INTERGOVERNMENTAL COMMITTEE ON DRUGS
WORKING PARTY ON FETAL ALCOHOL SPECTRUM
DISORDERS

MONOGRAPH

FETAL ALCOHOL SPECTRUM
DISORDERS IN AUSTRALIA: AN UPDATE

June 2012

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Foreword

This monograph is an outcome of the Intergovernmental Committee on Drugs (IGCD) Fetal Alcohol Spectrum Disorders (FASD) Working Party. The Working Party was first established in 2006, at the request of the Ministerial Council on Drug Strategy (MCDS), to advise on the developments in Australia and overseas in regard to FASD and to identify best practice approaches to reduce the incidence of FASD, particularly in Indigenous communities.

The monograph provides an opportunity to examine the current status of research, policy and practice regarding alcohol use in pregnancy in Australia, particularly in relation to FASD. The monograph notes areas where additional attention is required and enhancements to existing practices are needed to improve the current situation with regard to prevention, early intervention and long term management of this avoidable condition.

A first draft was completed in late 2009. During 2010 and 2011, a number of these activities were put in place and funded by government and non-government organisations, as summarised in Chapter 12.

Many people have contributed to the development of this monograph, notably the chapter authors. In July 2011, the Australian Government Department of Health and Ageing (DOHA) commissioned an update of the monograph. The original authors of each chapter were contacted and asked to update their contributions. To ensure the document included recent relevant literature, authors were asked to provide information about new publications. In addition, searches of the recent literature were conducted at the National Drug and Alcohol Research Centre. As the focus of the monograph is on the current Australian context, a list of references from Australian studies has been included (Appendix 2) with hyperlinks provided. Chapter 12 was added to highlight nationwide activities on FASD and to provide an update on progress since the original (2009) report. A table containing recent research into alcohol use in pregnancy and FASD research has also been included.

We would like to extend our thanks to the chapter authors and to the members of the FASD Working Party for their active participation and support.

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IGCD FASD Working Party
Editor FASD Monograph

Lucy Burns
Editor FASD Monograph
Acknowledgements

The Intergovernmental Committee on Drugs (IGCD) Working Party on Fetal Alcohol Spectrum Disorders (FASD) thanks the former Ministerial Council on Drugs (MCDS), the IGCD and the Australian Government Department of Health and Ageing (DOHA) for providing the opportunity and funding to produce this monograph. The Editors are grateful for support and assistance provided in reviewing the monograph by a range of organisations and individuals, including all the contributing authors and members of the IGCD Working Party on FASD.

Members of the IGCD Working Party on FASD included: Chair, Mr Keith Evans; Deputy Chair, Prof. Elizabeth Elliott; and Members Dr Lynette Cusack, Ms Jennie Shortt, Ms Kellie Fixter, Dr Matt Edwards, A/Prof Kei Lui, Dr Julee Oei, Dr Andrew White, Dr Kevin Lambkin, Mr Mark West, Prof. David Tudehope, Ms Lynne Biggs, Dr Cindy Clayton, Prof. Agnes Bankier, Prof. Carol Bower, Ms Louise Heuzenroeder, Dr Lucy Burns, Ms Lorian Hayes, Ms Michelle Ricketts and Ms Sarah Venner.

We thank the team within the Drug Strategy Branch from the Australian Government Department of Health and Ageing. We thank Ms Sarah Venner from Drug and Alcohol Services South Australia for secretariat support; A/Professor Jane Halliday of the Murdoch Children’s Research Institute, Dr Priscilla Pyett of the University of Melbourne and Dr Anton Clifford of the National Drug and Alcohol Research Centre for their input; and all delegates of the Fetal Alcohol Spectrum Disorders Workshop held in Adelaide, 19-20 August 2008.

We also thank the Aboriginal Community and Consumer Reference Groups from the Alcohol in Pregnancy Study in Perth and Associate Investigators Dr Julie Owen and Mrs June Councillor. Their assistance with the study into Alcohol and Pregnancy: Aboriginal women’s knowledge, attitudes and practice, which is included in this report, was invaluable.

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<th>Description</th>
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<tbody>
<tr>
<td>ACT</td>
<td>Australian Capital Territory</td>
</tr>
<tr>
<td>ADHD</td>
<td>Attention Deficit Hyperactivity Disorder</td>
</tr>
<tr>
<td>AIHW</td>
<td>Australian Institute of Health and Welfare</td>
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<tr>
<td>AMA</td>
<td>Australian Medical Association</td>
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<tr>
<td>ANCD</td>
<td>Australian National Council on Drugs</td>
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<tr>
<td>AOD</td>
<td>Alcohol and Other Drugs</td>
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<tr>
<td>APSU</td>
<td>Australian Paediatric Surveillance Unit</td>
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<tr>
<td>ARBD</td>
<td>Alcohol Related Birth Defects</td>
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<tr>
<td>ARND</td>
<td>Alcohol Related Neurodevelopmental Disorder</td>
</tr>
<tr>
<td>BDR</td>
<td>Birth Defects Registry</td>
</tr>
<tr>
<td>bn.</td>
<td>Billion</td>
</tr>
<tr>
<td>BSID</td>
<td>Bayley Scales of Infant Development</td>
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<tr>
<td>CDEP</td>
<td>Community Development Employment Project</td>
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<tr>
<td>CNS</td>
<td>Central Nervous System</td>
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<tr>
<td>CP</td>
<td>Cerebral Palsy</td>
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<td>DASSA</td>
<td>Drug and Alcohol Services South Australia</td>
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<tr>
<td>DOHA</td>
<td>(Australian Government) Department of Health and Ageing</td>
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<tr>
<td>FAE</td>
<td>Fetal Alcohol Effects (now known as ARBD and ARND)</td>
</tr>
<tr>
<td>FaHCSIA</td>
<td>(Australian Government) Department of Families, Housing, Community Services and Indigenous Affairs</td>
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<tr>
<td>FARE</td>
<td>Foundation for Alcohol Research and Education</td>
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<tr>
<td>FAS</td>
<td>Fetal Alcohol Syndrome</td>
</tr>
<tr>
<td>FASD</td>
<td>Fetal Alcohol Spectrum Disorders</td>
</tr>
<tr>
<td>g</td>
<td>Gram(s)</td>
</tr>
<tr>
<td>GP</td>
<td>General practitioner</td>
</tr>
<tr>
<td>HGSA</td>
<td>Human Genetics Society of Australasia</td>
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<tr>
<td>IGCD</td>
<td>Intergovernmental Committee on Drugs</td>
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<tr>
<td>IQ</td>
<td>Intelligence quotient</td>
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<tr>
<td>IUGR</td>
<td>Intrauterine Growth Restriction</td>
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<tr>
<td>MAST</td>
<td>Michigan Alcoholism Screening Test</td>
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<tr>
<td>MCDS</td>
<td>Ministerial Council on Drug Strategy</td>
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<tr>
<td>MCRI</td>
<td>Murdoch Children’s Research Institute</td>
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<tr>
<td>MDI</td>
<td>Mental Development Index (part of the BSID)</td>
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<tr>
<td>MH</td>
<td>Mental Health</td>
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<tr>
<td>NCETA</td>
<td>National Centre for Education and Training on Addiction</td>
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<tr>
<td>NCG</td>
<td>National Clinical Guidelines</td>
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<td>NDARC</td>
<td>National Drug and Alcohol Research Centre</td>
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<td>NDS</td>
<td>National Drug Strategy</td>
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<td>NDSHS</td>
<td>National Drug Strategy Household Survey</td>
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<td>NHMRC</td>
<td>National Health and Medical Research Council of Australia</td>
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<tr>
<td>NIAAA</td>
<td>National Institute on Alcohol Abuse and Alcoholism</td>
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<tr>
<td>NOFASARD</td>
<td>National Organisation for Fetal Alcohol Syndrome and Related Disorders</td>
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<tr>
<td>NPESU</td>
<td>National Perinatal Epidemiology and Statistics Unit</td>
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<tr>
<td>NPDC</td>
<td>National Perinatal Data Collection</td>
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<tr>
<td>NPV</td>
<td>Net present value</td>
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<tr>
<td>NS</td>
<td>Non significant</td>
</tr>
<tr>
<td>Abbreviation</td>
<td>Full Form</td>
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<tr>
<td>NSW</td>
<td>New South Wales</td>
</tr>
<tr>
<td>NT</td>
<td>Northern Territory</td>
</tr>
<tr>
<td>p/a</td>
<td>Per annum</td>
</tr>
<tr>
<td>pFAS</td>
<td>Partial Fetal Alcohol Syndrome</td>
</tr>
<tr>
<td>PBL</td>
<td>Problem Based Learning</td>
</tr>
<tr>
<td>QALYs</td>
<td>Quality adjusted life years</td>
</tr>
<tr>
<td>QLD</td>
<td>Queensland</td>
</tr>
<tr>
<td>RASCALS</td>
<td>Randomly Ascertained Sample of Children born in Australia's Largest State</td>
</tr>
<tr>
<td>RCT</td>
<td>Randomised controlled trial</td>
</tr>
<tr>
<td>SA</td>
<td>South Australia</td>
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<tr>
<td>SES</td>
<td>Socioeconomic status</td>
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<tr>
<td>TAS</td>
<td>Tasmania</td>
</tr>
<tr>
<td>UK</td>
<td>United Kingdom</td>
</tr>
<tr>
<td>UNSW</td>
<td>University of New South Wales</td>
</tr>
<tr>
<td>USA</td>
<td>United States of America</td>
</tr>
<tr>
<td>VACCHO</td>
<td>Victorian Aboriginal Community Controlled Health Organisation</td>
</tr>
<tr>
<td>VIC</td>
<td>Victoria</td>
</tr>
<tr>
<td>WA</td>
<td>Western Australia</td>
</tr>
<tr>
<td>WARDA</td>
<td>Western Australian Register of Developmental Anomalies</td>
</tr>
<tr>
<td>WTP</td>
<td>Willing to pay</td>
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</table>
GLOSSARY AND DEFINITIONS

Alcohol Related Birth Defects (ARBD)
Birth defects, including malformations and dysplasias associated with prenatal alcohol exposure in animal models and human populations. These may include cardiac, skeletal, renal, ocular, auditory and other malformations.

Alcohol Related Neurodevelopmental Disorder (ARND)
A diagnosis of ARND requires confirmed prenatal exposure to alcohol and at least one of the following:

- clinically significant structural abnormality (e.g. head circumference ≤ 3rd percentile, abnormal brain structure), or neurological abnormality (seizure disorder or hard neurological signs); and/or
- severe dysfunction (impairment in three or more domains of function at two or more standard deviations below the mean). Functional domains include cognition, academic performance, language, memory, executive function, attention/activity and adaptive behaviour/social skills.

Binge drinking
Binge drinking is often defined as five or more standard drinks in one occasion of use for women and as seven or more standard drinks for men. The definition of binge drinking varies in the literature, rendering comparisons between studies problematic (Henderson et al. 2007).

Dysmorphology
The study of human congenital malformations (birth defects).

Fetal Alcohol Effects and Alcohol-related Effects
These terms have been used previously in the literature to describe a range of problems associated with prenatal alcohol exposure, but where full criteria for Fetal Alcohol Syndrome, typically the distinctive facial characteristics, are not met (Aase et al. 1995; Stratton et al. 1996). The terms are not currently in use.

Fetal Alcohol Syndrome
A syndrome characterised by: specific facial abnormalities, reduced size of the newborn and/or poor growth after birth; and problems of behaviour and cognition due to structural and/or functional abnormalities of the central nervous system. FAS is most commonly seen in children born to mothers who consumed significant quantities of alcohol during early pregnancy.

Fetal Alcohol Spectrum Disorders (FASD)
Broad term for a range of outcomes that may be observed among individuals with prenatal alcohol exposure, that includes FAS, ARBD and ARND. FASD does not represent a clinical diagnosis but a group of diagnoses.
**Intrauterine growth restriction (IUGR)**
Failure of a fetus to achieve its growth potential, resulting in the birth of a baby whose birth weight is abnormally low in relation to its gestational age. Causes include maternal disease (e.g. infection, malnutrition, high blood pressure, smoking, and alcoholism), poor socioeconomic conditions, multiple pregnancy (e.g. twins) and fetal disease or chromosomal abnormalities. It may be, but is not necessarily, associated with preterm birth* (Oxford Reference Online).

**Microcephaly**
Abnormally small head, usually defines as measuring below the third percentile on population based charts appropriate for age and sex. May result from alcohol exposure causing abnormal development of the brain.

**Parity**
A term used to indicate the number of pregnancies a woman has had that have each resulted in the birth of an infant capable of survival (Oxford Reference Online).

**Partial Fetal Alcohol Syndrome**
This term is used for patients who present with significant structural, neurological and/or functional abnormalities of the CNS and most (but not all) of the growth and/or facial features of FAS and have a confirmed history of prenatal alcohol exposure.

**Standard drink**
In Australia, a standard drink contains 10 g of alcohol†. The quantity of alcohol considered to be a standard drink varies between countries. For example, it is 8 g in the United Kingdom and Ireland, 13.5 g in Canada and 14 g in the USA (International Centre for Alcohol Policies 1998).

**Substance (including alcohol) abuse**
DSM-IV diagnostic criteria for substance abuse is:
A maladaptive pattern of substance use leading to clinically significant impairment or distress, as manifested by one (or more) of the following, occurring within a 12-month period:
- recurrent substance use resulting in failure to fulfil major role obligations at work, school, or home;
- recurrent substance use in situations in which it is physically hazardous (e.g. driving while intoxicated);
- recurrent substance-related legal problems; and/or
- continued substance use despite having persistent or recurrent social or interpersonal problems caused or exacerbated by the effects of the substance.

The symptoms should have not met criteria for substance dependence. (American Psychiatric Association 1994).

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* Editors note: may also be independent of preterm birth.
Substance (including alcohol) dependence
DSM-IV diagnostic criteria for substance dependence describe a maladaptive pattern of substance use, leading to clinically significant impairment or distress, as manifested by three or more of the following occurring at any time in the same 12-month period:

1. Tolerance, as defined by either:
   - a need for markedly increased amounts of the substance to achieve intoxication or the desired effect;
   - Markedly diminished effect with continued use of the same amount of the substance;
2. Withdrawal, as manifested by either of the following:
   - A characteristic withdrawal syndrome;
   - The same or a closely related substance is used to relieve or avoid withdrawal symptoms;
3. The substance is taken in larger amounts or for a longer period than intended;
4. There is a persistent desire or unsuccessful efforts to cut down or control substance use;
5. A great deal of time is spent in activities necessary to obtain the substance, use the substance or recover from its effects;
6. Important social, occupational or recreational activities are reduced or given up because of substance use; and/or
7. Substance use is continued despite knowledge of having a persistent or recurrent physical or psychological problem that is likely to have been caused or exacerbated by the substance.

Relative Risk (RR)
The likelihood of developing a disease in an exposed group (e.g. those exposed to alcohol) relative to those who are not exposed (Hennekens and Buring 1987). A relative risk of >1 indicates increased risk.

Teratogen
A teratogen is an agent, such as a virus, a drug, or radiation that causes malformation of an embryo or a fetus. Alcohol is a known human teratogen. Teratology is the study of developmental abnormalities and their causes (Oxford Reference Online 2008).
EXECUTIVE SUMMARY

Alcohol is widely used in Australian society and is an integral part of the social and cultural aspects of Australian life. The majority of Australians consume alcohol at levels that pose a low risk to their health; however, increasing proportions of Australians, particularly young women, have been recorded drinking at risky and high risk levels. Given that approximately half of all pregnancies are reported to be unplanned, it is likely that many women inadvertently expose their unborn child to alcohol before they are aware of their pregnancy. Although the majority of women will abstain or reduce their alcohol intake following pregnancy awareness, a significant proportion will continue to drink alcohol during pregnancy, and some will drink at high risk levels.

Impact of alcohol use on the unborn child
Alcohol use during pregnancy has been associated with a number of adverse pregnancy outcomes including miscarriage, premature birth, stillbirth and low birth weight. Alcohol exposure in utero can also cause a range of abnormalities in the unborn child which are included under the umbrella term Fetal Alcohol Spectrum Disorders (FASD). These include, at the more visible end of the spectrum, Fetal Alcohol Syndrome (FAS) and Partial FAS (pFAS), as well as Alcohol Related Birth Defects (ARBD) and Alcohol Related Neurodevelopmental Disorders (ARND).

Importance of other factors in determining the effect of alcohol
The more a woman drinks during pregnancy, the higher the risk to the unborn child. There does not appear to be a linear relationship between the amount of alcohol used in pregnancy and expression of FASD, as not all children exposed to high levels of alcohol in utero will be affected or affected to the same degree. A number of factors moderate this relationship, including the pattern and quantity of alcohol consumption, the stage of development of the fetus at the time of exposure and maternal and socio-behavioural risk factors such as maternal genetics, body composition, nutrition, poverty, smoking, maternal age and increasing parity. This makes it difficult to predict risk in an individual pregnancy.

Women’s knowledge and attitudes to alcohol use in pregnancy
Women’s intention to consume alcohol during pregnancy is associated with: alcohol use in the last pregnancy; the belief that pregnant women should be able to drink alcohol; intention to smoke in a future pregnancy; and neutral or positive attitudes towards alcohol use during pregnancy. Knowledge of adverse effects is not as strong a determinant of intention to drink as are tolerant attitudes towards alcohol use in pregnancy. Thus, simply educating women about potential adverse effects of prenatal alcohol exposure will be insufficient to induce behavioural change. Societal attitudes about alcohol use, particularly during pregnancy, must also be addressed.

Safe use of alcohol in pregnancy
Alcohol is a teratogen; that is, exposure during pregnancy may cause birth defects including brain damage. There is sufficient evidence to show that chronic heavy alcohol use or frequent intermittent heavy alcohol use during pregnancy increases the risk of FASD. The most recent research suggests that there is no strong evidence to implicate low levels of prenatal alcohol exposure with clinically evident fetal harm. Recent studies have shown there is only a small margin before there is increased risk, therefore the precautionary approach is to recommend that women abstain from alcohol when planning pregnancy and during pregnancy. Also as stated above, modifiable maternal and fetal factors make prediction of risk in the individual
difficult. An abstinence message should be presented in a balanced and rational format and it should be made clear that FASD can be prevented by avoiding alcohol. The current NHMRC Australian Guidelines to Reduce Health Risks from Drinking Alcohol recommend that, for pregnant women and women who are planning pregnancy, ‘not drinking alcohol is the safest option’.

**Prevalence and incidence of FAS and FASD in Australia**
Currently, FAS in Australia is reported by health professionals to Birth Defects Registers in some jurisdictions. However, because contributors are asked to report birth defects rather than syndromes and knowledge about FAS and FASD is poor, it is likely that there is under-ascertainment of cases. Attempts have been made to estimate birth prevalence of FAS in Western Australia, the Northern Territory, and nationally through the Australian Paediatric Surveillance Unit (APSU). None of these studies was population based, all authors acknowledge under-ascertainment is likely, and data were not systematically collected on the full spectrum of FASD including ARBD or ARND. Routine assessment and recording of maternal alcohol use during pregnancy, education about diagnosis of FAS, population based studies in high risk communities and improved methods of collecting national data are required before we can confidently estimate prevalence rates of FASD in Australia.

**Prevention of FASD**
Primary, secondary and tertiary prevention strategies to decrease alcohol use in pregnancy and harm to the unborn child should be developed, delivered and evaluated. Prevention of FASD depends on the willingness and ability of women to avoid alcohol in pregnancy. Education of women of child bearing age regarding potential harms of alcohol use in pregnancy and FASD is required but may not change behaviour. A range of prevention initiatives are required across society to change attitudes and behaviour in respect to alcohol use, including during pregnancy. Health professional and community education, which could include a national public health awareness campaign and labelling of alcoholic beverages, is important, but behavioural change is likely to require broader public health strategies.

**Services for women**
Women planning pregnancy and pregnant women who drink at levels considered to be moderate and high risk should have access to support services and evidence based treatments. Information about the effectiveness of pharmacotherapies and psychosocial interventions for pregnant women who consume alcohol at risky levels is limited and research involving pregnant women is urgently needed. Several components have been identified as crucial to program success, including the need to consider the broader context in which women live when planning services. Many women who continue to drink at risky and dependent levels during pregnancy experience a range of other difficulties that may require services, including relationship problems, domestic violence, other substance use and mental health problems.

**Diagnostic and assessment services**
For children with FASD, early diagnosis and intervention may substantially reduce the risk of secondary medical, social, emotional and behavioural problems in later life. Early diagnosis of FASD also provides an opportunity for preventing alcohol exposure in future pregnancies. Currently, few specialised diagnostic and assessment services are available in Australia. A recent international audit of diagnostic and evaluation clinics for children exposed to alcohol in pregnancy and/or with FASD highlights the importance of a multidisciplinary approach using trained health professionals. A national approach is required to determine the service needs for Australia and the most appropriate models of care.
Professional education and workforce development
Additional education and training in FASD is required at undergraduate and postgraduate levels to increase the knowledge, skills and expertise of health professionals, few of whom have received specific training about FASD. Effective strategies to promote changes in clinical practice include: interactive educational sessions; educational outreach visits by FASD experts; prompts and reminders; auditing of organisational systems to ensure clinicians are able to implement new knowledge; and provision of feedback to clinicians and services. Training alone is insufficient to ensure that changes are successfully implemented and sustained: a wide range of broader organisational changes may also be required.

Interventions for children with FASD
At present, there is a lack of good evidence on the effectiveness of specific therapies for children (and adults) with FASD, although the international literature provides guidance on strategies that may be worth investigating or that are currently being evaluated. The management of children with FASD should be co-ordinated by a developmental paediatrician and/or clinic with access to appropriate medical, allied health professional, educational, disability and community service use.

Economic impact of FASD
FASD is associated with a number of poor health outcomes that typically result in high costs to individuals with FASD and their families/carers (private costs) and to the community as a whole (social costs). A number of international studies have estimated the economic cost of FASD (predominantly focusing on FAS), but it has not been possible to develop estimates for Australia. This is due to a lack of accurate data on prevalence and a paucity of details about the needs of families and the frequency of service.

Policy regarding alcohol in pregnancy
The inability to determine a safe level for alcohol intake during pregnancy is reflected in policies and guidelines domestically and internationally. These contain messages that range from abstinence to advice that the risk from low amounts of alcohol is minimal. All Australian medical and nursing organisations that provide guidelines on alcohol and pregnancy have promoted abstinence as either the only option or as the preferable/safest option. Messages about alcohol use need to be credible and well disseminated if they are to be effective and the risk from low levels of alcohol use should not be exaggerated lest women seek a termination when the risk is small. In 2009 the NHMRC published revised guidelines for alcohol use in Australia which included the message that for pregnant women or women planning pregnancy ‘not drinking alcohol is the safest option.’ There is evidence that community knowledge about the guidelines is inadequate, reinforcing that when public health policy is developed, it needs to be widely disseminated in the community and evaluated.
Chapter 12 includes an update on the progress within Australia with respect to FASD.
1. INTRODUCTION

Alcohol consumption is common among Australian women. Approximately one-third of adult women report drinking at least weekly and this pattern is most frequently reported by women of childbearing age. Although most of these women drink at safe levels, a minority will develop significant problems such as alcohol abuse or dependence; 11 percent drink at risky levels for alcohol-related harm over a lifetime, 30 percent drink at risky level for risk of injury on a single occasion and 5 percent of women report drinking daily (AIHW 2011). For women who drink at these levels and become pregnant there is special concern for the women and their unborn babies. This is because alcohol is a teratogen responsible for the range of abnormalities in the child that comprise the Fetal Alcohol Spectrum Disorders (FASD). At their November 2004 meeting, members of the Ministerial Council on Drug Strategy (MCDS) agreed that the Inter Governmental Council on Drugs (IGCD) should form a working party to provide advice about FASD, specifically of recent developments, both in Australia and internationally, that would inform policies to address issues associated with FASD, including identification of best practice approaches to reduce the incidence of FASD, particularly in Aboriginal communities.

A working party was established in 2006 comprising nominated jurisdictional representatives, clinicians and public health experts. One task of the working party was to update the 2002 Literature Review by the National Expert Advisory Committee on Alcohol, the findings of which are contained within this monograph. Information about the epidemiology of FASD, the economic and health service impacts of FASD, and international clinical services relating to FASD are also discussed.

Note: Whilst the umbrella term Fetal Alcohol Spectrum Disorders (FASD) comprises a range of disorders, much of the research in the field has focused on the more visible end of the spectrum, namely Fetal Alcohol Syndrome (FAS). This is mainly due to difficulties associated with diagnosis of the other disorders that comprise FASD, particularly Alcohol Related Neurodevelopmental Disorder. Consequently, much of the following document refers to FAS, with information on FASD included as appropriate and where available.
2. **PREVALENCE AND CORRELATES OF ALCOHOL USE IN PREGNANCY**

*Lucy Burns, Colleen O’Leary, Elizabeth Peadon, Emma Black, Heather D’Antoine and Courtney Breen*

2.1 Alcohol consumption in Australia

Alcohol is widely used in Australian society and is very much a part of the social and cultural aspects of Australian life (Commonwealth Department of Health and Ageing 2001). About 81 percent of people aged 14 years or more report that they drink alcohol, 40 percent drink weekly and seven percent report that they drink on a daily basis (AIHW 2011). Among women, 78 percent report having drunk in the past year, with about a third reporting weekly drinking and about 5 percent drinking daily (AIHW 2011).

The 2009 National Health and Medical Research Council Australian Guidelines to reduce health risks from drinking alcohol propose that for low risk of harm from alcohol-related disease or injury, no more than two standard drinks should be consumed per day for men or women. The guidelines propose that for low risk of alcohol related injury on a single drinking occasion, no more than four standard drinks should be consumed per day. These guidelines state that there are few gender differences in the risk of harm due to low risk alcohol consumption; however, at higher levels, the lifetime risk of alcohol-related disease increases more quickly for women, while the lifetime risk of alcohol-related injury increases more quickly for men (NHMRC 2009).

Previous research has indicated that the majority of Australians consume alcohol at levels that are low risk to their health, (NHMRC 2001); however, in 2010, 1 in 5 people aged 14 years or older reported alcohol consumption at a level that put them at risk of harm from alcohol-related disease or injury over their lifetime, and this remained stable between 2007 (20.3%) and 2010 (20.1%). The number of people drinking alcohol in risky quantities increased from 3.5 million in 2007 to 3.7 million in 2010 (AIHW 2011). This increase has been reported since 1995 with the percentage of Australians drinking at risky and high risk levels, rising from eight percent in 1995 to 13 percent in 2004-05 (NHMRC 2001). Although larger proportions of men report drinking at risky levels, the increase in adult women reporting drinking at risky and high risk levels has been greater than for men with the percentage doubling from six percent to 12 percent over this time period compared with an increase from 10 percent to 15 percent for men (Australian Bureau of Statistics 2006).

Indigenous Australians are less likely to consume alcohol than other Australians, with 21 percent of Aboriginal and Torres Strait Islander respondents in the 2004 National Drug Strategy Household Survey (NDSHS) reporting abstinence compared with 16 percent of other Australians (AIHW 2005). However, Indigenous people are more likely to drink at levels above the 2001 National Health and Medical Research Council of Australia (NHMRC)

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*Based on the 2001 NHMRC Guidelines which state that for males, consumption of up to four standard drinks per day over the longer term is considered low risk, five to six standard drinks per day is risky and seven or more standard drinks per day is high risk for development of alcohol-related diseases. For females, an average daily consumption of up to two standard drinks is considered low risk, three to four standard drinks per day is risky and five or more standard drinks per day is high risk. For short term risk of accident or injury, the consumption of 11 or more standard drinks for males or seven or more for females on any one day is considered to be high risk.*

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Chapter 2: Prevalence and correlates of alcohol use in pregnancy
guideline if they do drink. Twenty three percent of Aboriginal and Torres Strait Islander participants reported drinking above the guidelines for alcohol-related disease risks (i.e. over the longer term) and 39 percent reported drinking at levels above the recommended limits for accidents and injuries (short term risk). These figures compare with approximately 10 percent and 21 percent of other Australians, respectively (AIHW 2005).

Estimates of alcohol use among Indigenous Australians in the more recent NDSHS, including that conducted in 2004, have been criticised by Chikritzhs and Brady (2006; 2007). These authors cite a number of methodological problems, including the content of items on alcohol use and response rates (46 percent in 2004) leading to low numbers of Indigenous participants. These authors argue that the 1994 NDSHS, in which a separate national survey was conducted with 2,993 Indigenous people in urban areas to supplement data collected in the 1993 NDSHS remains the best estimates of the prevalence of alcohol use among Indigenous people (Commonwealth Department of Human Services and Health 1996; Chikritzhs and Brady 2007). The 1994 NDSHS findings showed a similar pattern to subsequent surveys, with higher rates of abstinence (37 percent of Indigenous Australians versus 22 percent of the general population) and higher rates of risky drinking among those who drank alcohol. However, among those who drank, higher proportions of Indigenous respondents (70 percent of males and 67 percent of females) reported drinking at levels considered to be high risk as compared with later NDSHS findings. General population figures were 24 percent and 11 percent, respectively (Commonwealth Department of Human Services and Health 1996)*.

In the general population, the pattern of alcohol consumption and the type of alcoholic beverage consumed shows distinct age-related patterns. The highest rates of drinking and risky patterns of alcohol consumption occur in adolescents and young adults who are among those in their childbearing years. Amongst 20-29 year olds, 17 percent of women drank at levels indicating risk of alcohol-related harm over a lifetime and 18.7 percent reported drinking more than 4 drinks on a single occasion at least monthly; 16.8 percent did so at least weekly, placing them at risk of alcohol related injury (AIHW 2011). Of women who gave birth in 2008, 41.2 percent were aged between 20-29 years (Laws et al. 2010).

2.2 Rates of unplanned pregnancy

The high rate of risky and high risk drinking by women of child bearing age raises cause for concern. The issue of alcohol exposure to the fetus is complicated by the fact that about half of all pregnancies are reported to be unplanned (Frezza et al. 1990; Naimi et al. 2003). Considering the high rates of drinking in young women, including in the three months before pregnancy, it is possible that a proportion of women will inadvertently expose their babies to alcohol before they are aware of their pregnancy.

2.3 Gender differences and the impact of alcohol

Women experience the effects of alcohol at lower levels than men because women have a higher blood alcohol content than men after consuming the same amount of alcohol (Frezza et al. 1990; McLeod et al. 1999; Mumenthaler et al. 1999; Stockwell and Single 1999). Holman et al. estimated that the absolute risk of death for women consuming between 2 and 2.9 standard drinks of alcohol per day is 1.13 when compared with abstainers, rising to 1.58 with the consumption of six or more drinks daily (Holman et al. 1996). For men the relative

* For a review, see Australian Indigenous HealthInfoNet http://www.healthinfonet.ecu.edu.au/
risk was 1.06 for between 4 and 4.9 drinks per day compared to abstainers and 1.37 for six or more per day. Alcohol is metabolized more slowly by women than by men and women who regularly consume more than two drinks per day or five or more drinks on one occasion have an increased risk of alcohol dependence (Frezza et al. 1990; Bradley et al. 1998; McLeod et al. 1999; Stockwell and Single 1999).

### 2.4 Predictors of drinking in pregnancy

A recent systematic review of fourteen studies from a range of countries examining predictors of alcohol use during pregnancy found that the most consistently reported predictors were pre-pregnancy alcohol use (quantity and frequency) and having been abused or exposed to violence. High income and a positive alcohol dependence screen were less consistent predictors of alcohol use in pregnancy. Unemployment, marital status and education level were found to be predictive infrequently (Skagerstrom et al. 2011).

An Australian study (included in the systematic review) that surveyed 248 pregnant women, found that family annual income was the only demographic variable significantly correlated with intention to drink and drinking during pregnancy. The higher the family income, the more likely women were to consume alcohol prior to pregnancy, respond that they intended to drink during pregnancy and to consume alcohol during pregnancy (Zammit et al. 2008). For women who drank after the pregnancy was confirmed, the quantity of alcohol consumed prior to pregnancy predicted the intention to drink in a future pregnancy, with heavier drinkers more likely to have the intention to drink. Drinking behaviour in pregnancy predicted fortnightly alcohol consumption in later pregnancy, after controlling for pre-pregnancy drinking and income.

Another Australian survey of women attending antenatal clinics in two South Australian hospitals found women with previous pregnancy losses were significantly more likely to report drinking alcohol during pregnancy. The only factor found to be independently associated with the likelihood of ceasing alcohol use during pregnancy was the pregnancy being the first pregnancy for the woman (Hotham et al. 2008). The prevalence of alcohol consumption in this study is lower than other samples of Australian women with 11.5, 12.5 and 15.6 percent reporting alcohol consumption for the different trimesters respectively.

In a national cross-sectional telephone survey, Peadon and colleagues found the majority (89.4%) of women reported recent (past 12 month) alcohol consumption. A third (34.1%) drank alcohol during their last pregnancy. The study found that a woman’s current drinking behaviour, their drinking behaviour during a past pregnancy and attitudes to alcohol use during pregnancy were the strongest predictors of alcohol consumption in pregnancy (Peadon et al. 2011). Women who drank more frequently or heavily, who had consumed alcohol in their past pregnancy, who intended to smoke in a future pregnancy or had neutral or positive attitudes to alcohol use in pregnancy were more likely to report they would consume alcohol in a future pregnancy.

### 2.5 Drinking in pregnancy: the Australian Alcohol Guidelines

The NHMRC 2009 guidelines to reduce health risks from drinking alcohol state that ‘For women who are pregnant or planning a pregnancy, not drinking is the safest option’. However, women who have consumed alcohol can be reassured that the risk to the fetus from low-level drinking (such as one or two drinks per week) during pregnancy are likely to be low (NHMRC 2009). An Australian standard drink is defined as 10g of alcohol.
2.6 Women’s drinking behaviour, knowledge and attitudes regarding alcohol use in pregnancy

Australian surveys have found that between 50 percent and 59 percent of women consumed alcohol at some time during pregnancy, with only 41 percent of women having abstained in all three trimesters (O’Callaghan et al. 2003; Colvin et al. 2007)*. Studies indicate that the majority of those who continue to drink alcohol during pregnancy typically do so at low or reduced levels. In the 2004 National Drug Strategy Household Survey (NDSHS), 38 percent of women reported that they abstained during pregnancy, 59 percent reported drinking less, while only three percent of women reported drinking ‘the same or more’ than when they were not pregnant (AIHW 2005). The proportion of pregnant women abstaining from alcohol during pregnancy increased in 2010 (from 40.0 percent in 2007 to 52.0 percent in 2010) (AIHW 2011).

With regard to the quantity of alcohol consumed, the study by O’Callaghan et al. found the average alcohol consumption was within the 2001 NHMRC guideline at two glasses per week in early pregnancy and approximately one glass per week in late pregnancy (O'Callaghan et al. 2003). Binge drinking in early pregnancy was reported by 20 percent of the women on at least one occasion.

Colvin and colleagues also noted an overall decrease in alcohol consumption over the course of the pregnancy. In their study of more than 4,000 women in Western Australia, 54 percent drank an average of less than one standard drink per day, four percent drank between one and less than five standard drinks per day and 0.1 percent averaged five or more standard drinks per day (Colvin et al. 2007). In this study, 15 percent of women drank outside the Australian guideline’s recommendation for alcohol consumption in pregnancy during the first trimester, a figure which decreased to 10 percent in the second and third trimesters. About 11 percent consumed more than two standard drinks and/or more than six drinks per week while around two percent binge drank during the second or third trimesters of pregnancy (Colvin et al. 2007). Timing of alcohol consumption in pregnancy has been identified as an important factor, both in relation to its potential impact on the fetus and for the design of targeted interventions for FASD prevention (Floyd et al. 1999; Maier and West 2001; Floyd et al. 2007; O’Leary et al. 2009).

Studies focusing on Indigenous Australians have typically reported lower rates of alcohol use in pregnancy than in non-Indigenous women. In the Western Australian Aboriginal Child Health Survey, 23 percent of women reported consuming alcohol during pregnancy (Zubrick et al. 2004). Measures of the frequency and quantity of alcohol intake were unavailable; however, the study authors point to research suggesting that Aboriginal women who do drink are more likely to do so at hazardous levels (Roche and Deehan 2002). The Bibbulung Gnarneep Study of Aboriginal women in Perth who had a baby in the mid 1990s, reported that 44 percent had consumed alcohol during their pregnancy and 23 percent had become intoxicated at least once during their pregnancy (Eades 2003). Recent data from the Fitzroy Valley in WA support these findings. In a cohort of 129 women, 51 percent drank alcohol during pregnancy, of whom 93 percent drank at high risk levels (Australian Human Rights Commission 2011; Elliott et al. 2012). Data from the Ord Valley in the East Kimberley reported 84.7 percent of 78 women during antenatal assessments reported alcohol use during pregnancy, often inadvertently before women were aware of being pregnant. Over half of these women reported to abstain from alcohol following initial FASD education, 14 percent

* Included only non-Indigenous women.
† Proportions of Indigenous and non-Indigenous participants not specified.
cut down and 1 percent continued to drink alcohol. Ten percent were unable to be contacted for follow-up (Bridge 2011).

