



# Addressing fetal alcohol spectrum disorder in Australia

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National Indigenous Drug and Alcohol Committee  
*The leading voice in Indigenous drug and alcohol policy advice*

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Under the auspices of the Australian National Council on Drugs, the National Indigenous Drug and Alcohol Committee (NIDAC) provides policy advice to government on Indigenous alcohol and other drug misuse.

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## Introduction

The term 'fetal alcohol spectrum disorder' (FASD) is an umbrella term to describe a range of adverse effects, which include the diagnostic terms 'fetal alcohol syndrome' (FAS), 'partial fetal alcohol syndrome' (PFAS), 'alcohol-related neurodevelopmental disorders' (ARND), 'fetal alcohol effects' (FAE), or 'alcohol-related birth defects' (ARBD), caused by prenatal exposure to alcohol.<sup>1</sup>

Children, youth and adults with FASD may present with a range of symptoms and impairments in development, learning and behaviour. Some of the symptoms related to neuropsychological impairment may be present in early childhood, while other symptoms may be recognised only after the commencement of formal education. Children displaying the complete array of characteristic facial anomalies, growth retardation and developmental abnormalities of the central nervous system are defined as having FAS.

FASD is entirely preventable and, if children are assessed and diagnosed early in life, it is also potentially treatable. If not prevented or diagnosed early, the condition can have a profound lifelong impact, initiating or perpetuating a cycle of intergenerational disadvantage and poor health.

<sup>1</sup> National Organisation for Fetal Alcohol Syndrome and Related Disorders (NOFASARD): <<http://www.nofasard.org/>>.

## Background

Currently, FASD is not well known or understood in Australia, with most research and work in this field undertaken overseas. Internationally, estimates of FASD range from 1–3 per 1000 live births in the general population to as many as 9.1 per 1000 live births among high-risk populations,<sup>2</sup> making FASD a substantial global concern.

While this information is helpful in guiding an understanding of FASD generally, it does not equip us with an understanding of the condition and its effects or of what is required to address it in Australia.

The National Indigenous Drug and Alcohol Committee (NIDAC) therefore acknowledges and commends the work currently being undertaken in Australia to address FASD.

Particular note is made of the following:

- the Lirilwan Study, currently being conducted in Fitzroy Valley, Western Australia: an Australian first in examining the prevalence of FASD and early life trauma. Further information about this study can be accessed at: <[www.georgeinstitute.org](http://www.georgeinstitute.org)>.
- Fetal Alcohol Spectrum Disorders: Development of a Screening and Diagnostic Instrument for Australia (FASD Project): this project aims to develop an evidence-based instrument for screening and subsequent diagnosis. Further information about this project can be accessed at: <<http://www.ichr.uwa.edu.au/fasdproject/about>>.
- Alcohol and Pregnancy and Fetal Alcohol Spectrum Disorders: resources for health professionals working in Aboriginal and Torres Strait Islander health care settings: this project aims to develop templates that can be used in the production of culturally secure and appropriate resources to assist health professionals in Aboriginal and Torres Strait health care settings across Australia to address the issues of alcohol and pregnancy and FASD. Further information about this project can be accessed at: <<http://ndri.curtin.edu.au/local/docs/pdf/centrelines/ndri032.pdf>>.

<sup>2</sup> Stratton, K., Howe, C. and Battaglia, F.C. (1996). *Fetal Alcohol Syndrome: diagnosis, epidemiology, prevention, and treatment*. Washington: Institute of Medicine; National Academy Press. Available online at: <[www.nap.edu/books/0309052920/html/index.html](http://www.nap.edu/books/0309052920/html/index.html)>.

- work by the Australian Senate to recognise and respond to FASD in Australia: this includes the call for government to give FASD the status of a recognised disability; to regulate the required appropriate warnings about the risks of alcohol consumption during pregnancy on alcohol product labels sold in Australia; to institute a national awareness campaign to raise community awareness of the risks to the unborn child when alcohol is consumed in pregnancy; and to give support to the development of models of care and helping strategies for families and individuals dealing with the impact of FASD. Further information on this work can be accessed at: <<http://www.aph.gov.au/hansard/senate/dailys/ds040711.pdf>>.
- an upcoming inquiry by the House of Representatives Standing Committee on Social Policy and Legal Affairs into the incidence and prevention of FASD, announced on 8 November 2011. The inquiry was referred to the Standing Committee by Ministers Jenny Macklin and Nicola Roxon. Further information can be accessed at: <<http://www.aph.gov.au/house/committee/spla/fasd/index.htm>>.
- work by families and communities through organisations such as the National Organisation for Fetal Alcohol Syndrome and Related Disorders Inc. (NOFASARD: <<http://www.nofasard.org/>>).
- the Foundation for Alcohol Research and Education (FARE)'s investment of over \$500 000 into seven projects across Australia to address gaps in FASD research and practice. Further information on this investment can be accessed at: <<http://www.fare.org.au/research-development/foetal-alcohol-spectrum-disorders-2/>>.

NIDAC considers FASD to be a serious issue which is likely to be contributing to poor educational outcomes, behavioural problems, and early and ongoing contact with the justice system. While NIDAC is particularly concerned about the impact of FASD on Indigenous Australians and communities, it does not see FASD as a uniquely Indigenous issue, nor does it view FASD as an issue only for pregnant women. Rather, NIDAC considers FASD to be an issue facing the country as a whole and one that needs to be addressed by the whole community.

Accordingly, NIDAC provides the following overview of FASD in Australia, including a list of recommendations, in the hope that as many Indigenous and non-Indigenous children, adults and families as possible are spared from the trauma of dealing with this disorder.

## Alcohol and fetal harm

There has been significant debate about the levels of alcohol consumption that can result in fetal harm. What is now generally accepted is that the expression of the full FAS characteristics results from large quantities of alcohol consumed during pregnancy where there is a history of either chronic heavy alcohol use or frequent intermittent heavy alcohol use.<sup>3, 4</sup>

Lower levels of alcohol consumption can, however, still result in harm to the fetus.<sup>5, 6, 7</sup> Risk to the fetus has been shown to occur from moderate levels of prenatal alcohol, including occasional heavy episodic drinking. This means that both the frequency and intensity of alcohol consumption are relevant to the risk of FASD.

Given the uncertainty concerning the amount of damage caused by alcohol to the fetus, the *Australian Guidelines to Reduce Health Risks from Drinking Alcohol* (2009) advise in Guideline 4 that 'maternal alcohol consumption can harm the developing fetus or breastfeeding baby and that for women who are pregnant or planning a pregnancy, or breastfeeding, not drinking is the safest option'.<sup>8</sup>

<sup>3</sup> Jacobson, J.L. and Jacobson, S.W. (1999). Drinking moderately and pregnancy: effects on child development. *Alcohol Research & Health* 23(1): 25–30.

<sup>4</sup> Rosett, H.L. (1980). A clinical perspective of the fetal alcohol syndrome. *Alcoholism: Clinical and Experimental Research* 4(2): 119–122.

<sup>5</sup> O'Leary, C.M., Nassar, N., Kurinczuk, J.J. and Bower C. (2009). The effect of maternal alcohol consumption on fetal growth and preterm birth. *British Journal of Obstetrics and Gynaecology* 116(3): 390–400.

<sup>6</sup> O'Leary, C., Zubrick, S.R., Taylor, C.L., Dixon, G. and Bower, C. (2009). Prenatal alcohol exposure and language delay in 2-year-old children: the importance of dose and timing on risk. *Pediatrics* 123(2): 547–554.

<sup>7</sup> Henderson, J., Gray, R. and Brocklehurst, P. (2007). Systematic review of effects of low–moderate prenatal alcohol exposure on pregnancy outcome. *British Journal of Obstetrics and Gynaecology* 114(3): 243–252.

<sup>8</sup> National Health and Medical Research Council (2009). *Australian Guidelines to Reduce Health Risks from Drinking Alcohol*. Canberra: NHMRC.

## Alcohol use in Australia

In Australia, alcohol is widely used and is very much a part of the social and cultural aspects of the Australian way of life.

