



LEGISLATIVE ASSEMBLY OF THE NORTHERN TERRITORY

**Select Committee on Action to Prevent
Foetal Alcohol Spectrum Disorder**

THE PREVENTABLE DISABILITY

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Chair's Preface

Foetal alcohol spectrum disorder (FASD) is doing untold harm to children in the Northern Territory; harm that will stay with them throughout their lives. Not only does this harm deny those children the life and opportunities they otherwise would have had, but it also puts an immeasurable burden on their families, carers and community. The special needs of FASD children increase the need for health services and require additional resources at school. The cognitive impairments of some FASD sufferers can cause antisocial behaviour and deny the person the capacity for independent living or employment. This can also cost the community with an increase in crime, and the challenge of justly managing individuals who do not understand the consequences of their actions.

This harm done to children, their families, and the community is preventable. FASD has a single cause: the consumption of alcohol while pregnant. The incidence of FASD can be reduced by decreased alcohol consumption of women who are or may become pregnant. This can be achieved by targeted education and support for women of or nearing childbearing age. It can also be achieved by reducing the risky consumption of alcohol throughout the population. Awareness of sexual health and contraception also plays an important role in helping women avoid unwanted pregnancies and avoid alcohol when there is a risk of being pregnant.

Although FASD is preventable, it cannot be cured. The damage done to the foetus generally cannot be reversed. However, the impact that damage has on a person's life can be reduced. Early intervention to help individuals manage their condition can improve their outcomes, and the earlier the intervention the better, with the greatest gains to be had in the first three years.

This report sets out 26 recommendations for action to reduce the terrible harm FASD is doing in the Northern Territory. These recommendations address alcohol management and support services, sexual health, pregnancy support, early childhood support and education services, and FASD diagnostic and support services. However, the greatest gains are to be obtained through prevention, and key to prevention is alcohol management and restriction of supply.

The Northern Territory has made significant progress in the management of alcohol over the last 20 years. Per capita consumption of pure alcohol continues to decrease from around 20 litres per annum prior to the 1990s to less than 13 in 2013. Alcohol related assaults have fallen by as much as up to 50% in regional centres with temporary beat locations recently. However, we need to build on these successes by evaluating what is effective and what is not, and continuing to innovate to bring down alcohol related harm. The Territory still has the highest rates of risky alcohol consumption in the country, and a higher rate of consumption than any other country in the OECD. We cannot afford the damage that the misuse of alcohol is doing in the Territory, and to get further gains we need a coordinated policy approach based on evidence and informed innovation.

Support for pregnancy and early childhood is also important for both preventing and managing FASD. Research is indicating more and more that support and education in

the first years has lifelong benefits, and that this is key for minimising the impact FASD will have on its sufferers and their carers.

Implementing the Committee's recommendations will require funding. The Committee is aware of the current Budget pressures. Nevertheless, we cannot afford the cost of inaction. Investing in FASD prevention will produce significant personal, social and Budget savings into the future.

The recommendations in this report are founded on evidence from 27 submissions and a number of hearings and public forums in Darwin, Katherine, Tennant Creek, Alice Springs and Nhulunbuy. The Committee heard from parents and carers, community members, health, education and community support professionals, business people, and academics. The Committee thanks all those who shared their time, experience and expertise. I thank also my fellow committee members for their work on the Committee and shared commitment to taking action to prevent FASD.

Hon Kezia Purick, MLA

Chair

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The Committee acknowledges the individuals and organisations that provided written submissions or oral evidence and attended public hearings and public forums. The Committee also acknowledges the work of the Parliamentary Library Service for their research assistance.

Acronyms and Abbreviations

ACCG	Australian Children's Commissioners and Guardians
ACFAS	Asante Centre for Fetal Alcohol Syndrome
ADCA	Alcohol and other Drugs Council of Australia
ADHD	Attention Deficit Hyperactivity Disorder
ADJC	Aboriginal Disability Justice Campaign
AEDI	The Australian Early Development Index
AHANT	Australian Hotels Association Northern Territory
AHRC	Australian Human Rights Commission
AMA	Australian Medical Association
AMP	Alcohol Management Plans
AMT	Alcohol Mandatory Treatment
ANPHA	Australian National Preventive Health Agency
ANZPAA	Australia and New Zealand Policing Advisory Agency
AOD	Alcohol and Other Drugs
APO	Alcohol Protection Order
APONT	Aboriginal Peak Organisations Northern Territory
ARBD	Alcohol Related Birth Defects
ARND	Alcohol Related Neurodevelopmental Disorders
ASCC	Alice Springs Correctional Centre
ASD	Autism Spectrum Disorders
BDR	Banned Drinker Register
Better Start	Better Start for Children with a Disability Initiative
CAACAC	Central Australian Aboriginal Congress Aboriginal Corporation
CAALAS	Central Australian Aboriginal Legal Aid Service
CNS	Central Nervous System
DCF	Department of Children and Families
DEEWR	Commonwealth Department of Education, Employment and Workplace Relations
DHHS	Department of Health and Human Services, Tasmania
DoE	Northern Territory Department of Education
DoH	Northern Territory Department of Health

DoHA	Commonwealth Department of Health and Ageing
DSICA	Distilled Spirits Industry Council of Australia
DSM	Diagnostic and Statistical Manual of Mental Disorders
FA/NB	Foetal alcohol/Neuro behavioural
FAE	Foetal Alcohol Effects
FaHCSIA	Commonwealth Department of Families, Housing, Community Services and Indigenous Affairs
FARE	Foundation for Alcohol Research and Education
FAS	Foetal Alcohol Syndrome
FASD	Foetal Alcohol Spectrum Disorder
FNA	Functional neuro behavioural assessment
FPDN	First Peoples Disability Network
HSUI	Health Services Utilization Inventory
IGCD	Intergovernmental Committee on Drugs
KPHU	Kimberley Population Health Unit
LWA	Living with Alcohol
McCusker Centre	McCusker Centre for Action on Alcohol and Youth
Menzies	Menzies School of Health Research
NAAA	National Alliance for Action on Alcohol
NAAJA	North Australian Aboriginal Justice Agency
NCID	National Council on Intellectual Disability
NDS	National Drug Strategy
NHMRC	National Health and Medical Research Council
NOFASARD	National Organisation for Foetal Alcohol Syndrome and Related Disorders
NPA	National Partnership Agreement
NRHA	National Rural Health Alliance
NTAHF	Northern Territory Aboriginal Health Forum
NTCOSS	Northern Territory Council of Social Services
NTDCS	Northern Territory Department of Correctional Services
NTER	Northern Territory Emergency Response
PAAC	People's Action on Alcohol Coalition
PAE	Prenatal alcohol exposure
PCAC	Per Capita Pure Alcohol Consumption

pFAS	Partial Foetal Alcohol Syndrome
PHAA	Public Health Association of Australia
RFFADA	Russell Family Foetal Alcohol Disorders Association
SWSBSC	Strong Women, Strong Babies, Strong Culture
TBLs	Temporary Beat Locations
Telethon Institute	Telethon Institute for Child Health Research
USA	United States of America
WET	Wine Equalisation Tax
WHO	World Health Organisation

Terms of Reference

The Legislative Assembly resolved on 26 March 2014 that:

1. A Select Committee on Action to Prevent Foetal Alcohol Spectrum Disorder be appointed.
2. The Committee shall inquire into and report on:
 - a. The prevalence in the Northern Territory of Foetal Alcohol Spectrum Disorder (FASD);
 - b. The nature of the injuries and effects of FASD on its sufferers; and
 - c. Actions the Government can take to reduce FASD based on evidence and consultation.
3. The Committee's membership shall comprise three Government Members, two Opposition Members and one Independent Member.
4. The Committee may elect a Deputy Chair of the Committee, who may act as the Chair when the Chair is absent from a meeting or there is no Chair of the Committee.
5. A quorum of the Committee shall be three members of the Committee.
6. The committee is to report in the October¹ sittings.
7. The provisions of this resolution, insofar as they are inconsistent with the Standing Orders, have effect notwithstanding anything contained in the Standing Orders.

¹ Amended by the Legislative Assembly to "November" on 19 August 2014 and "February 2015" on 25 November 2014.

Executive Summary

Foetal Alcohol Spectrum Disorder (FASD) is having a devastating effect on the lives of many people in the Northern Territory. This devastation is flowing on to the families of its sufferers and their communities. It also creates costs for Government in services to assist sufferers to manage their disabilities, and frequently in justice, correctional services and compensation when sufferers do not manage their behavioural issues and cognitive impairments.

The lack of an agreed diagnostic instrument and sufficient diagnostic services mean that the prevalence of FASD in the Territory is unclear. This must be addressed as a matter of priority, as without diagnosis, it is difficult to provide effective services to sufferers, to target prevention programs, or to know what prevention programs are most effective.

It is also vital that a lack of diagnosis is not interpreted as a lack of a problem. Feedback from health workers, educators and communities indicates a high incidence of FASD in the Territory. Internationally, studies have found prevalence rates of around 1 to 3 per 1,000 births in general populations and around 10 per 1,000 (or 1 percent) in high risk populations. Studies of Indigenous populations in South Africa have found a prevalence of FAS (the more severe form of the FASD) of around seven percent and, closer to home, some are predicting that the *Lililwan Project* in the Fitzroy Valley in Western Australia, the most thorough study of its type in Australia, is expected show that as many as 25 percent of children in that community suffer from FASD.

The effects of FASD vary in type and degree. They include physical effects such as growth retardation, certain facial features and birth defects such as cardiac, skeletal or renal abnormalities and sensory impairment. They also include neuropsychological and behavioural effects, such as diminished intellectual, adaptive and executive function, deficits in learning, memory, visual-spatial ability, language, motor function and attention. These effects result in both disabilities that require life-long support and can prevent independent living, and cause behavioural problems that pose risks to the individuals and the community which are founded on an inability to understand and learn and therefore are not responsive to punitive control measures.

Consequently, FASD can cause a huge cost to the community in terms of reduced opportunities for sufferers, support services for sufferers and their families, and coercive interventions, such as imprisonment, to control destructive behaviours.

Prevention of, and treatment for, FASD is therefore both a moral and an economic imperative for Government.

FASD is wholly preventable, inasmuch as avoiding alcohol prevents its occurrence. However, issues such as addiction to alcohol, ignorance of the dangers of alcohol and lack of awareness of a pregnancy make this simple solution difficult to implement.

The Committee found that preventing and treating FASD and alcohol management were inextricably intertwined. A pregnant woman's drinking may be affected by any

alcohol management measures. Further, a pregnant woman's drinking may also be affected by those around her, as drinking is frequently a shared experience and subject to peer pressure. Also, even though the damage done by alcohol to a foetus is largely irreversible, the effect of that damage can often be significantly ameliorated by the care the child receives, particularly during the early years. Consequently, the outcomes for a FASD child will be worse if he or she grows up in an environment where alcohol abuse is a factor.

The Committee notes that reducing alcohol abuse is not only vital for preventing FASD and improving the outcomes for FASD children but will also bring many other social, economic and health benefits. Addressing alcohol abuse therefore must remain a priority of the Government.

The Committee was pleased to see that progress had been made in reducing alcohol abuse in the Territory. It was evident in both Tennant Creek and Alice Springs that the Temporary Beat Locations had reduced the harmful consumption of alcohol and resulted in a large reduction in alcohol related assaults. The Committee also heard that the overall per capita consumption of alcohol in the Territory had reduced from around 20 litres of pure alcohol during the 1980s to less than 13 litres in 2012-13.

Despite these gains, the abuse of alcohol remains a major problem that requires further concerted action. Evidence received by the Committee led it to make a number of recommendations that will lead to further improvements in this area.

The Committee noted that while there were a number of initiatives that, overall, were having a positive effect on reducing alcohol related harm, there was a lack of a strategic framework to coordinate alcohol policy and enable an assessment of how each measure was performing. The Committee has recommended the development of such a framework, including targets for reducing alcohol related harm, regular publication of performance data in meeting those targets, and the review of programs in light of their performance. The Committee also recommends the Legislative Assembly re-establish a Standing Committee on Alcohol and Substance Abuse to enable ongoing public scrutiny of the effectiveness of alcohol management programs and to inquire into strategies to further reduce substance abuse.

One measure that received wide support from service providers, and community and industry representatives was a minimum floor price for alcohol. The evidence that a minimum floor price for alcohol would reduce harmful alcohol consumption was most compelling. The Committee also noted that the Territory's most effective previous alcohol management program, the 1991 *Living with Alcohol Program*, included a price mechanism as one of its primary levers. Given the benefits that would flow from such a measure, the Committee considers that it is worth the limited and targeted cost increases involved.

It was also clear that limiting trading hours at key high risk periods had been successful at reducing alcohol related harm and that this should be further pursued through alcohol management plans and liquor accords.

Some of the most striking evidence received by the Committee was the effectiveness of Temporary Beat Locations (TBLs) in reducing alcohol related violence. While the

measures remain controversial, their effectiveness was not denied. The Committee also noted while overall alcohol related assaults were decreasing across the Territory, they were increasing in centres without TBLs. The Committee recommends further analysis of the operation of personal point of sale restrictions, including lessons learnt from the former Banned Drinker Register (BDR), to enable socially and economically sustainable measures that can be extended across the Territory.

To target FASD specifically, the Committee found a need for further awareness raising of the dangers of drinking alcohol while pregnant. It is important that this include culturally appropriate campaigns for Aboriginal communities, as while there have been significant reductions in drinking while pregnant in the non-Indigenous population over recent years, the rate has not greatly changed in the Indigenous population. Related to this is a need for greater awareness of sexual health and access to contraception. The Committee received positive feedback on a number of sexual education programs aimed at adolescents and these should be expanded. Health services also provide a vital avenue for raising awareness, and the training and protocols need to be in place to ensure that health practitioners are aware of the risks of alcohol use and are equipped to ask and talk about this in a culturally sensitive manner.

The Committee also noted that the greatest proportion of FASD children come from alcohol dependent pregnant women, so programs assisting these women avoid alcohol during pregnancy and beyond will give the most direct gains in FASD prevention. Improving access and reducing barriers to such programs is therefore key for FASD reduction. Increased family friendly rehabilitation services and alcohol free, safe accommodation is needed to assist this. The Committee also considered that as accessing appropriate health services is key to reducing FASD, measures that could reduce the trust of health services and discourage women to reveal their use of alcohol or attend antenatal visits could cause significant harm. It therefore did not recommend any coercive treatment or penalties for women consuming alcohol while pregnant.

The Committee also considered what should be done to manage the effects of FASD. The primary issue to emerge was the need to improve support for children in the early years. Good postnatal support and quality child care can reduce the consequences of the damage caused by FASD and aid in prevention of FASD in future children. While the damage caused by FASD is irreversible, early intervention has been shown to reduce adverse outcomes or 'secondary disabilities', such as mental health problems, trouble with the law and alcohol and drug problems. The Committee has therefore recommended improvements to diagnostic services, parent support, and early childhood education. Greater coordination across government of FASD issues is also required to prevent critical gaps in service delivery, and improved FASD awareness in health, education and justice services.

Recommendations

Recommendation 1

The Committee recommends that the Department of Health develop a strategy for implementing the Australian FASD Diagnostic instrument, expected to be finalised in 2015. As part of that strategy development, the Committee recommends that the Department consider the cost effectiveness of multi-disciplinary paediatric teams.

Recommendation 2

The Committee recommends that the Government prioritise funding for early intervention services for FASD, including paediatric diagnosis, psychotherapy and other behavioural management measures, and early childhood support and education services.

Recommendation 3

The Committee recommends that the Department of Health promote protocols for screening alcohol use during pregnancy with a view to raising awareness of the risks or alcohol, assisting expectant mothers with any alcohol issues, and collecting data in accordance with the Australian Institute of Health and Welfare's National Maternity Data Development Project.

Recommendation 4

The Committee recommends that protocols for screening alcohol use during pregnancy include guidelines for support and referral for women struggling with alcohol use during pregnancy, including information on relevant local support services.

Recommendation 5

The Committee recommends that the Department of Health review options for screening for FASD, particularly targeted screening of high risk populations, having regard to the possible development of a national FASD screening instrument.

Recommendation 6

The Committee recommends that the Department of Health undertake an audit of current professional development needs of the health workforce in relation to FASD and develop a plan for ensuring an adequate level of awareness of FASD.

Recommendation 7

The Committee recommends that the Government improve support for caring for children in the first years, particularly for at risk populations, and:

- a) expand the Family as First Teachers Program;
- b) explore options for promoting early childhood education programs, such as Abecedarian day care, across the Territory; and

-
- c) explore options for improving support to new mothers, including the Family First Nurse Partnerships Program.

Recommendation 8

The Committee recommends that the Department of Education implement and strengthen its initiatives to address the needs of students with FASD, including the delivery of strategies, training and resources for teaching students with FASD and the establishment of a formal FASD reference group.

Recommendation 9

The Committee recommends that a multi-disciplinary diagnostic service is established to which child protection workers, legal practitioners, judicial officers and correctional staff may refer individuals suspected of having a cognitive impairment such as FASD. The service should be linked to government and community based treatment programs.

Recommendation 10

The Committee recommends that the multi-disciplinary diagnostic service maintain data on the prevalence of FASD individuals in contact with the criminal justice and child protection systems.

Recommendation 11

The Committee recommends that a FASD Support Service be established within the Department of Health to provide case management for FASD individuals and their carers through an appointed social worker.

Recommendation 12

The Committee recommends that additional funding be allocated to the development of more residential secure care facilities for the delivery of behavioural management programs to the cognitively impaired, including FASD individuals.

Recommendation 13

That the community based health organisations and social service providers be funded to provide evidence based behavioural management programs for FASD individuals. The programs should be linked to the FASD Support Service.

Recommendation 14

The Committee recommends that a high level FASD Working Group be established with representatives the Departments of Health, Education, Children and Families, Attorney-General and Justice, Corrections and Police, Fire and Emergency Services to develop and implement an action plan addressing:

- a) protocols for sharing information about persons diagnosed with FASD;
- b) training and awareness of FASD and related referral options for health, teaching, child protection, police, justice and corrections professionals; and
- c) continuity and coordination of FASD services.

Recommendation 15

The Committee recommends that the Government build on the Northern Territory's experience in tackling harmful alcohol consumption by developing an alcohol strategic framework that:

- a) Sets targets for reducing alcohol related harm;
- b) Provides a mechanism for regular publication of performance data in meeting those targets;
- c) Includes governance structures to ensure high level agency coordination and effective stakeholder engagement; and
- d) Provides mechanisms for review of alcohol management programs in light of their performance.

Recommendation 16

The Committee recommends that the Legislative Assembly establish a Standing Committee on Alcohol and other Substance Abuse to monitor alcohol management and supply programs and to inquire into strategies to reduce substance abuse.

Recommendation 17

The Committee recommends that the Government continue to support the development and implementation of Alcohol Management Plans and that these be evaluated on a regular basis to ensure their ongoing effectiveness.

Recommendation 18

The Committee recommends that the *Liquor Act* be amended to implement a minimum floor price ensuring that a standard drink would cost, at a minimum, \$1.30.

Recommendation 19

The Committee recommends that the Government restrict the trading of alcohol at times when the greatest harm from alcohol consumption occurs.

Recommendation 20

The Committee recommends that the Government:

- a) Conduct further analysis of the effectiveness of personal point of sale restrictions on purchasing alcohol such as the Temporary Beat Locations and the former Banned Drinker Register;
- b) Develop options for reducing the cost of enforcement of such restrictions, such as only considering sales over a certain value; and
- c) Implement personal point of sale restrictions where it is cost effective to do so.

Recommendation 21

The Committee recommends that the Government conducts a needs assessment for family rehabilitation facilities.

Recommendation 22

The Committee recommends that the Government support further campaigns raising awareness of the dangers of drinking alcohol while pregnant, particularly culturally appropriate campaigns for Aboriginal communities.

Recommendation 23

The Committee recommends that the Government ensure that all children receive a culturally appropriate sexual health awareness program, such as the Adolescent Sexual Education Program and Core of Life.

Recommendation 24

The Committee recommends that the Department of Health ensures that all training of health professionals includes information on FASD and the risks of drinking while pregnant, and that protocols for antenatal visits include discussion of the risks of alcohol and whether the woman is consuming alcohol.

Recommendation 25

The Committee recommends that the Department of Health implement programs to improve the awareness regarding, and availability of, contraception options.

Recommendation 26

The Committee recommends that the Department of Health assess the need for intervention and support services for alcohol dependent pregnant women, having particular regard to rehabilitation services that provide for families and children, and alcohol free, safe accommodation.

1 Introduction

- 1.1 FASD is the leading cause of non-genetic developmental disability in Australia.² It has a significant and adverse impact on the lives of affected individuals, on their families and on their local communities. At a broader level, the social and economic effects of FASD are increasingly evident across the health, education, child protection, and justice systems. The economic costs to society are considerable, with a recent Canadian study estimating the total direct and indirect costs to the Canadian economy at around \$7.6 billion annually.³ Unchecked, FASD will become a blight on our social landscape, all the more poignant because it is preventable. This Inquiry explores the impact of FASD in the Northern Territory and identifies actions the government needs to take in order to reduce its incidence and effects through appropriate prevention and management strategies.

Conduct of the Inquiry

- 1.2 The Legislative Assembly established the Committee on the 26 March 2014.
- 1.3 At its meeting on the 10 April 2014, the Committee called for submissions by 26 May 2014. The call for submissions was advertised on the Assembly's website and in the NT News and regional newspapers including newspapers circulating in Katherine, Tennant Creek, Alice Springs and Nhulunbuy. The Committee also directly contacted a number of individuals and organisations to advise them of the call for submissions.
- 1.4 The Committee received 27 submissions, listed at Appendix 1 and held public hearings in Darwin, Katherine, Tennant Creek, Alice Springs and Nhulunbuy. It also held public forums in Katherine, Tennant Creek and Nhulunbuy. Details of public hearings and public forums are included in Appendix 2.

² Foundation for Alcohol Research and Education (FARE), *The Australian Fetal Alcohol Spectrum Disorders Action Plan 2013–2016*, September 2012, p. 4.

³ S Clarren, (ed), *Prevention of Fetal Alcohol Spectrum Disorder FASD*, Wiley-Blackwell, Germany, 2011, p. 6.

2 What is Foetal Alcohol Spectrum Disorder?

- 2.1 FASD is an umbrella term first used in 2000 by Streissguth and O'Malley to describe a range of adverse effects caused by prenatal exposure to alcohol (PAE).⁴ These effects may include 'physical, mental, behavioural and/or learning disabilities with lifelong implications'.⁵ The degree of brain damage in individuals with prenatal exposure to alcohol varies across the spectrum, as does neuropsychological/behavioural dysfunction which ranges from 'mild developmental delay or learning disabilities to global developmental disability'.⁶ Due to its characteristic facial anomalies FAS is more likely to be diagnosed at an earlier age than are other conditions under the FASD umbrella, as clear indicators at birth are seldom apparent for the latter and may not emerge until the child goes to school and behavioural and learning difficulties become problematic.

Classification of Foetal Alcohol Spectrum Disorder Conditions

- 2.2 FASD does not represent a clinical diagnosis but commonly refers to the following group of medical diagnoses: Foetal Alcohol Syndrome (FAS); Partial Foetal Alcohol Syndrome (pFAS); Alcohol Related Neurodevelopmental Disorders (ARND); Alcohol Related Birth Defects (ARBD); Static Encephalopathy/Alcohol Exposed (SE/AE); and Neurobehavioral Disorder/Alcohol Exposed (ND/AE).
- 2.3 Although clear diagnostic criteria for FAS have been established for some time, the publication of a range of guidelines indicates that a similar consensus has not yet been reached on how to diagnose other conditions commonly included under the FASD umbrella. However, the variations between the guidelines are slight and all include the assessment of growth characteristics, facial features, neurological structure and function, and alcohol exposure in pregnancy.⁷ In describing the classification criteria for conditions under the FASD umbrella, this report draws on guidelines developed by the United States of America (USA) based Institute of Medicine.⁸
- 2.4 **Foetal alcohol syndrome:** A diagnosis of FAS, which is situated at the severe end of the FASD spectrum, is based on the presence of an abnormality in each of the following three categories: impaired growth prenatally and/or postnatally; characteristic facial abnormalities; and structural or functional abnormalities of the

⁴ Bertrand et al, 2005 cited in B Carpenter et al, 'A brief introduction to fetal alcohol spectrum disorders', in B Carpenter et al, (eds), *Fetal Alcohol Spectrum Disorders: Interdisciplinary Perspectives*, Routledge, New York, 2014, p. 4.

⁵ Carpenter et al, 'A brief introduction to fetal alcohol spectrum disorders', p. 4.

⁶ SJ Astley et al, 'Neuropsychological and behavioral outcomes from a comprehensive magnetic resonance study of children with fetal alcohol spectrum disorders', *Canadian Journal of Clinical Pharmacology*, vol. 16, no. 1, Winter, 2009, p. 178.

⁷ Burns et al, (eds) *Fetal Alcohol Disorders in Australia: An update. Monograph of the Intergovernmental Committee of Drugs Working Party of Fetal Alcohol Spectrum Disorders*, June 2012, p. 34.

⁸ Burns et al (eds), *Fetal Alcohol Disorders in Australia: An update*, p. 34.

central nervous system (CNS). CNS abnormalities may include ‘microcephaly, learning disabilities, developmental delay, hyperactivity disorders, seizures and brain structure abnormalities’.⁹ A more detailed description from the Institute of Medicine diagnostic criteria for FAS is set out in Table 1 below.

Table 1: Diagnostic criteria for Foetal Alcohol Syndrome

Growth Retardation
<ul style="list-style-type: none"> • Prenatal growth deficiency – decreased birth weight for gestational age • Postnatal growth deficiency – lack of catch-up growth in spite of adequate nutrition • Low weight to height ratio
Characteristic Facial Features
<ul style="list-style-type: none"> • Short palpebral fissures • Thin upper lip • Flattened philtrum (an absent or elongated groove between the upper lip and nose) • Maxillary hypoplasia, epicanthal folds and ptosis may also occur
Central Nervous System Anomalies or Dysfunction
<ul style="list-style-type: none"> • Decreased cranial size at birth • Structural brain abnormalities including microcephaly • Abnormal neurologic hard or soft signs such as impaired fine and gross motor skills

Source: Stratton et al, 1996¹⁰

2.5 Although diagnosis of FAS is more straightforward than other FASD conditions, due to the requirement that characteristic facial abnormalities be present, it is still a subjective process. Where diagnosis of FAS is in doubt it should be referred to a dysmorphologist or clinical geneticist for confirmation. In such cases, a diagnosis of FAS requires a history of maternal alcohol use during pregnancy, however, where this history is unavailable a diagnosis of FAS can still be recorded ‘providing that abnormalities ... are consistent with the syndrome and other possible diagnoses have been excluded’.¹¹

⁹ Carpenter, et al, ‘A brief introduction to fetal alcohol spectrum disorders’, p. 4.

¹⁰ Stratton et al (eds), *Fetal Alcohol Syndrome: Diagnosis, epidemiology, prevention, and treatment*, National Academy Press, Washington, DC, 1996.

¹¹ Stratton et al, cited in Burns et al, *Fetal Alcohol Disorders in Australia: An update*, p. 33.

- 2.6 **Partial foetal alcohol syndrome:** Individuals with pFAS have some of the characteristic facial features of FAS and 'at least one of the other FAS features: growth retardation; CNS neurodevelopmental abnormalities; or a complex pattern of behavioural and/or cognitive abnormalities which cannot be accounted for by familial background or environment alone'.¹²
- 2.7 **Alcohol Related Neurodevelopmental Disorders:** 'ARND is characterised by CNS abnormalities (e.g. decreased head size at birth or structural brain abnormalities) and/or neurological functional abnormalities which cannot be explained by familial background or environment alone (e.g. behavioural and cognitive dysfunction such as learning difficulties or poor impulse control and judgement)'.¹³
- 2.8 **Alcohol Related Birth Defects:** 'ARBD are characterised by physical anomalies such as cardiac, skeletal or renal anomalies or sensory impairment. These include sensorineural hearing loss and eye anomalies which are known from animal models and/or humans to be associated with alcohol exposure (Stratton et al. 1996)'.¹⁴
- 2.9 In the past, the classification of Foetal Alcohol Effects (FAE) has been used to describe children who had some but not all the features of FAS, however, use of this classification is not recommended as the criteria have not been adequately defined. Conditions which previously came under FAE are now included under ARND and ARBD.¹⁵
- 2.10 The key features of each type of FASD diagnosis are set out in Table 2.

Table 2: Fetal Alcohol Spectrum Disorders

Diagnosis	Alcohol Exposure	Facial Anomalies	Growth Retardation	CNS Anomalies	Birth Defects
FAS with confirmed alcohol exposure	✓	✓	✓	✓	
FAS without confirmed alcohol exposure	Unknown	✓	✓	✓	
Partial FAS	✓	Some facial anomalies present	Need at least one of these categories		
ARND	✓	-	-	✓	
ARBD	✓	-	-	-	

Source: Stratton et al 1996¹⁶

¹² Burns et al (eds), *Fetal Alcohol Disorders in Australia: An update*. p. 34.

¹³ Burns et al (eds), *Fetal Alcohol Disorders in Australia: An update*, p. 34.

¹⁴ Burns et al (eds), *Fetal Alcohol Disorders in Australia: An update*, p. 34.

¹⁵ Burns et al (eds), *Fetal Alcohol Disorders in Australia: An update*, p. 35.

¹⁶ Stratton et al (eds), *Fetal Alcohol Syndrome: Diagnosis, epidemiology, prevention, and treatment*.

Neuropsychological and Behavioural Effects Associated with FASD

2.11 Through its effect on the CNS (the brain and spinal cord), prenatal exposure to alcohol can result in a wide range of neurobehavioural effects. Individuals diagnosed with FASD experience both primary and secondary disabilities. Primary disabilities result directly from the brain injuries of PAE, are evident in some form from birth, and relate to factors such as intelligence, memory, and attention. Secondary disabilities are not present at birth but result from interactions between primary disabilities and environmental risk and protective factors. In theory, they are preventable, through the application of appropriate interventions.

Primary Disabilities

2.12 The most devastating primary effects are those which result from damage to the brain and the resulting neurobehavioural impairments.¹⁷ The key areas in which the primary disabilities associated with FASD are experienced are set out below.

2.13 **General intelligence:** Although the majority of individuals with FASD are not intellectually disabled (defined as overall IQ score <70 and adaptive disability), diminished intellectual function is one of the most common neurocognitive findings. Impaired intellectual function can occur right across the foetal alcohol disorder spectrum but is more frequently observed in individuals with FAS.¹⁸

2.14 **Adaptive functioning:** Is a functional impairment resulting from CNS damage and can be defined as:

the performance of daily activities required for personal and social self-sufficiency or the ability to respond successfully to everyday demands ... [they] are about developing skills that gradually enable an independent life, maintain social relationships, and allow the individual to become integrated into society.¹⁹

Lack of these skills contributes to the high rates of secondary disabilities and adverse life events experienced by people with FASD, with one study finding that in adolescents and adults with a mean age of 17, adaptive functioning skills were at the level of a seven year old.²⁰

2.15 **Executive function:** This refers to higher order cognitive processes that are under conscious control and which facilitate goal directed action. Executive function is a key factor in the ability to negotiate everyday life, and executive function deficits in FASD could well be seen as linked to impaired adaptive behaviour,²¹ with its critical role succinctly summarised by Jurado and Roselli:

¹⁷ Nguyen, et al, 'The effects of prenatal alcohol exposure on brain and behaviour', in Carpenter et al (eds), *Fetal Alcohol Spectrum Disorders: Interdisciplinary Perspectives*, Routledge, New York, 2014, p. 219.

¹⁸ Nguyen et al, 'The effects of prenatal alcohol exposure on brain and behaviour', p. 224.

¹⁹ Fagerlund et al, 'Adaptive behaviour in children and adolescents with foetal alcohol spectrum disorders: a comparison with specific learning disability and typical development', *European Child Adolescent Psychiatry*, vol. 21, 2012, p. 222.

²⁰ Streissguth cited in Rasmussen et al, 'Neurobehavioural outcomes of children with fetal alcohol spectrum disorders: A Canadian perspective', *Paediatr Child Health*, vol. 13, (3), 2008, pp. 185-191.

²¹ Fagerlund et al, 'Adaptive behaviour in children and adolescents', p. 223.

In a constantly changing environment, executive abilities allow us to shift our mind set quickly and adapt to diverse situations while at the same time inhibiting inappropriate behaviors. They enable us to create a plan, initiate its execution, and persevere on the task at hand until its completion. Executive functions mediate the ability to organize our thoughts in a goal directed way and are therefore essential for success in school and work situations, as well as everyday living. The concept of morality and ethic[a] behavior also represents an executive function.²²

Key cognitive processes that form part of executive function include:

- Problem solving and planning - the ability to think about and organise activities to reach a certain goal.
- Response inhibition (impulse control) – the ability to suppress irrelevant impulses to enable goal-directed behaviour,²³ for example, the capacity to think before you act, the capacity to delay or inhibit responding based on the ability to evaluate multiple factors. Children who have trouble with response inhibition are impulsive, saying or doing things without thinking, which often gets them into trouble with parents, teachers, or peers.
- Concept formation and set-shifting - difficulties in forming and identifying abstract concepts and thinking analytically, with this impairing the ability to problem-solve.
- Fluency – relates to cognitive flexibility and strategic thinking, which requires the generation of multiple responses under time constraints.
- Working memory – the ability to actively hold and manipulate information in the mind to perform more complex tasks such as reasoning.

2.16 Learning and memory: Children with FASD have learning and memory deficits in both verbal and non-verbal domains, for example, they remember less information and have difficulty recalling information. These results may relate to poor encoding practices rather than inadequate retention of information. Learning and memory has been shown to improve when information is presented in story form rather than in list form.

2.17 Visual-spatial ability: Children prenatally exposed to alcohol demonstrate impairments on tasks such as visual-spatial construction, for example, they have difficulty reproducing objects with spatial dimensions. If asked to draw a clock, they may understand the essential elements of the clock to be replicated but have no sense of how the numbers should be spaced.

2.18 Language: Findings with respect to language are mixed. Retrospective studies have found a range of deficits but more recent prospective studies suggest a

²² MB Jurado & M Rosselli, 'The elusive nature of executive functions: a review of our current understanding', *Neuropsychol Rev*, 17, 2007, p. 214.

²³ Paolozza et al, 'Response inhibition deficits in children with Fetal Alcohol Spectrum Disorder: Relationship between diffusion tensor imaging of the corpus callosum and eye movement control', *Neuroimage Clinical*, 5, 2014, pp. 53-61.

developmental delay rather than a persistent deficit in language abilities. In one recent study it has been argued that children with FASD 'have difficulty balancing the linguistic challenges and social demands of a given social interaction in order to produce contextually integrated conversation'²⁴ and that alcohol exposed children do not provide sufficient information and organisation for listeners when telling a story, are 'more likely to use ambiguous references', and to 'fail to appropriately distinguish concepts'.²⁵

2.19 **Motor function:** Impairments may occur in both gross and fine motor skills, for example, poor hand/eye coordination, weak grasp, tremors and balance/gait difficulties, postural instability, and delayed motor reaction time. For example, a child with FASD may have poor handwriting or find it difficult to ride a bicycle at the appropriate age.

2.20 **Attention and activity levels:** Hyperactivity and attention deficits are common and children with FASD consistently show impairment in areas such as reaction time and information processing. FASD children find it difficult to concentrate and are easily distracted. More than 60 percent display deficits in attention and, while FASD is frequently a co-morbid diagnosis with Attention Deficit Hyperactivity Disorder (ADHD), the nature of attention deficits in FASD and ADHD differ, with ADHD children having difficulty focusing and sustaining attention and FASD children finding more difficulty with shifting attention, encoding information and problem solving.²⁶

Secondary Disabilities

2.21 Research suggests that individuals with FASD have a high risk of experiencing a range of secondary disabilities, such as:²⁷

- **Mental health problems:** Depression, anxiety, ADHD, or other mental illnesses are common, with several studies finding high rates of psychiatric disorders (up to 90 percent) in children with FASD.
- **Disrupted school experience:** Children with FASD are at higher risk of being suspended, expelled or dropping out of school (around 60 percent of children over 12).
- **Trouble with the law:** Higher risk of having interactions with police, authorities, or the judicial system. Factors which contribute to this outcome, and which are associated with primary FASD disabilities, include difficulty

²⁴ Coggins et al 2003 cited in Nguyen et al, 'Prenatal alcohol exposure, FAS, and FASD: An Introduction', in EP Riley et al, (eds), *Fetal Alcohol Spectrum Disorder - Management and policy perspectives of FASD* p. 229.

²⁵ Coggins et al 2007 & Thorne et al 2007 in Nguyen et al, 'Prenatal alcohol exposure', p. 229.

²⁶ Nguyen et al, The effects of prenatal alcohol exposure on brain and behaviour, p. 230.

²⁷ Streissguth et al, 'Risk factors for adverse life outcomes in fetal alcohol syndrome and fetal alcohol effects', *Developmental and Behavioral Pediatrics*, vol. 5, iss 4, 2004, pp. 228-238; Streissguth et al, *Understanding the Occurrence of Secondary Disabilities in Clients with Fetal Alcohol Syndrome (FAS) and Fetal Alcohol Effects (FAE)*, Final Report to the Centers for Disease Control and Prevention, August, 1996, Seattle: University of Washington, Fetal Alcohol & Drug Unit, Tech. Rep. No. 96-06, 1996.

controlling anger and frustration, problems understanding the motives of others, and being easy to manipulate.

- **Confinement:** At higher risk for being confined to inpatient psychiatric care, inpatient chemical dependency care or incarceration for a crime – about 50 percent of those aged 12 or older.
- **Inappropriate sexual behaviour:** At higher risk for making inappropriate sexual advances, sexual touching, or promiscuity. Inappropriate sexual behaviours increase with age from 39 percent in children to 48 percent in adolescents and 52 percent in adults.
- **Alcohol and drug problems:** Alcohol abuse or dependency is experienced by around 35 percent of individuals with FASD, with more than half requiring in-patient treatment.
- **Dependent living:** Group home, living with family or friends, or some sort of assisted living is more common in adults with FASD (around 80 percent of adults with FASD).
- **Problems with employment:** Adults with FASD frequently find it harder to keep a job, require ongoing job training or coaching, and have greater risk of being unemployed (around 80 percent of adults with FASD).

2.22 Table 3 summarises a range of outcomes associated with FASD in the domains of behaviour, mental health and adaptive and executive functioning.

Table 3: Summary of outcomes associated with prenatal alcohol exposure²⁸

Behavioural	Mental Health	Adaptive and Executive Functioning
Antisocial behaviour	Alcohol problems	Socialization
Delinquent behaviour	Mood disorder	Employment difficulties
Classroom/school behaviours	Bipolar disorder	Independent living difficulties
Learning behaviours	Depression	Inhibitory control
Externalizing behaviour	Panic disorder	Cause and effect reasoning
Aggressive behaviour	Hyperkinetic disorders	Planning and organizing
Criminal activity	Emotional disorders	Learning from mistakes
Maladaptive behaviour	Conduct disorders	
Impulsivity	Sleep disorders	
Teasing/bullying	Abnormal habits	
Dishonesty	Stereotypical behaviour	
Avoiding work/school	Other psychiatric disorders	
Sexual inappropriateness	(post-traumatic stress disorder, obsessive-compulsive disorder and	
Self-injury	oppositional defiant disorder)	
Alcohol/drug use		

²⁸ Rasmussen et al, Neurobehavioural outcomes of children with fetal alcohol spectrum disorders, p. 186

The Importance of Diagnosis

2.23 Internationally, there are several systems in use for classifying FASD. These include the: Centres for Disease Control guidelines; Institute of Medicine criteria; University of Washington 4-digit diagnostic code; and the Canadian guidelines.²⁹ In Australia there are currently no nationally recognised clinical guidelines for the screening and diagnosis of FASD despite the fact that the implementation of uniform diagnostic and screening instruments, suited to the Australian context, is critical. In the absence of such instruments, Australian governments have no means of establishing the scope of the problem and hence no basis from which to make informed policy decisions. Consistent use of uniformly accepted screening and diagnostic criteria, coupled with specific training for health professionals, would enable:

- Collection of accurate data;
- Establishment of accurate prevalence rates;
- Identification of population groups most at risk;
- Early detection and treatment of children with FASD;
- More equitable access to disability services and supports;
- Better support for families and carers of individuals with FASD;
- A more confident workforce with improved diagnostic capacity; and
- Treatment that is relevant, for instance, similar learning difficulties may result from different causes and, for maximum effectiveness, treatment needs to be based on accurate diagnosis in which FASD are differentiated from other conditions.³⁰

2.24 Research indicates that early diagnosis is a critical factor in reducing a range of adverse outcomes (secondary disabilities) experienced by FASD affected individuals, with Streissguth et al noting that:

One of the strongest correlates of adverse outcomes is lack of an early diagnosis: the longer the delay in receiving the diagnostic information, the greater the odds of adverse outcomes.³¹

In their 2004 study, Streissguth and colleagues found that:³²

- The odds of five adverse outcomes (disrupted school experience, trouble with the law, confinement, alcohol and drug problems and inappropriate sexual behaviour) were increased two to four fold for diagnosis after age 12.
- For an adolescent at 18 years of age, older age at diagnosis (17 vs 9 years) nearly doubles the estimated odds of disrupted school experience, trouble with the law, and confinement.

²⁹ Professor Elizabeth Elliott in Committee Transcript 29 May 2014, p. 116.

³⁰ Fagerlund et al, 'Adaptive behaviour in children and adolescents', p. 228.

³¹ Streissguth et al, 'Risk Factors for Adverse Life Outcomes', p. 234-5.

³² Streissguth et al, 'Risk Factors for Adverse Life Outcomes', p. 234.

- For an adult of 26 years of age, older age at diagnosis more than doubles the estimated odds of inappropriate sexual behaviour, disrupted school experience, and alcohol and drug problems.

2.25 The study underscored the importance of diagnosis and noted that:

The finding that having FAE (compared to FAS) doubles the odds of Trouble With the Law (TWL) and Alcohol and Drug Problems (ADP) ... is puzzling until one considers that for many years FAE was thought to be essentially a "nondiagnosis" in contrast to FAS'.³³

2.26 Streissguth and colleagues also highlight important gender differences in relation to adverse outcomes, with promiscuity occurring in twice the fraction of females (22 percent) as males (11 percent) while, among adolescents and adults, being in trouble with the law for inappropriate sexual behaviour was twice as frequent among males (19 percent) as females (8 percent).³⁴ These differences have significant implications for the targeting of interventions, particularly in relation to contraception, as increased promiscuity in this group, combined with greater likelihood of alcohol abuse, may well become a factor in perpetuating FASD into future generations.

