

Fetal alcohol spectrum disorders

Current issues in awareness, prevention and intervention

Sara McLean and Stewart McDougall

This paper reviews the research and current policy surrounding prenatal alcohol exposure and fetal alcohol spectrum disorders (FASD). Alcohol use during pregnancy is linked to a spectrum of adverse fetal outcomes. This spectrum of abnormalities is collectively termed fetal alcohol spectrum disorders and may include physical, cognitive and/or developmental symptoms. The aim of this paper is to inform practitioners and other professionals working in a range of fields about the implications of FASD for children and their families. Current research on interventions or programs to work with families affected by FASD is also explored.

KEY MESSAGES

- Prenatal alcohol exposure can cause a range of cognitive and physical abnormalities in embryos that can lead to impairments in a range of functions: sensory systems, language and communication, processing pace, learning and memory, abstract thinking, and executive functioning.
- Misunderstanding and labelling of those with FASD can lead to a poor self-concept, disrupted peer relationships, fractured educational and placement experiences and contact with youth justice services.
- The prevalence of FASD is likely to be underestimated by current measures. Certain populations, including children in out-of-home care and children in contact with youth justice services are thought to include an over-representation of individuals living with an undetected FASD.
- Tackling FASD requires focused and coordinated multidisciplinary and cross sector approaches. More information about the prevalence and nature of FASD will allow for improved service planning and implementation.
- Policy directions are needed that prioritise the screening and prevention of FASD in the community.
- Current and future professionals, including those in traditionally adult-focused services, need awareness and knowledge about the significance of FASD and prenatal alcohol exposure on children's lives.

What are fetal alcohol spectrum disorders?

Fetal alcohol spectrum disorders (FASD) is a non-diagnostic umbrella term. FASD covers the full range of possible birth defects and/or developmental disabilities that can be caused by exposure to alcohol in utero. The term FASD emphasises the fact that prenatal alcohol exposure can lead to a spectrum of physical, cognitive and developmental outcomes (Drug Education Network, 2011; Riley, Infante, & Warren, 2011; Sokol, Delany-Black, & Nordstrom, 2003). FASD is often described as a “hidden” disability because physical changes resulting from prenatal alcohol exposure can be subtle and not easily recognised (Drug Education Network, 2011; House of Representatives Standing Committee on Social Policy and Legal Affairs, 2012).

FASD includes fetal alcohol syndrome (FAS), partial fetal alcohol spectrum (pFAS) and alcohol related neurodevelopmental disorder (ARND) or neurodevelopmental disorder-alcohol exposed (ND-AE, subject to approval of proposed national diagnostic criteria (see National Organisation for Fetal Alcohol Spectrum Disorders [NOFASD], n. d.; Watkins et al., 2013). These disorders reflect different combinations of physical and neurobehavioural outcomes, depending on how alcohol exposure affects the developing fetus (see Table 1 for a description of FAS and related disorders). In this paper, the term FASD will be used to capture this broad range of negative outcomes seen in children exposed to alcohol prenatally, unless specification is needed.

Table 1: Description of FAS and related disorders

Fetal alcohol spectrum disorders (FASD)	<p>FASD is a term used for a spectrum of conditions caused by fetal alcohol exposure. Each condition and its diagnosis are based on the presentation of characteristic features that are unique to the individual and may be physical, developmental and/or neurobehavioural (NOFASD, n. d.).</p> <p>FASD includes FAS, pFAS, ARBD, ARND/ND-AE (described below).</p> <p>FASD is not a clinical diagnosis but describes a group of related diagnoses.</p>
Fetal alcohol syndrome (FAS)	A syndrome characterised by: specific facial abnormalities; reduced size of the newborn and/or poor growth after birth; and problems of behaviour and cognition due to structural and /or functional abnormalities of the central nervous system (CNS). FAS is most commonly seen in children born to mothers who consumed significant quantities of alcohol during early pregnancy.
Partial fetal alcohol syndrome (pFAS)	A syndrome characterised by significant structural, neurological and/or functional abnormalities of the CNS and most, but not all, of the growth and/or facial features of FAS. Diagnosis requires a confirmed history of prenatal alcohol exposure.
Alcohol-related neurodevelopmental disorder or neurodevelopmental disorder-alcohol exposed	<p>The diagnostic categories of alcohol related neurodevelopmental disorder (ARND) and neurodevelopmental disorder-alcohol exposed (ND-AE) reflect severe CNS dysfunction in the absence of the facial anomalies. ND-AE is proposed as the Australian diagnostic category (Watkins et al., 2013).</p> <p>A diagnosis of ND-AE requires confirmed prenatal exposure to alcohol and at least one of the following:</p> <ul style="list-style-type: none"> ■ clinically significant structural abnormality (e.g., head circumference \leq 3rd percentile, abnormal brain structure), or neurological abnormality (seizure disorder or hard neurological sign); and/or ■ severe dysfunction (impairment in three or more domains of function at two or more standard deviations below the mean). Functional domains include cognition, academic performance, language, memory, executive function, attention/activity and adaptive behaviour/social skills.
Alcohol-related birth defects	Birth defects including malformations and dysplasia (abnormal growth or absence from birth) associated with prenatal alcohol exposure. These may include cardiac (heart), skeletal, renal (kidneys), ocular (eyes), auditory (hearing) and other malformations.

Source: Adapted from Watkins et al. (2013)

Alcohol has been long recognised as a teratogen—a substance that is capable of interfering with and damaging the development of a fetus, resulting in a range of birth defects. The impact of alcohol consumption during pregnancy is unique for each person, depending on the circumstances of each pregnancy. Ultimately, the impact on the developing fetus ranges widely according to

the timing and the amount of maternal alcohol consumption, as well as factors such as maternal nutritional status, age and socioeconomic status (May & Gossage, 2011).¹

In Australia, efforts to prevent FASD and address its impact have lagged behind efforts in countries such as the USA and Canada. There has been inconsistent attention paid to FASD, and the development and application of programs has been ad hoc across the various Australian jurisdictions (Foundation for Alcohol Research and Education [FARE], 2013). Awareness of the significance of FASD has been increasing more recently, influenced in part by a number of key publications and activities. Some of these are detailed in Box 1.

