research in practice

Frontline Briefing

Fetal alcohol spectrum disorder (FASD) – identifying and responding in practice with families

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Introduction – why should I read this?

Fetal alcohol spectrum disorder (FASD) is a complex, lifelong neurodevelopmental disorder that occurs in the fetus due to prenatal alcohol exposure (PAE), i.e. the pregnant woman/person drinking alcohol during gestation.

Recent research suggests that 2-4% of the population may have FASD, meaning it potentially exceeds the prevalence of autism, however only a minority of children receive a diagnosis (McCarthy et al., 2021). The prevalence could be even higher, as this study was conducted in mainstream primary schools and specialised education settings were not included. Where longitudinal data was used to retrospectively screen children, higher rates of 6-17% were found (McQuire et al., 2019). FASD disproportionately affects children in care and those who are adopted (Department for Education, 2024; Gregory et al., 2015; Mukherjee et al., 2017; Scottish Intercollegiate Guidelines Network [SIGN], 2019). An audit conducted by paediatricians found that 27% of the children in care who they supported had FASD, and 75% of those placed for adoption had been exposed to alcohol (Gregory et al., 2015).

Despite **statutory guidance** (2015) emphasising the need to consider conditions which are prevalent in children in care (including FASD in medical assessments for looked-after children) (Gov, 2015), FASD remains under-recognised. For example, 80% of FASD diagnoses were missed in a sample of adopted and fostered children (Chasnoff et al., 2015). This low diagnosis rate may be due to limited knowledge about FASD across social care and wider society, leading it to be overlooked as a cause of multiple health-related difficulties and hindering effective support and adjustments for children and families managing undiagnosed FASD (Ritfeld et al., 2024).

Children's social care practitioners are often the first to identify individuals and families at risk of FASD and play a critical role in supporting people with FASD – and their families – before, during and after the assessment and diagnosis process.

This briefing focuses on mothers and other pregnant people who have children's social care involvement. Child and family social care practitioners need to understand FASD because alcohol use during pregnancy occurs in the lives of many families, and practitioners are likely to work with children and young people with FASD. FASD is also an adult social care issue, and child and family practitioners can help adults receive the right support. For more information on supporting adults who have FASD see: National FASD's webpage for **Adults** and **Supporting success for adults with FASD**.

As FASD is preventable, the focus might be on the risk during pregnancy, but practitioners also need to recognise the lifelong impact throughout a child's life and into adulthood. A child or young person with FASD can thrive when their strengths are recognised, their needs are met and they are appropriately supported (FASD Hub Australia, 2024; Skorka et al., 2020).

This resource supports practitioners to:

- Understand their role in prevention of FASD.
- Understand the likely impact of FASD on families.
- Support children and families living with FASD.

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Inclusivity in language and practice

Social vs medical model of disability
This briefing using language from the medical as well as the social model of disability to reflect the terminology used in academic literature on FASD. The medical model of disability often focuses on deficits or 'impairments' that can be 'fixed' or treated (see Scope's website), whereas the social model of disability encourages a more holistic view, emphasising societal barriers such as a lack of support and understanding that contribute to challenges for people with FASD.

Fetal vs foetal
The resource uses 'fetal' because it is the medical spelling and the spelling used in the diagnostic guideline. You may see 'foetal' in some of the resources we signpost to.

Gendered language
This resource uses 'women and other pregnant people' and 'mothers/gestational parents' where possible to reflect the diverse experiences and identities of individuals and families. This language aims to encompass the spirit of compassionate and respectful practice, but recognises that language evolves and preferred terms will vary for each person. Where referring to specific research studies, the resource uses terminology from the article (e.g. women/mothers).

Practitioners should be mindful of:

- Avoiding assumptions. Ask individuals how they prefer to be referred and use their preferred terms.
- Taking opportunities to have genuine conversations about identity and experiences to build trusting and respectful relationships.

For more information on gender inclusive language see:
www.britishjournalofmidwifery.com/content/research/gender-inclusive-language-on-public-facing-maternity-services-websites-in-england

Part 1: About FASD

Why is it important to have awareness of FASD?

Low understanding of FASD has been linked to 'difficulty in managing children' suspected of having the condition, feelings of frustration and normalisation of behaviours which challenge (Gilbert et al., 2024). It can also have tragic outcomes and may have contributed to the deaths of children/young adults as described in:

- Two Tragedies (Badry, 2014; Pringle, 2014).
- A 2020 Derbyshire **multi-agency learning review**.

What are the key features of FASD?

Key facts about FASD include:

- All people with FASD have significant differences to typical neurodevelopment (SIGN, 2019), meaning that there is no mild version of FASD (Department of Health and Social Care [DHSC], 2021).
- Individuals will be affected differently and are likely to face different challenges (SIGN, 2019, p.26).
- There is no one neuropsychological measure to assess for FASD (Chudley et al., 2005).

A young adult with FASD explains:

> ***"Even though I had four other siblings with the same diagnosis, I still felt alone. I felt alone because it, like, impacts people with the condition differently. It's, like, as unique as a fingerprint, pretty much"***
>
> Young person with FASD, quoted from Jackson (ACAMH, 2023)

An important way to learn about FASD is by listening to young people and young adults who have FASD:

FASD Awareness: Maggie May - "MyFASD, My Voice"
www.youtube.com/watch?v=uEXF0l_o7QA

Sandra Butcher and Rachel Jackson provide insight into FASD in this ACAMH podcast
https://acamhlearn.org/Learning/FASD_(Fetal_Alcohol_Spectrum_Disorder)%3a_Understanding_the_Diagnosis/5d52e9ec-77d8-4a53-a1cf-a335ffb6ff7a

Factors that can result in FASD

While alcohol use at any stage of pregnancy is a risk and should be avoided, there are critical periods where alcohol has a more serious effect than other times; however the exact timing of these critical periods remains unclear (Nykjaer et al., 2014; Clarren & Cook, 2018).

- There is **no known safe level of alcohol use in pregnancy** (Chief Medical Officers, 2016), so a fetus that is exposed to any amount of alcohol could be affected.
- It is a myth that only those who binge-drink or who are dependent on alcohol are at risk of having babies with FASD.
- 1 in 13 alcohol exposed pregnancies will result in a child with FASD (Lange et al., 2017).

Not all children exposed to alcohol as a fetus will have FASD as there is variability in the level of vulnerability to prenatal alcohol exposure (PAE). These risk levels can be influenced by various factors such as:

- The dose, timing and pattern of PAE.
- Nutrition and lifestyle during pregnancy.
- Mothers/Gestational parent's genetics – e.g. the genetic variability to metabolise alcohol.
- Fetal genetics.

(Davis et al., 2013; Eberhart & Parnell, 2016; Kaminen-Ahola, 2020; Mukherjee, 2017)

The important role fetal genetics plays is shown in twin studies. There is 100% concordance rate in FASD diagnosis for monozygotic (identical) twins, meaning if one twin has FASD, then the other will also have it. In contrast, for dizygotic (fraternal) twins, the concordance rate is 56%, meaning if one twin has FASD there is a 56% chance the other twin will too (Hemingway et al., 2019). This suggests that genetic factors play an important role in how a fetus responds to prenatal alcohol exposure.

Genetic vulnerabilities that make FASD more likely to occur can be passed on by both parents but only a pregnant person's drinking can cause FASD itself. If the fetus is not directly exposed to alcohol during pregnancy, any influence from the father/sperm-giving parent is genetic and the disorder is not true FASD. However, recent evidence suggests that fetal growth can be affected if the father drinks before conception (Nie et al., 2020; van der Windt., et al., 2024; Zhou et al., 2021), including facial abnormalities associated with some instances of FASD (see **Figure 1**) (Thomas et al., 2023).

