ADCA
Alcohol and other Drugs Council of Australia

Response to the The House of Representative's Standing Committee on Social Policy and Legal Affairs Inquiry into Fetal Alcohol Spectrum Disorder (FASD)

22 December 2011

ABN: 39 008 455 525

ADCA Submission to the House of Representative's Standing Committee on Social Policy and Legal Affairs Inquiry into Fetal Alcohol Spectrum Disorder (FASD)

Thank you for the opportunity to provide comment to the Inquiry into Fetal Alcohol Spectrum Disorder (FASD) by the House of Representative's Standing Committee on Social Policy and Legal Affairs. ADCA is the national peak body representing the interests of the Australian non-government sector for alcohol and other drugs. It works collaboratively with the government, non-government, business and community sectors to promote evidence-based, socially just approaches aimed at preventing or reducing the health, economic and social harm caused by alcohol and other drugs to individuals, families, communities and the nation. In providing submissions ADCA has undergone a broad consultation process that includes its members and working groups, the state and territory peaks of the Alcohol and Other Drugs (AOD) sector, and other organisations with an interest in FASD.

Executive Summary

FASD is an umbrella term covering a range of disorders caused by foetal exposure to alcohol. It describes a range of potentially harmful effects including physical, mental, behavioural and learning disabilities that may remain with those affected for the whole of their life. FASD is caused by foetal exposure to alcohol during its development and can occur at any stage during pregnancy. The greater and more frequent the level of consumption, the greater the risk to the baby and the level of harm.

FASD is a serious public health, social and economic issue. While prevalence in Australia is not well understood, health researchers believe that it is underdiagnosed, underreported and underestimated. It is potentially preventable, with no effects seen on children of those who do not consume alcohol. There is no cure for FASD.

Early diagnosis and intervention are the most important factors in minimising the impact of FASD. The impact of FASD extends beyond the primary symptoms as children with FASD have a high risk of developing secondary difficulties particularly affecting integration with social norms. All health professionals and other members of the health workforce have an important role in recognising risk factors and symptoms associated with FASD and referring clients to appropriate interventions. In Australia 48% of women consume alcohol during pregnancy. As a significant number of pregnancies are unplanned and most pregnancies are not confirmed until sometime after conception, the developing embryo can be potentially exposed to alcohol inadvertently. This is a particular concern with the increasing trend of binge drinking amongst young women. As the foetus is most vulnerable to the effects of alcohol in the first trimester, there is an important opportunity for the health workforce to educate patients about alcohol consumption prior to pregnancy.

Cultural change around alcohol is required in Australia to alter attitudes to drinking and reduce the harm associated with its consumption. Women need support from their partners, families and the community to stop or reduce their alcohol consumption before, during and after pregnancy.

The following are ADCA's recommendations to the House of Representative's Standing Committee on Social Policy and Legal Affairs for consideration in their Inquiry into Fetal Alcohol Spectrum Disorder. Some of these have a broader focus and intent in relation to both contributors to, and consequences from alcohol harm.

- A holistic strategic approach to FASD that is culturally appropriate for community care and support services across the different states and territories within Australia
- FASD should be registered as a disability by the Federal Government
- Serious commitment by the Federal Government to changing the Australian drinking culture
- Awareness campaign around alcohol guidelines
- Awareness campaign around the risk of binge drinking and consumption during pregnancy that achieve a change in attitude to consumption
- Change to policy effecting the physical and economic availability of alcohol including availability, pricing and taxation, marketing and promotion, and health warning labelling
- Research and development of a FASD diagnostic tool
- Research into whether there is a safe level of consumption, whether stage of pregnancy is relevant to the types of effects seen, and the effect of consuming alcohol during breast feeding
- Research determine the prevalence, risk, health, social, economic and long term impact of FASD
- Greater promotion and public education surrounding FASD including the role of the community and health professionals in supporting women in avoiding alcohol during pregnancy
- Care to avoid stigmatisation of women, parents and affected groups to ensure support services are accessible for the individual, family and friends
- Educate health professionals that they all have a role in addressing FASD – the earlier the intervention the better the outcome
- Education addressing some of the common myths associated with FASD such as safe periods during pregnancy, and FASD stereotype of an indigenous communities issue rather than a greater population problem
- Prevention , intervention and management strategies of at-risk populations to achieve better outcomes for the individual and the community at large