The main source of data on alcohol consumption in the general community is the National Drug Strategy Household Survey (NDSHS),<sup>9</sup> which includes representative data from persons 12 years or older. NDSHS reports statistics on the frequency and intensity of drinking, particular patterns of drinking, drinking by level or risk, and a range of demographic, economic and social characteristics of respondents. However, because it does not include data from persons who are imprisoned or homeless, and there is a tendency for respondents to underestimate their drinking, the survey results tend to underestimate the true prevalence of alcohol consumption in Australia. While useful in generating an understanding of trends in alcohol consumption patterns, when these results are extrapolated to the population as a whole, they fall far short of the amount of alcohol sold in Australia.

The 2010 NDSHS<sup>10</sup> indicates that 81 per cent of people 14 years and older reported drinking alcohol in the previous 12 months; 40 per cent drink at least once per week; and 7 per cent drink every day.

The 2010 NDSHS also showed that while the majority of Australians consume alcohol at levels that are considered to be at low risk to their health, 20 per cent report drinking at levels that place them at risk of long-term harm. Additionally, 40 per cent drink at levels that place them at risk of harm in the short term; 11 per cent drink at these levels at least weekly; and 5 per cent drink at these levels every day.

Common patterns of drinking in Australia have been identified. Young people are likely to be occasional heavy drinkers, middle-aged people are likely to be frequent moderate drinkers, and older people tend not to drink at all.<sup>11</sup>

Persons in the 18–29 years age range are most likely to consume alcohol in a way that puts them at risk of alcohol-related harm in the long term. This age range also accounts for the highest proportion of Australians drinking at levels that place them at risk of short-term harm.<sup>12</sup> Consequently, it is important to recognise that risky alcohol consumption commonly commences in adolescence.

The *Australian Secondary School Students' Use of Tobacco, Alcohol, and Over-the-Counter and Illicit Substances in 2008* report<sup>13</sup> shows that experience with alcohol is high among secondary school students, and use becomes more common with increasing age. Sixty per cent of female students surveyed reported drinking alcohol in the past year, with 6.6 per cent reporting drinking five or more standard drinks on one occasion in the past week.

There is also evidence that some areas of Australia are more prone to risky drinking than others. Risky alcohol use is more prevalent in rural than in urban Australia. Male residents of rural Australia are more likely than their urban counterparts to report drinking at levels that put them at risk of harm. The rate of females in rural Australia drinking at these levels parallels the increase found in all areas of Australia.<sup>14</sup>

<sup>11</sup> Ibid.

<sup>12</sup> Ibid.

<sup>13</sup> White, V. and Smith, G. (2011). *Australian Secondary School Students' Use of Tobacco, Alcohol, and Over-the-Counter and Illicit Substances in 2008: report*. Canberra: Australian Government Department of Health and Ageing.

<sup>14</sup> Australian Institute of Health and Welfare (2011), op. cit.

<sup>9</sup> Australian Institute of Health and Welfare. *National Drug Strategy Household Survey Report*. Canberra: AIHW. Latest survey report, 2011 (AIHW cat. no. PHE 145).

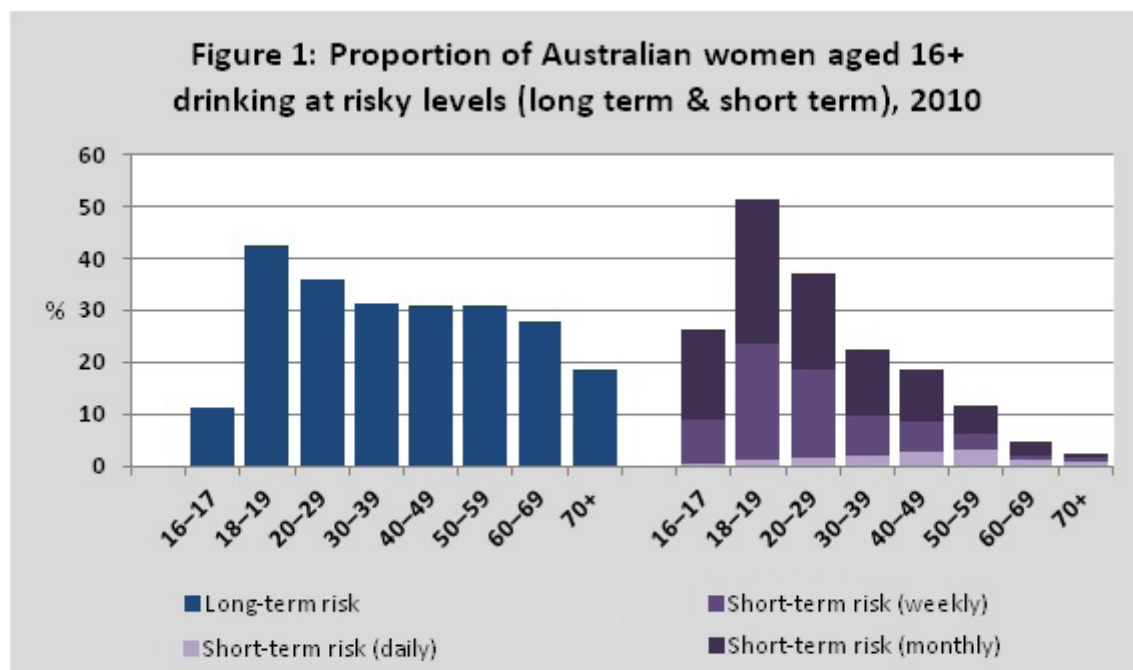
<sup>10</sup> Australian Institute of Health and Welfare (2011). *2010 National Drug Strategy Household Survey Report*. (Drug Statistics Series no. 25, 2011.) Canberra: AIHW. Available online at: <<http://www.aihw.gov.au/publication-detail/?id=32212254712>>.

## Alcohol use prior to and during pregnancy or breastfeeding in Australia

Alcohol consumption immediately prior to or during pregnancy can be harmful to unborn children. Drinking while breastfeeding is also associated with harms to the child. Consequently, females who are of childbearing age, pregnant or breastfeeding constitute important demographics for FASD.

## Alcohol use prior to pregnancy

Figure 1, with statistics from the 2010 NDSHS, presents the proportion of Australian women who drink at risky and high-risk levels of alcohol-related harm. The columns on the left show the proportion of women drinking at risky levels for alcohol-related harm in the long term. The left-hand columns indicate that more than 30 per cent of Australian women of childbearing age consume alcohol at risky levels for long-term harm, peaking at over 40 per cent among 18–19 year olds. The columns on the right show the proportion of women drinking at risky levels for harm in the short term at least weekly or daily. The right-hand columns indicate that young Australian women of childbearing age consume alcohol at risky levels more often than older women. More than 50 per cent of women who are 18–19 years old and 37 per cent who are 20–29 years old drink at levels that place them at risk of short-term harm at least monthly; approximately 20 per cent of women aged 18–29 years drink at these levels at least weekly.



## Alcohol use during pregnancy and breastfeeding

The 2010 NDSHS reports the proportion of women who consume alcohol during pregnancy and while breastfeeding. Findings show that, in 2010, 48 per cent of women who were pregnant in the last 12 months drank alcohol. However, 46 per cent of pregnant women did reduce the amount of alcohol they drank once they became aware that they were pregnant. Findings also show that 66 per cent of women who were breastfeeding consumed alcohol while doing so. While these figures are quite high, it is important to recognise that the proportion of women who drank during pregnancy or while breastfeeding has reduced significantly from the 2007 NDSHS findings.<sup>15</sup>

A number of other studies have investigated alcohol use during pregnancy.<sup>16, 17, 18, 19, 20</sup> The findings from these studies similarly indicate that anywhere from 30 to 59 per cent of women reported consuming alcohol at some time during pregnancy or while breastfeeding, with about 40

per cent of women abstaining in all three trimesters. Of particular concern is the significant minority of pregnant women who will continue to drink at high levels during pregnancy. Around 11 per cent consume more than two standard drinks per occasion and/or more than six standard drinks per week, while around 1.5 per cent consumed more than four standard drinks during the second or third trimesters of pregnancy.<sup>21</sup> Findings also indicate that 14 per cent of women of child-bearing age consumed five or more standard drinks per session during the three months prior to pregnancy, and that almost half of these pregnancies were unplanned. The consequence of this is that unborn babies are being exposed to high levels of alcohol before mothers become aware they are pregnant.<sup>22</sup>

<sup>15</sup> Ibid.