Studied of women’s practice, knowledge and attitudes
An Australian study by Peadon et al. investigated the knowledge, attitudes and practice in relation to alcohol use in pregnancy of more than 1000 Australian women aged 18-45 years (Peadon et al. 2010; Peadon et al. 2011). These women were not pregnant at the time of the telephone interview. With regard to drinking practice, the majority of these women (89 percent) had consumed alcohol in the last 12 months; 15 percent usually consumed alcohol at risky or harmful levels (five or more standard drinks per sitting) and 54 percent had consumed at risky or harmful levels at least once in the last twelve months. During their last pregnancy, 34 percent consumed alcohol (quantity not recorded) and 16 percent smoked tobacco. About one-third (32 percent) of women said they would continue to drink alcohol if they were planning a pregnancy and five percent would continue to smoke cigarettes. Thirty one percent reported they would be less likely to consume alcohol in a future pregnancy if their partner stopped drinking and 38 percent would be less likely to drink if their partner encouraged them to stop or cut back. Intention to consume alcohol if planning a pregnancy was strongly associated with: alcohol use in the last pregnancy; agreeing that pregnant women should be able to drink alcohol; intention to smoke in a future pregnancy and; feeling neutral or positive towards alcohol use during pregnancy.

With regard to knowledge about the effects of alcohol use in pregnancy, 62 percent had heard about adverse effects that alcohol could have on the fetus, including one third who nominated FASD as a possible outcome. Other identified problems included neurobehavioural issues, impaired growth and birth defects. Women with higher education levels or general knowledge about alcohol were more likely to have heard of the risk to the fetus from alcohol use in pregnancy.

Although 34 percent of women had consumed alcohol on one or more occasions during pregnancy, 81 percent believed that pregnant women should not drink alcohol. Most (93 percent) reported that alcohol could affect the unborn child but 84 percent did not know that alcohol exposure in utero could lead to lifelong disabilities. With regard to attitudes, 79 percent of women reported negative attitudes (such as concern, disappointment, disgust, annoyance or anger) when they were given a scenario of seeing a pregnant woman drinking alcohol. Negative feelings were associated with women knowing that alcohol use in pregnancy can affect the unborn child; awareness that alcohol can cause birth defects or neurobehavioral problems; and the belief that the disabilities are lifelong. In this survey a tolerant attitude to alcohol use (i.e. women did not report concern in response to the scenario above) during pregnancy strongly predicted intention to drink alcohol in a future pregnancy, even in women with knowledge of the adverse effects of alcohol on the fetus.

Another recent study conducted by D’Antoine and colleagues investigated the knowledge, attitudes and practice of Aboriginal women living in the Kimberley and Goldfield regions in Western Australia through focus groups (D’Antoine et al. 2008). The specific study aims were to describe the knowledge and attitudes of Indigenous women in relation to alcohol use in pregnancy and the unborn child; to gain insight into the current practice of alcohol consumption during pregnancy for Aboriginal women; to ascertain support for initiatives to provide women of childbearing age with information about the risks of alcohol consumption in pregnancy; and to identify the preferred mode/s of delivery of educational messages.
Thematic analysis of the data transcriptions from the focus groups show that many Aboriginal women are aware of a wide range of effects of alcohol consumption in pregnancy on the unborn child. Women provided a range of strategies that they felt would support Aboriginal women to abstain from alcohol use in pregnancy and the study findings have potential to inform future interventions to favourably influence women’s decisions regarding alcohol use in pregnancy. The women highlighted the importance of strategies being inclusive of the Aboriginal community but not targeting them. These findings have been disseminated widely to all key stakeholders and will further contribute to the process of developing prevention programs of particular relevance to alcohol use in pregnancy by Aboriginal women (D’Antoine et al. 2008).

The findings of Peadon et al. have implications for public health interventions and because they identify groups of women who are at higher risk of using alcohol in pregnancy and who might be targeted through education (Peadon et al. 2007). The findings also illustrate that knowledge about the adverse effects of alcohol in pregnancy will not change behaviour and that societal attitudes about alcohol use in the community and in pregnancy in particular, need to be addressed if we are to reduce alcohol consumption. Partners should also be included in such interventions, because maternal drinking is strongly correlated with partner alcohol use (Passaro et al. 1998).

2.7 Australian population level data on alcohol use in pregnancy

Several Australian surveys measure patterns of alcohol consumption in pregnancy. One of these is the National Drug Strategy Household Survey (NDSHS), a triennial survey series conducted under the auspices of The National Drug Strategy 2004-2009 (NDS). Ten surveys have been undertaken to date, designed to measure knowledge and attitudes towards drugs (including tobacco, alcohol and illicit drugs) and document drug use histories and related behaviours of the Australian population. In the most recent survey in 2010, more than 26,000 people aged 12 years and over completed the survey. The three most recent surveys gathered comprehensive Australian information on alcohol use in pregnancy. Results from the 2004 survey indicated that pregnant and breastfeeding women were significantly less likely to consume alcohol than other women of childbearing age (47 percent versus 85 percent) nonetheless, it is of concern that a proportion of pregnant women continue to drink above recommended levels (Wallace et al. 2007).

In the 2007 NDSHS data alcohol use was reported by 29 percent of women who were pregnant in the past 12 months. In addition, 43 percent of women who were breastfeeding in the past 12 months reported alcohol use, whereas 36 percent of women who were both pregnant and breastfeeding in the past 12 months reported alcohol use. Consistent with previous research, older age was significantly associated with alcohol use in pregnancy after controlling for other psychosocial characteristics. Most women (95%) reported a reduction in the quantity of their alcohol use while pregnant or breastfeeding (Maloney et al. 2011).

Women's Health Australia is a longitudinal study that has been examining the health and wellbeing of Australian women since 1996. Also known as the Australian Longitudinal Study on Women’s Health, the project conducts surveys with more than 40,000 Australian women who were aged 18-23, 45-50, and 70-75 when the study began. Women’s Health Australia has assessed physical health, mental health and a range of other factors including alcohol use among these women. The study has found that women who were currently pregnant were more likely to be abstinent or to rarely drink, although three percent reported drinking at risky levels (Young et al. 2005).
In addition to these sources of national data, data are available from individual research studies and jurisdictional reporting mechanisms (O’Callaghan et al. 2003; Colvin et al. 2007). In each state and territory the Midwives Data Collection provides perinatal data on obstetric conditions, procedures and outcomes, neonatal morbidity and birth defects for every birth in Australia (of at least 20 weeks gestation, or if gestation is unknown at least 400g birth weight). Self-reported alcohol use in pregnancy is included on perinatal forms in Tasmania, Northern Territory and Australian Capital Territory only (Table 2.1). In 2006 in the Northern Territory, eight percent of non Indigenous and 14 percent of Indigenous mothers reported alcohol use during the first visit with a midwife, decreasing to four percent of non Indigenous and eight percent of Indigenous mothers at 36 weeks (Tew and Zhang 2010). Data from the ACT and Tasmania have not yet been published. The lack of uniform data collection at the national level about alcohol use in pregnancy must urgently be addressed.

Table 2.1: Current alcohol questions on midwives’ data collection forms, by State and Territory

<table>
<thead>
<tr>
<th>Question</th>
<th>NSW</th>
<th>VIC</th>
<th>QLD</th>
<th>WA</th>
<th>SA</th>
<th>TAS</th>
<th>ACT</th>
<th>NT</th>
</tr>
</thead>
<tbody>
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<td>—</td>
<td>—</td>
<td>—</td>
<td>—</td>
<td>—</td>
<td>—</td>
<td>—</td>
<td>—</td>
</tr>
<tr>
<td><strong>Response code</strong></td>
<td>—</td>
<td>—</td>
<td>—</td>
<td>—</td>
<td>—</td>
<td>Yes/no</td>
<td>Yes/no</td>
<td>Yes/no /unknown</td>
</tr>
<tr>
<td>Q2</td>
<td>—</td>
<td>—</td>
<td>—</td>
<td>—</td>
<td>—</td>
<td>—</td>
<td>—</td>
<td>—</td>
</tr>
<tr>
<td><strong>Response code</strong></td>
<td>—</td>
<td>—</td>
<td>—</td>
<td>—</td>
<td>—</td>
<td>Less than 1 standard/day</td>
<td>NN (numeric field)</td>
<td>Yes/no /unknown</td>
</tr>
<tr>
<td>Q3</td>
<td>—</td>
<td>—</td>
<td>—</td>
<td>—</td>
<td>—</td>
<td>—</td>
<td>—</td>
<td>—</td>
</tr>
<tr>
<td><strong>Response code</strong></td>
<td>—</td>
<td>—</td>
<td>—</td>
<td>—</td>
<td>—</td>
<td>Was substance abuse documented?</td>
<td>—</td>
<td>—</td>
</tr>
</tbody>
</table>

The National Perinatal Data Collection (NPDC) is a population-based cross sectional data collection about pregnancy and childbirth. The data are based on births reported to the perinatal data collection in each state and territory in Australia. Midwives and other staff, using information obtained from mothers and from hospital or other records, complete notification forms for each birth. Information is included in the NPDC on both live births and stillbirths of at least 400 grams birthweight or at least 20 weeks gestation. Recently the Enhancing the Perinatal Minimum Data Set: Alcohol use in pregnancy project was undertaken by the Australian Institute of Health and Welfare (AIHW) National Perinatal Epidemiology & Statistics Unit (NPESU) as part of the COAG Close the Data Gaps. Based on consultation across a broad range of stakeholders, standard elements to collect data about frequency and amount of alcohol consumed in early and late pregnancy were drafted. Further consultation is being undertaken to assess the feasibility of introducing these items into perinatal data collections.
Key points

- Recent increases have been documented in the proportion of women of childbearing age who drink at risky levels.
- The majority of women reduce or cease alcohol consumption upon learning that they are pregnant; however, a significant proportion drink at some time during pregnancy and a significant minority of women continue to drink at high levels.
- Indigenous women are less likely to report alcohol use in pregnancy than their non-Indigenous counterparts; however, when they do drink, it may be at higher levels.
- About half of all pregnancies are unplanned, indicating that many women may inadvertently expose their unborn child to alcohol before becoming aware of their pregnancy.
- Women’s intentions to consume alcohol if planning a pregnancy are strongly associated with: alcohol use prior to and during the last pregnancy; agreeing that pregnant women should be able to drink alcohol; intention to smoke in a future pregnancy; and feeling neutral or positive towards alcohol use during pregnancy. These groups of women are at higher risk of using alcohol in pregnancy and might be targeted through educational initiatives.
- Knowledge about the adverse effects of prenatal alcohol exposure is insufficient for behaviour change; it is necessary to address societal attitudes about alcohol use in the community, particularly in relation to use during pregnancy.
- National population level data collections containing information on alcohol use in pregnancy include the National Drug Strategy Household Survey and Women’s Health Australia.
- There is an urgent need to implement a standardised collection of national data about alcohol use in pregnancy through the National Perinatal Data Collection, collected across each State and Territory. This will require training, resource allocation and a clear pathway of care onwards for identified clients.
3. SERVICES FOR PREGNANT WOMEN

Lucy Burns, Anna Woods and Courtney Breen

Only a small proportion of pregnant women who drink at problematic levels are identified and treated. Hankin et al. reviewed a number of studies and suggest that only 10 to 50 percent of substance-using pregnant women will access treatment services (Hankin et al. 2000).

3.1 Screening and brief intervention

As discussed in the previous chapter, screening of alcohol use in pregnancy varies by state in Australia. Pregnant women are typically not assessed for their drinking habits in most countries, although recent research from Sweden suggests it is feasible to implement systematic screening with a simple questionnaire to facilitate early recognition of women at risk (Nilsen 2009). Other research suggests that the use of one question could identify women at risk (Johnson et al. 2010).

A recent Australian study examined different questions for asking about alcohol use in pregnancy and suggested that women should be screened for alcohol intake with a validated clinical instrument that includes assessment of consumption patterns. The questions should be accompanied by clear instructions for the health practitioner on how to interpret and discuss the information. In addition, handouts of educational material should be provided to the woman (Muggli et al. 2010).

There is growing evidence for the effectiveness of brief intervention in reducing alcohol consumption during pregnancy. It has been proposed that brief intervention should be at least as effective with pregnant women as with other client groups (Nilsen 2009). Although only a few brief intervention trials have been conducted with pregnant women, these women are generally motivated to reduce their alcohol intake, and the contextual change provided by the pregnancy provides an opportunity to break drinking behaviour patterns.

Supportive counselling for pregnant women with alcohol-related problems has been shown to help women to reduce alcohol consumption prior to the third trimester in two-thirds of cases (Rosett et al. 1983).

3.2 Pharmacotherapies

Bogenschultz and Geppert noted that very few studies have investigated pharmacological treatments for pregnant women (Bogenschutz and Geppert 2003). They suggested reasons for this as the hesitation of pharmaceutical companies to conduct trials with women who may become pregnant, difficulties in recruiting women (particularly from minority groups), and the widespread academic and industry practice of almost exclusively recruiting men in treatment trials. As women are often excluded from pharmacological trials, the knowledge base of the effects of pharmacotherapies for women who use alcohol in pregnancy comes from animal studies, case reports and reports of adverse events.

The assessment of pharmacotherapies in pregnancy is limited. A systematic review of pharmacological treatments for pregnant women found no randomised or quasi-randomised studies comparing any pharmacologic intervention versus other pharmacologic treatment alone or in association with psychosocial treatment, placebo, non-intervention or psychosocial intervention (Smith et al. 2009). Case series, case reports and cohort studies of
women who have used pharmacologic treatments for alcohol use during their pregnancy provide the evidence for pharmacotherapy use in pregnancy.

Table 3.1 summarises findings to date and was used in the development of the National Clinical Guidelines for the Management of Drug Use During Pregnancy, Birth and the Early Development Years of the Newborn (NSW Department of Health 2006; NSW Department of Health 2006).

Although few studies have included pregnant women, a recent analysis of gender differences in pharmacological and behavioural treatments for alcohol dependence reported that alcohol-dependent women responded to naltrexone similarly to alcohol-dependent men (Greenfield et al. 2010). In this study, fewer women reported having ever received alcohol treatment and women tended to use primary health care as opposed to specialised alcohol and drug treatment services.

### 3.3 Supportive therapy

The following section provides a summary of the information contained in the Background Papers To the National Clinical Guidelines for the Management of Drug Use During Pregnancy, Birth and the Early Development Years of the Newborn (NSW Department of Health 2006).

**Framework of care**

Alcohol treatment is associated with improved maternal and neonatal outcomes, with more intensive treatment episodes associated with the best outcomes. Education, monitoring and screening throughout pregnancy is effective for women who are low-risk drinkers (Redding and Selleck 1993). Education and abstinence is suggested for those at moderate risk, and these programs should also include risk management, contracts and monitoring. Alcohol dependent women who choose to withdraw should be admitted to an inpatient unit and receive close medical supervision, including monitoring of both the mother and the fetus (Mitchell 1993).

If women are not dependent but wish to stop drinking, other settings are also appropriate and may include:

- partial hospitalisation;
- residential treatment;
- outpatient individual or group psychotherapy;
- family or couples therapy; and/or
- involvement in self-help groups.
Table 3.1: Pharmacotherapies for alcohol problems among pregnant women

<table>
<thead>
<tr>
<th>Drug</th>
<th>Used for</th>
<th>Risks</th>
<th>Australian TGA pregnancy classification</th>
</tr>
</thead>
<tbody>
<tr>
<td>Benzodiazepines</td>
<td>Management of alcohol withdrawal.</td>
<td>Early studies note minor congenital malformations, such as cleft palate after first trimester exposure. Later studies did not find this result. Pooled data indicated the risk is very small, especially with short-term exposure. Benzodiazepines in the third trimester or close to delivery may cause floppy infant syndrome.</td>
<td>Category C</td>
</tr>
<tr>
<td>Carbamazepine</td>
<td>Anticonvulsant medication used in alcohol patients who have multiple episodes of withdrawal.</td>
<td>Contraindicated in pregnant women. A twofold increase in major congenital abnormalities has been found in epileptic women who took the drug during the first trimester of pregnancy.</td>
<td>Category D</td>
</tr>
<tr>
<td>Valproate</td>
<td>Alcohol withdrawal.</td>
<td>Produces neural tube defects and is hence precluded from use in pregnancy.</td>
<td>Category D</td>
</tr>
<tr>
<td>Thiamine</td>
<td>Prevention of Wernicke’s encephalopathy and Korsakoff’s syndrome in the mother.</td>
<td>Recommended.</td>
<td>Unlisted: see product information</td>
</tr>
<tr>
<td>Folic acid</td>
<td>Prevention of neural tube defects.</td>
<td>Recommended.</td>
<td>Category A</td>
</tr>
<tr>
<td>Disulfiram</td>
<td>Used in the abstinence phase of alcohol treatment and inhibits aldehyde dehydrogenase, leading to a build up of acetaldehyde. This causes an unpleasant reaction when alcohol is consumed, with facial flushing, tachycardia, hypotension, nausea, vomiting, and general malaise.</td>
<td>Evidence on adverse effects during pregnancy are scant and it is therefore not recommended for use.</td>
<td>Category B2</td>
</tr>
<tr>
<td>Naltrexone</td>
<td>Opiate agonist that reduces the positive reinforcement of alcohol.</td>
<td>Contraindicated in pregnancy and lactation. An Australian case study of 18 women reported naltrexone did not increase fetal abnormalities (Hulse et al. 2004).</td>
<td>Category B3</td>
</tr>
<tr>
<td>Acamprosate</td>
<td>Reduces the hyperexcitable state that results from chronic alcohol use.</td>
<td>No information on studies in pregnant women was found.</td>
<td>Category B2</td>
</tr>
<tr>
<td>Clonidine</td>
<td>Alcohol withdrawal.</td>
<td>No controlled data from human pregnancy studies.</td>
<td>Category B3</td>
</tr>
</tbody>
</table>

Category A - Drugs which have been taken by a large number of pregnant women and women of childbearing age without any proven increase in the frequency of malformations or other direct or indirect harmful effects on the fetus having been observed.

Category B2 - Drugs which have been taken by only a limited number of pregnant women and women of childbearing age, without an increase in the frequency of malformation or other direct or indirect harmful effects on the human fetus having been observed. Studies in animals are inadequate or may be lacking, but available data show no evidence of an increased occurrence of fetal damage.

Category B3- Drugs which have been taken by only a limited number of pregnant women and women of childbearing age, without an increase in the frequency of malformation or other direct or indirect harmful effects on the human fetus having been observed. Studies in animals have shown evidence of an increased occurrence of fetal damage, the significance of which is considered uncertain in humans.

Category C - Drugs which, owing to their pharmacological effects, have caused or may be suspected of causing, harmful effects on the human fetus or neonate without causing malformations. These effects may be reversible. Accompanying texts should be consulted for further details.

Category D- Drugs which have caused, are suspected to have caused or may be expected to cause, an increased incidence of human fetal malformations or irreversible damage. These drugs may also have adverse pharmacological effects. Accompanying texts should be consulted for further details.

Following delivery, discharge planning should include relapse prevention and referral to community services, including a general practitioner. Parenting groups are also recommended (Greenfield and Sugarman 2001). Following birth, treatment should focus on keeping the baby with the mother and promoting attachment between them. Interventions that aim to increase the mother’s self-esteem and/or self-efficacy are suggested; however, at the present most treatment settings do not make provision for babies or for other children to remain in the care of their mothers (Bowie 2005).

Overall, women should be engaged in treatment as early as possible and will be best conducted in a supportive, culturally sensitive and non-judgemental environment. This will require a full health and psychosocial assessment (Mitchell 1993). Factors associated with early attrition from treatment programs include high levels of drug craving and withdrawal, more prior drug treatment episodes, fewer medical and drug problems and more family and social and psychiatric problems (Kissin et al. 2004).

There is no clear empirical evidence as to which modality is best suited to substance-using women (including inpatients and outpatients). A recent review of integrated treatment programs (programs that combine substance use treatment and pregnancy, parenting or child services) suggests that integrated programs result in significant reductions in substance use and are more effective than no treatment in reducing maternal substance misuse (Milligan et al. 2011). A number of components of successful programs have been identified including: positive parent role models and parent training; self-help groups; outreach; case management; life skills management; family support services; lengthy follow-up; and referrals and support across a range of domains including medical, pharmalogical, transportation, mental health, educational, vocational, legal and respite care (Lester et al. 2004).

There is a need to conduct further research to identify effective programs for pregnant women who use alcohol (Lester et al. 2004). In particular, there is little evidence on the effectiveness of the psychosocial treatment of pregnant women with alcohol dependence. A systematic review of psychosocial interventions for pregnant women enrolled in alcohol treatment programs found no randomised or quasi-randomised studies comparing any psychosocial intervention with other intervention for treating alcohol dependence in pregnancy (Lui et al. 2009). The authors of the review conclude that controlled trials need to be performed on this population of women to determine the most effective therapy for pregnant women seeking treatment for alcohol dependence. There have been trials designed to reduce alcohol use in pregnant women but these have not specifically focussed on pregnant women currently in alcohol treatment programs.

3.4 Alcohol treatment in Australia and barriers to care

Alcohol is the most commonly reported drug of concern among people seeking treatment in alcohol and drug services in every state of Australia except Tasmania (AIHW 2011). The most common source of referral in 2009-10 for alcohol treatment (37 percent of episodes) was self-referral. The most common main treatment for alcohol misuse was counselling (44 percent), and treatment was took place in a non-residential (61 percent of episodes) or a residential treatment facility (21 percent) (AIHW 2011). The type of treatment available and received differs by location. Counselling was the most common form of alcohol and drug treatment episode in very remote areas with two thirds (67 percent) of those seeking treatment receiving counselling, compared to major cities where 41 percent of episodes were counselled. Withdrawal management (detoxification) was lowest in very remote (0.7 percent) and remote areas (6 percent) compared to major cities (17.7 percent) (AIHW 2011).
For women seeking treatment, a number of issues have been identified that will affect the amount and type of treatment received (Roberts and Nanson 2000). Firstly, women are more likely to attribute their problems to mental health rather than alcohol use and will therefore be more likely to be seen in mental health or general practice rather than substance treatment centres (Weisner and Schmidt 1996; Greenfield et al. 2010). In addition to this discrepancy in women seeking treatment in specialised services, there are a limited number of specialist services that treat pregnant women in metropolitan areas and even fewer, if any, in many regional and rural areas.

Secondly, there are a number of barriers to treatment for substance use disorders for women that have been identified, including: a fear of losing of custody of their children; social stigma; lack of childcare; lack of transportation; and a lack of access or priority for pregnant women (Messer et al. 1996; Small et al. 2010). The most common reasons cited by women for not seeking treatment are: not wanting to give up alcohol; being afraid they would lose their children to care; being afraid there would be no-one there to look after the children if they went into treatment; and their partner did not want them to go into treatment. Messer et al. found that, compared to women who did not accept an offer of treatment, those who accepted treatment had more severe substance use problems, were more likely to have been in treatment previously, were more likely to have partners who also used alcohol and were much more likely to have experienced sexual or physical abuse during pregnancy (Messer et al. 1996). Factors that promote treatment seeking in women include support from someone significant and acknowledging that sharing the problem with others was a relief (Jakobsson et al. 2008). Feelings of shame and the perception that alcohol problems were incompatible with femininity were hindrances for treatment seeking. Awareness of these factors may be useful for health services providing treatment to women with alcohol problems.
Case study: Services for pregnant women who use alcohol in South Australia: A clinician’s perspective

Specialist alcohol and drug services exist in many large obstetric settings and referral follows identification of risky or harmful patterns of drinking. For example, at the Women’s and Children’s Hospital in Adelaide, protocols specify that if the clinician elicits a history of more than two standard drinks per day or a binge pattern of drinking (more than five standard drinks on a single occasion) at the booking visit, a referral to the Drug and Alcohol Service should be made. However, no further routine enquiries regarding alcohol use occur beyond the first visit.

Alcohol misuse is likely to be under-detected in pregnancy; nonetheless, women may be heeding the message regarding the risks of alcohol in pregnancy. In South Australia, there has been a prominent public health campaign regarding the risks of alcohol use in pregnancy and a recommendation that the safest choice for women is an alcohol-free pregnancy. (See http://www.wch.sa.gov.au/services/az/other/health_prom/programs/healthypregnancy.html).

It is worth noting less than five percent of referrals to the Drug and Alcohol Service are for alcohol misuse. Indeed, hospital data over the previous three years suggest low numbers (55 women with 47 of these recorded as polysubstance users) having alcohol abuse recorded as a diagnosis at birth.

The Drug and Alcohol Service at The Women’s and Children’s Hospital clinic includes a hospital midwife and obstetrician assigned to the clinic. Visiting clinicians from Drug and Alcohol Services South Australia (DASSA) include a clinical nurse and senior medical practitioner. Within the hospital, good working relationships exist between the clinic and social work and mental health services. Services include a comprehensive assessment regarding alcohol and other substance use; assessment of mental health and psychosocial stressors and provision of brief interventions and the use of motivational interviewing. Efforts are made to engage women’s partners in the process with emphasis on shared responsibility, to effect change in the home. Close review is provided in the clinic and referral for more intensive intervention is made when required. This may include inpatient withdrawal services, individual counselling, group work and residential support. The service also provides advocacy for the woman within the hospital and with other agencies.

Case study: Sally

Sally presented to the antenatal clinic aged 25 years old. She had a four-year-old daughter who was not in her care (residing with paternal grandparents). She was in a relatively new relationship of six months. She presented for a booking visit at nine weeks. At this visit she denied substance use including alcohol, cannabis, and stimulants; she smoked 15 cigarettes daily. She admitted to past intravenous drug use (amphetamines and opiates). Sally attended the women’s emergency service after-hours at 16 weeks gestation and disclosed domestic violence; following this, a social work referral was made (no patterns of substance use were recorded). Sally presented again for routine care at 21 weeks. At 26 weeks Sally disclosed alcohol, cannabis and amphetamine use. She was not seen in the Drug and Alcohol Clinic until 29 weeks. At this visit she reported daily alcohol use at dependent levels (up to 250g alcohol or 25 standard drinks per day). She agreed to hospital admission for withdrawal management; however, during negotiations with the senior obstetrician, Sally received distressing family news and left in crisis. She returned the following week and stated that she had managed to reduce substantially her intake, reporting that the stressor of the previous week was her aunt’s admission to hospital with alcohol related liver failure. She denied significant withdrawal symptoms and she agreed attend the clinic weekly for review.

Sally continued to binge drink at progressively lower levels. A case conference was arranged antenatally to consider supports and child protection issues. At this meeting the paternal grandparents agreed to care for the baby. It became clear Sally had long-term significant psychosocial stressors including homelessness, domestic violence and significant alcohol and opiate use by her partner. Sally reported longstanding substance use since early adolescence and was noted to be impulsive and...
emotionally labile. With a strong family history of alcohol dependence, including by her mother, the question was raised as to whether Sally herself had undiagnosed Fetal Alcohol Spectrum Disorder.

Crises continued to occur for Sally during the antenatal period and after an increase in alcohol consumption (a high level binge) in addition to reports of ongoing violence, Sally accepted admission to hospital at 37 weeks. Sally improved both physically and emotionally during her hospitalization. She was reviewed by social work and mental health whilst an inpatient. She remained abstinent from alcohol and other substances and reported feeling ready for the birth. Sally had a normal delivery of a baby boy at 38/40 weeks. The baby was a healthy weight (3050g) and had Apgars of 5/5. During the postnatal period Sally was noted to have good parenting skills and was comfortable with the care arrangements in place. Sally was discharged one week after delivery. It was concerning to note that, despite the clear documentation of alcohol use complicating this pregnancy and the lengthy hospitalisation, alcohol abuse was not recorded as a discharge diagnosis.

Sally attended for follow up in the early postnatal period. However, multiple address changes and difficulties with phone contact made it difficult to continue working with her.

**What can we learn from Sally’s experience?**

Sally’s case illustrates missed opportunities for intervention at an earlier stage in the pregnancy. Sally had a significant past history, including losing custody of a child and previous polysubstance use, which could have offered an earlier opportunity for further exploration of her circumstances. She presented mid-pregnancy with issues of domestic violence and the correlation between violence and alcohol misuse is well established. Once she disclosed these issues, there was a significant delay before she accessed specialist services. Following this, further barriers existed to her gaining admission to hospital to give birth. Sally’s case also raises questions of missed diagnoses for adults in our health system. Importantly, alcohol dependence was not recorded in her medical records. Also, loss to follow-up of the mother suggests that her infant was denied appropriate referral to paediatrician services for assessment for fetal alcohol spectrum disorders.

It is clear that opportunities exist to improve health services’ responses to alcohol use in pregnancy. A more proactive approach is required, with clinicians appropriately assessing women, providing information and referral at the earliest opportunity, and improving the health system to enable provision of a more coordinated and responsive approach to this very significant health issue.
Key points

- There is an urgent need to improve availability and access to services for women who drink during pregnancy, particularly those who drink at risky levels.
- The evidence to support pharmacotherapies and psychosocial interventions and treatments is limited; however, a holistic approach is important for program success. High quality intervention research is crucial.
- A multidisciplinary, supportive and culturally appropriate approach is required to address the complex needs of alcohol-dependent mothers and their families.
- The key objective is early identification and treatment of women with alcohol misuse to maximise the chance of FASD prevention.
4. THE EFFECTS OF ALCOHOL EXPOSURE IN UTERO

Colleen O’Leary, Elizabeth Peadon, Courtney Breen and Elizabeth Elliott

The first descriptions of prenatal alcohol effects in children of mothers with an alcohol-use disorder appeared in the late 1960s (Lemoine et al. 1968) and early 1970s (Jones and Smith 1973). Since this time researchers have been studying the relationship between prenatal alcohol exposure and fetal effects and a large body of research has been conducted. It is now well accepted that heavy maternal alcohol consumption during pregnancy places the baby at risk of a wide range of fetal effects (Stratton et al. 1996; ARND Consensus Statement 2011). These include birth defects, growth impairment, developmental disabilities and neurodevelopmental dysfunction. A complex pattern of neurodevelopmental dysfunction that is unrelated to developmental maturity or to family or home environment has been identified in children exposed to alcohol in utero. The central nervous system abnormalities include cognitive abnormalities, poor impulse control and problems in behaviour, mental health, social interactions, learning and school achievement. These indicators of brain dysfunction extend across a continuum that ranges from mild to severe impairment (Stratton et al. 1996).

This chapter describes the diagnostic classifications and the guidelines for diagnosis of the range of alcohol-related fetal effects and discusses the epidemiological evidence on the nature of the association between prenatal alcohol exposure and fetal effects.

4.1 Fetal Alcohol Spectrum Disorders

In 2004 the term Fetal Alcohol Spectrum Disorders (FASD) was introduced as an umbrella term to describe the range of effects that can occur in an individual whose mother drank alcohol during pregnancy (Gerberding et al. 2004). There are a number of diagnostic terms used to describe the range of fetal effects stemming from prenatal alcohol exposure including Fetal Alcohol Syndrome (FAS), partial FAS, Fetal Alcohol Effects (FAE), Alcohol Related Birth Defects (ARBD), and Alcohol Related Neurodevelopmental Disorders (ARND).

4.1.1 Fetal Alcohol Syndrome

Diagnosis of FAS relies on a triad of features: characteristic facial abnormalities; impaired growth prenatally and/or postnatally; and structural and/or functional abnormalities of the central nervous system (Table 4.1) (Stratton et al. 1996). The lack of an objective diagnostic test may lead to subjectivity in the diagnostic process, which increases the risk of diagnostic misclassification (Abel 1995). Although a number of syndromes have some features in common with FAS, most other birth defect syndromes do not have abnormalities in each of the three categories required for a diagnosis of FAS (Chudley 2008). If the diagnosis of FAS is in doubt, referral to a dysmorphologist or clinical geneticist is recommended both to confirm the diagnosis and exclude alternative diagnoses. Confirmation of the diagnosis requires a history of maternal alcohol use during pregnancy. However, when reliable information on maternal drinking behaviour is unavailable, a diagnosis of FAS can be recorded, providing that abnormalities in the child are consistent with the syndrome and other possible diagnoses have been excluded (Stratton et al. 1996). In 1996 the Institute of
Medicine (IOM) published the first diagnostic criteria for FAS, pFAS, ARBD, and ARND. Table 4.1 outlines the Institute of Medicine (IOM) diagnostic criteria for FAS.

Table 4.1: Institute of Medicine diagnostic criteria for Fetal Alcohol Syndrome (Stratton et al. 1996)

<table>
<thead>
<tr>
<th>Growth Retardation</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Prenatal growth deficiency – decreased birth weight for gestational age</td>
</tr>
<tr>
<td>• Postnatal growth deficiency – lack of catch-up growth in spite of adequate nutrition</td>
</tr>
<tr>
<td>• Low weight to height ratio</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Characteristic Facial Features</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Short palpebral fissures</td>
</tr>
<tr>
<td>• Thin upper lip</td>
</tr>
<tr>
<td>• Flattened philtrum (an absent or elongated groove between the upper lip and nose)</td>
</tr>
<tr>
<td>• Maxillary hypoplasia, epicanthal folds and ptosis may also occur</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Central Nervous System Anomalies or Dysfunction</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Decreased cranial size at birth</td>
</tr>
<tr>
<td>• Structural brain abnormalities including microcephaly</td>
</tr>
<tr>
<td>• Abnormal neurologic hard or soft signs such as impaired fine and gross motor skills</td>
</tr>
</tbody>
</table>

4.1.2 Other Fetal Alcohol Spectrum Disorders

Complete agreement on diagnosis of the diagnostic categories of FASD has not been reached and a number of diagnostic guidelines have been published in the past decade (Astley 2004; Bertrand et al. 2004; Chudley et al. 2005; Hoyme et al. 2005; Astley 2006). Although each of these guidelines has subtle differences in their diagnostic criteria, they all recognise the need to assess characteristics of growth, facial features, neurological structure and function and alcohol exposure in pregnancy (Western Australian Department of Health 2010).

The Institute of Medicine (IOM) guidelines created three categories to describe the outcomes in children who have some effects related to alcohol exposure in utero, but do not fulfil the criteria for Fetal Alcohol Syndrome (Stratton et al. 1996). The three categories, partial FAS (pFAS), Alcohol Related Neurodevelopmental Disorder (ARND), and Alcohol Related Birth Defects (ARBD) require confirmed maternal alcohol exposure.

A diagnosis of pFAS requires some of the characteristic facial features and at least one of the other FAS features: growth retardation; central nervous system neurodevelopmental abnormalities; or a complex pattern of behavioural and/or cognitive abnormalities which cannot be accounted for by familial background or environment alone.

ARND is characterised by central nervous system (CNS) abnormalities (e.g. decreased head size at birth or structural brain abnormalities) and/or neurological functional abnormalities which cannot be explained by familial background or environment alone (e.g. behavioural and cognitive dysfunction such as learning difficulties or poor impulse control and judgement).

Alcohol related birth defects (ARBD) are characterised by physical anomalies such as cardiac, skeletal or renal anomalies or sensory impairment. These include sensorineural hearing loss and eye anomalies which are known from animal models and/or humans to be associated with alcohol exposure (Stratton et al. 1996). The features of each are shown in Table 4.2.
Table 4.2. Fetal Alcohol Spectrum Disorders (Stratton et al. 1996)

<table>
<thead>
<tr>
<th>Diagnosis</th>
<th>Alcohol Exposure</th>
<th>Facial Anomalies</th>
<th>Growth Retardation</th>
<th>CNS Anomalies</th>
<th>Birth Defects</th>
</tr>
</thead>
<tbody>
<tr>
<td>FAS with confirmed alcohol exposure</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td></td>
</tr>
<tr>
<td>FAS without confirmed alcohol exposure</td>
<td>Unknown</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td></td>
</tr>
<tr>
<td>Partial FAS</td>
<td>✓</td>
<td>Some facial anomalies present</td>
<td>Need at least one of these categories</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Alcohol-related neurodevelopmental disorder (ARND)</td>
<td>✓</td>
<td>-</td>
<td>-</td>
<td>✓</td>
<td></td>
</tr>
<tr>
<td>Alcohol-related birth defects (ARBD)</td>
<td>✓</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>✓</td>
</tr>
</tbody>
</table>

Fetal Alcohol Effects (FAE) was a term used to describe children who had some but not all the features of Fetal Alcohol Syndrome. The criteria for FAE have not been delineated and the use of this term is not recommended (Sokol and Clarren 1989; Aase et al. 1995; Stratton et al. 1996).