2.27 The importance of early diagnosis was highlighted by several witnesses with Dr Jennifer Delima commenting that:

Ideally, if we can get these kids before the age of six. Before the age of six the impairment is not as evident, but if we identify a child with possible FASD, and we keep an absolute busy eye on that child and start putting in remediation - appropriate psychotherapy, appropriate behavioural measures - for these kids, then we actually minimise that and bring it down to less than 15 percent. If we do not do it, it goes towards that 94 percent. If we can even get these kids up into adolescence, pick them up in adolescence and support them, identify to them this is why they are having difficulties, then you are starting to break the chain. You are starting to identify it, you are starting to break the chain and help those families as well. However, once the person gets to adulthood, then it is support for that person. We cannot do any remediation really, not in a great way. It really is a big ask then.³⁵

The Impact of FASD on its Sufferers

2.28 The neuropsychological and behavioural effects identified above indicate the extensive impact that FASD can have on individuals. The cost, in terms of blighted lives, is incalculable. One of the key impacts is caused by deficits in adaptive behaviour and executive function, which make it difficult for individuals to carry out everyday living tasks. FASD affected individuals may need to be constantly reminded to undertake tasks that are performed routinely by individuals without a FASD condition (eg showering, dressing appropriately, attending appointments on time, shopping, paying bills).³⁶ Mr Danny Curtis talked to the Committee about how FASD affected his foster child's ability to function in the world and explained the

³³ Streissguth et al, 'Risk Factors for Adverse Life Outcomes', p. 235.

³⁴ Streissguth et al, 'Risk Factors for Adverse Life Outcomes', pp. 232-3.

³⁵ Committee Transcript, 1 August 2014, p. 43.

³⁶ Fagerlund et al, 'Adaptive behaviour in children and adolescents', p. 222.

need for supervision and support. He commented that his foster son Travis, who puts together furniture for IKEA:

is good in that sense with his eyes and hands, but you try and give him money - if he gets \$5 he thinks he is a millionaire. He has got no concept of money. ... it took us a long time for him to - he wanted a baseball glove, so we said, 'Right, here is \$5, put it to one side, put it in the jar, so when you get \$79, \$80, you can go and buy your baseball glove', but when he saw it all in that jar he reckoned, 'I can go and buy a car, a motorbike, a boat,' and everything like that. We are just trying to teach him around the value of money and life.³⁷

The Committee was told that as Travis entered adulthood he was moved into supported accommodation because 'He was becoming stronger, just growing into a young fellow, and a bit more violent, so we did not want to leave Suzie with that risk.'³⁸ The routine and close supervision associated with supported care accommodation has helped him to develop necessary life skills and Travis 'has really grown ... He does cooking, where at home he would not help'.³⁹ However, he will continue to need supported care whether this is in formal supported accommodation or in his own house on land close to that of his foster parents.⁴⁰

2.29 Attention deficits are common and FASD affected individuals may have difficulty linking cause and effect and understanding the consequences of their actions. Mr Danny Curtis noted that:

if he did not have one [a support person in school] he would just run totally amok. He would disrupt all the other kids in the class. They would either send him to the principal's office [and he would think], 'Why are they doing this, sending me over here?' Or they would send him out to the caretaker of the property of the school. I was just thinking about that now. I wonder if those guys were trained in that area. It is a lot of pressure to have, especially with Travis because he was full on - on the go, he was just like the Energiser battery. If you wanted an ad for that, he would be the one to do - even today he is 21.⁴¹

2.30 Equally, a FASD affected child may find it difficult to understand and follow rules which, in turn, can lead to potential difficulties with authority figures and peers. However, as Mr Danny Curtis demonstrated with reference to his son's ability to participate in a baseball game, if the condition is recognised, strategies can be developed to compensate:

he could hit the ball and he can run, but where would he run from first base to second? What we worked out with the parents who were coaching to say, 'Ready Travis?' then when he looks at you - because he looks at the parents saying, 'Yes' and he will be standing up there. The other kid is running up to first base, he is still standing there, 'Oh, am I meant to go there?' That is what I mean - got to go second. If you point him and show him, he will be right. Even out in the outfield, he will sit down there and, if a plane goes over that baseball diamond, the umpires have to pull up the game and say, 'Hang on, Travis is

³⁷ Committee Transcript, 1 August 2014, p. 63.

³⁸ Ms Michelle Nuske, Committee Transcript, 1 August 2014, p. 64.

³⁹ Mr Danny Curtis, Committee Transcript, 1 August 2014, p. 64.

⁴⁰ Mr Danny Curtis, Committee Transcript, 1 August 2014, p. 66.

⁴¹ Committee Transcript, 1 August 2014, p. 62.

having his moments'. When the plane goes, then they will start the game again.⁴²

Similarly, both foster parents who appeared before the Committee commented that their child had an absence of fear, with this arising from a failure to understand the consequences of their actions:

just trying to teach him about stranger danger - you would walk along the beach and see an old man walking with his dog. He would say, 'Oh, there is a dog', and start running up to him, grabbing him and also the dog. We were trying to say to him, 'You have to ask permission so you can play with the dog'. Big dogs, or any dog he would just go up to and play. It was frightening. They could end up turning around and biting him. He had no fear of anything.⁴³

and:

He climbs well and has no fear. It is a bit scary, and one of the indicators of FASD is no fear. We are not trying to push too much into it; we are just being aware of it. ... No consequences. Even with the dog - we have a camp dog and he will push the boundaries all the time. The dog will give a yap and it snapped at him once, just broke the skin a little, but they find it very hard to learn....⁴⁴

- 2.31 Although many individuals with FASD have an IQ within the normal range, the functional impairments or developmental disabilities caused by prenatal exposure to alcohol make it extremely difficult for the individual to become socially integrated. In particular, impairments to executive function and adaptive capacity can make it difficult for FASD affected individuals to meet age appropriate developmental milestones. In people diagnosed with FASD 'It is not uncommon to encounter a mix of abilities and lags in any one person' and the 'profile of maturation and strengths varies significantly between people with FAS/FAE'.⁴⁵ Figure 1 provides an example of the type of developmental mix that has been observed and demonstrates that significant developmental deficits in some areas can occur simultaneously with age appropriate development in other areas.

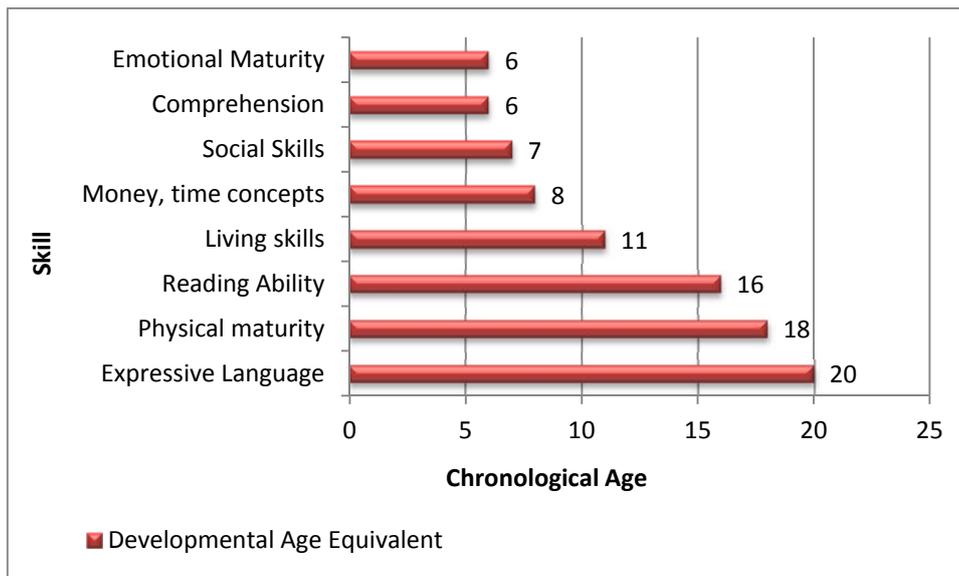
⁴² Committee Transcript, 1 August 2014, p. 64.

⁴³ Mr Curtis, Committee Transcript, 1 August 2014, pp. 62-63.

⁴⁴ Mr Jones, Committee Transcript, 31 August, 2014, Mr Jones, p. 51.

⁴⁵ D Malbin, *Timelines and FAS/FAE*, 1994, <www.come-over.to/FAS/timeline.htm>.

Figure 1: Chronological Age of 18 Compared with Developmental Age



Source: Adapted from: D Malbin 1994⁴⁶

2.32 Apart from FAS, the disabilities resulting from FASD conditions are invisible. This means that, in the absence of a diagnosis, the disjunction between chronological age and developmental age is unlikely to be taken into account, leading to unrealistic expectations on the part of parents, carers, peers, teachers, the law, and other agencies that interact with the FASD affected individual. Behaviour that is in line with the developmental age of such individuals is likely to be misinterpreted as naughty, criminal or deviant. This results in conflict and frustration in the home, trouble and failure at school, negative interactions with the law and greater likelihood of incarceration. As Dr Jennifer Delima noted:

What we are looking at is adolescents who then commit a crime because, 'That is what I was doing'. They get pulled up by police - how many times? I have seen that in the juvenile justice. They are pulled up by the police - 'You should not be throwing a brick through that window otherwise you will end up in trouble'. 'Ah yes, I do know that'. Two weeks later, same thing, and they have not learned it. Three weeks later, and we are doing this again and again and again, because they have not understood. Yes, at that point in time they can say, 'Yes I understand', but this is a different shop, this is a different brick, this is a different environment. They cannot actually match or join the dots.⁴⁷

The inability to measure up, and the consequences of this failure, impacts on self-esteem, confidence, and mental health and compounds the difficulties already posed by the condition.

2.33 In their submission to the Committee, the First Peoples Disability Network (FPDN) note the need to recognise FASD as a disability and comment that while 'there is a medical component to FASD, it must also be viewed as a social justice issue, ...'.⁴⁸ They highlight the importance of talking about disability from an impairment

⁴⁶ D Malbin, *Timelines and FAS/FAE*, 1994.

⁴⁷ Committee Transcript, 1 August 2014, pp. 41-42.

⁴⁸ First Peoples Disability Network (FPDN), Submission No. 1, 2014, p. 3.

perspective, for example, ‘my brother has trouble getting around (physical disability) or ‘my cousin has trouble understanding (intellectual disability)’⁴⁹, as this alerts others as to ‘what they need to look out for when supporting the person with disability in their community’.⁵⁰ If impairments associated with FASD are not recognised as disabilities then FASD affected individuals will continue to be blamed for behaviours over which they have little control. In addition, they will not receive the social and economic supports that enable them to integrate into society, and to contribute to society, as far as their condition allows.

⁴⁹ FPDN, Submission No. 1, 2014, p. 2.

⁵⁰ FPDN, Submission No. 1, 2014, p. 2.

3 Prevalence of Foetal Alcohol Spectrum Disorder

3.1 Although a number of Australian FASD prevalence studies have been undertaken, these can, at best, only provide a rough idea of the scope of the problem. This is largely due to the challenges inherent in obtaining a diagnosis of FASD and the consequent issues associated with collecting reliable data. The difficulty in establishing accurate prevalence rates for FASD in Australia has been well documented and is linked to a range of factors such as:

- Lack of routine screening and data collection for PAE and FASD;
- Lack of an effective diagnostic system and the complexity of the diagnostic process;
- Inadequate awareness of FASD among health professionals; and
- Methodological variations in prevalence studies.

Overall, these factors mean that there is a lack of reliable data on FASD through which to establish prevalence.

Screening for FASD

3.2 As pointed out in the Western Australian Inquiry into FASD, screening should not be equated with diagnosis, rather:

Screening for FASD identifies populations at risk while a diagnostic test is a procedure that is performed to detect the presence of a specific disease.⁵¹

3.3 Screening for FASD includes screening pregnant women for alcohol consumption and screening individuals for indicators of FASD. Screening is critical to the development of datasets that will enable more accurate prevalence rates to be established. Despite this, uniform screening methods for both maternal alcohol use and for FASD appear to be under-developed and under-implemented in Australia.

3.4 Routine screening for PAE enables populations at risk of FASD to be identified and so facilitates the diagnostic process by enabling follow up processes to be put in place following the birth of a child. The absence of routine screening means that many cases of FASD will go undiagnosed thus impacting on the accuracy of prevalence estimates and resulting in a lack of appropriate care and support for affected individuals. The two primary mechanisms available to screen for PAE include meconium screening and self-reporting of alcohol consumption.

3.5 Meconium testing can confirm an infant's exposure to alcohol up to the last two trimesters of development but cannot predict neurodevelopmental delays or other negative effects from alcohol exposure. Consequently, its primary use is to identify maternal alcohol consumption in situations where mothers do not voluntarily report

⁵¹ Western Australian, Legislative Assembly, Education and Health Standing Committee, *Foetal Alcohol spectrum disorder: The invisible disability*, Report No. 15, 2012, p. 25.

their consumption. However, there are ethical issues in using meconium screening to obtain information not voluntarily provided by the mother and it is likely that implementation of such a screening procedure would 'inhibit high risk mothers from seeking obstetric care in case they are deemed an unfit mother and lose their child to foster care'.⁵²

- 3.6 National data sources containing information on self-reported alcohol use during pregnancy include the National Drug Strategy (NDS) Household Survey and Women's Health Australia, a longitudinal study initiated in 1996. However, Burns and colleagues note that self-reported data on maternal alcohol consumption is not routinely collected, recorded or assessed in Australia.⁵³ At a jurisdictional level, the main reporting mechanism in relation to maternal data is through the Midwives Data Collection.⁵⁴ Although this Collection operates in all Australian jurisdictions, questions on prenatal alcohol consumption are only included in perinatal forms in Tasmania, the ACT and the NT and there is no uniformity across these jurisdictions in the questions asked. In the Northern Territory a question about alcohol consumption is scheduled for the first and 36th antenatal visit.⁵⁵
- 3.7 Research into the extent to which health professionals collect data on maternal alcohol consumption and provide patients with information, indicates considerable gaps. A study by the Australian Paediatric Surveillance Unit found that 'women were not routinely advised about the risks of drinking alcohol in pregnancy, nor were they advised not to drink alcohol in pregnancy'.⁵⁶ In a Western Australian survey of health professionals carried out in 2002, only 45 percent routinely asked questions about alcohol use and only 25 percent routinely provided information about the consequences of alcohol use in pregnancy, despite the fact that 96 percent agreed that information on the effect of alcohol on the foetus should be readily available to women of child-bearing age.⁵⁷ One witness providing evidence to the Committee indicated that screening for alcohol use usually occurs only on the first antenatal visit but does not happen continuously throughout the pregnancy.⁵⁸
- 3.8 There is clearly a need to improve the extent and nature of the data collected on maternal alcohol consumption. Results from a recent Australian study suggest that:
- women should be screened for alcohol intake with a validated clinical instrument that includes assessment of consumption patterns. The questions

⁵² Clarren et al cited in Education and Health Standing Committee, *Foetal Alcohol spectrum disorder: The invisible disability*, pp. 27-28.

⁵³ Burns et al (eds), *Fetal Alcohol Disorders in Australia: An update*, p. 46.

⁵⁴ Burns et al, 'Prevalence and correlates of alcohol use in pregnancy', in L Burns et al (eds), *Fetal Alcohol Disorders in Australia: An update*, pp. 22-23.

⁵⁵ Burns et al, 'Prevalence and correlates of alcohol use in pregnancy', p. 23.

⁵⁶ Education and Health Standing Committee, *Foetal Alcohol spectrum disorder: The invisible disability*, p. 26.

⁵⁷ Bower et al, 'Health professionals' knowledge and practice regarding alcohol use in pregnancy and FASD', in Burns et al (eds), *Fetal Alcohol Disorders in Australia: An update*, p. 64.

⁵⁸ Ms Raelene Wing, Committee Transcript, 29 July 2014; Witness, Committee Transcript 29 July 2014, p. 71.

should be accompanied by clear instructions for the health practitioner on how to interpret and discuss the information.⁵⁹

Although some research has found that women at risk could be identified through only one question,⁶⁰ a short but comprehensive questionnaire would also yield useful data regarding the links between patterns of alcohol consumption and relative impact on the foetus, as well as facilitating more targeted follow-up in contexts where resources for follow-up are constrained.

- 3.9 Routine screening through self-reports of PAE will not identify all women at risk because not all women are willing to acknowledge their alcohol use. In addition, women who are most at risk may also be the least likely to access antenatal care or to access it infrequently. Although it may be difficult to remedy these gaps, routine screening and the careful documentation of alcohol use on women who do attend antenatal clinics would significantly improve the ability to establish more accurate prevalence rates, not least because PAE is one of the key criteria used to diagnose FASD conditions (see Table 2, Chapter 2).

Diagnostic systems and complexities associated with diagnosis

- 3.10 A widely accepted diagnostic system suited to the Australian context is a prerequisite for collecting standardised data and the lack of such a system is one of the major barriers to assessing the prevalence of FASD in Australia. Currently, a range of diagnostic instruments developed overseas are used in the Australian context and, while many of the criteria are likely to be appropriate, some may need to be modified to fit the Australian context. As one witness noted,⁶¹ the facial characteristics associated with FAS may vary according to ethnic characteristics as shown in Figure 2.

⁵⁹ Muggli et al 2010 cited in Burns et al, 'Services for pregnant women', in Burns et al (eds), *Fetal Alcohol Disorders in Australia: An update*, p. 25.

⁶⁰ Johnson et al 2010 cited in Burns et al, 'Services for pregnant women', in Burns et al (eds), *Fetal Alcohol Disorders in Australia: An update*, p. 25.

⁶¹ Top End Women's Legal Service Inc (TEWLS), Submission No. 20, 2014, p. 2.

Figure 2: Characteristic facial characteristics of FAS for different ethnicities

Source: American Family Physician⁶²

3.11 Diagnosing FASD conditions is also considerably more complex than diagnosing chronic conditions such as diabetes, kidney disease, and heart disease, which can be definitively identified through medical tests. Although characteristic facial anomalies probably make FAS the easiest condition to diagnose in early childhood these anomalies are harder to detect at older ages. Other conditions under the FASD umbrella are difficult to detect at any age due to overlaps 'with other behavioural, developmental, educational or social problems with well documented determinants [that] may confound diagnosis'.⁶³ An accurate diagnosis of FASD is reliant on the use of a recognised diagnostic tool which, ideally, is administered by a multi-disciplinary team of skilled professionals. Ms Sarah Ward from the Foundation for Alcohol Research and Education (FARE) remarked that:

The diagnosis of FASD is a diagnosis of exclusion, so children are tested in terms of neurodevelopment and capability. They undergo psychological testing, physiotherapy testing and also have 3D photographs taken of their face to see any changes, the facial anomalies, the sort of differences from the standard deviations from normal, and all of these things together are then excluded from

⁶² American Family Physician, *Fetal Alcohol Spectrum Disorders*, <<http://www.aafp.org/afp/2005/0715/p279.html>>.

⁶³ Department of Health (DoH), Submission No. 9, 2014, p. 6.

other various diagnoses, say autism, or Asperger's or ADHD, or all those other similar developmental disabilities, to come to a diagnosis of FASD. They also need the confirmed exposure of alcohol, so they need to have some information about whether the mother was drinking or not.⁶⁴

- 3.12 The lack of uniform screening and diagnostic procedures means that accurate comparisons between prevalence studies cannot be made. In addition, the inability to standardise and compare data may compromise the ability to develop effective interventions, with Elliott and colleagues noting that:

It will be important to establish agreement about the most appropriate diagnostic criteria for use in Australia because this would enable standardization and comparison of data collected by clinical services and researchers and would be particularly important for intervention trials.⁶⁵

Awareness of FASD among health and medical professionals

- 3.13 The ability to effectively screen for, and diagnose, FASD, and hence to establish prevalence, is dependent on having a uniform and effective screening and diagnostic process in place, complemented by sufficient numbers of adequately trained personnel who have a sound knowledge of FASD. Surveys conducted in 2002 and 2004 have shown that: awareness and knowledge of FASD among health and medical professionals is limited; confidence to make the diagnosis is lacking; there is a reluctance to make the diagnosis because of potential stigmatisation; and there is a lack of knowledge about referral options and appropriate management.⁶⁶

- 3.14 Health professionals have also reported that obtaining information about alcohol use during pregnancy is difficult, particularly among Aboriginal women, who are likely to consider questions about alcohol use offensive or taboo.⁶⁷ In a 2002 survey of health professionals only 12 percent were able to identify all four essential diagnostic features of FAS and in the 2004 survey of paediatricians only 19 percent identified all four features.⁶⁸ The lack of confidence in making a diagnosis of FAS is reflected in the high proportions of paediatricians who had suspected but not diagnosed FAS (77 percent). Equally concerning is the fact that 12 percent had been convinced of but not recorded the diagnosis. In addition, a substantial proportion of health professionals lacked knowledge about, and failed to adhere to, the National Health and Medical Research Council (NHMRC) 2001 Guidelines for Alcohol Consumption. Only 11 percent of paediatricians surveyed in 2004 had read the NHMRC Australian alcohol guidelines for pregnancy use that were current at that time (2001 Guidelines) and less than a third of health professionals in the 2002 survey gave advice consistent with these guidelines.

⁶⁴ Committee Transcript, 29 May 2014, p. 60.

⁶⁵ Elliott et al, 'Services and interventions for children exposed to alcohol in pregnancy', in Burns et al (eds), *Fetal Alcohol Disorders in Australia: An update*, p. 80.

⁶⁶ Bower et al, 'Health professionals' knowledge and practice regarding alcohol use in pregnancy and FASD', pp. 64-69

⁶⁷ Personal communication from Ms Anne Hallett, Central Australian Health Service Tennant Creek, 31 August 2014.

⁶⁸ Bower et al, 'Health professionals' knowledge and practice regarding alcohol use in pregnancy and FASD', pp. 64-65.

Methodologies used for establishing prevalence

- 3.15 Three main methods for determining the prevalence of FASD have been documented: clinic based studies; passive surveillance; and active case ascertainment.⁶⁹ The most commonly used method is clinic based studies. These are generally conducted in prenatal clinics of large hospitals where information about alcohol use is collected from pregnant women. One advantage to this method is the collection of detailed maternal history data, however, there are also several disadvantages. First, women at highest risk for FAS children are less likely to regularly attend prenatal clinics. Second, clinic based studies are often carried out in places where disadvantaged populations predominate and may, therefore, overestimate the prevalence of FAS associated with disadvantage. Third, as FAS is not generally diagnosed at birth, clinic studies where long term follow up does not occur, may underestimate the prevalence.⁷⁰
- 3.16 Passive surveillance systems use existing record or data collections in a particular geographical area over a particular timeframe and involve 'researchers defining a set of criteria for diagnosis of FAS, ARBD or ARND and then looking for documented or probable cases of children born with the diagnosis'. The type of records used includes birth certificates, birth defects registers and medical charts of hospitals and physicians. Although passive surveillance methods are relatively inexpensive and easy to undertake, the full range of information required to make an accurate diagnosis of FAS may not be recorded on these data systems, 'or may not be identified as related to prenatal alcohol exposure'.⁷¹
- 3.17 Active case ascertainment can use various methods. One method is to identify and recruit children who may have FASD from a specified geographical area or population and, in some instances, to recruit the children's mothers as well, in order to collect data on maternal behaviour and risk factors. The first method has a number of advantages such as:
- It identifies children with FASD at an age when an accurate diagnosis can be made by clinical specialists;
 - The intense nature of the recruitment methods increases the likelihood that children with FASD will be identified;
 - Bias is reduced where a total population is studied; and
 - It enables individuals with FASD to be diagnosed and supported at the same time that knowledge of prevalence is increased.
- 3.18 Burns and colleagues note that this type of active case ascertainment 'produces the most complete assessment of the prevalence and characteristics of FAS in a particular population', however, it is also 'very labour intensive, time consuming, and

⁶⁹ May & Gossage 2001 cited in Burns et al (eds), *Fetal Alcohol Disorders in Australia: An update*, p. 46.

⁷⁰ Burns et al (eds), *Fetal Alcohol Disorders in Australia: An update*, pp. 46-47.

⁷¹ Burns et al (eds), *Fetal Alcohol Disorders in Australia: An update*, p. 47.

costly'.⁷² Active case ascertainment was the method used in the well documented *Lililwan Project*, a prevalence study carried out in the Fitzroy Valley of the Kimberley, which has been cited as having the potential to 'assist in educating the whole of Australia on the impact of alcohol use in pregnancy'.⁷³ The *Lililwan Project* was undertaken in the Fitzroy Valley in two stages. The first stage included interviewing parents or carers of all children born in the Fitzroy Valley in 2002 and 2003. Data was collected on antenatal exposures, early life trauma, and the health and development of each child. Stage two included a multi-disciplinary assessment of the health and development of these children to establish the prevalence of FASD. A detailed summary of this project is available in *The Lililwan Project: study protocol for a population-based active case ascertainment study of the prevalence of fetal alcohol spectrum disorders (FASD) in remote Australian Aboriginal communities*.⁷⁴

- 3.19 A second method is to target specialist groups such as paediatricians, who are likely to be involved in making FASD diagnoses, and to use a reminder mechanism to prompt central notification of new cases on a regular basis.⁷⁵ This method provides timely, detailed, clinical data and enables a minimum incidence rate to be estimated in the population of children seen by paediatricians.⁷⁶ However, as the evidence suggests that FASD is grossly under-identified and under-reported, this method has obvious limitations as it will not capture children with FASD who are not referred to specialists.
- 3.20 Based on a review of FAS prevalence studies to 2009, Fitzpatrick and colleagues draw attention to how the different methods discussed above influence prevalence rates. The review found a median prevalence of 0.27 per 1000 people for passive surveillance studies; 1.9 cases per 1000 people for clinic based studies; and 8.5 cases per 1000 people for active ascertainment studies. Fitzpatrick and colleagues further noted that study population demographics and inclusion of the entire foetal alcohol disorder spectrum also appeared to influence prevalence rates, with active ascertainment studies that included all diagnoses on the spectrum reporting a median prevalence of 19.0 cases per 1000 people, suggesting that:

Active case ascertainment studies are likely to be most accurate and that assessing the full range of diagnoses on the FASD spectrum in an entire population in high-risk communities is likely to result in high prevalence figures.⁷⁷

⁷² Burns et al, *Fetal Alcohol Disorders in Australia: An update*, p. 48.

⁷³ Education and Health Standing Committee, *Foetal Alcohol Spectrum Disorder: The invisible disability*, pp. 61-65,

⁷⁴ Fitzpatrick et al, *The Lililwan Project: study protocol for a population-based active case ascertainment study of the prevalence of fetal alcohol spectrum disorders (FASD) in remote Australian Aboriginal communities*, *BMJ Open*, vol. 2 (3) 2012.

⁷⁵ Burns et al, *Fetal Alcohol Disorders in Australia: An update*, p. 48.

⁷⁶ Burns et al, *Fetal Alcohol Disorders in Australia: An update*, p. 48

⁷⁷ Fitzpatrick et al, *The Lililwan Project*, p. 3.

Estimates of prevalence of FASD

- 3.21 To date, much of the research on Australian prevalence estimates appears to report on FAS rather than FASD. In addition, consideration of reported prevalence must take into account the wide range of factors that influence the accuracy of these estimates, as discussed above.
- 3.22 Internationally, estimates of the prevalence of FASD have been identified as ranging 'from 1-3 per 1,000 live births in the general population to as many as 9.1 per 1,000 births among high-risk populations'.⁷⁸ Much higher prevalence rates have been reported for FAS, with one study of Indigenous populations in South Africa reporting a prevalence rate of between 39 and 43 per 1,000 for children aged five to nine years⁷⁹ and, when the study was repeated five years later, prevalence had increased to between 65 and 74 cases per 1,000.⁸⁰
- 3.23 The first Australian estimate of birth prevalence of FAS was carried out by Bower who used multiple data sources, including the Birth Defects Registry and the Rural Paediatric Service database in Western Australia. Bower reported a rate of 0.02 per 1,000 live births for non-Indigenous children and 2.76 per 1,000 for Indigenous children.⁸¹ Subsequent studies found similar rates to Bower.
- 3.24 One study undertaken in the Top End of the Northern Territory used a retrospective chart review, which included medical records and outpatient letters relating to children seen by Royal Darwin Hospital paediatric staff between 1990 and 2000, to establish prevalence of FAS, pFAS and ARND. The live birth rate for the period is based on population data from the Australian Bureau of Statistics and the prevalence rate is expressed as the number of cases per 1000 live births. Total live births (Indigenous and non-Indigenous) were 25,209; 16,132 of these were non-Indigenous and 9,077 were Indigenous. The prevalence rate in relation to total live births was calculated as 0.68 per 1000 live births for FAS alone, but might reach 1.7 per 1000 live births if 'cases identified as partial FAS and ARND because of insufficient records, were assumed to have full FAS'.⁸² The prevalence rate in the Indigenous population alone, was calculated as 1.87 to 4.7 per 1000 live births. In this study there were no cases of FAS or related disorders in the non-Indigenous population, making the difference between Indigenous and non-Indigenous rates of FAS statistically significant ($p < 0.0001$).⁸³ While this shows FAS to be a significant issue for the Indigenous population, comparable to rates reported in North American Indigenous populations, the absence of any cases of FAS or ARND in the non-

⁷⁸ National Indigenous Drug and Alcohol Committee (NIDAC), Submission 4, 2014, p. 1.

⁷⁹ May et al cited in Burns et al (eds), *Fetal Alcohol Disorders in Australia: An update*, p. 48.

⁸⁰ Viljoen et al cited in Burns et al (eds), *Fetal Alcohol Disorders in Australia: An update*, p. 48.

⁸¹ Burns et al (eds), *Fetal Alcohol Disorders in Australia: An update*, p. 49.

⁸² KR Harris & IK Bucens, 'Prevalence of fetal alcohol syndrome in the Top End of the Northern Territory', *Journal of Paediatrics and Child Health*, vol. 39, 2003, p. 528.

⁸³ KR Harris & IK Bucens, 'Prevalence of fetal alcohol syndrome', p. 528.

Indigenous population is puzzling given that data on alcohol consumption in the NT 'indicates a high level of consumption in non-Indigenous males and females'.⁸⁴

- 3.25 Comments from witnesses suggest that prevalence rates in Australia are likely to be under-estimated.⁸⁵ In addition, several witnesses suggested that prevalence rates are higher in the Indigenous population and in communities with high rates of alcohol consumption and high-risk drinking patterns.⁸⁶ One witness drew attention to the following information on prevalence included in a Parliamentary Committee report into Indigenous Youth in the Criminal Justice system:

This report references submissions which place the rate of FASD as higher among Aboriginal children in Australia, including estimates of FAS affecting 2.97 Indigenous children per 1000, and the estimate by Professor Marcia Langton that FASD affects 1:40 Indigenous children.⁸⁷

- 3.26 The prevalence of FASD in the child protection system is significant, with 86 percent of cases involving alcohol use by one or both of the parents; this figure would indicate elevated risk of consumption during pregnancy.

⁸⁴ Australian Institute of Health and Welfare cited in Harris & Bucens, 'Prevalence of fetal alcohol syndrome', p. 531.

⁸⁵ Ms Prue Walker, Submission No. 17, 2014, p. 13; Foundation for Alcohol Research and Education (FARE), Submission No. 12, 2014, p. 7.

⁸⁶ Ms Prue Walker, Submission No. 17, 2014, p. 13; FARE, Submission No. 12, 2014, p. 7; McCusker Centre for Action on Alcohol and Youth (MCAAY), Submission No. 19, 2014, p. 2.

⁸⁷ Ms Prue Walker, Submission No. 17, 2014, p. 13.

4 Social and Economic Impacts of FASD

- 4.1 The social and economic impacts of FASD are profound and have flow on effects that reach beyond the individuals and families immediately affected. As the National Indigenous Drug and Alcohol Committee notes:

The social impact of FASD on individuals and their families in Australia is far-ranging and includes issues relating to mental health, alcohol and other drug use, disrupted school experience and consequent limits to employment, as well as contact with the criminal justice system. This impact is also felt on services attempting to address these issues. Access to appropriate services is vital. Services, including alcohol and other drug services, need to be in a position to respond to FASD-related issues with clients and their families.⁸⁸

- 4.2 This chapter provides an overview of some of the key ways in which FASD impacts on the broader community. It focuses primarily on: the economic impacts of FASD; the interactions between FASD and the justice and child protection systems; the impacts on families; and on the inter-generational transmission of Aboriginal culture.

Economic Impacts of FASD

*The economic costs to the NT associated with FASD cannot be reliably calculated with the information currently available; however they are likely to be significant. A greater appreciation of the prevalence of FASD and its role in incarceration, child protection, mental illness and unemployment in the NT will be a compelling call to action.*⁸⁹

- 4.3 The poor health outcomes associated with FASD result in high costs to the community and to individuals, families, and carers affected by FASD. Costs to individuals with FASD include loss of productivity (income), reduced quality of life and reduced longevity. Some of these costs are also incurred by families and carers of individuals with FASD. Community or social costs include direct costs to the government, such as the provision of health care and accommodation, and indirect governmental costs, such as the provision of special education and employment services, community services, income support, and justice services. Burns and Elliott note that 'costs to government may be viewed as an increase in tax payments or as the value of other services foregone because of the expenditures on FASD'.⁹⁰
- 4.4 In addition to the above, FASD can also result in high costs to individuals who do not have FASD but whose lives inadvertently collide with that of a FASD affected individual. One witness, a lawyer with the Northern Territory Legal Aid Commission, drew attention to the costs incurred by victims of crimes carried out by

⁸⁸ NIDAC, Submission No. 4, 2014, p. 17.

⁸⁹ DoH, Submission No. 9, 2014, p. 12.

⁹⁰ L Burns & E Elliott, 'Economic Impact of FASD in Australia', in Burns et al (eds), *Fetal Alcohol Disorders in Australia: An update*, p. 88.

individuals with FASD. In reference to the actions of a particular client, who almost certainly had FASD and had been incarcerated for murder, he asked:

What about the family of his two victims, one of whom survived but whose life has been blighted? What about all the appalling consequences for the rest of the family and the – you guys know. This is a gigantic problem.⁹¹

Costs to victims of FASD related crimes can be both private and social in nature, for example, loss of quality of life and medical costs.

- 4.5 Understanding and estimating the economic impact of FASD 'is necessary to justify and evaluate prevention programs and to inform the distribution of health care resources'.⁹² A prevention or early intervention service which is considered as too expensive to implement may be perceived as more viable if a clearly defined analysis shows the costs associated with not implementing it to be substantially higher. Due to the lack of prevalence data on FASD, and a consequent inability to accurately identify service use and needs, it is not possible to provide a realistic estimation of the economic impacts of FASD in Australia.
- 4.6 A number of international studies have examined the costs of FASD, however, 'these are limited in scope, both in terms of estimating the numbers of FASD cases and in terms of the types of costs included, and are also of limited comparability'.⁹³ Studies are difficult to compare due to a range of factors, such as the use of different methodologies, and variations in the population basis of the studies and what the studies are seeking to measure.
- 4.7 In estimating the costs of FASD, most studies have focused on the direct costs to government in relation to health care and accommodation and a few have examined costs to FASD individuals in relation to productivity loss. However, studies examining indirect costs to government, such as support services or justice services, are rare and there appear to be no studies examining costs in relation to reduced quality of life or reduced longevity, probably due to a lack of data on these factors.⁹⁴ Authors of a systematic review of studies examining the economic impact of FAS and FASD note that while there are limited studies available from the US and Canada, 'data from the rest of the world are largely absent'.⁹⁵
- 4.8 In their submission to the Committee, the McCusker Centre for Action on Alcohol and Youth noted that FASD cost up to \$5.4 billion per year in the US⁹⁶ while the 'lifetime costs in terms of service use and loss of productivity for an individual with Fetal Alcohol Syndrome (FAS) is estimated to be US\$2.5 million'.⁹⁷ However, these estimates excluded welfare and justice costs which are considered to add

⁹¹ Mr Russell Goldflam, Committee Transcript, 1 August 2014, p. 5.

⁹² L Burns & E Elliott, 'Economic Impact of FASD in Australia', p. 93.

⁹³ L Burns & E Elliott, 'Economic Impact of FASD in Australia', p. 88.

⁹⁴ L Burns & E Elliott, 'Economic Impact of FASD in Australia', p. 88.

⁹⁵ Popova et al, *Economic Impact of Fetal Alcohol Syndrome (FAS) and Fetal Alcohol Spectrum Disorder (FASD): A Systematic Literature Review*, Centre for Addiction and Mental Health, Social and Epidemiological Research Department, Canada, 2012, p. 6.

⁹⁶ MCAAY, Submission No. 19, 2014, p. 6.

⁹⁷ MCAAY, Submission No. 19, 2014, p. 6.

dramatically to the economic burden, with 25 percent of juveniles in detention estimated to have a diagnosis on the FASD spectrum.⁹⁸

- 4.9 Although US studies generally appear to focus on FAS, several Canadian studies have estimated the costs associated with FASD. Table 4 provides a brief summary of results from two Canadian studies. These two studies have been chosen for their relative recency and because they include some indirect as well as direct costs.

Table 4: Costs associated with FASD – two Canadian studies

Study	Year of Study	P/I ¹ per 1000	Age	Health Care	Education	Social Services	Productivity Losses	Out-of-pocket	Annual ² cost all people with FASD	Annual ² cost per individual
				Cost; percentage of total cost						
Stade et al 2006	2003	3 (P)	1-21	\$3,976 30.3%	\$4,275 32.6%	\$2,866 21.9%	\$1,055 8.1%	\$936 7.1%	\$390.2 million	\$16,259
Stade et al 2009	2007	10 ³ (P)	0-53	\$6,630 32.8%	\$5,260 26%	\$4,075 20.2%	\$1,431 7.1%	\$2,814 13.9%	\$5.5 billion	\$22,473

¹Prevalence/Incidence;

²Adjusted for inflation May 2010;

³There is a discrepancy between the prevalence rate shown in Table 2 of this article (3 per 1000) and the prevalence rate cited in the text on p.16 (10 per 1000). The latter prevalence rate has been used as it produces the annual cost of \$5.5 billion cited in the table.

Source: Popova et al 2012.⁹⁹

- 4.10 Both of the studies shown in Table 4 used a similar methodology but the 2009 study aimed to overcome some of the limitations of the earlier study by including the costs for: infants aged 0-1, adults beyond 21 years; and infants in institutions. In addition, the 2006 study population consisted of 148 parents (or caregivers) living with a child aged 1-21 while the 2009 study population included 250 participants of which 240 were parents or caregivers of individuals with FASD and 10 were adults with FASD. A major difference in the two studies is the prevalence rate used to calculate annual costs to the government. The 2006 study used a very conservative FASD prevalence rate of 3 per 1000 while the 2009 study used a prevalence rate of 10 per 1000.¹⁰⁰

⁹⁸ MCAAY, Submission No. 19, 2014, p. 6.

⁹⁹ Popova et al, *Economic Impact of Fetal Alcohol Syndrome*, p. 11, adapted from Table 2.

¹⁰⁰ Popova et al, *Economic Impact of Fetal Alcohol Syndrome*, pp. 14-16.

4.11 Data to assess direct and indirect costs associated with FASD were collected through a modified version of the Health Services Utilization Inventory (HSUI). Direct costs were assessed through questions about:¹⁰¹

- Medical care (hospital admissions, health professional services, medication);
- Educational services (home schooling, special schooling); and
- Social services (respite care, foster care).

In the 2009 study some additional items were included in the HSUI in relation to education and social services.

4.12 Indirect costs included productivity losses which were measured using a human capital approach and included days of missed work due to caring for a FASD child. Other, or private, costs included out-of-pocket expenses such as costs to parents or caregivers for parking and transportation and costs associated with externalising behaviours, which included acts of aggression such as damage to people or property and stealing.¹⁰²

4.13 Neither of these studies examined law enforcement costs and neither included individuals incarcerated at the time of data collection.

4.14 The total average annual expenditure per child was calculated by summing the costs for each child in each cost component and dividing the total by sample size. The annual cost of FASD to Canada was calculated by multiplying the annual expenditure for each child by the number of people estimated to have FASD within the age group used for each study population. The much lower annual cost to the Canadian government in the 2006 study is due to (a) the more limited age group used for the study population (1-21 compared to 0-53) and (b) the use of a very conservative prevalence estimate to establish the FASD population (3 per 1000 compared to 10 per 1000).

4.15 In the 2006 study, key predictors of cost included the severity of the disability and the age of the child. Children aged 6-15 years incurred higher health costs than other age groups while costs relating to older children reflected 'costs of educational needs and those due to externalizing behaviours'.¹⁰³ In the 2009 study costs were highest for children 0-3 years of age and decreased in line with older age. Costs begin to plateau for 18-25 year olds and the 36-53 age group had the lowest costs.

4.16 These studies provide some idea of the magnitude of costs associated with FASD and, to some extent, an insight into the key cost areas. However, with regard to the latter it is important to note that the costs incurred reflect a range of factors, including the policy settings current at the time of the studies. For example, the 2009 study found that there was a lack of services for older age groups and that it was difficult for young adults, and adults with FASD, to access services due to

¹⁰¹ Popova et al, *Economic Impact of Fetal Alcohol Syndrome*, pp. 10-16.

¹⁰² Popova et al, *Economic Impact of Fetal Alcohol Syndrome*, p. 12.

¹⁰³ Popova et al, *Economic Impact of Fetal Alcohol Syndrome*, p. 12.

cognitive and executive functioning difficulties and an unwillingness to accept services.¹⁰⁴ Consequently, these estimated costs do not necessarily reflect the full extent of the costs of FASD.

- 4.17 The findings from these studies cannot be transferred directly to the Australian context, however, there are sufficient similarities between conditions in the two countries for the results to provide some idea, at least at the individual level, of the costs associated with FASD. For example, the proportion of the Indigenous population in Canada is similar to that in Australia, with Aboriginal people comprising 4.3 percent of the Canadian population¹⁰⁵ and 3 percent of the Australian population.¹⁰⁶ Although FASD is not solely an Indigenous problem, prevalence studies suggest that the scope of the problem is more severe in Indigenous populations, with this view also supported by higher rates of binge drinking and higher levels of disadvantage in the Indigenous population (Chapter 5).
- 4.18 Costs relating to the justice system are commonly excluded from studies of the economic impact of FASD despite the fact that these are likely to be significant. In their submission to the Committee, Barkly Youth Services noted that, for 2012-13, the projected cost per detainee was \$629.44 per day with this translating into an annual cost per detainee of \$230,000. In addition, the rate for youth detention is 'allegedly around \$50,000 a year more'.¹⁰⁷ Statistics on youth detention are included in Table 5 and show a steady increase over the last four years.

