

Fetal Alcohol Spectrum Disorder.

Prevention, early intervention and stigma.

This paper explores Fetal Alcohol Spectrum Disorder (FASD) through a prevention lens.

It provides an overview of FASD, the impact of stigma on women, and outlines FASD prevention efforts that can be implemented by healthcare providers and in the community.

FASD affects all communities in which alcohol is consumed and it requires a community approach to prevention. There is a role for everyone to play. Women need support from partners, families, friends and healthcare and social service providers to avoid alcohol when planning a pregnancy, and during pregnancy.

Overview of FASD

What is FASD?

FASD is the diagnostic term for an acquired fetal brain injury.

It results from prenatal alcohol exposure. This is where the fetus is exposed to alcohol during any stage of pregnancy (before birth).¹ The physical, cognitive and developmental impairments in FASD vary between people.²

FASD characteristics and diagnosis

For people living with FASD, the impacts are lifelong.¹

Some of the characteristics associated with FASD are apparent in childhood, while others will be more obvious later in life.³ The effects of FASD may not be seen at birth.¹

Each person who has FASD may experience a range of different challenges and characteristics, including:

- structural and functional brain damage (sometimes a smaller head)
- other birth defects such as heart and eye problems
- distinctive facial features (but most do not)¹
- difficulty processing information

- lack of understanding and difficulty following social rules and expectations
- difficulty connecting cause and effect
- challenges remembering and learning from past experiences⁴
- difficulty controlling and/or regulating emotions.⁵

Some behaviours that children with FASD may display can be misjudged as typical to a particular phase of development, however when the behaviour continues as the child gets older it may be less tolerated.

For example, a person with FASD may not understand cause and effect, so they might repeatedly do something despite experiencing negative consequences the first time. This is accepted behaviour for children because they are learning social

skills, however adults are expected to understand the negative consequences and refrain from repeating the behaviour.

Accurate diagnosis and appropriate treatment are important as they can lead to better social and physical outcomes for people with FASD. Diagnosis can also help people with FASD and parents and carers to manage specific challenges.¹

The first clinical guidelines for diagnosis of FASD were developed in 2016, called the: 'Australian Guide to the Diagnosis of FASD'.⁶ (More information about the Guidelines is available at the end of this document.⁶)

Early diagnosis can ensure a person with FASD receives adequate care and assistance to help them reach their full potential. Early diagnosis also helps parents understand their child's challenges better, which can assist in seeking appropriate medical or social support as they grow up.

"The diagnosis itself hasn't changed anything for me – but it puts a name [on] it and I can now seek support for me and my child."⁷- parent/carer

There are, however, limited services offering FASD assessment and diagnosis in Australia. Consequently, people seeking diagnosis for themselves or their children may need to wait for an appointment, travel to the clinic (sometimes interstate) and potentially cover the cost.⁶

Impacts of FASD

A lack of diagnosis may leave the parents/carers of children with FASD with significant challenges in providing support and managing their behaviour.⁷ Support for people with FASD will vary depending on their specific challenges and needs and may involve physical, behavioural and/or social support. These may all require different healthcare providers.

Without diagnosis and support, many people with FASD are at increased risk of struggling with school³ and becoming involved with the legal system (as victims or offenders).³

A recent Australian study found that young people who are in contact with justice services include an over-representation of people with undiagnosed FASD.⁸



It was estimated that 36% of the 99 participants of the study had FASD, with the majority previously undiagnosed.⁹

In Australia, there is a lack of robust data to show how common FASD really is. Therefore, opportunity to fully identify the overall impacts is limited. The introduction of FASD diagnostic guidelines has helped in progressing our understanding of the impacts of FASD, including how commonly it occurs. However, more research needs to be done to collect data on FASD occurrence across the country.¹⁴

We do know that FASD affects a potentially large number of Australians and the impacts have the potential to be reduced with the implementation of effective prevention strategies.^{11, 12}

How common is FASD?

FASD can occur in any child if alcohol is consumed during pregnancy.

Globally, it is estimated that of every 1,000 births, 7.7 children are born with FASD.¹³

Australian estimates for how often FASD occurs are limited, however we can model on North American data, since the two populations are culturally similar with respect to alcohol.¹⁰

In North America, roughly 2-5% of the general population will have FASD.¹⁰ Estimates are higher among populations that have experienced historical trauma, dispossession and systematic discrimination, where the number of people experiencing FASD might be 15-25 times higher than the general population.¹³ It is likely that these data under-estimate how common FASD is.

The higher rates among high-risk populations shows the significance of early diagnosis to prevent repercussions that may otherwise be avoided.

Stigma and FASD

Stigma is a complex social process. It occurs where a person or a group of people are considered as less acceptable due to a specific trait or behaviour.¹⁵

Stigma plays a significant role in the experiences of people who are affected by FASD. It also restricts prevention and management of FASD throughout society.^{11, 12} Stigma is pervasive in all levels of society, particularly with respect to alcohol and other drugs, and even more so in terms of FASD.¹¹

The following section outlines what stigmatising experiences might look like for people with FASD, how this can impact women and how stigma can be reduced.

