



‘Ask the Expert’ Event notes:

**Hosted by FASD South West with Guest Speaker Dr Cassie Jackson
Clinical Psychologist, FASD Expert Witness
Tuesday 1st November 2022**

Parent Question 1: What therapy or interventions would be most effective in helping children with FASD control/manage their anger (especially in how it can manifest itself in social situations, such as in a classroom - eg becoming dysregulated v quickly with the trigger appearing to be almost paranoia about other children’s reactions eg facial expressions)?

There are two things to consider that could be causing this 1) the sensory side of things which can often lead to dysregulation and 2) mis-reading social cues and lack of social understanding. It is quite often the combination of the two.

Using ASD & FASD friendly strategies are often really useful for this. Things such as social stories, pictures and visual aids showing what people look like and what they are feeling. Using emotions and feelings charts explaining what each emotion means and how it feels in the body.

Comic book strips showing how people act and behave. Emotions diary using pictures of different feelings, you can use colours to depict each one for example red for angry down to green for calm.

You can then add strategies for ‘what to do when you feel that way’ etc. ie when I feel like this I do...

This needs to be used at school and home so consistency is key. It is suggested that School work alongside carers and parents to thread these strategies through a Home/School partnership. Particularly useful for working through strategies for EHCP and SEND/EHCP reviews. Some additional reading on this and very important for Schools to embed in individual learning plans are the frameworks for FASD linked below:

Primary Framework for FASD:

https://www.fasdsouthwest.org/files/ugd/29cd79_a74b4017ac404411839ea36834c20cba.pdf

Secondary Framework for FASD:

<https://nationalfasd.org.uk/documents/FASDeD%20SECONDARY%20FRAMEWORK.pdf>

As for therapy it is most useful to have sensory regulation and understanding of feelings.

The paranoia aspect is more likely to be misinterpretation of the moment. For example if they are already wound up about something, sounds, smells, etc and then see a face pulled they can be really sensitive and read it as a threat, often attributing the wrong things to the face. Social stories making them less personal so they aren't shamed ie not stating you are wrong but just showing what faces and emotions can look like and how it feels can help, make the social stories really individual and tailored.

Julie asked: is a lot of the paranoia aspect control based? Especially within their peer groups? For example if the child can't get a response in the right way then they immediately think negatively and that whatever the response is, is about them?

Cassie replied yes, definitely, it will be perceived as a threat. It is really important that school are aligned with what is being done at home ensuring a consistent approach between both settings.

Julie added that having a professional alongside to advocate for parents with the school is really important as professionals are sadly more listened too. Cassie agreed stating it isn't right but it is sadly true.

Parent Question 2: Child/young person who believes themselves to be equal to an adult in everything they say and do, and in their perceived rights. This has been a constant since toddler days and has caused many problems over the years.

Is this an aspect of FASD?

If so, are there any recommendations of how to manage / parent this? Our child is now 15.

This is not FASD specific. Cassie has seen it in FASD but more often in ASD and seen in attachment issues for children originally raised in a negative environment (neglect and/or trauma) where they didn't trust that adult to look after them so they have had to do it for themselves or siblings.

It is children who have a lack of social understanding of social hierarchy.

Management of it depends on case by case and what the cause would be. For example if it was caused by FASD/Austim you would use more PDA Pathological Demand Avoidance type strategies. That is not saying that would be used as a standalone diagnosis but that the same strategies would work for this cause. It is for children who need to feel in control so use of language would be very carefully used to give them a perceived appearance of control. For example if you want them to do something you would ask them if they want to do it first or after something else. Allowing them to feel like they have a choice but still getting the task done. Or giving them a little bit of control but not full control. It is incredibly hard for a parent to do as you have to be 3 steps ahead at all times.

As they become teenagers this often becomes harder with boundaries. This comes from a cognitive processing difficulty and the inability to imagine a world from other peoples perspectives.

Further reading on control and strategies can be found in this incredibly helpful leaflet; tucked away in it are lots of ideas that you can sneak in and find ways to adapt strategies, often with FASD what works on one day wont on the next: **FASD Strategies not Solutions:**

https://edmontonfetalalcoholnetwork.org/wp-content/uploads/2019/02/strategies_not_solutions_handbook.pdf

Parent question 3: What therapy would you recommend for a 17-year-old? My son is obsessed with engaging in sexual relationships online, without seeing the danger in it. He has no social life as he doesn't have any friends to go out with. I have tried a lot of therapies, behavioural, cognitive-behavioural, EMDR, Hypnotherapy (through recordings) ... but none of them is effective. Is there anything you could suggest?

