FASD Hub South West

'Ask the Expert' event notes and linked resources

28 February 2023 8:00 – 9:00pm

Guest Speaker: Dr Raja Mukhergee supported by FASD HUB South West

Raja Mukherjee; Background: FASD Expert and Lead Clinician UK National FASD Clinic Consultant Neuro Developmental Psychiatrist & clinical lead for services Family Futures / Surrey & Borders NHS

We started by welcoming Raja and chatting about the significant progress in recent years where research and knowledge of FASD has grown. Raja has been researching and working in the field of FASD for 21 years where he is now seeing a huge shift change. He feels the recent publication of the **NICE Quality Standards for FASD** & **SIGN 156** will continue to drive this necessary change forwards and where Autism was little known about a few years ago, now most people understand what it is or/and know someone with it.

Parents Questions answered:

1. If you have lots of evidence of drugs in pregnancy, child born with withdrawal, a strong epigenetic history of alcohol and addiction, but have no written words about alcohol in pregnancy, can a clinician give a rounded view based on this and evidence of the assessment?

Epigenetics' is a complex field – no specific markers as yet identified in children. Genes being switched off and on. Current research in Brighton and the US to see if they can develop an epigenetic test.

Previous epigenetic research being undertaken to focus on links where family history could have an impact on the likelihood of being more vulnerable of giving birth to a child with FASD (if drinking alcohol in pregnancy) – the area of research is very complex – not enough known yet and no specific markers.

Julie asked why many clinicians traditionally might give a diagnosis label of 'likely FASD' / 'possibly FASD' / or an 'FASD working diagnosis' – Raja explained that these terms are similar to 'strongly FASD' and are often just words given as the clinician is not completely confident enough of their own experience of FASD.

This is part of the work that he and Dr Cassie Jackson will be shortly undertaking to support and educate clinicians across the country through clinical supervision, where they might not be sure about a case but by clinical discussion and with encouragement, they will give a full diagnosis. Either way those 'labels are enough to get support and scaffolding. Raja says it is crucial that we get clinicians diagnosing.

Julie asked how can clinicians take a pragmatic view to diagnosis without the written evidence?

Raja explained it's all about confidence of the clinician, they have the skills to diagnose but need to look at the background first which gives the clues.

What should happen when diagnosing is to start with a general conversation about what the parent (birth, adopted, kinship) might know. Was the child was placed into care, alcohol use in the family, that there was a chaotic life involving alcohol and/or drugs before and after pregnancy, neglect etc.

Raja said ….. This is where the pragmatic view comes in and where he wants clinicians to get brave and encourage clinicians to give a diagnosis.

There will be pieces of a puzzle not necessarily evidence of actually drinking in pregnancy.

He went on to say that you can divide exposure of alcohol into categories:

'NO risk': ie no exposure to alcohol

Unknown risk: ie suspected alcohol exposure but no confirmed evidence

Suspected risk: ie from pre and post-natal alcohol history, chaotic lifestyle but **no** confirmed record during pregnancy (if everything else ruled out)

Known risk ie recorded alcohol intake during pregnancy

Chronic drinking leads to greater exposure and greater risk of FASD traits

Julie said that in time it is hoped that gathering of evidence will become informed by midwives and health visitors recording evidence; driven by the NICE Quality standards.

2. For parents of adopted children whose birth history is not available, what's the best way to get a diagnosis of FASD? How can we support this obvious need without recognition from School as they will only accept a diagnosis? We feel my child's symptoms very strongly point to FASD, but so far the NHS response has been that we need a birth history.

Move in education to consider needs rather than just a diagnosis but diagnosis points to the need.

Takes time for research to catch up with practice and the research goes out of date quickly, example given where already Raja's book has parts of it that are now out of date!

Julie added it is about 'educating the educators', Raja suggested making contact with Carolyn Blackburn who supported the education chapter in his new book **Prevention, Recognition and Management of Fetal Alcohol Spectrum Disorder**

Regarding Schools & education generally they will be 10 years behind current knowledge, lots of work in progress to improve standards and pathways. We (parents) will know more than the people that support us to we need to push the doors open, provide information and resources when we get them and signpost them to training.

Julie highlighted that often the lack of diagnosis leads to dismissal of the parent?

Where gaining diagnosis is important, again often due to confidence and experience of clinician. More support to address this via peer reviews etc

Julie agreed to get Carolyn Blackburn in as an ask the expert, her background is FASD/SEN and education. Raja to email contact details.

