2

FASD and alcohol consumption patterns

2.1 The chapter provides an overview of Fetal Alcohol Spectrum Disorders (FASD). The damaging effects of alcohol on a fetus, particularly the fetal brain, at different points of development are identified. The various conditions that exist within the spectrum are discussed, along with the range of symptoms as well as the many secondary conditions that can stem from FASD.

2.2 The chapter addresses the prevalence of FASD and the limitations on available data in Australia.

2.3 Alcohol consumption patterns in Australia have changed markedly over the last few decades with a greater social acceptance of drinking across genders and age groups. Across some groups a prominent drinking culture has emerged, including excessive and harmful levels of alcohol consumption.

2.4 The chapter concludes with a discussion on maternal alcohol consumption rates.

What are Fetal Alcohol Spectrum Disorders?

2.5 FASD is an overarching term describing the range of outcomes that can occur in an individual who had prenatal exposure to alcohol. These effects may include physical, mental, behavioural, and/or learning disabilities

with possible lifelong implications. The term FASD is not intended for use as a clinical diagnosis.[1]

2.6 The adverse effects of prenatal alcohol exposure exist along a continuum, with the complete Fetal Alcohol Syndrome (FAS) at one end of the spectrum and incomplete features of FAS, including more subtle cognitive-behavioural deficits with no physical features, at the other.[2] The terminology used to define the various adverse effects of prenatal alcohol exposure has evolved over the years.

2.7 In 1973, Jones and Smith coined the term FAS to describe a pattern of abnormalities observed in children born to alcoholic mothers.[3]

2.8 A literature review for the National Drug Strategy explains that a diagnosis of FAS is based on a set of criteria comprised of abnormalities in three main categories:

- growth retardation,
- characteristic facial features (small eye slits, thin upper lip and diminished groove between nose and upper lip), and
- central nervous system anomalies (including abnormalities of structure and function eg intellectual impairment).[4]

2.9 The literature review goes further to state that the intellectual impairment associated with FAS is permanent and FAS is now regarded as the leading, preventable cause of non–genetic intellectual handicap.[5]

2.10 The Substance Abuse and Mental Health Services Administration in the United States lists some of the other conditions contained within the overarching term FASD:

- Partial FAS: The Institute of Medicine coined this term in its 1996 report on FAS. The term refers to children who have some of the facial features of FAS, along with evidence of growth retardation, neurodevelopmental abnormalities, or a complex pattern of behaviour or cognitive abnormalities inconsistent with developmental level that cannot be explained by family background or environment alone.

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1 Substance Abuse and Mental Health Services Administration, *Curriculum for Addiction Professionals,* <http://fasdcenter.samhsa.gov/educationTraining/courses/CapCurriculum/competency1/terminology1.cfm> viewed 5 September 2012.

2 Rimrock Foundation, *Fetal Alcohol Syndrome*, <http://www.rimrock.org/resources/fact-sheets/alcohol-addiction/fetal-alcohol-syndrome> viewed 19 November 2012.

3 National Institute on Alcohol Abuse and Alcoholism, 'Fetal Alcohol Syndrome' *Alcohol Alert no. 13*, PH 297, July 1991, <http://pubs.niaaa.nih.gov/publications/aa13.htm> viewed 5 September 2012.

4 Commonwealth Government Department of Health and Ageing (DoHA), *Fetal Alcohol Syndrome: A Literature Review,* August 2002, p. 1.

5 DoHA, *Fetal Alcohol Syndrome: A Literature Review,* August 2002, p. 1.

- Alcohol-related neurodevelopmental disorder: The Institute of Medicine created this term to refer to neurodevelopmental abnormalities or a complex pattern of behaviour or cognitive abnormalities inconsistent with developmental level that cannot be explained by family background or environment alone.
- Alcohol-related birth defects: The Institute of Medicine created this term in its 1996 volume on FAS to describe physical anomalies only.
- Static encephalopathy: The University of Washington introduced this term in their development of the 4-Digit Diagnostic Code, first published in 1997.[6]

2.11 Additionally a number of terms have been established over the years to label the diagnostic sub classifications under the umbrella of FASD. These include:

- Fetal Alcohol Effects (FAE);
- Static Encephalopathy/Alcohol Exposed; and
- Neurodevelopmental Disorder/Alcohol Exposed.[7]

2.12 Other than the term FAS, which refers to a particular syndrome within the umbrella of disorders known generally as FASD, there is no international consensus on terms for the diagnostic descriptions of the effects of prenatal alcohol exposure. All of the terms above have been used at various times, though some such as FAE are no longer in use.

History

2.13 There has been a long history of recognition of the adverse effects of prenatal alcohol exposure. The book of Judges from the Bible warns that:

> Behold, thou shalt conceive, and bear a son: and now, drink no wine or strong drink.[8]

2.14 In early Roman and Greek mythology allusions were made to an association between maternal alcoholism and faulty development of the offspring.[9] In the ancient Greek city of Carthage, the bridal couple were

6 Substance Abuse and Mental Health Services Administration, *FASD The Basics Powerpoint Version*, slide 6, 'Other Diagnostic Terminology', <http://fasdcenter.samhsa.gov/educationTraining/fasdBasics.aspx> viewed 5 September 2012.

7 DoHA, *Fetal Alcohol Syndrome: A Literature Review,* August 2002, p. 1.

8 Bible, Judges 13:3-4.

9 E Abel, 'Was the Fetal Alcohol Syndrome recognised by the Greeks and Romans?', *Alcohol and Alcoholism*, vol. 34 (6), 1999, pp. 868-872.

forbidden to drink wine on their wedding night so that defective children would not be conceived.[10]

2.15 One of the first historical references to the connection between prenatal maternal alcohol consumption and the development of children was during the gin epidemic in England of the 1700s. Over this time the price of gin plummeted and consumption increased over five fold.[11]

2.16 In 1725, the College of Physicians warned the United Kingdom Parliament of:

> … the fatal effects of the frequent use of several sorts of distilled spirituous liquors upon great numbers of both sexes. … Too often the cause of weak, feeble, and distempered children.[12]

2.17 The first report about the effects of the abuse of spirits was released in 1734, noting that gin-drinking mothers gave birth to unusually small, old looking babies.[13] In 1834, a report to the House of Commons by a select committee investigating drunkenness indicated that infants born to alcoholic mothers sometimes had a starved, shrivelled and imperfect look.[14] In the early to mid 1900s, there were sporadic clinical reports suggesting an association between maternal alcoholism and serious abnormalities in the offspring.

2.18 Historically most of these references to fetal abnormalities from alcohol exposure relate to high levels of alcohol consumption by the mother. More recent research has demonstrated the risk of a range of impacts on fetal development at low levels of prenatal alcohol exposure.

The effect of alcohol on a fetus

2.19 This section outlines how alcohol can affect the development of a fetus in utero. Cell growth occurs at different stages and rates as a fetus matures. At critical stages this process can be disrupted with permanent impacts through the transfer of even small amounts of alcohol through the placenta.

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10 A Streissguth, *Fetal Alcohol Syndrome: A Guide for Families and Communities*, United States, 1997, p. 35.

11 E Abel, *Fetal Alcohol Syndrome*, United States, 1990, p. 4.

12 DoHA, *Fetal Alcohol Syndrome: A Literature Review,* August 2002.

13 P Dillon, *The Much Lamented Death of Madam Geneva: The Eighteenth Century Gin Craze*, United Kingdom, Headline Books, 2002.

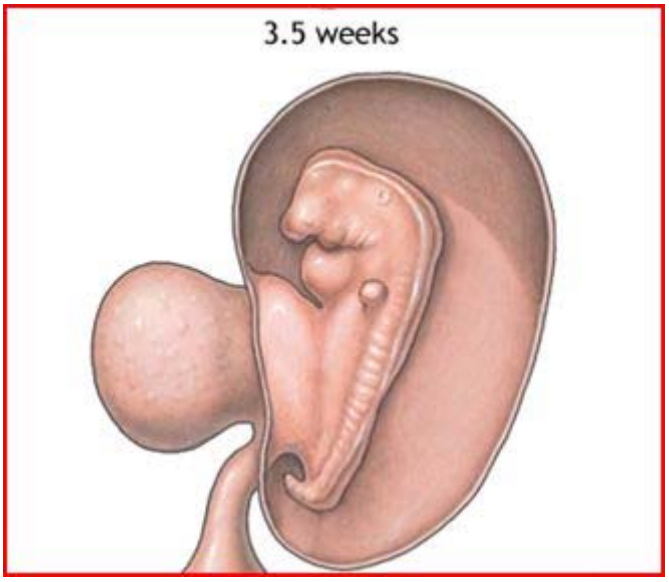
14 S Mattson et al, *Teratogenic Effects of Alcohol on Brain and Behavior*, <http://pubs.niaaa.nih.gov/publications/arh25-3/185-191.htm> viewed 4 July 2012.

Normal development

2.20 In the first two weeks of pregnancy, the zygote, the cell formed as a result of fertilisation, divides and implants. An embryo is formed.

2.21 During the third week, the cells of the embryo begin to multiply and take on specific functions in a process called differentiation. Differentiation results in the development of various cell types that make up a human being. Rapid growth occurs and during this critical period the growing fetus is particularly susceptible to damage.[15]

Figure 2.1 Fetus at 3.5 weeks gestation



Source *Untied States National Institutes of Health, <http://www.nlm.nih.gov/medlineplus/ency/imagepages/9578.htm>.*

2.22 At week five of pregnancy, the brain, spinal cord and heart begin to develop. During week six to seven, arm and leg buds become visible. The brain develops into five areas and some cranial nerves are visible.[16]

2.23 During week eight, the arms and legs continue to grow, with hands and feet becoming distinguishable. The brain continues to form. By week nine, all essential organs have begun to form. Elbows and toes are visible. At week ten, the eyelids are more developed, and the external features of the ear begin to take their final shape, with facial features continuing to develop.

15 United States National Institutes of Health (USNIH), *Fetal Development*, <http://www.nlm.nih.gov/medlineplus/ency/article/002398.htm> viewed 28 June 2012.

