



‘Ask the Expert’ FASD Learning Difficulty or Learning Disability?

Event notes: 26th June 2024

Host: Julie Furney Director of FASD Informed Education & FASD HUB South West

Guest Speaker: Clinical Psychologist & Director of FASD Dr Cassie Jackson

Julie welcomed everyone in supporting the evening and gave a warm introduction to Dr Cassie Jackson Clinical Psychologist specialising in paediatric neuropsychology and neuro disorders, she is a leading specialist nationally in FASD and is Director of her new clinic [The Psychology Clinic](#), Cassie also works part-time cascading good practice in supporting clinicians in diagnosing FASD through the Surrey Clinic with Dr Raja Mukherjee MBE

Her work has been pivotal in making a difference to so many families, informing the FASD community, NICE quality guidelines and is of great support to Julie through the support group and training they deliver.... *where Julie says she is going to coerce her to co-write a book together for families.... so watch this space!*

Thank you to Grace & Trina for supporting in the parents & professionals chat room with posting links and keeping diligent notes.

Julie: Cassie we have delivered together recently sessions around FASD and its complexities, where in a recent Ask the Expert session we previously tiptoed into the differences between Learning Disabilities and Learning Difficulties, where being mis-informed can be a major showstopper for lots of families as there is such a lack of understanding with clinicians around this subject area with FASD.

Cassie: Essentially the majority of people with FASD will not have global learning delay as well due to the FASD spiky cognitive profile, however many do, we will consider this tonight.

‘Learning Difficulties’ label is often used inaccurately to catch all issues. A ‘Learning Difficulty’ for example dyslexia, affects one special area where all other areas are generally ok.

©All rights reserved

A global 'Learning Disability' will affect [all brain domains](#) and will have an IQ lower than 70 the profile will look uncomplicated compared to an FASD profile.

In an assessment (for example an educational psychology assessment) completing a Wechsler Intelligence Scale (WISC) test and an IQ test they will look at all domains in line with working communication, you should see a straight line with a slight wave and with a learning disability it will be an IQ of 70 and below.

Over 90+ to 110 or bang on 100 is a 'normal' IQ

110/120 is high IQ and above 120 are superior.

80- 90 is a low average

70-80 borderline learning disability and lots of people with FASD will fall into this area.

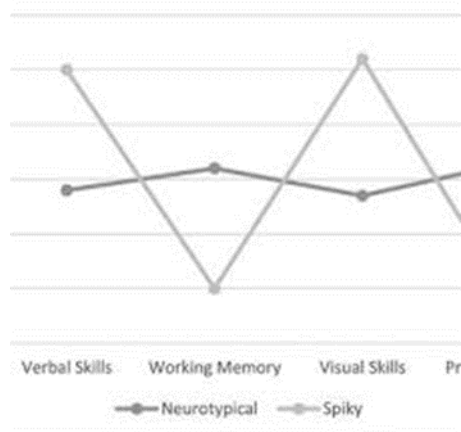
70 and below mild learning disability which can be adjusted to 55-66 falling into mild for FASD

55 and lower is a moderate learning disability

Down to the late 40's.

With FASD some people will have 'global learning disabilities but the majority wont as they will have the spiky profile..

The term 'mild' should be interpreted with caution in a young person with FASD, because the compound effect of their broader neurodevelopmental impairments often equates to functioning that is much lower than this score would otherwise predict.



Spiky profile of FASD

Remember the damage is caused by alcohol exposure, it is a brain connectivity disorder, some will do well in IQ tests and some tasks but it is a connectivity issue.

If there are any tasks that mean the brain has to use both the left and the right sides, crossing the midline will be difficult. Maths is an executive functioning task.

©All rights reserved

Its means the [parietal](#) and the prefrontal cortex have to talk to each other which people with FASD can't do.