3. How do we manage the damage to the vagus nerve through adolescence into adulthood and managing frustration and meaningful relationships ?

Vagus nerve complex, Raja a little confused with the question but how he reads it is the Parasympathetic and Sympathetic nervous systems and their role.

Ultimately need to focus on how to reduce arousal in each individual using a multimodal approach/recognize triggers/learn how to regulate. Look at how to decrease arousal. Chapter in Raja's book on PBS. Zones of regulation.

Positive behaviour support approach; reinforce the skills, focus on them at any opportunity.

Hot executive function – anxiety increases and brain switches off – stop functioning when arousal gets too high, emotions too high (ADHD/FASD) – try and identify trigger and address before gets too high – can involve meds. Good results to support ADHD & FASD. There are no medications for FASD specifically but there are medications for the co-morbid conditions linked to this.

Need to think about zones of regulation:

Will be a series of factors that escalates. Down regulation may be a problem for some.

How to support the individual in different situations – is it sensory, does it require medication.

Increase anxiety – brain switches off. The key is to identify before it gets too high.

Is their baseline on high alert?

Some discussion on how America over-prescribe due to lack of time with patients and limited follow up so rather than the child/young person spiralling medication is often looked at first. In this country when different styles of parenting have not had the required benefit then meds can be considered in some co-morbid conditions; ADHD is the example.

4. Many parents describe children or young people with addictions (binge eating, stealing, hoarding, vaping etc)… how can parents best support them to avoid the obvious route to seek alcohol/drugs?

These behaviours are a quick win to get a reward

FASD individuals are often prosocial and vulnerable

Frontal cortex damaged so unable to understand consequences and /or see other people's view point/ may need as part of their rigid reward/support demands

Manage by understanding strengths and weaknesses of individual with FASD

Drip feed their understanding of themselves so ultimately they will hopefully ask for help before making potentially vulnerable decisions

Not thinking about consequences

They need it now, so they cannot wait, this where the impulsivity kicks. To understand this a drip, drip, drip of self-awareness.

Strength based approach: Greatest wins he has seen is by the gradual drip, drip, drip of their own vulnerabilities, teaching them that they will get taken advantage of or where they do need support of others is Ok.

Try and find a group of children or young people with the condition as this will help them find their tribe. This way they will not feel like they have to 'compete' with others to be cool.

Reinforcement of finding their strengths and working on this to make them feel good at something.

5. FASD tired brain.

As young people move into adulthood & the workplace, how do they manage when they become brain tired much quicker than their peers? How do they manage the need for more rest time? Is it possible to work full-time? Or be a full-time college student?

'FASD Brain Tired' describes FASD very well, exhaustion. How do you feel when you are exhausted?

No two people are the same

FASD individuals work harder to succeed leading to a tired brain

Many have hypermobility and other co-morbid conditions which leads to having to work harder to process information and physically get exhausted

Drip, drip, drip again of strength and weaknesses

Make sure aware of own needs and limitation to avoid not getting overtired ….'Brain tired' – need to recognise this themself.

They can negotiate breaks with college/work; the law protects this through 'reasonable adjustments' should be made through (HR) human resource following disability legislation

Ensure they have awareness regards their FASD/need for > support; ask for help when they need it

Scaffold what they need by using the **FASD framework for primary** or **FASD framework for secondary/college education**

Focus on their strengths, build on something they are good at and want to do.

Some research shows that strength based approach will create a much more positive outcome. Scaffold the strength and support the rest.

6. Do people with fasd have physical disabilities as well as developmental delay in all areas. My daughters physical disability is very much not hidden?

Not all with FASD will have physical disabilities, direct teratogenic damage causes physical issues.

Greater than with more alcohol exposure

Only 2% have facial features in UK the figure is different globally but it is still only 10%

Rarer to have physical traits and often subtle

Huge range of presentations which can include significant physical disabilities. The **Lancet report 428 co-morbidities** demonstrate this well.

It is NOT uncommon to have multiple other co-morbid or connected conditions of un-diagnosed or diagnosis alongside FASD.

Recommended bitesize webinar: Raja & Neil's FASD Book Club - Session 8, Transition to Adulthood & Avoiding Secondary Disabilities

7. When fighting for a child's education and obtaining a EHCP how can we better link to professionals more easily to aide caseworkers cognition, as there is such a barrier in understanding where FASD is not recognised moreover a child is seen as willfully behaving?