Table 5: Youth Detention in the Northern Territory – 2009-10 to 2012-13¹⁰⁸

Key Deliverables	Current Year		Targets	Previous Years		
	2012-13 Budget Estimate	2012-13 Actual	2013-14 Estimates	2009-10	2010-11	2011-12
Daily average number of youth detainees	65	49	75	28	39	38
Expected peak beds	75	73	90	36	60	48
New admissions for the year	85	141	95	89	91	109

¹⁰⁴ Popova et al, *Economic Impact of Fetal Alcohol Syndrome*, p. 16.

¹⁰⁵ Employment and Social Development Canada, 'Canadians in Context: Aboriginal Population', *Indicators of Wellbeing in Canada*, < <http://www4.hrsdc.gc.ca/3ndic.1t.4r@-eng.jsp?iid=36> >.

¹⁰⁶ Australian Indigenous HealthInfoNet, *What details do we know about the Indigenous population?*, < <http://www.healthinfonet.ecu.edu.au/health-facts/health-facts/aboriginal-population> >.

¹⁰⁷ Barkly Youth Services (BYS), Submission No. 26, 2014, p. 6.

¹⁰⁸ Department of Correctional Services, *Annual Report 2012-2013*, Northern Territory Government, p. 49.

- 4.19 As shown above, the average number of youth detained in the Territory per day has increased from 28 in 2009-10 to 49 in 2012-13, with the Northern Territory Department of Correctional Services (NTDCS) estimating that this will increase in 2013-14 to 75 per day. Similarly, the peak beds required has increased from 36 in 2009-10 to 73 in 2012-13, with an estimate of 90 for the current year. The estimate of 95 new admissions for 2013-14 seems optimistic given that the estimate for 2012-13 was 85 with an actual admission rate of 141.
- 4.20 The costs arising from youth detention rates are significant, particularly when the total costs associated with detention are taken into account, for example, factors such as school disruption, police time, court time, travel, home care or rehabilitation, and administrative costs. Taking such costs into account, Barkly Youth Services commented that 'Conservatively, each young person who falls off the edge in the Barkly costs the government on average around \$500,000'.¹⁰⁹
- 4.21 This is a significant cost and, as Barkly Youth Services pointed out, some NT regions have more than their fair share, with the following statistics quoted in the submission to demonstrate the impact that alcohol and, by implication, FASD, has on communities in the Barkly region:¹¹⁰
- For the year to June 30, 2013, there were 17 sexual assaults. Across the rest of the Territory, there were 58. The Barkly has three per cent of the Territory's population.
 - There were 382 assaults in the Barkly for the first six months of 2013 which can be read as one for every 10 people. In the rest of the Territory, the average was around one in every 206 people.
 - In 2013, more than a third of the Territory's reported sexual assaults were committed at Tennant Creek.
 - Anecdotally, the youth recidivism rate in the Barkly is over 90 percent.
- 4.22 The submission further noted that estimates from the Department of Corrections indicate that the average number of youth detained is increasing significantly each year (20 percent increase in 2011-12) and similarly, the Department of Children and Families' annual report indicates that child protection notifications and children in out of home care, in the Territory, are also showing substantial increases (from 6,533 in 2010-11 to 9,967 in 2012-13).¹¹¹
- 4.23 These figures are alarming, particularly when both research and anecdotal evidence suggests that a substantial proportion of these individuals may be affected by FASD. Two studies, in particular, highlight this possibility.
- 4.24 In 2011, Anyinginyi Health Aboriginal Corporation, in conjunction with a Tennant Creek Youth Service organisation, used the Canadian Medical Association's

¹⁰⁹ BYS, Submission No. 26, 2014, p. 6.

¹¹⁰ BYS, Submission No. 26, 2014, p. 5.

¹¹¹ BYS, Submission No. 26, 2014, p. 6.

Guidelines to screen 220 clients for FASD. Of these clients, 70 percent exhibited one or more indicators of FASD. In addition, almost all of this group had:

some level of involvement with police and the courts and almost all have been recidivist during the past three years. Of those on BYS [Barkly Youth Service] programs in the 12 months to June 30 2014 who reoffended during that time, all exhibited FASD indicators.¹¹²

4.25 The second study examined foetal alcohol exposure among children in the child protection system in the NT and was based on:

a file-review of a random sample of 230 client files. 180 children in the sample were under protective investigation, and 50 children were in care on Protection Orders issued by the Northern Territory Magistrates Court, Family Matters.¹¹³

4.26 The study found that 38 percent of children in care had been foetally exposed to alcohol. Although not all children would be expected to develop a FASD, of those children with PAE:¹¹⁴

- 6 percent had a FAS diagnosis
- 8 percent had suspected FAS
- 10 percent experienced growth delay/prematurity/low birth weight
- 10 percent experienced speech or language delay
- 23 percent had behavioural problems

The overall 'rate of FAS in the study population was 13:1000 which is comparable to international estimates of 10-15:1000 children'.¹¹⁵

4.27 A substantial number of witnesses expressed concern to the Committee about the long term and widespread nature of the economic impacts that would occur if FASD is allowed to go unchecked. Ms Turner, from Anyinginyi Health Aboriginal Corporation commented that:

I appreciate this costs a hell of a lot of money – FASD - and I understand, in part, the reluctance by government of thinking how much is out there, how much it has to deal with? However, the flow-on effect, whether dementia, early kids schooling – all of that - is going to cost a hell of a lot more than starting this process now.¹¹⁶

4.28 Similarly, a participant at the Tennant Creek Public Forum noted that:

it is preliminary days, but if the numbers starting to emerge are anything to go by, the multiplier effects of these children make it highly likely that Justice department costs, Health department costs and youth program costs will go through the roof. Their [FASD affected individuals] employability will be seriously undermined so there are costs attached to not addressing this issue.¹¹⁷

¹¹² BYS, Submission No. 26, 2014, p.2.

¹¹³ Prue Walker, Submission No. 17, 2014, p. 19.

¹¹⁴ Prue Walker, Submission No. 17, 2014, p. 22-23.

¹¹⁵ Prue Walker, Submission No. 17, 2014, p. 23.

¹¹⁶ Committee Transcript, 31 July 2014, p. 16.

¹¹⁷ Witness, Committee Transcript, 30 July 2014, p. 22.

- 4.29 Mr Cain, from Barkly Youth Services demonstrated to the Committee how a lack of adequate resources and the absence of appropriate strategies could exacerbate the social and economic costs associated with FASD:

Mr Cain: We also have one of our young people who is on our books. He is one of those who has a letter saying he has FASD. As Anyinginyi said earlier, we do not have too many who have been completely diagnosed. He has. In the last four years, we have lost count of the number of places he has been put between foster care, state or Territory care, detention, and rehabilitation centres. In four years he has probably been put into 50 different places at a minimum.

Madam CHAIR: How old is he?

Mr CAIN: He is now 14. He was released from Don Dale two weeks ago and has case workers from every department following him around. There is still no plan for his treatment. In the last four years we estimate the Territory has invested \$4m in moving him around, putting him in care and there is still no plan for this young person. Seriously, if we are looking at \$1m a year cost for the average one who is diagnosed where do we end up getting the money from?¹¹⁸

- 4.30 FASD also has a significant effect within educational settings, with this having a flow on effect in terms of employability and productivity generally. Many children with FASD have memory deficits and difficulty comprehending mathematical concepts; abstract concepts such as time and space; and the relationship between cause and effect. These difficulties contribute to disruptions in the classroom setting and pose challenges for both teachers and students. Although the Northern Territory Department of Education (DoE) has a focus on 'building the capacity of schools and teachers to support students who display characteristics and behaviours consistent with FASD',¹¹⁹ under-diagnosis of FASD and a shortage of resources mean that FASD is likely to have a continuing impact on the classroom environment. The costs associated with providing appropriate resources to effectively manage FASD in schools are likely to be considerable.

- 4.31 Mr Ken Davies, Chief Executive of the Department of Education, noted the low levels of children officially diagnosed with FASD within both government and non-government schools across the Territory:

Mr DAVIES: It is fair to say the numbers - when you look at our numbers with 27 children diagnosed - the diagnosis remains a challenge for us and we are convinced there are many children in our system ... in classrooms who are not diagnosed with people making assumptions around, but the diagnosis would certainly assist us. Children at the lower end of the FAS spectrum present the greatest challenge to our system because ...

Madam CHAIR: Meaning those not so seriously affected?

Mr DAVIES: Yes. You can easily identify the seriously affected kids. Some are in our special schools so they have disabilities that come with it as well, but for those children in classrooms - classrooms are highly stimulating environments full of activity and action and for a child with foetal alcohol spectrum - an environment rich, active and very intensive is not necessarily the best environment for those kids in relation to their own learning.

¹¹⁸ Committee Transcript, 31 July 2014, pp. 100-101.

¹¹⁹ DoH, Submission No. 9, 2014, p. 11.

For us the numbers diagnosed at this stage are small - 27 across the Territory. We think there are many more undiagnosed. Any child coming in with a disability is a challenge for the system. We want to make sure we are on the front foot around supporting the children and, of course, their families to get the best possible outcomes.¹²⁰

Foetal Alcohol Spectrum Disorder and the Justice System

4.32 As discussed in Chapter 2, FASD individuals are highly susceptible to a range of secondary disabilities. Included in these are a greater likelihood of committing criminal offences and incarceration. Primary disabilities associated with FASD appear to be the major contributor to this trend, including impulsivity, difficulty controlling behaviour and an inability to plan actions and behaviours.¹²¹ As Mr Scott Wilson from the National Indigenous Drug and Alcohol Committee explained to the Committee;

'if they want that mobile phone, for example, that might be sitting on your desk, there is no thought pattern there that if I took that it is called stealing. They take it because they want it...'¹²²

FASD individuals exhibit high suggestibility¹²³ and difficulty with reasoning and recognising the consequences of actions,¹²⁴ all of which are more conducive to criminal behaviour. Some examples of typical criminal activities include stealing items for immediate consumption or benefit, offending behaviour triggered by fright or noise, inappropriate sexual behaviour and being drawn into secondary participation by more sophisticated offenders. Memory and associated retention problems also contribute to increased recidivism as noted by Ms Lynda Jarvis from the Alice Springs Correctional Centre:

As individuals with FASD are often unable to retain learning they are unable to readily adapt to new situations ... They are highly likely to be recidivist offenders, so they are people that we will see time and time again.¹²⁵

4.33 Fundamentally, these primary disabilities are at odds with a legal system which is premised on the assumption that individuals make voluntary, informed decisions about exercising their rights or infringing on the rights of others by committing a crime. Similar to most individuals with a mental illness or cognitive impairment, those who are FASD affected often interact negatively with criminal justice structures as they lack the cognitive ability to understand this rationale. These

¹²⁰ Committee Transcript, 29 May 2014, pp. 63-64.

¹²¹ M Rowley, *The invisible client: people with cognitive impairments in the Northern Territory's Court of Summary Jurisdiction*, 2013, p. 3; Commonwealth, House of Representatives, Standing Committee on Social Policy and Legal Affairs, *FASD: The Hidden Ham*, 2012, p.137; H Douglas, 'The sentencing response to defendants with foetal alcohol spectrum disorder', *Criminal Law Journal*, vol. 34, no. 4, 2010, p. 228.

¹²² Committee Transcript, 12 August 2014, p. 44.

¹²³ National Indigenous Drug and Alcohol Committee (NIDAC), *Addressing fetal alcohol spectrum disorder in Australia*, 2012, p. 10; Brown et al, 'Suggestibility and Fetal Alcohol Spectrum Disorders: I'll tell you anything you want to hear', *Journal of Psychiatry and Law*, vol. 39, 2011, p. 40.

¹²⁴ Standing Committee on Social Policy and Legal Affairs, *FASD: The Hidden Ham*, p.137; H Douglas, 'The sentencing response' p. 228.

¹²⁵ Committee Transcript, 1 August 2014, p. 41.

problems are well encapsulated in one description by a barrister who works closely with FASD affected individuals in the Yukon region of Canada who notes that they are:

an often likable rogue who rarely learns from experience, being unable to understand the association between their actions and the punishments meted out by the justice system. They are typically caught time and time again for the same crime, are the gang stooge, do not understand their rights under law, use the same implausible excuses, confess to things they have not done to please their interviewers, confabulate their story or are unable to understand how the justice 'game' works and forget, over the course of their incarceration, what they have been interned for.¹²⁶

- 4.34 FASD individuals also find themselves in these circumstances due to other postnatal adversities common to their disorder, many of which enhance the likelihood of contact with law enforcement personnel (as discussed in Chapter 2). These include poor nutrition and hearing, parental neglect, substance use disorders, school and employment difficulties, homelessness, additional mental health issues and a general inability to manage the requirements of daily living.¹²⁷ This is unfortunately compounded by the reality that most Australian jurisdictions lack appropriate health, education or welfare support services to divert FASD sufferers away from the courts and correctional facilities.¹²⁸
- 4.35 This heavy interaction coupled with the high needs of FASD individuals places considerable pressure on all areas of the criminal justice system. Under the current processes used to deal with these offenders, particularly incarceration and youth detention, the costs to government are high and likely to continue increasing (see 4.18).

Prevalence

- 4.36 An important starting point in understanding the interaction between FASD and the criminal justice system is ascertaining the number of individuals with the disorder who become involved with police personnel, the courts and correctional services in the Northern Territory. At present, there is no reliable data in this area.
- 4.37 Empirical studies conducted overseas provide a general impression of the number of FASD individuals interacting with the criminal justice system. Several submissions to this inquiry cited research from Canada and the USA¹²⁹ which indicates that there are particularly high rates of contact between individuals with

¹²⁶ DM Boulding cited in J Egerton, 'A step in time: Fetal alcohol spectrum disorders and transition to adulthood', Carpenter et al (eds), *Fetal Alcohol Spectrum Disorders: Interdisciplinary Perspectives*, Routledge, New York, 2014, p.154.

¹²⁷ Burd et al, 'Fetal Alcohol Spectrum Disorder as a marker for increased risk of involvement with correctional systems', *Journal of Psychiatry and Law*, vol. 38, no. 4, winter, 2010, p. 562.

¹²⁸ Standing Committee on Social Policy and Legal Affairs, *FASD: the Hidden Harm*, p. 138.

¹²⁹ Popova et al, 'Fetal Alcohol Prevalence Disorder Estimate in Correctional Systems: A Systematic Literature Review', *Canadian Journal of Public Health*, vol. 102, no. 5, 2011, p. 339.

FASD and the criminal justice system.¹³⁰ One US study found that as much as 60 percent of adolescents with FASD have come into contact with the criminal law.¹³¹

- 4.38 The situation in Australia is likely to be similar. In the Northern Territory, the incidence of contact may also be higher due to the increased rate of alcohol consumption compared to other states (see Chapter 5). One study conducted by Anyinginyi Aboriginal Corporation in the Barkly region found that 70 percent of the 220 participants screened had at least indicator of FASD and almost all had experienced some interaction with the justice system.¹³²
- 4.39 Anecdotal evidence from legal service providers in the NT suggests that this lack of data is partly due to limited detection or knowledge of the disorder amongst practitioners and judicial officers.¹³³ This also appears to be the case in other Australian jurisdictions.¹³⁴ Formal diagnoses during court proceedings are rare for a number of reasons¹³⁵. Most significantly, courts do not have clinical expertise on hand for diagnosis, and behavioural and physical indicators are not known to legal stakeholders, as Mr Mark O'Reilly from the Central Australian Aboriginal Legal Aid Service (CAALAS) explained to the Committee:

I have been at CAALAS for 16 or 17 years doing criminal work representing people before the courts and I have had, over that time, a particular involvement in dealing with matters where there are psychiatric issues or cognitive delay. I do some work within the mental health system as well, and out of that whole time I could only point to a few cases where there has actually been any kind of formal recognition and diagnosis of FASD. There is lots of recognition of cognitive impairment and cognitive delay, but putting the FASD label on it has been pretty minimal and there is a lot more out there than is diagnosed.¹³⁶

In addition, current legal definitions of 'mental impairment' or 'cognitive impairment' in NT legislation do not accommodate FASD,¹³⁷ and the disorder may be masked by other mental illnesses.¹³⁸ Clinical studies also suggest that the *indigeneity* of many FASD sufferers further impairs recognition and recording of the disorder due to cultural and language barriers and lack of appropriate assessment tools.¹³⁹

¹³⁰ Northern Territory Legal Aid Commission, Submission No. 6, 2014, p. 2.

¹³¹ Streissguth et al, 'Risk Factors for Adverse Life Outcomes', pp. 228–238.

¹³² BYS, Submission No. 26, 2014, p.2.

¹³³ Mr Jared Sharpe, Committee Transcript, 29 May 2014, p 17; North Australian Aboriginal Justice Agency & Central Australian Aboriginal Legal Aid Service (NAAJA/CAALAS), Submission No. 21, 2014, p. 8; TEWLS, Committee Transcript, 29 May 2014, p 30; TEWLS Submission No. 20, 2014, p 1; Rowley, *The invisible client*, p. 3; NT Legal Aid Commission, Submission No. 6, 2014, p 3.

¹³⁴ FARE, *Foetal Alcohol Spectrum Disorder: Knowledge, attitudes and practice within the Western Australian Judicial System*, 2013, p. 39; FARE, *Foetal Alcohol Spectrum Disorders within the Criminal Justice Sector in Queensland*, 2013, p. 20-21.

¹³⁵ Rowley, *The invisible client*, p. 3.

¹³⁶ Committee Transcript, 1 August 2014, p. 29.

¹³⁷ Rowley, *The invisible client*, pp. 10-14; Standing Committee on Social Policy and Legal Affairs, *FASD: the Hidden Harm*, p. 140.

¹³⁸ NAAJA/CAALAS, Submission No. 21, 2014, p. 9.

¹³⁹ Dingwall et al, "'People like numbers": a descriptive study of cognitive assessment methods in clinical practice for Aboriginal Australians in the Northern Territory', *BMC Psychiatry*, 2013, 13:42; Rowley, *The invisible client*, p. 3.

Interactions with Police

4.40 Police personnel often represent the first point of contact between FASD individuals and the general community outside of the family and school environment. Consequently, their response is important in shaping the experience of FASD individuals in the criminal justice system. Knowledge of police interactions with FASD individuals is, however, scarce as Mr Damien Griffiths, CEO of FPDN, explained to the Committee:

there is no sense of what their interactions are like with the service system. The way we invariably see it, it is usually the job of the frontline service system - the police really are the ones who engage with Aboriginal people with foetal alcohol [spectrum disorder], and that is problematic and very challenging for them...¹⁴⁰

This inquiry did not receive any information about current practices adopted by Northern Territory police when arresting, detaining and questioning offenders suspected of having a mental impairment. However, current research from other jurisdictions indicates that FASD sufferers are significantly disadvantaged at this stage in the legal process.¹⁴¹

4.41 From the outset, understanding of legal rights and the nature and consequences of their criminal behaviour is likely to be limited at the point of formal charging by police.¹⁴² For example, individuals with FASD may not understand the language or implications when a police officer explains the right to silence and the fact that statements may be used as evidence against them prior to interviewing.¹⁴³ During questioning, poor memory, high suggestibility and eagerness to please may lead FASD individuals to falsely confess or agree to statements resulting in a miscarriage of justice.¹⁴⁴ For similar reasons, they are also less reliable as witnesses and complainants, with the result that offenders are less likely to be convicted. This pattern of interaction with law enforcement is well demonstrated by a de-identified case study from CAALAS involving a client with suspected FASD:

Josh has impulsive and irrational behaviours. His offending is not pre-meditated. When arrested by the police, he is often confused and has difficulty remembering events and understanding the seriousness of his offending. He usually agrees to whatever version of events the police put to him following his arrest.¹⁴⁵

4.42 Some safeguards exist in current legislation to ensure that the rights of vulnerable offenders are upheld in these situations. For example, the *Youth Justice Act* (NT) requires a support person to be present when questioning a suspect under the age of 18 years.¹⁴⁶ The current *Anunga* Guidelines used by Northern Territory Police

¹⁴⁰ Committee Transcript, 12 August 2014, p. 35.

¹⁴¹ K Roach & A Bailey, 'The relevance of fetal alcohol spectrum disorder and the criminal law from investigation to sentencing', *University of British Columbia Law Review*, vol. 42, 2009, pp. 1–68.

¹⁴² Dingwall et al, "People like numbers", p 42; Mr Mark O'Reilly, Committee Transcript, 1 August 2014, p 3.

¹⁴³ see *Police Administration Act* (NT), s 140.

¹⁴⁴ Douglas et al, 'Judicial Views of Foetal Alcohol Spectrum Disorder in Queensland's Criminal Justice System', *Journal of Judicial Administration*, vol. 21, 2012, p. 180.

¹⁴⁵ Rowley, *The invisible client*, p 7.

¹⁴⁶ *Youth Justice Act* (NT) s 18.

also require a 'prisoner's friend' to be present where a person 'may have limited mental capacity' and measures to be implemented 'to ensure a fair interrogation'.¹⁴⁷

- 4.43 A current program aimed at implementing these safeguards is the Register of Appropriate Support Persons overseen by the Youth Justice Advisory Committee.¹⁴⁸ The program provides trained volunteers from the Australian Red Cross to support vulnerable youths during police interviews in Darwin, Katherine and Alice Springs when another responsible adult is not available.¹⁴⁹ Volunteer training is regularly provided through CAALAS, North Australian Aboriginal Justice Agency (NAAJA) and NT Police but does not include FASD specific guidelines.
- 4.44 A broader issue affecting police responsiveness to FASD individuals is lack of sufficient knowledge of the disorder amongst personnel. Empirical research on strategies for questioning and charging individuals with FASD is limited to one Western Australian study. The 2013 survey of 1000 police officers concluded that identification of FASD was inadequate and respondents were less likely to request training in this area.¹⁵⁰ Despite broad recognition that current interviewing, cautioning and detainment practices may require adjustment,¹⁵¹ a large majority of officers also considered the redressing of disadvantages faced by FASD individuals as a role left to the courts.¹⁵² This is particularly unfortunate as a number of witnesses have suggested that, where aware of FASD, police officers can play an important 'gate-keeping' role in flagging the cognitive impairment for consideration by the courts.¹⁵³ One witness, Mr Danny Curtis, particularly noted that building well informed relationships with local police has assisted in keeping his foster son with FASD out of trouble with the law:

I am lucky we have a good police officer at Tea Tree Gully or Holden Hill who checks on him every now and then to see how he is going. He is aware of Travis ... Even when he went missing, what we used to do was call the unit at Holden Hill and they would put an alert out to other officers.¹⁵⁴

FASD individuals and the criminal courts

*They are treated in the court system pretty much like everybody else, even when it is recognised and accepted that they may be suffering.*¹⁵⁵

- 4.45 Criminal courts in many Australian jurisdictions, including the Northern Territory, do not appear to be adequately cognisant of or equipped to deal with the special needs

¹⁴⁷ L Bartels, *Police Interviews with vulnerable adult suspects*, Research in Practice Paper No. 21, Australian Institute of Criminology 2011, p 10.

¹⁴⁸ A committee of government, non-government and community representatives tasked with monitoring compliance with the *Youth Justice Act (NT)*.

¹⁴⁹ NTDCS, *Youth Justice Advisory Council Annual Report: 2013-2014*, p. 21.

¹⁵⁰ FARE, *FASD within the WA justice system*, p.35.

¹⁵¹ FARE, *FASD within the WA justice system*, p. 37.

¹⁵² FARE, *FASD within the WA justice system*, p. 36.

¹⁵³ Ms Priscilla Collins, Committee Transcript, 29 May 2014, pp. 17, 22; Tangentyere Council, Committee Transcript, 1 August 2014, p. 32; First Peoples Disability Network, Committee Transcript, 12 August 2014, p. 36.

¹⁵⁴ Committee transcript, 1 August 2014, p. 66.

¹⁵⁵ CAALAS, Committee Transcript, 1 August 2014, p. 27.

of FASD individuals. The above statement from CAALAS is confirmed by the majority of evidence submitted to this inquiry about the experiences of FASD offenders and victims of crime.

4.46 In the courtroom and consultation process with legal practitioners, FASD affected individuals suffer from a range of impairments, which hinder the ability for the individual to effectively plead their case. These include:¹⁵⁶

- Hearing difficulties;
- Communication difficulties;
- Memory deficits; and
- Difficulty understanding courtroom language including sarcasm, idiom or metaphor.

In practical terms, these disabilities make it difficult for FASD affected individuals to secure legal representation, provide instructions to lawyers, give evidence to defend themselves and comprehend the content, strategy and procedures involved in their case.

4.47 However, these impairments are not necessarily uniform. A 2013 study involving 100 youth offenders from two Canadian provinces, 50 of whom were diagnosed with FASD, found that this diagnosis did not strongly correlate with reduced psycho-legal abilities. The study tested psycho-legal abilities relevant to rights comprehension and adjudication through interviews. Over half of the FASD participants did not adequately comprehend their arrest and interrogation rights and 76 percent demonstrated impaired performance in the assessment of fitness to stand trial. Yet the study also found that not all FASD offenders exhibited impaired psycho-legal abilities, and furthermore, many without the disorder demonstrated substantial impairments.

4.48 Evidence provided to this inquiry has overwhelmingly shown that similar difficulties are encountered in the Australian criminal justice system. These difficulties are best demonstrated by describing the life span of a criminal matter involving a FASD individual in the Northern Territory criminal justice system.

Initial consultation with a lawyer

4.49 After a FASD offender is formally charged for an offence and detained, legal representation will usually be sought for an application for bail. Due to the primary disabilities associated with FASD, communication with clients is often difficult. As Mr Mark O'Reilly from CAALAS explained to the Committee:

That first communication with clients ... is often very difficult ... Sometimes it is a language issue, a cultural issue, a hearing issue and, very often, it is a mental

¹⁵⁶ Western Australia, Legislative Assembly, Education and Health Standing Committee, Inquiry into Foetal Alcohol Spectrum Disorder: the invisible disability, Committee Transcript, 29 June 2012, p. 76.

health issue. For untrained people to pinpoint and diagnose that, or make their own assessment about what may be going on is very difficult.¹⁵⁷

Bail applications

- 4.50 An offender will next present at a bail hearing in the courts of summary jurisdiction. In determining a bail application, magistrates are not specifically required to consider relevant cognitive impairments or mental health problems of an applicant.¹⁵⁸ Minimal knowledge of FASD amongst judicial officers and legal practitioners also means that the disorder is unlikely to be detected and taken into account at this stage.
- 4.51 In the absence of a diagnosis, bail applications are usually unsuccessful for a number of reasons closely related to the cognitive disabilities associated with FASD. Individuals often have a history of non-appearance at hearings and are prone to reoffend, leading to the view that they are an unacceptable risk to the community. They also lack secure accommodation and support networks to assist in complying with bail conditions.¹⁵⁹ For example, there are no accommodation facilities specifically for applicants seeking bail who do not have permanent accommodation in the Northern Territory. Compliance with the requirement of a fixed address is accordingly difficult for FASD individuals who are at greater risk of homelessness.
- 4.52 Where bail is granted, conditions are often unrealistic and excessively rigid according to NT legal service providers. FASD individuals frequently do not understand the conditions read out in a courtroom due to problems understanding long and complex sentences and difficulty in concentrating.
- 4.53 The various symptoms associated with FASD also increase the likelihood that conditions will be breached.¹⁶⁰ For example, a FASD offender may not report to the court or a relevant agency when required as they cannot discern the time of day or the day of the week.¹⁶¹ CAALAS provided a case study exemplifying these issue in a recent submission to the Australian Human Rights Commission on access to justice for people with a disability:

CAALAS represents a male under an adult guardianship order. The client has an acquired brain injury which impairs his cognitive functioning. The client was initially bailed by police. The client was unable to understand the bail conditions and therefore was unable to comply ... He was remanded in custody for breach of bail pending review of his bail by a court. The client was ultimately released on bail again on essentially the same conditions.¹⁶²

¹⁵⁷ Committee Transcript, 1 August 2014, p 27.

¹⁵⁸ *Bail Act* (NT), s 24(1),

¹⁵⁹ NAAJA/CAALAS, Submission No. 21, 2014, p. 15.

¹⁶⁰ Western Australia, Legislative Assembly, Education and Health Standing Committee, Inquiry into Foetal Alcohol Spectrum Disorder: the invisible disability, Committee Transcript, 29 June 2012, p. 73; Mr Jared Sharp, Committee Transcript, 29 May 2014, p 18.

¹⁶¹ NAAJA/CAALAS, Submission No. 21, 2014, p. 21.

¹⁶² CAALAS, *Submission to the Australian Human Rights Commission: Consultation on access to justice in the criminal justice system for people with a disability*, 2013, p 10.

As indicated above, breach of bail also begins an unfortunate cycle of repeated incarceration where bail is revoked and subsequently refused for future offences due to a history of non-compliance.¹⁶³

The hearing process

- 4.54 After bail is determined, the criminal matter is set down for hearing in the court of summary jurisdiction (NT Magistrates Court) or the Supreme Court. At this point, a legal advocate can submit that a FASD individual is not fit to plead or stand trial, or raise a defence by reason of 'mental impairment' under Part IIA of the *Criminal Code* (NT). Where the Supreme Court finds that an individual is unfit to plead, stand trial or not guilty by reason of mental impairment, the matter is taken to a special hearing.¹⁶⁴ Here, the court has the opportunity to issue a special verdict for a supervision order.
- 4.55 Although this process aims to provide an alternative to incarceration, in practice, mentally impaired offenders are often placed under custodial supervision orders in mainstream correctional facilities. This is primarily due to the lack of secure care facilities available in the NT. The only adult secure care facility within the Territory is located in Alice Springs which can accommodate up to 8 adults. The facility was initially built as a 16 bed unit with an internal division, intended to provide separated secure care for adults and juveniles, with another facility with identical capacity built in Holtze in Darwin. It was later decided not to accommodate adults and juveniles within the same facility, subsequently the Alice Springs unit was earmarked for adult secure care and the Darwin facility assigned for juvenile secure care. At the time of tabling this report, one half of the Alice Springs unit is a secure care facility administered by the Office of Disability, while the other half is utilised for Alcohol Mandatory Treatment residential care. While the unit has the capacity to provide secure care for up to 8 adults, the number of occupants may be fewer, based on staffing resources, the level of support required by each occupant and the need for individuals to be able to effectively cohabit together. The Darwin facility is managed by the Department of Children and Families and provides secure out of home care for teenagers with complex needs who are under the care of the Department.
- 4.56 Under the legislation, offenders may serve custodial supervision orders in another 'appropriate place'; however this requires a certificate from the CEO of the Northern Territory Department of Health (DoH) stating that such facilities are available.¹⁶⁵ To date, no such certificate has been issued.¹⁶⁶ As a result of this scheme, FASD offenders are often unjustly detained under special verdicts for long periods and

¹⁶³ Western Australia, Legislative Assembly, Education and Health Standing Committee, Inquiry into Foetal Alcohol Spectrum Disorder: the invisible disability, Committee Transcript, 29 June 2012, p. 76.

¹⁶⁴ *Criminal Code* (NT), ss 43Z, 43ZA.

¹⁶⁵ *Criminal Code* (NT) s 43ZA(3).

¹⁶⁶ J Hunyor & M Swift, *A Judge Short of a Full Bench: mental health in the NT criminal justice system*, paper presented at the Criminal Lawyers Association of the Northern Territory Thirteenth Biennial Conference, Bali, 30 June 2011, p. 13.

denied appropriate treatment suited to their needs, as explained in a research paper by NAAJA on criminal justice and mental health in the NT:

Jail is clearly an inappropriate place for detaining people who are unfit to be tried and/or not guilty by reason of their mental illness. On a purely practical level, it makes treatment and ultimate re-integration much more difficult. It is also difficult to justify incarceration of persons whom we deem not subject to criminal penalty in a facility intended to punish.

Many criminal practitioners from Darwin who have visited the prison over the years would be aware of the continuous plaintive cries of one of our clients who is routinely placed back in prison when he breaches his supervision order.¹⁶⁷

- 4.57 Anecdotal evidence also indicates that these offenders routinely spend longer periods in correctional facilities than those dealt with in the summary courts where cognitive or mental impairment is not raised.¹⁶⁸ This leaves legal practitioners with the difficult choice of proceeding with a matter in the summary court jurisdiction without accounting for their client's special needs, or applying to have the matter heard in the Supreme Court with the high probability of an indefinite supervision order where facilities are not available.
- 4.58 If an offender has committed a low level offence, the options are further limited. At present, there is no legislative scheme to assist the NT Magistrates Court in dealing with mentally impaired individuals who are charged with lesser criminal offences. A number of legal service providers expressed strong concerns about this gap given that a majority of criminal offences in the NT are dealt with by the lower courts.¹⁶⁹ The court has the option to dismiss charges on the basis of mental illness or mental disturbance.¹⁷⁰ It may also order unconditional release or involuntary admission of individuals suffering from these conditions or a complex cognitive impairment based on reports received from a psychiatric practitioner.¹⁷¹ However, these provisions have limited application for individuals with a cognitive impairment such as FASD because of their restrictive application and the high threshold for demonstrating complex cognitive impairment.¹⁷²
- 4.59 This failure of legislative procedure to adequately account for all forms of cognitive impairment sees many FASD individuals passing through the summary courts without consideration being given to their special needs and vulnerabilities.

Sentencing

- 4.60 Where a Pt. IIA application is not made and offender is found guilty, the matter moves to the sentencing phase. Apart from a reference to 'intellectual capacity',

¹⁶⁷ Hunyor & Swift, *A Judge Short of a Full Bench*, p. 13.

¹⁶⁸ NAAJA/CAALAS, Submission No. 21, p. 21; Rowley, *The invisible client*, p. 11.

¹⁶⁹ Rowley, *The invisible client*, p. 5; NAAJA/CAALAS, Submission No. 21, p. 22; Mr Mark O'Reilly, Committee Transcript, 1 August 2014, p. 27.

¹⁷⁰ *Mental Health and Related Services Act 1998* (NT), s 77.

¹⁷¹ *Mental Health and Related Services Act 1998* (NT) Part 10.

¹⁷² Rowley, *The invisible client*, pp. 11-13.

there is no provision explicitly directing the court to consider cognitive impairment as a mitigating circumstance in the *Sentencing Act* (NT).¹⁷³

- 4.61 The inability of FASD offenders to understand the nature and consequences of their behaviour often renders normal sentencing options inappropriate. As one criminal lawyer from NAAJA commented:

Should they apply a deterrent model against someone who does not understand the consequences of the criminality of their behaviour, how can they understand – if they are not a vehicle for deterrence then it is pointless the court throwing the book at them and locking them up for a lengthy period.¹⁷⁴

Despite this, legal service providers have stated that courts frequently use deterrence and punishment as primary considerations in sentencing offenders with cognitive impairments (including FASD), resulting in repeated terms of imprisonment.

- 4.62 It must be acknowledged, however, that courts have few options in the current context. Without a formal FASD diagnosis, there is no capacity to include impaired functioning as a broad mitigating factor in their sentencing decision. Effective sentencing is also precluded by the non-existence of specific FASD management programs and relevant community services to connect with offenders. Lack of secure care facilities to support a rehabilitative approach to sentencing in the NT is particularly concerning, as Mr Mark O'Reilly explained to the Committee:

but that is the big problem, about placing people, because with the best will in the world courts might say, 'We need to do something for this person. We need to improve their situation and the consequence of that will be that it improves community safety,' but there is nothing and so people end up in gaol ... there are people in gaol simply because no one can think of where they might go.¹⁷⁵

- 4.63 As discussed below, this approach is not only inappropriate but potentially more damaging for FASD individuals than the average prisoner.

The corrections system

- 4.64 At present, there is no empirical data on the prevalence of FASD in Australian correctional systems. Data from correctional facilities in overseas jurisdictions is also scarce, apart from some reliable statistics from Canada and the USA.¹⁷⁶ One recent review of international studies by Popova and colleagues at the University of Toronto concluded that the number of incarcerated FASD individuals is likely to be high.¹⁷⁷ For example, Canadian data from a range of prison-based studies estimated that the number of FASD affected youth offenders in the correctional system ranged from 207 to 423 individuals on any given day. For adult offenders, the daily estimate was 3, 686.¹⁷⁸

¹⁷³ *Sentencing Act 1995* (NT), s 5.

¹⁷⁴ Mr Jared Sharp, Committee transcript, 29 May 2014, p. 20.

¹⁷⁵ Committee transcript, 1 August 2014, p. 29.

¹⁷⁶ Burd et al, 'FASD and involvement with the corrections system', p. 565.

¹⁷⁷ Popova et al, 'FASD Estimate in Correctional Systems', p.338.

¹⁷⁸ Popova et al, 'FASD Estimate in Correctional Systems', p.338.

4.65 In its evidence to this inquiry, the Alice Springs Correctional Centre (ASCC) indicated that it has four current inmates diagnosed with FASD under custodial supervision orders. Three of the offenders are managed in the general population and the remaining inmate is placed in the John Bench Unit, a 16 bed facility staffed by aged care and disability support workers.¹⁷⁹ Where FASD inmates behave inappropriately according to facility rules, they are temporarily managed by this unit. Staff indicated that numbers of undiagnosed inmates are, however, likely to be higher;

While we only have four who the remote health clinic have been able to advise us of, we see, on a daily basis, others who present with some of the same signs...¹⁸⁰

No equivalent estimates were available for the Berrimah Correctional Centre and other facilities in the Northern Territory.¹⁸¹

4.66 Anecdotal evidence suggests that prison time for a FASD affected individual is likely to be a harder experience than the average prisoner. Heightened difficulty in adjusting to new rules and understanding social cues will often result in victimisation by other inmates and prison staff.¹⁸² Chief Justice Wayne Martin of Western Australia explained these issues to a 2012 parliamentary inquiry in WA:

There are, of course, a number of rules and regulations imposed by prison authorities ... FASD sufferers are unlikely to be in a position to fully comply with those rules, with the result that they will find themselves in trouble with the authorities. And of course there are social hierarchies within prisons ... FASD sufferers are at a disadvantage in complying with those social rules, with the result that they are very likely to find themselves in trouble with their fellow inmates.¹⁸³

4.67 In the recent Northern Territory case of *R v Doolan; R v Leo* [2012],¹⁸⁴ this problem was broadly acknowledged. Both offenders suffered a mental impairment with similar characteristics to FASD and were placed under custodial supervision in correctional facilities due to the lack of alternative options. His honour observed that continued incarceration was causing significant distress to both individuals:

both persons have spent more time in custody, and at times in a high security unit of the prison, than their crimes would merit. Each at times becomes significantly frustrated and desperate. It is of significant concern that during some periods Mr Leo may have deteriorated, thus making it more difficult for him to pass through the planned stages to alternative arrangements. Mr Murdock, who closely monitors each of the supervised persons, emphasises the prison environment is not appropriate.¹⁸⁵

¹⁷⁹ ASCC, Committee Transcript, 1 August 2014, pp. 42-43.

¹⁸⁰ ASCC, Committee Transcript, 1 August 2014, p. 43.

¹⁸¹ Don Dale Juvenile Detention Centre (Berrimah) and Datjala and Barkly Work Camps are also under the management of DCS.

¹⁸² Boland, F. Chudley, A & Grant, B. 'The challenge of Fetal Alcohol Syndrome in adult offender populations', *Forum on Correctional Research*, vol. 14, no. 3, p 61.

¹⁸³ Western Australia, Legislative Assembly, Education and Health Standing Committee, Inquiry into Foetal Alcohol Spectrum Disorder: the invisible disability, Committee Transcript, 2 June 2012, p. 73.

¹⁸⁴ *R v Doolan; R v Leo* [2012] NTSC 46 (3 July 2012).

¹⁸⁵ *R v Doolan; R v Leo* [2012] NTSC 46.

- 4.68 On the other hand, prison may also provide a safe, routinized environment suitable to FASD individuals. Long periods of detention in these conditions may encourage an attitude of complacency and result in higher levels of dysfunction when they return to the community.¹⁸⁶
- 4.69 In all circumstances, prison based therapeutic treatment to address these complex needs is required. The NTDCS currently provides a range of rehabilitative programs to prisoners during their sentence, run by staff, psychologists and social workers. These include group programs on drug and alcohol education and treatment, problem solving and family violence and visits from community elders.¹⁸⁷ Assessment and case management is also made available on an individual basis for prisoners with mental health issues and complex behavioural problems (including FASD individuals).¹⁸⁸
- 4.70 ASCC staff indicated that inmates with FASD do not respond well to the services provided in a group environment. Treatment in the correctional system requires intensive case management linked to appropriate diagnostic services, therapy and post-release programs.¹⁸⁹ Ms Lynda Jarvis, Manager of Prisoner Services, commented:

Essentially, all the work done by the partners we work with in the community are [sic] group based. A lot of the prisoners we have with FASD will not do well in a group because it is too much for them to coordinate, think about and plan around all at once. To work with someone with FASD requires a different way of working.¹⁹⁰

As there are no diagnostic services, treatment programs and staff training in best practice management, working with a FASD individual to effectively modify their behaviour is not possible. The absence of specific post-release management through parole orders and ongoing treatment plans also contributes to recidivism amongst offenders with the disorder. As ASCC staff noted to the Committee;

Without those supports the individual may be released, may go back to a family that cares very much about them but, because of the nature of that disability, the family cannot always provide that support. Then, fairly rapidly unfortunately, things can escalate back to contact with the police then, potentially, back in with us.¹⁹¹

Parole and post-release support

- 4.71 Similar to other inmates, FASD offender may be offered the opportunity to be released into the community under a parole order. When applying for and complying with conditions under a bail order, difficulties arise which are similar to those outlined in the bail process.

¹⁸⁶ ASCC, Committee Transcript, 1 August 2014, p. 44.

¹⁸⁷ Department of Correctional Services, *Addressing Offending Behaviour*, Northern Territory Government, <<http://www.correctionalservices.nt.gov.au/RehabilitationAndIndigenousInitiatives/AddressingOffendingBehaviour/Pages/default.aspx>>.

¹⁸⁸ ASCC, Committee Transcript, 1 August 2014, p. 41.

¹⁸⁹ ASCC, Committee Transcript, 1 August 2014, p. 44.

¹⁹⁰ Committee Transcript, 1 August 2014, p. 44.

