Articles

FASD: The neurodevelopmental disorder frequently overlooked within Family Law

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Fetal Alcohol Spectrum Disorder (FASD) is a life-long neurodevelopmental condition that is more common than Autistic Spectrum Disorder (ASD), and yet to date does not benefit from similar levels of social understanding, or clinical and educational provision. In the UK general population, it is thought that up to 3.6 per cent of children may be born with FASD, compared with roughly 1 per cent for children with ASD – and this may be an under-estimate (McCarthy et al, 2021). FASD can result from any amount of prenatal alcohol exposure (PAE) at any point during pregnancy; there is no known safe amount or time to consume alcohol during pregnancy, and therefore the World Health Organisation advice is to avoid alcohol completely in the lead-up to and during pregnancy wherever possible.

So, what does this have to do with family law specifically? While FASD affects children and families from all walks of life, there are certain populations who are at significantly greater risk of having alcohol exposed pregnancies. This includes families within care proceedings. The percentage of children in care and adopted children who are thought to have, or be at risk of FASD, varies depending on the study. Lange et al (2013) suggested a world prevalence of 17 per cent for children in care, while Gregory et al (2015), in a UK-based study in Peterborough, found that 27 per cent of children in care met diagnostic threshold for FASD. The same study reported a history of prenatal alcohol exposure in 55 out of 160 health assessments for children in care (34 per cent), and 34 out of 45 medical assessments for adoption (75 per cent). One can therefore extrapolate from these figures that a significant proportion of children on the case load of a public children law solicitor may be affected by this condition.

Often it is substance misuse that receives the greatest attention and is most likely to be documented in social care chronologies, including suspected or confirmed use of substances during pregnancy. There is a common misconception that drugs do the greatest harm to developing babies, and yet alcohol, a 'socially acceptable' and readily available commodity, is one of the most teratogenic substances of all to a developing fetus. Conversely, with

opiates like heroin, following an initial neonatal abstinence syndrome, the long-term neurodevelopmental implications of prenatal exposure are far less severe than those resulting from prenatal exposure to alcohol (Behenke et al, 2013). Because this is not commonly understood, many babies and children within care proceedings may not have known prenatal alcohol exposure clearly documented, which can result in them not receiving appropriate diagnosis later in their childhoods.

FASD is best understood as a syndrome; a collection of symptoms and conditions that are caused by prenatal exposure to alcohol. While the most obvious manifestations of FASD are brain-based, FASD is a whole-body diagnosis, with multiple physical manifestations, including heart, kidney, eye (sight), and ear (hearing) disorders being linked with prenatal exposure (Popova et al, 2016). FASD is also associated with sentinel facial features. The three primary diagnostic sentinel facial features associated with prenatal alcohol exposure (in absence genetic aetiology) are short palpebral fissures, a thin upper lip, and a smooth, undefined philtrum. Only around 10 per cent of children with FASD have sentinel facial features however, and therefore the vast majority – 90 per cent – do not. The only time the presence of sentinel facial features may be clinically significant is when a child with suspected FASD does not have a documented history of prenatal alcohol exposure. In this

circumstance, if the child has all three facial features in absence of any known genetic cause, they can be diagnosed with FASD despite an undocumented history. This is due to the specificity to PAE of the three features occurring together.

Cognitive and neurodevelopmental difficulties associated with FASD have a significant impact on a child or young person's adaptive functioning. While many children with FASD have near-normal IQ (albeit with what is often described as a 'spiky' cognitive profile), their broader deficits in executive function (including attention, working memory and emotion regulation), receptive and/or expressive language, and social cognition results in significant functional deficits. Many of these deficits are associated with damage to the prefrontal cortex (PFC); an area of the brain most vulnerable to the teratogenic effects of alcohol. Relatedly, roughly three-quarters of children with FASD will meet diagnostic threshold for (secondary) ADHD, while just under half of children with FASD will meet diagnostic threshold for (secondary) Autistic Spectrum Disorder. The PFC plays a significant role in modulating social cognition and inhibitory control, and so it fits that PAE would result in these secondary conditions.

Prenatal alcohol exposure also impacts upon the development of the neuroendocrine system, such as the hypothalamic-pituitary-adrenal (HPA)

axis. The HPA axis is a homeostatic feedback system that mediates the effects of external stressors by regulating various physiological responses. Most notable for those with FASD is the role the HPA axis plays in emotion and behaviour regulation. For neurotypical individuals, the HPA axis effectively enables us to 'down-reg' our physiological systems in order to regain physical and emotional regulation in the presence of anxiety, anger or even excitement. While we can feel these emotions strongly, we are also able to calm ourselves down without intervention, and a well-functioning neuroendocrine system plays a significant role in this process. The HPA feedback system can be disrupted in individuals with FASD, which results in them struggling to regulate their emotional responses to stress. Affected children therefore frequently present with externalising behaviours, particularly in over-stimulating environments such as school. These behavioural challenges are compounded by impulsivity, poor inhibitory control, and poor social

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adults) with undiagnosed FASD can end up with a range of mental health diagnoses in an effort to explain their mood lability and poor emotion regulation, when the aetiology may in fact be organic in origin as described. This may also be the case for undiagnosed parents within care proceedings, whose poor adaptive behaviour and regulatory challenges

may have been misinterpreted as being solely due to childhood trauma and other experiential factors.