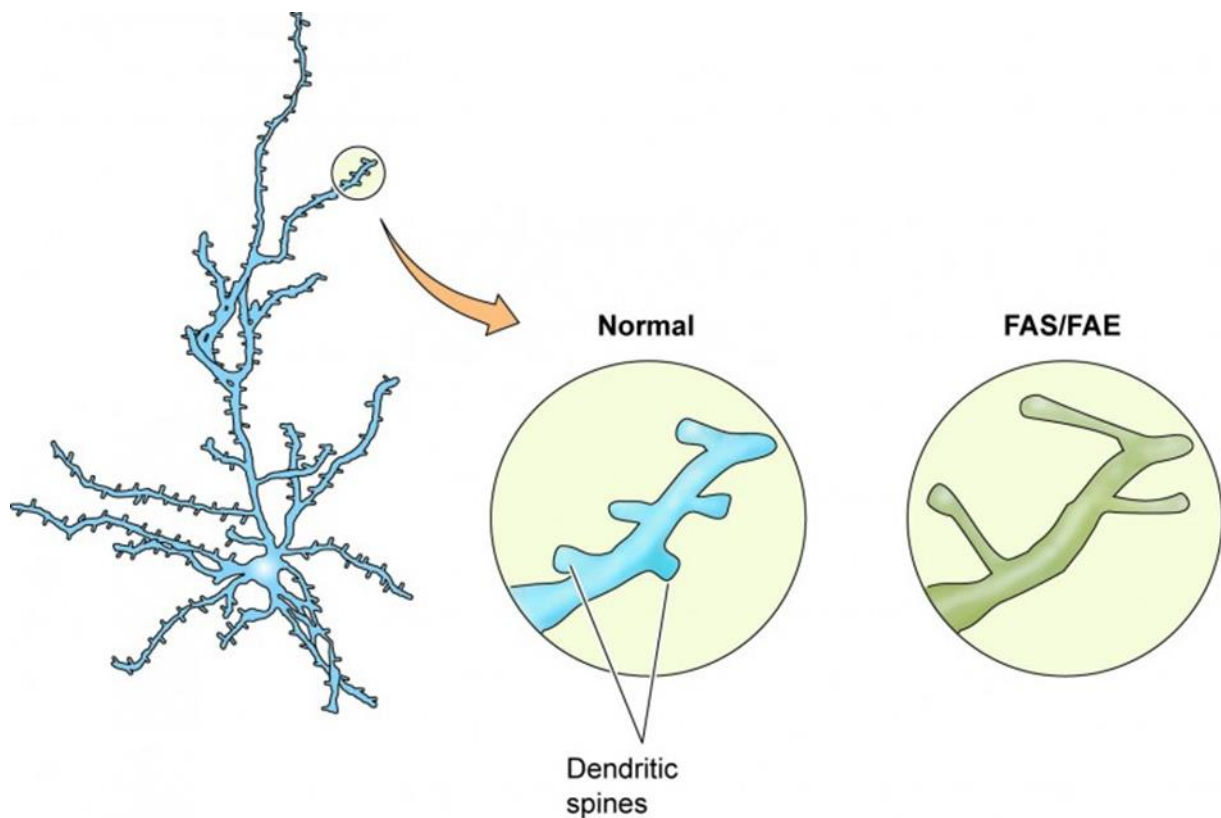
Prefrontal cortex is a primary function and parietal is secondary.

MRI scans mostly look 'normal' in those with FASD, they can show a loss of corpus callosum, it can look thinner or a mass of connections but it is not used as a diagnostic tool as you may not see it.

Julie said it is a concern as many parents contact her regionally saying they have been referred for an MRI.

Cassie explained that MRI's undertaken on the NHS are looking for structural differences not functional MRI's so it would only pick up on white matter damage which is hard to see.

Julie talked of making sense of this in how this impacts children/young people and adults with FASD day to day. Where she described the loss of dendritic spines (seen below) in the brain after exposure to alcohol in utero where alcohol disrupts the formation of synapses—the connections between neurons that allow them to communicate.



©All rights reserved

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



Julie went on to describe visualising this part of the brain as pieces of seaweed where the dendritic spines brain signal transmits from spine to spine, if that spine is mis-shapen, damaged or not there at all the message doesn't get through.

So think about communication and processing information where a child might hear ever third word if in a normal speed of speech which is why we need to slow things down and keep it simple.

The effect of alcohol on spine density and shape disrupts synaptogenesis, ensuring that neurons will not function normally after birth. These events are particularly evident when bingeing takes place in the 3rd trimester.

Further reference reading: <https://sites.duke.edu/fasd/chapter-3-effects-of-prenatal-exposure-to-alcohol-on-brain-development-and-post-natal-function/brain-imaging-reveals-structural-defects/>

Cassie added if you had a fishing net and yanked on the net you would cause problems with the whole network and disrupt all the connectivity.....

Julie: the whole brain.... the whole child's functioning.

Julie: There is a message in the chat from Sue asking if a temporal lobe arachnoid cyst is linked to FASD?

