



Foetal Alcohol Spectrum Disorder (FASD)

What is Foetal Alcohol Spectrum Disorder (FASD)?

The term FASD is commonly used to refer to the range of adverse clinical outcomes for the child that may result from alcohol exposure during pregnancy, and includes Foetal Alcohol Syndrome (FAS). FASD is known to cause or contribute to brain damage, birth defects, poor growth and learning and behavioural problems¹.

FASD is recognised internationally as the single biggest, preventable source of intellectual disability. It has lifelong consequences for affected individuals, who often do not achieve independent living,² and is associated with a range of social and economic impacts on the broader community.

In addition to primary disabilities arising from differences in brain structure and function, children affected by FASD often have a range of secondary disabilities resulting from the damage caused by prenatal alcohol exposure. Secondary disabilities include learning difficulties and disrupted education, unemployment, increased mental health problems, higher rates of juvenile crime and alcohol and drug problems.³

The evidence regarding the prevalence of FASD is limited and, coupled with factors that contribute to the under-diagnosis and under-reporting of FASD, it is difficult to accurately determine the extent of FASD in Australia. However, estimates of the prevalence of FAS alone are reported to be between 0.06 and 0.68 per 1,000 live births in Australia and 2.76 to 4.70 per 1,000 live births in Aboriginal women.⁴

Key Facts

In 2010 national data shows that in Australia:

- 1 in 5 people drank alcohol in a way that put them at risk of alcohol-related disease
- 1 in 3 women age 18 to 29 years drank more than 5 standard drinks on any one occasion at least once a year
- Approximately 50 per cent of Australian women drank alcohol at some stage during pregnancy

Who is at risk of FASD?

Whilst FASD has been particularly associated with chronic or intermittent heavy alcohol consumption, from the evidence currently available, it is not possible to accurately determine the impact of lower levels of alcohol consumption on foetal development.

The National Health and Medical Research Council's guidelines recommend that for women who are pregnant, breastfeeding or planning a pregnancy, not drinking alcohol is the safest option.⁵

The excessive consumption of alcohol in the Australian community is cause for concern. In 2010 national data indicates that 1 in 5 people drank alcohol in a way that put them at risk of alcohol-related disease over their lifetime, and 2 in 5 consumed enough alcohol on at least one occasion in the previous 12 months to put themselves at risk of an alcohol-related injury.⁶

This data also identified that approximately a third of women in the 18 to 29 year old age group drank at risky levels (more than 5 standard drinks on any one occasion) at some time in the previous 12 months, with two thirds of these drinking at risky levels at least monthly.

At present there is no consistent data collection on alcohol use in pregnancy in Australia. From the data available it appears that the percentage of women who did not drink alcohol during their pregnancy increased from 40 per cent in 2007 to 48 per cent in 2010.⁷ However, as nearly 50 per cent of pregnancies are unplanned,⁸ and, given the association between unplanned pregnancy and 'binge' drinking,⁹ the potential for the foetus to be exposed to alcohol prior to the mother realising she is pregnant is high. Evidence has also indicated that women with university educations and women with current high-risk drinking behaviour are at increased risk of continuing to drink when pregnant.¹⁰

It is therefore important that FASD is recognised as a community-wide problem and strategies to prevent, assess, diagnose and manage FASD are undertaken effectively.

In addition, there are two groups, who are at greater risk of FASD, that also require specific targeted interventions.

Aboriginal children and young people

While the relative proportion of non-drinkers in the Aboriginal population is greater than in the Australian population generally, it has been estimated that the burden of alcohol-related disease in the Aboriginal population is almost double that of the general population.¹¹

Of particular concern for FASD is the high rate of risky or high-risk drinking that peaks in the 25 to 34 year old age group for Aboriginal women.¹² Preliminary data from recent research with one Aboriginal community has indicated that approximately 50 per cent of women drank during pregnancy, similar to the non-Aboriginal population. However, *'as many as nine in ten of those women who do drink in pregnancy do so at high-risk levels.'*¹³ Given the increased burden of alcohol-related disease in the Aboriginal population generally, this finding may be replicated in other Aboriginal communities.

Children in out-of-home care

The reasons children are placed in out-of-home care are often based on multiple and complex issues. For example, excessive alcohol consumption is estimated to be involved in up to 77 per cent of child maltreatment cases.¹⁴

Given the complex histories of disadvantage of children in out-of-home care, it is suggested that not only is there likely to be a higher prevalence of children with FASD in this group than the general population, but their experiences may also have led to them being at higher risk of not having received the assistance and support they need and of their symptoms of FASD having been exacerbated before coming into care.