- To find out more see this summary of recent research: **Fetal alcohol syndrome: Why fathers need to watch what they drink too**.

During the COVID-19 pandemic, alcohol use in pregnancy increased in some countries (Kar et al., 2021; Rodriguez et al., 2020; Smith et al., 2022). This is significant for children conceived and born during this period, as most will not be identified with FASD at birth. Difficulties may take years to emerge, and without a history of prenatal alcohol exposure, other causes of developmental difference may be assumed (Sher, 2020).

Reflection:

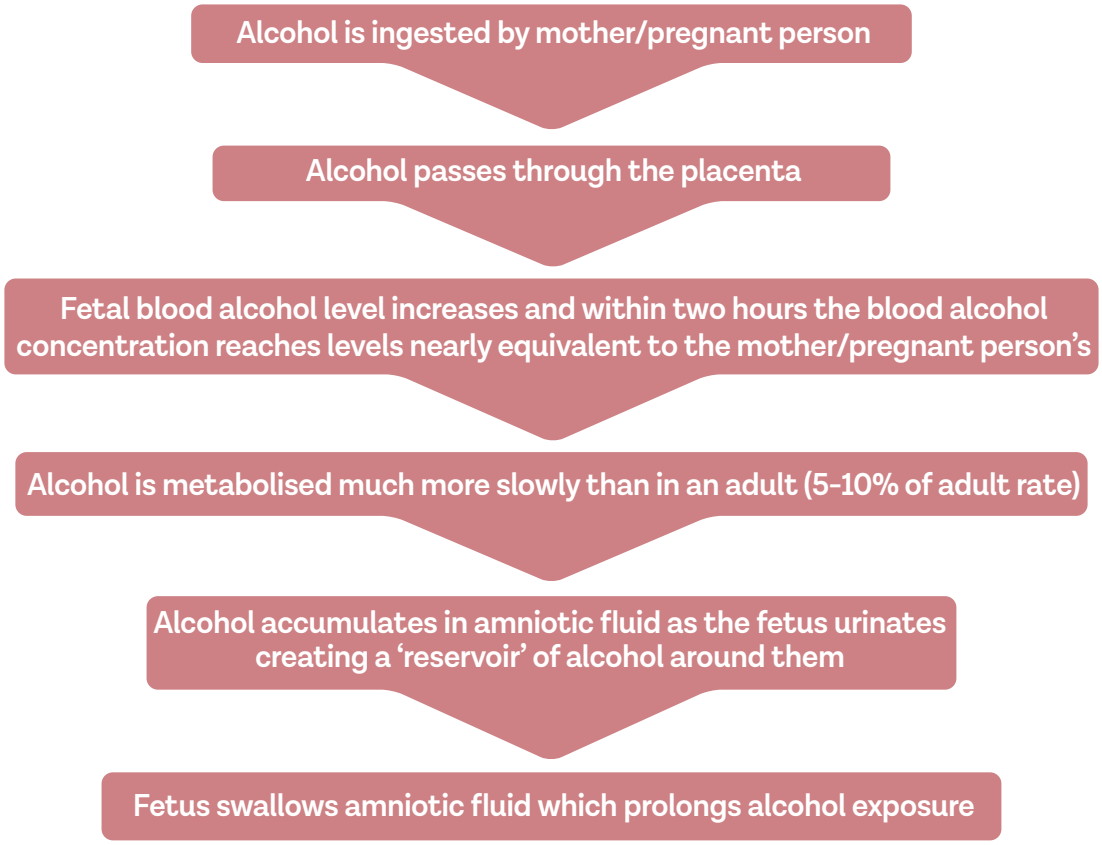
Think about a family you have worked with where there was prenatal alcohol use.

- Were any assumptions made about the level of risk based on the parent's alcohol use patterns (e.g. binge drinking vs occasional use)?
- How might your awareness of FASD risk factors change your approach to supporting families in future?

How does alcohol affect the fetus?

Alcohol is a teratogen, a substance that can affect fetal development. Compared to other substances (such as marijuana, cocaine and heroin), alcohol produces by far the most serious neuro-behavioural effects to the fetus (Stratton et al., 1996). Even low levels of alcohol exposure have been shown to lead to pervasive developmental abnormalities, at any stage of pregnancy (Lange et al., 2017).

Figure 1
Mechanism and potential impact of alcohol



(Burd et al., 2012; Gupta et al., 2016)

Many of the mechanisms of alcohol teratogenesis remain uncertain. However, alcohol can have characteristic impacts on development that persist after birth and throughout life. These may include a pervasive, lifelong impact on development of the central nervous system function (DHSC, 2021).

FASD is not the only risk arising from PAE. It also increases the risk of:

- miscarriage
- stillbirth
- premature birth.

(Henriksen et al., 2004; Kesmodel et al., 2002; Patra et al., 2011)

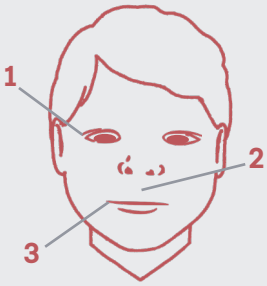
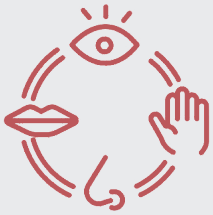
Recognising FASD

Neurodevelopmental disorders (e.g. FASD, attention-deficit/hyperactivity disorder (ADHD) and autism) are conditions that affect the development of the nervous system, which includes how the brain and spinal cord function. FASD is also a 'whole-body' diagnosis (Moritz et al., 2023). The range of effects on the individual are diverse. There are at least 428 co-occurring conditions which individuals with FASD may have (see Popova et al. 2016). Some examples are provided in Table 1.

Table 1
What you might see in a person with FASD

Area affected (as per diagnostic criteria in SIGN, 2019)	**Examples of what this might look like**
Attention 	> Struggle to filter out background noise, leading to overstimulation. > May be easily distracted or overwhelmed in busy environments.
Executive function 	> Too much information presented at once may be overwhelming and not fully understood due to slower information processing. > Finding it challenging to integrate different sources of information. > Finding it challenging to organise own thoughts and behaviours to meet long-term goals and may act impulsively. > Finds it difficult to plan routes, navigate, and follow multi-step instructions due to differences in spatial working memory, particularly for complex tasks.
Memory 	> Challenges in one or more aspects of memory such as visual and verbal memory. > May have gaps in their memories, sometimes appearing to 'fill in the blanks' or fabricate information.
Academic achievement 	> May have difficulty with abstract constructs, such as time and money. Difficulties with problem-solving, abstract thinking, memory and sequencing can make maths more challenging for people with FASD. Hands-on, visual approaches may support learning.