This question was discussed in question 2. We need to educate the educators

8. To attempt to get a working diagnosis of FASD for our daughter, we have been recommended something called a Maudsley Report. Do you have a view on this?

The Maudsley is the National Hospital for psychiatry not an FASD clinic

They have ND pathways

They have an adoption Centre

They do not have an FASD clinic

Bristol have done more research into FASD than the Maudsley and that is nearer!

Julie asked 'Could you give this clarity Raja as since the Centre of FASD closing parents are often offered a Maudsley report through ASF'.

They should not as there is really no such thing as a Maudsley report, the Hospital does not have the FASD expertise required.

9. Fascination with the darker elements... we don't know if this is FASD or trauma, but we see our children obsessively interested in horror, violence, etc - all things from the more dark, macabre element of life. Why might this be? How to manage it?

Raja talked about nature vs nurture – could be embedded.

Interest stems from hat your experiences or exposure is.

Cognitive rigidity applies here where they will stick with it; so what this means is a little bit like the addictive traits mentioned previously they become obsessed very easily. If you could take one element of their interest so using that example of horror find a way of channelling it. It might be developing games themselves where he has seen several web developers who loved horror games become skilled at this as it is all about order, routine and repetition.

Julie suggested encouraging a shift into more positive aspects of their interests ie redirect to embed a different interest. Using this example of horror could they be encouraged to try stage make-up where they can develop a love of the arts where there are courses on stage make-up. Julie described how her eldest daughter shifted her obsession to stage make-up and was amazing at it, went to college to study this which led to further art courses and then photography.

Raja said by making it a gentle shift it is less obvious than banning something where they will be triggered and do it more.

10. How might the combination of exposure to both alcohol and crack cocaine in utero, impact a person in the long term?

Cocaine is a dopamine inhibitor – it can give lasting damage (as opposed to heroin).

Together alcohol and crack cocaine – give a double whammy effect. Co-co ethylene.

Diagnosis may need professional support to guide clinician. If you add to this

prematurity = additional issues it chips away at the complexity of a profile….

Julie mentioned having seen Raja give a talk at conference and more recently through an interview with an adopted parent via family futures where it provides a visual clue to the impact of drugs alongside alcohol, premature birth, co-morbid conditions etc…***(video link below of the interview)***

Raja described as cracking a rock with 2 different hammers with alcohol having the biggest impact. Other factors will have a hit at that rock where it might become smaller or damaged this might include prematurity or other co-morbid conditions.

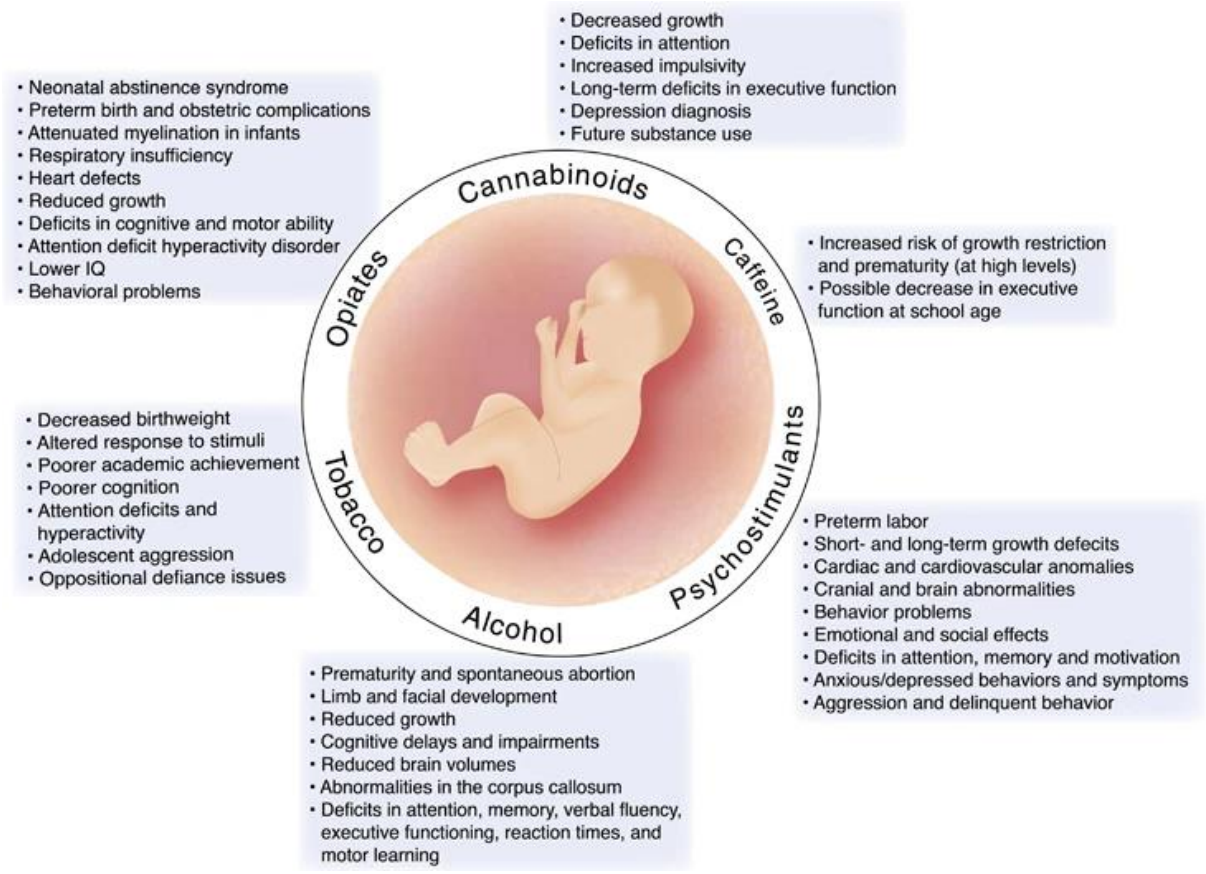
Cocaine is the double whammy regarding brain damage