Box 1: Selected Australian initiatives related to FASD awareness in Australia

The **National Organisation for Fetal Alcohol Spectrum Disorders Australia** (NOFASD; formerly the National Organisation for Fetal Alcohol Syndrome and Related Disorders: NOFASARD) formed in 1999 and is acknowledged as the peak non-government organisation representing individuals and their families. It is funded by the Commonwealth to deliver support, education and training, resources, advocacy and consultation. NOFASD aims to prevent alcohol-exposed pregnancies in Australia and to improve the quality of life for those living with FASD. The website provides a range of resources and links to national and international resources and support groups <www.nofasd.org.au>.

The **Australian FASD Collaboration** brings together leading consumer advocates with key Australian researchers. The Australian FASD Collaboration is working towards the development of a national diagnostic instrument for FASD.

The **Russell Family Fetal Alcohol Disorders Association** (RFFADA) was formed in 2007 and is a national 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" approach. The website provides links to a range of research, projects, information and support resources related to FASD. <www.rffada.org>.

The **Australian Indigenous Alcohol and Other Drug Knowledge Centre** recently published a website on FASD with key facts and links to health promotion and practice resources <pilot.aod.healthinfonet.ecu.edu.au/aodkc/alcohol/fasd>.

The **Foundation for Alcohol Research and Education** (FARE) launched the *Australian Fetal Alcohol Spectrum Disorder Action Plan 2013–16*, addressing the gaps in prevention and management of FASD in Australia. Retrieved from <www.fare.org.au/wp-content/uploads/2011/07/FARE-FASD-Plan.pdf>.

The inaugural Australasian Fetal Alcohol Spectrum Disorders Conference, hosted by FARE and the Public Health Association Australia, was held in Brisbane in November, 2013. Retrieved from <www.phaa.net.au/AFASDC_2013.php>.

Government initiatives

Intergovernmental Committee on Drugs Working Party on Fetal Alcohol Spectrum Disorders. *Fetal Alcohol Spectrum Disorders in Australia* (updated 2012). Retrieved from <[www.nationaldrugstrategy.gov.au/internet/drugstrategy/publishing.nsf/Content/55FEF3DF7E89405FCA257BB0007DF141/\\$File/FASD-2012-Monograph.pdf](http://www.nationaldrugstrategy.gov.au/internet/drugstrategy/publishing.nsf/Content/55FEF3DF7E89405FCA257BB0007DF141/$File/FASD-2012-Monograph.pdf)>.

House of Representatives Standing Committee on Social Policy and Legal Affairs. Commonwealth of Australia. *FASD: The hidden harm, Inquiry into the prevention, diagnosis and management of Fetal Alcohol Spectrum Disorders*. (November 2012). Retrieved from <www.aph.gov.au/parliamentary_business/committees/house_of_representatives_committees?url=spla/fasd/report.htm>.

Western Australia FASD Model of Care Implementation Plan: <www.healthnetworks.health.wa.gov.au/modelsofcare/fetal_alcohol_spectrum_disorder.cfm> and <www.healthnetworks.health.wa.gov.au/modelsofcare/docs/FASD_Model_of_Care.pdf>.

The Federal Government announced the release of targeted funding directed towards FASD: <www.nhmrc.gov.au/grants/apply-funding/fetal-alcohol-spectrum-disorder-targeted-call-research>.

¹ Most of what is known about the effect of alcohol exposure in utero comes from research on children with FAS, which falls at the more visible and severe end of the spectrum of disorders, possibly because it is easier to detect than the range of other disorders within in the FASD spectrum.

How common are fetal alcohol spectrum disorders?

It is difficult to estimate the prevalence of FASD. The true incidence and prevalence of FASD in Australia is currently unknown, as children are not routinely screened for FASD in infancy or childhood (Burns, Elliot et al., 2012; House of Representatives Standing Committee on Social Policy and Legal Affairs, 2012). Available figures are likely to underestimate the true incidence of FASD (Burns, Breen, Bower, O'Leary, & Elliot, 2013). Estimates for FAS (at the more severe end of the spectrum of disorders) range from between 0.01 to 1.7 per 1,000 live births (Burns et al., 2013), although this may be higher among Indigenous communities where FAS has been recorded. The Foundation for Alcohol Research & Education (FARE) reports that among Indigenous Australians, the incidence of FAS may be as high as 1.87 to 4.7 per 1,000 births (Burns et al., 2013). It has been suggested that as many as 2% of all Australian babies may be born with some form of FASD (House of Representatives Standing Committee on Social Policy and Legal Affairs, 2012).

Attempts to establish estimates are hampered by many factors, including incomplete or inconsistent information regarding the maternal history of alcohol use, lack of awareness of FASD among professionals, lack of specialised diagnostic and support services, and fear of stigmatising the mother. There may also be a reluctance to provide a formal diagnosis or label for the child brought about by an absence of background information, the perceived stigma attached to diagnosis and the absence of appropriate follow-up services (Elliott, Payne, Haan, & Bower, 2006; Payne et al., 2005). There is a need to establish agreed methods for the assessment of maternal alcohol consumption and for screening populations, particularly in high-risk communities, that are suitable for use in Australian settings. This will build the capacity to accurately assess the prevalence of FASD in Australian populations into the future (Burns, Elliot et al., 2012; Burns et al., 2013; Watkins et al., 2013).