Cognition 	> While some people living with FASD have a low IQ, many will have an IQ within the normal to high range. However, executive functioning and other brain function challenges are common.
Language 	> Being friendly, but not really understanding what is involved in two-way interactions. > Strong verbal skills but might not always understand the deeper meanings in conversations. > May experience delays in language acquisition, problems with comprehension, and challenges with expressive and receptive language skills. Two of the most common co-occurring conditions include: - **Expressive language disorder** - difficulty in the effective expression of messages and ideas to others. Can include delayed expressive language, not expressing wants and needs, limited vocabulary, grammar, syntax. - **Receptive language disorder -** affects how language (written and spoken) is received and processed. This affects understanding spoken information, such as following instructions and following a narrative such as a story.
Affect regulation 	> May behave socially and emotionally younger than chronological age. > High levels of emotional expression which may result in significant mental health issues like long-standing anxiety or depressive disorders. > May display behaviours that are often labelled as 'defiant' with oppositional defiant disorder or conduct dissocial disorder being common co-occurring diagnoses. These behaviours can be better understood as communicating a difficulty or a need for additional support.
Adaptive behaviour 	> Challenges in social communication and reading social cues. > May be easily taken advantage of as their suggestibility and difficulty in reading other people's intentions can be exploited by others.
Motor skills 	> Delays or difficulties with fine motor skills, gross motor skills, graphomotor skills, or visual-motor integration. > Challenges in relation to tone, reflexes, balance, co-ordination and strength.
Neuroanatomy/ neurophysiology 	> Head circumference below third percentile; a seizure disorder with no known postnatal influences; structural brain abnormalities associated with PAE.

May also experience:	
Sentinel facial features  	In only 5 to 10 per cent of cases: 1. Short palpebral fissures – eye openings (distance between the inner and outer corners of the eyes) are shorter than average. 2. Smooth/indistinct philtrum – vertical groove between the upper lip and the nose is flatter or absent. 3. Thin vermillion (upper lip) border – upper lip appears narrower than usual. There is no association between the presence of these features and 'severity' of developmental differences (Webster et al., 2023). Sentinel facial feature guides used in diagnosis acknowledge and seek to reflect racial/ethnic variations in facial morphology.
Sensory processing and integration issues 	People with FASD may show signs of being hyper-sensitive (very aware of sensory information) or hypo-sensitive (a lot of sensory information is needed for it to get through) to sensory information. Especially related to movement, tactile needs and hearing. Changing the environment can have a direct impact on how a person behaves and reacts.
A wide range of physical problems - including heart, eye and gut issues. 	Just one example of a common co-occurring condition is chronic serous otitis media – a condition affecting the middle ear. Symptoms can include pain, hearing loss, tinnitus (ringing in the ear). Can impact hearing and overall well-being. Abnormal function of peripheral nervous system and special senses. This could include: > Sensory nerve disorders (such as an inability to feel touch, sense hot or cold) (although see previous heading). > Motor nerve disorders (such as muscle weakness, twitching). > Autonomic nerve disorders (such as heart rate changes, digestive issues).

Adapted from NHS Ayrshire & Arran, unknown date; Popova et al., 2016; SIGN, 2019

Strengths and challenges: A spiky profile

While people with FASD may experience more challenges than those without, research has also highlighted their strengths. It is important to see the whole person.

The strengths of each person with FASD are unique, but strengths can include:

- That they can be loving, affectionate, helpful, generous, funny, resilient, adaptable, athletic, and creative (Kautz-Turnbull et al., 2022).

Individuals with FASD can have 'spiky' profiles (see **National FASD website**). This refers to a pattern of cognitive abilities and skills where an individual's strengths and challenges vary significantly. For example, somebody may have good expressive language skills, but experience challenges in receptive language and comprehension skills. One child may have challenges in emotional regulation, adaptive behaviour and attention while another may have challenges in executive function, motor skills and memory. This may change daily based on factors such as the surroundings, sensory sensitivities, and the individual's physical and emotional condition (Hanlon-Dearman, 2021).

While each person is affected differently, some domains are more commonly affected such as attention, adaptive behaviour, communication, mathematic skills, spatial working memory and executive function (SIGN, 2019). Everyone with FASD will experience executive functioning challenges and need trusting relationships to support them in this area. Some with FASD will have a learning disability (defined as an IQ <70) but most do not. However it should not be assumed that those without a learning disability will need less support (Seashell and National FASD, 2020).

FASD diagnosis

It is outside of the remit of social care practitioners to formally diagnose FASD; however, it is vital to have a basic understanding of general patterns of FASD (see Table 1), normative child development and how an FASD medical diagnosis is made. Equipped with this knowledge, practitioners will be better able to advocate for the individual and their support needs.

Further information on normative child development can be found here:

- **Social work and child development in the early and middle years (ages 0 to 11): Frontline Briefing (and chart)**

Practitioners do not need to be experts on FASD but do need to know how to draw on specialist expertise to ensure the right support is provided. This is because early recognition and diagnosis of FASD can be a protective factor, as it means appropriate support for the child and family can be put in place. Children diagnosed before the age of six tend to have better outcomes (Streissguth & O'Malley, 2000).

Practitioners also have a role in meeting the National Institute for Health and Care Excellence (NICE) 2022 quality standard statement:

> *'Children and young people with probable prenatal alcohol exposure and significant physical, developmental or behavioural difficulties are referred for assessment' (pg. 26)*

Children and young people with FASD usually present to services in four broad settings:

- GP or other health settings in relation to physical health issues.
- Child and adolescent mental health service (CAMHS) or other support services in relation to emotional and mental health concerns.
- School or other education settings in relation to learning and/or behavioural difficulties.
- Wider presentation (such as in the criminal justice system or social care) due to family breakdown or family's need for support.

Interplay with other neurodevelopmental differences

It can be difficult to distinguish FASD from other neurodevelopmental differences (neurotypes). For example, some FASD symptoms overlap with behaviours of people with ADHD and/or autistic people.

Practitioners need to be aware of multiple and potentially co-existing influences and acknowledge that they are not experts in providing diagnosis. Focussing on one factor can result in overlooking the complex interplay of various influences.

FASD and ADHD – Recent evidence confirms that a person is much more likely to have more than one neurodevelopmental condition (Popova et al., 2016). FASD will most often be first recognised as one of many associated conditions rather than as FASD in its own right (Popova et al., 2016), with ADHD being one of the most common presentations through which FASD is subsequently identified (Young et al., 2016). The behavioural presentation of ADHD is an outcome of the underlying brain function issues caused by multiple factors, of which alcohol in utero is only one. It is important to recognise the different factors, as the presentation of ADHD will differ dependent on cause - for example, characteristics of ADHD where there is alcohol in utero will differ from other genetic causes of ADHD (Young et al., 2016).

FASD and attachment – The observation of different styles of attachment is well established (Hanbury, 2025), but the reasons **why** these behaviours occur are not well understood. There are many things that affect an attachment relationship, including trauma and neurodivergence, and it is important to consider the full breadth of these. It shouldn't be simply considered as 'bad parenting'. In addition, many neurodivergent people express attachment differently, which means attachment assessments (by professionals trained to do these) should be completed with a neurodiversity-lens (Guthrie, forthcoming).

FASD and developmental trauma - When a child is known to have experienced trauma (e.g. due to abuse or neglect), interventions often focus on how a child's needs are impacted by this trauma. Prenatal alcohol exposure often fails to be considered, and the role of FASD in causing any observed difficulties may be under-emphasised (Gilbert et al., 2024).

Practical questions to ask when you are working with a child who may have FASD

Think about a child or young person you believe may have FASD:

- **Q.** Do they potentially have other 'conditions' or neurological differences such as ADHD, autism etc?
- **Q.** Who have you discussed your observations with?
- **Q.** What is the referral pathway for FASD assessment in your area? If you are not sure, who might you need to speak to find this out?
- **Q.** What information about FASD is available from other agencies?
- **Q.** Has a strengths and difficulties questionnaire been completed?