Overlap in presentation difficult to unpick what causes what presentation and of course the same can be true of trauma in the womb through domestic violence

Other drugs can have an effect but not as great as that of cocaine – knowledge of the drugs and their different forms and the likely impact enables clinician to understand likely impact

Damage to certain pathways will cause ADHD like presentation and other pathways will cause autism like traits

Picture source and article on drugs in pregnancy : https://www.nature.com/articles/npp2014147



Recommended viewing: Dr Raja Mukherjee discusses FASD with an adoptive parent

Raja Mukherjee interview with and adopter (Family Futures publication): excellent reference to the rock analogy given in point 10

11. My daughter is 12, academically excellent (at grammar school, highest 11+ score of the pupils in her class) but no diagnosis of FASD as we have no evidence of alcohol in pregnancy; birth mother says she was clean and sober throughout this pregnancy.

How common is it to see this level of academic achievement in people with FASD?

She has a lot of other traits and recently diagnosed with autism but I'm wondering if I could/should pursue an FASD diagnosis and what she would gain from this in the long term?

Most of the children I encounter it seems to severely hamper their ability to learn in school, like my 10 year old with an FASD diagnosis (same birth mother).

Alcohol exposure doesn't necessarily mean FASD, however there are a range of presentations, FASD is a broad spectrum

Average IQ is 85 but still a range outside of that.

Why is important to add FASD diagnosis? – to understand and scaffold their vulnerability, it is this that is key.

Still need to understand their difficulties and their presentation.

Julie said it is not necessarily about what the brain can do, more about what it cant.

Raja agreed and said that gaps in learning may appear later – drop off when things get more difficult or where scaffolding of being surrounded by nurturing parents or good support elsewhere.

Build on strengths, hyperfocus on something they are good at, use this positively

Understand vulnerabilities and strengths to understand aetiology *(the cause, set of causes, or manner of causation of a disease or condition)* and outcome

Possible that alcohol exposure affects ovary which can impact over 4 generations – being researched

12. What are the best ways to support an FASD-affected teen around risk taking (sex, drugs, drinking etc.)?

Answered previously in binge eating/drinking.

Re focus on strengths

Distract by finding something else to become obsessed with, re direct the obsession on sex, drugs, masturbation etc.

What are their interests, hyperfocus on this and expand where you can as the investment in time to do this will pay off.

If School is becoming challenging due to these influences about 'risk taking or fitting in' look to join a group of families with young people/adults with FASD; this will make them see they don't need to fit in as they can be who they want to be and others like them will have other interests that might influence change of pattern or risk taking.

