

**FASD
Friends**

'Ask the Expert' Event notes: 29th April 2024

Guest Speakers: Julie Furney Director of FASD & Dr Cassie Jackson Clinical Psychologist & FASD Expert Witness

Question 1. How do we enforce boundaries at teenager stage?

My son desperately needs boundaries to feel safe but he is pushing and breaking every single one we put in place despite discussion.

We always do natural consequences rather than enforced ones, he has no understanding of cause and effect and no regard for things so we don't remove them.

The only thing we could put in place is removal of after school sessions and fun things but it is essential we keep those in place at the moment.

Cassie: You are right not to remove fun or regulating things especially as if taking those things away will make things worse, there will be no learning from it so it is pointless and will only make everyone miserable so don't do that.

There is no magic solution only to be really, really consistent. Remember to keep your expectations in line with what we know about FASD, ie that we know they will make the same mistakes over and over, that in the moment when calm they are able to take on board and listen to the rules and what the boundaries are and agree to them but will then do the same thing again tomorrow.

You need to be able to redirect and keep repeating so that they can re-learn the same thing over and over and consistency is key.

Remember that this will be harder with FASD and adding in regulation, its really tricky.

©All rights reserved
FASD Hub South West
web: www.fasdsouthwest.org
FASD Informed Education UK
web: www.fasdinformed.co.uk

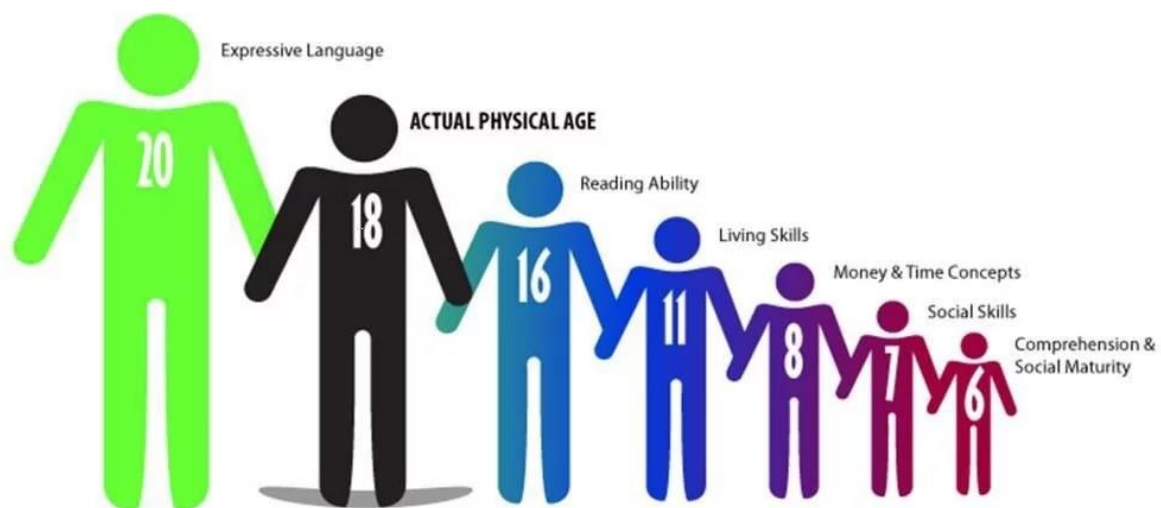
Ask us about our training for carers/parents, professionals, education: info@fasdinformed.co.uk

FASD
Informed:
UK

Natural consequences are good but needs repetition of the same consequence each time, there will be no learning after 1 or 2 times, they will be stuck at a certain stage longer than a neurotypical child.

Remember the half the age rule for social emotional development so if they are 14 they will be socially and emotionally age 7 developmentally/behaviour wise and so therefore you should aim the learning/teaching at that level.

What you see is NOT what you get...



Julie asked how do you put in boundaries when they can lead to child to parent violence?

Cassie: prevention won't stop all escalation either so it is important to put the boundaries in before they start to escalate.

©All rights reserved
FASD Hub South West
web: www.fasdsouthwest.org
FASD Informed Education UK
web: www.fasdinformed.co.uk

Ask us about our training for carers/parents, professionals, education: info@fasdinformed.co.uk

FASD
Informed:
UK

I have talked before about the book [5 against the law](#), a book where there can be a piece of work put in around social boundaries (not necessarily about the law as such but around boundaries).

There is an [incredible updated 5 point scale workbook](#) by the same authors (Kari Dunn Buron & Mitzi Curtis) which explores 'what am I feeling', 'what is ok' and 'what isn't ok', it is a visual support system workbook. It gives some really good examples around what is acceptable and not.

Useful extracts of the breakdown of gentle conversation starters below...

Meeting Girls

Rating	What This Looks Like	What Is the Girl Likely to Think?
5	Telling a girl she has a good body.	This is not really welcomed by most girls. It might sound creepy and might even seem aggressive.
4	Singing a song to a girl across a crowded room.	Even though this is not harmful, it might seem strange, and the girl might end up feeling embarrassed.
3	Fluttering your eyelashes at a girl	This is confusing. The girl will probably not know what to think.
2	Joining a club or theater group after school specifically to meet a girl	This is OK, but remember that you might not meet a girl you like or who likes you. Be patient.
1	Sitting next to a girl in class and introducing yourself.	This is good. Keep it simple.

Keep language very simple.

