

1. What is Fetal Alcohol Spectrum Disorder (FASD)?

Dr. Sara McLean, 2019

Key messages

- Fetal Alcohol Spectrum Disorder (FASD) refers to a range of distinct but related developmental difficulties caused by exposure of the developing fetus to alcohol in utero.
- FASD is more common in the community than previously thought. It is associated with significant damage to children's cognitive and physical development. FASD is also connected to the development of significant mental health issues, suicidality, and challenging behaviour over the course of a child's life.
- While the impact of alcohol on a child's brain development may be irreversible, there are some practices that can minimise the impact of FASD on the lives of children and families.
- All practitioners, regardless of their role, are likely to encounter children and adults who are affected by FASD. It is important, therefore, that all practitioners understand the likely impact of FASD on children's lives, and how they can best support children and families living with FASD.
- Practitioners in adult-focused services have an opportunity to provide tailored support to parents who may be raising a child affected by prenatal alcohol exposure, or who may be living with FASD themselves.
- Child and family practitioners are likely to encounter children living with the behavioural and mental health challenges related to prenatal alcohol exposure.
- Medical and allied health professionals are offered a unique opportunity to provide support and information to pregnant women and their partners, thereby minimising unintentional harm to a child caused by exposure to alcohol in utero.



What is this resource about?

Fetal Alcohol Spectrum Disorder (FASD) is an umbrella term used to describe a range of distinct but related developmental diagnoses and their associated symptoms, all of which are caused by alcohol exposure in utero. This resource is intended to highlight the significance of Fetal Alcohol Spectrum Disorders (FASD) to practitioners working in child, family and adult-focused services. It is one in a series of Emerging Minds resources on FASD and its impact on children and families.

Although the damage caused by prenatal alcohol exposure is likely to be permanent, the early identification of children, together with the provision of tailored support, can maximise a child's social, educational and vocational outcomes.

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Who is this resource for?

This resource is suited to practitioners working in both child and adult-focused services, as well as general practitioners and allied health professionals working with pregnant women.

It is important for all practitioners to understand the likely impact of FASD on children's lives. Child and family practitioners have the potential to support children living with behavioural or mental health challenges related to prenatal alcohol exposure. Practitioners in adult-focused services have the potential to provide additional support and tailored parenting techniques to parents who are raising a child affected by prenatal alcohol exposure. Medical and allied health professionals are amongst the first to meet pregnant women and their partners and can therefore minimise the potential harm to a child caused by exposure in utero.



What is Fetal Alcohol Spectrum Disorder?

Fetal Alcohol Spectrum Disorder (FASD) is a significant and life-long developmental condition that affects children and communities across the world. It is characterised by a range of cognitive and physical impairments that can also include intellectual disability. FASD is directly caused by maternal alcohol consumption during pregnancy and is 100% preventable if mothers-to-be avoid alcohol. As such, it is one of the most important and preventable forms of non-genetic birth defects (Roozen, Kok & Curfs, 2017).

FASD is an umbrella term used to describe a range of birth defects caused by prenatal exposure to alcohol. The range of diagnoses that fall under this umbrella term varies according to the diagnostic framework being employed; and there is not yet international consensus about the best way to describe and diagnose FASD in all its forms (see Appendix 1 for more information about the range of difficulties included under the umbrella description of FASD). FASD is sometimes referred to as an invisible disability, as the disorder is not always accompanied by any discernible physical characteristics.

Australia has recently developed and adopted its own diagnostic criteria for FASD, based on international guidelines and developed in collaboration with key Australian experts and stakeholders. The Australian diagnostic guidelines are presented in the following table.