What is the impact of FASD? Primary and secondary symptoms

Prenatal alcohol exposure can have a number of very damaging impacts on the developing fetus including birth defects, facial anomalies and significant brain damage. These impacts can be thought of in terms of primary and secondary symptoms (Streissguth et al., 2004).²

Primary symptoms are defined in terms of:

inherent functional problems associated with the impact on the central nervous system of having been exposed to alcohol. (Hume, Rutman, Hubberstey, Lentz, & Van Bibber, 2009, p. 6)

Secondary symptoms refer to the range of social, emotional and vocational consequences that arise over time:

as a function of chronic poor fit between the person and his or her environment. (Hume et al., 2009, p. 6)

Primary symptoms

Changes to facial features: Fetal alcohol syndrome (FAS) and partial fetal alcohol syndrome (pFAS) (but not the other disorders falling under the FASD umbrella) are characterised by facial anomalies. These include shorter palpebral fissures (the horizontal opening between the upper and lower eyelids) according to standard measures, a smooth philtrum (indistinct or lacking a vertical groove on the upper lip) and thin vermilion border (thin upper lip). It is important to note that these features do not occur in all children affected by prenatal alcohol exposure. They only occur in a small proportion of all alcohol-exposed births (O'Leary, 2002). Assessment of these facial features requires specialised training and many of these facial features become harder to detect as the child grows, even when they are present at birth (Spohr, Willms, & Steinhausen, 2007).

² Although the term "symptoms" will be used here as many now prefer to use this term, Streissguth and colleagues originally introduced the term "disabilities".

Other physical changes: Other physical abnormalities may or may not be present as a result of prenatal alcohol exposure. These include growth retardation, and defects of the eyes, teeth, skeleton and organs such as the heart and kidneys (Hofer & Burd, 2009).

Changes in brain functioning: Depending upon a number of factors, alcohol exposure may result in a smaller brain volume, and widespread damage to many areas of the brain (Lebel, Rousotte, & Sowell, 2011). As well as changes to the brain's structure, there can also be changes to the way the brain functions. These neuropsychological difficulties may be extensive and may seem similar to other neuropsychological difficulties such as ADHD but can be distinguished by specialised assessment (Kodituwakku, 2007; Mattson, Crocker, & Nguyen, 2011).

Cognitive and language difficulties: These include:

- difficulty with executive functioning—the coordinated planning and execution of cognitive functions (Kodituwakku, 2007);
- memory difficulties (Kodituwakku, 2007);
- language difficulties, including disorders of pragmatic language (i.e., being able to follow rules of conversation and adjust language according to the needs of listeners) (Carmichael Olson, King, & Jirikowic, 2008);
- delays in gross (larger movements, e.g., crawling, jumping, running) and fine (smaller movements, e.g., picking things up, tasting and feeling things) motor functioning (Kalberg et al., 2006);
- disordered attention and activity levels (Mattson et al., 2011); and
- delayed attainment of specific academic skills (Rasmussen & Bisanz, 2009).

In addition, overall IQ may be lower, although this is not always the case (Davis, Gagnier, Moore, & Todorow, 2013).

The combination of symptoms that children can experience can be complex. It may be more helpful to think in terms of the profound effect that these difficulties have on the daily lives of children. Examples of these include:

- memory problems (trouble learning and retrieving new information; remembering only inconsistently);
- language difficulties (may be talkative but understand little of conversation, especially when non-literal language is used such as a metaphor; has little understanding of social conventions of conversation such as taking turns; may have stereotyped conversation; may repeat instructions well but be unable to enact them);
- slower cognitive pace (can only understand instructions if given very slowly, may miss pieces of information);
- attention and organisation problems (slow to grasp new tasks, easily distracted, slow to move from one task to another);
- trouble in translating information gained from one modality or sense into actions and behaviour;
- trouble applying learning from one situation to another (repeating the same mistakes, unable to predict consequences, difficulty in applying a rule to a different social situation);
- trouble thinking in abstract (setting goals, planning time, money), trouble in seeing similarities or differences; and
- impulsive behaviour (acts before he/she thinks). (Adapted from NOFASD, n. d.; O'Leary, 2004; Russell Family Fetal Alcohol Disorder Association, n. d.).

For more information, see the NoFASD fact sheet *FASD Characteristics Across the Lifespan*. <www.nofasd.org.au/resources/fact-sheets> and the Western Australia Department of Communities fact sheet *FASD: Information for People With Children and Families*.<www.communities.wa.gov.au/Documents/Parents%20Families%20Education%20Care/CFS-FASD-foetal-alcohol-spectrum-disorder-service-providers.pdf>.

These characteristics mean that traditional methods of education and discipline may not be as effective for young people with FASD. Education, child welfare and justice systems need to be aware of the implications of these difficulties for service design.

Secondary symptoms

Without understanding and appropriate responses, the primary symptoms outlined above can lead to a number of secondary difficulties. These reflect poor social, educational and vocational outcomes arising from the chronic mismatch between the young person and their environment.

These difficulties include:

- disrupted schooling (Streissguth et al., 2004);
- trouble with the law (Streissguth et al., 2004; Temple, in Wheeler, Kenney & Temple, 2013);
- legal confinement (e.g., detention, jail, psychiatric care) (Streissguth et al., 2004);
- inappropriate sexual behaviour (Streissguth et al., 2004);
- vulnerability to alcohol or drug abuse (Streissguth et al., 2004; Temple, in Wheeler, et al., 2013); and
- comorbid (or co-occurring) mental health issues (O'Connor & Paley, 2009; Temple, in Wheeler, et al., 2013).

Secondary symptoms arise over time as a result of interaction between FASD impairments, environmental risks and protective factors (O'Leary, Peadon, Breen, & Elliot, 2012). Adaptive functioning is one of the key predictors of risk of developing secondary symptoms, with higher adaptive functioning resulting in lower overall risk (Clark, Lutke, Minnes, & Oullette-Kuntz, 2004). Streissguth and colleagues (2004) found that the risk for secondary symptoms can be reduced with appropriate and timely support and time spent in a stable caregiving household. They concluded that:

one of the strongest correlates of adverse outcomes is lack of an early diagnosis; the longer delay in receiving the diagnostic information, the greater the odds of adverse outcomes. (Streissguth et al., 2004, p. 234)

Taken together, these findings highlight the need to support caregivers, including foster carers, to ensure predictable, on-going caregiving relationships and to assist with early and accurate diagnosis.

How preventable is FASD?