©All rights reserved
FASD Hub South West
web: www.fasdsouthwest.org
FASD Informed Education UK
web: www.fasdinformed.co.uk

Ask us about our training for carers/parents, professionals, education: info@fasdinformed.co.uk



FASD
Informed:
UK

4	Singing a song to a girl across a crowded room.	Even though this is not harmful, it might seem strange, and the girl might end up feeling embarrassed.
3	Fluttering your eyelashes at a girl	This is confusing. The girl will probably not know what to think.
2	Joining a club or theater group after school specifically to meet a girl	This is OK, but remember that you might not meet a girl you like or who likes you. Be patient.
1	Sitting next to a girl in class and introducing yourself.	This is good. Keep it simple.

Julie said: The book has a 'check in' scale... I would make your own grid and take some of the words out if you were talking to your young person, so perhaps write out... Rating 5 'Out of Control' and ask them what they think that means (use their spoken word in the 'how it feels' column as shown below), then work your way down the list saying something like 'Rating 4, Very Upset or Angry, What does that mean? etc, etc

Sample Check-in Scale

Rating	How It Feels and What I Can Do
5	OUT OF CONTROL! I need to spend time in a safe place to calm my nerves. Listen to Adele on headphones.
4	Very upset or angry. I will stay in the resource room for a while and work through my nervous feelings with Mrs. Wilson.
3	Not very good. I am not feeling well today. I did not get much sleep or maybe I had a bad bus ride. I need to do some relaxation exercises to help.
2	OK. I can go back to class and continue my day. I can practice my positive self-talk to keep me calm.
1	Good day. I am having a good day. I feel calm and focused. Good to go to class.

©All rights reserved
 FASD Hub South West
 web: www.fasdsouthwest.org
 FASD Informed Education UK
 web: www.fasdinformed.co.uk

Ask us about our training for carers/parents, professionals, education: info@fasdinformed.co.uk



Extract below of some (not all as there are lots of examples) concepts the book could support...

Here are just a few examples of concepts or situations where a scale has been used to successfully teach individuals ranging in age and severity of challenges

- personal distance
- perspective taking
- voice volume
- is it a problem?
- speed in the hallway
- touching
- worry levels
- anger
- asking for help
- how other people think
- emotions
- words we use
- who is a friend?
- breaking the law
- sexual behavior

©All rights reserved
FASD Hub South West
web: www.fasdsouthwest.org
FASD Informed Education UK
web: www.fasdinformed.co.uk

Ask us about our training for carers/parents, professionals, education: info@fasdinformed.co.uk



- sexual behavior
- classroom rules
- self-advocacy
- bus rides
- energy level
- what is fair
- tone of voice
- what is funny?
- fear
- manners
- losing and winning
- competition

Julie added to remember to use very, very simple language to give time to process. It might be that you can break down the examples given above in the book into simpler terms or examples; its about the spectrum of needs so adapt accordingly.

None of this is a magic wand but it is a collection of strategies that may help if gently worked through over time..... remember to drip, drip, drip information in, nothing too heavy as it will be greeted with resilience. Choose a time when they are most regulated/calm to start a gentle discussion.

Cassie agreed and said don't use a lot of words as this allows time to take each part in very slowly.

©All rights reserved
FASD Hub South West
web: www.fasdsouthwest.org
FASD Informed Education UK
web: www.fasdinformed.co.uk

Ask us about our training for carers/parents, professionals, education: info@fasdinformed.co.uk

The logo for FASD Informed: UK is a red square with a white border. Inside the square, the text "FASD Informed: UK" is written in white, with "FASD" on the top line, "Informed:" on the second line, and "UK" on the third line.

In the Chat: NVR (non violent resistance training): mixed comments here with parents in the chat, where in the main it felt that it does not work really well with many children with FASD, if it is tried it should be adapted but don't use the stay in the room with the door closed aspect of the training as with a child with FASD and trauma that is a big risk and can trigger trauma responses.

Cassie added as with anything adaptations to it will help tailor the strategy to your child.

Julie stated there is no hard and fast rule with FASD, everything needs adapting often in the moment, some children need no language some need language, would Cassie advocate that?

Cassie: yes its all trial and error, what is a trigger for some children really calms other children and things change often, sometimes something works and the next time it doesn't. This is where in the moment having another adult to tag team when things get really tricky works really well, important having someone else to fall back on.

A safety plan to include a neighbour popping over can switch things or where a safety alarm can be triggered discretely to call a partner or a friend.

Julie mentioned a comment in the chat by a parent where she agreed that the philosophy about '*changing, adjusting and tweaking techniques all the time*' works well.

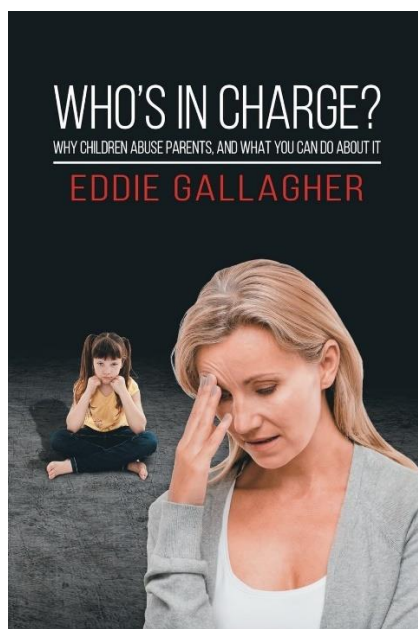
NVR might work with supporting the first signs or lower level Child to Parent Violence & Abuse but its finding what will fit your families needs as FASD is so complex, some things won't work and some things will.