Cassie: It's impossible to say sadly, it will never be possible to directly prove it was caused by alcohol.

Julie said many families ask if the learning disabilities issues can change when they get older?

Cassie stated it doesn't change.

Julie asked is global learning disability the same as global learning delay?

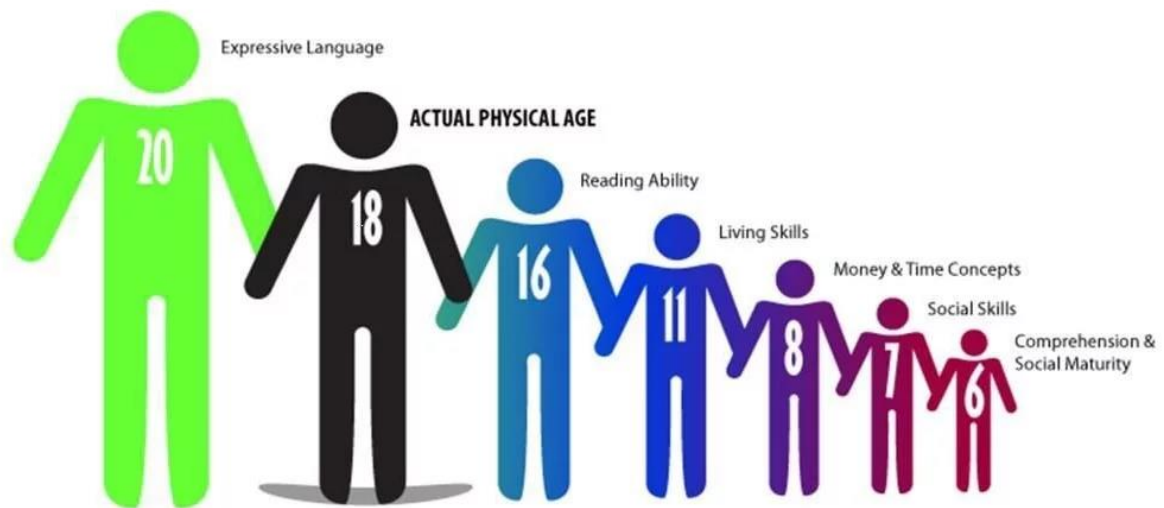
Cassie: **'A global development delay'** is usually given to pre-school children not meeting targets in social emotional, fine/gross motor skills, cognitive areas.

If they are still not meeting these targets past school age it becomes a 'learning disability'.

If a child has had a small period of neglect with no other issues and are displaying a 'global development delay', they can catch up, others will be diagnosed with a learning disability.

The key things with FASD is the spiky profile.

What you see is NOT what you get...



Children/Young People/Adults will have significant issues in some areas and better in others and you must not rely on IQ.

An adult with a learning disability may have poor adaptive functioning and a low IQ, with FASD they may have poor adaptive functioning but the IQ can be ok.

With global development delay everything is low.....with FASD there will be some 'normal' bits.

The working memory is much more impaired than episodic; to explain in summary....

Slide 1: TEXTBOOK NEUROCOGNITIVE PRESENTATION:

A Wechsler Intelligence Scale (WISC) is not enough – a full neuropsychological assessment is needed to identify learning disability for FASD & Capacity (*more details in resources about capacity page 12 of these notes*).

©All rights reserved

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



IQ is not a reliable predictor of functioning in FASD

Spiky cognitive profile more common than IQ in LD range. $>2SD$ between domains.

Working memory vs. episodic memory.

Receptive/expressive language deficits.

Executive functioning impairment $>$ poor adaptive behaviour.

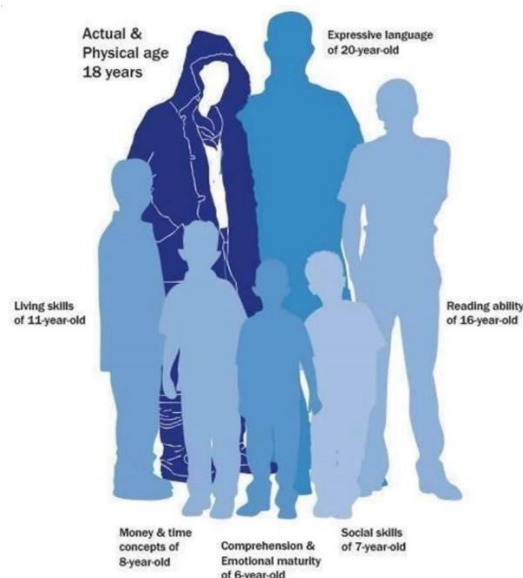
Often present as more capable than they are

Classically presentation example is Children/Young People/Adults may be able to remember every detail from a holiday 6 years ago but not remember what they had for breakfast.