16 USNIH, *Fetal Development*, <http://www.nlm.nih.gov/medlineplus/ency/article/002398.htm> viewed 28 June 2012.

2.24 The end of the tenth week of pregnancy marks the end of the embryonic period and the beginning of the fetal period. At this point all structures are formed. From weeks ten to 38, growth continues and the fetus continues to develop but less rapidly than the previous weeks.[17]

2.25 The brain and nervous system continue to develop throughout the pregnancy. In the second trimester, there is a critical period where the brain continues differentiation and cellular migration takes place. Exposure to alcohol during this time can result in abnormal migration or cell loss.

2.26 The final critical period of growth begins in the middle of the second trimester and peaks around birth. During weeks 27 to 30 of pregnancy, fetal brain growth occurs at its fastest rate.[18]

Alcohol exposure

2.27 Drugs taken by a pregnant woman follow the same route as oxygen and nutrients which are needed for growth and development, crossing the placenta to reach the fetus.

2.28 Some drugs taken during pregnancy can affect the fetus in several ways. For example:

- They can act directly on the fetus, causing damage, abnormal development (leading to birth defects), or death.
- They can alter the function of the placenta, usually by causing blood vessels to narrow (constrict) and thus reducing the supply of oxygen and nutrients to the fetus from the mother. Sometimes the result is a baby that is underweight and underdeveloped.
- They can cause the muscles of the uterus to contract forcefully, indirectly injuring the fetus by reducing its blood supply or triggering preterm labour and delivery.[19]

2.29 Alcohol is a teratogen meaning it is an agent which can disturb the development of an embryo or fetus. A teratogen may cause a birth defect

17 USNIH, *Fetal Development*, <http://www.nlm.nih.gov/medlineplus/ency/article/002398.htm> viewed 28 June 2012.

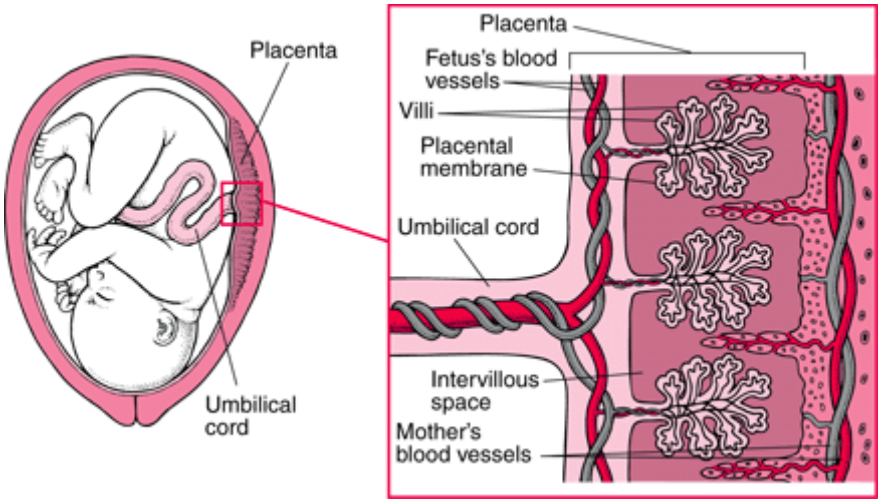
18 USNIH, *Fetal Development* <http://www.nlm.nih.gov/medlineplus/ency/article/002398.htm> viewed 28 June 2012.

19 The Merck Manual Home Health Handbook, *Drug Use during Pregnancy*, <http://www.merckmanuals.com/home> viewed 5 September 2012.

or may halt the pregnancy outright.[20] Alcohol is more damaging to neurobehaviour than other teratogens.[21]

2.30 When a pregnant woman drinks, the alcohol is passed directly to the fetus through the placenta. Some of the blood vessels of the fetus are contained within the villi of the placenta that connect it to the uterine wall. The mother's blood passes within the intervillous space, which is separated only by the thin placental membrane.

Figure 2.2 Teratogen passing from the placenta to the fetus



Source *North Carolina State University, WolfWikis, <http://wikis.lib.ncsu.edu/index.php/Group_7_Teratogens_Affecting_Fetal_Development_in_Humans>.*

2.31 Scientific research has proved the direct effects that alcohol can have on fetal growth and development. The fetus is unable to break down alcohol in the way that an adult does and so the blood alcohol level of the fetus becomes equal to or greater than the blood alcohol level of the mother. Further the fetus' blood alcohol level remains high for a longer period of time.[22]

2.32 Alcohol sets in motion different processes at different sites in the developing fetus. Consequently the effects of alcohol on the developing fetus can be wide-ranging. Further, developmental damage is not confined to high alcohol users. Even in moderate alcohol users, it was found that for

20 Medicinenet.com, *Definition of a Teratogen*, <http://www.medterms.com> viewed 5 September 2012.

21 DoHA, *Fetal Alcohol Syndrome: A Literature Review,* August 2002.

22 United States Department of Health and Human Services, Substance Abuse and Mental Health Services Administration, *Effects of Alcohol on a Fetus 2007*, pp. 1–2.

every two drinks consumed per day during late pregnancy, fetal birth weight decreased by 160 grams.[23]

2.33 Alcohol can trigger cell death in numerous ways, causing different parts of the fetus to develop abnormally. Defects caused by prenatal exposure to alcohol have been identified in virtually every part of the body, including the brain, face, eyes, ears, heart, kidneys and bones. Significantly, toxic by–products of alcohol metabolism may become concentrated in the brain.[24]

2.34 The teratogenic effect of alcohol is considered to be dose-related.[25]

2.35 Research continues into the scope of the effects of prenatal alcohol exposure on the brain. There exists a more extensive research base into FAS, therefore the following section draws on this research. However, many of these impacts are observed to varying degrees across the range of disorders encompassed by the term FASD.

Impact on the fetal brain

2.36 The brain is the organ which is most sensitive to prenatal alcohol damage, and alcohol exposure can have serious and permanent effects on the developing fetal brain.

2.37 Additionally, since the brain and central nervous system are constantly developing throughout pregnancy, the fetal brain is always vulnerable to damage from alcohol exposure.

2.38 Prenatal alcohol exposure can reduce the size and weight of the fetal brain and can reduce the size of different parts of the brain.[26] It can disrupt stem cell growth leading to a reduction in the generation of new nerve cells and delays in dendritic development. These are important for memory and other functions.

2.39 Prenatal exposure to alcohol can result in disorganised cortical architecture. This influences the pattern of communication in and across regions of the brain which are involved in higher cognitive function.[27]

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23 R Little, 'Moderate Alcohol Use during Pregnancy and Decreased Infant Birth Weight', *American Journal of Public Health*, vol. 67, 1977, p. 1154.

24 United States Department of Health and Human Services, Substance Abuse and Mental Health Services Administration, *Effects of Alcohol on a Fetus 2007*, pp. 1–2.

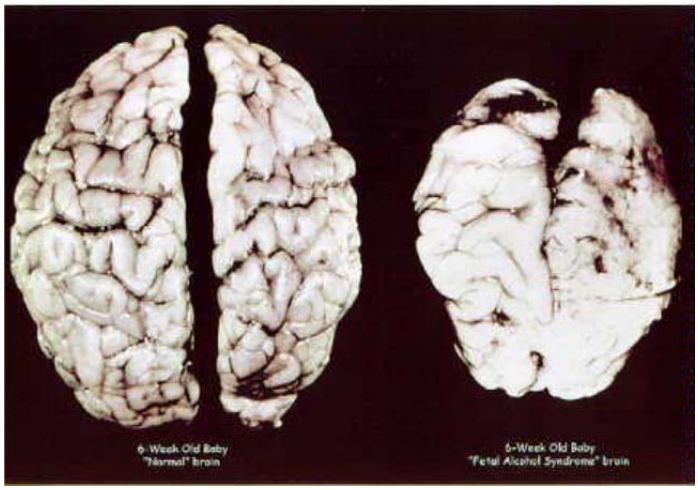
25 A Ornoy, Z Ergaz 'Alcohol Abuse in Pregnant Women: Effects on the fetus and newborn, mode of action and maternal treatment,' *International Journal of Environmental Research and Public Policy*, 2010, vol. 7, pp. 364-379.

26 S Mattson et al, *Teratogenic Effects of Alcohol on Brain and Behavior*, <http://pubs.niaaa.nih.gov/publications/arh25-3/185-191.htm> viewed 4 July 2012.

27 K Uban et al, 'Direct and Indirect Mechanisms of Alcohol Teratogenesis: Implications for Understanding Alterations in the Brain and Behaviour in FASD', in E Riley et al, eds, *Fetal*

Cognition is a group of mental processes that includes attention, memory, producing and understanding language, solving problems, and making decisions.

Figure 2.3 6 week old brains compared: a normal brain and a 'fetal alcohol syndrome' brain



Source *T Kellerman, FAS Community Resource Center Prenatal Alcohol Exposure and the Brain, <http://www.come-over.to/FAS/FASbrain.htm>.*

2.40 Alcohol can affect discrete parts of the brain. Structural abnormalities can occur in various regions of the brain, including the cerebellum, corpus callosum, and the basal ganglia.[28] These brain regions and the hippocampus are particularly sensitive to structural damage which, in turn, can be related to various neuropsychological impairments.

2.41 The brain is not uniformly sensitive to prenatal exposure to alcohol. Animal studies suggest that there are differences in the susceptibility of different brain regions to alcohol depending on the dose and timing of exposure.[29]

2.42 The hippocampus plays a fundamental role in memory, learning and emotion. During the third trimester, the hippocampus is particularly affected by alcohol. Prenatal exposure can cause abnormal hippocampal

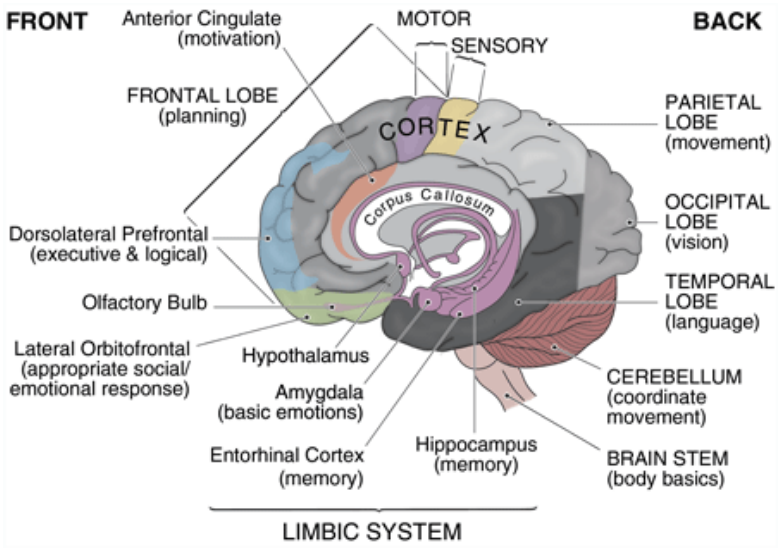
Alcohol Spectrum Disorder: Management and Policy Perspectives of FASD, Wiley-Blackwell, United States, 2011.