<sup>16</sup> O'Callaghan, F.V., O'Callaghan, M., Najman, J.M., Williams, G.M. and Bor, W. (2003). Maternal alcohol consumption during pregnancy and physical outcomes up to 5 years of age: a longitudinal study. *Early Human Development* 71(2): 137–148.

<sup>17</sup> Australian Institute of Health and Welfare (2005). *Statistics on Drug Use in Australia 2004*. (AIHW cat. no. PHE 62.) Canberra: AIHW.

<sup>18</sup> Zammit, S.L., Skouteris, H., Wertheim, E.H., Paxton, S.J. and Milgrom, J. (2008). Pregnant women's alcohol consumption: the predictive utility of intention to drink and prepregnancy drinking behavior. *Journal of Women's Health* 17(9): 1513–1522.

<sup>19</sup> Alcohol Education and Rehabilitation Foundation (2010). *Annual Alcohol Poll: community attitudes and behaviors: 2010*. Canberra: the Foundation. The study was commissioned by the Foundation for Alcohol Research and Education (FARE) (formerly the Alcohol Education and Rehabilitation Foundation) and undertaken by Galaxy Research. Conducted nationally (excluding the Northern Territory) from 5 to 18 January 2010, the online survey was weighted by age, gender and location (based on Australian Bureau of Statistics population estimates) to the national population, and comprised 1014 respondents aged 18 years and above. FARE has since published the 2011 Annual Alcohol Poll.

<sup>20</sup> Peadon, E.M., Bower, C. and Elliott, E.J. (2008). Teenage smoking in pregnancy and birthweight: a population study, 2001–2004. *Medical Journal of Australia* 189(4): 237–238. See also other studies undertaken by Peadon and colleagues at the Telethon Institute for Child Health Research, listed at <<http://www.ichr.uwa.edu.au/alcoholandpregnancy/publications>>.

<sup>21</sup> Colvin, L., Payne, J., Parsons, D., Kurinczuk, J.J. and Bower, C. (2007). Alcohol consumption during pregnancy in non-Indigenous West Australian women. *Alcoholism: Clinical and Experimental Research* 31(2): 276–284.

<sup>22</sup> See also O'Leary, C.M., Bower, C., Zubrick, S.R., Geelhoed, E., Kurinczuk, J.J. and Nassar, N. (2010). A new method of prenatal alcohol classification accounting for dose, pattern and timing of exposure: improving our ability to examine fetal effects from low to moderate alcohol. *Journal of Epidemiology and Community Health* 64(11): 956–962.

## Predictors of alcohol use during pregnancy

Pre-existing patterns of risky alcohol consumption; individual, family and community factors; and cigarette use are key predictors of alcohol consumption during pregnancy.

Women who consume greater quantities of alcohol prior to pregnancy are more likely to consume alcohol in the periods immediately after becoming pregnant, prior to becoming aware of their pregnancy.<sup>23</sup> Because many pregnancies are unplanned and there is some time before women become aware that they are pregnant, women are likely to continue their existing patterns of alcohol consumption until they become aware that they are pregnant. This potentially provides weeks or months of exposure to alcohol before any change in behaviour can eventuate. Consequently, both the frequency and quantity of alcohol consumed by women prior to pregnancy can have an impact on the likelihood of unintentional fetal exposure to alcohol in the first trimester. However, while alcohol consumption during the early stages of pregnancy may be relatively common, a significant proportion of women continue to drink throughout pregnancy.

Individual, family and community factors are associated with alcohol consumption during pregnancy. Recent research from Ireland<sup>24</sup> has identified that single marital status, being a single mother, being employed, having private health insurance, and smoking during

pregnancy predicted moderate alcohol consumption during pregnancy. These factors, as well as being younger than 25 years of age, having an unplanned pregnancy, and illicit drug use predicted heavy alcohol consumption during pregnancy. These findings are consistent with findings in Australia identifying high rates of FASD among severely disadvantaged Indigenous populations.<sup>25</sup> The findings also reinforce a need for a holistic approach to preventing FASD and a recognition that FASD is a potential concern among all sectors of Australian society.

Smoking during pregnancy is a predictor of alcohol consumption during pregnancy.<sup>26</sup> The impact upon the unborn children of both drinking and smoking by pregnant mothers is likely to be greater than on those whose mothers either only smoke or drink.

South Australian research found that miscarriages were often associated with alcohol and tobacco use during pregnancy and that cessation of alcohol use often occurred with first-time pregnancies once women became aware of their pregnancy.<sup>27</sup> Research from New South Wales identified a number of maternal characteristics associated with an alcohol-related hospital admission during pregnancy: residence in a remote/very remote area; being Australian-born; having had a previous pregnancy; smoking in the current pregnancy; and presenting late to antenatal care.<sup>28</sup>

<sup>25</sup> See notes 20 and 31, and the following section.

<sup>26</sup> Bolumar, F. et al. (1994), op. cit.

<sup>23</sup> Bolumar, F., Rebagliato, M., Hernandez-Aguado, I. and Florey, C.D. (1994). Smoking and drinking habits before and during pregnancy in Spanish women. *Journal of Epidemiology and Community Health* 48(1): 36–40.

<sup>24</sup> Mullally, A., Cleary, B.J., Barry, J., Fahey, T.P. and Murphy, D.J. (2011). Prevalence, predictors and perinatal outcomes of periconceptional alcohol exposure: retrospective cohort study in an urban obstetric population in Ireland. *BMC Pregnancy and Childbirth* 11: 27.

<sup>27</sup> Hotham, E., Ali, R., White, J. and Robinson, J. (2008). Pregnancy-related changes in tobacco, alcohol and cannabis use reported by antenatal patients at two public hospitals in South Australia. *Australian and New Zealand Journal of Obstetrics and Gynaecology* 48(3): 248–254.

<sup>28</sup> Burns, L., Black, E. et al. (2011). Geographic and maternal characteristics associated with alcohol use in pregnancy. *Alcoholism: Clinical and Experimental Research* 35(7): 1230–1237.

## Alcohol use among Indigenous Australians

The report *Substance Use among Aboriginal and Torres Strait Islander People* provides data on alcohol consumption among Indigenous Australians.<sup>29</sup> This report draws on original sources of data, including the National Aboriginal and Torres Strait Islander Health Survey (NATSIHS)<sup>30</sup> and the 2007 NDSHS. Drawing an accurate picture from these sources, however, is not possible. The size of the Indigenous sample in the NDSHS is too small to generalise with any degree of certainty and the methodology used in the NATSIHS has been widely criticised.<sup>31</sup> Additional information can also be drawn from the 2010 NDSHS, although again the size of the Indigenous population surveyed is small, and findings cannot be generalised to specific areas of Australia.

<sup>29</sup> Australian Institute of Health and Welfare (2011a). *Substance Use among Aboriginal and Torres Strait Islander People*. (AIHW cat. no. IHW 40.) Canberra: AIHW. Available online at: <<http://www.aihw.gov.au/publication-detail/?id=10737418268>>.

<sup>30</sup> Australian Bureau of Statistics (2006). *National Aboriginal and Torres Strait Islander Health Survey, 2004–05*. (ABS cat. no. 4715.0.) Canberra: ABS.

