FASD Specialist ‘Ask the Experts’ event with guest speakers:

Consultant Clinical Psycholgist Dr Cassie Jackson; B.Sc, D.ClinPsy, PgDip, AFBPsS Chartered Consultant Clinical Psychologist, Associate Fellow of the British Psychological Society

Lead Consultant Community Paediatrician; Dr Neil Jackson; MBBS MRCPCH

Host: Julie Furney Director & CEO FASD Informed UK & FASD HUB South West

Question 1: Causes and Nature of Confabulation in FASD?

Julie: Many caregivers and professionals who support children, young people and adults with Fetal Alcohol Spectrum Disorder (FASD) often ask us why do they ‘lie’ so much. ‘they tell stories about things that simply cannot be true’.

We know that this is called ‘confabulation’, a clinical symptom of FASD.

International FASD colleagues in Canada who lead at the forefront of FASD research and support intervention, state:

‘Confabulation is when people with FASD really believe at the time, that what they are saying is the truth.

Damage to the function of the frontal lobes in the brain means that a person with FASD may confabulate – make up things that may not be true’. - FASD Canada

Cassie: Confabulation is not lying although sometimes it can be misinterpreted or perceived as such, particularly sometimes by professionals who don't really understand enough about FASD, it is therefore critical to get professionally trained to support the safeguarding vulnerabilities and to avoid making assumptions.

Confabulation is really common in FASD, essentially it arises from memory problems, a combined impact of memory problems, executive memory deficits, for example, sequencing, understanding time & place, challenges in differentiating sense of reality monitoring; this compounds the effect of deficits or the brain damage which is why you get ‘confabulating’.

So in a moment of the time, children/young people or adults with damage to the frontal lobe of the brain will, because they'd rather not say they don't remember, or ‘don’t have the skills to say I don’t remember’ are more likely to find something in their memory to fill in the gaps of their poor memory with a story, any kind of story, not necessarily their story or memory, and added to that it is often a mix of reality and fantasy.

Julie: It might be a memory of something that someone else said, something they watched on TV but has become their story or something that happened to them a long time ago, where they see it might fill a gap.

Is it true to say that they need to find a story to tell without knowing it is a story?

Cassie: Yes, exactly this, they can merge in what they sort of hoped might have happened or what would have been nice to have happen with what actually happened and then you get sometimes some weird and wonderful story or just anything that will just fill in the gap, essentially.

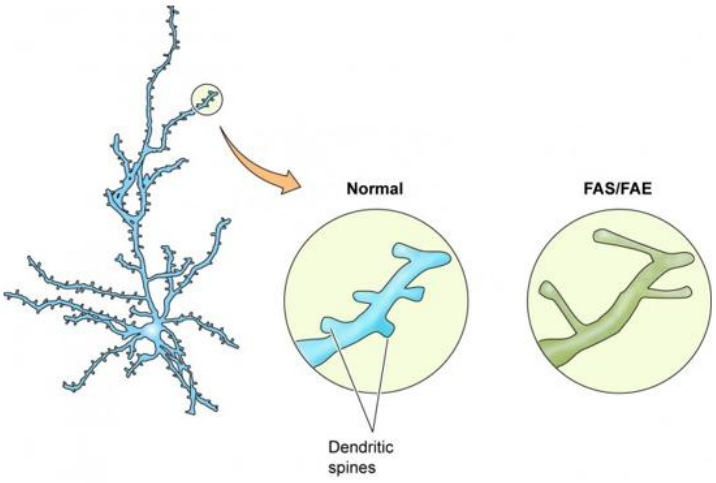
Julie: Because of the way they are accessing the memory or story do they think this is the truth?

Cassie: Yes absolutely, it is their truth to them. They would not necessarily know they are not telling the truth. That's what's what you see quite frequently with FASD.

The damage to the route to their information or memory is damaged so it might take them on another route to find it.

Loss of Dendritic Spines After Exposure to Alcohol in Utero

Alcohol disrupts the formation of synapses– the connections between neurons that allow them to communicate



Cassie: In terms of how to manage these challenges, the first thing is to understand and make sure that everybody who is coming into contact or supporting a child, young person or adult with FASD is trained; to understand the risks and the vulnerabilities as well as the brain damage whereas those with problems, are coming from a neuro developmental perspective.

It is important that it is not framed as 'lying' and it's understood as a neurodevelopmental difficulty associated with their FASD; their brain damage.

The next thing is, you don't want to directly confront it; this could lead to shame or hyper fixating on something *(that point we will come onto shortly).*

Choosing what you do or don't mention is very situational.

It doesn't mean you completely accept it and you don't carefully consider it at all but you might use a low demand approach.

It might be you could say for example:

Oh, isn't that an interesting story.

Wouldn't that be nice if that would happen?

Julie: Let's try and remember together……… *what might have happened, I think that Claire in your School went to Disneyland, she wore an Elsa costume.*

I would love to go to Disneyland.

I wonder if we could get an Elsa costume for your birthday.

Let's think back about when you went to tea at Grandmas house, we had angel cake. I love angel cake.

Cassie: So you're sort of gently introducing reality, but you're not 'shaming' them to the story that they've created.

Julie: Teacher might say, "What did you do at the weekend?

And they said, "I flew on a green Dragon".

Cassie: Those are the sort of things when you leave it and perhaps say,

"Oh, that sounds like a brilliant"

"Wouldn't that be lovely if that could have happened"?

Julie: "I think Mummy said that you went shopping on Saturday for a new sparkly T-shirt which had a dragon on it"

Cassie: You are introducing a timeline, a time frame, but without the shame.

Julie: Key here to have good communication between home and School, School and home.

The same can happen in reverse where a child might say things that has happen in School which could be misunderstood.

Using a communications book that can go back and forth to School can help where there is no direct conversation in front of the child to avoid shaming the child.

Cassie: Yes, exactly that it, its about open communication all of the time to understand the risks and to be proactive in supporting needs.

Important here for Schools to get FASD trained to avoid the assumptions and avoid the risks.

When they do tell the truth, this needs to be considered important too.

Julie: Not to miss this, as safeguarding needs to be risk assessed.

Cassie: And then to try to prevent excessive confabulation, to try to reduce memory demands, trying to not to be suggestive.

Julie: Very important to risk assess and treat safeguarding in a very bespoke tailored way to risk assess.

Cassie: Try not to have open-ended questions about historical events because those are the kind of questions that are more like to include confabulating.

Julie: It might be a more complex statement about a safeguarding risk. How do you go about picking this apart? Same principle, piece by piece?

Cassie: **First, and I cannot reinforce this enough, is that all professionals need training in FASD to avoid making false allegations or not misunderstanding when disclosures are factual.**

If these situations occur they should always call in a specialist to consider and support a better understanding of FASD.

Yes, so break it down, often it very hard to ever get to what happened, when and in what order, unless asked in the moment.

Julie: FASD is brain damage and poor processing speed.

Is it true to say that it is often hard to find 'the real story' but if the professional knows them well and are trained to tune into the needs then they might interpret the information, a little like you would with someone with dementia, it can be made up from fragments of other memories or stories.

Cassie: This is why children, young people and adults are so vulnerable and need high levels of supervision.

Julie: My other thought was that sometimes we get this question asked around safeguarding.

How do professionals understand the safeguarding risks to children, young people and adults?

How can professionals understand the risks around getting it right, in the sense of that that whole piece around ‘what is confabulation’ and what is the truth because what we know is that's hard to differentiate sometimes in terms of understanding?

And when to hand over to a specialist?

Cassie: **It is absolutely essential that professionals are trained. They need to do this to safeguard the child from suggestibility, so when answering questions about what has been said they could be unintentionally led.**

This training is to safeguard themselves and the person with FASD, to pause to consider the vulnerabilities of asking further questions.

It is very hard not to lead a person with FASD.

So vital for example, in the work that I do with teenagers with expert witness court work, if they are being formally interviewed by professionals or police or social workers.

So for example someone might be asked:

‘Have they asked leading questions to get their outcome?’.

As I mentioned before it is very easy to lead a young person with FASD. Too easy.

Those with FASD are highly suggestible.

They will often say what they think the person wants to hear.

So for example they might admit they have done something when they have not or where they might say they would like to do something when they do not.

They might say they understand when they do not.

Something that perhaps wasn't true.

Perhaps they don't remember or even in some circumstances, are making up confessions, because of the inability to see the consequences of doing that.

There have been many cases where young people with FASD have made a false confession simply because they thought that would end the whole thing.

That it would 'please' the person asking the questions.

Without being able to understand what that means.

Or if they are subject to coercion from others then could be very easily influence to agree to anything, for example we often hear of young people saying they want to stay somewhere when they don't. They say yes because that is what they have been told to say or what they thing they should be saying.

A specialist should always assess independently.

So yes, absolutely, training and understanding of FASD is absolutely key in terms of making sure that they vulnerability is not being exploited in that way.

Also assessment of suggestibility and capacity when that young person reaches 16 is key to safeguard needs.

Julie: Supporting professionals in all services is important in these difficult safeguarding situations where the following resources help advocate for needs.

For the Police they would need to be given a card so that they could be 'put on notice' that someone has complex needs and what that means if they were considering getting specialist assessment for 'being fit' to issue a caution or be interviewed under PACE law and the Mental Capacity Act.

All advocacy cards identify confabulation risk: '[FASD Informed' disability advocacy resources]

Cassie: To be able to ensure that that safeguarding needs are considered in those with FASD, it is really important to understand fully the vulnerabilities.

For the school or the social work care team or whoever to understand that the vulnerabilities of the likelihood of what is actually being said, we also need to be able to understand how to support that and that comes with training.

Question 2 in the chat from a professional?

Who can we go to get FASD essential training in FASD?

There are many providers of FASD training through the FASD Alliance.

If you are looking for a strong overview on FASD, in particular confabulation/risk assessments at the appropriate level for reflective consideration in professional practice, delivered online these courses are strong.

Each course is tailored around your child, young person or adult where any history, previous assessments and a conversation with carers/parents is had to carefully construct the course around the child/young person/adult.

'FASD Informed' Social Worker

'FASD Informed' Specialist School

FASD Informed Residential Team

'FASD Informed' School

'FASD Informed Alternative Provision'

'FASD Informed' Early Years

'FASD Informed Multi-Disciplinary Teams' (good for team around the child or Child in Need meetings)

FASD Informed Police

Other courses are available through FASD Informed UK courses

Further linked research and clinical path of evidence:

Suggestibility and confabulation among individuals with Fetal Alcohol Spectrum Disorder: A review for criminal justice, forensic mental health, and legal interviewers

Jerrod Brown, Erik Asp, Megan N. Carter,Vanessa Spiller, Deanna Bishop-Deaton

Foetal Alcohol Spectrum Disorder and its ethical impacts on society

Elaine Coates (The University of Salford), Dr David Junior Gilbert (The University of Salford)

Question 3: My son has a diagnosis of FASD with very strong Pathological Demand Avoidant 'PDA' traits?

Would you recommend any specific strategies to support him alongside those recommended by the PDA Society?

Cassie: The key here is about understanding where the 'PDA type needs' comes from, in terms of often anxiety…

….anxiety is about what's going to happen next, anxiety about what you know……everything often becomes perceived as a demand, that's frightening.

Sometimes it could be useful to take a scientific approach to looking at…

Are there specific times of the day or specific contexts where demand avoidant behaviour happens?

Are there sensory components?

What is tiredness?

Is it in a certain social situation?

So sometimes it could be looking at antecedents in terms of, is there something we could do to change the environment or change what we are doing at that point to reduce the likelihood of that behaviour and the likelihood of the escalation.

Julie: I was just going to add that there that the question asked ….our son has a diagnosis FASD with strong PDA traits. I don't see Autism mentioned in that diagnosis.

So is that worth considering Autism alongside FASD?

We know that autism is very difficult to see for some clinicians that are not experienced in FASD. Looking through the lens of FASD to see Autism has been discussed here before.

Julie: Is it better understanding the full diagnosis…Perhaps if someone has only FASD, is it advisable to go back again for autism, would that be something that should be considered?

Cassie: PDA is not something we would diagnose without Autism. ‘PDA traits’, ‘PDA type behaviour’ or a ‘PDA profile’ is something that accompanies an Autism diagnosis.

Julie: Or should do.

Could you expand it upon why it's difficult to see Autism with FASD?

Cassie: The presentation of Autism in FASD is different and unless you're looking at it through and assessing through an FASD lens, it can easily be either missed or be given an unsatisfactory description in a report……. like ‘autistic traits’, autistic tendencies’ or they ‘don’t meet the threshold for Autism’ and those kind of terms.

The phenotype of autism with FASD is a pro social variant.

So it often people think of Autism as a ‘classic autism’, which involves social disinterest, social withdrawal.

Whereas, the presentation of Autism and FASD is a complete opposite in both cases. Instead, you've got a child who's still not managing socially, but instead, they're socially too much, on your lap, not reading cues. They're too intense. They don't understand the social boundaries.

They can be very interested in social relationships, but they're not able to manage them appropriately.

What you also see is a bit of a difference in terms of seeing less of the repetitive and restrictive behaviour side of things.

Often some children with FASD and co-occurring Autism may have better basic social communication skills like eye contact. Classic Autism may not.

But they all have **huge sensory needs**.

It is a very significant component that you see.

Julie: And the demand avoidance of that, how does that interplay?

Cassie: The interplay of that is because of chronic dysregulated behavioural profile that you have in FASD.

That comes from both damage to the prefrontal cortex and damage to the neuro endocrine system, which creates a sort of chronic level of hyperarousal, anxiety and all of those kind of things combined.

So that lends itself to this anxious hypervigilant profile, which can often then be misconstrued as trauma when it's actually neurodevelopmental.

And therefore, any kind of additional demand, any kind of additional sensory stimulant or anything like that can tip that young person, child, adult over to dysregulated ‘symptoms’ very quickly.

And that's why you see this sort of externalising profile of behaviour classically in childhood in FASD.

Question 4 from Chat…..

So if you've already got FASD and ADHD diagnosis with support in place, do you think there's any additional benefits in looking at autism?

Julie: We know statistically they are linked as co-occuring conditions, and there is much better understanding of Autism than FASD. I will let you answer that one Cassie.

Cassie: Absolutely yes, it depends what you see.

Neil: Absolutely important to understand if there is Autism

Cassie: Yes agreed it what you see, the statistics are now up to 70% of children with FASD will have co-occurring Autism Spectrum Disorder (ASD) now known as Autism Spectrum Condition (ASC), and therefore it's more likely than not that that's going to be a component as a child's presentation.

Children with FASD are well over 86% likely to have ADHD with their FASD presenting in many different ways but Autism is up there at around 70% too, it can be completely missed but provides clues to the needs in so many.

And that can be a really important means of understanding the whole child, in many aspects of that child's behaviour, and of course, it can also, in some areas, in particular education, that it can open up better understanding and opportunities that might not have been there without that additional second diagnosis.

So I would say it's always important to look at Autism because it's a **'symptom of FASD'.**

Julie: That's the important way to look at it.