28 S Mattson et al, *Teratogenic Effects of Alcohol on Brain and Behavior*, <http://pubs.niaaa.nih.gov/publications/arh25-3/185-191.htm> viewed 4 July 2012.

29 See for example, D Bonthius and J West, 'Alcohol-Induced Neuronal Loss in Developing Rats: Increased Brain Damage with Binge Exposure', *Alcoholism: Clinical and Experimental Research*, vol. 14, no. 1, 1990, pp. 107–118.

development and function which may result in problems with encoding visual and auditory information.[30]

Figure 2.4 The human brain



Source *The Brainwaves Center, <http://www.brainwaves.com/>.*

2.43 Studies in rats prenatally exposed to alcohol indicate there are reduced numbers of neurons and neuron damage. Behaviourally, animals exposed prenatally to alcohol are impaired in spatial learning and memory tasks consistent with hippocampal damage, such as navigating mazes. Changes in synaptic activity in live hippocampal brain slices were observed. [31]

2.44 The hypothalamus controls appetite, emotions, temperature and pain sensation. Prenatal alcohol exposure can affect the areas of the hypothalamus that regulate the body's response to stress and control the reproductive system and the metabolism of tissues.[32]

30 S Mattson et al, *Teratogenic Effects of Alcohol on Brain and Behavior*, <http://pubs.niaaa.nih.gov/publications/arh25-3/185-191.htm> viewed 4 July 2012.

31 S Mattson et al, *Teratogenic Effects of Alcohol on Brain and Behavior*, <http://pubs.niaaa.nih.gov/publications/arh25-3/185-191.htm> viewed 4 July 2012.

32 S Barron et al, 'Effects of Prenatal Alcohol Exposure on the Sexually Dimorphic Nucleus of the Preoptic Area of the Hypothalamus in Male and Female Rats', *Alcoholism: Clinical and Experimental Research*, vol. 12, no. 1, 1988, pp. 59–64.

2.45 Prenatal exposure to alcohol can result in dysfunctional circadian systems, which may contribute to the behavioural problems seen in many children affected by FASD.[33]

2.46 The cerebellum controls coordination and movement, behaviour and memory. Studies have shown that prenatal alcohol exposure can damage the cerebellum.[34] Damage to the cerebellum has been implicated in learning deficits as well as balance and coordination.

2.47 The corpus callosum is a band of nerve fibres which connects the left and right sides of the brain to allow communication between the hemispheres. Research shows that prenatal alcohol exposure results in abnormalities of the corpus callosum.

2.48 Damage to the corpus callosum has been linked to deficits in attention, intellectual functioning, reading, learning, verbal memory, and executive and psychosocial functioning. Approximately seven per cent of children affected by FASD lack the corpus callosum, which is an incidence rate 20 times higher than in the general population.[35]

2.49 The basal ganglia are a group of nerve cell clusters involved in voluntary limb movement, eye movement and cognition. One study showed that children who had been prenatally exposed to alcohol had smaller basal ganglia. Damage to the basal ganglia impairs various cognitive processes in humans such as procedural memory, habit and skill learning, attention, perception and language.[36]

Effects at critical times of development

2.50 The type of defects in an individual affected by FAS relate to the time during pregnancy when alcohol is consumed.

2.51 Individual abnormalities may occur as a result of drinking during discrete periods of the pregnancy. Figure 2.5 indicates the effects of teratogens such as alcohol on the developing fetus at different stages of pregnancy.

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33 H Sakata-Haga, 'Alterations in circadian rhythm phase shifting ability in rats following ethanol exposure during the third trimester brain growth spurt', *Alcoholism: Clinical and Experimental Research*, vol. 30, 2006, pp. 899-907.

34 S Mattson et al, *Teratogenic Effects of Alcohol on Brain and Behavior,* <http://pubs.niaaa.nih.gov/publications/arh25-3/185-191.htm> viewed 4 July 2012.

35 S Mattson et al, *Teratogenic Effects of Alcohol on Brain and Behavior*, <http://pubs.niaaa.nih.gov/publications/arh25-3/185-191.htm> viewed 4 July 2012.

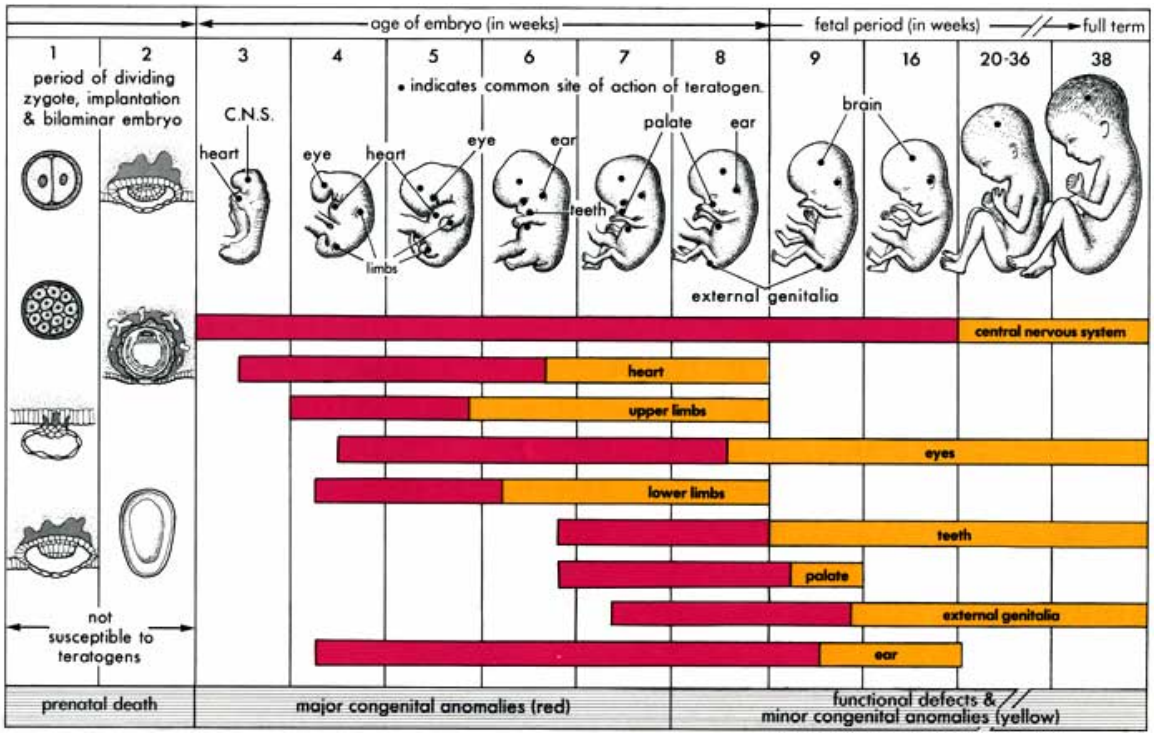
36 R Bannister, *Brain and Bannister's Clinical Neurology*, 7th ed, Oxford University Press, United States, 1992; A Stocco et al, 'Conditional Routing of Information to the Cortex: A Model of the Basal Ganglia's Role in Cognitive Coordination', *Psychological Review*, vol. 117, 2010, pp. 541-574.

2.52 For its first two weeks of gestation, the fetus is not susceptible to teratogens. Following this period and through the first trimester, the fetus is most susceptible to the teratogenic effects of alcohol during organogenesis, or the development of organs. During this first trimester, alcohol interferes with the migration and organisation of brain cells.

2.53 Research suggests that one or more episodes of heavy maternal drinking at critical periods in pregnancy may damage severely the embryo and may result in the features of FAS.[37]

2.54 Exposure to alcohol during the crucial period of three to nine weeks gestation can result in major congenital abnormalities of the central nervous system, eyes and ears. During the three to six week gestation period, major abnormalities can occur to the heart and upper limbs. During the six to eight week period of gestation, major abnormalities can arise in the teeth, palate and external genitalia.

Figure 2.5 Effects of teratogens at different stages of pregnancy



Source *Exhibit 17, Alcohol and other Drugs Council of Australia.*

2.55 Functional defects and minor congenital abnormalities can occur between nine and 38 weeks gestation. Additionally, scientists suggest that the third

37 W Webster et al, 'Some teratogenic properties of ethanol and acetaldehyde in C57BL/6J mice: Implications for the study of the fetal alcohol syndrome', *Teratology*, vol. 27, 1983, pp. 231–243.

trimester is a crucial period for prenatal alcohol exposure. The hippocampus may be affected, which can lead to problems with encoding visual and auditory information.[38]

2.56 While frequency and quantity of consumption clearly increase the risks to the fetus, research suggests that alcohol at any time can endanger the development of the fetus.

FASD symptoms

2.57 FASD encompasses a range of clinically significant effects, some of which include cognitive impairment, growth retardation, facial anomalies and developmental abnormalities of the central nervous system.[39] Only a minority of people with FASD will have a low IQ.[40] Conditions along the spectrum manifest in a variety of ways, and when untreated can lead to secondary disabilities or disadvantages.