¹⁹¹ Committee Transcript, 1 August 2014, p. 45.

- 4.72 The Northern Territory Parole Board considers a number of issues including the risk of reoffending and harm to the community, any rehabilitation courses undertaken in prison and assessments submitted by health professionals, legal practitioners, social workers and custodial staff.¹⁹² Where parole is granted, the board might impose additional parole conditions such as abstention from drugs and alcohol, completion of rehabilitation or treatment programs and an accommodation curfew.¹⁹³
- 4.73 The Community Corrections Division of Northern Territory Correctional Services provides a thorough care program designed to assist prisoners on parole to identify support networks and practical plans for reintegration into the community.¹⁹⁴ The transition is also supported by similar programs from NAAJA and CAALAS which provide individual needs assessment and case management plans in collaboration with community and government service providers.¹⁹⁵
- 4.74 However, these services have limited benefits for FASD offenders placed on standard parole conditions that are overly restrictive, complex and fail to account for their impairments. Due to their primary disabilities and lack of community support on release, parolees with the disorder are highly likely to breach usual conditions such as residing in one location, maintaining good behaviour and reporting to a parole officer. As NAAJA explained in relation to its clients:
- Many face conditions that are unrealistic or excessively rigid – for example, to reside at a particular address when they are in chronic housing stress or to report to Corrections on a particular day at a particular time when they do not have a sense of time that allows them to comply.¹⁹⁶
- 4.75 The absence of appropriate assessment services, residential care facilities and treatment programs also prevents the board from imposing conditions which will adequately treat and reintegrate a FASD individual.

Lack of FASD awareness amongst workers in the criminal justice system

- 4.76 An issue that permeates all stages of a criminal matter involving a FASD affected individual is the inability of legal stakeholders to identify the disorder. Early identification is pivotal in allowing the courts to account for the disabilities of FASD offenders and impose appropriate sentencing options for the benefit of the individual and the community. However, as the signs of FASD are less manifest than other disabilities and there is no reliable diagnostic instrument and general indicators, workers across the justice system rarely detect the disorder.
- 4.77 Current survey based studies of criminal justice professionals in other jurisdictions reveal a limited understanding of FASD in terms of identification, effects on the

¹⁹² *Parole Act* (NT)

¹⁹³ Parole Board of the Northern Territory, *Parole Board of the Northern Territory: Annual Report 2013*, pp. 18-19.

¹⁹⁴ Parole Board of the Northern Territory, *Parole Board of the Northern Territory: Annual Report 2013*, pp. 22-23.

¹⁹⁵ NAAJA manages the Prisoner Support Officer Project and Indigenous Throughcare Project. CAALAS also run a Prisoner Support Program and Youth Justice Advocacy Project.

¹⁹⁶ NAAJA/CAALAS, Submission No. 21, 2014, p. 15.

sufferer and relevance to legal processes. In the absence of primary data, these findings are also likely to apply in the Northern Territory.

4.78 For example, a survey conducted by FARE in April 2013 concluded that the Western Australian criminal justice system is 'poorly prepared and resourced'¹⁹⁷ to adequately manage FASD despite strong interest in enhancing knowledge and introducing new FASD specific tools/programs from respondents. Individuals surveyed included judicial officers, lawyers, police officers and correctional services staff. A further study conducted by FARE in Queensland yielded similar results, finding that there are significant gaps in knowledge of FASD, and criminal justice system responses are generally inappropriate for sufferers.¹⁹⁸

4.79 Anecdotal evidence confirms that this knowledge gap is also present in the Northern Territory. Mr Jared Sharp, a legal practitioner from NAAJA, explained to the Committee:

the problem is we are in this information vacuum, not just in the Territory, but all over Australia. We are not getting that diagnostic information, whether you are a lawyer, a police officer or a child protection worker. You do not have access to the crucial information of whether the person you are dealing with is FASD affected.¹⁹⁹

Impact on Families

4.80 FASD affected children have significant behavioural issues and this creates considerable stress for parents and other family members. The cognitive problems associated with FASD make behaviour management a challenge, as traditional parenting interventions are rarely effective. As DoH notes, the 'inability to retain information around rules and consequences create[s] unique difficulties for parenting practices'.²⁰⁰ This is particularly likely to be the case where FASD has not been diagnosed and parents do not have the resources, support or knowledge to assist them to manage behaviours. The stress associated with raising a FASD affected child is further aggravated by the tendency of welfare officers or child protection officers to attribute behavioural issues to poor parenting, abuse or neglect rather than to the disorder itself, as often a diagnosis has not been made.²⁰¹ However, the relationship between FASD and alcohol use also means that the parents of a FASD affected child are more likely to have substance abuse issues which make it even more difficult for them to meet the developmental and learning needs of a child with a FASD condition.²⁰² As Dr Jennifer Delima noted:

The problem is huge for the families because they are trying to deal with this chaotic child and, if alcohol was one of the precursors to that pregnancy because of chaos and poverty and lack of social supports, then this whole thing

¹⁹⁷ FARE, *FASD within the WA justice system*, p. 39.

¹⁹⁸ FARE, *FASD within the Queensland Justice Sector*, p. 20.

¹⁹⁹ Committee Transcript, 29 May 2014, p. 21.

²⁰⁰ DoH, Submission No. 9, 2014, p. 11.

²⁰¹ Ms Prue Walker, Submission No. 17, 2014, p. 16.

²⁰² Department of Children and Families (DCF), Submission No. 14, 2014, p. 3.

is magnified. The feeling of failure for that parent is magnified and we say, “Why can’t you look after and discipline your child?” but this is a very hard case.²⁰³

- 4.81 As noted in Chapter 2, individuals with FASD are more likely to have alcohol and drug problems and there is an increased risk of promiscuity in girls or women who have FASD. These characteristics, particularly when combined with a desire to please (a common trait in FASD affected individuals) increase the likelihood that FASD affected women will, in turn, give birth to a child who has been prenatally exposed to alcohol. The range of issues facing families where both parent and child are affected are extensive. Equally, families in which one or both parents have FASD are also likely to experience more intense impacts. CAALAS provides just one example:

In relation to care and protection, we have had situations at CAALAS where we have acted for mothers of children where the mothers are FASD affected and it has impacted on their ability to care for children. In the housing situation, it is hard to point to any specifics, but it is not hard to imagine the situation where the symptoms of FASD would make it very difficult for people to comply with obligations of public housing, and the placement situations where they are looking, potentially, at eviction and homelessness.²⁰⁴

- 4.82 Although the literature on the impact of FASD on families is sparse, research suggests that parents experience ‘feelings of loss, guilt, shame and blame’ while a systematic review of the limited research available found that:²⁰⁵

having a child/children with FASD was associated with financial strain, frustration with the lack of knowledgeable professionals, stress related to the judicial system and multiple time demands’.²⁰⁶

- 4.83 The stress consequent on raising a child with FASD contributes to the potential for family breakdown, violence, and involvement of child protective services. In addition:

Families may face significant financial burdens associated with raising and caring for FASD sufferers. Stigma or guilt attached to having a child with FASD may cause a reluctance of families to seek support and treatment.²⁰⁷

- 4.84 Catholic Care commented that their experience in working with communities indicates that women:

largely learn to live and adapt to having children who may have FASD and that it is not recognised as a particular disability and the cognitive, behavioural and emotional disorders are normalised.²⁰⁸

However, they also note that:

The enduring impacts are ... experienced through low educational attainment, high levels of incarceration and poor health outcomes.²⁰⁹

²⁰³ Committee Transcript, 1 August 2014, p. 42.

²⁰⁴ Committee Transcript, 1 August 2014, p. 48.

²⁰⁵ Menzies School of Health Research (MSHR), Submission No. 15, 2014, p. 4.

²⁰⁶ MSHR, Submission 15, 2014, p. 4.

²⁰⁷ DoH, Submission No. 9, 2014, p. 11.

²⁰⁸ Submission No. 13, 2014, p. 4.

²⁰⁹ Submission No. 13, 2014, p. 4.

Although these outcomes are a direct impact on the child with FASD they also have a profound impact on the emotional wellbeing and self-esteem of the parents.

4.85 As noted by the Menzies School of Health Research, there is a dearth of literature on the impact of FASD on families, with this indicating a significant research gap.²¹⁰ This lack of knowledge is problematic because it impedes the ability to provide appropriate interventions and support. In addition, Wurli-Wurlinjang Health Service noted that lack of awareness about the impacts and costs associated with FASD inhibits incentives for action at a local community level and commented that:

While the long-term clinical effects of FASD are well documented and its debilitating impact increasingly better understood, Wurli believes there should be benefit both in the research context and the health promotion context for the information regarding the impact of FASD, on Katherine Aboriginal families in particular, to be documented and disseminated - obviously, it has to be in an anonymous way - so as to highlight to our own community the recent costs of continuing with the lifestyle status quo.²¹¹

4.86 Northern Territory Council of Social Services (NTCOSS) commented that more needs to be done to support children in care with FASD and to support carers. It drew attention to the ad hoc nature of the services provided and the fact that carers had to advocate for the children in their care to access diagnosis and support. Some key recommendations identified in a review of the needs of families affected by FASD included:²¹²

- Biological mothers of affected children need support if FASD is to be prevented;
- There is little recognition of the disorder or the burden associated with FASD;
- Classification of FASD as a disability will improve services for those affected;
- Carers need to be provided with information about FASD and strategies for dealing with the behaviour and health of children;
- Out of home care placements need to be supported and sustained; and
- Effective interventions for families caring for children with FASD should be piloted and evaluated.

Inter-generational Impacts

4.87 The call for action on prevention, diagnosis and management of FASD is widespread and ranges from FASD support groups through to professionals working in alcohol harm minimisation, health, justice and education. It is particularly strong in Aboriginal communities who are 'at the forefront of these calls'.²¹³ FASD makes it difficult for affected individuals to participate in the cultural life of their

²¹⁰ Submission No. 15, 2014, p. 4.

²¹¹ Committee Transcript, 29 July 2014, p. 4.

²¹² Northern Territory Council of Social Services (NTCOSS), Submission No. 18, 2014, p. 22.

²¹³ MCAAY, Submission No. 19, 2014, p. 3.

communities²¹⁴ and Aboriginal communities ‘have grave concerns that FASD is threatening the continuation of their languages and culture’.²¹⁵

- 4.88 This is hardly surprising given the devastating consequences that both alcohol and FASD have in Aboriginal communities. As one witness noted, ‘oral traditions rely on memory and ... community development depends on growing children into strong future leaders’.²¹⁶ The impairments associated with FASD compromise cultural continuity, with this being a primary rationale for the Marulu Project in Fitzroy Crossing in Western Australia:

Marulu - The *Lililwan Project* grew from the needs within an Indigenous community. The need to heal the pain of past alcohol use and the need to preserve their future and culture is what guides this project. In a culture where traditions, stories, and ways of life are orally passed from one generation to the next, FASD threatens the very existence of Aboriginal culture in the Fitzroy Valley. The healing has already begun, but the work is just getting started.²¹⁷

Management of FASD in child protection and out of home care

Prevalence

- 4.89 There is presently no solid data indicating the number of children or parents diagnosed with FASD who come into contact with the NT child protection system and require out of home care. There is, however, strong evidence suggesting that FASD children are over-represented and exposure to alcohol increases the likelihood of entering care.²¹⁸ Abuse and neglect due to parental alcohol abuse and hampered growth and development are the main factors behind this increased risk of contact.
- 4.90 One 2014 study conducted by Prue Walker found that 86 percent of cases with children on child protection orders in the NT involve problematic alcohol abuse by one or more parents.²¹⁹ This high percentage suggests an increased risk of PAE and FASD diagnosis after birth. A further study by the NT Department of Children and Families (DCF) found that 6 percent of 230 children under review had a confirmed FAS diagnosis and one fifth were identified as prenatally alcohol exposed.²²⁰ In the same study, 63 percent of parents reported concerning alcohol use, with 50 percent of the children living in families with long term alcohol abuse problems.²²¹

²¹⁴ Patta Aboriginal Corporation, Committee Transcript, 31 August 2014, p. 50.

²¹⁵ MCAAY, Submission No. 19, 2014, p. 3.

²¹⁶ Ms Prue Walker, Submission No. 17, p. 5.

²¹⁷ The George Institute for Global Health, *Marulu - Overcoming Fetal Alcohol Spectrum Disorders (FASD)*, <<http://www.georgeinstitute.org.au/projects/marulu-overcoming-fetal-alcohol-spectrum-disorders-fasd>>.

²¹⁸ Office of the Children’s Commissioner (OCC), Submission No. 22, 2014 p 2; DCF, Submission No 14, 2014, p 2; Standing Committee on Social Policy and Legal affairs, *FASD: the Hidden Harm*, p. 118.

²¹⁹ OCC, Submission No. 22, 2014, p. 2; Ms Prue Walker, Submission No. 17 2014, p. 20.

²²⁰ DCF, Submission No. 14, 2014, p. 5.

²²¹ DCF, Submission No. 14, 2014, p. 6.

Experience of FASD children and parents in care

4.91 Children with FASD generally come into contact with the child protection system as a result of concerns related to parental substance abuse. They may also enter the system as a result of behavioural issues that cannot be handled by their existing parents or carers. FASD affected parents engage with the system in similar circumstances, with child protection services often removing their children as they cannot be adequately cared for.

4.92 FASD children have needs which are more advanced than those without the disorder, necessitating higher levels of support and interaction with health, education and other service providers. In her submission to this inquiry, Prue Walker outlined the following characteristics which are critical to the development of FASD children in care:²²²

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

4.93 Care arrangements often fail to meet these requirements due to:²²³

- Repeated attempts at reunification with family;
- Unplanned access with family;
- Placement breakdown;
- Multiple placements; and
- Changes in childcare or school depending on the placement.

4.94 There is also little recognition of the plight of FASD children with parents who are prone to substance abuse or themselves FASD affected. In these situations, children are highly vulnerable to abuse and neglect, and are less likely to receive the support required to address their complex needs.

4.95 As a result, recognition of FASD and access to allied health treatment is likely to be delayed. This may be due to failure to recognise developmental delays by parents and carers, lack of confidence in raising the sensitive issue of FASD, waiting periods for appropriate treatment and the impact of family access arrangements.²²⁴ Failure to intervene and provide treatment at this point increases the risk of

²²² Ms Prue Walker, Submission No. 17, 2014, p. 17.

²²³ Ms Prue Walker, Submission No 17, 2014, p. 17.

²²⁴ Ms Prue Walker, Submission No 17, 2014, pp. 16-17.

disengagement with school, anti-social behaviour and contact with the criminal justice system for the FASD individual.

- 4.96 The core reason for these delays however, is lack of education and awareness. Where FASD is suspected, parents, carers and child protection workers often do not have access to appropriate resources for managing the disorder, as Ms Vicki Russell explained to the Committee:

I was talking only last week to a parent carer from Alice Springs who is a single parent. She has a 14-year old boy who is exceptionally violent. She is frightened of him. She does not know what to do. She does not know whether to return him to the department or look for an alternative placement for him, but she has had him since he was seven months old....²²⁵

Current management

- 4.97 Evidence to this inquiry indicated that current support structures in the child protection system are not sufficient for FASD affected children and their primary caregivers. Child protection systems in many Australian jurisdictions are under-resourced and already beyond capacity.²²⁶ Finding additional resources and time to adequately provide support services for individuals with high needs and alcohol abuse problems is accordingly difficult.
- 4.98 In the Northern Territory, the child protection system does not provide any specific programs for the management of children with FASD. When a case is referred to DCF, the Family Strengths and Needs Assessment tool is used to assess needs and coordinate support for a family and child.²²⁷ There are currently no FASD support programs in other agencies or the community sector that can be linked to this primary assessment tool. DCF recognised this inadequacy in evidence provided to the Committee:

DCF on its own can provide, however, relatively limited responses to families. We are unable to effectively identify or respond to their addiction problems without assistance from drug and alcohol services, nor can we respond to the specific learning or behavioural needs of children diagnosed with FASD without advice from health or education services.²²⁸

- 4.99 In its submission, DCF indicated that it has implemented the following measures to cater for FASD children, families and carers:²²⁹
- Since 2012, a consultant has been engaged to provide training in FASD risk assessment and case planning for child protection staff and family support workers in non-government organisations;

²²⁵ Committee Transcript, 29 May 2014, p. 28.

²²⁶ Bamblett et al, *Growing them Strong, Together: Promoting the safety and wellbeing of the Northern Territory's children*, Report of the Board of Inquiry into the Child Protection System in the Northern Territory, Northern Territory Government, 2010, p 18.

²²⁷ DCF, Submission No. 14, 2014 p. 9.

²²⁸ Committee Transcript, 29 May 2014, p. 57.

²²⁹ DCF, Submission No. 14, 2014, pp. 8-9.

- Staff training on infant development under the Tune Into Little Ones program includes FASD resource information; and
- Foster and Kinship Carer training is being reviewed to accommodate for the special needs of FASD children.

4.100 Anecdotal evidence suggests that these measures are not sufficient to address the needs of families, carers and children. NAAJA commented that lawyers acting for parents and children cannot rely upon DCF to initiate the screening, assessment, diagnosis or planning for dealing with the needs of a FASD affected child.²³⁰ This leaves children and parents without support or direction with managing the disorder. Evidence from NTCOSS also indicates that despite additional staff training, there is still insufficient information about successful models of management for FASD affected children, parents and their carers.²³¹

²³⁰ Committee Transcript, 29 May 2014, p. 18.

²³¹ NTCOSS, Submission No. 18, 2014, p. 28.

5 Alcohol Consumption and FASD

- 5.1 Chapters 2, 3 and 4 have highlighted the complex nature of FASD and drawn attention to the issues associated with establishing accurate prevalence rates, and achieving timely diagnosis. The devastating impact of FASD on individuals, families, communities, and society more broadly, has also been elucidated.
- 5.2 This chapter sets the overall parameters of the problem. It first discusses the causes of FASD and the extent to which secondary factors might influence the outcomes of FASD conditions. It then focuses on rates of alcohol consumption and the factors influencing consumption.

The Causes of Foetal Alcohol Spectrum Disorder

- 5.3 The fundamental cause of FASD is exposure of the developing foetus to alcohol,²³² basically, if there is no exposure to alcohol there will be no FASD. However, not all children who are exposed to alcohol in utero develop FASD and those who do are affected to varying degrees. Consequently, while alcohol is the primary cause, there are a range of other factors that influence (a) whether prenatal exposure to alcohol results in FASD and (b) the nature and severity of the impact of PAE. This section looks at biological and environmental factors that are implicated in FASD.
- 5.4 Alcohol is a teratogen, which is defined as ‘any environmental factor that can produce a permanent abnormality in structure or function, restriction of growth, or death of the embryo or fetus’.²³³ Examples of teratogens include ‘medications; drugs; chemicals; and maternal conditions or diseases, including congenital infections’.²³⁴ Alcohol is the most commonly used teratogen in the western world and of all the ‘substances of abuse (including cocaine, heroin, and marijuana), alcohol produces by far the most serious neurobehavioral effects in the fetus’.²³⁵
- 5.5 Alcohol is passed from the mother to the foetus through the following mechanism:
- Some of the blood vessels of the fetus are contained within the villi of the placenta that connect to the uterine wall. The mother’s blood passes within the intervillous space, which is only separated by the thin placental membrane. Teratogens in the mother’s blood can then be passed across the placental membrane into the villi, umbilical cord, and finally into the fetus.²³⁶

Figure 3 illustrates how the maternal and foetal blood vessels are involved in the placental transfer of nutrients and oxygen.

²³² Public Health Association Australia (PHAA), Submission No. 7, 2014, p. 4.

²³³ AE Chudley, ‘Genetic Factors Contributing to FASD’, in Riley et al, *Fetal Alcohol Spectrum Disorder - Management and policy perspectives of FASD*, Wiley-Blackwell, Weinheim, 2011, p. 109.

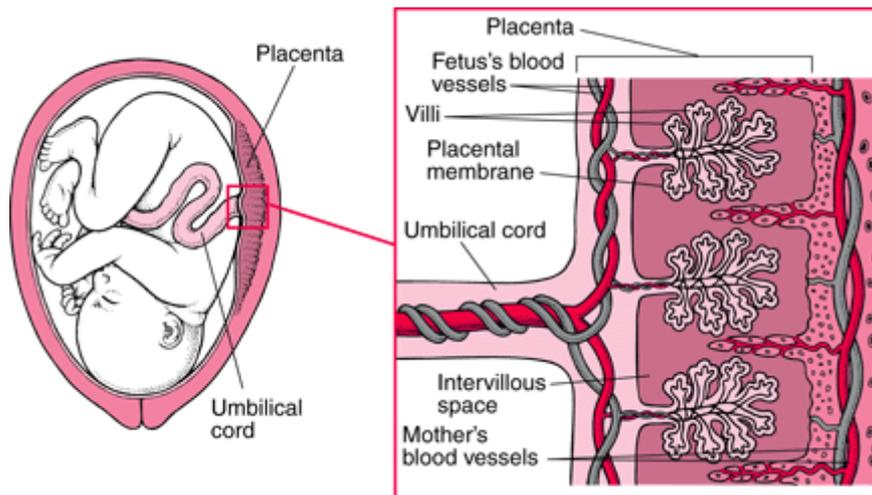
²³⁴ AE Chudley, ‘Genetic Factors Contributing to FASD’, p. 109.

²³⁵ Stratton et al (eds), *Fetal Alcohol Syndrome: Diagnosis, epidemiology, prevention, and treatment*, p. 35.

²³⁶ Foley 2007 cited in North Carolina State University, *Group 7 Teratogens Affecting Fetal Development in Humans*, WolfWikis,

<http://wikis.lib.ncsu.edu/index.php/Group_7_Teratogens_Affecting_Fetal_Development_in_Humans>

Figure 3: Teratogen passing from the placenta to the fetus



Source: North Carolina State University.²³⁷

5.6 Some research indicates that the amount of alcohol consumed is highly correlated with the severity of outcome. Higher levels of alcohol consumption, together with longer duration of exposure, have been found to result in more adverse effects. However, the pattern of alcohol consumption, whether it is binge drinking, or moderate drinking on a regular basis, may also influence the severity of the outcome. Nguyen and colleagues, in reporting findings from the research literature note that.²³⁸

- A binge-like exposure results in more severe neuropathology and behavioural alterations than does chronic exposure;
- Women who binge drink are at higher risk of having a child with neurobehavioral deficits than those who drink chronically during pregnancy; and
- A high peak blood alcohol concentration induced during binge episodes appears to be a significant risk factor for prenatal injury.

However, as one submission noted, while the burden of harm is concentrated with heavy use and binge drinking, there is also evidence for harm from moderate drinking while the evidence for low alcohol consumption is conflicting.²³⁹ With respect to moderate drinking, data from the University of Washington FASD clinic found that one in every 14 children diagnosed with FAS was exposed to one drink of alcohol per day while one in every seven children diagnosed with FAS was exposed to between 1-8 drinks per week.²⁴⁰ In short, as one submission concluded, it is difficult to determine what level of consumption is safe, due to the

²³⁷ North Carolina State University, *Group 7 Teratogens Affecting Fetal Development in Humans*, WolfWikis, <http://wikis.lib.ncsu.edu/index.php/Group_7_Teratogens_Affecting_Fetal_Development_in_Humans>.

²³⁸ Nguyen et al, 'Prenatal alcohol exposure', pp. 4-5.

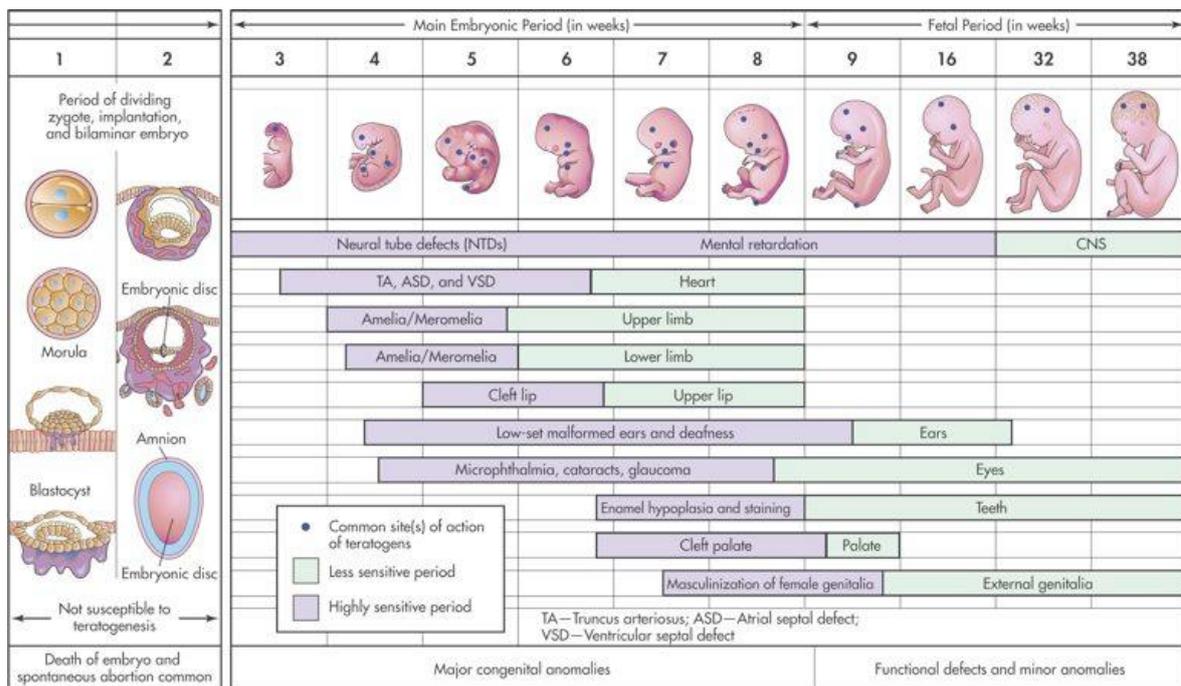
²³⁹ National Drug and Alcohol Research Centre (NDARC), Submission No. 10, 2014, p. 3.

²⁴⁰ Ms Prue Walker, Submission No. 16, 2014, p. 25.

‘complex association between dose, timing, frequency and individual maternal characteristics’.²⁴¹

5.7 The impact of PAE on a child also varies according to the ‘developmental timing of alcohol exposure’.²⁴² Exposure to alcohol at critical periods of development influences which systems are affected and also the severity of the deficit. This is because ‘different organ systems develop at different rates and times during gestation’.²⁴³ Figure 4 provides a broad indication of the effect of alcohol exposure during different stages of pregnancy.

Figure 4: Effects of teratogens at different stages of pregnancy



Source: North Carolina State University.²⁴⁴

5.8 Although more research is needed into the specific nature of the impacts that are likely to occur at different stages of the pregnancy, existing research leaves little doubt that, apart from the first two weeks, alcohol can cause damage at any stage of the pregnancy. This is particularly the case in relation to CNS damage, which can occur throughout the pregnancy and, as Dr Jennifer Delima commented in relation to Figure 4:

That chart shows little foetal images going along the page and you see the top line is the central nervous system - CNS. That is our central nervous system, our nervous tissue, our brain and our nerves continue to develop right

²⁴¹ NDARC, Submission No. 10, 2014, p. 3.

²⁴² Nguyen et al, ‘Prenatal alcohol exposure’, p. 5.

²⁴³ Nguyen et al, ‘Prenatal alcohol exposure’, p. 5.

²⁴⁴ http://wikis.lib.ncsu.edu/index.php/Group_7_Teratogens_Affecting_Fetal_Development_in_Humans

throughout the pregnancy. That is why this is so important that there is no alcohol throughout the pregnancy. It is not like some of the other things we see with toxoplasma - your most sensitive period is in the second or third trimester. This one is right through.²⁴⁵

5.9 A large body of research has shown that CNS abnormalities are among the most devastating consequences of FASD 'and generally persist throughout the life span'.²⁴⁶ In addition, where CNS abnormalities, or neurological functional abnormalities, are the primary impact of PAE, as in ARND, they are much more likely to go undetected and hence to result in a range of secondary conditions as described in Chapter 2. Although there is sometimes a tendency to focus on the severe end of the spectrum, diagnoses of FAS are a minority under the FASD umbrella and form 'only about one-tenth of the whole of FASD spectrum disorder'.²⁴⁷

5.10 Paternal alcohol consumption prior to conception may also have the potential to impact on foetal development, although research in this area is still in the early stages. In their submission to the Committee, the National Drug Research Institute noted that:

There is emerging evidence that paternal alcohol use contributes to DNA damage to sperm and fetus (low birth weight, congenital heart defects, reduced cognitive ability). Animal studies support impact of paternal alcohol consumption on fetus even in the absence of maternal alcohol exposure.²⁴⁸

In addition, Andrew notes that alcohol use by the male partner can indirectly cause damage 'by contributing to maternal stress, with subsequent damage being mediated through the HPA [hypothalamic-pituitary-adrenal axis ie stress response] stimulation and increased cortisol production in both mother and fetus'.²⁴⁹

5.11 Other factors which are thought to modify the effect of alcohol exposure on the developing foetus include nutrition, the environment, and genetics. In her presentation to the Committee, Professor Bower noted that 'high [alcohol] consumption in association with other socioeconomic or nutritional aspects, and almost certainly genetics, determines whether any given child will be affected and to what extent'.²⁵⁰ Research suggests that the early childhood environment can also have a significant influence. In this respect, Andrew notes that 'early deprivation, abuse and a lack of appropriate stimulation can result in brain damage...', with this being even more likely 'if the brain has already been exposed to alcohol *in utero*'.²⁵¹ Similarly, research suggests that a deprived environment has a significant effect on the extent to which primary FASD disabilities are compounded by secondary disabilities, with a study by Streissguth and colleagues finding that:

²⁴⁵ Committee Transcript, 1 August 2014, p. 41.

²⁴⁶ R Eme & MA Millard, 'Fetal alcohol spectrum disorders: A literature review with screening recommendations', *The School Psychologist*, vol. 66, no. 1, American Psychological Association, 2012, p. 15.

²⁴⁷ Dr Jennifer Delima, Committee Transcript, 1 August 2014, p. 39.

²⁴⁸ Committee Transcript, Submission No. 2, 2014, p. 7.

²⁴⁹ G Andrew, 'Screening for FASD', in Riley et al, *Fetal Alcohol Spectrum Disorder - Management and policy perspectives of FASD*, Wiley-Blackwell, Weinheim, 2011, p. 131.

²⁵⁰ Committee Transcript, 29 May 2014, p. 73.

²⁵¹ G Andrew, 'Screening for FASD', p. 131.

odds of all or almost all adverse outcomes are increased with a low percent of life in a Stable/Nurturing Home, fewer Years per Household by age 18, or ever being a Victim of Physical, Sexual Abuse, or Domestic Violence.²⁵²

Overall, Streissguth's study found that 'A stable/nurturing home is the most influential protective factor in these analyses, reducing by three- or four-fold the risk of four of the five adverse outcomes examined' while 'Years per household was the single significant environmental risk factor for one adverse outcome, namely Confinement [for psychiatric or addiction conditions or for incarceration for a crime]'.²⁵³

5.12 Genes influence how alcohol is metabolised and it is probable that the genetic background of both the mother and the foetus will influence how alcohol affects the developing foetus.²⁵⁴ Genetic differences are also likely to be an explanatory factor in differences that occur between ethnic population groups. Chudley notes that:²⁵⁵

- Some genetic differences may be protective, resulting in a flushing effect which would put individuals in this group at low risk for having affected children; and
- Certain genotypes may increase the likelihood for binge drinking and alcoholism resulting in a higher incidence of FASD.

5.13 Prenatal care and nutrition are also considered to be important in modifying the risk of FASD. As Nguyen and colleagues note, there is a complex interaction between nutrition and alcohol, with food affecting the rate at which alcohol is absorbed and metabolised and alcohol often altering the requirement for and absorption of nutrients.²⁵⁶ Hence, alcohol exposure in conjunction with low nutrient levels is regarded as increasing the risk for FASD.

5.14 May and Gossage draw attention to the complexity associated with identifying risk factors for FASD and note that risk is multi-dimensional, incorporating personal and lifestyle factors relating to the mother; foetal exposure to alcohol based on the mother's habits; and a range of socio-economic factors.²⁵⁷ Table 6 provides a broad summary of maternal risk factors as discussed in the literature.

²⁵² Streissguth et al, 'Risk Factors for Adverse Life Outcomes', p. 234.

²⁵³ Streissguth et al, 'Risk Factors for Adverse Life Outcomes', p. 234.

²⁵⁴ Nguyen et al, 'Prenatal alcohol exposure', p. 5.

²⁵⁵ AE Chudley, Genetic Factors Contributing to FASD, p. 119.

²⁵⁶ Nguyen et al, Prenatal alcohol exposure, FAS, and FASD: An introduction, p. 5.

²⁵⁷ PA May & JP Gossage, 'Maternal risk factors for fetal alcohol spectrum disorders: Not as simple as it might seem', *Alcohol Research & Health*, vol. 34, No. 1, 2011, p. 17.

Table 6: Commonly Recognized Maternal Risk Factors for FASD from the Literature: A Public Health Variable Summary

Host	Agent Exposure	Environment
<ul style="list-style-type: none"> • Mother's age \geq 25 • Gravidity \geq 3 • Parity \geq 3 • Higher rates of stillbirth and miscarriage • Infrequent practice of religion/spirituality • Low maternal education • Smokes cigarettes • Depression/psychological distress • Short stature • Low weight • Low BMI • Nutritional deficiency • Particular alcohol dehydrogenase polymorphisms 	<ul style="list-style-type: none"> • High BAC from large quantities of ETOH • Binge drinking (3+ per occasion) • Length of drinking career • Frequent smoker (lower birth weight) • Beer is beverage of choice of a majority of FASD mothers in most populations • Drinking outside of meals • Polysubstance abuse in urban studies • Change in gastric ADH activity • Change in nutritional status during pregnancy 	<ul style="list-style-type: none"> • Low SES • Not married, but living with partner • Culture accepting of heavy drinking • Family of origin of heavy drinkers • Partner is a heavy & frequent drinker • Alcohol-centered recreation popular • Social isolation from mainstream economy & society • Little or no knowledge or awareness of FASD

Source: May and Gossage ²⁵⁸

Alcohol Consumption

It is vital that the Northern Territory Government explores evidence-based strategies to prevent, diagnose and manage FASD. This action is particularly urgent for the Northern Territory because the risk and prevalence of FASD is likely to be higher than in other areas of Australia. This is because women in the Northern Territory are more likely than women in other parts of Australia to consume alcohol at risky levels. ²⁵⁹

- 5.15 Alcohol consumption data is available from a range of sources and there are substantial differences in definitions and in the methods used to collect and analyse data. Consequently, care needs to be taken when interpreting data and when making comparisons between different sources or years. Measurement of consumption can be both direct, such as self-reported data collected through surveys, and indirect, such as per capita pure alcohol consumption (PCAC) which is estimated by dividing the total alcohol supplied in a specified area by an estimate of the population likely to be drinking. National statistics include those people aged 15 years and above as the likely drinking population. ²⁶⁰
- 5.16 Self-reported alcohol consumption survey data generally uses the *Australian Alcohol Guidelines* defined by the NHMRC. It is important to note that the Guidelines developed in 2001 have since been replaced by a new set developed in 2009. Some of the data presented here are based on the 2001 Guidelines and some are based on the 2009 Guidelines. Risk in relation to alcohol consumption is frequently divided as follows:

²⁵⁸ PA May & JP Gossage, 'Maternal risk factors', p. 23.

²⁵⁹ FARE, Submission No. 12, 2014, p. 4.

²⁶⁰ Department of Business, *Northern Territory Wholesale Alcohol Supply for the years 2005 to 2012*, p. 3, <<http://www.dob.nt.gov.au/gambling-licensing/alcohol-policy/Pages/alcohol-data.aspx>>.

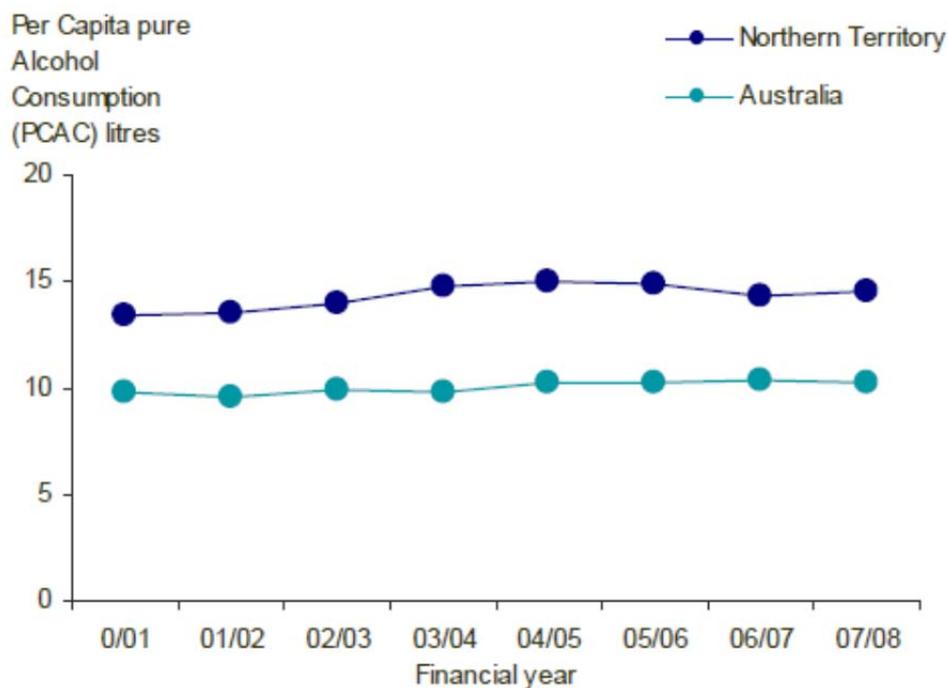
- Chronic or life-time risk - based on the person's self-reported amount of alcohol (in mls) consumed on a usual drinking day, as well as the frequency of consumption, in the previous 12 months; and
- Short-term risk, or binge drinking, based on the self-reported largest quantity of alcohol consumed in a single day.

In the 2009 NHMRC Guidelines, chronic or life-time risk increases with the amount consumed, with drinking no more than two standard drinks on any day reducing the lifetime risk of harm from alcohol related disease or injury. Short term risk, or binge drinking, is based on whether more than four standard drinks were consumed on any single occasion.

Per capita pure alcohol consumption in Australia and the Northern Territory

5.17 In 2003, Australia's PCAC was 9.02 litres, ranking Australia as 30th out of 180 countries in the world.²⁶¹ By 2007, Australia's per capita consumption had increased to 9.88 litres. However, as Figure 5 shows, PCAC in the Northern Territory is even higher, with Territorian residents aged 15 years and over consuming approximately 14.6 litres compared to the national figure of 10.3 litres.²⁶²

Figure 5: Per Capita pure Alcohol Consumption (PCAC) by persons aged 15 years and over in the NT^a and Australia^b



²⁶¹ National Preventative Health Taskforce, *Technical Report No 3: Preventing alcohol-related harm in Australia: a window of opportunity*, prepared for the National Preventative Health Taskforce by the Alcohol Working Group, Commonwealth of Australia, 2008, p. 5.

²⁶² DoH, *Alcohol Use in the Northern Territory*, Northern Territory Government, p. 2, <http://www.territorystories.nt.gov.au/bitstream/handle/10070/245741/Alcohol_use_in_the_Northern_Territory.pdf?sequence=1>.

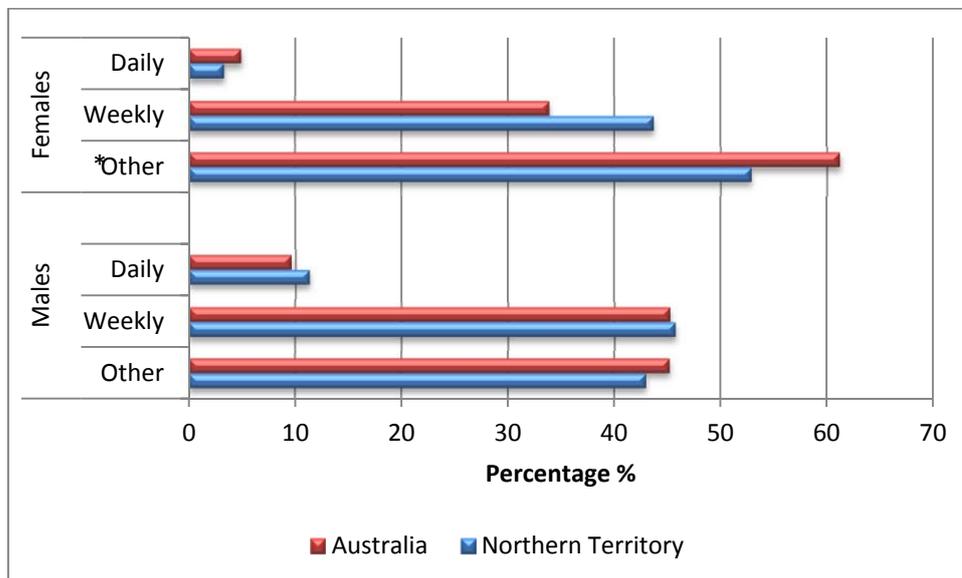
Notes: ^aCalculated by dividing the quantity of pure alcohol available for consumption by the estimated resident population, with an adjustment for the estimated number of visitors of the same age. ^b Apparent consumption of alcohol, Australia, 2007-08 (ABS Cat. No. 4307.0.55.001). Sources: NT registered wholesale returns of Alcohol, Racing, Gaming and Licensing Division, Northern Territory Treasury; ABS population estimates (ABS Cat. No.3218.0.55.001) and Tourism NT unpublished data.

Source: Department of Health. ²⁶³

Self-reported Alcohol Consumption – Australia and the Northern Territory

5.18 Although Territorians' PCAC is higher than that of Australians overall this is not due to higher proportions drinking on a daily basis. In fact, as shown in Figure 6, slightly fewer Territorian women drank on a daily basis and the proportion of Territorian men who drank daily was only 1.7 percent more than Australians overall.²⁶⁴

Figure 6: Alcohol drinking status, people aged 14 years or older, Australia and the Northern Territory



*Other = Less than weekly, never a full serve of alcohol, ex-drinker.