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- Childhood intervention should include educational and learning strategies, cognitive control therapy, social and behavioural strategies, communication strategies and a broad management plan
- Early intervention to minimise primary and secondary effects of FASD
- Ongoing financial support for families to provide the interventions necessary to achieve the best outcomes for the child. This has the added benefit of minimising the health, social and economic cost of FASD to society.
- Establish appropriate strategies to support those diagnosed with FASD who are involved in the criminal justice system
- Introduction of FASD to the medical school curricula to raise awareness of the role of all health professionals and workforce to improve diagnoses, recognise symptoms and manage FASD

What is FASD?

FASD an umbrella term covering a range of disorders caused by foetal exposure to alcohol, which includes Fetal Alcohol Syndrome, Partial Fetal Alcohol Syndrome, Alcohol Related Neurodevelopmental Disorders, Alcohol Related Birth Defects, and Fetal Alcohol Effect. FASD is not a clinical diagnosis in itself, but describes a range of potentially harmful effects including physical, mental, behavioural and learning disabilities[1] that may remain with those affected for the whole of their life.

Specifically, children diagnosed with FASD may have brain damage, birth defects, poor growth, cognitive and/or developmental delay, social, behavioural and mental health problems, problems with speech, hearing and vision, high levels of activity, difficulty remembering, a short attention span, low IQ, problems with abstract thinking, poor judgement, and difficulty forming and maintaining relationships[1]. These children require ongoing management of their development to provide support and minimise the impact of their condition. Without this, children with FASD have a high risk of developing secondary disabilities such as mental health problems, trouble with the law, dropping out of school, unemployment, homelessness and/or developing alcohol and other drug problems[2]. This has a devastating impact on society.

FASD is a serious public health, social and economic issue[2] that affects people regardless of their cultural background or socio economic groupings. In economic

[1] Alcohol and pregnancy project (2009) *Alcohol and pregnancy and Fetal Alcohol Spectrum Disorder: a resource for health professionals* (1st Revision). Perth: Telethon Institute for Child Health Research

[2] Popova, S, Stade, B, Bekmuradov, D, Lange, S, & Rehm, J; (2011) *What do we know about the economic impact of fetal alcohol spectrum disorder? A systematic literature review* Alcohol and Alcoholism Vol 46. No. 4, pp 490- 97

terms, Stade et al (2009)[3] have estimated the prevalence of FASD in Canada to be 1 in 100 live births at a cost of $21 642 per individual per annum. With a population of over 34 million, this represents a cost to the Canadian community of more than $5 billion dollars per year. However, as a condition it is under recognised, under diagnosed, and under reported and therefore its reach is probably much greater that we currently understand. Although FASD has been a particular issue in some Indigenous communities, it is not just an indigenous issue; it is occurring in indigenous and non indigenous communities across Australia, and affects both children and adults.

The saddest thing to note about FASD is that it is preventable. It occurs because the embryo and/or foetus is exposed to alcohol during its development with the greatest risk evident when high levels of alcohol are consumed frequently throughout pregnancy. It is not clear however whether there is a safe level of consumption and whether stage of pregnancy is relevant to the types of effect seen [4] (2009 NHMRC p67). What is clear is that if no alcohol is consumed during pregnancy then there is no risk of FASD, and that if someone develops FASD, there is no cure.

Australian context

The trouble is that alcohol consumption is embedded in Australian society and is the most widely used drug (AIHW 2011)[5]. We consume it to socialise, celebrate, console, accompany food, or as a way to unwind at the end of the day. We have developed a culture of drinking that positions us in the second highest category of consumers in the world.

Extensive consumption of alcoholic beverages causes substantial health and social harm to the individual drinker and to others. Alcohol related harm is estimated at $36 billion[6] annually in Australia, with higher levels of consumption and associated harms evident in rural and remote compared to urban areas. According to the 2010 National Drug Strategy Household Survey (AIHW 2011), the proportion of those drinking at risky levels increases with increasing remoteness.