2.58 People with FASD have an 'observable abnormality in the structure and size of the brain; that is, a physical condition which causes a change in function'.[41] The functions usually affected by FASD are learning and behavioural functions. The National Rural Health Alliance (NRHA) explained that these problems are:

> … primarily the result of impairment of the brain's 'executive functions', including the ability to plan, learn from experience and control impulses. Children affected might be regarded as being wilful or undisciplined when in fact they have little control over their behaviour.[42]

2.59 However, these functions may not be physically visible to others. Dr Jacki Mein explained to the Committee that people with FASD:

> [have] a functional impairment. It is not how they speak to you. It is more about that executive functioning. They just make poor

38 Prenatal Alcohol Exposure, <http://come-over.to/FAS/PDF/FASbrainColor.pdf> viewed 12 September 2012.

39 Australian National Preventive Health Association, *Submission 45*, p. 1.

40 A Russell, Executive Officer, Russell Family Foetal Alcohol Disorders Association (RFFADA), *Committee Hansard*, Cairns, 31 January 2012, p. 6; Foundation for Alcohol Research and Education and Public Health Association of Australia, *Submission* 36, p. 22; Professor E Elliott, Professor of Paediatrics and Child Health, University of Sydney, *Committee Hansard*, Sydney, 13 April 2012; Ashurst Australia, *Submission 49*, p. 7.

41 Ashurst Australia, *Submission 49*, p. 8.

42 National Rural Health Alliance, *Submission 40,* p. 4.

> choices. They do not relate well to people. It gets them into trouble.[43]

2.60 Barbara Smith explained how a group of foster parents realised that some of the children they cared for shared particular symptoms:

> Many years ago some foster families recognised there was a group of children in care who seemed to display similar problems – behaviour issues, learning and relationship difficulties, understanding consequences, social issues etc. It was not until one carer researched FASD and its related problems for children and families that the penny dropped.[44]

2.61 Depending on where their condition lies on the spectrum, children with FASD may exhibit the following symptoms:

Infants:

- Low birth weight/poor growth
- Irritability
- Sensitivity to light, noises and/or touch
- Feeding problems
- Failure to thrive

Toddlers:

- Memory problems
- Hyperactivity
- Lack of fear
- Poor sense of boundaries
- Impairment of gross or fine motor skills

Children:

- Poor growth
- Developmental delay
- Problems with vision
- Memory problems
- Language and speech deficits
- Poor judgement
- Birth defects
- Improperly formed bodies and organs
- Social and behavioural problems
- Cognitive problems
- Sleeping difficulties
- Hyperactivity

43 Dr J Mein, Medical Officer, Apunipima Cape York Health Council, *Committee Hansard*, Cairns, 31 January 2012, p. 17.

44 B Smith, *Submission 4*, p. 1.

- Impulsiveness
- Difficulty concentrating
- Problems with abstract thinking (time, money)
- Difficulty forming and maintaining relationships.[45]

Figure 2.6 The Story of Tristan

Tristan is an Australian film depicting the life of a young boy exposed to alcohol during his mother's pregnancy. *Tristan*, along with the documentary *Maralu*, was produced as part of the Lililwan project and was shown at the United Nations headquarters in New York in May 2012. *Tristan* was part of a presentation at the UN in the 11th Permanent Forum on Indigenous Issues on Australian research on the disorder.

The Lililwan project's submission noted that 'Alcohol exposure *in-utero* may result in a range of disorders that include brain injury, birth defects and lifelong learning, and behavioural and mental health issues. FASD are the most common causes of preventable intellectual impairment.'

Tristan brings the effects of *in-utero* exposure to alcohol to life, telling the story of a 12-year old boy from the Fitzroy Valley born with the disorder. It follows Tristan's struggles with communication and attention problems. The film is both confronting and courageous in its ability to transport the viewer to north-west Australia to experience the hopes, dreams and challenges facing Tristan.

The documentary, produced by the University of Sydney's Associate Professor Jane Latimer and directed by Melanie Hogan, also highlights the efforts by members of the Fitzroy Valley community to deal with the disease.

Source: *Submission 22*, *The Lililwan Project Collaboration, p.6.*

2.62 People with FASD often share positive traits as well, such as:

- friendly, cheerful, loving, affectionate
- caring, kind, concerned, compassionate
- gentle, nurturing towards younger children
- funny, with a great sense of humour
- persistent and hard-working, with a sense of determination
- curious
- creative, artistic, musical
- fair, cooperative
- interested in animals
- interested in activities like gardening and constructing
- highly verbal, good storytellers.[46]

45 P Walker, *Submission 29*, p. 7.

2.63 Robert Chataway described his foster son as 'a poor feeder and a poor sleeper [who] did not respond to things. When it came to crawling, he never crawled. He did not speak until he was four.'[47]

2.64 Individuals with FASD are unlikely to learn from past experience or understand cause and effect and may act 'about half their chronological age in their ability to live in society independently'.[48]

2.65 Carolyn Travers observed children transform during adolescence into 'absolute horrors. It was not just that normal change; it was changes that these children did not realise themselves: violence, anger, throwing things.'[49]

2.66 This was corroborated by other foster carers. The behaviours of one foster child 'had escalated to a point where he was targeting his carers, physically assaulting them, and causing property damage'[50] and another 12-year-old boy had been expelled from school due to violent behaviour:

> He struggles with the self-knowledge that he is not normal, even though he desperately wants to be normal. He is actually at an age of awareness at the moment. He does not have one friend in the whole world, because he lacks social skills and he has bad behaviour. He struggles with self-loathing for the relationships that he is constantly breaking, but he cannot stop the cycle of breaking them. He has started to self-harm, and he verbalises that he thinks he is a waste of oxygen. He has trouble with fine motor control, memory, retaining information and sequencing, and if you give him any more than two instructions at one time then he cannot follow them. He is very intelligent in some ways, but he is lacking in many areas—for instance, social skills, aggression and impulse control. His prospects of being a valued member of society in the future are very low. His future relationships are probably going to be volatile and dysfunctional, and he will probably have difficulty in finding and keeping employment due

46 Healthy Child Manitoba, *What Early Childhood Educators Need to Know about Fetal Alcohol Spectrum Disorder (FASD)*, 2010, p. 8, <http://www.gov.mb.ca/healthychild/fasd/resources.html> viewed 11 September 2012.

47 L Chataway, *Committee Hansard*, Townsville, 31 January 2012, p. 14.

48 S Miers, Chair, National Organisation for Fetal Alcohol Syndrome and Related Disorders (NOFASARD), *Committee Hansard*, Melbourne, 22 June 2012, p. 22.

49 C Travers, Team Leader, Wee Care Shared Family Care, *Committee Hansard*, Townsville, 31 January 2012, p. 1.

50 D Jenrick, Regional Manager, Barnardos, *Committee Hansard*, Sydney, 13 April 2012, p. 29.

> to his lack of social skills and his oppositional and defiant behaviours.[51]

2.67 FASD is not a diagnostic term itself; diagnoses of FASD include Fetal Alcohol Syndrome (FAS), partial Fetal Alcohol Syndrome (pFAS), alcohol-related neuro-developmental disorder (ARND) and alcohol-related birth defects (ARBD).

2.68 Professor Elizabeth Elliott stated that to fulfil diagnostic criteria for either FAS or ARND, children must demonstrate dysfunction in at least three domains of the central nervous system, such as academic achievement, communication problems, fine and gross motor problems or behavioural problems.[52]

2.69 Instances of FAS are in the minority across the FASD spectrum.[53] The syndrome is distinguished by structural or functional brain abnormalities, growth impairments, and the presence of three particular facial features: small eye slits, a smooth philtrum, and a thin upper lip.[54] FAS is the only FASD diagnosis that can be made without confirmation of prenatal alcohol exposure, if the abnormalities are consistent with the syndrome and other possible diagnoses have been excluded.[55]

2.70 Other symptoms of FAS can include:

> … growth delays, intellectual impairments, problems with learning, memory, attention problems, communication problems, vision or hearing impairments, or damage to the skeleton or major organs of the body such as the heart and kidneys [or possibly] a mix of these problems.[56]

2.71 One foster parent whose son was diagnosed with FAS stated that he had:

> … major learning disabilities, poor impulse control, poor memory and concentration, inability to understand or learn social mores and consequences, no empathy, poor gross and fine motor skills, inability to grasp abstract concepts such as numbers.[57]

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51 T Harth, Foster Carer, Barnardos, *Committee Hansard*, Sydney, 13 April 2012, p. 32.

52 Professor E Elliott, University of Sydney, *Committee Hansard,* Sydney, 13 April 2012, p. 4.

53 NOFASARD*, Submission 46*, p. 3; National Drug Research Institute, *Submission 20*, p. 5.

54 Dr J Fitzpatrick, Paediatric Senior Registrar, University of Sydney, *Committee Hansard,* Canberra, 24 November 2011, p. 4.

55 Intergovernmental Committee on Drugs Working Party on Fetal Alcohol Spectrum Disorders, *Fetal Alcohol Spectrum Disorders: An Update*, 2009, p. 34.

56 NOFASARD, *Submission 46*, p. 3.

57 Name withheld, *Submission 8*, p. 1.

2.72 The Committee heard evidence from another foster carer with five children who have received a diagnosis of FAS:

> [T]hey cannot even manage their daily hygiene and simple things like wiping your bum when you go to the toilet.
>
> …
>
> The 10-year-old girl did brilliantly up to grade 2 and that is as far as she has progressed.
>
> …
>
> Every day is a new day. Yesterday is forgotten. It is the same process every day you come home: 'Take your shoes off outside, empty the sand out and go and put them in your room. Put the socks out to be washed. Bring your lunchbox and put it on the sink for mum to fix up.' It is the same thing over and over again. We could make a tape recording and play it.[58]

2.73 The signifying features of pFAS are two of the three FAS facial characteristics plus brain abnormalities and known prenatal alcohol exposure.[59]

2.74 People with ARND, the largest FASD category,[60] do not possess any identifying facial features but a confirmed history of maternal alcohol use is a requisite for this diagnosis. As such, FASD is generally an 'invisible birth defect'.[61] The National Organisation for Fetal Alcohol Syndrome and Related Disorders (NOFASARD) states that ARND means that:

> Sometimes there can be significant learning disorders and developmental delays but not necessarily a low IQ. Most often there will be problems with behaviour. Neurodevelopmental Disorders can mean children do poorly in school and have difficulties with maths, memory and attention, judgment, experience poor impulse control and lack social skills. When there are no visible signs of disability other than behaviours, the behaviours are targeted for change with no recognition that alcohol exposure during pregnancy is the cause of individual difficulties.[62]

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58 R Metzger, *Committee Hansard*, Cairns, 31 January 2012, pp. 30-31.