Other diagnostic systems, such as the 4-Digit Diagnostic Code, use different terminology and criteria to describe children who do not have sufficient features to fulfil the diagnosis of FAS (Astley 2004). The 4-digit code enables objective description of the severity and mix of abnormalities seen in children with FASD (Table 4.3). The 4-Digit Diagnostic Code was developed at the University of Washington and a specialist diagnostic service was established (Astley 2010). Eleven percent of the first 1400 patients at the specialist clinic with confirmed prenatal alcohol exposure (newborn to adult) were diagnosed with FAS/pFAS, 28 percent with static encephalopathy, 52 percent with neurobehavioral disorder, and 9 percent with no evidence of CNS abnormality (Astley 2010). FASD outcomes varied significantly by age, race, gender, alcohol exposure, and presence of other risk factors. These results suggest the range of diagnosis that may be seen within a clinical group. Demand for the diagnostic service was reportedly high (Astley 2010).

It is important to note that diagnosis is particularly problematic for disorders in the FASD spectrum in which characteristic facial abnormalities are not seen, as none of the other characteristic problems (such as growth restriction, CNS abnormalities) are unique to FASD and are often associated with factors such as low SES and poor maternal nutrition (O’Leary 2004). Studies estimating prevalence should therefore control carefully for confounders.

Table 4.3 Example of use of the 4-digit diagnostic code (Astley 2004)
In Australia, a challenge for health professionals is agreement on a model for diagnosing FASD. It is suggested that the diagnostic method must be evidence based, sensitive and specific, and account for other exposures during pregnancy and early life events. Training in the diagnostic method needs to be readily available in both metropolitan and regional Australia. A uniform diagnostic capacity, agreed and applicable across Australia, would assist in identifying opportunities for intervention, prevention and treatment for FASD. This is discussed in more detail in Chapter 9.

4.1.3 Neurocognitive differences between FAS and other FASD
Clinic based studies involving neuropsychological testing show that performance of children with ARND is similar to children with FAS and different from normal controls (Mattson and Riley 1998). Recently, Chasnoff and colleagues examined the neurodevelopmental profiles of children with FAS, pFAS, or ARND and found that children who met tightly defined physical criteria for a diagnosis of FAS demonstrated significantly poorer neurodevelopmental functioning than children with pFAS and ARND. Children with pFAS and ARND were similar in all neurodevelopmental domains that were tested (Chasnoff et al. 2010).

4.1.4 Effects of alcohol on pregnancy outcomes and the health of the neonate
Prenatal alcohol exposure also increases the risk of a number of adverse pregnancy outcomes that are not classified as FASD. Children born to mothers with alcohol-related problems are at increased risk of pre-term delivery, perinatal death, having an Apgar at five minutes of less than seven, being transferred to special care nursery and having a significantly longer hospital stay than infants born to women without these diagnosis (Olegard et al. 1979; Little et al. 1990; Burns et al. 2006; O’Leary et al. 2009; Astley 2010). The risk of mortality in the offspring is also increased following heavy maternal alcohol consumption including stillbirth (Kesmodel et al. 2002; Aliyu et al. 2008; Strandberg-Larsen et al. 2008; O’Leary et al. 2012) and infant mortality (Kesmodel et al. 2002; Strandberg-Larsen K 2009). Children of mothers with an alcohol-use disorder have a three-fold increased risk of pre/perinatal cerebral palsy, although the fraction of pre/perinatal cases of cerebral palsy attributable to prenatal alcohol exposure is low at 0.25 percent (O’Leary et al. 2012).

4.1.5 Long-term effects of FASD: Secondary disabilities
Many of the adverse effects from alcohol consumption in pregnancy persist over time and result in significant challenges in adulthood. Prospective longitudinal studies have reported a range of adverse life outcomes including disrupted education and persistent behavioural and mental health problems (Streissguth et al. 2004; Sayal 2007; Spohr et al. 2007; Sayal et al. 2009; O'Leary et al. 2010; Robinson et al. 2010) Individuals with FASD are at increased risk of problems in adulthood classified as ‘secondary disabilities’ (Streissguth and O'Malley 1997; Clark et al. 2004; Streissguth et al. 2004). These secondary disabilities are thought to occur through interaction between environmental risk and protective factors and FASD impairments such as neurodevelopmental and mental health problems (Steinhausen and Spohr 1998; Clark et al. 2004). Adaptive functioning has been identified as a key predictor of the development of secondary disabilities with better outcomes for individuals with high adaptive functioning (Clark et al. 2004). Risk factors for secondary disabilities include disrupted family life and exposure to violence, while living with a foster caregiver is a significant protective factor.

Secondary disabilities include:
- Mental health problems including anxiety and depression (Famy et al. 1998; Streissguth et al. 2004; Barr et al. 2006; Sayal 2007; Hellemans et al. 2010);
- Vulnerability to substance use disorders (Yates et al. 1998; Baer et al. 2003; Alati et al. 2006);
• Vulnerability to manipulation (Streissguth 2007);
• Suicide (O'Malley and Huggins 2005);
• Inappropriate sexual behaviour (Streissguth et al. 2004);
• Educational and employment difficulties (Clark et al. 2004; Spohr et al. 2007);
• Requiring supported living (Clark et al. 2004);
• Parenting problems (Clark et al. 2004); and
• Trouble with the law and incarceration (Streissguth et al. 2004).

Streissguth and colleagues examined the relationship between personal and environmental characteristics and adverse life outcomes in an American cohort of 415 subjects, aged six to 51 years, with FAS or FAE (Streissguth et al. 2004). The median age at follow-up was 14 years and the median age at diagnosis was 10 years. Inappropriate sexual behaviours were the most frequently reported adverse life outcomes and the prevalence increased with age (39 percent in children to 52 percent in adults). Fourteen percent of school children and 61 percent of adolescents and adults with FAS/FAE reported experiencing disrupted schooling; 53 percent of adolescents had been suspended, 29 percent expelled and 25 percent dropped out of school. Learning, behavioural and social problems were common at school. Trouble with the law was reported for 60 percent of adults, including shoplifting, theft, assault, burglary and domestic violence. Half of adolescents and adults had been confined, 35 percent gaol; 23 percent admitted for psychiatric problems; and 15 percent admitted for drug and alcohol treatment. Drug and alcohol problems were present in 29 percent of adolescents and 46 percent of adults. A stable, nurturing home environment and early age of diagnosis were protective for the adverse life outcomes. Inappropriate sexual behaviours and substance use problems were more common in participants who had been the victims of abuse or domestic violence. Adults with FAE had similar outcomes to those who had FAS. This study had a large sample size and adjusted for some potential confounders including family environment, giving weight to its findings; however, it used superseded diagnostic criteria.

Spohr et al. have reported findings from a 20-year follow-up of a German cohort of individuals with FAS and FAE (Spohr et al. 2007). Thirty-seven of fifty-two participants (71 percent) took part in the 20-year follow-up and the average age at re-assessment was 23 years. Facial features were much less marked, although long philtrums and thin upper lips were still prominent findings. Microcephaly persisted in 17 (46 percent) and this finding was associated with intellectual disability. Many individuals exhibited catch-up growth; however, 35 percent had a height below the third percentile and 24 percent had a weight below the third percentile. Almost half (49 percent) had received only special education; 38 percent completed primary school and 13 percent had a secondary school education. Thirteen percent had held ordinary jobs, although 69 percent had received some job training. A mismatch between abilities and skill requirements was identified as an obstacle to completing job training. Twenty-seven percent lived in institutions, 35 percent lived in a dependent-living situation with assistance from others, 30 percent lived independently and eight percent lived with a parent. Emotional and behavioural problems reported included attention problems, thought problems and aggressive and intrusive behaviours. These were independent of cognitive ability and did not differ between individuals with FAS and FAE. There was a strong persistence of attention and aggression problems from childhood, while intrusive behaviours and thought problems were emerging issues. The protective factors identified in Streissguth et al. were present in this sample but did not mediate outcomes (Streissguth et al. 2004). Limitations of this study include the use of superseded diagnostic criteria, a small sample size with 29 percent lost to follow-up and lack of adjustment for confounders such as the family environment.
It is difficult in these studies to disentangle potential contributors to adverse life outcomes. For example, disrupted school education is likely to lead to employment difficulties regardless of FASD. However, these studies consistently report difficult life trajectories which are not explained by IQ alone and are not confined to individuals with FAS as they are reported across the spectrum of FASD. The risk of these adverse life outcomes, described as the secondary disabilities or outcomes of alcohol exposure in utero, may be modified by environmental factors such as early diagnosis and by experiencing a stable and nurturing home environment (Streissguth et al. 2004).

4.2 Patterns of maternal alcohol consumption and risk to the fetus

It is generally accepted that the principal determinant of functional deficit is the dose and frequency of alcohol consumption but alcohol dependence is not required for alcohol-related problems to occur in the prenatally exposed child (Jacobson and Jacobson 1999). Expression of the full clinical features of FAS results from large amounts of alcohol consumed during early pregnancy. The mothers often have a history of either chronic heavy alcohol use or frequent intermittent heavy alcohol use.

It is important to recognize that not all children exposed to high levels of alcohol in utero will be negatively affected or affected to the same degree, indicating that expression of the anomalies requires the presence of other ‘component’ factors. A number of component factors have been identified, including the pattern and quantity of alcohol, the stage of development of the fetus at the time of exposure (the first 3-6 weeks of embryonic development identified as a critical time for the full teratogenic effects to occur) and socio-behavioural risk factors such as poverty, smoking, maternal age of 30 years or more and increasing parity (O'Leary 2004).

The lack of a universally accepted definition for a standard drink adds a level of complexity when comparing studies across countries. For instance, in the UK the term ‘unit’ is used rather than standard drink and reflects 8 grams of alcohol. A standard drink is 10 g alcohol in Australia, France, Hungary, Ireland, New Zealand, Poland and Spain; it is 12 g in Denmark, Italy and South Africa; 13.6 g in Canada; and 14 g in the USA and Portugal. To further complicate our ability to compare studies is the variation in the definition of ‘binge’ drinking according to the study. The conventional definition of binge drinking for women is five or more standard drinks per occasion, equating to 50 g or more per occasion (Strandberg-Larsen et al. 2008; O'Leary and Bower 2009). However, a UK study defined binge drinking as four or more UK units per occasion (32 g or more) (Sayal et al. 2009), equivalent to three Australian standard drinks or higher.

4.2.1 Binge drinking and risk to the fetus

A weekly binge pattern of alcohol consumption (5+ drinks/occasion) during pregnancy is reported to contribute 80 percent of functionally impaired infants (Jacobson and Jacobson 1999). However, a systematic review of the research on binge drinking and fetal outcomes found no convincing evidence of adverse effects, except possibly in relation to neurodevelopment (Gray and Henderson 2006; Henderson et al. 2007). However, these authors noted that methodological issues (discussed in section 5.3) precluded them from determining the impact on the fetus from occasional binge drinking.

Since the systematic review by Henderson et al. (Henderson et al. 2007), there have been a number of studies to support an increased risk to the fetus from exposure to a binge pattern of
alcohol consumption. Studies using the conventional definition of binge drinking (5+ drinks/occasion) have demonstrated increased risk of stillbirth (Strandberg-Larsen et al. 2008) and language delay following occasional (weekly or less frequently) binge drinking in late pregnancy (O'Leary et al. 2009). Increased risk of hyperactivity and inattention were reported in a UK study following four or more UK units per occasion during pregnancy (Sayal et al. 2009). An Australian study found increased risk of anxiety/depression and aggressive behaviour following prenatal exposure to 3-4 standard drinks/occasion and no more than 70g/week (i.e. one to two drinking sessions per week). However, this pattern of drinking was defined as ‘moderate’ drinking in the Australian study (O'Leary et al. 2010).

4.2.2 Effects of low to moderate alcohol exposure in pregnancy

In contrast to the evidence of increased risk of fetal effects and poor pregnancy outcomes from heavy prenatal alcohol exposure, the effect from low to moderate levels of prenatal alcohol exposure remains unclear. Debate about the exact nature of the relationship between prenatal alcohol exposure and fetal effects is ongoing (Nathanson et al. 2007; O'Brien 2007). Whether there is a threshold effect below which there is no harm to the developing child is yet to be fully determined (Henderson et al. 2007; O'Leary and Bower 2011; Andersen et al. 2012).

A number of reviews of the literature on alcohol use and pregnancy outcomes have been conducted and are summarised in Table 4.4. Most research findings do not support a relationship between low levels of alcohol consumption and fetal growth abnormality, preterm birth, stillbirth, malformations, abnormal neurodevelopment and leukaemia.

The exception relates to an increase in risk of spontaneous abortion/miscarriage reported by both the Makarechian and the Henderson reviews (Makarechian et al. 1998; Henderson et al. 2007). Henderson, however, cautions about this finding as two of the five studies that showed an increased risk due to alcohol use had significant limitations. In one of these studies the women were also heavy smokers and the results of two of the studies were only of borderline statistical significance (Henderson et al. 2007). However, a large cohort study published after the Henderson review found that even 2–3½ alcoholic drinks per week during early pregnancy increased the risk of spontaneous abortion, indicating that the fetus is particularly susceptible to alcohol exposure in early pregnancy. The authors found no increased risk of fetal death after 16 weeks of pregnancy at low levels of exposure (Andersen et al. 2012). Moderate levels of prenatal alcohol exposure have also been reported to increase the risk of neonatal asphyxia (defined as 2-4 drinks per week) (Meyer-Leu et al. 2011) and infant mortality (an average of 4+ drinks per week).

A number of other epidemiological studies examining the relationship between the pattern of maternal drinking and fetal effects have been published between 2009 and 2011, after the reviews documented in Table 4.4 (O'Leary and Bower 2011). The studies are from a range of countries including Australia, the USA, the UK, Ireland and one from Denmark. As with the evidence from the systematic reviews, there is no strong evidence to support an increased risk to the fetus from low levels of prenatal alcohol exposure (O'Leary and Bower 2011). Further research and new techniques investigating the effect of low levels of prenatal alcohol exposure are required.
### Table 4.4: Systematic reviews and meta analyses of the literature on alcohol and pregnancy

<table>
<thead>
<tr>
<th>Authors</th>
<th>Number of studies included</th>
<th>Outcomes</th>
<th>Reference Group</th>
<th>Alcohol Categories</th>
<th>Results</th>
</tr>
</thead>
<tbody>
<tr>
<td>Abel and Hannigan (1995)</td>
<td>Not specified</td>
<td>Low birth weight and/or prematurity</td>
<td>Abstainers</td>
<td>Average drinks per day; 6 categories: 0, &gt;0 and &lt;0.5, 0.5-1, 1.5-2, 2-3</td>
<td>Evidence of a threshold relationship with a decrease in birth weight following an average of 2 or more drinks per day</td>
</tr>
<tr>
<td>Polygenis et al. (1998)</td>
<td>7</td>
<td>Malformations</td>
<td>2 or less drinks per week</td>
<td>More than 2 drinks per week to 2 drinks per day (24-168 g per week)</td>
<td>N/S</td>
</tr>
<tr>
<td>Makarechian et al. (1998)</td>
<td>8</td>
<td>Spontaneous abortion, stillbirth, premature birth</td>
<td>2 or less drinks per week</td>
<td>More than 2 drinks per week to 2 drinks per day (20-140 g per week)</td>
<td>Spontaneous Abortion§, Stillbirth§*, N/S Premature Birth</td>
</tr>
<tr>
<td>Testa et al. (2003)</td>
<td>9</td>
<td>Infant Development (BSID MDI)</td>
<td>Abstainers</td>
<td>Less than 1 drink per day ** 1-1.99 drinks per day 2+ drinks per day</td>
<td>USA studies N/S, less than 1 drink per day European studies Protective less than 1 drink per day N/S less than 1 drink per day</td>
</tr>
<tr>
<td>Gray and Henderson (2006); Henderson et al. (2007)</td>
<td>Number of studies included varied by outcome</td>
<td>Miscarriage (8 studies), Stillbirth (5 studies), Growth (7 studies), Birthweight (19 studies), Preterm Birth (16 studies), Malformations (6 studies), Neurodevelopment (7 studies)</td>
<td>Abstainer OR infrequent drinker (Less than 6g per week)</td>
<td>Up to 12g per day (Less than 84g per week)</td>
<td>Miscarriage 5 of 8 studies§, Stillbirth N/S Others each had only one study reporting significant § Some findings indicated a protective effect</td>
</tr>
<tr>
<td>Swedish National Institute of Public Health (Holmgren 2009)</td>
<td>6</td>
<td>Cognitive and socio-emotional development</td>
<td>Abstainer or infrequent drinker</td>
<td>Low to moderate -1-4 glasses per week (12-48 g); &lt;1 glass per week; binge and max per occasion</td>
<td>Moderate prenatal exposure (approx &lt;1/2 drink per day) reduced attention, &lt;1 glass per week associated with high total strengths and difficulties scores in girls but not higher doses.</td>
</tr>
<tr>
<td>Number of studies included</td>
<td>Outcomes</td>
<td>Reference Group</td>
<td>Alcohol Categories</td>
<td>Results</td>
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<tr>
<td>Dolan et al. (2010)</td>
<td>14</td>
<td>Attention – cognitive performance task</td>
<td>Abstainers or infrequent drinkers (&lt; 3 drinks per week)</td>
<td>No specific component of CPT consistently associated with prenatal alcohol exposure. Trends indicate more commission and omission errors in exposed than comparison group.</td>
<td></td>
</tr>
<tr>
<td>Latino-Martel et al. (2010)</td>
<td>19 total, 9 with dose ranging from 0.5 drinks per week to &gt;7 drinks per week</td>
<td>Leukaemia- acute lymphoblastic leukaemia (ALL); acute myeloid leukaemia (AML)</td>
<td>Abstainers</td>
<td>No increased odds of ALL. Increased odds of AML in: i) analysis of binary exposure, ii) analyses restricted to AML diagnosed 0-4 years iii) with increased odds with an increase of one drink per week.</td>
<td></td>
</tr>
<tr>
<td>Patra et al. (2011)</td>
<td>36 total, 24 with dose – response information. Number of studies included varied by outcome.</td>
<td>Low birthweight (28 studies) Preterm birth (21 studies) Small for gestational age (11 studies)</td>
<td>Abstainers</td>
<td>No effect for low birthweight and SGA up to an average of 10/g per day (approx 1 drink). No effect for preterm birth up to an average of 18g/day (approx 1.5 drinks), thereafter increasing risk.</td>
<td></td>
</tr>
<tr>
<td>Odendaal et al. (2009)</td>
<td>13 total, 3 with combined effect of alcohol and tobacco</td>
<td>Preterm birth (4 studies alcohol alone, 1 combined effect of alcohol and tobacco) Low birthweight (2 combined effect of alcohol and tobacco)</td>
<td>Abstainers</td>
<td>Increased odds of preterm labour among women who smoked and drank. This was more than the sum of the effects of either smoking or drinking.</td>
<td></td>
</tr>
</tbody>
</table>


§ Significant results

*The authors suggest that while the significant decrease may either be due to a true beneficial effect of alcohol or it may be a result of the ‘healthy drinker effect’ in which women with a poor obstetric history are more likely to abstain from drinking alcohol

**Quantity of alcohol for a standard drink is not mentioned

N/S non significant.
4.3 Methodological Limitations of the Evidence

Many studies of FAS, FASD, and alcohol and pregnancy more generally, are limited by small sample size, retrospective collection of potential confounders and use of different diagnostic criteria, all of which impede comparison between studies. The methodology varies between studies and findings need to be interpreted with caution due to issues of bias and confounding. Issues of selection bias (e.g. case control studies often rely on clinical samples to select cases), bias in relation to reporting of alcohol consumption need to be considered (Sayal 2007), and loss-to-follow-up in longitudinal studies.

The most recent examination of systematic reviews, meta-analyses and new articles suggest that the reported significant effects from low levels of prenatal alcohol exposure are likely to be due to methodological issues such as confounding or misclassification of the exposure or outcome (O'Leary and Bower 2011). Of the large body of research that has been conducted on the impact of low levels of alcohol during pregnancy there are fewer than thirty papers for any outcome and most outcomes have fewer than ten eligible studies that meet the stringent inclusion criteria used in a systematic review. This is due to a range of factors such as:

- inadequate reporting of raw data
- inadequate blinding to case/control status
- inadequate delineation of alcohol consumption
- lack of a control group that was not exposed to alcohol (although some systematic reviews have included studies with infrequent drinkers in the reference group as shown in Table 4.4)
- the timing of questions about maternal alcohol consumption (antenatal versus postnatal data collection)
- failure to define the trimester(s) in which drinking took place.

Higher quality studies used validated questionnaires, ascertained maternal alcohol consumption in the antenatal period, and asked about alcohol consumption in specific time periods including prior to pregnancy recognition (Henderson et al. 2007).

There is some evidence that the lack of consistency in research findings across countries may be due to differences in the patterns of drinking during pregnancy and the quantity of alcohol consumed at each occasion (Testa et al. 2003; Henderson et al. 2007). Henderson et al. also question whether the findings from the USA, where the majority of the studies have been conducted, can be generalised to other countries where there may be differences in the extent to which alcohol use in pregnancy is under-reported and in the ascertainment of outcomes (Henderson et al. 2007).

The issue of misclassification of the dose or pattern of exposure can be addressed by a ‘composite’ classification method which considers the dose, pattern and timing of maternal alcohol consumption. A recent study compared traditional methods of classifying prenatal alcohol exposure, such as averaging alcohol consumption, with the ‘composite’ method (O'Leary et al. 2010). This study found that the traditional methods lacked discrimination and resulted in some women who reported drinking at binge and heavy levels to be classified as low to moderate drinkers and vice versa. Using the composite method the lowest level of alcohol consumption to increase fetal effects was an increased odds of child behaviour problems following moderate
alcohol exposure (30-40g per occasion and no more than 70g per week) (O'Leary et al. 2010). This finding was completely masked by the traditional methods of classification (O'Leary et al. 2010). It is therefore critical for future studies to consider the dose, pattern and timing of consumption.

Controlling for potential confounding factors is important when trying to elicit the independent effect of maternal alcohol consumption during pregnancy on child development. However, there is a lack of consistency in the adjustment for confounders across studies (Testa et al. 2003; Henderson et al. 2007). Some studies have not adjusted for factors well known to be confounders such as smoking, low socioeconomic status and ethnicity and this may have resulted in residual confounding (Henderson et al. 2007). The impact of residual confounding is well demonstrated by the findings of the systematic review by Testa et al., which showed that at the 12-13 month assessment there was a negative effect from prenatal alcohol exposure prior to adjustment for known confounders and a lessening of the effect following adjustment. Other studies have over adjusted by controlling for previous malformations or miscarriages which may have been associated with alcohol exposure leading Testa et al. to recommend an ‘a priori selection’ of confounding factors.

4.4 Summary

Despite more than 40 years of research into this area, there remains confusion about the relationship between alcohol and fetal harm. Debate continues around whether this relationship is linear or whether there is a threshold effect below which there is no harm to the developing child. The lack of clarity in the published literature and the lack of consensus about whether there is a safe level of alcohol consumption has been reflected in the policies and guidelines across Australia and other English speaking countries (O'Leary et al. 2007).

There is sufficient evidence to show that chronic heavy alcohol use or frequent intermittent heavy alcohol use during pregnancy increases the risk of FASD (Jacobson et al. 1993; Mattson and Riley 1998; Jacobson and Jacobson 1999; DeRoo et al. 2008). The most recent research suggests that there is no strong evidence to implicate low levels of prenatal alcohol exposure with fetal harm. However, as recent studies have shown increased risk of neurodevelopmental problems (Sayal et al. 2009; O'Leary et al. 2010) and preterm birth (O’Leary and Bower 2011) following exposure of as little as 30-40g per occasion and 70g per week, there is at most only a small margin before there is increased risk (O'Leary and Bower 2011). The conservative approach is therefore to recommend that women abstain from alcohol during pregnancy. This abstinence message should be presented in a balanced and rational format.

With the high rate of drinking and binge drinking among young Australian women of child bearing age including during pregnancy and the high rate of unplanned pregnancies in Australia, we need to ensure that we have a sound evidence base (Koren 1996; Australian National Council on Drugs 2003; O'Callaghan et al. 2003; White and Hayman 2004; Colvin et al. 2007; Todorow et al. 2010). This will enable policy makers and health professionals to provide consistent and accurate advice without generating unnecessary fear or guilt, which may lead a woman to seek a termination of pregnancy when the absolute risk to the fetus is likely to be been small.
Rosett and Weiner (1982) clearly pointed out more than two decades ago that there were many unanswered questions about dose and timing of fetal alcohol exposure, most of which remain unanswered today. They argued that the most conservative policy is to recommend abstinence (Rosett and Weiner 1982). They also state, however, that it is important not to exaggerate the danger from light drinking, which they defined as less than two standard drinks per day, since ‘exaggeration will decrease credibility concerning the established adverse effects of heavy drinking’.
Key points

- Fetal exposure to alcohol during pregnancy increases the risk of a range of poor outcomes, which are classified under the umbrella term ‘Fetal Alcohol Spectrum Disorders’ (FASD). FASD comprises a number of diagnostic categories including Fetal Alcohol Syndrome (FAS), partial FAS (pFAS), Fetal Alcohol Effects (FAE), Alcohol Related Birth Defects (ARBD), and Alcohol Related Neurodevelopmental Disorders (ARND).
- A number of diagnostic approaches have been used to classify FASD. A uniform diagnostic capacity, agreed and applicable across Australia, would assist in identifying opportunities for intervention, prevention and treatment for FASD.
- Secondary outcomes such as behavioural and mental health problems, alcohol and drug problems, disrupted school education and trouble with the law are among the long-term sequelae for adults with FASD. These secondary disabilities may be ameliorated by protective factors including early diagnosis and treatment.
- The effect from low levels of prenatal alcohol exposure is unclear and controversy remains. Further research and new techniques are required.
- The lack of evidence regarding a safe level of alcohol use leads many policies to recommend abstinence or that avoiding alcohol is the safest choice. Messages about low level drinking need to be credible and well disseminated if they are to be effective and should not exaggerate the risk from low levels of alcohol use lest women seek a termination when the risk is small.
Chapter 5: Epidemiology of FASD

Lucy Burns, Carol Bower, Colleen O’Leary and Elizabeth Elliott

5.1 Challenges in monitoring the incidence and prevalence of FASD

A number of challenges exist in monitoring rates of Fetal Alcohol Spectrum Disorders (FASD). The diagnosis of FASD requires recognition of children at risk, knowledge of the diagnostic criteria and confirmation of the diagnosis. Even the diagnosis of Fetal Alcohol Syndrome (FAS), the most visible condition in the spectrum in which there are characteristic facial features, is often missed. Facial abnormalities may not be recognised at birth, are most distinct in early childhood and may become less obvious in adolescents and adults. By definition, children with ARND or ARBD do not have all the characteristic facial features of FAS, making diagnosis more difficult than FAS. Furthermore, the behavioural and developmental problems associated with these diagnoses may not manifest until primary school age. Because data on maternal alcohol consumption during pregnancy are not routinely collected in Australia, there is the added difficulty of linking prenatal alcohol exposure with symptoms of ARND in the clinical setting or establishing a causal relationship. There are documented barriers to health professionals making the diagnosis of FAS, including lack of knowledge of the diagnostic criteria and reluctance to make the diagnosis of FAS/D for fear of stigmatising the mother, child and/or family (Payne et al. 2005; Elliott et al. 2006). Health professionals also express lack of confidence to manage with a child with FAS; lack of knowledge about where to refer children for confirmation of the diagnosis and management; and lack of proof of effective interventions (Payne et al. 2005; Elliott et al. 2006). Given these difficulties, it is important to use multiple datasets to provide more robust prevalence data wherever possible. To make a diagnosis of FASD, all children require a full developmental, physical, neuropsychological, language, hearing and visual assessment to identify their strengths and functional problems and inform referral for specialised intervention.

There are a number of ways in which the incidence and prevalence of FASD can be monitored. May and Gossage identified three main methods that have been used to determine the prevalence of FAS, Alcohol-Related Birth Defects (ARBD) and Alcohol-Related Neurodevelopmental Disorder (ARND): clinic-based studies (the most common method); passive systems; and active case ascertainment (May and Gossage 2001).

Clinic-Based Studies

Clinic-based studies are generally conducted in prenatal clinics of large hospitals where information is collected from pregnant women about their alcohol use. This may involve use of standard screening instruments and collection of biological specimens during pregnancy and some studies collect data at multiple time points. There are numerous standardised measures of alcohol use and evidence suggests the T-ACE (Tolerance, Annoyed, Cut Down, Eye Opener) (Sokol et al. 1989) and the TWEAK (Tolerance, Worry, Eye Opener, Amnesia, Cut Down) (Russell 1994) are most successful in identifying alcohol dependent women who may benefit from alcohol treatment interventions during pregnancy (Sokol et al. 1989; Russell 1994; Chudley et al. 2005). The AUDIT (Alcohol Use Disorders Identification Test), was not specifically developed to screen for drinking in pregnancy but includes questions related to frequency, quantity and binge drinking (Saunders et al. 1993). The AUDIT-C (a
shorter version of the AUDIT that includes the three consumption questions) has been validated in pregnant women in the US but not in Australia (Dawson et al. 2005).

A recent systematic review of prenatal screening instruments to identify high risk drinking in pregnancy estimated that the TWEAK, T-ACE and AUDIT-C had the highest sensitivity in detecting risky drinking (Burns et al. 2010). The higher sensitivity comes at a cost of lower specificity (i.e. more false positives), indicating that for every woman identified correctly, as many as three women could be identified as drinking at risky levels when they are not. As these screening tools focus on high alcohol intake they may miss women drinking at low to moderate risk levels. It can, however, be argued it is more important to detect risky drinkers in this population. A recent Australian study recommended use of validated instruments such as the AUDIT-C as a rapid screening in clinical practice to assist with assessment and management of alcohol consumption during pregnancy (Muggli et al. 2010).

Clinic-based studies have many advantages. Detailed maternal history data are collected (this can be done prospectively) and it is possible to study a large number of pregnancies involving various levels of alcohol exposure. However, there are also disadvantages. Firstly, women at highest risk for FAS children are less likely to attend prenatal clinics regularly, and many do not attend at all, making access to the very highest risk cases less likely. Secondly, many clinic-based studies have been carried out in publicly funded hospitals and clinics where disadvantaged populations pre-dominate. These studies may therefore overestimate the prevalence of FAS associated with disadvantage. Thirdly, since FAS is not generally diagnosed at birth, but between the ages of three and 12 years, these studies may further underestimate the prevalence of FAS in studies where women are not followed up long term (May and Gossage 2001).

Passive Surveillance Systems
Some passive surveillance systems use existing record or data collections in a particular geographical area over a particular timeframe. This method involves researchers defining a set of criteria for diagnosis of FAS, ARBD or ARND and then looking for documented or probable cases of children born with the diagnosis. Records reviewed generally include: birth certificates, special registries for children with developmental disabilities or birth defects, and/or the medical charts of hospitals and physicians. Passive surveillance studies often use multiple types of records to identify as many cases as possible, since a case of FAS is often documented in more than one place over time. The major advantage of the passive method is that it uses existing records and it is therefore relatively inexpensive and easier to undertake than more time-intensive methods. The disadvantages are that FAS involves multiple indicators of physiology, development and behaviour, many of which are not obvious, or are at least difficult to identify at particular ages. Consequently the information required to make a diagnosis may not be recorded on these data systems, or may not be identified as related to prenatal alcohol exposure (May and Gossage 2001). Other passive surveillance systems rely on reporting of cases with pre-defined inclusion criteria by particular groups e.g. clinicians or midwives to particular databases e.g. birth defects registers in Australia. Data may be collected prospectively in this way but case ascertainment is lower than with active methods of ascertainment, even if reporting is mandatory.

Active Case Ascertainment Methods
One approach to active case ascertainment is to identify and recruit children with a possible diagnosis of FAS from large populations. Once identified, children are examined to determine the final diagnosis. In some studies, the children’s mothers are also recruited to collect information about maternal behaviour and risk factors. This type of active case
ascertainment methods has at least three advantages. Firstly, the primary focus is on finding children with FAS at an age at which an accurate diagnosis can be made by clinical specialists. Secondly, the active and intense methods of recruitment mean a higher possibility of identifying children with FAS. Thirdly, by studying total populations, bias is reduced. Active case ascertainment therefore produces the most complete assessment of the prevalence and characteristics of FAS in a particular population. However, this method of research is very labour intensive, time consuming, and costly. Furthermore, access to particular populations may be selective and, frequently, only high-risk populations where FAS is more common have been studied using these methods. In this situation the prevalence of FAS may be overestimated (May and Gossage 2001). Another approach to active case identification is to target specialist groups, such as paediatricians and geneticists, who are likely to make the diagnosis of FASD and to use a reminder mechanism to prompt central notification of new cases on a regular basis. This method has been used nationally by the APSU to identify cases of FAS seen by paediatricians. This type of system provides timely, detailed, clinical data from which a minimum incidence rate can be estimated in the population of children seen by these health professionals.

5.2 International prevalence data

The birth prevalence of FAS is high in some Indigenous populations with the highest reported prevalence from South Africa (Table 5.1). In the Western Cape studies, active ascertainment was used to identify cases in a high-risk South African community via examination of all children in the first year of school. The reported prevalence in the initial investigation was between 39 and 43 per 1,000 children aged five to nine years (May et al. 2000). When the study was repeated in the same community five years later, results indicated an alarming rise in the FAS prevalence to between 65 and 74 cases per 1,000 (Viljoen et al. 2005). Higher prevalence has been reported in a recent study in the Northern Cape province of South Africa involving year one school children in two large towns whose parents consented (Urban et al. 2008). The study screened 1830 children, although the participation rate was not reported. The estimated prevalence of FAS and partial FAS was 119.4 children per 1000 (95% CI 93.2-149.9) and 74.7 per 100 children (95% CI 61.0-93.3) for the two towns, respectively. The study used a two tiered screening and diagnostic method and utilised the Institute of Medicine (IOM) diagnostic criteria.

Active ascertainment has also been applied to school children in Italy, demonstrating high rates of FAS and related diagnoses (May et al. 2006). The prevalence of FAS in a province of Italy was 4 to 7 per 1,000 children and the rate of FASD was 20 to 41 per 1,000 or between two percent and four percent of all children. Similar to the South African data, a more recent study in Italy found prevalence rates substantially higher than previous estimates. In two wave study with 48% and 50% participation rates, the prevalence of FAS was reportedly between 4.0 to 12.0 per 1,000 children, partial FAS ranges from 18.1 to 46.3 per 1,000 children and the rate of FASD was between 2.3 percent and 6.3 percent of all children (May et al. 2011). Dysmorphology scores were highly correlated with drinks per current drinking day and current drinks per month.

A recent study of Croatian school students in years one to four reported an estimated prevalence of 6.44 per 1000 children for FAS and 34.33 per 1000 children for partial FAS. The estimates were based on 466 children and a 51% participation rate. The revised Institute of Medicine (IOM) diagnostic criteria was used for diagnosis (Petkovic and Barisic 2010).
5.3 Monitoring FAS in Australia

One method used to monitor FAS in Australia is through Birth Defects Registers in Victoria, South Australia and Western Australia. These registers are population based, passive surveillance systems established to monitor birth defects detected during pregnancy or at birth or diagnosed in infants up to a certain age. Birth defects are defined as alcohol-related if identified as such by the contributing clinician. However, because contributors are asked to report birth defects rather than syndromes by some registers, and as information on maternal alcohol consumption during pregnancy is not routinely collected, it is likely that there is under-ascertainment of FAS.

FAS was studied between 2001 and 2004 by the Australian Paediatric Surveillance Unit (APSU), a national resource established in 1993 to facilitate active, national surveillance of selected uncommon childhood diseases, with monthly reporting of incident cases by child health specialists. The diseases investigated are chosen for their public health significance and impact on health resources.

Currently a population based study using active case ascertainment is being conducted to estimate FASD prevalence in primary school aged children in the remote high risk setting of the Fitzroy Valley, WA (Australian Human Rights Commission 2011; Fitzpatrick et al. 2012). The study, Marulu: The Litilwan Project, was initiated by the Fitzroy Valley community. This project is a collaboration between Nindilingarri Cultural Health Service and Marninwarntikura Women’s Resource Centre in the Fitzroy Valley and the George Institute for International Health and the Discipline of Paediatrics and Child Health at University of Sydney. It involves assessment of exposure to alcohol in a cohort and utilises the expertise of a multidisciplinary team (including paediatricians, allied health professionals and psychologists) to perform health and development assessments on children and exclude or allocate a diagnosis of FASD (Elliott et al. 2012; Fitzpatrick et al. 2012).