A significant percentage of the female population in Australia consume alcohol with 37% of women aged 18-29 years consuming four or more standard drinks on a single

[3] Stade, B, Ali, A, Bennett, D, Campbell, D, Johnston, M, Lens, C, Tran, S, Koren, G 2009, *The Burden of Prenatal Exposure to Alcohol: Revised Measurement of Cost* Can J Clinical Pharmacol Vol 16 (1) Winter: e91 – e102; January 23 2009

[4] *Australian Guidelines to reduce health risks from Drinking alcohol* (2009), NHMRC

[5] Australian Institute of Health and Welfare (AIHW) 2011, *2010 National Drug Strategy Household Survey*

[6] AER Foundation, 2010 *Beyond the drinker: Alcohol's hidden costs* A Summary of the Study *The Range and Magnitude of Alcohol's Harm to Others*

occasion at least once a week[7]. Many women also drink during pregnancy, with 48% of women in Australia consuming alcohol during pregnancy (AIHW 2011, NDSHS). It should be noted that most women are not putting their baby at serious risk, but a small group is. The effects of alcohol on the developing foetus occur throughout pregnancy but the foetus is most vulnerable in the first trimester, during the early stages of which the majority of women are unaware that they are pregnant. Hence, and in light of the unknown and potentially varying effects of level of consumption, the 2009 NHMRC Guideline was developed that the safest option for women is to avoid alcohol if they are pregnant or planning a pregnancy.

A significant number of pregnancies are unplanned and most pregnancies are not confirmed until some time after conception, potentially exposing the developing embryo to alcohol inadvertently. This is a particular concern since women in Australia are drinking more and consuming alcohol in more harmful ways than in the past[1] (p5). Many young women are adopting high risk drinking patterns, deliberately consuming vast quantities of alcohol to become highly intoxicated. Binge drinking by women in the first trimester is particularly risky for the developing embryo.

The National Health and Medical Research Council has developed guidelines for alcohol consumption to help people make informed choices about their alcohol consumption and reduce the risks associated with it. These Guidelines are outlined in the box below. A public campaign is required to increase awareness and understanding of the Guidelines since research has shown that there is low awareness of the Guidelines and that people are ignoring them[8].

[7] Australian Institute of Health and Welfare 2011, *Drugs in Australia 2010: tobacco, alcohol and other drugs* Drug statistics series no. 27. Cat. No. PHE 154. Canberra: AIHW

[8] Parnell, S 2011 *Report shows alcohol guidelines considered unrealistic, ignored* The Australian, 2 December 2011

2009 Australian Guidelines to Reduce Health Risks from Drinking Alcohol NH&MRC

Guideline 1: Reducing the risk of alcohol-related harm over a lifetime

The lifetime risk of harm from drinking alcohol increases with the amount consumed.

For healthy men and women, drinking no more than two standard drinks on any day reduces the lifetime risk of harm from alcohol-related disease or injury.

Guideline 2: Reducing the risk of injury on a single occasion of drinking

On a single occasion of drinking, the risk of alcohol-related injury increases with the amount consumed.

For healthy men and women, drinking no more than four standard drinks on a single occasion reduces the risk of alcohol-related injury arising from that occasion.

Guideline 3: Children and young people under 18 years of age

For children and young people under 18 years of age, not drinking alcohol is the safest option.

A. Parents and carers should be advised that children under 15 years of age are at the greatest risk of harm from drinking and that for this age group, not drinking alcohol is especially important.

B. For young people aged 15–17 years, the safest option is to delay the initiation of drinking for as long as possible.

Guideline 4: Pregnancy and breastfeeding

Maternal alcohol consumption can harm the developing fetus or breastfeeding baby.

A. For women who are pregnant or planning a pregnancy, not drinking is the safest option.

B. For women who are breastfeeding, not drinking is the safest option.

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FASD and the criminal justice system

There is a high prevalence overseas of FASD in young people and adults in the criminal justice system[9]. According to the National Organization on Fetal Alcohol Syndrome (NOFAS), 61% of adolescents and 58% of adults with FASD in the USA have been in legal trouble, and 35% of those with FASD over the age of 12 had been incarcerated at some point in their lives. Individuals affected by FASD are more likely to get in trouble with the law because of the behavioural issues associated with FASD. They are typically impulsive and have trouble foreseeing the consequences of their actions; they may have a poor sense of personal boundaries; many are very susceptible to peer pressure, and they can be easily led; and their judgment is often poor[10].