Fetal Alcohol Spectrum Disorder		
Diagnostic criteria	Diagnostic categories	
	FASD with 3 Sentinel Features	FASD with < 3 Sentinel Features
Prenatal alcohol exposure	Confirmed or unknown	Confirmed
10 Neurodevelopmental domains <ul style="list-style-type: none"> Brain structure/Neurology Motor skills Cognition Language Academic achievement Memory Attention Executive function, impulse control and hyperactivity Affect regulation Adaptive behaviour, social skills or social communication 	Severe impairment in 3+ domains	Severe impairment in 3+ domains
3 Sentinel facial features <ul style="list-style-type: none"> Short palpebral fissure Smooth philtrum Thin upper lip 	Presence of 3 sentinel facial features	Presence of 0, 1 or 2 sentinel facial features

Fetal exposure to alcohol during the first trimester affects development of facial features, particularly the eyes and mid-face. This may result in the development of sentinel facial features: facial features that are associated with a diagnosis of FASD, including short palpebral fissure, smooth philtrum and thin upper lip. The palpebral fissure refers to the horizontal length of the eye opening, which is shortened in many children living with FASD. The philtrum refers to the ridge that normally occurs between a child's mouth and their nose, which may be diminished or missing in children with FASD. The upper lip may be also be thinned or reduced in volume in children living with FASD. For more detailed information about the sentinel facial features and diagnosis of FASD, or to access training regarding the Australian Diagnostic Criteria for FASD, visit the FASD Hub: (<https://www.fasdhub.org.au/siteassets/pdfs/section-c-assessing-sentinel-facial-features--appendices-c-and-d.pdf>)

What causes FASD?

The more a woman drinks during pregnancy, the higher the risk to the unborn child (Burns, Elliot et al., 2012), although not all children will be affected to the same degree (O'Leary, 2004).

The extent of brain and physical damage to the unborn baby can vary, depending on factors that are not yet fully understood. These factors are likely to include the pattern of alcohol consumption and amount consumed; the stage(s) of fetal development during which exposure occurred; and parental factors unrelated to alcohol exposure such as genetics, epigenetic changes, socio-economic factors, age at conception and maternal nutritional status (May & Gossage, 2011).



There can be confusion amongst practitioners and medical professionals about the acceptable safe lower limits for alcohol consumption during pregnancy (McLean & McDougall, 2014). It is widely accepted that binge drinking behaviour produces both higher and longer-lasting maternal blood alcohol levels; thereby prolonging fetal exposure to alcohol (Flak et al., 2014; Maier & West, 2001; Paintner, Williams, & Burd, 2012). However, it is now believed that even low levels of alcohol exposure may affect children's development and later behaviour (Flak et al., 2014; O'Leary & Bower, 2012).

Accordingly, the National Health and Medical Research Council (NHMRC) (2009) guidelines (currently under review) recommend avoiding alcohol altogether during pregnancy. The current NHMRC guidelines state:

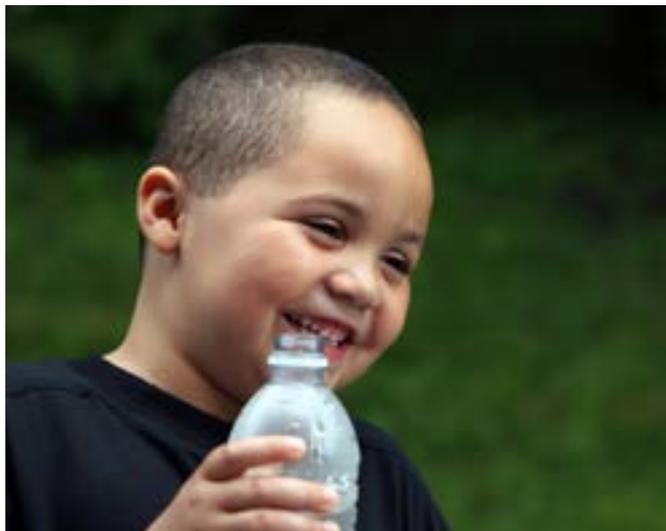
For women who are pregnant or planning a pregnancy, not drinking is the safest option. (NHMRC, 2009, p. 78)

In light of this, there is a clear mandate for any professional who may come in contact with pregnant women to ask about their alcohol consumption, when able to do so in the context of a supportive relationship.