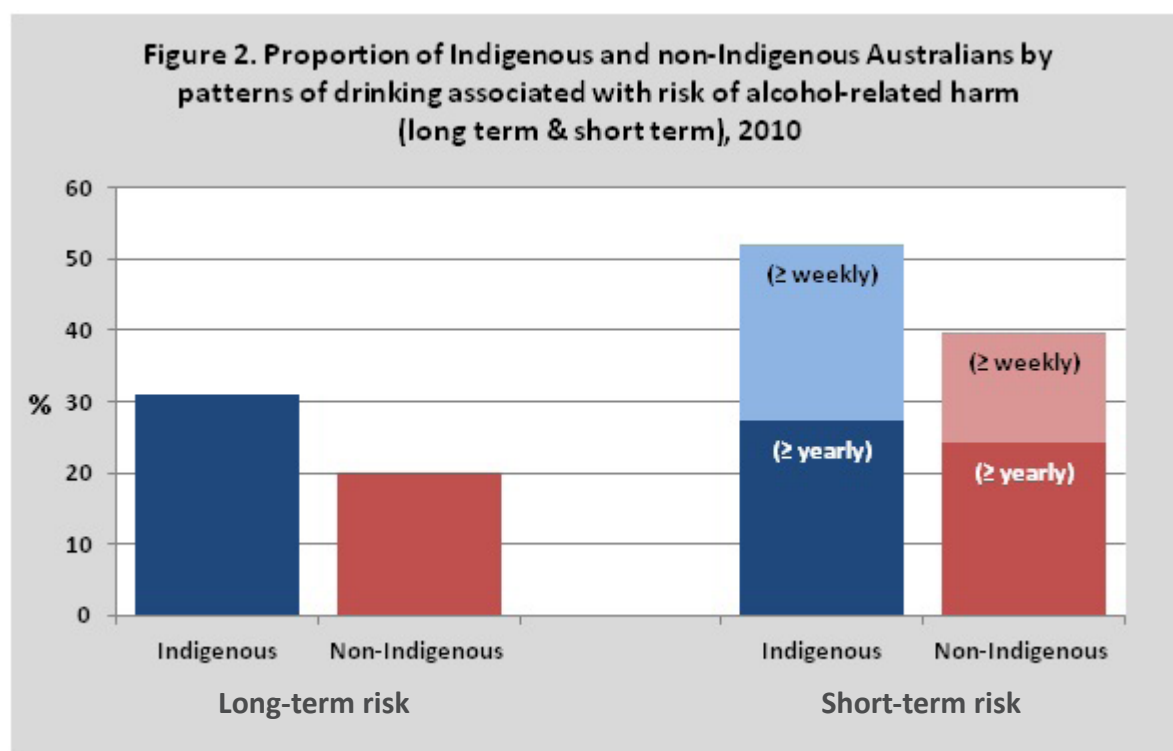
<sup>31</sup> Chikritzhs, T. and Brady, M. (2006). Fact or fiction? A critique of the National Aboriginal and Torres Strait Islander Social Survey 2002. *Drug and Alcohol Review* 25(3): 277–287.

Using risk levels in the 2001 *Australian Alcohol Guidelines*,<sup>32</sup> the NATSIHS in 2004–05<sup>33</sup> found that, based on consumption reported in the week prior to interview, 32 per cent of Indigenous people aged 15 years and over consumed alcohol at a low level of risk for alcohol-related harm in the long term, while 16 per cent drank at risky or high-risk levels. Changes to the guidelines in 2009 mean that the proportion of Indigenous Australians consuming alcohol at risky levels is substantially greater than reported here. Consequently, it is necessary to look to the 2010 NDSHS to identify the proportion of Indigenous Australians drinking at risky levels, as defined by the 2009 guidelines.

The 2010 NDSHS shows Indigenous Australians were 1.4 times more likely than non-Indigenous Australians to abstain from drinking alcohol, but were also about 1.5 times more likely to drink alcohol at risky levels for both single occasion and lifetime harm. Figure 2 presents the proportion of Indigenous and non-Indigenous Australians according to risk of alcohol-related harm, as reported in the 2010 NDSHS.

<sup>32</sup> National Health and Medical Research Council (2001). *Australian Alcohol Guidelines: health risks and benefits*. Canberra: NHMRC.

<sup>33</sup> Australian Bureau of Statistics (2006), op. cit.



## Alcohol use prior to and during pregnancy and breastfeeding among Indigenous Australians

No representative data are available on the prevalence of alcohol consumption prior to or during pregnancy among Indigenous women in Australia. Neither the National Aboriginal and Torres Strait Islander Social Survey (NATSISS)<sup>34</sup> nor the three-yearly National Health Survey (NHS)<sup>35</sup> reports on measures related to alcohol consumption prior to or during pregnancy or breastfeeding.

The Australian Institute of Health and Welfare (AIHW)<sup>36</sup> does, however, report information on smoking among pregnant Indigenous women, enabling an indication of the prevalence of alcohol consumption during pregnancy to be drawn from the prevalence of smoking during pregnancy. The NATSISS collected information on smoking during pregnancy from the mothers of Indigenous children aged 0–3 years. Among these mothers, 42 per cent reported that they used tobacco during pregnancy and 24 per cent reported that they used less tobacco than usual during pregnancy. Given that alcohol consumption, problematic alcohol consumption, and risky drinking are more common among Indigenous women of child-bearing age than is smoking, it is likely that at least 42 per cent of Indigenous pregnant women will have used alcohol while pregnant. The percentage of Australian women using alcohol while pregnant is estimated to be 50–60 per cent,<sup>37</sup> making the estimate concerning Indigenous women a conservative one. Information on comparative rates of risky drinking levels while pregnant in different Australian communities requires further research.

<sup>34</sup> Australian Bureau of Statistics (2009). *National Aboriginal and Torres Strait Islander Social Survey, 2008*. (ABS cat. no. 4714.0.) Canberra: ABS.

<sup>35</sup> Australian Bureau of Statistics (2009a). *National Health Survey: summary of results, 2007–2008*. (ABS cat. no. 4364.0.) Canberra: ABS.

<sup>36</sup> Australian Institute of Health and Welfare (2011a), op. cit.

<sup>37</sup> Burns, L., Black, E. et al. (2011). op. cit.

## Fetal alcohol spectrum disorder in Australia

The prevalence of FASD in Australia is somewhat difficult to determine, as there is a lack of accurate research data across all population groups as well as confusion between FAS and FASD, with FAS more clinically recognisable. Nevertheless, current findings of the prevalence of FASD are believed to be greatly underestimated.

The first report to estimate the prevalence of FAS in Australia indicated a rate of 0.02 per 1000 for non-Indigenous children and 2.76 per 1000 for Indigenous children.<sup>38</sup> This report was based on research conducted in Western Australia.

Since this first research paper, other Australian studies have found similar estimates in Australia. One study conducted in the Northern Territory estimated the prevalence of FAS in the Top End of the Northern Territory to be 0.68 per 1000 live births, with the comparable prevalence for Indigenous children calculated to be 1.87. As many as 4.7 per 100 000 live Aboriginal births were deemed to have either FASD or a similar alcohol-related developmental condition.<sup>39</sup> However, a prospective study to actively identify cases of FAS across Australia found considerably lower rates than those reported in earlier studies.<sup>40</sup>

The prevalence of FAS in Indigenous children in Australia is similar to the reported high rates for Indigenous people in other countries, but the birth prevalence for non-Indigenous Australians<sup>41,42</sup> is one-tenth that reported for other countries.<sup>43,44</sup> This is thought to be due to the under-reporting of cases in the non-Indigenous community.<sup>45</sup>

<sup>38</sup> Bower, C., Silva, D., Henderson, T.R., Ryan, A. and Rudy, E. (2000). Ascertainment of birth defects: the effect on completeness of adding a new source of data. *Journal of Paediatrics and Child Health* 36(6): 574–576.

<sup>39</sup> Harris, K.R. and Bucens, I.K. (2003). Prevalence of fetal alcohol syndrome in the Top End of the Northern Territory. *Journal of Paediatrics and Child Health* 39(7): 528–533.

<sup>40</sup> Elliot, E.J., Payne, J., Morris, A., Haan, E. and Bower, C. (2008). Fetal alcohol syndrome: a prospective national surveillance study. *Archives of Disease in Childhood* 93(9): 732–737.