There is also a book called '[who's in charge](#)' and a course that runs alongside it, this supports increasing or high level Child to Parent Violence & Abuse around safety planning and supporting boundaries. For more details have a look at the '[Whos in Charge](#)' website where there is options for contacting the trainer to request new dates.

©All rights reserved
FASD Hub South West
web: www.fasdsouthwest.org
FASD Informed Education UK
web: www.fasdinformed.co.uk

Ask us about our training for carers/parents, professionals, education: info@fasdinformed.co.uk

The logo for FASD Informed: UK is a red square with a white border. Inside the square, the text "FASD Informed: UK" is written in white, with "FASD" on the top line, "Informed:" on the second line, and "UK" on the third line.



Some Foster/Adoption*/SGO agencies will fund the 'Whos in Charge' course through the Adoption Support Fund or may have trained the trainer where they run discrete courses online for carers and parents.

*For example Adopt South West currently runs the scheme.

Question 2. When my son does something like being physical towards us and he sees that we are hurt he then dysregulates and his behaviours worsen.

He name calls and totally loses it. I am thinking that it is that feeling of guilt that he cannot manage this emotion and so it is coming out as negative behaviour.

I know he is sorry and that he feels empathy, it is just in those moments he cannot control how he is presenting his response to us being hurt etc.

Is this normal and how can we help him to manage this better because I know deep down he is not really finding it funny etc

©All rights reserved
FASD Hub South West
web: www.fasdsouthwest.org
FASD Informed Education UK
web: www.fasdinformed.co.uk

Ask us about our training for carers/parents, professionals, education: info@fasdinformed.co.uk

FASD
Informed:
UK

Cassie: it's worth saying that it is very normal for young neurotypical children to struggle with complex emotion and if you remember the half the age rule for FASD.

Shame is a very complex emotion and we as parents have to regulate and contain shame and once you add in the endocrine system and the executive functioning issues its even more likely to lead to dysregulation and overwhelm.

[Author Poppy O'Neil Be Brave, Be Strong, Be Happy & You're a Star!](#) writes a selection of books on feelings, they are not specific to FASD but work really well and cover self-esteem and shame etc and are useful to call upon in terms of visuals.

Also remember to talk about behaviour when calm, not in the moment.

When talking about the behaviour later keep in mind FASD points about half the age and ability to learn from past mistakes, remember to frame it with I love you but not the behaviour.

When managing shame it is important to incorporate touch as long as it doesn't trigger them, if you can stroke their feet when calm or give them a cuddle when delivering a message it helps remove them from the shame and they are more able to hear it.

Julie added that it can also be that they don't know how to react with appropriate emotions ie they may see mum fall over and laugh.

Cassie: Yes exactly, neurotypical children can do this too as they are unable to express or cope with the overwhelming emotion, it is about the social immaturity level and inability to read emotions and what comes out actually surprises them too.

You can start helping them by recognising and labelling the emotions, naming feelings...

"You must have been feeling really sad"

"Sounds like you feel nervous about your first day back to school. I feel nervous when I'm meeting new people too. I'm right here with you."

"You feel really angry that mummy said no more cake. It's so hard when you don't get what you want."

©All rights reserved

FASD Hub South West

web: www.fasdsouthwest.org

FASD Informed Education UK

web: www.fasdinformed.co.uk

Ask us about our training for carers/parents, professionals, education: info@fasdinformed.co.uk

The logo consists of a red square with a white border. Inside the square, the text "FASD Informed: UK" is written in white, with "FASD" on the top line, "Informed:" on the second line, and "UK" on the third line.

"You seem really frustrated by that. I bet you'd rather be riding your bike right now?"

Using visuals and to do this on repeat and they will begin to recognise them but remember to keep your expectations low and remember progress will be significantly longer than a neurotypical child.

Repetition is key!

Visual examples might include:

[Free resources Me & My FASD Emotions Thermometer;](#) (only use work when regulated & calm)

[Free Resources Me & My FASD Whats Happening;](#) (only use work when regulated & calm)

[Free Resources Me & My FASD Break it down board extension cards](#) (scroll to end of page to access the free resources)

[Free Resources Me & My FASD What makes a difference](#) (only use when regulated and calm)

[Free Resources Me & My FASD Traffic Light Cards](#) (these are good laminated and for young person to stick on their door... its like a do not disturb sign but for tuning in and supporting own emotional intelligence)

Question 3. We have just had a diagnosis of FASD & Autism in our daughter, where do we go from here?

Cassie: you have made an excellent start by coming here! I am joking but it is also true, [peer support](#) is really key! What this group gives is huge, it is a lifeline.

Start at the beginning with communicating the diagnosis to school, ensure they have good information and strongly suggest they undertake FASD training; [FASD Informed Education supports a range of bitesize courses delivered to suit you, your school or your professionals online.](#)

If you haven't got one, start building towards getting an [EHCP in place](#). Start to get a sense of where they are functioning now; have a multi disciplinary assessment now where that can help track where they are over transition points.

©All rights reserved

FASD Hub South West

web: www.fasdsouthwest.org

FASD Informed Education UK

web: www.fasdinformed.co.uk

Ask us about our training for carers/parents, professionals, education: info@fasdinformed.co.uk

The logo for FASD Informed: UK, featuring the text "FASD Informed: UK" in white on a red square background.