5.4 Incidence and birth prevalence in Australia

The first estimate of the birth prevalence of FAS in Australia was by Bower et al. who demonstrated the importance of using multiple data sources to increase ascertainment (Bower et al. 2000). When the authors linked the Birth Defects Registry (BDR) and the Rural Paediatric Service database in Western Australia they found the birth prevalence of FAS increased by 38 percent from that estimated from the BDR alone, giving a rate of 0.02 per 1,000 live births for non-Indigenous children and 2.76 per 1,000 for Indigenous children (Bower et al. 2000) (Table 5.1).

Two subsequent studies estimated birth prevalence of FAS in Australia with both finding similar rates to those reported by Bower et al. (Table 5.1). In an passive ascertainment study, the medical charts of all children seen at the Royal Darwin Hospital in the Northern Territory over a 10 year period were reviewed to identify children with FAS and partial FAS (Harris and Bucens 2003). All children identified were Indigenous children. The estimated birth prevalence of FAS was 1.9 per 1000 Indigenous live births and of FAS plus partial FAS was 4.7 per 1000 Indigenous live births. The birth prevalence of FAS for the population overall was 0.68 per 1000 live births and the birth prevalence of FAS plus partial FAS for the population overall was 1.7 per 1000 live births.

In Victoria, estimates of birth prevalence for FAS were calculated using linked data from two passive surveillance systems, the Victorian Perinatal Data Collection and the Victorian Birth
Defects Register (Allen et al. 2007). Findings suggested a birth prevalence for FAS of 0.01 to 0.03 per 1000 live births in the general population and no Indigenous cases of FAS were identified.

In a third study, national incidence and birth prevalence figures for FAS were estimated using the Australian Paediatric Surveillance Unit (APSU), an active surveillance system (Elliott et al. 2008). Data between January 2001 and December 2004 were examined. A total of 92 children with FAS were reported to the APSU between 2001 and 2004, of whom 53 percent were male, 35 percent were preterm (less than 37 weeks gestation), and 65 percent were of low birth weight (less than 2.5kg). Most (94 percent) had high risk exposure to alcohol in utero and over three-quarters (78 percent) had been exposed to one or more additional drugs, typically nicotine (six percent) or cannabis (25 percent). The median age at diagnosis was 3.3 years, with a range from newborn to 11.9 years. Almost two-thirds had been diagnosed by five years of age but only a small proportion (seven percent) was diagnosed at birth.

A range of physical abnormalities were reported among the 92 children with FAS reported to the APSU, including growth deficiency (five percent), microcephaly (53 percent) and central nervous system dysfunction (84 percent). Just under one-quarter (24 percent) had birth defects additional to the facial features required for the diagnosis and a small proportion had sensorineural deafness (five percent) and/or visual impairment (four percent). Behavioural, cognitive and emotional problems were reported in 84 percent of children. In terms of demographic characteristics, 65 percent of the children were Indigenous, half (51 percent) had a sibling with FAS; and only 40 percent lived with a biological parent. The estimated incidence of FAS (based on all 92 children) was also considerably higher in Indigenous than non-Indigenous children, despite the likelihood that many Indigenous communities are not served by the child health specialists who report to the APSU. The only incidence data on childhood FAS in Australia have come from this prospective national surveillance study (Elliott et al. 2008). The overall incidence was 0.58 per 10⁵ children aged less than 15 years (0.18 in non-Indigenous and 8.11 in Indigenous children), and 1.14 per 10⁵ children under 5 years (0.37 non-Indigenous and 14.60 in Indigenous children) per annum.

The overall birth prevalence (based on children born during the study period) was 0.06 per 1,000 live births (0.004 per 1,000 non-Indigenous children and 0.146 per 1,000 Indigenous children). As can be seen in Table 5.2, the birth prevalence figures are considerably lower than those reported from WA but higher than those reported from SA and Victoria. Although the rates of FAS are likely to have been underestimated in this study, these are the only prospective national data available on FAS throughout the world. The data highlight: the severity, complexity and impact of FAS; the need for effective strategies for prevention; and the need for education to facilitate earlier diagnosis, referral and reporting of cases.
Table 5.1 Prevalence of FAS and FASD in Australia and internationally

<table>
<thead>
<tr>
<th>Region</th>
<th>Study type</th>
<th>Outcome</th>
<th>Total Population</th>
<th>Non-Indigenous</th>
<th>Indigenous</th>
<th>African American</th>
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</thead>
<tbody>
<tr>
<td><strong>International</strong></td>
<td></td>
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<tr>
<td>Review of 35 studies 1973-92 <em>(Abel 1995)</em></td>
<td>Clinic-based studies</td>
<td>FAS</td>
<td>1.95</td>
<td>0.26</td>
<td>NA</td>
<td>2.29</td>
</tr>
<tr>
<td>Alaska 1977-92 <em>(Egeland et al. 1998)</em></td>
<td>Active case ascertainment: population-based</td>
<td>FAS</td>
<td>0.80</td>
<td>0.20</td>
<td>3.00</td>
<td></td>
</tr>
<tr>
<td><strong>Surveys of Cohorts of Primary School-Aged Children</strong></td>
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<tr>
<td>South Africa – SW Cape 2001 <em>(May et al. 2000)</em></td>
<td>Active case ascertainment: population-based</td>
<td>FAS</td>
<td>-</td>
<td>-</td>
<td>39.2 to 42.9</td>
<td></td>
</tr>
<tr>
<td>South Africa – SW Cape 2005 <em>(Viljoen et al. 2005)</em></td>
<td>Active case ascertainment: population-based</td>
<td>FAS</td>
<td>-</td>
<td>-</td>
<td>65.2 to 74.2</td>
<td></td>
</tr>
<tr>
<td>South Africa – Northern Cape 2001- 2002 <em>(Urban et al. 2008)</em></td>
<td>Active case ascertainment</td>
<td>FAS</td>
<td>67.2 (95% CI 56.2-79.7)</td>
<td>-</td>
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</tr>
<tr>
<td>-</td>
<td>FAS plus partial FAS</td>
<td>119.4 (95% CI 93.2-149.9) 74.7 (95% CI 56.2 - 79.7)</td>
<td>-</td>
<td>-</td>
<td>-</td>
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<tr>
<td>Italy <em>(May et al. 2006)</em></td>
<td>Active case ascertainment</td>
<td>FAS</td>
<td>3.7 to 7.4</td>
<td>-</td>
<td>-</td>
<td>-</td>
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<tr>
<td>-</td>
<td>FASD</td>
<td>20.3 to 40.5</td>
<td>-</td>
<td>-</td>
<td>-</td>
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<tr>
<td>Italy 2005-2007 <em>(May et al. 2011)</em></td>
<td>Active case ascertainment</td>
<td>FAS</td>
<td>4.0 to 12.0</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>-</td>
<td>FASD</td>
<td>23.1 to 62.6</td>
<td>-</td>
<td>-</td>
<td>-</td>
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<tr>
<td>USA Washington State 2001 <em>(Clarren et al. 2001)</em></td>
<td>Active case ascertainment</td>
<td>FAS</td>
<td>3.1</td>
<td>-</td>
<td>-</td>
<td>-</td>
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<tr>
<td>USA Western City Pilot 2007 <em>(May et al. 2009)</em></td>
<td>Active case ascertainment</td>
<td>FAS</td>
<td>1.4-2.5</td>
<td>-</td>
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<td>-</td>
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<tr>
<td>-</td>
<td>FASD</td>
<td>8.1-14.8</td>
<td>-</td>
<td>-</td>
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<tr>
<td>USA Western City Pilot 2008 <em>(May et al. 2009)</em></td>
<td>Active case ascertainment</td>
<td>FAS</td>
<td>6.4 - 11.3</td>
<td>-</td>
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<tr>
<td>-</td>
<td>FASD</td>
<td>7.7-13.5</td>
<td>-</td>
<td>-</td>
<td>-</td>
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<tr>
<td>Croatia <em>(Petkovic and Barisic 2010)</em></td>
<td>Active case ascertainment</td>
<td>FAS</td>
<td>6.44</td>
<td>Partial FAS</td>
<td>34.33</td>
<td>-</td>
</tr>
<tr>
<td>Region</td>
<td>Study type</td>
<td>Outcome</td>
<td>Total Population</td>
<td>Non-Indigenous</td>
<td>Indigenous</td>
<td>African American</td>
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</tr>
<tr>
<td>Western Australia</td>
<td>Passive surveillance: multiple sources of reports</td>
<td>FAS</td>
<td>0.18</td>
<td>0.02</td>
<td>2.76</td>
<td>-</td>
</tr>
<tr>
<td>Birth Defect Register plus Rural Paediatric Service 1980-1997 (Bower et al. 2000)</td>
<td>Passive surveillance: multiple sources of reports</td>
<td>FAS</td>
<td>0.4</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Western Australia</td>
<td>Passive surveillance: multiple sources of reports</td>
<td>FAS</td>
<td>0.68</td>
<td>-</td>
<td>1.87</td>
<td>-</td>
</tr>
<tr>
<td>Birth Defect Register (including Rural Paediatric Service) 2000-2004 (Bower et al. 2007)</td>
<td>Passive surveillance: retrospective medical case notes review</td>
<td>FAS plus partial FAS</td>
<td>1.7</td>
<td>-</td>
<td>4.70</td>
<td>-</td>
</tr>
<tr>
<td>Northern Territory</td>
<td>Passive surveillance: multiple sources of reports</td>
<td>FAS</td>
<td>0.01 to 0.03</td>
<td>0.01 to 0.03</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>(Harris and Bucens 2003)</td>
<td>Passive surveillance: retrospective medical case notes review</td>
<td>FAS</td>
<td>0.02</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Victorian Perinatal Data Collection and Birth Defects Register (Allen et al. 2007)</td>
<td>Passive surveillance: multiple sources</td>
<td>FAS</td>
<td>0.06</td>
<td>0.004</td>
<td>0.146</td>
<td>-</td>
</tr>
<tr>
<td>South Australian Birth Defects Register 1986-2005 (van Essen et al. 2008)</td>
<td>Passive surveillance</td>
<td>FAS</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Australian Paediatric Surveillance Unit (Elliott et al. 2008)</td>
<td>Active, prospective surveillance: reporting by child health specialists</td>
<td>FAS</td>
<td>-</td>
<td>-</td>
<td>-</td>
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</tr>
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</table>
Chapter 5: Epidemiology of FASD

The Western Australian Birth Defects Registry recorded 74 children born with FAS between 1980-2002 and notified by 2003 (Figure 5.2). Following a Royal Australian College of Physicians workshop on FAS held in May 2004, an additional nine cases were notified for children born 1980-2003, representing a 15 percent increase in birth prevalence. With increasing awareness of FAS resulting from several national research studies and educational seminars and a particular focus being placed in WA on alcohol and pregnancy in recent years, the birth prevalence has increased over time from 0.1 per 1000 in 1980-84 to 0.4 per 1000 for the five year period 2000-2004 (Bower et al. 2007). Variations in birth prevalence of FAS between SA, WA and the NT may reflect variations in case ascertainment, reporting mechanisms, health professional knowledge about FAS and willingness to make a diagnosis, access of populations to specialist paediatric services and/or true differences.

Figure 5.2: Birth prevalence of FASD in Western Australia 1980-2005

5.5 Potential for under-ascertainment of FASD in Australia

Studies in Australia have predominantly been based on passive surveillance systems, which have a number of limitations, particularly under-ascertainment (May and Gossage 2001). In addition to under-reporting of cases there may also be a lack of recognition and screening of children at risk from alcohol exposure. In the Victorian study, where estimates were based on cases identified from two such systems, the authors noted that inadequate documentation of maternal alcohol use limited their findings (Allen et al. 2007). In particular, there was no record of maternal alcohol use in either the antenatal or infant’s records in 28 percent of the audited population and 39 percent of the microcephalic cases (Allen et al. 2007). Recent Australian research has shown that fewer than half (45 percent) of health professionals surveyed (including Aboriginal health workers, allied health professionals, community nurses, general practitioners and obstetricians) routinely ask pregnant women about alcohol use during pregnancy and only 23 percent of paediatricians do so when taking a pregnancy history (Payne et al. 2005; Elliott et al. 2006). Routine assessment and recording of maternal alcohol use during pregnancy and examination of exposed infants is required before we can confidently estimate the true birth prevalence of FAS in Australia.
Under-diagnosis of FAS may also occur in infants whose mothers are known to have an alcohol-related problem (Little et al. 1990; Stoler and Holmes 1999). In a study by Stoler and Holmes, the medical records of 124 obstetric patients and their offspring were examined (Stoler and Holmes 1999). Sixty-one (49 percent) mothers attended a substance abuse obstetric clinic; however, only 19 (15 percent) of the medical records indicated that a health professional (paediatrician or nurse) had documented alcohol use by the mother during prenatal care. By contrast, the study investigators recorded alcohol use in 34 (27 percent) cases. None of the alcohol-exposed children had been diagnosed with FAS although one was noted to have possible fetal alcohol effects by a paediatrician. However, the study investigators identified two children with FAS and seven with FAE in whom the diagnosis had been missed. This illustrates the need for health professionals to have sufficient knowledge and diagnostic skills to identify children at risk and make the diagnosis.

Little et al. examined 40 infants of women known to have misused alcohol during pregnancy (defined as consumption of four or more alcoholic drinks per day) for signs of FAS or other alcohol-related harms (Little et al. 1990). Six infants of mothers who drank at least six drinks per day (n=15) were found to have FAS and eleven infants were diagnosed with FAE. Seventeen of the 40 infants had postnatal growth retardation and developmental problems. Although six infants in an unexposed control group had Intrauterine Growth Retardation (IUGR) none of these infants had evidence of either FAS or FAE. It was concerning that none of the infants diagnosed with FAS or FAE in this study had the diagnosis recorded in their medical records, although microcephaly was recorded in 13 medical records. In contrast, all of the infants with a diagnosis of IUGR recorded in the study had this notation in their medical record. These findings are consistent with Australian data in the Australian Paediatric Surveillance Unit (APSU) study: 13 (27 percent) of 92 children who met study criteria for FAS had microcephaly documented at birth (a further 22 children were noted to have microcephaly when diagnosed at a later stage). However, only six (seven percent) had the diagnosis of FAS made at birth (Elliott et al. 2008). Failure to record a diagnosis of an alcohol-related disorder may reflect fear by health professionals of stigmatising the patient and their family (Payne et al. 2005; Elliott et al. 2006).

The reported birth prevalence and incidence of FAS in Indigenous Australian children is much higher than for non-Indigenous children, a finding also reflected in a number of other Indigenous populations (May 1991; Stratton et al. 1996; Sampson et al. 1997; Bower et al. 2000; Harris and Bucens 2003). However, the birth prevalence of FAS for non-Indigenous Australians is one-tenth that reported for other countries (Table 5.1) (Abel 1995; Egeland et al. 1998). This may reflect under ascertainment of cases or the distribution of maternal risk factors and/or lower alcohol intake in our population (Bower et al. 2000; Allen et al. 2007; Peadon et al. 2007). There may also be reluctance to diagnose conditions related to alcohol use in pregnancy because of a lack of services to deal with the condition once diagnosed. For example, a third of WA health professionals surveyed said that lack of referral resources affected their practice of assessing alcohol intake in pregnant women (Payne et al. 2005).

Accurate data are required about rates of FASD in Australia and in specific communities identified as being at risk. Knowledge of the size and nature of the problem is essential to inform service needs and service development for mothers and babies and to inform prevention initiatives. Documenting FASD rates also requires accurate diagnosis which in turn requires training of health professionals.
Key points

- Birth prevalence of FASD is most commonly measured through clinic-based studies, passive surveillance systems and active case ascertainment, the latter of which will provide the most accurate data.
- Alcohol use in pregnancy and FASD in Australia are predominantly monitored through passive surveillance systems and under-ascertainment of cases is likely. Use of multiple data sources is beneficial.
- State and Territory-based studies have reported birth prevalence rates of FAS of between 0.01 and 0.68 per 1,000 live births. Prevalence of the other disorders in the FASD spectrum has not been estimated in Australia.
- Several Australian studies have found higher rates of FAS among some Indigenous communities - a finding reflected in the international literature. This likely reflects patterns of alcohol use and other socioeconomic risk factors.
- Under-recognition of FASD in Australia in part reflects a lack of training or awareness among health professionals. Fear of stigmatizing children and families, a lack of diagnostic and support services and interventions for treating children with FASD have also been identified as important.
- Accurate measurement of FASD prevalence is crucial to inform policy, resource and service development in the areas of health, education, justice and community.
6. PREVENTION OF FASD

Carol Bower, Lorian Hayes and Agnes Bankier

Fetal Alcohol Spectrum Disorders (FASD) are the end point of a complex interaction between genetic, social, political and environmental risks (Elliott and Bower 2004). The causal pathway to FASD is complex and prevention requires consideration and modification, where possible, to the antecedent risk factors. Prevention of FASD is not a problem for health alone but for a range of government portfolios including education, housing, justice and community services. Nevertheless, most strategies to prevent FASD will depend on both health professionals and women of childbearing age being knowledgeable about the effects of alcohol use in pregnancy including FASD and a willingness and ability of women to avoid alcohol in pregnancy.

Prevention of alcohol use in pregnancy and FASD requires a comprehensive and multifaceted approach that includes a range of prevention initiatives undertaken at three levels: primary, secondary and tertiary. As alcohol use in pregnancy is higher in some subgroups, prevention initiatives at each level should incorporate contextual information, including an understanding of cultural and sociological frameworks. Targeted strategies will be strengthened significantly by ongoing measures to address broader community attitudes towards and behaviours around alcohol consumption.

Consuming alcohol at risky levels is associated with a higher incidence of FASD. As there is evidence to suggest that per capita alcohol consumption is an indicator of heavy drinking in a community, population based strategies to reduce overall consumption may reduce harms (Rose 1992). Therefore reducing the prevalence of risky drinking at the population level should reduce alcohol-related harms including the incidence of FASD.

Primary prevention requires an integrated approach that combines evidence-based social marketing initiatives with policy practices that influence the way alcohol is portrayed and is made available. This approach requires coordinated action nationally, jurisdictionally and locally for optimal impact. Primary prevention includes universal education messages to reduce acceptance of risky drinking and to inform both health professionals and the public, particularly young people, about the dangers of drinking during pregnancy. Messages may be communicated through a range of media, employment, educational and recreational outlets as well as through activities such as warning labels on the containers of alcoholic beverages, and provision of written information at a range of locations such as health care centres.

These education messages must be supported by policy initiatives and legislation that are effective and sustained. They include, but are not limited to, supply and demand strategies such as alcohol pricing (taxation), labelling, availability and the way that alcohol is advertised and promoted in the community. Legislative restrictions on outlets, the alcohol content of beverage, take-away availability and dry communities through community agreement (with legislation) may be beneficial (Australian Human Rights Commission 2011).

Secondary prevention involves actions targeting persons at risk. In this situation this refers to women who drink alcohol and are in the reproductive age range and/or who are pregnant. A range of strategies should be developed for this group including screening and early intervention programs and services. The importance of partners in supporting women not to
drink has also been identified (Centers for Disease and Control 2006). To reduce prenatal alcohol exposure, prevention efforts should include contraceptive advice to women who are having unprotected sex. A USA study by Floyd et al. reported a positive effect from a brief intervention (including motivational interviewing to reduce drinking and increase contraception use) on reducing the risk of an alcohol affected pregnancy (Floyd et al. 2007).

Women who are drinking at risky levels during pregnancy and those who have previously given birth to a baby with a FASD should be targeted in tertiary prevention programs. These initiatives will need to incorporate broad interventions that recognise the complexity of the problems faced by these women often including poverty, disadvantage, lack of support and poor mental and physical health.

6.1 Risk factors for FAS and FASD
Prevention initiatives should be driven by information that describes the correlates of FAS and FASD. Data from the Australian Paediatric Surveillance Unit (APSU) indicate some of these correlates. Many of the mothers of children with FAS used a range of substances in addition to alcohol in pregnancy (including heroin, solvents and cocaine) and few progressed beyond secondary education. As few as one-third of children reported with FAS were currently living with a biological parent, many having been placed in foster care and about half the mothers had more than one child with FAS (Elliott and Bower 2004). Women who were aged more than 30 years have been found to be more likely to have babies with Alcohol-Related Birth Defects, possibly because maternal body fat-to-water ratio increases with age, leading to higher and longer peak alcohol levels (Jacobson et al. 1996). Women over 30 years are also less likely to reduce alcohol use after learning they are pregnant, indicating greater alcohol dependence and difficulty in reducing or eliminating alcohol use during pregnancy (Centers for Disease and Control 2002).

Low socioeconomic status has been associated with FAS (Jones et al. 1973). An interaction between FAS and poor nutrition, genetic and social factors, and the cumulative effect of intergenerational maternal alcoholism has also been noted (O'Leary 2004). Other factors associated with low socioeconomic status (SES) including exposure to environmental pollutants such as lead, which can directly affect the CNS, psychological stress, physical abuse and smoking, are thought in combination to increase susceptibility to the teratogenic effects of alcohol. There are also contributory issues specific to the Indigenous population, such as the effects of colonisation, marginalisation, and loss of traditional culture (Elliott and Bower 2004).

The finding that concordance for alcohol-related birth defects is higher among monozygotic twins than among dizygotic twins born to women who drink during pregnancy suggests the importance of genetic factors in determining susceptibility to FAS (Streissguth and Dehaene 1993). A number of potential genetic markers have been identified, including the presence or absence of particular gene polymorphisms involved in alcohol metabolism, which may impact on ethanol clearance rates (McCarver 2001; Chambers and Jones 2002; Gemma et al. 2007). Genetic differences in serotonergic function have also been identified (Kraemer et al. 2008). Serotonin has an influence on the formation of neural circuits during development, particularly those involved in emotional behaviour (Ansorge et al. 2008). In this way, prenatal alcohol exposure may alter the development of neurobiological systems underpinning responses to stress and affect regulation in the fetus (Kraemer et al. 2008).
The place of alcohol in Australian society and the changing way that women drink in risky patterns is described by Roche, later in this publication. There is a strong association between overall consumption levels, rates of risky drinking and levels of long and short-term harm experienced by that population (Chikritzhs et al. 2003), and it would be helpful to know if there is also an association between rates of consumption and the incidence of FASD in a population. It may be reasonable, however, to assume that if decreases in risky drinking across the population are associated with a reduction in harms, then reductions in FASD across that population may also be possible.

6.2 International approaches to the prevention of FAS and FASD

There are few published studies evaluating strategies for prevention of FASD and most of them are from the USA. One example of a study to improve knowledge amongst African-American women about alcohol use and pregnancy was conducted in Missouri in 2002-2004 (Mengel et al. 2005). The authors used a relatively high intensity media campaign in one city, with before and after surveys of women in the target group in that city and a control city with no intervention. They found that 70 percent of women recalled the campaign, although there was a small but statistically significant decline in knowledge about alcohol and pregnancy over time. Women needed to hear the messages 10 or more times for them to be retained. In a randomised controlled trial aiming to prevent alcohol-exposed pregnancies, women at high risk (18-44 years old, risky drinkers using no contraception) were randomly allocated to receive information only or information plus five motivational intervention sessions (Floyd et al. 2007). Nine months after the intervention, there was a reduction in risky drinking (more than five drinks per day or more than eight drinks per week) and an increase in use of effective contraception in the intervention group. Either or both of these positive outcomes were almost twice as likely to occur in the intervention compared with the control group (odds ratio 1.90; 95 percent confidence interval 1.36 to 2.66). Data from Washington State, in the USA, showed a reduction in alcohol use in pregnancy (from 14.6 percent to 3.9 percent) over an extended period (1993-1998), when there were a series of public health education and training programs and programs specifically involving women at high risk in place (Astley 2004). There was also a reduction in the number of cases of FAS identified in a foster care screening program conducted in Washington State over the time period, although this aspect of the evaluation was based on only five cases over the entire study period.

A recent study used FASD prevalence as an outcome measure and reported reductions in FASD prevalence following interventions highlighting the harms of drinking while pregnant using local media and health promotion. The study was conducted in the Northern Cape, South Africa where population knowledge of the harms of drinking while pregnant are low and FASD prevalence is high. The study assessed whether FASD prevalence would be reduced by universal interventions to raise community and health worker awareness of the harms of maternal drinking. Using a before and after design the prevalence of FASD was determined in birth cohorts of babies born in a one year period pre- and post- the universal prevention interventions. The babies were assessed at 9 and 18 months. The intervention increased knowledge levels and the prevalence of FASD decreased from 8.9% pre-intervention to 5.7% post-intervention. There was no change in FAS prevalence (Chersich et al. 2011). This study suggests universal prevention is beneficial in areas where knowledge of the harms of maternal drinking is low. Universal prevention needs to be supported by other intervention and treatment strategies to lower the prevalence FAS (Chersich et al. 2011).
A review of evidence for the prevention of FASD highlighted effective interventions to decrease use of alcohol and reduce alcohol-exposed pregnancies and concluded that using evidence-based alcohol screening tools and brief counselling interventions were effective population-based strategies (Floyd et al. 2009).

### 6.3 Australian approaches to the prevention of FAS and FASD

In a survey of health professionals in Western Australia, knowledge of FAS was limited – only 12 percent of health professionals identified the four diagnostic features of FAS, only 44 percent who saw pregnant women routinely asked women about alcohol use in pregnancy and only 25 percent routinely provided information on the consequences of alcohol use in pregnancy (Payne et al. 2005). Most health professionals wanted educational resources for themselves and for women about alcohol and pregnancy. In a recent telephone survey of women of childbearing age in WA, most women themselves thought that health professionals should be asking women about how much and how often they drink during pregnancy and 92 percent agreed that health professionals should advise women not to drink (Peadon et al. 2007). Nevertheless, amongst women who drink alcohol (90 percent of those surveyed), only 75 percent said that they would stop drinking if they were pregnant. In a survey conducted a decade earlier, only 41 percent of women abstained from alcohol in pregnancy (Colvin et al. 2007).

In WA a project was conducted to provide health professionals with information about alcohol and pregnancy and FASD. Based on a thorough literature review, focus groups and key informant interviews with health professionals and women of childbearing age, three resource materials were developed: an A4 laminated fact sheet; a 38 page information booklet; and a wallet card for women. The resources were distributed to all general practitioners, obstetricians and paediatricians in WA, as well as to all allied health professionals in the public sector, all Aboriginal health workers and all community nurses. A day-long symposium, three satellite broadcasts to rural areas and presentations to several other professional groups were also conducted. Six months after distribution of the resources, the earlier health professional survey was repeated (Payne et al. 2005) to measure any changes in knowledge or practice.

Over two thirds of health professionals were aware of the resources and a third to a half of health professionals stated that the resources had changed or had influenced their intention to change their practice (Payne et al. 2011; Payne et al. 2011). This study has gone some way to improving knowledge about FASD in Australia and is an important step in preventing FASD (see also Chapter 7). However, there is still much to be done in this area and even these small gains need to be maintained.

In addition to improving knowledge and practice regarding alcohol use in pregnancy amongst health professionals and women, there are several other factors to bear in mind when considering strategies for prevention of FASD. Any strategy used must be appropriate for the target group – for example, a different strategy would be needed for risky drinkers compared with low-moderate drinkers and for some Indigenous communities. The acceptance of alcohol use in Australia and the social contexts in which alcohol is consumed are critically important issues to consider, as are perspectives other than health (e.g. education, justice,

* Further details of Australian health professionals’ knowledge and practice in this area may also be found in Chapter 7: Health professionals’ knowledge and practice regarding alcohol in pregnancy and FASD.
child protection) and perspectives other than alcohol (e.g. concomitant cigarette smoking, use of other drugs). Perhaps the most important issue in Australia is the lack of use of consistent and reliable methods of ascertaining and recording both alcohol use in pregnancy and the diagnosis of FASD. Early identification of women and infants at risk may enable prevention of FASD in a family in subsequent children.

There have been some notable universal strategies used in Australian communities to decrease consumption and risky alcohol use on a population basis. These strategies are well documented in the literature and have resulted in sustained reductions in harm (Loxley et al. 2004). However, FAS and FASD have not been listed in many of these studies. It is unlikely that the extent of this effect will be demonstrated prior to routine diagnosis of FASD in the population.

There have been a number of community initiated education programs in remote Aboriginal communities including campaigns in Kununurra and community education program in association with the Lililwan project in the Fitzroy Valley, WA. Responding to community concern over the risks of maternal alcohol use, a 2008 a prevention program was initiated in the East Kimberley region of WA through the Ord Valley Aboriginal Health Service (OVAHS) which services Kununurra. The prevention program targeted numerous groups including antenatal clients who were assessed through their pregnancy and information was obtained on their alcohol use and knowledge of FASD. In addition to targeting antenatal clients, all women of child bearing age were targeted through local schools, the crisis centre and community events. Contraceptive advice was a key component given the link between unplanned pregnancy, high levels of alcohol consumption and FASD. The program also targeted all OVAHS staff to provide education and training on alcohol awareness, FASD and contraception. Education was also provided to Aboriginal men; although appreciating men are not traditionally involved in the antenatal process it was acknowledged they could support partners to avoid alcohol during pregnancy. There was also broad and continual community consultation in the wider Aboriginal community and organisations that provide services (Bridge 2011). The program developed a number of resources, including a brochure called “No grog for 9” promoting abstinence throughout pregnancy.

**Case study: The Victorian Aboriginal Community Controlled Health Organisation**

The Victorian Aboriginal Community Controlled Health Organisation (VACCHO), the peak body for Aboriginal community controlled health organisations in Victoria, has developed a holistic approach for Aboriginal communities and community health services around health, nutrition and alcohol use in pregnancy through the research and awareness project ‘Healthy pregnancies, healthy babies for Koori communities’. Conducted in collaboration with Onemda VicHealth Koori Health Unit, the aim of the project was to identify levels of knowledge and concern around the effects of alcohol use during pregnancy and to develop appropriate resources and training material based on these findings. The project was funded by the Victorian Premier's Drug Prevention Council (http://www.health.vic.gov.au/pdpc/index.htm). A resource kit is available and includes information on FAS (see http://www.onemda.unimelb.edu.au/research/projects/healthypregnancies.html). The project affirms that there is no safe level of alcohol intake, asserting that ‘Less is better, none is best’. The approach is based on Victoria having a largely urban Indigenous community, with lower rates of nutritional risk factors, and aims to engage the moderate drinker rather than women with a serious drinking problem (see http://www.health.vic.gov.au/pdpc/projects/cdp.htm). The effectiveness of this strategy remains to be evaluated.
Case Study: A Queensland Indigenous community’s response to preventing Fetal Alcohol Syndrome

The prevalence of FASD in Australian Indigenous communities is not known. It is likely that Indigenous children with FASD are not being diagnosed and are thus missing opportunities for treatment to minimise secondary disabilities. Information about alcohol use in Indigenous pregnant women is limited due to a lack of routine antenatal screening and under-reporting of alcohol use. For example, in one rural Indigenous community in Queensland, during a twelve month period, 92 percent of women drank alcohol at harmful and hazardous rates (more than seven drinks in any one session), 100 percent used cannabis and 17 percent used paint as another form of substance use. In the community binge drinking was common and women gave a number of reasons to explain why they drank, including domestic violence, sexual abuse, physical abuse and shame.

A total of 614 children aged between 0-12 years were born between 1993-2005, 540 of whom were exposed to alcohol in utero. Many of these children have abnormal facial features, behavioural, developmental, language and learning problems, and growth failure: however, few have had adequate medical assessments and none has received a diagnosis of FASD. Failure to assess children exposed to alcohol in utero and to diagnose FASD when appropriate limits opportunities for educational and medical interventions for the child and access to government support. Failure to identify mothers at risk limits opportunities for providing treatment of alcohol misuse and for preventing the birth of another affected child (Hayes 2002; Hayes 2003; Apunipima Cape York Health Council 2007).

Raising awareness of FASD in Indigenous communities (including in women and men of all ages, health professionals and teachers) could potentially contribute to preventing a range of problems in childhood that are associated with fetal exposure to alcohol, including intellectual disability, cognitive impairments, learning difficulties, speech and language delay and behavioural, emotional and mental health problems.

The Health Literacy Program

Education programs regarding alcohol in pregnancy must be culturally sensitive and acceptable to Indigenous communities and developed in collaboration with Indigenous people. Adaptation of programs developed for one community may be necessary for use in different communities because levels of literacy and numeracy and language and patterns of alcohol use vary widely.

A community-based health literacy model that aimed both to increase awareness of the dangers of alcohol use in pregnancy and FASD and to improve health literacy was developed and trialled in two communities in Cape York. A health literacy approach is part of a life-long learning strategy which not only provides information but also encourages a lifelong approach to seeking health advice and modifying behaviour accordingly.

The aim of the project was to use an education intervention to decrease maternal alcohol consumption and consequently the incidence of FASD in the community. The four specific aims were to:

- increase community awareness and knowledge of the effects of alcohol on unborn babies;
- increase literacy skills in relation to health promotion materials to increase participants’ sense of control over their own health decisions;
- identify and develop appropriate FASD resources for use during community events and activities;
- facilitate the development of a sustainable health education ethic within the communities.

The program spans six months and is facilitated by a project team, including Aboriginal facilitators trained in health literacy and a public health researcher experienced in health literacy and action.
research methods. The team visits communities to facilitate problem-based workshops with community participants and health workers. The workshops facilitate:

- development of resource materials about FASD that are specific to each individual community;
- improvement in health literacy skills (through reading, writing and comprehension tasks and critical evaluation of health information);
- understanding of alcohol use and misuse and its effects on the body;
- understanding of the effects of alcohol use in pregnancy including FASD and its impact on child development and;
- improved knowledge of reproductive health.

One way to break the cycle of alcohol use is to empower the individual and the community through education and training. Participants involved in workshops are encouraged to become involved in training others, both formally and informally.

Prior to program implementation, baseline surveys were carried out to measure the literacy levels of participants in the program and to determine participants’ levels of current knowledge, attitudes and perceptions regarding the effects of alcohol on unborn babies. Information gained was used to develop a Memorandum of Understanding and a strategic plan for sustaining health promotion in relation to the effects of prenatal alcohol exposure. The plan included strategies to manage FASD and was tailored to the needs of each community participating in the project. Following program completion, participants’ knowledge, attitudes and practice were reassessed to determine the impact of the program.

**Kowanyama Community, Cape York**

A twelve month program was initiated in Kowanyama on May 21, 2002. The community council, Justice Group and the Mothers and Babies Centre were contacted in writing regarding a preliminary visit to community to introduce the team and the type of education program it would provide. The FASD team made twenty visits (ten blocks of two weeks) to the community throughout the year, returning to Cairns in between. On its preliminary visit, the project team discussed the community’s needs regarding alcohol misuse in depth. The team was introduced to various organisations in the community. It was a major concern of the community that too many external service providers do not stay in the community for very long. Consequently it became a priority for the team to spend a considerable time in the community to engage with community in their own time and space. A range of community meetings and informal discussions took place with pregnant women, their families, women in their reproductive years, partners and young women and men. Discussions were also held with health staff, community workers, and other relevant government agencies including education, police, community groups, mothers and babies’ centres, kindergartens and Community Development Employment Project (CDEP) workers, to encourage their support and cooperation with the development and implementation of the FAS strategy.

The first workshop was held on the 17th June 2002. A meeting was held with the women’s group at the mothers and babies centre regarding recruitment for the two week workshop, with a list of names provided to the team by the Coordinator. This is an example of a community owned program for sustainable education. A series of FAS presentations were made to ensure the broadest possible coverage of the community. The workshops introduced communities to the basic facts surrounding FAS and assess their awareness and concern regarding the issue.

A variety of community-based initiatives continue to operate in the Cape York area.
Key points

- High levels of per capita consumption and risky drinking levels are associated with high levels of harm in the community. There is a range of universal strategies that are known to reduce consumption and risky alcohol use that can be implemented and will reduce associated harm at a population level.

- Prevention strategies should be informed by known correlates of FASD if they are to be appropriately targeted and effective.

- There is a lack of published evidence on evaluated prevention strategies to inform development in the Australian context.

- Health professionals’ knowledge of FASD is often limited and they may lack confidence to address the issue of alcohol use in pregnancy with their clients or patients. However, women feel that health professionals should ask questions about alcohol use in pregnancy and provide advice.

- Knowledge about FASD should be part of the core competencies of new graduates in the health professions and part of postgraduate training.

- A range of resources have been developed in WA for health professionals and have been shown to be effective in improving knowledge and influencing clinical practice.

- Prevention efforts should be appropriate for the target group, considering the context in which drinking occurs and the complexity of issues that women may be facing. Strategies should be aimed at primary, secondary and tertiary levels.