59 Dr J Fitzpatrick, University of Sydney, *Committee Hansard,* Canberra, 24 November 2011, p. 4

60 A E Chudley,' Fetal Alcohol Spectrum Disorder: Counting the invisible—mission impossible?', *Archives of Disease in Childhood*, vol. 93, no. 9, September 2008, p. 721; NOFASARD, *Submission* 46, p. 7.

61 National Rural Health Alliance (NHRA), *Submission 40*, p. 4.

62 NOFASARD, *Submission 46,* p. 3.

2.75 The US Fetal Alcohol Spectrum Disorders Study Group notes that individuals with ARND:

> … have a behavioral phenotype that is true to the wide-ranging and individually variable physiological impact of alcohol exposure in utero. Individuals with ARND show clinically significant problems in multiple domains. These domains can include communication, abstract reasoning, memory, learning, executive function, adaptive behavior and attention, to name a few. Unlike earlier research, recent findings show that a majority of individuals with prenatal alcohol exposure do not have mental retardation; rather their problems are seen more in their inability to function adaptively in their environments.[63]

2.76 One of the US diagnostic classification systems splits ARND into two categories: a severe form, static encephalopathy/alcohol exposed, and a moderate form, neurodevelopmental disorder/alcohol exposed.[64]

2.77 ARND is difficult to identify. Dr James Fitzpatrick described neurodevelopmental disorder/alcohol exposed as a condition:

> … when you have a child that looks perfectly normal, who can be well grown, however, has specific abnormalities of the brain function or structure, plus confirmed alcohol exposure.[65]

2.78 People with ARBD have birth defects, perhaps in the heart, kidney or ears, combined with confirmed prenatal alcohol exposure, without any effects on the central nervous system.[66]

Secondary conditions

2.79 Children with FASD who do not receive appropriate treatment are disproportionately likely to develop other, secondary conditions as they grow into adolescence and beyond:

> The impact of FASD extends beyond the primary symptoms as children with FASD have a high risk of developing secondary difficulties particularly affecting integration with social norms.[67]

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63 R and L Chataway, *Submission 7,* p. 2.

64 S J Astley, 'Diagnosing Fetal Alcohol Spectrum Disorders (FASD)', in SA Adubato and DE Cohen (eds), *Prenatal Alcohol Use and Fetal Alcohol Spectrum Disorders: Diagnosis, assessment and new directions in research and multimodal treatment*, Bentham Books: Oak Park, 2011, p. 17.

65 Dr J Fitzpatrick, University of Sydney, *Committee Hansard,* Canberra, 24 November 2011, p. 4

66 Foundation for Alcohol Research and Education and Public Health Association of Australia, *Submission 36*, p. 10.

67 Alcohol and other Drugs Council of Australia, *Submission 33,* p. 2.

2.80 The NRHA explained that:

> FASD and organic brain damage can come with a host of other problems called secondary disabilities. Mental health problems are the most common but addictions are also seen. Children tend to start with having attention and anxiety problems, then move on to depression in adolescence and adulthood. There is also an increased risk for suicide.[68]

2.81 According to the Australian Human Rights Commission (AHRC), international research reports poor long-term outcomes for children with FASD; 90 per cent will have mental health problems, 80 per cent will remain unemployed, 60 per cent will come into aggravated contact with the law and less than 10 per cent will be able to work independently by the age of 21.[69]

2.82 Anne Russell of the Russell Family Fetal Alcohol Disorders Association (RFFADA) revealed that her son, diagnosed with FAS as an adult, has experienced 'drug and alcohol addiction; terrible problems at school, including not being able to learn the way he was taught; suicide attempts; self-harm; depression; anxiety; psychosis; and bullying'.[70]

2.83 Treatment for secondary conditions can be more difficult to access when transitioning through adolescence. Professor Elliott noted that society has little capacity to deal with adolescents who have problems with the criminal justice system, mental health or substance abuse, and indicated that children's hospitals usually only treat children up to the age of 16.[71]

2.84 Professor Elliott emphasised that:

> If you speak to the parents, [adolescence] is when this condition becomes a major issue for families.[72]

2.85 The combination of FASD and secondary symptoms invariably leads to social and economic problems, further entrenching the individual in a negative life trajectory. Sue Miers stated that:

> Not only did I discover that foetal exposure to alcohol has a profound impact on child development and behaviour, but I also began to grasp its links with failed education outcomes, crime statistics and recidivism, inappropriate sexual behaviour,

68 NRHA, *Submission 40*, p. 4.

69 Australian Human Rights Commission, *Submission 54*, p. 13.

70 A Russell, RFFADA, *Committee Hansard*, Cairns, 31 January 2012, p. 2.

71 Professor E Elliott, University of Sydney, *Committee Hansard*, Sydney, 13 April 2012, p. 6.

72 Professor E Elliott, University of Sydney, *Committee Hansard,* Sydney, 13 April 2012, p. 6.

> unemployment, substance abuse and inability to parent successfully.[73]

2.86 NOFASARD explained how people with FASD may react when they are expected to change their behaviour without an understanding of FASD:

> When individuals whose lives are affected by FASD have not been diagnosed, or are improperly assessed or mis-diagnosed, there is an expectation and insistence that behaviours change. Anger and frustration towards self and the community can be an understandable reaction. Criticism and punishment is a very common experience for this group and can lead to the development of secondary issues such as the incompletion of schooling, mental health problems, trouble with the law, unemployment and homelessness, alcohol and drug problems and a heightened vulnerability to physical, sexual (victim and/or offender), financial, social and emotional abuse. Isolation and loneliness can lead to a range of other behaviours such as unsafe relationships including relationships with violent and unsafe partners.[74]

2.87 Anne Russell described in detail how people with FASD could end up experiencing homelessness, poverty and isolation:

> Isolation is a very big thing. When [FASD] is not identified and the family are unable to support the person, they become homeless or they are couch surfing or are living in hostels. They are not living in private rental because they have done it once and they have been blacklisted because they have not been able to pay rent, or they have had millions of people round and had parties every night. … They will not actively seek support because they do not have insight into what they need. I think that is why we have a lot of people [with FASD] who are homeless but who are not on the Centrelink allowance, because they cannot plan. They cannot manage that. So there is isolation from peers only to the extent that they cannot find someone in the same situation as they are in.[75]

2.88 Individuals along the FASD spectrum will each experience a specific set of symptoms, and each will experience a specific set of secondary conditions according to the environment they grow up in. It is important to remember that not all people with FASD will have visible facial

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73 S Miers, NOFASARD, *Committee Hansard*, Melbourne, 22 June 2012, p. 18.

74 NOFASARD, *Submission 46*, p. 4.

75 A Russell, RFFADA, *Committee Hansard*, Cairns, 31 January 2012, p. 7.

characteristics, low IQ, mental illness, violent behaviour, or substance addiction.

FASD prevalence in Australia

2.89 The National Organisation for Fetal Alcohol Syndrome and Related Disorders (NOFASARD) stated that the true incidence and prevalence of FASD in Australia is currently unknown. They note that children are not routinely screened in infancy or early childhood, and that data which accurately reflects estimates of FASD incidence and prevalence in Australia is lacking.[76]

2.90 Similarly, the Tasmanian Department of Health and Human Services (DHHS) and the Australian Women's Health Network report that FASD is under diagnosed and under reported in Australia.[77] An estimate provided by DHHS suggests that at least two per cent of all Australian babies are born with FASD.[78]

2.91 The Foundation for Alcohol Research and Education (FARE) and the Departments of Health and Ageing and Families Housing, Community Services and Indigenous Affairs (FaHCSIA) report that recent research estimates the prevalence of FAS to be between 0.06 and 0.68 per 1 000 live births. Other experts consider this to be a significant underestimation.[79] The occurrence of FAS is a smaller subset of the occurrence of FASD.

2.92 FARE reports that among Indigenous Australians, the incidence of FAS is estimated to be 2.76 and 4.7 per 1 000 births.[80]

2.93 A study in far north Queensland estimated a FASD prevalence of 1.5 per cent in the Aboriginal child population, with one Cape York community having a prevalence of 3.6 per cent.[81]

2.94 A comprehensive and detailed incidence study of FASD in Fitzroy Crossing will soon be released; a recent media report suggested that half

76 NOFASARD, *Submission 46*, p. 8.

77 Tasmanian Department of Health and Human Services, *Submission 6,* p. 1; Australian Women's Health Network, S*ubmission 58*, p. 2.

78 Tasmanian Department of Health and Human Services, *Submission 6,* p. 1.

79 Foundation for Alcohol Research and Education (FARE), *Submission 36,* p. 8; P Walker, *Submission 29*, p. 3.

80 FARE, *Submission 36,* p. 17.

81 Cape York Institute for Policy and Leadership, *Submission 68*, p. 1.

of the babies born in Fitzroy Crossing are born with disabilities from FASD.[82]

2.95 Evidence suggests that FAS is presenting in rural and farming families in Queensland, but there was a lack of acknowledgement around its occurrence.

> It was almost a bit like sticking your head in the sand because 'that doesn't happen to our families'.[83]

2.96 The Australian National Preventative Health Agency (ANPHA) contends that there needs to be routine assessment and recording of maternal alcohol use during pregnancy, education about diagnosis of FASD, and methods for collecting national data before accurate prevalence rates of FASD can be estimated in Australia.[84]

FASD and Indigenous communities

2.97 Although data is limited, there are indications that FASD is more prevalent in Indigenous communities compared to non-Indigenous communities.[85] This finding is consistent with the history of harmful alcohol consumption in some Indigenous populations. However, it is likely that FASD is more easily recognised in Indigenous populations than in some non-Indigenous populations due to the concentration of occurrence in some remote communities, whereas the occurrence of FASD may be more dispersed across larger populations.

2.98 Further, a focus on reducing alcohol consumption and addressing health issues caused by high rates of alcohol consumption has brought FASD into the spotlight in some Indigenous communities.