Talk to the child, but drip feed the information in over a period of years, at the stage they are at as early as possible.

[Go to FASD.me as they have comic book strips that explain things clearly and have one about diagnosis.](#)

Julie added set this at the age and stage they are at no need to rush it, drip feed it over time. You don't have to tell them everything at once and it depends hugely on their developmental stage, NOT chronological age... think half the age.

Cassie: absolutely agree, yes drip feed over time as and when appropriate, especially when they start to see differences between them and their peers.

This also relates to question 8.

Question 4. Our 15yr old son (FASD/ADHD) doesn't get to sleep until the early hours. Melatonin doesn't work. Sleeps all day but cannot sleep at night. Missing school but doesn't want to. Has just slept for 17 hours through. Desperate for a solution!

Cassie asked what dose of melatonin they are on? And parent replied 5ml.

Cassie stated that to remember she is a clinical psychologist not a psychiatrist but they or Paediatrician can often increase the dose but that needs to be discussed with the prescriber.

The person has got their sleep pattern all the wrong way around and needs time to adjust that and get into better sleep hygiene. This does take time to change.

Are they getting enough exercise to wear themselves out during the day, are sensory needs being met in School or in holidays, are they getting enough stimulation, are they on screens really late (this can keep them awake as over stimulated), are they anxious, is there something else going on for them?

You need to be able to physically move them out of sleep at a reasonable time in the morning, I appreciate at 15 this is incredibly difficult, then get them to sleep at a normal time at night to change the pattern back.

©All rights reserved
FASD Hub South West
web: www.fasdsouthwest.org
FASD Informed Education UK
web: www.fasdinformed.co.uk

Ask us about our training for carers/parents, professionals, education: info@fasdinformed.co.uk

The logo for FASD Informed: UK is a red square with a white border. Inside the square, the text "FASD Informed: UK" is written in white, with "FASD" on the top line, "Informed:" on the second line, and "UK" on the third line.

If things are this severe then recommend going to the GP.

How is he if you are able to wake him up? Does he then continue to sleep? Understand that this is very, very difficult but if you don't do it he will continue to be in the nocturnal rut, go to the GP for help.

Julie asked if this needs to be a gradual turnaround?

Cassie replied yes but needs to be done, get him up as early as possible, appreciate it isn't easy.

Julie stated there is no magic wand, it is really exhausting to make that change.

Cassie: yes I fully appreciate it is not easy to make this change to re-jig the pattern. Reach out for help.

Some helpful sources of support here:

[Cerebra Brain Injury Sleep Support](#)

[Cerebra Sleep Advice Service](#)

[Young Minds Sleep Disorders](#)

Question 5. How early should we be talking about starting to plan supported living, what needs to be considered?

Julie stated the neuro psychological assessment is really important for supported living and they are hard to find an FASD experienced so you need to start planning as early as you can.

Cassie said if a child is in care you need to be looking at year 9 onwards, the plan may need to be adapted and it will give you more time to plan.

©All rights reserved
FASD Hub South West
web: www.fasdsouthwest.org
FASD Informed Education UK
web: www.fasdinformed.co.uk

Ask us about our training for carers/parents, professionals, education: info@fasdinformed.co.uk

The logo for FASD Informed: UK is a red square with a white border. Inside the square, the text "FASD Informed: UK" is written in white, with "FASD" on the top line, "Informed:" on the second line, and "UK" on the third line.

If not in care: They need to be done in secondary school in the late teens and need to look at social vulnerability and suggestibility in terms of independence skills.

You need to track the progression to be able to predict what support needs they will need in late adolescence.

Julie added you need to consider how the EHCP fits in to this, is there any transition planning in it? Where are the gaps, what assessments will need to be done? It will need revision so inform school or college to book the LA Educational Psychologists after the neuro psychological assessment or multi-disciplinary assessment who will consider transition planning and add to the EHCPso start early!

Parents in the audience asked if Cassie carries out neuropsychological assessments where she confirmed that she did; her contact details can be [found here through the Psychology Clinic, detailed in our services pages on our support website](#) where also Clinical Psychologist Dr Michelle Blundy Blossoming Minds carries out assessments of this type with FASD informed expertise.

Cassie added: you need to consider the intellectual disability aspect and the adult learning disability team can be explored but it's not about IQ alone, there are so many considerations with transitions to work towards supported living.. mostly considering risk and vulnerabilities.

We will discuss Learning disability more in Question 7.

[Social Care transition to Adulthood a must legal Webnair to watch!](#)

[Your rights for 'a service' from children to adults services](#)

[Supporting success for adults with FASD](#) (particularly good safeguarding recommendations at page 21 onwards)

Question 6. Child has become fixated on something that could lead to limiting anything else, are there other needs emerging?

©All rights reserved
FASD Hub South West
web: www.fasdsouthwest.org
FASD Informed Education UK
web: www.fasdinformed.co.uk

Ask us about our training for carers/parents, professionals, education: info@fasdinformed.co.uk

The logo for FASD Informed: UK is a red square with a white border. Inside the square, the text "FASD Informed: UK" is written in white, with "FASD" on the top line, "Informed:" on the second line, and "UK" on the third line.

How do you support this level of need, how do you get support from professionals to see this as a risk as well as superpower?

Cassie asked if there is any ASD, she is curious if there is ASD as a co-occurring presentation, it is important to have an assessment and diagnosis as it will help supporters and agencies understand as the world is more informed & understanding and further along with ASD than FASD.