The more a woman drinks during pregnancy, the higher the risk to the unborn child (Burns, Elliot et al., 2012). The relationship between alcohol consumption and the expression of FASD is complex; not all children who are exposed to high levels of alcohol during gestation will be affected to the same degree (O'Leary, 2004). A number of complex and interrelated factors influence the relationship between alcohol exposure and risk to the unborn child. These include the pattern and amount of alcohol consumption, the stage(s) of fetal development during which exposure occurred, and maternal factors unrelated to alcohol exposure such as genetics, socio-economic factors, age at conception and nutritional status (May & Gossage, 2011).

It is widely accepted that binge drinking behaviour (4–5 or more standard drinks per occasion) is one of the biggest risk factors for FASD (Flak et al., 2014; Maier & West, 2001; Paintner, Williams, & Burd, 2012). This is thought to be because binge drinking leads to a higher peak alcohol concentration. Alcohol crosses readily into the placenta and the fetus from the maternal bloodstream (Paintner et al., 2012) and is metabolised at a constant rate regardless of the amount consumed. Binge drinking episodes produce both higher blood alcohol concentrations and longer exposure than regular, lower level alcohol consumption does (Maier & West, 2001).

While there may be agreement about the harm caused by binge drinking, there is still significant debate around the acceptable safe lower limits for alcohol consumption, resulting in unclear messages regarding safe levels of alcohol consumption during pregnancy (O’Leary & Bower, 2012).

There is evidence that even low levels of alcohol exposure are related to observable changes in children’s behaviour later in their development. A meta-analysis of the association between mild, moderate, heavy and binge drinking patterns noted that there was an association between drinking at levels of less than 1 drink per day (3 to 6 drinks per week) and behaviour concerns in children between 9 months and 5 years of age (Flak et al., 2014). Similarly, O’Leary and Bower (2012) found an increased risk of neurodevelopmental problems and of pre-term birth associated with the consumption of the equivalent of only 2–2.5 standard drinks once or twice per week.

What should practitioners advise women?

National Health and Medical Research Council (NHMRC) (2009) guidelines recognise the current ambiguous state of knowledge regarding low levels of alcohol consumption in pregnancy and state that:

A no-effect level has not been established, limitations in available evidence make it impossible to set a safe or not-risk level of drinking for women to avoid harm to their unborn children, although the risks to the fetus from low level drinking (such as one or two drinks per week) during pregnancy are likely to be low. A conservative public health approach has therefore been taken in recommending that “not drinking alcohol is the safest option” for pregnant women and women planning a pregnancy. (NHMRC, 2009, p. 68)

At present, while there is inconclusive evidence as to the impact of low levels of alcohol consumption during pregnancy, the safest choice is not to drink: the only known way to prevent FASD is to abstain from consuming alcohol during pregnancy. Prenatal alcohol exposure is the *only* cause of FASD and the leading cause of preventable brain damage (O’Leary, 2002).

Family counsellors, obstetricians and allied health practitioners in traditionally adult-focused services need to be aware of the potential impact of alcohol use on the developing child and ask about alcohol use during pregnancy. When asked, pregnant women reported positive experiences of discussing alcohol use and risk reduction 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.

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

What are the factors that influence whether women consume alcohol during pregnancy?

Alcohol consumption is seen by many as an integral part of the fabric of Australian life (Department of Health and Ageing, 2001). The Australian Institute of Health and Welfare household survey of alcohol use (AIHW, 2011) suggests that 34% of Australian women consume alcohol weekly and 5% consume alcohol daily. In addition, binge drinking is highest among women aged 18–29, a group that are within childbearing age (AIHW, 2011; Burns, Elliot et al., 2012). The high rate of risky alcohol consumption among women of childbearing age is concerning as it is thought that around 45% of all pregnancies may be unplanned (Burns, Elliot et al., 2012; Colvin, Payne, Parsons, Kurinczuk, & Bower, 2007; Naimi, Lipscomb, Brewer, & Gilbert, 2003). A study of Australian women recently reported that around 30% of women with children now aged up to 5 years, retrospectively reported alcohol consumption during pregnancy (Hutchinson, Moore, Breen, Burns, & Mattick, 2013).

Research exploring the dynamics of alcohol consumption during pregnancy suggests groups of high-risk women who could be targeted through public health approaches. The following factors appear associated with greater alcohol consumption during pregnancy:

- pre-pregnancy and current rates of alcohol use (both higher quantity and frequency) (Skagerstrom et al., 2011; Zammit, Skouteris, Werthein, Paxton, & Milgrom, 2008);
- socio-economic advantage and family income: higher income tends to be associated with increased alcohol consumption pre-pregnancy and during pregnancy (Hutchinson, et al., 2013; Skagerstrom et al., 2011; Zammit et al., 2008);
- being an older woman with higher educational attainment (Hutchinson et al., 2013);
- smoking during pregnancy (Hutchinson et al., 2013);
- a history of abuse or exposure to violence (Skagerstrom et al., 2011).

In Australian research, intention to consume alcohol in pregnancy was associated with alcohol use in past pregnancy, the belief that pregnant women should be able to drink alcohol, intention to smoke during pregnancy, and holding a neutral or positive attitude towards alcohol use during pregnancy (Peadon et al., 2010; Peadon et al., 2011). While around one-third of women indicated that they would continue to consume alcohol if they were planning a pregnancy, over one-third also indicated they would be less likely to drink if their partner stopped drinking, or encouraged them to reduce or cease their drinking. This suggests the benefit of involving partners in interventions aimed at reducing prenatal alcohol exposure (Burns, Elliot et al., 2012).

Providing information about FASD alone is unlikely to be sufficient to change behavioural intentions with respect to future alcohol consumption during pregnancy (Burns, Elliot et al., 2012). Multiple strategies, including engaging with partners and addressing societal and community views towards alcohol consumption may be necessary (FARE, 2013).

What factors influence whether women seek help?