Changing diagnostic terminology/criteria - what we now know about FASD

FASD terminology and diagnostic criteria have changed over time. Someone you are working with may have been assessed using past criteria and terminology, which practitioners need to be aware of:

> Prior to **1996**, it was assumed that babies without sentinel facial features (see Table 1) were not affected by prenatal alcohol exposure. However, The Institute of Medicine (1996) recognised that a person without these facial features could have been affected by prenatal alcohol exposure, leading to an array of diagnostic terms and understanding (see Table 2). This means that all children exposed to any level of alcohol as a fetus should receive medical follow-up and appropriate support to ensure risk of FASD is recognised.

> In **2019**, The Scottish Intercollegiate Guidelines Network (SIGN) published the first UK guideline on diagnosing FASD: SIGN 156. This guideline is accepted by the National Institute for Health and Care Excellence (NICE) and therefore SIGN 156 is also the guideline for diagnosing FASD in England and Wales. SIGN 156 (2019, p.15) states:

> *'Prenatal alcohol exposure should be actively considered as a possible underlying cause for neurodevelopmental delay, or an unexplained departure from a typical developmental profile.'*

> FASD diagnosis requires evidence of pervasive and long-standing 'brain dysfunction'. This is defined by 'severe impairment' (greater than two standard deviations below the mean) in three or more neurodevelopmental areas of assessment (**SIGN 156, 2019**). Table 1 outlines these. The diagnostic criteria (in Table 2) reflect medical terminology, and in line with a neurodiversity perspective, young people with FASD often prefer the term 'differences' rather than deficit-based language (Eodanable et al., 2024).

Table 2
Current and past diagnostic terminology

SIGN 156 (2019) diagnostic terminology and criteria	Formerly known as ...
FASD with sentinel facial features In order to diagnose **FASD with sentinel facial features**, the person must have: > The three sentinel facial features. This presentation affects **less than 10%** of those with FASD. > 'Severe impairment' in at least three neurodevelopmental areas. > OR in the case of infants and young children, the presence of microcephaly (head circumference two standard deviations below the mean). > If an infant has sentinel facial features but does not have a small head circumference, they should be referred to a geneticist. > There is high specificity of the presence of all three facial features to prenatal alcohol exposure and FASD, so confirmation of alcohol exposure is not required when they are present.	> Fetal alcohol syndrome
FASD without sentinel facial features In order to diagnose **FASD without sentinel facial features**, the person would need to meet the following criteria: 1. A known history of PAE. 2. 'Severe impairment' in at least three neurodevelopmental areas.	> Alcohol-related neurodevelopmental disorder (ARND) > Alcohol-related birth defects (ARBD) > Partial fetal alcohol syndrome (PFAS)
At risk for neurodevelopmental disorder and FASD Children with confirmed PAE who do not yet meet diagnostic criteria for FASD but require ongoing monitoring.	

Key messages

FASD is under identified and diagnosed. Where it is not identified, children and young people experience poorer outcomes. There is a call for greater focus on FASD to increase identification as early as possible in a child or young person's life so that appropriate support is provided and to prevent crisis later on (see Part Two). Therefore, it is crucial that social care practitioners consider FASD across all assessments and areas. Including, but not limited to:

- pre-birth assessment
- initial assessment
- fostering and adoption
- leaving care
- Adult Services.

Reflections:

- What might be your role in FASD assessments and referrals?
- Is FASD training available to you within your organisation? If not, how can you advocate for this to be provided?
- How can you 'think FASD' in your everyday practice?

Part 2: Implications for practice

Multi-disciplinary working

It is crucial that child and family social care practitioners work closely with midwives and health visitors to support families and children where there is a potential risk of prenatal alcohol use. The NICE quality standard QS204 on FASD (NICE, 2022) is primarily health-focused for GPs, midwives, and health visitors. However, the standard emphasises collaboration between social care and health sectors to address risks of alcohol exposure during pregnancy.

The Children's Wellbeing and Schools Bill 2024-25 (Bill 151, UK Parliament) seeks to enhance early family support and, where safe, prevent children from entering care. A key feature of the Bill is the integration of child protection social work and multi-agency partners into locality-based teams.

The NICE quality standard contains these five statements:

1. Pregnant women are given advice throughout pregnancy not to drink alcohol.
2. Pregnant women are asked about their alcohol use throughout their pregnancy and this is recorded.
3. Children and young people with probable prenatal alcohol exposure and significant physical, developmental or behavioural difficulties are referred for assessment.
4. Children and young people with confirmed prenatal alcohol exposure or all three facial features associated with prenatal alcohol exposure have a neurodevelopmental assessment if there are clinical concerns.
5. Children and young people with a diagnosis of fetal alcohol spectrum disorder (FASD) have a management plan to address their needs.

Taken from NICE (2022, p. 4)

Read the full quality standard here: **Overview | Fetal alcohol spectrum disorder | Quality standards | NICE**. The current policy landscape for FASD hasn't gone uncriticised, with Lee et al. (2021, p.15) referring to it as 'evidence-based paternalism'.

Discussing risks of alcohol use

Social care practitioners, alongside midwives, play a key role in ensuring the people they support are given the Chief Medical Officers' advice if there is the possibility of a planned or unplanned pregnancy. The advice states that abstaining from alcohol completely is the best way to reduce FASD risks to a fetus (NICE, 2022).

The multi-agency team should consistently communicate this information throughout pregnancy, providing it both verbally and in written form, such as:

- National FASD's leaflet (which can be bought in bulk). **https://nationalfasd.org.uk/product/alcohol-pregnancy-leaflet**
- #DRYMESTER resources including the Alcohol Exposed Pregnancy Booklet: this booklet includes a section on how family members can support efforts to reduce alcohol use. **www.drymester.org.uk/categories/drymester-resources**

It can be beneficial for child and family social care practitioners to have the above information to hand and be prepared to talk about the contents with parents, unpicking myths and explaining the associated risks (see **How does alcohol affect the fetus?**).

Understanding why people drink alcohol during pregnancy

To provide sensitive and effective support to families, we need to be informed about the risks of alcohol but also commit to exploring why a person consumes alcohol during pregnancy. **National FASD's website** emphasises that it is a myth that FASD is the fault of the pregnant parent. It is alcohol which causes FASD. There is a need to challenge narratives of personal responsibility and punishment; it is rare for pregnant individuals to drink alcohol with the intent to harm their baby, raising questions about the factors leading to alcohol-exposed pregnancies (Popova et al., 2022).

Alcohol consumption during pregnancy is common

Alcohol use is widespread in the UK, where drinking is accepted societally. The UK has the fourth highest number of alcohol exposed pregnancies compared to other countries across the world, estimated at 41% (Popova et al. 2017). Another UK study which included 14,000 pregnant women, found that 79% of them drank alcohol in the first trimester, with rates declining in later trimesters (Nykjaer et al., 2014).

FASD affects people from all socio-economic backgrounds. The **Infant Feeding Survey (2010)** found that higher drinking rates during pregnancy were found among mothers aged 35 or over (52%), those in managerial and professional occupations (51%), and individuals from a White ethnic background (46%). In contrast, a Canadian study identified younger women and those with a history of mental health issues as more likely to drink during pregnancy (Popova et al., 2021). With alcohol use being so common, the assumption that all pregnant parents will know to cease drinking, be aware of the risks of alcohol in pregnancy, and be able to stop with ease is inaccurate.

It is important for practitioners to consider the implications of these statistics for who is likely to come into contact with children's social care and how this might affect children who were alcohol exposed in utero as they get older.