Julie asked why is it more common within FASD?

Cassie said that ASD within FASD looks quantifiably different to standard ASD as FASD is more pro social and able to make eye contact but will have ASD traits such as fixations and different social cognition they are more likely to alienate others or take risks.

Julie added that the fixation is more of an issue when it can be misinterpreted or seen as dangerous or damaging for example things such as sex, if it is on a screen and becomes obsessive in that way it is about how to switch that obsession.

Cassie said yes absolutely and important to frame it as an 'obsession and fixation' rather than a sexually motivated issue.

The child or young person might be repeating the behaviours because it makes them feel regulated, it is important it is not seen as sexual behaviours if it isn't.

Julie asked, is it a hyper focus on something rather than sexual behaviour?

Cassie said it can be sexualised behaviour which is normal in adolescence but often have no understanding. For example masturbation is fine but they don't understand that it shouldn't be talked about so openly (with FASD with ADHD or ASD, there is no impulse control so it seems 'normal' to talk openly or do such things. A young person will need to be gently persuaded without shame that this should be done in their room with the door shut, but it is also difficult to re-direct onto other things but not impossible if it is a sensory regulation need. For example if it is a sensory fixation you can slowly re-direct and distract onto something else ensuring no shaming language or stigmatising behaviours.

©All rights reserved
FASD Hub South West
web: www.fasdsouthwest.org
FASD Informed Education UK
web: www.fasdinformed.co.uk

Ask us about our training for carers/parents, professionals, education: info@fasdinformed.co.uk

The logo for FASD Informed: UK, featuring the text "FASD Informed: UK" in white on a red square background.

Julie added that if it is a fixation with watching you tube for example where they will skip work, miss deadlines, not see friends maybe find something he can fixate on that excites him related to something he is watching.

Cassie agreed and said it is about reducing the time they can access it for example cutting off the wi fi at a certain point but ensuring you replace it with something that has the same level of positive feedback.

Also if it is happening elsewhere out of the home then it is about ensuring the team of adults around you are able to re-direct as well.

Julie stated that the fixation is also a way of distraction and dissociation and a way to cope with stress.

Cassie agreed and said it is the same as stimming, it removes the stress but it can get them into trouble if it is all encompassing.

Julie said to switch the fixation it is important to tune into any slightest thing they say they are interested in and run with it, but it is difficult especially if they move from one thing to another fixation.

Cassie said yes, be prepared for them to change and keep an eye on it to see if it needs redirection or not. Remember to recognise the ASD traits even if the child is sociable, keep in mind that it is possible there is also ASD and use those strategies to help manage.

One of the questions will be answered in more detail in our Ask the Expert for our May is ["My son has FASD with Autism where he has 'Monotropism', could you tell me a bit more about this? This focus of their attention on a small number of interests is overwhelming at times."](#)

Question 7. 'Learning Disability' or 'Learning Difficulty'; how do we find this out, how do we support these needs?

Cassie: Neuro psychological assessment would help even with a straight forward global learning disability.

Learning disability is generally a global impairment in all areas of cognition, normal IQ can be verbal or non verbal.

©All rights reserved

FASD Hub South West

web: www.fasdsouthwest.org

FASD Informed Education UK

web: www.fasdinformed.co.uk

Ask us about our training for carers/parents, professionals, education: info@fasdinformed.co.uk

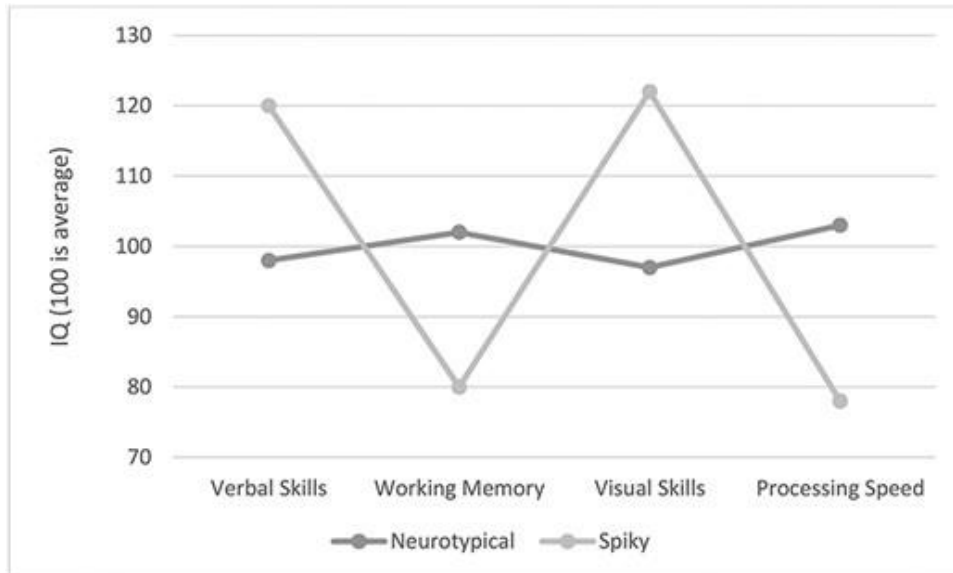
The logo for FASD Informed: UK is a red square with a white border. Inside the square, the text "FASD Informed: UK" is written in white, with "FASD" on the top line, "Informed:" on the second line, and "UK" on the third line.