Think of the dementia patient for this example above; how would you support someone with this level of need?

Initially you wouldn't necessarily see the deficits in conversation and in FASD teenagers can present much more capable than they are but are highly vulnerable to the chronological age v developmental age difference of approximately half age.

Look again at the risk here, the 18 year has social skills of a 7 year old, what age is his capacity? He is at risk of coercion and exploitation.



©All rights reserved

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



Julie: Speech and language is an area of difficulty where because of this hidden disability where expressive language can be high functioning young people/adults can appear to be much more able than they are.

Cassie: You cannot say that one area of deficit is definitely FASD it has to be several areas affected and recorded history. We do know that receptive language tends to be more damaged and it is very pro-social where they tend to be 'over familiar' and can mask well.

Julie: [Blending in and masking to stay safe in School](#)

Slide 2: SPEECH AND LANGUAGE PRESENTATIONS IN FASD

80-86% of children with FASD have Speech & Language challenges.

Deficits are heterogenous (*has several possible causes*), but receptive language generally more severely affected.

Expressive language skills often used to mask poor comprehension (children with FASD are often very pro-social and over-familiar).

Poor inference skills, very literal understanding of world.

Source: Winnipeg et al (2014) – CELF-4 with 124 children with FASD aged 5-18.

80% had significant Speech & Language problems.

Two thirds = 'severe' rating.

Difficulties appear to become more severe and more specific with age.

Only one third had ever received SLT intervention despite most having a high level of need.

Julie added if the person diagnosing is not FASD trained or not experienced with this with FASD they can mis-diagnose or might appear 'more able than they are'.

Cassie stated: absolutely yes, the pro social masking can make things very difficult as those that are not trained or experienced cannot see the safeguarding risks.

Julie: How do parents navigate all this? EHCP's and management plans generally don't have learning disabilities identified or a strong FASD informed Speech & Language assessment where they have looked through the FASD lens? What differences can they tune into?

©All rights reserved

Cassie: they would need a formal assessment to see where the deficits lie.
Test the adaptive functioning, how are they functioning in the real world?
Can they follow a routine, can they do several tasks?
See how they are **'functioning'**. This is VERY different to IQ.

[The neuropsychological assessment](#) is highly predictive of how they function. The assessor will also speak to home and school to see how they work in every environment.

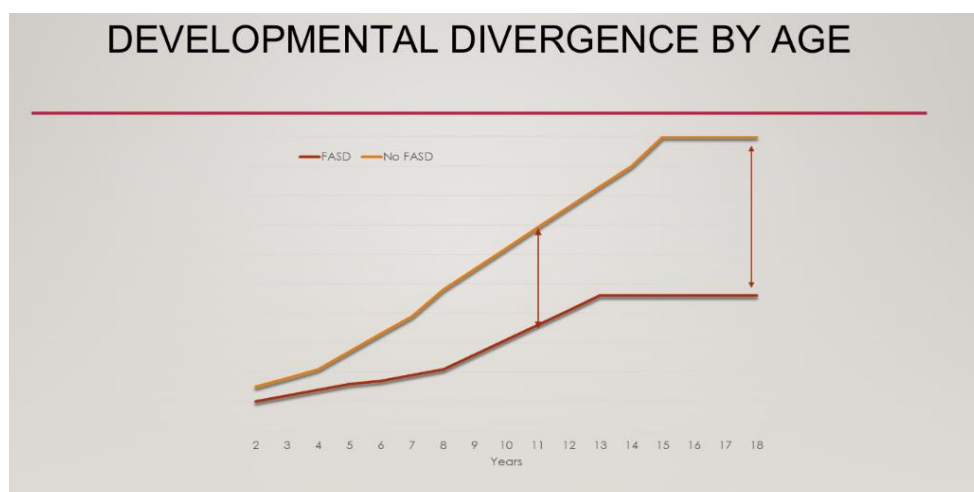
The executive functioning is where the skill sets sit, it managing the direction of the brain. An example is a person Cassie knows who has a really high IQ of 130+ but the executive functioning is so low they need full time 1-1 they cannot function without support, both parents are very intelligent.