Cassie:

- FASD is a 'syndrome'.
- This needs to be highlighted more as this is really important for teachers and support staff to understand this.
- With FASD there is certain neurocognitive profile. Most of those presenting with FASD will also have ADHD. Also, many will have Autism. So these are 'symptoms' of this broader primary etiological diagnosis and so therefore it is important to look at all of those symptoms in order to understand what's going on with the child or young person with prenatal alcohol exposure.

Julie: Would it be true to say that using the PDA strategies if you haven't got an autism diagnosis with FASD could they help, so by 'ruling in those strategies' could support that FASD profile?

So therefore considering the demand avoidance as being potentially Autism with the primary need of FASD?

Cassie: When you say 'rule them in', do you mean use the strategies with FASD?

Julie: Yes, that's it so if you haven't got a diagnosis of autism or ADHD even, to be able to consider the PDA strategies.

Cassie: Yes, it is always useful to do this as even the smallest of changes can be the biggest of wins.

From language used, changes to the environment…. but of course it's not always possible or easy to create this wonderfully low emotional environment all around you at home; Any small changes you can make, even the way that you place expectations on a child can alter the way they perceive that, and therefore can stop things before they start if that makes sense, so that tuning into the demand can sometime stop escalations in behaviour.

Resources for Demand Avoidance, FASD, PDA Strategies:

Julie: ‘Strategies not Solutions’ a very helpful free downloadable booklet packed with different helpful strategies to support FASD.

For young people transitioning into adulthood and adulthood an excellent tool in our toolkit that supports really helpful strategies (particularly useful from page 16) Supporting Success for Adults with FASD

Clinical Psychologist Dr. Naomi Fisher leads the way on demand avoidance strategies through her work in autism and trauma where she's focusses on PDA specifically so that's quite a useful Bank of resources on her website and in our previous hosted ‘Ask the Expert session with Dr Naomi Fisher’ which tunes in to demand avoidance in so many ways with FASD & Autism.

Julie: ‘Ruling PDA Strategies in’ is really helpful to be able to really support.

Question 5: Where can I find support and help with my child who needs very little sleep? Why does my child not need as much sleep?

Julie: It's really interesting we have juts talked of the ‘spectrum of need’ where this is a good example of this as in FASD where some children need lots of sleep, others need hardly any, why is this Neil?

The example given by the parent, is there is the child has tried melatonin and struggled with it.

Are there any other options that you could consider?

Neil: Looking for support, it depends on where you looking. I mean, you should be able to access support from primary care (GP or Health Visitor), for advice, and they often have a greater capacity to speak to you on a regular basis than some medical clinicians would do, and that's often what you need with sleep is a kind of a friend in your corner while this is going on what you're trying to introduce new strategies, because it is the challenging time for everybody…. not just the individual that you're trying to support better sleep with.

Children with neuro developmental difficulties with FASD that don't often need a lot of sleep, I routinely see children that can get away with four or five hours of sleep.

And it’s often a problem with ‘maintenance and initiation’ and where you see many who can often have a kind of almost like a power down. Once you finally get children to sleep, they often then are up three/four hours later, and they're ready to go again……because they've lost that initial sleep pressure that got them to sleep at the beginning of the night.

Julie: There's lots of nodding heads in our audience on this point Neil!

Neil: For sure. And that's the challenge. They don't ‘need’ that extra sleep. They feel they don't feel tired anymore. The fact that it's dark and it's quiet and so forth doesn't mean what it means for everybody else.

And so they think, this is fine, I feel okay, I might need mum for reassurance, I might need mum because I'm bored and I want to play.

It varies, obviously, from child to child.

Where melatonin comes in, we all have natural melatonin, our brain produces it when the light levels go down of an evening.

You can affect that somewhat yourself, as a carer or parent. If you have a bright lights up until 10 p.m, you're going to have a tougher time of it, then if you have lower light levels, in the few hours before bedtime. Screens are notorious for not helping, with your undulous melatonin production.

And visa versa, where those who struggle to get out of bed in the morning need brighter light levels so if you wake up in the morning, it's advised to be exposed to as much bright light as possible, so you're essentially rebooting your **‘circadian rhythm’** each day and cueing it into the right experiences.

In terms of **Melatonin**, clinicians can prescribe it and some families whose children do not like the NHS tablet or solution version, parents can buy gummies or various types of more manageable solutions online. It's generally a very safe option, we don't see very many problems with it.

The challenges can come with some children are that their not ‘staying asleep’ because of complete lack of melatonin, so that it's not going to cure every sleep problem.

It can be good for sleep difficulties for *sleep initiation*.

It's often quite poor in keeping children to sleep. It's not as sedative, it won't knock you out.

So it's understanding that it's an adjunct to all these other things in terms of routine, reducing light levels early, lavender spray in room and so forth, that we were talking about.

If melatonin isn't cutting it and you optimised everything else, then there are other options, but they tend to be the domain of tertiary centres, generally, rather than secondary centres.

Most secondary centres won't prescribe things like Clonidine.

If the melatonin is not working, those often have to be a tertiary centre.

Julie: You will have to explain that, Neil, the terminology

Neil: Sorry. Yes….

Primary care is your is the first level with your GPs,

Secondary is your Paediatrician, and then there are kind of more regional centres, which we call 'Tertary centres', and often they have sometimes have sleep clinics within those, and they will be the ones to advise onto things like **Clonidine**.

Now sometimes you can use **Phenergan** and it gets used both at primary & secondary care level, which is sedating antihistamine.

The challenge with that is that you tend to become habituated to it quite quickly and it works for maybe a couple of weeks, and then your body gets used to that dose, you can increase a dose and get a little bit more effect, but it diminishing.

Whereas melatonin, you can use long term and you don't have that same effect.

So, it depends on what the needs are, and sometimes you would prescribe a short course of Phenergan to try and get a child back into it into the rhythm cycle.

Cassie: I just going to add to pick up on this, sometimes where a child's ADHD symptoms aren't medicated.

Neil: Yes, for sure.

Cassie: Ironically, simulant medication controlling ADHD symptoms in the day can actually better medicate sleep at night.

Neil: Yes, absolutely. And I mean, we all know, if you've got something on your mind, if your mind is carrying in 10 to a dozen, because you're anxious about something or you are excited about something, you're not going to sleep as effectively as if you're in calm kind of low kind of arousal situation.

Therefore; ADHD in that heightened state that you can be in with ADHD, if you medicate that correctly, even though you are using a stimulant, then you can see better sleep patterns in children as a result.

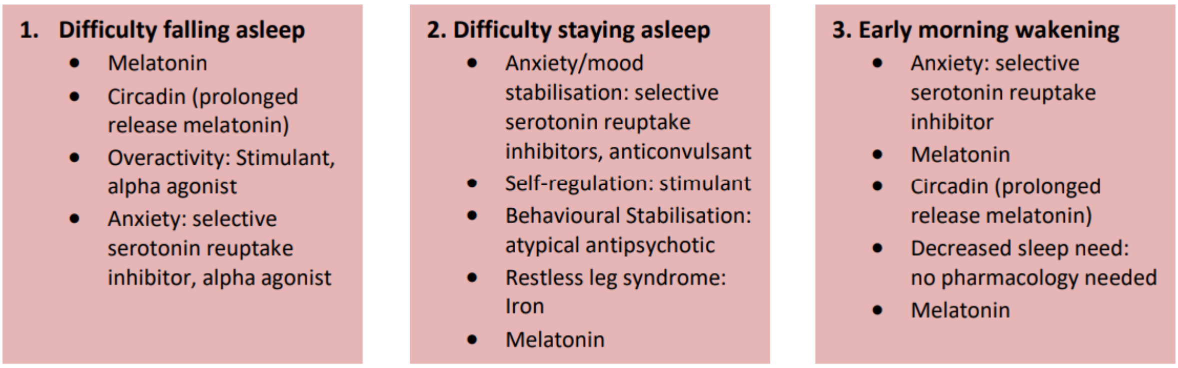
Helpful sources of information:

Our FASD Friends at FASD HUB Australia provide a very well considered factsheet that relates to medication and Regulating Circadian Rhythm:

They say that the *'medication will depend on the type of sleep behaviour and underlying cause.*

Medication should be used in conjunction with behavioural strategies, if behavioural strategies alone are not successful.

Melatonin or other medications should only be prescribed by an experienced clinician. The following recommendations below are provided by a developmental paediatrician and diagnostic researcher for CanFASD'



1. Difficulty falling asleep
- Melatonin
- Circadin (prolonged release melatonin)
- Overactivity: Stimulant, alpha agonist
- Anxiety: selective serotonin reuptake inhibitor, alpha agonist

2. Difficulty staying asleep
- Anxiety/mood stabilisation: selective serotonin reuptake inhibitors, anticonvulsant
- Self-regulation: stimulant
- Behavioural Stabilisation: atypical antipsychotic
- Restless leg syndrome: Iron
- Melatonin

3. Early morning wakening
- Anxiety: selective serotonin reuptake inhibitor
- Melatonin
- Circadin (prolonged release melatonin)
- Decreased sleep need: no pharmacology needed
- Melatonin

Cerebra brain injury charity provides very helpful free sleep advise & a sleep advise service

Neil: Sometimes stimulants can cause children to have difficulties with sleep, but more often than not, it seems to help and when you've got a diagnosis if FASD & ADHD in the mix.

For a much deeper dig into FASD & Sleep this really interesting research webnair from our FASD Friends from Canada FASD discusses strategies and reasons why Sleep is so impacted with prenatal alcohol exposure: Sleep in Children with FASD

Question 6 from the audience:

Do you think melatonin breaks are helpful?

Melatonin worked for them for four to five years and then stopped working?

Neil: We would suggest a break of every term, if you can, and kind of synchronise that with holidays, if you can bear it.

Melatonin, as per some other medications, do seem to work a little bit better if you have breaks compared to if you have them full time.

Julie: And what would a break period because you say, if you can bear it… and many of us cannot as we start from a place of exhaustion.

Neil: It doesn't need to be a long break, we are not talking weeks worth of breaks or anything like that.

Chat answers saying they leave it for a couple of days.

Neil: Yes, just that, exactly.

Julie: I think it's really important to reinforce this, because sometimes there's a mixed message that goes out with that, so that's good to know.

Because 48 hours is hard to do. But you will know when it starts wearing off that's the key thing, isn't it? It's about tuning in to the change of it being less effective, you might need a break to make it more effective?

Neil: Yes, you know when that break is ready. We hear from our families in the centres that instead of ramping dosage up and up and up….. and if you get to around 6 - 8 milligrams, it's not because you've not got enough melatonin going in, it is that you need to have a bit of a break, reset things a little bit and then come back to it.

Sometimes the smallest of those doses can be just as effective with breaks. It's one of those idiosyncratic kind of response with melatonin. **There is no one size fits all.**

Jamie's just asked, would you time that with a break with ADHD meds?

My question would be, why would you have a break with ADHD meds?

Neil: So to qualify my earlier point, the **nonstimulants, for example Atomoxetine, Guanfacine, Clonidine; you don't have breaks with those.**

But the stimulants, **Methylphenidates & Amphetamines** you can. Some people use them just for the school days, some for the middle of the working week so to speak, and then they have a weekends off.

A guide for clinicians considering trials of medication can be found (note page 2): https://www.fasdinformed.co.uk/_files/ugd/29cd79_9905dc2bfc7641dc97f3b2d0ad960991.pdf

Neil : It depends always on what the needs are.

As with any of these things, it's not that these breaks are mandatory, and some people find that they have a much better time of it (due mostly to firm routine) having seven days a week medication.

Even though there's a theory that you could have a break in there. It depends on how things are going for that individual.

The stimulants are in and out of a body quite quickly, you don't build up a certain level in your blood stream that you do with the nonstimulants.

So that's why you can have breaks of those without causing too many problems. All meds need monitoring by the ADHD team and your primary care giver, your GP.

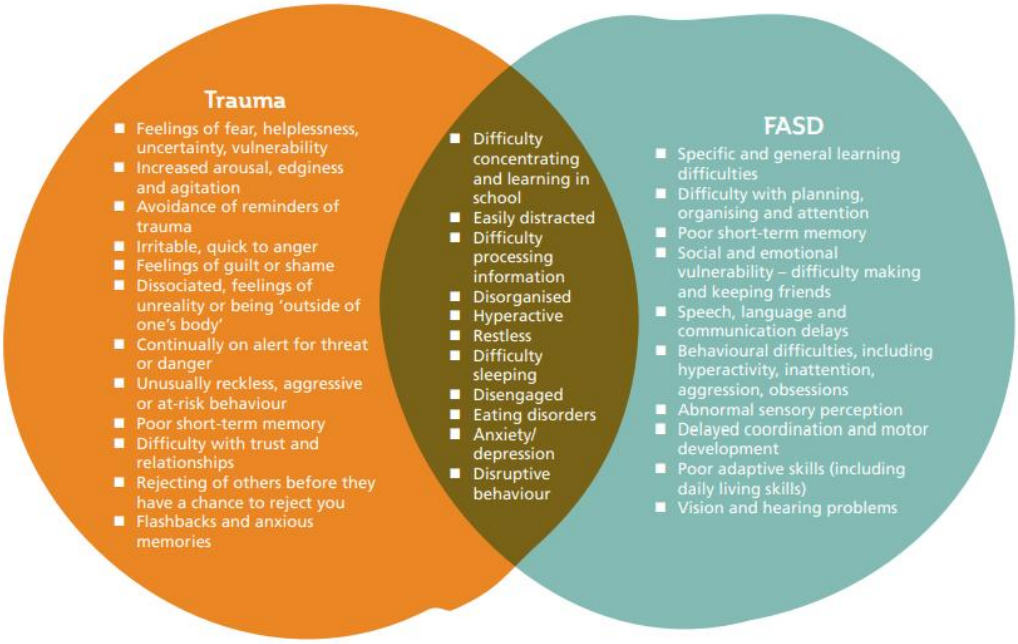
Question 7: How can complex trauma mask FASD and how do you support that when it's in a clinical report about trauma?

Julie: Quite often ‘trauma’, ‘developmental trauma’ or ‘complex trauma’ can be written in clinical or educational reports as the ‘primary diagnosis’, or if there is prenatal alcohol suspected and there is trauma, FASD might be overlooked or not investigated.

Cassie: Most children who have been fostered, adopted or kinship will be described as ‘having trauma’, and many rightly so. Some may have had trauma from domestic violence in the womb; all different sources of trauma which should not be dismissed.

Sometimes FASD symptoms can be the same as trauma symptom. Children can have both.

Sometimes depending on the lens of the clinician’s expertise, they might overlook the primary needs where sometimes overlapping FASD symptoms are misunderstood or mis construed as being trauma. **There is clearly an overlap and should never be dismissed.**



Source: Adapted from National Child Traumatic Stress Network, *Is it ADHD or child traumatic stress? A guide for clinicians*, NCTSN, Los Angeles, 2016, p. 5, www.nctsn.org/sites/default/files/resources//is_it_adhd_or_child_traumatic_stress.pdf.

And what often happens when well-meaning professionals might not understand FASD fully, but they do understand trauma well .Therefore; that's what is described or seen. **Where there is prenatal alcohol FASD always should be assessed and considered carefully.**

And the problem is with labelling trauma and sticking rigidly to it is that people ‘stop looking’ for other possible reasons to the ‘behaviour’.