Cognition would show as a gentle wave, with global learning disability it would still be a gentle wave but it would be at a lower level.

With FASD cognition shows as mountains and valleys and would look like a very spiky profile.



Examples of spikey profile in cognitive functioning



©All rights reserved
 FASD Hub South West
 web: www.fasdsouthwest.org
 FASD Informed Education UK
 web: www.fasdinformed.co.uk

Ask us about our training for carers/parents, professionals, education: info@fasdinformed.co.uk



Learning difficulties such as dyscalculia and dyslexia only affect one area which tends not to be the case with FASD but they are often misdiagnosed with dyscalculia or dyslexia before the FASD diagnosis.

People who are not looking and not understanding of FASD will diagnose only 'learning difficulties'.

Rarely if FASD has global learning disabilities and rarely only affect 1 area of cognition.

It's also complicated by the fact that professionals will use the terms differently.

Julie said it's about understanding the disability and understanding the spiky profile which is really key, they may have dyscalculia or dyslexia diagnosis but you need to look through the FASD lens to see the differences.

Cassie added if the professionals are not assessing executive functioning, they will diagnose the surface disability. It isn't helped that the terms are used differently in all sectors.

Executive functioning lives in the prefrontal cortex so a child with a high IQ can have low executive functioning skills. Having a lower executive functioning than IQ would suggest FASD.

Julie added we need a session just on this topic, families that have a learning disability diagnosis quite often have doors open to a wider range of services quicker than with an FASD diagnosis.

Cassie added FASD is not necessarily a learning disability because of the IQ but the neuropsychological assessment shows the 'adaptive behaviour' and 'executive functioning' issues which shows a 'disability'.

Julie added the diagnosis benefits the EHCP which supports supported living and a wide range of support unfortunately there aren't many professionals with the skills to diagnose.

For a brief overview on the spikey profile described please see this [short clip](#) where in June we will dig deeper into how we can support learning disability and where Dr Cassie Jackson said that she will pull together a few slides to break it down so that the key differences can be seen.

©All rights reserved

FASD Hub South West

web: www.fasdsouthwest.org

FASD Informed Education UK

web: www.fasdinformed.co.uk

Ask us about our training for carers/parents, professionals, education: info@fasdinformed.co.uk

The logo for FASD Informed: UK is a red square with a white border. Inside the square, the text "FASD Informed: UK" is written in white, with "FASD" on the top line, "Informed:" on the second line, and "UK" on the third line.

Question 8. How best can we have a cognitive assessment for our daughter that highlights her FASD? How best can we determine how her FASD affects her learning disabilities, autism and therefore her social skills?

Cassie: Important to get a really good neuro cognitive assessment. Everyone is welcome to come and see me!

[A list of parent recommended FASD informed services can be found on our website.](#)

Cassie: The neuro psychological assessment doesn't just assess IQ it assess broader functioning such as adaptive behaviour and executive functioning so you get a better understanding of real world functioning skills. IQ doesn't predict how they will be able to function in the real world in school exams for example.

It's good to have one done in primary school then one in mid to late teens (consider here the need to get this embedded early in the EHCP review) to be able to track progression then one at 16 onwards to look at supported independence and what support needs they may have for example potential supported living.

Question 9. Child to Parent Violence, what is safety / management planning?

Julie asked when safety planning which profession can support in making a robust safety plan?

Julie clarified what a safety plan might be where for example it would state that if one of the parents is coming in from work when child was starting to build anxiety where parent 2 is calming child when child is dysregulating. Often parent 1 coming in unannounced triggers the child further and escalates behaviour.... then the plan might be for example that dad takes a walk around the block for 10 mins if he sees the blind is pulled down in the bathroom where when it goes up again to signal it's a good time.

Where a 'code word' can be used for swapping over relief care support with partners might be used. This can be really helpful if child has been raging for

©All rights reserved
FASD Hub South West
web: www.fasdsouthwest.org
FASD Informed Education UK
web: www.fasdinformed.co.uk

Ask us about our training for carers/parents, professionals, education: info@fasdinformed.co.uk

The logo for FASD Informed: UK, featuring the text "FASD Informed: UK" in white on a red square background.

sometime where 1st carer/parent is burning out so they say code word where parent 1 walks out the room and the other changes the topic or just sits depending on the circumstances.

Cassie started with what preventative measures are in place first, what way works best to de-escalate behaviours before it gets to this point.

In the safety plan it should state 'what happens if the police have to be called'. To support safeguarding risks the police should be called if the child, parent or sibling are at risk.

Calling the police - You may feel reluctant to call in the police as you may not want your child to get into serious trouble or for other reasons. The police have been working with many families on child/adolescent to parent violence and abuse and understand the impact. If you are in fear for your safety or you are feeling threatened it is ok to call the police to help diffuse the situation and for you to feel safe.

It is a really important component that local services need to understand FASD and what is needed when they are called.

If the police are involved it's vital they know how to communicate to the child.

Julie: it is good practice for the to undertake FASD training ([FASD Informed Education will deliver this to your local police service professionals which includes language and pace of language](#)), to understand the clear triggers so they don't just barge in.

When things are calm think about what happens in escalation and how can you get yourself to a place of safety.

Cassie: And make sure the child in a place of safety.

Julie: Training is vital for the police and a conversation with them before you have the need to call is really important

Safety Planning; a social worker can facilitate this and take the lead.