This is a really difficult area for parents and professionals. What you have is a person with 'normal' sexual desires who doesn't understand 'normal' boundaries, a lot of teenagers don't but it is harder with FASD as they struggle with social boundaries. There is no real way to 'therapy it out' of someone, and nor should you, it is more about keeping them and others safe. They must not be put into shame about wondering about themselves and others, this inquisitiveness needs to be supported where you build an open discussion in little steps.

Really helpful book called a **"5 is against the law"**:

https://www.amazon.co.uk/Against-Law-Boundaries-Compassionate-Incredible/dp/B09SHTX7PJ/ref=sr_1_1?crd=1EF1YGP2EX2JL&keywords=5+is+against+the+law&qid=1667494905&qu=eyJxc2MiOilxLjAwliwicXNhIjoIM S4wMCIslInFzcCI6IjAuODcifQ%3D%3D&s=books&sprefix=5+is+against+the+law%2Cstripbooks%2C264&sr=1-1

.....which is used for helping people with ASD understand social boundaries and goes into the law and how to keep safe and out of trouble. Parents can look into getting children engaged in activities outside of the home.

Look into peer mentoring, youth support worker to take them out and connect with them in a common theme (e.g sports, art etc). It might be this worker is trauma trained so to talk gently and casually about how they feel, also to talk to them about boundaries and what is appropriate as they are often more receptive to people outside of the family. Expose them to real world activities and situations, keeping them engaged in projects, hobbies and connections with people in a positive way helps. Helping and playing a part in community etc.... diverting the brain into other things.

Julie added it is hard to know 'what is normal'. She gave an example as a parent of a child who first starts talking about sex it can be daunting but it is normal to explore and search for answers.

When children first start looking on the internet and exploring sexual desires it is hard to know what to do. With FASD its managing that and allowing them to explore but within safe parameters.

It is important to restrict content on the computer, TV and devices by having parent controls. Remember that FASD 'spikey profile' (*where children do not present the same age as their chronological age*) children are not emotionally ready to support some adult content.

There are many options and products that do this, further reading on how to support this can be found through the NCPCC here:

<https://www.nspcc.org.uk/keeping-children-safe/online-safety/parental-controls/>

Many parents find 'Google Family Link' - a very useful app to manage a range of features such as restricting content, approving or disapproving apps, setting screen time and more. More details of this can be found on the link above.

Cassie added that it is tempting to 'de-sexualise' children and young people to keep them safe but you can't do that, it is about keeping them safe whilst exploring. It's tricky but possible with careful support and scaffolding!

Parent Question 4: Should I keep trying to teach about knife / fire safety etc or just lock everything down ie will he ever learn or am I just taking unnecessary risks?

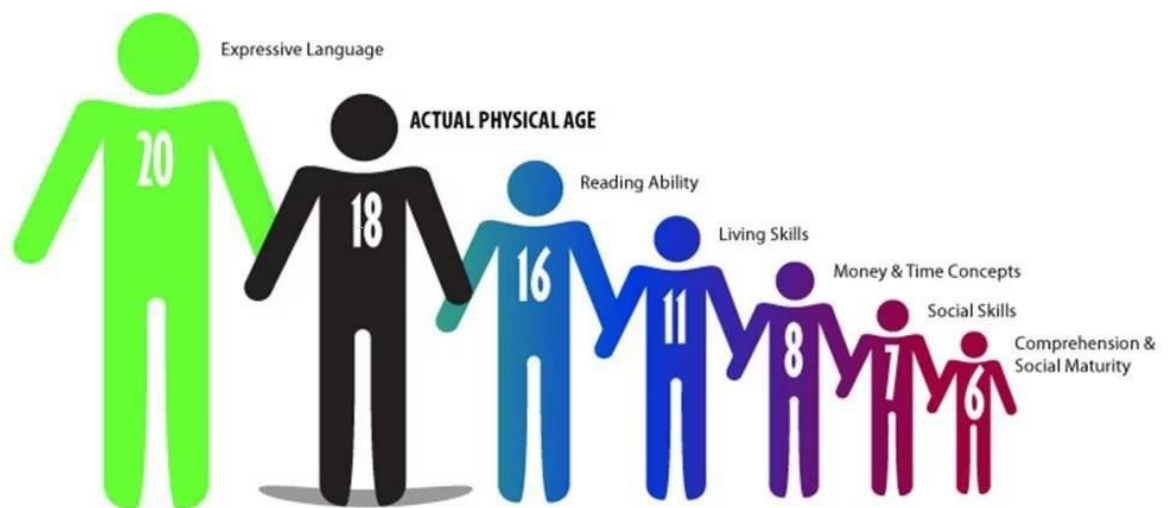
Do both! Yes, lock it all away and keep it all out of temptation but also use short key messages to keep reminding them about safety. You could use social stories in a visual way to repeat the message rather than nag them.