The accessibility and effectiveness of treatment services for substance-abusing pregnant women needs to be improved (Burns, Woods, & Breen, 2012) as there is some evidence that only 10–50% of women who fall into this category will actually access treatment (Hankin, McCaul, & Heussner, 2000). There are various reasons why women may not seek help. There may be high levels of shame or stigma associated with help seeking and practitioners need to guard against conveying blame towards women who seek support (Burns & Breen, 2013; NoFASD, n. d.; Russell Family Fetal Alcohol Disorders Association [RFFADA], 2014). Women may feel anxious about accessing treatment and support services, when available, due to fears of involving child welfare services. Practical concerns, such as a lack of transportation and childcare or services not prioritising the needs of pregnant women, may also act as deterrents (Burns & Breen, 2013; Greenfield et al., 2007).

The quality of a woman's relationship with her partner may also influence whether or not she seeks out and remains in treatment. Among the factors that influence help seeking are the partner's attitude to alcohol consumption and treatment and the presence of abuse during pregnancy (Burns, Woods et al., 2012; Messer et al., 1996) Those with a partner who also uses alcohol and/or those experiencing sexual or physical abuse during pregnancy were also more likely to accept an offer of treatment (Messer et al., 1996).

What services might be helpful for pregnant women who are drinking?

At this stage, there does not yet appear to be enough high quality information about the relative effectiveness of psychological and pharmacological interventions to support affected women (Burns, Woods et al., 2012). In the absence of good evidence for effective intervention, screening for alcohol consumption remains an important step. At present, there is no systematic approach to screening women for at-risk alcohol consumption in Australia. The potential for using a standard questionnaire to facilitate early detection of women at risk has been explored (Nilsen, 2009; Johnson

et al., 2011). The Western Australian model of care recommends using the AUDIT-C protocol for the screening of women of childbearing age (Department of Health, Western Australia, 2010). The AUDIT-C is a series of brief screening questions that provides a measure of risk in relation to alcohol consumption in pregnancy.

For women who are considered low-risk drinkers, education and monitoring may be sufficient, whereas risk assessment and engaging clients in behavioural contracts related to drinking (see Neale, 1991) may be advisable for those at moderate risk (Burns, Woods, & Breen, 2012). High-risk and/or alcohol-dependant women may require inpatient admission and supervision (Burns, Woods et al., 2012).

Integrated treatment programs may be effective in reducing substance use. In these programs, substance-use treatment is incorporated with pregnancy, parenting or child-focused services. Adult-focused service providers, such as drug and alcohol counsellors, should ask about the possibility of pregnancy among their clients. Other potentially effective supports may include outpatient therapy, group therapy, couples therapy and self-help groups (Burns, Woods et al., 2012), active and extended case management and referrals and support across a range of services including medical, transportation, mental health, vocational and legal support (Lester, Andreozzi, & Appiah, 2004).

Are there groups that are particularly affected by FASD?

FASD may be more common among some populations but the reasons for this are likely to be complex. Although FAS, at the more severe end of the spectrum, may be more common among lower socio-economic groups, this is likely to reflect an interaction of alcohol use with nutritional, genetic and social factors (O'Leary, 2002). FAS is frequently associated with early maternal death, living with an alcoholic parent, child abuse and neglect, being removed into care, experiencing repetitive periods of foster care or being raised by adoptive or foster families (May, Hyumbaugh, Aase & Samet, 1983; Russell, Henderson & Blume, 1984; Streissguth et al., 1991; Werner, 1986). Intergenerational alcohol use may also mean that parents of children living with FASD are themselves affected by the same condition. The multiple psychosocial stressors associated with FASD mean that children affected by FASD may come in contact with many service systems.

Indigenous Australians

Although Indigenous Australians report lower levels of alcohol consumption than non-Indigenous Australians, when they do consume alcohol, they are more likely to consume it at levels above the NHMRC guidelines. According to the 2010 National Drug Strategy Household Survey (AIHW, 2011) 25% of Aboriginal and Torres Strait Islanders, compared to 19% of non-Indigenous respondents, reported being abstainers or ex-drinkers. Thirty-one per cent of Aboriginal and Torres Strait Islanders, compared to 20% of non-Indigenous respondents, reported drinking at levels deemed to be risky over the lifetime. It is important to note that these figures have been subject to criticism on methodological grounds (National Indigenous Drug and Alcohol Committee [NIDAC], 2012).

Numerous studies indicate elevated rates of FAS among Indigenous populations generally, although these figures are thought to have been inflated by both systematic sampling bias (studying populations already known to have high levels of drinking) and associated socio-economic stressors (O'Leary, 2004). It should also be noted that there is no incidence or prevalence rate known for the general population for comparative purposes.

Research exploring Aboriginal women's knowledge and attitudes towards alcohol use in pregnancy suggested that education strategies should be culturally sensitive and consider the experiences/needs of Aboriginal women, but not directly target them (Burns, Elliot et al., 2012). This may encourage the community to understand that FASD is not an issue exclusive to Indigenous populations. If incidence and prevalence rates are elevated in Indigenous populations, it will be difficult to disentangle the influence of increased surveillance, and methodological issues related to measuring

patterns of alcohol consumption in Indigenous communities. FASD should not be considered an issue that occurs only in Indigenous communities (NIDAC, 2012). Rather, FASD will occur in any community where alcohol is consumed.

The Australian Indigenous Alcohol and Other Drug Knowledge Centre has recently published a website on FASD with key facts and links to health promotion and practice resources <pilot.aod.healthinfonet.ecu.edu.au/aodkc/alcohol/fasd>.

Children and young people in out-of-home care

There is increasing awareness of the significance of prenatal alcohol exposure for children in the child welfare and alternative care populations (Parkinson & McLean, 2013). Children with FASD can often be placed in out-of-home care (OOHC) due to ongoing issues related to alcohol consumption in the family of origin. Parental substance abuse is a major contributor to children entering out-of-home care, with alcohol being the most commonly used substance (Jeffreys, Hirte, Rogers, & Wilson, 2009).