2.99 For these reasons, there is more awareness of FASD and thus greater recognition of its prevalence in some Indigenous communities. FASD is clearly not an Indigenous specific problem although FASD affects Indigenous communities and culture in significant and particular ways.[86]

2.100 FaHCSIA states that FASD has an impact across the broader community, although on the basis of the limited evidence available there was a higher

82 R Skelton, 'Grog Hits Indigenous Babies', *Sydney Morning Herald*, 12 November 2012.

83 R Emerson, Support Worker, Wee Care Shared Family Care, *Committee Hansard,* Townsville, 31 January 2012, p. 2.

84 Australian National Preventive Health Agency (ANPHA), *Submission 45*, p. 3.

85 Dr L Studdert, Manager, Policy and Programs, ANPHA, *Committee Hansard,* Canberra, 15 March 2012, p. 1.

86 D Harriss, *Submission 69,* p. 2.

incidence of FASD in some rural and remote Indigenous communities.[87] Consequently while acknowledging FASD as a whole-of-community issue, the Department maintains a particular focus on Indigenous communities.[88]

2.101 The National Congress of Australia's First Peoples has registered their concern regarding the impact of FASD on Indigenous Australians.[89]

2.102 Anyinginyi Health Aboriginal Corporation described how FASD exists in its community, explaining it is an issue:

> … intertwined with a complex web of interrelated socio-economic factors, including poverty, alienation, isolation, domestic violence, other substance-related issues, and decades of the poisoning of culture by alcohol. Regular, frequent and excessive alcohol consumption is so entrenched in some places that it has become the norm. This applies to both Indigenous and non-Indigenous populations.[90]

2.103 Rachel Emerson from Wee Care Shared Family Care stated that Indigenous communities were judged, often very harshly, on the basis of typical FASD behaviours and health conditions:

> … often these children and their difficult and challenging behaviours or ill health were just blamed on that community. 'It's an Indigenous community. It's a mission community. There's bad parenting skills there.' … It was just like those communities were so dysfunctional that that was all we could expect of them. It was a generational thing.[91]

2.104 Professor Sven Silburn outlined a study documenting the developmental state of Indigenous and non-Indigenous children at the time of their entry to school. The study found very significant disparities between Indigenous and non-Indigenous children, and these disparities rise substantially for Indigenous children from remote areas.[92]

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87 C Edwards, Group Manager, Strategic Priorities and Land Group, Commonwealth Government Department of Families, Housing, Community Services and Indigenous Affairs (FaHCSIA), *Committee Hansard,* Canberra, 28 June 2012, pp. 2-3.

88 C Edwards, FaHCSIA, *Committee Hansard,* Canberra, 28 June 2012, p. 3.

89 National Congress of Australia's First Peoples, *Submission 87,* p. 3.

90 Anyinginyi Health Aboriginal Corporation, *Submission 3,* p. 1.

91 R Emerson, Wee Care Shared Family Care, *Committee Hansard,* Townsville, 31 January 2012, p. 2.

92 Professor S Silburn, Director, Centre for Child Development and Education, Menzies School of Health Research, *Committee Hansard*, Darwin, 21 June 2012, pp. 1-2.

2.105 Professor Silburn indicated that the study provides valuable linkages to document the extent of fetal alcohol effects on children's neurodevelopment.[93]

2.106 The Principal of Fitzroy Valley District High School told the Committee that, on returning to the school after over 10 years away, she observed a greater number of students who appeared to be affected by fetal alcohol exposure than was evident previously. However, she acknowledged that this could be an increase in awareness rather than an increase in numbers.[94]

2.107 The Australian Indigenous Doctors Association contended that FASD among Indigenous people needs to be addressed from a holistic perspective. They noted that the causes of excessive drinking extend well beyond the circumstances of the individual:

> It is the product of a complex mix of interrelated socio-economic and cultural factors including dispossession and trans-generational grief, isolation, poverty and trauma.[95]

2.108 It is clear that FASD, while not confined to Indigenous communities, is causing widespread and devastating damage in some Indigenous communities. June Oscar from the Marninwarntikura Women's Resource Centre reiterated that FASD is everyone's problem:

> It is a community issue. Everyone has to get together. Like we said earlier, it is not an Aboriginal problem; it is for all society. So we should see it across the board in this country.[96]

Alcohol use in Australian society

2.109 Given that the sole cause of FASD is prenatal alcohol exposure, understanding the use and prevalence of alcohol consumption and its role in Australian society is critical to formulating national FASD prevention measures.

2.110 While many Australians are unaware of the risk of FASD, the contribution of alcohol to traffic accidents, acts of violence, fatalities, crime and health

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93 Professor S Silburn, Menzies School of Health Research, *Committee Hansard*, Darwin, 21 June 2012, pp. 1-2.

94 D Bridge, Principal, Fitzroy Valley District High School, *Committee Hansard*, Mimbi, 11 July 2012, p. 2.

95 Australian Indigenous Doctors' Association, *Submission 67,* p. 1.

96 J Oscar, Chief Executive Officer, Marninwarntikura Women's Resource Centre, *Committee Hansard,* Mimbi, 11 July 2012, p. 4.

problems is well known. Alcohol consumption at social events is widely accepted and is part of Australian culture and enjoyment. Patterns of alcohol consumption have changed over recent decades with an increase in young female drinkers.

2.111 FARE argues that FASD does not occur in isolation; it is only one of a number of harms attributable to alcohol, and it is part of the wider and complex issue of alcohol use in the community.[97]

2.112 The ANPHA consider that in relation to community attitudes, knowledge and awareness, a comprehensive approach to reducing harmful drinking across the population is needed.[98]

2.113 The following sections consider changing patterns in alcohol consumption in Australia and factors accompanying these changes such as the increased availability and promotion of alcohol and decreasing prices.

Patterns of consumption

2.114 The National Preventive Health Taskforce identified the significant role that alcohol plays in contemporary Australian society. Alcohol is part of celebrations, used to relax at social events, a major export and source of tax revenue, and is intrinsically part of Australian culture.[99]

2.115 Most people do not drink to excess. However, short-term consumption of alcohol at harmful levels, or binge drinking, while only occasional, is a prominent feature of Australia's drinking culture. One in five Australians aged 14 or older drinks at short-term risky or high-risk levels at least once a month.[100]

2.116 The Australia and New Zealand Policing Advisory Agency (ANZPAA) reported that alcohol is present in a substantial proportion of incidents that police attend, with around 40 per cent of people detained by police attributing their offence to alcohol consumption.[101]

2.117 In addition, ANZPAA reported that alcohol-related crime is estimated to cost Australia $1.7b with $750m spent on policing. They reported other research which indicates that a large proportion of assaults are alcohol-related, with a significant portion of these ending in hospitalisation.[102]

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97 M Thorn, FARE, *Committee Hansard,* Canberra, 31 May 2012, p. 4.

98 Dr L Studdert, ANPHA, *Committee Hansard,* 15 March 2012, p. 2.

99 National Preventative Health Taskforce, *Australia: the healthiest country by 2020 National Preventive Health Strategy – the roadmap for action*, 2009, p. 236.

100 National Preventative Health Taskforce, *Australia: the healthiest country by 2020 National Preventative Health Strategy – the roadmap for action*, 2009, p. 236.

101 Australia and New Zealand Policing Advisory Agency (ANZPAA), *Submission 86,* p. 2.

102 ANZPAA, *Submission 86,* p. 2.

2.118 Professor Ian Webster told the Committee that many people are drinking in a way which they consider is socially acceptable, but which puts them at high risk of road traffic accidents, suicide events, mental health problems, personal violence, and assaults.[103]

2.119 Over the past 50 years, total consumption of pure alcohol per capita has fluctuated. From the early 1960s onwards, apparent consumption[104] increased steadily, peaking at 13.1 litres of pure alcohol per person in 1974–75. Apparent consumption per capita has appeared to remain steady since then, varying between 9.8 and 10.6 litres per person. Over the past three years, data suggests consumption rates have declined to 10.0 litres per person.[105]

2.120 However, different data reveals an increase. Professor Tanya Chikritzhs told the Committee there was a mistaken belief that consumption rates were flattening or decreasing since the 1990s.[106] This did not factor in the increase in alcohol content of wine. In 2008-09 the ABS estimates took into account increased alcohol content of wine over time and indicated that from the mid-1990s to about 2008-09, consumption was rising.[107]

2.121 By world standards, per capita consumption of alcohol in Australia is high with Australia ranked within the top 30 highest alcohol-consuming nations, out of a total of 180 countries.[108]

2.122 In 2010, among all the states and territories, Queensland had the largest proportion of people who drink daily and the Australian Capital Territory had the smallest. Queensland, Western Australia and the Northern Territory had the highest proportions of males drinking daily, while New South Wales had the highest proportions of females drinking daily.[109]

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103 Professor I Webster, Patron, Alcohol and other Drugs Council of Australia, *Committee Hansard,* Canberra, 31 May 2012, p. 5

104 The Australian Bureau of Statistics provides estimates on the apparent consumption of alcohol, which measures the amount of alcohol available based on excise, import and sales data, but does not estimate the actual amount consumed as it does not account for factors such as waste or storage.

105 Australian Bureau of Statistics, *Apparent Consumption of Alcohol, Australia, 2010-11,* cat. no. 4307.0.55.001, 3 May 2012.

106 Professor T Chikritzhs, Advisory Council Member, McCusker Centre for Action on Alcohol and Youth (McCusker Centre), *Committee Hansard,* Perth, 12 July 2012, p. 13.

107 Australian Bureau of Statistics, Explanatory Notes 26, *Apparent Consumption of Alcohol: Extended Time Series, 1944-45 to 2008-09,* cat. no. 4307.0.55.002, 18 January 2011.

108 National Preventative Health Taskforce, *Technical Report 3 Preventing alcohol related harm in Australia, a window of opportunity*, p. 5.

109 Australian Institute of Health and Welfare (AIHW), *2010 National Drug Strategy Household Survey report*, July 2011, p. 63.

