

Fetal Alcohol Spectrum Disorder: Current research and future directions

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FASD: A quick overview

FASD is a common neurodevelopmental disorder in the same family as Autism and ADHD

It is caused by prenatal alcohol exposure

Around 40% of pregnancies in the UK are exposed to some level of alcohol, and around 4% of children in the UK have FASD, so about 1 in 10 pregnancies exposed to alcohol will result in a child with FASD

Reasons for this inconsistency include the pattern of alcohol exposure, genetics, and nutrition

Fetal Alcohol Syndrome (FAS) was first described in the 1970's – since then we have learned more about the variation of effects and now use the term fetal alcohol spectrum disorder



Strengths



People with FASD tend to be good at –
Creative arts, sports, music, caring, expressive language and vocabulary, functioning in a well-structured environment, self-awareness, building and mechanical skills, second languages, resilience, adaptability, motivation and determination, kindness.

Difficulties

People with FASD tend to struggle with –
Understanding abstract concepts, cognitively shifting from one task to another, processing information quickly, making decisions based on multiple considerations, understanding social cues, linking cause with effect, recalling episodic memories, making sense of sensory information, regulating their own emotions.

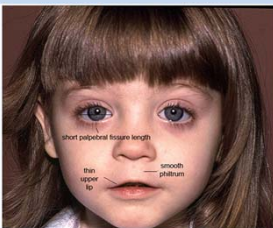


Terminology – The “alphabet soup”

Fetal Alcohol Syndrome (FAS) - First described by Jones and Smith in 1973 – focuses on physical birth defects
Partial Fetal Alcohol Syndrome (pFAS) – Sub threshold for ‘full’ FAS
Fetal Alcohol Effects (FAE), later Alcohol Related Neurodevelopmental Disorder (ARND) – Added in the 1990s to account for the neurodevelopmental presentation without the physical signs
Alcohol Related Birth Defects (ARBD) – Physical signs without neurodevelopmental presentation – rarely used
Neurodevelopmental disorder associated with prenatal alcohol exposure (NDPAE) – included in DSM-5 – broadly same as FAE/ARND
Fetal Alcohol Spectrum Disorder (FASD) – umbrella term capturing all of the above



The facial features of FAS



Key characteristic of Fetal Alcohol Syndrome
The Sentinel Facial Features
Palpebral fissure length ≥ 2 SD below the mean
Philtrum rated 4 or 5 on 5-point scale of the University of Washington Lip-Philtrum Guide
Upper lip rated 4 or 5 on 5-point scale of the University of Washington Lip-Philtrum Guide
Still diagnostically relevant in some cases...

New UK diagnostic criteria

FASD **with** sentinel facial features (about 10% of cases)

1. Three sentinel **facial features** (short palpebral fissures, smooth philtrum and thin upper lip)
2. Prenatal alcohol exposure **confirmed or unknown**
3. Evidence of **severe** impairment in **three or more** of the identified neurodevelopmental areas of assessment or, in infants and young children, presence of **microcephaly**.

New UK diagnostic criteria

FASD **without** sentinel facial features (about 90% of cases)

1. **Confirmation** of prenatal alcohol exposure
2. Evidence of **severe** impairment in **three or more** of the identified neurodevelopmental areas of assessment

(This system also used in Canada and Australia)

New UK diagnostic criteria

Neurodevelopmental assessment

- **Severe** impairment in 3 or more (≥ 2 SD below mean or clinical range)
 - motor skills
 - neuroanatomy/neurophysiology
 - cognition
 - language
 - academic achievement
 - memory
 - attention
 - executive function, including impulse control and hyperactivity
 - emotional regulation
 - adaptive behaviour, social skills or social communication

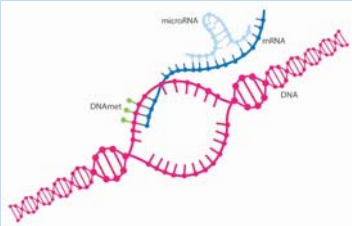
How do you test for PAE?



How do you know if a child was exposed to alcohol prenatally?
 This is needed for diagnosis in most cases (facial features can be used but that is at most 10% of cases)
 Mostly it is done through official records or careful interviewing of parents
 Often, that information is missing by the time an adopted child comes for an FASD assessment
 Would it be great if there was a blood test for PAE?
 This is possible in newborn infants, but not later than that
 But there is some hope...

How do you test for PAE?

University of Salford study ongoing now
 To test the hypothesis that prenatal alcohol exposure leaves a characteristic 'fingerprint' on micro-RNA



More on this here:
<https://hub.salford.ac.uk/fasd/2023/09/11/novel-approaches-for-identification-of-prenatal-alcohol-exposure/>

Assessment of FASD: Information and training



NICE quality standard on FASD published in 2022 - <https://www.nice.org.uk/guidance/qs204>
 SIGN156 - <https://www.sign.ac.uk/our-guidelines/children-and-young-people-exposed-prenatally-to-alcohol/>
 RCPCH: How to Manage FASD in Community Paediatric Services <https://learning.rcpch.ac.uk/live-courses/how-to-manage-fasd-in-community-paediatric-services/>
 University of Edinburgh: <https://www.faast.ed.ac.uk/our-services/training/>
 National FASD Clinic: <https://www.fasdclinic.com/>

How common is FASD in the UK?