Julie: Or the symptoms of unmet needs.

Cassie: Yes, exactly that where things can start spiralling very quickly as the child gets older and the divergence of needs is seen.

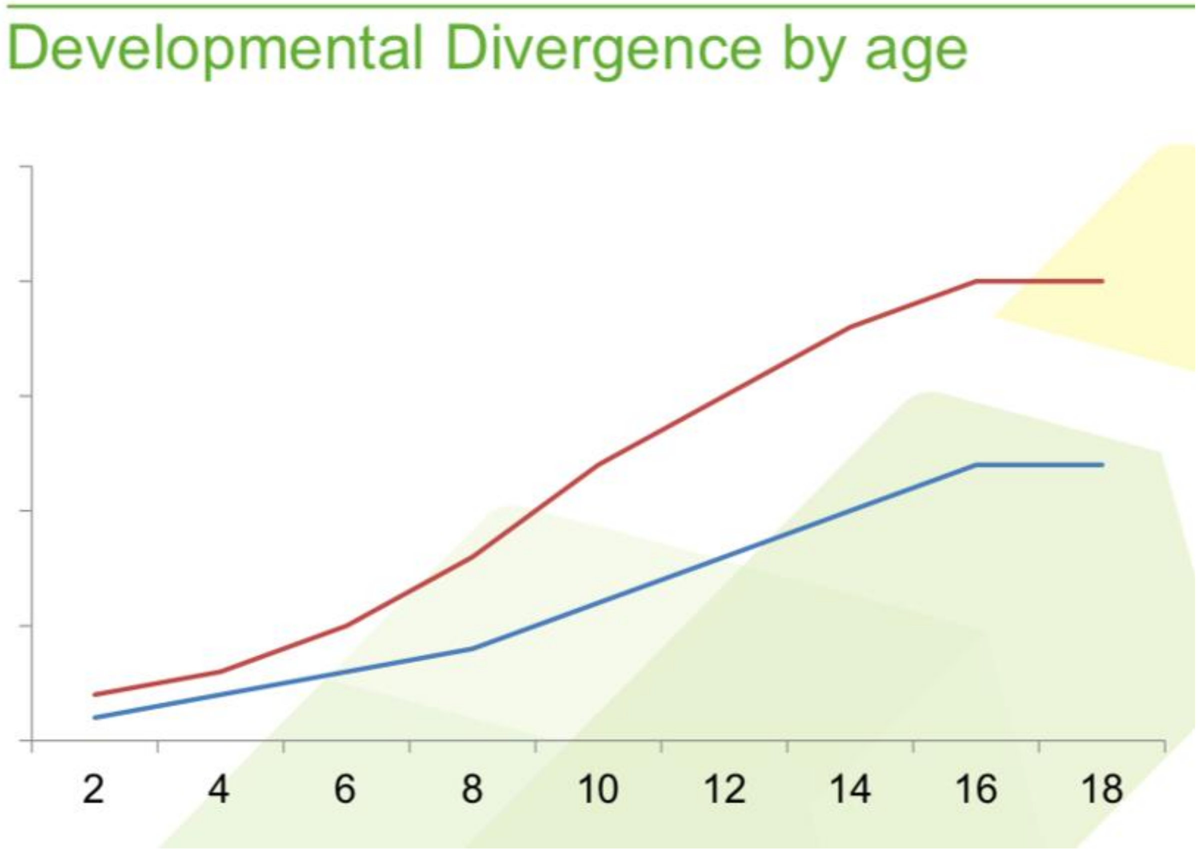


Image with kind permission of NHS Clinic Surrey; FASD Divergence of needs

Blue line ___ FASD (developmentally half the chronological age)

Red line ___ without FASD

Cassie: When children might get a diagnosis of ‘trauma’ their FASD needs might not be emerging as rapidly, so are therefore ‘hidden disabilities’ . **If there is prenatal alcohol or likely prenatal alcohol they should always be considered at the**

earliest possible opportunity to ‘rule it in’ to support good practice in early intervention.

Cassie: Families can feel like they're failing because what they often experience is lots of ‘trauma informed’ therapies, therapeutic trauma based parenting courses, which are sadly not the correct support for those looking after FASD with complex needs & trauma.

Sadly, when these interventions or courses are not bringing about the results that they would for a child *with trauma*, it can make adopted/foster/kinship parents feel like they are doing something wrong, placements can fail as too much demand or pressure is placed on the carer, which put simply, they are not getting it wrong, they are **tuning in to the wrong need**.

If the symptoms look like trauma symptoms, because what you have is dysregulation ‘symptoms’…… dysregulation symptoms include intense emotional reactions, mood swings, and difficulty calming down, which can lead to impulsive behaviours and relationship problems. Other signs are persistent irritability, feeling easily frustrated, and a tendency to either shut down or have outbursts in response to stress.

Cassie: Lots of attachment disorder type symptoms look like this, but ironically, children with FASD present with symptoms that *look like attachment disorder*, even when they have *no trauma histories whatsoever*.

The neurodevelopmental problems associated with FASD create those sort of cascading effects in their social relationships, their attachment relationships, the level of anxiety and sort of hypervigilance they have because of the *damage to the neuro endocrine system*, because of the *frontal lobe damage*, all of those things set up for that kind ‘behavioural’ response.

One of the key differentiators is that actually in a child who has trauma, but ‘no other problems’, I have noticed when they are placed in a loving, nurturing family home and they've had access to therapeutic interventions, there's a trajectory of <u>significant improvement over time.</u>

When those attachment relationships are building, you see a significant improvement over the course of time.

On the other hand, with FASD, the trajectory looks really very different. As instead of improvement of those symptoms you see the reverse, the image further above where the divergence of need widens.

And instead of improvement over time those behavioural symptoms, you often see, actually exacerbate and an increasingly widening gap in developmental development behaviour, socially emotional presentation over the course of time.

- **And that's very, very different to what you see in trauma.**

So the trajectory of improvement is one way of being able to pick this apart to some extent, because if you're doing all of the therapeutic parenting and your child has had all the interventions with no meaningful change.

There is a developmental divergence that keeps widening as your child is getting older in terms of how they're relating to their peers, how they're managing, their adaptive behaviour, their independent skills, difficulties in school, emotional regulation, problems that aren't actually getting better, despite all the input they're having. Then it is worse thinking this is more likely to be neurodevelopmental, that's when you want to be thinking about FASD.

Now, of course, there are children who are *both traumatised and have FASD*. But we can still pick that apart to some extent because **with trauma, you don't see the broad range of neurodevelopmental and cognitive deficits in the brain domains that you see in children with FASD.**

And to add to that, the FASD & Trauma research tells us that when you look at the neurodevelopment or cognitive profile of those with FASD, this doesn't change very much from children who had no trauma to children who had a really significant history of trauma.

Professor Alan Price writes: *'A brain affected by FASD has permanent organic damage and neurological dysfunction. The struggles are life-long for the affected person. A brain affected by trauma has the neuroplasticity to form new neural pathways for better long-term outcomes. When trauma and FASD mix, the result can be very complex. This explains why support at home and school must be FASD-informed.*

Cassie: Therefore; developmental outcomes and presentation is broadly similar across all those ranges when they've been separated out into different groups of children, depending on level of trauma.

So that again tells us that these symptoms relate to the alcohol exposure first and foremost, and if a child has a trauma history or a strongly suspected history of prenatal alcohol exposure, for instance, it is really, really important to look into that regardless of whatever trauma history they might have.

Julie: And that is critical there, because at that we are making here is that it may well be actually the training of that clinician that's made that assessment, where they have a trauma lens, so that's their clinical experience can be.

Sometimes the Educational Psychological assessment might state that it's trauma.

The trauma is the assumption…. this can mask the primary hidden needs.

An undiagnosed child can be misinterpreted, misunderstood and then instead of helping by having a trauma diagnosis it can hinder as the strategies are the wrong strategies.

So for example a child might present as having Trauma, ADHD and Autism rather than FASD with ADHD, Autism and Trauma; *FASD is the primary need*; the irreparable brain damage.

Cassie: Its well intended I am sure, but it's hugely detrimental for that child and family because then nobody's going to look any further.

It's not appropriate to say that without understanding FASD, that if the child has likely or known prenatal alcohol exposure, you absolutely cannot rule it out.

Julie: In those situations of likely prenatal alcohol, I think it's about going back to the adoptive, foster placing social worker or kinship social worker team to be able to ask on medical grounds for them to dig for alcohol evidence again to be able to consider that that broader need, that primary need FASD.

For support in writing this initial request for alcohol evidence in pregnancy please find a template to support the request: https://www.fasdinformed.co.uk/_files/ugd/29cd79_29f0030a1e31449bbf3ffc0215591c4d.pdf

Julie: I think Cassie, that's a really strong good advice for both professionals and carers as **early intervention is vital for those with prenatal alcohol exposure (PAE).**

Some clinicians might not have the confidence yet to diagnose but to write in their trauma focussed report that FASD needs consideration as there is PAE or that there are traits of FASD or where it could be likely, is a game changer for a child and their outcomes and support for the future.

FASD could be the primary diagnosis and you know, it's really key to be able to make sure that professionals and caregivers ‘rule it in’ first to benefit from strategies tailored to support FASD.

Of course, that child might have trauma and have experienced other types of trauma for example institutional trauma, but in order to support that, that divergence of needs seen in FASD, that developmental vs chorological separation as they go up the school years must be *supported early.*

It's going to widen and it's importance and to recognise that.

Cassie: Absolutely Julie, we think of development like layers of an onion.

The core is the development of the brain, and everything is neurodevelopment**. If the brain is affected by prenatal alcohol exposure or any other exposure, that impacts on how everything develops.**

Anything on top of that postnatally is over that layer of that brain that's already been injured by alcohol exposure or whatever else it is, and therefore their attachment strategies and how they manage trauma and/or how they navigate social relationships in the context of all of that. It is also based on whatever damage they have had to their developing brains in utero.

Cassie: FASD also impacts how they understand and how they navigate their postnatal environment as well and how their attachment disorder, if they have an attachment disorder, presents itself.

So unless you understand about the child’s brain development, you can't really understand anything else either. You can't fully understand how they're managing their trauma, and how that's affected them. FASD training for all professionals is vital for this reason.

Metaphorically, you have to look at the whole onion.

You cannot think trauma first and then neurodevelopment, it has to be the other way around.

Julie: Rule alcohol in for early intervention.

Cassie: Vital.

Neil: Yes agreed.

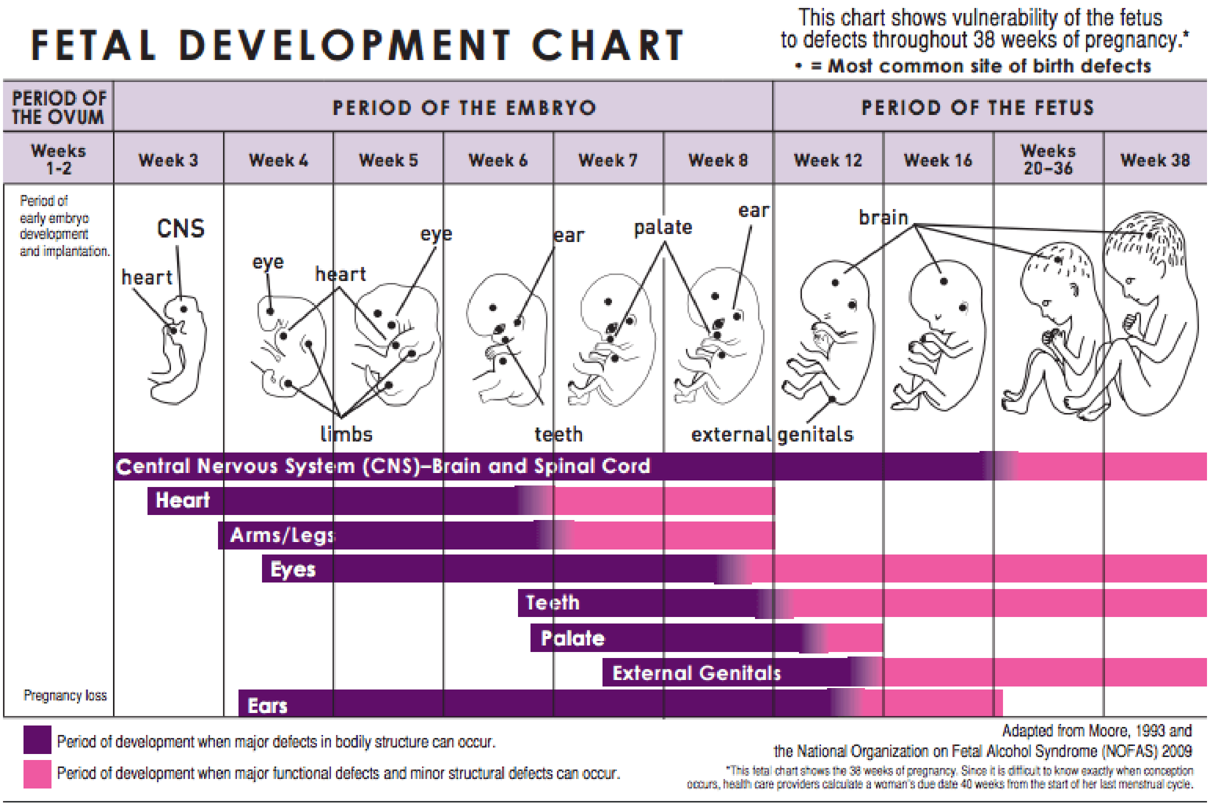
Question 7 in the chat; someone has just commented on the points around prenatal alcohol exposure thanking you for its consideration.

So we are investigating FASD currently. Mum says she drank twice. Is this possible after only two exposures? This was binge drinking.

Neil: Although it says they were binges there are graduations of exposure and binge drinking can be harmful.

The NHS guidance is there is no safe time in pregnancy to drink alcohol.

It can depend on when the alcohol was taken what impact there is but damage can be caused throughout the pregnancy.



Adapted from Moore, 1993 and the National Organization on Fetal Alcohol Syndrome (NOFAS) 2009

*This fetal chart shows the 38 weeks of pregnancy. Since it is difficult to know exactly when conception occurs, health care providers calculate a woman's due date 40 weeks from the start of her last menstrual cycle.

Neil: There is no safe time to drink, and to the question asked, it is not a binary yes or no kind of answer.

Some clinicians might hesitate, perhaps get very hung up on proving a certain amount of alcohol exposure and missing the bigger picture in seeing the child who they are and how they're behaving.

If the way they are symptomatic fits with that of FASD, and there is an alcohol exposure there, even if it's sometimes small amounts, some children are genetically sensitive where it must be considered.

Some children genetically are more able to resist the alcohol effects.

Julie: So on that point then, Neil, just if I might pause you just for a moment, with regards to genetically sensitive, are we talking about the epigenetics of a child, so that there is a school of thought that if there is a background of alcohol in the family history, in previous generations that can make the birth mum more susceptible to alcohol?

Neil: It can be both genetics and epigenetics

So it could genetically where for example fraternal (not identical) twins are in the same womb at the same time, having been exposed to alcohol exposure at the same time but can give different results.