- Programs for Indigenous communities must be culturally sensitive and informed by local needs, including patterns of drinking and literacy levels. They should be developed and implemented with input from the local community.

- A variety of work needs to be undertaken before informed development of effective, evidence-based prevention strategies can occur. A health literacy program currently underway in two Aboriginal communities will contribute to this process.

- In order to develop strategies for FASD prevention in Australia, we need:
  - Documentation of existing prevention strategies in Australia.
  - A systematic review of the effectiveness of prevention programs.
  - A national prevention strategy of alcohol use in pregnancy and FASD.
  - A commitment to evaluating prevention strategies implemented in Australia.
7. HEALTH PROFESSIONALS’ KNOWLEDGE AND PRACTICE REGARDING ALCOHOL USE IN PREGNANCY AND FASD

Carol Bower, Elizabeth Elliott and Jan Payne

Improving health professionals’ knowledge about the effects of alcohol use in pregnancy is the key to early diagnosis, appropriate management and prevention of adverse outcomes. In Australia, there is a need to increase knowledge about Fetal Alcohol Spectrum Disorders (FASD) among health professionals.

7.1 Health professionals survey, 2002

In 2002, Payne et al. surveyed 1,143 health professionals throughout Western Australia (WA) via a postal questionnaire, to determine their awareness about Fetal Alcohol Syndrome (FAS) and the effects of alcohol use in pregnancy (Payne et al. 2005). The response rate to the survey was 79 percent. Survey participants included Aboriginal health workers, allied health professionals, community nurses, general practitioners and obstetricians.

Just over half of respondents identified at least one of the essential features of FAS; however, only 12 percent identified all four essential diagnostic features. This suggests that many health professionals would not recognise even the most severe end of the FASD spectrum. Most (82%) health professionals believed that making a diagnosis of FAS might improve treatment plans for the affected child and 85% agreed FAS was preventable. Most respondents reported never having diagnosed FAS, although half (51%) had seen a child diagnosed with FAS by someone else. About one-third (34%) had suspected but did not diagnose FAS and 4% were, on occasion, convinced of the diagnosis of FAS but did not record it. This may be explained in part by the fact that half (53%) believed that making a diagnosis might stigmatise the child or their family (Payne et al. 2005).

Of the 659 health professionals in the survey who cared for pregnant women, most (87%) advised pregnant women that they should consider not drinking at all. However, less than one-third gave advice consistent with the 2001 NHMRC Australian alcohol guideline on alcohol consumption in pregnancy (NHMRC 2001) and advised women not to become intoxicated (29%) or to have fewer than seven drinks during a week (29%). Overall, only 13% provided advice that incorporated all aspects of the 2001 NHMRC Australian alcohol guideline. Sixty-seven percent of health professionals surveyed agreed that it was easy to ask pregnant clients how much and how often they drank alcohol but 10% agreed with the statement that discussing alcohol use during pregnancy would frighten or anger pregnant women (Payne et al. 2005).

Less than half the health professionals caring for pregnant women (45%) said they routinely asked pregnant women about alcohol use in pregnancy. About one-third asked “sometimes”, one-third only asked if there were certain risk factors and 12% did not ask about alcohol use. Only 25% routinely provided information on the consequences of alcohol use in pregnancy and 21% did not provide such information. More than 96% agreed that education/information about the effect alcohol may have on the fetus should be readily available to women of child-bearing age (Payne et al. 2005).
7.2 Paediatricians’ survey, 2004

A similar study of 132 paediatricians conducted in WA in 2004 examined their knowledge, attitudes and practice with respect to FAS and alcohol use in pregnancy (Elliott et al. 2006). Using a questionnaire modified from that developed by Payne et al., 90 consultant paediatricians and 42 trainee paediatricians completed a two-page postal survey. With regard to the features required for diagnosis of FAS, 81% of respondents nominated abnormal facial appearance, 71% identified growth restriction, and 63% indicated central nervous system (CNS) abnormalities. Only 19 percent of respondents identified all four of the essential diagnostic feature for FAS (Elliott et al. 2006).

Just over one-fifth (23%) of paediatricians reported routinely asking women about alcohol use in pregnancy; 38% stated that they ‘sometimes’ asked about alcohol use; 33% asked only when other risk factors were identified, such as smoking or drug use; and 13% reported that they did not ask patients about alcohol use in pregnancy (categories were not mutually exclusive). Forty-one percent of the paediatricians reported that they did not provide patients with information on the effects of prenatal alcohol exposure. With regard to FAS diagnosis, only 49% of paediatricians or trainees had previously diagnosed FAS themselves; however, 92% had seen children with FAS who had been diagnosed by others. Just over three-quarters (77%) had suspected but not diagnosed FAS, 12% had been convinced of but not recorded the diagnosis, and 32% had referred children to others for diagnostic confirmation. Although 80% agreed early diagnosis might be advantageous, 70% (a higher proportion than in the earlier health professional survey) said diagnosis might be stigmatising. In addition, 36% thought parents of children diagnosed with FAS might resist referral for assessment and treatment.

Only one-tenth (11%) had read the NHMRC Australian alcohol guideline regarding alcohol use in pregnancy that was current at the time (NHMRC 2001) and 9% provided advice entirely consistent with this guideline (i.e. that women should consider abstinence, avoid intoxication, drink less than seven standard drinks per week and that they should have no more than two standard drinks on one day, consumed over at least a two-hour period. The vast majority (87%) reported that they advised women to consider abstinence, 38% stating that this was the only advice they offered. One-third (33%) reported that they advised pregnant women to avoid alcohol intoxication, just over one-third (37%) advised women to have fewer than seven standard drinks per week and almost half (46%) advised women to have no more than two standard drinks on one day spread over at least two hours.

Almost four-fifths (78%) of paediatricians surveyed agreed that avoiding binge drinking might reduce FAS, while 44% believed women should abstain from using alcohol in pregnancy. Just over half the respondents (55%) felt that there was a lack of sufficient awareness of FAS among health professionals and 56% perceived that there was a paucity of services to treat FAS in the community. Only 5% felt ‘prepared to deal with a patient with FAS’ and most wanted educational materials for themselves, parents or carers, and children. When surveyed regarding the types of resources that they would find most helpful, 71% wanted information for distribution to patients/carers; 70% wanted materials for themselves/doctors; 67% felt a FAS diagnostic checklist would be useful; and 51% wanted information for referral (Elliott et al. 2006).
7.3 Educational resources for health professionals
In 2006, qualitative interviews and focus groups were conducted with health professionals to identify the barriers that health professionals encounter in addressing alcohol use with pregnant women and to elucidate the strategies they use to overcome them (France et al. 2010). Data were collected to inform the development of resources on alcohol use in pregnancy appropriate for Western Australian health professionals to enhance their knowledge and support their practice with pregnant clients. Four educational resources were developed for health professionals about the prevention of prenatal alcohol exposure and FASD. A 38-page booklet, a double-sided laminated fact sheet, a wallet card for health professionals to give to women* and a desktop calendar were distributed to over 3,000 health professionals in WA in 2007. Health professionals were surveyed six months after the distribution of the educational resources, to assess their knowledge, attitudes and practice about FAS and alcohol consumption in pregnancy using similar methods to the previous studies. Responses in 2007 were compared with responses to the same questions in 2002 (for Aboriginal health workers, allied health professionals, community nurses, general practitioners and obstetricians) and 2004 (for paediatricians and paediatric trainees).

7.4 Health professional surveys, 2007
A total of 1,001 (67.5%) WA health professionals (Aboriginal health workers, allied health professionals, community nurses, general practitioners and obstetricians) responded to the survey in 2007. Compared to 2002, an increased proportion of health professionals surveyed in 2007 knew all the essential features of FAS (11.7% in 2002 versus 15.8% in 2007) (Payne et al. 2005; Payne et al. 2011). Health professionals surveyed in 2007 had gained more experience with FAS: there was an increased proportion who had diagnosed FAS (4.8% in 2002 versus 7.3% in 2007) and who had seen FAS diagnosed by another person (51.3% in 2002 versus 59.8% in 2007). There was also an increase in the proportion surveyed in 2007 who suspected but did not diagnose FAS (34.1% in 2002 versus 42.3% in 2007) and were convinced of the diagnosis but did not record it (3.8% in 2002 versus 8.4% in 2007). There was an increase in the proportion of health professionals surveyed that had referred children to confirm a diagnosis of FAS (12.7% in 2002 versus 17.7% in 2007). There was an increase in the proportion of health professionals surveyed who were fairly prepared (7.7% in 2002 versus 15.0% in 2007), or somewhat prepared (22.8% in 2002 versus 33.2% in 2007) to deal with FAS and a decrease in the proportion who were not very prepared to deal with FAS (66.4% in 2002 versus 46.7% in 2007). There was nearly a two-fold increase in the proportion of health professionals surveyed in 2007 who agreed that health professionals are sufficiently aware of FAS (14.2% in 2002 versus 27.5% in 2007). In 2007, a greater proportion agreed there was a lack of community services to treat FAS effectively (43.5% in 2002 versus 53.3% in 2007) and that members of the community were concerned about FAS (24.1% in 2002 versus 33.8% in 2007). In 2007, there was little change from 2002 in the proportion of health professional surveyed who agreed that: making an early diagnosis of FAS may improve treatment plans for the affected child (84.4%); it was possible to prevent FAS (88.5%); the diagnosis of FAS may lead to a child or their family being stigmatised (54.7%); and parents may resist referral of their child for assessment and treatment services if FAS was diagnosed (40.4%) (Payne et al. 2011).

Compared to 2002, a decreased proportion of health professionals surveyed in 2007 said they would provide advice to women that was consistent with components of the current NHMRC Australian Alcohol Guideline for women who are pregnant or might soon become pregnant. These components were: to consider not drinking at all (89% in 2002, 68.3% in 2007); not to become intoxicated (27.8% in 2002, 11.0% in 2007); to have less than seven standard drinks over a week (29.1% in 2002, 11.0% in 2007) and on any one day to have no more than two standard drinks spread over at least two hours (38.2% in 2002, 20.1% in 2007) (Payne et al. 2011). Of health professionals surveyed in 2007, 85.8% said they offered advice that was consistent with the most recent (2009) NHMRC Australian alcohol guideline and said they would advise according to the message contained in the educational resources distributed in WA, that ‘No Alcohol in Pregnancy is the Safest Choice’. Overall, 98.1% of health professionals surveyed in 2007 said they would advise women either to consider not drinking at all or that ‘No Alcohol in Pregnancy is the Safest Choice’. Compared with 2002, an increased proportion of health professionals surveyed agreed that pregnant women should completely abstain from consuming alcohol (61.5% in 2002 versus 88.1% in 2007) and that women planning to become pregnant in the near future should completely abstain (56.9% in 2002 versus 78.2% in 2007). Health professionals surveyed agreed that drinking five or more standard drinks on one drinking occasion whilst pregnant may harm the fetus (83.3% in 2002 versus 91.5% in 2007). In 2007, there was a reduction in the proportion of health professionals surveyed who agreed that infrequent consumption of one standard drink of alcohol during pregnancy is not harmful to the mother or fetus (from 56.5% in 2002 to 29% in 2007). For health professionals who cared for pregnant women, there was no overall increase in 2007 in the proportion who routinely asked pregnant women about alcohol use (44.5% in 2002 versus 46.0% in 2007). There was an increase in the proportion of obstetricians (57.1% in 2002 versus 76.5% in 2007) who routinely asked about alcohol use. There was also an increase in the proportion of health professionals who routinely provided information about the consequences of drinking alcohol during pregnancy (24.7% in 2002 and 32.4% in 2007).

Of health professionals surveyed in 2007, 69.8% had seen the educational resources developed and distributed as part of this study. Of these professionals, 77.1% had used the resources and 48.5% said the resources had assisted them to change their practice or their intention to change their practice. Fewer health professionals surveyed in 2007 requested resources about FAS (83.9% in 2002 versus 54.0% in 2007) or written information for clients (78.7% in 2002 versus 54.3% in 2007) (Payne et al. 2011).

In 2007, a total of 82 WA consultant paediatricians (61.7%) completed the postal survey (Payne et al. 2011) using the questionnaire modified from that developed and used in the 2002 survey (Payne et al. 2005). Despite access to educational materials, there was no improvement in paediatricians’ knowledge of the essential features of FAS (20.0% in 2004 and 18.3% in 2007). In 2007, there was little change from 2004 in the proportion of surveyed paediatricians who had: ever seen a case of FAS diagnosed by another person (90.2%); themselves diagnosed FAS (58.5%); suspected but not diagnosed FAS (78.0%); and been convinced of the diagnosis but did not record it (13.4%) (Elliott et al. 2006). There was a small increase in the proportion of paediatricians surveyed in 2007 who referred children to confirm a diagnosis of FAS (33.3% in 2004 versus 39.0% in 2007). Few paediatricians (about 6% in the surveys in 2004 and 2007) reported being very prepared to deal with FAS. There was an increase in the proportion of paediatricians surveyed in 2007 who agreed that members of the community were concerned about FAS (27.8% in 2004 and 35.4% in 2007). A smaller proportion agreed that FAS is easy to diagnose in the first year of life (30.0% in
2004 and 14.6% in 2007) and fewer paediatricians agreed that making an early diagnosis of FAS may improve treatment plans for the affected child (74.7% in 2004 and 65.9% in 2007).

In 2007, there was little change from 2004 in the proportion of paediatricians surveyed who agreed that: it was possible to prevent FAS (90.2%); the diagnosis of FAS may lead to a child or their family being stigmatised (67.1%); there was a lack of community services to treat FAS effectively (53.7%); the physical features consistent with FAS may be more difficult to diagnose in Australian Aboriginal children (53.7%) (Payne et al. 2011).

There was a reduction in 2007, compared with 2004, in the proportion of paediatricians who said they would advise women according to components of the 2001 NHMRC Australian Alcohol Guideline for women who are pregnant or might soon become pregnant, that was current in 2004 and 2007. These components were: to consider not drinking at all (88.9% in 2004, 68.3% in 2007); not to become intoxicated (31.1% in 2004, 18.3% in 2007); to have less than seven standard drinks over a week (35.6% in 2004, 14.6% in 2007); and on any one day to have no more than two standard drinks spread over at least two hours (47.8% 2004, 11.0 in 2007) (Payne et al. 2011). In 2007, 81.7% of paediatricians surveyed offered advice that was consistent with the 2009 NHMRC Australian alcohol guideline and in accordance with the message contained in the educational resources that ‘No Alcohol in Pregnancy is the Safest Choice’. Also, 96.3% said they would advise women to consider not drinking at all or that ‘No Alcohol in Pregnancy is the Safest Choice’. There was a significant increase from 2004 in the proportion of paediatricians surveyed who agreed with the statements that pregnant women should completely abstain from consuming alcohol (48.9% in 2004 versus 75.6% in 2007) and that women planning pregnancy should completely abstain from consuming alcohol (42.2% in 2004 versus 74.4% in 2007). There was a significant reduction in the proportion of paediatricians that agreed infrequent consumption of one standard drink of alcohol during pregnancy is not harmful to the mother or fetus (from 66.7% in 2004 to 43.9% in 2007). Amongst paediatricians surveyed in 2007 who took pregnancy histories (n=69), there was little change in the proportion who routinely asked about alcohol use in pregnancy (22.4% in 2004 versus 21.7% in 2007). In 2007 a higher proportion routinely provided information about the consequences of alcohol use in pregnancy (5.3% in 2004 versus 10.1% in 2007) (Payne et al. 2011).

In 2007, 65.9% of paediatricians surveyed had seen the educational resources distributed and of these, 66.7% had used them and 29.6% said the resources assisted them to change or their intention to change their practice. There was a significant decrease in the proportion of paediatricians surveyed who requested resources about FAS (61.1% in 2004 versus 43.9% in 2007) or written information for clients (67.8% in 2004 versus 48.8% in 2007)(Payne et al. 2011).

There remains a need for regular educational and training opportunities and dissemination of locally relevant, evidence based resources for a range of professionals who deal with FASD in Australia. These include health professionals, educators, and individuals who work in disability and community services and the justice system. Workforce development could be achieved by funding local or international experts to conduct formal training courses and/or the dissemination of resources such as those developed by the Alcohol and Pregnancy group convened by the Telethon Institute for Child Health Research in Perth. These are available at http://alcoholpregnancy.childhealthresearch.org.au/alcohol-and-pregnancy-resources.aspx.
Key points

- Surveys of Australian health professionals in 2002 and 2004 indicated that they: lacked knowledge about FAS; lacked the confidence to make the diagnosis; were reluctant to make the diagnosis because of stigmatisation; and lacked knowledge about referral options and appropriate management.
- Surveys of health professionals in 2002 and 2004 indicated that less than half of these professionals routinely asked about alcohol use in pregnancy, that there was a lack of knowledge about or adherence to the NHMRC 2001 Australian alcohol guidelines and that there was uncertainty about what to advise regarding alcohol use during pregnancy.
- In 2002 and 2004 health professionals reported that they wanted educational resources for themselves and their clients.
- Educational resources about the prevention of prenatal alcohol exposure and FASD were distributed to over 3,000 health professional in WA. Changes in their knowledge, attitudes and practice about alcohol and pregnancy and FASD were assessed in 2007.
- The educational resources were used by over two thirds of health professionals who saw them. Some health professionals had changed their knowledge, attitudes and practice about alcohol and pregnancy. Health professionals’ knowledge of FAS had improved only slightly (there was no improvement in paediatricians’). There was no increase in the proportion who routinely asked about alcohol consumption in pregnancy (with the exception of obstetricians); however, a larger proportion provided information on the consequences of alcohol consumption in pregnancy. Nearly all health professionals surveyed offered advice that was consistent with the 2009 NHMRC Australian alcohol guideline and advised abstinence from alcohol during pregnancy.
- Undergraduate and post-graduate training, and professional and workforce development opportunities for health professionals about the potential adverse effects of alcohol consumption in pregnancy and the diagnosis and management of FASD are required and should be implemented throughout Australia.
8. WOMEN, WORKERS AND SYSTEMS CHANGE: PROFESSIONAL EDUCATION AND WORKFORCE DEVELOPMENT IN FASD

Ann M. Roche

An important issue in relation to the prevention, detection and management of Fetal Alcohol Spectrum Disorders (FASD) is the upskilling of the wide range of workers involved in this area. Even more importantly, the question of improved service system responses should also be considered. These two issues are inextricably linked and this paper addresses both issues and tackles them from a workforce development perspective. The following chapter is presented in two sections. The first provides important background data on the dynamic patterns of alcohol consumption by young women in Australian society. Also addressed is a range of important social changes that impact on the role of young women of child bearing age and the behaviours that might impact on their health and that of their unborn children. The second section of the paper addresses factors related to professional practice change and knowledge translation and research transfer. Changing practitioner behaviour and achieving organisational change is not easy or straightforward. The ultimate goal of achieving better prevention and intervention responses to FASD requires not just individual behaviour change but also a raft of organisational changes. Evidence is presented on some of the more effective ways that might be applied to achieve this end.

8.1 The Role of Alcohol in Australian Society

To address FASD it is essential to first appreciate and understand the place and role of alcohol in Australia society. Alcohol plays a significant part in the social life of Australians today, as it has done since European settlers first arrived, and is integral to the Australian way of life. It is used to celebrate and commiserate significant life events such as births, deaths, marriage, graduation, promotions and sackings. It is also represented through literature, music and visual arts, and the alcohol industries sponsor major sporting events and music festivals. Alcohol plays a role in many social occasions and is embedded in the Australian vernacular; for example Australians ‘wet the baby’s head’ at christenings and ‘drown our sorrows’ if their sporting team loses. Alcohol is the most popular and widespread psychoactive substance available in Australia. It is legal, socially sanctioned and widely promoted. The consumption of alcohol in Australia is considered a sociable occasion, to be shared with others, with the principles of mateship and reciprocity exercised through buying rounds or shouts.

8.2 The Changing Role of Women in Australian Society

One of the biggest social changes seen in Australia in recent years is in relation to women and alcohol (Roche et al. 2008). Traditionally, women did not drink. This was the preserve of males. If women did drink, they did so only very lightly. Intoxication by women was subject to extreme social opprobrium. In recent decades this has changed dramatically and women now drink in increasingly similar ways to men. This substantial change in drinking patterns and changes in a range of related social norms are highlighted below.

* This section draws heavily on work undertaken by NCETA examining the role of cultural influences on young people’s drinking. The reader is referred to Roche et al. (2008) Young People and Alcohol: The Role of Cultural Influences. This report can be obtained from NCETA or downloaded from www.nceta.flinders.edu.au.
8.3 Social trends and interpersonal factors

A number of major social changes have occurred over recent decades that impact significantly on the social and cultural world of young people, and young women in particular, which can have a powerful influence on a wide range of behaviours including drinking behaviours.

Key changes include the following:

- Women’s roles in society have altered greatly. Women now participate in the workforce to a much greater extent, marry later, have fewer children, more independence and wider life aspirations than ever before.
- Young people, and young women in particular, drink more than any previous generation.
- Today’s 14-24 year olds were raised by ‘baby boomers’ (or their children) who hold substantially less rigid and authoritarian views than previous generations.
- Family structures have changed significantly over the last century. People marry much later in life and have fewer children. There are more marriages with no children and a greater proportion of women who have not borne a child. Hence, child bearing and rearing does not play the prominent role in a women’s life today as it did even 10 years ago.
- The proportion of single parent families has increased substantially over the past 15 years with the result that family socialisation for young persons living with a sole parent may be significantly altered.
- Young women delay starting their own families, remain living in the family home for longer periods and delay home ownership in order to participate in other activities such as study and travel. Hence, young women have longer periods of independence often with high levels of expendable income.
- Young people stay in education longer than previously.
- Delayed entry into traditional markers of adulthood such as employment, leaving home, marriage and child rearing has resulted in the emergence of an apparent period of extended adolescence.
- People in Australian society report lower levels of religious affiliation than previously. Religious affiliation is known to be associated with lower levels of drug and alcohol use in general.
- Transition to work or higher study is associated with changed patterns of alcohol use. Some workplace environments, for example the hospitality industry where many young women find their first job, as a bar attendant, are particularly conducive to adopting risky alcohol use patterns.
- Young women are often introduced to alcohol by their parents. Parental supply of alcohol is associated with lower levels of consumption than supply from other sources.
- Young people’s drinking behaviours are substantially influenced by peers. As an adolescent matures, peers become more influential than parents. Young women often drink large amounts to mimic peers.

The age at which young Australians start to drink has decreased significantly with every ten year cohort over the past 50 years drinking at an earlier and earlier age. The average age of commencing to drink is now 15 for both males and females. Drinking to the point of intoxication, by males and increasingly by females, is also more socially acceptable than it has ever been in contemporary times. The ability to buy and consume alcohol is also facilitated by the increased number of licensed outlets and the substantial reduction in the real
cost of alcohol products, coupled with intense and skilful campaigns that market alcohol products designed specifically to appeal to the young female palate.

Importantly, what young people drink has also changed with a significant shift in beverage preference to spirits, or spirit based drinks, having occurred over the past 5-10 years. Many spirit based drinks are sweetly flavoured, milk-based and taste more like a soft drink than an alcohol beverage. This shift in beverage preference is important in the context of FASD as it is easier to reach the point of intoxication or consume more alcohol than intended when consuming these types of products.

Drinking plays a central role in the social lives and leisure lifestyles of most young Australians. For young women it is especially linked to freedom, independence and equality. All principles that are held in high esteem by young people in general. Hence, drinking alcohol is increasingly common among young Australian women of child bearing age and its centrality in their lives is likely to increase rather than decrease over the coming years. Young women start to drink earlier, with more potent forms of alcohol and have established drinking patterns well before they are likely to consider having a child. Interventions and preventive strategies need to be mindful of the well established, if not entrenched, nature of drinking patterns and its social and symbolic significance in young women’s lives.

8.4 Professional Development Needs

Given the above, important questions arise regarding the most appropriate strategies to guard against FASD and to mitigate against its potential consequences. Training professionals who are likely to encounter FASD or to have prevention opportunities available to them is often considered as an appropriate starting point, especially as FASD is a relatively recently recognised phenomenon. To date, few professionals would have received much, if any, training about FASD. Training, however, while important, is not an adequate solution in itself. From a workforce development perspective, training represents the small tip of a large and more complex set of factors that must also be tackled, as illustrated in Figure 9.1, if an adequate response to this important issue is to be achieved.

Figure 8.1. The different levels and components of workforce development

* Attached in Appendix 1 is information is a list of the AOD courses available in Australia that indicate some inclusion of FASD content (this list was derived from a recent NCETA review of 1,144 AOD and mental health training courses; other courses may also contain FASD-relevant content that were not included in our database). It is important to not only focus on training, but see it as part of a comprehensive suite of intervention and access points.
Until relatively recently, addressing issues related to young women’s drinking and its implications for FASD was not an area of interest for the vast majority of health and human services professionals. It is a new issue of concern and it faces the challenges that most innovations or new issues face. As such, it encounters similar challenges and barriers that the introduction of any new development, especially where a change in behaviour or systems response is entailed.

Professor Elizabeth Elliott has argued that ‘Failure to provide information about the dangers of alcohol consumption in the antenatal consultation represents a lost opportunity. Accurate recording of antenatal alcohol exposure will help identify children who require paediatric assessment. More importantly, identifying the women who are unable to stop drinking provides an important opening for the management of problem drinking and prevention of exposure to alcohol in future pregnancies (Boey 2008; Elliott and Bower 2008).

This description captures several features of relevance to a workforce development and systems change perspective including the need for better and improved information for workers; the need for better records to be kept (systems change); and the scope for early identification and intervention. A range of simultaneously implemented strategies covering all these points of access is needed. Simply focusing on education and training alone is not likely to be adequate or successful in either the short or long term.

8.5 Barriers to Change
Various factors operate as barriers to professional practice and systems change and the introduction of innovations and new approaches. The levels at which these barriers work include the following:

- Healthcare system – resources, policies
- Political environment – ideology
- Social environment – disadvantaged groups
- Education environment - curricula
- Practice environment – time, resources, organisational structure
- Practitioners – knowledge, beliefs and attitudes
- Patient/client – demands, perceptions.

To ensure a comprehensive and sustained response to FASD, strategies are required to be implemented across each of the above areas. The levels at which professional change and workforce development strategies might be introduced are also broad and varied. At a minimum, they include prevention, early intervention, early identification and remediation.

8.5.1. Prevention:
There is considerable work that needs to be undertaken of a preventive nature, especially given the changing patterns of drinking among young women. Changing cultural norms about drinking is an important preventive strategy for FASD. Such strategies must be cognisant of the extended period of adolescence-adultescence that young people now experience and all the attended behaviours and risks associated with it. Little attention has been directed to the pre-pregnancy period as an opportunity for prevention, and similarly greater preventive

*In the context of FASD particular attention needs to be paid to the support and resources required by Indigenous workers or workers with Indigenous clients.
attention is required in early pregnancy for all women in relation to basic information about alcohol and its risks in pregnancy. This requires a whole of community response including the schools, parents and the media.

8.5.2. Early Intervention:
All pregnant women require basic information about alcohol use, but more importantly all pregnant women should be appropriately assessed for their drinking levels and patterns using standardised assessment tools by trained and skilled health professionals. Data should be recorded in standard formats that can be readily shared among health professionals. Women drinking at risky levels should receive appropriate counselling and support. Staff and services involved in the above need to have adequate knowledge and skills and the systems need to be in place for the necessary screens and assessments to be undertaken.

8.5.3. Early Identification:
The early identification of FASD at the time of birth or soon after is important and involves obstetric and postnatal care staff. The application of standardised assessment and screening procedures embedded within normal medical care systems is essential.

8.5.4. Remediation:
Once a diagnosis is made the long term ongoing support of a range of different health and human workers and organisations is required. This support extends well beyond the health care system to the wider child protection services and education system. The latter have been largely neglected as key players in this area until relatively recently. Important issues in terms of empathic care and support for the parents, and the mothers in particular, is paramount.

8.6 Dissemination and Knowledge Transfer
To achieve the above wide ranging changes to individual workers and organisational and systems responses is a large and complex task. The introduction of any new area or innovation is challenging, as noted earlier. Underscoring this challenge is evidence that indicates that transfer of knowledge and best practice into organisations is often slow, costly and prone to failure, with approximately 70 percent of all change programs failing after initiation (By 2005).

To identify the evidence of the most effective means by which to facilitate the uptake of new innovations, the National Centre for Education and Training on Addiction (NCETA) has undertaken a systematic review of the research on different strategies used to improved practice (Bywood et al. 2008)*. We examined research evidence on the effectiveness of the 16 different strategies shown in Table 8.1.

* Copies of the three documents in this series are downloadable from the NCETA website
www.nceta.flinders.edu.au
Table 8.1 Types of strategy used to improve practice (Bywood et al. 2008)

<table>
<thead>
<tr>
<th>Professional interventions</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Educational materials</td>
</tr>
<tr>
<td>2. Local consensus processes</td>
</tr>
<tr>
<td>3. Educational meetings</td>
</tr>
<tr>
<td>4. Educational outreach (academic detailing)</td>
</tr>
<tr>
<td>5. Local opinion leaders</td>
</tr>
<tr>
<td>6. Patient-mediated interventions</td>
</tr>
<tr>
<td>7. Prompts and reminders</td>
</tr>
<tr>
<td>8. Audit and feedback</td>
</tr>
<tr>
<td>9. Financial incentives</td>
</tr>
<tr>
<td>10. Electronic educational sources</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Organisational interventions</th>
</tr>
</thead>
<tbody>
<tr>
<td>11. Record and office systems</td>
</tr>
<tr>
<td>12. Multi-disciplinary collaborative approaches</td>
</tr>
<tr>
<td>13. Alternative care approaches</td>
</tr>
<tr>
<td>14. Continuous quality improvement</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Other interventions</th>
</tr>
</thead>
<tbody>
<tr>
<td>15. Mass media</td>
</tr>
<tr>
<td>16. Multi-faceted interventions</td>
</tr>
</tbody>
</table>

The strongest strategies for effectiveness in achieving professional practice change was for:

- 1. Interactive educational meetings
- 2. Educational outreach visits
- 3. Prompts and reminders
- 4. Audit and feedback.

These strategies have applicability in the upskilling of workers and associated systems change in relation to FASD. Strategies 1. (interactive educational meetings) and 2. (educational outreach visits) involve interaction between the worker and a change agent and also on-site sessions. Strategies 3. (provision of prompts and reminders) and 4. (auditing and feedback) address organisational issues and require changes to the operating systems to ensure that workers are able to implement the new knowledge they have acquired or the new practice regime. For example that might involve in this context a reminder to assess all new pregnant mothers for risky drinking.

In much the same way that there is a range of factors that predispose, precipitate and perpetuate risky behaviours among individuals, similar factors operate in regard to professional practice. Change is complex and requires a multi-level approach that incorporates not just training for individual workers but also a raft of broader systems change components to address the full range of barriers and stigma associated with FASD.

NCETA has recently examined the theories which underpin professional behaviour and organisational change (Bywood et al. 2008). While no theory fully or adequately accounts for the change process, the Theory of Planned Behaviour (TPB) contains elements that may be of value in the present context (Ajzen 1985). TPB defines the behaviour of interest in terms of the target, action, context and time. For example, if the behaviour of interest is to persuade practitioners to advise women to stop drinking alcohol during pregnancy, then applying the TPB would involve:
• Target - general practitioners / obstetricians

• Action - advise pregnant female patients to stop drinking

• Context - during a routine visit

• Time - in practice hours.

As appreciation and understanding of FASD and its causes and consequences is still a relatively recent phenomenon, a comprehensive set of strategies will be required to bring about change in health and human services workers and the service delivery systems in which they function. Such a comprehensive strategy should include, but extends well beyond, provision of training. Encouragingly, there is increased interest in issues pertaining to child protection and parenting in general in the community and by relevant service sectors. Dealing more effectively with FASD is therefore likely to be more positively received than was previously the case. Nonetheless, to successfully tackle this issue there are crucial impediments related to stigma and negative and punitive attitudes must also be addressed.
Key points

- Alcohol is the most popular and widely used psychoactive substance in Australia and plays a significant role in a wide range of social activities. One of the largest social changes that has occurred in recent years relates to the increased similarity in patterns of alcohol use by men and women.
- Changes in drinking behaviours have occurred in the broader context of a large number of changes in the social and cultural norms for young people, particularly among young women.
- To be effective, interventions and prevention strategies for FASD need to consider the well established nature of drinking patterns, and the social and symbolic significance of alcohol in young women’s lives.
- Evidence suggests that uptake of new knowledge and best practice into organisations is often slow, costly and prone to failure. The most effective strategies to achieve change in professional practice are: interactive educational sessions; educational outreach visits by FASD experts; prompts and reminders; and auditing of organisational systems to ensure clinicians are able to implement new knowledge and provision of feedback to clinicians and services.
- Training of health professionals is essential to achieve better prevention and intervention responses to FASD; however, a raft of organisational changes are also required if strategies are to be successful. These changes face a range of barriers, which may be found across a variety of areas, including resource availability, policy approaches, and the political, practice, social and educational environments in which change must take place.
- Finally, crucial impediments to change relate to stigma and to negative and punitive attitudes surrounding problematic alcohol use and FASD. These should also be addressed.
Early diagnosis and intervention will allow children with conditions comprising the spectrum of Fetal Alcohol Spectrum Disorders (FASD), to reach their potential, and substantially reduce the risk of secondary social, emotional and behavioural problems in adult life (Streissguth et al. 1991; Streissguth et al. 2004). Diagnosis of FASD in a child also provides an opportunity for offering treatment to the mother and thus preventing alcohol exposure and hence adverse outcomes for both the mother and baby in future pregnancies.

Diagnostic guidelines for assessing children suspected to have FASD have been published in North America (Stratton et al. 1996; Astley 2004; Bertrand et al. 2004; Chudley et al. 2005; Hoyme et al. 2005). Recommendations for services offering assessment of children at risk include: the establishment of multidisciplinary teams whose members should have specific training in assessing children to diagnose or exclude FASD; the ability to assess the child's and family's strengths (and needs) and to make referrals for further investigation or management, as appropriate.

Specialised diagnostic and assessment services have only recently become available in Australia and have neither sufficient nor sustainable funding. A recent international audit of diagnostic and evaluation clinics for children exposed to alcohol in pregnancy or with suspected FASD highlights the value of a multidisciplinary approach and will inform service development in Australia (Peadon et al. 2008). The Foundation for Alcohol Research and Education (FARE) has recently funded a pilot FASD diagnostic clinic at the Children's Hospital at Westmead in Sydney.

9.1 International diagnostic services

In the study by Peadon and colleagues, FASD clinics were identified by searching literature databases (MEDLINE, CINAHL, EMBASE and PsycINFO) and the internet using the Google search engine (Peadon et al. 2008) and reviewing references in published papers. In countries in which no clinic was identified in the initial search, researchers and organisations identified as being involved with people with FASD (e.g. through having published papers or presented research at scientific meetings) were contacted. A self-administered, three-page postal questionnaire, piloted by structured telephone interview, was used to collect information from clinics about their patient population (e.g. number of patients, age, referral procedures), staff (including health professional group, role and training), assessment process (including diagnostic tools and diagnostic criteria used) and other services or roles provided (e.g. management, research). For clinics that did not respond to the survey, published evaluation reports were used by the researchers, when available, to complete questionnaires. Questionnaire recipients were also asked to provide contact details of other clinics known to them.

Questionnaires were completed for 34 clinics: 29 were in North America (the majority in the USA and Canada); two in Africa (both were in South Africa); two in Europe (in Italy and the UK); and one in South America (Chile). Characteristics of these clinics are shown in Table 9.1. There were no clinics identified in Asia or Australasia. There was considerable variation
between clinics in services offered, clinic populations, type and numbers of health professionals, methods of assessment and funding sources. Clinics saw between 20 and 1600 new patients per year. In 24 of the clinics, the majority of children seen lived in out-of-home care, including foster and extended family care, and in 20 of these clinics more than 75 percent of children lived away from their biological parents. Three clinics saw predominantly Indigenous children. Most clinics accepted referrals from multiple sources, including eight clinics with no specific criteria for referral. All clinics offered a diagnostic service and 16 also screened at-risk children who had been exposed to alcohol in utero. However, only 15 clinics offered short-term management and nine offered long-term management of children with FASD.

All but one of the 33 clinics employed a multi-disciplinary team, the most common professional team members being paediatricians and psychologists. All clinics employed medical staff, 33 employed psychologists, 23 employed allied health staff (e.g. physiotherapists, occupational therapists) and 29 employed family support staff (e.g. social workers, mental health workers, case managers, family advocates). In most (32) clinics at least one member of the team had specialist training in the assessment of children for FASD. Assessment methods varied: 23 routinely performed physical examination; 32 did neuro-behavioural assessments; 25 took photographs; and 17 used facial diagnostic software. The median duration of consultation was 3.25 hours with a range between 30 minutes and six hours.