Will they learn? Yes, its hard to generalise but it will get better over time, they will always be impulsive and they will be stuck at certain stages for a long time where it feels like they don't improve but they can learn, it just takes longer. It will feel like you are stuck on repeat for several years but they will get there. Don't ever assume they will be OK, take away the temptation and back it up with supporting the skill.

Parent Question 5: With FASD many things are assumed to be half the chronological age but with support this I assume can be different for some children; which tests are used to assess this please? Can you focus scaffolding to each of these areas to encourage the development?

The half the chronological age is not a specific number there is no specific test for it. It is more of a way for professionals to use that term to explain the 'spikiness' of the FASD profile to schools etc.

What you see is NOT what you get...



It isn't specific or across the board just because they may be 14 but functioning at 7 in one area it doesn't mean that this will be for all areas but it is a very helpful way for professionals to educate staff that support children, young people and adults with undiagnosed and diagnosed FASD.

It is more about cognition versus functioning which will explain to people why children with a high IQ function at a lower level.

There are specific test for functioning and adaptive behaviour and this can show the discrepancy between those tests.

The key is to scaffold and keep safe, label emotions and spot when they are becoming dysregulated and to have a plan in place for that. See what the individual child's needs are and scaffold their needs.

Julie added **repetition, repetition, repetition** and to scaffold the child's learning. There are lots of negatives within FASD but the key thing to remember is they can move forwards. Progress can be made if support is given.

Cassie added it is an executive functioning impairment, they won't stay there, they will improve, some aspects may not reach neurotypical levels but with scaffolding they can lead meaningful and productive lives. Which is what she is keen to teach and explain to professionals; early intervention is vital.

Parent Question 6 & 7: Treating the FASD or the co-morbid conditions? I would be interested to hear more about FASD and the overlap with ADHD. I know so many of our children have a diagnosis for both, and to my mind, ADHD is almost a symptom of FASD

Combined answer to 6 & 7:

Treatment, the key thing to remember is FASD is a syndrome, which means it is a lot of different symptoms clustered to become FASD.

Any 1 symptom won't mean a FASD diagnosis but several symptoms together with recorded alcohol usage will.

If you think about treating the co-morbid conditions then you will in turn be treating the FASD. For example for some children the ADHD really making a big interference in the child's functioning so focus on treating that aspect, for other children it will be the sensory aspect etc it will be different for each child.

The problem with diagnosis is FASD is in the pre frontal cortex area of the brain which is solid cognition. All children will struggle with social cues. Because of this the diagnostic tools for ASD may not pick up the ASD as they won't necessarily reach the threshold for diagnosis; I will add to this point further below as diagnosis of ASD (Autism) should be seen or viewed through an FASD lens. Children with FASD are likely to have high functioning language.

All FASD children will struggle with impulsivity as that lives in the pre frontal cortex so they will display ADHD (attention deficit hyperactivity disorder) symptoms but may not meet the threshold for diagnosis.

Girls tend to be more inattentive mostly and boys tend to be bouncier.

In FASD you will see hyperactivity but ¾ will meet diagnostic ADHD tools. So the assessor needs to move the lens slightly and realise that ASD looks different within FASD.

FASD children are very pro social, too much rather than too little so from a clinician's perspective it doesn't look like traditional ASD (Autism) so they might say he has 'traits of autism' rather than diagnose.

They need to widen the lens so just because they have good eye contact doesn't mean they are understanding the social world.

A lot of professionals will say they have ADHD so go to that lane for diagnosis, they are ASD (Autistic) so stay in that lane and if they don't fit they bump you with no service. This needs to change.