2.123 Further, the level of apparent consumption of different alcoholic beverages has changed substantially. There has been a decrease in the consumption of beer while the consumption of wine has increased. The consumption of spirits has increased slightly.[110]

2.124 In 2010, the type of alcohol that male drinkers aged 14 years or older drank most often was regular strength beer. In particular, males in the 18-60 year age group preferred regular strength beer. Female drinkers aged 30 years or older preferred bottled wine.[111]

2.125 In contrast, female drinkers aged 20–29 named bottled spirits or liqueurs as their drink of choice. Pre-mixed spirits are popular amongst drinkers aged 12–17, especially female drinkers.[112]

Young people

2.126 The Australian Institute of Health and Welfare reported that adolescence and young adulthood is a peak period for what it describes as heavy episodic alcohol consumption, with over a third of all people aged 14-19 years having been at risk of acute alcohol-related harm at least once in the prior 12 months.[113]

2.127 Age is an important variable in the health burden caused by alcohol, as harm from alcohol-related accident or injury is disproportionate among younger people. Over half of all serious alcohol related road injuries occur among 15–24 year olds.[114]

2.128 The usual place where people preferred to drink differed by age group. Of drinkers aged 14 years or older, 79.1 per cent usually drank alcohol in their own home. Younger drinkers were more likely to drink alcohol at a private party than at home (59.2 per cent for those children 12-15 years and 72.4 per cent for those aged 16-17 years). People aged 18-19 years were more likely to drink at licensed premises.[115]

2.129 There is a perception that excessive alcohol consumption is a male problem, however there has been a gradual shift towards a social

110 Australian Bureau of Statistics, *Apparent Consumption of Alcohol, Australia, 2010-11,* cat. no. 4307.0.55.001, 3 May 2012.

111 AIHW, *2010 National Drug Strategy Household Survey report*, July 2011, p. 77.

112 AIHW, *2010 National Drug Strategy Household Survey report*, July 2011, p. 77.

113 Queensland University of Technology (QUT), *Young Women's Drinking Experiences in Public Drinking Venues*, 2011, p. 5.

114 National Preventative Health Taskforce, *Australia: the healthiest country by 2020 National Preventive Health Strategy – the roadmap for action*, 2009, p. 236.

115 AIHW, *2010 National Drug Strategy Household Survey report*, July 2011, p. 82.

acceptance of female drinking which has resulted in a diminishing gap in drinking quantity and style between men and women.[116]

2.130 A report on young women's (aged 18–23 years) drinking found that when it came to having five or more drinks on one occasion:

- 18 per cent did this often (once a week or more);
- 21 per cent did this sometimes (about once a month);
- 32 per cent did this rarely (less than monthly); and
- 29 per cent never had five or more drinks on one occasion.[117]

2.131 There is evidence that women are at greater risk than men of detrimental physical, medical, social and psychological effects from at-risk alcohol consumption.[118] The increase in drinking patterns amongst sexually active women and especially those who may engage in unplanned and/or unprotected sex is alarming.

2.132 At low levels of drinking there is little difference between men and women in the risk of alcohol related harm. At higher levels of drinking, the lifetime risk of alcohol-related disease increases more dramatically for women, and the lifetime risk of alcohol-related injury increases more dramatically for men.[119]

2.133 Aside from the risks posed by alcohol–related disease and injury, alcohol can significantly impact the developing brain of young people.

2.134 Children's brains have a significant growth spurt when they are very young. By the time they are six, their brains are already close to 90–95 per cent of adult size. However, the brain still requires a degree of remodelling before it is able to function as an adult brain.[120] This remodelling happens intensively during adolescence and continues until into the mid 20s.

2.135 Children's Hospital Boston neuroscientist Frances Jensen commented that this plasticity is paradoxical. Through this process adolescents are able to learn and retain significant information; however, the plasticity also makes them susceptible to negative influences such as alcohol. The process of addiction uses the same neurochemistry as general learning.

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116 QUT, *Young Women's Drinking Experiences in Public Drinking Venues*, 2011, p. 5.

117 Australian Longitudinal Study on Women's Health, *Australian Women and Alcohol Consumption 1996-2003*, 2005, p. iii.

118 QUT, *Young Women's Drinking Experiences in Public Drinking Venues*, 2011, p. 5.

119 National Preventative Health Taskforce, *Australia: the healthiest country by 2020 National Preventive Health Strategy – the roadmap for action*, 2009, p. 236.

120 Raising Children.net, *Your Teenager's Developing Brain*, <http://raisingchildren.net.au/articles/brain_development_teenagers.html/context/1152> viewed 3 October 2012.

2.136 The consequence is that when teens drink or smoke, they are laying down a lasting sensitivity that can easily lead to addiction.

> If a teen's nervous system sees alcohol or a drug, their synapses have locked onto that drug and form strong connections that underlie their affinity for it. … Specific neuronal connections readily form from exposure to stimuli, like drugs and alcohol, and become irreversibly imprinted on their brains.[121]

2.137 Further, the effect of alcohol can be longer lasting for adolescents. Alcohol can hamper learning by blocking synapses from sending any signals, and when alcohol is consumed in excess, it kills vastly more brain cells in teens than adults.

- In the case of binge drinking, this can have longer lasting effects:

> If a 17-year-old pounds down Jack Daniels with Uncle Joe, Uncle Joe will have a wicked hangover, but will function in a few days… But that teenager has a low threshold for brain injury and may not bounce back 100 percent.[122]

Indigenous communities

2.138 Levels of alcohol consumption and alcohol consumption patterns are concerning in many Indigenous communities. While there are a range of historical and socio-economic contributors to this, the consequence is that many Indigenous communities are at greater risk of alcohol-related harm.

2.139 The National Indigenous Drug and Alcohol Committee reported that Indigenous Australians were 1.4 times more likely than non-Indigenous Australians to abstain from drinking alcohol, but were also about 1.5 times more likely to drink alcohol at risky levels for both single occasion and lifetime harm.[123]

2.140 The 2006 NT Alcohol Consumption and Related Attitudes Household Survey results found that while fewer NT Indigenous than non-Indigenous people aged 18 years and over consumed alcohol, Indigenous drinkers consumed more than their non-Indigenous counterparts.[124]

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121 Children's Hospital Boston, *The Teenage Brain*, <http://www.childrenshospital.org>, viewed 3 October 2012.

122 Children's Hospital Boston, *The Teenage Brain*, <http://www.childrenshospital.org>, viewed 3 October 2012.

123 National Indigenous Drug and Alcohol Committee, *Addressing Foetal Alcohol Spectrum Disorder in Australia,* 2012, p. 7. This report noted that there are issues with both the sample size and methodology respectively in the surveys that provided the original sources of material.

124 Northern Territory Government, *Alcohol use in the Northern Territory*, 2010.

2.141 Prue Walker told the Committee that 21.4 per cent of indigenous women consumed alcohol at risky levels.[125]

2.142 From the limited data collected at women's first antenatal visits, approximately 1 in 8 Indigenous women compared to 1 in 12 non-Indigenous women reported consuming alcohol. At 36 weeks into a pregnancy, this had fallen to around 8.4 per cent of Indigenous women compared to 4.2 per cent of non-Indigenous women who continued to consume alcohol.[126]

2.143 The grief that has been caused by alcohol in some Indigenous communities is well documented. Suzi Lodder told of her experience with Indigenous women who cried about the 'grog babies' in their communities, and expressed anger that no-one had told them beforehand of the dangers to babies of drinking while pregnant.[127]

2.144 Some consider that alcohol and the alcohol industry are destroying lives. At the 2012 Marninwarntikura Women's Bush Camp, June Oscar argued that:

> The alcohol industry has got a lot to answer for and governments over the last 200 years have got a lot to answer for in terms of the survival and the devastation of the right to life of Indigenous peoples in Australia. How can the government continuously allow for one sector of this community to destroy people?[128]

2.145 Many Indigenous communities have enacted voluntary alcohol restrictions. Professor Chikritzhs explained that in many instances it was the Indigenous women in communities who were behind the push to instigate restrictions on alcohol and on the sale of alcohol from licensed premises.[129]

Pregnant women and alcohol consumption rates

2.146 Consumption of alcohol by pregnant women is not measured by the Australian Bureau of Statistics, however there are several agencies and groups who have undertaken research into alcohol consumption during pregnancy.

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125 P Walker, *Submission 29,* p. 3.

126 P Walker, *Submission 29,* p. 3.

127 S Lodder, *Submission 81,* p. 1.

128 J Oscar, Marninwarntikura Women's Resource Centre, *Committee Hansard,* Mimbi, 11 July 2012, p.12.

129 Professor T Chikritzhs, McCusker Centre, *Committee Hansard,* Perth, 12 July 2012, p. 16.

2.147 Studies indicate that the majority of women either reduce consumption or abstain during pregnancy. The 2010 National Drug Strategy Household Survey by the Australian Institute of Health and Welfare reported that 48.7 per cent of pregnant women reduced their alcohol consumption but still continued to drink and 48.9 per cent abstained. The remaining percentage of women either drank the same or more.[130]

2.148 These figures represented an increase from 2007 in the number of women who abstained from drinking while pregnant and breastfeeding.[131]

2.149 However, the study indicates that a high number of women continue to drink, albeit at reduced levels, during pregnancy. Dr Colleen O'Leary suggested that a higher proportion of women continue to drink while pregnant. She provided evidence arguing that societal tolerance of drinking in Australia has carried through to acceptance of drinking during pregnancy and suggested that around 50–60 per cent of Australian women continue to consume alcohol during pregnancy.[132]

Table 2.1 Rates of drinking alcohol in pregnancy by maternal age and socioeconomic status

	Drank alcohol during pregnancy	
	%	*No. of observations*
Mother's age at birth of child		
Under 25 years	19.8	116
25-29 years	32.4	373
30-34 years	44.2	738
35-39 years	44.4	335
40 years or older	42.3	70
Family socio-economic position		
Lowest 25%	22.9	213
Middle 25%	38.3	829
Highest 25%	51.8	590

Source Adapted from Table 11.5 Drinking alcohol and cigarette smoking, by maternal age at birth and by family socio-economic position, B cohort, Wave 1, <http://www.growingupinaustralia.gov.au/pubs/asr/2010/asr2010k.html>.

2.150 A different study indicated that over a third of women continued to drink. *The Longitudinal Study of Australian Children: Annual statistical report 2010*

130 AIHW, *2010 National Drug Strategy Household Survey report*, July 2011, p. 73.

131 AIHW, *2010 National Drug Strategy Household Survey report*, July 2011, p. 73.

132 Dr C O'Leary, *Submission 92,* p. 1.

by the Australian Institute of Family Studies found that 38 per cent of women drank alcohol while pregnant.[133]

2.151 This study found that pregnant older mothers were more likely to report drinking alcohol at some stage during pregnancy. Women who were 40 years or older when their child was born were more than twice as likely as women under 25 years to report drinking while pregnant.[134]

2.152 Further it was found that alcohol consumption at some stage during the pregnancy was more likely as a family's socio–economic position increased.[135] Table 2.1 provides more detailed data on consumption of alcohol during pregnancy against age and socio-economic position.