Other reasons for consuming alcohol during pregnancy include:

- **Misinformation:** A belief that only 'strong' alcohol and alcohol in large quantities is harmful.
- **Lack of awareness:** Not aware of the risks of drinking alcohol during pregnancy including the adverse effects on the fetus. Unlike smoking during pregnancy, and despite alcohol being more dangerous to a developing fetus (Behnke et al., 2013), the UK lacks a public health campaign about alcohol use in pregnancy.
- **Coping with problems, stresses and adverse life experiences:** Drinking as a way to manage these.
- **Social and cultural norms:** Consumption based on intuitive decision-making and/or influenced by personal/peer experiences including encouragement from others.
- **Out-of-date advice from medical practitioners:** Belief in the beneficial properties of alcohol such as the iron in stout or the antioxidants in red wine. Previous 2008 guidance from NICE advised that alcohol should be avoided for the first 12 weeks but following this 1-2 units once or twice a week was ok. This was removed from NICE in 2018, however it is still used on some sources of information, which means some may believe a little bit of alcohol is ok.
- **Unwanted or unplanned pregnancy**: Nearly half of pregnancies are unplanned and the woman/other pregnant person may not know they are pregnant (Public Health England, 2018).
- **Alcohol dependence:** Difficulty stopping without support.

(Popova et al., 2022)

Watch this video by Balance North East, who work to reduce alcohol harm. A mother tells her story: www.youtube.com/watch?v=AqMkJto1Yco

> *"It's the shame that makes you not want to tell anyone about the problems but you need the help. Go and seek the help [...] what I never knew was when you consume a glass of alcohol it goes straight to the baby's brain".*

Stigma and under-reporting

Shame and a fear of blame may prevent parents with alcohol-exposed pregnancies from disclosing alcohol use or seeking a diagnosis for their child (Bell et al., 2016). Concerns that confirming alcohol use will lead to child protection involvement, and even the removal of their children, may contribute to underdiagnosis of FASD. A Scottish study, analysing new-borns' first stools (meconium), found that at least 15% of pregnant women consumed significant amounts of alcohol in the later stages of pregnancy, despite none reporting heavy use (Abernethy et al., 2018).

Professionals can be worried about creating stigma, but this fear creates an obstacle to decreasing the chances of FASD, and identification and support for children and their families. Without intervention, FASD is highly recurrent at 75%, meaning that younger siblings have an increased risk of having FASD (Burd et al., 2012).

Given the widespread consumption of alcohol in pregnancy, the reasons for this, and the under-reporting, practitioners should remain curious about what has been recorded previously. It may reflect an inaccurate or incomplete picture.

Sensitive and confident approaches

Child and family social care practitioners regularly need to talk about difficult subjects with the people they support. Social care professionals are likely to be working with parents (and broader family):

- Who have experienced significant and multiple adverse experiences in their own childhood.
- Who may continue to face trauma and difficulties as adults.
- Where there are current concerns about risk to children in the family.

There are two guaranteed ways to prevent FASD:

- Consume no alcohol throughout pregnancy.
- Avoid becoming pregnant while continuing to drink alcohol.

However, for some, pregnancies may be unplanned, alcohol may be a form of self-medication and/or it may be difficult to make conscious decisions around alcohol use. Children's social care's conversations with families will extend beyond whether there is alcohol use. For example, when assessing and supporting a family, it can be relevant to try to understand what function alcohol serves in their life and how it helps them cope.

Pregnancy is recognised as a critical window of opportunity for intervention, often prompting reflection and increased motivation to seek help to address difficulties. This is especially relevant given recent rises in the number of new-borns subject to care proceedings (**Pattinson et al., 2021**).

A shame-sensitive approach that is respectful and non-judgemental can help build the trust and emotional safety needed for open conversations. Without this, the sense of guilt many birth parents experience can remain unaddressed (Thomas & Mukherjee, 2019). Where midwives or health visitors are involved, it is important to work together on how best to support the person and have such conversations.

See this article for **shame-sensitive practice principles**.

Dialogue and true listening are crucial to help build a picture of family life before the child was conceived, during the pregnancy and after (Parton & O'Byrne, 2000). An example:

- To build rapport and establish trust it can be helpful to acknowledge something positive and to seek permission to ask them questions:

  "I can see how much you love (child's name), because you're asking for help. To help figure this out together, would it be ok to go back to the very beginning and ask you some questions about life before you got pregnant?"

- If the person agrees then go back to what life was like before they got pregnant in terms of lifestyle, how they would typically use alcohol and when they found out they were pregnant. Depending on the age of the child the guidance at that time may have been that some alcohol was safe. It may be useful to acknowledge that.

Findings on effectiveness are mixed, but motivational interviewing (MI) might be used as a brief intervention to help reduce alcohol use in pregnancy, increase use of contraception or ask about alcohol and pregnancy (Chang, 2023). MI is a person-centred, directive counselling style which aims to increase a person's intrinsic motivation for change through the MI spirit of partnership, acceptance, compassion, and evocation (Miller & Rollnick, 2009). Four principles guide MI:

1. Establishing empathy.
2. Developing discrepancy.
3. Rolling with resistance.
4. Supporting self-efficacy.

An outcome could be that it feels safe for the parent to provide information about alcohol use without feeling blamed.

Confirming a 'known history of prenatal alcohol exposure (PAE)'

Social care practitioners are considered a reliable source in confirming PAE making it easier for a child to get an FASD diagnosis (SIGN, 2019). Therefore, and in accordance with NICE QS204 (2022), it is important practitioners record and work with the family to share information regarding:

- Number of type(s) of alcoholic beverages consumed.
- Pattern of drinking.
- Frequency of drinking in pregnancy.

Midwives are required to record this in the antenatal notes and communicate it to the GP and health visitor so that it is recorded in the child's health record (SIGN, 2019).

Biases (e.g. racial, cultural, gender and class belief biases) impact perceptions of groups of people and can influence practice with families, undermining practitioner efforts to be fair and equitable. These biases may directly influence the assessment of safety and risk, and may alter our own threshold for intervention (Coons et al., 2017, Ruhl, 1999, Tedam, 2022).

Reflect on a scenario (adapted from Ted Daszkiewicz, Research in Practice Associate)
Consider the following two scenarios:

1. A couple walking down a busy high street drinking a can of Special Brew each. One of their cans is still wrapped in the blue carrier bag from the off licence. The pregnant parent is pushing another child in a buggy and is wearing a tracksuit and t-shirt. They are talking animatedly and loudly to each other about money about not being able to pay 'the electric'. People around them are tutting and giving each other 'looks'.
2. A family are having a Marks and Spencer's picnic in a park. The parents, including the pregnant parent are sharing a bottle of wine and 'cheers' each other with their wine glasses. The parents are both dressed smartly. They are talking about needing to relax after a busy day at work. Their toddler is eating houmous with carrot and has a takeaway babyccino.

   The wine contains more units, and yet would the behaviour of both sets of parents be considered equally risky, and who would be more likely to have social care involvement? When might each child be most likely to come to the attention of services?

Reflections

- Consider the beliefs and assumptions you hold about parents who drink during pregnancy. What are these? How do these influence your practice?
- How confident do you feel talking about the risks of alcohol during pregnancy with parents?
- How do you work with other professionals to support families and reduce the likelihood of drinking in pregnancy? What might you do differently?
- What are non-judgemental, shame sensitive questions you could ask parents who are drinking alcohol during pregnancy?
- How could you evoke the parent's own motivations and goals in relation to alcohol use during pregnancy?
- How do you follow up where there is a suspicion of pre-natal alcohol exposure? Who do you speak to about these concerns?