Children and young people with FASD are often outwardly very sociable (possibly over-familiar) and engaging individuals, which can mask their underlying deficits. They would pass ‘the mingle test’; if you were to have a short conversation with them, you would not necessarily be aware that there are problems. As a result of this outward presentation, in education and other social settings, children and young people with undiagnosed FASD can be misunderstood as simply having a behavioural problem, rather than the acquired brain injury that FASD represents.

Individuals with FASD are extremely socially vulnerable, which is at its most explicit during adolescence and beyond. They are easily exploited due to their poor social cognition, and often end up as the ‘fall guy’ in peer groups. These are young people who seem not to learn from past mistakes, and fail to consider the possible consequences of their actions. There is a strong association with FASD and falling into trouble with the law; young adults with FASD have been found to be nineteen times more likely to be sent to prison than those without FASD (Popova et al, 2011).

The dysregulated and emotionally labile behaviour associated with FASD presents an additional challenge when it comes to children involved in care

proceedings. This is because FASD-related behavioural challenges can masquerade as behaviour associated with attachment disruption and trauma. If a child has suffered maltreatment and neglect, it can be tempting to reductively assume that any presenting behavioural and neurodevelopmental difficulties may be fully explained by these experiences. This can prevent professionals from remaining curious as to whether there may be anything else contributing to the child's difficulties. It has also been found that children with FASD frequently present with what appears to be 'disorganised' attachment behaviour, even when they do not have a history of significant trauma. This is because the cortical and neuroendocrine damage caused by FASD results in changes to the way children understand social relationships, and how they behave toward their primary attachment figures (Mukerjee et al, 2019). These findings can have huge implications for adoptive families for example, who can often be referred for inappropriate therapeutic intervention because the child's difficulties have been assumed to be predominantly attachment-related, when if they are instead due to FASD, they would require a very different approach to intervention and support.

I am frequently asked by professionals, if a child has trauma and is receiving support for this, what is the point in assessing for FASD, what will it add to the picture? The developmental trajectory for a child

with ‘uncomplicated’ trauma compared with a child who has both FASD and trauma, is very different. The child with FASD is likely to present with broader and more severe functional deficits throughout their lifetime, which is not correlated with the severity of trauma they have suffered (Mukherjee et al, 2018). Children with FASD also respond differently to traditional approaches to treating trauma, and require a specific approach to managing behaviour and facilitating regulation. Therefore, not acknowledging the possibility of FASD means a child is unlikely to receive the support and intervention they need throughout their lifetime, which leaves them extremely vulnerable.

It is also important to be mindful that the presence of neurodevelopmental conditions like FASD impacts upon the way trauma presents itself behaviourally. Without knowing about underlying neurodevelopmental conditions, there is a risk of misinterpreting the reasons for children’s behaviour, and misattributing aetiology. Psychological assessment of children and young people within care proceedings should therefore always consider the possibility of cognitive and neurodevelopmental impairments, including FASD, and formulate accordingly.

FASD-related difficulties are often not apparent until a child is school-aged, particularly from year one onwards as the curriculum becomes more formal

and less based on free play. A developmental divergence occurs over the course of childhood such that from the age of six or seven onwards, there is increasing deviation away from the mean, with the gap in adaptive functioning between neurotypical children and those with FASD, widening incrementally over time. This means the needs and vulnerabilities of affected children also become greater over time. As described, the onset of adolescence represents a peak period of social vulnerability for children with FASD, with disrupted secondary education, trouble with the law, inappropriate sexual behaviour, and drug and alcohol difficulties being common manifestations of this vulnerability (Streissguth et al, 2004).

In day-to-day family law practice, it is worth being mindful that where there is reference to alcohol and substance misuse in social care chronologies, there may be an increased risk that children have been prenatally exposed. Seeking confirmation of exposure is pertinent, because documented evidence is key for health professionals to be able to diagnose FASD. Sufficient evidence does not always need to be confirmation by parents, but could also take the form of police records or social care professionals witnessing alcohol exposure during pregnancy. Occasionally it may be appropriate to discuss the possibility of FASD with a client. In this situation, it is of vital importance that the mother feels reassured, and that language used in

relation to alcohol use during pregnancy is not shaming or blaming. Women may have an alcohol-exposed pregnancy for many reasons, such as not realising they were pregnant, not knowing the harm it causes, environmental pressure, or struggling with acute addiction. It is extremely rare that a mother drinks with the aim of harming her baby.

Where PAE or FASD is suspected, it is important to highlight this within court proceedings, particularly if the child is to be adopted. Adoptive families rely on information provided in Child Permanence Reports (CPR) and social care chronologies when seeking assessment and diagnosis, often many years down the line. Children with suspected FASD should be referred to their local community paediatric service via their GP. While there are currently difficulties with the provision of FASD assessment at a regional level, the NICE Quality Standard in FASD published in 2022 has set a precedent that paediatric services must move toward providing a pathway for assessment. Planning and improvement is ongoing. The Surrey FASD Clinic is another tertiary option to be explored if local services are currently unable to support assessment.

In summary, FASD is a condition that needs to be highlighted, not just within family law, but also more widely. By de-stigmatising this common neurodevelopmental disorder in the way we think and speak about it, we

can hope to have some impact on prevention for future generations, and also to facilitate in identifying at-risk children, for whom receiving appropriate and timely diagnosis can mean the difference between receiving appropriate support and intervention, and enduring a lifetime of vulnerability and associated poor outcomes.

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For further information about FASD and relevant services and guidelines:

- nationalfasd.org.uk
- preventfasd.info
- https://www.sign.ac.uk/media/1092/sign156.pdf
- https://www.nice.org.uk/guidance/qs204
- fasdclinic.com

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