Professionals can feel unsure about whether or not to ask women about their alcohol consumption. However, when asked, pregnant women reported positive experiences of discussing their alcohol use with professionals (Jones, Telenta, Shorten, & Johnson, 2011). This suggests that the relationship between professionals and pregnant women need not be harmed by conversations about alcohol use during pregnancy (McLean & McDougall, 2014).

Adult-focused practitioners and health professionals such as obstetricians, alcohol and other drug (AOD) counsellors, general practitioners and allied health practitioners need to be mindful of the opportunity they have to educate future parents about the significance of alcohol consumption during pregnancy (McLean & McDougall, 2014).

Why is it important to understand FASD and its impact on development?



FASD may be more prevalent in the community than previously thought. Across the world, we now believe the prevalence ranges between 1-5% of the community (May et al., 2009; Roozen et al., 2016; Stade et al., 2008; Thanh, Jonsson, Salmon, & Sebastianski, 2014). The prevalence of FASD is thought to be particularly high in certain vulnerable populations, including children who are living in foster care, and those in residential care and youth detention facilities (Fast and Conry, 2011; Lange, Shield, Rehm, & Popova, 2013; Popova, Lange, Bekmuradov, Mihic, & Rehm, 2011; Streissguth, Barr, Kogan, & Bookstein, 1996).

Children who are exposed to alcohol in utero can experience a range of significant developmental issues that are related to underlying damage to their developing brain and other organs. At this stage, evidence suggests that these underlying difficulties are permanent and life-long and can have a significant impact on a child's developmental, social and

educational opportunities. In particular, children and young people living with FASD are at risk of developing significant mental health issues over the course of their lives. (Roozen et al., 2017)

[Related: Understanding the impacts of Fetal Alcohol Spectrum Disorder \(FASD\) on child mental health](#)

While researchers are beginning to understand how to better support affected children and families, there is not yet any therapeutic or pharmacological intervention that can fully address the challenges faced by these children. However, practitioners can minimise the negative repercussions these issues have on children's lives. Early identification and appropriate and tailored support can help to minimise the impact (Streissguth et al., 2004). Practitioners who understand the challenges faced by children living with FASD and the principles for supporting children and families living with FASD can have a significant impact on children's developmental opportunities.

[Related: How to support children living with FASD](#)

[Related: How to support caregivers and families of children living with FASD](#)

What are the challenges faced by children living with FASD and what might help?

Most of what is written about FASD focuses on the impact of prenatal alcohol exposure on a child's brain functioning, but alcohol exposure in utero can affect all aspects of children's physical and brain development.

FASD is beginning to be recognised as a "whole-body disorder" (Anderson et al., 2017, p.69). Children living with FASD are also extremely likely to experience a range of other medical conditions and physical difficulties – the impact of which aren't yet fully understood (Popova et al., 2016). It is an extremely heterogeneous disorder, meaning that the impact on each child is highly unique; and no two children living with FASD are affected in precisely the same way.

Most is understood about the impact of alcohol on children's cognitive functioning. In general, there are cognitive challenges that appear to be common amongst children living with FASD:



- Difficulty in paying attention and organising themselves (e.g. being slow to grasp a new task or to move from one task to another; being more easily distracted).
- Poor and fluctuating memory (e.g. trouble learning and remembering new information; remembering inconsistently, despite having successfully learnt information previously).
- Difficulty with language and social communication (e.g. appearing talkative but masking difficulty with comprehending verbal information; difficulty with consistently understanding verbally presented information, especially if the communicator talks quickly or uses words with double meanings or metaphors; not understanding the social rules of conversations, such as taking turns; being able to repeat instructions, but unable to carry them out due to lack of comprehension).
- Reduced pace of information processing (e.g. only able to understand instructions that are given slowly; may need lots of repetition and may still miss key pieces of information).
- Difficulty applying what they have learned in one situation to another setting (e.g. trouble linking actions to consequences – may repeat the same mistakes or have difficulty generalising a rule from one setting to another, such as from home to school).
- Difficulty with executive functioning (e.g. difficulty starting tasks, staying on task and monitoring their progress, and switching from one activity to another).
- Less ability to regulate their behaviour (e.g. difficulty in foreseeing danger; impulsive and disinhibited behaviour; may be easily influenced).
- Difficulty thinking in abstract terms (e.g. finding it hard to plan and set goals about abstract concepts like time and money; difficulty reflecting on actions; trouble seeing similarities and differences between situations).