<sup>41</sup> Bower, C., Silva, D., Henderson, T.R., Ryan, A. and Rudy, E. (2000), op. cit.

<sup>42</sup> Allen, K., Riley, M., Goldfeld, S. and Halliday, J. (2007). Estimating the prevalence of fetal alcohol syndrome in Victoria using routinely collected administrative data. *Australian and New Zealand Journal of Public Health* 31(1): 62–66.

<sup>43</sup> Abel, E.L. (1995). An update on incidence of FAS: FAS is not an equal opportunity birth defect. *Neurotoxicology and Teratology* 17(4): 437–443.

<sup>44</sup> Egeland, G.M., Perham-Hester, K.A., Gessner, B.D., Ingle, D., Berner, J.E. and Middaugh, J.P. (1998). Fetal alcohol syndrome in Alaska, 1977 through 1992: an administrative prevalence derived from multiple data sources. *American Journal of Public Health* 88(5): 781–786.

<sup>45</sup> Burns, L., Black, E. et al. (2011). op. cit.

Factors thought to contribute to the under-reporting of children with FASD include:

- the absence of routine screening for alcohol use during pregnancy
- the lack of standardised routine data collection
- the lack of routine screening of infants and children known to be at risk of harm from prenatal alcohol exposure
- limited knowledge of the diagnostic criteria for FASD and reluctance by health professionals to make a diagnosis for fear of stigmatising the family, and
- few health professionals assessing children for FASD.<sup>46</sup>

It is important to note that FASD is not a problem unique to Indigenous Australians or to Indigenous people generally. While in some parts of Australia and overseas, particularly in Canada and the United States, prevalence estimates of FAS in Indigenous communities are higher than that reported for the wider community, most researchers agree that the difference reflects other factors such as socioeconomic status, drinking patterns and differences in diet rather than racial characteristics.

Also most studies of FAS in Indigenous populations have been conducted in communities already known to have high levels of alcohol consumption. These figures should therefore not be generalised to other Indigenous communities or to the Indigenous population as a whole. Nevertheless, it is recognised that some rural and remote Indigenous communities have a high prevalence of FASD which impacts on the community and their ability to respond to the effects of FASD on individuals, families and the whole community.<sup>47</sup>

## Social impact of fetal alcohol spectrum disorder in Australia

The social impact of FASD in Australia is believed to be far-ranging.

An American study<sup>48</sup> conducted with individuals with FAS/FAE aged between 6 years and 51 years found that:

- 90 per cent had mental health problems such as cognitive disorders, psychiatric illness or psychological dysfunction (6 years and over)
- 30 per cent had alcohol and other drug use issues (12 years and over)
- 60 per cent had disrupted school experience (12 years and over), and
- 50 per cent exhibited inappropriate sexual behaviour (12 years and over).

This study found other social issues facing individuals with FASD included: early maternal death; living with a parent who has alcohol abuse problems; child abuse and neglect; removal from the home by children's protective services; repetitive periods of foster care and other transient home placements; being raised by adoptive or foster parents; and victims of discrimination.

The impact on families, the health care system, the social service system, the criminal justice system, and the education and employment systems has also been significant.

<sup>46</sup> Western Australia Department of Health (2010). *Fetal Alcohol Spectrum Disorder Model of Care*. Perth: Western Australia Department of Health, Health Networks Branch.

<sup>47</sup> Pyett, P., Waples-Crowe, P., Loughron, K.H. and Gallagher, J. (2008). Healthy pregnancies, healthy babies for Koori communities: some of the issues around alcohol and pregnancy. *Aboriginal and Islander Health Worker Journal* 32(1): 30–32.

<sup>48</sup> Streissguth, A.P., Bookstein, F.L., Barr, H.M., Sampson, P.D., O'Malley, K. and Young, J.K. (2004). Risk factors for adverse life outcomes in fetal alcohol syndrome and fetal alcohol effects. *Journal of Developmental and Behavioral Pediatrics* 25(4): 228–238.

## Fetal alcohol spectrum disorder and the criminal justice system in Australia

Limited research has investigated the relationship between FASD and contact with the criminal justice system in Australia. The limited Australian literature, complemented by international research, indicates that FASD should be considered at every stage of the criminal justice system, from offending behaviour, through to court proceedings, as well as throughout incarceration and post-release.

There is no Australian estimate of the number of offenders with FASD. Overseas studies of individuals with FASD, however, demonstrate high rates of contact with the criminal justice system. Streissguth and colleagues' study in Washington found that, of individuals with FASD, 60 per cent had been in trouble with the law and half had experienced confinement (detention, prison, or a psychiatric or alcohol and other drug inpatient setting).<sup>49</sup> A Canadian study indicated that youth with FASD, in particular, are disproportionately represented in the juvenile justice system.<sup>50</sup>

There is growing recognition that courts should take into consideration a diagnosis of FASD. People with FASD often have poor memory and can be highly suggestible. This means that they may not make reliable witnesses, or may be disadvantaged or provide inaccurate information during police questioning.<sup>51, 52</sup> Additionally, the degree to which an individual is affected by FASD may raise questions concerning diminished responsibility.<sup>53</sup> Findings from a survey of Canadian judges and prosecutors suggested that access to accurate and timely assessment and diagnosis of FASD would be beneficial.<sup>54</sup>

A 2010 article in the *Criminal Law Journal*<sup>55</sup> outlined issues relevant to sentencing defendants with FASD. Drawing on a wealth of Australian and international common law cases, the author discusses the circumstances in which FASD could be considered a mitigating factor, as well as appropriate penalties for such defendants, and provides a series of recommendations related to increasing knowledge about FASD in the criminal justice system. Additionally, reports by the Human Rights and Equal Opportunity Commission (subsequently the Australian Human Rights Commission) have highlighted the role that FASD plays in the high rates of crime and incarceration among Indigenous youth in Australia and suggested possible means of addressing this issue.<sup>56, 57</sup> These include a range of interventions recommended in the Pathways to Prevention initiative from the late 1990s: crime prevention; early intervention; and diversion from the courts or prison.<sup>58</sup>

<sup>55</sup> Douglas, H. (2010). The sentencing response to defendants with foetal alcohol spectrum disorder. *Criminal Law Journal* 34: 221–239.

<sup>56</sup> Aboriginal and Torres Strait Islander Social Justice Commissioner (2005). *Indigenous Young People with Cognitive Disabilities and Australian Juvenile Justice Systems*. Sydney: Human Rights and Equal Opportunity Commission.

<sup>57</sup> Aboriginal and Torres Strait Islander Social Justice Commissioner (2008). *Preventing Crime and Promoting Rights for Indigenous Young People with Cognitive Disabilities and Mental Health Issues*. Sydney: Australian Human Rights Commission.

<sup>58</sup> Australia Attorney-General's Department (2001). *Pathways to Prevention: Developmental and Early Intervention Approaches to Crime in Australia: full report*. Canberra: Attorney-General's Department.

<sup>49</sup> Ibid.

<sup>50</sup> Cox, L.V., Clairmont, D. and Cox, S. (2008). Knowledge and attitudes of criminal justice professionals in relation to fetal alcohol spectrum disorder. *Canadian Journal of Clinical Pharmacology* 15(2): e306–e313.

<sup>51</sup> Roach, K. and Bailey, A. (2009). The relevance of fetal alcohol spectrum disorder and the criminal law from investigation to sentencing. *University of British Columbia Law Review* 42(1): 1–68.

<sup>52</sup> For example, *Western Australia v Cox* [2008] WASC 287 per Martin C.J. at [1]–[8].

<sup>53</sup> For example, *R v Korhonen* [1999] NSWSC 933 per Hulme J.

<sup>54</sup> Cox, L.V., Clairmont, D. and Cox, S. (2008), op. cit.

## Economic costs of fetal alcohol spectrum disorder in Australia

The economic costs associated with FASD in Australia are unknown. This lack of information is affected by prevalence data for FASD in Australia being both underestimated and incomplete, thus making impossible any determination of actual current population costs.