What does stigma look like for people affected by FASD?

Stigma can be perpetuated in many ways. Language and communication play a key role.^{11, 16} Using person-first language, such as saying 'person with FASD', helps to minimise stigma. It is also important to use language that avoids passing judgement.

Women who are planning a pregnancy, or are pregnant, may experience stigma in different ways when using a health service.¹² This may include:

- judgmental language during an appointment
- a healthcare provider avoiding the topic of alcohol because they are worried about passing judgement on the woman
- misinformation about low-level drinking during pregnancy
- direct judgement of women who have consumed alcohol during pregnancy.¹¹

What are the impacts of stigma on women?

Women who are planning a pregnancy, or are pregnant, may experience stigma related to alcohol consumption at different times.^{11, 12}

For example, if a woman tells her healthcare provider that she has been/is drinking, and she feels judged, she might be less inclined to talk about this issue again.^{12, 17} She may also delay using services for diagnosis and support for her children, particularly if she fears that child protective services may become involved.¹²

Some research indicates that up to 50% of pregnancies in Australia are unplanned.¹⁸

These women may drink alcohol before discovering that they are pregnant.¹¹ Drinking during the early stages of pregnancy, before the pregnancy is known, can result in FASD. It is not something that the woman does knowingly, and it may have long term impacts on the baby. These women may experience stigma partially due to their unplanned pregnancy and partially because they drank alcohol before realising they were pregnant.¹² This can have significant impacts in terms of how a woman perceives herself, and she may start to feel shame as a result. This can have the impact of reducing her willingness to access appropriate health and support services.^{11, 12, 17}

How to reduce stigma

Stigma is complex and requires time and effort to reduce.

One approach that has been recommended by Australian peak body, FASD Hub, is to focus on language and communication. FASD Hub has developed the 'Language Guide', a set of guidelines focused on 'suggested language for use in conversations, presentations and reports about FASD in Australia'.

The Guide emphasises that people with FASD are more than their diagnosis, have hopes and fears, families and friends, and can contribute to society. It offers a range of preferred terms to use in place of stigmatising terms, as well as a thorough explanation of why some terms or phrases perpetuate stigma. (More information on the 'Language Guide' is provided at the end of this document.)

Additionally, stigma can be reduced by taking a whole-of-society approach to preventing FASD, whereby the focus of prevention campaigns is on all members of society. This approach acknowledges that all members of society have a role to play in preventing FASD.

Some research suggests that supporting fathers and broader networks around pregnant women can be useful in preventing FASD and can therefore reduce some of the stigma that birth mothers experience if their child has FASD.^{11, 12}



What can be done to prevent FASD?

Prevention of FASD is a national priority area in the Australian Government's National Fetal Alcohol Spectrum Disorder Strategic Action Plan 2018–2028.¹⁹

This strategy highlights the need to focus on partners, families, and broader social norms around alcohol in Australia instead of presenting FASD as a women's issue. The Plan includes two Prevention Objectives:

- reduce access to and consumption of alcohol in the Australian community
- increase community knowledge and awareness about the harms and consequences of drinking during pregnancy or when planning a pregnancy.¹⁹

The following section provides a brief overview of what healthcare providers, communities, families, partners and friends can do to prevent FASD.

What support can healthcare providers offer?

Healthcare providers play a critical role in having conversations with women during pregnancy about alcohol use. There are several ways that they can do this. These include providing accurate and timely information and universal screening.

Provide accurate and timely information

There is growing awareness in the community that abstinence is the safest option during pregnancy.²⁰ However, as mentioned above, some research indicates that up to 50% of Australian pregnancies are unplanned¹⁸, meaning that prenatal alcohol exposure may often occur in the period between a woman becoming pregnant and before the discovery of pregnancy.¹⁸

Some women will be at high risk for unplanned pregnancies (sexually active but not using effective contraception) and also drinking alcohol at risky levels. For these women, motivational interviewing could be used by healthcare providers to help them change their drinking patterns.

This could also involve a counselling session about contraception options.²¹ Combining these conversations can increase awareness of risks associated with drinking while pregnant and contraception options to prevent an unplanned pregnancy.

All women of childbearing age could benefit from being informed about the impact of alcohol in pregnancy. All women should be aware that drinking alcohol in the very early stages of pregnancy, including before they know they're pregnant, can be harmful. Healthcare providers can provide women of childbearing age with accurate information regarding alcohol consumption during pregnancy.

The most recent version of the Draft Australian Guidelines to Reduce Health Risks from Drinking Alcohol state that:

- A. To reduce the risk of harm to their unborn child, women who are pregnant or planning a pregnancy should not drink alcohol.**
- B. For women who are breastfeeding, not drinking alcohol is safest for their baby.²²**

The FASD Hub provides useful, up-to-date information on FASD. It also provides training and support for health practitioners. (A link for the FASD Hub is provided at the end of this document.)

The Women Want to Know initiative also provides tools and skills for health professionals who want to provide information about alcohol to women who are planning a pregnancy or are pregnant. (More information is provided at the end of this document.)

Universal screening

Universal screening offers a way for healthcare providers to have conversations with women who are planning to have a baby, are pregnant or breastfeeding.