In Suffolk for example, they are fantastic at supporting FASD but if you put on the form FASD they can't admit you, they can only accept an ASD diagnosis for example but whilst diagnosing they may see traits of FASD and then reach a diagnosis that way.

Comment from a parent in our group: son has just received a ASD diagnosis on top of FASD and Attachment and they really did look at all aspects. **Other parent comments in chat** saying they were surprised as this was unusual but encouraging.

This is brilliant and something we need to keep pushing for within the south west.

FASD South West: We know of some clinics now where a referral with the ASC request they will look at the FASD. For example one parent recently had a FASD and ASC diagnosis with '*Total Childrens Therapy*' in Bournemouth funded through the Adoption Support Fund. For more examples of this contact FASD South West or review services on their website:

<https://www.fasdsouthwest.org/projects-3>

Parent Question 8: Life expectancy? I've not seen anything other than mid-thirties quoted. How can we help our children have long and fulfilling lives?

It is really important to remember that FASD is not necessarily a life limiting condition. The 'mid-thirties' quote in much research is mainly aimed at those that go undiagnosed or unsupported and easily fall into a life of dangerous activities such as drug taking and damaging behaviours and it is that that will limit life not FASD itself.

If they have early diagnosis and are well supported they can live as long as anyone else. If they are engaging in difficult behaviours then mental health services are key in this area.

Cassie gave an example of a mother she had supported in court where it was clearly in her records that she had FASD but had engaged in many dangerous risk taking behaviours and no one within the court at all had addressed or picked up on her diagnosis causing those behaviours.

Parent Question 9: Confabulation, could you tell us how that works please and why do we see it in FASD?

Julie gave an example of her son recently explaining in great detail about a trip he had taken, she is the only person who would have been on that trip with him and it didn't happen, there were several details of lots of trips taken into one story. Where she said the filing cabinets in his brain had taken a memory of something nice on each visit (where often things had also ended in a meltdown) yet he had captured that part which he melted into one story. Julie says that he would not budge on this not being true or it being different places, he thinks it is all true, he doesn't not believe he is not telling the truth and is not telling it to deceive yet it is not real... this is 'confabulation'.

Cassie explains... there are 2 main causes of this, one is the child is filling in the gaps, they have a poor working memory and it is always better to say something rather than nothing.

The other is they really think they have done it, for example they have thought about it and their brain 'makes it real', ie they thought about cleaning their teeth so they think they really have.

There is a lot of blurring between reality and fantasy, this is due to FASD being in the pre-frontal cortex of the brain where the truth and fantasy all gets bashed together coupled with the fact they want to please and they want to entertain and speak or they want something to happen so badly they easily believe it themselves; it's a false memory really. Yes it can happen to any FASD child at any age young or older.

Julie added in that with her neurotypical child he came home once and swore blind he hadn't thrown an apple at a car but one look in his face and she knew he absolutely had done, with her FASD child and a similar incident she couldn't tell at all as the child genuinely believed they hadn't done it.

Cassie added that if you couple this with the fact that time means nothing either so 10 mins could be 10 hours the child who said they had brushed their teeth could be talking about three days ago. How to respond? Don't

consequence it as a deliberate lie, **don't pull apart a story unless really necessary to do so but reality isn't a bad thing either.**

Parent Question 10: I am really keen to see what Dr Jackson says around sexualized behaviours. My son 9, is quite quick to remove his clothes (which could be sensory) but then school are saying he is playing with himself and being inappropriate towards female staff. Just interested if this is another trait of not understanding boundaries etc? How is it best to support this?

Professionals are quick to label behaviours as 'sexual' and quote often they are 'sexualised behaviours' but they are more likely to be sensory issues, especially with the taking off of clothes.

It is more about not realising that it is not ok to play with themselves in front of others and to only keep it in the bedroom, but not to shame them in doing so (very important for School to do this or they are likely to get a trauma response or putting that child into chronic shame).

Social stories can be very useful in explaining when it's ok to do something and when it isn't, making sure you aren't using them in a shameful way.

If a child very clearly has a history of sex abuse then yes it is sexual behaviour but usually it is 'sensory seeking' and 'regulating' behaviours and 'not understanding social boundaries'.

In this case with the child having inappropriate interactions with the teachers it could be not understanding their social world and trying to make connections inappropriately or not knowing how to make connections.

Also remember that it feels nice and they won't have an understanding of social boundaries, don't shame them it is **not** abnormal.