Jan's point in the chat example about a genetic link, she's got twins, both have FASD, one affected very differently than the other.

And so it can be quite challenging to understand why some children are more severely affected than others and so unfortunately, the genetics is not at a point where we can use it on a clinical basis because we need more research.

For example, we cannot take a child's blood sample and say right, you're going to be extra sensitive or not sensitive. Some things are at a research level.

Julie: It's about having that pragmatic view, isn't it, to consider the bigger piece?

Neil: It is. I think that sometimes where clinicians can get caught up, which can hinder a diagnosis.

It is not dissimilar than what we way were talking about trauma. So if you come at it from a medical lens rather than a trauma lens, you can see things very differently.

And sometimes clinicians might see things more holistically, from a different perspective before you can move on and everybody needs to be pulling in the same direction.

If a clinician is suggesting strongly otherwise, you're going to have a harder path to tread obviously.

Cassie: There is lots to be said around reporting of alcohol exposure, or seen alcohol where often drugs are recorded but not alcohol.

Julie; So where there are drugs there is always alcohol, to consider cases where drugs is identified and to take the view that alcohol is likely. Or where perhaps alcohol was recorded before and after pregnancy.

Cassie: So for the person asking the question, was this under reported? if the reporting is twice, it may not have been at other times. It is very hard for a biological mother to admit they drank in pregnancy but it doesn't mean they didn't.

Julie: We see many cases reported where there has been under reporting or where the question is asked in the wrong way where birth mothers say to makes them feel shame. One birth mum said its like saying how many cigarettes do you smoke in one day, who knows exactly.

That question to a pregnant woman is very difficult, and we know that midwives are now asked through the NHS, to ask if a birth mother's been drinking and pregnancy, but they've no requirement to answer and so equally, if the information isn't there and quite often the information is there, somewhere, but it's about going back to have a deeper dig for information.

If its not in the adoption or kinship files, then look at other routes of evidence in the red book, care records, health visitor notes, social care reports, etc.

Midwife home visit might give a vital clue into environmental status of the family having a vigilant.

Julie : It only needs to be a line, doesn't it really, Cassie and Neil, where there is alcohol. It's about that pragmatic view. You know, is it chaotic before and after pregnancy?

Cassie: Absolutely, often it's the lifestyle of the birth mother that is also very important.

So if you have got a chaotic lifestyle, a history of alcohol, even if it doesn't say anything specific to the pregnancy, if you've both a chronic history of alcohol use which is before and after the pregnancy, sometimes there's known exposure in other pregnancies, even if not in this one, all of those kind of lifestyle factors would enable us to look at FASD.

Question 9: Why do we see fluctuating capacity in those with FASD?

Cassie: The term ‘fluctuating’ can be misleading, it's so much that it's ‘fluctuating’, but it is ‘capacity or no capacity in different environments with those with FASD’.

The problem is the marked discrepancy and how a young person can present in a structured, supported scaffold environment, compared to how they present in an unstructured environment, aka the real world.

And what is so often the case in so many of the young people and young adults that I see with FASD, is that particularly when they are presenting to professionals who don't know much about FASD, they can, in the moment, in a structured and calm environment, when they're not openly aroused, they can present as very capable.

Julie: This is arguably a false positive?

Cassie: Yes, they can present as having insight into any kind of sort of risky or dangerous behaviour that they may have been presented with, they can say all the right things because they're expressive language could often be quite a bit stronger than their receptive language skills.

They can present as having capacity and they might arguably pass, some of the key capacity points, for example can they describe something, can they weigh up pros in cons in a calm environment about making a decision?

So they may pass some of those points in a calm environment, but the bit where they would come unstuck is the self monitoring points

This is part that you only see in the unstructured environment.

So much of the time, what will happen is these young people will be able to say all of these things in a calm assessment with a professional.

But the very next day, they'll go out and do the same risk taking behaviour, put themselves or others at risk, whatever the problem is with capacity.

Potentially doing the same perseverative behaviour again and again and again.

Despite the fact that in a calm environment, they would be able to say why they shouldn't do that, and what's the right thing to do.

Because of the executive functioning problems in FASD, because of those difficulties with self monitoring, because of the impulsivity and the poor inhibitory control, they just keep doing the same thing anyway.

This can be misunderstood as ‘behavioural’.

That's where we say about fluctuating capacity, because what we would say is actually in the real world environment, they lack capacity to, for example, keep themselves safe from whether this is exploitation or something along those lines.

We call it like a coping collapse in the real world.

When you remove the structure and the scaffolding with those with FASD, that's when those adaptive behaviour and the executive function deficits come into play, that means that young person is unable to do what they are able to say they will do when they are in a structured calm environment.

So that's where the capacity falls down at that self-monitoring level, and that's the bit that makes them really vulnerable.

Julie: If arguably the person asking those capacity assessment questions was not FASD trained, that they were not ‘a specialist’ in FASD, where the young person is highly suggestible. Is it possible that the young person or adult might answer the question in a way that they think the person asking the question wants them to answer?

Would that be fair to say?

Cassie: Yes, absolutely that is very fair.

Cassie: **It is very easy to unintentionally lead the young person or adult with FASD into saying something they don’t understand.**

Particularly if you are a well-meaning professional invested in supporting a young person or adult where you are thinking this young person deserves the right to make their own decisions; where you can very unintentionally ask questions in a way that leads them to the answer.

Julie: By this you mean that they would be answering it because they thought they had to say the answer, rather than because they understood what it meant?

Cassie: The very definition of FASD in children, young people and adults will all be very suggestible.

I have assessed hundreds of young people with FASD who do, even without asking ‘leading questions’, are able to, in that calm environment, give some quite reflective responses.

But unfortunately, what you need to look at is not just what they're doing and saying in that environment. It's what they're doing in the ‘real world’.

Julie: Yes agreed.

Neil: Absolutely.

Cassie: What's so important is to look at the **pattern of behaviour in conjunction with their diagnosis**, and that's what you've got to look at when you're thinking about capacity.

Julie: How do professionals safeguard and protect children, young people, adults with these needs around capacity?

With regards to considering the suggestibility and making sure that a mental capacity assessment is accurate, how do professionals support these vulnerabilities?

For those with prenatal alcohol exposure, likely FASD or with a confirmed diagnosis of FASD, the mental capacity assessment should be carried by someone who understands and is trained in FASD.

Those with FASD are highly suggestible.

Point of law: In the criminal justice system FASD and other brain damage must be considered under PACE legislation & the Mental Heath Act 1983, where Officers must consider and request to assess suggestibility in order to consider if a person is 'fit to be interviewed, fit to take a caution.

The law is very clear about professionals offering leading questions where those that are not trained cannot interview and so only those are trained to avoid the use of leading questions and suggestibility but only if 'fit to be interviewed'.

Reference Point: The Mental Capacity Act 2005 Code of Practice (the Code) and the NICE Guidelines On Decision Making And Mental Capacity (the Guidelines).

4.51 of the Code of Practice states:

When should professionals be involved?

'4.51 Anyone assessing someone's capacity may need to get a professional opinion when assessing a person's capacity to make complex or major decisions. In some cases this will simply involve contacting the person's general practitioner (GP) or family doctor. If the person has a particular condition or disorder, it may be appropriate to contact a specialist (for example, consultant psychiatrist, psychologist or other professional with experience of caring for patients with that condition). A speech and language therapist might be able to help if there are communication difficulties. In some cases, a multi-disciplinary approach is best. This means combining the skills and expertise of different professionals.

4.52 Professionals should never express an opinion without carrying out a proper examination and assessment of the person's capacity to make the decision. They must apply the appropriate test of capacity. In some cases, they will need to meet the person more than once – particularly if the person has communication difficulties. Professionals can get background information from a person's family and carers. But the personal views of these people about what they want for the person who lacks capacity must not influence the outcome of that assessment.

4.53 Professional involvement might be needed if:

- the decision that needs to be made is complicated or has serious consequences
- an assessor concludes a person lacks capacity, and the person challenges the finding
- family members, carers and/or professionals disagree about a person's capacity

- there is a conflict of interest between the assessor and the person being assessed
- the person being assessed is expressing different views to different people – they may be trying to please everyone or telling people what they think they want to hear
- somebody might challenge the person's capacity to make the decision – either at the time of the decision or later (for example, a family member might challenge a will after a person has died on the basis that the person lacked capacity when they made the will)
- somebody has been accused of abusing a vulnerable adult who may lack capacity to make decisions that protect them
- a person repeatedly makes decisions that put them at risk or could result in suffering or damage'

Assessments of capacity are time and decision-specific.

The Mental Capacity Act 2005 Code of Practice (the Code)

Julie: If there is evidence of prenatal alcohol exposure, professionals should take specialist advise as it is likely that the individual is highly vulnerable.

If the person has likely FASD or diagnosed FASD specialist advise is required.

Cassie: If you are a professional assessing and have got a report that clearly notes that while they may pass certain sections of the capacity assessment, the parts about 'real world functioning' are vitally important to safeguard and the parts that a clinician could only pay robust attention to.

In a court of law the judge would ask for a clinical view on mental capacity of those with FASD.

So therefore, this means of predict that they're going to need this level of support and scaffolding in adult life and that if you remove that support and scaffolding, you're going to make that young person incredibly vulnerable.

So it's about how having professionals or a team around that young person or adult that understands it vulnerability and doesn't remove that scaffolding simply because the young person says they're fine.

Julie: They will say they are fine because they want to be compliant, not because they understand what is being asked of them.

Cassie: Yes exactly this.

Its all about their understanding. This will look different for each individual or each young adult or adult with FASD.

Some young adults with FASD, at the higher end of the functioning spectrum, might live semi supported lives, in high order executive functioning tasks.

And others need a really significant and high level of support.

Importance to have FASD training that is personalised, not generic, where it considers individualised support planning.

Question 10 from the audience: What is the best age to do a capacity assessment?

Julie: So there's are legal parameters around capacity assessments, with regard to the Mental Capacity Act a young person must be 16 or over because effectively the the rights change with regards to parental rights.

*****Important supporting guidance can be found here to expand on areas to consider **BEFORE** your child turns 16. A very important read. : https://www.fasdinformed.co.uk/_files/ugd/29cd79_17f92cdf9e5a46569b9cd012ced9a60c.pdf

Julie: One of our later questions is about considering making sure you have enough assessment information about your child before they get to key transition points 16 or 18 years.

Perhaps we answer that now, Cassie. I think that would be helpful for transitions into adulthood.

Cassie: A further point before we move on, on capacity it has to be time, place and subjects specific.

So you have got to be asking quite specific questions in the assessment so that the assessor is not plucking questions out of the air.

So for example:

Does this young person have the capacity to make decisions about where they're going to live?

Or does this young person have capacity to keep themselves safe in the community?

Julie: The specialist would then carefully construct questions around this to avoid being leading in any way.

Cassie: Yes exactly.

So it has got to be very specific, not just a blanket general capacity assessment, it's capacity for a purpose, specific.

To find out more about who to ask r a specialist assessment please read the linked document: https://www.fasdinformed.co.uk/_files/ugd/29cd79_17f92cdf9e5a46569b9cd012ced9a60c.pdf

Question 11: We have heard lots about the importance of understanding the vulnerabilities of a child, to safeguard them and others.

What is there to support a child or young person if you get just a diagnosis on a piece of paper without any recommendations to support the complexity of needs that we know comes with FASD?

What assessment document considers other existing assessments that only talk about trauma and so something specific is needed to provide recommendations for future support and scaffolding?

Can you tell us what a neuropsychological assessment is?

Cassie: So I see a lot of families several times during the journey of their child or young persons journey.

Most commonly the times we see them at the clinic is ideally early, so FASD diagnosis around to the **seven or eight years old** where we also screen for Autism and ADHD at the same time as part of the package**.**

The neuropsychological report supports planning of key transitions or where needs change rapidly.

It's really useful to see children before going up to **second school**, particularly if they're in mainstream school and the plan is for them to continue in mainstream school **or earlier if specialist is required.**

So as I said in earlier questions, the trajectory of FASD is this increasing the developmental divergence away from neurotypical over the course of childhood.

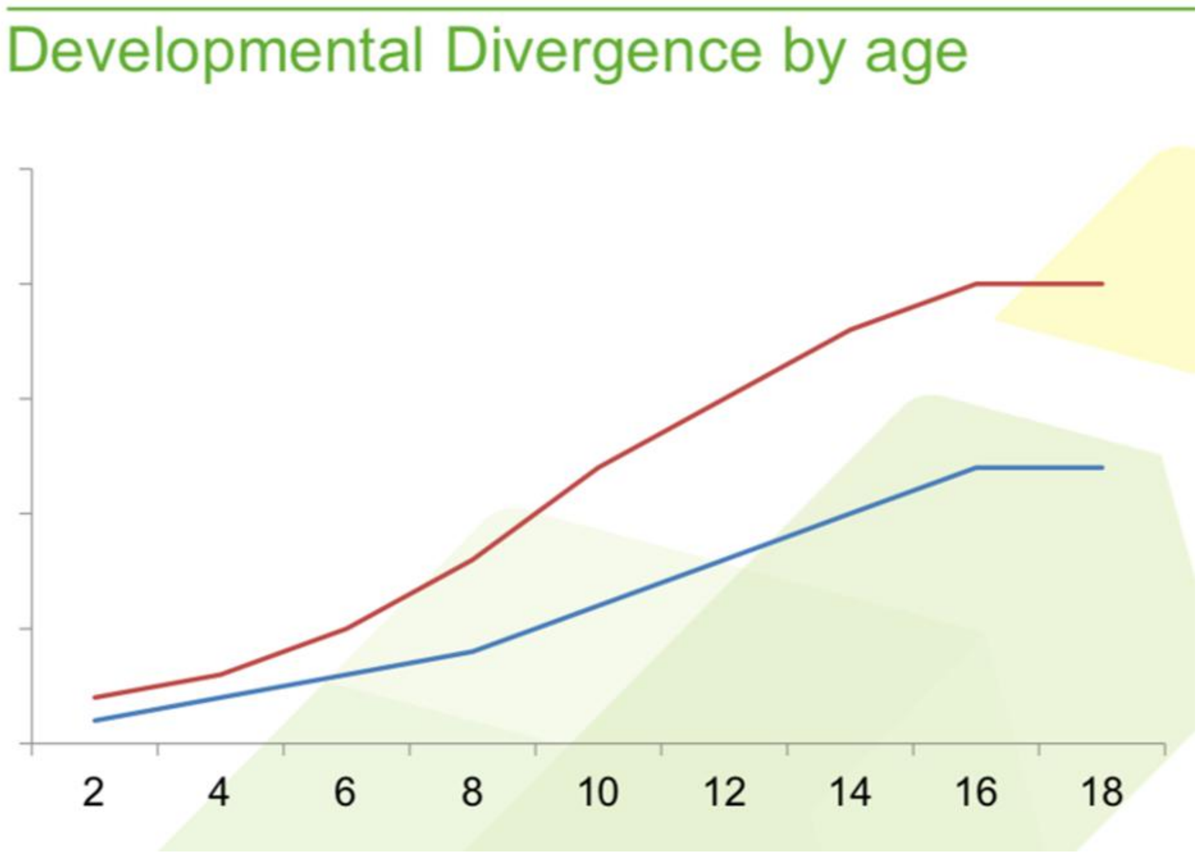


Image with kind permission of NHS Clinic Surrey; FASD Divergence of needs

Blue line ___ FASD (developmentally half the chronological age)

Red line ___ without FASD

Cassie: So if you look at the divergence in the image above, what you want to be doing is *tracking that trajectory and how that's impacting your child.*

When do you need up to date information in enough time to influence changes in health, social care and education through the EHCPs to make sure the support they are getting is appropriate to the level of needs.