Five different sets of diagnostic criteria were used by clinics and 11 clinics either simultaneously used more than one set of diagnostic criteria or used an adaptation of standard published criteria (Stratton et al. 1996; Astley 2004; Bertrand et al. 2004; Chudley et al. 2005; Hoyme et al. 2005). Funding came from a variety of sources, including charitable and community organizations and few clinics had stable ongoing funding. Four clinics outside North America were funded partially or wholly by research grants from the USA, suggesting they may not be sustainable. Only two clinics (both in the USA) relied wholly on patient fees (Table 9.1).

9.2 Implications for development of diagnostic and assessment services in Australia

The study by Peadon et al. confirms that diagnostic and assessment services for children exposed to alcohol in pregnancy or with FASD are concentrated in North America and that clinical services outside North America are mostly dependent on research funding from the USA (Peadon et al. 2008). Countries such as Australia, in planning diagnostic services, should aim to develop multidisciplinary teams of specialists trained in the screening, diagnosis and management of FASD. Ideally, an interdisciplinary approach, such as that used recently for the Lililwan study in remote Western Australia should be taken (Latimer et al. 2010; Fitzpatrick et al. 2012). This requires that the multidisciplinary team comes together to assess the child, to ‘case conference’, and to jointly assign a diagnosis and develop a management plan and a strategy for feedback to parents, teachers and other health professionals. However, models for service provision need to be adapted to the population distribution and needs. For example, it may be most appropriate to train core teams of professionals working in the area of child development in each Australian State and Territory in the diagnosis and assessment of children exposed to alcohol in pregnancy. Alternatively, specialized clinics could be set up in one or more states to provide a national referral service. A mobile team, visiting intermittently, may be appropriate in remote settings. In Indigenous
communities the assessments may need to be adapted to account for language and cultural needs of the population. For rural and remote settings telemedicine could be used by specialised clinicians to complement local expertise (Elliott et al. 2012; Fitzpatrick et al. 2012).

Professionals working in the clinics identified in Peardon’s study used a variety of diagnostic criteria, including those proposed by the University of Washington, the Centres for Disease Control, the Institute of Medicine and Hoyme (Peardon et al. 2008). Clinics frequently used two different sets of criteria in combination or used modifications of published criteria (Peardon et al. 2008). It will be important to establish agreement about the most appropriate diagnostic criteria for use in Australia because this would enable standardization and comparison of data collected by clinical services and researchers and would be particularly important for intervention trials. Currently, the FASD Collaboration*** is funded by the Australian Government Department of Health and Ageing to review the medical literature and to seek input from clinicians nationally regarding their preference for diagnostic criteria for use in Australia and the justification for a screening program. The diagnostic method must also be evidenced-based, sensitive and specific, and account for other exposures during pregnancy and early life events (Astley and Clarren 2001).

Mutch and colleagues suggest that the University of Washington FASD 4-digit diagnostic code (Astley 2006) fulfils these best practice criteria and recommend it as the method of choice for Australia (Mutch et al. 2009). The FASD Collaboration concluded that elements of both the University of Washington and Canadian criteria were the best fit for clinical practice in Australia. A uniform diagnostic capacity, agreed and applicable across Australia, would assist in identifying opportunities for intervention, prevention and treatment for FAS.

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*** The Australia FASD Collaboration members are: Carol Bower1, Elizabeth J Elliot2,3, Raewyn C Mutch1,4, Janet M Payne1, Jane Latimer5, Elizabeth Russell6, James Fitzpatrick2, Lorian Hayes7, Lucinda Burns8, Jane Halliday9, Heather D’Antoine8, Amanda Wilkins5,4, Elizabeth Peardon1,3, Sue Miers1, Maureen Carter12, Colleen O’Leary1,13, Anne McKenzie1, Rochelle E Watkins1, Heather M Jones1.
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2 Discipline of Paediatrics and Child Health, University of Sydney, Sydney
3 The Children’s Hospital at Westmead, Sydney
4 Child and Adolescent health Service, Department of Health Western Australia, Perth
5 The George Institute for Global Health, Sydney
6 Russell Family Fetal Alcohol Disorders Association, Cairns
7 Centre for Chronic Disease, School of Medicine, University of Queensland, Brisbane
8 National Drug and Alcohol Research Centre, University of New South Wales, Sydney
9 Public Health Genetics, Laboratory and Community genetics, Murdoch Children’s Research Institute
10 Menzies School of Health Research, Darwin
11 National Organisation for Fetal Alcohol Syndrome and Related Disorders, Adelaide
12 Nindilingarri Cultural Health Service, Fitzroy Crossing
13 National Drug Research Institute, Curtin University, Perth
## Table 9.1 Clinic characteristics (adapted from reference 8)

<table>
<thead>
<tr>
<th>Clinic Site</th>
<th>Funding Source</th>
<th>Services Offered</th>
<th>Referral Criteria</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Canada</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Province A</td>
<td>State, fee for service</td>
<td>Diagnostic, short term management</td>
<td>None</td>
</tr>
<tr>
<td>Province B</td>
<td>State, research, community</td>
<td>Diagnostic, short term management</td>
<td>Children with verified prenatal exposure to alcohol selected from the waiting list for the psychology clinic</td>
</tr>
<tr>
<td>Province C</td>
<td>Federal, charitable</td>
<td>Screening, diagnosis, management</td>
<td>Children of women in a drug treatment programme only</td>
</tr>
<tr>
<td>Province C</td>
<td>Federal funding now ceased; clinic not operational</td>
<td>Diagnostic, short term management</td>
<td>None</td>
</tr>
<tr>
<td>Province C</td>
<td>State</td>
<td>Screening, diagnosis, management</td>
<td>Prenatal alcohol exposure and evidence of CNS (behaviour)</td>
</tr>
<tr>
<td><strong>USA</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>State A</td>
<td>Federal</td>
<td>Diagnosis, short term management</td>
<td>Prenatal alcohol exposure</td>
</tr>
<tr>
<td>State B</td>
<td>Self-pay, insurance</td>
<td>Diagnosis</td>
<td>None</td>
</tr>
<tr>
<td>State B</td>
<td>Insurance, research grants</td>
<td>Screening, diagnosis, management</td>
<td>None</td>
</tr>
<tr>
<td>State B</td>
<td>Fee for service</td>
<td>Diagnosis</td>
<td>None</td>
</tr>
<tr>
<td>State B</td>
<td>State</td>
<td>Screening, diagnosis, management</td>
<td>Prenatal alcohol exposure and contacted telephone information service</td>
</tr>
<tr>
<td>State C</td>
<td>State and federal funding, fee for service, insurance</td>
<td>Screening, diagnosis, management</td>
<td>Prenatal exposure to alcohol or other drugs</td>
</tr>
<tr>
<td>State D</td>
<td>Research grants</td>
<td>Screening, diagnosis</td>
<td>Children of heavy drinkers</td>
</tr>
<tr>
<td>State E</td>
<td>Fee for service, charitable foundation</td>
<td>Diagnosis</td>
<td>FASD highly suspected, but may not be confirmed</td>
</tr>
<tr>
<td>State F</td>
<td>State and federal</td>
<td>Screening, diagnosis</td>
<td>None</td>
</tr>
<tr>
<td>State G</td>
<td>Federal</td>
<td>Screening, diagnosis</td>
<td>Developmental delay, growth parameters less than 25th centile, known prenatal alcohol exposure, or previous diagnosis of FAS/FASD</td>
</tr>
<tr>
<td>State H</td>
<td>State and federal funding, fee for service</td>
<td>Screening, diagnosis, management</td>
<td>None</td>
</tr>
<tr>
<td>State I</td>
<td>Sliding fee scale, adoption subsidy, children services, contributions</td>
<td>Screening, diagnosis, management</td>
<td>Prenatal alcohol exposure suspected and referrals screened for suitability</td>
</tr>
<tr>
<td>State J</td>
<td>State</td>
<td>Screening, diagnosis</td>
<td>Any prenatal alcohol exposure</td>
</tr>
<tr>
<td>State K</td>
<td>Contract, federal, state, fee for service</td>
<td>Screening, diagnosis, short term management</td>
<td>Prenatal alcohol exposure, developmental and/or behavioural concerns</td>
</tr>
</tbody>
</table>

Chapter 9: Services and interventions for children exposed to alcohol in pregnancy 

81
<table>
<thead>
<tr>
<th>Clinic Site</th>
<th>Funding Source</th>
<th>Services Offered</th>
<th>Referral Criteria</th>
</tr>
</thead>
<tbody>
<tr>
<td>Chile</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Clinic A</td>
<td>Research grants (US NIH)</td>
<td>Screening, diagnosis, management</td>
<td>Protocol (unspecified)</td>
</tr>
<tr>
<td>South Africa</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Clinic A</td>
<td>Research (US and local)</td>
<td>Screening, diagnosis, management</td>
<td>Birth records from local hospitals</td>
</tr>
<tr>
<td>Clinic B</td>
<td>Federal (US research)</td>
<td>Screening, diagnosis, management</td>
<td>Developmental delay, growth parameters less than 25&lt;sup&gt;th&lt;/sup&gt; centile, known prenatal alcohol exposure, or previous diagnosis of FAS/FASD</td>
</tr>
<tr>
<td>Italy</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Clinic A</td>
<td>Federal (US research)</td>
<td>Screening, diagnosis</td>
<td>Developmental delay, growth parameters less than 25&lt;sup&gt;th&lt;/sup&gt; centile, known prenatal alcohol exposure, or previous diagnosis of FAS/FASD</td>
</tr>
<tr>
<td>UK</td>
<td></td>
<td>Diagnosis</td>
<td>none</td>
</tr>
</tbody>
</table>

<sup>a</sup> Aggregate data for network of 11 clinics

<sup>b</sup> These clinics also have research focussed satellite clinics; however, insufficient separate information was given for separate inclusion

<sup>c</sup> Clinics are a linked research network
Case study: The University of Washington Fetal Alcohol Diagnostic and Preventive Network: a model of care for Australia?

The FASD Diagnostic and Preventive Network, based at the Centre on Human Development and Disability in the University of Washington, has developed a model for diagnosing, treating and preventing FASD (Astley and Clarren 1995; Astley et al. 1995; Astley et al. 1999; Astley et al. 2000; Astley and Clarren 2000; Astley and Clarren 2001; Astley et al. 2002; Astley 2004; Astley 2006). The fulcrum to the University of Washington FASD Diagnostic and Preventative Network is the FASD 4-Digit-Diagnostic Code, an evidence-based, specific and sensitive diagnostic tool. The University of Washington’s FASD 4-Digit-Diagnostic code allows clinicians to assign a code to a broad range of clinical domains that are assessed using an interdisciplinary approach and also to report the severity of abnormalities. In 2008 the University of Washington’s interdisciplinary team included a clinic coordinator, paediatrician, speech and language pathologist, occupational therapist, paediatric clinical psychologist, social worker, family advocate and research staff. The detail afforded by the UW interdisciplinary assessment is efficiently completed during one outpatient visit. The FASD 4-Digit-Code ensures the individual phenotype is understood, the child’s strengths and weaknesses are identified and that a therapeutic plan is tailored to meet the measured needs of each child.

The 4-Digits of the University of Washington Code denote four principal domains examined during diagnostic assessment: growth, facial appearance; central nervous system structure and function; and history of alcohol exposure. The code considers two additional domains: prenatal and postnatal exposures to other teratogenic and harmful substances; and consideration of early life environmental, psychological and physical events. The specificity and sensitivity afforded by the categorical outcomes of the FASD 4-Digit-Diagnostic code allows for exclusion of and research into other factors, such as genetic and metabolic phenomena, that may protect against, promote or mimic a phenotype resembling FASD.

On-line training in the FASD 4-Digit-Diagnostic code is available through the University of Washington website (see http://depts.washington.edu/fasdpn/htmls/online-train.htm). The on-line course is clearly structured for easy learning and amenable to busy professionals completing the brief modules when convenient. The University of Washington diagnostic method is evidence based and the diagnostic terms describe measured clinical findings. The University of Washington method does not employ labels such as alcohol-related and therefore may reduce clinicians’ concerns and reticence to diagnose FASD for fear of stigmatising their clients (Payne et al. 2005).

9.3 Interventions for children with FASD

Early intervention is recommended for children with conditions comprising Fetal Alcohol Spectrum Disorders (FASD) because longitudinal studies suggest that interventions may reduce the secondary disabilities seen in adults by 2-fold to 4-fold (Streissguth et al. 2004; Spohr et al. 2007). However, the evidence for specific interventions is often anecdotal. A systematic review of the published literature was conducted by Peadon et al. to identify and evaluate the efficacy of interventions for FASD, including pharmacological, behavioural and educational strategies (Peadon et al. 2007).

A comprehensive search strategy was used, identifying 5,899 studies about FASD. After exclusion of ineligible studies (e.g. animal studies, studies which did not evaluate an intervention, and studies with an inappropriate patient population), only eleven met the review’s inclusion criteria. The two pharmacological interventions, both small, placebo-controlled randomised controlled trials (RCTs) showed some beneficial outcomes, particularly from stimulant medication (Snyder et al. 1997; Oesterheld et al. 1998). In one trial, methylphenidate significantly improved hyperactivity and impulsivity but not attention (Oesterheld et al. 1998). In the other trial the child’s usual stimulant medication did not
benefit attention but significantly improved hyperactivity. Harms reported for stimulant medications included decreased appetite, headache and insomnia (Snyder et al. 1997).

Six studies evaluating educational and learning strategies, including three small RCTs, were identified (Meyer 1998; Riley et al. 2003; Stromland et al. 2005; Padgett et al. 2006; Coles et al. 2007; Kable et al. 2007). Children with FASD were able to learn new skills through using a virtual reality computer game but not through modelling of a task (Meyer 1998; Padgett et al. 2006; Coles et al. 2007). Classroom interventions may improve language skills, classroom and adaptive behaviour and mathematical skills (Riley et al. 2003; Stromland et al. 2005). There was evidence of benefit from social skills training in one quasi-RCT and weak evidence for the value of social communication interventions (one pre- and post- intervention study) (Timler et al. 2005; O'Connor et al. 2006). Attention Process Training, evaluated in an RCT led to a significant improvement in sustained attention (Vernescu 2007).

In summary, there is limited high quality evidence of the benefits of specific interventions for children with FASD. The strongest evidence is for social skills training, for stimulant medications (which may improve hyperactivity and impulsivity but not attention) and for Attention Process Training (Peadon et al. 2008). However, there were significant methodological weaknesses in all the intervention studies identified, including small sample sizes, inadequate study design (e.g. lack of blinding and allocation concealment) and short term follow up. These issues must be addressed in future studies to strengthen the evidence base for the management of children with FASD. We are aware of several large, well-designed RCTs currently underway in North America to evaluate either behavioural interventions, communication strategies or use of non-stimulant medications for attention deficit/hyperactivity in children with FASD.

A protocol for a systematic review of the pharmacological interventions for ADHD symptoms in children with FASD has been published in the Cochrane Collaboration library (Peadon et al. 2012) and another protocol, under development, will review the non-pharmacological interventions available for children with FASD. This builds on previous work by Peadon and colleagues (Peadon et al. 2008).

In the absence of good evidence of effectiveness of specific therapies, it is recommended that the management of children with FASD be co-ordinated by a developmental paediatrician and/or child development clinic with access to appropriated medical, other health professional, educational and community services and to family support and education. Optimal management required co-operation between health and education professionals and community services.

Although emphasis in this document is placed on the recognition and management of FASD in childhood, the problems associated with fetal exposure to alcohol are lifelong. It is therefore important that a wide range of professionals (including teachers, lawyers and criminal justice personnel) are aware of the adverse outcomes that may persist into adolescence and adulthood and know where to refer these people for assessment and management.
The National Organisation for Fetal Alcohol Syndrome (FAS) and Related Disorders Inc (NOFASARD) is a voluntary organisation established in Adelaide in 1998 in response to a perceived need to raise awareness in Australia of the issues surrounding the damage caused by prenatal exposure to alcohol, and to provide assistance to individuals with FASD, their families, carers and other service providers. It also aims to promote good practice in the management of FAS and related disorders resulting from prenatal alcohol exposure and to support prevention efforts.

**National Organisation for Fetal Alcohol Syndrome and Related Disorders Inc offers the following services:**

- Workshops and keynote presentations to a range of community groups and professional organisations, both nationally and internationally (more than 200 to date).
- Provision of information and support to enquiring families, community members and professional service providers such as teachers, allied health and medical professionals.
- Advocacy services for individuals affected by FASD and their parents and caregivers across a range of sectors, including health, education, disability, social service and justice.
- Establishment and co-ordination of a network of relevant national and international agencies, community action groups and individuals.

The organisation may be contacted on tel. 0418 854 947 (Sue Miers), email: sue@nofasard.org.au, website: [http://www.nofasard.org.au/](http://www.nofasard.org.au/)
Key points

- Early diagnosis provides an opportunity for preventing alcohol exposure in future pregnancies and enables early intervention to reduce the risk of secondary problems in adolescents and adults with FASD.
- Assessment and diagnostic guidelines developed internationally recommend the use of multidisciplinary teams; however, no sustainable diagnostic or assessment services currently exist in Australia.
- A number of diagnostic clinics operate worldwide, the majority in the USA and Canada. Variation exists between clinics in the referral processes, services offered, populations seen, staff profile, assessment protocols and funding sources. Virtually all clinics employ multidisciplinary teams.
- A number of implications for service development in Australia have been identified in an international clinic survey. Options include the establishment of teams of specially trained health professionals, or of specialised clinics, in some or all States and Territories. Other service models, including models for use in remote or Indigenous communities and telemedicine, should also be considered.
- National agreement regarding the diagnostic criteria for FASD and the protocol for assessment is required.
- Clinical teams could be trained in specially convened workshops by national or international experts and would have a responsibility for training other health professionals in diagnosis and assessment of FASD. On-line training is also available.
- Early diagnosis allows for early intervention, which is recommended for children with FASD to enable them to reach their potential and to reduce secondary problems in adult life.
- There is a paucity of good quality information about the efficacy of specific interventions for FASD. Further research, using randomised controlled trials with adequate samples sizes, as is currently underway in North America, is required to improve the evidence base for management.
- A wide range of information and support services for individuals, families, carers and services providers are provided by the National Organisation for Fetal Alcohol Syndrome and Related Disorders (NOFASARD). Resources for use by justice system personnel are planned for the future.
10. **ECONOMIC IMPACT OF FASD IN AUSTRALIA**  

*Lucy Burns and Elizabeth Elliott*

FASD is associated with a number of poor health outcomes including birth defects, developmental, behavioural and learning difficulties and premature death (Streissguth 1994; Habbick et al. 1997; Applied Economics 2008; Elliott et al. 2008). These outcomes result in high costs both to individuals with FASD and their families/carers (private costs) and to the community as a whole including health and education services (social costs). The IGCD commissioned a consultant to estimate the estimate the economic costs of FASD in Australia. Due to limitations in the availability and quality of data this estimate was not possible. Below we provide a summary of the Applied Economics 2008 report on FASD including the methods for calculating these costs and a review of international estimates (Applied Economics 2008).

10.1 Costing FASD: Approaches taken and international evidence

10.1.1 Cost concepts

The costs of morbidities can be defined and estimated in various ways. Costing FASD is no exception. Four main issues were identified when considering costing FASD.

1. **Individual and aggregate community costs.**

The costs of FASD may be estimated for individuals in each diagnostic group of FASD (FAS, ARBD, ARND) or for all individuals with FASD in the community. Community costs are essentially an aggregation of the costs incurred in individual cases. Accordingly, we focus on how to estimate government and non-government costs of FASD for individual cases for different components of FASD. These costs can be aggregated according to the number of FASD cases in each group.

2. **Annual or lifetime costs for individuals with FASD.**

The costs of FASD may be estimated on a per annum basis or a lifetime basis (from age 0 to death). When lifetime costs are estimated, these may be expressed as a simple total or on a present value basis by discounting all future costs back to a present date.

3. **Aggregate community costs may be estimated on an incremental flow or as a prevalence cost.**

We define an incremental cost as the cost associated with incident FASD cases in a given period. However, this would include any lifetime costs associated with these births. Thus if there are 1000 new FASD cases in a year, the cost of FASD in that year could be calculated as the cost of these 1,000 cases over their lifetime discounted back to that year.

On the other hand, the costs of FASD in any one year could be estimated (in principle at least) as the cost of all FASD cases alive in that year, regardless of when they were born. This could be viewed as an estimate of the prevalence cost FASD that does not take lifetime costs into account.

For policy purposes the former of these estimates is more useful as policy makers want to know how policies may reduce FASD costs going forward. However, some studies of disease...
costing estimate prevalence costs as well as incremental lifetime costs for example, Applied Economics, 2005 for hepatitis C (Applied Economics 2005).

4. The elements of FASD costs.
These may be considered as follows:
- (a) the direct costs to government of health care and accommodation for FASD cases
- (b) other costs to government including special education and employment support services, community services, income support, and justice services
- (c) costs borne by FASD individuals, including loss of productivity (income), reduced quality of life and reduced longevity.

The costs to government may be viewed as an increase in tax payments or as the value of other services foregone because of the expenditures on FASD.

10.1.2 International evidence
As shown below and elsewhere (Applied Economics 2008), most studies of the costs of FASD focus on direct costs to government for the health care and accommodation for people with FASD, i.e. the elements discussed in 4 (a) above. A few studies have also included estimates of costs borne by FASD individuals (see 4(c) above), specifically productivity loss (Lupton et al. 2004). These authors were unable to identify any studies that estimated the costs associated with 4(b), that is, other costs to government such as support services; similarly, no studies were found to estimate the other costs borne by people with FASD (as per 4(c) above), such as of reductions in quality of life or reduced longevity. The reason for these exclusions is a lack of data. There are no systemic data on the social costs associated with FASD cases or on longevity.

To date, there have been no Australian studies of the costs of FASD for individuals or for the community. As reported in Applied Economics and summarised below, there have been some international studies of the costs of FASD (Applied Economics 2008). However, most of these are limited in scope, both in terms of estimating the numbers of FASD cases and in terms of the types of costs included, and are also of limited comparability.

Several studies have been conducted into the cost of fetal alcohol exposure. These have included those conducted by Harwood and Napolitano and by Weeks, both of which considered the health system in the United States and the lifetime cost of FAS (Harwood and Napolitano 1985; Weeks 1989). Another study by Klug and Burd considered the lifetime health costs of FAS, while a further paper by Stade et al. included the patient costs per year of FAS/Fetal Alcohol Effects (Klug and Burd 2003; Stade et al. 2006). Between 1984 and 1991 Abel and Sokol undertook a series of studies on the cost impact of FAS to the United States health system in which they progressively edited and updated their data (Abel and Sokol 1987; Abel and Sokol 1991; Abel and Sokol 1991). A meta analysis of various cost studies by Lupton and colleagues is summarised in Table 10.1, with an additional study by Stade 2006, (Study H) also included (Stade et al. 2006). These studies may be broadly classified as seeking to measure either annual costs (studies A to H) or lifetime costs (studies I and J).

To help compare the definition of cost in these studies, Table 10.1 adapts the basis of each of their original cost estimates so that (a) incidence in the case of studies A to F is standardised on two per 1,000 live births; and (b) residential care up to the age of 65 is included, but in
some cases only for care for mental retardation, and in study H up to the age of 21 (Stade et al. 2006). All studies exclude costs associated with the loss of productivity, apart from study H, which includes the productivity loss of the child and carer and study J which includes the productivity loss of the child (Weeks 1989; Stade et al. 2006).

All costs in Table 10.1 are measured in constant 2002 $US, with the exception of study G which uses 2003 $US prices and study H which uses 2006 SCAD (Klug and Burd 2003; Stade et al. 2006)

These are as follows:
- total costs with a standardised incidence (two per 1,000) on a United States population of 301 million with the age up to which total costs are included varying from 21 to 65 years (the exception are study H which relates to Canada) (Stade et al. 2006)
- case costs (total costs divided by the number of cases)
- lifetime costs are calculated with assumptions based on study I regarding the incidence of costs up to the age of 65, as most studies only included costs up to the age of 21 (Harwood and Napolitano 1985).

Notwithstanding the attempt by to introduce some comparability between these diverse studies, they exhibit considerable variation (Lupton et al. 2004). For studies A to F, total costs per annum vary by some $US9 billion in the USA and annual costs per case by some $US20,000. In the case of studies A to F, I and J, the variance in lifetime costs is some $US2.6 million. The NPV of lifetime cost, discounted at three percent ranges from $US100,000 million to $US1.4 million.

As further explored by Applied Economics, it is clear that the variation between the population basis of the studies, what the studies are seeking to measure and the assumptions concerning measurement are too great to provide meaningful comparisons (Applied Economics 2008). There is a need for additional work on the costs associated with FASD.

In addition to the studies reported in Table 10.1. There have been four recently published FASD costing studies. Stade and colleagues revised the estimated direct and indirect costs associated with FASD using a cross sectional study of 250 participants. Costs were expressed in 2007 SCAD. The adjusted annual cost per child with FASD was $21642. The study was not designed to estimate the costs at the population level, but given the need to illustrate the cost to the nation, population estimates were calculated using an estimate prevalence of 1 in 100 people. The annual cost of FASD to Canada for people aged 0-53 was estimated to be $5.3 billion 2007 SCAD (Stade et al. 2009).

In another Canadian study the short and long term costs of FASD were estimated for the period 2002-2005 in Alberta using an incidence rate of 3-9 per 1000 live births. The number of live births for each year 2002-2005 inclusive were used in the estimations (ranging from 38 313 in 2002 to 41 355 in 2005). The long term costs included the projected annual costs incurred by a cohort of children born with FASD. The short term costs included the amount of money incurred by people presently living with FASD. The total annual costs were estimated to be $48 to $143 million. The long term costs rose from $130 to $400 million each year. The authors acknowledge this is likely to be significant underestimate as it does not include individuals living in institutions (e.g. disability and justice) or homeless people (Thanh and Jonsson 2009).
A recently published paper from the US reported higher medical expenditure costs than have been previously reported for children with FAS (Amendah et al. 2011). The study examined annual medical expenditure for children with FAS, including those with and without intellectual disability, using paediatric Medicaid data from unidentified states. Children with FAS incurred annual expenditures that were nine times greater than for children without FAS ($16 782 compared to $1859 in 2005 $US). Intellectual disability was more common among children with FAS than in children without FAS. The annual mean expenditure was 2.8 times greater among children with FAS and intellectual disability than in children with FAS who did not have an intellectual disability.

Another recent study examining health service use by children in the Western Cape of South Africa found that the median number of annual visits to public health care facilities by children with FAS was 8, much greater than the 2.57 annual visits made by all children across all public health care facilities. The average annual cost to society of providing health care to a child with FAS/PFAS was $1039.38 (SUS 2009). At the population level the estimated annual health cost is $70 960 053.68 which equates to 5% of the Western Cape Department of Health’s budget for 2010/11) (Crede et al. 2011).

10.2 Developing an aggregate cost model

Both government and non-government costs of FASD can be aggregated from all the costs incurred by individuals. To measure government costs, individual categories of costs incurred by mothers and carers (such as attendance at health services, community services, education, justice services, carer services, accommodation support and income support, etc.) can be defined and measured on a unit basis e.g. the cost of one GP service or one week of public housing, etc. By multiplying each of the unit costs of government services by their number consumed by persons at different levels of FASD severity (‘mild’, ‘moderate’ and ‘severe’) and for different age cohorts, it is possible to calculate the total lifetime case costs of government services. The net case cost of FASD to government will be the excess cost of FASD per case, relative to individuals in the general population.

To measure the private, non-government costs of FASD it is necessary to model lost workforce and household productivity of people with FASD and their carers, as well as the reduction in their years of life and their diminished quality of life. The amounts that individuals are willing to pay (WTP) to avoid various FASD conditions would capture the monetary cost of both the loss of productivity as well as the emotional cost of FASD attributable to illness and premature mortality. By making assumptions about the value of a healthy life, it is possible to estimate what people are willing to pay to avoid disability associated with varying levels of FASD severity, based upon their departures from full health and their premature death.

The sum of the lifetime government service costs and private costs for Indigenous and non-Indigenous people with FASD and their carers at each level of severity would represent average lifetime case costs. Multiplied by the population of cases for each level of severity, this would represent the dollar burden of FASD to Australia, based upon the cohort for the relevant year. If assumptions were made about the survival of people with FASD, it would be possible to calculate the present value of lifetime costs and the FASD burden.
10.3 Data to be collected

Applied Economics reports on the unit costs for services used by persons with FASD and their carers in Australia relating to the year 2005-06 for each State and Territory for both Indigenous and non-Indigenous persons (Applied Economics 2005; Applied Economics 2008). However, data on the total number of people with FASD by level of severity are not available. Nor are there data on the service frequency for individuals in each age cohort.

To estimate the true costs of FASD, it remains necessary to estimate the prevalence of FASD by levels of severity and the volume of services provided by governments to people with FASD as well as the private costs of FASD. Collection of data on the prevalence of FASD in any year in each State and Territory would probably have to be based on estimates or opinions of experts in the field in each jurisdiction.

Data on the frequency of service use could be collected by conducting a survey by way of a series of focus groups with samples of parents/carers to obtain information about their actual service use experience.
### Table 10.1: Summary of international studies estimating the costs of FASD

<table>
<thead>
<tr>
<th>Study</th>
<th>Publication</th>
<th>Prices</th>
<th>Estimated</th>
<th>Health</th>
<th>Residential</th>
<th>Lost</th>
<th>Disability</th>
<th>Other</th>
<th>Annual cost</th>
<th>Constant cost</th>
<th>NPV @ 3 percent discount</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td>Year</td>
<td>incidence</td>
<td>care costs</td>
<td>Care and support till age</td>
<td>productivity</td>
<td>years/ QALYs</td>
<td>social problems</td>
<td>National Per case</td>
<td>of 65 years</td>
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<tr>
<td><strong>FAS annual cost studies</strong></td>
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<td></td>
<td></td>
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<td></td>
<td></td>
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</tr>
<tr>
<td>A. Abel &amp; Sokol a</td>
<td>1991a</td>
<td>US$2002</td>
<td>2/1000</td>
<td>21</td>
<td>65 b</td>
<td>N</td>
<td>N N N</td>
<td>4.75 bn c</td>
<td>9,058</td>
<td>589,000</td>
<td>278,000</td>
</tr>
<tr>
<td>B. Abel &amp; Sokol a</td>
<td>1987</td>
<td>US$2002</td>
<td>2/1000</td>
<td>21</td>
<td>65 b</td>
<td>N</td>
<td>N N N</td>
<td>3.60 bn c</td>
<td>6,865</td>
<td>446,000</td>
<td>210,000</td>
</tr>
<tr>
<td>C. Abel &amp; Sokol a</td>
<td>1991b</td>
<td>US$2002</td>
<td>2/1000</td>
<td>21</td>
<td>65 b</td>
<td>N</td>
<td>N N N</td>
<td>2.3 bn c</td>
<td>4,386</td>
<td>285,000</td>
<td>134,000</td>
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<tr>
<td>D. Rice a</td>
<td>1990</td>
<td>US$2002</td>
<td>2/1000</td>
<td>21</td>
<td>65 b</td>
<td>N</td>
<td>N N N</td>
<td>3.6 bn c</td>
<td>6,865</td>
<td>446,000</td>
<td>210,000</td>
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<tr>
<td>E. Harwood a</td>
<td>1984</td>
<td>US$2002</td>
<td>2/1000</td>
<td>65</td>
<td>65</td>
<td>N</td>
<td>N N N</td>
<td>11.1 bn c</td>
<td>21,167</td>
<td>1,376,000</td>
<td>649,000</td>
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<tr>
<td>F. Harwood a</td>
<td>1998</td>
<td>US$2002</td>
<td>2/1000</td>
<td>21</td>
<td>65</td>
<td>N</td>
<td>N N N</td>
<td>5.95 bn c</td>
<td>11,346</td>
<td>738,000</td>
<td>348,000</td>
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<tr>
<td>G. Klug &amp; Burd d</td>
<td>2003</td>
<td>US$2003</td>
<td>21</td>
<td>N</td>
<td>N N N</td>
<td>N N N</td>
<td>N N N</td>
<td>2,342</td>
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<tr>
<td><strong>FAS annual cost study</strong></td>
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<tr>
<td>H. Stade et al.</td>
<td>2006</td>
<td>Cn$2006</td>
<td>3/1000</td>
<td>21</td>
<td>21</td>
<td>for carer</td>
<td>N N</td>
<td>0.34 bn</td>
<td>14,342</td>
<td>753,000^</td>
<td>348,000</td>
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<td><strong>FAS lifetime cost studies</strong></td>
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<tr>
<td>I. Harwood &amp; Napolitano a</td>
<td>1985</td>
<td>US$2002</td>
<td>65</td>
<td>65</td>
<td>Y</td>
<td>N</td>
<td>N N</td>
<td>2,000,000</td>
<td>942,000</td>
<td></td>
<td></td>
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<tr>
<td>J. Weeks a</td>
<td>1989</td>
<td>US$2002</td>
<td>65</td>
<td>65</td>
<td>N</td>
<td>N</td>
<td>N N</td>
<td>2,900,000</td>
<td>1,367,000</td>
<td></td>
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</tbody>
</table>

(a) Lupton et al. adjusted for incidence, residential care and productivity as described in the text. Refers Harwood and Napolitano.  
(b) These include only residential costs for mental retardation. They exclude semi-residential care and care for moderate severity.  
(c) As quoted in Lupton et al.  
(d) This study includes medical costs only and is based on ages up to 21 years. Basic costs for normal cases are subtracted.  
^ Refers to Canadian Dollars (C$.). Remainder refer to US Dollars (US$).
Key Points

- FASD results in a wide range of costs to affected individuals and their families/carers (private costs) and the community (social costs). These include direct costs for health care and accommodation, education, employment support services, income support, community services and justice services. Costs to individuals with FASD may include loss of income, reduced quality of life and reduced longevity.

- A recent Canadian study estimates the annual cost of FASD to be $5.3 billion 2007 $CAD.

- There have been no studies of the costs of FASD in Australia. International studies indicate that costs are high, but we have insufficient Australian data to enable comparisons to be made internationally.

- Estimating the economic impact of FASD is necessary to justify and evaluate prevention programs and to inform the distribution of health care resources.

- In order to estimate costs of FASD in Australia, we require accurate data on prevalence of FASD, the health and developmental needs of individuals, frequency of service use including contact with the criminal justice system.
11. POLICY REGARDING ALCOHOL USE IN PREGNANCY

Colleen O’Leary, Courtney Breen, Louise Heuzenroeder, Elizabeth Elliott and Carol Bower

11.1 International policy

Policies and guidelines on the use of alcohol during pregnancy have generated considerable debate in many Western countries, including Australia (Nathanson et al. 2007; O’Brien 2007; O’Leary et al. 2007; Whitehall 2007). As discussed in previous chapters, moderate and heavy prenatal alcohol exposure have been shown to increase the risk of a wide range of health and developmental effects in the fetus (Olegard et al. 1979; Abel and Sokol 1986; Jacobson et al. 1993; Sayal et al. 2007; DeRoo et al. 2008; O’Leary et al. 2009; Sayal et al. 2009; O’Leary et al. 2011). Although there is no strong evidence of increased risk to the fetus from low levels of prenatal alcohol exposure, determining whether there is a threshold effect below which there is no harm to the developing fetus is difficult and research into this continues. The lack of clarity in the published literature about the effect of prenatal exposure to low levels of alcohol has resulted in a range of opinions about whether women should be recommended to abstain from alcohol when pregnant or advised that low levels of alcohol consumption are likely to pose a low risk to the developing fetus (Payne et al. 2005; O’Leary and Bower 2011).

In 2006 a review of the policies in Australia, Canada, the UK, the USA, Ireland, New Zealand, and South Africa was conducted (Table 11.1) (O’Leary et al. 2007). Findings reflected the range of policies found within Australia, from an abstinence message to advice that the risk from low amounts of alcohol is minimal (See Table 11.2). Although abstinence from alcohol was recommended as the safest/prudent choice in all the policies from overseas countries, many of the policies advised that the risk from low amounts of alcohol is minimal. Almost every policy emphasised that the risk to the fetus was highest with heavy, frequent alcohol consumption and in particular, a binge pattern of drinking. Three policies highlighted that when women have consumed alcohol early in pregnancy, cessation or reduction of alcohol consumption will reduce the risk to the fetus (South African Department of Health 2001; Ireland Department of Health 2003; American College of Obstetricians and Gynecologists 2006).

The Royal College of Obstetricians and Gynaecologists in the UK was the only organisation included in the 2006 review to have undertaken a systematic review of the literature, which appears to be the basis for government policies in the UK. Six other organisations indicated that their policy was based on a review (not systematic) of the literature (see Table 11.1).

