



DEPARTMENT *of the* HOUSE *of* REPRESENTATIVES

## **FASD: THE HIDDEN HARM**

Inquiry into the prevention, diagnosis and management of Fetal Alcohol Spectrum Disorders



November 2012

House of Representatives Standing Committee on Social Policy and Legal Affairs

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The Parliament of the Commonwealth of Australia

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management of Fetal Alcohol Spectrum Disorders**

House of Representatives  
Standing Committee on Social Policy and Legal Affairs

November 2012  
Canberra

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ISBN 978-0-642-79762-9 (Printed version)

ISBN 978-0-642-79763-6 (HTML version)

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## Foreword

Children are our hope distilled. At birth they are a launching pad for all of society's dreams and aspirations. They personify humanity's unlimited potential. Yet tragically, for too many babies in Australia, their opportunities and circumstances are severely diminished even before they draw their first breath.

The harm caused by Fetal Alcohol Spectrum Disorders (FASD) is hidden in the damaged brain. It may masquerade as naughty behaviour, poor parenting, lack of discipline, or simple-mindedness. However, it is none of these things.

FASD is an entirely preventable but incurable condition caused by a baby's exposure to alcohol in the womb. The consequences are expressed along a spectrum of disabilities including: physical, cognitive, intellectual, learning, behavioural, social and executive functioning abnormalities and problems with communication, motor skills, attention and memory.

While the risk of FASD increases with the quantity of alcohol a pregnant woman consumes, what is not widely understood is that even small amounts of alcohol, at critical times, can result in irrevocable damage to the developing fetus. In many cases, the damage is not physically apparent but can manifest itself in lifelong learning difficulties and cognitive impairment.

Awareness of FASD is increasing in Australia, but much work needs to be done. The series of recommendations made by the Committee outline a national strategy to prevent, identify and manage FASD in Australia. This national strategy can spearhead progress in all sectors – health, education, criminal justice, social support – toward understanding, treating and most importantly eliminating FASD.



The Committee is grateful for the unstinting work of individuals and organisations that have contributed to increasing awareness and knowledge of FASD and its prevalence in Australia and have lobbied for action, often without recognition or remuneration. These efforts have been the catalyst for this parliamentary inquiry and the actions that will follow.


Time and again during the inquiry, the Committee heard about the devastation that can be caused by prenatal alcohol exposure. Foster carers spoke about children in their care and the enormous challenges they face. Paediatricians spoke about the lack of awareness and lack of diagnostic resources for FASD. Indigenous community leaders spoke about communities and culture in crisis due to FASD. Women spoke about the conflicting health messages given and the desperate need for clear advice from health professionals.

Amidst all these voices, the most moving was that of Tristan, a young man affected by FASD. Tristan says:

I wish I can be a policeman just when I grow up ... Nah ... I just want to be normal first. I just want to be normal.

We owe it to Tristan, and to every child and every woman and every family in Australia, to bring to light the risk of FASD. We cannot keep hidden the devastating harms being caused by prenatal alcohol exposure.

Mr Graham Perrett MP  
Chair



## Membership of the Committee

Chair            Mr Graham Perrett MP

Deputy Chair   Hon. Judi Moylan MP

Members        Mr Shayne Neumann MP

Ms Michelle Rowland MP  
(to 07 February 2012)

Ms Laura Smyth MP


Hon. Dr Sharman Stone MP

Mr Mike Symon MP  
(from 07 February 2012)

Mr Ross Vasta MP

## Committee Secretariat

Secretary	Dr Anna Dacre
Inquiry Secretary	Ms Natalya Wells Ms Pauline Cullen
Administrative Officers	Katrina Gillogly Rebeka Mills



## Terms of reference

Fetal Alcohol Spectrum Disorder (FASD) is an overarching term used to describe a range of cognitive, physical, mental, behavioural, learning and developmental disorders that result from fetal exposure to alcohol.

The Standing Committee on Social Policy and Legal Affairs is to inquire into and report on developing a national approach to the prevention, intervention and management of FASD in Australia, with particular reference to:

- Prevention strategies – including education campaigns and consideration of options such as product warnings and other mechanisms to raise awareness of the harmful nature of alcohol consumption during pregnancy,
- Intervention needs – including FASD diagnostic tools for health and other professionals, and the early intervention therapies aimed at minimising the impact of FASD on affected individuals, and
- Management issues – including access to appropriate community care and support services





## List of abbreviations and acronyms

ACCG	Australian Children’s Commissioners and Guardians
ADCA	Alcohol and other Drugs Council of Australia
ADJC	Aboriginal Disability Justice Campaign
AHAWA	Australian Hotels Association Western Australia
AHRC	Australian Human Rights Commission
AIHW	Australian Institute of Health and Welfare
AMA	Australian Medical Association
ANPHA	Australian National Preventive Health Agency
ANZPAA	Australia and New Zealand Policing Advisory Agency
APONT	Aboriginal Peak Organisations Northern Territory
ARBD	Alcohol-Related Birth Defects
ARND	Alcohol-Related Neurodevelopmental Disorders
ASD	Autism Spectrum Disorders
Better Start	Better Start for Children with a Disability Initiative
DEEWR	Commonwealth Department of Education, Employment and Workplace Relations
DHHS	Department of Health and Human Services, Tasmania

DoHA	Commonwealth Department of Health and Ageing
DSICA	Distilled Spirits Industry Council of Australia
FAE	Fetal Alcohol Effects
FaHCSIA	Commonwealth Department of Families, Housing, Community Services and Indigenous Affairs
FARE	Foundation for Alcohol Research and Education
FAS	Fetal Alcohol Syndrome
FASD	Fetal Alcohol Spectrum Disorders
FPDN	First Peoples Disability Network
GP	general practitioner
KPHU	Kimberley Population Health Unit
McCusker Centre	McCusker Centre for Action on Alcohol and Youth
NAAA	National Alliance for Action on Alcohol
NCID	National Council on Intellectual Disability
NDIS	National Disability Insurance Scheme
NHMRC	National Health and Medical Research Council
NOFASARD	National Organisation for Fetal Alcohol Syndrome and Related Disorders
NRHA	National Rural Health Alliance
pFAS	Partial Fetal Alcohol Syndrome
PHAA	Public Health Association of Australia
RACP	Royal Australasian College of Physicians
RFFADA	The Russell Family Fetal Alcohol Disorders Association
Telethon Institute	Telethon Institute for Child Health Research
the Blewett Report	<i>Labelling Logic: Review of Food Labelling Law and Policy</i>

(2011)

the Collaboration	The Australian FASD Collaboration
the Forum	The Legislative and Governance Forum on Food Regulation
the Guidelines	Australian Guidelines to Reduce Health Risks from Drinking Alcohol
WANADA	Western Australian Network of Alcohol and other Drug Agencies
WFA	Winemakers' Federation of Australia
WHO	World Health Organization







# List of recommendations

## 1 Introduction

### Recommendation 1

The actions set out in this report should constitute the Commonwealth Government's National Plan of Action for the prevention, diagnosis and management of Fetal Alcohol Spectrum Disorders (FASD). This FASD National Plan of Action should be publicly released by 1 June 2013.

### Recommendation 2

The Committee recommends that the Commonwealth Government immediately establish an ongoing Fetal Alcohol Spectrum Disorders (FASD) Reference Group reporting to the relevant Commonwealth Government Ministers, consisting of a select group of appointed practitioners, professionals and stakeholders who are experts in the field of prevention and management of FASD.

The role of the FASD reference group would be to oversee and advise on the FASD National Plan of Action.

### Recommendation 3

The Committee recommends that the Commonwealth Government publicly report:

- within 12 months on the progress of the implementation of a national Fetal Alcohol Spectrum Disorders (FASD) diagnostic and management services strategy, a critical element of the FASD National Plan of Action, and
- within five years on the progress towards eliminating FASD in Australia.

### 3 FASD awareness and prevention

#### Recommendation 4

The Committee recommends that the Commonwealth Government work with the National Health and Medical Research Council and professional peak bodies to ensure that all health professionals are:

- fully aware of the National Health and Medical Research Council Guidelines that advise women not to drink while pregnant;
- have alcohol consumption impacts on pregnancy and the developing fetus incorporated into all general practice and midwifery training;
- trained in discussing the National Health and Medical Research Council Guidelines and alcohol consumption with women; and
- skilled in asking women about alcohol consumption and recognising and responding to women at risk.

By 1 January 2014, all health professionals, including sexual health advisors, midwives, general practitioners and obstetric professionals should be promoting the consistent message that not drinking while pregnant is the safest option, in line with the National Health and Medical Research Council Guidelines.

#### Recommendation 5

The Committee recommends that the Commonwealth Government establish mechanisms for health professionals to record women's alcohol consumption during pregnancy, or at the time of birth for women who have not presented for prenatal care, and to ensure such information is recorded in midwives data collections or notifications across Australia.

#### Recommendation 6

The Committee recommends that the Commonwealth Government implement a general public awareness campaign which promotes not drinking alcohol when pregnant or when planning a pregnancy as the safest option, consistent with the National Health and Medical Research Council Guidelines.

Specific awareness campaigns should be developed to target youth and Indigenous communities.

Nationwide campaigns should be started no later than 1 July 2013.

#### **Recommendation 7**

The Committee recommends that the Commonwealth Government mandate a health advisory label advising women not to drink when pregnant or when planning a pregnancy to be included on the packaging of all pregnancy and ovulation testing kits. These labels should be in place by 1 October 2013.

#### **Recommendation 8**

The Committee recommends that the Commonwealth Government raise with the States and Territories the critical importance of strategies to assist Indigenous communities in managing issues of alcohol consumption and to assist community led initiatives to reduce high-risk consumption patterns and the impact of alcohol.

#### **Recommendation 9**

The Committee recommends that the Commonwealth Government work with State and Territory governments to identify and implement effective strategies for pregnant women with alcohol dependence or misuse.

#### **Recommendation 10**

The Committee recommends that the Commonwealth Government seek to include health warning labels for alcoholic beverages, including a warning label that advises women not to drink when pregnant or when planning a pregnancy, on the Legislative and Governance Forum on Food Regulation's December agenda.

The Commonwealth Government should determine the appropriate format and design of the labels by 1 March 2013, to assist the alcohol industry in adopting best practice principles and preparing for mandatory implementation.

### Recommendation 11

The Committee recommends that the Commonwealth Government mandate the range of health warning labels for alcoholic beverages as decided by the Legislative and Governance Forum on Food Regulation.

- The warning labels should consist of text and a symbol and should be required to be displayed on all alcohol products, advertising and packaging by 1 January 2014;
- The minimum size, position and content of all health warning labels should be regulated; and
- The introduction of mandated warning labels should be accompanied by a comprehensive public awareness campaign.

### Recommendation 12

The Committee recommends that the Commonwealth Government commission an independent study into the impacts of the pricing and availability of alcohol and the influence of these factors in the changing patterns of alcohol consumption across age groups and gender.

The study should be completed by 1 October 2013.

### Recommendation 13

The Committee recommends that the Commonwealth Government commission an independent study into the impacts and appropriateness of current alcohol marketing strategies directed to young people. The study should have regard to these strategies and the volume and frequency of alcohol consumption amongst young people, the links being made between alcohol and sport, the efficacy of efforts to promote responsible drinking behaviours, and the adequacy of current regulations to respond to marketing through digital platforms such as the internet, social media and smartphones.

The study should be completed by 1 October 2013.

### Recommendation 14

The Committee recommends that, following the completion of the study into the pricing and availability of alcohol and the study into alcohol marketing strategies, the Commonwealth Government develop a National Alcohol Sales Reform Plan aimed at reducing the harms caused by irresponsible alcohol consumption across Australia.

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## 4 Diagnosis

### Recommendation 15

The Committee recommends that the Commonwealth Government expedite the rollout of the Fetal Alcohol Spectrum Disorder (FASD) diagnostic instrument and the development of a training and user manual. These should be available for use by 1 October 2013.

Following the rollout, the Commonwealth Government should establish a mechanism to collect and monitor diagnostic data in order to assess the effectiveness of prevention strategies and patterns of FASD occurrence.

### Recommendation 16

The Committee recommends that the Commonwealth Government develop and implement a national Fetal Alcohol Spectrum Disorders (FASD) diagnostic and management services strategy.

This strategy should be monitored and informed by the FASD Reference Group, and should establish capacity by 1 July 2014 for the following:

- awareness amongst all general practitioners and child and maternal health professionals of the causation and clinical features of FASD and the importance of early diagnosis and intervention;
- establishment of a model for diagnostic services such that regional as well as metropolitan areas are properly serviced; and
- identification of effective methodologies of management including international best practice.

## 5 Management needs

### Recommendation 17

The Committee recommends that the Commonwealth Government develop educational material to raise awareness about Fetal Alcohol Spectrum Disorders (FASD). These materials should be monitored and informed by the FASD Reference Group.

In particular, targeted training and materials should be developed for:

- special education teacher aides and class teachers;
- parents, foster carers and foster care agencies;
- police and court officials;
- youth workers and drug and alcohol officers; and
- officers in correctional facilities and juvenile detention centres.

**Recommendation 18**

The Committee recommends that the Commonwealth Government include Fetal Alcohol Spectrum Disorders in the List of Recognised Disabilities and the Better Start for Children with a Disability Initiative.

**Recommendation 19**

The Committee recommends that the Commonwealth Government recognise that people with Fetal Alcohol Spectrum Disorders have, amongst other disabilities, a cognitive impairment and therefore amend the eligibility criteria to enable access to support services and diversionary laws.

## Introduction

- 1.1 'I just want to be normal' are the words of Tristan, a young Australian boy affected by Fetal Alcohol Spectrum Disorders (FASD).<sup>1</sup>
- 1.2 FASD is the largest cause of non-genetic, at-birth brain damage in Australia. 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'.<sup>2</sup> 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.<sup>3</sup>
- 1.3 FASD is the overarching term for the range of conditions that can occur in an individual with prenatal exposure to alcohol. It can result in learning difficulties, a reduced capacity to remember tasks from day to day, anger management and behavioural issues, impaired speech and muscle coordination, and physical abnormalities in the heart, lung and other organs. The effects can range from mild impairment to serious disability.
- 1.4 Tristan, like many children affected by FASD, experiences a range of these challenges in everyday his life.
- 1.5 It is likely that if FASD were a preventable disease occurring across Australia causing such lifelong disabilities and learning difficulties in children, there would public awareness campaigns outlining the causes,

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1 Marninwarntikura Women's Research Centre and Nindlingarri Cultural Health Services, *Tristan – Hopes, dreams and challenges of a young boy living with FASD*, DVD directed by M Hogan, produced by J Latimer, The Lililwan Project, 2012.

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

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



symptoms and preventative measures. There would be public advocacy mobilised to fight for the best outcome for babies and the eradication of the condition.

- 1.6 However, the causes, effects and the prevalence of FASD are largely unknown or hidden in Australia. It is a totally preventable condition which has no place in a modern developed world, and yet in Australia over 60 per cent of women continue consume alcohol when pregnant. It is expected that FASD is becoming more prevalent. There is no cure – there is only prevention. While much remains to be understood how best to prevent, diagnose and then manage the impacts of FASD on the population.
- 1.7 FASD is caused by prenatal exposure to alcohol. If a woman has zero alcohol consumption during pregnancy, then the fetus has zero risk of developmental abnormalities from exposure to alcohol. While greater exposure to alcohol increases the risk, there are critical fetal developmental stages during which small levels of exposure may carry significant risk.
- 1.8 Tragically, many Australians are unaware of the risk that prenatal exposure to alcohol poses and the irreversible lifelong damage that may ensue.

## **International FASD response**

- 1.9 While Australia has lacked a national approach to FASD, internationally efforts to combat FASD are well advanced.
- 1.10 North America leads the world in the recognition, diagnosis and response to FASD. A parliamentary report on the problems of FASD was tabled in the Canadian Parliament as early as 1992.<sup>4</sup>
- 1.11 Diagnostic tools and guidelines, early intervention services, and screening programs are available in North America.<sup>5</sup> For example, in the state of Washington, multi-disciplinary diagnostic clinics have been operating since 1993:

These clinics have helped to raise awareness of FASD among health professionals and improve diagnosis, with 61 to 90 per cent

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4 Canadian Government, *Fetal Alcohol Syndrome: From Awareness to Prevention: Government Response to the Fifth Report of the Standing Committee on Health and Welfare, Social Affairs, Seniors and the Status of Women*, June 1992.

5 South Australian Government, *Submission 52*, p. 5; P Walker, *Submission 29*, p. 12; Royal Australasian College of Physicians, *Submission 27*, p. 4.

of North American paediatricians being able to correctly identify the essential diagnostic features of [foetal alcohol syndrome].<sup>6</sup>

- 1.12 In Canada, public awareness campaigns about FASD have been conducted since 1999.<sup>7</sup> That same year, funding for FASD was allocated in the Canadian budget, and a FASD Framework for Action subsequently launched in 2002.<sup>8</sup>

## Australian FASD response

- 1.13 Australia currently lags behind other countries in recognising the prevalence of FASD and the impact on the individual as well as social and economic impact on families and society. It is clear that urgent measures must be taken to reduce the incidence of FASD and to better manage those diagnosed with FASD. This parliamentary inquiry and report are long overdue.
- 1.14 The Foundation for Alcohol Research and Education (FARE) notes that there has been a 'government policy void' in Australia for the past two decades, that individuals and researchers have been trying to fill.<sup>9</sup>
- 1.15 The National Organisation for Fetal Alcohol Syndrome and Related Disorders (NOFASARD) was founded in 1999 as a national peak body to provide support for those with FASD and to lobby for awareness and action. In its submission, NOFASARD pointed out that, over a decade later:

The true extent of the incidence and prevalence of FASD in Australia is currently unknown. There is no nationally consistent definition; diagnostic criteria for FASD; nor biomarker for all conditions within the spectrum. Children are not routinely screened in infancy or early childhood and data which accurately reflects estimates of FASD incidence and prevalence in Australia are lacking.<sup>10</sup>

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6 Foundation for Alcohol Research and Education and Public Health Association of Australia (FARE/PHAA), *Submission 36*, p. 20.

7 FARE/PHAA, *Submission 36*, p. 12.

8 Public Health Agency of Canada, *Prevention of FASD: The Canadian Experience*, October 2010, <[http://www.drogenbeauftragte.de/fileadmin/dateien-dba/DrogenundSucht/Alkohol/Downloads/Prevention\\_of\\_FASD\\_The\\_Canadian\\_Experience\\_Vortrag\\_Johnston\\_101005\\_Drogenbeauftragte.pdf](http://www.drogenbeauftragte.de/fileadmin/dateien-dba/DrogenundSucht/Alkohol/Downloads/Prevention_of_FASD_The_Canadian_Experience_Vortrag_Johnston_101005_Drogenbeauftragte.pdf)> viewed 18 October 2012.

9 Foundation for Alcohol Research and Education (FARE), *The Australian Fetal Alcohol Spectrum Disorders Action Plan 2013–2016*, September 2012, p. 4.

10 National Organisation for Fetal Alcohol Syndrome and Related Disorders, *Submission 46*, p. 8.

- 1.16 The Telethon Institute for Child Health Research commenced a research program into alcohol and pregnancy in 2001, which has resulted in Australian-specific information, data and publications on FASD that contribute to public health policies.<sup>11</sup> The Telethon Institute later received funding from the Commonwealth Government to develop a national screening and diagnostic tool.
- 1.17 In 2006, the Intergovernmental Committee on Drugs Working Party on FASD was established. Their 2009 monograph titled *Fetal Alcohol Spectrum Disorders in Australia: An update* was made public only in June 2012. The Committee is aware that there is now an updated version of the monograph which provides more detail on responses to FASD in Australia.
- 1.18 It is disturbing that a lack of agreement across levels of government prevented the later monograph from being made available to this Committee to inform the report. National action on FASD will require a significantly more cooperative intergovernmental environment than has currently been demonstrated.
- 1.19 In recent years, concern has been increasing about the damages that alcohol can cause to individuals, families and society. These harms include long-term mental and physical health problems, absenteeism, crime, domestic violence, violence in and near drinking venues resulting in injury or death, and drink-driving. There has been a recent emphasis on the consequences of Australia's growing culture of risky and binge drinking.
- 1.20 There has been increasing concern regarding the harmful impacts of irresponsible consumption of alcohol. For example, in 2009 the National Preventive Health Taskforce produced a report on reducing harmful drinking. In 2011, a review of food labelling recommended that alcohol be labelled with warnings about the risk of drinking alcohol when pregnant.
- 1.21 In 2011, the House of Representatives Standing Committee on Aboriginal and Torres Strait Islander Affairs tabled their report, *Doing Time – Time for Doing: Indigenous youth in the criminal justice system*. The Committee received evidence about alcohol and substance abuse, alcohol reforms and the incidence of FASD in Indigenous communities, and recommended that the Commonwealth Government take action on addressing FASD and refer an inquiry to the Social Policy and Legal Affairs Committee.<sup>12</sup>
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11 Telethon Institute for Child Health Research, *Submission 23*, p. 2.

12 Parliament of Australia, House of Representatives Standing Committee on Aboriginal and Torres Strait Islander Affairs, *Doing Time – Time for Doing: Indigenous youth in the criminal justice system*, June 2011.

- 1.22 That same year, the Western Australia Parliamentary Education and Health Committee commenced an inquiry into improving educational outcomes for Western Australians of all ages, which included terms of reference to investigate FASD. The Committee published its report, *Foetal Alcohol Spectrum Disorder: the invisible disability*, on 20 September 2012.
- 1.23 On 12 September 2012, FARE launched *The Australian Fetal Alcohol Spectrum Disorders Action Plan 2013–2016*. The Committee commends FARE for their work on FASD and considers that the actions from this plan are a useful adjunct to the recommendations of this report.

## The inquiry

- 1.24 On 8 November 2011, the Minister for Families, Housing, Community Services and Indigenous Affairs, the Hon Jenny Macklin MP, and the then Minister for Health and Ageing, the Hon Nicola Roxon MP, asked the Committee to inquire into and report on developing a national approach to the prevention, intervention and management of FASD in Australia.
- 1.25 The Committee was asked to investigate three main areas:
- Prevention strategies - including education campaigns and consideration of options such as product warnings and other mechanisms to raise awareness of the harmful nature of alcohol assumption during pregnancy,
  - Intervention needs - including FASD diagnostic tools for health and other professionals, and the early intervention therapies aimed at minimising the impact of FASD on affected individuals, and
  - Management issues - including access to appropriate community care and support services across education, health, community services, employment and criminal justice sectors for the communities, families and individuals affected by FASD.
- 1.26 The Committee received 92 submissions and a number of exhibits from sources including Commonwealth, state and territory government departments, academic and research groups, non-profit organisations, Indigenous representative organisations and communities, and individuals such as birth and foster parents. A list of submissions received by the Committee is at Appendix A and a list of exhibits received by the Committee is at Appendix C.
- 1.27 The Committee held 13 public hearings and community forums in Canberra, Cairns, Townsville, Sydney, Melbourne, Perth, Mimbì and

- Broome, including a videoconference with witnesses from the Northern Territory. A list of public hearings and witnesses is at Appendix B.
- 1.28 Submissions received and transcripts of evidence can be found on the Committee website at [www.aph.gov.au/spla](http://www.aph.gov.au/spla).
- 1.29 During the inquiry the Committee visited the Royal Women's Hospital in Melbourne and attended the Marninwarntikura Women's Bush Camp in Mimbi, Western Australia.

## Scope and structure of the report

- 1.30 This report discusses how a national approach to the prevention, identification and management of FASD can be developed and achieved.
- 1.31 Chapter 2 provides an introduction to the history and science of FASD, a spectrum of disorders caused by alcohol consumption during pregnancy. It outlines the effect of alcohol on the developing fetus, and the primary and secondary symptoms including the behavioural impacts observable in those affected by FASD.
- 1.32 Chapter 2 then addresses the prominent role that alcohol plays in Australian society and the harms that certain consumption behaviours can cause to individuals and those around them. The factors which promote or contribute to high-risk alcohol consumption are discussed.
- 1.33 The prevention of FASD is considered in Chapter 3. National guidelines on alcohol were recently changed to state that not drinking is the safest option for women who are pregnant or planning a pregnancy. However, statistics demonstrate that much of the general community and the medical profession are unfamiliar with or do not understand these guidelines. This chapter explores strategies for supporting parents, including those with alcohol dependence, to stop or reduce alcohol consumption during pregnancy.
- 1.34 In addition Chapter 3 examines arguments surrounding the labelling of alcohol products with health warnings and specific FASD awareness campaigns.
- 1.35 Chapter 4 discusses the complexities of diagnosing and managing FASD. FASD is a spectrum rather than a single medical condition. The need for a national screening and diagnostic instrument is discussed, alongside diagnostic tools and services.
- 1.36 Chapter 5 addresses the paucity of data on FASD prevalence in Australia, and the importance of such data in mobilising public awareness and informing better management services and resourcing. The Chapter then discusses the challenges in managing young adults with FASD in terms of

their care, education and involvement in the criminal justice system. The benefits of legal recognition of FASD are identified.

## Terminology

- 1.37 Throughout this report, the use of the word 'parent' and 'carer' refers to those exercising a parental role, such as caregivers who live with the child and are the primary caretakers. This includes birth mothers, foster parents and legal guardians.
- 1.38 The Committee has adopted the accepted medical spelling of 'fetus', rather than the common usage spelling of 'foetus'.
- 1.39 The Committee uses the term FASD to broadly encompass all conditions associated with prenatal exposure to alcohol. Where witnesses or submitters have used specific diagnostic terms to refer to certain conditions (such as Fetal Alcohol Syndrome which is a subset of FASD), the Committee has retained the terminology provided.

## National action required

- 1.40 In Australia FASD has been the subject of a growing number of inquiries and increased research. There are a small number of dedicated individuals and organisations working in the area of FASD, and it has reached the policy agenda of some states and territories and some federal programs.
- 1.41 However, national efforts to eliminate FASD and efforts to optimise the lives of those already affected by FASD are inadequate. Essentially Australia's response to FASD is underfunded and uncoordinated. The responsibility for this lies with all levels of government and the medical profession who have failed to recognise the severity of FASD, who have failed to take on the alcohol industry and the general harms caused in society by the abuse of alcohol, and failed to educate the public regarding the risks posed by prenatal exposure to alcohol.
- 1.42 Fostering behavioural and community attitudinal changes to alcohol consumption during pregnancy will require leadership, expertise and inter-governmental cooperation. The purpose of this report is not to add to the volume of inquiries into FASD, but to establish a national plan to eliminate FASD.
- 1.43 Eliminating FASD will not be achieved by medication or vaccine, but by ensuring that every woman knows the risk through providing accurate health information and advice, and fostering a changed attitude to alcohol consumption during pregnancy and across the wider community.

- 1.44 Further, this report sets out to optimise the lives of those who have been affected by FASD. This will be achieved by better therapeutic services, greater understanding of the conditions characteristic of FASD and how these may manifest, enhanced support for carers, and improved pathways for those facing a lifetime disability caused by FASD.
- 1.45 Accordingly the actions set out in this report are high-level and bold. These actions should constitute the National Plan of Action to prevent, diagnose and manage FASD in Australia. While the plan to effect national change may be long term, the start of this process should be considered immediately and many of the actions should be immediately implemented.
- 1.46 Progressing the FASD National Action Plan will not be straightforward. It will require oversight across a number of areas: from awareness campaigns to health guidelines and training, alcohol regulation, diagnostic and therapeutic services, and disability support.
- 1.47 The Committee considers it essential that the Commonwealth Government draw on the research and expertise of professionals currently working in the field. The Committee notes the comprehensive report *Foetal Alcohol Spectrum Disorder: the invisible disability* which was recently published by the Education and Health Standing Committee of the Western Australian Legislative Assembly.<sup>13</sup> A number of the recommendations of that report align with this Committee's recommendations.
- 1.48 The Committee commends the detailed reports produced by FARE, and in particular the report *The Fetal Alcohol Spectrum Disorders Action Plan 2013-2016*, which details a number of costed actions to address FASD.
- 1.49 The FARE report recommends, as part of the governance structure of a FASD Action Plan, the establishment of a FASD Expert Advisory Committee whose membership should include representation from a number of Commonwealth Departments, state and territory Health and Justice Departments, consumer and carer groups, academics, clinicians and Indigenous communities.<sup>14</sup>
- 1.50 The Committee finds similarly that a FASD reference group should be established to oversee and advise on national initiatives to prevent, identify and manage FASD in Australia. The Committee considers that, to function effectively, this group should consist of a small group of

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13 Western Australian Legislative Assembly Education and Health Standing Committee, *Foetal Alcohol Spectrum Disorder: The invisible disability*, September 2012.

14 FARE, *The Australian Fetal Alcohol Spectrum Disorders Action Plan 2013-2016*, September 2012, p. 13.

appointed expert health practitioners and professionals. Departmental, governmental and community consultation can take place under the auspices of the FASD Reference Group and assist to inform them in their development of the detail of the action plan and oversight of implementation.

- 1.51 However, the FASD Reference Group itself should have a limited number of appointed members in order to have the capacity to conduct regular meetings and to act expeditiously to drive forward the national plan of action.
- 1.52 It is the considered view of the Committee that the effectiveness of any national actions is dependent on the priority establishment of an oversight FASD Reference Group. The national response to FASD prevention and management must be driven as a coordinated response that garners public support for change and ensures a sustained and coordinated set of policy and regulatory measures.
- 1.53 For this reason, the Committee sets out the establishment of a National Plan of Action for FASD as its priority recommendation. The Committee recommends that a FASD Reference Group oversee the implementation of the FASD National Plan of Action. In the following chapters the report makes a number of further recommendations as part of the FASD National Plan of Action.

### **Recommendation 1**

- 1.54 **The actions set out in this report should constitute the Commonwealth Government's National Plan of Action for the prevention, diagnosis and management of Fetal Alcohol Spectrum Disorders (FASD). This FASD National Plan of Action should be publicly released by 1 June 2013.**

### **Recommendation 2**

- 1.55 **The Committee recommends that the Commonwealth Government immediately establish an ongoing Fetal Alcohol Spectrum Disorders (FASD) Reference Group reporting to the relevant Commonwealth Government Ministers, consisting of a select group of appointed practitioners, professionals and stakeholders who are experts in the field of prevention and management of FASD.**

**The role of the FASD reference group would be to oversee and advise on the FASD National Plan of Action.**



- 1.56 The Committee considers monitoring and reporting on the effectiveness of implemented actions to be critical. A key issue hampering current initiatives is a lack of standardised data regarding numbers of women who consume alcohol while pregnant, FASD diagnosis and consequently the estimated prevalence of FASD in Australia. Issues associated with the collection of this data are addressed in later chapters.
- 1.57 The Committee recommends that the Commonwealth Government publicly report annually on the effectiveness of the national action plan for implementing FASD diagnostic and management services and for eliminating FASD in Australia.

### **Recommendation 3**

- 1.58 **The Committee recommends that the Commonwealth Government publicly report:**
- **within 12 months on the progress of the implementation of a national Fetal Alcohol Spectrum Disorders (FASD) diagnostic and management services strategy, a critical element of the FASD National Plan of Action, and**
  - **within five years on the progress towards eliminating FASD in Australia.**

## 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.<sup>1</sup>
- 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.<sup>2</sup> 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.<sup>3</sup>
- 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).<sup>4</sup>
- 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.<sup>5</sup>
- 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.<sup>6</sup>
- 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.<sup>7</sup>
- 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.<sup>8</sup>
- 2.14 In early Roman and Greek mythology allusions were made to an association between maternal alcoholism and faulty development of the offspring.<sup>9</sup> In the ancient Greek city of Carthage, the bridal couple were

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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.<sup>10</sup>

- 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.<sup>11</sup>
- 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.<sup>12</sup>
- 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.<sup>13</sup> 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.<sup>14</sup> 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.

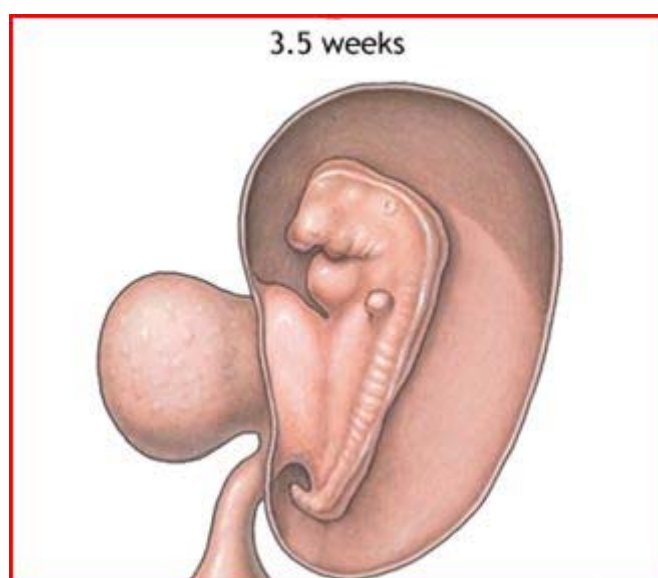
13 P Dillon, *The Much Lamented Death of Madam Geneva: The Eighteenth Century Gin Craze*, United Kingdom, Headline Books, 2002.