Prevention, intervention and management of these populations are equally important to achieve better outcomes for the individual and the community at large. Early identification of FASD will allow adequate supports to be put in place which will help deter young people and adults affected by FASD from offending behavior. Should they have contact with the criminal justice system, special considerations need to be given to support the client throughout the process. The SAMHSA Center for Substance Abuse Administration in the USA provides important advice on how best to manage people affected by FASD in these circumstances.

Preventive action to address FASD

Education and information campaigns and other clinical and community-led strategies are needed to help prevent FASD (National Drug Strategy 2010-2015 p22). Such campaigns should address some of the common myths associated with FASD, including themes such as whether there is a 'safe' time to drink while pregnant and whether FASD is only a problem for indigenous communities or an issue for non indigenous communities as well.

However, any campaign to raise awareness of and diagnosis of FASD needs to be done in a way that does not stigmatise women, and in particular the parents of FASD affected individuals, or high risk groups. Stigmatisation of the parent, particularly the mother, may inhibit access to support services for the individual and family which could lead to increased likelihood of detrimental effects. Messages should be factual and be presented in a non-blaming way, as well as show how the family and community can support women. It should be noted that men have an important role

[9] Professor Elizabeth Elliott AM, *personal communication* Professor of Paediatrics & Child Health University of Sydney and Paediatrics & Child Health, Children's Hospital, Westmead 7 Dec 2011

[10] SAMHSA Center for Substance Abuse Administration 2007, *Fetal Alcohol Spectrum Disorders Juvenile Justice: How professionals can make a difference* US Department of Health and Human Services, downloaded from **http://fasdcenter.samhsa.gov/documents/WYNK_JuvJust_Profs.pdf on 16 December 2011**

in supporting women in not drinking and this should also be portrayed in education campaigns.

Peadon et al (2010)[11] conducted a national study of the knowledge and attitudes of Australian women of child bearing age about the effects of alcohol consumption during pregnancy on the foetus and their intention to drink during pregnancy. One in three women of child bearing age said they did not know of any of the adverse effects of alcohol consumption in pregnancy and many women that were aware of the adverse effects could not name anything specifically. Their research identified that awareness of the effects of alcohol in pregnancy on the foetus is not sufficient to change women's behaviour. Attitudes were a much stronger predictor of drinking in pregnancy than knowledge[12] and hence they concluded that targeted interventions are needed to change the perception of risk and hence behaviour.

For women that continue to drink during pregnancy, it is important that they are provided with information that explains the risk to the developing foetus. This needs to be managed in a way that doesn't attribute blame or create guilt, remembering that many women are unaware that they are pregnant in the early stages of pregnancy. The important thing is that women are not deterred from accessing health care and other support services,

Elliott et al[13] recommend that prevention of FASD should comprise primary, secondary and tertiary prevention strategies. The primary education strategies would be directed at the general population to raise awareness about the risks of drinking alcohol during pregnancy, the secondary strategies would be directed at pregnant women, and the tertiary strategies would be targeted at women with a higher risk of having a child with FASD. ADCA suggests that while policies and programs should address the full spectrum of FASD, resources should be spent primarily on the higher risk end of the spectrum and not on the relatively low risk end.

The NHMRC Guidelines refer to a recent survey of Australian women of child bearing age (p71) which indicates that women are likely to be receptive to the advice in the NHMRC Guideline. The research revealed that 80% of those women surveyed agreed that women should not drink during pregnancy, 99% said that information on the effect of alcohol on the foetus should be readily available, 97% said that health

[11] Peadon, E, Payne, J, Henley, N, D'Antoine, H, Bartu, A, O'Leary, C, Bower, C, Elliott, E, 2010, *Women's knowledge and attitudes regarding alcohol consumption in pregnancy: a national survey* BMC Public Health 2010, 10:510

[12] Peadon, E, Payne, J, Henley, N, D'Antoine, H, Bartu, A, O'Leary, C, Bower, C, Elliott, E, 2011, Attitudes and behaviour predict women's intention to drink alcohol during pregnancy: the challenge for health professionals BMC Public Health 2011, 11:584

[13] Elliott, L, Coleman, K, Suebwongpat, A, & Norris, S (2008) *Fetal Alcohol Spectrum Disorders (FASD) Systematic reviews of prevention, diagnosis and management* HSAC Report 1 (9)

professional should ask women and provide advice about their alcohol consumption in pregnancy. Finally, 91 % said that health professionals should advise women who are pregnant or thinking of becoming pregnant to give up drinking alcohol.