Find out more to support work with parents:

Read

- **Difficult conversations in social care: Frontline Briefing**
- **Promoting anti-racism in children and family services: Practice Briefing**

Watch

- **Non-violent communication** (7 minutes)
- **Dialogic practice: Garavan's six steps** (4 minutes)
- **Working with trauma-experienced parents in children's social care: Video Learning Resources**

Listen

Working with parents in children's social care

- Part one: The context of social work and working with parents (44 minutes)
- Part two: The practice of working with parents (44 minutes)

Explore

- **Pre-birth Change Project resources** which provide a wealth of practical guidance and examples.
- Supporting parents who have experienced recurrent care proceedings resources
  - **https://supportingparents.researchinpractice.org.uk/resources**
  - **Working with recurrent care-experienced birth mothers: Online Resources**

Supporting children with FASD

What people with FASD want

A National FASD committee of young adults and adults with FASD created a UK FASD Manifesto of how they want to be treated:

Practice principles

1. Provide emotional containment to children, young people and families

Practitioners can play an important role in providing emotional support and information to process an FASD diagnosis. The Association for Child and Adolescent Mental Health (ACAMH) podcast with Sandra Butcher (CEO of National FASD) and Rachel Jackson who has FASD, recommends the following:

- Provide a space for grief, shame and optimism to be well-aired and consider your role in providing emotional containment. Diagnoses open doors to support and understanding but can also function as a label and stigmatise, as exemplified in the following quote:

> ***"With the whole diagnosis and everything, I went into a dark place where it was just – I felt like I was, like I said, on my own and I looked like this alien, 'cause I knew I was different from all the other kids, how I used to cope with it was talking to myself. I still do that to this day really. But I would always be told, "Hush, hush," and I would be picked on [...] and that just, you know, affected me, and not just me, my family, but, yeah, I didn't have a lot of support other than – you know, social workers not understanding my condition either was really terrible because I also had, I think it was ADHD and autistic diagnosis as well."***
>
> Young person with FASD, quoted from Jackson (ACAMH, 2023, 19:11)

- Help the young person with FASD (and their network) understand what FASD means for them including strengths and abilities as well as areas they may need more support. While the Health team will lead on developing a neurodevelopmental profile and management plan, if a social care team is involved, practitioners can advocate for the child/young person. This can also help them come to terms with the diagnosis and address difficult feelings:

> ***"If I understood back then that, 'Yeah, okay, fine, I'm different, but it makes me who I am,' and I think that its important just to say, 'It is who you are, but we are here for you and we love you.'"***
>
> Young person with FASD, quoted from Jackson (ACAMH, 2023, 21:20)

2. Signpost and support families to better understand FASD and connect with others

Web-based resources have been developed directly for children and young people. These can also support families and practitioners to have conversations about FASD with young people. The information can empower individuals with FASD to self-advocate:

Me and My FASD website Includes comics, booklets and activities to help a young person with FASD: 1. Understand their diagnosis and how their brain works to support self-esteem. 2. Advocate for themselves. 3. Find strategies that work for them. 4. Expand their community.	**https://fasd.me** Examples of specific resources: **My Brain, Me and FASD Booklet** **Me and My FASD passport and manifesto** **FASD club**
FASD think differently animation Aimed at children who are ages 8-13 but great for all ages. FASD Hub Scotland's animation walks through some of the challenges which the character Charlie faces and what helps him have a positive day.	**www.youtube.com/watch?v=b7zDpufe1XE&t=1s**
This is Me website Centres around the character 'Me' as they discover some of the strengths and challenges in having a brain that thinks differently.	**https://mefasd.com**
FASD Alliance Connect people with FASD and their families with support via groups	**https://fasd-uk.net**

3. Listen to and provide support to parents/carers

Caregiver stress, along with anxiety and depression, pose a significant risk and strain when families lack the necessary support and training in FASD (APPG on FASD, 2015). Other children in the household may also be affected. Providing adequate resources and education for families is essential to mitigate these challenges (Mukherjee et al., 2013).

Beyond diagnosis, families (whether birth parents, foster carers or adoptive families) report that what they seek most is:

- Someone who will listen and direct them to appropriate support.
- Honest, reliable and clear information from practitioners including recommendations with predictions for the future.
- Help to support and understand their children.

(Mukherjee et al., 2013)

It's also crucial to consider the impact on other children in the household.

National FASD has information for **all shapes of families**.

Missing information may make FASD diagnosis difficult. However, practitioners can still be sensitive to and be aware that it may be present and work in a way that supports someone with FASD and/or refer into services that can support with diagnosis. Fostering and adoption social workers and the child's social worker should inform prospective and current adopters and foster carers:

- That a child who has been exposed to alcohol and is currently meeting milestones may begin to exhibit difficulties later.
- What to look out for, how to get a diagnosis and the potential long-term needs of a child who has been exposed to alcohol prenatally.
- That services often won't know if there has been alcohol use during pregnancy and caregivers need to know the potential outcomes if there has been exposure.

Placing multiple siblings with FASD together is important to maintain family bonds and provide stability, but it also presents unique challenges. Caregivers need to understand the specific needs of each child, including potential differences in developmental delays and behavioural issues, and be prepared to support them in a way that meets their individual needs.

4. Use preferred language and avoid stigmatising terms

It is important to check in with children and young people to explore their preferred terminology in relation to FASD. **FASD: Preferred UK language guide** (Seashell and National FASD, 2020) is a useful tool. A few key examples include:

Do say	Why
FASD	FASD is becoming used as the diagnostic term in England. The acronym puts less attention on the causality if people prefer to keep that private. Use FASD rather than shortening to 'foetal alcohol' for this reason.
Person with FASD Child with FASD Young people with FASD Adult with FASD	Person first language is the general preference. It emphasises that an individual is more than just their FASD diagnosis. However, a person with FASD may also identify as neurodivergent which is identity first language.

(Adapted from Seashell and National FASD, 2020)

5. Understand and contribute to diagnosis and management plan

NICE (2022) guidelines provide a framework for the assessment and diagnostic process which includes:

1. A neurodevelopmental assessment which outlines the needs of each young person and what support they and their family will need.
2. A management plan which is then co-developed with the child/young person with FASD and their parents/carers and the team who carried out the assessments. Discussion includes: what it should cover, priorities and goals and who the plan should be shared with to help coordinate care across a range of healthcare, education and social care professionals (NICE, 2022). Although the guidelines do not specifically discuss children's social care involvement in the management plan, wherever possible establish good communication with the assessing team to determine how the child/family's social care team can contribute to the plan's success and delivery. To get a sense of a management plan format, see SIGN's **sample management plan form**.

Education and health care plans (EHCP) are essential for young people with FASD and need to look holistically at the needs of the child within school, not just in academic support that they may need. Within social care, some organisations have adopted a needs-led eligibility framework using strengths-based descriptors. This can help ensure that all professionals working with disabled children understand their collective responsibility in enabling disabled children and their families to access the level of support they need (Coady et al., 2024):

> **Using a needs-led eligibility framework to provide services to disabled children and their families**

6. Support children/young people with FASD to flourish

Although the FASD care/support plan will be led by the Health team, social care practitioners play an important role in supporting children/young people with FASD to use the strategies in the plan through using strength-based approaches, which are unique to each person. For example, one young man with FASD, described some of his strengths as visual and hands-on learning, spatial memory and being adaptable and observant of others. He explained that being aware of his strengths informed his career goals and fostered a sense of motivation, and that having an attitude of optimism and persistence is crucial for success (Brenna et al., 2017).