Source: AIHW ²⁶⁵

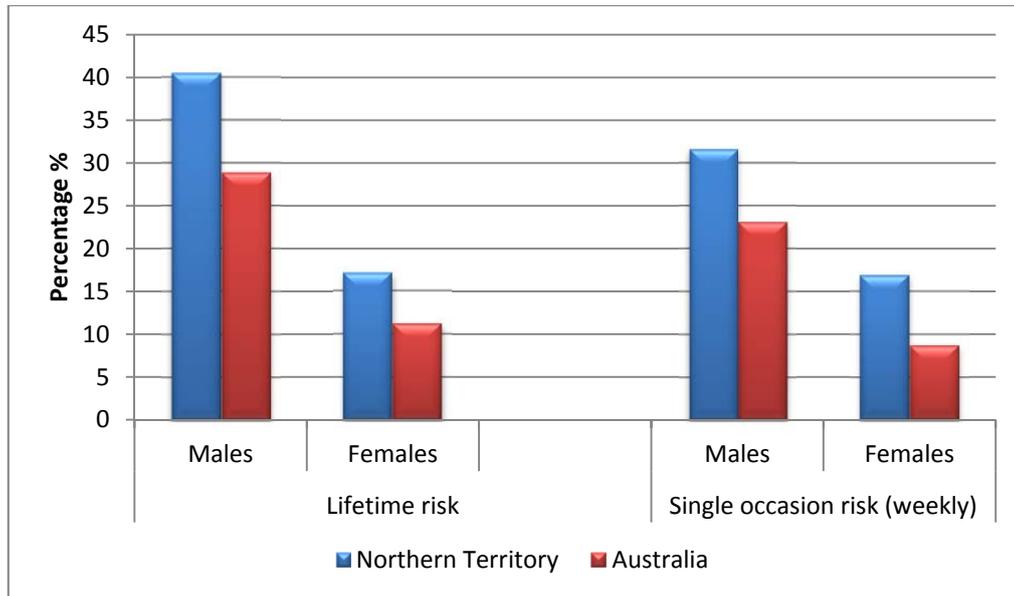
5.19 The most significant differences between the drinking patterns of Territorians and other Australians occur in relation to the proportion drinking at risky levels. This is demonstrated in Figure 7 which shows that a greater proportion of men and women in the Northern Territory have drinking patterns characterised by chronic or life-time risk and short term or single occasion risk.

²⁶³ DoH, *Alcohol Use in the Northern Territory*, figure 1, p. 1.

²⁶⁴ Australian Institute of Health and Welfare (AIHW), *2010 National Drug Strategy Household Survey Report*, Drug statistics series no. 25. Cat. no. PHE 145. Canberra: AIHW, 2011, p. 72.

²⁶⁵ AIHW, *2010 National Drug Strategy Household Survey Report*, Table 4.8, p. 63.

Figure 7: Lifetime risk and single occasion risk - Northern Territory and Australia



Source: AIHW.²⁶⁶

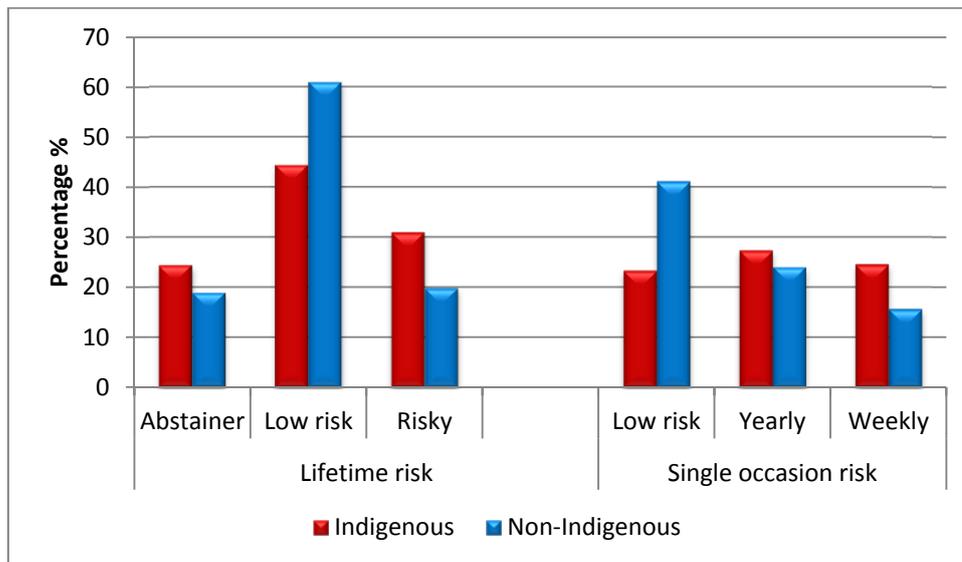
Drinking Patterns – Indigenous and Non-Indigenous Populations

5.20 At the national level, differences between the Indigenous and non-Indigenous population are also marked. As Figure 8 shows, while fewer Indigenous than non-Indigenous people consumed alcohol, in those who do drink, the proportion drinking at a level to cause lifetime harm (31 percent compared to 19.9 percent), and to cause single occasion risk on a weekly basis (24.6 percent compared to 15.7 percent), is much higher than in the non-Indigenous population. These differences remain comparable when data has been standardised for differing age structures within these populations.²⁶⁷

²⁶⁶ AIHW, 2010 National Drug Strategy Household Survey Report, Table 4.9, p. 64.

²⁶⁷ AIHW, 2010 National Drug Strategy Household Survey Report, Appendix 3, See Tables A3.3 and A3.4, pp. 227-228.

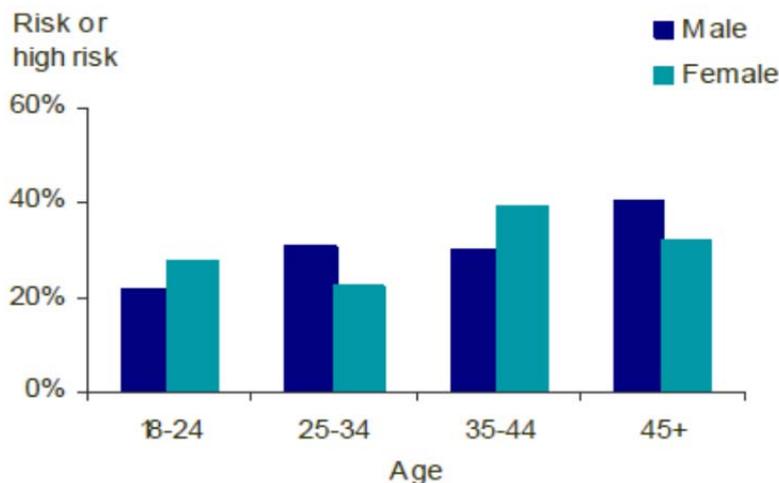
Figure 8: Lifetime risk and single occasion risk – Indigenous and non-Indigenous in Australia



Source: AIHW.²⁶⁸

5.21 Based on data from the 2008 National Aboriginal and Torres Strait Islander Social Survey, DoH found that among Indigenous adults who consumed alcohol, 30.1 percent reported drinking at a risky or high risk level.²⁶⁹ As shown in Figure 9, age groups of particular concern included males aged 45 or more (40 percent) and females aged 35-44 (39 percent).

Figure 9: Proportion of Indigenous adults at risky/high risk^a levels of alcohol consumption by age group and sex, Northern Territory.



^aMeasures based on amount of alcohol consumed in a single day and frequency of consumption in last 12 months. For males, 50 mls and above (4 and above standard drinks) and females, 25 mls and above (2 and above standard drinks).

Source: Department of Health.²⁷⁰

²⁶⁸ AIHW, 2010 National Drug Strategy Household Survey Report, Table 4.7, p. 60.

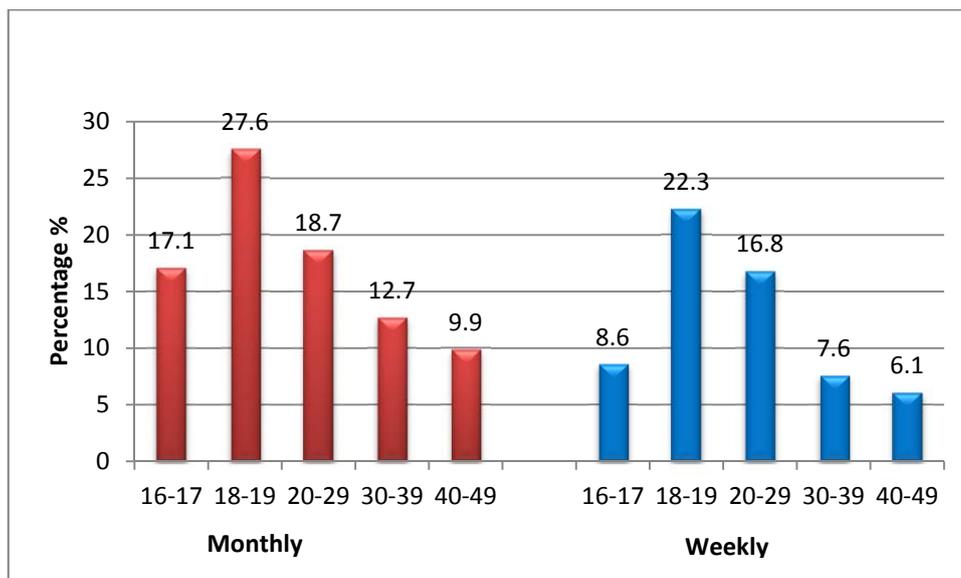
²⁶⁹ DoH, Alcohol Use in the Northern Territory, p.3

²⁷⁰ DoH, Alcohol Use in the Northern Territory, Figure 1, p.1.

Alcohol Consumption during Pregnancy

5.22 Although only 8.8 percent of Australian women aged 14 and over binge drink on a weekly basis,²⁷¹ when disaggregated by age group it is evident that binge drinking rates among young women, particularly the 18-29 year age group are much higher than for older women (Figure 10). A similar pattern is evident for monthly binge drinking. As these are important child bearing years, and many pregnancies are unplanned, women in this age group are particularly at risk for giving birth to a child with FASD.

Figure 10: Monthly and Weekly Binge Drinking – Females aged 16-49



Source: AIHW.²⁷²

5.23 Evidence from several studies tend to confirm this view and suggest that alcohol consumption during pregnancy could be as high as 50 to 60 percent and that a high proportion of women could be binge drinking during pregnancy, 'with figures ranging from 4 to 20 percent, for non-Aboriginal pregnant women, and 22 percent of Aboriginal women'.²⁷³

5.24 A much lower figure was reported by the Longitudinal Study of Australian Children,²⁷⁴ which showed that over a third of women continued to consume alcohol while pregnant. It is noteworthy that the proportion of women who reported drinking at some stage during the pregnancy was substantially greater for older women and for those in higher socio-economic groups (Table 7). However, these results need

²⁷¹ AIHW, 2010 National Drug Strategy Household Survey Report, p. 54.

²⁷² AIHW, 2010 National Drug Strategy Household Survey Report, Table 4.5, p. 57.

²⁷³ C. O'Leary, Commonwealth, House of Representatives Standing Committee on Social Policy and Legal Affairs, Inquiry into the prevention, diagnosis and management of Fetal Alcohol Spectrum Disorders, Submission No. 92, 2012, p. 1.

²⁷⁴ Australian Institute of Family Studies (AIFS), *The Longitudinal Study of Australian Children Annual Statistical Report 2010, 2011*, < <http://www.growingupinaustralia.gov.au/pubs/asr/2011/> >.

to be interpreted with caution as they could be influenced by the accuracy of the self-reporting of the different groups.²⁷⁵

Table 7: Drinking Alcohol during Pregnancy by Maternal Age and Socioeconomic Status

<i>Mother's age at birth of child</i>	<i>%</i>	<i>No. of observations</i>
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
<i>Family socio-economic position</i>	<i>%</i>	<i>No. of observations</i>
Lowest 25%	22.9	213
Middle 25%	38.3	829
Highest 25%	51.8	590

Source: AIFS.²⁷⁶

5.25 Data from the 2010 NDS Household Survey Report shows that, at a national level, the proportion of women drinking in pregnancy has reduced substantially between 2007 and 2013, with 52 percent of women abstaining in 2013 compared with only 40 percent in 2007 (Table 8).

Table 8: Amount of alcohol pregnant women, aged 14 to 49, drank compared with when they were neither pregnant nor breastfeeding, 2007 to 2013 (per cent)

Drinking alcohol while pregnant	While pregnant ^(a)			While breastfeeding ^(b)		
	2007	2010	2013	2007	2010	2013
More	0.6	**0.4	**<0.1	0.2	**0.1	*1.2
Less	56.6	48.9	46.0	70.1	62.3	59.5
Same amount	2.8	*2.0	*1.2	4.5	3.5	2.7
Don't drink alcohol	40.0	48.7	52.8	25.0	34.1	36.7

* Estimate has a relative standard error of 25% to 50% and should be used with caution.

** Estimate has a relative standard error greater than 50% and is considered too unreliable for general use.

²⁷⁵ AIFS, *The Longitudinal Study*, p. 129.

²⁷⁶ AIFS, *The Longitudinal Study*, adapted from Table 11.5.

(a) Base is only pregnant women or women pregnant and breastfeeding.

(b) Base is women who were only breastfeeding or pregnant and breastfeeding.

Source: AIHW.²⁷⁷

5.26 Data provided to the Committee by DoH suggests a widening gap in the prevalence of alcohol consumption between Indigenous and non-Indigenous women, with Table 9 showing a dramatic decrease in alcohol consumption at the first antenatal visit and at 36 weeks gestation for non-Indigenous women but not present for Indigenous women.

Table 9: Proportion of pregnant women reporting alcohol consumption at first antenatal visit and at 36 weeks gestation, Northern Territory, 2003-2011

	2003	2004	2005	2006	2007	2008	2009	2010	2011
	% Alcohol Consumption at First Antenatal Visit								
Indigenous	11.9	11.8	13.0	14.4	13.0	12.1	14.3	11.8	12.5
Non-Indigenous	9.1	9.6	8.1	8.1	6.4	4.2	4.1	3.8	3.2
Total	10.1	10.3	9.7	10.4	8.8	6.9	7.6	6.4	6.3
	% Alcohol Consumption at 36 Weeks Gestation								
Indigenous	8.0	8.0	8.7	8.4	8.6	8.8	10.8	7.5	7.1
Non-Indigenous	4.2	4.7	3.6	3.8	2.7	1.7	1.8	1.7	1.5
Total	5.5	5.9	5.4	5.4	4.8	4.1	4.9	3.6	3.3

Note: The prevalence of alcohol consumption was calculated after removing missing data.

Source: Department of Health.²⁷⁸

Factors Influencing Alcohol Consumption

5.27 Alcohol contributes significantly to a range of social ills, such as traffic accidents, violent behaviour, fatalities, crime and health problems. Despite this, the consumption of alcohol is a widely accepted part of Australian culture and there is little evidence of this changing in the near future. As FARE noted:

Across Australia, alcohol is more affordable than it has been in over three decades, it is more available than it ever has been and it is more heavily promoted.²⁷⁹

²⁷⁷ AIHW, 2013 National Drug Strategy Household Survey Supplementary Data, Table 17.

²⁷⁸ Submission No. 9, 2014, p. 9.

²⁷⁹ FARE, *Out-dated WA Liquor Act Failing to Protect Against Harms*, 2013.

- 5.28 Patterns of alcohol consumption, and the likelihood of drinking at risky levels, are influenced by personal factors that influence the demand for alcohol, and by supply factors which influence the availability and price of alcohol. The former are discussed in this chapter but supply factors will be discussed in Chapter 6, Alcohol Policy.
- 5.29 Alcohol is frequently a central part of religious and cultural celebrations, social and business functions, and recreational and sporting events. In Australia it is linked with 'mateship' and community while local pubs and clubs frequently provide an informal setting for 'airing local concerns and facilitating social interaction'.²⁸⁰ This widespread acceptance of alcohol, and the integral part it is perceived as playing in lubricating the wheels of social discourse, presents alcohol consumption as a benign pleasure, a means of relaxation and achieving a sense of bonhomie with like-minded companions. Although this experience is certainly true for some, the toxicity of alcohol, and its addictive qualities, means that regular consumption at risky levels can result in highly adverse outcomes for the consumer, the family and society more broadly.
- 5.30 This broad socio-cultural acceptance of moderate alcohol consumption as a legitimate form of relaxation and recreation is a core factor underpinning the widespread use of alcohol in Australian society. However, within this broad context, individual patterns of consumption are likely to be influenced by age, religious affiliation, cultural background, social disadvantage, mental health, and stress and trauma. As noted in the NDS:

Disadvantaged populations are at heightened risk of drug misuse and its associated harms. People can also be at risk of different patterns of use at different ages. For example, younger people may be more at risk of short-term harms from alcohol use while older people may be more at risk from chronic alcohol misuse.²⁸¹

Binge Drinking in Adolescents and Young Adults

- 5.31 Of significant concern are the high rates of weekly and monthly binge drinking in adolescents and young adults, with 64.6 percent of 18-19 year old Australian males drinking at risky levels at least monthly and 40.6 percent at least weekly. These proportions reduce slightly in 20-29 year old males to 54.9 percent (monthly) and 32.9 percent (weekly).²⁸² Fewer 18-19 year old females binge drink on a weekly basis (23.6 percent) but more drink at risky levels on a monthly basis (51.2 percent).²⁸³ Although binge drinking in 20-29 year old females is lower than for males (37.2 percent monthly; 18.5 percent weekly) it is still unacceptably high,

²⁸⁰ Ministerial Council on Drug Strategy, *Alcohol in Australia: Issues and Strategies, A background paper to the National Alcohol Strategy: A Plan for Action 2001 to 2003/04*, Commonwealth of Australia, 2001, p. 6.

²⁸¹ Ministerial Council on Drug Strategy, *National Drug Strategy 2010-2015*, Commonwealth of Australia 2011, p. 9.

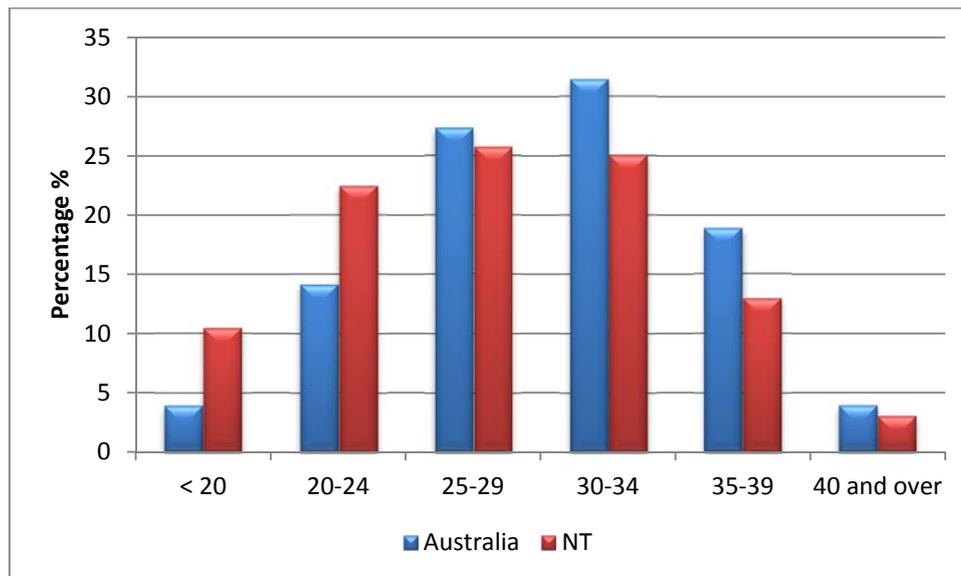
²⁸² AIHW, *2010 National Drug Strategy Household Survey Report*, p. 55.

²⁸³ AIHW, *2010 National Drug Strategy Household Survey Report*, p. 56.

particularly as this continues to be a core age range for giving birth despite an overall increase in the average age of mothers Australia wide.²⁸⁴

- 5.32 The high proportion of adolescents and young adults who regularly binge drink is of particular concern in the Northern Territory, as the average age of mothers giving birth is substantially lower than in other jurisdictions, with more than twice as many mothers in the Northern Territory being in the 20 or under age group (Figure 11).

Figure 11: Age at Giving Birth – Australia and Northern Territory



Source: AIHW.²⁸⁵

- 5.33 One reason for this is the comparatively high proportion of Indigenous people in the Northern Territory population compared to the proportion in other jurisdictions (Figure 12). Indigenous mothers tend to give birth at a younger age than non-Indigenous mothers. At a national level the average maternal age at birth for Indigenous mothers was 25.3 years, compared with 30.2 years for non-Indigenous mothers.²⁸⁶ When disaggregated by age group, 51.7 percent of Indigenous women who gave birth in 2009 were aged 24 or under compared to only 16.9 percent of non-Indigenous women.²⁸⁷ These data suggest that the risk of giving birth to a child with FASD in the Northern Territory is proportionally higher than in other jurisdictions due to its particular social and demographic characteristics ie, higher proportion of Indigenous people in the NT; higher proportions of women giving birth at younger ages; higher rates of risky alcohol consumption in the Indigenous population; and higher rates of risky consumption in younger age groups, both male and female.

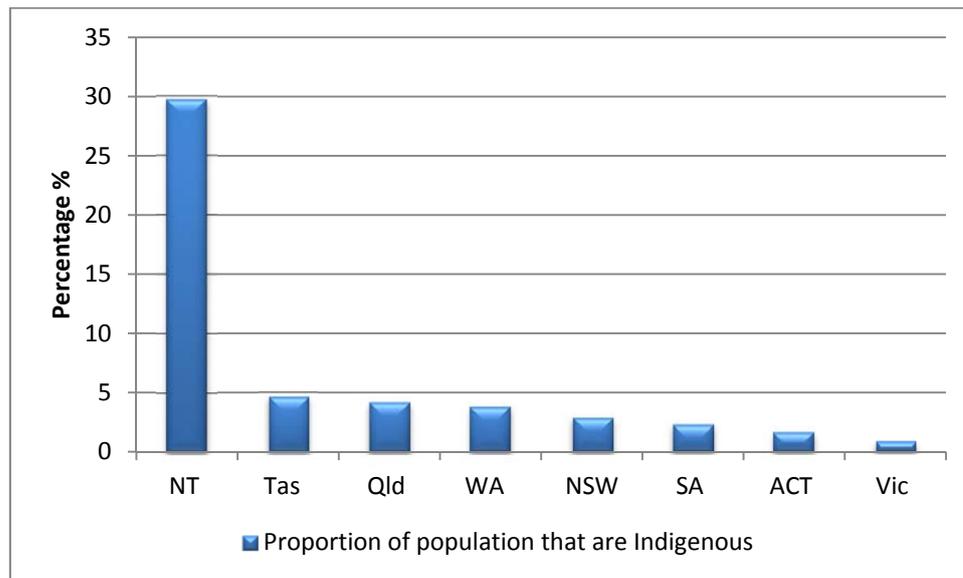
²⁸⁴ Li et al, 'Australia's mothers and babies 2009', *Perinatal statistics series no. 25*. Cat. no. PER 52. Sydney: AIHW National Perinatal Epidemiology and Statistics Unit, 2011, p. 10.

²⁸⁵ AIHW, 'Australia's Mothers and Babies 2009', adapted from Table 3.1, p.10

²⁸⁶ Li et al, Australia's mothers and babies 2009, p. viii.

²⁸⁷ Li et al, Australia's mothers and babies 2009, p. 12.

Figure 12: Proportion of population in each Australian jurisdiction that is Indigenous



Source: Australian Indigenous HealthInfoNet.²⁸⁸

Indigenous Alcohol Use

5.34 The social context of alcohol consumption in Aboriginal and Torres Strait Islander communities 'is complicated by a history of prohibition and by negative stereotypes', with this resulting in alcohol related 'experiences that are quite different to those of the majority of Australians'.²⁸⁹ The high rates of binge drinking in the Indigenous population can, in part, be traced back to earlier times when Indigenous people were banned from drinking alcohol and, as a consequence, 'would buy large quantities of alcohol and drink it quickly to avoid being caught and incarcerated'.²⁹⁰ Such drinking also had a strong social element and would often occur 'in groups in the open air, on riverbanks and in parks'.²⁹¹ Although this may well have been the genesis of patterns of risky drinking it also, according to one source, afforded 'a sense of identity and belonging often denied as part of the colonisation process'.²⁹² In this respect, Professor John Boulton commented that in Indigenous culture, refusing a drink has a particular significance and is perceived as insulting:

[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,

²⁸⁸ Australian Indigenous HealthInfoNet, *What details do we know about the Indigenous population?*

²⁸⁹ Ministerial Council on Drug Strategy, *Alcohol in Australia*, p. 4.

²⁹⁰ Ministerial Council on Drug Strategy, *National Drug Strategy: Aboriginal and Torres Strait Islander Peoples Complementary Action Plan 2003-2009*, 2006, p. 2.

²⁹¹ Ministerial Council on Drug Strategy, *Aboriginal and Torres Strait Islander Peoples Complementary Action Plan 2003-2009*, p. 2.

²⁹² Ministerial Council on Drug Strategy, *Aboriginal and Torres Strait Islander Peoples Complementary Action Plan 2003-2009*, p. 2.

'You're going gudiya²⁹³ way' – which is profoundly insulting. It is much more insulting than 'You don't support Essendon' or whatever.²⁹⁴

5.35 It is well documented that Indigenous people experience considerably more cumulative or multiple disadvantage than non-Indigenous people. Consequently, it is not surprising to find that associated factors such as 'economic marginalisation, discrimination, cultural dispossession and cultural assimilation difficulties, family conflict and/or violence and family history of alcohol misuse' are thought to contribute to risky alcohol use in this population.²⁹⁵ One witness commented that Aboriginal people:

are in a constant state of sorrow. It is one death after another ... and it affects us all every day and that is why a lot of people drink, drown out what they cannot ... Not so much process, but what they cannot move forward on.²⁹⁶

Excess alcohol consumption appears to be associated with the inability to break the cycle, to move forward to a way of life that is not marred by alcohol, as much as with the deaths of community members. Connection to the land as a means of healing, and of breaking the cycle of alcohol abuse, is a common theme. Mr Richard James, Chairperson of Patta Aboriginal Corporation highlighted the need for Aboriginal people to reconnect with their land and culture but also spoke of the difficulties associated with reclaiming their homelands, in spirit as well as in fact:

I have always gone on about the homelands as my grandfather's movement. It was a movement set up not to fail but, over the years, royalty money that was identified to go with communities is now being directed and spent on other things, maybe on larger communities and stuff like that. ... Homelands is what we are failing to look at or failing to address because that is our connection to our land, our culture, lack of alcohol - all those things happen out there. While our kids are walking around here chasing grog they are not out there sitting down with the old fella trying to help him put up the fence, put up the shed, whatever it takes on the community. I can speak because I have my own community. ... I have been with the shire for two years and out there all I found was old men sitting in their communities with no young fellas because they are all in town. There is nothing to keep them there.²⁹⁷

Similarly, Mr Danny Curtis, foster parent of a child with FASD noted that:

I find the boys, even though they are living in Adelaide, yearn for the country. For me, living in Adelaide for 10 years was daunting because I am not from that area and I wanted to come back and re-energise my battery, my soul and my spirit. That is what needs to be done for the likes of Travis. If they are living in a carer situation they need to go back to country.²⁹⁸

²⁹³ Gudiya means white person.

²⁹⁴ Standing Committee on Social Policy and Legal Affairs, *Inquiry into the Prevention, Diagnosis and Management of Fetal Alcohol Spectrum Disorders*, Committee Transcript, 12 July 2012, p. 8.

²⁹⁵ Australian Institute of Health and Welfare, *Substance use among Aboriginal and Torres Strait Islander people*. Cat. no. IHW 40. Canberra: AIHW, 2011, p. 11.

²⁹⁶ Mr Richard James, Committee Transcript, 31 July 2014, p. 58.

²⁹⁷ Committee transcript, 31 July 2014, pp. 58-59.

²⁹⁸ Committee transcript, 1 August 2014, p. 118.

Social Change

5.36 The significant social changes that occurred in the aftermath of World War II had a particularly strong impact on women and on their role in society. Today's women are more educated, more independent and have more choices than in the past. A less authoritarian and paternalistic society means that women are less constrained and feel freer to choose how they will behave. One effect of these changes is an increase in the proportion of women who consume alcohol at risky levels. As Roche notes:

Traditionally, women did not drink. This was the preserve of males. If women did drink, they did so only very lightly. Intoxication by women was subject to extreme social opprobrium. In recent decades this has changed dramatically and women now drink in increasingly similar ways to men.²⁹⁹

Reasons for Alcohol Consumption by Pregnant Women

5.37 A common theme throughout the Inquiry has been the need to change cultural attitudes to alcohol consumption across the whole Australian population, with Dr Colleen O'Leary arguing that:

The societal tolerance of alcohol use in Australia has led to the perception that there is a relatively low rate of harm from prenatal alcohol exposure and a false sense of security about the risks from consuming alcohol during pregnancy.³⁰⁰

5.38 Increasing the social awareness that no amount of alcohol is safe during pregnancy, together with re-framing social norms around alcohol use so that risky patterns of consumption (including drinking in pregnancy) are no longer socially acceptable, are important initial steps in reducing the proportion of women who drink alcohol while pregnant.

5.39 This is particularly important if changes are to be made to a youth culture in which binge drinking is considered a normal and 'enjoyable behaviour that plays a meaningful role in socialisation'.³⁰¹ However, risk is not confined to young women who binge drink. Older women and women with higher levels of education have been identified as sub-groups that are more likely to continue to drink when pregnant than younger women or those with lower levels of education. Results from the 2010 NDS indicated that:

Over 90 per cent of those aged 25 or under who were drinking before their knowledge of pregnancy stopped drinking when they became aware of their pregnancy, while only approximately half of those aged 36 or over did.³⁰²

²⁹⁹ A Roche, 'Women, workers and systems change: Professional education and workforce development in FASD', in Burns et al (eds), *Fetal Alcohol Disorders in Australia: An update. Monograph of the Intergovernmental Committee of Drugs Working Party of Fetal Alcohol Spectrum Disorders*, June 2012, p. 70.

³⁰⁰ C. O'Leary, Commonwealth, House of Representatives Standing Committee on Social Policy and Legal Affairs, Inquiry into the prevention, diagnosis and management of Fetal Alcohol Spectrum Disorders, Submission No. 92, 2012, p. 1.

³⁰¹ Anderson et al, 'Risky Drinking Patterns Are Being Continued into Pregnancy: A Prospective Cohort Study', *PLOS ONE*, vol. 9, No.7, 2014, p. 5.

³⁰² S Callinan & R Room, *Alcohol consumption during pregnancy: Results from the 2010 National Drug Strategy Household Survey*, Foundation for Alcohol Research and Education, 2012, p.7.

Analyses suggested that, in relation to social and demographic factors, age, rather than educational attainment was most likely to be the factor influencing continued drinking in pregnancy. The study authors also note that while the amount of alcohol consumed was not assessed in the 2010 survey, data from previous surveys suggests that:

it may be that while the rates of women drinking during pregnancy are still high, they are not drinking at the levels that research has more confidently linked to adverse alcohol exposure related effects.³⁰³

5.40 Another recent study, using data from the Longitudinal Study of Australian Children found that women with risky drinking patterns prior to pregnancy are likely to continue these patterns into the pregnancy, with only a small likelihood that they would abstain from alcohol completely.³⁰⁴ However, a substantial proportion of women in this study *reduced* these risky patterns when pregnant. Women who binge drank appeared to have a lower socio-economic status and it is likely that they were less knowledgeable about the impact of alcohol use during pregnancy.

5.41 The above findings show that levels of awareness regarding the risks associated with consuming alcohol while pregnant are not sufficient, on their own, to motivate women to be vigilant about alcohol consumption prior to pregnancy or, for some women, sufficient to motivate the cessation of alcohol use while pregnant. This is likely to be so for a number of reasons. First, it suggests that knowledge of the link between alcohol and FASD is quite superficial and does not include a detailed understanding of how and when alcohol affects the developing foetus. Second, women who drink at risky levels may be alcohol dependent and live in situations that make it difficult to abstain or reduce their drinking despite knowing the possible consequences. Third, one perspective that has been observed as possibly being instrumental in overriding the documented dangers of alcohol use during pregnancy is the individual's tendency to believe that it 'will not happen to them', as Ms Vicki Russell from NOFASD commented:

Professor Steve Allsop reminded me of the old well known philosophical term called othering, where everybody else has got a problem but me. ... There is this thing of, 'Oh, well, my mother drank when she was pregnant with me and there is nothing wrong with me, or my friend drank and there is nothing wrong with her child'.³⁰⁵

Ms Russell interpreted this as indication of a need to further increase awareness and knowledge of FASD:

So that calls for consideration of the spectrum of harms of foetal alcohol disorder, because we are so fixated on the face and the biomarkers, the physical indicators of foetal alcohol exposure, that we have not yet alerted the public to the more subtle forms that this condition can take, whether that is a learning disability or a behavioural problem.³⁰⁶

³⁰³ S Callinan & R Room, *Alcohol consumption during pregnancy*, p. 19.

³⁰⁴ Anderson et al, 'Risky Drinking Patterns Are Being Continued into Pregnancy', p. 5.

³⁰⁵ Committee Transcript, 29 May 2014, p. 43.

³⁰⁶ Committee Transcript, 29 May 2014, p. 43.

5.42 Previous research has found that a history of abuse, poor psychological wellbeing, use of other drugs, having a substance-using partner, and not regarding alcohol as potentially harmful can all contribute to alcohol consumption during pregnancy.³⁰⁷ For Aboriginal people, intergenerational and ongoing trauma has been identified as:

a significant and underlying factor that can result in feelings of powerlessness, victimisation or maladaptive coping strategies, including alcohol and substance use to cope with psychological distress.³⁰⁸

This is considered a particular problem for Aboriginal women, many of whom:

have experienced, or are experiencing, problematic alcohol abuse in their families as children or as adults with their partner's substance use, as well as violence or trauma in the context of family or intimate relationships, poverty and hardships of many kinds.³⁰⁹

5.43 Indeed, the high prevalence of family violence in Indigenous communities is 'disproportionately directed towards women and associated with alcohol consumption'.³¹⁰ The Top End Women's Legal Service drew attention to the difficulties that Aboriginal women face in distancing themselves from environments characterised by violence and alcohol abuse and commented that women frequently cited cultural obligations as a reason for staying in abusive relationships. They also pointed out that leaving these relationships was made more problematic by the lack of support available to these women:

These women are often faced with the impossible situation of leaving the only external support structures they have ever known and moving away with no support, limited employment opportunities and no access to childcare, ...³¹¹

5.44 More specifically, focus group work with Aboriginal women suggests that:

reasons for drinking include lack of knowledge about harms to the fetus, unemployment, having a partner who drinks, domestic violence, loss of traditional land and culture and the legacy of the 'stolen generation' when children were forcibly removed from their mothers by government authorities between 1909 and 1969.³¹²

5.45 Another key reason for drinking alcohol while pregnant is lack of knowledge of the pregnancy. Unplanned pregnancies are common, with one witness commenting that 47 percent of pregnancies were unplanned and consequently were exposed to the potential for alcohol related harm from conception.³¹³

³⁰⁷ Powers et al, 'Assessing pregnant women's compliance with different alcohol guidelines: an 11-year prospective study', *Medical Journal of Australia*, vol. 192, no. 12, 2010, p.692.

³⁰⁸ Aboriginal Peak Organisations NT (APONT), Committee Transcript, 29 May 2014, p. 25.

³⁰⁹ APONT, Committee Transcript, 29 May 2014, p. 25.

³¹⁰ Ministerial Council on Drug Strategy, *Aboriginal and Torres Strait Islander Peoples Complementary Action Plan 2003-2009*, p. 8.

³¹¹ TEWLS, Submission No. 20, 2014, p. 3.

³¹² H D'Antoine cited in J Fitzpatrick et al, *The Lililwan Project*, p. 3.

³¹³ Dr Jennifer Delima, Committee Transcript, 1 August 2014, p. 38.

6 FASD Policy Context

International Policy Context

6.1 FASD prevention and management is well advanced in the USA and Canada³¹⁴. Both the USA and Canada provide a range of useful policy models on which Australia can draw, and have also developed a substantial body of research, much of which has relevance for FASD in relation to the Indigenous population.

United States of America

6.2 The USA has a federally funded *Fetal Alcohol Spectrum Disorders (FASD) Center for Excellence* which sits under the Substance Abuse and Mental Health Services Administration, an agency within the USA Department of Health and Human Services. The FASD Center works with a range of partners, provides national leadership, and facilitates collaboration across states and territories. Key objectives of the Center include:³¹⁵

- Promotion of FASD awareness, education, prevention, and treatment;
- Assistance to states in development and implementation of plans to address FASD;
- Support for implementation of evidence based practices; and
- Facilitation of information sharing among states and territories.

6.3 A key feature of the US FASD response is the implementation of multi-disciplinary diagnostic clinics which have been in operation since 1993.³¹⁶ These operate across states and territories, for example, the state of New Jersey has six FAS/ARND Diagnostic and Education Service Centres in which children's physical growth and intellectual and emotional development is evaluated and recommendations made. These centres effectively 'concentrate expertise into single locations, where evidence based diagnosis and intervention plans can be created'.³¹⁷ According to FARE, multi-disciplinary clinics have been instrumental in raising awareness of FASD among health professionals and in improving diagnostic outcomes, with '61 to 90 percent of North American paediatricians being able to

³¹⁴ Standing Committee on Social Policy and Legal Affairs, *FASD: The Hidden Harm*, p. 2.

³¹⁵ Public Health Agency of Canada, *Evaluation of the Fetal Alcohol Spectrum Disorder (FASD) Initiative 2008-2009 to 2012-2013*, prepared by the Evaluation Directorate Health Canada and the Public Health Agency of Canada, March 2014, Appendix 4, International Comparisons, <http://www.phac-aspc.gc.ca/about_apropos/evaluation/reports-rapports/2013-2014/efasdi-eietaf/index-eng.php>

³¹⁶ Foundation for Alcohol Research and Education and Public Health Association of Australia (FARE/PHAA), Commonwealth, House of Representatives Standing Committee on Social Policy and Legal Affairs, Inquiry into the prevention, diagnosis and management of Fetal Alcohol Spectrum Disorders, Submission 36, 2012, p. 20.

³¹⁷ AIHW, Submission 8, 2014, p. 12.

correctly identify the essential diagnostic features of [foetal alcohol syndrome]'.³¹⁸ In addition, the US has contributed significantly to the research literature on FASD and developed a diverse range of FASD related resources such as the widely used *University of Washington 4-digit diagnostic code* and *Fetal Alcohol Syndrome: Guidelines for referral and diagnosis* developed by the USA Center for Disease Control.³¹⁹

Canada

6.4 FASD initiatives in Canada are underpinned by *FASD: A Framework for Action (2003)*, which was developed through a national process involving both government and non-governmental organisations. The Framework covers community, provincial/territorial and national levels and provides an overarching strategy for the planning, coordination and implementation of policies and programs at all tiers of government. It identifies five key goals including:³²⁰

- Increase public and professional awareness and understanding of FASD;
- Develop and increase capacity;
- Create effective national screening, diagnostic and data reporting tools and approaches;
- Expand the knowledge base and facilitate information exchange; and
- Increase commitment and support for action on FASD.

6.5 Canada provides a wide range of services and support for diagnosis and care which are funded through FASD multi-disciplinary clinics and service networks located across the country. Services are provided to expectant mothers and to children and adults diagnosed with FASD. Examples include:³²¹

- Community based coordinated assessment and diagnosis;
- Targeted and indicated prevention;
- Support services for people affected by FASD and their caregivers;
- Provision of information;
- Case management;
- Supports for daily living;
- Rehabilitation/behavioural interventions;
- Opportunities for meaningful activities; and
- Respite.

³¹⁸ FARE/PHAA, *FASD: The Hidden Harm*, Submission 36, p. 20.

³¹⁹ FARE, *Action Plan 2013–2016*, p. 23,

³²⁰ Public Health Agency of Canada, *Evaluation of FASD Initiative*.

³²¹ AIHW, Submission 8, 2014, p. 12.

Examples of the types of education programs provided include.³²²

- Parent-Child Assistance Program (PCAP) – provides targeted prevention of FASD to mothers at risk; and
- FASD Learning Series – aims to increase community and individual capacity to support individuals with FASD and their carers.

6.6 In addition to the services described above, Canada has developed a range of resources and strategies to assist teaching children with FASD and has also run pilot programs aimed at facilitating workforce entry for adults with FASD.³²³

6.7 Resources and strategies developed in Canada provide Australian policy makers with a useful resource, as the similarities between the two countries, in particular, the demographic similarities in the Indigenous and non-Indigenous composition of the population, mean that there is scope for adaptation to the Australian context. Useful examples and models include:

- *The Fetal Alcohol Spectrum Disorder (FASD) Initiative 2008-09 to 2012-13*, which was implemented at the national level;³²⁴
- *Foetal Alcohol Spectrum Disorder, Building on Strengths: A Provincial Plan for British Columbia 2008-2018*;³²⁵ and
- *Prevention of Fetal Alcohol Spectrum Disorder (FASD): A multi-level model*.³²⁶

6.8 The *Prevention of Fetal Alcohol Spectrum Disorder (FASD): A multi-level model* has been workshopped in both Alice Springs and the Northern Territory and identifies:

four mutually reinforcing prevention approaches as effective in delivering FASD prevention, linked to overall alcohol strategies. The four levels span general and specific practices that assist women to improve their health and the health of their children, with support from family, support networks, services and community.³²⁷

The four levels of FASD prevention are identified in Figure 13 below.

³²² AIHW, Submission 8, 2014, p. 12.

³²³ AIHW, Submission 8, 2014, p. 12.