Specific attention to these groups is important to reduce the impact of FASD for these children and young people.

What needs to be done to reduce the impact of FASD?

The high rates of alcohol consumption across the community, particularly in women of child bearing age, indicate that strategies to address FASD are required at a population-based level. The importance of a whole-of-community approach is also demonstrated through the impact of other people's drinking on a woman's alcohol consumption during pregnancy, with one study showing that a third of women would modify their alcohol consumption during pregnancy if their partner also stopped drinking or was encouraging them to stop during pregnancy.¹⁵

The sensitive nature of FASD and the shame, stigma and guilt associated with a FASD diagnosis require careful management in the development of strategies to ensure that they are effective and those affected by FASD are adequately supported.

The WA Department of Health has released a *Fetal Alcohol Spectrum Disorder Model of Care*¹⁶ which sets out a comprehensive approach to responding to the issue of FASD in the community including prevention, assessment, early intervention and management strategies.

Targeted strategies to populations considered to be at greater risk of alcohol consumption during pregnancy are also required to ensure that prevention, intervention and management strategies are culturally appropriate and effectively reaching those most in need.

A number of examples of targeted strategies to Aboriginal communities already exist including the WA Drug and Alcohol Office, *Strong Spirit Strong Future* program, the Ord Valley Aboriginal Health Service FASD project and the Lililwan Project in the Fitzroy Valley. Importantly, these strategies have been developed in consultation with the relevant community to ensure they are culturally secure and effectively meeting the needs of the community.

The Maternal and Child Health Program, operated by the Townsville Aboriginal and Islander Health Service, has achieved significant improvements in infant health through engaging Aboriginal women in antenatal care during pregnancy and is an example of a broader-focused program targeting infant health.

It is also important to recognise that alcohol consumption can be part of a complex picture with other issues such as poverty, mental health problems, alcohol and drug dependency, child abuse and neglect.

Strategies need to be mindful of this and respond with appropriate adjunct services and supports to address FASD issues in this context.

The impact of community-initiated liquor restrictions, and other community development activity in the Fitzroy Valley, as a precursor to the development of the Lillilwan Project, is noted here as an example of the benefit of addressing broader issues at a community level.

Given the paucity of data about the consumption of alcohol in pregnancy, FASD and the effectiveness of strategies across all aspects of the prevention and response to FASD, investment in further research into FASD to strengthen the evidence base and guide strategy development and implementation should be a national priority.

Additionally the development and implementation of strategies should be monitored and evaluated to ensure that they are achieving the intended outcomes and effectively reducing the impact of FASD in the community.

What types of strategies are required?

Prevention

Strategies to prevent FASD from occurring need to include a range of methods targeted at reducing excessive alcohol use across the community. In particular, educational programs, such as national public health campaigns, to raise awareness in the general population of the impact of alcohol consumption during pregnancy are required. A recent campaign in Western Australia designed to educate women of child-bearing age about the impact of alcohol in pregnancy and promoting the National Health and Medical Research Council's recommendation that not drinking alcohol in pregnancy is the safest option, provides an example of such strategies.

Targeted education campaigns for high risk groups and communities should also be developed and implemented. It is also recommended that strategies such as health warning labels on alcohol products be implemented. Warning labels have been compulsory in a number of countries for several years including France, South Africa and the United States of America.

It is important that all education strategies are based on evidence of what works in changing behaviour as, whilst knowledge is important, research has found high rates of alcohol consumption during pregnancy amongst women with tertiary level education and stated that, '*awareness of the effects of alcohol in pregnancy alone is not sufficient to change women's behaviour.*'¹⁷ Further, the message about alcohol abstinence throughout pregnancy needs to be carefully managed to reduce the possibility of inadvertent negative outcomes, such as women not disclosing alcohol consumption out of fear and/or shame.¹⁸

Strategies to improve the knowledge and skills of the health and welfare workforce to adequately deliver effective preventative information and to identify and support women who are at risk of continuing to drink during pregnancy, should also be a priority.

These strategies should include the importance of advice about effective contraception for women who continue to drink, particularly at risky levels. *The Grog Brain Story*¹⁹ resources provide an example of tailored resources for health professionals to provide appropriate preventative information to specific populations.