It is important to recognise and leverage the environments and activities that support (rather than hinder) success. Using a strengths-based approach could be:

1. Talking to the child/young person and their family **to identify their interests and strengths.**
2. **Identifying a few challenges** to address by either creating strategies or putting additional support in place.
3. **Using strengths and interests to develop strategies.** For example, if they like to paint, help them paint visual reminders or step-by-step reminders around the house.
4. **Celebrate every success**, no matter how small.

To find out more about strengths-based practice and strategies which can support children with FASD read: **www.fasdnetwork.org/uploads/9/5/1/1/9511748/fasd_caregivers.pdf**

Practitioners can encourage the child's education setting to engage in specialist FASD training and resources such as **Teaching a student with FASD**. This includes strengths-based approaches and more.

7. Adjust communication

Adjustments should be individualised, but research shows that when working with people with FASD it is important to choose communication strategies that meet their developmental stage (Brintnell et al., 2019). Some examples include:

- using plain language (Sparrow et al., 2013)
- avoiding abstract concepts (Mattson et al., 2011)
- speaking slowly
- keeping instructions to one at a time.

8. Understanding behaviour as brain-based and communicating need

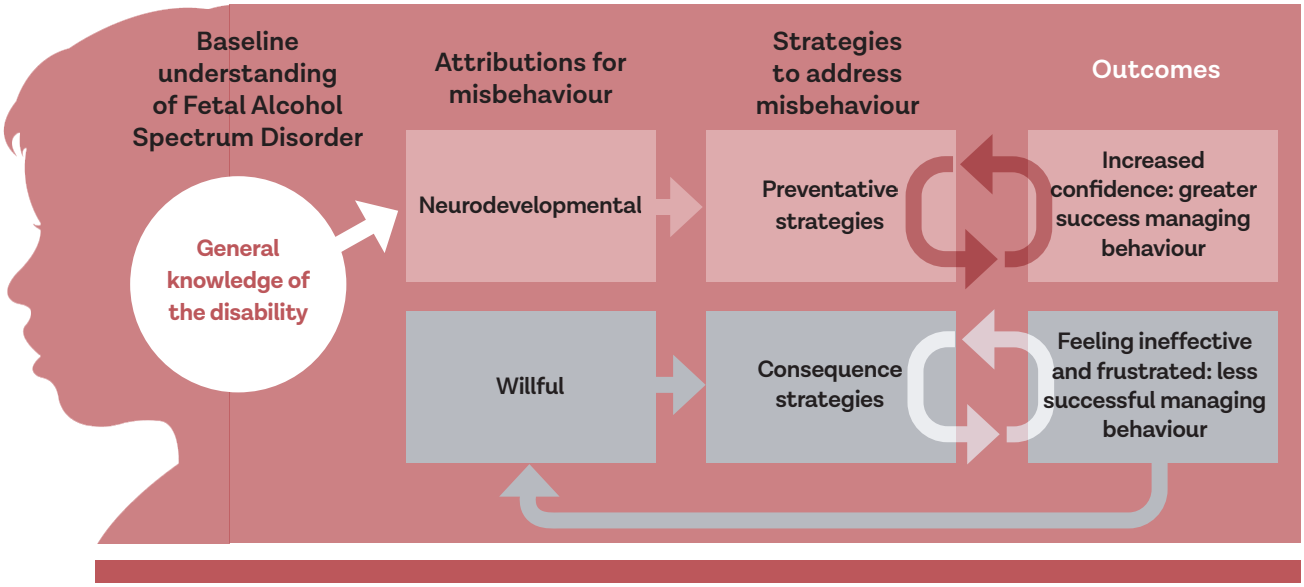
Punitive techniques for 'modifying behaviour' may be ineffective and unfair:

> ***"...thankfully had one good teacher, and that's why ... I also worry that kids are always going to be known as the naughty kid, 'cause that's what I was always told."***
> Young person with FASD, quoted from Jackson (ACAMH, 2023)

Approaches to support and intervention are often neuro-normative, with an expectation that people can link their actions to consequences and that consequences will be remembered for next time. However, many people with FASD have challenges linking cause and effect and with memory. Approaches that don't consider brain differences can cause harm such as a chronic experience of failure, so it's important to be cautious and careful about applying 'let's see if this works' methodology (FASD Hub Australia, 2024). Chronic experiences of failure, frustration, poor sense of self-efficacy, can translate to defensive behaviours and mental health issues.

Practitioners can help the child/young person, families, education, broader network and support system to recognise behaviour as brain-based rather than intentional. What may be labelled as unwanted or defiant behaviour should be considered as communication of a difficulty or a need for additional support. For example, filling in the blanks due to memory differences can be misconstrued as lying.

Appropriate strategies can lead to the child being validated and their needs responded to, supporting their sense of self-efficacy and success (Petrenko et al., 2016), as illustrated below:



(Petrenko et al., 2016)

Reflections:

- In your own practice, are you reframing a child or young person's behaviours to identify and meet underlying needs?
- How can you work together with a child/young person and their network to adapt their environment so that it is a good fit?
- What support do you need to be confident in advocating for strengths-based and ethical approaches across all settings (parenting/caring, education etc)?.
- How do you assess and understand the unique developmental needs, strengths, and challenges of the children and young people you support?

Supporting young people with FASD into adulthood

"I was supported through foster care but as I became independent, I really started to struggle. After a particularly difficult time sofa-surfing I was prescribed antidepressants and got support from [mental health] team to secure a bedsit. Earlier diagnosis could have helped to signpost me to support and help."
(Adult with FASD, National FASD Advisory Committee, 2018)

Adulthood typically includes greater expectations and responsibilities, including problem solving, managing finances and sustaining independent housing. A person with FASD may require support to meet the expectations of adulthood (Pepper et al., 2019).

By adulthood, people with FASD are more likely to experience intersecting challenges such as homelessness or involvement in the criminal justice system (Popova et al., 2023; Streissguth et al., 2004). They have high rates of difficulty with daily living including:

- independent living (63%)
- problematic alcohol use (38%)
- problematic substance use (46%)
- employment challenges (37%)
- legal problems with offending (30%)
- assisted or sheltered housing (21%)
- education disruption (18%)
- legal problems with victimisation (4%)
- incarceration (3%).

(McLachlan et al., 2020)

Due to under-diagnosis and unique patterns of strengths and challenges, young people may fall through the cracks risking negative outcomes with their needs overlooked. A significant lack of statutory support in adulthood for people with FASD may increase risk factors for poor health, homelessness, exploitation and criminal justice system involvement (Buckard, 2022).

Exploitation and criminal justice system

Without adequate support people with FASD are vulnerable to different forms of exploitation: financial, sexual, county-lines, mate-crime and modern slavery (Buckard, 2022). Exploitation can also lead people with FASD into contact with the criminal justice system. Popova et al. (2011) estimate that young people with FASD are 19 times more likely to be incarcerated in any given year than those without FASD. International studies have estimated up to 36% of young prisoners have FASD (Bower, 2018).

Contact with the criminal justice system, whether as a suspect, witness or victim, can be affected by prenatal alcohol exposure because people with FASD are vulnerable to interrogative suggestibility including leading questions and negative feedback. They also are more likely to have poorer memory recall, lower IQ and higher rates of impulsivity. Evidence shows that the IQ range for people with FASD was lower than for people in a control group. However, it was generally over 70 which is above the minimum threshold needed to access support in legal proceedings (IQ < 70). This is a significant vulnerability which could lead to false confessions or miscarriages of justice (Gilbert et al., 2024). If people with FASD are not given appropriate support within the criminal justice system (CJS) they are disadvantaged, affecting equity of justice and potentially increasing the risk of recidivism (Buckard, 2022).