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.<sup>15</sup>

Figure 2.1 Fetus at 3.5 weeks gestation



Source United 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.<sup>16</sup>
- 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.<sup>17</sup>
- 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.<sup>18</sup>

## 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.<sup>19</sup>
- 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

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

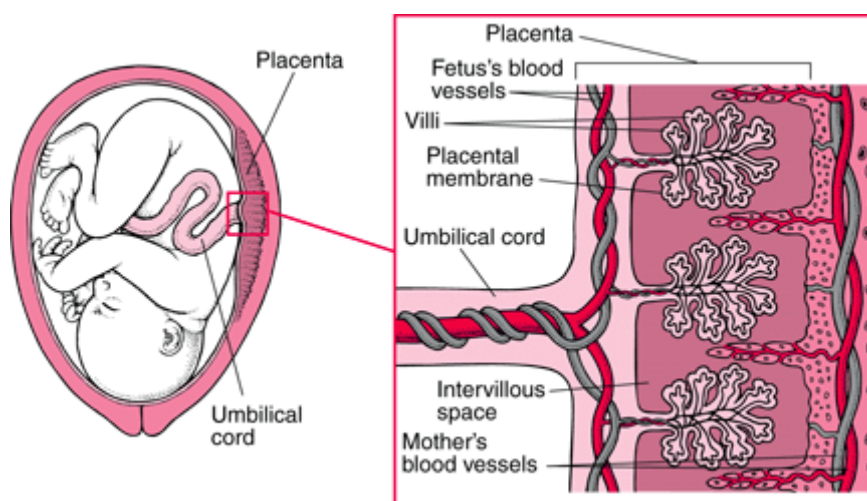
18 USNIH, *Fetal Development* <<http://www.nlm.nih.gov/medlineplus/ency/article/002398.htm>> viewed 28 June 2012.

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.<sup>20</sup> Alcohol is more damaging to neurobehaviour than other teratogens.<sup>21</sup>

- 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](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.<sup>22</sup>
- 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.<sup>23</sup>

- 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.<sup>24</sup>
- 2.34 The teratogenic effect of alcohol is considered to be dose-related.<sup>25</sup>
- 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.<sup>26</sup> 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.<sup>27</sup>

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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.

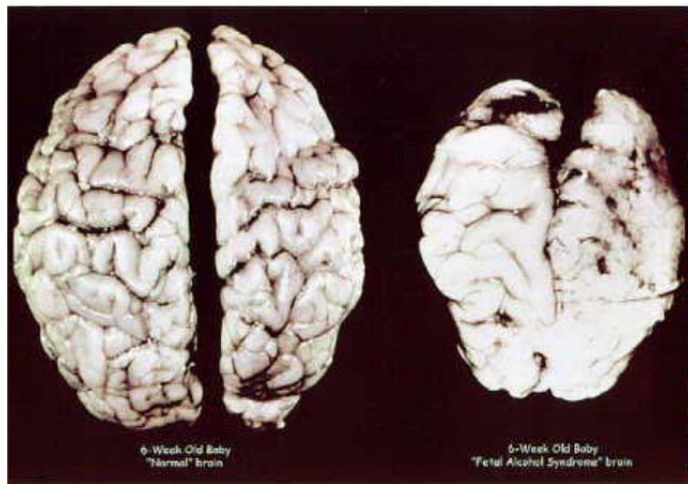
25 A Ornoy, Z Ergaz 'Alcohol Abuse in Pregnant Women: Effects on the fetus and newborn, mode of action and maternal treatment,' *International Journal of Environmental Research and Public Policy*, 2010, vol. 7, pp. 364-379.

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.<sup>28</sup> 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.<sup>29</sup>
- 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

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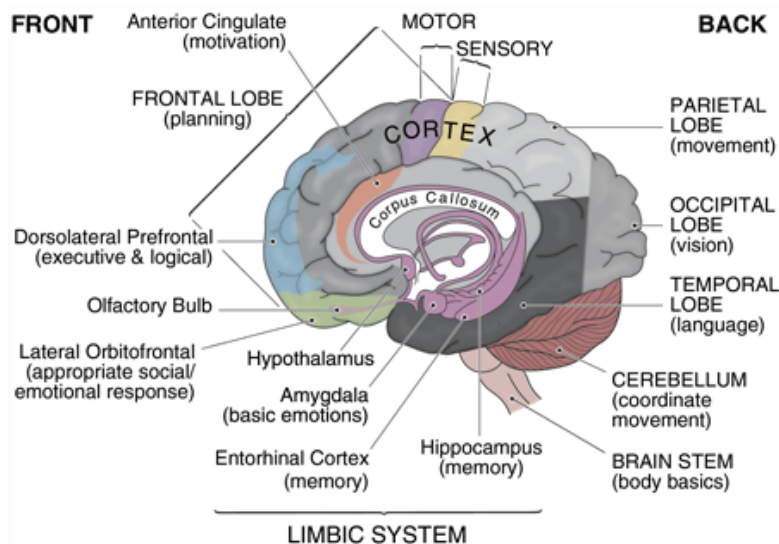
*Alcohol Spectrum Disorder: Management and Policy Perspectives of FASD*, Wiley-Blackwell, United States, 2011.

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 Bonthuis 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.<sup>30</sup>

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.<sup>31</sup>
- 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.<sup>32</sup>

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.<sup>33</sup>
- 2.46 The cerebellum controls coordination and movement, behaviour and memory. Studies have shown that prenatal alcohol exposure can damage the cerebellum.<sup>34</sup> 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.<sup>35</sup>
- 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.<sup>36</sup>

## 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.

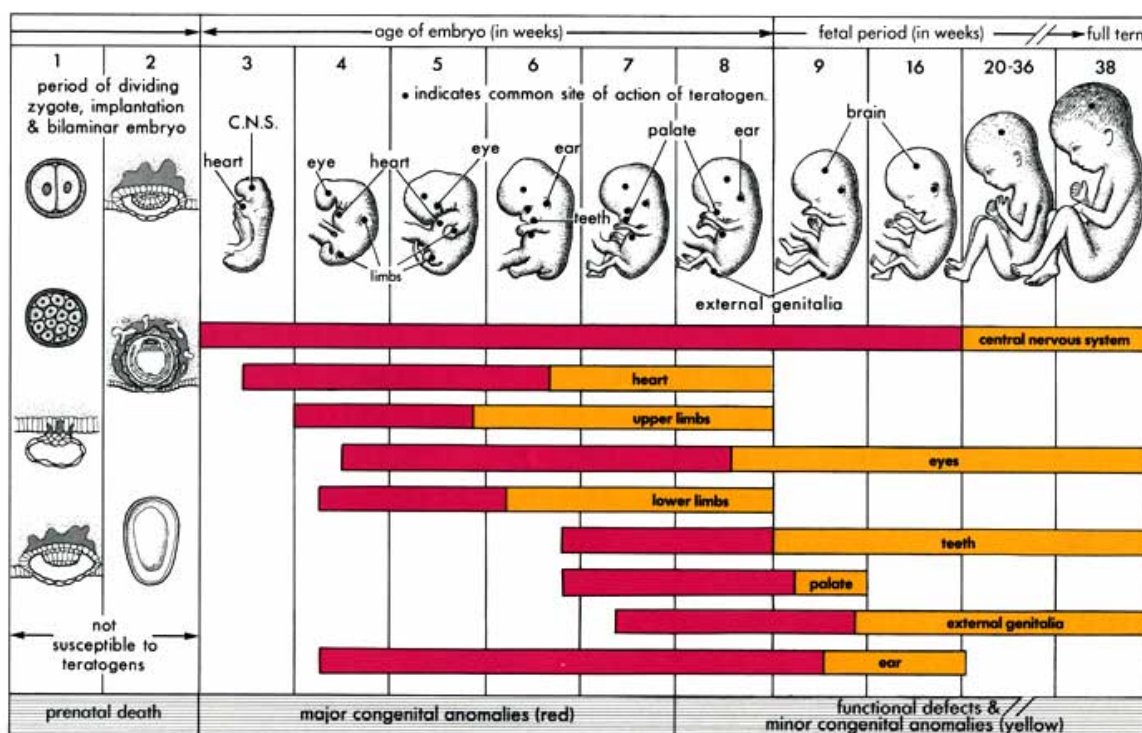
34 S Mattson et al, *Teratogenic Effects of Alcohol on Brain and Behavior*, <<http://pubs.niaaa.nih.gov/publications/arh25-3/185-191.htm>> viewed 4 July 2012.

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*, 7<sup>th</sup> 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.<sup>37</sup>
- 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.<sup>38</sup>

- 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.<sup>39</sup> Only a minority of people with FASD will have a low IQ.<sup>40</sup> 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'.<sup>41</sup> 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.<sup>42</sup>

- 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

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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.<sup>43</sup>

- 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.<sup>44</sup>

- 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.<sup>45</sup>

#### 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 Lirilwan 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 Lirilwan 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 Lirilwan 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.<sup>46</sup>

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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.’<sup>47</sup>
- 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’.<sup>48</sup>
- 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.’<sup>49</sup>
- 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’<sup>50</sup> 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

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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.<sup>51</sup>

- 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.<sup>52</sup>
- 2.69 Instances of FAS are in the minority across the FASD spectrum.<sup>53</sup> 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.<sup>54</sup> 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.<sup>55</sup>
- 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.<sup>56</sup>
- 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.<sup>57</sup>

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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.<sup>58</sup>

- 2.73 The signifying features of pFAS are two of the three FAS facial characteristics plus brain abnormalities and known prenatal alcohol exposure.<sup>59</sup>

- 2.74 People with ARND, the largest FASD category,<sup>60</sup> 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'.<sup>61</sup> 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.<sup>62</sup>

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.<sup>63</sup>
- 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.<sup>64</sup>
- 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.<sup>65</sup>
- 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.<sup>66</sup>

## 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.<sup>67</sup>

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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.<sup>68</sup>

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.<sup>69</sup>

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'.<sup>70</sup>

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.<sup>71</sup>

2.84 Professor Elliott emphasised that:

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

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,

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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.<sup>73</sup>

- 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 incompleteness 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.<sup>74</sup>

- 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.<sup>75</sup>

- 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.<sup>76</sup>
- 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.<sup>77</sup> An estimate provided by DHHS suggests that at least two per cent of all Australian babies are born with FASD.<sup>78</sup>
- 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.<sup>79</sup> 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.<sup>80</sup>
- 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.<sup>81</sup>
- 2.94 A comprehensive and detailed incidence study of FASD in Fitzroy Crossing will soon be released; a recent media report suggested that half

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

77 Tasmanian Department of Health and Human Services, *Submission 6*, p. 1; Australian Women's Health Network, *Submission 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.<sup>82</sup>

- 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’.<sup>83</sup>

- 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.<sup>84</sup>

## 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.<sup>85</sup> 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.<sup>86</sup>
- 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

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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.<sup>87</sup> Consequently while acknowledging FASD as a whole-of-community issue, the Department maintains a particular focus on Indigenous communities.<sup>88</sup>

2.101 The National Congress of Australia's First Peoples has registered their concern regarding the impact of FASD on Indigenous Australians.<sup>89</sup>

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.<sup>90</sup>

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.<sup>91</sup>

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.<sup>92</sup>

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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.<sup>93</sup>
- 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.<sup>94</sup>
- 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.<sup>95</sup>
- 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.<sup>96</sup>

## 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.<sup>97</sup>
- 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.<sup>98</sup>
- 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.<sup>99</sup>
- 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.<sup>100</sup>
- 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.<sup>101</sup>
- 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.<sup>102</sup>

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

100 National Preventive Health Taskforce, *Australia: the healthiest country by 2020 National Preventive 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.<sup>103</sup>
- 2.119 Over the past 50 years, total consumption of pure alcohol per capita has fluctuated. From the early 1960s onwards, apparent consumption<sup>104</sup> 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.<sup>105</sup>
- 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.<sup>106</sup> 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.<sup>107</sup>
- 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.<sup>108</sup>
- 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.<sup>109</sup>

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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.<sup>110</sup>
- 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.<sup>111</sup>
- 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.<sup>112</sup>

## 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.<sup>113</sup>
- 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.<sup>114</sup>
- 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.<sup>115</sup>
- 2.129 There is a perception that excessive alcohol consumption is a male problem, however there has been a gradual shift towards a social

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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.<sup>116</sup>
- 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.<sup>117</sup>
- 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.<sup>118</sup> 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.<sup>119</sup>
- 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.<sup>120</sup> 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](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.<sup>121</sup>

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.<sup>122</sup>

## 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.<sup>123</sup>

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.<sup>124</sup>

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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.<sup>125</sup>
- 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.<sup>126</sup>
- 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<sup>127</sup>
- 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?<sup>128</sup>
- 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.<sup>129</sup>

## 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.<sup>130</sup>
- 2.148 These figures represented an increase from 2007 in the number of women who abstained from drinking while pregnant and breastfeeding.<sup>131</sup>
- 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.<sup>132</sup>

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.<sup>133</sup>

- 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.<sup>134</sup>
- 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.<sup>135</sup> 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.<sup>136</sup>
- 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.<sup>137</sup> 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.<sup>138</sup>

## 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

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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.<sup>139</sup> Consequently, many women may consume alcohol during the early weeks of a pregnancy because they do not realize that they are pregnant.<sup>140</sup> 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<sup>141</sup> 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.<sup>142</sup>
- 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.<sup>143</sup>
- 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](http://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.<sup>144</sup>
- 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.<sup>145</sup> She stressed that in these situations it is not as simple as telling someone 'Don't drink or you might harm your child'.<sup>146</sup>
- 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.<sup>147</sup>
- 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 ...<sup>148</sup>
- 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.<sup>149</sup>

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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.<sup>150</sup>
- 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.<sup>151</sup>
- 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.<sup>152</sup>
- 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.<sup>153</sup>

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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<sup>154</sup>way' – which is profoundly insulting. It is much more insulting than 'You don't support Essendon' or whatever.<sup>155</sup>

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.<sup>156</sup> 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.

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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.



## FASD awareness and prevention

- 3.1 Fetal Alcohol Spectrum Disorders (FASD) are caused by prenatal exposure to alcohol. Prevention can only be effected by a woman choosing not to drink while pregnant. However, there are a number of factors influencing this decision, ranging from lack of awareness to misinformation, lack of support or alcohol dependency.
- 3.2 This chapter discusses first the current national guidelines on alcohol and pregnancy, and their emphasis on making the safest choice of total abstinence. Current obstacles to promoting abstinence as the safest choice are considered, such as the low level of awareness among health professionals, low public awareness, and lack of support services for women with alcohol dependence or misuse.
- 3.3 The chapter examines the factors claimed to be contributing to increasing alcohol consumption and in particular risky and anti-social patterns of consumption. These factors include alcohol availability, pricing and promotion.
- 3.4 The chapter concludes by discussing health warning labels on alcohol containers as part of a campaign to improve community awareness of the harms of alcohol and the effects of alcohol on fetal development.

### **Prevention through education and support**

- 3.5 As outlined in the previous chapter, there are a number of factors which may influence a women's decision to consume alcohol while pregnant. The following sections consider the role of health professionals in educating women about the risks of FASD and the national health guidelines on drinking and pregnancy.



- 3.6 Raising public awareness of the risk of FASD posed by even small levels of alcohol consumption is critical to prevention. Currently a number of myths persist regarding a 'safe' level of alcohol consumption and in some instances this misinformation is perpetuated by poor media reporting. Essential to raising public awareness and supporting the behavioural change of pregnant women is an attitudinal change across the wider community.
- 3.7 While FASD is not confined to a particular population group, those women who drink more heavily and more regularly place the developing fetus at greater risk of FASD. In situations where physical or emotional dependency on alcohol is an issue, there may be need for specialised support services.

### The role of health professionals

- 3.8 The role of health professionals is critical in providing information for those who are pregnant or planning pregnancies. It is also important that clear and consistent advice is provided, particularly to counteract the prevalence of alcohol in Australian society and the low level of current public awareness of the risk of FASD.
- 3.9 Most women planning a pregnancy or newly pregnant will consult their general practitioner to seek advice regarding the health of the developing fetus and on managing their health during the pregnancy.
- 3.10 One of the key recommendations that should be provided to women at this time is that not drinking alcohol is the safest option for the developing fetus.
- 3.11 This recommendation comes from the Australian Guidelines to Reduce Health Risks from Drinking Alcohol (the Guidelines) which are a series of best practice 'non-mandatory rules, principles or recommendations' issued by the National Health and Medical Research Council (NHMRC).<sup>1</sup>
- 3.12 The Guidelines are not specific to pregnancy, but provide clear advice as the safest option for a woman who is pregnancy or planning a pregnancy:

#### GUIDELINE 4

##### Pregnancy and Breastfeeding

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

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

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1 National Health and Medical Research Council (NHMRC), *How NHMRC develops its guidelines*, <<http://www.nhmrc.gov.au/guidelines>> viewed 30 July 2012.

- For women who are breastfeeding, not drinking is the safest option.<sup>2</sup>
- 3.13 However, this has not always been the advice provided in the Guidelines.
- 3.14 The first set of Guidelines, issued in 1987, did not provide any advice or recommendations in relation to the consumption of alcohol while pregnant. The second version of the Guidelines, issued in 1992, included advice not to drink when pregnant.
- 3.15 In 2001 the third version of the Guidelines changed this advice and specified a limit of no more than seven drinks in a week and no more than two standard drinks per day. This was based on what was described as limited available evidence whilst indicating that more high quality research was needed.<sup>3</sup>
- 3.16 The 2001 Guidelines were in place for eight years. Current levels of public awareness (discussed further in later sections) suggest that many parts of the community still consider 'moderate' amounts of alcohol consumption to not pose harm to the developing fetus.
- 3.17 The current Guidelines were issued in 2009 following an extensive review of the 2001 Guidelines including a substantial literature review, a public consultation and both national and international peer review.
- 3.18 It is likely that the successive changes in the Guidelines from 1987 to 1994, 2001 and 2009 have resulted in a low level of awareness amongst health professionals and members of the public, and some confusion as to the reasons leading to the changed advice.
- 3.19 Although there has been some criticism of this changed approach<sup>4</sup> and the recommendation that women should not consume any alcohol when pregnant, there is general support for the 'safest option' approach of the current Guidelines.<sup>5</sup>
- 3.20 While the risk to the fetus from heavy drinking is well known, the evidence of fetal effects from low or moderate consumption is less well understood. Commentators such as Dr Colleen O'Leary have noted that it is important that women are informed that not all pregnancies exposed to alcohol, including heavy levels of alcohol, will necessarily be harmed.

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2 NHMRC, *Australian Guidelines to Reduce Health Risks from Drinking Alcohol*, 2009.

3 NHMRC, *Australian Alcohol Guidelines: health risks and benefits*, 2001.

4 Parliament of Australia, Parliamentary Library, *Background Note Alcohol Warning Labels – Do they work?*, 9 May 2012.

5 For example see, Kimberley Population Health Unit (KPHU), *Submission 31*, p. 1; Family Planning New South Wales, *Submission 61*, p. 1; E Pearson, *Submission 48*, p. 6; First Peoples Disability Network Australia, *Submission 75*, p. 4; Western Australian Department of Health, Drug and Alcohol Office, *Submission 28*, p. 5.

However, as there is no established knowledge as to the degree of risk from different levels of exposure, and how this may vary during stages of fetal development, health professionals need to take a pragmatic approach when advising women about the risks of alcohol during pregnancy.<sup>6</sup>

- 3.21 The Winemakers' Federation of Australia (WFA) informed the Committee about recent studies into alcohol consumption by pregnant women investigating the effects of drinking in moderation. The WFA reported that in their opinion the results indicate that there is no significant risk of harmful effects and they argued that this should direct future guidelines and advice to pregnant women.<sup>7</sup> Their view is that:

Given that the evidence against very low levels of consumption is unclear or non-existent, public health campaigns should avoid alarmist statements about the impact of low levels of alcohol on fetal development with the goal of scaring women into abstinence.<sup>8</sup>

- 3.22 Dr Bernie Towler agreed that the evidence currently available suggests that at low levels of consumption there is low risk, but added that the individual factors of the woman and her pregnancy need to be taken into consideration.

In the absence of evidence, we do not really know how it is going to be one on one. So it is really the safest message and it is not uncommon to take that kind of preventative and cautious approach.<sup>9</sup>

- 3.23 To this end, the Guidelines for reducing health risks from drinking alcohol now include a section with practical advice for health professionals that states:

- the risk to the foetus is higher with high alcohol intake, including episodic intoxication, and appears to be low with low level intake
- it is impossible to determine how maternal and foetal factors will alter risk in the individual.<sup>10</sup>

- 3.24 However, research indicates that a number health professionals are not even aware of the advice provided in the Guidelines and so are not

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6 C O'Leary, 'Alcohol and Pregnancy: Do Abstinence Policies Have Unintended Consequences?' *Alcohol and Alcoholism*, vol. 47, no. 6, November/December 2012, pp. 638-639.

7 Winemakers' Federation of Australia (WFA), *Submission 39*, p. 9.

8 WFA, *Submission 39*, p. 3.

9 Dr B Towler, Principal Medical Adviser, Commonwealth Government Department of Health and Ageing (DoHA), *Committee Hansard*, Canberra, 28 June 2012, p. 4.

10 Vic Health, *Submission 37*, Attachment A – AQUA-Asking Questions about Alcohol in Pregnancy, p. 1.

- providing this information to women. Professor Elizabeth Elliott, a member of the working party to revise the 2001 Guidelines, informed the Committee that the previous Guidelines were not well known by health professionals. Research indicated only 12 per cent of health professionals were able to identify the components of the Guidelines that related to pregnancy.<sup>11</sup>
- 3.25 Over the three years since the new Guidelines have been in place, research suggests many health professionals are not aware of the changes and do not necessarily endorse the Guidelines as best practice. Although the Guidelines are clear on the ‘no alcohol during pregnancy’ message, a recent evaluation of the promotion of the Guidelines reported a low level of awareness of the Guidelines, with messages considered ‘unrealistic and confusing’.<sup>12</sup>
- 3.26 The Committee received evidence that some doctors and midwives continue to tell pregnant woman that moderate drinking while pregnant is safe and should not be a concern.<sup>13</sup>
- 3.27 Despite this alarming and irresponsible lack of awareness of the current Guidelines amongst some health professionals, evidence suggests that the changed Guidelines may be assisting to influence the consumption patterns of pregnant women. *The Longitudinal Study of Australian Children: Annual statistical report 2010* reported that alcohol consumption of mothers from a cohort that was subject to the less stringent Guidelines was higher than mothers from a cohort where the Guidelines recommended that women not drink alcohol during pregnancy (although the study found that further investigation was required).<sup>14</sup>
- 3.28 Alongside concerning evidence regarding a lack of knowledge of the Guidelines amongst some health professionals, substantial evidence was provided to the Committee that health professionals often lack the skills or do not consider it relevant to discuss alcohol consumption with a woman who is pregnant.
- 3.29 The Telethon Institute for Child Health Research (Telethon Institute) provided research which indicated that health professionals infrequently

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11 Professor E Elliott, Professor of Paediatrics and Child Health, University of Sydney, *Committee Hansard*, Sydney, 13 April 2012, p. 5.

12 Foundation for Alcohol Research and Education (FARE), *Submission 36*, p. 12.

13 M Williams, Maternal and Child Health Coordinator, KPHU, *Committee Hansard*, Broome, 12 July 2012, p. 4; Russell Family Fetal Alcohol Disorders Association, *Submission 1*, p. 2.

14 Australian Institute of Family Studies, *The Longitudinal Study of Australian Children: Annual statistical report 2010*, p. 129.

- ask about alcohol use in pregnancy and most feel ill-equipped to advise women about alcohol use in pregnancy or its potential adverse effects.<sup>15</sup>
- 3.30 They reported that a 2007 survey in Western Australian found that only half the health professionals who cared for pregnant women routinely asked women about alcohol consumption in pregnancy and only 33 per cent routinely provided information to pregnant women about the effects of alcohol use in pregnancy.<sup>16</sup>
- 3.31 A 2011 poll conducted by the Foundation for Alcohol Research and Education (FARE) found that less than half (42 per cent) of pregnant or breastfeeding women who were surveyed could say that a health professional discussed the risks of alcohol consumption.<sup>17</sup>
- 3.32 Professor Elliott claimed that there is reluctance on the part of health professionals to ask about alcohol use in pregnancy or to provide advice on not drinking in pregnancy.<sup>18</sup>
- 3.33 The Australian Wine Research Institute cited research that attributes lack of effective screening of pregnant women to:
- ... inadequate knowledge and skills among health care providers, including obstetricians, general practitioners, midwives and nurses, reinforced by limited education and training in medical school and in general practice, lack of time, and system barriers such as lack of intervention tools, protocol, referral or treatment resources.<sup>19</sup>
- 3.34 The Australian National Preventive Health Agency (ANPHA) clarified that some health professionals believe that they lack the necessary skills and tools to identify women and families at risk and thus to provide the necessary advice, support and referrals to bring about early intervention.<sup>20</sup>
- 3.35 At the Royal Women's Hospital in Melbourne, maternity intake processes usually include measures of alcohol consumption. Staff told the Committee that they try initially to develop a rapport with women in order to facilitate this discussion.<sup>21</sup>

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15 Telethon Institute for Child Health Research (Telethon Institute), *Submission 23*, p. 3.

16 Telethon Institute, *Submission 23*, p. 3.

17 Foundation for Alcohol Research and Education and Public Health Association of Australia, *Submission 36*, p. 18.

18 Professor E Elliott, University of Sydney, *Committee Hansard*, Sydney, 13 April 2012, p. 5.

19 Australian Wine Research Institute, *Submission 12*, p. 23.

20 Dr L Studdert, Manager, Policy and Programs, Australian National Preventive Health Agency (ANPHA), *Committee Hansard*, Canberra, 15 March 2012, p. 2.

21 Site Inspection: Royal Women's Hospital Melbourne, 22 June 2012.

- 3.36 Tools are available to assist health professionals discuss the issue of alcohol consumption with a woman during any stage of a pregnancy.
- 3.37 Representatives from Commonwealth Government Departments, including the Department of Health and Ageing and the Department of Families, Housing, Community Services and Indigenous Affairs, discussed the recently revised Alcohol and Pregnancy Lifescripts Kit. This is a resource to aid primary healthcare professionals interview patients and discuss issues health and pregnancy management issues. The Lifescripts kit is informed by the NHMRC Guidelines.<sup>22</sup>
- 3.38 The advantage of the Lifescripts is that it enables the general practitioner (GP) to openly raise alcohol consumption during pregnancy and to advise, refer and treat a pregnant woman. It also serves to help GPs identify a woman who may have been drinking excessively during pregnancy and who may need additional support.
- 3.39 Dr Raewyn Mutch from the Telethon Institute advised that it is important for GPs and Child Health Nurses to be equipped and capable of asking about lifestyle risk factors, such as alcohol consumption, as these are the professionals closest to the families.<sup>23</sup>
- 3.40 Further discussion on the role of health professionals in screening women for alcohol consumption during pregnancy is provided in the following chapter as part of diagnosis and management of FASD.

## Raising public awareness

- 3.41 It is apparent that across the field of health professionals, there are a number of practitioners who lack up to date information, who spread misinformation or who are reluctant to raise the topic of alcohol consumption with women who are pregnant or planning to become pregnant.
- 3.42 This is a serious failing and is no doubt a major contributor to the lack of public awareness of the risks of FASD, and to the myths and the misinformation that currently exist across the wider community.
- 3.43 Research indicates that although the risk of birth defects is greatest with high and frequent maternal alcohol intake during the first trimester, alcohol exposure throughout pregnancy can have consequences for the development of the fetal brain.<sup>24</sup>

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22 DoHA/Commonwealth Government Department of Families, Housing, Community Services and Indigenous Affairs, *Submission 78*, p. 3.

23 Dr R Mutch, Telethon Institute, *Committee Hansard*, Perth, 10 July 2012, p. 20.

24 National Alliance for Action on Alcohol (NAAA), *Submission 26*, p. 4.

- 3.44 The National Rural Health Alliance (NRHA) contended that the social norms governing drinking alcohol in Australian society may mean that women continue to drink when pregnant without being aware of the consequences of alcohol exposure to the fetus.<sup>25</sup>
- 3.45 The WFA considers that as alcohol is an accepted part of Australian culture, women will need to make the choice to consume alcohol when pregnant based on the best available information.<sup>26</sup>
- 3.46 The National Alliance for Action on Alcohol (NAAA) considered that the community needs to be better informed that maternal alcohol consumption can result in a spectrum of harms to the fetus.<sup>27</sup>
- 3.47 Janet Falconer from the Langton Centre regularly encounters a lack of awareness of the harm of alcohol in pregnancy compared to illicit drugs: 'What alcohol does to an unborn child is not out there. [Alcohol] is almost put into a different category because it is legal.'<sup>28</sup>
- 3.48 A Telethon Institute study found that pregnant women had some level of knowledge about not drinking too much. They had little idea, however, of the impact of alcohol and how it actually affected a baby's development in either the early stages when they do not know they are pregnant or throughout their pregnancy.<sup>29</sup>
- 3.49 Professor Elliott told the Committee that a survey of women found that they wanted a clear message; they wanted to be advised of the safest option not to drink in pregnancy:<sup>30</sup>
- 80 per cent agreed that pregnant women should not drink alcohol
  - 99 per cent said information about the effects of alcohol on the fetus should be readily available
  - 97 per cent said health professionals should ask women about their alcohol use in pregnancy and 97 per cent said they should provide advice about alcohol use in pregnancy
  - 91 per cent said that health professionals should advise women who are pregnant or thinking of becoming pregnant to give up drinking alcohol.<sup>31</sup>

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25 National Rural Health Alliance (NHRA), *Submission 40*, p. 6.

26 WFA, *Submission 39*, p. 8.

27 NAAA, *Submission 26*, p. 4.

28 J Falconer, Chemical Use in Pregnancy Service, New South Wales Health, *Committee Hansard*, Sydney, 13 April 2012, p. 15.

29 Ms H Jones, Manager, FASD Projects, Telethon Institute, *Committee Hansard*, Perth, 10 July 2012, p. 22.

30 Professor E Elliott, University of Sydney, *Committee Hansard*, Canberra, 24 November 2011, p. 6.

- 3.50 Despite the desire for a clear and consistent message regarding the risks of alcohol consumption during pregnancy, community perceptions of the risk seem to vary greatly. Figure 3.1 provides a sample of comments from an article on drinking in pregnancy featured on a popular Australian news site.

Figure 3.1 Online comments on news article

- The No alcohol in pregnancy message has nothing to do with telling pregnant women what to do. It is all about telling them what is the safest choice for the optimum health and development of their unborn child. *Patricia, Adelaide Jul 11, 2012, 01:34PM*
- But the research shows that the occasional glass of wine doesn't cause any harm - so why should people abstain because popular opinion is in conflict with the evidence that scientific studies have produced? *Claire, Jul 11, 2012, 02:44PM*
- Ridiculous. Pregnant women had a glass of wine if they felt like it in the seventies and no-one got paranoid about it. They also ate soft cheese, seafood and processed meats and gave birth - usually naturally - to healthy and intelligent children. I know because I did it and watched those children arrive and grow up into their forties. These idiotic rules forced on pregnant women are meaningless and utterly unnecessary. *R.Ross, Jul 11, 2012, 03:41PM*
- As a registrar at a major hospital in Darwin I see the terrible results of pregnancy and drinking. FAS is no joke, does happen and leaves a massive burden on families and the tax community who inevitably pick up the bill. So how much alcohol is OK during pregnancy? -zero. Once again for the dull. How much alcohol is OK during pregnancy? - zero. *Sean, Jul 11, 2012, 03:45PM*

Source *L Malone, "I can't serve you. You're pregnant", The Canberra Times, 11 July 2012.*

- 3.51 This confusion as to the recommended approach, and an understanding that this recommendation is based on the safest option rather than a risk

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31 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](http://www.biomedcentral.com/1471-2458/11/584)> viewed 27 August 2012.