Any such program should be part of an overall effort to achieve cultural change in Australia and alter attitudes towards alcohol. ADCA is a member of the National Alliance for Action on Alcohol (NAAA) and supports its submission to the Inquiry. ADCA's key priorities in relation to alcohol include:

- pricing and taxation,
- marketing and promotion, and
- access and availability of alcohol.

Changing the physical and economic availability of alcohol is one of the most effective and reliable ways of reducing the harmful consumption of alcohol. Since these priorities are addressed in detail in the NAAA submission, this submission will not discuss them further.

Appropriate labelling of products containing alcohol is another important strategy and ADCA welcomes the support by the Federal Government for mandatory pregnancy health warning labels within two years (30 Nov 2011, Nicola Roxon Media Release) as a first step towards across-the-board health warning messages for alcohol products. ADCA recommends that alcoholic beverages should carry warning labels on the risks of alcohol in all instances, not just prior to or during pregnancy. Labelling is of course just one part of the story and a broad education and public awareness campaign is required that addresses the full range of alcohol related harm, together with a specific campaign on the potential risks of alcohol related harm associated with pregnancy.

Research is required to better understand the scope of the problem in Australia and address the myths associated with FASD. For example, evidence is needed on the prevalence, risk, health and social impact (on child, parent, family, society), and economic impact of FASD, noting that many cases are thought to go unreported. Longitudinal research will provide further insight into the long term impact of FASD. Maternal alcohol use would also be useful in addition to extending our knowledge on the physical and brain related impact of FASD eg facial anomalies, growth retardation, neuro-development disorders, and birth defects. The prevalence of at-risk alcohol use among pregnant women needs to be understood along with any association with socio-demographic groups.

There is a need for additional research on the effect of alcohol on lactation and on breastfed infants. Research on this is limited however there is sufficient evidence to indicate that alcohol enters breast milk and may remain for several hours, and that it affects lactation, infant behaviour and psychomotor development[3] (2009 NH&MRC p79). Hence, the 2009 Alcohol Guidelines advise breastfeeding mothers that avoiding alcohol whilst breastfeeding is the safest option and to especially avoid alcohol in the first month until breastfeeding is well established.

Intervention with women pre, post and during pregnancy

Health professionals are considered to be the best source of information about alcohol use in pregnancy[1] (2009, Alcohol & Pregnancy project p 11) for pregnant women or women planning pregnancy. Although not defined, all health professionals have a role to play in addressing alcohol use in pregnancy whether it is a general visit to a GP or gynaecologist by a woman considering or in the early stages of pregnancy, visits to an obstetrician or midwife as the pregnancy progresses, after pregnancy and associated with breastfeeding, or an appointment with the paediatrician. As an independent authority, health professionals are able to talk in a non judgmental way about a range of issues associated with pregnancy, including consumption, in a private and confidential setting. Therefore through brief, targeted interventions, they have the opportunity to influence patterns of consumption[1].

Alcohol and Pregnancy and Fetal Alcohol Spectrum Disorder: a resource for Health Professionals was developed by the Alcohol and Pregnancy project[1.] Comprehensive in its scope, this resource details a range of brief and effective interventions that health professionals can use to address alcohol use before, during and after pregnancy. It also provides a guide to some of the barriers to addressing the issue, the health and social factors that might influence women to drink during pregnancy, working with different cultural groups, suggestions on how to raise the issue and how to assist in addressing alcohol use. Importantly, it adopts a holistic approach to addressing alcohol use and recognises that alcohol consumption may be influenced by much broader health, social and emotional factors. In addition, the resource recognises that fathers (and potential fathers) have an important role to play in supporting women to stop or reduce their alcohol consumption before, during and after pregnancy.

Appropriate education and training is needed for all health professionals and others in the health care workforce to prevent, intervene and manage issues associated with FASD. This is particularly important in areas where access to specialist health services is limited and opportunities for intervention are limited. FASD could be introduced to medical school curricula and provided as part of ongoing education and training within the AOD sector.