2.153 Dr O'Leary provided statistics on women binge drinking during pregnancy. Figures range from 4 to 20 per cent of non-Indigenous pregnant women reporting binge drinking, and 22 per cent of Indigenous women.[136]

2.154 Dr Gurmeet Singh reported on her work with the Aboriginal Birth Cohort Study, a project tracking the health of over 600 Indigenous people from birth in the Northern Territory.[137] In 1987, when the study commenced, the rate of drinking in pregnancy of the mothers of the cohort was 11 per cent. When the cohort was seen at 18 years of age, a third of the girls had already had babies and 30 per cent of them had consumed alcohol during pregnancy.[138]

Reasons pregnant women continue to consume alcohol

2.155 While alcohol consumption places the fetus at risk of FASD, there are many reasons why women may continue to consume alcohol while pregnant. Evidence to the inquiry suggests four key contributing factors:

- A woman may be unaware she is pregnant, especially in the early weeks;
- Lack of awareness regarding the impact on the developing fetus of alcohol consumption;
- Trauma factors which contribute to a woman's emotional and/or physical dependency on alcohol; and

133 Australian Institute of Family Studies (AIFS), *The Longitudinal Study of Australian Children: Annual statistical report 2010*, p. 129.

134 AIFS, *The Longitudinal Study of Australian Children: Annual statistical report 2010*, p. 129.

135 AIFS, *The Longitudinal Study of Australian Children: Annual statistical report 2010*, p. 129.

136 Dr C O'Leary, *Submission 92,* p. 1.

137 More information on this study can be found at http://www.clancohort.com.au/index.htm.

138 Dr G Singh, Senior Research Fellow, Menzies School of Health Research, *Committee Hansard,* Darwin, 21 June 2012, p. 2.

- A cultural context which does not support a woman to stop drinking when pregnant.

2.156 Nearly half of all pregnancies are unplanned.[139] Consequently, many women may consume alcohol during the early weeks of a pregnancy because they do not realize that they are pregnant.[140] As outlined earlier in the chapter, following differentiation in the third week of pregnancy, cells undergo rapid development and are highly susceptible to damage from exposure to alcohol at this stage.

2.157 The increasing rates of regular drinking and binge drinking in young women[141] can result in serious risk to the developing fetus, before the women is aware she is pregnant and so able to make a choice whether to abstain from alcohol.

2.158 A further reason why women may continue to consume alcohol later into the pregnancy is lack of awareness regarding the risk of harm.

2.159 Lack of awareness appears widespread across the population. A recent national study on women's awareness of the risks from alcohol consumption during pregnancy found that one in three women of child bearing age were not aware of any adverse effects of alcohol consumption in pregnancy. Of those women who were aware of adverse effects, many could not name any specific effects.[142]

2.160 In addition, research indicates that some of the predictors of alcohol consumption during pregnancy are a woman's age, past pregnancy and current alcohol consumption, as well as attitudes towards alcohol consumption during pregnancy.[143]

2.161 Amongst this population, lack of awareness regarding the risks of alcohol consumption can be in part attributed to changing health messages. Over the last two decades in Australia, there has not been a consistent health message regarding the consumption of alcohol during pregnancy (the national pregnancy health guidelines are discussed further in the following chapter). Indeed for older women who are not bearing their first child, they are likely to have been previously advised that small quantities

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139 Marie Stopes International Australia, *Real Choices: Women, contraception and unplanned pregnancy*, 2008.

140 Health Network Branch, Child and Youth Health Network, Department of Health Western Australia, *Submission 13,* p. 2.

141 Professor E Elliott, University of Sydney, *Committee Hansard,* 13 April 2012, p. 3.

142 Alcohol and other Drugs Council of Australia, *Submission 33,* p. 9.

143 E Peadon et al, 'Attitudes and behaviour predict women's intention to drink alcohol during pregnancy: the challenge for health professionals,' BioMed Central *Public Health* 2011, 11/584. <www.biomedcentral.com/1471-2458/11/584> viewed 27 August 2012.

of alcohol or drinking in moderation was not harmful to the developing fetus.

2.162 Trauma or distress, which may lead a woman to develop an emotional or physical dependency on alcohol, is shown to be a risk indicator for women who continue to drink while pregnant. The ADCA explained that a history of abuse, poor psychological wellbeing, use of other drugs, having a substance-using partner, and not viewing alcohol as potentially harmful can contribute to alcohol intake during pregnancy.[144]

2.163 Renee McAllister from ACT for Kids explained that there are many contributors to why someone may drink in pregnancy, such as low levels of emotional health, domestic violence, childhood trauma and lack of financial stability.[145] She stressed that in these situations it is not as simple as telling someone 'Don't drink or you might harm your child'.[146]

2.164 Vicki Russell from NOFASARD told the Committee that:

> Where you are talking about women with risky drinking, you are also talking about histories that may be marked with a whole range of precedents, trauma and poverty.[147]

2.165 Anne Russell suggested that:

> It would be a very unusual woman who actually deliberately did it. I am sure there are, but we are talking about the majority. The majority do not set out to hurt their children. They drink either because they are not aware of the full impact on their child and their family or because they are in a situation of domestic violence where they just cannot get out of that cycle of drinking. There is a reason and we need to find out what the reason is …[148]

2.166 The Australian Women's Health Network and Top End Mental Health provided evidence indicating that poverty is a major factor in maternal alcohol use in women, with the consumption of harmful levels of alcohol used as a coping mechanism in dealing with a history of despair, trauma, abuse and stress.[149]

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144 J R Powers et al, 'Assessing pregnant women's compliance with different alcohol guidelines: An 11-year prospective study', *Medical Journal of Australia*, 192(12), 2010, pp. 690–693.

145 R McAllister, Regional Manager, ACT for Kids, *Committee Hansard,* Townsville, 31 January 2012, pp. 11-12.

146 R McAllister, ACT for Kids, *Committee Hansard,* Townsville, 31 January 2012, pp. 11-12.

147 V Russell, NOFASARD, *Committee Hansard,* Melbourne, 22 June 2012, p. 20.

148 A Russell, RFFADA, *Committee Hansard,* Cairns, 31 January 2012, p. 10.

149 Australian Women's Health Network, *Submission 58,* p. 2; Top End Mental Health, *Submission 83*, p. 3.

2.167 Similarly, the Kimberley Population Health Unit (KPHU) outlined reasons why Indigenous women may drink. These include a history of physical or sexual abuse, grief, addiction, low self-esteem, fear, shame, and loss of culture and a sense of identity. They suggested many women in these situations of trauma drink to get drunk and numb their emotions and feelings.[150]

2.168 The Telethon Institute provided results of a study that identified multiple reasons why Indigenous women may drink in pregnancy including stress, role-modelling, intergenerational effects of alcohol consumption in pregnancy and the partner's behaviour.[151]

2.169 In Broome, the Committee heard that 70 per cent of pregnant women who drink have a history of mental health issues, violence and trauma. Melissa Williams explained that:

> …they do not drink to deliberately harm their unborn babies and that there is a reason why women, and men, are drinking to excess. We have got to look at the mental health issues, self-esteem, grief, sexual and physical abuse, domestic violence, and all the socioeconomic factors that are related to poverty and disempowerment that are causing these problems in the community.[152]

2.170 For some women, alcohol consumption is part of the cultural context in which they reside. Evidence suggests that amongst some sectors of youth culture, binge and/or regular drinking is an expected part of socialising. Consumption patterns of young women have increased, especially for young women living in regional areas. These changes in drinking behaviour are accompanied by greater sexual activity at an earlier age amongst young women, thereby increasing the risk of unplanned pregnancies and potentially babies born with FASD.

2.171 Similarly, in some Indigenous communities where there are high levels of alcohol consumption and social dysfunction, drinking is the expected and accepted behaviour.

2.172 Arlene Manado, a Community Midwife in Broome, described drinking as so much a part of family life that in some Indigenous communities you would be seen as being unusual if you did not participate.[153]

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150 Kimberley Population Health Unit (KPHU), *Submission 31*, p. 2.

151 Telethon Institute for Child Health Research, *Submission 23,* p. 12.

152 M Williams, Maternal and Child Health Coordinator, KPHU, *Committee Hansard,* Broome, 12 July 2012, p. 5.

153 A Manado, Community Midwife Generalist, KPHU, *Committee Hansard,* Broome, 12 July 2012, p. 6.

2.173 Professor John Boulton told the Committee that in Indigenous culture, where relationships have a profound importance, refusing a drink has a particular significance. He stated that:

> [There is] the profound importance of my relationship to you as my cousin. Therefore, if I say to you, 'No, I'm not going to have a drink,' you will say, 'You're going gudiya[154]way'—which is profoundly insulting. It is much more insulting than 'You don't support Essendon' or whatever.[155]

2.174 Alcohol consumption patterns amongst youth and in some Indigenous communities are often high, increasing the risks of FASD. However, amongst other sectors of the population with lower overall consumption patterns, there is evidence of cultural expectations which make it more difficult for a woman to abstain from drinking while pregnant.

2.175 For example, women with higher education are more likely to consume alcohol while pregnant.[156] It is suggested that women in this category may be accustomed to enjoying alcohol in moderation at social events, or in the context of an evening meal. Where the customary behaviour has been for alcohol to be an accepted part of social life or relaxation, women may not change their daily or social patterns without a clear cultural shift in community attitudes to support them to do so.

2.176 There are factors which may influence a women's decision to consume alcohol while pregnant. The following chapter discusses prevention measures to increase awareness of the risks of FASD, to foster changes in drinking behaviours and the decisions made by pregnant women, and to support attitudinal changes across the broader community.

154 This was explained to the Committee as being gudiya – white person.

155 Professor J Boulton, Senior Regional Paediatrician, Kimberley Health, Western Australia Country Health, *Committee Hansard,* Broome, 12 July 2012, p. 8.

156 S Callinan, R Room, 'Alcohol consumption during pregnancy: Results from the 2010 National Drug Strategy Household Survey', 2012, Foundation for Alcohol Research and Education.