- It should always be at different times of their life.

Secondary school transition is very important, as is, the one after that as this next really big one is that transition to young adulthood time.

Cassie: I often see young people between **ages of 16 and 18** when we can do a really, really thorough neuropsychological assessment, and that includes some of those tests that dig deeper where for example you can do standardised assessments relating to suggestibility, for example, where you can actually get sentinels in relation to how suggestible or how susceptible somebody is to leading questions and all of those kind of thing.

Julie: **Always ask for suggestibility to be considered as part of an assessment as the record of this could really help later on if needed to consider vulnerabilities around mental capacity, risk of coercion and exploitation**

Cassie: It can be really important as a proxy for that social vulnerability in adulthood.

So when you look at executive functioning, young person's level of adaptive behaviour, you can then predict in adulthood, what sort of support is this young person going to need?

And that's the time where you can really map out what that support need is going to look like for their adult life.

Question 12, in the chat

Julie: A really important point in the chat, which is around mental capacity as it is required at 16, but assessments are 'time and decision specific'.

Cassie: So what that effectively means is that you might have a mental capacity assessment done several times over for different reasons… because of changes to needs, environmental changes, perhaps the person has moved accommodation, or moved into a different College/School, where actually they're a bit more stable, a bit more settled, a bit more anchored.

Julie: So, *decision making is absolutely in the mental capacity assessment* and is there to be used. It's there to be able to consider capacity in both ways, whether they have or they haven't got capacity.

Is that fair Cassie?

Cassie: Yes, that's exactly it.

Julie: It's really important that those key milestones are supported.

Question 13: You touched on 'perseveration' a little bit in your earlier points Cassie. Could you perhaps expand on what that is and that how that impacts a child, young person or adult with FASD?

Cassie: Preservation is one of the symptoms of executive functioning deficit, a repetition of actions or behaviour that a child finds hard to move on from.

So you can see it in different contexts.

I can see it when I'm directly assessing a child in clinic. When you give them an instructive problem solving task, for example, and what tends to happen is they become stuck on a loop of doing the same thing over and over again and not able to move their problems solving on.

What's quite interesting and very important from a school/college perspective is often this kind of behaviour can look ‘wilful’ from a teacher's perspective, because what can happen, is that a child is often able to verbalise a plan of action and they'll say exactly what they're going to do to solve a problem.

But when it comes to actually doing it, they just don't do it, or they do something completely different.

And that's not wilful behaviour.

It's **executive functioning problems** in action and part of that can be this perseveration where they just get stuck on a loop the same thing over and over.

They can't move their thinking or problem solving on.

That extrapolated into when they are older, you can get stuck in certain patterns of unhelpful or risky or unsafe behaviour as well, or thinking or fixations that becomes, and again, sort of ASD like sort of special impress or fixation, where they are perseveratively talking about a perseveratively doing the same action over and over again, despite the consequences not being positive.

So it's this perseveration of response that they're not able to get out of without structure or specialist support from those that understand FASD to look at techniques to support or switch this to something else.

Julie: Children can get incorrectly ‘labelled’ with sexualised behaviour or fixated stealing or whatever the or ‘preservative’ hyper fixation is.

Its about understanding what perseveration is, understanding the executive functioning deficit in some of these cases where it can be a symptom of FASD.

Could you expand on some of those dangerous hyper fixations and their labelling?

Cassie: I think sexualised ‘behaviour’ is particularly tricky because once a child is labelled, it is so harmful for them.

Neil you have had a case like this recently.

Neil: Yes absolutely agree, this is very common and if not supported carefully can be very damaging.

Cassie: **Once a child is ‘labelled’ with ‘sexualised behaviour’, it's so harmful for them. And while there can be sexualised behaviour, lots of behaviour that ‘looks’ sexualised, often isn't at all, and relates more to sort of social immaturity, not really understanding social boundaries.**

Having learnt something and not really understood but needs to understand or getting quite perseverative with it and then mentioning it over and over again.

But and is very important to capture this point, it's not really sexually motivated, it's just become something of a fixation.

And it's <u>so important to unpick what's going on underneath</u> whatever that behaviour is, because more often than not in my experience, it's not really sexually motivated.

It's just become sexual adjacent, if you like, and it's interpreted by those that are not FASD trained, likes that.

Julie: Which when mentioned by professionals or those around them it fixes in their head.

Cassie: Yes, exactly this, it then leads to sort of shaming and panic responses from schools and all this sort of thing, when actually what you really want to be doing is distracting and trying to nudge that young person away from that topic onto something else more interesting.

Julie: The results can be incredible to see where we have supported several of these cases together by working with the family and the team around the child we consider what could be a good topic to 'switch' to… a safe topic. Where then this is focussed on over and over in casual conversations, posters on the wall, visits to whatever the switch topic might be etc.

Cassie: **Very important to highlight this work Julie supports, as it is absolutely this, a gamechanger, where that fixation can grow on and on if mentioned because of course, the more you go on about that 'behaviour' whatever it is, the more you can ingrain that fixation and pattern of behaviour.**

Neil: It's a developmental normal stage for lots of children to have exploration and curiosity and I think when children look older and are older, I think and they get misinterpreted through that.

And I think we project as adults our own understanding of what these 'behaviours' could mean and miss the bigger point.

Julie: Around understanding FASD 'symptoms'…. perseveration.

Neil: I think it triggers alarm bells for people when there is 'behaviour' that could be interpreted as sexualised.

Sometimes that can be for the right reasons, but sadly more times it can be for the wrong reasons and once a label is applied, it can be very hard to steer everybody back away from that and look at it.

Julie: Especially if everybody's saying, 'don't do this', 'don't do this', 'don't do this'….. it fixes.

So that switching technique helps, to try and switch to something else, be it fishing or marbles, rock climbing or some really fixated type of hobby or topic that is accessible to the young person can sometimes work.

We will come on to this again in other sessions because I think it's a really key topic to support parents.

Equally, it could be Cassie & Neil also be true of signs that children, young people or adult is being groomed or are being easily coerced, where suddenly they become the centre of attention for doing something they are asked to do, perhaps stealing or for some other criminal activity where a fixation could be 'encouraged'.

Or could be anything that that is the same as perhaps a child being absolutely fixated on trains as a young child or looking for road signs or anything they are hyper focussed on.

It's the same kind of pattern, right?

Cassie & Neil: Yes

Julie: Preservative symptoms.

Julie: We leave this topic but promise to return on our next session.

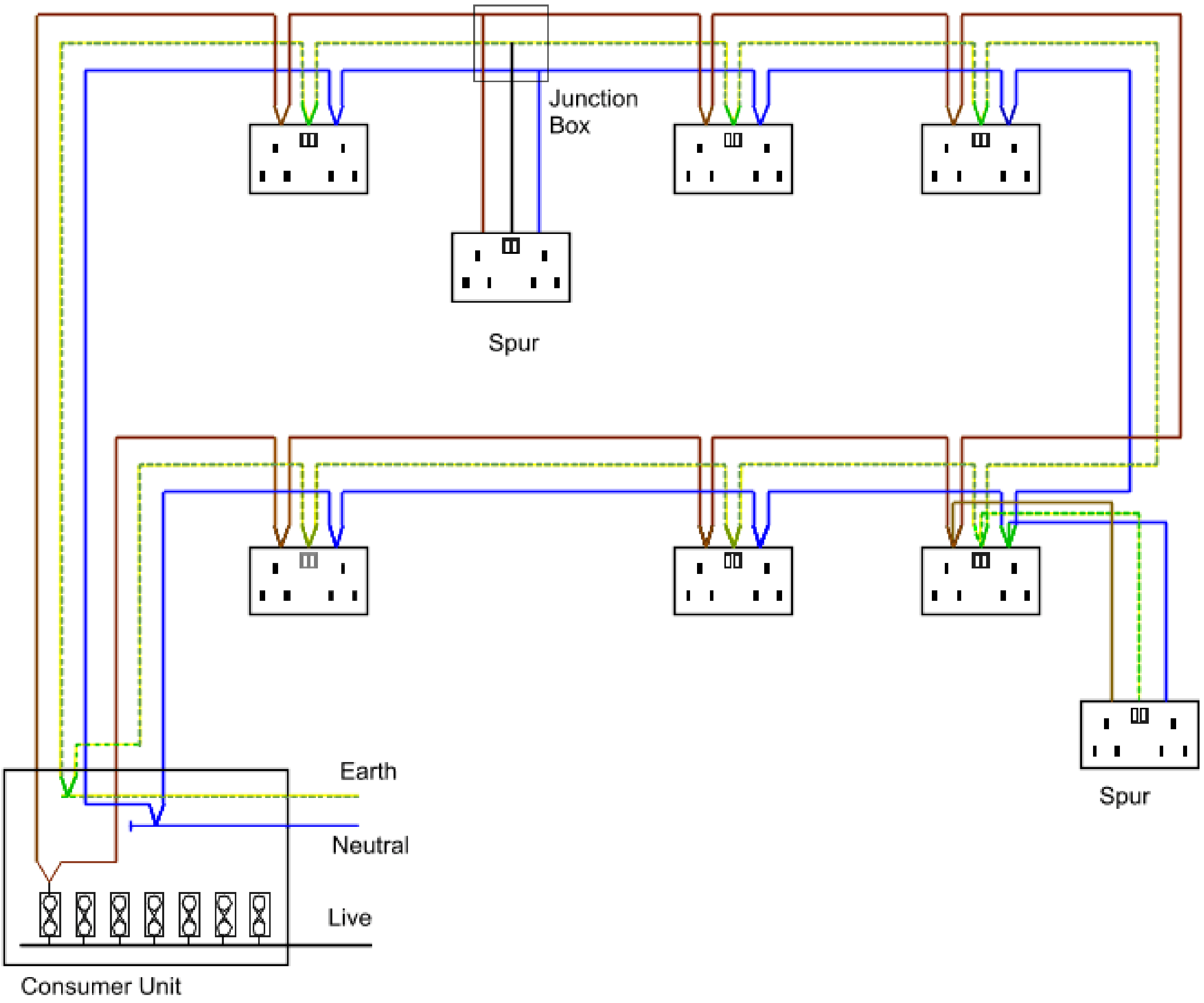
Question 14:

Julie: We touched on this subject a little earlier Neil, with regards to the difference between stimulant and non-stimulant ADHD medications and what might be effective for ADHD secondary to FASD?

Neil: Lets take the second part of the question first, so pure ADHD or 'classical' ADHD, however you want to phrase it is thought to be a '**neurotransmitter issue'**.

Whereas the ADHD that we see within FASD is often more of a '**structural wiring'** issue rather than neurotransmitter.

Neil: So think of it as the 'plug' spur's *(plug sockets)* are your 'neurotransmitters' (classic ADHD) in your wiring in your house, and then the wiring and the consumer unit (electrical circuit board) in the centre of the house is where the FASD is affected.



Neil: And if you try to medicate something that isn't related to the neurotransmitters, you are not going to necessarily see the same effect.

And that is the challenge with ADHD in a child/ young person or adult with FASD.

The effect size is often a lot smaller than we see, it is not zero, it's not that you don't try medications, but you must be pragmatic about the kind of medication you trial and keep trialling, and what the potential outcomes are going to be.

And *sometimes the choices of medication can differ.*

Supporting resource: *psychotropic drugs and FASD; medications that can support clinicians with supporting FASD with linked co-morbid conditions

For example the dexamphetamines (Dextroamphetamine is a central nervous system stimulant) were felt to be more effective than the methylphenidate variations however these may have good results with those with FASD.

Sometimes using what we would usually use as third lines(refer to the 1st, 2nd and 3rd line approach in the drug trial link previously mentioned on page 33*), and things like guanfacine (Guanfacine extended-release (long-acting) tablets (Intuniv) can be more effective because they help damp down some of this hyper arousal; however this doesn’t work for everyone.

Clinicians trialling meds have to tailor it to the child situation, so if you've got a child who's not sleeping, then some can have quite a positive impact give it a bedtime as it can have a slightly sedative effect plus helping with the ADHD symptoms.

Like I said earlier, the stimulus and nonstimulants are given in a slightly different way, and they have different side effect profiles as well.

But how you give them, this non stimulants you should be taking them every day, irrespective of what's happening, whereas stimulants you can use it just for the school week and have weekends off if you so choose, you can have it seven days a week. It's not a problem.

In terms of the actual ‘neurotransmitters’ that they work on, they're not necessarily enough difference to get hung up on with FASD and ADHD. They do have slightly different areas of effect, and they work on slightly different systems, but you're not to the point where there's enough, it's much more looking at kind of what effects you're seeing on the individual.

Medication for ADHDs, unfortunately, as much an art as a science and you have to find the solution that works for the individual rather than ‘all children’ with FASD; It's much more about what works for the family and the child.

Julie: Its all part of the clinician understanding the child better by taking part that trial, isn't it? We hear caregivers say once found it can be a showstopper result or where others say it dulls down symptoms to be manageable or more manageable with other things.

So one might suggest that actually, in taking part in a trial with a child that's got FASD, it may take longer to find that right medication and things will impact on that medication working or not working in different environments in different situations as well.

Neil: Yes exactly. Children are not just an easily quantifiable situation in all self they exist within a context, within a situation, and if behaviour comes from child's interplay between their environment and their own development.

So you can have very different response profiles to medication depending on the situation.

Julie: What does that means in the sense of side effects as well, with different meds. So it's about adapting and looking at other options?

Neil: Exactly.

So for example some children may already have a restricted diet because of sensory needs and so putting them on a type of medications that can potentially suppress their appetite even further isn't sensible. Its about looking for alternatives.

They may be very hyper aroused and their mood may be very laboured as a result. So you must be careful about which medication you choose as a result of that, and some almost get ruled out because of that, because you can inflame them a challenging mood situation with some of these medications.

So you do have to be very careful and start off often with a much lower dose and test what the side effects profiles again are, like for that particular medication before you get up to therapeutic dose levels.

But like I said, at the beginning, it can be a challenge to treat ADHD in the conventional way when you have a FASD in the mix, unfortunately, because of the differences, it's less of a neurotransmitter issue, more of a wiring, essentially diamond wiring that's happened and through the prenatal alco exposure.

Julie: So lets pause to understand what you mean there Neil.

Is it because of the way that the brain has been damaged, that they interpret that medication or the effectiveness of that medication?

Neil: Yes exactly, it’s the damage creates like an ‘ADHD like’ image, the behaviours look very similar, but they're stemming from different origins, essentially.

And so the medication will have less effect if it's more of a ‘wiring’ issue than if it's a pure ‘neurotransmitter’ issue.

Question 15 in chat: a parent has just mentioned there that for some clinicians that are not experienced in FASD, is there a source of information with regards to trials that have been supporting FASD, so you wouldn't necessarily need to see a clinician that was an experienced clinician in FASD?

