathering information about how the young person is managing in other situations outside the clinic” comes from. There is no specific guideline recommendation which requires this. It also overlaps with the first bullet point “Finding out about... any problems the young person is having.” You could add in that a complete physical examination may be required, as this</p> | <p>√</p> <p>√</p> <p>√</p> <p>Agree. Perhaps have last bullet as intro text to the assessment?</p> <p>Move to</p> | <p>√</p> <p>√</p> <p>√</p> |
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| | <p>is recommended in guideline section 3.2.</p> <p>Page 21</p> <p>Make the language consistent for this table, ie either have all the right column be an extended noun phrase “Affect regulation – your child’s ability to control and adjust emotions”, or have it as a verb phrase “Motor skills – looks at how a person moves and uses their body and hands”, but don’t mix them up randomly.</p> <p>Academic achievement – “Focuses on your child’s skills in reading and writing, and maths”, exam results and</p> <p>Communication and language – This is just language in the guideline. Also just language in the list of areas of assessment on page 5 of this patient booklet.</p> <p>“Sometimes in younger children parts of the assessment may need to be repeated when the child is older if the results are difficult to interpret.” Might it be worth pointing out that some things might not be able to be included in the assessment for younger children, so it’s not a case that it needs repeating, it may be deferred and carried out for the first time at an older age?</p> | <p>beginning and use real life examples gathered from those we spoke to.</p> <p>Agree</p> <p>Revised</p> | <p>√</p> <p>√</p> <p>Changed at editorial</p> <p>√</p> |
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| | <p>Page 22</p> <p>Please consider use of the term “alcohol history” in this section. I’m not sure it will be obvious to all readers that this refers to the birth mother during pregnancy, and not, for example, the child themselves becoming exposed to alcohol in childhood. A definition could help with this.</p> <p>First recommendation – I suggest changing to “all three facial characteristics described as specific to FASD”. An individual with some but fewer than three facial features cannot receive this diagnosis.</p> <p>Add “confirmed or unknown alcohol use by the child’s birth mother”.</p> <p>Second recommendation – I suggest changing to “If your child does not have the all three typical facial characteristics but has confirmed or unknown alcohol use and severe difficulties in at least three of the areas of assessment, they may receive a descriptor of FASD without sentinel facial features.” The healthcare professionals will also consider other possible genetic causes, as well as measure growth, other birth or health issues and look at a family tree to consider other possible factors.</p> <p>Page 23</p> <p>First recommendation – this definition doesn’t exactly match the diagnostic criterion for “at risk of for NDD and PAE”. There is no description in the guideline about the severity of impairment being non-severe which might prompt this label. The guideline specifies existence of alcohol history, and</p> | <p>Agree</p> <p>Agree</p> <p>Group advised to keep as it is but to take out ‘descriptor’.</p> | <p>√</p> <p>√</p> <p>√</p> |
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| | <p>CNS diagnostic criteria not being met but there is some indication of neurodevelopmental disorder. So, the key point is that the guideline does not specify <u>why</u> the CNS criteria are not met – it does not state that it is not met due to the severity of the impairments being too low. It could be that there is impairment in fewer than three areas of assessment. Maybe the group could look at this and see if it might be possible to make it more similar to what is in the guideline?</p> <p>Second recommendation – This recommendation is not included in the SIGN guideline, so should not be listed as “Strong recommendation based on good-quality research evidence”. The guideline states that contribution of genetic factors should be considered in all cases of FASD with or without sentinel facial features and referral may be indicated in atypical cases or when PAE is uncertain. This is only included in the FASD diagnoses, not the at-risk diagnosis.</p> <p>The section of the guideline which includes the recommendation for “at-risk” diagnosis associated with three sentinel facial features is 3.1.2 and this does not mention genetics.</p> <p>Page 24</p> <p>Some of this page needs to be made more consistent. There are three possible scenarios – the child could get a FASD diagnosis, a different diagnosis or no diagnosis. Some bullet points include two of these, but none cover all three. The implications are different for some of these. The SIGN guideline was an adaptation of the Canadian guideline which focused on FASD, so there is no specific provision for a management plan for non-</p> | <p>This is recommendation from section 3.5 so need to make clearer.</p> <p>Revise and incorporate content from p26</p> | <p>√</p> <p>√</p> |
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| | <p>FASD diagnoses, nor follow up for these children. The children with FASD diagnosis should get a management plan and be followed up. There are <u>no recommendations on management or follow up</u> for individuals with no diagnosis.</p> <p>“Provide a definite referral...” this is not included in the guideline. The supplementary materials document “Information and resources for clinicians after a diagnostic assessment” suggests that healthcare professionals develop a management plan with individuals and their parents/carers, however this management plan will be individualised and in some cases will involve self-management or adaptations which can be made at home. In some cases there will be no FASD diagnosis and no further referral required. So, to include “provide a definite referral” is not appropriate for all individuals.</p> <p>You could add in “follow up the child’s management plan with you after a period of time to make sure that their needs are being met” as this is a guideline recommendation (section 4.1.2)</p> <p>Page 25</p> <p>I don’t think we can say that the team should speak to you about “The need for individuals, parents and caregivers living with FASD to educate teachers, health and other professionals about FASD. “ I recognise this may be the view of some of the patient booklet development group, but this is effectively telling parents to educate healthcare professionals. It seems problematic for a national guideline aimed at HCPs to tell patients to educate the HCPs –</p> | <p>Remove ‘definite referral’</p> <p>Unhelpful if cant specify time</p> <p>Agree</p> <p>Include quotes from parents/kinship carers about</p> | <p>√</p> <p>√</p> |
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| | <p>especially when the guideline doesn't actually state this. I'm happy to say that awareness about FASD needs to be raised and HCP skills and confidence needs to be improved, but there are no recommendations about how to tackle this, and it is currently being taken on by Scottish Government on an ongoing basis. I don't think it is a specific task for parents, as not all will be equipped to educate HCPs or willing to adopt this role.</p> <p>Page 26</p> <p>The first box seems to duplicate the bullet point on page 24. I suggest removing one or other of these.</p> <p>Page 27</p> <p>I can't see which guideline recommendation this 'Recommendation based on the research evidence' is based on.</p> | <p>educating teachers etc and remove bullet.</p> <p>Combine</p> <p>Change to plain box</p> <p>Definition for</p> | <p>√</p> <p>√</p> |
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| | <p>Page 29</p> <p>I suggest that a little more detail is added to the “slanting boards” and “wobble cushions” items as these terms are not clear to a general audience.</p> <p>Page 32</p> <p>“Some professionals are still learning about FASD and some services....”</p> <p>Pages 33-34</p> <p>We need to credit the source if we are reproducing the 8 Magic Keys in the SIGN patient booklet. I now think that the attribution we included in the “Information for clinicians” supplementary material for this is wrong. While there was a link at SAMHSA, I believe this was not the original source. As far as I can tell, the original source is Deb Evensen and Jan Lutke (1997) who developed it for the Fasalaska Project (http://come-over.to/FAS/brochures/EightMagicKeysBroch.pdf) and published it on behalf of Fasstar Enterprises (Fetal Alcohol Syndrome: Support, Training, Advocacy, and Resources)</p> <p>Page 35</p> <p>The Recommendation on page 26 could be moved to this section. Both appear side by side in SIGN 156</p> | <p>slanting boards but remove wobble cushions as don’t work for all FASD children</p> <p>Agree – inserted ‘some’</p> <p>√</p> <p>√</p> <p>√</p> <p>Agree</p> | <p>√</p> <p>√</p> <p>√</p> <p>√</p> |
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| | <p>Page 36</p> <p>Scottish Government is setting up a 3rd sector FASD hub. It may be possible to cross-refer here.</p> <p>Page 39</p> <p>You could link to the SIGN qualitative synthesis here as this captured the views and experiences of caregivers of individuals affected by FASD</p> | <p>√</p> <p>√</p> | <p>√</p> <p>√</p> |
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| | <p>We would suggest that more details needs to be added to help readers understand the latest evidence. This should be both reference to the SIGN 156 guidelines, research into the area of FASD and known historical context.</p> <p>We would suggest that there need to be included information or signposting to where parents can find diagnosis services across Scotland. The work the Scottish Government has been undertaking recently through the NHS Ayrshire and Arran team to train clinicians across the country and Manitoba training that will take place in Edinburgh during June 2019.</p> <p>Direct parents to training resources they can easily access themselves to support their learning on the subject.</p> | <p>State that this is based on SIGN 156 and the Canadian guideline</p> <p>Agree</p> | <p>√</p> <p>√</p> |
| | <p>Feeling of there being a disconnect between what is described in the booklet and what happens on the ground. For example when a carer is told that child cannot be seen by CAMHS unless they have the Sentinel features! will the full SIGN Guideline ensure practice is consistent across the country?</p> <p>Management Plan p.26 - who is responsible for the management Plan? Is this the lead professional as not all children will have one. Or the Named Person Service? And again this would be someone in Education when it would be more appropriate to be in Health.</p> | <p>Work done by Adoption UK and investment from Scottish</p> <p>Parents/child gets a copy. Named person now removed</p> | <p>√</p> <p>√</p> |