Other sectors, such as social services, housing, mental health and criminal justice system would also benefit from greater awareness of FASD to better understand and work with affected clients. Burns et al have identified the need for informal screening of alcohol use in pregnancy and where problematic use is detected, for clear clinical guidelines on management and referral[14].

[14] BURNS, L, **BLACK E**, **POWERS JR**, **LOXTON D**, **ELLIOTT E**, **SHAKESHAFT A**, **DUNLOP A** (2011) *GEOGRAPHIC AND MATERNAL CHARACTERISTICS ASSOCIATED WITH ALCOHOL USE IN PREGNANCY* **ALCOHOL CLIN EXP RES.** 2011 JUL;35(7):1230-7. DOI: 10.1111/J.1530-0277.2011.01457.X. EPUB 2011 APR 4.

Intervention and ongoing management with those affected

Once a baby is born, the most important factor in reducing the impact of FASD is early diagnosis and early intervention[15]. Diagnosis often involves a multi disciplinary team. Understanding the underlying causes of a child's behaviour and learning difficulties enable parents to take action to address the problems and better cope with challenging times. Special parenting and education strategies can improve outcomes for children with FASD.

ADCA supports the call by the recent inquiry into Indigenous youth and the justice system by the Committee on Aboriginal and Torres Strait Islander Affairs urging the Federal Government to recognise FASD as a registered disability. `

Interventions that have been recommended for children include pharmacological, educational behavioural, social skills and communication interventions. A review of intervention strategies by Peadon et al[16] highlighted the range of intervention strategies that may benefit children with FASD. These included educational and learning strategies, virtual reality training, cognitive control therapy, language and literacy therapy, mathematics intervention, rehearsal training for memory, social and behavioural strategies and Attention Process Training. Generally, FASD sufferers benefit from a broad management plan that uses a range of services and requires the support of family and/or other caregivers, clinical staff and teachers[4]. Again, all health professionals have a role to play in recognising the symptoms of FASD and referring children and adults for further assessment and interventions.

The National Drug Strategy 2010-2015[17](p22) identifies that action is needed to improve the diagnosis and clinical management of children affected by FASD and appropriate supports made available to those children and their families. An important first step is the development of an accurate and reliable diagnostic tool that will make diagnosis easier and faster. Such a tool may have relevance to other drugs.

It is worth noting that currently, the international classification of disease ICD 9CM has a category incorporating FASD under Subcategory 760.71. The Diagnostic and Statistical Manual of Mental Disorder (DSM) does not have a similar category but this is being considered for the next edition, DSM-V. NOFAS and other FASD organisations support inclusion of FASD in DSM-V to enable greater diagnostic accuracy, fewer treatment delivery problems, better medication management, and increased resources for affected individuals.

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[15] Nicholson, P. (2009) *Beyond bad, mad behaviour Targeting the needs of people with FASD and mental health issues* Crosscurrents pp12-13

[16] Peadon, E, Rhys-Jones, B, Bower, C, & Elliott, E (2009) *Systematic review of interventions for children with Fetal Alcohol Spectrum Disorders* BMC Pediatrics 9:35

[17] National Drug Strategy 2010-2015 (2011) Department of Health and Aging

ADCA supports the recommendations of the National Drug Strategy 2010-2015 (2011, p22) to enhance child and family sensitive practice in alcohol and other drug treatment services, the development of links and integrated approaches with community, family and child welfare services together with coordinated measures to prevent, diagnose and manage FASD, and make available appropriate supports to affected children and families.

A strategic approach is required that is holistic in nature and culturally appropriate for community care and support services across the different states and territories within Australia. Such an approach needs to address the diversity of cultural influences and the availability of resources in a variety of socioeconomic locations. It also needs to take into consideration the different approaches used by groups to access information, noting that not everyone has access to or utilises information technology.

A really important added benefit of greater awareness and early diagnosis is that it may prevent the same condition arising in subsequent pregnancies. This is particularly significant since overseas evidence shows exponentially increased risk and severity of FASD conditions in second and subsequent children to the same mother[18].

ADCA would be pleased to discuss ADCA's response in more detail. Please contact Meredythe Crane at meredythe.crane@adca.org.au or on 02 6215 9808.

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16 December 2011

[18] NOFASARD and SANDAS, 2007 *The conundrum of FASD in Australia,* South Australian Network of Drug and Alcohol Services

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