©All rights reserved
FASD Hub South West
web: www.fasdsouthwest.org
FASD Informed Education UK
web: www.fasdinformed.co.uk

Ask us about our training for carers/parents, professionals, education: info@fasdinformed.co.uk

The logo consists of a red square with a white border. Inside the square, the text "FASD Informed: UK" is written in white, with "FASD" on the top line, "Informed:" on the second line, and "UK" on the third line.

[More support on safety planning, calling the police and what child to parent violence abuse can be found here](#)

Talk to the police so they can record your child as a vulnerable person and have that information before engaging with the child.

Julie: Ideally Police need to know ahead of time about FASD and any previous trauma. At recent strategy meetings that she had attended they have stated it's important to have it on record that a child is vulnerable living in the home & why, this will protect their rights if called.

[For more on legal rights of the child and a free downloadable medical card to give the police if called or picked up by the police](#)

Question 10. Confabulation, where some don't know my young person well might see this as lying or where some might totally believe the story that is being told.

Where it has become a safeguarding risk; how do you get services or schools to support this level of need?

How should professionals recognise confabulation and risk assess appropriately against this?

Cassie: It is about seeing that a child is not lying deliberately but accessing different parts of their memory, some totally believe what they are saying.

It is really hard for professionals initially, they have to really get to know that child and their presentation.

Remember that children with FASD can believe it's better to say something than nothing and they will be accessing different memories and putting them together to form a new story.

Often it is an imagined reality that they really want to be true or it can be complete fabrications of their past to create new memories.

©All rights reserved
FASD Hub South West
web: www.fasdsouthwest.org
FASD Informed Education UK
web: www.fasdinformed.co.uk

Ask us about our training for carers/parents, professionals, education: info@fasdinformed.co.uk

The logo for FASD Informed: UK, featuring the text "FASD Informed: UK" in white on a red square background.

The key is training to understand why and have all the teams and agencies on board especially if the confabulation becomes a safeguarding risk as the child will have no understanding of the consequences of what they are saying.

For example Cassie worked with a family whose child continually rang the NHS as they needed the nurture and care that was given to them by the NHS team.

Is the confabulation fulfilling a need? Are they getting a specific response to saying something?

Are the rewards nurture, attention, excitement in seeing the responses of the agencies? Is it happening in a specific place?

It is important to re-direct the conversation and give a low level response.

Julie: for example if the parent knows it isn't true, understand why they may have said it and what response they got from it.

Cassie agencies need to understand that there is no risk to the child in this situation and give a low level response.

Julie added it is important to 'risk assess' against confabulation as the blame and shame of parents is so damaging. Understand confabulation and consider any allocation of resources needed.

Cassie: yes agree totally, understanding is key and training in FASD!

[For a brief training video by our FASD international FASD Friend Nate Sheets, confabulation click here](#)

11. Talking about 'abilities' and 'disabilities' with children; how do we start the conversation about FASD, how do we explain without scaring them?

Cassie and Julie re-iterated the drip drip very slowly and age and stage appropriate approach.

Some very helpful information when the child is ready (but NOT before):

©All rights reserved

FASD Hub South West

web: www.fasdsouthwest.org

FASD Informed Education UK

web: www.fasdinformed.co.uk

Ask us about our training for carers/parents, professionals, education: info@fasdinformed.co.uk

The logo for FASD Informed: UK, featuring the text "FASD Informed: UK" in white on a red square background.

[FASD Makes Me, Me Video](#)

My Brain Me & FASD [Read aloud FASD Book](#)

[Hearing Song FASD Video](#)

[The misunderstood game \(video with young people with FASD\)](#)

[The misunderstood game](#) (shop)

Question 12. *Many of us may have seen Rossi on the [BBC 3 competition 'Glow-Up](#) where he describes his FASD as 'his strength'*

Cassie stated that every child has this brilliance and it is about plugging into that whilst ensuring there is enough scaffolding around them to help them achieve it.

Cassie had a conversation with Jan, Rossi's mum who felt that Glow up was a fantastic show and it was amazing he could show his brilliance but it had been very difficult.

Cassie read a section of an email shared to the group with Jan's permission:

"It's so important for people to know that he might look capable, confident and almost Neuro able, this couldn't be further from the truth".

"Not wanting to throw water over anyone's fireworks, but the same brain damage exists, it's just a different outlook on what is or isn't achievable."

"I've always said, find their brilliant and put that above everything else. Yes he has so much ability and does have confidence in his makeup, but to be able to achieve there is a network of support around him".

It's so important for people to know that although Rossi appeared to be confident and competent he has the same brain damage.

©All rights reserved
FASD Hub South West
web: www.fasdsouthwest.org
FASD Informed Education UK
web: www.fasdinformed.co.uk

Ask us about our training for carers/parents, professionals, education: info@fasdinformed.co.uk

The logo consists of a red square with a white border. Inside the square, the text "FASD Informed: UK" is written in white, with "FASD" on the top line, "Informed:" on the second line, and "UK" on the third line.

[Interview with Rossi \(young person with FASD can be found clicking the link HERE\)](#)

"Its not all sunshine and rainbows behind the camera"

"Cast & crew made adjustments for me"

"I was glad to have a mother like mine who understands me and is very accommodating!"

He talks about how he coped with meltdowns on set..... lots of adjustments to support his needs but he did it with lots of sleep.