Being caught up in the criminal justice system is not an inevitable outcome for people with FASD, but direct work which prepares them for adulthood from age 13 years old, and earlier, if possible, is needed to reduce the likelihood of this (FASD Awareness, 2024).

Holistic and consistent support

> ***"I had a conversation with my mum, and said, 'What am I going to do when you go?' I know that sounds quite a morbid fact, but I'm scared what will happen. I know by the time she probably goes, I'll be a lot older and that hopefully by that time there'll be more resources, but that plays on my mind. I'm like, 'What am I going to do without my structure?' 'Cause if I didn't have my daily structure, I probably would either go to be on the streets or causing problems, continuous problems that could easily have been avoided, pretty much"***
>
> Young person with FASD, quoted from Jackson (ACAMH, 2023)

The significant and complex difficulties young adults with FASD face highlight the high level of services they require. Social care practitioners can help to ensure that some of the neurodevelopmental assessments such as executive functioning, adaptive behaviour and speech and language are re-done ahead of/during major transitions for those with an FASD diagnosis. It can be difficult to get an assessment, so contacting an FASD charity for advice may provide guidance. It is vital in order to understand the functional level of the individual to ensure appropriate levels of support are implemented and mitigate against adverse outcomes.

Young people with FASD may have had support within school appropriate to their needs, however that support may no longer exist afterwards, despite their needs continuing into adulthood (Brenna et al., 2017). Adults with FASD often face barriers to Adults' Services for other neurodevelopmental disabilities such as autism or learning disability (Petrenko et al., 2014).

Adults with FASD live in a variety of settings: with family; in residential care; in a shared-lives setting; in a supported living environment; independently. An extension of care, such as Staying Put (or When I'm Ready in Wales) or Staying Close, for young people transitioning to adulthood could provide better levels of support. However, services for adults with FASD may not be sufficient if they do not take into account the functional needs of the individual.

The presence of a consistent advocate is key during the transition to adulthood to ensure holistic and consistent support is provided. This could be carers, a social worker, or a formal advocate. Caregiver advocacy has been found to be a specific factor of homelife stability that supported young peoples' successful experiences of transition to adulthood (Gault et al., 2023).

Mental capacity assessments

The *Mental Capacity Act 2005* was implemented to both protect and empower people aged over 16, who may lack the mental capacity to make their own decisions regarding their care and treatment. When working with a young person/adult with FASD it is important to maintain the principle that they have capacity unless proved otherwise, while also recognising that people who do not have appropriate levels of support may be left vulnerable. Where an assessment is needed:

> ***"Any mental capacity and best interest assessments should be conducted by somebody who has undertaken FASD training"*** (Buckard, 2020, p. 2).

Children's social care can have a role in:

- Advocating to have an FASD-trained assessor.
- Alongside the young person/adult and network, sharing observational real-world evidence and other relevant assessment results such as executive functioning or adaptive behaviour scores.

You may find the following resources useful:

FASD Awareness webinar: Tracy Allen -Transitioning into adulthood and supported living. Webinar #24 . The webinar discusses a number of themes, including (from 13 minutes in):

- The transition into adulthood.
- Supporting young adults to flourish.
- The cliff edge at 18 years old.
- The importance of early diagnosis and person-centred, holistic management plan.
- Support into adulthood, including revisiting this management plan.
- The importance of consistency during transition.

Case Law where the Court of Protection concluded that an 18-year-old, with FASD and a moderate learning disability, had capacity to consent to sexual relations, but did not have the capacity to make decisions about care, contact, social media use and finance: **[2021] EWCOP 28, [2021] COPLR 415, (2021) 24 CCL Rep 387**

Article about the possible impact of FASD on defendants **and their interaction with the criminal justice system** (Garside, n.d.).

Reflections

It is important to consider what support a young person with FASD may need in the transition stage towards adulthood. Some example prompts are:

- If the individual might be easily influenced or exploited by others, what safeguarding considerations may be needed?
- What could interdependence with others look like for this person? E.g. What opportunities are they interested in? Could you (or another professional) provide direct work to support them to navigate healthy and unhealthy relationships?
- Are any mental capacity and best interest assessments needed? This could be in relation to a decision about managing finances and care and support arrangements, including for self-neglect, managing medication, managing safety online, decisions about sexual relations or capacity to conduct court proceedings.
- What is their current housing situation? How is this likely to change and how will you determine what the best housing solution is?
- Do they need an advocate?
- What services are they drawing on which may come to an end after age 18?
- What other services could they be referred to?
- If they come to the attention of the criminal justice system, how can you advocate for them and ensure FASD is considered?
- Would it be beneficial for the young person to have functional assessments (such as speech and language therapy, executive functioning and adaptive behaviour) repeated? How can you ensure this is achieved?
- What support do they need around managing money?
- What support do they need to manage and attend appointments?

Conclusion

By being FASD-informed, practitioners can help to prevent or reduce the impact of prenatal alcohol exposure. They can also assist people with FASD and their families to get a diagnosis, offer support to a child with FASD and their family and support adolescents during transition and into adulthood. This can be life changing for people with FASD and enable them to have brighter futures.

Find out more about FASD

Continue to learn about FASD and become FASD informed:

FASD-UK Alliance	www.fasd-uk.net
National FASD Resources for professionals and families as well as a helpline.	www.nationalfasd.org.uk
Me and My FASD Resources for young people with FASD and their families.	www.fasd.me
Alcohol and Pregnancy Resources for professionals working with pregnant women, or women who could become pregnant.	www.alcoholandpregnancy.info
Prevent FASD Resources for young people aged 15-25 to learn about the risks of alcohol and pregnancy, before planning a pregnancy.	www.preventfasd.info
SIGN 156 (2019) A national clinical guideline – children and young people exposed prenatally to alcohol	www.sign.ac.uk/media/1092/sign156.pdf
DHSC FASD Health Needs Assessment (2021)	www.gov.uk/government/publications/fetal-alcohol-spectrum-disorder-health-needs-assessment/fetal-alcohol-spectrum-disorder-health-needs-assessment
NICE Quality Standard 204 (2022) - Fetal Alcohol Spectrum Disorder	www.nice.org.uk/guidance/qs204
FASD: Preferred UK Language Guide (National FASD and Seashell, 2020)	https://nationalfasd.org.uk/languageguide
FASD Hub Primarily provides help to parents/carers of children and young people affected by PAE. Includes Facebook peer support groups as well as workshops for families and health and social care professionals.	www.adoptionuk.org/fasd-hub

Relevant Research in Practice resources

Read:

- Flood, S., Coady, C., Macqueen Black, G., & Joseph, N. (2025). *Disabled children's social care: Frontline Briefing*. Research in Practice. www.researchinpractice.org.uk/children/publications/2025/march/disabled-childrens-social-care-frontline-briefing-2025
- Taylor, A., & Flood, S. (2020). *The impact of parental substance use on child development: Frontline Briefing*. Research in Practice. www.researchinpractice.org.uk/children/publications/2020/december/the-impact-of-parental-substance-use-on-child-development-frontline-briefing-2020

Watch:

- **3 minutes:** Why do people use alcohol and drugs despite the harm? (Blood, 2021)
- **16 minutes:** The Cycle of Change (Blood, 2021)

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