One study conducted in Canada<sup>59</sup> examined key cost components associated with FASD. These included direct costs such as medical, education, social services, and out-of-pocket expenses, as well as indirect costs such as productivity losses. The estimated annual costs associated with FASD per person were over \$21,000 Canadian, or around \$20,000 Australian. Costs of FASD to the Canadian community from birth to 53 years old were estimated at \$5.3 billion Canadian, or around \$5.04 billion Australian, each year.

<sup>59</sup> Stade, B., Ali, A., Bennett, D., Campbell, D., Johnston, M., Lens, C., Tran, S. and Koren, G. (2009). The burden of prenatal exposure to alcohol: revised measurement of cost. *Canadian Journal of Clinical Pharmacology* 16(1): e91–e102.

## Identifying fetal alcohol spectrum disorder in Australia

### Diagnosis

One of the strongest correlates of adverse outcomes from FASD is lack of an early diagnosis — the longer the delay in receiving diagnostic information, the greater the odds of adverse outcomes. An early diagnosis provides greater opportunities for preventing or at least ameliorating adverse outcomes.<sup>60</sup>

Early diagnosis enables intervention strategies to be implemented which could prevent or greatly reduce the development and impact of secondary disabilities, including mental illness, alcohol and other drug issues, and problems with the law.

There is currently no single internationally accepted classification system for FASD. The two dominant classification systems, both originating in North America, are the Hoyme revised Institute of Medicine criteria and the University of Washington 4-digit diagnostic code.<sup>61</sup> Common to the different classification systems for FASD is the need to assess characteristics of growth, facial features, neurological structure and function, and alcohol exposure during pregnancy.

In Western Australia, the *Fetal Alcohol Spectrum Disorder Model of Care*, which was developed by a working group convened by the Western Australian Child and Youth Health Network, recommends the University of Washington 4-digit diagnostic code for use by health professionals.<sup>62</sup> This model of care was released in 2010 and contains a series of recommendations to guide agencies across government and non-government sectors to prevent, diagnose and treat FASD.

Meanwhile, the American Psychiatric Association is currently undertaking the development of the fifth edition of the *Diagnostic and Statistical Manual of Mental Disorders* (DSM–5), which is due for release in 2013. According to the DSM–5 website, fetal alcohol syndrome has been proposed for inclusion in the forthcoming edition. Working groups are currently assessing the evidence in support of including FAS in DSM–5 and will make recommendations concerning its inclusion.<sup>63</sup>

<sup>60</sup> Yazdani, P., Motz, M. and Koren, G. (2009). Estimating the neurocognitive effects of an early intervention program for children with prenatal alcohol exposure. *Canadian Journal of Clinical Pharmacology* 16(3): e453–e459.

<sup>61</sup> Astley, S.J. (2006) Comparison of the 4-digit diagnostic code and the Hoyme diagnostic guidelines for fetal alcohol spectrum disorders. *Pediatrics* 118: 1532–1545.

<sup>62</sup> Western Australia Department of Health (2010), op. cit.

<sup>63</sup> See <<http://www.dsm5.org/Pages/Default.aspx>>.

## Screening

The effects of FASD present early in childhood and persist throughout life. Without intervention early in life, adverse consequences are most likely to manifest in adolescence and adulthood. Early detection of possible FASD in babies and children exposed to alcohol is therefore crucial to allow for early intervention in order to improve the long-term outcomes for affected children and adults.

Currently there is no existing standardised screening test for FASD in Australia. In addition, there is ample evidence that FASD is poorly recognised by health professionals and that diagnosis is often missed or delayed.<sup>64, 65, 66</sup>

For screening to be effective it needs to be targeted at populations at high risk of the disorder, namely:

- children in the care of state child protection services
- children of mothers attending alcohol treatment services
- youth in juvenile justice services, and
- regional areas and communities identified as having high levels of alcohol consumption.

## Prevention of fetal alcohol spectrum disorder, and intervention, in Australia

In the past, prevention and intervention strategies relating to FASD in Australia have largely been ad hoc and, where provided, have primarily focused on select Indigenous regions or communities.<sup>67</sup> This is starting to change, with some states such as Western Australia developing blueprints to guide agencies and professions on how to prevent and address FASD.<sup>68</sup>

In the implementation of any prevention or intervention strategies, it is important that any barriers, such as community and professional staff attitudes, firstly be addressed if such strategies are to be successful. Some of these barriers are highlighted below in sections on Community Attitudes towards Drinking during Pregnancy and Breastfeeding, and Workforce Issues and Professional Development and Training.

The role of men is also important in undertaking any prevention and intervention strategies. Their support, particularly in certain cultural groups, is crucial for women to be able to make and sustain the change not to drink during preconception, pregnancy and breastfeeding stages.

<sup>64</sup> Pyett, P. (2007). *Fetal Alcohol Syndrome: a literature review for the 'Healthy pregnancies, healthy babies for Koori communities' report*. Melbourne: Victoria Department of Human Services, Premier's Drug Prevention Council.

<sup>65</sup> The Western Australian Fetal Alcohol Spectrum Disorder (FASD) Prevention Aboriginal Consultation Forum 2010: *Strong Spirit Strong Future – Promoting Healthy Women and Pregnancies*. Perth, Western Australia Drug and Alcohol Office, 31 May 2011.

<sup>66</sup> Elliott, L., Coleman, K., Suebwongpat, A. and Norris, S. (2008). *Fetal Alcohol Spectrum Disorders (FASD): systematic reviews of prevention, diagnosis and management*. (HSAC Report 1(9).) Christchurch, New Zealand: University of Canterbury, Health Services Assessment Collaboration.

<sup>67</sup> On the paucity of evaluated interventions worldwide, see Elliott, L., Coleman, K., Suebwongpat, A. and Norris, S. (2008), *ibid*.

<sup>68</sup> See notes 59 and 62.

## Prevention

Addressing FASD adequately will require a range of prevention measures, including strategies aimed at the whole population as well as specific groups, especially school-age children and adolescents, women of child-bearing age, pregnant women and high-risk women.<sup>69</sup>

### Primary prevention

Primary prevention strategies to reduce the incidence of FASD must focus not only on women of child-bearing age but also on the general population, and be embedded in broader alcohol harm-reduction strategies. Primary prevention measures need to include strategies to change individual behaviour as well as the community attitudes and systems that support the current drinking culture and environment. As limited education is a primary social determinant of risky drinking, such changes may require interventions or programs for high-risk groups in early childhood (see also the section below on Interventions).<sup>70</sup>

Reducing harmful drinking across the population will require an integrated approach that combines evidence-based social marketing initiatives with policy practices that influence the way alcohol is portrayed and made available.

This approach requires coordinated action nationally, statewide and locally for optimal effect. At-risk groups in particular need to be targeted.

<sup>69</sup> Pyett, P., Waples-Crowe, P., Loughron, K.H. and Gallagher, J. (2008), op. cit.

<sup>70</sup> Steering Committee for the Review of Government Service Provision (2011). *Overcoming Indigenous Disadvantage: key indicators 2011*. Canberra: Productivity Commission.

### Secondary prevention

Secondary prevention strategies addressing the issue of FASD need to be aimed at reducing the risk of alcohol-related harm to the fetus.

Strategies will generally be implemented by health professionals and aim to:

- prevent or minimise alcohol consumption by pregnant women
- routinely screen pregnant women for alcohol consumption
- identify and intervene with women who have harmful patterns of alcohol consumption.

### Tertiary prevention

Tertiary prevention strategies target women who are known to have a child with FASD and/or women with an alcohol-related dependency.

Tertiary prevention strategies are generally implemented by health professionals and aim to:

- promote the health and wellbeing of the mother during and after pregnancy
- promote the health, wellbeing and development of the child
- address the mother's substance use problems and associated issues
- prevent further alcohol-exposed pregnancies in women identified as having an alcohol-related dependency during pregnancy and women who have a child diagnosed with FASD.