Julie: If you have children where school might say 'everything is fine in school'. If they are doing well in tests, how do you support school to understanding the executive functioning difficulties and to be aware of the risks?

Cassie: if they are not working at the level they should be for executive functioning, can't focus, can't stay on task, cant plan or organise and not meeting age expectations for their chronological age then they can't run with that IQ in the real world.

IQ of around 70/80 is borderline but they are not functioning at the level the IQ suggests.
Adaptive functioning is the ability of the child to function at the age they are developmentally.

'Developmental divergence' is the difference between neurotypical and FASD where the needs are increasing while others are gaining independence skills.
The actual 'chronological' age is superficial, you should look at the functioning age.



© Dr Cassie Jackson 2024

©All rights reserved

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



Julie: EHCPs should tune into adaptive functioning, as this clearly presents a risk if viewed as child of their chronological age.

Those that view this hidden disability can often focus on how 'well they are doing' and presenting IQ, but need to dig deeper into functioning skills to understand the whole child/young person/adult.

Cassie: Absolutely agree, some children will have global learning disabilities as well as FASD and not have the spiky profile as it will still look flat but be even lower with FASD.

Julie: the spiky profile can change but it will always be spiky?

Cassie: yes it can look different but still be there.

Julie: the WISC assessment to look for adaptive functioning who does those?

Cassie: its not really a big enough test to refer and do on its own. Its usually done alongside ABAS questionnaires with parents and teachers and done alongside everything else.

Julie: so for example a multi-disciplinary assessment alongside Adaptive Behaviour Assessment System (ABAS)?

Cassie: Yes and if you are doing an IQ test you need to do a functioning test.

Julie: Donna in the chat has commented that her child has an above normal IQ but needs a 1-1. Can you explain why that might be?

All of the tgings we have talked about here where a child/young person/adult could have a normal IQ but cannot tie their own shoe laces, wipe their own bottom or need prompting to drink or eat; they have poor adaptive functioning.

Important to note that they are also vulnerable to coercion and have deficits socially to be safe or understand rules.

Question: why is dyslexia and dyscalculia often misdiagnosed FASD?

Cassie because often well-meaning teachers, therapists etc will have a dyslexia screen or dyscalculia test and they will likely be diagnosed.

It is highly inheritable so if they have it in the family.

They can be high risk screening tests that can show poor working memory and poor processing speed both of those you find in FASD.

When trying to do maths the brain has to jump between the parietal and the prefrontal cortex.

©All rights reserved

If you are only looking at literacy problems they will diagnose dyslexia but they need to look further.

If you only have a hammer it all looks like a nail.

Julie: this is vital for parents and professionals to know as to get the right services to support need you need to look deeper for clues, look at what else is going on where you may find FASD or ADHD or ASD.

The first sign might often be dyslexia but always consider the background of needs and if alcohol could have been present.

Cassie: if there is prenatal exposure and you have cognitive needs and ASD and ADHD then you have 3 boxes ticked for diagnosis. [You can ask the social care team to request looking through birth files for evidence of alcohol](#), in other areas they will already meet the threshold.

Julie: is there any harm in having a dyscalculia diagnosis if it gives more support in that area?

Cassie: no harm at all, the only harm is if that is all that is diagnosed and all others are missed.

Dyslexia programmes really help as long as you start with low expectations. Always key point is to come back to functioning.

Question: Does every child with FASD have learning disabilities?

Cassie: no, every child with FASD will have cognitive differences and will have a spiky profile, they will have strengths and weaknesses.

A textbook FASD case will have poor verbal communication skills (appear to be high functioning verbal skills but do not understand context/content and social skills) and slightly stronger non-verbal communication.

There are two standard deviations between the domains.

The profile will be remarkably stable

Question in chat from Tandi does this stay consistent through young adulthood into later adulthood?

Cassie: Yes IQ sometimes looks like it has dropped if tested at age 6 and again at age 16. Its not that its a loss of skills but the expectations are higher.

You need to be looking at a neuropsychological assessment going into adulthood.

©All rights reserved

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



Julie: Yes, its a vital tool when transitioning into adulthood to unpick where they are functioning. A neuropsychological assessment can massively support this identification of need where you can then update the EHCP or management plan for that young person/adult.

Cassie: it is a clear way of showing agencies such as College, supported internships, supported living; that you cannot assume they will be independently carrying out tasks/ performing / living at a certain chronological age especially if they are in supported living or care.