The current NHMRC (2009) Guidelines now advise that for women who are pregnant or planning a pregnancy, not drinking is the safest option. The level of risk to the fetus is:
- highest when there is high, frequent maternal alcohol intake;
- likely to be low if a woman has consumed only small amounts of alcohol before she knew she was pregnant or during pregnancy;
- hard to predict as it is influenced by maternal and fetal characteristics.
### Table 11.1: Policies on alcohol and pregnancy reproduced from O’Leary et al (2007) [1]

<table>
<thead>
<tr>
<th>Source</th>
<th>Abstinence</th>
<th>Occasional small amounts</th>
<th>Comments</th>
<th>Evidence base†</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Canada</strong></td>
<td></td>
<td></td>
<td></td>
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</tr>
<tr>
<td>Health Canada – National guidelines for the childbearing years</td>
<td>Prudent choice</td>
<td>Risk from low levels of alcohol is minimal</td>
<td>The risk is relative to the amount of alcohol consumed Women who have consumed small amounts of alcohol during pregnancy should be reassured that the risk is likely to be minimal</td>
<td>2</td>
</tr>
<tr>
<td>Public Health Agency of Canada</td>
<td>Safest</td>
<td>No safe amount</td>
<td>During pregnancy there is no safe amount, type or time to drink</td>
<td>2</td>
</tr>
<tr>
<td>Canadian Medical Association</td>
<td>Prudent choice</td>
<td>No specific advice</td>
<td>Physicians can play a leading role in educating and counselling about the dangers of alcohol Pregnant women should receive high priority for alcohol and drug addiction treatment services</td>
<td>5</td>
</tr>
<tr>
<td>Society of Obstetricians and Gynaecologists</td>
<td>Prudent choice</td>
<td>Occasional intake unlikely to cause harm</td>
<td>Excessive or persistent alcohol intake has been associated with fetal alcohol syndrome</td>
<td>2</td>
</tr>
<tr>
<td><strong>United Kingdom</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Royal College of Obstetricians and Gynaecologists</td>
<td>Safest</td>
<td>1-2 standard units once or twice a week</td>
<td>Binge drinking in early pregnancy may be particularly harmful Alcohol offers no benefits in relation to the outcomes of pregnancy</td>
<td>1</td>
</tr>
<tr>
<td>UK Department of Health, National Health Service</td>
<td>Safest</td>
<td>As above</td>
<td>Heavy or frequent drinking can harm your baby; avoid getting drunk</td>
<td>1</td>
</tr>
<tr>
<td>Health Scotland</td>
<td>Safest</td>
<td>As above</td>
<td>Heavy drinking may seriously harm your baby’s development</td>
<td>1</td>
</tr>
<tr>
<td><strong>United States</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>US Surgeon General (2005)</td>
<td>Advised</td>
<td>No safe amount</td>
<td>During pregnancy there is no safe amount, type or time to drink Health professionals should take a history of oral consumption, provide information on the risks and advise abstinence</td>
<td>3</td>
</tr>
<tr>
<td>National Institute on Alcohol Abuse and Alcoholism (NIAAA)</td>
<td>Advised</td>
<td>No safe amount</td>
<td>During pregnancy there is no safe amount, type or time to drink Each pregnancy is different and alcohol may harm one baby more than another</td>
<td>2</td>
</tr>
<tr>
<td>US Department of Health and Human Services, Department of Agriculture Dietary guidelines for Americans 2005</td>
<td>Advised</td>
<td>Not recommended</td>
<td>NIAAA has published on its website a review of drinking moderately and pregnancy by Jacobsen and Jacobsen , which states ‘moderate drinking has much more impact on child development when the mother consumes several drinks in a single day than when she drinks the same quantity in doses of one to two drinks over several days’ The review recommends using a safety factor of 10 to determine a safe drinking level. Although not stated, O’Leary et al.  assumed that this review influenced NIAA policy</td>
<td>5</td>
</tr>
</tbody>
</table>
### Chapter 11: Policy regarding alcohol in pregnancy

<table>
<thead>
<tr>
<th>Source</th>
<th>Abstinence</th>
<th>Occasional small amounts</th>
<th>Comments</th>
<th>Evidence base†</th>
</tr>
</thead>
</table>
| American College of Obstetricians and Gynecologists | Safest     | Small amounts unlikely to cause harm | • Although small amounts of alcohol are unlikely to cause serious harm, women are best advised to refrain from alcohol entirely  
• Even when heavy drinking in early pregnancy has occurred, risk of further harm can be reduced by cessation of alcohol use | 2              |
| American Academy of Pediatrics              | Advised    | No safe amount           | • Potential for harm to the fetus is much stronger with large amounts of maternal alcohol consumption  
• Maternal age, parity and health may contribute to infant outcome                                                                                                                                   | 2              |
| Others                                      |            |                          |                                                                                                                                            |                |
| Ireland Department of Health, Health Promotion Unit | Safest     | Avoid binge drinking     | • A safe level of alcohol consumption during pregnancy has not yet been determined;  
  cutting down or stopping protects your baby                                                                                                                                                    | 5              |
| New Zealand Ministry of Health 39 and Alcohol Advisory Council of New Zealand | Safest     | -                        | • During pregnancy there is no safe amount, type or time to drink  
• Not all women who drink during pregnancy will have a child with fetal alcohol syndrome                                                                                                          | 5              |
| South African Department of Health          | Advised    | Safe level has not been determined | • Women are advised to attend antenatal clinics as early as possible  
• Damage to the baby can be limited by reducing alcohol misuse during pregnancy  
• Men should support their partners to avoid alcohol                                                                                                                                             | 5              |

* Standard drink: UK unit = 8g, Ireland and New Zealand = 10g, South Africa = 12g, Canada = 13.5g and US = 14g.  
† Key to evidence base: 1= systematic literature review, 2= literature review (not systematic review), 3= broad statement or indication that the policy is based on the evidence, but no specific references provided, 4= consensus of authors and 5=not mentioned.
11.2 History of the Australian policy

Alcohol and pregnancy policy in Australia has undergone a number of changes over the past 20 years. In the 1990s the National Health and Medical Research Council (NHMRC) recommended that women abstain from alcohol during pregnancy (NHMRC 1992). Following a review of the literature, the policy was changed in 2001 to advise that a woman who is pregnant or might soon become pregnant ‘may consider not drinking at all’. The policy went on to state that if a woman consumes alcohol during pregnancy she ‘most importantly, should never become intoxicated’ and ‘if a pregnant women chooses to drink, over a week, she should have less than 7 standard drinks, and, on any one day, no more than 2 standard drinks (spread over at least two hours)’. The guidelines also advised ‘that the risk is highest in the earlier stages of pregnancy, including the time from conception to the first missed period’ (NHMRC 2001).

The 2001 NHMRC guidelines were not universally supported across Australian jurisdictions and health professional organisations. They were adopted without alteration by only three organisations in Australia: the Australian Government Department of Health and Ageing, the Western Australian Drug and Alcohol Office and the Tasmanian Department of Health and Human Services. The perception that there is insufficient evidence to conclude that any level of alcohol consumption during pregnancy is low-risk is prevalent in policy from across Australian State and Territory governments. The National clinical guidelines (NCG) for the management of drug use during pregnancy, birth, and the early development years of the newborn (2006), commissioned by the Ministerial Council on Drug Strategy, provide the NHMRC 2001 recommendations with a caveat that they are not, in the opinion of the authors, supported by sufficient evidence to conclude what, if any, level of alcohol consumption during pregnancy is completely safe (Ministerial Council on Drug Strategy 2006). The Victorian Department of Health provides the NHMRC recommendations while advising that a safe level of alcohol consumption during pregnancy has not been determined. However, none of the Australian policies and guidelines reviewed in 2006 mentioned the basis for their recommendation of abstinence. All the Australian medical and nursing organisations that provide guidelines on alcohol and pregnancy promoted abstinence as either the only option or the preferable or safest option. None of the policies, with the exception of that of the Australian College of Midwives, which endorses the National clinical guidelines for the management of drug use during pregnancy, birth and the early development years of the newborn, refers to a review of the evidence.

In 2009, the NHMRC undertook a systematic review of the literature and revised the 2001 national alcohol guidelines to advise that ‘For women who are pregnant or planning a pregnancy, not drinking is the safest option’ (NHMRC 2009). Advice is also given that the level of risk to the fetus is: highest when there is high, frequent maternal alcohol intake; likely to be low if a woman has consumed only small amounts of alcohol before she knew she was pregnant or during pregnancy; and hard to predict as it is influenced by maternal and fetal characteristics. Women who drank alcohol before they knew they were pregnant or during their pregnancy should be reassured that the majority of babies exposed to alcohol suffer no observable harm. The policy also states that women who find it difficult to decrease their alcohol intake during pregnancy will require support and treatment and it is important that they are referred to the appropriate services (NHMRC 2009).

There appears to be some improvement regarding the consistency of policy recommendation since the implementation of the 2009 NHMRC guidelines. A recent audit of the organisations
listed in Table 11.2 found that all government websites (except ACT and TAS) refer to or have links to the NHMRC 2009 recommendations. The ACT Health website refers to the NCG guidelines. Although the NCG guidelines are not consistent with the 2009 NHMRC guidelines, they are currently in the process of being revised. Drug and Alcohol Services within the ACT and TAS were contacted and the representatives noted that abstinence was the safest option during pregnancy and recommended that women be referred to the national guidelines. Some state health organisations refer to both the NHMRC guidelines and the NCG on their websites (e.g. NSW Health). The Victorian Government Health Information page advises women to follow NCG and the Alcohol and other Drugs services in Victoria refer to the NHMRC guidelines. In addition to the information presented in Table 11.2, the Northern Territory Government Department of Health have the 2009 NHMRC guidelines on their website http://www.health.nt.gov.au/Alcohol_and_Other_Drugs/Alcohol/index.aspx.

The medical and nursing organisations presented in Table 11.2 have updated their websites and either quote the NHMRC 2009 guidelines or provide links to the guidelines. An exception is the Australian College of Midwives which refers to NCG. The Royal Australian College of GPs recommends that all patients should be asked about quantity and frequency of alcohol use and those with risk patterns of alcohol consumption should be offered brief intervention.

11.3 Evidence base for policy

A recent review focused on whether there is sufficient evidence about the effect of low to moderate prenatal alcohol exposure on the fetus to advise women to abstain from alcohol during pregnancy (O'Leary and Bower 2011). The review found no strong research evidence of fetal effects from low levels of alcohol exposure and the authors determined that the reported significant protective effects from low level alcohol exposure are likely due to methodological issues such as confounding and/or misclassification of exposure or outcome. Recent studies have shown increased risk of neurodevelopmental problems (Sayal et al. 2009; O'Leary et al. 2010) and preterm birth following in utero exposure to 30-40g per occasion (3-4 standard drinks/2-2.5 serves of wine/full strength beer) and as little as 70g per week (O'Leary et al. 2009; O'Leary et al. 2010). The authors concluded that with such a small margin before there is increased risk to the fetus, it is morally and ethically responsible for policies to promote abstinence during pregnancy. It is, however, important to be pragmatic and acknowledge that not all women will follow this advice: some will continue to consume alcohol while pregnant and some will inadvertently consume alcohol before becoming aware of their pregnancy. If poorly handled these situations have the potential to generate stress and anxiety and may lead women to consider terminating an otherwise wanted and potentially unaffected pregnancy. If the abstinence message is mishandled women who have consumed alcohol in pregnancy may not reveal their drinking and women with alcohol related problems may be reluctant to seek antenatal and treatment services. Situations where the mother consumes alcohol require non judgemental and rational advice on the likelihood of risk to the fetus, indicating that low levels of alcohol exposure appear to be low risk and recognising that alcohol exposure is a risk factor but not all exposed pregnancies, even those exposed to heavy levels will be harmed (O'Leary and Bower 2011).

It is important to acknowledge that abstinence during pregnancy requires adopting an approach that is different from that of the general community in Australia, where 81% of people over 14 years report alcohol consumption (AIHW 2011). As per capita alcohol consumption is an indicator of heavy drinking in a community, population based strategies to
reduce overall consumption may reduce harms (Rose 1992) including the number of alcohol-exposed fetuses (O'Leary and Bower 2011).

**11.4 The importance of dissemination and implementation of policy**

Alcohol and pregnancy policy should be evidence-based and have the support of policy makers, health professionals, women and the community. National policies need to be delivered consistently by all State and Territory governments and medical and nursing organisations. Variation in alcohol and pregnancy policy around Australia is confusing and hinders implementation. Public health policy should be widely disseminated to health professionals, women, and the general community and ideally its implementation should be evaluated.

Recent Australian research suggests there is little knowledge of the official NHRMC 2009 guidelines among the general population (Livingston 2012). The study did not specifically examine knowledge about the guideline referring to alcohol consumption in pregnancy but found that Australians do not have a good sense of low risk drinking levels. Two-thirds of males and one-third of females estimated low-risk drinking in the short-term to be more than the current NHMRC guidelines (i.e. no more than four drinks on an occasion). A clear association was found between age, the amount the respondent drank and estimates of low-risk drinking, with younger, heavier drinkers estimating higher thresholds for low-risk (Livingston 2012).

Powers and colleagues used data from the Australian Longitudinal Study on Women’s Health to examine pregnant women’s compliance with the NHMRC low alcohol (2001) and abstinence (1992) guidelines (Powers et al. 2010). The data allowed them to compare drinking during pregnancy among women who had been pregnant when the different recommendations for alcohol consumption during pregnancy were in effect. The study found that guidelines for low alcohol intake (2001) or abstinence (1992) had little effect on the alcohol intake during pregnancy, with around 80% of pregnant women in both time periods consuming alcohol. The strongest predictor of women drinking alcohol during pregnancy was alcohol consumption prior to pregnancy.

Consistent messages from health professionals are very important. As discussed in Chapter 7, surveys of health professionals in 2002/03 found that the majority do not routinely provide information on the consequences of alcohol use in pregnancy (Payne et al. 2005). Only 23 percent of Australian paediatricians routinely ask about alcohol use when taking a pregnancy history and only four percent routinely provide information on the consequences of alcohol use during pregnancy (Elliott et al. 2006). There have been some improvements in Australian health professionals’ knowledge about alcohol and pregnancy and an increase in the percentage advising women to abstain from alcohol during pregnancy in recent years (Payne et al. 2011; Payne et al. 2011).

However, there are still improvements to be made. Health professionals should endorse the NHMRC 2009 guidelines, promote abstinence during pregnancy, and provide clear and consistent messages about the risk to the fetus from prenatal alcohol exposure. All women of child bearing age and pregnant women should be routinely asked about their alcohol consumption and advised of the risk to the fetus from alcohol. Where indicated, brief interventions should be implemented and women referred to alcohol treatment programs as appropriate. Newborn infants heavily exposed to alcohol in utero should be referred for paediatric assessment.
### Table 11.2 Australian policies on alcohol and pregnancy (reproduced from O’Leary et al. 2007) ¹×*  

<table>
<thead>
<tr>
<th>Source</th>
<th>Abstinence</th>
<th>Occasional small amounts</th>
<th>Comments</th>
<th>Evidence base†</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Commonwealth Government</strong></td>
<td></td>
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</tbody>
</table>
| National Health and Medical Research Council (2001) | May be considered | 2 per day and less than 7 per week is low risk | • Should never become intoxicated  
• Risk is highest in the early stages of pregnancy | 2 |
| Australian Government Department of Health and Ageing | May be considered | 2 per day and less than 7 per week is low risk | • Should never become intoxicated, but the evidence about low to moderate alcohol consumption is less clear  
• Risk is highest in the early stages of pregnancy | 2 |
| Ministerial Council on Drug Strategy National Clinical Guidelines‡ | Safest | 2 per day & 7 per week is low risk, but no level can be assumed to be completely safe | • Provide NHMRC recommendations  
• State that no alcohol consumption has been determined as completely safe  
• All pregnant women should be asked about their alcohol consumption and given information on the risk associated with drinking alcohol during pregnancy | NHMRC 2; Point 2, 4 |
| **State and Territory Government** |  |  |  |  |
| ACT: no policy | - | - | • The ACT Drug and Alcohol Office advised that the information provided to women varies across health service providers | - |
| NSW Health | Safest | Even a small amount may be harmful | • Binge drinking, particularly during the first trimester, is harmful  
• A safe level or safe time for drinking has not yet been determined | 5 |
| NSW Health, Centre for Drug and Alcohol | Safest | Moderate alcohol use may be harmful | • Heavy drinking is known to be dangerous  
• Moderate use of alcohol defined as 2 drinks per day, 3-4 times a week | 5 |
| Queensland Health | Optional | Reduction | • Alcohol reduction or cessation advised, but no level of alcohol consumption specified | 5 |
| South Australian Department of Health | Safest | Not advised | • Reduce alcohol when planning pregnancy and abstain when pregnant  
• The risks increase with increasing quantity, with harm occurring with high exposure, and a safe level has not yet been determined | 5 |
| Tasmanian Department of Health and Human Services | safest | 2 per day and less than 7 per week is low risk | • Follow the NHMRC guidelines | 2 |
| Victorian Department of Health | Safest | 2 per day and less than 7 per week is low risk | • There are varying opinions about the harm from drinking alcohol during pregnancy, but a safe level has not yet been determined  
• Present the NHMRC guidelines (2001) | 2 |
<table>
<thead>
<tr>
<th>Source</th>
<th>Abstinence</th>
<th>Occasional small amounts</th>
<th>Comments</th>
<th>Evidence base†</th>
</tr>
</thead>
<tbody>
<tr>
<td>Western Australian Drug and Alcohol Office</td>
<td>Safest</td>
<td>2 per day and less than 7 per week is low risk</td>
<td>• Follow the NHMRC guidelines (2001)</td>
<td>2</td>
</tr>
<tr>
<td>Western Australian Department of Health</td>
<td>No specific advice</td>
<td>No specific advice</td>
<td>• Drinking alcohol at hazardous or harmful levels during pregnancy increases the risk of low birthweight, intrauterine growth retardation and prematurity</td>
<td>2</td>
</tr>
<tr>
<td>Medical and nursing organisations</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
| Royal Australian College of General Practitioners                      | Preferable | Limit drinking           | • Pregnant women and those planning pregnancy should be assessed annually on their quantity and frequency of alcohol intake and the number of alcohol-free days each week  
• High-risk drinkers should receive brief interventions                | 5              |
| Royal Australian and New Zealand College of Obstetricians and Gynaecologists | -   | -                        | • No policy guidelines identified                                                            | -              |
| Australian College of Midwives#                                       | Safest     | 2 per day and less than 7 per week is low risk | • Follows the recommendations set out in the National Clinical Guidelines (NCG) As per NCG |                |
| Royal Australasian College of Physicians, Royal Australian and New Zealand College of Psychiatrists | Safest     | No level has been determined completely low risk for the fetus | • All pregnant women should be given information on the risk associated with drinking alcohol during pregnancy | 5 “usually based on NHMRC” |
| Australian Medical Association (AMA)                                  | Desirable  | Not advised              | • The position statement was written in 1998 and is based on the 1992 NHMRC recommendations  
• In 2005, the AMA President stated that the NHMRC should revise the guidelines on alcohol consumption during pregnancy, indicating that an abstinence message should be given | Point 2,4      |


* Australian standard drink equals 10g of alcohol.
† Key to evidence base: 1= systematic literature review; 2= literature review (not systematic review); 3= broad statement or indication that the policy is based on the evidence, but no specific references provided; 4= consensus of authors; 5=not mentioned.
‡ National clinical guidelines for the management of drug use during pregnancy, birth and the early development years of the newborn.
Key points

- Few policies and guidelines on alcohol use in pregnancy are based on a systematic review of the evidence.
- Australia’s current guidelines (NHMRC, 2009) were based on a systematic review and recommend that for women who are pregnant or planning a pregnancy, not drinking is the safest option.
- Although there has been some improvement regarding consistency of messages since the publication of the 2009 NHMRC guidelines, policies for alcohol use in pregnancy vary across State and Territory health departments and medical and nursing organisations within Australia. The policies range from abstinence-based to providing advice that a low level of alcohol consumed during pregnancy poses a low risk to the fetus.
- It is essential that Australia’s alcohol and pregnancy policy is based on the evidence and consistently adopted across States and Territory governments and medical and nursing organisations.
- To influence health professionals’ practice and reduce the prevalence of alcohol consumption during pregnancy, national policy must be disseminated to policy-makers in each of the State and Territory governments and medical and nursing organisations, to health professionals, and to women and the wider community.
- Evidence suggests that the most responsible policy is to promote abstinence in pregnancy, acknowledging that some pregnancies will be exposed prior to pregnancy awareness and not all women will take the advice. Therefore, non-judgemental and rational advice on the likelihood of risk to the fetus to these women is important.
12. NATIONAL ACTIVITY ON FETAL ALCOHOL SPECTRUM DISORDERS

Elizabeth Elliott, Lucy Burns and Courtney Breen

Government and nongovernment organisations have initiated a number of treatment programs and research projects since the 2009 Monograph ‘Fetal Alcohol Spectrum Disorders in Australia: An update’ (Burns et al. 2009). A number of initiatives have been funded as indicated below and detailed in Table 12.1. In November 2011, the Australian Government House of Representatives Standing Committee on Social Policy and Legal Affairs initiated an Inquiry into the prevention, intervention needs and management of FASD in Australia. Further information on the Inquiry, including submissions, can be accessed at http://www.aph.gov.au/Parliamentary_Business/Committees/House_of_Representatives_Committees?url=spla/fasd/index.htm.

A summary of some of the projects include:

1. Better data collection about alcohol use in pregnancy to assist in identifying at-risk mothers and inform treatment and prevention efforts.

In 2010 Victoria Health funded a project to develop an approach for clinicians and researchers to ask appropriate questions about alcohol use during pregnancy. This project was expanded with funding from the Department of Health and Ageing and the outcomes are documented in Alcohol in pregnancy: what questions should we be asking? (AQUA) (Muggli et al. 2010) (Table 12.1, Study 1).

In 2010 the NHMRC funded a Victorian birth cohort using the questions developed in AQUA to assess outcomes of children exposed to low and moderate levels of alcohol during pregnancy (Table 12.1, Study 2).

The Australian Institute of Health and Welfare’s National Perinatal Epidemiology and Statistics Unit (NPESU) was funded by the Department of Health and Ageing to assess what FASD related information is available in existing data collections (Table 12.1, Study 3).

The NPESU have also developed standard elements to collect self reported data about frequency and amount of alcohol consumed in pregnancy following consultation with a broad range of stakeholders. Consultation is being undertaken to assess the feasibility of introducing these items into the National Perinatal National Minimum Data Set. (Table 12.1, Study 4).

The draft WA FASD Model of Care Implementation Plan (currently under development) considers strategies to measure and record alcohol use in pregnancy. Strategies to date include identifying opportunities for health professionals to record alcohol consumption patterns of pregnant mothers during each trimester, using a modified Audit-C tool. The modified tool would screen levels of risk to developing fetus. It is proposed this information will be collected statewide.
2. Research to accurately determine the prevalence of FASD in Australia.

The Lililwan Project is a research collaboration between Marninwarntikura Women’s Resource Centre and Nindilingarri Cultural Health Services in Fitzroy Crossing and The George Institute for Global Health and the Discipline of Paediatrics and Child Health at the Sydney Medical School, The University of Sydney. The Lililwan Project was initiated by Aboriginal communities in the Kimberly region of WA to determine the prevalence of FASD in remote communities throughout the Fitzroy Valley (Table 12.1, Study 5) (Latimer et al. 2010; Australian Human Rights Commission 2011; Clark 2011; Elliott et al. 2012; Fitzpatrick et al. 2012; Kirby 2012). In 2010 a cohort was identified and a comprehensive multidisciplinary health and development assessment was conducted for each child during 2011 and 2012. The study protocol is outlined in Fitzpatrick et al and analysis of data is currently underway. This project is funded by the Commonwealth Departments of Health and Ageing (DOHA) and Families, Housing, Community Services and Indigenous Affairs (FaHCSIA), the National Health and Medical Research Council (NHMRC) (#1024474), Save the Children, the Foundation for Alcohol Research and Education (FARE), and Australian philanthropists. This project forms part of the Marulu strategy developed by the community to address the diagnosis and prevention of FASD and to support children with FASD and their families (Table 12.1, Study 6).

The prevalence of FASD in Western Australia will also be estimated using cases born in WA between January 1980 and November 2010 and notified to the Western Australian Register of Developmental Anomalies (WARDA) (Table 12.1, Study 7). Birth prevalence will be calculated by year of birth to examine trends over time and demographic characteristics of cases will be described. This project is being conducted at the Telethon Institute for Child Health Research.

A Western Australian data linkage study is investigating the health and social outcomes of children of mothers with an alcohol-related diagnosis, a proxy for heavy alcohol consumption, recorded on health datasets. The children’s birth data has been linked with a range of linked administrative datasets to examine the relationship between heavy maternal alcohol consumption and the health, developmental (intellectual disability, cerebral palsy) (O’Leary et al. 2012), mortality (stillbirth) (O’Leary et al. 2012) and social outcomes (education, justice, child protection) across the lifespan (Table 12.1, Study 8). This research is examining the effect of both heavy prenatal alcohol exposure and the effect of maternal alcohol-use disorders occurring during the early years of their child’s life.

3. Research into the relationship between alcohol use in pregnancy and FASD in Australia.

The Impact of Parental Alcohol, Tobacco and Other Substance Use on Infant Development and Family Functioning study (also known as The Triple B study: Bumps, Babies and Beyond) was initiated by the National Drug and Alcohol Research Centre and has been funded by the National Health and Medical Research Council (#630517), Rotary, FARE and the University of NSW (Table 12.1, Study 9). The aim of this birth cohort, which includes participants living in NSW and WA, is to examine substance use patterns, including use of alcohol, in a cohort of pregnant women and their partners during the prenatal period. The relationship between drug and alcohol use during pregnancy and infant outcomes is also being examined. Data are also being collected on infant development (physical, cognitive,
behavioural and emotional), and family functioning (marital/intimate partner relationship quality, conflict and violence, parenting behaviour and parent–infant relationship quality). To date 1,200 families have been recruited to the study and preliminary data analysis has commenced.

The Victorian birth cohort (AQUA) funded by the National Health and Medical Research Council (#1011070) will examine the association of low to moderate quantities of alcohol intake at various stages of pregnancy and problems in health and development of children at birth and at 12-24 months of age (Table 12.1, Study 2). In this study data are being collected on maternal DNA variations, specific dietary factors or other environmental influences that can moderate the impact of alcohol use in pregnancy.

Data from the Randomly Ascertained Sample of Children born in Australia's Largest State (RASCALS) cohort from Western Australia were linked with health educational data to examine the effect of the dose, pattern, and timing of prenatal fetal effects (Table 12.1, Study 10). The results of this project demonstrated the importance of the pattern and timing of prenatal alcohol exposure on fetal effects (O'Leary et al. 2009; O'Leary et al. 2009; O'Leary et al. 2010; O'Leary et al. 2010; O'Leary et al. 2011). The study is continuing with an investigation of the educational outcomes of children in year 3. The National Drug and Alcohol Research Centre, University of NSW and the University of Sydney have initiated a systematic review of the literature for interventions to prevent alcohol use in pregnancy with particular reference to programs that address prevention in high risk groups.


Protocols for two systematic reviews to inform management guidelines have been approved by the Cochrane Collaboration. One protocol, which was recently published, outlines the review that will be undertaken of pharmacological interventions for ADHD symptoms in children with FASD (Peaon et al. 2012). The other will examine the efficacy of non-pharmacological interventions available for children with FASD. The emphasis will be on identifying high quality evidence for interventions based on data from randomised controlled trials. This work builds on previous work by Peaon and colleagues (Peaon et al. 2008). (Table 12.1, Study 11).

The Strengthening Links program in South Australia is managed by the Women’s and Children’s Hospital in collaboration with Drug and Alcohol Services South Australia and other social and community agencies. This is an antenatal program which aims to support vulnerable women during pregnancy as identified during assessments at antenatal appointments. The program aims to increase the safety and wellbeing of the unborn infant in vulnerable circumstances through assessment, hospital and community engagement, support, care planning and referral to community services. The Women’s and Children’s Hospital social workers collaborate with Drug and Alcohol Services South Australia for relevant treatment and support. The program is governed by a number of guidelines including a nursing and clinical antenatal model of care, referral and assessment pathways and agency partnership arrangements.
5. Diagnosis of FASD in Australia.

In a recent editorial, Mutch and colleagues recommended the adoption of the University of Washington criteria for the diagnosis of FASD in Australia (Mutch et al. 2009).

In 2010 the Department of Health and Ageing funded the Australian FASD Collaboration to review international criteria and clinical guidelines for the diagnosis of FASD and to recommend a screening and diagnostic tool for Australia (Table 12.1, Study 12). Following review of the literature, a modified Delphi process was used to obtain information from health professionals regarding their diagnostic and screening practices. Information was also collected on their agreement with diagnostic criteria included in published guidelines used internationally and their preferences for diagnostic criteria to be used in Australia. A report has been submitted to the Department of Health and Ageing based on the findings. This includes the agreed diagnostic criteria and diagnostic instrument for FASD in Australia that now requires testing and validation in the Australian setting. The initial paper from this study has recently been published (Watkins et al. 2012).

A model of care has been developed proposing practice interventions to prevent and manage FASD in Western Australia (Department of Health Western Australia 2010). An across sector, state-wide Implementation Plan for the Model of Care is currently under development. It includes strategies across the continuum of care to prevent and manage FASD symptoms based on public health principles and which consider issues of access, equity and the current resource and workforce environments in WA. The development of diagnostic and treatment pathways for metropolitan and country regions, including the development of workforce capacity are considered in the Plan.

6. Training of service providers to support prevention and intervention responses to FASD

Following surveys of health professionals that suggested a lack of knowledge and inadequate skills to diagnose and manage alcohol use in pregnancy and FASD (Payne et al. 2005; Elliott et al. 2006; Peadon et al. 2007), Payne and colleagues developed educational resources for distribution in Western Australia. An evaluation of the resources was undertaken and assessed paediatricians and other health professionals’ knowledge, attitudes and practice about prenatal alcohol exposure and FASD (Payne et al. 2011; Payne et al. 2011) (Table 12.1, Study 14). Many of the recipients rated these resources positively. Compared to previous surveys, a greater proportion of health professionals asked women about alcohol use in pregnancy and advised women that the safest option was not to use alcohol. A greater number of professionals also reported greater confidence in making the diagnoses of FASD and fewer identified the need for resources for themselves and their clients. Resources for health professionals are also freely available online.


In 2010 the Department of Health and Ageing funded the National Drug Research Institute in Perth to carry out a research project on the development of templates of resources that will: provide Aboriginal and Torres Strait Islander women, men and communities with culturally appropriate templates of resources about the risks of alcohol consumption during pregnancy and breastfeeding; and assist health professionals in Aboriginal and Torres Strait Islander health care settings address the issues of alcohol, pregnancy and FASD (Table 12.1, Study 15).
In 2011 the Australian General Practice Network revised the Alcohol in Pregnancy Lifescripts. The Lifescripts project involved the development and dissemination to general practitioners of information regarding alcohol in pregnancy for use with patients in general practice. After the assessment women identified as being at risk from alcohol-related harms are given advice and referred for follow up as necessary.

In 2011 the Foundation for Alcohol Research and Education (FARE) funded the National Drug and Alcohol Research Centre to identify best practice care for pregnant women, including women who are alcohol dependent or drinking at risky levels (Table 12.1, Study 16). This project includes a review of the literature on treatment for alcohol dependence in pregnancy. In addition, clinicians will be interviewed about their current treatment practices and suggestions for improvement to services. Interviews with women will also be conducted to document their experiences of treatment of alcohol-related disorders in pregnancy and to seek feedback on how services could be improved.

The Western Australian Drug and Alcohol Office’s ‘Strong Spirit Strong Future- Promoting Healthy Women and Pregnancies’ project includes the development and delivery of training and education for health professionals and other workers. The project aims to improve professional awareness, competence and confidence to deliver evidence-based culturally secure early interventions, treatment and referral to Aboriginal women with respect to alcohol and other drug use in pregnancy and FASD.

Drug and Alcohol Services South Australia (DASSA) in conjunction with University of Adelaide has produced a number of clinical resources relating to alcohol use during pregnancy. These include the ‘Alcohol, Tobacco and Other Drugs: Clinical Guidelines for Nurses and Midwives’ which has an accompanying framework for policy and standards and a training package. DASSA has also produced the booklet titled – Fetal Alcohol Spectrum Disorders: A Guide for Midwives. This publication includes information on prevention strategies, alcohol assessment procedures and brief intervention approaches.

In terms of jurisdictional activity Action 18 of the ACT Alcohol, Tobacco and Other Drug Strategy 2010-2014 is to “Implement national clinical guidelines for the management of drug use during pregnancy, birth and the early years of the newborn.” The action requires that a best practice guide be developed for ACT ATOD services working with pregnant women, families with young children. Development of the Guide is expected to be completed in 2013.

7. Community education to raise awareness of the potential harms associated with alcohol use during pregnancy.

Two films have been developed in association with the Lililwan Project. ‘Marulu’ highlights the need for action on FASD in the remote Indigenous communities of the Fitzroy Valley WA (Clark 2011). ‘Tristan’ follows the life of a boy with FASD living in the Fitzroy Valley. It was made to raise awareness of the challenges faced by such children and their families. Both films were supported by philanthropic donations. Tristan was launched in Sydney in April 2012 by the Governor General who is the patron of the National Organisation for Fetal Alcohol Syndrome and Related Disorders (NOFASARD). It was shown at the United Nations Permanent Forum for Indigenous Issues in New York in May 2012. A DVD for professionals dealing with FASD will be made to complement this film with a contribution from the Foundation for Alcohol Research and Education (FARE).
France and colleagues conducted research to examine different methods for promoting abstinence from alcohol during pregnancy. A media campaign, promoting the ‘No Alcohol in Pregnancy is the Safest Choice’ message has been launched recently. Television advertisements will be run in Western Australia in conjunction with targeted online digital advertising. The campaign is the first of its kind in Australia and based on research with women in Perth conducted by France and colleagues at Edith Cowan University (Table 12.1, Study 17) [http://www.mediastatements.wa.gov.au/Pages/Results.aspx?ItemID=150319).

In 2012 the Foundation for Alcohol Research and Education (FARE) funded a media campaign in the Kimberley and Pilbara Regions of Western Australia. The project aims to raise awareness in the Indigenous Kimberley community of the preventative measures and outcomes of FASD through a media promotions strategy incorporating television and radio adverts focused on FASD (Table 12.1, Study 18).

The Western Australian Drug and Alcohol Office initiated ‘The Strong Spirit Strong Future-Promoting Healthy Women and Pregnancies’ project with funding from the Council of Australian Governments (COAG). The Western Australian FASD Prevention Aboriginal Consultation Forum was held in 2010 and sought the input and guidance of senior Aboriginal professionals, Aboriginal community members, and people who provide services to Aboriginal people. This included discussion regarding the development, consultation framework and direction of the project (Drug and Alcohol Office 2011). This prevention project is designed for Aboriginal people and communities to raise awareness of the NHMRC’s 2009 guidelines on alcohol use when planning a pregnancy, during pregnancy and when breastfeeding.

It involves the development of culturally sensitive resources, a community awareness media campaign and training and education for health professionals and other workers. In addition, the project provides access to small grants to enable communities to localise resources and develop capacity to respond to local needs. (Table 12.1, Study 19)

The Western Australian Drug and Alcohol Office also launched the ‘No Alcohol During Pregnancy is the Safest Choice’ campaign in 2012. This mainstream campaign promotes the message that no alcohol is the safest choice when pregnant or planning a pregnancy to the primary target group of women of child-bearing age (25-39 years). The campaign is based on the findings from a National Health and Medical Research Council and Healthway joint-funded formative research project. The research was conducted to develop and test messages suitable for a mass media campaign targeting women who may consume low to moderate levels of alcohol during pregnancy. It promoted the NHMRC low risk drinking guideline regarding alcohol use during pregnancy. See [http://www.alcoholthinkagain.com.au/Campaigns/NoAlcoholInPregnancyIsTheSafestChoice.aspx]. A commissioned evaluation showed that overall, the alcohol and pregnancy campaign performed strongly on a range of key advertising metrics.

The National Drug Research Institute has been funded by the Department of Health and Ageing to develop culturally appropriate resources to assist health professionals in Aboriginal and Torres Strait health care settings to address the issues of alcohol and pregnancy and Fetal Alcohol Spectrum Disorders (FASD).