Julie: Is it about considering the range of medication?

Is it about understanding the range within that clinical trial.

Supporting resource: *psychotropic drugs and FASD; medications that can support clinicians with supporting FASD with linked co-morbid conditions

Neil: Absolutely. I think clinicians can get quite stuck on what they know as work before with a hundred other children, but sometimes you have to think outside of that box and seeing new information coming in and be steered as a clinician, it's important not to not listen to families. I mean we were talking about the beginning the importance of listening to the caregiver, the expert in their child, because we (clinicians) don't know everything about that child.

We have seen lots of situations, sure, but sometimes you have to look at a situation afresh and try different kind of medication, different steps that you wouldn't usually experience as a clinician, and some are flexible to that kind of change of that, and some are less so.

Julie: And also, it's worth mentioning that, there are so many families that have benefitted hugely. It's been an absolute game changer and we hear about it in our group all the time, the showstopper.

There is an anxiety about trialling medication, just because it's your child, isn't it? You don't want your child to be medicated, but sometimes, again, it can it can change everything.

Cassie: Its fair to say that what tends to happen with the medication is that with FASD, it's better managing the impulsivity and hyperactivity symptoms, but the inattention seems to be a bit more stubborn to treat. Is that fair?

Neil: Yes agreed, that you seem to be a little bit more hardwired in the inattention less responsive.

Cassie: It can be for children in terms of damping down the hyperactivity it can be huge in making a difference to their education and accessing that, and also at home, including reducing some of those ‘risky’ behaviours if they are led by impulsivity.

Julie: And just being still in your own body.

For some children that have got FASD and ADHD, they just cannot keep a sense of still.

So being able to go to a table for an activity is just not possible. So if you've got one part of that, then potentially, that eases the other side of things.

Neil: Yes very much so.

Question 16: My child is constantly unwell. Why might this be, and how could we support the immune system?

You get different infection profiles over at different ages, and so it depends on the environment the child is exposed to.

So often we see the preschool years being a third of the time unwell, a third of the time they're recovering, and a third of the time they're healthier at some point. And that's normal to have that profile.

The challenge with children with FASD, because of their **high cortisol levels** and the hyperarousal that we often see

Cortisol does dampen down your immune system, it stops it working as efficiently as it should.

We can all have those experiences where you suddenly become unwell for months because you've had a lot of stress at work as a crude metaphor.

But the cortisol unfortunately, is useful in the short term, but our bodies are not designed to have higher levels for extended periods of time.

And it does affect the ability to fight off infections.

Nutrition is also an important factor with how you respond to infections and children sometimes don't have the best eating choices due to sensory based issues or other eating disorders.

So supporting some of the basics in a healthy diet is really important in trying to manage children's infections, but also really difficult if your child is very picky or particular with food.

So making sure their diets are as optimised as possible.

Multivitamins, if you can get them to take them.

Trying to optimise sleep, getting some exercise, can all be quite helpful in that regard.

You do have to be careful that you're not ignoring some illnesses because they are getting lots. If you are getting infections that are land you up in hospital, for extended periods of time, you're getting boils or ulcers or you're not growing very well.

That can be a sign that is something more fundamentally different about a child's immune system, that might need exploring, but if we're talking about recurrent tonsillitis, recurrent ear infections, then those are expected infections to a degree, and the numbers of infections that you should you expect is not terribly helpful, I think, it's more about optimising the situation around the child.

Unfortunately, because infections are common, and we don't like to have them, we don't like our children to have them, there are products out there that suggest that they can help in this regard and I personally would suggest that you'd steer away from those, they can be costly. There's the evidence based for them is often poor.

Julie: Are you talking about these nutritious of liquid drinks.

Neil: There can be lots. I mean, some things are however a better than others.

Julie: Probiotic?

Neil: Yes, these kind of things.

It about making sure you've got the right vitamins on board, that other type of thing can suggest that they can boost your immune system in all themselves and often that's a little bit of pan of marketing rather than science behind it, and you have to be a little bit careful.

It's human nature to try and fill a vacuum or find a solution if you are struggling with infections, you want to try everything you can.

But you don't want to go down a path that's going to cost you lots of money and I am sure it will get very far.

Julie: But understanding that first part that you talked about the cortisol levels, that that is something that we don't talk a lot in the FASD community. Perhaps we just don't know about it enough so that does make sense when you consider that the way that the brain is damaged in that way.

Neil: We have to have a certain amount of cortisol, it’s rare for an individual to have cortisol levels that are measurably aberrant (*not acceptable or a usual standard*).

Some conditions, you can have very high, very low levels of cortisol, your GP may want to check those at certain times a day to see those kind of numbers are different.

But what I am talking about here is a more sub clinical change to the cortisol levels that are still important because we are not designed to have high cortisol levels persistently.

But it has to be considered within that frame (*is common to)* of FASD because we know that the HBA Axis is so affected compared to average.

Julie: For those that don't know about the HBA Axis, we ran a previous session on this topic and have linked here to our ‘Ask the Expert’ event notes in our resources.

Thank you, Neil that's really, important and helpful, it makes me think about if a parent is concerned with multiple illnesses that they feel are being overlooked, to ask for a screening blood test.

It might be iron levels, where the child's very sleepy or diabetes where the GP might miss the obvious due to all of the other conditions.

Indeed, don’t dismiss, you know your child, if a child's is suddenly very sleepy or the child’s very overactive, all those kind of similar traits, whereas again, *don't dismiss the cluster of symptoms*, I think we' probably be good practice to consider.

And as you said, it is normalised in the world of FASD to have lots of throat infections and other conditions listed above. But when things are ‘different’, that's important to get medical advice.

Neil: Absolutely, we have mentioned this several times and this is something we cannot mention enough of where there is a danger of **‘diagnostic overshadowing’** (*when a healthcare professional assumes that a patient's complaint is due to their* *disability or coexisting mental health condition rather than fully exploring the cause of the patient's symptoms*)…… that you have come to a situation, you have explored a situation and through us, you've got a certain presumption as to what the issue might be, but it could blind you to looking for other conditions.

That might be just as common and you can miss those, whether it be Autism getting overlooked, whether it be infections getting overlooked and indeed low iron levels, it can affect all areas.

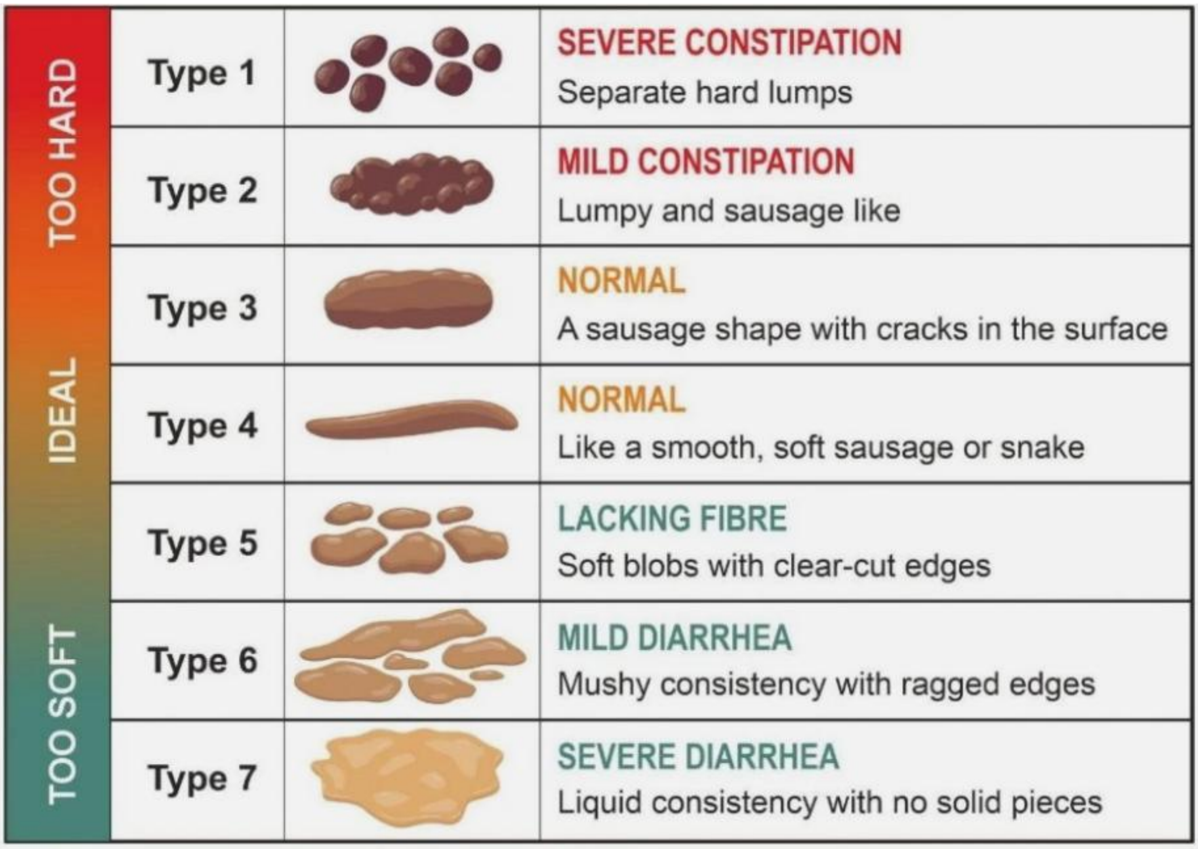
Important to try and take a step back when you are a clinician, or a parent or otherwise to look at the whole situation, to really understand it.

It's easier said than done sometimes when you're in the middle of life.

But there is a risk of overshadowing, absolutely. Julie: Thank you.

Question 16: Why might a child with FASD have chronic constipation?

Many of the children in our community have this. How do you manage constipation from a medical perspective?



TOO HARD	Type 1	SEVERE CONSTIPATION Separate hard lumps
	Type 2	MILD CONSTIPATION Lumpy and sausage like
IDEAL	Type 3	NORMAL A sausage shape with cracks in the surface
	Type 4	NORMAL Like a smooth, soft sausage or snake
TOO SOFT	Type 5	LACKING FIBRE Soft blobs with clear-cut edges
	Type 6	MILD DIARRHEA Mushy consistency with ragged edges
	Type 7	SEVERE DIARRHEA Liquid consistency with no solid pieces

Adapted from Bristol Pooh Scale

Resource: How can I prevent my child from becoming constipated?

- Make sure they have at least 6-8 water based drinks every day
- Include where possible fruit and vegetables in their diet
- Encourage them to follow a regular toilet routine: sitting on the toilet or potty after every meal and using a footstool to support their feet in a more upright knees position
- Blow on a windmill whilst on the toilet or blow bubbles; this can relax and contract muscles
- Give them plenty of opportunities to exercise and move around

So to consider this let's look at what is constipation.

ERIC the Bladder & Bowel Charity define common constipation symptoms in children as:

- Doing fewer than 4 poos in a week. Ideally, children should pass some soft poo every day, or at least every other day.
- Pooing more than 3 times a day. This can show that their bowel is full, and poo is being passed a bit at a time.
- Soiling – in other words leaking poo. It might be hard bits of poo, soft or even liquid poo called overflow.
- Poo that looks like little pellets or rabbit droppings.
- Big poos, or lots of poo all at once.
- Pain when they poo and needing to strain. There may even be some bleeding when they poo or afterwards. Hard, large poos can cause an 'anal fissure' or small tear in the bottom.
- Having a swollen, painful tummy. They might not feel like eating, or even feel sick.
- Smelly poo, wind, and bad breath.
- Bladder problems such as doing lots of small wees, needing to wee urgently, bedwetting and urinary tract infections.
- Difficulty with potty training including children who refuse to poo unless they are wearing a nappy.

Neil: In complex conditions often the pattern of going to the toilet can be interrupted for many reasons.

Constipation is common in children whether you are looking at the FASD population or more generally, lots of children do have an element of constipation over their years, however children can get into a vicious cycle quite quickly with constipation.

Children who forget or are not reminded to drink at School to drink and/or are poor eaters (lack of fibre).

Children who hold where the pooh backs up.

Children who have poor muscle tone, saggy bowels from previous chronic constipation.

Some medications or vitamin supplements.

Children suddenly have harder stools, it's uncomfortable to go, the child withholds, as a result, doesn't go as often as they probably should do, it then becomes harder and so on and so forth.

So it is a normal variant to have a degree of constipation, but children with FASD are thought to be more vulnerable differences that we see, so your gut has a certain set of **neurons within it that control how it works.**

How stalls (*poo)* is moved within the gut, and that is thought not to work as effectively in FASD.

Children can have low tones so they can find it harder, literally harder to open their bowels. You have to exert a certain amount of pressure within your bowel to open it, especially if you're constipated.

Julie: If you can't feel it due to sensory needs and lack of body tone?

Neil: Yes and that's common for lots of children with FASD to have that difficulty understanding whether you're full or not because the neurons get stretched and essentially don't understand and I'm not able to give the body the right signal to say that you are absolutely full up and you need to go.

So there's a behavioural overlay, there's a physical overlay.

Sometimes diet doesn't help if you're on a low fibre diet.

Sometimes constipation can be a voluntary, there is a behavioural aspect to constipation that children sometimes will hold. It can be one of the things that children can fixate on. And it can become a problem.

This can be the perseverance where if we talk about it a lot it fixates or people talk about it in front of the child, they hide it or they might feel shame.

Clinically you need to look at all of those different areas as well as thinking about medication, so you can't jump in with just the medication, it is not going to often solve the situation on its own.

Julie: Particularly if you are demand avoidant, so if somebody's saying, you must go to the toilet, that hyper-fixation kicks in.

Neil: Yes, and it's something you can control, essentially, as a child.

Sometimes there's not a lot a child can control.

Children are. They don't have a lot of agency, and sometimes these are things that they can focus on and control, but more of a subconscious level often, rather than they are making a conscious decision to do this, but they can come to that decision quite quickly, unfortunately and it can stick in their head.

Cassie: Sometimes unintentionally parents start visually being worried and panicking, where children are hypervigilant.

Psychologically attention can come around you, very, very quickly and so it become a thing.

Julie: Yes. So what would you suggest then, if that's started to become more of a pattern, to go to the GP first?

Resource: Pooh Diary downloadable here

- Write down every poo that is passed, even if it is a little stain in the child's pants.
- In the Type column, write down the number from the Bristol Stool Chart that best describes the poo (see below).
- Fill in the diary for a whole week, or longer if your doctor or nurse asks for it.
- At the end of every day, check to make sure no poos were forgotten. Write in whatever laxatives have been taken that day, including the dose.
- Record the amounts of stool passed as small/medium/large etc.
- In the Comments column, write down anything you think may be helpful, such as if your child had tummy pain or was sick.

Neil: Yes your GP can be the start. Start discretely by tracking going to the toilet, what comes out, what goes in.

Medication can make a huge difference and softening up the stool (*pooh),* making stools happen more regularly, having some positive experiences, can an enormous difference to breaking that cycle that we spoke about at the beginning.