A recommended universal screening strategy for healthcare providers is to use the 'Screening, Brief Intervention and Referral to Treatment (SBIRT)' approach with each woman for each pregnancy. This involves the following:

1. screening (ask about alcohol consumption) using a validated screening tool
2. provide a brief conversation based on how much a woman drinks
3. refer to appropriate support/treatment if necessary.²³

An example of a simple validated screening tool is the AUDIT-C, which focuses on identifying problematic alcohol use through a fast, 3-question survey.

Screening, using tools such as these, provides the healthcare provider with information about the woman's alcohol consumption. If a woman is identified as being at low risk, health practitioners can provide a brief intervention about alcohol use. This might include education about the effects of alcohol use on the developing fetus and child. If a woman is identified as being at high risk, health practitioners can refer her to support/treatment with an appropriate service.

This approach, provided as part of standard practice received by all pregnant women, can help:

- normalise the process of universal screening
- reduce stigma associated with the topic of drinking during pregnancy
- reduce bias in administration
- help identify trends across time and locations to guide FASD prevention efforts.

Training should be provided to healthcare staff so that they feel comfortable having these conversations.²⁴

Community-led prevention

Community-led prevention is where community members identify a health problem and work towards reducing the impact of that problem through prevention work. The community members may work collaboratively with specific groups like health agencies or community organisations to do this work. An example of community-led prevention is provided below.

An Australian example

The Marulu Strategy is an example of a community initiative to overcome the challenges associated with FASD and early life traumas in the Fitzroy Valley, Western Australia.²⁵

The Marulu Strategy was initiated in 2007. It came about because Aboriginal and Torres Strait Islander community leaders became aware of learning and behavioural difficulties in children in their community.²⁵ Unusual facial features and poor growth were also identified. Community leaders initiated a campaign in partnership with Marninwarntikura and Nindilingarri Cultural Health Services to

address the identified problems. That campaign resulted in the development of the Marulu Strategy. Other benefits were also realised, including legal restrictions on the sale of full-strength alcohol, access to diagnostic services, and help and support for families affected by FASD.²⁵ The Strategy focused on prevention by building knowledge and awareness of FASD.²⁶

What can families, friends and partners do to prevent FASD?

‘Pregnant Pause’ is the primary FASD prevention program in Australia.

This program focuses on encouraging pregnant women and their families, friends and partners to stop drinking during the woman’s pregnancy. It focuses on a whole community in the prevention of FASD, rather than just the women.

The overall impact of broad prevention programs like Pregnant Pause is limited. However, there is some evidence to suggest that about a third of Australian women would abstain from drinking if their partner encouraged them to cut back, or if their partner also stopped drinking for the duration of the pregnancy.²⁷

Partners, families and friends of pregnant women can take a pledge to stop drinking while their loved one is pregnant. This reduces the peer pressure a woman might feel to drink (even in small amounts) throughout pregnancy and make her feel less socially alone.

More information for pregnant women and their support networks can be found on the Pregnant Pause website at: <http://www.pregnantpause.com.au/>

Further information and opportunities for action

There is a range of resources available on FASD which may assist healthcare providers to integrate prevention approaches and provide support services. Healthcare providers are encouraged to take the following key steps:

1. Provide accurate and timely information to patients and families about the risks associated with drinking during pregnancy and the cause of FASD.
2. Equip yourself with the appropriate resources for patients and obtain necessary training from an accredited organisation regarding FASD.
3. Talk to all women of childbearing age, who are sexually active, about the risks associated with drinking during pregnancy. This may also provide an opportunity to have a conversation about appropriate contraception.

The links below provide information, tools and services relevant to healthcare providers about FASD.

FASD Language Guide

A guidelines document that provides suggested wording to use during conversations, presentations and reports about FASD in Australia.

https://www.fasdhub.org.au/siteassets/pdfs/language-guide_fasd-hub.pdf

Women Want to Know

An Australian Government initiative focused on providing health professionals with the skills to discuss alcohol and pregnancy with women.

<https://www.health.gov.au/initiatives-and-programs/women-want-to-know-initiative>

The Power of Words

A practical language guideline focused on person-first language when discussing alcohol and other drugs with a patient.

<https://adf.org.au/resources/power-words/>

FASD Hub

An Australian organisation with a website that provides a range of FASD-related resources, including content for healthcare providers. It also offers training specific to FASD for healthcare providers.

<https://www.fasdhub.org.au/>

NOFASD

An Australian organisation focused on connecting people with lived experiences of FASD to researchers and clinicians. It also offers information and training specifically designed for healthcare providers.

<https://www.nofasd.org.au/>

Australian Guide to the Diagnosis of FASD

Provides clinical support to practitioners in diagnosing FASD in Australia.

https://www.fasdhub.org.au/siteassets/pdfs/australian-guide-to-diagnosis-of-fasd_all-appendices.pdf

Canada Fetal Alcohol Spectrum Disorder Network (CanFASD)

A Canadian national interdisciplinary research network, that collaborates on research in various FASD areas to build prevention strategies and improved support services.

<https://canfasd.ca/>

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