- level was highlighted by media reporting of a limited Danish study into the effects of low alcohol consumption in early pregnancy.<sup>32</sup>
- 3.52 Results of the Danish study were released during the course of this inquiry and the findings of that study were reported alongside media coverage of this FASD inquiry.
- 3.53 It was reported that the results of the study showed significant effects were not observable from low to moderate alcohol consumption during pregnancy on executive functioning of children at the age of five years.<sup>33</sup>
- 3.54 These results were 'translated' in some media coverage with headlines such as:
- *The Truth about Women and Alcohol*<sup>34</sup>
  - *Moderate Drinking in Early Pregnancy Branded 'Safe'*<sup>35</sup>
  - *A Little Alcohol while Pregnant may be OK?*<sup>36</sup>
  - *Pregnant Women can Binge Drink Safely, says Research*<sup>37</sup>
- 3.55 The media reporting bore little resemblance to the findings of the study and the claims made in some media reports did not equate with the limited findings of the research. Further, this reporting indicated little understanding of the approach of the NHMRC Guidelines which is to recommend the safest option based on current best practice research evidence.
- 3.56 Professor Jane Halliday spoke generally about some of the issues with research supporting alcohol consumption when pregnant:
- Anyway, there are methodological problems in a lot of these studies, and they are all conflicting, so I think the story is still not fully told and there is a lot more research that needs to be done to

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32 Å Skogerbø et al, 'The effects of low to moderate alcohol consumption and binge drinking in early pregnancy on executive function in 5-year-old children', *British Journal of Obstetrics and Gynaecology* 2012, vol. 119, pp. 1201-1210.

33 Å Skogerbø et al, 'The effects of low to moderate alcohol consumption and binge drinking in early pregnancy on executive function in 5-year-old children' *British Journal of Obstetrics and Gynaecology* 2012, vol. 119, pp. 1201-1210.

34 T Jourdan, 'The truth about women and alcohol', *The Courier Mail*, 27 June 2012, <<http://www.couriermail.com.au/ipad/the-truth-about-women-and-alcohol/story-fn6ck8la-1226409230886>> viewed 27 August 2012.

35 The BBC News Health, 'Moderate drinking in early pregnancy branded 'safe'', <<http://www.bbc.co.uk/news/health-18506174>> viewed 27 August 2012.

36 WebMD, 'A little alcohol while pregnant may be okay', <<http://www.webmd.com/baby/news/20120622/studies-a-little-alcohol-while-pregnant-may-be-ok>> viewed 27 August 2012.

37 Metro.co.uk, 'Pregnant women can binge safely says research', <<http://www.metro.co.uk/news/902611-pregnant-women-can-binge-drink-safely-says-research>> viewed 28 August 2012.

try to address what are the true risks associated with low and moderate levels of drinking, which is what we are focused on.<sup>38</sup>

3.57 The National Health Service in the UK commented that:

Coverage in the [UK] media was confusing, potentially misleading and damaging. Several papers, such as the Metro and the Mail, claim that binge and heavy drinking during pregnancy is safe, while the BBC and the Telegraph report that low or moderate drinking does 'no harm' to the child. The claim made by the Express and the Mail that pregnant women can safely consume 12 alcoholic drinks a week is particularly worrying.<sup>39</sup>

3.58 Dr Mutch noted that the Danish study was misrepresented in the media.<sup>40</sup> Commenting on the damage caused by such inaccurate media reporting, Dr David Reeve noted the numbers of people who read the newspaper and will take such claims as reliable information.<sup>41</sup>

3.59 Similarly Professor Elliott commented on the serious consequences of misinformation, and how the Australian media have represented alcohol consumption during pregnancy:

We have to be very careful and the media has to be careful of these issues that are potentially harmful. If you've got someone who does drink during pregnancy they will be reassured with that sort of message and they'll think, 'Oh, that's fine. I can keep going.' One of the problems that women tell us is that they get mixed messages. They get messages that it's okay, not okay, one drink can hurt them, binge drinking is the only thing that hurts them. What we are saying is that the safest option – as the National Health and Medical Research Council and Department of Health and Ageing propose in their guidelines – is that women avoid alcohol during the period of pregnancy and when planning a pregnancy.

3.60 It is clear that community awareness of the risks of FASD is low and community understanding of abstinence as the safest option is low. Ensuring health professionals undertake a more educative role is key to improving the knowledge and awareness of pregnant women. Clear and

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38 Associate Professor J Halliday, Principal Research Fellow, Murdoch Children's Research Institute, *Committee Hansard*, Melbourne, 22 June 2012, p. 5.

39 United Kingdom National Health Service, 'Daily drinking in pregnancy 'not safe'', <<http://www.nhs.uk/news/2012/06june/Pages/daily-drinking-pregnancy-risk-not-safe.aspx>> viewed 28 August 2012.

40 Dr R Mutch, Paediatric Fellow, Telethon Institute, *Committee Hansard*, Perth, 10 July 2012, p. 26.

41 Dr D Reeve, Acting Director, KPHU, *Committee Hansard*, Broome, 12 July 2012, p. 11.

consistent public awareness campaigns are required for women to understand the risks involved and make choices to change their behaviour and not consume alcohol when pregnant.

- 3.61 It is necessary for these public awareness campaigns to inform all women of the risks posed to the developing fetus by prenatal exposure to alcohol, and also to target particular populations of women who, due to their higher levels of alcohol consumption, are placing the developing fetus at higher risk. This includes young women in the 18 to 24 year group, including those in metropolitan, regional areas, and Indigenous women.
- 3.62 In addition, there is a need to raise the awareness of the broader community about the risks of FASD and the safest approach advocated by the Guidelines.

### Community and family engagement

- 3.63 There was substantial evidence indicating a significant need to educate men about the harmful effects of alcohol on a pregnancy and for men to take an active role in helping partners to prevent FASD in their baby.<sup>42</sup>
- 3.64 The Western Australian Network of Alcohol and other Drug Agencies (WANADA) asserted that men should be aware of the dangers of drinking in pregnancy, highlighting that it is important that families, partners and the community are aware of why a woman may decide not to drink, particularly if she is planning a pregnancy or if she is pregnant.<sup>43</sup>
- 3.65 The Tasmanian Department of Health and Human Services argued that ‘women who are pregnant find it difficult not to drink if they have partners and networks of friends where alcohol is at the centre of socialisation’.<sup>44</sup>
- 3.66 The NRHA stated that men have been ‘let off the hook’ for too long in the FASD story:
- Their understanding, support and assistance can be very valuable in the prevention, identification and management of FASD. It is critical not to see FASD as a women’s issue.<sup>45</sup>
- 3.67 The NRHA further added that assistance for women to stop drinking during pregnancy may include assistance with other issues affecting their

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42 Public Health Association of Australia – NT Branch, *Submission 73*, p. 2; National Women’s Health Network, *Submission 58*, p. 5; Dr Rosalie Schultz, *Submission 15*, p. 2.

43 D Ferris, Western Australian Network of Alcohol and other Drug Agencies (WANADA), *Committee Hansard*, 10 July 2012, p. 4.

44 Tasmanian Department of Health and Human Services, *Submission 6*, p. 3.

45 NRHA, *Submission 40*, p. 2.

- wellbeing. Their partners may also need to be encouraged to be supportive, even if this means to stop drinking themselves.<sup>46</sup>
- 3.68 The Australian College of Children and Young People's Nurses raised their concern that not enough is done with young men around early intervention strategies for drinking. They contend that young men as well as young women need to be targeted.<sup>47</sup>
- 3.69 The National Drug Research Institute reported that male partners can affect a woman's choice to drink when pregnant. Their study showed that 75 per cent of women who drank during pregnancy usually drank with their partner, with 40 per cent noting that their partner usually initiated drinking occasions.<sup>48</sup>
- 3.70 FARE told the Committee that partners who drink can foster an environment where alcohol use is tolerated and encouraged. They shared research which showed that 30.5 per cent of women would stop or reduce their drinking if their partner also stopped drinking for the duration of the pregnancy and 38 per cent would drink less if their partner encouraged them to stop or cut back.<sup>49</sup>
- 3.71 Dr Rosalie Schultz argued that a fundamental change in attitude is needed where society can accept that it is normal and healthy for pregnant women to abstain from alcohol. She considers that this will be a considerable challenge given that alcohol is present at almost all social events. Dr Schultz stated:

While only women drinking alcohol leads directly to foetal alcohol spectrum disorder, men drinking alcohol contributes to women drinking alcohol. Therefore interventions leading to reduction in alcohol-consumption across society are needed.<sup>50</sup>

### Voluntary alcohol restrictions in Indigenous communities

- 3.72 A number of Indigenous communities have voluntary alcohol restrictions in place in order to reduce the harms of alcohol in their communities. This may include violence and social dysfunction as a result of excessive drinking, and the high rates of FASD which have been recognised in some Indigenous communities.

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46 NRHA, *Submission 40*, p. 13.

47 Dr J Fraser, Board Member, Australian College of Children and Young People's Nurses, *Committee Hansard*, Sydney, 13 April 2012, p. 12.

48 National Drug Research Institute, *Submission 20*, p. 4.

49 FARE, *Submission 36*, p. 19.

50 Dr R Schultz, *Submission 15*, p. 1.

- 3.73 A leading expert in alcohol consumption in Indigenous communities, Dr Maggie Brady, said that:
- ... somewhat ironically, and unlike mainstream Australia with its national antipathy towards any (even implied) interference with our enthusiastic consumption of grog, Aboriginal people in some regions have embraced prohibition.<sup>51</sup>
- 3.74 In Queensland, 19 Indigenous communities have alcohol management plans that restrict the type and quantity of alcohol allowed into the community to varying degrees. In addition, the Queensland Government has set up a scheme that allows households in designated communities to choose to be 'dry places'. Once designated as a 'dry place', anyone who drinks or has any type of alcohol in the home will be breaking the law and could be fined up to \$2 090. These communities include Cherbourg, Hope Vale, Doomadgee and Palm Island.<sup>52</sup>
- 3.75 However, the Queensland Government announced a review of the alcohol management plans in October this year, raising concerns about a return to previous high levels of alcohol-related violence.<sup>53</sup>

Figure 3.2 The Lिलilwan Project

**Marulu: the Lिलilwan project** is an innovative and highly successful community-led strategy developed to address FASD and early life trauma in the Fitzroy Valley of Western Australia. The community recognised that FASD threatens the very existence of Aboriginal culture in the Fitzroy Valley—where traditions, stories, and ways of life are passed from one generation to the next through oral communication. The strategy is guided by the community's need to heal the pain of past alcohol abuse, to preserve their local culture and to ensure a bright future for their children.

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- 51 M Brady, 'Out from the Shadow of Prohibition,' in Jon Altman and Melinda Hinkson (eds.), *Coercive Reconciliation: Stabilise, Normalise, Exit Aboriginal Australia*, Melbourne, Arena Publications Association, 2007, pp. 186.
- 52 Queensland Government Department of Aboriginal and Torres Strait Islander and Multicultural Affairs, *Dry Places*, <<http://www.datsima.qld.gov.au/atsis/aboriginal-torres-strait-islander-peoples/health/drugs-and-alcohol-prevention-and-support/dry-places>> viewed 15 November 2012.
- 53 S Wardill and K Helbig, 'Indigenous Councils to Rule on Liquor Bans', *The Courier Mail*, 3 October 2012 <<http://www.couriermail.com.au/news/indigenous-councils-to-rule-on-liquor-bans/story-e6freon6-1226486894437>> viewed 10 October 2012; J Walker and S Elks, 'Noel Pearson's Hometown of Hopevale Divided over Grog Bans', *The Australian*, 5 October 2012 <<http://www.theaustralian.com.au/national-affairs/indigenous/noel-pearsons-hometown-of-hopevale-divided-over-grog-bans/story-fn9hm1pm-1226488539971>> viewed 10 October 2012.

June Oscar, Lirilwan Project Chief Investigator, said: 'This whole process of initiating the Lirilwan Project and developing the overarching *Marulu* strategy by our community is something the community has been discussing and planning over a number of years.' The project 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 partnership with experts in Indigenous health, paediatric medicine, human rights advocacy and child protection, the Lirilwan project represents Australia's first ever prevalence study of FASD. The project noted that past attempts to document the prevalence of FASD have been hampered by under-recognition and under-reporting. The unique data derived from the project will enable the community to advocate for improved health care, and community and education services.

Ms Oscar described the development of the strategy: 'It all came to a head in July 2007 when the women in our community decided that it was time we took a strong stance on the way in which alcohol was devastating the lives of many in our community. We focused on pursuing alcohol restrictions which gave respite to the community and in the months that followed the women made FASD a priority area that we wanted to address from the community.'

Ms Oscar said: 'We sought out the assistance of government and our current partners. We noted that we cannot do this alone as a community and government cannot do it on its own. It needs a whole network of people and hence we have come up with a collaborative model of how to pursue this issue.'

In Bunaba, a local language of the Fitzroy Valley in Western Australia, *Marulu* means 'precious, worth nurturing', while in Kimberley Kriol, *Lirilwan* means 'all of the little ones'. The Lirilwan project has been extremely successful in addressing FASD locally and has provided valuable lessons for the development of strategies to address FASD elsewhere in Australia. In addition, the project has received international recognition at the United Nations for its considerable achievements.

*Source: <http://www.georgeinstitute.org.au/marulu/our-story> and Ms June Oscar, Chief Executive Officer, Marninwarntikura Women's Resource Centre, Lirilwan Project Chief Investigator, Committee Hansard, Canberra, 24 November 2011, p. 2.*

- 3.76 In Fitzroy Crossing and Halls Creek in Western Australia, strong local women have led voluntary alcohol restrictions where responsible serving of alcohol is now being enforced. In these communities there has been a

- noticeable decline (between 20 and 40 per cent) in the number of alcohol-related crimes and alcohol-related admissions to hospitals.<sup>54</sup>
- 3.77 Since 1979, more than 100 Indigenous communities in the Northern Territory have used the restricted areas provisions under the *Northern Territory Liquor Act 1978* to either ban or restrict the consumption and possession of alcohol in their communities.<sup>55</sup> Dr Brady noted that these provisions ‘vary according to local circumstances and expressed need’.<sup>56</sup>
- 3.78 Similarly to Queensland, the Chief Minister of the Northern Territory has suggested that alcohol bans could be lifted.<sup>57</sup>
- 3.79 The Commonwealth Government has announced that, as part of the *Stronger Futures in the Northern Territory* initiative, minimum standards for Alcohol Management Plans will be introduced for all Indigenous communities in the Northern Territory. These standards are designed to help improve safety for Indigenous communities in the Northern Territory, and will support voluntary alcohol restrictions that are already in place. The Government is conducting consultations with Indigenous people and other stakeholders on these arrangements prior to the introduction of minimum standards.<sup>58</sup>

## Specialised intervention and support services

- 3.80 Alcohol dependency, whatever the factors leading to this situation, poses particular problems in terms of supporting a woman not to drink during pregnancy. Where alcohol dependency exists, a woman is likely to have a history of regular and heavy alcohol consumption, which places the developing fetus at high risk of FASD.
- 3.81 In these instances, even awareness of the high risk may not be sufficient for a woman to cease or reduce her alcohol consumption. Specialised support and assistance is required.

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54 S Kinnane and K Golson, *Halls Creek Alcohol Restriction Report: An evaluation of the effects of alcohol restrictions in Halls Creek relating to measurable health and social outcomes, community perceptions and alcohol related behaviours after twelve months*, December 2010.

55 M Brady, ‘Out from the Shadow of Prohibition,’ p. 185.

56 M Brady, ‘Out from the Shadow of Prohibition,’ p. 185.

57 A Aikman, ‘Outsiders “drown out Aborigines” on Grog Bans, says Terry Mills’, *The Australian*, 15 October 2012 <<http://www.theaustralian.com.au/national-affairs/indigenous/outside-drown-out-aborigines-on-grog-bans-says-terry-mills/story-fn9hm1pm-1226495761553>> viewed 26 November 2012.

58 The Hon Jenny Macklin MP, ‘Tackling Alcohol Abuse in the Northern Territory’, *Media Release*, 8 November 2012, <<http://jennymacklin.fahcsia.gov.au/node/2155>> viewed 15 November 2012.

- 3.82 Most hospitals that provide maternity services have some provision for women who drink heavily or use drugs. These services can often form a team of professionals that provide care and support for pregnant women with ongoing drug and alcohol issues.
- 3.83 The Committee visited the Women's Alcohol and Drug Service at the Royal Women's Hospital in Melbourne, which provides multi-disciplinary care for pregnant women with drug and alcohol issues and their infants.<sup>59</sup> The Committee also heard from the Chemical Use in Pregnancy Service which operates in the South East health region of New South Wales.
- 3.84 Research has found that illicit drug users generally tend to be truthful about their use when reporting in a research or clinical situation, however this is not necessarily the case when the drug user is pregnant. When pregnant illicit drug users were asked whether there had been recent illicit substance use only 2 per cent of the sample reported that they had, but 16 per cent tested positive in hair analyses.<sup>60</sup>
- 3.85 Neonatologist Dr Ju Lee Oei's experience supports this research. She advised the Committee that 'what we have also noticed in our work is that there is a reticence of admitting to alcohol or drug use, especially in the privately insured population'.<sup>61</sup>
- 3.86 Professor Elliott suggested that women not already known by community or social services to be drinking may slip through the net:
- What we have not really explored is the number of people out in the general community who are not attached to [substance use] services who are drinking significant amounts and who potentially should be helped and who may be unaware of the potential harm that they are doing.<sup>62</sup>
- 3.87 WANADA stated that they saw a need for health professionals able to work with women who may find it difficult to give up alcohol during pregnancy:

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59 The Royal Women's Hospital, 'Women's Alcohol and Drug Service - WADS' <<http://www.thewomens.org.au/womensalcoholanddrugservicewads>> viewed 29 August 2012.

60 S Darke and LA Burns, 'Commentary on Friguls et al. (2012): Illicit drugs and pregnancy? Testing is not a substitute for good clinical rapport', *Addiction*, vol. 107, no. 8, pp. 1480-1481, 2012, <<http://onlinelibrary.wiley.com/doi/10.1111/j.1360-0443.2012.03898.x/full>> viewed 12 November 2012.

61 Dr J Oei, Neonatologist, Royal Hospital for Women, *Committee Hansard*, Sydney, 13 April 2012, p. 11.

62 Professor E Elliott, University of Sydney, *Committee Hansard*, Sydney, 13 April 2012, p. 15.



... so that they are not turned away or forced to lie about their alcohol use but instead can be offered effective strategies to reduce their alcohol consumption during that time.<sup>63</sup>

- 3.88 Others raised concerns about mothers who continue to drink heavily through multiple pregnancies. They may already have children diagnosed or suspected of having FASD and yet continue to drink during subsequent pregnancies.<sup>64</sup>
- 3.89 Professor Elliott explained that there was very little evidence to support what should be done when it is identified that a woman is drinking during pregnancy. She considers that more research is required to establish what services should be provided.<sup>65</sup>
- 3.90 The Public Health Association of Australia agreed that it is not as simple as just stopping drinking in all cases. They stated that if an individual has a serious drinking problem, that is a clinical issue which needs to be managed in the appropriate way. They highlighted the risk of harm to people through unsupported alcohol withdrawal.<sup>66</sup>
- 3.91 Many submitters to the inquiry suggested that brief interventions could be used where appropriate.<sup>67</sup> Interventions may take the form of voluntary residential care, alongside a range of therapeutic services and work across family and support networks to assist in changing behaviours and providing alternatives to the lifestyle of alcohol use.
- 3.92 Such interventions would bring together drug and alcohol support services with maternity care providers to provide holistic approaches that optimise outcomes for the woman and the developing fetus. Many of these services are delivered by State programs, however it is essential that they are considered as part of an integrated national plan for FASD prevention.

## Committee Comment

- 3.93 There is a perception amongst many in the community that low levels of alcohol consumption when pregnant do not pose a risk to the developing fetus. However, research has not established if there is any 'safe' level of

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63 D Ferris, WANADA, *Committee Hansard*, Perth, 10 July 2012, p. 5.

64 E Pearson, Manager, AOD Service, Pormpur Paanth Aboriginal Corporation, *Committee Hansard*, Cairns, 31 January 2012, p. 24.

65 Professor E Elliott, University of Sydney, *Committee Hansard*, Sydney, 13 April 2012, p. 16.

66 Ms Melanie Walker, Chief Executive Officer, Public Health Association of Australia, *Committee Hansard*, Canberra, 31 May 2012, p. 7.

67 For example see: National Council on Intellectual Disability, *Submission 9*, p. 5; Uniting Church in Australia, *Submission 21a*, p. 3; Australian Women's Health Network, *Submission 58*, p. 5.

alcohol consumption when pregnant. What is known is that even small amounts of alcohol have the potential to impact the healthy development of the fetus with lifetime consequences for the child.

- 3.94 The Guidelines are clear that the safest option for women is not to drink when pregnant or planning a pregnancy. The Committee is deeply concerned that this advice is not widely known, and the best practice approach of advocating the safest option is not widely understood.
- 3.95 Perhaps even more alarming is the low level of awareness of the Guidelines amongst health professionals and a lack of skills and training in discussing alcohol consumption with pregnant women. The Committee considers this a devastating failing in our health system.
- 3.96 The community relies on all types of health professionals to provide the most up to date and informed advice. Currently this is not being provided and the Committee recommends targeted training to ensure all health professionals are fully cognisant of the Guidelines and the risk posed by prenatal alcohol exposure.
- 3.97 FASD prevention starts with information. It is a simple message and health professionals play a vital role in advising and counselling pregnant women, and ensuring accurate information is provided to the community. The Committee recommends urgent action to ensure all health professionals fulfil this important role in regards to FASD prevention.

#### **Recommendation 4**

- 3.98 **The Committee recommends that the Commonwealth Government work with the National Health and Medical Research Council and professional peak bodies to ensure that all health professionals are:**
- **fully aware of the National Health and Medical Research Council Guidelines that advise women not to drink while pregnant;**
  - **have alcohol consumption impacts on pregnancy and the developing fetus incorporated into all general practice and midwifery training;**
  - **trained in discussing the National Health and Medical Research Council Guidelines and alcohol consumption with women; and**
  - **skilled in asking women about alcohol consumption and recognising and responding to women at risk.**
- By 1 January 2014, all health professionals, including sexual health**

**advisors, midwives, general practitioners and obstetric professionals should be promoting the consistent message that not drinking while pregnant is the safest option, in line with the National Health and Medical Research Council Guidelines.**

- 3.99 The Committee recognises the need to collect data about women drinking while pregnant so consumption patterns may be identified, monitored and additional support or awareness programs can be targeted to where there is most need.
- 3.100 The Committee recommends that health professionals record the consumption of alcohol during pregnancy or at the time of birth for women who have not presented for prenatal care. This would inform future health planning and assist in FASD screening.

### **Recommendation 5**

- 3.101 **The Committee recommends that the Commonwealth Government establish mechanisms for health professionals to record women's alcohol consumption during pregnancy, or at the time of birth for women who have not presented for prenatal care, and to ensure such information is recorded in midwives data collections or notifications across Australia.**
- 3.102 Awareness of the risk posed by prenatal alcohol exposure can be radically improved by health professionals raising the issue with patients and providing clear advice in line with the NHMRC Guidelines. Knowledge about FASD needs to include both specialist medical advice and general public awareness.
- 3.103 FASD and the risks posed by prenatal alcohol exposure must become *common* knowledge. This must be achieved by widespread awareness initiatives run through media campaigns, health forums, pamphlets, posters and other forms of advertising.
- 3.104 The Committee commends the work of the Western Australian government in its series of advertisements encouraging women not to drink when pregnant, and encouraging friends and families to actively support this decision. However, more is needed nationwide to effect change.
- 3.105 The lack of accurate information means women are not always able to make informed choices about their alcohol consumption, and may unknowingly be placing their child at risk. In addition, the lack of broader

- community knowledge can result in poor family and community support for women to stop drinking when pregnant.
- 3.106 Key to preventing FASD is raising community awareness of the Guidelines, and changing societal expectations so that it is the norm that women do not drink when pregnant or when planning a pregnancy.
- 3.107 It is the view of the Committee that partners, families and the community at large all play a role in ensuring that a pregnant woman is not placed in a position where she is coerced or made to feel that the only option available is to have a drink.
- 3.108 This social change will require a range of targeted nationwide campaigns that raise awareness across the community, not just among women. Specific campaigns should be developed to raise awareness in Indigenous communities and amongst youth who are more likely to engage in risky levels of alcohol consumption and be in situations where the social expectation is to engage in drinking alcohol.
- 3.109 However, it is important that these awareness campaigns promote the message that FASD is a risk for the baby of any woman who drinks at any level while pregnant, and the risk of FASD is not confined to a particular population group or to particular levels of alcohol consumption.

## **Recommendation 6**

- 3.110 **The Committee recommends that the Commonwealth Government implement a general public awareness campaign which promotes not drinking alcohol when pregnant or when planning a pregnancy as the safest option, consistent with the National Health and Medical Research Council Guidelines.**
- Specific awareness campaigns should be developed to target youth and Indigenous communities.**
- Nationwide campaigns should be started no later than 1 July 2013.**
- 3.111 As part of these nationwide awareness raising initiatives, the Committee concurs with the Western Australia parliamentary committee's recommendation that the Guidelines regarding alcohol and pregnancy be printed on pregnancy testing and ovulation kits.<sup>68</sup>

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68 Western Australian Legislative Assembly Education and Health Standing Committee, *Foetal Alcohol Spectrum Disorder: The invisible disability*, September 2012, p. 99.

- 3.112 Women who are planning a pregnancy or who consider they may be pregnant are likely to purchase pregnancy and ovulation testing kits. Requiring these products to display information about the risks of drinking while pregnant will assist in providing a targeted message to women who may become pregnant.
- 3.113 These labels should be consistent with information provided through the public awareness campaign and will enable women to receive clear advice about the risks posed by consuming alcohol.

### **Recommendation 7**

- 3.114 **The Committee recommends that the Commonwealth Government mandate a health advisory label advising women not to drink when pregnant or when planning a pregnancy to be included on the packaging of all pregnancy and ovulation testing kits. These labels should be in place by 1 October 2013.**
- 3.115 The Committee acknowledges that high levels of alcohol consumption has been a feature of many Indigenous communities, and many of these communities have been proactive in taking steps to control the use of alcohol within communities. Some state and territory governments have introduced measures to assist Indigenous and other communities restrict the accessibility of alcohol.
- 3.116 However, recent moves in some states and territories have suggested the lifting of alcohol restrictions and abolishment of alcohol management plans.
- 3.117 The Committee considers that these community endorsed approaches are vital in changing patterns of consumption and creating a space where women, families and communities can make positive choices around their use of alcohol.
- 3.118 The Committee welcomes the recent announcement by the Commonwealth Government in regards to draft minimum standards for Alcohol Management Plans in the Northern Territory, and the consultation process being undertaken with Indigenous communities.<sup>69</sup>

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69 The Hon Jenny Macklin MP, 'Tackling Alcohol Abuse in the Northern Territory', *Media Release*, 8 November 2012, <<http://jennymacklin.fahcsia.gov.au/node/2155>> viewed 15 November 2012.

- 3.119 FASD is disabling the children of many Indigenous communities. It is the role of Government to provide a concerted education program on the risks of prenatal alcohol exposure and, where an Indigenous community wishes to institute an alcohol management plan, to support this initiative.
- 3.120 The Committee urges state and territory governments to show leadership and acknowledge the self-determination and decision making capabilities of Indigenous communities who want restrictions on alcohol. Government should support these important measures as part of the national strategy to eliminate FASD which in turns supports a strong Indigenous people.

### **Recommendation 8**

- 3.121 **The Committee recommends that the Commonwealth Government raise with the States and Territories the critical importance of strategies to assist Indigenous communities in managing issues of alcohol consumption and to assist community led initiatives to reduce high-risk consumption patterns and the impact of alcohol.**
- 3.122 The Committee acknowledges that for some women not drinking when pregnant is difficult due to other life circumstances. These women will require specialised assistance and support.
- 3.123 The reasons why a woman in this situation may continue to drink, despite knowledge of the risks posed to the fetus, are rarely simple. It is critical that women are able to engage with the health system without fear or judgement.
- 3.124 The Committee considers that voluntary intervention and support services across remote, regional and metropolitan Australia are essential for women with alcohol dependency issues. Services must be culturally appropriate in their response to women and families, and able to provide a range of options to assist women manage their life circumstances and ensure the best health for the developing baby.

### **Recommendation 9**

- 3.125 **The Committee recommends that the Commonwealth Government work with State and Territory governments to identify and implement effective strategies for pregnant women with alcohol dependence or misuse.**

## Prevention through reforms of alcohol sales and labelling

- 3.126 FASD prevention and better support for those with FASD and their carers is the focus of the inquiry. However substantial evidence was received regarding the wider range of harms caused by alcohol. The changes in alcohol consumption patterns in Australia were often linked to changes in the accessibility and marketing of alcohol.
- 3.127 Michael Thorn from FARE told the Committee that the issue of managing the risky consumption of alcohol can be triangulated around price, availability and promotion.<sup>70</sup> Others stated that strategies for general alcohol harm reduction were critical to FASD prevention, and this required changes to the physical availability and price of alcohol.<sup>71</sup>
- 3.128 The following sections consider the pricing, availability, promotion and labelling of alcohol in Australia, and the contribution of these factors to social attitudes and behaviours around alcohol consumption.

### Pricing and availability

- 3.129 There is a volume of research on the harms of the misuse of alcohol, the associated social and economic costs of these harms, and the effect of pricing on consumption patterns when combined with a culture of heavy drinking.
- 3.130 Amongst the research providing detailed empirical evidence linking price changes to alcohol harm reduction is the 2009 World Health Organization (WHO) paper *Evidence for the Effectiveness and Cost-effectiveness of Interventions to reduce Alcohol-related Harm* which states that:
- There is indisputable evidence that the price of alcohol matters. If the price of alcohol goes up, alcohol-related harm goes down. Younger drinkers are affected by price, and heavy drinkers are more affected than light drinkers; in fact, if a minimum price were established per gram of alcohol, light drinkers would hardly be affected at all.<sup>72</sup>
- 3.131 Further, many submitters to the inquiry provided evidence as to the benefits of price increases on reducing excessive drinking patterns and

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70 M Thorn, FARE, *Committee Hansard*, Canberra, 31 May 2012, p. 7.

71 For example see, McCusker Centre for Action on Alcohol and Youth (McCusker Centre), *Submission 30*, p. 4; National Drug Research Institute, *Submission 20*, p. 2; Australian Children's Commissioners and Guardians, *Submission 62*, p. 6; NAAA, *Submission 26c*, p. 2.

72 World Health Organisation Regional Office for Europe, *Evidence for the effectiveness and cost-effectiveness of interventions to reduce alcohol-related harm*, 2009, p. 8.

fostering a more informed and responsible attitude to alcohol consumption.

- 3.132 For example, the NAAA cited international scientific evidence which consistently shows that alcohol consumption and harm are influenced by price.<sup>73</sup>
- 3.133 Todd Harper from the NAAA stated that there is good modelling to suggest that a 10 per cent increase in pricing leads to a 5 per cent decrease in consumption.<sup>74</sup>
- 3.134 The Western Australia Drug and Alcohol Office referred to research that shows women are more likely to reduce their alcohol consumption due to price increases than men. This suggests that increasing the price of alcohol may be amongst effective measures for reducing drinking by pregnant women.<sup>75</sup>
- 3.135 Some submitters argued that price increases unfairly target responsible drinkers and do not impact on risky drinking behaviours. The WFA contend that the abuse of alcohol by high risk consumers does not change as price goes up. They suggested that while overall national alcohol consumption may decrease with price changes, those consumers who represent the high end users have an 'inelastic demand' for alcohol.<sup>76</sup>
- 3.136 Similarly, the Australian Hotels Association Western Australia (AHAWA) argued that pricing measures may punish the overwhelming majority of Australians who consume alcohol in a way which does not impose risks for themselves or others. They noted that increases in pricing may force some at-risk drinkers from the market but does not address the key issue at hand.<sup>77</sup>
- 3.137 These claims have been disputed by a number of independent studies and reports. For example Professor Ian Webster provided evidence from Canadian studies on the effectiveness of minimum pricing. These studies showed that the consumption of alcohol across all groups fell when the minimum price was increased, contradicting the position taken by the alcohol industry that those who are heavy drinkers are not affected by pricing policies.<sup>78</sup>

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73 NAAA, *Submission 26c*, p. 2.