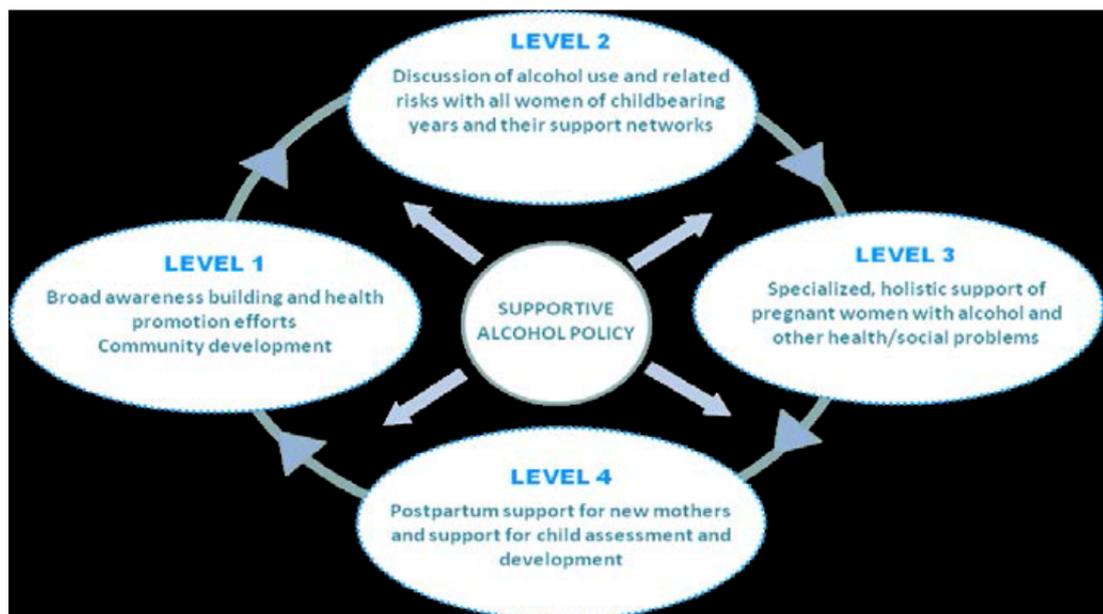
³²⁴ Public Health Agency of Canada, *Evaluation of FASD Initiative*.

³²⁵ Ministry of Children and Family Development, *Foetal Alcohol Spectrum Disorder, Building on Strengths: A Provincial Plan for British Columbia 2008-2018*, British Columbia, Canada, <http://www.mcf.gov.bc.ca/fasd/pdf/FASD_TenYearPlan_WEB.pdf>.

³²⁶ Canada FASD Research Network, *Prevention of Fetal Alcohol Spectrum Disorder (FASD): A Multi-level Model*, <http://fasd.alberta.ca/documents/CanFASD_4_levels_of_prevention_brief.pdf>.

³²⁷ Canada FASD Research Network, *Prevention of Fetal Alcohol Spectrum Disorder (FASD)*, p. 1.

Figure 13: Four Levels of FASD Prevention



6.9 Examples of each level of prevention were provided by Menzies School of Health Research and include:³²⁸

Level 1: Development of culturally appropriate health education materials, awareness campaigns and warning labels;

Level 2: Health professionals providing brief interventions for women of child bearing age;

Level 3: Enhanced case management of women with alcohol misuse;

Level 4: A home visiting program.

6.10 In its submission, Menzies noted that it is important to complement these FASD prevention strategies with an over-arching and supportive alcohol policy framework which includes broad supply reduction strategies as well as locally driven alcohol policy such as through Alcohol Management Plans (AMP).

Australian Policy Context

Recognition and status of FASD

6.11 Recognition of FASD in Australia has lagged behind that of countries such as the US and Canada, with FARE commenting that where 'FASD programs have been developed, they have often been ad hoc and inconsistently applied across states and territories.³²⁹ Over the past two decades, individuals, researchers and non-government organisations have been trying to fill this policy void but it is only recently that governments have begun to acknowledge and address the significant

³²⁸ MSHR, Submission No. 15, 2014, p. 7.

³²⁹ FARE, *Action Plan 2013-2016*, p. 49.

impact of FASD on individuals and society more broadly. This has resulted in an increasing focus on the development of a more coordinated approach to addressing FASD issues at a national strategic level. The growing recognition of FASD in Australia is evident from the flurry of activity occurring in 2012, which saw the release of two parliamentary inquiry reports on FASD, the release of a monograph on FASD published by the Intergovernmental Committee on Drugs Working Party and the publication of *The Australian Fetal Alcohol Spectrum Disorders Action Plan 2013–2016* by FARE. Subsequent sections of this chapter focus on the current status of major FASD policies and initiatives across Australia.

Federal Government

- 6.12 The Federal Government's first major FASD related initiative was implemented by the Intergovernmental Committee on Drugs which established a Working Party on FASD in 2006.³³⁰ Research foci supported by the Working Party included the economic impact of FASD and services and treatment for FASD, and culminated in the completion of a monograph titled *Fetal Alcohol Spectrum Disorders in Australia: An update*, which was completed in 2009 but not made public until 2012. The monograph provides a comprehensive overview of FASD and covers a wide range of FASD related issues including, but not limited to: prevalence; epidemiology of FASD; effects of alcohol in utero; services for pregnant women; prevention of FASD; workforce development; and services and interventions.³³¹
- 6.13 In 2011, the Federal Minister for Health and Ageing requested that the House of Representatives Social Policy and Legal Affairs Standing Committee inquire into and report on the incidence and prevention of FASD in Australia, with this resulting in *FASD: The Hidden Harm* report being released in November 2012. The report highlighted the inadequacy of existing responses to FASD and recommended the establishment of a National Plan of Action to prevent, diagnose and manage FASD in Australia.
- 6.14 Following on from the 2012 Federal inquiry into FASD, the Australian Government released the *Commonwealth Action Plan: Responding to the Impact of Fetal Alcohol Spectrum Disorders in Australia*.³³² The Action Plan is led by the Minister of Health along with the Minister for Families, Community Services and Indigenous Affairs, and allocates \$20.2 million over 2013-14 to 2016-17 on top of an existing \$18.5 million. The five key priorities include:
- Enhancing efforts to prevent FASD in the community - \$5.0 million;
 - Secondary prevention targeting women with alcohol dependency - \$4.8 million;

³³⁰ FARE, *Action Plan 2013- 2016*, p. 50.

³³¹ Burns et al, *Fetal Alcohol Disorders in Australia: An update*.

³³² Australian Government, *Responding to the Impact of Fetal Alcohol Spectrum Disorders in Australia – A Commonwealth Action Plan 2013-14 to 2016-2017*, <<http://www.nofasd.org.au/policy-and-advocacy/national-fasd-action-plan>>.

- Better diagnosis and management of FASD - \$0.5 million;
- Targeted measures to prevent and manage FASD within Indigenous communities and families in areas of social disadvantage - \$5.9 million; and
- National coordination, research and workforce support - \$4.0 million.

6.15 In its response to the Inquiry, the Government noted that the proposed Action Plan for FASD was 'contextualised and supported more broadly by a range of related Commonwealth activity' with this including:³³³

- Broader action to reduce alcohol related harm (pricing; pregnancy warning labelling; community level initiatives eg National Binge Drinking Strategy; Stronger Futures - Tackling alcohol abuse in Indigenous communities; and Breaking the Cycle of Alcohol and Drug Abuse in Indigenous Communities);
- National Disability Insurance Scheme; and
- Educational support for students with disabilities and special needs.

6.16 The *Commonwealth Action Plan* and associated initiatives have been greeted positively by a range of interested organisations, however, FARE has noted that, in several respects, it comes up short.³³⁴ There is no dedicated funding to support people with FASD and their parents and carers, with responsibility for this being placed within the domain of DisabilityCare Australia and the *More Support for Students with Disabilities Initiative*. One problem with this approach is that access to some of these programs relies on a child having a formal diagnosis of FASD. This will result in many children being excluded due to the significant level of cases which go undiagnosed due to the absence of a standard diagnostic instrument, inadequate funding for diagnosis, and a shortage of appropriately trained professionals. FARE further notes that the \$500,000 allocated to the development of a diagnostic tool is not sufficient to cover the training of health professionals on use of the Diagnostic Instrument or to establish new diagnostic clinics. In June 2014, the Australian Government announced that \$9.2 million would be allocated to the Action Plan, however, it is unclear whether this is in addition to the \$20.2 million announced previously.³³⁵

6.17 Overall, the major concern relates to the lack of specific support programs for people with FASD, their parents and carers. However, underfunding of the completion of the diagnostic tool is also of significant concern, as for this to be utilised effectively it is essential to also have health professionals who are trained in its implementation. Despite this, the *Commonwealth Action Plan*, and associated measures, provide a platform from which further policies can be developed and, in some degree, fills the policy void that previously characterised FASD.

³³³ Australian Government, *Responding to the Impact of FASD*, pp. 5-7.

³³⁴ Australian Government, *Responding to the Impact of FASD*.

³³⁵ Senator, the Hon Fiona Nash, Minister for Health, Media Release, 25 June 2014, accessed through NOFASD, < <http://www.nofasd.org.au/policy-and-advocacy/national-fasd-action-plan>>.

6.18 In addition to the above initiatives, the Commonwealth House of Representatives Standing Committee on Indigenous Affairs is currently holding an *Inquiry into the Harmful Use of Alcohol in Aboriginal and Torres Strait Islanders*. This includes a focus on FASD, with relevant FASD related terms of reference including:³³⁶

- Trends and prevalence of alcohol related harm, including alcohol-fuelled violence and impacts on newborns e.g. FAS and FASD; and
- The implications of FAS and FASD being declared disabilities.

Key Initiatives in Other Jurisdictions

6.19 Western Australia is particularly active in the FASD domain, with significant policy support provided through the FASD related research and development undertaken by the Telethon Institute over the last decade and a half. Key actions and initiatives in WA include:

- Development of the *Fetal Alcohol Spectrum Disorder (FASD) Model of Care* by the WA Department of Health in 2010;
- The Strong Spirit Strong Future – Promoting Healthy Women and Pregnancies Project, 2010;
- Ord Valley Aboriginal Health Service;
- A parliamentary inquiry into FASD culminating in the report entitled *Foetal Alcohol Spectrum Disorder: the invisible disability* tabled in the WA Parliament in September 2012; and
- The *Lililwan Initiative* in the Fitzroy Valley.

6.20 The *FASD Model of Care* provides health professionals with a comprehensive manual on FASD including guidance on screening and diagnosis, prevention and interventions.

6.21 The *Strong Spirit Strong Future – Promoting Healthy Women and Pregnancies Project* was designed for Aboriginal people and communities and aims to raise awareness of the NHMRC 2009 guidelines about alcohol use in relation to pregnancy and breastfeeding. It includes the following strategies:³³⁷

- Development of culturally secure resources;
- Community awareness media campaign; and
- Training and education for health professionals and other workers.

³³⁶ Commonwealth, House of Representatives, Standing Committee on Indigenous Affairs, *Inquiry into the Harmful Use of Alcohol in Aboriginal and Torres Strait Islander Communities – Terms of Reference*, <http://www.apf.gov.au/parliamentary_business/committees/house_of_representatives_committees?url=indigenousaffairs/harmfulalcohol/tor.htm>.

³³⁷ Government of Western Australia Drug and Alcohol Office, *Strong Spirit Strong Future* <<http://www.dao.health.wa.gov.au/Informationandresources/Engagingthecommunity/CommunityPrograms/StrongSpiritStrongFuture.aspx>>.

6.22 The Ord Valley Aboriginal Health Service has been conducted in Kununurra and surrounding areas over the past 3 years. It includes a FASD team which prioritises the education and support of antenatal clients and their families, and provides sessions throughout their pregnancy on FASD, AOD and contraception. The focus is on program plans and resources that are appropriate in terms of culture, gender and age. The FASD team networks with other service providers, such as medical services, work-ready programs, rehabilitation, Aboriginal corporations, child care centres and government agencies, targeting workers and clients to develop opportunities to provide information about FASD prevention to the whole community.³³⁸

6.23 The key aims of the *Lililwan Project* were:³³⁹

- Establish the prevalence of FASD and other health and developmental problems in all children born in 2002 and 2003 and residing in the Fitzroy Valley; and
- Determine relationships between pregnancy exposures and neuro-developmental outcomes.

More detailed information on the *Lililwan Project* has been provided in Chapter 3.

6.24 A key initiative in New South Wales is the establishment of Australia's first FASD screening and diagnostic clinic at Westmead Hospital. This project is a collaboration of health professionals, researchers, community organisations and government. A crucial component of the project involves testing and refining a new diagnostic tool, and building consensus on nationally agreed clinical guidelines. The project will inform evidence based practice and provide training and education to more health professionals in the use of screening and diagnostic tools. The research team will collate prevalence data on FASD and also survey the impact of FASD on families, parents and carers, to enable the provision of more relevant and improved services. As part of the project evaluation, the research team will estimate the costs of setting up and running a FASD assessment service to inform the development of screening and diagnostic services elsewhere in Australia.

FASD Related Non-Government Organisations in Australia

6.25 Non-government organisations have played an important role in lobbying for support for FASD affected individuals and in funding FASD research and initiatives. Table 10 provides examples of non-government organisations with an interest in FASD.

³³⁸ Ord Valley Aboriginal Health Service, 'FASD Prevention Program', *Social Support Unit Services and Programs*, <<http://www.ovahs.org.au/what-we-do/social-support-unit/>>.

³³⁹ Education and Health Standing Committee, *Foetal Alcohol Spectrum Disorder: the invisible disability*, pp. 64 -65.

Table 10: Non-Government FASD Organisations

- National Organisation for Fetal Alcohol Syndrome and Related Disorders (NOFASD) - established in 1999 as a peak national non-government organisation representing the interests of parents, carers and others interested in or affected by FASD, with a focus on education, training and advocacy. NOFASD delivers support to families living with FASD and education and training workshops for both government and non-government agencies throughout Australia.³⁴⁰
- The Russell Family Fetal Alcohol Disorders Association (RFFADA) – established in 2007, RFFADA is a national not-for-profit health promotion charity dedicated to ensuring that individuals affected prenatally by alcohol have access to diagnostic services, support and multi-disciplinary management planning in Australia.³⁴¹
- National Indigenous Corporation for Fetal Alcohol Syndrome Education Network (NICFASEN) – established in 2011, NICFASEN has provided education on FASD to over 40 Aboriginal and Torres Strait Islander communities across Australia.³⁴²
- Foundation for Alcohol Research and Education – funds research and initiatives related to FASD and is a major advocate in relation to harm minimisation alcohol policy and the prevention and management of FASD. FARE’s, *The Australian Fetal Alcohol Spectrum Disorders Action Plan 2013–2016*, provides an excellent resource for anyone working in this area.³⁴³

Development of the Australian Diagnostic Instrument

6.26 As noted in Chapter 2, the implementation of a uniformly accepted diagnostic instrument, suited to Australian conditions, is critical to the effective management of FASD. In 2010, the Commonwealth provided funding to the Australian FASD Collaboration to develop an *Australian Diagnostic Instrument*, with the project being led by Winthrop Research Professor Carol Bower and Professor Elizabeth Elliot. The project was completed, and a final report submitted to the Department of Health and Ageing, in May 2012.³⁴⁴ However, it is only recently that additional funding has been allocated under the Commonwealth FASD Action Plan to evaluate the instrument and develop clinical guidelines. Development of the *Australian Diagnostic Instrument* included a review of a range of diagnostic guidelines used in North America but has largely drawn on the diagnostic criteria set out in the Canadian Guidelines and some of the tools used in the University of Washington 4-

³⁴⁰ NOFASD, *Our history*, <<http://www.nofasd.org.au/about-us/our-history>>

³⁴¹ RFFADA website, <<http://rffada.org/>>

³⁴² FARE, *Action Plan 2013-2016*, p. 50.

³⁴³ FARE, website, <<http://www.fare.org.au/>>

³⁴⁴ FARE, *Action Plan 2013–2016*, pp. 23-24.

digit diagnostic code.³⁴⁵ This project is now underway and is expected to be completed by the end of 2015.³⁴⁶

FASD Policy in the Northern Territory

6.27 There is currently no framework or strategy for FASD in the Northern Territory and coordination of FASD related initiatives is limited. Until recently, FASD has typically been 'managed' under a mix of initiatives, usually as a component of family or early childhood interventions. There have been several attempts to develop a more holistic approach but these have not proved sustainable.

6.28 In 2010, the Northern Territory Government set up an inter-agency FASD Working Group led by the former Department of Health and Families and then the Department of Children and Families, with the aim of developing a framework for a coordinated and informed approach to FASD in the NT.³⁴⁷ The Working Group completed a discussion paper and action plan in August 2011 but this does not appear to have been implemented. More recently, the DoE established an informal cross-agency reference group consisting of representatives from DoH, DCF and Menzies School of Health Research. The aim of the reference group is to provide the members with opportunities to 'share information and align effort'.³⁴⁸

6.29 The Northern Territory has a number of initiatives that are likely to contribute to more positive FASD outcomes. A number of these were outlined by DoH in their submission to the Committee and include:³⁴⁹

- Health checks, brief assessments for alcohol consumption during pregnancy, and referral pathways, have been put in place by the Remote Health teams.
- Risks associated with alcohol consumption during pregnancy are included in training packages, such as those delivered by the Alcohol and Other Drugs (AOD) services to AOD workers and by Remote Health to Aboriginal Health Practitioners.
- AOD services funds a range of non-government organisations to deliver AOD treatment and support services in both urban and remote locations in residential and non-residential settings across the NT.
- Assessment, counselling (individual/group), case management and brief interventions address alcohol misuse including alcohol consumption during pregnancy, where appropriate.

6.30 In addition to the above initiatives, the DoH is responsible for the *Strong Women, Strong Babies, Strong Culture* (SWSBSC) program which is a bi-cultural, community development program that supports an Aboriginal way of promoting good health in

³⁴⁵ Professor Elizabeth Elliott, Committee Transcript, 29 May 2014, p. 116.

³⁴⁶ Professor Elizabeth Elliott, email communication, 24 October 2014.

³⁴⁷ MSHR, Submission No. 15, 2014, p. 5.

³⁴⁸ DoE, Submission No. 16, 2014 p. 4.

³⁴⁹ DoH, Submission No. 9, 2014, p. 4.

women and babies during pregnancy and early parenting. The aims of the program are to:

- Provide culturally appropriate education regarding pregnancy and birth to adolescent girls;
- Provide pregnancy, birth, postnatal, women's health and child health education to pregnant women and mothers of infants and young children; and
- Address the modifiable risk factors during pregnancy for low birth weight eg nutrition, substance abuse, hygiene, homemakers program, male partners support, early pregnancy care attendance.

6.31 A Northern Territory Government publication notes:

a trial of the SWSBSC program in the three Top End communities (Milingimbi, Galiwin'ku and Port Keats) showed a decrease in the rate of low birth weight babies born to mothers in these communities compared to other communities in the Top End. Based on these results the SWSBSC program was introduced to other communities throughout the Northern Territory NT) to a total of seventeen communities at one time. It met with varying degrees of success and is currently running in ten NT communities.³⁵⁰

6.32 The Office of Disability provides a number of services to support children and adults with a range of disabilities identified on an assessment of functional impairment and associated needs rather than a specific diagnosis e.g. of FASD. Services for children are undertaken through a multi-disciplinary allied health assessment and intervention based on identified needs.³⁵¹

6.33 The Anyinginyi FASD project which commenced in September 2011 in Tennant Creek has developed some innovative and well received FASD specific projects. Key foci of the project included: increase community awareness of FASD through the development and delivery of tools and teaching aids for preventing FASD; lobby for the development of clinical pathways and best practice treatment of FASD; lobby for effective treatment for those with FASD and their families; and lobby for funding for FASD. Key outcomes from the project include:

- Production of a hip-hop video *No drink while pregnant*;
- Development of a range of educational materials that have been adopted by the NT DoE for use in schools;
- Television advertisements – currently in English but to be translated into four local Aboriginal languages;
- Production of *Pregnancy Pamper Packs* which provide women with information on alcohol;

³⁵⁰ Department of Health and Families, *Strong Women, Strong Babies, Strong Culture: Information for Strong Women Workers, Government and Non Government Professionals*, <http://www.territorystories.nt.gov.au/bitstream/handle/10070/245915/Strong_Women_Babies_Culture_TE.pdf?sequence=2>.

³⁵¹ DoH, Submission No. 9, 2014, p. 4.

- Regular education sessions for schools and communities;
- Stage play on FASD developed by students.³⁵²

6.34 The Ngaanyatjarra Pitjantjatjara Yankunytjatjara Women's Council developed the "No safe amount - The Effects of Alcohol in Pregnancy" early intervention and prevention campaign to raise awareness of the harmful and permanent effects on the unborn child of using alcohol during pregnancy. It included an educational/advertising campaign and DVD resource using a combination of media including animation and live action.

6.35 The three components of the campaign are: Ititjara (pregnancy); The Growing Brain; and Responsible Fathers. In 2010 the TV commercials were aired for three months on Imparja Television, which has the largest broadcasting footprint in Australia, ensuring the message was spread far and wide. The commercials have been recognised with a 'highly commended' at the 2011 National Drug and Alcohol Awards and the project won the 2011 Deadly Award for Outstanding Achievement in Aboriginal and Torres Strait Islander Health.³⁵³

³⁵² Anyinginyi Health Aboriginal Corporation, Submission 3, 2014, p. 2; Anyinginyi website, <http://anyinginyi.org.au/programs-services/mens-health/foetal-alcohol-spectrum-disorder-project>

³⁵³ Referred to in Telethon Kids Institute website <http://alcoholpregnancy.telethonkids.org.au/our-research/research-projects/other-projects-and-initiatives.aspx>

7 Alcohol Policy Context

7.1 As previously noted in Chapter 5, alcohol contributes to a range of social ills, such as traffic accidents, violent behaviour, fatalities, crime and health problems. Despite this, the consumption of alcohol is a widely accepted part of Australian culture and there is little evidence of this changing in the near future:

Across Australia, alcohol is more affordable than it has been in over three decades, it is more available than it ever has been and it is more heavily promoted.³⁵⁴

In addition, the proportion of women who consume alcohol today has risen significantly, with this increasing the risk that children will be born with FASD.

7.2 A common theme throughout the Inquiry has been the need to change the culture around drinking. This is regarded as integral to achieving a reduction in alcohol consumption in women who are pregnant, as some of the key factors influencing their consumption are socially based and associated with patterns of alcohol consumption in peer groups and communities.

7.3 Alcohol policy is guided by the *National Drug Strategy 2010-2015* which provides a framework to guide action on alcohol, tobacco and other drugs. This is supplemented by the *National Drug Strategy Aboriginal and Torres Strait Islander Peoples' Complementary Action Plan 2003-2006* which was developed in 2003 to ensure that the needs of Indigenous peoples are met.³⁵⁵ The NDS uses a harm minimisation approach based on the core principles of demand reduction, supply reduction and harm reduction. As part of the NDS, seven sub-strategies are to be developed, one of which is the *National Alcohol Strategy*. As this has not yet been released, the primary resource for policy makers continues to be the *National Alcohol Strategy 2006-2009*.³⁵⁶ The work of the NDS is managed by the Inter-governmental Committee on Drugs, a federal, state and territory government forum of senior officers representing health and law enforcement agencies.

7.4 Responsibilities for key alcohol policies are shared between the Australian Government and State and Territory governments. The Australian Government is primarily responsible for alcohol pricing and taxation policies, as well as policies regarding restrictions on marketing. State and Territory governments are mainly responsible for: policies regulating physical availability; modifying the drinking environment; drink driving countermeasures; and delivering treatment and early intervention programs. Local governments also play a role through land use management, social planning, community safety, event and facilities management,

³⁵⁴ FARE, Submission to the Public Accounts Committee, 26 May 2014, p. 11.

³⁵⁵ Ministerial Council on Drug Strategy, *Aboriginal and Torres Strait Islander Peoples Complementary Action Plan 2003-2009*.

³⁵⁶ Ministerial Council on Drug Strategy, *National Alcohol Strategy 2006-2009*, 2006, <[http://www.alcohol.gov.au/internet/alcohol/publishing.nsf/Content/B83AD1F91AA632ADCA25718E0081F1C3/\\$File/nas-06-09-1.pdf](http://www.alcohol.gov.au/internet/alcohol/publishing.nsf/Content/B83AD1F91AA632ADCA25718E0081F1C3/$File/nas-06-09-1.pdf)>.

and liaising with local businesses and communities. In Australia, alcohol policy is also characterised by partnerships between health and law enforcement sectors and engagement across government, with the non-government sector and with the community.³⁵⁷

National Policy Context

7.5 Through the *Northern Territory National Emergency Response Act 2007* (Clth) (NTER) and the *Stronger Futures in the Northern Territory Act 2012* (Clth), the Australian Government has had, and continues to have, a greater involvement in alcohol policy in the Northern Territory than it does in other jurisdictions. Areas of Commonwealth involvement under the *National Partnership Agreement on Stronger Futures in the Northern Territory* include: recruitment of AOD workers in primary and other health services; community alcohol management planning; enhanced long term alcohol licensing compliance; and respectful signage.³⁵⁸ The National Partnership Agreement (NPA) commenced in 2012 and expires in June 2022. It includes nine implementation plans to ensure that Stronger Future objectives are met, one of which is the *Tackling Alcohol Abuse Implementation Plan*.

7.6 Key elements of this Plan include:³⁵⁹

- Facilitation and support of community alcohol management planning;
- Enhancement of long term Northern Territory *Liquor Act* compliance in alcohol protected areas, community managed alcohol areas, regional centres and supply routes;
- Ensuring that alcohol and prohibited material signs in remote communities and town camps are respectful;
- The collection, maintenance, reporting and analysis of specific agreed alcohol related data;
- Alcohol mitigation – complement and support harm minimisation initiatives through a fund to support community participation in AMPs; and
- Legislative review – to assess effectiveness of laws in reducing alcohol related harm and to amend accordingly.

7.7 One of the primary reforms introduced by the Commonwealth under the *Northern Territory National Emergency Response Act 2007*, was the imposition of extensive prescribed areas, in which the possession and consumption of alcohol was

³⁵⁷ National Alliance for Action on Alcohol, *National Alcohol Policy Scorecard*, 2013, p. 8, <<http://www.actiononalcohol.org.au/downloads/alcohol-policy-scorecard-2013.pdf>>.

³⁵⁸ Council of Australian Governments, *National Partnership Agreement on Stronger Futures in the Northern Territory*, Outputs 15 (a) iv; 15(c) v; vi; vii, 2012, <http://www.federalfinancialrelations.gov.au/content/npa/community_services/stronger_future_NT/National_Partnership.pdf>.

³⁵⁹ Council of Australian Governments, 'Schedule D: Tackling Alcohol Abuse Implementation Plan', *National Partnership Agreement on Stronger Futures in the Northern Territory*, 2013, pp. D-3 to D-4, <http://www.federalfinancialrelations.gov.au/content/npa/community_services/stronger_future_NT/Tackling_Alcohol_Abuse_IP.pdf>.

prohibited. This initiative was accompanied by increased penalties and signposted ban notices, with many of the latter deemed offensive by the Aboriginal community.³⁶⁰ Strategies arising from the NTER have been critiqued because of their unilateral imposition and the absence of community consultation, an approach which failed to acknowledge the fact that 'over 100 Aboriginal communities had already been declared general restricted areas, all of them by community application'.³⁶¹

7.8 A move towards greater autonomy in alcohol management occurred with amendments to the NTER in 2010 and has been continued with Stronger Futures. These changes have led to more emphasis on community-established AMP and less emphasis on government-imposed restrictions. Under Stronger Futures the following modifications have been made:³⁶²

- Prescribed areas have been rebranded as 'alcohol protected areas' and tougher penalties for breach have been introduced;
- Community consultation must be conducted before erecting signposting of alcohol restrictions;
- An assessor can now be appointed to investigate the activities of a licensed premises suspected of contributing to alcohol related harm through its sales on and off premises; and
- The Act restricts sales only in alcohol protected areas.

7.9 Despite this move towards greater autonomy, the Stronger Futures legislation has been critiqued as being too focused on:

consumer regulation, criminalisation of individual behaviour, the continuation of externally imposed restrictions, and the lack of broader policy measures to address the multi-causal nature of alcohol related harm such as public health and social welfare.³⁶³

Equally, it has been argued that there is an absence of clear, standardised measures to restrict supply even though 'It is well established that supply reduction including restricting trading hours, decreasing the number of licensed premises, and price controls and taxation are effective in decreasing alcohol related harm'.³⁶⁴ Concerns have also been expressed that blanket bans, and the criminalising of behaviour for breaking these bans contributes to:³⁶⁵

- The relocation of violence and drinking to unseen and unsafe areas such as camps outside community limits;
- Migration to larger towns where alcohol is available; and

³⁶⁰ E Walker, 'Stronger Futures: alcohol regulation in the NT', *Indigenous Law Bulletin*, vol. 8 no. 3, 2012, p. 21.

³⁶¹ E Walker, 'Stronger Futures: alcohol regulation in the NT', p. 21.

³⁶² E Walker, 'Stronger Futures: alcohol regulation in the NT', p. 21.

³⁶³ E Walker, 'Stronger Futures: alcohol regulation in the NT', p. 21.

³⁶⁴ E Walker, 'Stronger Futures: alcohol regulation in the NT', p. 21.

³⁶⁵ E Walker, 'Stronger Futures: alcohol regulation in the NT', p. 21.

- A shift by some to illicit drugs.

Northern Territory Policy Context

- 7.10 As noted in Chapter 5, the Northern Territory's per capita pure alcohol consumption is substantially higher than the national average, with this primarily due to higher rates of risky consumption than the amount drunk on a daily or weekly basis. In addition, the proportion of Indigenous people in the Northern Territory is significantly higher than in other jurisdictions, with this contributing to a more complex policy context.
- 7.11 Alcohol policy in the Northern Territory is developed by the Department of Business and sits within the *National Alcohol Strategy 2006-2009*, however, in the absence of a clearly defined Northern Territory Alcohol Strategy, the extent to which NT policy links in with the goals and objectives of national policy cannot be readily assessed.
- 7.12 Alcohol policy in the Northern Territory appears to be most developed in relation to: measures for reducing drink driving; treatment and early intervention; regulation of the physical availability of alcohol; and modification of the drinking environment, through, for example, the enforcement of liquor laws. Key policy elements include: AMP;³⁶⁶ health related initiatives such as AOD programs;³⁶⁷ Alcohol Mandatory Treatment (AMT);³⁶⁸ measures related to drink driving; and a range of strategies to increase community safety and reduce public drunkenness.³⁶⁹ Strategies in relation to community safety and public drunkenness include the use of legislation to enable the restriction of alcohol consumption in defined areas through permit systems and restricted areas (private, public, general and special restricted areas). Compliance is enforced through the use of banning notices and exclusion notices with varying penalties applied.³⁷⁰ This chapter focuses on policies related to: AMP; BDR; TBLs; liquor accords; pricing and taxation of alcohol; AOD programs; rehabilitation programs; and social marketing and education.

Alcohol Management Plans

- 7.13 Alcohol Management Plans are used to regulate alcohol supply and consumption and are primarily used where Indigenous drinking is defined as a major issue in the community. They use a combination of demand, supply and harm reduction strategies, with the aim of minimising the nature and extent of harm caused by the excessive consumption of alcohol.³⁷¹ These strategies are defined below:³⁷²

³⁶⁶ Department of Business, *Gambling and Licensing*, Northern Territory Government, <<http://www.dob.nt.gov.au/gambling-licensing/alcohol-policy/Pages/default.aspx>>.

³⁶⁷ Department of Health, *Alcohol and Other Drugs*, Northern Territory Government, <http://health.nt.gov.au/Alcohol_and_Other_Drugs/index.aspx>.

³⁶⁸ Department of Health, *Alcohol Mandatory Treatment*, Northern Territory Government, <http://health.nt.gov.au/Alcohol_Mandatory_Treatment/index.aspx>.

³⁶⁹ Department of Business, *Liquor Restrictions*, Northern Territory Government <<http://www.dob.nt.gov.au/gambling-licensing/liquor-restrictions/Pages/default.aspx>>.

³⁷⁰ Department of Business, *Gambling and Licensing*.

³⁷¹ Smith et al, 'Alcohol management plans and related alcohol reforms', *Indigenous Justice Clearinghouse*, Brief 16, October 2013, p.1.

- Supply reduction refers to reducing alcohol consumption and related harm by managing the availability, accessibility and convenience of alcohol supply;
- Demand reduction refers to changing individual attitudes, personal knowledge and behaviours to drinking alcohol. It also looks at changing the community's tolerance of irresponsible and risky drinking patterns; and
- Harm reduction refers to influencing safer drinking choices and drinking environments to reduce harm to individuals and the community through the provision of interventions that prevent further harm.

7.14 Currently, there are 24 remote community AMPs that are either in development, being redeveloped, or have been completed under the Federal Government's Stronger Futures legislation as set out in the *Tackling Alcohol Abuse Implementation Plan* developed under the National Partnership Agreement on Stronger Futures in the Northern Territory.³⁷³ This Plan, which commenced in 2013, will be in force until completion or termination of the NPA. AMPs which come under federal legislation must comply with five minimum standards as defined in *Rule 2013* and which are set out below.³⁷⁴

- Standard 1: Consultation and engagement;
- Standard 2: Managing the Alcohol Management Plan;
- Standard 3: Alcohol Management Plan strategies – supply, demand and harm reduction;
- Standard 4: Monitoring, reporting and evaluation; and
- Standard 5: Clear geographical boundaries.

The aim of these standards is to reduce the harm 'that results from alcohol abuse in Aboriginal communities, with a particular focus on the safety of community members, particularly women, children and families'.³⁷⁵

7.15 As set out in the *Tackling Alcohol Abuse Implementation Plan*, the Northern Territory Government has lead responsibility for facilitating the development of remote community AMPs; licensing and compliance activities, including maintenance of signage; and the provision of alcohol data to the Commonwealth. The Commonwealth's primary responsibilities are to fund complementary alcohol mitigation initiatives; facilitate consultation with remote communities and town camps in relation to signage; and commission an independent review under the

³⁷² Department of Business, *Alcohol Management Plans*, Northern Territory Government, <<http://www.dob.nt.gov.au/gambling-licensing/alcohol-policy/Pages/amp.aspx>>.

³⁷³ Department of Business, *Alcohol Management Plans (AMPs) in the Northern Territory as at 14 August 2014*, Northern Territory Government, <<http://www.dob.nt.gov.au/gambling-licensing/alcohol-policy/amp/Documents/amps-nt.pdf>>.

³⁷⁴ Department of Business, *Stronger Futures in the Northern Territory*, Northern Territory Government, <<http://www.dob.nt.gov.au/gambling-licensing/alcohol-policy/Pages/stronger-futures.aspx>>.

³⁷⁵ Department of Business, *Stronger Futures in the Northern Territory*.

Stronger Futures Act of the effectiveness of alcohol related laws for Aboriginal people in the NT.³⁷⁶

- 7.16 The Northern Territory Government is responsible for the ongoing oversight of AMPs in the regional towns of Nhulunbuy, Katherine, Tennant Creek, and Alice Springs. AMPs are currently being developed or re-developed in Nhulunbuy, Tennant Creek, and Alice Springs, and the AMP for Katherine has recently been completed and approved by the Minister for Alcohol Policy.³⁷⁷ These AMPs come under the jurisdiction of the Northern Territory Government and are not governed by any particular legislation.³⁷⁸
- 7.17 AMPs have been used to regulate the supply and demand of alcohol in Indigenous communities since 2002, when the first plan was implemented in Queensland. Research shows that the effectiveness of AMPs is significantly influenced by the extent to which strategies are implemented and supported by the community rather than by the actual policies. The development and implementation of the regional AMPs is undertaken by an Alcohol Reference Group which is comprised of members from stakeholder groups and organisations with an interest in alcohol management. The Northern Territory Government identifies the stakeholder groups from which the Reference Group is formed but stakeholder groups nominate their own representatives.
- 7.18 A key characteristic of an AMP is its facilitation of strategies that can be tailored to the needs of the community. This means that AMPs may differ substantially from each other and can include a diverse range of strategies under the core principles of supply, demand and harm reduction. However, Smith and colleagues note that supply reduction strategies are the most common with substantially less evidence of demand reduction strategies related to treatment and rehabilitation.³⁷⁹ Consultation with, and commitment from, the community, is considered vital, consequently, the development of a regional AMP requires extensive negotiation. Prior to implementation the AMP must proceed through the following steps:
- The plan must be agreed to by the community and signed off by the Alcohol Reference Group;
 - Signed off by the Department of Business, this includes discussion and negotiation regarding policies and strategies within the draft AMP; and
 - Endorsement by the Minister for Alcohol Policy.
- 7.19 The effectiveness and relevance of an AMP is frequently seen as being directly related to the extent of community support and involvement in its development.³⁸⁰ This was highlighted by Ms Barb Shaw, the President of the Tennant Creek Alcohol

³⁷⁶ COAG, 'Tackling Alcohol Abuse Implementation Plan'.

³⁷⁷ Department of Business, *Alcohol Management Plans (AMPs) in the Northern Territory*.

³⁷⁸ Mr Des O'Brien, Regional Coordinator Alcohol Management, email communication, 10 October 2014.

³⁷⁹ Smith et al, 'Alcohol management plans and related alcohol reforms', p. 4.

³⁸⁰ Smith et al, 'Alcohol management plans and related alcohol reforms', p. 6.

Reference Group, who also noted the importance of involving all sectors of the community – business as well as non-government organisations:

the big thing that is going to make a difference out of this is the process, how this reference group actually manages in talking and engaging with the community. I think if you have the community behind it and the community support for the final alcohol management plan then ... it is probably more likely to have success. I do not think a management plan can be developed and adopted without the full support of the community and when I say the full community it has to be everyone across the board. It is not just about NGO service providers, I think it is about the whole sector of the community, which includes the licensees and the businesses. So I think it is getting that process right and then getting everyone behind it and to make that commitment.³⁸¹

However, Ms Shaw also commented that government commitment and support are also essential ingredients to the successful implementation of community AMPs:

the government of the day has to make that commitment to it as well, in relation to monitoring and compliance and whatever is required under legislation. ... I do not think the community can necessarily make the plan work on its own. I think the government has to back it up and ... stand behind it as well.³⁸²

Supply Reduction Policies

- 7.20 Supply reduction policies focus on reducing alcohol consumption and related harm by managing the availability, accessibility and convenience of alcohol supply through measures such as reducing take-away outlets, reducing trading hours and increasing the cost of alcohol through taxation and pricing mechanisms.
- 7.21 There is a substantial body of literature on the effect of pricing on alcohol consumption, particularly in relation to risky drinking³⁸³. Supply reduction policies were also strongly espoused by many witnesses and organisations making submissions to the Inquiry. The Public Health Association noted that increasing price is an effective method for reducing consumption, particularly harmful consumption among disadvantaged or lower socio-economic groups and considered it a more effective approach than ‘trying to teach people how much alcohol is safe’.³⁸⁴ Similarly, the People’s Action on Alcohol Coalition and the Central Australian Aboriginal Congress Aboriginal Corporation (CAACAC) advocated for supply reduction measures which they considered would ‘make a major difference to alcohol misuse in Aboriginal communities, including the specific problem of FASD’.³⁸⁵

³⁸¹ Committee Transcript, 31 August 2014, pp. 30-31.

³⁸² Committee Transcript, 31 August 2014, p. 31.

³⁸³ World Health Organisation Regional Office for Europe, *Evidence for the effectiveness and cost-effectiveness of interventions to reduce alcohol-related harm*, 2009, p. 76-81.

³⁸⁴ Dr Rosalie Schultz, Committee Transcript, 1 August 2014, p. 33.

³⁸⁵ Central Australian Aboriginal Congress Aboriginal Corporation (CAACAC), Submission 24, 2014, p. 6.

Volumetric Tax

7.22 A volumetric tax is a tax on all or some alcohol products according to their alcohol content. In so doing, it gives a price disincentive that directly links to the amount of alcohol in the product. It also generates income for government which can be used for alcohol treatment programs or other strategies to reduce alcohol related harm. However, under current constitutional arrangements, a tax on alcohol can only be undertaken by the Federal Government. This was clarified through a High Court ruling made in 1997 in relation to the then NT Government's Living with Alcohol (LWA) program. The LWA program, implemented between 1992 and 2002, introduced a small levy on all alcoholic beverages sold in the NT containing 3 percent alcohol by volume or greater. However, the levy had to be abolished in 1997 as it was found by the High Court to be invalid.³⁸⁶ The LWA initiative, which included a range of programs and services funded by the levy, continued to operate until 2002. After the levy was ruled invalid in 1997, these services 'were funded from redirected taxes collected by the Commonwealth'.³⁸⁷

Minimum Floor Price

7.23 A minimum floor price imposes a minimum price per standard drink (or unit of alcohol) and by doing so prevents the sale of very cheap alcohol. Minimum pricing is a regulatory measure rather than a tax and, unlike a tax:

it cannot be circumvented by discounting, loss leading, or below cost selling, because retailers cannot sell below the mandated unit price. By comparison, the impact of alcohol tax increases can be mitigated, especially by large retailers.³⁸⁸

7.24 Although there is little dispute that a floor price is an effective means of reducing alcohol consumption and alcohol related harm at a population level, evidence of its effectiveness across different types of drinkers or across different sub-groups of the population is more mixed. The Australian National Preventive Health Agency (ANPHA) recently undertook a study to review the evidence regarding the effectiveness of a minimum floor price and concluded that it would:³⁸⁹

- Result in a decrease in alcohol consumption and in alcohol related harms;
- Impact most on the cost of cask and clean skin wines, with beer and other beverage prices not generally affected until the level of a regulated minimum price reached \$1.30 - \$1.50;
- Have differential impacts on various groups of consumers but, because it would raise the cost of the cheapest alcohol, would disproportionately affect

³⁸⁶ People's Alcohol Coalition, Submission 23, 2014, pp. 9-10.

³⁸⁷ Chikritzhs et al, *The impact of the Northern Territory's Living With Alcohol program, 1992-2002: revisiting the evaluation*, National Drug Research Institute, Curtin University of Technology, Perth, Western Australia, 2004, p. vi.

³⁸⁸ Australian National Preventive Health Agency (ANPHA), *Exploring the Public Interest Case for a Minimum (Floor) Price for Alcohol Final Report*, 2013, p. 33.

³⁸⁹ ANPHA, *Exploring the Public Interest Case for a Minimum (Floor) Price for Alcohol*, p. 57.

heavy drinkers who drink cheaper alcohol regularly at harmful levels in excess of the NHMRC Guidelines; and

- Result in increased revenue for the private sector.