There are different laxatives that you can use and a lot of the time we will default to what we call the Macrogol's so for example CosmoCol is a laxative for constipation and faecal impaction. It contains Macrogol, which softens stools, and provides electrolytes to maintain body levels. They are powders that you make up into a drink, and take that way rather than the kind of a syringe of medication.

Sometimes you need to use stimulants like Senokot (syrup or tablet).

Sodium Picosulfate is a stimulant laxative. after metabolism in the colon it stimulates the mucosa thereby increasing the motility of the large intestine which clinicians generally don't go straight to but it is helpful combination approach for chronic compaction

Macrogol is used a lot.

Julie: But tricky if your child isn't drinking

Neil: Yes where there might be a different route to take in the Senokot and Sodium Picosulfate.

Sometimes parents have to be quite creative as to how to get the medication in, because they do have a certain amount to work. I have heard of families putting it yoghurts, into lollipops.

As long as the medication's going in it often doesn't make a lot of difference how it goes in.

I think the manufacturers might suggest otherwise, but it is all going to the same gut at the end of the day.

The volume of water intake is an important one as much as making sure you've got enough fibre on board.

But the Macrogol helped soften the stool, you cant get addicted to them, it doesn't damage how the body understands how to open its valves.

It's they stay within the bowel wall and don't get absorbed into your body, so they're not harmful in that sort of sense.

And they can be extremely useful. And the nice thing about them, you can titrate them up and down, depending on what output you're getting. So some medications, you take a certain dose every day and you don't change it and your doctor might suggest a change.

But with these, you can some people can be very sensitive. Some people need much bigger doses and you essentially can titrate (liquid levels increase amount used) the dose that you're using depending on what you're seeing, and finding out what your happy medium may be. As an individual rather than a strict protocol of you need to take two on this day, four and then six on this day.

Because we are all individual with our bowels. There's a huge ‘range of normal’ within how our sometimes you open bowels. Some people, it's twice a day, some people, it's once a week. Neither of those are wrong.

Julie: Yes, absolutely. I think that also it's worth considering too because of the support factor that's needed over a long period of time for continence needs or chronic continence in FASD, is to get help, to go to the GP or to get a referral or self refer to the **Continence Service team** or in some areas known as the **Bladder and Bowel Service**.

It should not be underestimated however how hard this is to support as many children can dig out their pooh, smear it everywhere and hold it in until it leaks our foul smelling fluid and we also hear of how normal it is for children to deposit it in various places of the house or when it comes out it comes out so there is no warning and it can be horse pooh size where for many they cannot feel it.

We also know from our families that Sensory Integration Occupational Therapy can help to get things moving, this point that was made earlier around the significant sensory needs where essentially this helps support this central nervous system damage.

Many children who are holding stools are fearful of moving, often with the movement comes the relaxation of those muscles that are keeping those stools there. This often needs support from a multi-disciplinary team but there are some forms of helpful support from ERIC

Resource: With kind permission of ERIC the Bladder & Bowel Charity

Downloadable document for Schools found here: Individual health care plan;

It is advised that an Individual Health Care Plan (or IHCP) is completed for all pupils who have continence difficulties that affect their school day.

This should be a discrete plan to avoid shaming a child or to cause any form of fixation.

Question 18: What are your thoughts on cranial osteopathy for FASD if retained or primitive flexes are suggested is that possible with FASD?

Neil: I think the challenge with both of those is that the evidence base is not terribly robust.

Unfortunately, some conditions get some therapy funding, to explore research more and others. And both of these haven't had a terribly consistent or controlled way of exploring the evidence base and behind them.

We would not routinely recommend osteopathy or children to receive management of retained reflexes.

In certain conditions, you can see ‘retained reflexes’, but sometimes it gets perhaps the term gets a little overused and you have to be a little bit careful when you are seeing clinicians who maybe in the private sector often will be using this kind of phrasing more than those within the NHS.

I am not saying the NHS is the only way to look at conditions, because that's obviously not the case, but it's the evidence base is quite thin for those two areas.

I think if it's found to be helpful, and you're happy to persist with it, then there's very little harm is going to come from there apart from perhaps the cost that's going to be incurred, because like I said, you're not going to get these on the NHS.

But it's in terms of recommendations, it would be very unusual to access this outside of the private sector.

Question 19: What are the most likely conditions to look out for in co-occurring conditions with FASD?

Cassie: We discussed earlier ADHD and Autism; recent studies have found **86% of children with FASD will also have ADHD.**

70% when it comes to Autism Spectrum Disorder (ASD).

So for example, if you come to our clinic, for an assessment of FASD we also include ADHD & Autism, in addition to neuropsychological assessment with the speech language assessment.

Speech and language problems, are very common although presentation with highly expressive language can camouflage needs.

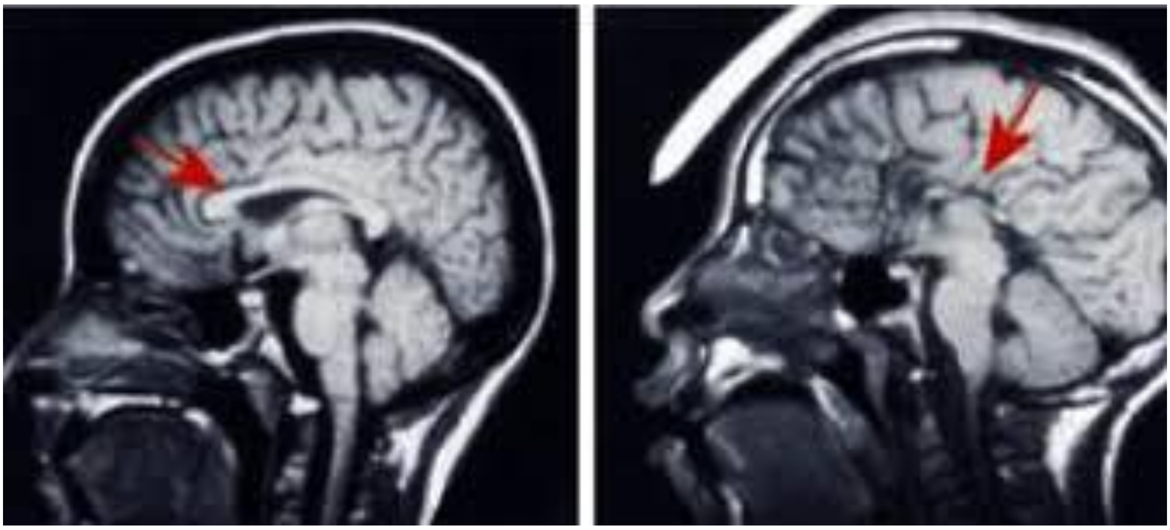
Interestingly, a lot of the speech and language needs we often talk about is there being a discrepancy between expressive language and receptive language.

It's not just about receptive language difficulties, it's the **functional use of language socially**.

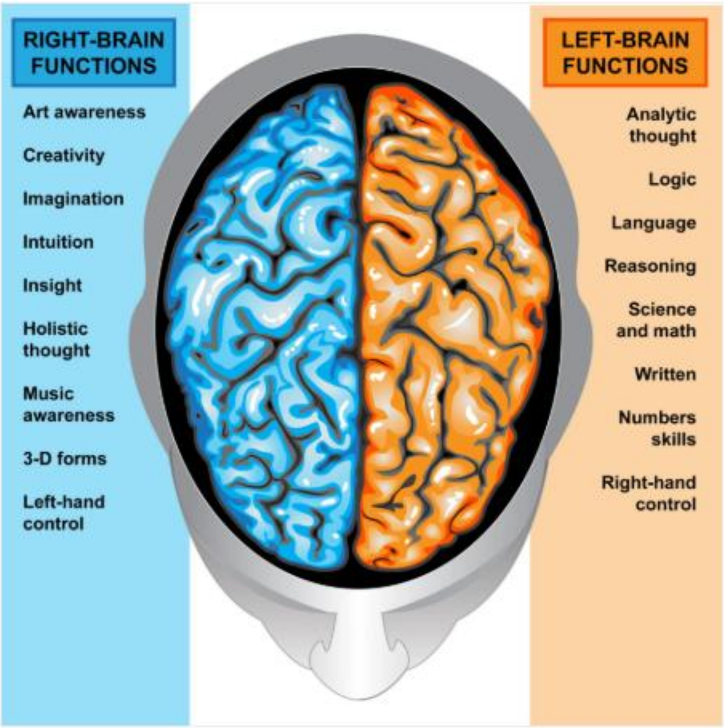
A lot of challenges with FASD is auditory processing problems; so again, when you think about the parts of the brain that are damaged through alcohol exposure, a lot of the areas damage are the central areas of the brain, while the lateral areas are relatively spare.

The prefrontal cortex, and the corpus colosseum; the nerve bundle of fibres that connects the two hemispheres of the brain that is often implicated as being thinner in those with FASD.

Corpus Callosum: The corpus callosum is a bundle of nerve fibers that allow your brain's left and right hemispheres to communicate. It plays a role in how you think, remember and coordinate your movements.



FASD is a disorder of connectivity; that's the best word of describing it.



Left Hemisphere: Processes language (including grammar and vocabulary), handles math and logic, and controls the right side of the body. It includes Broca's area, which manages speech production, and 'Wernicke's area', which supports language comprehension.

Right Hemisphere: Specialises in spatial awareness, facial recognition, emotional processing, and controls the left side of the body. It is also more active in interpreting negative emotions and visualizing complex patterns.

Cassie: So rather than often looking structurally abnormal it is the connections between brain regions and across hemispheres that is the problem.

Any tasks or any functions that required by hemispherical functioning, they are the ones that are going to be implicated in FASD brain damage.

So that's why you have your executive functional problems, your social cognition problems.

Julie: To pause there, to interpret what you have said relevant to the Speech and Language part of the question, for clarity please Cassie

Is that sometimes because of those with FASD who have highly advanced expressive language, that the speech and language might be overlooked 'as an important need?'

Cassie: Yes exactly this, so often classically missed.

We use standardised tests like CELF, for example, which is a **Clinical Evaluation of Language Fundamentals**, that looks core language skills expressive, perceptive language.

Some more able children will come out with reasonable scores in some of those, but the problem is the auditory processing, the processing of speech and language, and how the understanding of that.

This complex, higher order language processing, including the social processing of language and the social use of language, which are the bits that are tricky.

So it's not a co-occurring condition as such, but it's a component of the FASD, which really, really impacts all functioning.

And that's why it's really important to get that speech and language and auditory processing considered by an FASD informed specialist, to understanding of all through 'auditory processing' as a component of that understanding of why a child and FASD struggles with processing issues, because the processing is a component of the disorder connectivity in FASD.

Julie: In order to get that, I think it's really important for families to understand, because quite often that there is not a service, which has this level of training within the NHS.

But what is possible is to request that this is required through your child's EHCP as it is a specific need to support FASD

So if you've got Prenatal Alcohol Exposure, likely FASD or an FASD diagnosis where it's been identified that you have got high functioning expressive language, where to the non FASD informed case manager/clinician they might suggest that the child has got good language skills, but what you are saying here Cassie very clearly is because of the processing, because of the auditory needs that needs should to be considered in a very, very specialist way within the speech and language assessment, particularly to have that higher level understanding of what's going on a specialist assessment is required.

It is that which should be considered through the EHCP process.

Cassie: It is being able to analyse the results of this holistically, alongside the broader neuropsychological profile that tells us that this is what's going on.

These are the processing issues that are going on.

Julie: In order to have that collective look at the whole child, you need to have that level of specialism as well.

Cassie: That's the issue where children get kind of looked at in silos and different symptoms, for different clinicians. And then what happens is they end up either with a collection of unconnected diagnoses or they don't get anything much because they' not understood as a whole child and what's the overriding aetiology (*the cause, set of causes, or manner of causation of a condition)* behind all of these different things?

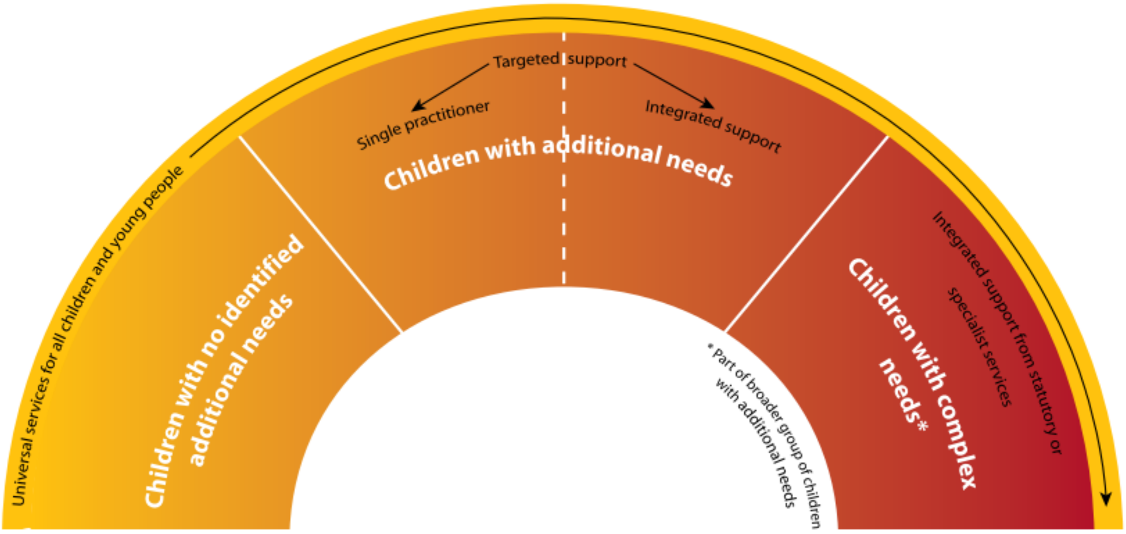
Julie: I like the way that Charlotte has summarised this point.

'They're fantastic with words but not able to communicate the need via the language'.

Cassie: Yes, the use of language?

And that's part of adaptive behaviour. That's all part the adaptive functioning difficulties that those with FASD have.

Question: So finally, about understanding the services that can support FASD.