Julie: Yes and it is important to get that information into an EHCP and inform a change to ensure they are getting the right support. Booking in multi-disciplinary assessments or neuropsychological assessments periodically and crucially well before College or supported living is key. Services take a long time to make the amendments of the assessments so these need to be booked in well ahead of the transition.

Cassie: Yes it's important to get a section in an EHCP about FASD, if the Educational Psychologist is FASD informed almost add in the textbook information and how it affects that person.

Question in the chat from Nikky: Her daughter age 8 has an IQ 82 but her executive functioning brings that to 68 her verbal is high but her comprehension is low, processing is slow and her maths is significantly behind, her reading is not far off age appropriate.

Cassie agrees: the discrepancy can be really big. Classically spiky.

Julie: Can Learning disability & FASD be intertwined and confused with trauma?

Cassie: Yes trauma will have a functioning discrepancy if a child is treated for trauma in a safe environment for a long time they can improve, if the functionality is still impaired by how much and for how long despite therapy then need to look at other causes.

There is also a drive to understand trauma that can stop people looking for other things.

Julie: Looking for the clues..... if you look through the lense of FASD you will then see the trauma responses due often to unmet needs or triggers of early life trauma.

Cassie: Yes that exactly it, if there is considerable trauma and removed at for example age 3 / 4 and then placed into care and have prolonged trauma you need to look at the birth history.

If you have a child removed at birth, 1 set of foster parents and adopted at 8 months then trauma wouldn't explain what you are seeing, it will impact.... and I'm not underplaying how much it will impact but neurodivergence comes first with trauma over the top of that.

©All rights reserved

How they process that trauma and deal with it will depend on exposure to alcohol
Good reference material from Dr Alan Price in our resources section further below

Julie: many families are told they are 'doing fine' and are not encouraged to push for diagnosis why is it important?

Cassie: Children can appear to do ok in the early years but when they get to age 7 / 8 it's not necessarily the case and when they get to get 13 / 14 you need to understand what's going on and put support into place, they essentially grow into their diagnosis.

I've had children in my clinic at age 7 that do not meet the threshold but I won't send them away, I say they are 'at risk' of FASD as 4 years later they have grown into it....

Julie: If parents/schools/professionals have more evidence to see the FASD can you diagnose later?

Cassie: yes absolutely, very common.

Julie: is dysgraphia a learning disability?

Cassie: it is a specific learning disability and you can support that but you need to look broader in FASD

Julie: So it's a clue if this is seen first or part of a cluster of things?

Cassie: Yes if you see a clinician specialising in 1 specific area with a background of need they are not understanding the broader implications.

Julie: Very important to consider a broader picture.

Julie: Question in the chat from Marianne: how do we distinguish between FASD and other conditions that may cause learning disabilities/difficulties, we have a working FASD diagnosis pending genetics but the tests showed 'Turners syndrome' where learning disability can be present.

Cassie: Genetics trumps everything else, FASD is a diagnosis of exclusion you have to look at all the other reasons and look at FASD after.

For example: the genetics microarray test ([essential as part of the NICE Quality Standards for FASD diagnosis](#)) sometimes will highlight Fragile X a genetic condition, 3 percent is a significant result. 10 percent global delay will increase the chance of genetics and there is an increase if there are any facial features, not FASD features but others that are present in genetic issues.

©All rights reserved

You can't say you have a primary FASD diagnosis if you have a genetic abnormality identified where symptoms are a specific learning difficulty. That comes first.

Alcohol comes second to genetics. If there is a genetic abnormality that is not linked to a learning disability then FASD will be diagnosed as a secondary.

Another example is if the genetic abnormality is linked to causing ASD or ADHD you can't say it is FASD for sure as you can't prove its caused by alcohol so you would say for example 'ASD with additional alcohol issues'. It's just the rules clinically where genetics wins.

FASD support and strategies will be helpful in all things as it will still be there but genetics is top trump.

Julie: How can we support the learning disability as it's suggests a huge range of needs?

Cassie: you need to support the dominant needs in that child.
Schools need to be FASD trained so they can understand the whole profile.

But it's about supporting the key areas that affect the child the most so some will be ASD, PDA features in others ADHD etc. Tune into those needs.