Julie added that people are talking about stimming in the comments section, ADHD/ASD really needing the sensory input and is this stimming and regulating and calming behaviours.

Cassie agreed and said it may be useful to get input from a Sensory Integration OT to find socially acceptable replacements to help regulate them and to keep that to private time.

Children may seem to have no inhibitions, will strip off in a home normally but not in a school but FASD children will not understand the social boundary and will do both, also remember the half chronological age rule here so a 4 yr old taking their clothes off at school would be not unusual and would be ignored or encouraged to re-dress but an 9 yr old would be labeled sexually inappropriate.

School really need to understand that 'spiky profile' of FASD in this instance so they handle the situation differently between a 4.5 yr old or a 9yr old. Sadly schools then put in a safety plan so that the child is never allowed to go to the toilet with another child and it becomes shameful. **It's not sexual its sensory!**

A question in the comments was asked if we could share our social stories in the group. Julie replied that yes this would be very useful and can then be tweaked to make it individual. If anyone has a social stories they could email that could be anonymised and shared the group would be grateful.

Parent question 11: Layers of underinvestment in services make the private route often the only way to go however not everything is covered by Adoption Support Funding..... if you could focus on one thing what makes the most impact with FASD?

Neuropsych assessment supported by a Clinical Psychologist. This is really important to differentiate between cognition and functioning and put support in place for those areas.

Cassie recommended Clinical Psychologist she supervises Michelle Blundy from Blossoming Minds working across the South West

<https://www.blossomingminds.org.uk/>

Once you have this level of assessment it gives you the ability to argue points in the EHCP, not vague but specific, it will help the school to understand especially if the IQ is normal.

It is important to have a couple of these assessments throughout the child's life, yr 6, to help understanding of support needed to go into secondary school and 15/16 yrs old to focus on strategies needed to forward into adulthood.

Julie asked, if we can't get this would it be an Ed Psych report be helpful?

Not really they only have a limited range of assessments that won't show the difference it would more likely be clinical psychology. There are some FASD informed Ed Psych's in the area but that is the exception.

Sensory integration therapy with an OT would be a huge thing, this would be to support regulation and provide school with a level of detail for EHCP. Many, many parents have seen huge benefits in children and young people with this support. This is available through Post Adoption support via Adoption Support Funding.

Parent Question 12: Lack of interest in eating and ways to support. I have so much empathy for FASD related issues but sometimes run out of patience with this issue. Our son struggles with eating generally but will eat hardly anything at school (despite having 1/1 support away from distractions) and then dysregulates. He is not on meds. How can we support him generally to eat?

Does the child have ARFID* (Avoidant/restrictive food intake disorder) which is related to Trauma and Adverse Childhood experiences? *If they do then you will need to let them eat what they like to gain weight. Specialist support on this can be found through asking your GP for a referral to a dietitian, more information can be found here : <https://www.arfidawarenessuk.org/copy-of-what-is-arfid-1>

Firstly, rule out if this is a sensory issue? How would you know this.... Does he keep food in his mouth for a long time to chew it, this is where a child is getting oral stimulation/regulation, do they only like certain coloured food e.g some children with Autism have this need.

Pick your battles if the child is not losing weight maybe don't push this issue too far. Don't make it a huge control issue, if they aren't eating too much at school but they eat at home don't worry about it.

If they are not eating at school you could ask for them to be placed in a quieter space as it might be overstimulating or noisy. They might not like the smell or noise of others eating so again this can be supported by 'reasonable adjustments' where school need to recognise the need.

Encourage them but if the child is thriving don't worry, don't make it a massive battle ground. Eating in a separate space to other family members can help to be less triggering.

Julie added with a history of trauma it is quite common for children to be diagnosed with ARFID, not necessarily an FASD trait, mainly trauma based. Notes in the chat by other parents agreeing with this.

It is quite common for ASD children to only eat one colour of food or find the sound of people eating or smells overwhelming.

Cassie agreed, don't put them into a 'shame' state or make it into something they can control or let them know it really triggers you as a parent.

Parent question 13: We are aware of many de-escalation strategies related to angry outbursts. What is the most tried and tested one with kids who have FASD? We are aware it will vary from child to child but open to anything!?

I can't really think of a tried and tested method that always works. The best thing to do is think of a plan and follow that at home and school, this was discussed well in parent question 2. Prepare a safe space for the child that they can help design, have a regulating thing in there and sensory space and use emotion diaries to help them express how they are feeling and what to do to help themselves.