At a broader level, a World Health Organisation international review of alcohol-related research found that regulating the physical availability of alcohol (for example, the trading hours and density of liquor outlets) and taxation and pricing were the top two most effective types of intervention for reducing alcohol-related harm.²⁰

Strategies such as the introduction of volumetric taxation and a minimum floor price for alcohol to reduce the availability of cheap discounting of alcohol may therefore be particularly effective in addressing excessive alcohol consumption in the general community. Such strategies have also been shown to reduce alcohol-related harm in young people.²¹

Intervention

For children who are affected by FASD, the earlier this is identified and intervention strategies put in place, the more likely adverse outcomes will be minimised.²² As such, early intervention strategies will provide considerable cost savings to the community and substantial improvements in the quality of life for the individual.^{23 24} To achieve this, development and implementation of a national screening and diagnostic tool is essential. FASD requires a multi-disciplinary response²⁵ and the capacity of existing child health services to implement screening and diagnostic processes will require additional resourcing.

Children in out-of-home care face some particular challenges and, as a high prevalence group for FASD, it is important that they receive access to relevant services and continuity of care in the assessment and management of their health needs. Foster families will also require appropriate resourcing to facilitate this access.

Management issues

FASD, as an umbrella term, covers a range of disabilities and these vary significantly across affected individuals. An individualised management plan would be required to address the specific needs of each affected individual.

This may also change over time as the nature of the damage caused by foetal alcohol exposure often impacts on the affected individuals' ability to undertake more complex cognitive tasks and *'these children may be more and more challenged the older they get by the demands placed on them within the school system and within their day-to-day social interactions.'*²⁶ This highlights the need for ongoing systems of support for affected individuals and their families that can be responsive to their changing needs.

There is a need for considerable across-agency collaboration and involvement in the management of affected individuals to ensure that those with suspected FASD receive appropriate assessment and intervention services. Health, education, justice, child protection and employment and training staff need to be educated in strategies to best identify and manage issues associated with FASD.

Importantly, educational resources that support the learning of children with FASD are urgently required. Maintaining engagement with the educational system is an important protective factor in children's lives and has significant bearing on their life outcomes.²⁷ Improving the diagnosis of FASD will also assist children and young people to receive the help they need in the classroom.

Similarly, the need for children to grow up in a supportive and stable family environment is essential to maximising their potential and minimising the adverse outcomes of FASD. Support for families caring for children with FASD is therefore essential so that families can provide appropriate support to affected children. Families in regional and remote areas also need to be provided with the necessary resources to access those services not readily available in their own communities. Formal recognition of FASD as a disability and access to resources to care for these children is paramount.

In summary, we need:

- A national strategy is required to provide a comprehensive and coordinated approach to the prevention, identification and management of FASD to ensure that this wholly preventable disability is effectively addressed and that those currently affected by FASD get the treatment and support they need.
- Prevention strategies need to include a range of strategies targeted at reducing excessive alcohol use across the community in addition to targeted strategies for women considered at increased risk of alcohol consumption during pregnancy.
- FASD requires a multi-disciplinary response and the capacity of existing child health services to implement screening and diagnostic processes is likely to require additional resourcing.
- Support for families caring for children with FASD is essential. Formal recognition of FASD as a disability and access to resources to care for these children is paramount.

For more information on FASD see:

- Department of Health, WA (2010) Fetal Alcohol Spectrum Disorder – Model of Care. Perth Health Networks Branch. www.healthnetworks.health.wa.gov.au
- House of Representatives Standing Committee on Social Policy and Legal Affairs – Inquiry into Foetal Alcohol Spectrum Disorder. www.aph.gov.au
- The National Organisation for Fetal Alcohol Syndrome and Related Disorders (NOFASARD). www.nofasard.org.au

¹ Bower, C (2012) Submission to House Standing Committee on Social Policy and Legal Affairs Inquiry into Foetal Alcohol Spectrum Disorder. Telethon Institute for Child Health Research W.A. www.aph.gov.au

² Department of Health, Western Australia. Fetal Alcohol Spectrum Disorder Model of Care. Perth: Health Networks Branch, Department of Health, Western Australia; 2010 pp15

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⁴ Peadon E, Fremantle E, Bower C & Elliott E (2008) International survey of diagnostic services for children with Fetal Alcohol Spectrum Disorders. *BMC Paediatrics* 2008, 8:12 BioMed Central www.biomedcentral.com

⁵ National Health and Medical Research Council (2009) *Australian Guidelines to Reduce the Health Risks from Drinking Alcohol*. Commonwealth of Australia. www.nhmrc.gov.au

⁶ Australian Institute of Health and Welfare 2011. 2010 National Drug Strategy Household Survey report. Drug statistics series no. 25. Cat. no. PHE 145. Canberra: AIHW. pp45

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