Source: Adapted from McLean, McDougall & Russell, 2014.

These cognitive, language and learning issues can mean that children can have difficulty with regulating their social behaviour, coping with change and with taking part in learning environments. While the underlying cognitive issues may be permanent, the impact of these difficulties can be minimised by providing tailored and consistent support (Streissguth et al., 2004; McLean et al., 2014), in keeping with an ecological understanding of children's needs (Broffenbrenner, 1979; Streissguth et al., 2004). Some of the key environmental factors that can positively shape the development of children living with FASD include:

- providing access to stable, nurturing relationships with adults that understand FASD
- providing access to early diagnosis and consistent, tailored support from services
- increasing the capacity of service providers to create FASD-responsive environments and interactions with children and young people.

[Related: How to support children living with FASD](#)

[Related: How to support caregivers and families of children living with FASD](#)

Summary

Fetal Alcohol Spectrum Disorder (FASD) is an umbrella term used to describe the range of distinct but related difficulties caused by exposure to alcohol in utero. FASD affects the developing child in a range of ways, including permanent changes in the development of the brain and other organs. Some children living with FASD will have sentinel facial features, but many may not look any different from their peers. This is why FASD is known as an 'invisible' disability.

The prevalence of FASD in the community is now recognised. FASD may be even more common amongst children in care and amongst those in contact with the justice system.

At present, it appears that the underlying cognitive difficulties related to FASD cannot be reversed. FASD is a significant issue in child development because it is associated with higher rates of mental health concerns, suicidality, contact with youth justice, and placement and educational instability over the child's lifetime. Practitioners and services that are aware of FASD can take steps to minimise its impact on children and families over time by providing tailored and consistent support.

Further information:

For support and information regarding FASD please see:

FASD Hub: The FASD Hub is an Australian website that aims to provide a one-stop shop for Australian FASD information, tools and resources that are current and evidence-based: <https://www.fasdhub.org.au/fasd-information/about-us/>

NoFASD Australia: NoFASD is an organisation funded by the Australian government that provides a voice for individuals and families living with FASD, while supporting initiatives across Australia to promote prevention, diagnosis, intervention and management: <https://www.nofasd.org.au/>

The Russell Family Fetal Alcohol Disorders Association (RFFADA): The Russell Family Fetal Alcohol Disorders Association is a not-for-profit health promotion charity dedicated to ensuring that individuals affected prenatally by alcohol have access to diagnostic services, support and multidisciplinary management planning in Australia and that carers and parents are supported with a 'no blame no shame' ethos: <http://www.rffada.org/about-us>

[For more information about the connection between FASD and mental health difficulties, click here.](#)

[For more information about supporting families living with FASD, click here.](#)

[For more information about what works in supporting children and young people living with FASD, click here.](#)

[For more information about creating supportive environments for young people living with FASD, click here.](#)

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Acknowledgments

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Appendix 1. The range of symptoms that are included under the umbrella of FASD

Scientists have attempted to categorise the effects of prenatal alcohol exposure in different ways. This has resulted in several different diagnostic categories that fall under the umbrella term Fetal Alcohol Spectrum Disorders (FASD). It is useful to consider these as attempts to impose order on diverse clusters of symptoms.