## Intervention

Although there is no specific treatment for FASD — and there is currently a lack of evaluated FASD interventions worldwide — a number of interventions need to be provided for children, youth and adults with FASD and their families to lessen the subsequent cognitive, behavioural and social impacts of FASD.

Although many with FASD will not have the primary physical stigmata of FAS, they will nevertheless have clear intellectual, academic and adaptive behaviour deficits, which need to be addressed. It is therefore important that the focus of interventions is not solely on FAS but also on these related areas.

Alertness to the possibility of FASD problems among children of all ages, as well as in the youth and adult community, is important. Access to appropriate early childhood education and developmental services, as well as to behavioural, mental health and drug and alcohol services, is vital.<sup>71</sup>

In relation to alcohol and other drug use problems, evidence highlights that, as an individual ages, the adverse life outcomes of alcohol and other drug problems and confinement increase into adulthood. The earlier these issues are addressed, the better the outcomes for the individual, their family and the community.

Protective factors against issues such as alcohol and other drug use problems have been shown to include:

- a high percentage of life spent in a stable/nurturing home, and
- younger age at diagnosis: earlier diagnosis allows for better planning for the transition from adolescence to adulthood.<sup>72</sup>

Also important is the need to integrate the means of detecting and managing youth and adults with FASD in the juvenile and adult judicial system.

Research findings indicate that good stable families, with enduring relationships with their children with FASD, are critical protective factors for helping children to avoid adverse life outcomes. Therefore, interventions must be designed to enable families to support the person with FASD and to manage problem behaviours.

Financial assistance for families may also be warranted in some situations. Currently FASD is not listed as a disability in Australia, thus preventing individuals, families and carers from accessing government financial assistance. The Australian Senate has, however, called for the Australian Government to give individuals with FASD access to disability support funding, where required.<sup>73</sup>

## Community attitudes towards drinking during pregnancy and breastfeeding

Any prevention and intervention undertaken in Australia will need to address community attitudes towards drinking during pregnancy.

A 2010 survey,<sup>74</sup> commissioned by the Foundation for Alcohol Research and Education (formerly the Alcohol Education and Rehabilitation Foundation) into community attitudes towards alcohol, revealed that despite the fact that 90 per cent of Australians believe alcohol should be avoided while pregnant, almost one in 10 (8 per cent) survey respondents still think it is acceptable to drink alcohol in moderation while pregnant, and 9 per cent believe it is acceptable while breastfeeding. Nevertheless, and despite understanding the dangers of consuming alcohol while pregnant or breastfeeding, new and expectant mothers still choose to drink. The 2011 survey by the same organisation found that 62 per cent of Australians supported health information labels on products containing alcohol, with the highest level of support (71%) for labels warning about the dangers of drinking while pregnant.<sup>75</sup>

Other sources indicate that community awareness of the impact of alcohol on the developing fetus lacks understanding and accuracy.<sup>76, 77</sup>

<sup>74</sup> Alcohol Education and Rehabilitation Foundation (2010), op. cit. See note 19.

<sup>75</sup> Ibid.

<sup>76</sup> Aboriginal and Torres Strait Islander Social Justice Commissioner (2005), op. cit.

<sup>77</sup> Aboriginal and Torres Strait Islander Social Justice Commissioner (2008), op. cit.

<sup>71</sup> Ibid.

<sup>72</sup> Streissguth, A.P., Bookstein, F.L., Barr, H.M., Sampson, P.D., O'Malley, K. and Young, J.K. (2004), op. cit.

<sup>73</sup> Australian Senate, *Official Daily Hansard*, Monday 4 July 2011: 3879–3880.

## Workforce issues and professional development and training

Health and related professions play an essential role in responding to FASD in Australia. It is therefore imperative that workforce issues be addressed and FASD-specific training and resources be provided to professionals working with individuals and their families and carers dealing with FASD.

Reports indicate a recognised lack of awareness and knowledge of FASD by health professionals, with poor identification of mothers at risk, and of children, youth and adults affected by FASD, as well as limited capacity and competency of health workers to deliver identified prevention strategies and interventions.

A project conducted to determine the level of awareness of key workers in Victorian Aboriginal communities about the health effects of drinking alcohol during pregnancy found that workers in Koori maternity services had some awareness of the effects on a baby of alcohol use during pregnancy, but they felt there was limited awareness of such effects within their communities.<sup>78</sup> Health workers identified shame and stigma around drinking as making it difficult for them to talk with women about this subject. These workers stressed the need not only to focus on the drinking, but also to consider all other aspects of the woman's life.

As part of the Victorian project, a survey of all general practitioners working in Victorian Aboriginal community-controlled health services<sup>79</sup> indicated that GPs need accurate information about the effects of alcohol on pregnant women and on the fetus throughout pregnancy; the symptoms and diagnostic criteria for FAS; the current Australian guidelines for alcohol consumption during pregnancy; and the importance of screening for all pregnant women regarding alcohol use. GPs also identified the lack of appropriate resources to provide to pregnant women and other community members.

A survey conducted in Western Australia showed that the majority of health professionals did not routinely ask pregnant women about alcohol use nor inform them of its possible consequences.<sup>80</sup> Health professionals also had limited knowledge about alcohol use during pregnancy and its effects, and did not feel well prepared to deal with the subject. The survey also identified the need for educational resources for health professionals on the effects of alcohol use during pregnancy.

An online consultation survey conducted in 2011 by the National Indigenous Drug and Alcohol Committee found that there was a lack of awareness of the National Health and Medical Research Council's *Australian Guidelines to Reduce Health Risks from Drinking Alcohol* (2009), with only 38.2 per cent of 330 workers who responded to the question indicating that they were definitely familiar with the new guidelines.<sup>81</sup>

Health professionals may also experience organisational and social barriers in discussing alcohol use with pregnant women, given that it can be a sensitive and complex issue for some women and may carry notions of judgement and stigma. Drinking is often associated with violence, and with welfare issues. A pregnant woman who drinks may be more concerned about the reality of losing the baby to welfare than about the possible effects of alcohol. She may also be under pressure to drink from her partner or others. This is an extremely important issue for health professionals to be aware of and address, as any interventions need to avoid stigmatising women and blaming people who themselves are often victims.

Another study conducted in Western Australia<sup>82</sup> examined the barriers that health professionals encountered in addressing alcohol use with pregnant women and recommended strategies to overcome them. Identified barriers included assumptions and perceptions of professionals concerning the consumption of alcohol by their pregnant clients, namely that most women consumed little alcohol during pregnancy, therefore the topic was seen to be of limited relevance; that pregnant women know not to drink during pregnancy so that raising the topic was seen to be unnecessary; and that women who drink at high-risk levels during pregnancy have other contextual issues that need to be addressed, making it difficult for many health professionals to support them.

In the context of antenatal care, alcohol was not on the list of priorities for many health professionals. Instead, issues such as smoking and diet were identified as more important. The burden of time was another issue of concern for the client and the health professional–client relationship.

Health professionals also identified the need for further skills and resources to support their practice.

Training and education of all relevant health and related professionals, workers, trainees and students therefore need to be a high priority. Education and training must be available at multiple levels, including undergraduate and in-service training programs.

<sup>78</sup> Pyett, P., Waples-Crowe, P., Loughron, K.H. and Gallagher, J. (2008), op. cit.

<sup>79</sup> Allen, K., Riley, M., Goldfeld, S. and Halliday, J. (2007), op. cit.

<sup>80</sup> Elliot, E.J., Payne, J., Morris, A., Haan, E. and Bower, C. (2008), op. cit.

<sup>81</sup> National Indigenous Drug and Alcohol Committee (2011). *NIDAC Online Consultation 1: Alcohol: summary of findings*. Canberra: NIDAC. Available online at: <[http://www.nidac.org.au/images/PDFs/NIDACpublications/alcohol\\_survey.pdf](http://www.nidac.org.au/images/PDFs/NIDACpublications/alcohol_survey.pdf)>.

<sup>82</sup> France, K., Henley, N. et al. (2010). Health professionals addressing alcohol use with pregnant women in Western Australia: barriers and strategies for communication. *Substance Use and Misuse* 45(10): 1474–1490.