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| | <p>We very much hope that the missing text in the speech boxes which are as yet blank will bring the text alive and make it more personalised to real live stories and people.</p> | <p>Yes, explained in information.</p> | |
| | <p>No. See above. It should be saying very clearly, preferably near the beginning that there is no test for FASD. If the facial features are not present, which is the case for most children, we cannot be sure if alcohol exposure during pregnancy is the cause of the child's problems.</p> <p>It would be more helpful if it was also explained that the approaches to management are general approaches which are helpful for any children with neurodevelopmental problems.</p> | <p>Page 5 and 7 improved to help people understand about assessment. Group wanted to stay away from term 'tests',</p> | <p>√</p> |
| | <p>Yes</p> | <p>√</p> | |
| | <p>Not really If it is in its infancy - what evidence? It explains a bit about what might be assessed but no evidence around barriers to diagnostic pathways, professional attitudes to diagnosis, barriers to assessment</p> <p>there needs to be a section on advocacy</p> <p>The section "What the team should talk to you about" doesnt really work for me- what team. also carers and families are under a lot of stress- to add an educational responsibility to health care professionals- thats a big ask- from my experience so far -(and I am a health professional and carer) - there is a power inequity.</p> | <p>These questions were nor addressed in the guideline. Hopefully the guideline together with support from government will bring about change in time</p> | <p>√</p> |

Patient version of SIGN 156 - consultation report

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| | Probably but we need the professionals: doctors, teachers, therapists, psychiatrists social workers to read this first.. | We will raise awareness of this and disseminate as widely as possible. | √ |
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