In a recent review of the prevalence of FASD in children in out-of-home care, Lange, Shield, Rehm, and Popova (2014) reported the prevalence of FASD as between 11% and 24% (mean = 17%). A large number of the papers included in the Lange et al. (2014) review drew samples from Eastern European orphanages where the primary reason for child abandonment was maternal alcohol consumption/prenatal alcohol exposure, which may have inflated the prevalence estimates. Markedly fewer studies have been conducted drawing samples from child welfare/child protection samples. Studies drawing samples from a child welfare population found a rate of 17% of children with FASD (Fuchs, Burnside, Marchenski, & Mudry, 2005 as cited in Fuchs et al., 2010). A related finding is the high rate of children with FASD who are not raised by birth parents. Estimates of the percentage of children with FASD raised by people other than their biological parents range from 60% to 80% across Australia, Canada and North America (Streissguth et al., 2004; Elliot, Payne, Morris, Haan, & Bower, 2008; Hume et al., 2009). These studies suggest that there is a large number of children with FASD in the OOHC system.

The secondary symptoms of children with FASD place additional burden upon their carers. Children with FASD who are in OOHC can suffer multiple placement breakdowns as a result of their complex support needs and challenging behaviour (Brown, Bednar, & Sigvaldason, 2007; Paley & Auerbach, 2010). Consistent, stable caregiving is an important protective factor in the lives of children with FASD, highlighting the need to support birth parents and carers of children with FASD (Green, 2007; Kalberg & Buckley, 2007; Streissguth et al., 2004). Burnside and Fuchs (2013) suggested that the continuity of relationships with carers is an important protective factor for children who are “ageing” out of care.

Foster carers may not receive adequate information and support from professionals (Brown et al., 2007). Carers may not suspect that a child is living with FASD because they don't have access to a child's social and medical background (Drug Education Network, 2011). This can lead foster carers to use parenting approaches that may be less effective than when used with non-affected children (Drug Education Network, 2011). Professionals may not have the knowledge necessary to support foster carers. Two recent studies of Australian foster carers highlighted the need to improve knowledge of FASD among the health care professionals foster carers rely on for support and advocacy (Breen & Burns, 2012; Wilkins, Jones, Watkins, & Mutch, 2013). Foster carers in these studies expressed the desire for improved diagnostic services and for FASD to be recognised as a disability, akin to autism, with associated financial support (Breen & Burns, 2012; Wilkins et al., 2013).

Children and young people in contact with youth offending and justice programs

Given the significance of this issue among adult and youth offending populations, it is important for those who work within the youth justice system to be aware of FASD (Mutch, Watkins, Jones,

& Bower, 2013). In one study, for example, 23% of children remanded in a North American youth forensic assessment unit were assessed as having FASD (Fast, Conry, & Look, 1999). Streissguth and colleagues (2004) found that 14% of children and 60% of adolescents with FASD had been in trouble with the legal system. Of these, 13% of children and 67% of adolescents were charged, arrested and/or convicted.

Young people with FASD are more likely than others to interact with the criminal justice system as either victims or offenders (Mutch et al., 2013). Cognitive and language vulnerabilities associated with FASD, including impaired self-regulation, and poor cognitive flexibility and decision-making, mean that children and adolescents with FASD are more vulnerable to victimisation, exploitation, negative peer pressure and being led to take part in antisocial conduct (Fast et al., 1999; Snow & Powell, 2004a).

Once part of judicial proceedings, limited oral language competence means they may not have the capacity to understand judicial decision-making processes (Snow & Powell, 2004b). Young people with FASD require specific adaptations to all aspects of judicial proceedings to accommodate their cognitive deficits at all points of the youth justice system, including strategies to enhance engagement in restorative proceedings and the adaptation of bail conditions to ensure the young persons' needs are accommodated (Institute of Health Economics, 2013). Custodial sentencing may not be effective in deterring future offending due to difficulties in linking actions and consequences. Alternative sentencing options with high levels of external supervision may be more appropriate (Mutch et al., 2013). For youth with significant language difficulties, it may be questionable whether the use of restorative conferencing between victim and offender is appropriate (Snow & Powell, 2004b).

FASD: Prevention and intervention in Australia

What do we know about prevention strategies?

In Australia, attempts to address FASD through prevention and intervention strategies have been ad hoc and largely directed towards select Indigenous communities (Elliot, Coleman, Suebwongpat, & Norris, 2008; FARE, 2013; NIDAC, 2012). The growing recognition of FASD has led to the desire for a more strategic approach to the evaluation and implementation of effective prevention and intervention programs. However, there is still little empirical guidance about effective strategies, particularly in the Australian context.

A range of preventative approaches has been suggested. These include educational approaches targeting the community and health professionals, as well as specific groups such as adolescents and women of childbearing age, pregnant women, women at high risk of alcohol abuse and partners of pregnant women (NIDAC, 2012; Pyett, 2007).

Primary prevention approaches include universal education messages directed towards public and professionals alike about the dangers of consuming alcohol when pregnant or when considering pregnancy. These approaches aim to reduce the per capita alcohol consumption, thereby reducing the risk of all alcohol-related harms, including FASD (Bower, Hayes, & Bankier, 2012). Universal prevention strategies have been shown to decrease the prevalence of FASD (but not FAS) and to increase knowledge about the effects of alcohol consumption during pregnancy. This suggests that universal strategies have a positive impact on lower risk groups (Chersich et al., 2012).

Secondary prevention approaches target women at risk, in this instance women of reproductive age and/or who may be pregnant and who consume alcohol. Secondary prevention strategies might include the adoption of screening tools for determining alcohol consumption, the provision of contraceptive advice to women at risk, the development of early intervention or brief intervention services for women at risk and the development of programs targeting partners of women at risk (Burns, Elliot et al., 2012; Floyd et al., 2009). There is some evidence in support of the use of screening tools and brief motivational-oriented interventions for women at risk (Floyd, Weber,

Denny, & O'Connor, 2009; Rendall-Mkosi et al., 2013). The Pregnant Pause campaign is one example of an initiative targeting partners of pregnant women (see <www.pregnantpause.com.au> for more information).