In July 2012, the NSW Ministry of Health launched a social marketing campaign; “Stay Strong and Healthy - it's worth it". The campaign specifically aims to raise awareness of
Aboriginal pregnant women and their partners and families of the risks of drug and alcohol consumption during pregnancy, as well as the potential challenges of dealing with a mental illness at this time.

Developed in consultation with Aboriginal child and maternal health, drug and alcohol and mental health professionals the campaign involved radio, print and online advertising, Facebook (https://www.facebook.com/StayStrongAndHealthy/info), postcards and an illustrated storybook. The tone and content of the storybook format cartoon resonated with the target audience, speaking in appropriate language and not causing shaming, or authoritative lecturing. The campaign also encourages women to seek the support of friends, family, GPs and other professional services when they are pregnant or have a new baby.

Another key strategy to address the difference in health outcomes between Aboriginal and non-Aboriginal women and babies in NSW, and a key part of the NSW Government’s commitment to closing the gap in life expectancy between Aboriginal and non-Aboriginal Australians, is the Aboriginal Maternal and Infant Health Service (AMIHS).

AMIHS builds on universal maternity services that are available in NSW while adding an innovative approach to make these services more accessible and appropriate for Aboriginal women. This involves midwives working together with Aboriginal Health Workers in small teams to provide a high quality service that is culturally sensitive, woman centred, based on primary health care principles, and provided in partnership with Aboriginal people.

All AMIHS services include activities aimed at reducing maternal alcohol consumption, for example, the use of FASD simulator dolls, use of local information (eg. "When you drink alcohol ...so does your Boori" brochure), and referral to family support services that help reduce stresses that may be contributing to maternal drinking.

A number of AMIHS resources have been developed that contain culturally appropriate information about FASD. These include the Strong Women Strong Babies Pregnancy Diary and the “Stay Strong and Healthy - it’s worth it” prenatal mental health and drug and alcohol social marketing campaign (2012-2013).

Within the Closing the Gap initiatives, a number of new programs are being implemented to support AMIHS programs. These programs include secondary mental health, and drug and alcohol services in selected AMIHS sites.

8. Research into the development and evaluation of programs and services for individuals with FASD and their families.

There is limited documented information on the resources available for the diagnosis and management of FASD and the service requirements of families affected by FASD. In 2011 the Foundation for Alcohol Research and Education (FARE) funded the National Drug and Alcohol Research Centre to characterise the service use, needs and issues involved for families caring for children and adults affected by FASD (Table 12.1, Study 20). Qualitative interviews have been conducted with carers from across Australia. The study will be extended in collaboration with the Australian Paediatric Unit, to evaluate the financial and psychosocial impacts of FASD on individuals and their families.
The Foundation for Alcohol Research and Education (FARE) has also funded an evaluation of available resources that provide information and support for parents and carers of children with FASD (Table 12.1, Study 21). The study is being conducted through the Telethon Institute of Child Health Research. In addition to documenting resources currently available for parents and carers it will investigate specific information needs.

In 2011 the Foundation for Alcohol Research and Education (FARE) funded the Telethon Institute of Child Health Research to conduct interdisciplinary research on the knowledge, attitudes and practice of FASD within the WA criminal justice system (Table 12.1, Study 22). In this study the training and information needs of professionals working within the criminal justice system with people who have FASD will be investigated. A similar study has been funded by FARE to examine the knowledge and training deficits of professionals working in the Queensland criminal justice system. It is being conducted through the University of Queensland Centre for Clinical Research (Table 12.1, Study 23).

In 2012 the Foundation for Alcohol Research and Education (FARE) funded the National Organisation for Fetal Alcohol Syndrome and Related Disorders (NOFASARD) to develop a FASD training program in Tasmania aimed at building the capacity of service providers in the child protection sector to support carers of individuals living with FASD (Table 12.1, Study 24).
### Table 12.1 Recent and current FASD related research in Australia

<table>
<thead>
<tr>
<th>Project Title</th>
<th>Aims of project</th>
<th>Researcher institution, contacts and funders</th>
<th>Status and location</th>
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<tbody>
<tr>
<td>1 Alcohol in Pregnancy: What questions should we be asking?</td>
<td>To identify or develop a tool for the assessment of alcohol intake in pregnancy in routine clinical practice.</td>
<td>Murdoch Children’s Research Institute (MCRI)</td>
<td>Completed</td>
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<td></td>
<td></td>
<td>Contact: Evi Muggli <a href="mailto:evi.muggli@mcri.edu.au">evi.muggli@mcri.edu.au</a></td>
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<td>Funded by: Australian Government Department of Health and Ageing (DOHA)</td>
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<tr>
<td>2 Asking Questions about Alcohol in Pregnancy (AQUA)</td>
<td>To determine whether low to moderate alcohol intake at various stages of pregnancy are associated with adverse health and development outcomes at birth and for young children at 12-24 months of age. To investigate whether maternal DNA variations, specific dietary factors or other environmental influences can modify the impact of fetal exposure to low to moderate quantities of alcohol in pregnancy. A sample of 2,000 pregnant women will be recruited to participate in this project.</td>
<td>Murdoch Children’s Research Institute</td>
<td>Current</td>
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<tr>
<td></td>
<td></td>
<td>Contact: Jane Halliday or Evi Muggli <a href="mailto:aquastudy@mcri.edu.au">aquastudy@mcri.edu.au</a></td>
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<td></td>
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<td>Funded by: NHMRC Project Grant (1011070) 2011-15</td>
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<tr>
<td>3 Assessing fetal alcohol spectrum of disorders data collection in Australia</td>
<td>To assess FASD related information in existing data collections. Undertaken by the National Perinatal Epidemiology and Statistics Unit (NPESU).</td>
<td>AIHW National Perinatal Epidemiology and Statistics Unit (NPESU), University of New South Wales, on behalf of AIHW</td>
<td>Pending</td>
</tr>
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<td></td>
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<td>Contact: Lisa Hilder <a href="mailto:lhilder@unsw.edu.au">lhilder@unsw.edu.au</a> or Michelle Bonello <a href="mailto:michelle.bonello@unsw.edu.au">michelle.bonello@unsw.edu.au</a></td>
<td>finalisation of the report</td>
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<tr>
<td>4 Standard collection of information about maternal alcohol use in pregnancy</td>
<td>Standard elements to collect self reported data about frequency and amount of alcohol consumed in early and late pregnancy have been developed following consultation with a broad range of stakeholders. Consultation is being undertaken to assess the feasibility of introducing these items into the National Perinatal National Minimum Data Set. Note: The National Perinatal National Minimum Data Set is a population-based data collection of pregnancy and childbirth as defined in the National Health Data Dictionary.</td>
<td>AIHW National Perinatal Epidemiology and Statistics Unit (NPESU), University of New South Wales, on behalf of AIHW</td>
<td>Current</td>
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<td></td>
<td></td>
<td>Contact: Lisa Hilder <a href="mailto:lhilder@unsw.edu.au">lhilder@unsw.edu.au</a> or Michelle Bonello <a href="mailto:michelle.bonello@unsw.edu.au">michelle.bonello@unsw.edu.au</a></td>
<td>National</td>
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<td></td>
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<td>Funded by: The Council of Australian Governments (COAG)</td>
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<td>Aims of project</td>
<td>Researcher institution, contacts and funders</td>
<td>Status and location</td>
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<td>5 The Lililwan Project - tackling fetal alcohol spectrum disorders</td>
<td>To undertake a prevalence study of FASD in the Fitzroy Valley. As part of a broader strategy to address the diagnosis and prevention of FASD and support of affected children and their families. The study was initiated by Indigenous women June Oscar and Maureen Carter and supported by community leaders in the Fitzroy Valley. A partnership was formed between the Nindilingarri Cultural Health Services, Marninwarntikura Women’s Resource Centre, the George Institute for Global Health and the Discipline of Paediatrics and Child Health at the University of Sydney Medical School to conduct the Lililwan project. Lililwan is a Kriol, or Aboriginal English word meaning ‘little ones or children’.</td>
<td>Nindilingarri Cultural Health Services and Marninwarntikura Women’s Resource Centre, the George Institute for Global Health and the Discipline of Paediatrics and Child Health at the University of Sydney Medical School Contact: Professor Elizabeth Elliott <a href="mailto:elizabeth.elliott@health.nsw.gov.au">elizabeth.elliott@health.nsw.gov.au</a> Funded by: DOHA, FaHCSIA and NHMRC #1024474, Save the Children Australia, FARE and Australian philanthropists.</td>
<td>Current 2010-2013 Western Australia</td>
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<td>6 Marulu Film Project</td>
<td>To produce a documentary and an educational film to raise awareness of FASD and their impact on children, their parents and carers, and whole communities. A group of Indigenous leaders has partnered with experts in Indigenous health, paediatric medicine, human rights advocacy, child protection and a world-class production company to progress a community-led strategy developed to address FASD in the Fitzroy Valley of WA. The strategy, Marulu, has three components: diagnosis and prevention of FASD, support for parents and carers of children with FASD, and advocacy and awareness-raising about FASD. In line with the third component of the strategy the project team will produce two films to raise awareness of FASD and their impact on the lives of children living in the Fitzroy Valley.</td>
<td>The George Institute for Global Health <a href="http://www.georgeinstitute.org.au/marulu">http://www.georgeinstitute.org.au/marulu</a> Contact: Associate Professor Jane Latimer <a href="mailto:jlatimer@georgeinstitute.org.au">jlatimer@georgeinstitute.org.au</a> Funded by: the DOHA, FaHCSIA and NHMRC. Save the Children Australia, FARE, and Australian philanthropists also provided support.</td>
<td>Current 2011-2013 Western Australia</td>
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<td>7 Prevalence of FASD in Western Australia</td>
<td>To determine the prevalence of FASD in WA. This study will use un-named information on all cases of Fetal Alcohol Syndrome (FAS) notified to the Western Australian Register of Developmental Anomalies (WARDA), born in WA from 1980 to November 2010. Birth prevalence per 1000 births will be calculated by year of birth to examine trends over time. Prevalence ratios will be used to describe the demographic and clinical characteristics, such as maternal age, socio-economic status and place of residence, and age of the child when FAS was diagnosed.</td>
<td>Telethon Institute for Child Health Research Contact: Clinical Professor Carol Bower <a href="mailto:carolb@ichr.uwa.edu.au">carolb@ichr.uwa.edu.au</a> Funded by: NHMRC Program Grant #572742</td>
<td>Current 2011 – 2013 Western Australia</td>
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<tr>
<td>Project Title</td>
<td>Aims of project</td>
<td>Researcher institution, contacts and funders</td>
<td>Status and location</td>
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| Population based data linkage study | To identify the proportion of children in Western Australia harmed by maternal alcohol use disorder and to assess their risk of poor health and social outcomes. The cohort comprises all mothers with an alcohol-related diagnosis recorded on health datasets and a randomly selected comparison group of mothers without an alcohol diagnosis who are recorded as giving birth in between 1983-2007 in the Midwives Notification System. The children’s data have been linked with a wide range of health and social datasets. | Curtin University  
Contact: Dr Colleen O’Leary  
Colleen.oleary@curtin.edu.au  
Dr O’Leary is supported by an NHMRC Public Health (Australia) Fellowship, #594451. | Current 2010-2013  
Western Australia |
| Triple B study: Bumps Babies and Beyond | The three aims of this longitudinal birth cohort study are:  
To identify substance use patterns in a cohort of pregnant women and their partners during the prenatal period and the characteristics associated with substance use.  
To examine the relationship of maternal and paternal substance use with pregnancy outcomes for mothers and their infants.  
To determine the extent to which substance use in pregnant women and their partners predicts problems in (a) infant development (physical, cognitive, behavioural and emotional), and (b) family functioning (marital/intimate partner relationship quality, conflict and violence, parenting behaviour and parent–infant relationship quality). | National Drug and Alcohol Research Centre, UNSW  
Contact: Dr Delyse Hutchinson  
d.hutchinson@unsw.edu.au  
Funded by: NHMRC Project Grant #630517, Rotary, FARE and UNSW Gold Star Award | Current 2010-2014  
New South Wales and Western Australia |
| Population based data linkage study | To identify the effect of the dose, pattern, and timing of prenatal alcohol exposure and educational outcomes for children in year. Data from the Randomly Ascertained Sample of Children born in Australia’s Largest State (RASCALS) cohort from Western Australia have been linked with educational data to examine the effect of the dose, pattern, and timing of prenatal alcohol and educational outcomes at year 3. | Curtin University  
Contact: Dr Colleen O’Leary  
Colleen.oleary@curtin.edu.au  
Dr O’Leary is supported by an NHMRC Public Health (Australia) Fellowship, #594451. | Current 2010-2013  
Western Australia |
| Cochrane Collaboration systematic reviews: FASD interventions | To review the published literature for the efficacy of pharmacological and non-pharmacological interventions for FASD. Two protocols have been approved by the Cochrane Collaboration. | Contact: Professor Elizabeth Elliott  
elizabeth.elliott@health.nsw.gov.au  
Dr Elizabeth Peadon  
elizabP5@chw.edu.au  
Professor Elliott is supported by an NHMRC Practitioner Fellowship # 457084 and 1021480 | Current |
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<th>Project Title</th>
<th>Aims of project</th>
<th>Researcher institution, contacts and funders</th>
<th>Status and location</th>
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<tr>
<td><strong>12</strong> Development of a screening-diagnostic instrument for FASD in Australia</td>
<td>To develop an instrument that can be used to improve the identification and/or diagnosis of FASD in Australia.</td>
<td>Australian FASD Collaboration includes health professionals, researchers and consumer and community members. The lead researchers were from the Telethon Institute for Child Health Research and the University of Sydney. Contact: Clinical Professor Carol Bower <a href="mailto:carolb@ichr.uwa.edu.au">carolb@ichr.uwa.edu.au</a> or Professor Elizabeth Elliott <a href="mailto:elizabeth.elliott@health.nsw.gov.au">elizabeth.elliott@health.nsw.gov.au</a> Funded by: DOHA</td>
<td>Pending finalisation of report 2010 – 2011 National</td>
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<td><strong>13</strong> Development of the first screening and diagnostic service for FASD in NSW</td>
<td>To establish the first diagnostic clinic for FASD in Australia by a collaboration of health professionals, researchers, community organisations and government.</td>
<td>The Children’s Hospital at Westmead Contact: Professor Elizabeth Elliott <a href="mailto:elizabeth.elliott@health.nsw.gov.au">elizabeth.elliott@health.nsw.gov.au</a> or Dr Elizabeth Peardon <a href="mailto:elizabP5@chw.edu.au">elizabP5@chw.edu.au</a> Funded by: FARE</td>
<td>Current 2011-2013 New South Wales</td>
</tr>
<tr>
<td><strong>14</strong> Development of educational resources for health professionals</td>
<td>To develop a resource to support health professionals address the issue of alcohol use in pregnancy.</td>
<td>Teleton Institute for Child Health Research Contact: Jan Payne or Clinical Professor Carol Bower <a href="mailto:carolb@ichr.uwa.edu.au">carolb@ichr.uwa.edu.au</a></td>
<td>Western Australia</td>
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<td>Project Title</td>
<td>Aims of project</td>
<td>Researcher institution, contacts and funders</td>
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<td>National Indigenous Fetal Alcohol Spectrum Disorders (FASD) resources project</td>
<td>To provide Aboriginal and Torres Strait Islander women, men and communities with culturally appropriate templates of resources about alcohol, pregnancy and FASD. To develop templates that can be used in the production of culturally secure and appropriate resources to assist health professionals in Aboriginal and Torres Straight health care settings across Australia to address the issues of alcohol, pregnancy and FASD. To roll out a national train-the-trainer program for ensuring workforce development and dissemination and uptake of the FASD templates of resources across Australia.</td>
<td>National Drug Research Institute <a href="http://www.healthinfonet.ecu.edu.au/key-resources/programs-projects?pid=1013">http://www.healthinfonet.ecu.edu.au/key-resources/programs-projects?pid=1013</a> Contacts: Lynn Roarty <a href="mailto:l.roarty@curtin.edu.au">l.roarty@curtin.edu.au</a> or Kate Frances <a href="mailto:k.frances@curtin.edu.au">k.frances@curtin.edu.au</a> Funded by: DOHA</td>
<td>Current 2010 -2012 Western Australia /National</td>
</tr>
<tr>
<td>Improving services for pregnant women dependent on alcohol</td>
<td>To improve treatment practices of chronic alcohol dependence in pregnancy. This study will examine attitudes to FASD, problems in identification and diagnosis and other barriers in accessing services. Through this project, a new resource will be produced for use by clinicians to improve practices in the management of alcohol dependence in pregnancy</td>
<td>National Drug and Alcohol Research Centre Contact: Dr Lucy Burns <a href="mailto:l.burns@unsw.edu.au">l.burns@unsw.edu.au</a> or Dr Courtney Breen <a href="mailto:courtney.breen@unsw.edu.au">courtney.breen@unsw.edu.au</a> Funded by: FARE</td>
<td>Current 2011-2012 New South Wales</td>
</tr>
<tr>
<td>Alcohol and Pregnancy: Health Promotion Messages that Work</td>
<td>To develop a range of messages about alcohol use in pregnancy suitable for a communication campaign for women of childbearing age, pregnant women and women planning a pregnancy. To identify the messages that most effectively increase the intentions of women of childbearing age, pregnant women and women planning a pregnancy to reduce or abstain from alcohol during pregnancy.</td>
<td>Edith Cowan University Contact: Dr Kathryn France <a href="mailto:k.france@ecu.edu.au">k.france@ecu.edu.au</a> or Professor Rob Donovan <a href="mailto:r.donovan@curtin.edu.au">r.donovan@curtin.edu.au</a> Funded by: Healthway</td>
<td>2009-2010 Western Australia</td>
</tr>
<tr>
<td>Media Campaign on Fetal Alcohol Spectrum Disorder (FASD) in the Kimberley and Pilbara Regions</td>
<td>To undertake a media promotions strategy incorporating television and radio adverts focused on FASD. This is aimed at raising awareness in the Indigenous Kimberley community of the preventative measures and outcomes of FASD.</td>
<td>Broome Aboriginal Media Association trading as Goolarri Media Enterprises Contact: Kira Fong Funded by: FARE</td>
<td>Commenced April 2012 Western Australia</td>
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<tr>
<td>Project Title</td>
<td>Aims of project</td>
<td>Researcher institution, contacts and funders</td>
<td>Status and location</td>
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| The Strong Spirit Strong Future-Promoting Healthy Women and Pregnancies project | To raise awareness of the National Health and Medical Research Council's (NHMRC) 2009 guidelines about alcohol use when planning a pregnancy, during pregnancy and when breastfeeding. This prevention based project, designed for Aboriginal people and communities includes the following strategies:  
- development of culturally secure resources  
- community awareness media campaign  
- training and education for health professionals and other workers. | Government of Western Australia, Drug and Alcohol Office  
Funded by: The Council of Australian Governments (COAG) | Current 2010 – 2014 Western Australia |
| Improving services to families affected by FASD | To establish a benchmark for service delivery for families affected by FASD. To date, there has been little systematic work undertaken with the families of children with FASD to determine their experiences and needs. This is of critical importance, given that FASD is a lifelong disability requiring constant care by parents and carers.  
Research will be undertaken with families to determine their experiences in raising children with FASD through semi-structured interviews. | National Drug and Alcohol Research Centre  
Contact: Dr Lucy Burns [l.burns@unsw.edu.au](mailto:l.burns@unsw.edu.au) or Dr Courtney Breen [courtney.breen@unsw.edu.au](mailto:courtney.breen@unsw.edu.au)  
Funded by: FARE | Current 2011-2012 National |
| Screening and Diagnosis of Fetal Alcohol Spectrum and Related Disorders in Children in State Care; and evaluation of information and support for parents and carers of children with a FASD | To determine the prevalence of FASD in a cohort of children aged between birth and 12 years and living in the Perth metropolitan area, who are placed in state care over a 12 month period, to screen this population for developmental delays and learning difficulties and to coordinate further assessment and therapeutic and educational interventions.  
To evaluate currently available FASD resources and information for parents and foster carers. To evaluate currently available FASD resources and information for key government and non-government foster care and support agencies. To investigate specific information needs of parents and foster carers of children with a FASD | Telethon Institute for Child Health Research  
Contacts: Dr Amanda Wilkins [awilkins@ichr.uwa.edu.au](mailto:awilkins@ichr.uwa.edu.au) or Heather Jones [hjones@ichr.uwa.edu.au](mailto:hjones@ichr.uwa.edu.au)  
Funded by: FARE | Current 2011 – 2012 Western Australia |
| Interdisciplinary research on the knowledge, attitudes and practice of FASD within the WA criminal justice system | To find out what people within the justice sector know about FASD, their attitudes towards children and adolescents who may have FASD, and their current practices in dealing with FASD.  
To identify the training and information needs relating to FASD within the justice system, so that people with FASD may receive appropriate consideration within the justice system and referral for appropriate services within and outside the justice system. | Telethon Institute for Child Health Research  
Contacts: Dr Raewyn Mutch [rmutch@ichr.uwa.edu.au](mailto:rmutch@ichr.uwa.edu.au) or Heather Jones [hjones@ichr.uwa.edu.au](mailto:hjones@ichr.uwa.edu.au)  
Funded by: FARE | Current 2011 – 2012 Western Australia |
<table>
<thead>
<tr>
<th>Project Title</th>
<th>Aims of project</th>
<th>Researcher institution, contacts and funders</th>
<th>Status and location</th>
</tr>
</thead>
</table>
| 23 The medical, developmental, educational and social consequences of FASD: A survey of the knowledge and training deficits within the Queensland criminal justice agencies in regards to FASD | To inform and provide the impetus to reform the policing, judicial and corrections systems while optimising effective service delivery, and contribute to the development of appropriate rehabilitation, support and management strategies for people with FASD and their families. Researchers will survey the knowledge, attitudes, practices and training deficits within Queensland criminal justice agencies in regards to FASD. Survey data will be collected from representatives from probation and parole services, correctional services, the police service, lawyers, judiciary, defence counsel, legal aid and other staff as appropriate. The survey results will inform recommendations for training across the Australian criminal justice sector. | The University of Queensland Centre for Clinical Research  
Contact: Professor Heather Douglas  
h.douglas@law.uq.edu.au  
or Dr Jan Hammill  
janet.hammill@uq.edu.au  
Funded by: FARE | Current  
Queensland  
2011-2012 |
| 24 Fetal Alcohol Spectrum Disorder (FASD) Training Program | To develop a FASD training program aimed at building service provider capacity in the Child Protection sector to support those who care for children living with FASD. | National Organisation for Fetal Alcohol Syndrome and Related Disorders (NOFASARD)  
Contact: Vicki Russell  
admin@nofasard.org.au or  
Sue Miers  
sue@nofasard.org.au  
Funded by: FARE | Commenced  
March  
2012  
Tasmania |
APPENDICES
### Appendix 1: Courses containing information about FASD

**Table 1. Accredited training courses that include information on Fetal Alcohol Spectrum Disorder**

<table>
<thead>
<tr>
<th>Area</th>
<th>Institution</th>
<th>Campus</th>
<th>State</th>
<th>Title</th>
<th>Level</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>MH</td>
<td>NSW Institute of Psychiatry</td>
<td>Cumberland Hospital (East Campus)</td>
<td>NSW</td>
<td>Mental Health (Infant)</td>
<td>Graduate Diploma</td>
<td>The Graduate Diploma in Mental Health (Infant) provides theoretical and practical knowledge and skills for therapeutic work using a relationship based approach with infants, care givers and families in a variety of settings, and for roles in service and policy development and delivery.</td>
</tr>
<tr>
<td>MH</td>
<td>NSW Institute of Psychiatry</td>
<td>Cumberland Hospital (East Campus)</td>
<td>NSW</td>
<td>Mental Health (Infant) (Clinical Stream)</td>
<td>Master</td>
<td>The Master of Mental Health (Child &amp; Adolescent) (Clinical Stream) is designed to prepare students for positions of leadership in the area of child and adolescent mental health. Candidates follow the clinical stream in this program. The program emphasises independent study and enquiry and is structured to develop integrated theoretical and practical skills and competencies.</td>
</tr>
<tr>
<td>MH</td>
<td>NSW Institute of Psychiatry</td>
<td>Cumberland Hospital (East Campus)</td>
<td>NSW</td>
<td>Mental Health (Infant) (Research Stream)</td>
<td>Master</td>
<td>The Master of Mental Health (Child &amp; Adolescent) (Research Stream) is designed to prepare students for positions of leadership in the area of child and adolescent mental health. Candidates follow the clinical stream in this program. The program emphasises independent study and enquiry and is structured to develop integrated theoretical and practical skills and competencies.</td>
</tr>
<tr>
<td>MH</td>
<td>University of Melbourne</td>
<td>Parkville Campus</td>
<td>VIC</td>
<td>Mental Health Science (Infant and Parent Mental Health)</td>
<td>Graduate Diploma</td>
<td>The Graduate Diploma in Mental Health Sciences (Infant and Parent Mental Health) is aimed at health care professionals working in the infant mental health field, who wish to develop their understanding and clinical skills in working with infants and parents or who are interested in participating in service development, delivery and evaluation. The course has been developed out of clinical teaching work of the Infant Mental Health Group at the Royal Children's Hospital and draws on the disciplines of psychiatry, developmental psychology and psychoanalysis for its theoretical basis.</td>
</tr>
<tr>
<td>MH</td>
<td>University of Melbourne</td>
<td>Parkville Campus</td>
<td>VIC</td>
<td>Infant and Parent Mental Health (Course work)</td>
<td>Master of Health Sciences</td>
<td>The Master of Health Sciences (Infant and Parent Mental Health) (Course work) provides clinically focussed training to equip clinicians with clinical and planning responsibility for the mental health of infants and their families. The enhancement of specific professional or vocational skills which may be undertaken by directed coursework, involving more than one third of the course undertaken by coursework.</td>
</tr>
<tr>
<td>AOD</td>
<td>University of South Australia</td>
<td>Adelaide Campus</td>
<td>SA</td>
<td>Alcohol and Other Drugs (Specialty Area)</td>
<td>Graduate Certificate of Nursing</td>
<td>Bachelor's degree in nursing or equivalent; and Eligible to be licensed to practice as registered nurses/midwives in their own country or place of residence; and A minimum one-year of clinical experience as a registered nurse.</td>
</tr>
</tbody>
</table>

**Key:**
- No shading – unconfirmed at time of printing
- Pink shading – includes information on FASD
- Blue shading – may include information on FASD (assumption based on course content)
- MH= mental health AOD= alcohol and other drugs
- *Derived from NDETA See Chapter 8*
### Table 2. Non-accredited courses that include information on Fetal Alcohol Spectrum Disorder

<table>
<thead>
<tr>
<th>Area</th>
<th>Institution</th>
<th>Campus</th>
<th>State</th>
<th>Title</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>AOD</td>
<td>Centre for Nursing &amp; Midwifery Education &amp; Research</td>
<td>Sydney Campus</td>
<td>SA</td>
<td>Alcohol, tobacco &amp; other drug use in Pregnancy, Birth and Breastfeeding - Clinical Focus</td>
<td>Provides up-to-date education for health professional and other workers who care for women during their antenatal, birth and postnatal experience</td>
</tr>
</tbody>
</table>
| AOD  | Centre for Excellence in Child and Family Welfare | Flinders Medical Centre | VIC | Impact of Substance use on Families | **AIM OF TRAINING**  
To develop participants’ knowledge of:  
• the impact of parental substance-use from pregnancy to adolescence  
• the context in which problematic parental substance-use occurs  
• assessment of parenting capacity  
• effective interventions with children and parents  
**TOPICS**  
• the risks to children of parental substance use from pregnancy through to adolescence  
• assessment of parenting including the impact of various drugs  
• engaging parents as partners in a process of change  
• therapeutic services for substance-dependent parents and their children  
• working collaboratively with other service providers to improve outcomes for children and parents  
**LEARNING OUTCOMES**  
• improved assessment of parenting capacity and substance-use  
• strategies to engage parents in a process of change  
• strategies to reduce worker stress and improve safety  
• designing and implementing child-focused interventions to reduce risk and improve children’s resilience and outcomes |
| AOD  | Drugs and Alcohol Office (Next Step Specialist Drug and Alcohol Services) | DAO | WA | Talking about alcohol use with women before and during pregnancy | Alcohol use before and during pregnancy can have permanent major physical, intellectual and psychosocial effects on children and families. It is preventable and there is a clear opportunity for the health and social services workforce to make a difference. The evidence consistently supports the role of health professionals in providing information, advice and support to assist women to reduce risk. Raising the issue with all women including Aboriginal women, brief intervention and brief motivational interviewing techniques will be explored in this workshop. |
| AOD  | Drugs and Alcohol Office (Next Step Specialist Drug and Alcohol Services) | DAO | WA | Analysing child risk within the AOD sector - Introduction to models of assessment for workers engaging with substance using parents | Sound risk assessment is an essential component in assisting practitioners to explore more explicitly with families what needs to change if children are to be kept safe and healthy. It enables workers and families to identify help and services needed to support family strengths and welfare needs, and assists in the development and maintenance of supportive parenting plans.  
This session will provide an introduction to various models of family assessment to support improved assessment of child risk and potential for harm. |
<p>| AOD  | Drugs and Alcohol Office (Next Step Specialist Drug and Alcohol Services) | DAO | WA | How to better support parenting skills with drug using clients | The impact of an alcohol or other drug problem on the parenting role can be significant. This one-day event will provide workers with the information and tools to better explore the issues, understand and support parent clients. The session will also offer strategies for the clinician aimed at enhancing confidence, and improving clinical effectiveness when engaging these families. |</p>
<table>
<thead>
<tr>
<th>Area</th>
<th>Institution</th>
<th>Campus</th>
<th>State</th>
<th>Title</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>AOD/MH</td>
<td>Centre for Nursing &amp; Midwifery Education &amp; Research</td>
<td>Flinders Medical Centre</td>
<td>SA</td>
<td>Emergency Mental Health, Alcohol &amp; Drugs</td>
<td>This course was developed by Mental Health &amp; Emergency staff from Flinders Medical Centre and the School of Nursing &amp; Midwifery Flinders University, supported by The Centre for Nursing &amp; Midwifery Education &amp; Research and funded by the SA Department of Health. The course covers emergency issues relating to the assessment and management of clients with Mental Health / Alcohol / Drugs /Co-morbidity issues who present to emergency services in crisis and participants include a mixture of staff disciplines and services. The course has a practical &amp; interactive focus with scenario-based teaching, role-plays &amp; discussion. All participants receive a CD-ROM or hardcopy of pre-course readings and an interactive CD with workbook for flexible learning. Further resources &amp; relevant articles &amp; information are provided each day.</td>
</tr>
</tbody>
</table>

**Key:**
- No shading – unconfirmed at time of printing
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- Blue shading – may include information on FASD (assumption based on course content)
- MH= mental health   AOD= alcohol and other drugs
### Table 3. Psychology courses that include information on Fetal Alcohol Spectrum Disorder

<table>
<thead>
<tr>
<th>Area</th>
<th>Institution</th>
<th>Campus</th>
<th>State</th>
<th>Title</th>
<th>Level</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>MH</td>
<td>Monash University</td>
<td>Caulfield Campus</td>
<td>VIC</td>
<td>Psychology in Clinical Neuropsychology</td>
<td>Doctor</td>
<td>The Doctor of Psychology in Clinical Neuropsychology prepares psychology graduates for academic/research and professional careers by providing advanced training in both research and the skills required for practice in clinical neuropsychology. It consists of a combination of coursework, supervised practical experience and a major research component culminating in a thesis of about 70,000 words. A feature of the course is that training in clinical neuropsychology is extended through specialisation in a choice of areas, including rehabilitation, child and adolescent neuropsychology, geriatric neuropsychology, psychiatric neuropsychology and forensic psychology. Clinical neuropsychology is a field which applies an understanding of the neural basis of cognition, behaviour and emotion to the assessment and treatment of adults and children with neurological disorders.</td>
</tr>
<tr>
<td>MH</td>
<td>Monash University</td>
<td>Clayton Campus</td>
<td>VIC</td>
<td>Psychology in Clinical Neuropsychology</td>
<td>Doctor</td>
<td>The Doctor of Psychology in Clinical Neuropsychology prepares psychology graduates for academic/research and professional careers by providing advanced training in both research and the skills required for practice in clinical neuropsychology. It consists of a combination of coursework, supervised practical experience and a major research component culminating in a thesis of about 70,000 words. A feature of the course is that training in clinical neuropsychology is extended through specialisation in a choice of areas, including rehabilitation, child and adolescent neuropsychology, geriatric neuropsychology, psychiatric neuropsychology and forensic psychology. Clinical neuropsychology is a field which applies an understanding of the neural basis of cognition, behaviour and emotion to the assessment and treatment of adults and children with neurological disorders.</td>
</tr>
<tr>
<td>MH</td>
<td>Swinburne University of Technology</td>
<td>Hawthorn Campus</td>
<td>VIC</td>
<td>Psychology (Clinical Psychology)</td>
<td>Doctor</td>
<td>This Doctor of Psychology (Clinical Psychology) combines intensive high-level research training with training in the professional skills of clinical psychology. Clinical psychology is a specialisation focusing on psychopathology and the assessment and treatment of clinical disorders across the life span. Students will develop advanced knowledge/skills and experience in psychopathology, assessment and therapeutic interventions for adults and children suffering from clinical disorders.</td>
</tr>
<tr>
<td>MH</td>
<td>Swinburne University of Technology</td>
<td>Hawthorn Campus</td>
<td>VIC</td>
<td>Clinical Psychology</td>
<td>Graduate Diploma of Science</td>
<td>Clinical psychology is a specialisation focusing on psychopathology and the assessment and treatment of adults and children who are suffering from clinical disorders. This Graduate Diploma of Science (Clinical Psychology) is designed to meet the need for professional psychologists to re-specialise in clinical psychology. An admission requirement for the program is completion in the past five years of master or doctoral level training in professional psychology (e.g. counselling, health, clinical neuropsychology, forensic).</td>
</tr>
<tr>
<td>Area</td>
<td>Institution</td>
<td>Campus</td>
<td>State</td>
<td>Title</td>
<td>Level</td>
<td>Description</td>
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</tr>
<tr>
<td>MH</td>
<td>Swinburne University of Technology</td>
<td>Hawthorn Campus</td>
<td>VIC</td>
<td>Psychology (Clinical Psychology)</td>
<td>Master</td>
<td>Clinical psychology is a specialisation focusing on psychopathology and the assessment and treatment of clinical disorders across the life-span. This Master of Psychology (Clinical Psychology) provides high-level training in psychopathology, assessment and therapeutic interventions for adults and children suffering from clinical disorders.</td>
</tr>
</tbody>
</table>

**Key:**
- No shading – unconfirmed at time of printing
- Pink shading – includes information on FASD
- Blue shading – may include information on FASD (assumption based on course content)
- MH= mental health
- AOD= alcohol and other drugs
Appendix 2: Recent Australian literature

2012


Recent Australian literature
http://dx.doi.org/10.1002/14651858.CD009724

2011

http://dx.doi.org/10.1111/j.1530-0277.2011.01457.x


http://dx.doi.org/10.1016/S0140-6736(11)60884-2

http://bestpractice.bmj.com/best-practice/monograph/1141/resources/credits.html

http://dx.doi.org/10.1111/j.1523-536X.2010.00445.x

http://dx.doi.org/10.1111/j.1465-3362.2011.00331.x

http://dx.doi.org/10.1097/OGX.0b013e31821684bc

http://dx.doi.org/10.1186/1471-2458-11-424

http://dx.doi.org/10.1111/j.1365-3016.2011.01197.x

http://dx.doi.org/10.1111/j.1440-1754.2011.02037.x


2010


2009


2008


2007


2006


2005


2004


2003


2002


2000

1994


1980

Monograph References


ARND Consensus Statement (2011). Consensus statement on Recognizing Alcohol-Related Neurodevelopmental Disorder (ARND) in primary health care of children. A conference organized by the Interagency Coordinating Committee on Fetal Alcohol Spectrum Disorders (ICCFASD), Rockville, MD.


Centers for Disease and Control. (2006). How can we prevent FASDs?


Department of Health Western Australia (2010). Fetal Alcohol Spectrum Disorder model of care. Perth, Health Networks Branch, Department of Health, Western Australia.


Monograph of the Intergovernmental Committee on Drugs Working Party on Fetal Alcohol Spectrum Disorders


National Health and Medical Research Council (1992). Is there a safe level of daily consumption of alcohol for men and women? Canberra, National Health and Medical Research Council.
NSW Department of Health (2006). Background papers to the national clinical guidelines for the management of drug use during pregnancy, birth and the early development years of the newborn. Sydney, NSW Department of Health.


Snyder, J., Nanson, J., Snyder, R. and Block, G. (1997). A study of stimulant medication in children with FAS. Overcoming and Preventing Secondary Disabilities in Fetal...