74 T Harper, Co-Chair, NAAA, *Committee Hansard*, Melbourne, 22 June 2012, p. 16.

75 Western Australia Department of Health, Drug and Alcohol Office, *Submission 28*, p. 2.

76 A Wilsmore, General Manager, Policy and Government Affairs, WFA, *Committee Hansard*, Canberra, 24 May 2012, p. 6.

77 Australian Hotels Association Western Australia (AHAWA), *Submission 76*, p. 19.

78 Professor I Webster, Patron, Alcohol and other Drugs Council of Australia, *Committee Hansard*, Canberra, 31 May 2012, p. 12.



- 3.138 These results are consistent with those published by the WHO<sup>79</sup> and by research commissioned by FARE<sup>80</sup>.
- 3.139 Recognising the impact of pricing, the Commonwealth Government has tasked ANPHA with developing the concept of a public interest case for a minimum (floor) price of alcohol, 'to discourage harmful levels of consumption and promote safer consumption.'<sup>81</sup> The final report is due in December 2012.
- 3.140 Several submitters raised the need for reviewing approaches to pricing, and in particular questioned the current tax and excise regime and the alcohol pricing inequities it creates.
- 3.141 Currently, wine is subject to a tax while other forms of alcoholic beverages incur an excise. The tax on wine (known as the Wine Equalisation Tax) is calculated based on wholesale value. In contrast, in most instances excise is based on the proportion of alcohol content, and varies across beverage type. Beer is subject to a different excise calculation again.
- 2.1 These variations result in cheaper wine attracting less tax and in some cases alcoholic beverages are cheaper than bottled water or milk. A number of submitters expressed concern at the impact of this pricing structure.<sup>82</sup>
- 2.2 A volumetric approach to pricing alcohol would resolve these inequities, as outlined in the FARE commissioned report:
- Alcohol taxation reform would improve the efficiency of the Australian taxation system and improve the resource allocation efficiency by removing current distortions in favour of cheap wine. AS recommended by the Henry Tax Review, this involves shifting all alcohol taxation to a volumetric basis. Importantly an increase in alcohol taxation would reduce consumption and the associated adverse externalities.<sup>83</sup>

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79 World Health Organisation Regional Office for Europe, *Evidence for the effectiveness and cost-effectiveness of interventions to reduce alcohol-related harm*, 2009.

80 FARE, *Bingeing, collateral damage and the benefits and costs of taxing alcohol rationally*, October 2012.

81 ANPHA, *Exploring the Public Interest Case for a Minimum (Floor) Price for Alcohol*, <<http://www.anpha.gov.au/internet/anpha/publishing.nsf/Content/min-floor-price-alc>> viewed 12 November 2012.

82 See for example Professor T Chikritzhs, McCusker Centre, *Committee Hansard*, Perth, 10 July 2012, p. 12.

83 FARE, *Bingeing, collateral damage and the benefits and costs of taxing alcohol rationally*, October 2012, p. iv.

3.142 The report also notes that:

Ideally, a full and comprehensive assessment of alcohol taxation reform needs to be multi-faceted and examine the benefits, costs and their distribution of each major component including:

- The reduction in direct externalities (i.e., direct harms to others);
- The reduction in indirect externalities including the cost of health harms to drinkers subsidised/paid for by others via Australia's tax, welfare and health systems;
- The correction of private consumption decisions which are ill-informed, irrational or not based on the full incremental costs of the drinking decision;
- Changes in tax efficiency; and
- Changes in the efficiency of resource allocation, recognising the short-term disruption to business and suppliers.<sup>84</sup>

3.143 In addition to sale pricing reforms, several witnesses noted the increased number of alcohol retail outlets and the expansion of venues at which alcohol is sold. An increase in lower priced alcoholic beverages over the last few years has been accompanied by an increase in the sale points of alcohol. Many argued that it was not just the cheap access of alcohol but the physical availability of alcohol which must be addressed as part of harm reduction strategies.<sup>85</sup>

3.144 The increased number of sale points for alcohol is caused to a large degree by the deregulation of liquor control laws.<sup>86</sup>

3.145 Liquor licensing laws and regulations in most states and territories have been relaxed over the past decade, due in part to the requirements of National Competition Policy.<sup>87</sup> One result of this has been the increase in the number of new licensed premises in some jurisdictions. For example, the number of outlets in Victoria has increased from around 4 000 to 16 000 from 1986 to 2006.<sup>88</sup>

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84 FARE, *Bingeing, collateral damage and the benefits and costs of taxing alcohol rationally*, October 2012, pp. iv-v.

85 See for example McCusker Centre, *Submission 30*, p. 4; National Drug Research Institute, *Submission 20*, p. 2; Australian Children's Commissioners and Guardians, *Submission 62*, p. 6.

86 NAAA, *Submission 26*, Attachment C: Reducing harm from alcohol – Creating a healthier Australia, p. 5.

87 While not completely deregulated, liquor licensing laws and regulations in most jurisdictions have been relaxed over the past decade, generally coinciding with the required reviews under the National Competition Policy.

88 National Preventative Health Taskforce, *Technical Paper 3: Preventing Alcohol-related harm in Australia: a window of opportunity*, 2009, p. 21. The Victorian liquor licensing data was quoted in the technical paper and sourced from Consumer Affairs Victoria.

- 3.146 In addition, there has been an increase in the numbers of premises with extended trading hours, the numbers of licences to sell packaged liquor and an increased concentration of licences held by just a few businesses.<sup>89</sup>
- 3.147 The Alcohol and Other Drugs Council of Australia detailed the link between outlet density and the increase in violence and assaults.<sup>90</sup> Others proposed that the substantial and wide-ranging effects of liquor stores on alcohol-related harms may have been underestimated in the literature and by policy makers.<sup>91</sup>
- 3.148 The NAAA contend that there is a need for national guidelines on alcohol outlet density and opening hours. They consider there is a lack of cohesive policy guidance among liquor licensing agencies, planning departments and local government over the relationship between alcohol outlet density, opening hours and alcohol-related problems and on how this relationship should inform decision making.<sup>92</sup>

## Promotion

- 3.149 A number of concerns were raised regarding the promotion of alcohol to younger people and the contribution of these strategies to the growing harms of alcohol and the risk of FASD.
- 3.150 The American Medical Association (AMA) has noted the changing communications landscape and the greater exposure to alcohol marketing that occurs across a range of technologies. They note that:
- This is particularly true of young people who use digital technologies and are exposed to alcohol marketing on mobile phones, online video channels, interactive games, and social networks such as Facebook and Twitter. Marketing of alcohol is increasingly sophisticated and multidimensional, integrating online and offline promotions with the sponsorship of music and sporting events, the distribution of branded merchandise, and the proliferation of new alcoholic brands and flavours.
- 3.151 A number of submitters expressed concern at the marketing techniques being employed by some sectors of the alcohol industry.

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89 National Preventative Health Taskforce, *Technical Paper 3: Preventing Alcohol-related harm in Australia: a window of opportunity*, 2009, p. 21.

90 D Templeman, Chief Executive Officer, Alcohol and other Drugs Council of Australia *Committee Hansard*, Canberra, 31 May 2012, p. 8.

91 W Liang and T Chikritzhs, 'Revealing the link between licensed outlets and violence: Counting venues versus measuring alcohol availability', *Drug Alcohol Review*, 2011, vol. 30, pp. 524-535.

92 NAAA, *Submission 26*, p. 5.

3.152 For example, the NAAA referred to the range of products and promotions which are directly designed to appeal to young people.<sup>93</sup>

3.153 The McCusker Centre for Action on Alcohol and Youth (McCusker Centre) expressed apprehension about the growing range of alcohol products which appear to be designed, packaged and promoted specifically for young people and for young females in particular.<sup>94</sup>

They noted a range of promotions where the alcoholic beverage and the associated give-aways appear specifically targeted to teenage girls or young women:

... they taste sweet, they come in a range of bright colours and we have seen examples where lip gloss or nail polish are offered as gifts with purchase.<sup>95</sup>

3.154 As a peak body the AHAWA have adopted a strong position against what it considers to be irresponsible marketing promotions. They stated that retailers offering these types of promotions were in the minority, and emphasised that the AHAWA had raised with the Western Australian government instances where product marketing was inappropriate.<sup>96</sup>

Our very public, strong view is that alcohol is a product of adult choice. It is a drug. It is a drug of adult choice that needs to be regulated and sold responsibly. If we do not sell it responsibly and ensure that we do that in an effective manner, we will ultimately lose the right of the privilege to dispense and sell that product. So we need to take a commercial and responsible approach to it as well as a community and social approach.<sup>97</sup>

3.155 The advertising, marketing and promotion of alcohol are regulated by the Alcohol Beverages Advertising Code. This is a quasi-regulatory system for alcohol advertising whereby guidelines for advertising have been negotiated with government, consumer complaints are handled independently, but all costs are borne by industry.

3.156 It would appear this regulatory approach has not kept pace with the options for alcohol marketing across new technologies. This is concerning, given that marketing across new technologies and social media can target a younger audience.

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93 NAAA, *Submission 26*, p. 7.

94 J Stafford, Executive Officer, McCusker Centre, *Committee Hansard*, Perth, 10 July 2012, p. 11.

95 McCusker Centre, *Submission 30*, p. 3.

96 B Woods, Chief Executive Officer/Executive Director, AHAWA, *Committee Hansard*, Perth, 10 July 2012, p. 40.

97 B Woods, AHAWA, *Committee Hansard*, Perth, 10 July 2012, p. 40.

- 3.157 In September 2012 the AMA conducted a national summit on alcohol marketing to young people. The AMA summit featured public health and non-government organisations, law enforcement bodies, youth associations and experts in alcohol and leading academics and researchers in the field.
- 3.158 The AMA summit recognised the emergence of new technologies and how these were being utilised in new forms of marketing techniques that may not be adequately covered by existing regulations. It concluded that there were significant issues with how alcohol is marketed to young people, across traditional advertising forms as well as newer digital technologies and social media. In relation to the regulatory approach to alcohol advertising, it found that:
- The current policy regime is totally inadequate in protecting young people from continued exposure to alcohol marketing. Industry self-regulation is deeply ineffective and has failed. It is time for a robust regulatory response that is independently and impartially applied, and which carries the force of meaningful sanctions.<sup>98</sup>
- 3.159 A key outcome of the AMA summit was the recommendation for an analysis of alcohol advertising and promotion directed at children and teenagers. The Summit found that a comprehensive inquiry into the marketing and promotion of alcohol should:
- include a substantial focus on marketing techniques in digital platforms and in new and emerging social media, and the extent to which these platforms and media are targeted;
  - include a focus on alcohol industry sponsorship of sporting and youth cultural and music events and alcohol promotion targeting tertiary education students; and
  - use its powers to require leading alcohol companies and their communications agencies to table their annual expenditure, and to provide research and planning documents on alcohol promotion and marketing.<sup>99</sup>

## Labelling

- 3.160 The issue of advisory or warning labels on alcoholic beverages was raised by a number of witnesses and the topic continues to attract media
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98 Australian Medical Association (AMA), *Communique - National Summit on Alcohol Marketing to Young People*, 19 September 2012 <<https://ama.com.au/media/communique-national-summit-alcohol-marketing-young-people>> viewed 8 November 2012.

99 AMA, *Communique - National Summit on Alcohol Marketing to Young People*, 19 September 2012 <<https://ama.com.au/media/communique-national-summit-alcohol-marketing-young-people>> viewed 8 November 2012.

attention.<sup>100</sup> Industry advocates cited the success of the voluntary scheme currently in place and disputed the need for a mandatory approach to warning labels.

- 3.161 Others disputed this claim and provided detailed research on the importance of warning labels as a public education tool targeting not just FASD prevention, but a range of alcohol related health consequences.

### Current voluntary labelling initiatives

- 3.162 In the 2011 review of food labels, *Labelling Logic: Review of Food Labelling Law and Policy (2011)* (the Blewett Report), four key recommendations were made to the Commonwealth Government concerning alcoholic beverage labelling and packaging. This included the following two recommendations:

- Recommendation 24: That generic alcohol warning messages be placed on alcohol labels but only as an element of a comprehensive multifaceted national campaign targeting the public health problems of alcohol in society.
- Recommendation 25: That a suitably worded warning message about the risks of consuming alcohol while pregnant be mandated on individual containers of alcoholic beverages and at the point of sale for unpackaged alcoholic beverages, as support for ongoing broader community education.<sup>101</sup>

- 3.163 The Legislative and Governance Forum on Food Regulation (the Forum), which comprises of Ministers from the Commonwealth, States and Territories and New Zealand, agreed that warnings about the risks of consuming alcohol while pregnant should be pursued.
- 3.164 The Forum noted the voluntary steps that industry had taken in this area and gave industry the opportunity to introduce appropriate labelling on a voluntary basis for a period of two years before deterring whether to regulate for this change.<sup>102</sup>
- 3.165 The voluntary labelling period commenced in late 2011 and is to last for two years. Some parts of the industry claimed a wide uptake of the labels. The Distilled Spirits Industry Council of Australia (DSICA) told the

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100 See for example, M Davey, 'Drink labels don't deter, study finds', *Sydney Morning Herald*, 10 November 2012, and M Metherell, 'Promised alcohol warning labels barely visible or missing completely', *Sydney Morning Herald*, 2 August 2012.

101 DoHA, *Labelling Logic: Review of Food Labelling Law and Policy*, pp. 80-82.

102 ANPHA, *Submission 45*, p. 14.

- Committee that they were anticipating approximately 75 per cent of their members' containers to be labelled by the end of 2013.<sup>103</sup>
- 3.166 However, an independent audit of the DrinkWise Australia warning labels has found that a full year after the voluntary initiative was launched, fewer than one in six (or 16 per cent) of alcohol products carry the consumer information messages.<sup>104</sup>
- 3.167 Currently there is a range of different symbols, advisory labels and warning labels that can appear on alcoholic beverages. There is no direction as to the size, colouring, positioning or prominence of the labels. These decisions are at the discretion of the manufacturer. The labels or icons appear on the beverage container itself and not on any associated packaging or promotional material or advertising of the beverage.
- 3.168 A number of the symbols and labels have been developed by DrinkWise Australia, a not-for-profit organisation which describes itself as being focused on promoting change towards a healthier and safer drinking culture in Australia. The alcohol producers who contribute to DrinkWise Australia account for approximately 80 per cent of all alcohol sales by volume in Australia.<sup>105</sup>
- 3.169 Some voluntary labels refer people to the DrinkWise Australia website which provides information on topics such as:
- Kids and Alcohol Don't Mix;
  - Is Your Drinking Harming Yourself or Others?; and
  - It is Safest Not to Drink While Pregnant.<sup>106</sup>
- 3.170 The WFA, the Brewers Association of Australia and the DSICA indicated their support for the work of DrinkWise Australia and the voluntary approach to labelling.<sup>107</sup>
- 3.171 While supportive of warning labels on alcoholic beverages, most submitters to the inquiry were critical of the voluntary labelling scheme. Generally it was regarded as having a low uptake and featuring labels that were largely hidden from sight and designed for minimum exposure.

103 S Riden, Manager, Information and Research, Distilled Spirits Industry Council of Australia (DSICA), *Committee Hansard*, Canberra, 24 May 2012, p. 4.

104 IPSOS Social Research, *Alcohol Label Audit – prepared for the Foundation for Alcohol Research and Education*, 2012, p. 11.

105 DrinkWise Australia, <[www.drinkwise.org](http://www.drinkwise.org)>, viewed 9 October 2012.

106 DrinkWise Australia, *DrinkWise Labels on Alcohol Products and Packaging*, <<http://www.drinkwise.org.au/our-work/get-the-facts-labelling-initiative/>> viewed 29 August 2012.

107 A Wilsmore, WFA, *Committee Hansard*, Canberra, 24 May 2012, p. 1; D Wawn, Chief Executive Officer, Brewers Association of Australia and New Zealand, *Committee Hansard*, Canberra, 24 May 2012, p. 4; G Broderick, DSICA, *Committee Hansard*, Canberra, 24 May 2012, p. 8.

- 3.172 The Department of Health and Human Services, Tasmania asserted that many academics and experts in the Public Health and alcohol and other drugs field consider these industry warnings weak in the messages they portray around alcohol.<sup>108</sup>
- 3.173 Even DrinkWise Australia refer to the labels as consumer information messages, rather than warnings. Further, the most commonly occurring DrinkWise Australia message is the innocuous and uninformative slogan ‘Get the facts – visit DrinkWise.org.au’.
- 3.174 A May 2012 research paper into alcohol warning labels provides a comprehensive review of responses to the DrinkWise Australia labelling from leading researchers across a range of fields. It provides an extensive analysis of the failings of the DrinkWise Australia labels and concludes that:
- If alcohol warning labels are to have any chance of spurring positive changes in drinking behaviours, then the messages they convey need to be, firstly, arresting (similar to tobacco warning labels) and, secondly, varied reasonably frequently. It is debatable whether the DrinkWise Australia consumer information messages meet the first of these criteria.<sup>109</sup>
- 3.175 Similarly a FARE commissioned survey found the DrinkWise Australia labels to be lacking and the voluntary scheme to be ineffective. Participants in the survey were asked to select the best labels from DrinkWise Australia and FARE against a set of criteria including:
- noticeability;
  - comprehensibility of the message;
  - capacity to raise awareness and prompt conversations about alcohol-related harms; and
  - impact on alcohol consumption.<sup>110</sup>
- 3.176 It was found most DrinkWise Australia messages have low visibility, with 98 per cent of the messages taking up less than 5 per cent of the label or face of the packaging.<sup>111</sup> The FARE developed labels were considered superior on all measures. Figures 3.3 and 3.4 provide examples of the labels from DrinkWise Australia and FARE.

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108 Tasmanian Department of Health and Human Services, *Submission 6*, p. 4.

109 M Thomas, *Alcohol warning labels – do they work?*, Australian Parliamentary Library, May 2012, <[http://www.aph.gov.au/About\\_Parliament/Parliamentary\\_Departments/Parliamentary\\_Library/pubs/BN/2011-2012/AlcoholLabels](http://www.aph.gov.au/About_Parliament/Parliamentary_Departments/Parliamentary_Library/pubs/BN/2011-2012/AlcoholLabels)> viewed 22 November 2012.

110 FARE, ‘Research shows industry regulated alcohol labels won’t work’, *Media Release*, 30 November 2011.

111 IPSOS Social Research, *Alcohol Label Audit – prepared for the Foundation for Alcohol Research and Education*, 2012, p. 18.



Figure 3.3 DrinkWise Australia consumer information label



Source Foundation for Alcohol Research and Education, *Alcohol Health Labelling: Community perceptions of the FARE and DrinkWise model alcohol labels*, 2011, p. 11.

Figure 3.4 FARE health warning labels



Source Foundation for Alcohol Research and Education, *Alcohol Health Labelling: Community perceptions of the FARE and DrinkWise model alcohol labels*, 2011, p. 13.

- 3.177 FARE has criticised the format of the voluntary labels in use, claiming they are ambiguous, contain a weak message, and are small in size and difficult to locate on the alcohol product. As the labels are voluntary, FARE notes there is no certainty that all alcohol producers will adopt these labels.<sup>112</sup>

### Mandating health warnings

- 3.178 Various representatives from the alcohol industry claimed that there is no evidence to demonstrate that warning labels on alcohol beverages are effective.
- 3.179 Gordon Broderick from DSICA stated that an extensive survey of the situation in America shows that labelling has raised awareness but has not made any impact on behaviour.<sup>113</sup>
- 3.180 The Wine Research Institute of Australia supported this by citing the results of studies undertaken after the introduction of alcohol warning labels in the US. These showed an increase in awareness of the label but did not show changed consumer behaviour particularly in 'at risk' groups.<sup>114</sup>
- 3.181 The WFA and the DSICA suggested that warning of the dangers associated with alcohol during pregnancy has the potential to alienate and worry women who may be at very low risk.<sup>115</sup> The WFA raised concerns that advisory labels such as those prepared by FARE could negatively impact on pregnant women and stated that:
- There is also the possibility of some pregnancies ending in termination before actual harmful effects of alcohol have been adequately assessed. Some expectant mothers may be so concerned or in such a state of depression and guilt as to terminate the pregnancy based on their expectation that the foetus has been damaged.<sup>116</sup>
- 3.182 WFA's claims of possible negative effects of warning labels resulting in terminations or pregnant women experiencing undue anxiety and guilt are based on anecdotal stories, and misrepresentation of some media commentary.<sup>117</sup> Further, graphic warnings indicating the harm caused by tobacco to the developing fetus have not ceased due to any claimed

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112 FARE, *Submission 36*, p. 14.

113 G Broderick, Executive Director, DSICA, *Committee Hansard*, Canberra, 24 May 2012, p. 3.

114 The Wine Research Institute of Australia, *Submission 12*, p. 14.

115 WFA, *Submission 39*, p. 11; S Riden, DSICA, *Committee Hansard*, Canberra, 24 May 2012, p. 10.

116 WFA, *Submission 39*, p. 11.

117 FARE, *Booze before babies – Analysis of alcohol industry submissions to the FASD Inquiry*, 2012, p. 10.

anxiety caused to pregnant women or claims of terminations due to fears caused by warnings.

3.183 The DSICA expressed concern that labelling could go too far:

... if there were to be mandatory labelling, those people who oppose the industry would want to go down the tobacco road. The lettering would not be big enough; the wording would not be big enough; the pictures would not be horrific enough; and before we know it we would have our labels looking like a bottle of angostura bitters or a page out of the white telephone book.<sup>118</sup>

3.184 The Committee notes that each of these claims against mandated warning labels claims has been clearly refuted and substantial evidence cited to the contrary in FARE's detailed paper 'Booze before Babies – Analysis of alcohol industry submissions to the FASD inquiry'. The FARE paper cites international moves to regulate warning labels in Europe and acknowledgement by the United Kingdom Department of Health that ten years of self-regulation has not resulted in an effective labelling program.<sup>119</sup>

3.185 Alcohol industry advocates claim that warning labels are ineffective in changing behaviours. International and FARE research finds that the limited alcohol warnings of the type favoured by industry are indeed weak and ineffective.

3.186 Contrasting this, FARE cite substantial evidence confirming the effectiveness of warning regimes when that regime is based on best practice principles.<sup>120</sup> According to this research, health warning labels can create behaviour change and the labels should:

- be mandatory so the label appears on all products
- be applied consistently across all products so they are visible and recognisable
- be developed by health behaviour and public health experts
- include the text 'HEALTH WARNING'
- involve rotating messages on a range of harms, including during pregnancy and
- be accompanied by a national public education campaign.<sup>121</sup>

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118 G Broderick, DSICA, *Committee Hansard*, Canberra, 24 May 2012, p. 3.

119 FARE, *Booze before babies – Analysis of alcohol industry submissions to the FASD Inquiry*, 2012, p. 8.

120 FARE, *Booze before babies – Analysis of alcohol industry submissions to the FASD Inquiry*, 2012, pp. 12, 14.

121 FARE, *Submission 36*, p. 15.

- 3.187 Similarly, a wealth of research confirming the effectiveness of warning labels as part of an broader alcohol health campaign is reviewed in the Parliamentary library paper 'Alcohol Warning Labels – do they work?'.<sup>122</sup>
- 3.188 The evidence reviewed in these papers is consistent with further evidence provided by a number of other submitters, and finds warning labels effective in raising awareness and changing consumption patterns.
- 3.189 The Uniting Church in Australia stated that a comprehensive review of the effects of alcohol warning labels concluded the use of warning labels did raise awareness.<sup>123</sup>
- 3.190 The McCusker Centre provided evidence that multiple expert groups have recommended health warning labelling of alcohol products with clear, specific messages as an important component within a wider strategy to raising awareness of the risks to health of alcohol consumption. Warning labels related to the risks of alcohol consumption during pregnancy have been specifically recommended as part of this approach.<sup>124</sup>
- 3.191 The Women's Christian Temperance Union made the point that poisons are labelled and prescription drugs have leaflets explaining their effects and possible side effects. They stated that the public has the right to the latest information regarding alcohol and the health of a developing fetus.<sup>125</sup>
- 3.192 The AMA advocates that:
- Alcohol products should have simple and clearly visible front-of-pack labels that warn of health risks of excessive consumption, and urge pregnant women not to consume alcohol.<sup>126</sup>
- 3.193 The Tasmanian Department of Health and Human Services considers that mandatory labelling of alcohol with generic health warnings and specific pregnancy warning messages is urgently needed. They believe that this will help to change the perceptions of the community about alcohol and ensure that alcohol is not considered an 'ordinary' household product.<sup>127</sup>
- 3.194 NAAA considers that it is not appropriate to leave policy development in this vital area to the alcohol industry. They advocate Government

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122 M Thomas, *Alcohol warning labels – do they work?*, Australian Parliamentary Library, May 2012, <[http://www.aph.gov.au/About\\_Parliament/Parliamentary\\_Departments/Parliamentary\\_Library/pubs/BN/2011-2012/AlcoholLabels](http://www.aph.gov.au/About_Parliament/Parliamentary_Departments/Parliamentary_Library/pubs/BN/2011-2012/AlcoholLabels)> viewed 22 November 2012.

123 Uniting Church in Australia, *Submission 21*, p. 2.

124 McCusker Centre, *Submission 30*, p. 5.

125 Women's Christian Temperance Union, *Submission 17*, p. 1.

126 AMA, *Alcohol Consumption and Alcohol-Related Harms – AMA Position Statement*, 2012, p. 3.

127 Tasmanian Department of Health and Human Services, *Submission 6*, p. 3.

adopting the recommendations from the Blewett Report and the many other expert reports which support warning labels.<sup>128</sup>

- 3.195 Along with others, NAAA argues it is critical that any implementation of health warning labels is accompanied by a comprehensive public education campaign, using various forms of media to reinforce the messages of the health warning labels.<sup>129</sup>

### Committee Comment

- 3.196 It is the view of this Committee, informed by experts and the response of the alcohol industry itself, that current regulation and voluntary programs regarding alcohol labelling are not functioning effectively and are unlikely to ever do so given the commercial realities of the alcohol industry.
- 3.197 Consequently the Commonwealth Government must mandate greater controls to ensure responsible attitudes to alcohol labelling and sales, and mechanisms to reduce the easy access to alcohol that promotes harmful levels of drinking.
- 3.198 In particular, the issue of warning labels on alcoholic beverages advising women not to drink while pregnant was a contentious one through the inquiry.
- 3.199 The Committee was frustrated by some within the alcohol industry. While claiming to support responsible marketing and sales of alcohol, some industry advocates provided widely inflammatory and unfounded claims to the Committee.
- 3.200 The Committee considers that Australians have a right to be fully informed around the impact of choices they make to consume alcohol and it is the role of governments to employ a range of mechanisms to ensure public health messages are widely disseminated.
- 3.201 Research indicates a low level of public awareness regarding the risks posed by prenatal exposure to alcohol. Providing warnings on alcohol products is an essential step in raising awareness amongst women, and fostering community support for women's decision to not drink while pregnant.
- 3.202 While some parts of the alcohol industry claim to support labels advising women not to drink while pregnant, the Committee notes that large sectors of the industry have not adopted the voluntary labelling scheme. Furthermore, in many instances where a warning icon is present on the

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128 NAAA, *Submission 26*, p. 6.

129 NAAA, *Submission 26*, Attachment A: Alcohol Product Labelling: Health Warning Labels and Consumer Information, p. 3.

label, the icon is small, in faint colours, and placed in the least visible part of a label. Some labels took up less than 0.1 per cent of the container's surface area.

- 3.203 The Committee disputes wild claims made by some in the alcohol industry about early terminations due to women's fears of having consumed alcohol while pregnant. There is no credible evidence to support such claims.
- 3.204 Conversely, there is a volume of credible evidence to indicate that health warnings on alcohol containers are effective as part of a wider strategy to raise awareness and enable people to make informed choices around their consumption patterns.
- 3.205 Recognising the range of harms that can be attributed to alcohol, the Committee recommends that a comprehensive warning label regime reflect this range of harms. FASD disabling babies is just one serious consequence of irresponsible alcohol consumption. In addition, there are a range of other health consequences and social harms which may be attributed to alcohol and patterns of alcohol consumption. Further, best practice research indicates that a rotating range of health warnings are more effective in raising awareness.
- 3.206 The Committee recommends that the appropriate format and design of health warning labels be determined by 1 March 2013. This will enable the alcohol industry to be fully prepared for the implementation of mandated health warning labels by 1 January 2014. The introduction of the labelling scheme should be accompanied by a comprehensive public awareness campaign.

## **Recommendation 10**

**The Committee recommends that the Commonwealth Government seek to include health warning labels for alcoholic beverages, including a warning label that advises women not to drink when pregnant or when planning a pregnancy, on the Legislative and Governance Forum on Food Regulation's December agenda.**

**The Commonwealth Government should determine the appropriate format and design of the labels by 1 March 2013, to assist the alcohol industry in adopting best practice principles and preparing for mandatory implementation.**

## **Recommendation 11**

- 3.207 **The Committee recommends that the Commonwealth Government mandate the range of health warning labels for alcoholic beverages as decided by the Legislative and Governance Forum on Food Regulation.**
- **The warning labels should consist of text and a symbol and should be required to be displayed on all alcohol products, advertising and packaging by 1 January 2014;**
  - **The minimum size, position and content of all health warning labels should be regulated; and**
  - **The introduction of mandated warning labels should be accompanied by a comprehensive public awareness campaign.**
- 3.208 Anecdotal evidence was received regarding trends to mix high caffeine drinks with alcohol, sales of alcohol to under-age drinkers and service of alcohol to intoxicated customers. The range of harms caused across the community from binge drinking amongst young people and other forms irresponsible alcohol consumption is concerning and must be addressed.
- 3.209 A review of regimes around the availability, pricing and promotion of alcohol is essential to reduce the wider harms of alcohol as well as to eliminate FASD in Australia.
- 3.210 A more comprehensive review of this nature is beyond the capacity of this Committee and the scope of the inquiry terms of reference. While actions to eliminate FASD in our population must commence immediately, studies on broader alcohol reform are needed and appropriate regulatory responses developed.
- 3.211 It is the clear view of this Committee that widespread reforms are required to address the harms of irresponsible alcohol consumption and that these reforms are best achieved through public information accompanied by appropriate controls on alcohol pricing, availability and marketing.
- 3.212 Accordingly, the Committee recommends that two independent studies are commissioned by the Commonwealth Government, and that the findings of these studies are used to inform a National Alcohol Sales Reform Plan.
- 3.213 The first study should consider how the availability and pricing of alcohol is contributing to changes in alcohol consumption patterns across different sectors of the population and in different regions. The Committee notes that ANPHA is reporting on a minimum pricing of alcohol, and the study should take this work into account.

- 3.214 The second study should consider marketing strategies for alcohol. The Committee is concerned that changes in technology may be enabling forms of alcohol advertising and promotion that are not addressed by existing regulations. The Committee recommends a study into current alcohol marketing strategies, with a focus on the marketing of alcohol to young people through the use of new technologies.
- 3.215 In addition, this study should focus on the relationships and impact of linking on the sport sponsorship and success with alcohol consumption.
- 3.216 These two studies should provide the platform for the Commonwealth Government to develop a National Alcohol Sales Reform Plan. These reforms, while part of a broader plan to reduce harms of alcohol, will form a critical element in the national FASD prevention strategy.

### **Recommendation 12**

- 3.217 **The Committee recommends that the Commonwealth Government commission an independent study into the impacts of the pricing and availability of alcohol and the influence of these factors in the changing patterns of alcohol consumption across age groups and gender.**

**The study should be completed by 1 October 2013.**

### **Recommendation 13**

- 3.218 **The Committee recommends that the Commonwealth Government commission an independent study into the impacts and appropriateness of current alcohol marketing strategies directed to young people. The study should have regard to these strategies and the volume and frequency of alcohol consumption amongst young people, the links being made between alcohol and sport, the efficacy of efforts to promote responsible drinking behaviours, and the adequacy of current regulations to respond to marketing through digital platforms such as the internet, social media and smartphones.**

**The study should be completed by 1 October 2013.**



**Recommendation 14**

- 3.219 **The Committee recommends that, following the completion of the study into the pricing and availability of alcohol and the study into alcohol marketing strategies, the Commonwealth Government develop a National Alcohol Sales Reform Plan aimed at reducing the harms caused by irresponsible alcohol consumption across Australia.**

## Diagnosis

- 4.1 This chapter discusses some of the obstacles to improving the diagnosis and management of Fetal Alcohol Spectrum Disorders (FASD) in Australia.
- 4.2 Early intervention is a critical factor in ameliorating both the primary and secondary symptoms of FASD, therefore the ability to recognise and diagnose FASD at a young age is important. In cases where prenatal alcohol exposure has occurred, all instances of FASD need to be diagnosed.
- 4.3 Currently there are a number of obstacles to comprehensive FASD diagnosis. The chapter addresses how perceived stigma, limited understanding and capacity of some health professionals, the complexity of FASD, and the lack of a national diagnostic tool and diagnostic clinics hinder the opportunities for a person with FASD to be diagnosed accurately.
- 4.4 It is also essential that therapeutic intervention services are properly-funded and available to all who have been disabled by fetal alcohol exposure. At present, the training and capacity of general practitioners, paediatricians and allied health professionals to manage FASD is limited.