Resource Source: **T**eam **A**round the **C**hild (**TAC**) for Complex needs

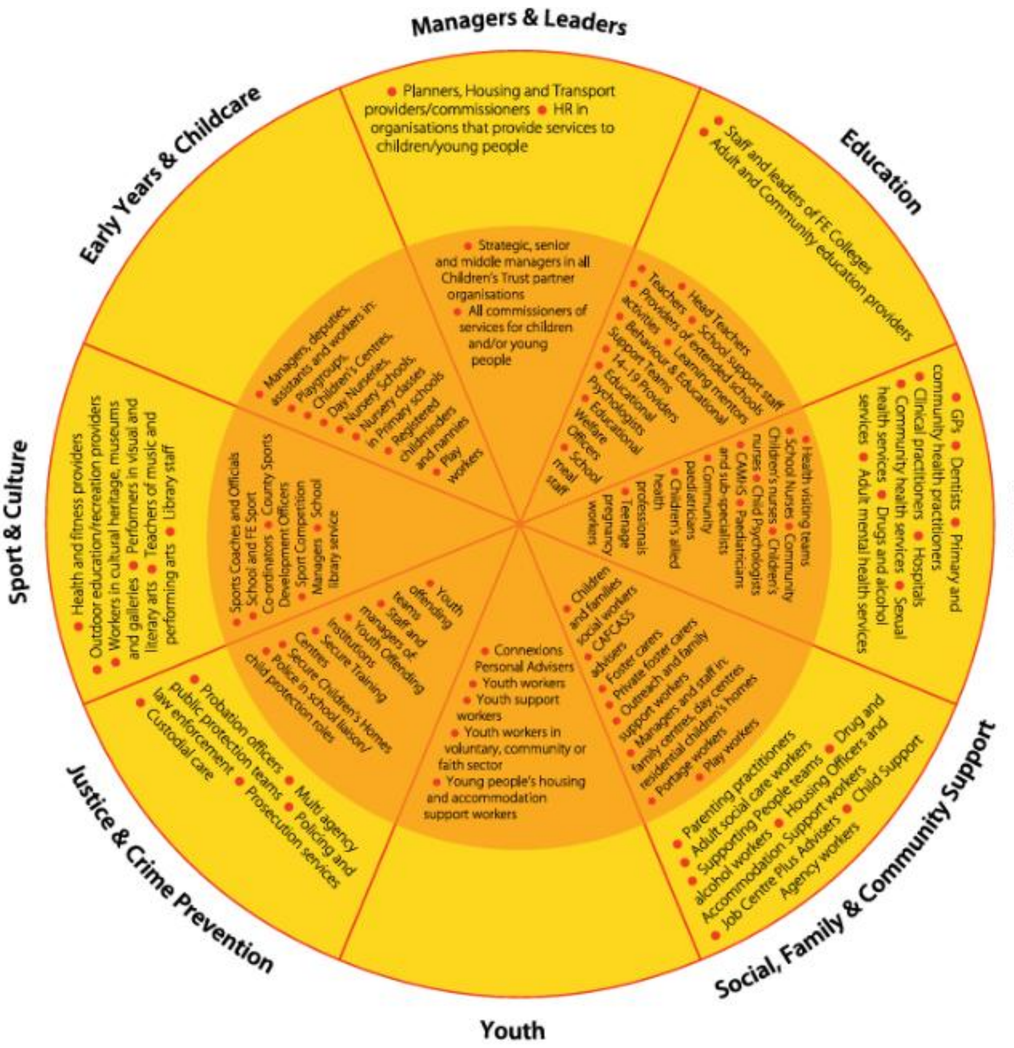
Julie: We had a question that we skipped over in order to understand and unpick the needs of children. We can't obviously consider individual cases, but what we do know is that knowing what your rights are really help with regards to team around the family, team around the child.

You can request a Team Around the Child (TAC) meeting through your school, through social care, or in fact through any professional or advocate to lead on.

To co-ordinate and pull in an experienced team where depending on the needs or the child/young persons stage/age that might include people like speech and language, social worker, post adoption, youth worker, family therapist, SENCO, enabler/personal carer, teacher, TA, Sensory Integration OT, learning disability team member, other lead specialists involved for a view.

It really depends what the topic that the Team around the Child were considering so the team could be flexible to invite other wider members of a professional network, so for example if the young person was transitioning to adulthood it would be good practice to invite supported living, housing etc. It should not be restrictive as the guidance for professionals around a Team Around the Child supports a strong team to make decisions and act responsively.

Children and young people’s workforce:



Source: This diagram has been provided by the Department for Children, Schools and Families

Question 20: Who else would you consider really helpful in that consideration of supporting the child?

Cassie: Ideally if the child was part of a Specialist School then these therapists would all be part of that Team Around the Child, as this would be embedded as part of their weekly and ongoing curriculum.

You would want to see in both mainstream and specialist that there was a sensory timetable to consider the sensory needs and breaks for a child with FASD.

If you are in a mainstream setting you will need to invite those specialists in including FASD leads for your local area.

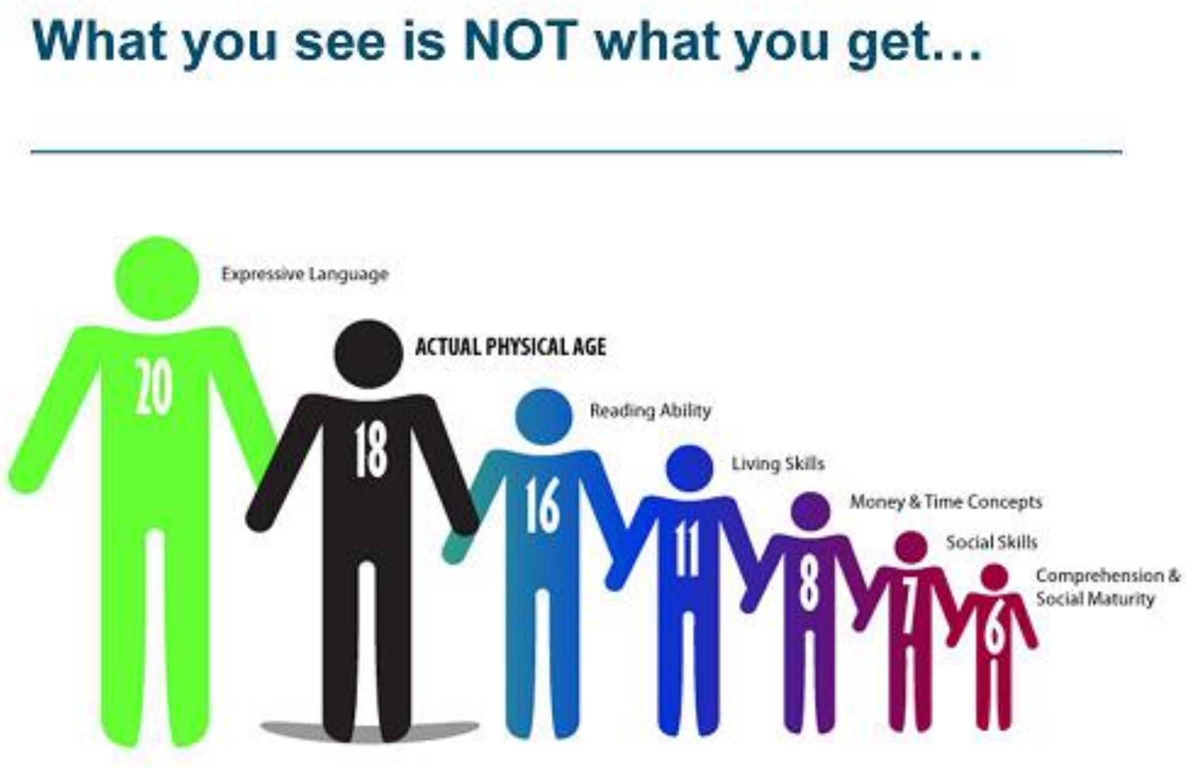
A lead therapist or at the very least if there is not a named person then someone who can identify who is supporting the speech and language/auditory processing needs input every week; giving an oversight.

Someone who will remind the room that these are the things to work on, these are the difficulties. These are the best strategies to overcome & scaffold around those difficulties.

For some the learning disability team, particularly for adults or transitioning to adults social care.

That's where the concept of intellectual disability equivalent is really important in terms of understanding that just because a childhood with FASD has an near to normal IQ, it doesn't mean that functioning at that level.

Children with FASD can be developmentally half their chronological age or much less.



We know that FASD creates the most severe functional impairment over every other neurodevelopmental disorder aside from intellectual disability.

And we call it 'intellectual disability equivalent' because generally speaking, the functioning of a child with FASD is two standard deviations below where their IQ is.

And that's why it's really important to be firm as the clinical evidence is there to support this and argues the point that that a child or a young person, has the right to have that service or have input from that service.

The other thing, of course, is support from education, support from an EHCP where the EHCP is really tailored to the child or young person.

It almost needs to be a textbook about FASD because lots of people picking it up won't know what FASD is and won't really understand about it.

So you really need to almost have an introduction to what FASD is before you read and draw down into your child and their specific needs.

Julie: To clarify this point Cassie, to do that, many families that are listening and reading who might have just applied for an EHCP or are having an annual or interim review can legally use their EHCP '**parents' voice'** section to include these words.

What you write in that section is what you want heard, what you want considered by all who support your child and all whom abide by the statutory framework to deliver it.

If you write a parents' voice these words legally have to stay in there, it has to be included. Not as an appendices, as the Local Authority will not include lots of attachments about FASD or other conditions; unless they are clinical reports about your child.

So as way of an example if you included something like…

Dear Education and Support Professionals,

I am writing to you regarding the vital importance of understanding the impact that Fetal Alcohol Spectrum Disorder (FASD) has on my child, who lives each day with the effects of irreversible brain damage caused by prenatal alcohol exposure. It is absolutely essential that all staff supporting my child receive robust FASD Informed training. Only with this foundation can assumptions be avoided, risks and vulnerabilities be truly understood, and meaningful support be provided.

My child may often appear to have understood what has been communicated, but due to very slow processing speed, this is rarely the case in reality. When asking questions or giving instructions, it is extremely important to use short, simple sentences and to allow around 20 seconds for a response.

Please do not rephrase the same sentence, as this can cause confusion—my child may begin to process multiple instructions at once, which blocks true understanding. A nod or verbal affirmation does not necessarily mean my child has understood; I kindly ask you to check comprehension by repeating the question in the same way or by gently probing their understanding.

My child thrives when communication is slow, direct, and free from hidden meanings or sarcasm. They are highly suggestible and, as a result, are vulnerable to coercion. High levels of supervision are needed, especially when making friends, to ensure relationships are safe and genuinely supportive.

Due to brain damage, my child's developmental age is much younger than their chronological age, so I ask that the curriculum be adapted using FASD strategies and techniques suitable for a younger child.

It is my heartfelt wish that my child's voice is heard, that their strengths are recognised, nurtured, and celebrated.

By fostering a sense of achievement and self-worth, you can help my child discover their own superpowers and abilities. Social development is also crucial; I encourage you to help my child make and maintain friendships with peers who are at a similar developmental stage, and to promote inclusive clubs and activities that reflect this need.

My child's life journey is deeply personal. I ask that I am the one to discuss their diagnosis and care needs, as our family has received specialist training to do so. Please avoid any accidental or overheard conversations about their complex needs.

We are guided by FASD specialists to use the appropriate language for auditory processing deficits, and I request that this practice is respected by everyone involved in supporting my child.

To ensure best outcomes, I urge that all professionals receive 'FASD Informed' Stage 4 training, in alignment with the NICE Quality Standards for FASD.

Transparency and responsiveness are critical as my child transitions through school, college, alternative provision, or supported internships. Regular Team Around the Child meetings should be held to discuss challenges and celebrate successes.

My child may sometimes say 'yes' simply to please, blend in, or minimise their own confusion or discomfort. Their compliance and risk should be continually assessed, using preferred FASD-informed strategies, to safeguard their wellbeing.

My child may also confabulate—making up stories without realising, or filling gaps in memory. This is a result of brain injury, not dishonesty, and I ask that staff respond with understanding, never shame.

Regular sensory integration occupational therapy is needed to address central and peripheral nervous system damage, with sensory regulation techniques embedded into a weekly timetable.

I also request a formal speech and language assessment from an FASD-informed therapist, with attention given to higher order processing and the social use of language, which currently affects my child's ability to build and maintain friendships.

As Consultant Clinical Psychologist Dr Cassie Jackson has advised:

“FASD is the most severe of the neurodevelopmental disorders in terms of its far-reaching impact on functioning across the lifespan, and requires a unique approach to support and understanding.

Those who are not appropriately trained or knowledgeable can often make assumptions due to the fact that many individuals with FASD can superficially present as more able than they actually are or where their ‘symptoms’ are misinterpreted as ‘behaviour’ due to spiky cognitive and neurodevelopmental profile.

There is also often the assumption that symptoms of FASD will improve over time, or a child will outgrow their emotion regulation challenges or poor adaptive functioning for example, when unfortunately, the opposite is true; the developmental gap continues to widen and diverge away from the norm over the course of childhood. This necessitates increased, rather than decreased, need for support and services. FASD must be understood as an enduring brain injury, similar to any other acquired brain injury.”

Your understanding, dedication, and commitment to FASD-informed support are vital to my child’s wellbeing and future.

Thank you for your continued partnership.

Yours sincerely,

[Parent/Carer Name]

Julie: It is important to educate and support the staff or specialists around your child where you are the specialist in your child’s needs.

You can of course request training where we recommend the

FASD Informed Stage 4 Early Years Foundation

FASD Informed Stage 4 training for Schools

FASD Informed Stage 4 training for Specialist Schools

FASD Informed Stage 4 training for Alternative Provision

FASD Informed Stage 4 training Post 16

FASD Informed Stage 4 Multi-disciplinary team

FASD Informed Transition Support

We also have a wide selection of other courses HERE

Critically in summary you have a carer/ parent voice every time you have an annual review.

Cassie: Make sure you name ‘Irreparable brain damage caused through Prenatal Alcohol, Fetal Alcohol Spectrum Disorder FASD, so that you have a strong and hard-hitting robust report.

When that team around you start being curious and starting to want to know more' where you push in every Team around the Child meeting with helpful ways of explaining what you know, what an FASD is and what the impact is and all that.

That's really, really important.

And then the part is the post adoption or kinship team where the Adoption & Special Guardianship can commission some therapies like the Sensor Integration Therapy, in some areas FASD Informed Therapeutic Parenting and other therapists. It's just really important that they do have FASD, they understand through the FASD lens, first and foremost, over trauma because the FASD informs everything else.

Great, thank you Cassie, I am just going back to a couple of questions from parents in our chat.

Question 21 from the audience:

Is stammering a common occurrence with FASD?

Cassie: It is a processing problem as much as anything else in addition to the speech and language challenges.

So, it's going to be more common in many neurodevelopmental conditions where it is certainly not unusual.

Neil: Its often a mismatch between what children, young people or adults are able to think and do. There is a developmental element to stammering as well where the ability literally control their mouths doesn't automatically equate to what their brain is asking it to output.

So sometimes you might see this mismatch, which is a developmental stage that a child or young person might go through. But yes, there is obviously a processing element to it as well.

A child or young person can get stuck in loops of trying to say things in a circular way.

It's how to manage the stammering is not that different if you've got FASD.

The support is needed in similar ways.

Julie: Slowing everything down because of the processing speed?

Neil, Yes, not speaking for them, not trying to fill in for them.

It can be tricky as you need to learn to step back.

It doesn't help with self-esteem if you help with words, if you are constantly having somebody speaking for you it's trying to be as patient as you can be.

Julie: And that brings us nicely to the beginning of our session, where that statement I read out from the family where they felt empowered by having a silent pause, to give people permission to wait for that child to respond, to just wait.

And so that can be quite often up to 20 seconds or more with some children, depend again on the environment and all the other things that are coming in to filter out noise.

But critically to not ask that question after 20 seconds in any other way.

To phrase it exactly in the same way, otherwise they might think they're answering another question.

If the first question is changed in any way, then they may start processing the first question and then start trying to find pathways to process the other question.

For more resources and access to our previous Ask the Expert Events please click into our resources pages at FASD Informed UK

Thank you all for supporting our evening where we look forward to the next!