Have a plan to de-escalate ahead of time and have a safe environment that isn't used as a punishment area, each child will be individual and will choose to be alone or have someone sit with them, work out what works most of the time.

Julie added to remember that what works one day may be the absolute worst thing the next day, to be flexible....just when you think you have found the magic wand the next day it doesn't work at all but its about accepting that is ok and sharing ideas and support in the group is vital in this case, don't think it failed as it may work again next time; always have to be creative and think outside the box.

Parent question 14: I'd like to understand more about the links between FASD and fatigue, particularly in relation to education. My lad is so utterly exhausted all the time and other medical reasons for this have been ruled out so I can only assume his exhaustion is due to the huge effort he puts into holding everything together at school and processing so much information. Has there been any research into impaired executive functioning and fatigue at all?

Cassie didn't know of any specific research related to FASD for this reason but to think of the brain as the London underground where all the connections are muddled up and not quite joining properly with disorganised connections which increases the work load and processing times which makes the child more tired and needing more sensory input, more breaks.

Cassie sees this all the time it's a very common thing within FASD they are more tired and the more tired they are the more dysregulating behaviours you will see and more often they will be in a dysregulated state. Getting regular breaks and a sensory timetable in school are vital.

Julie added there is research where children who have experienced trauma have a higher likelihood of being hypermobile which makes them more tired, it's not necessarily an FASD thing but it is very common in all children, they have to rely on muscles rather than joints to help them stand and everything has to work harder to stay upright then if you add in brain processes too, its exhausting.

Paediatricians focussing on hypermobility describe doing a basic task or piece of work can be like running a marathon. More information and support

techniques for hypermobility can be found here:
<https://www.hypermobility.org/>

Parent question 15: Are there any links between FASD and some physical traits or conditions like flat feet or reduced liver function?

This is a normal condition for a lot of people anyway about half the population have flat feet so it is not necessarily FASD. This is why brain scans aren't overly effective in diagnosing FASD as you can see some things that will be FASD but could easily be caused by other things as well. These studies are limited in numbers too so if you widen the study you don't necessarily see a pattern, a lot of the studies don't tell you very much unless they are large scale research projects.

More details of the research into the 428 Co-morbid conditions that can be linked to FASD can be found here: <https://www.camh.ca/-/media/files/pdfs---reports-and-books---research/comorbidity-of-fetal-alcohol-spectrum-disorder-a-systematic-review-and-meta-analysis.pdf>

Parent Question 16: What evidence or research is there in regards to epigenetics, particularly interested in evidence of birth fathers drinking where probably father has FASD due to genetic history of grandparents.

Julie added to this question by asking to discuss research findings that identify the link here as we often find it difficult to find enough evidence for a diagnosis through birth mother alcohol intake as it is often not recorded is it likely that we can start having birth fathers evidence considered for example as police are often called and can evidence alcohol usage in fathers at around the time of conception and grandparents and it is often recorded in a family alcoholism or a history of alcohol abuse or death by alcohol.

There is a growing body of evidence that it can change the gene expression down the generations, none of that is currently included in FASD diagnostics. That may change in the future but it will be very difficult to prove. FASD is a diagnosis of exclusion anyway where everything else has to be ruled out before they will consider diagnosis so will be really hard to prove for different generations.

There is more research commissioned on dads which will be really interesting to see where it goes.

Julie added since the publication of the NICE quality standards that midwives are now collating data with birth mothers which has started to enable the conversation and it is going into the training now that it will be monitored and recorded. The key thing here is that mothers will be asked and supported not shamed. Social workers now have to report on all alcohol consumption so it is hopeful that things will change.

FASD Summary for EHCP's: https://61d0cba4-119c-4ef5-9aaf-52f67fefbca3.filesusr.com/ugd/29cd79_328816e883c145409856f3dee94270a1.pdf

SIGN 156 FASD Quality Standards FASD:
<https://www.sign.ac.uk/media/1092/sign156.pdf>

FASD Health Needs Assessment:
<https://www.gov.uk/government/publications/fetal-alcohol-spectrum-disorder-health-needs-assessment/fetal-alcohol-spectrum-disorder-health-needs-assessment>

NICE Quality Standards for FASD 2022:
<https://www.nice.org.uk/guidance/qs204>