### **Critical importance of early diagnosis and intervention**

- 4.5 It is of critical importance that FASD is diagnosed as early as possible to enable the individual to receive the accurate intervention and

understanding. A foster carer warned that ‘failure to recognise, diagnose and understand this disorder has huge ramifications for all society’.<sup>1</sup>

4.6 Without an accurate diagnosis, the problems exhibited by individuals with FASD may be misunderstood as a different condition. This can result in the incorrect treatment or patient care and increase the risk of developing secondary conditions.<sup>2</sup>

4.7 A number of carers and people involved in child protection confirmed to the Committee the cost of delayed or incorrect diagnosis. Barbara Smith explained that:

Instead of understanding the child and catering for their [FASD] needs these children were given little appropriate support. Now as adults they have dropped out of school, suffered relationship difficulties, homelessness, mental health issues, antisocial behaviour and unemployment. With recognition and appropriate intervention they may have achieved much more.<sup>3</sup>

4.8 Prue Walker stated that:

Without an understanding of FASD, interventions are likely to be counter-productive as the young person engages in a service system which promotes a model of increasing self reliance and independence, a goal which is not often appropriate for a young person with a lifelong brain-based condition that impairs judgement and decision making.<sup>4</sup>

4.9 Anne Russell’s work with the Russell Family Fetal Alcohol Disorders Association (RFFADA) involves educating people about FASD and the importance of early intervention. She stated that:

Early intervention has been shown to make a huge difference in the life of a child with FASD, so we need early diagnosis, early intervention and understanding by all the people around that person that their brain works differently. Among the things that really make a negative difference to a person with FASD are the expectations of other people. The expectations of somebody who does not look different and who, on the surface, can talk quite well are that they can do what everybody else can do when in fact they cannot, so their experience of the world from when they are young is failure after failure. Consequently – though this is not the only

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

2 A E Chudley et al, ‘Fetal Alcohol Spectrum Disorder: Canadian guidelines for diagnosis,’ *Canadian Medical Association Journal*, vol. 172 (5 suppl), March 2005, p. S2.

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

4 P Walker, *Submission 29*, p. 9.

reason – they are drawn to criminal activities, because that is a place where they belong. So early intervention can prevent an awful lot and save an awful lot of money down the track.<sup>5</sup>

- 4.10 Upon finally having FASD confirmed for her daughter on a trip to Canada, Sue Miers said:

I was, of course, relieved to learn that my daughter's developmental and behavioural problems were most likely based in organic brain damage rather than being intentional or the result of my poor parenting, which I was beginning to feel at that stage. I also felt a great sadness as I realised the frustration she must have experienced during a lifetime of failure, being told to do better when in reality she was unable to do so. She was being the best she could be, despite school reports to the contrary. I realised my expectations of her would have to change dramatically, and I realised what a difference it could have made to her life if I had had that knowledge during her formative years. I grieved for her lost potential and opportunity, and wondered why I had had to travel to Canada to get information and support that should have been available in Australia.<sup>6</sup>

- 4.11 Prue Walker noted that young people with FASD who did not receive the appropriate management are 'likely to enter the care system as an angry, confused young adult who has had negative experiences at school, at home and among peers'.<sup>7</sup>

- 4.12 Although FASD cannot be cured, there is overwhelming evidence that accurate, early diagnosis, followed by appropriate intervention, can be successful in achieving better outcomes for children with FASD, as 'some symptoms can be remediated partially through early intervention'.<sup>8</sup>

- 4.13 Barnardos discussed a foster child who has benefited enormously from early diagnosis and management:

Because she got that diagnosed at a really young age, at 13 months, there was a lot of intervention put in place with speech therapy, occupational therapy, physiotherapy and regular paediatric reviews. That has assisted her to make enormous gains. She is now sort of functioning at a level where there are still some

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5 A Russell, Executive Officer, The Russell Family Fetal Alcohol Disorders Association (RFFADA), *Committee Hansard*, Cairns, 31 July 2012, p. 5.

6 S Miers, Chair, National Organisation for Fetal Alcohol Syndrome and Related Disorders (NOFASARD), *Committee Hansard*, Melbourne, 22 June 2012, p. 18.

7 P Walker, *Submission 29*, p. 9.

8 Australian National Preventative Health Agency (ANPHA), *Submission 45*, p. 3.

issues with her speech and language and she does present with behaviours that you would associate with [Attention Deficit Hyperactivity Disorder] but we have got huge hope for her prospects for the future and the possibility of adoption down the track for her with her permanent foster carers.<sup>9</sup>

- 4.14 UnitingCare offers an Intensive Playgroup that provides important skills for children with FASD who might not fit in at school:
- ... it addresses some of the issues for young children, like being able to share, to sit in a room with other children, to play, to listen, to read and to sing. These are the sorts of behaviours that make these kids, when they start kindergarten and school, stand out already as being the problem kids.<sup>10</sup>
- 4.15 Moreover, early intervention may substantially reduce the risk and impact of secondary social, emotional and behavioural difficulties.<sup>11</sup> Sue Miers regrets that her 'daughter's diagnosis came too late to give us the knowledge we needed that may have helped prevent the many secondary disabilities she has since experienced'.<sup>12</sup>
- 4.16 Screening for mothers and children at risk can detect FASD at an early stage and improve the chances of individuals with FASD receiving early intervention.
- 4.17 The Royal Australasian College of Physicians (RACP) recommended screening for all children who come into contact with an obstetric drug dependency service, child protection service, or the criminal justice system.<sup>13</sup> The Western Australia FASD Working Party proposed direct links between child welfare and early intervention services.<sup>14</sup>
- 4.18 Screening for alcohol consumption could be conducted for all women during pregnancy, and screening of all children at birth and at enrolment

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9 B Hijniakoff, Case Manager, Barnardos, *Committee Hansard*, Sydney, 13 April 2012, p. 28.

10 D J Ribton-Turner, Director, Clinical Services, UnitingCare ReGen, Uniting Church in Australia Synod of Victoria and Tasmania, *Committee Hansard*, Melbourne, 22 June 2012, p. 26.

11 For example see, South Australian Government, *Submission 52*, p. 4; A Russell, RFFADA, *Committee Hansard*, Cairns, 31 January 2012, p. 5; National Council on Intellectual Disability, *Submission 9*, p. 5; Alcohol and other Drugs Council of Australia, *Submission 33*, p. 2; Northern Territory branch of the Public Health Association of Australia, *Submission 73*, p. 2; Foundation for Alcohol Research and Education/Public Health Association of Australia (FARE/PHAA), *Submission 36*, p. 10; National Rural Health Association (NRHA), *Submission 40*, p. 15; NOFASARD, *Submission 46*, p. 11.

12 S Miers, NOFASARD, *Committee Hansard*, Melbourne, 22 June 2012, p. 19.

13 Royal Australasian College of Physicians, *Submission 27*, p. 4.

14 Fetal Alcohol Spectrum Disorders Working Party, Department of Health, Western Australia, *Submission 25*, p. 2.

in school.<sup>15</sup> The National Organisation for Fetal Alcohol Syndrome and Related Disorders (NOFASARD) further suggested that children in child and family centres could be screened.<sup>16</sup>

4.19 John McKenzie noted that:

There is already testing on entry into kindergarten. That should be included so that there is some FASD type of [screening] component to that. Then you move on, to the kids who are in out-of-home care.<sup>17</sup>

## Obstacles to diagnosis

4.20 It cannot be emphasised enough that a diagnosis is crucial to improving the life trajectory of individuals with FASD and their families. NOFASARD stated that 'diagnosis gives visibility, and visibility expands options and leads to solutions'.<sup>18</sup>

4.21 The National Council on Intellectual Disability noted a number of benefits from diagnosing FASD:

- Early diagnosis is a protective factor associated with fewer secondary disabilities;
- Diagnosis assists families and the person with FASD to understand their behaviours in terms of neurological damage, and not that they are wilfully misbehaving;
- A diagnosis helps parents and caregivers set realistic and appropriate expectations for their child;
- Diagnosis can be a dual diagnosis of child and birth mother. The birth mother may be able to receive counselling from this point; and
- Diagnosis of one child may mean successful intervention with the mother to prevent the birth of another child with FASD.<sup>19</sup>

4.22 Dr Raewyn Mutch advised the Committee that the ideal scenario would be a 'broad spectrum of health care' that provides national uniformity of diagnosis, training and management teams.<sup>20</sup>

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15 WA Health, Health Networks Branch (Child and Youth Health Network), *Submission 13*, p. 6.

16 NOFASARD, *Submission 46*, p. 6.

17 J McKenzie, Chief Legal Officer, Aboriginal Legal Service (New South Wales and the Australian Capital Territory), *Committee Hansard*, Sydney, 13 April 2012, p. 21.

18 S Miers, NOFASARD, *Committee Hansard*, Melbourne, 22 June, p. 19.

19 National Council on Intellectual Disability, *Submission 9*, pp. 6-7.

20 Dr R Mutch, Telethon Institute for Child Health Research (Telethon Institute), *Committee Hansard*, Perth, 10 July 2012, p. 23.

- 4.23 Unfortunately, the Committee heard that there are many obstacles to obtaining a diagnosis in Australia. These include the stigma attached to acknowledging maternal alcohol consumption; low level of knowledge among health professionals; the scope and complexity of the FASD spectrum; lack of a nationally-recognised diagnostic tool; and lack of diagnostic services. This section addresses these obstacles.

## Stigma

- 4.24 The Committee heard that health professionals can be reluctant to consider or diagnose FASD because it is a highly stigmatising label.<sup>21</sup>
- 4.25 Di Harriss stated that such reluctance can have significant implications for children who are then deprived of 'appropriate and effective early interventions in order to maximise the child's potential to address the disabilities, and associated problems'.<sup>22</sup>
- 4.26 A foster carer related his experience with a doctor who was reluctant to discuss FASD:
- Actually, he might have said once, 'Why would you want that diagnosis?' I said, 'Because it would help me know what is wrong with him.' I think it is a bit like HIV. People would say, 'Why would you want your child to be diagnosed?'<sup>23</sup>
- 4.27 Anecdotal evidence suggested a preference for a diagnosis of Attention Deficit/Hyperactivity Disorder, Autism Spectrum Disorder or general developmental delay, even in the case of confirmed prenatal alcohol exposure.<sup>24</sup>
- 4.28 The Australian National Preventive Health Agency considers that better education of health professionals with a focus on prevention rather than cure could help with the stigma. They contend that not having to focus on a particular outcome or condition will enable health professionals to talk about the benefits of reducing harmful alcohol consumption for a whole range of outcomes without having to point the finger at particular children or particular conditions.<sup>25</sup>
- 4.29 Prue Walker, when undertaking her Churchill Fellowship in the US and Canada, found that instead of being stigmatising, diagnosis could be

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21 Dr L Studdert, ANPHA, *Committee Hansard*, Canberra, 15 March, p. 1; Anyinginyi Health Aboriginal Corporation, *Submission 3*, p. 2.

22 D Harriss, *Submission 69*, p. 1.

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

24 Anyinginyi Health Aboriginal Corporation, *Submission 3*, p. 2; Dr Chataway, *Committee Hansard*, Townsville, 31 January 2012, p. 13; R and L Chataway, *Submission 7*, p. 1.

25 Dr L Studdert, ANPHA, *Committee Hansard*, Canberra, 15 March 2012, p. 4.

liberating for families who were struggling to understand and manage their children.<sup>26</sup>

4.30 In contrast, Dr David Hartman registered his concern that FASD could be over diagnosed where it is required to access resources 'because people would, quite rightfully, be seeking out help for their children'.<sup>27</sup>

4.31 Dr Mutch believes that it is possible for the perceived stigma around FASD to be minimised, as it has in the case of ASD:

Autism was perceived as a diagnosis to be feared, I think. Now, in some places, it is a diagnosis that is warmly embraced because it is chased with high-level care and guaranteed aid and education. The stigma has fallen away as support, understanding and research has been provided, and allowing people to have this condition has elevated it to normality not stigma.<sup>28</sup>

4.32 Dr Mutch further predicted that:

... if you allow [FASD] children to be diagnosed and you chase this with appropriate educational support and appropriate therapeutic intervention, you will unlock the legitimacy and the okay for having this diagnosis.<sup>29</sup>

## Current capacity of health professionals to diagnose FASD

4.33 The Telethon Institute for Child Health Research (Telethon Institute) stated that there is good evidence indicating that FASD is poorly recognised in Australia and diagnoses can often be missed or delayed. They attributed this to health professionals' reluctance to ask about alcohol use and lack of knowledge about the clinical indications of FASD.<sup>30</sup>

4.34 NOFASARD provided the Committee with one family's unsuccessful experience with health professionals:

I have an 11 year old adopted son whom I suspect suffers with some form of FASD. I have been from doctor to doctor only to be told by one paediatrician that it was unlikely to be that even after we [told him the child's] birth mother ... admitted to drinking a lot of alcohol during her pregnancy, daily even. I learnt about FASD

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26 P Walker, *To study models of care for children with Foetal Alcohol Syndrome*, 2008, p. 17; Winston Churchill Memorial Trust, <[http://www.churchilltrust.com.au/site\\_media/fellows/Walker\\_Prudence\\_2008.pdf](http://www.churchilltrust.com.au/site_media/fellows/Walker_Prudence_2008.pdf)> viewed 14 August 2012.

27 Dr D Hartman, Consultant Child and Adolescent Psychiatrist, Townsville Child and Youth Mental Health Service, *Committee Hansard*, Townsville, 31 January 2012, p. 20.

28 Dr R Mutch, Telethon Institute, *Committee Hansard*, Perth, 10 July 2012, p. 26.

29 Dr R Mutch, Telethon Institute, *Committee Hansard*, Perth, 10 July 2012, p. 26.

30 Telethon Institute, *Submission 23*, p. 1.



about a couple of years ago and since then have been trying to find a doctor who is aware of this.<sup>31</sup>

- 4.35 The Committee heard from many submitters that there is a need for more FASD training for health professionals. Professor Elizabeth Elliott acknowledged that FASD was not covered in the medical curricula that she studied in the late 1970s, although there was exposure to the condition through paediatric training in hospital.<sup>32</sup> Dr Mutch confirmed that ‘there still is no mandatory teaching of about FASD within medical training at all’.<sup>33</sup>
- 4.36 An Apunipima Cape York Health Council report suggested that FASD should constitute one of the medical training modules for doctors, nurses and Indigenous health workers.<sup>34</sup> In addition to medical school curricula, the Alcohol and other Drugs Council of Australia recommended that FASD be introduced to the training for health professionals working in the alcohol and other drug sector.<sup>35</sup> The RACP recommended:
- ... formal training of a range of health professionals including community nurses, allied health professionals, general practitioners, paediatricians, physicians and psychiatrists to better identify and diagnose FASD and to recognise the needs of the diagnosed individuals.<sup>36</sup>
- 4.37 A Western Australian FASD Prevention Aboriginal Consultation Forum identified a lack of FASD training opportunities and limited resources for regional and non-maternal health environments.<sup>37</sup>
- 4.38 In the Northern Territory, the Child and Adolescent Mental Health Team acknowledged that:
- ... through recent readings, discussion and through our practical experiences and observations we have come to realise that FASD has not been a widely discussed phenomenon within our work community.<sup>38</sup>
- 4.39 A study, which looked at paediatricians’ knowledge, attitudes and practice after being given educational resources about preventing prenatal

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31 NOFASARD, *Submission 46*, Attachment A, p. 2.

32 Professor E Elliott, Professor of Paediatrics and Child Health, University of Sydney, *Committee Hansard*, Sydney, 13 April 2012, p. 6.

33 Dr R Mutch, Telethon Institute, *Committee Hansard*, Perth, 10 July 2012, p. 23.

34 E Pearson, *Submission 48*, p. 8.

35 Alcohol and other Drugs Council of Australia, *Submission 33*, p. 11.

36 Royal Australasian College of Physicians, *Submission 27*, p. 4.

37 ANPHA, *Submission 45*, p. 4.

38 Top End Mental Health Service, *Submission 83*, p. 1.

alcohol exposure and FASD, found that asking women about alcohol use during pregnancy should be emphasised in paediatric training. It concluded that, unless paediatricians' capacity to recognise and diagnose FASD is improved, FASD 'will remain under-diagnosed in Australia and opportunities for management, early intervention and prevention will be overlooked'.<sup>39</sup>

#### Figure 4.1 Russell Family Fetal Alcohol Disorders Association

RFFADA, the Russell Family Fetal Alcohol Disorders Association, is a not-for-profit health promotion charity dedicated to ensuring that individuals affected prenatally by alcohol have access to diagnostic services, support and multidisciplinary management planning in Australia and that carers and parents are supported with a 'no blame no shame' ethos. Their mission is to provide information, training and education to increase the capacity of communities, organisations and individuals to support those people living with FASD to live to their full potential.

Based in Brisbane, RFFADA was founded by Elizabeth Anne Russell, whose two children were diagnosed with a FASD. Mrs Russell has authored several books on FASD and promotes FASD training for health professionals, educators, and others who come into contact with people living with FASD.

Mrs Russell said, 'I could not find medical professionals who understood the condition, so in 2007 I established the Russell Family Fetal Alcohol Disorders Association and since then I have been liaising with people and organisations around Australia.'

Source: <http://www.rffada.org/> and <http://www.elizabethrussell.com.au/home/> and Committee Hansard, Cairns, 31 January 2012, pp. 1.

#### 4.40 It is not expected that a single health practitioner would diagnose FASD. Dr Mutch, a paediatrician, acknowledged that:

I as a doctor feel I cannot diagnose FASD on my own. I need the skills of my allied health team to inform me about the jigsaw puzzle of the child before me.<sup>40</sup>

However, all health practitioners need to be aware of the risks and symptoms of FASD so that an early referral can be made to the appropriate specialists.

39 J M Payne et al, 'Paediatricians' Knowledge, Attitudes and Practice Following Provision of Educational Resources about Prevention of Prenatal Alcohol Exposure and Fetal Alcohol Spectrum Disorder', *Journal of Paediatrics and Child Health*, vol. 47, no. 10, 2011, p. 6.

40 Dr R Mutch, Telethon Institute, *Committee Hansard*, Perth, 10 July 2012, p. 23.

- 4.41 Prue Walker explained that without knowledge of FASD, health professionals may only consider individual behaviour and development in isolation without reference to the impact of prenatal alcohol exposure and the spectrum of effects.<sup>41</sup>
- 4.42 Professor Elliott pleaded the case for a 'concerted national effort':
- We need to identify and train up teams that could be either based in individual states and/or be mobile clinics that could service communities that are in need. The longer we delay, the greater the number of children that will be born with foetal alcohol spectrum disorders.<sup>42</sup>
- 4.43 The joint submission from the Foundation for Alcohol Research and Education and Public Health Association of Australia advocated for funding allocation to 'train health professionals working in multi-disciplinary teams to have the capacity to diagnose FASD'.<sup>43</sup>

## Complexity of FASD

- 4.44 As described earlier, there are a number of diagnoses under the umbrella of FASD. The range of conditions, and their even greater range of symptoms and indications, can be challenging to diagnose. Dr Susan Astley from the University of Washington, a leading organisation for research into FASD, wrote that:
- Individuals with prenatal alcohol exposure present with a wide range of outcomes, most of which are not specific to prenatal alcohol exposure and often manifest differently across the lifespan. ... The pattern and severity of outcomes are dependent on the timing, frequency, and quantity of alcohol exposure (which is rarely known with any level of accuracy), and is frequently confounded by other adverse prenatal and postnatal exposures and events.<sup>44</sup>
- 4.45 FASD conditions that do not feature characteristic facial abnormalities can be difficult to diagnose as none of the other characteristic problems are unique to FASD; all can be associated with other factors, such as low

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41 P Walker, *Submission 29*, p. 9.

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

43 FARE/PHAA, *Submission 36*, p. 21.

44 S J Astley, 'Diagnosing Fetal Alcohol Spectrum Disorders (FASD)', in S A Adubato and D E 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. 3.

socio-economic status and poor maternal nutrition.<sup>45</sup> Professor Elliott explained:

That is where the confounding comes in. How can you attribute those developmental problems to alcohol, particularly if there are other issues in the family? That is the thing that clinicians grapple with. The approach we have taken is to do a very comprehensive assessment of speech and language, fine motor skills, gross motor skills, learning, IQ et cetera.<sup>46</sup>

4.46 Moreover, 'invisible' damage to the central nervous system may not manifest until a child starts school and demonstrates learning or behavioural difficulties.<sup>47</sup>

4.47 Individuals with FASD may have other medical conditions that complicate the recognition of FASD. For example, Tracey Harth acknowledged that for her foster son:

... a diagnosis of FASD would be hard to get because there were so many different things that were being abused at the [pregnancy] so he cannot be put into that small little box and he might be a bit wider on the spectrum.<sup>48</sup>

4.48 Associate Professor Heather Douglas found that the complexity of a diagnostic process means that several appointments with different professionals may be required. Yet, the deficiencies of attention and planning that are linked to FASD may make completion of the diagnosis difficult without adequate support.<sup>49</sup>

4.49 When individuals present with secondary disabilities, which can be caused by any number of factors, finding the correct diagnosis can be even more difficult.<sup>50</sup>

4.50 Extensive assessments are required to rule out other conditions and to determine an individual's dysfunction. Dysfunction in three domains of the central nervous system constitutes one of the criteria for FASD, but all domains must be tested as each individual could present with a different combination of deficiencies. This cannot be accomplished by a single

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45 Intergovernmental Committee on Drugs Working Party on Fetal Alcohol Spectrum Disorders, *Fetal Alcohol Spectrum Disorders: An Update*, 2009, p. 36.

46 Professor E Elliott, University of Sydney, *Committee Hansard*, Canberra, 24 November 2011, p. 4.

47 R Mutch et al, 'Need to establish a National Diagnostic Capacity for Foetal Alcohol Spectrum Disorders', *Journal of Paediatrics and Child Health*, vol. 45, no. 3, 2009, pp. 79-81.

48 T Harth, Foster Carer, Barnardos, *Committee Hansard*, Sydney, 13 April 2012, p. 33.

49 H Douglas, 'The Sentencing Response to Defendants with Foetal Alcohol Spectrum Disorder', *Criminal Law Journal*, vol. 34, 2010, p. 226.

50 Catholic Education Office of Western Australia, *Submission 5*, p. 1.

practitioner or even by several practitioners working in isolation from each other.

- 4.51 At the pilot diagnostic clinic at Westmead Hospital in Sydney and the Fitzroy Valley clinic, assessments are made by multiple medical staff from a wide range of disciplines who work together to reach a diagnosis and recommend a management plan. These assessments take four to eight hours per child.<sup>51</sup>

### Nationally consistent diagnostic tool and guidelines

- 4.52 A number of diagnostic guidelines or criteria for FASD were created in North America that are currently used internationally:
- The United States Institute of Medicine;
  - Washington State 4-digit Diagnostic Code;
  - Hoyme revision of Institute of Medicine criteria;
  - The United States Center for Disease Control;<sup>52</sup> and
  - The Canadian Guidelines.<sup>53</sup>
- 4.53 An international survey of diagnostic clinics found that they used either one set or combined multiple sets of the above guidelines, sometimes with modifications, to aid diagnosis.<sup>54</sup>
- 4.54 At present, Australia does not have nationally-agreed diagnostic criteria or guidelines. A 2008 study of Australian health professionals endorsed the need for national diagnostic guidelines for FASD, and the need for their evaluation in the Australian context to ensure that the guidelines are feasible, nationally applicable, valid, and acceptable to both health professionals and consumers.<sup>55</sup>
- 4.55 In 2010, the Australian FASD Collaboration (the Collaboration) undertook the FASD Project, tasked with developing an instrument for standardising the screening and diagnosing of FASD in Australia. The Collaboration includes medical specialists, paediatricians, researchers and academics,

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

52 E Peadon et al, 'International Survey of Diagnostic Services for Children with Fetal Alcohol Spectrum Disorders', *BMC Pediatrics*, vol. 8, 2008.

53 S J Astley, 'Diagnosing Fetal Alcohol Spectrum Disorders (FASD)', p. 16.

54 E Peadon et al, 'International Survey of Diagnostic Services for Children with Fetal Alcohol Spectrum Disorders', *BMC Pediatrics*, vol. 8, 2008.

55 E Peadon et al, 'International Survey of Diagnostic Services for Children with Fetal Alcohol Spectrum Disorders', *BMC Pediatrics*, vol. 8, 2008.

and consumer and community representatives from across the country.<sup>56</sup> The Collaboration collected data which:

... supported the need for standard, locally appropriate and evidence based diagnostic criteria and a user-friendly instrument and training resources not only to improve awareness of FASD among health professionals but to improve diagnostic capacity.<sup>57</sup>

- 4.56 The FASD Project was completed in September 2011 and the recommended diagnostic instrument is currently being reviewed by the lead agency, the Department of Health and Ageing (DoHA).
- 4.57 In the meantime, the Sydney and Fitzroy Valley pilot FASD clinics use their own set of criteria, adopted from the Canadian guidelines, which resemble the FASD Project's.<sup>58</sup>

### Lack of diagnostic services in Australia

- 4.58 Internationally there are a range of clinics providing diagnostic and assessment services for children exposed to alcohol in pregnancy. The majority of these clinics are located in North America, with some in South Africa, Europe and South America.<sup>59</sup>
- 4.59 A study by Australian researchers into international diagnostic services for FASD found that Australia is lagging behind other countries when it comes to the provision of screening and diagnostic services.<sup>60</sup>
- 4.60 The Catholic Education Office of Western Australia submitted that screening services at present are 'limited, scattered, [and] lacking some coordination'.<sup>61</sup> DoHA agreed that it had received advice indicating that clinical services for FASD 'vary enormously' between states.<sup>62</sup>
- 4.61 Paediatricians at Royal Darwin Hospital submitted that making a diagnosis is very difficult and 'involves working with multidisciplinary

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56 Australian FASD Collaboration, *Submission 19*.

57 Dr R Watkins, Research Fellow, Telethon Institute, *Committee Hansard*, Perth, 10 July 2012, p. 28.

58 Professor E Elliott, University of Sydney, *Committee Hansard*, Canberra, 24 November 2011, p. 3 and *Committee Hansard*, Sydney, 13 April 2012; Dr J Fitzpatrick, Paediatric Senior Registrar/Research Chief Investigator, University of Sydney, Canberra, 24 November 2012, p. 6.

59 Intergovernmental Committee on Drugs Working Party on Fetal Alcohol Spectrum Disorders, *Fetal Alcohol Spectrum Disorders: An Update*, 2009, p. 82.

60 Intergovernmental Committee on Drugs Working Party on Fetal Alcohol Spectrum Disorders, *Fetal Alcohol Spectrum Disorders: An Update*, 2009, p. 82.

61 Catholic Education Office of Western Australia, *Submission 5*, p. 1.

62 Dr B Towler, Principal Medical Adviser, Australia Government Department of Health and Ageing, *Committee Hansard*, Canberra, 28 June 2012, p. 14.

teams, which is an informal arrangement in Darwin with community health, occupational therapists, speech therapists and psychologists'.<sup>63</sup>

4.62 In the absence of multi-disciplinary teams in Central Australia, paediatricians are diagnosing FASD. However, paediatricians are unlikely to be in contact with post-adolescent individuals whose symptoms may not manifest until they are older and bigger.<sup>64</sup>

4.63 Professor Elliott advised the Committee that specialised clinics for FASD are necessary:

These children should be able to be seen in child development clinics, which exist in our major cities; but, if you speak to people who work in and run those clinics, they are absolutely swamped. They try to run a multidisciplinary model, but they are swamped by children with multiple different developmental needs.<sup>65</sup>

4.64 The Committee heard about the diagnostic work that has been conducted in the temporary pilot clinics in Fitzroy Valley and at Westmead Hospital in Sydney, where multidisciplinary teams work together to assess children. For example, in Fitzroy Crossing, a team comprising of a paediatrician, speech therapist, physiotherapist, child psychologist and occupational therapist travelled to the area to undertake an eight hour assessment of each child over two days. In addition, hearing and vision was tested and a comprehensive history of antenatal exposures taken from the parents.<sup>66</sup>

4.65 The Foundation for Alcohol Research and Education (FARE), which funded the Westmead clinic, advised that evaluation of the pilot project will include an assessment of the costs of establishing and maintaining such a screening and diagnostic service.<sup>67</sup>

4.66 Professor Elliott explained that this is a very cost-efficient and satisfactory way of running a clinic:

All the health professionals are there together. We can talk about our findings, we can identify where there is supportive evidence from different assessments, we can come to a joint allocation of a diagnosis and we can develop an individual management plan for

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63 Dr L Martin, Paediatrician, Royal Darwin Hospital, *Committee Hansard*, Canberra (Videoconference), 21 June 2012, p. 5.

64 Aboriginal Peak Organisations Northern Territory, *Submission 38*, p. 19.

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

66 Professor E Elliott, University of Sydney, *Committee Hansard*, Sydney, 13 April 2012, p. 2.

67 FARE/PHAA, *Submission 36*, p. 21.

that child. We are able to provide feedback to the parents within the next couple of days.<sup>68</sup>

- 4.67 Professor Elliott suggested that it was the sort of model that would be appropriate to use in all states. She considers that full-time clinics would not be necessary but it is essential to have a highly trained group of professionals who can work as a team.<sup>69</sup>
- 4.68 Nonetheless, training health specialists in FASD diagnosis is challenging, and even more so for regional and remote areas that already lack adequate health facilities. For example, Warren Harvey explained that:
- We are still on our journey of trying to obtain a complete diagnosis as living approximately 750 km away from Perth [makes this] rather difficult.<sup>70</sup>
- 4.69 Donna Smith from Halls Creek Kimberley Language Resource Centre queried how such an intensive assessment can be achieved in a location where 'it is really hard to even get a post-natal depression assessment. If we are looking at eight hours for one child, it is going to be a big thing'.<sup>71</sup>
- 4.70 The Australian Children's Commissioners and Guardians pointed out that given the:
- ... vast distances familiar to many regional areas of Australia and the shortage of skilled professionals ... considerable resourcing to meet the needs of children in regional areas will inevitably be required.<sup>72</sup>
- 4.71 The Kimberley Population Health Unit noted that a lack of infrastructure in remote communities hindered the attraction and retention of qualified health professionals:
- In places like Fitzroy Crossing, I cannot put a [staff] family in Fitzroy Crossing because I have no houses for a family to live in. People have to share houses, so it only suits single people. So even though we could get extra money for all these positions, you need a whole infrastructure to be part of it.<sup>73</sup>

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68 Professor E Elliott, University of Sydney, *Committee Hansard*, Sydney, 13 April 2012, p. 2.

69 Professor E Elliott, University of Sydney, *Committee Hansard*, Sydney, 13 April 2012, p. 2.

70 Warren Harvey, *Submission 41*, p. 5.

71 D Smith, Halls Creek Kimberley Language Resource Centre, *Committee Hansard*, Mimbi, 11 July 2012, p. 8.

72 Australian Children's Commissioners and Guardians, *Submission 62*, p. 6.

73 Dr D Reeve, Acting Director, Kimberley Population Health Unit, *Committee Hansard*, Broome, 12 July 2012, p. 15.



- 4.72 Professor Elliott acknowledges the difficulties that are compounded by distance, but believes that trained mobile teams are the best model for regional and remote areas:

It is very hard, as you know, to get people to come and work in these communities, and then it is hard to get them to stay. That is because these communities are very remote. We are suggesting that the best model, the most sustainable model, is one where all the professionals can work together, travel together and get to know the communities. Even if they are not there every day of the year, they can come back – so that there is continuity and there is support from the team, rather than individuals working in isolation [where] the paediatrician comes one day, the speech therapist the next week, the physio the following week, and they can never talk to each other. If they could all see a child together, get the assessment done, make a diagnosis and get the report done, it would be much more efficient, and it would be much cheaper for the government.<sup>74</sup>

## After the diagnosis

- 4.73 A diagnosis should be followed up with a management plan and access to specialist and allied health services and professionals that enable the implementation of the plan. However, the Committee received few details of existing management services.
- 4.74 Dr Charles Kilburn, from Royal Darwin Hospital, told the Committee that:
- It is a little bit of an empty diagnosis if you make a diagnosis of foetal alcohol syndrome disorder but you do not have any services to apply to those children. If there were increased recognition from which some funding for remedial therapy flowed, then I think that would drive the recognition of the condition and certainly help improve diagnosis and status of the condition.<sup>75</sup>
- 4.75 The Telethon Institute and the Intergovernmental Committee on Drugs Working Party on Fetal Alcohol Spectrum Disorders confirmed that there is little good evidence on the forms of management that are effective for

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74 Professor E Elliott, University of Sydney, *Committee Hansard*, Mimbi, 11 July 2012, p. 8.