"I cannot organise myself so it takes the right community of people to help"

He has a brilliant ability but there is a strong network of support behind that. The BBC undertook FASD training and ensured he had space and breaks and framed FASD well for viewers but it didn't show all the scaffolding around him. Because of that Jan has had a lot of comments such as he cant have FASD as he isn't showing any problems. Parents want their children to be brilliant but to also have the scaffolding in place and for agencies to do their bit.

Julie added it is about recognising strengths and tuning into it but doing what you can to get support to drive it onwards.

One of our founding members of FASD Southwest Susanna isn't here tonight but is very much in my thoughts as she is taking her son to Rolls Royce for a supported internship apprenticeship interview, to get to this point is huge for the family. He is supported in everything he does but due to the determination of his advocate, his Mum and best friend she has encouraged him to go for it!

Cassie added that when the scaffolding is working it looks invisible but it is still there, that was Jan's point.

Julie added it is important to point out that Jan's brother is a make up artist so Rossi grew up with it around him and naturally gravitated towards it from a very early age and ran with it. It is about seeing these opportunities for something whatever it is and trying to get the young person interested in it. Using the fixated interests can work well in this example.

Cassie said to celebrate the tiny wins and to remember that in FASD sometimes it won't look like a win to anyone elsebut it absolutely is!

©All rights reserved

FASD Hub South West

web: www.fasdsouthwest.org

FASD Informed Education UK

web: www.fasdinformed.co.uk

Ask us about our training for carers/parents, professionals, education: info@fasdinformed.co.uk

The logo for FASD Informed: UK is a red square with a white border. Inside the square, the text "FASD Informed: UK" is written in white, with "FASD" on the top line, "Informed:" on the second line, and "UK" on the third line.

Our next 2 events include:

[21st MAY 1:00 – 2:00 EVENT: Book here for our 'Ask the Expert' Dr Naomi Fisher Clinical Psychologist, author of 'Changing our Minds' & 'A Different Way to Learn'.... clinical expert in Trauma, Autism, Demand Avoidance PDA & Alternative ways of learning outside and inside School](#)

Parents questions so far include:

1. I can't get my child out of the house, we are always late for everything, he refuses to put on a coat, everything is a struggle, how can I support these type of needs?
2. My child has FASD with Autism where he has 'Monotropism', could you tell me a bit more about this? This focus of their attention on a small number of interests is overwhelming at times.
3. How can we get support with exams in School, with so many needs is it realistic to take exams?
4. We have been made to choose options for subjects next year where there is no chance of getting any qualifications as she cant even write her own name. How do we get School to see that that need to do things differently?
5. How can we create an environment with less demands, he is diagnosed with Demand Avoidance where pushing him to do anything is a firm 'no' or where we face a meltdown?
6. My child is not progressing in School, we think he cruises from one lesson to the next, how can I get support for my son?
7. What can we do, he just wont go into School, his anxiety is overwhelming him? I cant home school as I have to earn money. What support can I get?
8. School sees a child who is 'awkward', who is 'running off', who is getting in trouble for 'acting inappropriately' but she doesn't know what inappropriate means! How can we support School in supporting her?
9. What is self – directed education?

Naomi has over 17 years clinical experience in the NHS, third sector and private practice.

©All rights reserved
FASD Hub South West
web: www.fasdsouthwest.org
FASD Informed Education UK
web: www.fasdinformed.co.uk

Ask us about our training for carers/parents, professionals, education: info@fasdinformed.co.uk

The logo for FASD Informed: UK is a red square with a white border. Inside the square, the text "FASD Informed: UK" is written in white, with "FASD" on the top line, "Informed:" on the second line, and "UK" on the third line.

Dr Naomi Fisher will chat to us about the challenges and what might make a shift change in supporting neurodevelopmental conditions.

This is a unique opportunity to look at how we can hyperfocus on strengths and dig deep into why an approach of "what works works! "

She has much experience in the use of PDA strategies which can support FASD well in some childrenwaiting until the child or young person is ready; this approach has supported many children with complex needs.

Ticket holders are encouraged to email ahead of the evening to ask confidential questions that will be asked for you by the host, where a wide range of topics will be discussed openly.

Book now as tickets are limited.

Please note: Sessions will not be recorded due to confidentiality but we will provide detailed minutes that will have linked resources

Email your 'Ask the Expert' questions to: info@fasdinformed.co.uk

[26th JUNE 8:15-9:15 EVENT: Ask the Expert 'FASD & Learning Difficulty or Disability?' with Clinical Psych Dr Cassie Jackson](#)

Dr Cassie Jackson Clinical Psychologist leads a presentation with questions and answers around FASD, Learning Difficulties and Learning Disability.... this will be a bespoke session drilling down into Learning Disability.

We will unpick the importance of getting a 'learning diagnosis', where we hope the session will give you tools in your FASD toolbelt to enable you access a broader range of services to support this need.

We aim to incorporate information from Learning Disability services into the session and where we will provide a clear definition around your rights.

Don't miss out on this chance to learn more and ask your burning questions!

Ticket holders are encouraged to send questions ahead of the session so that they can be asked for you, please email: info@fasdinformed.co.uk

©All rights reserved

FASD Hub South West

web: www.fasdsouthwest.org

FASD Informed Education UK

web: www.fasdinformed.co.uk

Ask us about our training for carers/parents, professionals, education: info@fasdinformed.co.uk

The logo for FASD Informed: UK is a red square with a white border. Inside the square, the text "FASD Informed: UK" is written in white, with "FASD" on the top line, "Informed:" on the second line, and "UK" on the third line.