Ensure you are putting in scaffolding around the executive functioning; [go line by line in reviewing the brain domains in your EHCP](#)

Some will benefit from sensory integration therapy and other therapies to help them feel as regulated as possible; regulation is everything to support a very sensitive nervous system.

RESOURCES:

What is the point of doing a capacity assessment?

The purpose of any 'capacity assessment' is not to judge the decision a person makes; it is to determine whether a person is able to make the decision. To be able to make a decision you have to be able to:

- *understand the information relevant to the decision*
- *retain that information (if only for a short amount of time)*
- *use or weigh up that information as part of making the decision, or*
- *communicate the decision (whether by talking, using sign language or any other means).*

This is particularly important if ever cautioned by the police.

©All rights reserved

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



An FASD neuropsychological assessment can include a 'capacity assessment', more information about Dr Cassie Jackson's new clinic can be found [HERE](#)

VERY helpful guidance on all key things relating to right, power of attorney, becoming a deputy, transitions to adulthood, safeguarding and more can be found [HERE](#)

For Professionals and families: what I can do to help?

Core principles for professionals include:

- accessing suitable training on [learning disability & FASD](#)
- using [hospital passports](#) and [health action plans](#) to help ensure that people with a learning disability are well supported
- [annual health check](#) for all people over 14 years with learning disabilities uk
- networking with the professional learning disability community, including local learning disability nurses
- identifying and proactively adding people with a learning disability (and their carers) on primary and secondary healthcare registers
- anticipating the likely needs of people with a learning disability and making reasonable adjustments
- listening to people with a learning disability, their family and carers
- understanding and adhering to the [Mental Capacity Act \(2005\)](#) code of practice at all times
- ensuring inclusivity and consideration to people with a learning disability whose first language is not English through greater awareness and capability building
- co-ordinating care and sharing information

Recommendations:

Note: in some parts of the world 'intellectual disability' is the preferred terminology for learning disability, so if seeking to read internationally more widely, this may be a useful search term

[Learning Disability or Disability](#) : A new factsheet on FASD – diagnosis of disability or learning difficulty has just been published by our FASD Friends the FASD Network, working collaboratively with FASD Hub South West help support families navigate the terminology and to seek additional support where needed.

[FASD & Trauma](#): Dr Alan Price; looking through the lense of FASD to see the trauma

[Unable to make decisions, rights and access to services](#)

For ADHD strategies; [try the 5 point scale method](#), all key areas of challenge focus on supporting that scaffold the executive functioning then they can access the curriculum.

©All rights reserved

Julie: the [Strategies not solutions book](#); some great ideas towards the end of the book

Julie:

Fantastic strategies for Schools after page 12

[PRIMARY FRAMEWORK TEACHING AND LEARNING STRATEGIES TO SUPPORT FASD](#)

Fantastic strategies for Schools after page 14

[SECONDARY FRAMEWORK: TEACHING AND LEARNING STRATEGIES TO SUPPORT FASD](#)

Julie: This very useful legal rights document has just been released of support to young people/adults with or without diagnosis [here](#)

Book recommended by Cassie '[Smart but Scattered Teenagers](#)' not FASD specific but still a useful tool to use bits and pieces that apply to needs (remember half chronological age)

UK Government legislation that relates to Learning Disabilities:

Learning disability, human rights and equality

We all have human rights; children, young people and adults with a learning disability have the same rights to the same opportunities, to live satisfying and valued lives and to be treated with the same dignity and respect, as anyone else. This includes prejudice & the rights to be diagnosed.

The [Human Rights Act](#) (1998) is the main law protecting human rights in the UK. The act places a clear legal duty on public officials and bodies to 'respect' the 16 rights it outlines and to take action to ensure people's rights are 'protected'.

The [Equality Act](#) (2010) places a statutory duty on employers, healthcare settings and wider society to make [reasonable adjustments](#) to ensure equity of access to services for people with a disability, by making changes in their approach or provision.

The [Health and Care Act](#) (2022) introduced a requirement that all regulated health and social care service providers ensure their staff receive training on learning disability and autism which is appropriate to the person's role.

Further sources of support for Learning Disabilities *however may not be FASD Informed:*

['Contact' for Learning Disabilities](#)

[Supported Living for Learning Disabilities](#)

[Learning Disabilities Allies](#)

[Foundation for Learning Disabilities UK](#)

[BOOK HERE for a place at our next 'Ask the Expert' with Dr Cassie Jackson 16th September 2024 8:15 -9:15pm](#)

©All rights reserved

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