75 Dr C Kilburn, Chief Paediatrician, Royal Darwin Hospital, *Committee Hansard*, (Videoconference) Darwin, 21 June 2012, p. 8.

individuals with FASD, due to a lack of proper trials and evaluation studies of FASD therapies.<sup>76</sup>

4.76 In contrast, the NRHA submitted that:

The most promising ways of helping people with FASD appear to be behavioural, environmental and relationship-driven interventions ... Building upon strengths and assets is proving to be a better approach than focusing solely on difficulties. Five evidence-based intervention strategies have been shown to have positive results in the United States and funding should be made available to provide such programs in Australia.<sup>77</sup>

4.77 Legal Aid New South Wales and Aboriginal Legal Service (New South Wales/ Australian Capital Territory) claimed that:

... the solutions are fairly simple in a sense. They are not cheap, but they are simple. In modern disability sciences there are any number of well-proven, early intervention methodologies, disability support methodologies, that are not rocket science and they are fairly simple to institute, but they simply do not exist. We have seen pilot examples in Central Australia where people who have reached this critical stage of extremely challenging behaviours have had those behaviours modified and brought down to a manageable level where they can go and live good quality of lives with a moderate level of disability support.<sup>78</sup>

4.78 Two Australian models of care, incorporating strategies for management, were brought to the attention of the Committee. The Lililwan Project in Fitzroy Valley developed 'Circle of Community Care', a model of care for 'a collaborative circle of community care really to support parents and carers and to coordinate the health, education and other needs of these children and their families'.<sup>79</sup>

4.79 In Western Australia, the Child and Youth Health Network developed a state FASD model of care 'which sets out the key directions across the continuum from prevention through to management of FASD' that 'aligns to the national agenda'.<sup>80</sup> The state Department of Health is coordinating

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76 Telethon Institute, *Submission 23*, p.11; Intergovernmental Committee on Drugs Working Party on Fetal Alcohol Spectrum Disorders, *Fetal Alcohol Spectrum Disorders: An Update*, 2009, p. 86.

77 NRHA, *Submission 40*, pp. 15-16.

78 J McKenzie, Chief Legal Officer, Aboriginal Legal Service, (New South Wales and the Australian Capital Territory) Ltd, *Committee Hansard*, Sydney, 13 April 2012, p. 22.

79 Professor E Elliott, University of Sydney, *Committee Hansard*, Canberra, 24 November 2011, p. 2.

80 B Whitworth, Senior Development Officer, WA Health, *Committee Hansard*, Perth, 10 July 2012, p. 6.

the whole-of-government, multi-sector approach to implementing the model.<sup>81</sup> However, no additional funding has been allocated to the FASD model of care, which relies instead on funds drawn from other areas.<sup>82</sup>

4.80 As discussed in the previous section, remote areas suffer from a shortage of health professionals and services, compromising access to ongoing care and management. The WA Model of Care takes into account the remote nature of many of its communities, which often lack health services, and recommended the following models of service delivery:

- Workforce training and development in regional centres to provide a local service. This should be prioritised according to level of need, ie according to established or estimated prevalence of FASD in local communities.
- Scheduled rural visits by metropolitan-based teams with the opportunity of assessing whole subpopulations within a short time period and providing education and support to local services. Involvement of the local health service providers in the visiting team's assessment process will enable building of local expertise.
- Telehealth models for individual assessment.<sup>83</sup>

4.81 A number of organisations, including the Ngaanyatjarra Pitjantjatjara Yankunytjatjara Women's Council, the Aboriginal Disability Justice Campaign, and the Northern Territory branch of the Public Health Association of Australia expressed concern that individuals with FASD living in remote areas would miss out on intervention and management therapies due to the paucity of health services in general.<sup>84</sup>

4.82 For example, the First Peoples Disability Network stated that it 'is very unlikely that speech pathology could be provided intensively in regional and remote parts of the country because of a lack of availability'.<sup>85</sup>

4.83 Dr Mutch, who spent a brief time in Tennant Creek in the Northern Territory, said that:

I was deeply moved and saddened by the evident need for more services to support and enable health, diagnosis and therapy for developmental needs including specifically meeting the requirements of FASD. Professionals outside of health told me

81 WA Health, Health Networks Branch (Child and Youth Health Network), *Submission 13*, p. 7.

82 Western Australian Legislative Assembly Education and Health Standing Committee, *Foetal Alcohol Spectrum Disorder: The invisible disability*, September 2012, p. iii.

83 NRHA, *Submission 40*, pp. 14–15.

84 Ngaanyatjarra Pitjantjatjara Yankunytjatjara Women's Council, *Submission 74*, p. 7; Aboriginal Disability Justice Campaign, *Submission 43*, p. 5; Public Health Association of Australia – NT Branch, *Submission 73*, p. 3.

85 First Peoples Disability Network, *Submission 75*, p. 4.

how they were providing basic health services to facilitate wellbeing and education attendance as no other capacity was available to meet these needs. They spoke of the evident cognitive difficulties manifest in the children and their concern with how few amenities they had to meet their diverse needs.<sup>86</sup>

- 4.84 A submission from a number of allied health services in Fitzroy Valley outlined the needs for increased capacity and stronger linkages with the Kimberley Paediatrics and Child Health Team in response to the raft of FASD diagnoses and management plans arising out of the Lililwan Project.<sup>87</sup>
- 4.85 The Aboriginal and Torres Strait Islander Social Justice Commissioner stated that :
- It is ... imperative that children with FASD – wherever they live in Australia – have equitable access to the services they need to optimise their health, development and educational outcomes.<sup>88</sup>
- 4.86 This problem is not confined to remote communities. Dr Louise Martin noted that an appropriate increase in capacity and resources in Darwin is required to ensure that the therapeutic response can match any increase in diagnosis levels.<sup>89</sup> The capacity of allied health services and infrastructure in the Top End of the Northern Territory is already limited, with long waiting lists, meaning that children’s therapeutic needs often are not being met.<sup>90</sup> In Townsville, a foster carer told the Committee that she occasionally took children herself to private hospitals to avoid the lengthy public waiting lists.
- 4.87 FARE considers that there is much to be learned from other examples from the disability area and how governments have responded.<sup>91</sup> The FARE submission outlined the changes in how Autism Spectrum Disorders (ASD) has been managed in Australia over the last few years. In 2007 a report from the Australian Advisory Board on ASD identified the following four areas that needed concerted national effort:

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86 Dr R Mutch, *Submission 77*, p. 1.

87 Allied Health Services –The Lililwan Project, *Submission 88*, p. 5.

88 Aboriginal and Torres Strait Islander Social Justice Commissioner, *2010 Social Justice Report*, Australian Human Rights Commission, Sydney, 2011, p. 93.

89 Dr L Martin, Royal Darwin Hospital, *Committee Hansard*, Canberra (Videoconference), 21 June 2012, p. 5.

90 Paediatricians at Royal Darwin Hospital, *Submission 79*, p. 3.

91 M Thorn, Chief Executive Officer, Foundation for Alcohol Research and Education (FARE), *Committee Hansard*, Canberra, 31 May 2012, p. 3.

- access to timely and affordable diagnosis with a wait time of no longer than three months for diagnosis and assessment by multidisciplinary teams;
  - early intervention services to allow for better outcomes for children;
  - specific educational services to assist children to transition to mainstream schools; and
  - improved data collection to help future research into causes, diagnostic pathways, effective interventions and outcomes.<sup>92</sup>
- 4.88 Of course, there are still difficulties accessing diagnoses, early intervention, and support for children with ASD.<sup>93</sup> As with ASD, access to diagnosis, early intervention, and specialised services for FASD are all areas which need further attention. However, FASD has not received the same attention, support or public recognition in Australia.<sup>94</sup>
- 4.89 The next chapter discusses non-health sector management strategies and services for carers, the education sector and the criminal justice system.

## Committee Comment

- 4.90 Australia's need for increased capacity to recognise, diagnose and manage the primary and secondary symptoms of FASD was a common refrain throughout the inquiry.
- 4.91 The Committee is convinced of the necessity and benefit of early intervention to improve the life outcomes of individuals born with FASD. Without a diagnosis, or with the wrong diagnosis, the treatment of individuals with FASD by their families, educators, physicians and society in general can inadvertently cause great damage and lead to severe secondary disabilities such as mental illness or substance abuse which may then lead on to incarceration. Early intervention is critical to unlocking a better future.
- 4.92 The Committee appreciates the difficulty of diagnosing conditions within the FASD spectrum. The Committee is concerned, however, that perceptions of stigma attached to FASD can obstruct accurate and timely diagnosis. The stigma of overlooking or ignoring the needs of individuals with FASD should be greater than any stigma linked to maternal alcohol consumption.

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92 FARE, *Submission 36*, p. 8.

93 For example see, Western Australian Legislative Assembly Education and Health Standing Committee, *Foetal Alcohol Spectrum Disorder: The invisible disability*, September 2012, p. 67.

94 FARE, *Submission 36*, pp. 8-9.

- 4.93 In addition to a fear of stigmatising families, health professionals appear to have low levels of training and knowledge about FASD. The Committee is of the view that the capacity of health professionals to identify FASD must be improved, and that a national effort should be mounted to ensure uniformity across all states. All health professionals who deal with children should be educated on the prevalence, aetiology and clinical features of FASD, and on the appropriate diagnostic and management services for referral.
- 4.94 The Committee understands that FASD is very complex, and requires the expertise of a number of specialists to diagnose. This makes the introduction of a standard diagnostic and screening instrument even more imperative, so that the prevalence of FASD can be measured and monitored consistently across the country.
- 4.95 The Committee is encouraged that the Commonwealth Government commissioned an Australian diagnostic tool. The diagnostic tool is yet to be trialled and evaluated, so the Committee recommends that no more time is lost and the diagnostic tool released along with guidelines for its use.

### **Recommendation 15**

- 4.96 **The Committee recommends that the Commonwealth Government expedite the rollout of the Fetal Alcohol Spectrum Disorder (FASD) diagnostic instrument and the development of a training and user manual. These should be available for use by 1 October 2013.**

**Following the rollout, the Commonwealth Government should establish a mechanism to collect and monitor diagnostic data in order to assess the effectiveness of prevention strategies and patterns of FASD occurrence.**

- 4.97 Use of the nationally-recognised diagnostic instrument would enable the establishment of diagnostic clinics or teams. At present, there are few options in Australia for people who suspect and are seeking a diagnosis of FASD. The Committee is saddened that some families had to consult doctor after doctor, or even travel overseas, in order to receive confirmation of a suspected FASD diagnosis.
- 4.98 However, the Committee acknowledges that a diagnosis of FASD would be empty without a viable management plan. The Committee commends the models of care created by the WA Government and the Lililwan Project community. These models seek to integrate the many practitioners

necessary for a holistic approach to FASD prevention, diagnosis and management.

- 4.99 Unfortunately, just as the capacity of health professionals in Australia to recognise FASD is limited, so is their capacity to provide effective therapies and support services. This is evident in rural and remote areas that struggle to achieve adequate health services for other disabilities. The Committee recognises that studies into the efficacy of various management strategies need to be conducted to inform the establishment of therapeutic programs.
- 4.100 The Committee is of the view that a national diagnostic and management strategy should be established to overcome the obstacles discussed in this chapter. This strategy should take into account existing models and programs in Australia and best-practice examples from North America.
- 4.101 The Committee considers that the FASD Reference Group is best placed to develop this national strategy. The strategy should increase health professionals' awareness of FASD and the importance of early diagnosis and management. The Committee suggests that rigorous screening of pregnant women and children in high-risk groups be instituted in every state and territory to enable the earliest detection of FASD or other disabilities.
- 4.102 The strategy should identify the ideal diagnostic service models so that access to the national diagnostic and screening tool is available to all, regardless of geographic residence. There was strong evidence in the inquiry pointing to the benefits of mobile interdisciplinary teams, but the Committee is not qualified to comment on the most appropriate model.
- 4.103 Finally, the strategy should ensure that management services are properly researched and evaluated so that evidence-based recommendations can be made for individuals' management plans.

### **Recommendation 16**

- 4.104 **The Committee recommends that the Commonwealth Government develop and implement a national Fetal Alcohol Spectrum Disorders (FASD) diagnostic and management services strategy.**

**This strategy should be monitored and informed by the FASD Reference Group, and should establish capacity by 1 July 2014 for the following:**

- **awareness amongst all general practitioners and child and maternal health professionals of the causation and clinical features of FASD and the importance of early diagnosis and intervention;**
- **establishment of a model for diagnostic services such that regional as well as metropolitan areas are properly serviced; and**
- **identification of effective methodologies of management including international best practice.**





## Management needs

- 5.1 Individuals with Fetal Alcohol Spectrum Disorders (FASD) have a range of special needs and require a variety of sometimes intensive support for the duration of their lifetime.
- 5.2 This chapter addresses the lack of data on the prevalence of FASD in Australia. This data is important for a number of reasons, including devising and targeting management strategies appropriately, adequately resourcing areas of high prevalence, measuring the potential economic and social cost of FASD, and confirming the need for improved FASD awareness and funding.
- 5.3 As discussed in the previous chapter, health treatment and intervention for people with FASD and support for their carers can be difficult to access even when armed with a professional diagnosis. Similarly, appropriate management strategies in other areas are not readily available, in part due to the limited knowledge of FASD prevalence.
- 5.4 Professor Elizabeth Elliott cautioned that:

There is no point making a diagnosis and then leaving people in the lurch. We have to have follow-up – follow-up with families coping with the grief of a diagnosis, follow-up in the schools, follow-up in the justice system and follow-up in the health system.<sup>1</sup>
- 5.5 This chapter considers the common experiences of children and young adults with FASD in relation to care, education and the criminal justice system, and the lack of follow-up in these domains. The chapter outlines the challenges in each of these areas and considers actions that have been

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1 Professor E Elliott, Professor of Paediatrics and Child Health, University of Sydney, *Committee Hansard*, Mimbi, 11 July 2012, p. 9.

identified through the inquiry. The primary obstacles to improving management of FASD appear to be a lack of public information and understanding of FASD, reinforced by the fact that FASD is not currently recognised by the Commonwealth Government as a disability.

## Lack of prevalence data to inform management

5.6 As discussed in Chapter 2, the prevalence of FASD in Australia is not well-documented. Prevalence data is an essential foundation for developing and implementing management strategies.

5.7 Dr Lisa Studdert stated that:

... to get a handle on [FASD] and be able to craft our responses, both prevention and management, we do need to have good data on what the current prevalence is and the trends over time – are we seeing an increase in this problem or is it stable? – and then on the overall situation in terms of the quantity of the problem.<sup>2</sup>

5.8 However, the Department of Health and Ageing (DoHA) stated that there are deficits in the knowledge and research base:

We still do not know enough about the factors which contribute to FASD, its prevalence or what the most effective models of early intervention are to reduce its secondary impact on mental health, education and social dysfunction.<sup>3</sup>

5.9 This was supported by health experts. Dr Jane Latimer and Dr Colleen O’Leary pointed out that prevalence studies conducted so far primarily investigate Fetal Alcohol Syndrome (FAS) only, leaving a data gap on other conditions on the FASD spectrum where FAS facial features are not present.<sup>4</sup>

5.10 However, it is difficult to measure prevalence without consistent screening and diagnostic practices. As discussed in the previous chapter, Australia is lagging behind in national screening and diagnostic practices. Yet the Australian National Preventive Health Agency argues that:

Before accurate prevalence rates of FASD can be estimated in Australia, routine assessment and recording of maternal alcohol

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2 Dr L Studdert, Manager, Australian National Preventive Health Agency (ANPHA), *Committee Hansard*, Canberra, 15 March 2012, p. 3.

3 D Butt, Deputy Secretary, Commonwealth Government Department of Health and Ageing (DoHA), *Committee Hansard*, Canberra, 28 June 2012, p. 2.

4 Dr J Latimer, Senior Research Fellow, Lililwan Project Chief Investigator, *Committee Hansard*, Canberra, 24 November 2011, p. 5; Dr C O’Leary, *Submission 92*, p. 2.

use during pregnancy, education about diagnosis of FASD, and methods for collecting national data would need to be established.<sup>5</sup>

- 5.11 The result is a vicious circle where collecting prevalence data is hindered by the lack of routine, nation-wide assessments of maternal alcohol consumption and uniform diagnosis of FASD, which in turn are more difficult to implement without good data on the extent of FASD. The Telethon Institute for Child Health Research (Telethon Institute) stated that 'without diagnostic data, it is difficult to define the prevalence [of FASD] and therefore lobby for health training in this area'.<sup>6</sup>
- 5.12 The Anyinginyi Health Aboriginal Corporation argued that:
- This lack of concrete evidence has contributed to the neglect of FASD and Australia's failure to address its issues despite clear knowledge of its existence dating back decades.<sup>7</sup>
- 5.13 The Committee heard evidence from some contemporary prevalence studies that will contribute to national data on FASD. The Lililwan Project measured the prevalence of FASD in 45 communities in the Kimberley region of Western Australia<sup>8</sup> and last year a study commenced into the prevalence of FASD among children up to 12 years of age in Perth.<sup>9</sup> DoHA advised that the Australian Institute of Health and Welfare undertook a scoping study on best-practice methods of collection and reporting FASD prevalence data.<sup>10</sup>
- 5.14 Quality prevalence data is 'vital to being able to better determine the extent of FASD in Australia and develop programs to support people with FASD'.<sup>11</sup>

## Carers

- 5.15 Caring for children with FASD is all-consuming and difficult, and early intervention strategies can be expensive. Carers of people with FASD need financial support in the same way that other carers of people with

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5 ANPHA, *Submission 45*, p. 3.

6 Telethon Institute for Child Health Research (Telethon Institute), *Submission 23*, p. 2.

7 Anyinginyi Aboriginal Health Service, *Submission 3*, p. 2.

8 Professor E Elliott, University of Sydney, *Committee Hansard*, Canberra, 24 November 2012, p. 1.

9 Foundation for Alcohol Research and Education/Public Health Association of Australia (FARE/PHAA), *Submission 36*, p. 18.

10 DoHA, *Submission 78*, p. 3.

11 FARE/PHAA, *Submission 36*, p. 17.

disabilities are supported in recognition of their limited income-earning capacity due to caring responsibilities.

- 5.16 Children with FASD require intensive care and supervision, as described earlier, and can often be in need of a high level of health service coordination. Sue Miers explained that:

In order to reach any kind of sustained function, successful strategies often involve adapting the environment to prevent inappropriate behaviour from occurring in the first place. This is really hard work. It usually requires constant total supervision, highly structured and significantly altered physical environments and time-consuming interventions.<sup>12</sup>

- 5.17 This places great stress on carers, who may be unaware of the needs of children with FASD or unable to manage the severe behavioural problems. Without adequate information or resources, carers struggle to access the necessary intervention strategies.

- 5.18 The National Organisation for Fetal Alcohol Syndrome and Related Disorders (NOFASARD) advised the Committee that they receive many queries from parents and carers and support workers seeking assistance for children who they suspect of having FASD. For example, Sue Miers said:

I am a Family Counsellor and Support Worker and am seeing more children which I suspect have effects of alcohol and I am often at a loss as to where to send them or the help I can give. Parents/carers and guardians appear to be quite frustrated that the level of recognition and support is just not available.<sup>13</sup>

- 5.19 A large number of carers raising children with FASD are foster carers or grandparents and other kin, rather than biological parents. It is not uncommon for women with FASD to consume alcohol during their own pregnancy.

- 5.20 Prue Walker informed the Committee that there is strong international evidence that children with FASD are over-represented in the child protection system, and that prenatal alcohol exposure greatly increases the risk of children entering care, including foster care, residential care, or family placements.<sup>14</sup>

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12 S Miers, Chair, National Organisation for Fetal Alcohol Syndrome and Related Disorders (NOFASARD), *Committee Hansard*, Melbourne, 22 June 2012, p. 19.

13 NOFASARD, *Submission 46*, Attachment A, p. 2.

14 P Walker, *Submission 29*, p. 4.

- 5.21 The two main factors which have an influence on whether children with FASD might enter the care system are:
- Abuse and neglect due to parental alcohol use; and
  - Risks to growth and development, including failure to thrive.<sup>15</sup>
- 5.22 The Telethon Institute told the Committee that American and Canadian research has found 75 per cent of children in foster care come from family histories of mental illness or drug and alcohol abuse. These children are often a higher risk group for FASD.<sup>16</sup>
- 5.23 NOFASARD reported that a South Australian study found that parental drug or alcohol misuse was associated with 70 per cent of the children who entered out of home care for the first time in 2006 (in 40 per cent of cases, mothers were the users). This study also claims that parental drug and alcohol misuse is the driving factor for children entering into care.<sup>17</sup>
- 5.24 Prue Walker made the important point that intervention by the child protection system for behavioural problems is more likely to focus on addressing parenting issues, obtaining behavioural support through the school system, and working with parents or carers to manage the child's behaviour rather than considering FASD.<sup>18</sup> However, an understanding of organic brain damage is necessary for people to realise that the behaviour of individuals with FASD is about what they 'cannot do' rather than 'will not do'.<sup>19</sup>
- 5.25 Barbara Smith told the Committee that:
- None of the children who I believe suffer from FASD have had an easy life and their problems are getting worse in adulthood. None have reached the potential we would hope for our children, despite very committed and caring foster homes.<sup>20</sup>
- 5.26 Prue Walker stated that there needs to be more research into the experience of children with FASD who are in out of home care. She outlined some of the difficulties for children with FASD who come to the attention of the child protection system:
- FASD is more complex to diagnose when facial features are not present;
  - Focus may be on keeping the family healthy and safe;

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15 P Walker, *Submission 29*, p. 4.

16 H Jones, Manager, FASD Projects, Telethon Institute, *Committee Hansard*, Perth, 10 July 2012, p. 25.

17 NOFASARD, *Submission 46*, p. 11.

18 P Walker, *Submission 29*, p. 8.

19 A Foale, *Submission 24*, p. 2.

20 B Smith, *Submission 4*, p. 2.

- Child protection workers may not be able to predict that the child may also experience speech and language problems or other developmental delays due to lack of resources or information;
- It may take some time before the carer can identify that the child is not meeting developmental milestones and be slow to get on waiting lists to visit health professionals; and

5.27 There could be other possible explanations for behaviour problems, learning difficulties or developmental delays.<sup>21</sup>

Figure 5.1 The impact of FASD on children in care

Typically, children with FASD require:

- Stable, safe environments
- Structure and routine
- Repetition and predictability
- Consistency
- Reward and redirection rather than punishment
- Close supervision
- Role modelling

Children in care can experience changes and instability which are particularly difficult for children with FASD to process. These include:

- Repeated attempts at reunification with birth or extended family
- Access with family which may be planned or unplanned
- Placement breakdown
- Multiple placements prior to long term placements being identified
- Changes in childcare or school depending on placement

These children already have a background of abuse or neglect which impacts on their ability to cope with change. For Indigenous children in the Northern Territory in particular, these changes and transitions can be very challenging. Moving between family of origin, kinship care and foster care involves changes in culture, language and location. All of these are a challenge for a child with FASD to manage.

Source Ms Prue Walker, *Submission 29*, p. 8.

5.28 NOFASARD is concerned about the problems of children transitioning to independence from the care system at the age of 18. They state that maturation is delayed for children and young people with FASD and if

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21 P Walker, *Submission 29*, pp. 8-9.

they leave state care systems without lifelong supports in place, they could experience repeated crises on their own.<sup>22</sup>

- 5.29 Prue Walker stated that it is likely that young people with FASD who do not receive adequate support and management in care will become adults who continue to rely on social services through life, even when they achieve a level of success.<sup>23</sup> Many will become involved in the criminal justice system.

## Challenges

- 5.30 Unfortunately, the out of home care system in Australia is already stretched beyond capacity. One foster carer believes that FASD has 'affected the foster care system itself which is currently in crisis with the numbers of difficult children who need placement'.<sup>24</sup>
- 5.31 The Committee heard from a number of committed foster organisations and carers who are struggling to get information on FASD or financial support to provide the intensive therapies that are required to manage developmental and learning delays.
- 5.32 Raymond Metzger and his wife are fostering five children with FASD, but were not given any indication from the child protection department that these children might have FASD-related issues.<sup>25</sup> He stated that once the children had been diagnosed by a paediatrician, they were not eligible for any carers' funding as the children were not regarded as having special needs.<sup>26</sup>
- 5.33 Another foster couple could not get respite care for their son who was diagnosed with FAS:

Both government and non-government agencies, and individual professionals all abdicated responsibility for him over and over again, saying that 'he did not meet their criteria'. Apparently he did not meet anyone's criteria, because no one was required to acknowledge FASD as a legitimate disability. He, and by association the whole family, became a hot potato in nearly every context.<sup>27</sup>

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22 NOFASARD, *Submission 46*, p. 11.

23 P Walker, *Submission 29*, p. 9.

24 B Smith, *Submission 4*, p. 2.

25 R Metzger, *Committee Hansard*, Cairns, 31 January 2012, p. 30.

26 R Metzger, *Committee Hansard*, Cairns, 31 January 2012, p. 31.

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



- 5.34 Barnardos described the difficulties of aligning FASD with the current eligibility criteria for support services:

One of the unexpected difficulties that I came across is that, even though I have a nearly three-year-old who has quite a clear diagnosis of FAS, they are unable to actually access [NSW Family and Community Services] funded services because there is no global developmental delay or a delay in at least two areas. ... When you are looking at a very uncertain future of what to expect in terms of her needs much later in life, the carers will have to look at funding speech therapy, occupational therapy and other different therapy services because they cannot access them through the public system.<sup>28</sup>

- 5.35 The Australian Children's Commissioners and Guardians (ACCG) stated that support for families caring for children with FASD is essential so that families are able to provide appropriate support to affected children.<sup>29</sup> Carers and parents particularly need FASD information, extra support, guidance and respite.<sup>30</sup>

#### Figure 5.2 National Organisation for Fetal Alcohol Syndrome and Related Disorders

Established in 1999, the National Organisation for Fetal Alcohol Syndrome and Related Disorders (NOFASARD) is an independent and charitable national organisation working to prevent fetal alcohol exposure and support those living with an FASD and those who support them. NOFASARD is a registered Health Promotion Charity and the national peak community organisation representing the interests of parents, carers and others interested in or affected by FASD.

NOFASARD provides resource and reference information; education and training; online information and electronic resources; and support, advocacy and referral options for parents/caregivers and families supporting children/adolescents and adults who have been diagnosed with an FASD or are assessed as being at risk.

'The stress on family relationships in particular cannot be understated. NOFASARD receives many inquiries from family members struggling to care for children/adolescents and adults with FASD because professional service providers do not recognise or understand the disability nor do they respect parent/carer efforts to describe FASD. Parents/carers/families are often

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28 B Hijniakoff, Case Manager, Barnardos, *Committee Hansard*, Sydney, 13 April 2012, p. 30.

29 Australian Children's Commissioners and Guardians (ACCG), *Submission 62*, p. 7.

30 NOFASARD, *Submission 46*, p. 11.

overwhelmed if not physically and emotionally exhausted from dealing with challenging behaviours that arise from this brain based disability. Too often, professional assessment assumes the behaviours to be an individual's choice; the product of a dysfunctional family; poor parenting practices; or other environmental factors.'

Source: <http://www.nofasard.org.au/> and Submission 46, p. 8.

5.36 The Commonwealth Government provides support payments that may be available to individuals with FASD and their carers. For the carers of eligible individuals with a disability, two support mechanisms are relevant:

- the Carer Payment and
- the Carer Allowance.

5.37 The Department of Families, Housing, Community Services and Indigenous Affairs (FaHCSIA) explained that:

Carers of people with FASD may ... be eligible for financial assistance through the carer allowance or carer payment, and some carers may be entitled to receive child disability assistance payment, available to carers of a child with a disability under 16 years who attract the payment of carer allowance for their carer... We will continue to provide financial support such as carer payments, carer allowance and the disability support pension in cases where people with FASD have significant functional impairments or high care needs.<sup>31</sup>

5.38 The Carer Payment is an income and assets tested income support payment available to people who, because of the demands of their caring role, are unable to support themselves through substantial paid employment.<sup>32</sup> The payment can be made to carers of children (up to the age of 16) and adults.

5.39 The Carer Payment is available to carers who care for a child with an 'intense' rating against the Disability Care Load Assessment (Child) Determination and a medical certificate indicating that six or more months of personal care is required.<sup>33</sup> The Disability Care Load Assessment (Child) Determination takes into account two behavioural domains, functional abilities, and special care needs. Thus a person caring for

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31 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, p. 3.

32 FaHCSIA, *Submission 8*, Answer to Question on notice, p.1.

33 Ashurst Australia, *Submission 49*, p. 17.

someone with FASD could receive this payment if they fulfil the level of care required.<sup>34</sup>

- 5.40 For carers of adults, the Carer Payment is assessed not on the level of care needs but on a type of disability, that is 'a physical, intellectual or psychiatric disability' assessed against the Adult Disability Assessment Tool.<sup>35</sup> This does not include a cognitive disability. Accordingly, carers of adults with FASD who do not have any of the above recognised forms of disability are not eligible, even though they may have received the Carer Payment previously when the care recipient was under 16, due to the level of care required.<sup>36</sup>
- 5.41 The Carer Allowance is a supplementary payment for carers who provide daily care and attention in a private home for people with a disability who need significant care and attention.<sup>37</sup> The Carer Allowance is not subject to income or means testing.
- 5.42 To receive the Carer Allowance when caring for a child, the carer must care for a child who is a 'disabled child'. This child must either have a disability on the List of Recognised Disabilities or be given a qualifying rating of 'intense' under the Disability Care Load Assessment (Child) Determination.<sup>38</sup> When caring for an adult, the Carer Allowance is available when caring for a 'disabled adult', which is defined in the same way as for the Carer Payment.<sup>39</sup> Thus, carers of adults with FASD who do not have a physical, intellectual or psychiatric disability would not be able to receive the Carer Allowance.
- 5.43 Individuals with FASD may be able to access some Commonwealth Government disability support payments themselves once they turn 16, to assist with their housing and care needs. These are:
- the Disability Support Pension;
  - the Youth Disability Supplement; and
  - the Mobility Allowance.
- 5.44 The Disability Support Pension is available to individuals aged 16 years or over with a 'physical, intellectual or psychiatric impairment'. This impairment must be severe, registering 20 points or more under the

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34 L Corver, Acting Branch Manager, Disability and Carers Payment Policy Branch, Disability and Carers Group, FaHCSIA, *Committee Hansard*, 28 June 2012, p. 10.