British Paediatric Surveillance Unit: 10 confirmed and 37 probable cases of FAS reported in 12 months between Oct 2018 and Oct 2019 in UK and Ireland – incidence rate of 3.4 per 100,000 live births (Burleigh et al, 2023)

University of Bristol: 6% - 17% of ALSPAC cohort (n=14,500) screened positive for possible/probable FASD (McQuire et al, 2018)

International modelling / meta-analysis: 3.24% (Lange et al, 2017)

University of Salford: Active Case Ascertainment (ACA) study: 2% - 4% of children in mainstream schools in Greater Manchester (McCarthy et al, 2021)

ACA studies in other countries: USA 3%-5%, Canada 3%, Italy 5%, Croatia 5%



Salford FASD prevalence study: What our participants told us

- That overall, they had a positive experience of taking part
- Children either enjoyed or were indifferent to taking part
- Even though the result was sometimes a shock, the report on their child was accessible and helpful
- Often parents felt school were dismissive of their concerns
- We found cases of quiet, well-behaved children (girls) with significant deficits undetected by school



FASD in sub-populations

International Meta Analysis (Popova et al, 2019)

Indigenous / Aboriginal: Up to **6.1%**

Special educational settings: Up to **8.4%**

Prisons: Up to **15%**

Childcare settings: Up to **31%**

UK clinical study (Gregory et al, 2015)

34% of children coming into care, and **75%** of children being put forward for adoption had prenatal alcohol exposure

27% of referrals for looked after children had FASD



Pre and Post Natal Adversity

Adverse Childhood Experiences (ACEs)

Abuse, neglect and household dysfunction between birth and adulthood

Score from 0-10 – score of around 4+ is a strong predictor of many adverse outcomes (mental health, physical health, academic achievement, life outcomes...)

Around **15%** of people in the **general population** have an **ACE score of 4+**

Around **40%** of people with **FASD** have an **ACE score of 4+**



Pre and Post Natal Adversity

A small number of studies have investigated the combined impact of PAE and ACEs

We need more data, but what we can say with some confidence is:

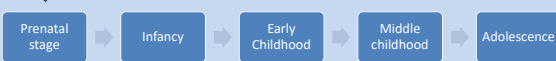
1. There is a high level of postnatal adversity in the FASD population
2. In children with a history of both prenatal alcohol and postnatal adversity, prenatal alcohol is one of the strongest predictors of the severity of their developmental difficulties

Pre and Post Natal Adversity

Almost all studies into ACEs (AKA trauma, early life adversity...) have ignored the prenatal stage

Almost all studies into FASD have ignored ACEs

WE NEED TO ACKNOWLEDGE THE IMPACT OF BOTH PRE AND POSTNATAL ADVERSITY!!



FASD and the criminal justice system

People with FASD up to 19x more likely to be incarcerated (Popova et al 2011)

Why?

- People with FASD may struggle to link cause and effect, They may struggle with abstract concepts such as rules and laws
- They may be easily led and suggestible
- They may struggle to control their own emotions and behaviours
- They may be impulsive and not stop to think



FASD and the criminal justice system

University of Salford research study on police interviewing

Young adults with FASD made significantly more mistakes in recalling a story than young adults without FASD.

They were more likely to make up new details and report that they believed those details (confabulation)

And they were more likely to endorse new details added by the researcher which were not in the original story (suggestibility)
(Gilbert et al, 2023)



FASD and the criminal justice system

University of Salford research project:
Are young adults with FASD likely to be 'fit to plead'?

In England and Wales, fitness to plead is defined by the Pritchard criteria. Defendants must be able to:

1. Understand the proceedings of the trial
2. Understand the evidence involved in the case
3. Instruct their legal representatives
4. Challenge a juror to whom they may object

A person with FASD would potentially not meet this criteria, but the question has never been asked in the UK (Some special courts in Canada for this)



Interventions, treatment & support



SPECIFIC: The Salford Parents and carers' Education Course for Improvements in Fasd outcomes in Children

7-session online group training in FASD for parents and caregivers

Written and delivered by academics, clinicians and people with lived experience of raising a child with FASD

Based on a neurobehavioural approach (behavioral difficulties as the result of brain differences)

Practical advice on FASD-informed parenting

Signposting to existing resources

Currently in feasibility (pilot) trial stage

Potential to be delivered as post-diagnostic support package to 1,000s of families across the UK

Interventions, treatment & support



SPECIFIC: The Salford Parents and carers' Education Course for Improvements in Fasd outcomes in Children

Preliminary results suggest the course is well received, useful, and enjoyable

Full RCT (coming soon) to show effect on parents' stress and confidence in parenting, children's behavioural difficulties

"This course has been the first training course I have been on which it's totally relevant to my child and the information fits him and so therefore the strategies suggested are useful. Thank you."

"I have learnt so much more in these 7 weeks, than 4 years of my own research and strategies used by our own professionals."

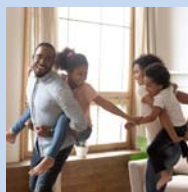
Trauma therapy for children with FASD

Chrysalis associates: Yorkshire Clinical Psychology team specialising in attachment and trauma therapy for children and families (play therapy, eye-movement desensitisation and reprocessing (EMDR), dialectical behaviour therapy (DBT))

Chance meeting at conference led to collaboration

Usual approach seems not to work in children with FASD

Service evaluation followed by development of therapy package



Interventions, treatment & support

Some key lessons learned along the way:

1. Some families have severe and complex needs and are so far along that a parenting course would be too little too late – they need something much more intensive (but these are a minority)
2. The earlier you recognise FASD, the better the outcomes (Streissguth et al, 2004; Alex & Feldman, 2012; Price, 2019)
3. What most families want is not difficult: A little extra support in school, to be believed, to not have to fight for services, service providers who have had FASD training
4. The current full economic cost of FASD is likely in the billions – if we can do better at recognising and supporting in early years, that would save money

Salford FASD

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Professor Clare Allely | Dr Alan Price
Dr David Gilbert | Robyn McCarthy
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<https://hub.salford.ac.uk/fasd/>