There is ongoing debate about the best approach to diagnosing and categorising the symptomatology of FASD. The classifications and diagnostic labels that fall under this umbrella are likely to evolve over time as our scientific understanding of the nature of FASD evolves.

The various diagnostic categories that have been applied to FASD all attempt to highlight the core diagnostic features related to alcohol's impact on the developing fetus. There is not yet consensus about which diagnostic approach best reflects the reality of FASD; nor which approach is most useful in terms of directing intervention or predicting life outcomes for young people that are affected. Essentially, the debate about proposed diagnostic categories revolves around:

1) whether or not prenatal alcohol exposure is confirmed or unknown; and whether this is necessary to make a diagnosis of FASD. There is increasing recognition that obtaining an accurate history of alcohol consumption during pregnancy is not always possible, especially in vulnerable populations of children such as those being raised in foster care; adopted children; or where the complexity a family is facing might make it difficult for them to give a full account of the experiences and events surrounding the child's early years.

2) whether or not the typical (diagnostic or 'sentinel') facial features associated with fetal alcohol exposure are present, and if so, how many of these are evident. There is increasing recognition that FASD is a 'whole body' condition, related to a range of malformations in body structure and function. These abnormalities may include the sentinel facial features, depending on the timing and duration of alcohol exposure. Therefore, while the presence of sentinel facial features indicates prenatal alcohol exposure, the absence of sentinel facial features does not rule it out.

3) the range and impact of damage to the developing brain and subsequent neuropsychological and neuroanatomical structure and functioning. This is probably the most difficult and complex area to assess and for scientists to agree on.

The Institute of Medicine of the National Academies (IOM) diagnostic categories are the most well-known and long-standing diagnostic categories:

Fetal Alcohol Spectrum Disorder	
Fetal Alcohol Syndrome (FAS)	<ul style="list-style-type: none"> • Specific sentinel facial abnormalities • Reduced size of the newborn and/or poor growth after birth • Problems of behaviour and cognition due to structural and/or functional abnormalities of the central nervous system (CNS). <p>FAS is most commonly seen in children born to mothers who consumed significant quantities of alcohol during early pregnancy.</p>
Partial FAS (pFAS)	<ul style="list-style-type: none"> • Most, but not all growth/sentinel facial features. • Significant structural, neurological and/or functional abnormalities of the central nervous system (CNS). <p>Diagnosis requires a confirmed history of prenatal alcohol exposure.</p>
Alcohol-Related Neurodevelopmental Disorder (ARND)	<p>The diagnostic category of alcohol related neurodevelopmental disorder (ARND) reflects severe CNS dysfunction in the absence of facial anomalies.</p>
Alcohol-related birth defects	<p>Birth defects including malformations and dysplasia (abnormal growths or missing body parts, e.g. fingers or toes) associated with prenatal alcohol exposure.</p> <p>These may include cardiac (heart), skeletal, renal (kidneys), ocular (eyes), auditory (hearing) and other malformations.</p> <p>Alcohol-Related Birth Defects (ARBD) is rarely seen alone but rather as a secondary disorder accompanying other FASD conditions.</p>

Source: adapted from McLean & McDougall, 2014; NIAAA (2015).

In addition to the IOM diagnostic criteria (summarised above), the latest edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-5, APA 2013) also includes a description of Neurobehavioral Disorder Associated with Prenatal Alcohol Exposure (ND-PAE), based on research on the neuropsychological difficulties experienced by children living with FASD. For a more complete description of this condition and the associated symptoms, see Hagan, Balachova, & Bertrand, 2016. People who meet the criteria for a FASD diagnosis according to the IOM may also meet criteria for ND-PAE.

There is considerable debate about the relative accuracy and utility of the different diagnostic approaches. A complete discussion of these issues is outside the scope of this resource; and for simplicity only the Australian guidelines are presented in detail. For a more complete discussion regarding diagnostic criteria, please see Hoyme, Kahlberg, Elliott et al., 2016.

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