35 Ashurst Australia, *Submission 49*, p. 18.

36 Ashurst Australia, *Submission 49*, p. 18.

37 FaHCSIA, *Submission 8*, Answer to Question on notice, p.1.

38 Ashurst Australia, *Submission 49*, p. 19.

39 Ashurst Australia, *Submission 49*, p. 19.

- Impairment Tables. The person must be unable to work or participate in the supported wage system.<sup>40</sup>
- 5.45 Disability Support Pensioners can receive the Youth Disability Supplement if they are younger than 21 and can only work up to 30 hours per week.<sup>41</sup>
- 5.46 To receive the Mobility Allowance, a person must be aged over 16, have a physical or mental disability, and be unable to use public transport without substantial assistance either permanently or for an extended period due to this disability. They must also be undertaking employment, vocational training, a vocational rehabilitation program or voluntary work, or seeking work.<sup>42</sup>
- 5.47 As discussed in earlier, people with FASD can have serious cognitive impairments that require intensive care and supervision, but may not have physical disabilities, low IQ, or psychiatric or mental illness. These people would then be ineligible for these disability support payments. For example, the Committee heard about a young woman with FASD whose IQ is just above the threshold of 70 for intellectual disability:
- Her IQ is 74 and she just falls outside disability support and yet at 16 she still has to be reminded how to wash, clean her teeth and dress appropriately.<sup>43</sup>
- 5.48 The Commonwealth Government provides a variety of other support for people with disabilities. These include:
- the Australian Disability Parking Scheme;<sup>44</sup>
  - community care services;<sup>45</sup>
  - the National Companion Card;<sup>46</sup>
  - the National Disability Advocacy Program;<sup>47</sup>
  - Outside School Hours Care for Teenagers with Disability;<sup>48</sup>
  - Special Disability Trusts;<sup>49</sup>
  - Australian Disability Enterprises;<sup>50</sup>

40 Ashurst Australia, *Submission 49*, p. 14.

41 Ashurst Australia, *Submission 49*, p. 16.

42 Ashurst Australia, *Submission 49*, p. 20.

43 Name withheld, *Submission 50*, p. 1.

44 FaHCSIA, *Australian Disability Parking Scheme*.

45 DoHA, *Help to stay at home - community care*.

46 Australian Government, *The National Companion Card Scheme*.

47 FaHCSIA, *National Disability Advocacy Program*.

48 FaHCSIA, *Outside School Hours Care for Teenagers with Disability*.

49 FaHCSIA, *Special Disability Trusts*.

- Disability Employment Services;<sup>51</sup>
  - CRS Australia (formerly known as the Commonwealth Rehabilitation Service);<sup>52</sup>
  - the Disabled Australian Apprentice Wage Support Program;<sup>53</sup>
  - Job in Jeopardy Assistance;<sup>54</sup> and
  - Job Access.<sup>55</sup>
- 5.49 Eligibility for these services often hinges on having a diagnosed 'disability', which is undefined.<sup>56</sup> Ashurst Australia analysed the eligibility criteria for these services, and found that most would be available to some people with FASD if their condition was severe, but that there was no guarantee or clarity on determining eligibility.<sup>57</sup>

## Actions

- 5.50 Currently access to the above support payments is unpredictable and unclear for individuals with FASD and their carers. The eligibility criteria and terminology need to be changed to include cognitive impairment to ensure access for all people with FASD. As the payment system does not include a specific code for FASD, FaHCSIA is unaware how many people with FASD or their carers receive income support.<sup>58</sup>
- 5.51 FaHCSIA explained that even though FASD is not on the List of Recognised Disabilities:
- ... people can still test their eligibility for carer allowance under the disability care load assessment, which is something that measures the level of care required by the child and the level of

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50 Australian Government, *Australian Disability Enterprises*.

51 Commonwealth Government Department of Education, Employment and Workplace Relations (DEEWR), *Disability Employment Services*.

52 Australian Government, *CRS Australia*.

53 Commonwealth Government Department of Human Services, *Disabled Australian Apprentice Wage Support*.

54 Commonwealth Government Department of Human Services, *Job in Jeopardy Assistance*.

55 Australian Government, *Job Access*, <<http://jobaccess.gov.au/Home/Home.aspx>> viewed 9 July 2012.

56 See for example, FaHCSIA, <<http://www.fahcsia.gov.au/our-responsibilities/disability-and-carers/program-services/for-people-with-disability/outside-school-hours-care-for-teenagers-with-disability>>; DEEWR, *Support for Job Seekers – Overview*, <<http://www.deewr.gov.au/Employment/Programs/DES/SJS/Pages/home.aspx>>; Commonwealth Government Department of Human Services, *Disabled Australian Apprentice Wage Support*, <<http://www.humanservices.gov.au/customer/services/centrelink/disabled-australian-apprentice-wage-support>> viewed 10 July 2012.

57 Ashurst Australia, *Submission 49*, pp. 26–39.

58 L Corver, FaHCSIA, *Committee Hansard*, 28 June 2012, p. 9.

care provided by the carer – or, in the case of carer allowance adult, using the adult disability assessment tool which measures the functional ability of the care receiver. So the carers of people with fetal alcohol spectrum disorder who are severely affected would qualify.<sup>59</sup>

5.52 Ashurst Australia pointed out that this method is ‘more time consuming and difficult’ than the streamlined process of identifying a disability on the List of Recognised Disabilities.<sup>60</sup>

5.53 Moreover, Ashurst Australia emphasised that ‘impairment’ is not defined in legislation, and considers that:

The adoption of a broader and clearer term than ‘intellectual impairment’ would create greater certainty for people with FASD and other cognitive impairments about whether or not they fall within this limb of the test for a Disability Support Pension.<sup>61</sup>

5.54 Ashurst Australia prefers the term ‘cognitive impairment’ as it is more inclusive:

Cognitive impairment encompasses, but is not limited to, intellectual impairment, and is not measured by reference to IQ. ... a cognitive impairment or disorder means a loss of brain function affecting judgment and resulting in a decreased ability to process, learn or remember information.<sup>62</sup>

5.55 Including FASD on the List of Recognised Disabilities and defining disability to include cognitive impairment would enhance access for people with FASD to the Carer Allowance for children, Carer Payment for adults, the Disability Support Pension and other disability support payments.

5.56 Some witnesses recommended that FASD should be included in the Commonwealth Government’s Better Start for Children with a Disability Initiative (Better Start).<sup>63</sup> Better Start provides funding for early intervention services and treatments for children diagnosed with Down syndrome, cerebral palsy, Fragile X syndrome, or a moderate or greater vision or hearing impairment, including deafblindness, and from 2013, Prader Willi, Williams, Angelman, Kabuki Make Up, Smith-Magenis,

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59 L Corver, FaHCSIA, *Committee Hansard*, 28 June 2012, p. 8.

60 Ashurst Australia, *Submission 49*, p. 19.

61 Ashurst Australia, *Submission 49*, p. 15.

62 Ashurst Australia, *Submission 49*, p. 9.

63 See National Rural Health Association, *Submission 40*; National Council on Intellectual Disability (NCID), *Submission 9*; NOFASARD, *Submission 46*; Russell Family Fetal Alcohol Disorders Association (RFFADA), *Submission 1*; FARE/PHAA, *Submission 36*.

CHARGE, Cornelia de Lange or Cri du Chat syndromes or microcephaly.<sup>64</sup> Additional funds are available for children who live in rural or remote locations.

- 5.57 The Foundation for Alcohol Research and Education and Public Health Association of Australia noted that as currently relatively few children are diagnosed with FASD, the cost of expanding Better Start to include FASD would not be prohibitive, whereas the benefit would be enormous.<sup>65</sup> Ms Russell stated that people with FASD and their carers need a funding initiative for early intervention for FASD similar to Better Start.<sup>66</sup>

### Figure 5.3 Helping children with autism

The Australian Government has committed ongoing funding to address the need for services for children with Autism Spectrum Disorder, their families and carers.

The package includes:

- Autism Advisors who provide information regarding eligibility, available funding and Early Intervention and other support services.
- Funding for early intervention services to facilitate improved cognitive, emotional and social development prior to a child starting school.
- PlayConnect Playgroups, providing play-based learning opportunities.
- Early Days family workshops, aimed at equipping parents and carers to more effectively manage the pressures they face in raising their children at home.
- A website that provides information, online resources and interactive functions to support parents, families, carers and professionals.
- An additional one-off payment for families who reside in outer regional or remote areas who have difficulty accessing early intervention services.

Source <http://www.fahcsia.gov.au/our-responsibilities/disability-and-carers/program-services/for-people-with-disability/helping-children-with-autism>

- 5.58 The Commonwealth Government already funds Helping Children with Autism, an Autism Spectrum Disorder-specific early intervention package that is similar to Better Start. See Figure 5.3 above for information on Helping Children with Autism initiative.

64 FaHCSIA, *Better Start for Children with Disability Initiative*, <<http://www.fahcsia.gov.au/our-responsibilities/disability-and-carers/program-services/for-people-with-disability/better-start-for-children-with-disability-initiative>> viewed 7 November 2012.

65 FARE/PHAA, *Submission 36*, p. 5.

66 A Russell, Executive Officer, RFFADA, *Committee Hansard*, Cairns, 31 January 2012, p. 3.

- 5.59 There may be more hope for support for people with FASD when the National Disability Insurance Scheme (NDIS) is implemented after its planned roll-out next year. DoHA and FaHCSIA stated that the NDIS:
- ... will ensure that people with significant and permanent disability receive the care and support they need over their lifetimes, regardless of where they live or how they acquired their disability.<sup>67</sup>
- 5.60 The Australian Human Rights Commission is very supportive of the NDIS, claiming that it:
- ... has the potential to transform the way services are funded and delivered, ensuring people with significant and ongoing disability, which would include many people with FASD, are better supported and have greater choice and control. The NDIS will also mean better support for the families and carers of people with disability.<sup>68</sup>

## Education

- 5.61 Children with FASD typically have learning and behavioural disabilities that manifest or become more apparent in the classroom context. Just like any other child with a disability, children with FASD should receive the support necessary to function and progress in school. In a similar way to disability income support, schools struggle to access resources and funds to provide the extra supports for children with FASD as it is not currently a recognised disability.
- 5.62 Children with FASD may have difficulty with the stimulating, demanding and complicated environment of school.<sup>69</sup> They may need a different education model:
- It is not right to keep them struggling in the classroom which they find hard and often boring. We need to have a curriculum for life, rather than an academic curriculum, to suit these kids.<sup>70</sup>

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67 DoHA/FaHCSIA, *Submission 78*, p. 5.

68 Australian Human Rights Commission, *Submission 54*, p. 11.

69 Manitoba Government Canada, *What Early Childhood Educators need to know about Fetal Alcohol Spectrum Disorder (FASD)*, p. 8, <[http://www.gov.mb.ca/healthychild/fasd/fasdearly\\_en.pdf](http://www.gov.mb.ca/healthychild/fasd/fasdearly_en.pdf)> viewed 11 September 2012.

70 Professor E Elliott, University of Sydney, *Committee Hansard*, Canberra, 24 November 2012, p. 2.



Figure 5.4 Performance problems associated with FASD

Prenatal alcohol exposure often results in central nervous system dysfunction that affects a student's ability to successfully perform in an academic setting. The frequency and magnitude of these problems varies greatly among affected students and is not correlated to IQ scores.

- Compromised executive functioning; may have difficulty planning, predicting, organizing, prioritizing, sequencing, initiating, and following through. Difficulty setting goals, complying with contractual expectations, being on time, or adhering to a schedule.
- Difficulty with memory; information input, integration, forming associations, retrieval, and output. Difficulty learning from past experiences. Often repeats the same mistake over and over again in spite of increasingly severe punishment.
- Inconsistent memory or performance; may remember on Monday but forget by Thursday.
- Difficulty with abstract concepts such as time, math, or money.
- Impaired judgment; often unable to make decisions. Difficulty differentiating safety from danger, friend from stranger, or fantasy from reality.
- Inability to generalize information; difficulty forming links and associations, unable to apply a learned rule in new setting.
- Communication challenges; appears to understand instructions, but actually does not comprehend. Often repeats rules verbatim, then fails to apply them.
- Language problems; difficulty comprehending the meaning of language and accurately answering questions. May agree or confabulate, comply or fill in the blanks. May talk excessively, yet be unable to engage in a meaningful exchange. The sheer volume of words may create the impression of competence.
- Slow cognitive pace; may think more slowly, may require minutes to generate an answer rather than seconds. Students with FASD are 'ten-second people in a one-second world.'
- Slow auditory pace; central auditory delays means language is processed more slowly, requiring more time to comprehend. Many students only grasp every third word of normally paced speech.
- Perseveration; may be rigid, get stuck, have difficulty switching gears, stopping an activity, or transitioning to a new one. Often reacts strongly to changes in setting, program, and/or personnel.
- Dysmaturity; often functions socially, emotionally, and cognitively at a much younger level of development than chronological age.
- Impulsivity coupled with inability to abstract and predict outcomes; acts first and then is able to see the problem after the fact.

Source: Adapted from D Malbin, 'Fetal Alcohol Spectrum Disorder and the Role of Family Court Judges in Improving Outcomes for Children and Families', *Juvenile and Family Court Journal*, Spring 2004, p. 9.

- 5.63 The Australian Special Education Principals' Association noted that FASD is identified as the largest cause of non-genetic learning disabilities.<sup>71</sup> Moreover, the National Council on Intellectual Disability (NCID) stated that at least 35 per cent of children at school with FASD have an intellectual disability.<sup>72</sup>
- 5.64 Children with FASD may have a cognitive rather than intellectual impairment or low IQ, but nonetheless have difficulties with numeracy, literacy, memory, attention, and judgement.<sup>73</sup> Other symptoms, such as speech, hearing or vision problems, behavioural issues, hyperactivity, short attention span and difficulties forming social relationships, contribute to the high risk of children with FASD not completing school.<sup>74</sup>
- 5.65 When the source of behavioural and social problems is not recognised, children with FASD are considered to be uncontrollable or troublesome. The NCID stated that children with FASD were often branded as difficult, obstructive, defiant and wilful.<sup>75</sup>
- 5.66 Students with FASD are often suspended or removed from schools due to their behaviour. At a FAS workshop in Cape York, Queensland, a participant noted that some local children that had been expelled from school were not to blame as they had symptoms of FAS.<sup>76</sup> One foster carer said that her child was removed from the mainstream school system at the age of seven due to his failings at school.<sup>77</sup> Another carer is home-schooling her child:
- ... due to an expulsion for violent and threatening behaviour and we do not know how long this situation will last because there are no positions available in the foreseeable future in a school that is able to cope with his needs.<sup>78</sup>

## Challenges

- 5.67 Such situations can occur when there is insufficient knowledge and understanding of FASD or resourcing of support. Many parents and carers

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71 F Forbes, 'Towards Inclusion: An Australian Perspective', *Support for Learning*, vol. 22, no. 2, 2007, p. 67.

72 NCID, *Submission 9*, p. 8.

73 Professor E Elliott, University of Sydney, *Committee Hansard*, Sydney, 13 April 2012, p. 5; NOFASARD, *Submission 46*, p. 3.

74 Alcohol and other Drugs Council of Australia (ADCA), *Submission 33*, p. 4.

75 NCID, *Submission 9*, p. 8.

76 L Hayes, *Submission 80*, p. 19.

77 Name withheld, *Submission 8*, p. 2.

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

were placed in the position of having to educate schools on FASD, with varying degrees of success.

- 5.68 In one situation the parents had provided information to the school and the teacher about FASD and their child, but the teacher continued to view FASD-related behavioural issues as naughtiness:

Even though we had given her all the information and done all that sort of stuff, she still thought it was a behaviour issue – which drives me crazy.<sup>79</sup>

- 5.69 In contrast, another teacher was keen to learn all she could about FASD after receiving an educational DVD from the foster carer:

She asked if I minded if she kept [the DVD] at school to let the other teachers see it because there would be other children who may have the same behaviours, which may come under the same diagnosis.<sup>80</sup>

- 5.70 In his submission, Paul Harper compared and contrasted the schools that his foster daughter attended. Some were not willing to listen to and work with parents or carers, whereas others were cooperative and proactive:

Ashwood School performed wonderfully in teaching Debbie to read and do everyday tasks like tie her laces. The energy and attitude in tailoring programs that actually work was obvious to see. They kept us on our toes, introducing new things on their own initiative and involving us in every aspect of curriculum development. They always had multiple staff at meetings and always resolved issues by following them up promptly. This developed over 5 years into a truly collaborative approach to Debbie's learning.<sup>81</sup>

- 5.71 The Commonwealth Disability Standards for Education 2005 clarify the obligations of education and training providers to ensure that students with disabilities are able to access and participate in education and training on the same basis as those without disability.<sup>82</sup>

- 5.72 However, a recent review of these standards noted that the effectiveness of the Standards is somewhat compromised by a lack of resources, such as funding allocations, professional development for educators and the provision of support services.<sup>83</sup> Another concern was the lack of

79 L Chataway, *Committee Hansard*, Townsville, 31 January 2012, p. 17.

80 D O'Leary, Foster Carer, Wee Care Shared Family Care, *Committee Hansard*, Townsville, 31 January 2012, p. 7.

81 P Harper, *Submission 14*, p. 7.

82 DEEWR, *Disability Standards for Education*, 2005.

83 DEEWR, *Report on the Review of Disability Standards for Education 2005*, 2012, p. 48.

transparency about funding decisions and how funds for students with disability were allocated in the school setting. It was suggested that the consultation process would be improved if parents were advised of how funding decisions were determined.<sup>84</sup>

- 5.73 The Committee heard evidence that supported these findings. In Fitzroy Crossing, the Committee heard that the funding structure of the Department of Education does not permit the employment of Allied Health professionals.
- 5.74 Barnardos claimed that they have been asked by schools that lacked sufficient funding to provide teachers' aides to enable their foster children to attend class.<sup>85</sup>
- 5.75 Despite advice from the Queensland Government that students should receive assistance based on their needs rather than their diagnosis, Robert Chataway's foster son was initially denied assistance under the Education Adjustment Program as he did not fit into the six categories of disability and would therefore not attract 'a bucket of funds'.<sup>86</sup>
- 5.76 Another foster carer in South Australia contacted NOFASARD out of concern at the lack of funding from the Department of Education and Child Services for FAS 'as it seems that no one knows what it really is'.<sup>87</sup>
- 5.77 The Committee heard from schools and teachers who are committed to ensuring the best education for students with FASD but who lack funding and resources to accomplish this. Dale Vaughan, a School Health Nurse in Broome, stated that:
- ... one of the biggest issues we have in the school system is that there is no funding for these children. ... there is no funding under the Schools Plus system to assist the teachers with these children, who have very significant needs and are very difficult to teach.<sup>88</sup>
- 5.78 In Fitzroy Valley, the Lililwan Project has resulted in a number of children being diagnosed with FASD and provided with management plans. Although the management plans should result in appropriate strategies, including educational strategies, for the children:
- ... what we find now is that the workload for teachers and for administrators in the school is going up exponentially in terms of the recommendations that are being made in these reports to help

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84 DEEWR, *Report on the Review of Disability Standards for Education 2005*, 2012, p. 48.

85 E Cox, Senior Manager, Barnardos Australia, *Committee Hansard*, Sydney, 13 April 2012, p. 30.

86 Dr R Chataway, *Committee Hansard*, Townsville, 31 January 2012, pp. 14-15.

87 NOFASARD Disorders, *Submission 46b*, p. 1.

88 D Vaughan, School Health Nurse, Broome Community Health, *Committee Hansard*, Broome, 12 July, p. 1.

us provide the support for these kids but not having the resources to do it effectively.<sup>89</sup>

## Actions

- 5.79 The principal of Fitzroy Valley District High School informed the Committee what the Australian Government needed to do:

From a schooling perspective, what the government can do is to start by recognising that [FASD] is a disability. We cannot do anything while it is just words and is not supported. Obviously the state system provides the support staff to work with the kids, but they will not recognise it if the federal government does not recognise it as a disability.<sup>90</sup>

- 5.80 According to the Department of Education, Employment and Workplace Relations, the Commonwealth Government has committed extra funding for schools to provide the support that students with a disability require:

The *More Support for Students with Disability* initiative will provide \$200 million in additional funding over two years to government and non-government education authorities to support their work with students with disability and/or learning difficulties. ... Education authorities will be able to use funding to increase support for students with disability by building the capacity of schools and teachers to better meet their individual needs. This will be accomplished through selection of a range of activities that may include the provision of coordinated services by health specialists within a school (e.g. occupational therapy), adapted curriculum tailored to students' needs based on the latest expert advice and provision of assistive technology to support students' learning in the classroom.<sup>91</sup>

- 5.81 Such funding is essential for teachers to be able to work in tandem with allied health professionals:

The availability of health professionals such as psychologists in the education system would reduce the stress to students with FASD and other students. The role of these health professionals would be to support teachers on how to manage children with FASD. This

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89 B Wagner, Teacher, Fitzroy Valley District High School, *Committee Hansard*, Mimbi, 11 July, p. 10.

90 D Bridge, Principal, Fitzroy Valley District High School, *Committee Hansard*, Mimbi, 11 July, pp. 2-3.

91 DEEWR, *Submission 55a*, p. 3.

- would enable capacity building within the education system on the management of children and young people with FASD.<sup>92</sup>
- 5.82 In addition to funding, educating teachers about FASD and how to teach students with FASD is crucial. The Telethon Institute noted that education and support for teachers 'is important to enable them to understand the different approaches required to aid a child with a FASD through school'.<sup>93</sup>
- 5.83 Wendy Takle, who is a foster carer, agreed and recommended 'more resources and more education for the teachers on how to actually teach the children' as each child with FASD may have different learning abilities and needs.<sup>94</sup>
- 5.84 The ACCG submitted that:
- ... educational resources that support the learning of children with FASD are urgently required. Maintaining engagement with the educational system is an important protective factor in children's lives and has significant bearing on their life outcomes.<sup>95</sup>
- 5.85 The NCID called upon the Commonwealth Government to work with states and territories to improve FASD training for teachers and teachers' aides.<sup>96</sup>
- 5.86 There are some information sources on FASD for teachers and education providers in Australia. These resources have been developed by a range of organisations and are available online.
- 5.87 The *Count Us In!* teaching resource package from Western Australia outlines the disability requirements that must be met in schools and provides information on a variety of disabilities, including FASD.<sup>97</sup> The Office for Disability in Victoria provides similar information on disabilities, including FASD, for schools through the Bar None Community Awareness Kit.<sup>98</sup>
- 5.88 *Physical as anything.com* is a website on medical conditions, written for teachers, schools, healthcare professionals, students and families and endorsed by the New South Wales Department of Education and

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92 Australian College of Children and Young People's Nurses, *Submission 63*, p. 2.

93 Telethon Institute, *Submission 23*, p. 4.

94 W Takle, Foster carer, Barnardos, *Committee Hansard*, Sydney, 13 April 2012, p. 34.

95 ACCG, *Submission 62*, p. 7.

96 NCID, *Submission 9*, p. 8.

97 Disability Service Commission WA, *Count Us In! Teacher Information: Book 1*, 2005.

98 Office for Disabilities, *Bar None Community Awareness Kit for Schools*, <[www.officefordisability.vic.gov.au](http://www.officefordisability.vic.gov.au)> viewed 18 September 2012.

- Communities and NSW Health.<sup>99</sup> It includes a detailed description of FASD and its educational implications, written by experts in the field of FASD.
- 5.89 However, none of these resources compare to those available to teachers in Canada. The province of Manitoba has issued a comprehensive document titled *What Educators Need to Know about Fetal Alcohol Spectrum Disorder (FASD)*.<sup>100</sup> This booklet provides detailed information on the needs of children with FASD at school and appropriate teaching strategies. A companion document, *What Early Childhood Educators Need to Know about Fetal Alcohol Spectrum Disorder (FASD)*, is also available.<sup>101</sup>
- 5.90 Alberta has published a textbook, *Teaching students with Fetal Alcohol Spectrum disorder: Building strengths, creating hope*, in its special needs series of education resources.<sup>102</sup>

## Criminal Justice System

- 5.91 Individuals with FASD who come into contact with the criminal justice system may not have their disabilities taken into account by judicial officers. Due to the broad spectrum of FASD, some people with FASD may fit within current definitions of disability for the purpose of sentencing that takes into account reduced culpability. Others, however, may not, despite having significant impairments that should be considered mitigating factors.
- 5.92 In the *Doing Time – Time for Doing* report, the Standing Committee on Aboriginal and Torres Strait Islander Affairs highlighted the connection between FASD and the involvement of young people with the criminal justice system in Australia.<sup>103</sup>

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99 NSW Department of Education and Communities, <[www.physicalasanything.com.au](http://www.physicalasanything.com.au)> viewed 18 September 2012.

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

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

102 Alberta Learning, Special Programs Branch, *Teaching students with Fetal Alcohol Spectrum disorder: Building strengths, creating hope*, 2010, <[www.learning.gov.ab.ca/k\\_12/specialneeds/resource.asp](http://www.learning.gov.ab.ca/k_12/specialneeds/resource.asp)> viewed 5 November 2012.

103 Parliament of Australia, Standing Committee on Aboriginal and Torres Strait Islander Affairs, *Doing Time – Time for Doing: Indigenous youth in the criminal justice system*, June 2011, pp. 96-103.

- 5.93 International research shows that there is a high prevalence of youth and adults with FASD in the criminal justice system. The Alcohol and Other Drug Council of Australia (ADCA) cited statistics from the National Organization on Fetal Alcohol Syndrome in the US, which stated that 61 per cent of adolescents and 58 per cent of adults with FASD in the US have been in trouble with the law, and that 35 per cent of those with FASD over the age of 12 had been incarcerated at some point in their lives.<sup>104</sup> Another US study found that 60 per cent of people with FASD have been in contact with the criminal justice system.<sup>105</sup>
- 5.94 Anecdotal evidence suggests that people with FASD are over-represented in the Australian legal system as well, but the lack of diagnostic and prevalence numbers mean that currently the problem is difficult to quantify.<sup>106</sup>
- 5.95 The First Peoples Disability Network (FPDN) stated that:
- Our evidence is anecdotal but in the experience of the FPDN it is not uncommon to meet Aboriginal people who are either in jail or are in contact with the criminal justice system who it would appear have some form of FASD ... The FPDN is not aware of any quantitative data on the prevalence of FASD amongst the Aboriginal prison population for instance which may serve to highlight the significance of FASD as an issue.<sup>107</sup>

## Challenges

- 5.96 Legal Aid NSW stated that the behaviours that are symptomatic of FASD are what bring people with FASD to the attention of the criminal justice system.<sup>108</sup> Individuals with FASD tend to behave impulsively, which 'may lead to stealing things for immediate consumption or use, unplanned offending and offending behaviour precipitated by fright or noise'.<sup>109</sup> ADCA added that people with FASD:
- ... are typically impulsive and have trouble foreseeing the consequences of their actions; they may have a poor sense of

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104 ADCA, *Submission 33*, p. 8.

105 H Douglas et al, 'Judicial Views of Foetal Alcohol Spectrum Disorder in Queensland's Criminal Justice System', *Journal of Judicial Administration*, vol. 21, no. 3, February 2012, p. 178.

106 Dr B Towler, Principal Medical Advisor, DoHA, *Committee Hansard*, Canberra, 28 June 2012, p. 8; National Drug Research Institute, *Submission 20*, p. 5; FARE/PHAA, *Submission 36*, p. 22.

107 First Peoples Disability Network, *Submission 75*, p. 5.

108 D Maher, Solicitor in Charge, Children's Legal Service, Legal Aid New South Wales, *Committee Hansard*, Sydney, 13 April 2012, p. 17.

109 H Douglas, 'The Sentencing Response to Defendants with Foetal Alcohol Spectrum Disorder', *Criminal Law Journal*, vol. 34, 2010, p. 223.



personal boundaries; many are very susceptible to peer pressure, they can be easily led, and their judgment is often poor.<sup>110</sup>

- 5.97 A Canadian judge noted that ‘governments now know people with FASD will increasingly fill the prisons because they have a high rate of re-offending, act on impulse and do not consider the consequences’.<sup>111</sup>
- 5.98 Lack of appropriate health, education or welfare support services can lead to individuals with FASD being diverted to, rather than away from, the criminal justice system. A joint submission from NSW and ACT legal services advised that they have noticed that behavioural problems associated with disabilities are being addressed by schools, care workers and parents with apprehended violence orders instead of referral to relevant health and welfare organisations. This is particularly the case for people with FASD as it is not a registered disability and therefore not linked to any specific support services.<sup>112</sup>
- 5.99 Such situations are particularly acute in remote areas where support services are non-existent, leading to the criminal justice system acting as the first point of contact for people with behavioural problems stemming from disabilities.<sup>113</sup> The ADJC expressed their general concern about what they describe as the widespread and unwarranted use of prisons for the management of unconvicted Indigenous people with cognitive impairments.<sup>114</sup>
- 5.100 Although people with FASD are more likely to come into contact with the criminal justice system, the system is not designed for people with the type of impairments associated with FASD. Individuals with FASD may confess or agree to any statement due to high suggestibility and eagerness to please.<sup>115</sup> Moreover, they may have little understanding of the various legal processes and the gravity of their situation.<sup>116</sup>

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110 ADCA, *Submission 33*, p. 8.

111 H Douglas, ‘The Sentencing Response to Defendants with Foetal Alcohol Spectrum Disorder’, *Criminal Law Journal*, vol. 34, 2010, p. 228.

112 Legal Aid New South Wales and Aboriginal Legal Service (New South Wales/Australian Capital Territory), *Submission 44*, p. 4.

113 P McGee, Coordinator, Aboriginal Disability Justice Campaign (ADJC), *Committee Hansard*, Sydney, 13 April 2012, p. 25.

114 ADJC, *Submission 43*, p. 1.

115 H Douglas et al, ‘Judicial Views of Foetal Alcohol Spectrum Disorder in Queensland’s Criminal Justice System’, *Journal of Judicial Administration*, vol. 21, no. 3, February 2012, p. 180.

116 Western Australia Department of the Attorney-General, *Equality Before the Law Bench Book*, 2009, p. 4.2.7 <[www.supremecourt.wa.gov.au/\\_files/equality\\_before\\_the\\_law\\_bench\\_book.pdf](http://www.supremecourt.wa.gov.au/_files/equality_before_the_law_bench_book.pdf)> viewed 5 November 2012.

- 5.101 Ian McKinley, a member of the Aboriginal Disability Justice Campaign described the tragic pathway from cradle to prison of many children with FASD:

Most of these children are born in remote communities to mothers who are alcoholics. They have no parental care. They fail to thrive. They are in and out of the local clinics. They end up in hospital with gastro and other ailments from the early infant years. Their care usually defaults to aunts or grandmothers on a community. By that stage they are on Territory child welfare, or state child welfare in the other states. They go through to early schooling. They drop out of school. It is probably misdiagnosed as attention deficit syndrome. They are teased and rejected by the other children in the community. Their challenging behaviours are starting to manifest by that stage. By the age of six or seven, they start to become victims of physical abuse and sexual abuse, especially the young females. They have no peer inclusion. They are still under child welfare at that stage. By the early teen years, they have probably been referred to the Territory's aged and disability services, but no services are offered at all... Then they start to fall within the reach of the criminal justice system. At the age of 18, they come under adult guardianship. There are still no services offered, so virtually they are coming off the communities to prison as the first intervention of any significance, and that is where they remain. And they are either under this unfitness-to-plead legislation on indefinite prison based custodial supervision orders or they are in and out of jail as recidivists, virtually full-time prisoners. The recidivists perhaps represent the greater number than those on custodial supervision orders – and there is simply no proposed solution.<sup>117</sup>

- 5.102 Individuals with FASD also have difficulty understanding consequences and connecting cause and effect. As such, responding to orders, sentences or rehabilitation is often unsuccessful:

As a result of deficits in executive function resulting in memory difficulties, inability to plan and failure to recognise the consequences of actions, many of those with FASD are likely to fail to pay fines and to breach probation orders and good behaviour bonds.<sup>118</sup>

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117 I McKinley, Member, ADJC, *Committee Hansard*, Sydney, 13 April 2012, p. 18.

118 H Douglas, 'The Sentencing Response to Defendants with Foetal Alcohol Spectrum Disorder', *Criminal Law Journal*, vol. 34, 2010, p. 228.

5.103 Dr David Hartman agreed:

Because of the nature of their disability they are not very good at learning from experience and do not respond very well to normal juvenile justice measures like a community service order or a good behaviour order or something of that nature, which requires a bit of ability to plan and learn from experience.<sup>119</sup>

5.104 However, identifying individuals with FASD is not straightforward:

People with brain impairments often act like everyone else. They learn what is called a 'cloak of competency.' They walk and talk and act completely normal. They mimic the behaviours of others and learn coping strategies to hide their struggles.<sup>120</sup>

5.105 In addition to disproportionately frequent interactions with the criminal justice system, submitters were concerned that people with FASD are not receiving justice or appropriate treatment in the courts. This is primarily due to limited understanding and diagnosis of FASD, and the specific terminology used in the law:

As with welfare-related law and policy, the terms used to determine who may have their disability taken into account in the criminal law, and the definitions of those terms, are varied and often inconsistent.<sup>121</sup>

5.106 Ashurst Australia, a law firm that has been providing pro bono legal services for people with mental illness or cognitive impairment, made a comprehensive submission to the inquiry on how criminal law affects individuals with FASD. Ashurst Australia explained that mental impairment can be recognised as a defence under both the *Criminal Code Act 1995 (Cth)* in the higher courts and the *Crimes Act 1914 (Cth)* in the lower courts.<sup>122</sup> However, the definition of 'mental impairment' differs; in the former, mental impairment includes brain damage, which could apply to people with FASD, whereas the latter only provides for defendants with a mental illness or intellectual disability.<sup>123</sup>

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119 Dr D Hartman, Consultant, Townsville Child and Youth Mental Health Service, *Committee Hansard*, Townsville, 31 January 2012, p. 21.