Tertiary programs may be suitable for women who are drinking at high-risk levels during pregnancy or already have a child with FAS or FASD (Bower et al., 2012). These approaches are generally implemented by health professionals, ideally in a multi-disciplinary setting. They target mothers' substance-use issues, aiming to prevent further alcohol-exposed pregnancies and support the health and nutritional status of the mother (and fetus) (NIDAC, 2012). These interventions should seek to address as many of the multiple antecedent risk factors as possible.

What do we know about interventions that support children with FASD?

While FASD is likely to reflect permanent changes to brain development, early and coordinated interventions may nonetheless make a significant difference to the lives of children with FASD. Early intervention may reduce the risk of the longer-term negative social impacts of FASD (often referred to as *secondary* disabilities) that come from poor understanding and management of children's *primary* difficulties (Spohr et al., 2007; Streissguth et al., 2004).

Service models and interventions for children with FASD

Diagnostic clinics and multidisciplinary teams

The Australian FASD collaboration recommends the adoption of interdisciplinary clinics, similar to those in North America and Canada. These are principally staffed by paediatricians and psychologists trained in FASD assessment, with many also employing occupational therapists and family therapists/ case workers. Interdisciplinary diagnostic models can be adapted to suit the needs of regional and remote settings and assessment methods can be adapted to account for the cultural needs of Australian children. Examples of how this might be done include employing local Indigenous community expertise, the use of telemedicine facilities, mobile team models and the modification of standardised psychometric assessments to suit local populations (Elliot, Peadon, & Mutch, 2012). An agreed upon procedure for diagnosis and assessment is needed to advance prevention and intervention efforts in Australia (Watkins et al., 2013).

Case-management models

FASD is a lifelong disability affecting many areas of the child's life. Therefore the best outcomes for children are likely to be when there is good coordination between medical, educational and community services and other professionals.

The key worker model originated in the United Kingdom as a model of care for families with a child with a disability (Greco, Sloper, Webb, & Beecham, 2005). It advocates that those surrounding the child recognise that FASD is a brain-based disability, and aims to develop a common understanding of FASD as such:

the model holds that when all who live and work with the child/youth have a common understanding of the disability, then the behavioural symptoms associated with FASD will be reinterpreted, expectations for the child/youth will shift, and appropriate environmental accommodations can be identified and implemented, and positive outcomes for families, including reduced stress and increased stability will ensue. (Hume et al., 2009, p. i.)

Through this approach, the program aims to reduce the risk of the child developing some of the secondary difficulties identified by Streissguth and colleagues (2004). The key worker plays a central role in enacting this treatment orientation. Their role is to educate family, service providers, teachers and any other individuals in a child's life; to develop accommodations, particularly within the area of education, and provide advocacy and linking to other services as needed. The key worker model typically also incorporates some form of parent support program. Evaluations of

the key worker program indicate families gain knowledge about FASD, report positive gains in emotional and mental health, and report a trend towards increased parental confidence. The holistic, family-centred approach, flexibility regarding the duration and frequency of contact with family, and the multifaceted nature of the support are cited as the effective elements of this model (Hume et al., 2009, p. 75). However, evaluations of this model are limited in size, program components vary between them and there does not yet appear to be any assessment of whether or not this model leads to improvements in placement stability over time for children in foster care (Hume et al., 2009).

The promising practices (also called communities of practice model), originating in Canada, is another casework practice model, specifically designed to meet the needs of children placed in out-of-home care (Badry & Pelech, 2011). The promising practices revolve around the provision of respite, high quality collaboration, training, and consistent and on-going worker contact (Badry & Pelech, 2011). Specific recommendations include the screening and follow-up assessment of all children in care suspected of having experienced prenatal alcohol exposure; education and awareness raising for families of children with FASD; 12 hours of specialised FASD training for workers and foster carers prior to placement; a minimum of once a month face-to-face meetings with caseworkers and family and 48 hours of respite care per month per child (Pelech, Badry, & Daoust, 2013). Evaluations suggest that implementation of these practices is linked to more positive interactions between parents and children, and a trend towards a decrease in risk behaviours and lowered incidence of placement change (Badry & Pelech, 2011). Frequency of worker contact was associated with the quality of parent–child interactions and a decline in risk behaviour. Communication with a support worker trained in FASD is seen an important contributor to placement stability in this model (Pelech et al., 2013).

Targeted skills interventions

There is some support for the utility of targeted interventions, aimed at specific skills affected by FASD. The conclusions that can be drawn are limited by the diverse nature of the interventions that have been assessed and the lack of longer-term follow-up in these studies. There is still a need for quantitative, longitudinal research into interventions for children with FASD.

Recent reviews of the published literature (Paley & O'Connor, 2011; Peadon, Rhys-Jones, Bower, & Elliott, 2009), however, identified a number of interventions that showed promise. Although these were diverse, many involved parallel caregiver training (see Table 2 on page 14 for examples of targeted skill interventions). Interventions incorporating a parent/caregiver training component include Children's Friendship Training (O'Connor et al., 2006; 2012), neurocognitive habilitation using the Alert program (Wells, Chasnoff, Schmidt, Telford, & Schwartz, 2012); parent–child interaction therapy (Bertrand, 2009), and the Families Moving Forward behavioural consultation (Bertrand, 2009).

While these interventions showed promise, the evidence is not yet substantial enough to support any one of these interventions over another. The published interventions were very narrow in focus; studies generally lacked blind or adequate control groups and were drawn almost exclusively from clinic-referred populations. Therefore, it is difficult to isolate the contribution of parental factors—such as changes in perception, stress and skill attainment over time—from child-related changes.