7.25 Some argue that minimum pricing unfairly penalises moderate drinkers (two standard drinks per day). However, there is substantial evidence to suggest that moderate drinkers are only marginally affected by minimum pricing,³⁹⁰ more specifically, Record and Day found the largest effect to be on the 30 percent of the population who consume 80 percent of the alcohol and noted that:

For the top 30 per cent of consumers, off-trade alcohol purchasing would decrease by 16 units per week (32 per cent) compared to an overall fall of 3.4 units per week (for all consumers).³⁹¹

7.26 Regardless of whether it is the moderate or risky drinkers who are most affected, the evidence clearly points to a decrease in consumption for both groups. In addition, research suggests that reducing consumption in moderate drinkers is also likely to deliver positive social benefits, with several studies finding that the greatest burden of alcohol related harm is derived from moderate rather than harmful drinkers, as the ANPHA Report notes:

While the heaviest drinkers have a significantly higher risk for alcohol-related harm compared to moderate drinkers, they are small in number, thus the majority of harms arises from moderate drinkers.³⁹²

7.27 Although ANPHA notes that minimum pricing is undoubtedly an effective policy option for reducing harmful use of alcohol, it argues that introduction of a minimum floor price at a national level is not in the public interest, with the public interest being dependent on the resultant economic benefits and costs to the community. Such a policy would deliver benefits such as reductions in alcohol related crime and violence, alcohol related disease and productivity losses but would also result in costs such as regulatory impacts on business and loss of satisfaction from reduced consumption by low-risk drinkers (a reduction in consumer surplus). The analysis in the ANPHA report suggests that while the decrease in consumption flowing from a minimum pricing policy would deliver benefits (as noted above) these would not be of sufficient magnitude to outweigh the costs, particularly when taking into account the fact that the loss of consumer surplus would be substantial due to the high proportion (about 80 percent) of Australians who consume alcohol. In addition, not only would the financial benefits from price increases flow to the private sector, but reduced consumption of alcohol implies reduced revenue for government.³⁹³

7.28 It is noteworthy that the ANPHA report specifies that national implementation of a minimum floor price may not be in the public interest. This specification reflects an implicit acknowledgement that under certain conditions, and in some places,

³⁹⁰ ANPHA, *Exploring the Public Interest Case for a Minimum (Floor) Price for Alcohol*, p. 49.

³⁹¹ Record & Day cited in ANPHA, *Exploring the Public Interest Case for a Minimum (Floor) Price for Alcohol*, p. 49.

³⁹² ANPHA, *Exploring the Public Interest Case for a Minimum (Floor) Price for Alcohol*, p. 50.

³⁹³ ANPHA, *Exploring the Public Interest Case for a Minimum (Floor) Price for Alcohol*, pp. 57-58.

minimum pricing can be a useful tool for reducing consumption and alcohol related harm. The Committee considers that in the Northern Territory that the benefits of reduced alcohol related crime, disease and productivity loss from a minimum floor price would far outweigh the reduced consumer surplus (ie, the cost of those wishing to buy the cheapest alcohol not being able to buy below a minimum price).

Alcohol Taxation Reform

7.29 The current alcohol taxation and excise regime results in inequities in how alcohol is priced. Wine is subject to a tax while other forms of alcoholic beverages incur an excise.³⁹⁴ Generally, the excise is based on the proportion of alcohol content and thus varies across different types of alcoholic beverages. The current Wine Equalisation Tax (WET) is based on the wholesale value of the wine, ‘the cheaper the wine, the less it is taxed, irrespective of alcohol content’.³⁹⁵ This allows wine to be sold at significantly cheaper prices than many other alcoholic beverages and results in price distortions in the alcohol market that particularly favour cheap wine. The alcohol by volume for wine is generally higher than that for beer. Consequently, as there is good evidence from individual studies that hazardous drinkers tend to seek out the cheapest forms of alcohol,³⁹⁶ reforming the WET could have a positive effect in terms of reducing harmful consumption and reducing alcohol related harm generally. As the ANPHA Report noted, ‘Preferential treatment of wine, particularly at the lower value end, is likely to be contributing to social and health harms.’³⁹⁷

7.30 A wide range of organisations that work in the field of harm reduction favour the implementation of both a volumetric tax and minimum floor pricing, with a combined approach also favoured in the Henry Taxation Review.³⁹⁸ One reason for this is the ability of retailers to circumvent volumetric taxation by discounting, loss-leading or below cost selling. As noted by the Alcohol and Other Drugs Council of Australia:

The introduction of a floor price, in conjunction with a volumetric taxation regime, would prevent alcohol retailers from undermining the effect of such a tax through heavy discounting and product bundling and reduce alcohol related harm. The dual issues of an alcohol floor price and the alcohol taxation regime are complementary.³⁹⁹

7.31 As noted earlier, states and territories do not have the power to tax alcohol. Consequently, in the absence of alcohol taxation reform at the federal level, their options with regard to the use of price mechanisms to reduce alcohol consumption and related harm are largely limited to the implementation of a minimum floor price and the placing of restrictions on the size of the casks used to sell wine and fortified

³⁹⁴ Standing Committee on Social Policy and Legal Affairs, *FASD: The Hidden Harm*, p. 74.

³⁹⁵ ANPHA, *Exploring the Public Interest Case for a Minimum (Floor) Price for Alcohol*, p. 10.

³⁹⁶ T Stockwell, CM Auld, J Zhao & G Martin, ‘Does minimum pricing reduce alcohol consumption? The experience of a Canadian province’, *Addiction*, vol.107, 2011, p. 912.

³⁹⁷ ANPHA, *Exploring the Public Interest Case for a Minimum (Floor) Price for Alcohol*, p. 11.

³⁹⁸ K Henry et al, *Australia’s Future Tax System: Report to the Treasurer, Part Two – Detailed Analysis 2009*, Commonwealth of Australia, 2010, <www.taxreview.treasury.gov.au>.

³⁹⁹ Alcohol and Other Drugs Council of Australia cited in ANPHA, *Exploring the Public Interest Case for a Minimum (Floor) Price for Alcohol*, p. 63.

wine. Restrictions on cask size is effectively a minimum pricing approach as the price of wine rises when sold in smaller quantities. This mechanism was used in the *Alice Springs Liquor Supply Plan* and resulted in a significant shift away from the consumption of wine to an increase in the consumption of beer. The National Drug Research Institute noted that the positive outcomes associated with this initiative demonstrate 'the effectiveness of using a minimum unit pricing approach to achieve a planned substitution to more expensive, less harmful forms of alcohol'.⁴⁰⁰

Banned Drinker Register, Alcohol Protection Orders and Temporary Beat Locations

- 7.32 The BDR was introduced in the Northern Territory by the then Government in July 2011. It was part of the *Enough is Enough* reforms and was implemented under the *Alcohol Reform (Prevention of Alcohol-Related Crime and Substance Misuse) Act*. The BDR operated between July 2011 and August 2012 when it ceased operating following a change of government.⁴⁰¹ The BDR was underpinned by banned drinker and alcohol mandatory treatment orders under which police could issue a ban for up to 12 months.⁴⁰²
- 7.33 The BDR consisted of an electronic record of all banned drinkers and operated across the Northern Territory. It linked into the existing Alcohol Restriction Monitoring System that was implemented in Alice Springs and Katherine in 2008.⁴⁰³ Under the BDR everyone purchasing alcohol had to have a photo ID scanned at the point of sale. If their name came up on the register they would not be permitted to buy alcohol. The Northern Territory wide operation of the system meant that banned drinkers could not buy alcohol anywhere in the Territory. A key purpose of the BDR was to ensure the capacity to enforce the bans.
- 7.34 Some witnesses to the Committee indicated strong support for the BDR, with the People's Action on Alcohol Coalition (PAAC) requesting that consideration be given to its reintroduction.⁴⁰⁴ Similarly, CAACAC, recommended a BDR or its equivalent as one of several key supply reduction measures:
- The reintroduction of photo-licensing at the point of sale coupled with an electronic register that has the capacity to ban people from accessing take-away alcohol based on defined criteria that mean the banned person has a serious alcohol problem.⁴⁰⁵
- 7.35 The BDR ran for only a short time and no formal evaluation of the program appears to have been undertaken. However, an initial assessment of the effect of the BDR

⁴⁰⁰ National Drug Research Institute (NDRI), *Alcohol Control Measures: Central Australia and Alice Springs* in CAACAC, Submission 24, 2014, Attachment C, p. 3.

⁴⁰¹ NDRI, *Alcohol Control Measures: Central Australia and Alice Springs*, p. 6.

⁴⁰² A brief summary of provisions around the banning and Treatment order notices is included in PAAC Submission 23, 2014, p. 11 and a more detailed overview in Lawrie, D, 'Ministerial Statement - Enough is Enough – Proposed Alcohol Reforms', *Ministerial Statement*, Hansard, 26/10/2010.

⁴⁰³ Tangentyere Council Inc, Commonwealth, House of Representatives, Inquiry into the Harmful Use of Alcohol in Aboriginal and Torres Strait Islander Communities, Submission No. 95, 2014, p. 18.

⁴⁰⁴ Committee Transcript, 1 August 2014, p. 16.

⁴⁰⁵ CAACAC, Submission 24, 2014, p. 6.

in Alice Springs, undertaken by the National Drug Research Institute and commissioned by PAAC, concluded that 'the BDR was effective in reducing alcohol related harms to health in Alice Springs'.

- 7.36 Although the BDR ceased in August 2012, evidence from the Alice Springs Chamber of Commerce indicates that the devices are still functional and, in Tennant Creek, are being used by licensees as a means of enforcing purchasing restrictions which form part of the Tennant Creek Liquor Accord:

Even though the BDR is not used anymore, in Tennant Creek the devices are still used for the ID because they have the restrictions in place. What it does is allows you to scan the ID, like your driver's licence, so you know you have bought one bottle of spirits and one bottle of wine. So, they cannot go from one hotel to another because they are all linked up.⁴⁰⁶

- 7.37 Subsequent to the cessation of the BDR, the current Government introduced several new initiatives, in particular, the AMT program; Alcohol Protection Order (APO); and TBLs.
- 7.38 AMT is a mandated assessment, treatment and aftercare initiative for people who chronically misuse alcohol; are either unlikely or unable to voluntarily access treatment options; and who have been taken into protective custody for public intoxication at least three times in two months.
- 7.39 APO were introduced under the *Alcohol Protection Orders Bill* in 2013 and can be issued to individuals who have been charged with committing an offence that carries a penalty of a minimum of six months imprisonment while under the influence of alcohol. Once issued with an APO it is illegal to possess or consume alcohol or to be present on licensed premises anywhere in the Northern Territory. An APO can be issued regardless of whether a person is found guilty of the original offence and, if breached, may result in imprisonment for up to three months. In addition, the supply of alcohol to someone subject to an APO is also an offence under the Act.
- 7.40 The onus for compliance with the APO is on the individual. In regional areas compliance is monitored by police through bottle shop patrols (commonly referred to as TBLs) and initiatives such as Operation Leyland in Alice Springs. In contrast to the BDR, licensees are not required to monitor APO, however, police can provide licensees or a person in charge of licensed premises, with the name and photograph of a person subject to an APO.
- 7.41 TBLs operate in Katherine, Tennant Creek and Alice Springs but not in Darwin or Palmerston. Under the Liquor Act, police can, without a warrant, search a person and seize any container they believe contains liquor if they suspect that an offence has been or will be committed in relation to the possession or consumption of alcohol. TBLs are used to monitor compliance with APOs and with rules regulating various restricted areas under the *Liquor Act* and Stronger Futures legislation. Using an iPad, police stationed at a bottle shop can check names and addresses of individuals buying alcohol and determine whether they are barred from purchasing

⁴⁰⁶ Committee Transcript, 1 August 2014, p. 25.

alcohol due to either an APO or because they live in an alcohol restricted area and do not have a permit to drink.

Liquor Accords

7.42 Under Northern Territory legislation, a local Liquor Accord is:

any written code of practice, memorandum of understanding or other arrangement that:

- (a) *affects the supply of liquor, the opening and closing of licensed premises or other aspects of the management of, or conduct of business on, licensed premises; and*
- (b) *is made under this Part for the purpose of preventing or reducing alcohol-related violence.*⁴⁰⁷

7.43 A Liquor Accord is a mechanism which enables licensees to work collaboratively with regulators, local police, local councils and other community stakeholders to develop locally based solutions to reduce alcohol related crime, anti-social behaviour and alcohol related harm within the community. Under the *Liquor Act*, liquor accords must include a licensee and at least one of the following parties: Director responsible for gambling and licensing; Commissioner of police; local government council; local organisation representing business interests in the area; and concerned community or residents' group. The *Liquor Act* provides for liquor accords to operate in the NT without requiring special authorisation from the Australian Consumer and Competition Commission, however, an Accord must be approved by the director responsible for gambling and licensing. As a Liquor Accord is intended as a local solution, the items included in an Accord will vary across different communities.

7.44 An Accord may provide for a range of actions such as authorising or requiring licensees who are a part of the Accord to:⁴⁰⁸

- Cease or restrict the sale of liquor (including takeaway liquor) on the licensed premises, from a time of day that is earlier than the time which would be required by the relevant license or, similarly, to restrict the public's access to licensed premises as set out in the Accord;
- Prohibit or restrict the use of glass containers;
- Maintain an incident register; and
- Charge a particular price for liquor.

⁴⁰⁷ *Liquor Act 2014*, Northern Territory of Australia, Part XA Local liquor accords, 120A Definitions.

⁴⁰⁸ Northern Territory Government, Commonwealth, House of Representatives, Standing Committee on Indigenous Affairs, *Inquiry into the Harmful Use of Alcohol in Aboriginal and Torres Strait Islander Communities*, Submission No. 60, 2014, p. 8.

Demand and Harm Reduction

7.45 Demand reduction encompasses a range of strategies at both the individual and the population level. It aims to prevent the uptake of harmful alcohol use and to minimise harm among those who already use at harmful levels. Key strategies associated with demand reduction include:⁴⁰⁹

- Providing alternatives to the use of AOD – this strategy particularly targets young people through encouraging alternatives such as sporting and cultural activities, mentoring programs and school retention and employment programs;
- Education and persuasion – social marketing campaigns and education in schools;
- Treatment – residential and community based, can include brief or longer term interventions, detoxification, counselling and cognitive behavioural therapy;
- Diversion to treatment – diversion of individuals who have committed alcohol related offences into treatment or including treatment as part of the sentencing process; and
- Ongoing care – alcohol dependence is a chronic relapsing condition and ongoing or follow-up care is essential and has been shown to reduce the frequency of relapse.

7.46 Harm reduction strategies aim to reduce alcohol related harm without necessarily reducing use. Common strategies in the Northern Territory include night patrols and sobering-up shelters which aim to reduce harm by removing intoxicated persons to safe locations.

Northern Territory Government Policies and Initiatives for Demand and Harm Reduction

7.47 The Northern Territory Government provides an integrated AOD service system that delivers prevention, early intervention, treatment, harm reduction and recovery responses designed to minimise the harms of alcohol misuse. In terms of service delivery, it aims to deliver culturally sensitive programs that are provided by both mainstream and Aboriginal controlled services. This is facilitated through the Northern Territory Aboriginal Health Forum (NTAHF or 'the Forum'), which was established to consult on key issues about regional planning and to contribute to policy and planning development in Aboriginal Comprehensive Primary Health Care in the Northern Territory. The Forum includes the Aboriginal Medical Services Alliance of the Northern Territory (AMSANT), DoH and the Commonwealth Department of Health and Ageing (DoHA) through its Office of Aboriginal and Torres

⁴⁰⁹ D Gray & E Wilkes, 'Reducing alcohol and other drug related harm', *Resource Sheet No. 3 produced for the Closing the Gap Clearing House*, Cat. No. IHW 35, Australian Institute of Health and Welfare and Australian Institute of Family Studies, Australia, 2010, pp. 7-8, <<http://www.aihw.gov.au/uploadedFiles/ClosingTheGap/Content/Publications/2010/ctgc-rs03.pdf> >.

Strait Islander Health (OATSIH). More recently, under the Stronger Futures in the Northern Territory program, the Department of Families, Housing, Community Services and Indigenous Affairs (FaHCSIA) has also joined NTAHF.

- 7.48 Demand and harm reduction programs are delivered through the DoH and NTDCS.⁴¹⁰ AOD services provided through DoH include a workforce training unit, Aboriginal workforce development, community development programs, education and counselling, withdrawal management, residential rehabilitation, interventions in emergency departments, hospitals and prisons and AMT.
- 7.49 Programs through NTDCS include adult interventions provided in both correctional centres and at the community level. Interventions are delivered by external providers as well as NTDCS. Many of the programs, particularly those delivered by non-government organisations, focus on education and prevention of relapse behaviours, however, the Intensive Alcohol and Drugs Program delivered in correctional centres by NTDCS is a five month psycho-therapeutic program. Additional programs run by the NTDCS include the Youth Justice program focused on young people aged between ten and eighteen and a variety of youth intervention program options for young people in detention facilities and in the community.
- 7.50 Programs administered by both DoH and NTDCS use evidence based best practice approaches, with one example being the Remote Alcohol and Other Drugs Workforce Program run by DoH. This program received a positive evaluation from the Menzies School of Health Research and won the Chief Minister's Award in 2013. It has 28 funded positions for 2013-14 with workers based in eight remote Department of Health Primary Health Care Centres and in six Aboriginal Community Controlled Health Organisations. Key features of this program include:⁴¹¹
- The embedding of social and emotional wellbeing and AOD into a primary care model;
 - A broad focus on children, families, young people and communities through capacity building using a culturally appropriate approach;
 - High quality clinical and educational support for program staff;
 - A shift away from fly in fly out visiting services to frontline local workers;
 - An emphasis on employing Indigenous staff - 85 percent of workforce in 2013;
 - Two distinct areas of focus: direct service delivery and community development;

⁴¹⁰ Northern Territory Government, Standing Committee on Indigenous Affairs, Inquiry into the Harmful Use of Alcohol in Aboriginal and Torres Strait Islander Communities, Submission No. 60, 2014, Attachments E and F, pp. 49-57.

⁴¹¹ Northern Territory Government, Standing Committee on Indigenous Affairs, Inquiry into the Harmful Use of Alcohol in Aboriginal and Torres Strait Islander Communities, Submission No. 60, 2014, Attachment D, pp. 43-47.

- An emphasis on training and education which includes raising awareness about FASD;
- Professional development and close links with the Program Support Unit; and
- Culturally appropriate resources.

7.51 In addition to operating their own AOD services, both DoH and NTDCS fund non-government organisations to deliver services. Although data on the amount of funding provided to non-government organisations for this purpose has not been provided to the Committee it is likely that the cost impact of providing these services is considerable. For example, funding provided to non-government organisations in 2012-13 for residential rehabilitation services was \$10.7 million; for counselling and education services it was \$4.5 million; and for withdrawal services it was \$505,575.⁴¹²

7.52 A more detailed overview of programs run by the Northern Territory Government is available in the Northern Territory Government Submission to the *Inquiry into the Harmful Use of Alcohol in Aboriginal and Torres Strait Islander Communities*, in particular in Attachments D, E and F.⁴¹³

⁴¹² Northern Territory Government, Standing Committee on Indigenous Affairs, *Inquiry into the Harmful Use of Alcohol in Aboriginal and Torres Strait Islander Communities*, Submission No. 60, 2014, pp. 50-52.

⁴¹³ Northern Territory Government, Standing Committee on Indigenous Affairs, *Inquiry into the Harmful Use of Alcohol in Aboriginal and Torres Strait Islander Communities*, Submission No. 60, 2014.

8 Action to Manage the Effects of FASD

- 8.1 The Committee could not examine the effects of FASD on its sufferers without considering how to respond to those effects.
- 8.2 The starting point for an effective response is a means of diagnosis. Understanding the cause of the range of disabilities and impairments that can manifest as FASD can inform how best to respond to them. This is particularly the case for cognitive impairments that lead to bad behaviour and learning difficulties that can easily be misinterpreted as naughtiness or low intelligence. Diagnosis is also needed to inform the extent of the incidence of FASD and the effectiveness of action in response to the problem. As early intervention is important for limiting the effects of FASD, awareness and referral pathways in the health system are also important. The unique challenges of FASD also need to be understood by those who interact with its sufferers, and services and governmental systems need to be able to manage these challenges. Finally, there needs to be coherence in agencies' responses to FASD, allowing a more integrated service for sufferers.

Diagnosis and Screening

While integrated and coordinated service delivery is important to meet the complex needs of FASD affected children and their families, a standardised and diagnostic tool for FASD and increased services and access to specialists for treatment are essential.⁴¹⁴

Diagnosis of FASD

- 8.3 Enabling effective diagnosis of FASD is crucial for both management and prevention of FASD. Sufferers need diagnosis to be able to understand their condition and obtain treatment. Families and services can better respond to a sufferer's needs if they have a diagnosis. Policies and programs can only be evaluated for their effectiveness and funded according to need when the extent of the problem is understood.
- 8.4 There are two major barriers to diagnosis. The first is having a diagnostic tool. Such a tool for Australia is in the final stages of testing and should be available for implementation in 2015. The second barrier is having services with trained staff that can provide the diagnosis.
- 8.5 Best practice in diagnosis of FASD is the use of multi-disciplinary teams and, as noted in Chapter 7, is the approach commonly used in the US and Canada. Multi-disciplinary teams include a wide range of professionals such as: developmental paediatrician, nurse, psychologist, physical and occupational therapist, speech pathologist, social worker and/or family counsellor, and can be based within a FASD

⁴¹⁴ DCF, Committee Transcript, 29 May 2014, p. 93.

diagnostic centre or operate as a mobile unit.⁴¹⁵ Based on her experience in diagnosing FASD in the Fitzroy Valley, Professor Elizabeth Elliott commented:

as we know with any complex chronic disorder, it is much more efficient, effective and supportive for clinicians if there is a trained diagnostic team who can work together and at the same time. It facilitates communication and saves time and cost. It is very supportive for people, particularly working in remote settings, where otherwise they might be by themselves. It is efficient in that, having put together and discussed everyone's findings, we are able to make a diagnosis and develop a management plan. In that particular study, we fed back immediately to parents and carers, teachers and health professionals and then provided the information to go into the electronic medical records.⁴¹⁶

8.6 Implementation of a diagnostic model in the Northern Territory poses considerable challenges due to the difficulties associated with achieving service delivery in remote areas. It is more difficult to recruit and retain staff, and service delivery costs are higher, particularly given that diagnosis of FASD is complex and requires input from a range of specialists. Multi-disciplinary teams that visit communities are considered to be an efficient and cost effective means of ensuring that a comprehensive diagnostic service is available where it is needed.⁴¹⁷ As Professor Elizabeth Elliott notes:

From the Northern Territory's point of view, if you are looking at a diagnostic capacity, it would be very valuable to have a team of people who could work together, who were trained together and who could visit communities and efficiently examine children and come to a joint conclusion about a FASD diagnosis, or not, and an appropriate management plan.⁴¹⁸

8.7 In addition, such teams have the potential to treat children with other disorders on the same visit and would reduce communication barriers that may arise from having sequential visits from different specialists. As Professor Elizabeth Elliott further points out:

It would be a cost saving to government to run paediatric services in remote areas using those types of teams. If you have an occupational therapist coming in one week, a physiotherapist the next week and a paediatrician the next week it is extremely difficult to communicate properly – and they are all overloaded. Furthermore, it is very difficult in remote settings to keep medical staff because of the problems of isolation. It is a very supportive way to work as well as an efficient way.⁴¹⁹

8.8 The most cost effective and efficient way of delivering diagnostic services in the Northern Territory needs to be determined. Options to consider include: establishing a multi-disciplinary diagnostic centre in a central location; a diagnostic centre which also includes mobile teams; and contracting of diagnosis services to mobile multi-disciplinary teams sourced from outside the Northern Territory. In

⁴¹⁵ AIHW Submission 8, 2014, p. 12.

⁴¹⁶ Professor Elizabeth Elliott Committee Transcript, 29 May 2014, p. 117.

⁴¹⁷ Committee Transcript, 29 May 2014, p. 117-118.

⁴¹⁸ Committee Transcript, 29 May 2014, p. 117.

⁴¹⁹ Committee Transcript, 29 May 2014, p. 118.

addition, consideration should be given to the potential for application of the *Lililwan* model in the Northern Territory.⁴²⁰

- 8.9 Whatever delivery model is chosen, a significant issue will be the training of staff. Dr Jo Wright noted that:

what is definite is that the clinical community in the Northern Territory, involving general paediatricians, psychologists and some of the other allied health workers currently does not have the skills necessary to actually perform the complex assessments required to recognise and diagnose some of the FASD features. For instance, there are workshops that are planned to be run by some of the Fitzroy Valley people in the Top End and central Australia. While it is not something that is being actively done to date it would certainly be a recommendation from me that we continue to develop our existing workforce to improve their ability to diagnose and intervene for this group.⁴²¹

Recommendation 1

The Committee recommends that the Department of Health develop a strategy for implementing the Australian FASD Diagnostic instrument, expected to be finalised in 2015. As part of that strategy development, the Committee recommends that the Department consider the cost effectiveness of multi-disciplinary paediatric teams.

Recommendation 2

The Committee recommends that the Government prioritise funding for early intervention services for FASD, including paediatric diagnosis, psychotherapy and other behavioural management measures, and early childhood support and education services.

Screening for Prenatal Alcohol Exposure

- 8.10 Screening of pregnant women for PAE enables health practitioners to provide targeted advice and support regarding use of alcohol in pregnancy and the follow-up of children at risk of FASD once they are born. This is particularly important given that early intervention is crucial for minimising the adverse effects of FASD, but without such screening many FASD affected children will not be noticed until after the age of three. Screening also identifies populations at risk of FASD and data collection on changes to that risk, which is necessary for the targeting and evaluation of programs.
- 8.11 Currently, the Northern Territory collects data on prenatal alcohol consumption at the first and 36 week antenatal visit. Data collection takes the form of a single question and does not provide scope for recording the extent and patterns of alcohol consumption. The Committee agrees with DoH that:

⁴²⁰ MSHR, Submission No. 15, 2014, p. 8.

⁴²¹ Committee Transcript, 29 May 2014, pp. 82-83.

100 per cent screening of alcohol consumption in antenatal visits should be the goal, using a consistent approach. Health professionals and other service providers engaging with pregnant women need to be supported to appropriately ask all women about their alcohol use and advise women in a supportive manner that not drinking is the safest option when pregnant or planning pregnancy.

DoH should ensure relevant staff are trained to deliver evidence based brief interventions and be aware of referral pathways and support services for women who consume alcohol in pregnancy.⁴²²

- 8.12 The Western Australian *FASD Model of Care* recommends that routine collection of data on alcohol use should be collected each trimester to “aid in the implementation of health promotion and prevention strategies, identification of high-risk pregnancies, and early intervention for both affected infants and women requiring referral for further management.”⁴²³ The Australian Institute of Health and Welfare’s National Maternity Data Development Project is developing nationally consistent perinatal data, including data on alcohol consumption.⁴²⁴ The Committee considers that the implementation of screening of all women for alcohol consumption during pregnancy in a manner that is culturally appropriate, therapeutically beneficial and assists with the national collection of data is a priority.
- 8.13 Barriers to asking these questions include the awareness of health practitioners, the stigma that can be felt regarding alcohol consumption during pregnancy, and sensitivity regarding reproduction and sexual health. Health practitioners need appropriate training and tools to address these barriers.
- 8.14 The Committee notes that training in appropriate interventions and referrals must also accompany such screening. The Committee affirms Dr Steven Skov’s comments regarding FASD diagnosis and considers them equally relevant for alcohol screening:

One of the issues that always comes back to bite people, if you are going to actively seek out cases whatever it is, is that if you cannot actually then offer that person something, then you find yourself in an ethical situation. You called this person - ‘You have got this but I cannot actually do anything for you’. From a health service perspective it is really super discouraging for health staff if they find themselves in that situation. They do not want to get in that situation. So you might have a good diagnostic tool, but health staff will not actually do the work to use it if they do not feel as though they can actually offer that person something.

So it is a good thing to talk about diagnostic tools and training staff, but at the same time we have got to make sure that if they do find cases of whatever it is that you are looking for, that we have got to be able to try and offer them something so that they can offer their patients something. Otherwise it is a fatal break in that system of trying to address an issue.⁴²⁵

- 8.15 These issues are further examined under “Health Workforce Development” below.

⁴²² DoH, Submission No. 9, 2014, p 15.

⁴²³ Department of Health (DoH), Western Australia. *Fetal Alcohol Spectrum Disorder Model of Care*, Perth: Health Networks Branch, Department of Health, Western Australia, 2010, p. 25.

⁴²⁴ J Walker, *Maternity data in Australia: A review of sources and gaps*, Bulletin No. 7, Cat No. AUS136, Canberra, AIHW, p. 4.

⁴²⁵ Committee Transcript, 29 May 2014, p. 86.

Recommendation 3

The Committee recommends that the Department of Health promote protocols for screening alcohol use during pregnancy with a view to raising awareness of the risks of alcohol, assisting expectant mothers with any alcohol issues, and collecting data in accordance with the Australian Institute of Health and Welfare's National Maternity Data Development Project.

Recommendation 4

The Committee recommends that protocols for screening alcohol use during pregnancy include guidelines for support and referral for women struggling with alcohol use during pregnancy, including information on relevant local support services.

Screening for FASD

- 8.16 Screening for FASD enables health practitioners to identify people who show symptoms of FASD, who may then be referred for diagnosis and support.
- 8.17 Screening can be conducted for all people or targeted to specific sub-populations.
- 8.18 Universal screening may be done for women during pregnancy; newborns; and early childhood or at enrolment in full-time education (age 4-6 years).
- 8.19 Targeted screening involves identifying sub-populations at high risk of the disorder. The Royal Australasian College of Physicians recommends that targeted screening be applied to:⁴²⁶
- All children discharged from a drug dependency service in any obstetric unit;
 - All children apprehended into child protection; and
 - All juveniles going through justice, into probation, community/first line sentencing.

Additional target groups cited in the Western Australian *FASD Model of Care* include: children of mothers attending alcohol treatment services, children referred to child development services for developmental delay, and children from regional areas and communities identified as having high levels of alcohol consumption.⁴²⁷

- 8.20 Given the importance of early intervention for minimising the effect of FASD the Committee considers that the screening of high risk populations for FASD to be a priority. The Committee is also of the view that DoH should assess whether the benefits of universal screening of FASD would outweigh the costs.
- 8.21 There is currently no uniformly accepted instrument for FASD screening in Australia and the new *Australian Diagnostic Instrument* will not include a screening

⁴²⁶ Education and Health Standing Committee, *Foetal Alcohol Spectrum Disorder: The invisible disability*, pp. 25-26

⁴²⁷ DoH Western Australia, *Fetal Alcohol Spectrum Disorder Model of Care*, p. 26.

component.⁴²⁸ In the absence of an Australian based FASD screening instrument, it is possible to apply a variety of screening tests used to detect (a) developmental delay in childhood and (b) behavioural and social/emotional difficulties in children, as these may be markers for FASD. A model for applying these tests in the FASD context can be found in the *FASD Model of Care*.⁴²⁹ FASD screening could also be included within the *Healthy Kids Under Five Program*. An adapted version of the *Ages and Stages Questionnaire* recently developed by Menzies for culturally appropriate use with Indigenous children in remote locations could also be considered.⁴³⁰

Developing and implementing such a system [surveillance and monitoring] would require careful consideration, planning across government agencies and a considerable investment in health professional training and workforce.⁴³¹

8.22 The Committee notes that it is particularly important that data collected through screening processes is clearly documented, and concurs with findings from the Western Australian Inquiry into FASD that:

There should be data linkage ability between government sectors. Such linkage should record, evaluate and share the health and other needs and service access of individuals with FASD.⁴³²

Recommendation 5

The Committee recommends that the Department of Health review options for screening for FASD, particularly targeted screening of high risk populations, having regard to the possible development of a national FASD screening instrument.

Health Workforce Development - Education, Training, and Resources

8.23 The antenatal interface is a critical site for harm minimisation, prevention, awareness raising, and data collection. It can contribute to harm minimisation by informing women of the risks associated with alcohol consumption and assist those who have difficulty abstaining by referring them to appropriate support services. Similarly, it can assist with prevention of FASD for future pregnancies even if the client is drinking in the current pregnancy, because it can facilitate protective factors such as contraception, increased knowledge, support to overcome alcohol dependency, and other lifestyle changes. The antenatal interface is also the primary source from which to collect data on alcohol use during pregnancy, with this being essential for monitoring and surveillance and for research into developmental origins

⁴²⁸ Professor Elizabeth Elliott, email communication, 24 October 2014.

⁴²⁹ DoH Western Australia, *Fetal Alcohol Spectrum Disorder Model of Care*, p. 24.

⁴³⁰ MSHR, Submission No. 15, 2014, p. 11.

⁴³¹ MSHR, Submission No. 15, 2014, p. 9.

⁴³² Education and Health Standing Committee, *Foetal Alcohol Spectrum Disorder: The invisible disability*, p. 30.

of other longer-term diseases that may be related to foetal alcohol exposure.⁴³³ The effectiveness of the antenatal interface is influenced by a range of factors including:

- The extent to which staff are well-informed and knowledgeable about alcohol use and FASD;
- The provision of clear guidelines and appropriate training to assist staff to manage this interface effectively;
- The extent to which staff have the knowledge and capacity to know when and where to refer clients who may need additional support;
- The provision of resources to assist staff to increase clients' knowledge and understanding of the link between alcohol and FASD; and
- The extent to which staff understand the importance of accurately recording information about alcohol use in pregnancy.

8.24 Both Menzies School of Health Research and DoH have commented on the incompleteness of the data recorded at antenatal visits, while Danila Dilba Health Service has commented on the need to 'develop a performance measure for antenatal care, relating to alcohol screening at first antenatal visit for inclusion in child and maternal health data sets'.⁴³⁴ This should also 'enable the separation of Aboriginal and non-Aboriginal data' as this would improve 'the knowledge base about alcohol consumption during pregnancy'.⁴³⁵ In addition, it is clear that many health workers are not comfortable with asking pregnant women about alcohol use, have insufficient knowledge of the NHMRC Guidelines on Alcohol Use, and have little knowledge of FASD or of strategies for its prevention and management.⁴³⁶

8.25 In the short term, there is an urgent need to address knowledge and skill gaps in the antenatal workforce and to ensure that staff commencing work in this area are appropriately trained with respect to alcohol use and FASD. It is particularly important that staff are provided with strategies for overcoming barriers, such as stigma, associated with discussing alcohol use, and have the capacity to effectively:

- Discuss the risks associated with alcohol use during pregnancy;
- Identify the extent and patterns of alcohol use in pregnant women;
- Implement brief interventions as appropriate;
- Provide advice;
- Refer patients to relevant services (eg alcohol and drug services) as required; and
- Accurately and consistently record data on the electronic health record.

⁴³³ MSHR, Submission No. 15, 2014, p. 10.

⁴³⁴ MSHR, Submission No. 15, 2014, p. 10; DoH, Submission No. 9, 2014, p. 8; Danila Dilba Health Services (DDHS), Submission No. 5, 2014, p. 2.

⁴³⁵ DDHS, Submission No. 5, 2014, p. 2.

⁴³⁶ NIDAC, Submission No. 4, 2014 p. 15.

8.26 In addition to addressing skill gaps in the antenatal interface it will be important to ensure that current antenatal practice guidelines emphasise the importance of discussing alcohol use with clients. As NTCOSS has noted, information about the dangers of alcohol use during pregnancy are often crowded out by other health messages:

it is important that the FASD prevention message is not lost in amongst other issues such as smoking, nutrition and hygiene. When the impact of alcohol is presented alongside a long list of health messages, the important message about damage caused by alcohol in pregnancy can be lost.⁴³⁷

Similarly, the National Indigenous Drug and Alcohol Committee noted that:

In the context of antenatal care, alcohol was not on the list of priorities for many health professionals. Instead, issues such as smoking and diet were identified as more important.⁴³⁸

8.27 Chapter 3 noted that many health and medical workers lacked a sound knowledge of FASD and the effects of alcohol use during pregnancy. This needs to be remedied through the provision of education and training at multiple levels.⁴³⁹ This should include in-service training programs and inclusion of an alcohol and FASD related component in relevant undergraduate⁴⁴⁰ and post-graduate courses. This will facilitate better care for FASD affected individuals and increase the capacity of the workforce to provide effective service system responses. It will be important to ensure a consistent approach to the content provided in education and training courses. As Roche notes, the effectiveness of both health workers and service systems are mutually dependent and if the benefits of training and education are to be realised it will be necessary to complement improved workforce education with a review of relevant organisational systems to ensure they are adequate to the task of providing workers with better information, better record keeping procedures, and the development of systems for early identification and intervention.⁴⁴¹

8.28 DoH should undertake an audit of current professional development needs of the health workforce in relation to FASD and identify which health worker training and tertiary level courses would benefit from the inclusion of a module on FASD. Once gaps have been identified, a plan for remedying these gaps should be developed and implemented. While keeping a degree of consistency, presentation will need to be culturally appropriate and tailored to different levels of competence. Equally, it will be important to consult with experts in the field, health professionals and Aboriginal health organisations.

8.29 There are a range of areas which require workforce development, with the following being highlighted during the course of the Inquiry:

- Antenatal interface (understanding safe alcohol use, assessing and recording alcohol use, advice, brief interventions);

⁴³⁷ NTCOSS, Submission No. 18, 2014, p. 14.

⁴³⁸ NIDAC, Submission No. 4, 2014, p. 15.

⁴³⁹ NIDAC, Submission No. 4, 2014, pp. 15 & 18; APONT, Committee Transcript 29 May 2014, p. 27.

⁴⁴⁰ NIDAC, Submission No. 4, 2014, p. 15.

⁴⁴¹ AM Roche, 'Women, workers and systems change', p.73.

- Treatment and management of substance abuse during pregnancy;
- Identifying FASD (competent use of screening tools);
- Diagnosis of FASD (use of diagnostic instrument, skill building for different elements of diagnosis when performed as part of multi-disciplinary team);
- Skills in implementing treatment and management programs for children with FASD;
- Skills in supporting parents of children with FASD; and
- Facilitating social change in relation to alcohol use and FASD.

8.30 The FARE Action Plan notes programs developed in the USA and more recently in Australia.⁴⁴² There are also some excellent materials for Aboriginal communities, such as those developed by Anyinginyi Health Aboriginal Corporation.

Recommendation 6

The Committee recommends that the Department of Health undertake an audit of current professional development needs of the health workforce in relation to FASD and develop a plan for ensuring an adequate level of awareness of FASD.

Early years support

8.31 Early childhood programs, such as the Nurse Family Partnership Program and the Abecedarian model of educational day care, are a 'best buy' because they have the potential to address health and social inequity and break the cycle of harmful alcohol use over the long term. This view has substantial support from the research sector, with CAACAC noting that many studies have identified a 'link between poor development in the early years and the subsequent development of addictions and other life-long problems'.⁴⁴³ One study noted that, in disadvantaged populations, harmful alcohol consumption is related to a dangerous feedback loop:

harmful alcohol use by parents and carers is known to be associated with a lack of responsive care and stimulation in early childhood; children brought up in these environments are more likely to lack self-control and self-regulation as they grow to adulthood themselves, and will therefore be more susceptible to addictions, including to alcohol; they will be, in turn, less likely to provide their own children with the care and nurture they need. This cycle is reinforced by emerging evidence that every generation born to parents with an alcohol addiction is more genetically predisposed to an addiction.⁴⁴⁴

8.32 Professor Sven Silburn also outlined the importance of the first three years to the Committee:

we are particularly interested in the early years of a child's development, in the years before they go to school, because almost 80 percent of their brain mass

⁴⁴² FARE, *Action Plan 2013-2016*, pp. 29-30

⁴⁴³ CAACAC, Submission No. 24, 2014, p. 8.

⁴⁴⁴ CAACAC, Submission No. 24, 2014, p. 9.

will have developed by the time they enter school. The environmental conditions during that time of most rapid brain development have lifelong implications and all the current research is showing that this period of life is much more important in determining how children will do in their life, for example, how they are going to manage school and how they are going to develop in terms of their behaviour and wellbeing. The work that is happening through the education system where schools are now reaching out to families before children arrive at school through programs like Families as First Teachers is a very important mechanism for engaging with parents of very young children to give them the knowledge and skills that they need to successfully rear their children.⁴⁴⁵

8.33 This view was supported by comments from DoH:

One of the most promising is in the early childhood development area. There is a concept known as early childhood visiting, which is something that developed in the United States. Essentially the concept is that there is support provided for young families and young families who are particularly having difficulties whether it is social economic difficulties or just struggling with life in general. If you can provide support to those young families to help them deal with life, then it has been proven that you can have benefits for those children, the children in those families, in terms of better school performance, less involvement with alcohol and other drugs, less involvement with the criminal justice system as they go through their life.⁴⁴⁶

8.34 CAACAC expressed concern that despite strong evidence that early childhood programs for children aged zero to three can have a significant positive impact, there is a major gap in funding for this age group:

there is not enough investment in that space. Federally, there has been investment into preschool, and that is a good thing, but at the end of the day if we do not get in any earlier we are actually not preparing our kids on that trajectory of doing really well. So yes, we are advocating that we need to get more investment from nought to three.⁴⁴⁷

8.35 Danila Dilba noted that initial evaluation of the Family Nurse Partnerships Program was showing positive results for early care of children, including reduced rates of alcohol and drug use among mothers and, over time, among children born to those mothers and recommends that the Northern Territory Government take advantage of the Commonwealth Government's plans to expand the program.⁴⁴⁸

8.36 Improving support for the first years of children of at risk populations would improve long term social outcomes generally and, given the gaps in diagnostic and screening services, help improve the outcomes for FASD children. In this regard the Committee received positive feedback about the Family as First Teachers Program as a program to assist with early childhood targeting remote communities, Abecedarian day care as a proven aid to early education, and the Family First Nurse Partnership Program as an effective support for new mothers.

⁴⁴⁵ Committee Transcript, 29 May 2014, p. 5.

⁴⁴⁶ Committee Transcript, 29 May 2014, p. 80.

⁴⁴⁷ Committee Transcript, 1 August 2014, p. 90.

⁴⁴⁸ DDHS, Submission No. 5, 2014, p. 11.

Recommendation 7

The Committee recommends that the Government improve support for caring for children in the first years, particularly for at risk populations, and:

- a) expand the Family as First Teachers Program;**
- b) explore options for promoting early childhood education programs, such as Abecedarian day care, across the Territory; and**
- c) explore options for improving support to new mothers, including the Family First Nurse Partnerships Program.**

The Education System Interface

8.37 Effective management of FASD within the education system is influenced by: the extent to which children with FASD have been formally diagnosed; teachers and support staff trained in strategies for teaching children with FASD; the availability of resources to assist teachers develop appropriate teaching strategies; and the availability of resources to develop the types of programs required by FASD students. Inter-agency communication is also essential to ensure that where a pre-school child has been diagnosed with FASD that this information is passed on to the DoE prior to the child starting school.