120 R Denfeld, *Catching the Subtle Signs of Cognitive Impairment, FASD, and other "Invisible" Disabilities*, 2011, Library of Defense <[www.libraryofdefense.org](http://www.libraryofdefense.org)> viewed 22 October 2012.

121 Ashurst Australia, *Submission 49*, p. 24.

122 Ashurst Australia, *Submission 49*, p. 24.

123 Ashurst Australia, *Submission 49*, p. 24. Ashurst Australia further notes that the proportion of people dealt with in courts of summary jurisdiction compared to higher courts means that the limited definition under the *Crimes Act 1914 (Cth)* has a broader impact.

- 5.107 As discussed earlier, individuals with FASD have brain damage that affects their cognitive development, but may not necessarily have an intellectual disability or a mental illness. Such defendants would then be 'precluded from having their lesser culpability taken into account in the lower courts when charged with a federal offence'.<sup>124</sup> Similar inconsistencies occur in state and territory criminal law systems.<sup>125</sup>
- 5.108 In an article on FASD and the criminal justice system, Associate Professor Heather Douglas observed that intellectual disability has been accepted as a mitigating factor of reduced culpability in Australia. However, in these cases intellectual disability has been defined as 'below average intelligence', which would exclude people with FASD who have normal intelligence despite a lowered cognitive capacity.<sup>126</sup>
- 5.109 Aboriginal Peak Organisations Northern Territory (APONT) submitted that people suspected of having developmental or cognitive impairments will 'enter the criminal justice system without appropriate consideration of their impaired functioning by the court'.<sup>127</sup> The Aboriginal Disability Justice Campaign emphasised the need for 'understanding that there are in fact these categories of people that are not culpable for their actions'.<sup>128</sup>
- 5.110 Individuals who have lesser or no culpability for criminal offences should be treated rather than imprisoned. However, diverting individuals with FASD from the criminal justice system can be difficult when FASD is not recognised as a disability.
- 5.111 Legal aid services note that the lack of diagnostic criteria in Australia leaves individuals with FASD to 'fall between the cracks in terms of diversion into treatment'.<sup>129</sup>
- 5.112 Moreover, there are few diversionary programs available for people with FASD, as it is a non-recognised and under-diagnosed disability. The lack of diversionary options limits the sentencing options for people diagnosed with, or suspected of having, FASD. The APONT stated that:

Without a formal medical diagnosis of FASD, it is difficult for magistrates to rely upon impaired functioning as a mitigating factor in sentencing. Moreover, the dearth of specific management

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124 Ashurst Australia, *Submission 49*, p. 24.

125 Ashurst Australia, *Submission 49*, p. 24.

126 H Douglas, *The sentencing response to defendants with foetal alcohol spectrum disorder*, 2010, 34 Crim LJ 221, p. 231

127 J Paterson, Chief Executive Officer, Aboriginal Medical Services Alliance Northern Territory, *Committee Hansard*, Darwin, 21 June 2012, p. 16.

128 P McGee, ADJC, *Committee Hansard*, Sydney, 13 April, p. 20.

129 Joint Legal Aid, *Submission 44*, p. 7.

services or a centre to coordinate access to community services that may assist an individual with FASD, provide few options for magistrates to effectively and creatively sentence offenders with FASD before the courts. Consequently, sentencing dispositions are rarely able to reflect the difficulties experienced by FASD affected individuals and instead offenders with FASD are subject to the same sentences and punishments, such as imprisonment, as fully functioning offenders, despite this being inappropriate.<sup>130</sup>

## Actions

5.113 In North America, FASD is recognised as a mitigating factor that must be taken into account in sentencing.<sup>131</sup> Associate Professor Douglas noted that:

The explicit identification of FASD in sentencing judgements may help to establish a consistent and appropriate approach to sentencing and may also assist in drawing attention to the need for specific services for this group of offenders.<sup>132</sup>

5.114 Ashurst Australia concurs, arguing that:

For a defendant, the identification of FASD may enable:

- appropriate assistance to be provided to enable the person to better understand the process and their options;
- avoidance of miscarriages of justice arising from the fact that the person does not understand what is being asked of him or her or cannot respond as required by the system;
- diversion from the criminal justice system;
- any reduction in culpability on account of their FASD to be considered in determining the person's guilt or innocence or in sentencing;
- support to be provided to a person to carry out their sentence without being set up to fail; and
- any symptoms of FASD which are causing the person's offending behaviour to be addressed.<sup>133</sup>

5.115 Some steps have been taken in this direction by the Western Australia Supreme Court, which is the first to include FASD in its *Equality Before the*

130 Aboriginal Peak Organisations Northern Territory, *Submission 38*, p. 20.

131 H Douglas, *The sentencing response to defendants with foetal alcohol spectrum disorder*, 2010, 34 Crim LJ 221, p. 231.

132 H Douglas, *The sentencing response to defendants with foetal alcohol spectrum disorder*, 2010, 34 Crim LJ 221, p. 235.

133 Ashurst Australia, *Submission 49*, p. 23.

*Law Bench Book*.<sup>134</sup> Such bench books provide legal practitioners with information that enables them to identify disadvantages that need to be addressed to ensure equal treatment of all individuals. Dr Raewyn Mutch explained:

... we know that these people are in the system, and you cannot offer them equity before the law easily because of their cognitive impairment ... So I wrote to the WA Chief Justice – a remarkable man – and his immediate response was: ‘I fully support you in this endeavour. Here are your letters of introduction to every single criminal body. Could you please provide us more information? We will put that information into our *Equality Before the Law Bench Book*.’ ... So now in this state ... any person who presents to a court, if they have been afforded the diagnosis of FASD, which has not happened very often yet, potentially will be treated with equity before the law.<sup>135</sup>

5.116 However, in law people with FASD are potentially excluded from recognition of their limited competency or from diversionary sentences. Accordingly, Ashurst Australia recommended:

That the threshold criteria for diversion from the criminal justice system and for a person’s disability to be taken into consideration in criminal proceedings be amended in the Commonwealth criminal law to ensure people with FASD can fall within the relevant legislative provisions.<sup>136</sup>

5.117 Ashurst Australia considers that the term ‘cognitive impairment’ is the most appropriate, broadest definition to use in legislation in place of intellectual disability or impairment.<sup>137</sup>

5.118 Ashurst Australia does not believe that using the term ‘cognitive impairment’ would increase the numbers of people eligible for consideration of reduced culpability in the courts, as people with FASD would still have to:

... prove that they have a particular type of illness or disability and that they have functional impairments to a requisite degree. We say that the definition of cognitive impairment should be that

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134 Western Australia Department of the Attorney-General, *Equality Before the Law Bench Book*, 2009, <[www.supremecourt.wa.gov.au/\\_files/equality\\_before\\_the\\_law\\_benchbook.pdf](http://www.supremecourt.wa.gov.au/_files/equality_before_the_law_benchbook.pdf)> viewed 5 November 2012.

135 Dr R Mutch, *Committee Hansard*, Perth, pp. 24–25.

136 Ashurst Australia, *Submission 49*, p. 25.

137 M Seely, Ashurst Australia, *Committee Hansard*, Sydney, 13 April 2012, p. 19.

threshold. It would be broadening the threshold yet relying on a test of the actual impairment that a person lives with.<sup>138</sup>

## Identifying FASD as a disability

5.119 Formally recognising FASD as a disability is seen as the key that unlocks the door to support and assistance for those living with FASD:

It means that ... schools will get support and children will get support in schools. It also means that families will get support. It means that people with a disability themselves can get support throughout their lives. It means that justice outcomes will be fair and equal because of this disability if it is recognised. It means that people with this disability throughout their adult lives can not only get the support they need but make the contributions to their communities that they want to make.<sup>139</sup>

5.120 Ashurst Australia acknowledged that:

People who care for or work with people with FASD consistently tell us that one of the things which must change if people with FASD are to receive the support they need is that FASD needs to be recognised by government as a disability. We hear of people denied benefits and services on the basis that a diagnosis of FASD does not qualify them for the support they are seeking.<sup>140</sup>

5.121 Submitters to the inquiry consistently advocated for FASD to be recognised as a disability on the List of Recognised Disabilities.<sup>141</sup> This would enable carers of children with FASD to automatically receive the Carer Allowance, in the same way that carers of children with Down syndrome or cystic fibrosis automatically receive the Carer Allowance.

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138 M Seely, Ashurst Australia, *Committee Hansard*, Sydney, 13 April 2012, p. 19.

139 M White, *Committee Hansard*, Mimbì, 11 July 2012, p. 4.

140 Ashurst Australia, *Submission 49*, p. 7.

141 Catholic Education Office, *Submission 5*, p. 1; NCID, *Submission 9*, p. 7; Legal Aid NSW and Aboriginal Legal Service NSW/ACT, *Submission 44*, p. 8; Dr R Chataway, *Committee Hansard*, Townsville, 31 January 2012, pp. 14, 20; NOFASARD, *Submission 46*, p. 5; WA Health Country Health Service – Kimberley Population Health Unit Response, *Submission 31*, p. 3; FARE/PHAA, *Submission 36*, p. 6; Australian Women’s Health Network, *Submission 58*, p. 5; Telethon Institute, *Submission 23*, p. 4; Australian Indigenous Doctors Association, *Submission 67*, p. 2; Fetal Alcohol Spectrum Disorder Research Network, *Submission 47*, p. 2; ADCA, *Submission 33*, p. 12; Ashurst Australia, *Submission 49*, p. 19.

- 5.122 Moreover, the impairments associated with FASD need to be treated as seriously as those associated with low IQ, mental illness and psychiatric disorders. Ashurst Australia stated that:
- ... people with other forms of cognitive disability or impairment are often ineligible for benefits which are available to people with mental illness or intellectual disability. They may also fall outside diversionary and other criminal laws which reflect the lesser culpability of a person with mental illness or cognitive disability.<sup>142</sup>
- 5.123 Broadening the definition of disabilities in relevant legislation to include the entire spectrum of severe impairments that affect people with FASD would address this inequity. At present, the terms 'intellectual disability', 'intellectual impairment', 'mental illness' and 'psychiatric illness' do not necessarily encompass a person with FASD, nor others with cognitive deficiencies such as acquired brain injury.<sup>143</sup>
- 5.124 The Committee heard that a favoured term is 'cognitive impairment', which:
- ... encompasses, but is not limited to, intellectual impairment, and is not measured by reference to IQ. The American Psychiatric Association in its *Diagnostic and Statistical Manual of Mental Disorders (DSM- IV-TR)* stated that generally, a cognitive impairment or disorder means a loss of brain function affecting judgment and resulting in a decreased ability to process, learn or remember information.<sup>144</sup>
- 5.125 The Telethon Institute agreed that cognitive impairment is a more effective measurement of disability, particularly as individuals with FASD may not have a low IQ, and that legislation should be amended accordingly.<sup>145</sup>
- 5.126 Ashurst Australia concluded that the Commonwealth Government should lead the way in the use of the term 'cognitive impairment' as a model definition in the appropriate legislation.<sup>146</sup>
- 5.127 Consequently, Ashurst Australia advocated for:
- A nationally consistent definition, which is not exhaustive but which provides strong guidance to those implementing the law and policy, would increase certainty for government and people

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142 Ashurst Australia, sub 49, p. 7.

143 Ashurst Australia, sub 49, p. 9.

144 Ashurst Australia, *Submission 49*, p. 9.

145 H Jones, Telethon Institute, *Committee Hansard*, Perth, 10 July 2012, p. 23.

146 M Seely, Ashurst Australia, *Committee Hansard*, Sydney, 13 April 2012, p. 19.



with FASD about when particular laws and policies apply to people with FASD. It would also assist to remove the barriers faced by people with FASD to the support and services they need.<sup>147</sup>

## Committee Comment

- 5.128 The critical importance of diagnosis was explored in the previous chapter. However, diagnosis is only part of the answer for people with FASD and their families; they must have access to support and management for their disabilities and any secondary conditions for their entire lives.
- 5.129 The Committee heard from a range of witnesses about the difficulties in obtaining financial, educational and justice support for people with FASD.
- 5.130 These difficulties stem from two main problems – lack of understanding of FASD and lack of recognition of FASD as a disability. The Committee considers that improving these two deficiencies will lead to greater awareness of FASD as well as boost funding, research, pilot studies and programs, and policies for FASD support and management strategies.
- 5.131 The Committee advocates for improved understanding and knowledge of FASD, particularly in the education and criminal justice sectors. The behavioural issues that people with FASD may exhibit need to be recognised as disabilities arising from prenatal alcohol exposure, rather than naughty, anti-social or criminal conduct.
- 5.132 The Committee commends the examples of state resources for teachers and judicial officers referred to in this chapter. In line with the Committee’s stance on a cohesive, national FASD strategy, the Committee considers that the production and dissemination of educational material should be managed at a national level rather than left to the political will and resources of each state.

### Recommendation 17

- 5.133 **The Committee recommends that the Commonwealth Government develop educational material to raise awareness about Fetal Alcohol Spectrum Disorders (FASD). These materials should be monitored and informed by the FASD Reference Group.**

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147 Ashurst Australia, *Submission 49*, p. 10.

**In particular, targeted training and materials should be developed for:**

- **special education teacher aides and class teachers;**
- **parents, foster carers and foster care agencies;**
- **police and court officials;**
- **youth workers and drug and alcohol officers; and**
- **officers in correctional facilities and juvenile detention centres.**

- 5.134 Establishing FASD as a recognised disability would increase awareness and knowledge of FASD. The Committee is disappointed that the recommendation made by the Standing Committee on Aboriginal and Torres Strait Affairs in 2011 for FASD to be added to the List of Registered Disabilities was not accepted by the Commonwealth Government.<sup>148</sup>
- 5.135 The Committee finds it inequitable that people with FASD, who often require high levels of care and have significant cognitive impairments, are not eligible for support services in the disability and education sectors in the same way that people with other disabilities are. People with FASD are no less deserving or in need of disability income support or educational assistance and resources.
- 5.136 The Committee is concerned that the reduced culpability of individuals with FASD may not be taken into account in judicial courts, resulting in such people being imprisoned instead of treated.
- 5.137 The Committee received compelling evidence that legislating a clear and inclusive definition of disability would remove the confusion around the eligibility of individuals with FASD for support services and ensure equity before the law for defendants with FASD.

### **Recommendation 18**

- 5.138 **The Committee recommends that the Commonwealth Government include Fetal Alcohol Spectrum Disorders in the List of Recognised Disabilities and the Better Start for Children with a Disability Initiative.**

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<sup>148</sup> Parliament of Australia, Standing Committee on Aboriginal and Torres Strait Islander Affairs, *Doing Time – Time for Doing: Indigenous youth in the criminal justice system*, June 2011, p 103.

**Recommendation 19**

- 5.139 **The Committee recommends that the Commonwealth Government recognise that people with Fetal Alcohol Spectrum Disorders have, amongst other disabilities, a cognitive impairment and therefore amend the eligibility criteria to enable access to support services and diversionary laws.**



## Appendix A – List of Submissions

- 1 The Russell Family Fetal Alcohol Disorders Association
- 2 Dr Mike McDonough
- 3 Anyinginyi Health Aboriginal Corporation
- 4 Ms Barbara Smith
- 5 Catholic Education Office of Western Australia
- 6 Department of Health and Human Services, Tasmania
- 7 Dr Robert Chataway and Mrs Lynette Chataway
- 8 Name Withheld
- 9 National Council on Intellectual Disability
- 10 Mr Michael Stevens
- 11 Confidential
- 12 The Australian Wine Research Institute
- 13 Health Networks Branch (Child and Youth Health Network),  
Department of Health Western Australia
- 14 Mr Paul Harper
- 15 Dr Rosalie Schultz
- 16 Victorian Drug and Alcohol Association
- 17 Women’s Christian Temperance Union
- 18 Brewers Association of Australia and New Zealand
- 19 Australian FASD Collaboration
- 20 National Drug Research Institute
- 21 Uniting Church in Australia
- 21a Uniting Church in Australia - Supplementary Submission
- 22 University of Sydney

- 23 Telethon Institute for Child Health Research
- 24 Ms Anne Foale
- 25 Fetal Alcohol Spectrum Disorder Working Party, Department of Health Western Australia
- 26 National Alliance for Action on Alcohol
- 27 The Royal Australasian College of Physicians
- 28 Drug and Alcohol Office, Department of Health Western Australia
- 29 Ms Prue Walker
- 30 McCusker Centre for Action on Alcohol and Youth, Curtin University
- 31 Kimberley Population Health Unit, Department of Health Western Australia
- 32 Distilled Spirits Industry Council of Australia
- 33 Alcohol and other Drugs Council of Australia
- 34 Barnardos
- 35 The Country Women's Association of Victoria
- 36 Foundation for Alcohol Research and Education
- 36a Foundation for Alcohol Research and Education - Supplementary Submission
- 37 VicHealth
- 38 Aboriginal Peak Organisations Northern Territory
- 39 Winemakers' Federation of Australia
- 40 National Rural Health Alliance
- 41 Mr Warren Harvey
- 42 Confidential
- 43 Aboriginal Disability Justice Campaign
- 44 Legal Aid New South Wales and Aboriginal Legal Service (New South Wales/ Australian Capital Territory)
- 45 Australian National Preventive Health Agency
- 46 National Organisation for Fetal Alcohol Syndrome and Related Disorders
- 47 Fetal Alcohol Spectrum Disorder Research Network
- 48 Ms Elizabeth Pearson
- 49 Blake Dawson (now known as Ashurst Australia)
- 50 Name Withheld

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- 51 New South Wales Ministry of Health
- 52 South Australian Government
- 53 Wuchopperen Health Service
- 54 Australian Human Rights Commission
- 55 Commonwealth Government Department of Education,  
Employment and Workplace Relations
- 55a Commonwealth Government Department of Education,  
Employment and Workplace Relations - Supplementary  
Submission
- 56 National Council of the Women Coalition Tasmania Inc.
- 57 Dr Wendy Hoy
- 58 Australian Women's Health Network
- 59 Drug and Alcohol Nurses of Australasia
- 60 Dr Toni Delany
- 61 Family Planning New South Wales
- 62 Australian Children's Commissioners and Guardians
- 63 Australian College of Children and Young People's Nurses
- 64 Ms Gillian Turner
- 65 Country Women's Association of the Northern Territory
- 66 The Benevolent Society
- 67 Australian Indigenous Doctors' Association Ltd
- 68 Cape York Institute for Policy and Leadership
- 69 Ms Di Harriss
- 70 Steps Group Australia
- 71 Name Withheld
- 72 Ms Jane Montz
- 73 Public Health Association of Australia - Northern Territory  
Branch
- 74 Ngaanyatjarra Pitjantjatjara Yankunytjatjara Women's Council
- 75 First Peoples Disability Network Australia
- 76 Australian Hotels Association Western Australia
- 76a Australian Hotels Association Western Australia  
Supplementary Submission
- 77 Dr Raewyn Mutch

- 78 Commonwealth Government Department of Health and Ageing  
and Commonwealth Department of Families, Housing,  
Community Services and Indigenous Affairs
- 79 Royal Darwin Hospital
- 80 Ms Lorian Hayes
- 81 Ms Suzi Lodder
- 82 People's Alcohol Action Coalition
- 83 Department of Health Northern Territory
- 84 Northern Territory Families and Children Advisory Council
- 85 Name Withheld
- 86 Australia New Zealand Policing Advisory Agency
- 87 National Congress of Australia's First Peoples
- 88 Marulu - The Lililwan Project
- 89 Commonwealth Department of Families, Housing, Community  
Services and Indigenous Affairs
- 90 Australian Government Department of Health and Ageing
- 91 Confidential
- 92 Curtin University



## Appendix B – List of witnesses appearing at public hearings

### **Thursday, 24 November 2011 – Canberra, ACT**

#### **Lililwan Project**

Prof Elizabeth Elliott, University of Sydney

Dr James Fitzpatrick, Paediatric Senior Registrar/Research Chief Investigator, University of Sydney

Prof Jane Latimer, Senior Research Fellow, University of Sydney

Ms June Oscar, Chief Executive Officer

### **Tuesday, 31 January 2012 – Townsville City, QLD**

#### **Individuals**

Mr Robert Chataway

Mrs Lynette Chataway

#### **ACT for Kids**

Ms Renee McAllister, Regional Manager

#### **Townsville Child and Youth Mental Health Service**

Dr David Hartman, Consultant Child and Adolescent Psychiatrist

#### **Wee Care Shared Family Care**

Mrs Rachael Emerson, Support Worker

Mrs Deborah O’Leary, Foster Carer

Mrs Carolyn Travers, Team Leader



**Tuesday, 31 January 2012 – Cairns, QLD**

**Individuals**

Mr Raymond Metzger

Ms Elizabeth Pearson

**Apunipima Cape York Health Council**

Ms Ruth Bullen, Family Health Program Manager

Mr Bernard David, Team Leader, Men's Health

Dr Jacki Mein, Medical Officer, Public Health

Ms Fiona Millard, Health Promotion Officer

Ms Dorelle Pascoe, Health Officer

**Royal Flying Doctor Service**

Ms Marita Box, Primary Health Care Nurse

Ms Gayle Rusher, Child and Family Health Coordination

**Russell Family Fetal Alcohol Disorders Association**

Ms Anne Russell, Executive Officer

**Thursday, 15 March 2012 – Canberra, ACT**

**Australian National Preventive Health Agency**

Mr Jack Quinane, Director, Alcohol Policy and Tobacco Control

Dr Lisa Studdert, Manager, Policy and Programs

**Friday, 13 April 2012 – Sydney, NSW**

**Individuals**

Prof John Whitehall

**Aboriginal Disability Justice Campaign**

Mr Patrick McGee, Coordinator

Mr Ian McKinley, Member

**Ashurst Australia**

Ms Laura Lombardo, Sydney Pro Bono Coordinator/Lawyer

Ms Mary Seely, Senior Associate

**Australian College of Children and Young People's Nurses**

Dr Jennifer Fraser, Board Member

**Barnardos**

Mrs Yvette Bowen, Foster Carer  
Ms Elizabeth Cox, Senior Manager  
Ms Tracey Harth, Foster Carer  
Mr David Jenrick, Regional Manager  
Ms Wendy Takle, Foster Carer  
Miss Bianca Hijniakoff, Case Manager

**Legal Aid New South Wales**

Ms Debra Maher, Solicitor in Charge, Children's Legal Service

**Legal Aid New South Wales and Aboriginal Legal Service (NSW/ACT)**

Mr John McKenzie, Chief Legal Officer

**New South Wales Health**

Ms Janet Falconer, Chemical Use in Pregnancy Service, the Langton Centre

**Royal Hospital for Women**

Dr Ju Lee Oei, Neonatologist

**Royal Australasian College of Physicians**

Prof Elizabeth Elliott

**The Children's Hospital at Westmead/University of Sydney**

Prof Elizabeth Elliott, Professor of Paediatrics and Child Health

**Thursday, 24 May 2012 – Canberra, ACT****Brewers Association of Australia and New Zealand**

Ms Denita Wawn, Chief Executive Officer

**Distilled Spirits Industry Council of Australia Inc**

Mr Gordon Broderick, Executive Director  
Mr Stephen Riden, Manager, Information and Research

**The Australian Wine Research Institute**

Ms Creina Stockley, Manager, Health and Regulatory Information

**Winemakers' Federation of Australia**

Mr Andrew Wilsmore, General Manager, Policy and Government Affairs

**Thursday, 31 May 2012 - Canberra, ACT****Alcohol and other Drugs Council of Australia**

Ms Meredythe Crane, Senior Policy Officer

Mrs Jeannie Little, Chair, Aboriginal and Torres Strait Islander Peoples Working Group

Mr David Templeman, Chief Executive Officer

Prof Ian Webster, Patron

**Foundation for Alcohol Research and Education**

Ms Caterina Giorgi, Manager, Policy and Research

Mr Michael Thorn, Chief Executive Officer

Ms Sarah Ward, Senior Policy Officer

**Public Health Association of Australia**

Ms Melanie Walker, Deputy Chief Executive Officer

**Thursday, 21 June 2012 - Canberra, ACT****Aboriginal Medical Services Alliance Northern Territory**

Mr Chips Mackinolty, Manager, Research Advocacy and Policy

Mr John Paterson, Chief Executive Officer

**Aged Disability Program**

Ms Annie Riley, Section Manager

**Association of Alcohol and Other Drug Agencies NT**

Mr Russell Flynn, Coordinator

**Larrakia Nation Aboriginal Corporation**

Ms Ilana Eldridge, Chief Executive Officer

**Menzies School of Health Research**

Ms Heather D'Antoine, Associate Director, Aboriginal Programs

Prof Sven Silburn, Director, Centre for Child Development and Education

Dr Gurmeet Singh, Senior Research Fellow

**Royal Darwin Hospital**

Dr Charles Kilburn, Director, Maternal and Child Health

Dr Ruth Lennox, Paediatrician

Dr Louise Martin, Paediatrician

**Friday, 22 June 2012 - Melbourne, VIC****Individuals**

Ms Kerry Harper

Rev Paul Mannix Harper

**Murdoch Children's Research Institute**

Associate Prof Jane Halliday, Principal Research Fellow

Ms Evi Muggli, Senior Research Officer

**National Alliance for Action on Alcohol**

Mr Todd Harper, Co-Chair

**National Organisation for Foetal Alcohol Syndrome and Related Disorders**

Ms Sue Miers, Chair

Mrs Vicki Russell, National Project Coordinator

**Synod of Victoria and Tasmania, Uniting Church in Australia**

Dr Mark Zirnsak, Director, Justice and International Mission Unit

**UnitingCare ReGen**

Ms Donna June Ribton-Turner, Director, Clinical Services

**Thursday, 28 June 2012 - Canberra, ACT****Department of Education, Employment and Workplace Relations**

Dr Russell Ayers, Branch Manager, Policy and Strategic Coordination Branch

**Department of Families, Housing, Community Services and Indigenous Affairs**

Ms Leonie Corver, Acting Branch Manager, Disability and Carers Payment Policy Branch, Disability and Carers Group

Ms Caroline Edwards, Group Manager, Strategic Priorities and Land Group

Mr Robert Ryan, Branch Manager, Remote Priorities Branch, Strategic Priorities and Land Group

Ms Karen Wilson, Branch Manager, Disability and Carers Policy, Disability and Carers Group

**Department of Health and Ageing**

Mr David Butt, Deputy Secretary

Ms Colleen Krestensen, Assistant Secretary, Drug Strategy Branch

Dr Bernie Towler, Principal Medical Advisor

**Tuesday, 10 July 2012 – Perth, WA****Australian Hotels Association Western Australia**

Mr Bradley Woods, Chief Executive Officer

**Department of Health Western Australia**

Ms Belinda Whitworth, Senior Development Officer

**Drug and Alcohol Office, Department of Health Western Australia**

Ms Judi Stone, Manager, Workforce Development

Ms Carla Vitale, Senior Project Officer

**Health Networks Branch (Child and Youth Health Network), Department of Health Western Australia**

Ms Sarah McKerracher, Development Officer

**McCusker Centre for Action on Alcohol and Youth**

Prof Tanya Chikritzhs, Advisory Council member

Ms Julia Stafford, Executive Officer

**Telethon Institute for Child Health Research**

Ms Heather Jones, Manager, FASD Projects

Dr Raewyn Mutch, Paediatric Fellow, Alcohol and Pregnancy Research

Dr Janet Payne, Senior Research Officer

Dr Rochelle Watkins, Research Fellow

**Western Australian Network of Alcohol and other Drug Agencies**

Ms Angela Corry, Manager Sector Development Coordination

Ms Deanne Ferris, Communications Officer

**Wednesday, 11 July 2012 – Mimbi, WA****Individuals**

Ms Saraiha Bin-Maurus, Nyul Nyul Ranger

Mrs Olive Knight, School Liason Officer

Ms Chantelle Murray, Nyul Nyul Ranger

Ms Gentilla Rilen, Midwife

Ms Maggie White, Consultant

**Fitzroy Valley District High School**

Ms Donna Bridge, Principal

Ms Amy Goldman, Teacher

Ms Bree Wagner, Teacher

**Kimberley Language Research Centre**

Ms Patsy Bedford, Research Training and Development Officer

Ms Donna Smith, Project Officer

**Marninwarntikura Women’s Resource Centre**

Ms Emily Carter, Deputy Chief Executive Officer

Ms June Oscar, Chief Executive Officer

**New Start Warmun Community Committee**

Ms Tracy Wilkinson, Project Manager

**The Lililwan Project**

Mrs Marmingee Hand, Teacher and Community Education Consultant

Ms Annette Kogolo, Cultural Navigator

**Unity of First People of Australia**

Ms Jane Bieundurry, Community Worker

**University of Sydney**

Prof Elizabeth Elliott, Professor, Paediatrics and Child Health

**Yiramalay Wesley Studio School**

Dr Helen Drennen, Principal

**Yiyili School**

Ms Elizabeth Gilligan, Indigenous Education Officer

**Thursday, 12 July 2012 – Broome, WA****Broome Community Health**

Mrs Dale Vaughan, School Health Nurse

**Broome Regional Aboriginal Medical Service**

Ms Tamsen Prunster, Community Midwife

**Kimberley Population Health Unit, Department of Health Western Australia**

Mrs Arlene Manado, Community Midwife Generalist

Dr David Reeve, Acting Director

Ms Melissa Williams, Maternal and Child Health Coordinator

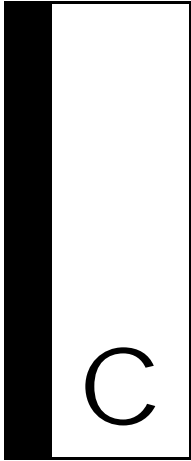
**School Drug Education and Road Aware**

Mr Paul Searle, Regional Education Consultant

**Western Australia Country Health**

Prof John Boulton, Senior Regional Paediatrician, Kimberley Health





## Appendix C – List of exhibits

- 1        Townsville Hospital Foundation (provided by Wee Care Shared Family Care)  
*Foetal Alcohol Syndrome - DVD*
  
- 2        NOFASARD  
*Alcohol and pregnancy – pamphlet (copy)*
  
- 3        NOFASARD  
*Fetal Alcohol Spectrum Disorders: The preventable disability – Pamphlet (copy)*
  
- 4        University of Sydney  
*Marulu - The Lililwan Project*  
*Fetal Alcohol Spectrum Disorders Prevalence Study in the Fitzroy Valley: A Community Consultation - Booklet*
  
- 5        University of Sydney  
*Marulu Trailer - The Lililwan Project - DVD*
  
- 6        Apunipima Cape York Health Council  
*It's in your hands - give your baby the best start in life - DVD*
  
- 7        Apunipima Cape York Health Council  
*Baby Basket Initiative - Brochure*



- 8 Australian Human Rights Commission  
*From community crisis to community control in the Fitzroy Valley – Report extract*
- 9 Royal Flying Doctor Service  
*Report papers*
- 10 National Drug Research Institute, Drug and Alcohol Office, National Drug and Alcohol Research Centre and Public Health Advocacy Institute (provided by Foundation for Alcohol Research and Education)  
*Report 2: Alcohol warning labels: Evidence of impact on alcohol consumption amongst women of childbearing age - Report*
- 11 Food Standards Australia New Zealand (provided by Foundation for Alcohol Research and Education)  
*Fetal alcohol spectrum disorder: Exploratory economic analysis of different prevention strategies in Australia and New Zealand*
- 12 Institute of Health Economics, Canada  
*Consensus Statement on Fetal Alcohol Spectrum Disorder (FASD) - Across the Lifespan - Booklet*
- 13 Institute of Health Economics, Canada  
*Fetal Alcohol Spectrum Disorder (FASD) - Across the Lifespan – Book*
- 14 Institute of Health Economics, Canada  
*Fetal Alcohol Spectrum Disorder - Management and Policy Perspectives of FASD - Book*
- 15 Institute of Health Economics, Canada  
*Prevention of Fetal Alcohol Spectrum Disorder FASD - Who is responsible? - Book*
- 16 Alcohol and other Drugs Council of Australia

*Alcohol Advertisements*

- 17 Alcohol and other Drugs Council of Australia  
*Effect of Exposure to Alcohol during Specific Periods of Pregnancy - Diagram*
- 18 Alcohol and other Drugs Council of Australia  
*Facial characteristics of FAS - Diagram*
- 19 Foundation for Alcohol Research and Education  
*Booze before Babies: Analysis of alcohol industry submissions to the FASD inquiry May 2012 - Report*