Table 2: Examples of targeted skill interventions

Intervention	Author	Focus of intervention	Outcomes
Children's Friendship Training	O'Connor et al., 2006; O'Connor et al., 2012.	Social skills	Children and their parents/carers took part in 12 weekly sessions teaching children the skills to better interact with peers such as making friends, playing together, entering a group of children already playing and conflict resolution. Parents were taught how to support their children in social situations and to practice the skills with their children outside the therapy sessions. Parents noted improved social skills and reduced problem behaviours in the children who received the Friendship Training compared to children in a "standard treatment" comparison group.
Parent-child interaction therapy	University of Oklahoma Health Science Centre (Bertrand, 2009)	Parent-child interaction	Parent-child interaction therapy and the comparison parent support intervention (parent working with therapist to manage behaviour and self-care) both reduced levels of parenting stress. There were no differences between the two interventions—that is, they reduced stress by similar levels. Parent-child interaction therapy is limited as it focuses on the parent-child interaction and doesn't place enough weight on the brain damage caused by prenatal alcohol exposure.
Families Moving Forward	University of Washington (Bertrand, 2009)	Parenting skills, connection with other services	Families Moving Forward aimed to modify parent attitudes and responses to the child's problem behaviour. Practitioners also aimed to link families with other services. Parents were more satisfied and felt their needs were better met and perceptions of their child's behaviour problems were less negative.
Parent Education Workshop	Kable, Coles, Strickland, & Taddeo, 2012	Parenting skills and knowledge	A face-to-face workshop improved knowledge of FASD and taught principles to assist their child to regulate their behaviour. Parents and carers reported the workshop to be more useful than an Internet program or being given reading material. Parents and carers who attended the workshops reported lower scores on a measure of child behaviour problems.
Using video games to teach fire and street safety skills	Coles, Strickland, Padgett, & Bellmoff, 2007; Padgett, Strickland, & Coles, 2006	Safety skills	Video games were effective in teaching children basic steps of what to do when crossing a street or in case of a fire in the house. Most children were able to remember the safety skills a week later.
Maths Interactive Learning Experience	Kable, Coles, & Taddeo, 2007; Coles, Kable, & Taddeo, 2009	Mathematics training, parenting skills and knowledge	A maths program that included a slower pace of instruction, tangible tools to help children visualise the number operations and repetitive experiences to assist children with FASD to improve their mathematics skills more than with their peers in a regular classroom. Parents and teachers were all educated about FASD and how to work with the children to support their learning.
Language and literacy intervention	Adnams et al., 2007	Literacy training	After half-hour sessions, twice weekly for 19 weeks focusing on improving the basic skills necessary for reading and writing. Children with FASD showed minor improvements in their basic language skills. Parents or carers were not involved.
Working memory intervention	Loomes, Rasmussen, Pei, Manji, & Andrew, 2008	Short-term memory training	Teaching children with FASD to whisper what they have to remember over and over in their head did help them to hold on to more information. Older children were better at taking up the skill than younger children.
Computerised attention training	Kerns, Macsween, Wekken, & Gruppuso, 2010	Attention training	16 hours of computer-based attention training, with support from a research assistant or teacher, improved attention on a range of measures. Children also showed small improvements in reading and maths abilities from being better able to sustain attention.
Neurocognitive habilitation training (based on the ALERT program)	Wells et al., 2012	Self-regulation and parenting skills training	Over 12 weeks children with a FASD and their families were taught skills to improve their self-regulation in the home and school environments. Children showed improved executive functioning and emotional regulation.

Promising principles

At this point, it may be more helpful to think in terms of *promising principles* when working with families and children affected by FASD. These include:

- early diagnosis and intervention to prevent the likelihood of secondary disabilities;
- ensuring a no-blame, no-shame approach when engaging with families affected by FASD;
- education and training for all services and professionals surrounding the child about the brain-based nature of the cognitive, learning and language difficulties experienced by the child;
- providing an emphasis on supportive case management involving regular face-to-face support and advocacy, ensuring a common language and understanding;
- placing an emphasis on developing caregiver skills in managing and advocating for environmental accommodations and consistency across settings;
- explicitly teaching memory, attention, organisation and social skills to children and to caregivers in parallel, in order to assist children's learning and transitions; and
- increasing awareness among a range of professionals including doctors, teachers, family support workers, and youth justice professionals about the nature and implications of FASD for young people.

Summary

FASD reflects a range of preventable and lifelong disorders that arise as a direct result of prenatal alcohol exposure. The primary symptoms associated with FASD mean it is difficult for young people to learn from past experience, to generalise and apply what they have learnt in one situation to another, and to predict the consequences of their actions. They may also have difficulty in transitioning from one situation to another, or one task to another, or in learning and applying social rules in new settings.

Currently in Australia, awareness and expertise in FASD is relatively underdeveloped. Current developments include the development of national diagnostic criteria and ongoing collaborative prevalence research, conducted in partnership with local Indigenous communities (Fitzpatrick et al., 2012).

FASD is a “hidden” disability, and easily confused with wilful disobedience or other conditions such as ADHD. Children affected by FASD are in contact with multiple services and systems by virtue of their complex needs. Doctors, teachers, family therapists, child welfare and youth justice case workers, among others, need to be aware of the behavioural symptoms of FASD and of the risk factors for alcohol consumption during pregnancy. Research is needed into the effectiveness of prevention and early intervention programs for mothers, children and families affected by this lifelong condition.

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Dr Sara McLean is a registered psychologist and research fellow at the Australian Centre for Child Protection. Sara McLean has extensive experience working in child and adolescent mental health, and holds a special interest in children who have experienced a range of early life adversities—including prenatal substance exposure, abuse, trauma and neglect—and display challenging and aggressive behaviour. Her research focuses on supporting the foster carers, professionals and children in out-of-home care placements to experience more stable and continuous relationships in care. **Stewart McDougall** first joined the Australian Centre for Child Protection in 2011 as a Summer Vacation Research Scholarship holder, and then as Honours student with the Centre. Since 2013, Stewart McDougall has been a part of the Centre's research team and during this time has worked with Dr Sara McLean on expanding the Centre's FASD research program. He has an interest in the overlap of FASD and child welfare concerns. He has presented his work on a systematic review of interventions for children with FASD to a number of audiences, including the inaugural Australasian Fetal Alcohol Spectrum Disorders Conference in 2013 and has co-authored several papers on FASD in conjunction with Dr Sara McLean.

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Australian Institute of Family Studies
 Level 20, 485 La Trobe Street
 Melbourne VIC 3000 Australia
 Phone: (03) 9214 7888 Fax: (03) 9214 7839
 Internet: <www.aifs.gov.au>

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