Alternative Provision or other forms of education can have a positive impact where young adults are listened to and their interests focussed on; they are likely to start to believe in themselves again and want to be like everyone else there instead. Looking at a vocational environment or learning independent skills placement. It is a spectrum so what works for one might not work for another but worth trying.

13. What realistic probability do our children have of not repeating the life choices of their birth families?

Drip, drip, drip understanding of strengths and weaknesses and FASD

There is a greater risk of addiction/criminality and chaotic lifestyle enhanced by prosocial traits/impulsive ADHD and autism traits; diagnosis of FASD or and ADHD / ASD important, early intervention, support with sensory needs and support with medication is needed

Change their pathway/narrative by redirection and tuning in to their interests

Recognising quickly influences that are negative e.g peer pressure to fit in; this is hard. Redirect with focusing on what they like even if it is not ideal (refer back to the horror example here where it can be side stepped into something else that can be positive)

Increased risk if individual isn't properly supported or understood. If we do nothing or heavily influenced by others then there is a chance of repeated cycle.

Understanding the person and their needs rather than treating the condition.

14. Young people with multiple diagnoses - would it be easier, especially when in education, to focus on just FASD? We've found education settings tend to zoom in on Autism because it's more familiar to them and never really provide for FASD.

Get what helps! But keep looking for the diagnosis.

Many individuals with FASD subthreshold (below a threshold) for ADHD and Autism diagnosis due to their traits and inexperience of clinicians to view this via FASD lens

Look through the lens of FASD for an autism diagnosis; Julie explained that sometimes to get a diagnosis of Autism without looking at FASD first they might not get a diagnosis of Autism but they would have it. This is due to the clinician not seeing or recognising the FASD first. Young people with FASD and Autism may be high functioning verbally or not afraid to be social but just don't get the rules or cannot maintain that level of friendship without being the risk taker or the relationship ends badly. Seeing FASD first allows the clinician to see both diagnosis.

In education get what support helps to address needs as far as possible

FASD pathways should in future improve diagnosis and support

Get what helps then add on/challenge to get more support

15. We are really interested to learn about how puberty may present with FASD - in particular emotions, cognitions, energy.

This question will be asked in the next session with Raja

16. Is there an advantage to having an FASD diagnosis as well as an autism diagnosis? We wonder if just the autism one alone might be enough for purposes of getting better support in school.

Covered above from question 14

17. Is it harder to get an autism diagnosis because it presents differently to the norm if in conjunction with FASD?

Covered above from question 14

18. Can you give us some examples of cases you have worked with where children/young people with FASD have excelled.... is there a common theme to the areas of learning or interest where they have superpowers?

Raja recommends 'Me and FASD' videos: https://www.youtube.com/watch?v=msu31F4o17I

& FASD Makes me, me: https://www.youtube.com/watch?v=b7zDpufe1XE

Different strength in different individuals – often visuospatial abilities are not affected

(examples of 'visuospatial' activities/jobs might include: Painters, sculptors, photographers, illustrators, printmakers and graphic designers are examples of artistic careers that use visual-spatial intelligence. Fine artists tap their visual-spatial intelligence to imagine how they might use colour, shapes, textures, lines and space to create a work of art.)

Build on individual strengths of what they show an interest for (for example bike repair, chopping wood, climbing mountains, skiing, making food, bowling, running, stamp collecting, looking for fossils)

Scaffold weaknesses

19. Any tips on managing the aggression we get from a child with FASD with an ADHD diagnosis

Lots of reasons for this

Complex profile

Hyper-arousal

Future – parent programmes will support this

Referenced **BMC psychiatry Young et al 2016 ADHD and FASD**

This research gives an overview of research into the relationship of FASD & ADHD:

“Intervention and treatment guidelines: Treatments for ADHD and associated FASD require an individualized approach”

Also referenced psychotropic drugs and FASD: this is the list of suggested medications that can support patients with FASD & co-morbid conditions

Some medications will not work so clinicians are encouraged trying to find the right fit for the patient.

Recommended by group viewing:

Dr Raja Mukherjee discusses FASD with an adoptive parent

Raja Mukherjee interview with and adopter (Family Futures publication): excellent reference to the rock analogy given in point 10

Summary of the event by a parent:

Drip, drip, drip

Build on his strengths

Scaffold his weaknesses

Educate him about his specific difficulties and build his confidence to ask for help and support

Educate his teachers, the professionals around him, and the wider community