## **Fetal alcohol spectrum disorder and alcohol and other drug services in Australia**

No known research has investigated the relationship between FASD and contact with alcohol and other drug services in Australia.

There are, however, a number of important implications for alcohol and other drug services that relate to FASD. These include:

- individuals accessing alcohol and other drug services who may also have FASD
- individuals accessing alcohol and other drug services who may have children with FASD
- women accessing alcohol and other drug services who may fall pregnant or be pregnant or breastfeeding.

It is therefore important that services providing alcohol and other drug interventions in Australia be aware of FASD and be able to provide appropriate interventions that take FASD into account, as well as alcohol and other drug issues. Consideration needs to include the client accessing the service as well as any of their family members, including children. Alcohol and other drug services may need to expand their existing services or to refer clients onto specialist FASD services.

## Conclusion and recommendations

This position paper aims to provide an overview of FASD in Australia and recommendations on how best to address it. The key issues highlighted in the paper are briefly summarised below.

A significant issue is the lack of reliable data on the prevalence of alcohol consumption among child-bearing, pregnant and breastfeeding females, across all population groups in Australia. This is particularly the case with Indigenous populations. Available information indicates that patterns of alcohol consumption in Australia put females of child-bearing age at risk of drinking while pregnant or breastfeeding. Determining the prevalence of FASD in Australia is also difficult. Estimations have been made but the lack of routine screening and diagnostic criteria and awareness of FASD among health and related professionals make any estimation unreliable. The unavailability of data on the prevalence of FASD in Australia is concerning and unacceptable, particularly given Australia's drinking culture. Greater investment, therefore, needs to occur to ensure that relevant data can be collected at both local and national levels.

Another key issue is the lack of awareness and understanding of FASD within the Australian community, with many people unaware of the risk to the fetus or baby if the mother consumes alcohol while pregnant or breastfeeding. This is particularly the case with low to medium levels of drinking or occasional or episodic use. The community, therefore, needs to be provided with consistent, clear messages about the potential risk to the developing fetus and young baby of females consuming alcohol during pregnancy and while breastfeeding and to be clearly advised that no level of alcohol consumption is safe during this time. This information campaign needs to occur within a broader context of addressing harmful drinking, to ensure that attitudes towards drinking are changed, and that women are not stigmatised but receive the support they need in order to adhere to such advice. These clear messages should also be part of a national social marketing approach tailored to different cultural and high-risk groups and presented in a non-judgemental way. The information provided should be consistent with the *Australian Guidelines to Reduce Health Risks from Drinking Alcohol*.

The social impact of FASD on individuals and their families in Australia is far-ranging and includes issues relating to mental health, alcohol and other drug use, disrupted school experience and consequent limits to employment, as well as contact with the criminal justice system. This impact is also felt on services attempting to address these issues. Access to appropriate services is vital. Services, including alcohol and other drug services, need to be in a position to respond to FASD-related issues with clients and their families.

The lack of any integrated, coordinated response to FASD in Australia does little to support individuals and families affected by FASD. This lack must be addressed to ensure the subsequent cognitive, behavioural, social and economic impacts of FASD are significantly reduced.

Also of note is the lack of recognition of FASD as a disability by the Australian Government. This needs to change to enable those diagnosed with FASD to access disability and Centrelink supports, including Commonwealth Rehabilitation Services and Medicare.

The relationship between FASD and contact with the criminal justice system in Australia is of particular interest and concern to NIDAC, given the over-representation of Indigenous youth and adults in the justice system. Interventions are essential to prevent individuals with FASD from entering the justice system in the first place or, where contact has already been made, to respond to the needs of those individuals.

Significant issues relating to diagnosis and screening have also been highlighted. Australian-based screening and diagnostic instruments need to be developed. This work has commenced but much more needs to be done. Such tools need to be evidence-based and able to be adapted to suit different cultural groups. Once developed, the tools should be adopted by relevant professions, including those working in the education, social services, health and justice sectors. Regular screening of alcohol use by all child-bearing females also needs to occur. For pregnant clients, screening should be conducted during the first antenatal visit.

This paper also highlights the issues associated with the workforce and their professional development and training. Many professionals from the health, education, social services, and justice systems lack awareness and knowledge of FASD, with limited capacity to deliver prevention strategies and interventions. Health and related professionals must play an important role in responding to FASD in Australia. To support this workforce, effective evidence-based practice guidelines need to be developed. A significant commitment also needs to provide for professional development and training of relevant workers to ensure that this workforce is well equipped to effectively respond to FASD within the whole community.

To address these key issues, recommendations are provided below to assist government and other relevant stakeholders in addressing FASD in Australia.

## Recommendations

These recommendations have been designed to apply to the Australian community as a whole in the hope that as many Indigenous and non-Indigenous children, adults and families as possible are spared from the trauma of dealing with FASD.

### Social marketing

1. That the Australian Government continue to develop and conduct national social marketing campaigns that (a) discourage tolerance of harmful drinking in the general population; and (b) raise awareness in the community of the potential impact of alcohol on the developing fetus. These campaigns need to be tailored to different cultural and high-risk groups and presented in a non-judgemental way.
2. That the Australian Government develop and actively disseminate alcohol and pregnancy information, including information on the *Australian Guidelines to Reduce Health Risks from Drinking Alcohol*, to the general population, for example through mandatory warning labels on alcohol products, and notices in pubs and other public places.

### Policy and practice guidelines

3. That the Australian Government develop an integrated national policy framework on fetal alcohol spectrum disorder linked to the National Drug Strategy, with targeted funding objectives.
4. That the Australian Government continue to support the development of specific nationally based clinical guidelines, including screening and diagnostic instruments for diagnosis and treatment/intervention of fetal alcohol spectrum disorder for relevant sectors based on available evidence-based research.

### Workforce development and training

5. That government and non-government health services ensure that all health care professionals are familiar with and actively incorporate the recommendations from the National Health and Medical Research Council's *Australian Guidelines to Reduce Health Risks from Drinking Alcohol* (2009) into their practice, and particularly with females of child-bearing age.
6. That government and non-government health services require all health professionals to screen every pregnant female for alcohol use during their first antenatal visit and ensure all health professionals are well trained to carry out this screening process.
7. That government and non-government health services ensure all relevant health professionals receive training and education on safe alcohol use, fetal alcohol spectrum disorder and ways to support healthy behavioural change.
8. That Australian, state and territory governments support the development and provision of fetal alcohol spectrum disorder training programs for all relevant sectors, e.g. criminal justice system staff including prison staff, magistrates and judges as well as schools, to increase the understanding of appropriate responses to the needs of affected children, adolescents and adults with fetal alcohol spectrum disorder.

### Prevention and service provision

9. That services ensure that all women of reproductive age, regardless of age, ethnicity, socioeconomic status or pregnancy, be screened for alcohol use, using brief intervention screening tools accompanied by appropriate advice and referral to an alcohol and drug service or other service where appropriate.
10. That access to specialist services and appropriately trained health professionals be provided for the diagnosis, support and management of children, adolescents and adults with fetal alcohol spectrum disorder.
11. That services ensure that individuals with fetal alcohol spectrum disorder and their families have access to specifically targeted integrated support services from trained professionals.
12. That services ensure that high-risk groups and communities receive the services and supports necessary to improve their general social conditions, such as holistic early interventions enhancing transition to school.

### *Data*

13. That the Australian Government extends and improves relevant national surveys on alcohol and other drug use among both Indigenous and non-Indigenous Australians to include measures of alcohol consumption among child-bearing and pregnant women.

### *Recognition of fetal alcohol spectrum disorder as a disability*

14. That the Australian Government allows individuals diagnosed with fetal alcohol spectrum disorder full access to disability and Centrelink supports, including Commonwealth Rehabilitation Services and Medicare reimbursements.
15. That the Australian Government ensures that eligibility for government-funded support and services includes criteria that reflect the functional and behavioural deficits of developmental disorders like fetal alcohol spectrum disorder.