8.38 According to statistics from the DoE, Territory schools only have 27 students with a formal diagnosis of FASD. These students are supported through the same model of care provided to other students diagnosed with disabilities, which means they receive professional advice and have access to disability funding. FASD affected students are also provided with Educational Adjustment Plans and Learning and Engagement Plans which 'include explicit goals focussed on appropriate curriculum'.⁴⁴⁹ However, as noted in the Department of Education's submission:

Anecdotal evidence coupled with the Northern Territory's high alcohol consumption rates and the recent attendance strategy, [Remote Schools Attendance Strategy] suggests there are many undiagnosed students in Northern Territory schools exhibiting the learning and behavioural characteristics of FASD.⁴⁵⁰

8.39 This means that teachers currently have to manage significant numbers of students who are likely to have FASD without the support provided for children with a formal diagnosis. In the long term, this situation can be remedied by the implementation of an effective screening and diagnostic program to ensure that children with FASD are identified before they start school and that schools are informed accordingly. In the short term, there are still a number of strategies which can be implemented to facilitate better educational outcomes for these students, whether formally diagnosed with FASD or only suspected of having a FASD condition.

⁴⁴⁹ DoE, Submission No. 16, 2014, p. 2.

⁴⁵⁰ DoE, Submission No. 16, 2014, p. 2.

8.40 Research on the Canadian experience of addressing FASD in education settings has found that key issues which need to be addressed include:⁴⁵¹

- FASD related professional development training for people working in education, including principals, teachers, education assistants and Aboriginal and Torres Strait Islander education officers;
- The provision of specialist support services to students with FASD; and
- Close collaboration between education departments and diagnostic services (when they exist) so that an appropriate support system can be developed immediately after diagnosis.

8.41 Although development of materials for teachers to use in schools is only in the very early stages in Australia, a range of resources have been developed in Canada and the USA that can be adapted to the Australian context. Examples of these resources include:⁴⁵²

- *Special Education Services: A manual of policies, procedures and guidelines* (British Columbia Ministry of Education, 2011);
- *Teaching students with Fetal Alcohol Spectrum disorder : Building strengths, creating hope* (Alberta);
- *K-12 FASD Education & Prevention Curriculum* (National Organization on Fetal Alcohol Syndrome); and
- *Teaching students with Fetal Alcohol Spectrum Disorders: A resource guide for Florida Educators* (Florida State University Center for Prevention and Early Intervention Policy, 2005).

8.42 Current management of FASD in Territory schools is impeded by under-diagnosis and a shortage of staff with the necessary expertise to identify and teach students with FASD behaviours. At present there appears to be scope to improve the former through better data linkage and information sharing between DoH and DoE. Similarly, there are opportunities for increased collaboration in relation to program partnerships and joint case management that are not currently being utilised.⁴⁵³ For example, there should be protocols to ensure that DoE is notified, when possible, of FASD cases or formal FASD diagnoses are made by a health provider. Current methods for notification of hearing health issues could provide a model for the development of these protocols.⁴⁵⁴

8.43 The Department of Education has recently started to address the need to increase staff skills in relation to FASD through implementation of the initiatives set out below:⁴⁵⁵

⁴⁵¹ FARE, *Action Plan 2013–2016*, p. 35.

⁴⁵² FARE, *Action Plan 2013–2016*, p. 35.

⁴⁵³ DoH Submission No. 9, 2014, p. 17.

⁴⁵⁴ DoE, Committee Transcript, 29 May 2014, p. 114.

⁴⁵⁵ DoE, Submission No. 16, 2014, pp. 4-5.

- Signing an agreement under the Stronger Futures Northern Territory Partnership to develop training, resources and teaching strategies and to provide small grants for the intervention and support of FASD in the NT;
- Plans to develop a FASD webpage with resources and information for the community and for teachers in both government and non-government schools;
- The provision of a unit on FASD as part of a current special education online course;
- A comprehensive NT specific educational package for schools to assist in the support and management of FASD students; and
- The formation of an informal cross-agency reference group with representatives from Menzies School of Health Research, DoH and DCF.

Recommendation 8

The Committee recommends that the Department of Education implement and strengthen its initiatives to address the needs of students with FASD, including the delivery of strategies, training and resources for teaching students with FASD and the establishment of a formal FASD reference group.

The Justice and Child Protection Interface

- 8.44 Without intervention, individuals with FASD will continue to pass in and out of the criminal justice system with their vulnerabilities unnoticed, each interaction bringing them no closer to the support that they require to enhance their quality of life and live productively. Lack of targeted support in the child protection system will result in similar outcomes for individuals and families living with the effects of this disorder. Putting aside costs to the individual and family, FASD will also continue to place pressure on the broader Northern Territory community and service providers in these sectors.
- 8.45 Submissions from government departments in the Northern Territory indicate that there has been some discussion around inter-agency collaboration and a small number of FASD specific projects have been implemented.⁴⁵⁶ An Inter-Agency FASD Working Group consisting of DoH, DoE, DCF and the Menzies School of Health Research has been established to promote information sharing across agencies. None of these initiatives, however, are targeted at supporting FASD individuals through specific engagement with child protection or the criminal justice system.
- 8.46 Suggestions for better management of FASD in these areas have focused on three main themes:

⁴⁵⁶ DoH, Submission No. 9, 2014 p 17; DCF, Submission No. 14, 2014 p. 9; DoE, Submission No. 16, 2014, p. 4.

- Establishing a multi-disciplinary diagnostic service and referral pathways linked to the courts, correctional system and child protection services;
- Developing intensive, behavioural management programs for FASD individuals linked to the justice system and child protection and coordinated by a centralised case management model; and
- Educating workers in the criminal justice and child protection sectors about general features of FASD and best practice strategies for management.

Diagnostic services

8.47 Diagnosis of FASD is the critical starting point if individuals affected by the disorder are to have their cognitive impairments recognised and appropriately managed by the criminal justice and child protection systems. Submissions from stakeholders working in both of these areas strongly support the development of collaborative programs with health professionals to achieve this end.⁴⁵⁷

8.48 As discussed earlier in this chapter, best practice from other jurisdictions indicates that diagnostic services which incorporate multi-disciplinary teams of professionals from health and allied services are highly effective. Similar models may be applied to aid FASD individuals in receiving appropriate treatment through the criminal justice and child protection systems.

8.49 One approach raised in submissions is the establishment of a diagnostic service for mental illness and cognitive impairment in Northern Territory courts to ensure that FASD impairments are recognised and accorded treatment. As Mr Blair McFarland from the Central Australian Aboriginal Youth Link Up Service observed:

The easier access to that sort of diagnosis - and it cannot often happen on the spot in a busy courtroom - the knowledge there was an avenue to explore that when it was suspected would make a really big difference from the outset to practitioners, the court and looking towards ultimate dispositions.⁴⁵⁸

8.50 Similar services linked to the summary jurisdiction in New South Wales, Queensland, Western Australia, Victoria and Tasmania allow the court to direct offenders with a known or suspected mental health or cognitive impairment to private clinicians, government services or community based support programs for assessment.⁴⁵⁹ These providers may then report to the court and suggest individually tailored options to include in court orders after a discharge due to unfitness to plead or in relation to bail, sentencing and parole. The service is usually linked to a special list to which matters may be referred in the course of ordinary court business for hearing on a later day. Importantly, this provides the court with

⁴⁵⁷ NTCOSS, Submission No. 18, 2014 p. 15; Ms Prue Walker, Submission No. 17, 2014, p. 34;

NAAJA/CAALAS, Submission No. 21, 2014, p. 7; ASCC, Committee Transcript, 1 August 2014, p. 41.

⁴⁵⁸ Committee Transcript, 1 August 2014, p. 29.

⁴⁵⁹ Mental Health Court Liaison Service, Magistrates Court Diversion Program and Court Referral of Eligible Defendants into Treatment (Victoria); Court Integrated Services Program (NSW); Queensland Magistrates Court Referral Program; Youth Supervised Treatment Intervention Program, Supervised Treatment Intervention Program and Pre-Sentence Opportunity Program (WA); and the Magistrates Court Diversion List (Tasmania).

the opportunity to obtain a confirmed diagnosis for FASD individuals and opens the door to appropriate treatment programs in the community, secure care facilities or prisons which specifically address their impairments.

- 8.51 A program of this nature could be connected to a multi-disciplinary FASD diagnostic service to which offenders may be referred. In the Magistrates Court of Victoria for example, the Assessment and Referral Court List (ARC) employs four social workers and number of neuropsychologists and forensic psychiatrists from the private sector. Clinical staff provide a diagnostic assessment for offenders with a mental illness or cognitive impairment who are referred to the program from the Magistrates Court. Drawing on this assessment, the offender, the magistrate and an appointed ARC social worker meet and develop a treatment plan linked to government and community services. Progress is monitored through monthly meetings across the 12 month program, all of which take place in a less formal court environment. A service based on this model could be utilised outside of the court environment by NT correctional services through referrals from the Family Responsibility Centre, other community based programs linked to community corrections and prison staff generally. Child protection staff may also refer clients to the service if FASD is suspected during the assessment phase.
- 8.52 In Canada, links to diagnostic services have enabled some courts to develop a set of 'flags' which suggest an individual is FASD affected and prompt referral by legal practitioners, judges and other court personnel. In the Youth Justice Program in Manitoba, these markers include a repeated history of failure to comply with court orders, an inability to connect actions with consequences, participation in opportunity crimes, superficial relationships and friends and a failure to be affected by past punishments. This initiative may be considered in conjunction with the establishment of a court-based service, however care should be taken in developing flags that reflect diagnostic experience in the Australian context.

Recommendation 9

The Committee recommends that a multi-disciplinary diagnostic service is established to which child protection workers, legal practitioners, judicial officers and correctional staff may refer individuals suspected of having a cognitive impairment such as FASD. The service should be linked to government and community based treatment programs.

Recommendation 10

The Committee recommends that the multi-disciplinary diagnostic service maintain data on the prevalence of FASD individuals in contact with the criminal justice and child protection systems.

Implementing a case management model

- 8.53 Evidence to this Inquiry indicates that treatment available to FASD individuals and their carers in the Northern Territory is non-specific, uncoordinated and limited in duration. As a result, FASD sufferers function within the criminal justice and child

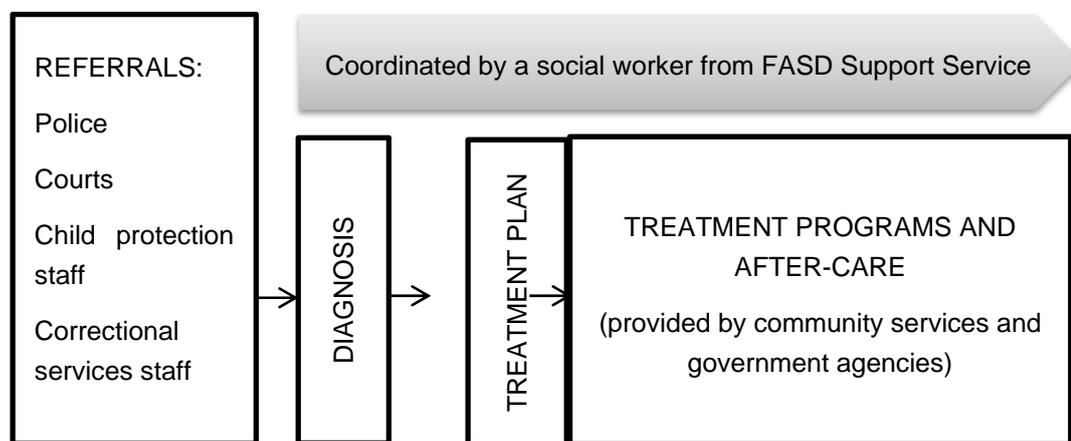
protection systems without an understanding of their condition or a plan for their treatment that is supported by community and government services.

8.54 Submissions from community based organisations and government agencies largely support the establishment of a body to coordinate access to these services within a case management model. Mr Kevin Bird from Anglicare explained the benefits of a coordinated approach linked to community services in relation to the Nhulunbuy community:

The difficulty of single agencies, whether they are NGO or government-based, still confounds communities. Who is turning up today? We are working with AOD, BSA, the NT and mental health. They come with us. If we are identifying behavioural issues or results of abuse issues, whatever they may be, we pass them on. To me, that is a good way to operate.⁴⁶⁰

8.55 FASD support services have been successfully implemented in Canada. There, social workers are assigned to an individual and family, develop a treatment plan, assist in accessing relevant services and provide ongoing monitoring and support. The Youth Justice Project in Manitoba and Youth Outreach Program in the Lakes District of Canada are individualised, outreach programs that provide intensive support to at risk youth through a Project Officer. The project officer in the Youth Outreach Program tailors a treatment plan to each offender, connects them to services from different agencies and organisations and supervises their progress. The goal of the program is to reduce recidivism and provide a supported reintegration into the community.

8.56 A similar FASD support service could be established within DoH and operate using components from these programs, expressed in the following diagram:



8.57 Agencies and organisations that could collaborate to provide case management based on the above models include:

- Department of Children and Families;
- Department of Health (Remote Health Teams);

⁴⁶⁰ Committee Transcript, 7 November 2014, p. 11.

- Department of Attorney General and Justice;
- Community health organisations (e.g. Danila Dilba, Anyinginyi); and
- Other community outreach services (e.g. Barkly Youth Services).

8.58 The service could be linked to FASD individuals at the following stages in the criminal justice and child protection systems:

- Child protection – suspected FASD children could be referred to the service for assessment and diagnosis. Treatment programs could also be incorporated into DCF case management for families;
- Interactions with police – police personnel could make referrals to the service where contact is made with a suspected FASD individual;
- Criminal proceedings – judges, magistrates and legal practitioners could refer individuals to the multi-disciplinary diagnostic service and FASD Support Service if discharged due to unfitness to plead/not guilty due to mental impairment or placed on a custodial supervision order;
- Sentencing – treatment plans coordinated by the FASD support service could be incorporated into sentencing as an alternative to incarceration;
- The correctional system – correctional services staff could refer suspected FASD inmates to the service for diagnosis and treatment options; and
- Parole and post-release – treatment plans linked to the FASD Support Service could be included in parole conditions.

8.59 The Committee is considering this issue from the point of view of FASD. It could be that such a service could best be delivered if it catered for mental disabilities and cognitive impairments more generally.

Recommendation 11

The Committee recommends that a FASD Support Service be established within the Department of Health to provide case management for FASD individuals and their carers through an appointed social worker.

Behavioural management programs

8.60 Whilst research into FASD intervention strategies with children is growing, information on appropriate interventions and treatment for adults with FASD is highly limited. This is particularly problematic as there is evidence to suggest that deficits attributed to FASD are enhanced during and after adolescence.⁴⁶¹

⁴⁶¹ C Rasmussen & K Wyper, 'Decision making, executive functioning, and risky behaviours in adolescents with prenatal alcohol exposure', *International Journal on Disability and Human Development*, 6, 2007, pp. 405-416.

8.61 A number of submissions have nevertheless suggested that treatment approaches incorporating supervised care are more appropriate for FASD individuals interacting with the justice system. Adults with FASD require high levels of support and assistance due to their disabilities, with one longitudinal study finding that 83 percent of FASD affected individuals over the age of 21 years are unable to live independently.⁴⁶² Accordingly, programs that divert offenders away from the justice system are likely to be more effective in reducing recidivism and arming FASD individuals with the tools to live a productive and stable life if they incorporate supervised care.

8.62 Mr Mark O'Reilly explained the potential benefits of the Alice Springs Disability Services secure care group home for his clients:

So you have got eight beds across the Territory that I am aware that cater for people who are potentially affected by FASD and other cognitive impairments and it is a situation that allows people a much better quality of life ... the people out there at the moment are getting regular day release. They will visit the community. They will be under constant care, but they are housed within this secure facility that lets family come in, that lets them visit family, that actually implements behavioural management plans so that people are progressing their ability to function in the community.⁴⁶³

8.63 There is limited research available on the benefits associated with these court based assessment and treatment programs for the mentally and cognitively impaired. In a 2012 report, the NSW Law Reform Commission nevertheless concluded that such 'diversionary' programs are largely beneficial for individuals and the criminal justice system. A potential decrease in reoffending, greater protection of human rights, therapeutic benefits for individuals and cost savings in comparison to incarceration were all identified as positive outcomes.⁴⁶⁴ Submissions from NAAJA and CAALAS support this, indicating that the cost of implementing these programs is likely to 'quickly pay for itself' in light of the increasing costs of incarceration in the Northern Territory.⁴⁶⁵

8.64 To be effective however, any court ordered treatment program in secure care facilities must involve continued collaboration with community organisations and government agencies, particularly in providing 'after-care'. 'After-care' refers to ongoing support in the form of intensive case management which is required for FASD individuals to improve their quality of life and avoid reoffending after they complete treatment programs and return home to communities. One successful model is the Barkly Youth Services 'At-risk' program which targets individuals aged 10-17 years at risk of contact with the criminal justice system in the Tennant Creek area. Staffed by five local social workers, the program includes:

- Intensive individual case management including after-care support;

⁴⁶² Streissguth et al, *Understanding the occurrence of secondary disabilities*.

⁴⁶³ Committee Transcript, 1 August 2014, p. 29.

⁴⁶⁴ NSW Law Reform Commission, *People with cognitive and mental health impairments in the criminal justice system – Diversion* (Report No 135), 2012, pp. 29-40.

⁴⁶⁵ NAAJA/CAALAS Submission No 21, 2014, p. 10.

- Case workers to coordinate access to relevant government and community services for treatment and holistic wellbeing;
- An alternative learning program incorporating approaches to numeracy and literacy beyond mainstream schooling;
- A counselling and mentoring service for individuals and their extended family; and
- Strong links with Indigenous community leaders.

8.65 For this approach to succeed in the Northern Territory, however, more secure care facilities for the cognitively and mentally impaired will need to be available for referral to programs by the courts. As discussed in Chapter 4, at the time of this report the Disability Services Secure Care group home in Alice Springs is the only facility available to service these needs in the NT and only accommodates up to 8 adults at any one time. Anecdotal evidence suggests that adequate care facilities are urgently needed in the Northern Territory and would be critical to the effectiveness of a court based screening service, as one criminal lawyer observed:

I think if there were expanded resources within the community to actually house people appropriately that would be a huge step forward...

with the best will in the world courts might say, 'We need to do something for this person. We need to improve their situation and the consequence of that will be that it improves community safety,' but there is nothing and so people end up in gaol...⁴⁶⁶

8.66 Funding for the provision of additional secure care facilities and court based diagnostic services is accordingly vital to improving management of FASD.

Recommendation 12

The Committee recommends that additional funding be allocated to the development of more residential secure care facilities for the delivery of behavioural management programs to the cognitively impaired, including FASD individuals.

Recommendation 13

That the community based health organisations and social service providers be funded to provide evidence based behavioural management programs for FASD individuals. The programs should be linked to the FASD Support Service.

Awareness of workers in the justice and child protection systems

8.67 A strong recommendation emerging from submissions to this inquiry and recent parliamentary reports from other jurisdictions is the fostering of increased FASD

⁴⁶⁶ Mr Mark O'Reilly, Committee Transcript, 1 August 2014, p. 29.

awareness amongst stakeholders in the justice and child protection systems.⁴⁶⁷ This would entail developing resources and training programs to assist child protection workers, police, legal practitioners, court officers, judges and magistrates and correctional service personnel in identifying potential FASD affected individuals and utilising best practice strategies to support their interaction with these systems.

8.68 The benefits of enhanced FASD education are clear. Improved knowledge amongst these personnel is likely to enhance recognition and diagnosis of the disorder, ensuring that it is accounted for and opportunities are opened for appropriate treatment of an individual.

8.69 Some provinces in Canada have made significant headway in developing resources for professionals. Based on these resources, materials for different target groups could include:

- Police personnel – guidelines for detaining, questioning and managing FASD offenders in custody drawing on their particular vulnerabilities. Important areas for instruction could include questioning procedures that account for high suggestibility, allow a support person and incorporate concrete, simple and repeated communication with referral pathways. A good model is the *FASD Guidebook for Police Officers* developed by the Royal Canadian Mounted Police in conjunction with the University of Manitoba and the Asante Centre for Fetal Alcohol Syndrome (ACFAS).⁴⁶⁸
- Legal practitioners and court officers – instructions on how to identify FASD, communicate with clients and assist the court in supporting a FASD individual. Useful tools may include using a support person and providing model questions to use when communicating with a client and gauging their understanding and cognitive capacity for legal purposes. ACFAS has developed a comprehensive curriculum for training legal stakeholders in managing youth offenders with FASD in Canada. Content includes instructional videos from the perspective of a FASD individual, a current judicial officer and specialist FASD advocate and guide to referral pathways for probation officers.⁴⁶⁹ An instruction booklet developed by the Nogemag Healing Lodge in New Brunswick also contains practical tips for interacting with clients.⁴⁷⁰ These guides, tailored for legal professionals and caregivers of FASD affected youth, provide useful models for equivalent resources in Australia.

⁴⁶⁷ NAAJA/CAALAS Submission No. 21, 2014; NT Legal Aid, Submission No. 6, 2014; Standing Committee on Social Policy and Legal Affairs, *FASD: The Hidden Harm*; Education and Health Standing Committee, *Foetal Alcohol Spectrum Disorder: The invisible disability*.

⁴⁶⁸ Laporte et al, *FASD: a guidebook for Police Officers*, Royal Canadian Mounted Police, 2002, <<http://www.asantecentre.org/Library/docs/latestfasguide.pdf>>.

⁴⁶⁹ Asante Centre for Fetal Alcohol Syndrome, *FASD and Communication disability: Strategies for Youth in the Legal System – A Curriculum for Professionals working with Youth with FASD in the legal system (Participant's Manual)*, 2011.

⁴⁷⁰ L, Vitale Cox, *FASD-Implications For Legal Professionals (Police, Duty Council, Crown, Bench, and Restorative Justice) - FASD-Developing an Appropriate Response In The Justice System*, Nogemag Healing Lodge, New Brunswick, 2005.

- Judges and magistrates – information on identification, ‘FASD-friendly’ court communication, screening pathways and treatment based options for various court orders. This could be compiled as an information package for judicial officers in the Northern Territory. For example, the Western Australian Judicial Benchbook, *Equality before the Law* provides useful reference materials for judges and magistrates enabling them to identify FASD and address specific vulnerabilities. Information is included on screening and referral pathways, suggested communication techniques and special considerations when assessing culpability and gathering evidence from FASD individuals in court.⁴⁷¹
- Corrective services personnel – information about identifying potentially FASD affected inmates, screening pathways, managing the behaviour and particular vulnerabilities of FASD offenders and links to treatment programs both within and outside of the corrections system.

8.70 Resources and intensive training which incorporate similar features would be effective for case workers in the child protection system with an additional focus on parent and carer needs.

Coordination Systems

8.71 FASD services are provided by a number of government agencies and non-government organisations. FASD affected individuals are likely to access services from multiple sectors and it will be essential to ensure a high degree of integration across the range of departmental systems that impact on FASD outcomes. Ms Jodeen Carney, from DCF, described the challenges faced by her department and highlighted the importance of cross-sectoral coordination:

DCF is one of a number of agencies that families and children with FASD come into contact with. DCF on its own can provide, however, relatively limited responses to families. We are unable to effectively identify or respond to their addiction problems without assistance from drug and alcohol services, nor can we respond to the specific learning or behavioural needs of children diagnosed with FASD without advice from health or education services.⁴⁷²

8.72 A number of witnesses reflected on how a lack of coordination impeded the effective prevention and management of FASD. One example is poor information flows from the antenatal team to the postnatal team. As Ms Heather D’Antoine notes:

If a child has been exposed to alcohol prenatally it would be good to see that that information just slots across, so when they see the paediatrician or the speech therapist that information is right there in front of them, rather than trying to ascertain what happened back here. One of the things that showed up in the surveillance that was done nationally is that the average age of diagnosis is around three years of age. What you have is the exposure has happened here, and when the child presents at three because they are maybe not speaking

⁴⁷¹ Department of the Attorney General (WA), *Equality before the Law Benchbook*, 1st edition, November 2009, paras 4.1.8.1, 4.2.3.5 and 4.4.3.

⁴⁷² Committee Transcript, 29 May 2014, pp. 92-93.

properly or something like that, it is really hard to then backtrack. If you can have a nice flow of information that would be a really important starting point.⁴⁷³

8.73 DoH also noted the need for higher level coordination:

I would have to say there is not a lot of visible work happening between departments at the moment. There is plenty of work that happens at the level of clinicians and of services, but I do not think there is any strategic work happening between departments at the present time. There has been extensive work done with education and child protection and health over the years, but just at the moment I would have to say there is no specific agency.⁴⁷⁴

8.74 Information is collected by a variety of entities at various stages of a child's development as they interact with different service systems. However, in the absence of a deliberately planned system for integrating this information, there is a failure to record, share and utilise that data in a systematic and coherent manner. This contributes to significant systemic inefficiencies which have a major impact on the quality and timeliness of the services provided to FASD affected individuals and their families. In addition, the accumulated costs associated with 'backtracking' to find relevant information, must be significant for both government and non-government organisations.

8.75 Other barriers to coordination, such as a reluctance to provide other organisations with access to data, were also identified, with Mr Ken Davies from DoE noting that:

there is no doubt that if you operate at the Chief Executive level people will say, 'You should be doing that', but once you get down into agencies sometimes there are protocols around privacy and that sort of thing where barriers occur.⁴⁷⁵

Inefficient practices and procedures in government departments were also identified as an issue with Ms Jodeen Carney commenting that:

it is the case that not everything in every government department, ... is as good as it should be. There needs to be very clear language between bureaucrats and departments about what it is you are actually trying to do and how can we make it happen.⁴⁷⁶

8.76 Recognition of FASD as a significant issue is relatively recent in Australia and the current lack of an agreed diagnostic tool makes coordination difficult. For example, Ms Vicki Baylis from DoE commented that:

Health does share and has a precedent of sharing information with Education, but it predominantly starts with babies when they are born - around hearing. ... all newborns are checked for hearing. If there is any suspicion or any understanding we might have a child that is deaf or with a significant hearing impairment, immediately our team are also part of the small hearing team or a part of that conversation with families.

However, this does not currently happen in a seamless way for FASD, as Mr Ken Davies noted:

As Vicki is saying, we have existing protocols. If there was a recommendation that identification at a health clinic - that foetal alcohol syndrome was identified

⁴⁷³ Committee Transcript, 29 May 2014, p. 14.

⁴⁷⁴ Committee Transcript, 29 May 2014, p. 81.

⁴⁷⁵ Committee Transcript, 29 May 2014, p. 113.

⁴⁷⁶ Committee Transcript, 29 May 2014, p. 94.

as a possible issue early, even if it was not a full diagnosis - if that could be flagged with us in the same way [as] the hearing health issues are, then that would be a good start.⁴⁷⁷

- 8.77 Ms Jodeen Carney noted that the lack of standardised diagnosis was an impediment to cooperation between agencies:

I think the sharing of information is there. It is always obviously harder in reality than it is in theory, but it is there. I think it comes back to a problem of there not being a standardised definition. Anecdotally, a lot of people, either in our agency, others or in some NGO services - you would have heard this yourself, in people saying, 'Oh, that child has got FASD'. It may not be based on anything except instinctively knowing or an educated guess, but if we had a better starting point of a better diagnostic tool I think that probably would assist the information sharing.⁴⁷⁸

- 8.78 Several mechanisms for improving coordination and communication were flagged. DCF commented on the importance of protocols which they perceived as providing 'effective road maps for where agencies want to get to in terms of working together and solving a specific problem'.⁴⁷⁹ Ms Lee-Ann Jarret-Sims pointed out that protocols systematise the approach to particular children and allow different intervention points to be linked, and provided the following example:

[for] children in out-of-home care, if there is a diagnosis or a concern that there may be FASD or a developmental delay, there is a standardised process for getting that child assessed within Health departments. That flows on to what are the best interventions and supports for that child? How do we support and encourage that carer to care for that child? And what are the relationships then and the supports for the education system as that child moves through the system? It is about linking all of those intervention points for that particular child.⁴⁸⁰

- 8.79 Menzies School of Health Research highlighted the *Pre-birth to Four Initiative* as an effective means of overcoming silos and achieving genuine coordination and collaboration. This initiative, originally an offshoot of the Alice Springs redevelopment plan and led by Anglicare and the Desert Knowledge Centre, resulted in a 'collective impact group of all the non-government agencies and government agencies that provide services to children and families'.⁴⁸¹ This group developed a framework for collaboration that would enable issues which could not be addressed by a single organisation to be addressed as a joint endeavour, thus enabling better outcomes to be achieved overall. The group identified key areas for action and developed a set of performance indicators to determine whether all Alice Springs children were doing better developmentally by the time they reached age five. Professor Sven Silburn noted that:

[this] kind of initiative is a very good example of overcoming the silos between agencies. One of the artificial causes of those silos has been the way in which services have been funded between NT government funded services and

⁴⁷⁷ Committee Transcript, 29 May 2014, p. 114.

⁴⁷⁸ Committee Transcript, 29 May 2014, p. 94.

⁴⁷⁹ Committee Transcript, 29 May 2014, p. 95.

⁴⁸⁰ Committee Transcript, 29 May 2014, p. 95.

⁴⁸¹ Professor Sven Silburn, Committee Transcript, 29 May 2014, p. 12.

Commonwealth funded services. There has been an absolute patchwork of separate agencies being funded to do certain things with an enormous amount of duplication and wasted resources.⁴⁸²

8.80 This initiative is a useful example of what can be achieved even in the face of external obstacles and indicates the benefits of improving coordination at a Territory wide level. However, it also points to the need for ongoing liaison with the Federal Government to ensure that the allocation of federal funds complements rather than duplicates Territory initiatives.

Recommendation 14

The Committee recommends that a high level FASD Working Group be established with representatives the Departments of Health, Education, Children and Families, Attorney-General and Justice, Corrections and Police, Fire and Emergency Services to develop and implement an action plan addressing:

- a) protocols for sharing information about persons diagnosed with FASD;**
- b) training and awareness of FASD and related referral options for health, teaching, child protection, police, justice and corrections professionals; and**
- c) continuity and coordination of FASD services.**

⁴⁸² Committee Transcript, 29 May 2014, p. 7.

9 Action to Prevent FASD

- 9.1 FASD is wholly preventable, inasmuch as avoiding alcohol prevents its occurrence. However, issues such as addiction to alcohol, ignorance of the dangers of alcohol and lack of awareness of a pregnancy make this simple solution difficult to implement.
- 9.2 While a pregnant woman's consumption of alcohol is a necessary factor in causing FASD, it is not the only determinant of whether a child will get FASD or the severity of any disability suffered. Other factors such as genetics and nutrition and perhaps the father's pre-conception drinking levels affect whether foetal exposure to alcohol will lead to FASD.
- 9.3 While there is no known safe amount of alcohol for a foetus, not all alcohol consumption, or even all heavy alcohol consumption, leads to a diagnosis of FASD. According to Australian Institute of Health and Welfare statistics, around half of Australian women drink while pregnant, and around 2 percent of pregnant women drink three or more drinks at a time.⁴⁸³ Most estimates of FAS in Australia have put the rate at less than 0.07 percent of births (there being no reliable estimates of FASD).⁴⁸⁴
- 9.4 The care a child harmed by alcohol exposure receives also affects the outcomes for the child. While the physical and neurological damage caused by FAE is permanent, the impact that damage has on a child can vary depending on nutrition, education and other environmental factors, particularly during the child's early years.
- 9.5 It is also acknowledged that while a pregnant woman's consumption of alcohol is the prime cause of FASD, that level of consumption is not only affected by that woman's choices. The availability of alcohol, family and community attitudes to alcohol, and the support the woman receives all have a significant impact on the foetus' exposure to alcohol. As Dr Steven Skov noted:

the alcohol consumption of pregnant women takes place within the alcoholic consumption of the whole society and it is extremely difficult to just pick on one particular group in the society and their alcohol consumption and hope to have a positive impact, when all the rest of society is continuing to drink with all the other influences that are still going on.

The evidence is quite clear about this, if you want to reduce alcohol related harms, the best way is to overall reduce alcohol consumption in the whole of the society. In relation to that, again, the evidence is quite clear. The most effective measures go to the price of alcohol, the availability of alcohol, as the two sort of best buys if you like. And secondly, there are interventions in terms of identifying people and offering them what we call brief interventions, some sort of counselling and support to get them to reflect upon their drinking. Broadly speaking the best measures go to supply and availability of alcohol and that has

⁴⁸³ AIHW, *Alcohol use: NDSHS 2013 key findings*, <<http://www.aihw.gov.au/alcohol-and-other-drugs/ndshs/2013/alcohol/>>.

⁴⁸⁴ Burns et al (eds), *Fetal Alcohol Disorders in Australia: An update*, p. 52.

been demonstrated throughout the world. It has also been demonstrated in particular in relation to Aboriginal people within Australia in a number of different settings, including in the Northern Territory, on a number of occasions.⁴⁸⁵

9.6 A woman's ability to control conception can also reduce the incidence of FASD. Unknown pregnancies run a higher risk of alcohol exposure, as do unwanted pregnancies, where the woman may not consider that she has the necessary resources or support to manage any alcohol issues.

9.7 Measures to help prevent FASD can therefore occur at many levels, including:

- Reducing community wide harmful alcohol consumption through supply and demand control measures;
- Reducing the alcohol consumption of pregnant women; and
- Improving family planning.

Reducing harmful alcohol consumption

9.8 The Northern Territory has a mixed history in managing harmful alcohol consumption. It continues to have the highest alcohol consumption in Australia, which is a country with one of the highest consumptions in the world. Also, because there is a high level of abstinence from alcohol, particularly in the Indigenous population, these average figures hide the fact that a significant portion of the population uses alcohol at very harmful levels. A study estimated that alcohol misuse cost the Northern Territory \$642 million in 2004-05, or \$4,197 per adult, more than four times the national cost of \$942 per adult⁴⁸⁶ and the impact of such high abuse is also reflected in a higher proportion of alcohol related deaths (3.5 times the national average) and over twice the rate of alcohol attributable hospitalisations.⁴⁸⁷ As noted in Chapter 4, FASD is also taking a significant economic, social, and personal toll in the Territory. As Skov and colleagues note, 'alcohol consumption and subsequent harm in the NT are at unacceptable levels and well in excess of those in Australia as a whole'.⁴⁸⁸

9.9 At the same time, the Northern Territory has implemented a range of alcohol management measures that have proved to be effective. The foremost of these was the LWA program, which saw a per capita alcohol consumption reduce from around 16 litres in 1992-93 to 14 litres in 1998-99.⁴⁸⁹ Although consumption rose after the program to over 15 litres in 2004-05, it resumed its decline after the introduction of the *Northern Territory Alcohol Framework* and has generally continued to decline since then, more recently, declining from 13.36 to 12.84 in the year to 2012-13.

⁴⁸⁵ Committee Transcript, 29 May 2014, p. 79.

⁴⁸⁶ Northern Territory Government, Commonwealth, House of Representatives, Inquiry into the Harmful Use of Alcohol in Aboriginal and Torres Strait Islander Communities, Submission No. 60, 2014, p. 3.

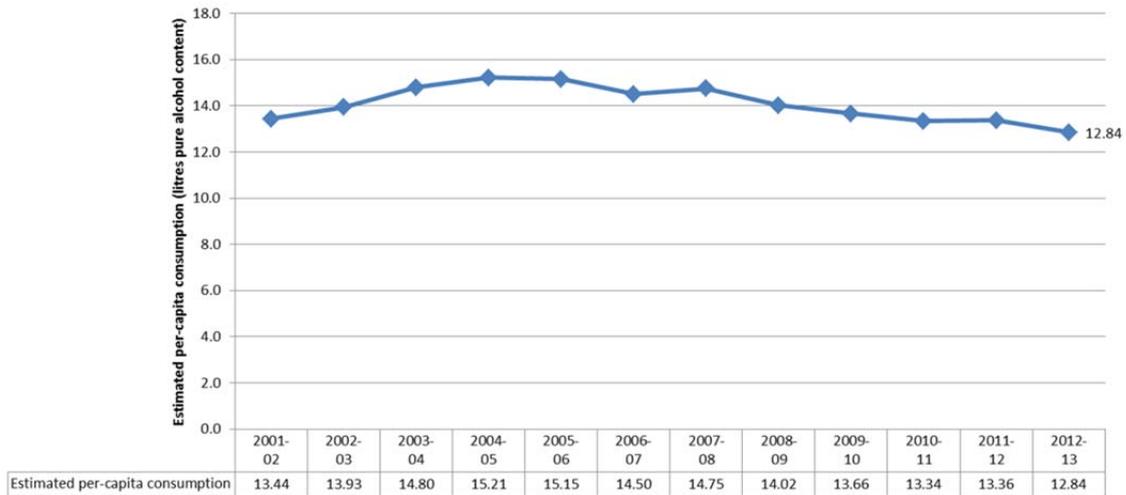
⁴⁸⁷ Skov et al, 'How much is too much? Alcohol consumption and related harm in the Northern Territory', *Medical Journal of Australia*, vol. 193, 2010, p. 271.

⁴⁸⁸ Skov et al, 'How much is too much?', p. 270.

⁴⁸⁹ Chikritzhs et al cited in Skov et al, 'How much is too much?', p. 271.

There is also evidence that some alcohol management measures are resulting in significant reductions in harms such as alcohol related violence.

Figure 14: Estimated per-capita consumption of alcohol in the Northern Territory by financial year



Source: Department of Business.⁴⁹⁰

9.10 The Committee did not specifically inquire into alcohol management. Nevertheless, its consideration of FASD highlighted the need for more to be done to reduce harmful alcohol consumption and it received evidence on the both the effectiveness of and issues with current measures. In particular, the Committee thinks that the Government should strengthen the coordination and scrutiny of alcohol policy, introducing a minimum floor price for alcohol, and continue to review its current measures and adapt them in light of the evidence of their effectiveness.

Strengthening the coordination and scrutiny of alcohol policy

9.11 Effective alcohol management requires a multi-faceted approach including supply reduction, demand reduction and harm minimisation strategies. Cross government coordination is required to ensure these different facets work together most effectively. Also, alcohol strategy requires balancing conflicting interests, as reducing consumption can involve reducing individual choices and liquor industry profits in order achieve other economic, health and social gains. Managing these conflicting gains require high level leadership, and public scrutiny and accountability.

9.12 The Committee considers that recent innovations need to followed up with public evaluation of their effectiveness. The net effect of recent measures has been an overall reduction in alcohol consumption and related assaults. Examination of available data suggests that some measures, such as TBLs, have been highly effective. It is important that lessons learnt from such successes are capitalised on. It is also important that the effectiveness of such programs does not mask the

⁴⁹⁰ Department of Business, *Wholesale Alcohol Supply to June 2013*.

possible ineffectiveness of others. The fact that alcohol related assaults have gone up in centres without TBLs, as outlined below, requires a close examination of what benefits are being obtained from measures employed in those centres.

9.13 The most effective alcohol strategy in the Northern Territory to date was the LWA program introduced in 1991. The LWA program had the objective of bringing 'levels of alcohol related harm in the NT down to the national level by the year 2000'.⁴⁹¹ It used a multi-faceted strategy, which included 'education, controls on alcohol availability and expanded treatment and rehabilitation services'.⁴⁹² The reforms implemented by the LWA program were underpinned by a new pricing system consisting of a levy on the sale of alcohol products containing more than 3 percent alcohol by volume. Proceeds from the levy were paid into a 'Living with Alcohol' Trust Account and used to fund program initiatives. The LWA program was considered highly innovative because:⁴⁹³

- It was based on a comprehensive and inter-sectoral strategic framework which brought together health, law enforcement and regulatory sectors and incorporated an explicit harm-minimisation objective;
- The Government committed to the LWAP for 10 years thus acknowledging the complexity of the problem and the need to quarantine the policy from short-term electoral cycles; and
- It included the imposition of a levy which ensured that alcohol related programs would receive a significantly higher level of per capita funding than corresponding programs in other jurisdictions (which was ceased in 1997 when the High Court found the Territory could not impose such a levy).

9.14 Several analyses suggest that the LWA program had a significant and positive impact on alcohol related harm in the Northern Territory,⁴⁹⁴ with Skov and colleagues noting that it resulted in:⁴⁹⁵

- Significant reductions to alcohol consumption – prior to the LWA program the PCAC in the NT was consistently about 20 litres of pure alcohol per year but by 1992-93 had reduced to less than 16 litres and by 1998-99 had reduced to less than 14 litres where it remained until 2000-01;
- Estimated reductions of 34 percent in alcohol related road fatalities; 23 percent in deaths from other acute conditions, and 28 percent for road crash hospitalisations in the 4 years after the commencement of the LWA program; and
- Savings to the NT economy of \$124 million in the 4 years to 1995-96.

⁴⁹¹ P d'Abbs, 'Alignment of the policy planets: behind the implementation of the Northern Territory (Australia) Living with Alcohol program', *Drug and Alcohol Review*, 2004, vol. 23, p. 56.

⁴⁹² P d'Abbs, 'Alignment of the policy planets', p. 56:

⁴⁹³ P D'Abbs, 'Alignment of the policy planets', p. 57.

⁴⁹⁴ D'Abbs, 'Alignment of the policy planets'; Chikritzhs et al, *The impact of the Northern Territory's Living With Alcohol program*; Stockwell et al, 'The public health and safety benefits of the NT's Living with Alcohol program', *Drug and Alcohol Review*, vol. 20, 2001.

⁴⁹⁵ Chikritzhs et al cited in Skov et al, 'How much is too much?', p. 271.

9.15 Although there is little doubt as to the efficacy of the *LWA* program, d'Abbs noted that much of its success was due to 'a remarkable alignment of agencies and actors in the political, fiscal, administrative and industrial domains. ... which owed as much to contingency as to planning and did not endure'.⁴⁹⁶ He identifies six key factors that contributed to this success as set out in Table 11 below.

Table 11: Key factors in implementation of the Living with Alcohol Program

Domain	Key Components
Parliamentary authority	Origins of LWAP in Sessional Committee of NT Legislative Assembly
Political (executive) authority	Political commitment of NT Chief Minister, Marshall Perron MLA
Fiscal foundation	Establishment of Living with Alcohol Trust Fund
Administrative capacity	Intersectoral collaboration among health, police and liquor licensing agencies
Liquor industry: producers	Common interests between LWAP and brewers in marketing 'light' beers
Liquor and hospitality industry: retailers	Acceptance by NT Branch of Hotels Association of the need to promote responsible serving practices

Source: d'Abbs.⁴⁹⁷

9.16 The Committee notes that per capita alcohol consumption rose, although not to the same extent, following the end of the *LWA* program but started to decline again with the introduction of the *Northern Territory Alcohol Framework* developed in 2004. This Framework:

provides a broad structure for Government, individual agencies, community interests, licensees and other industry participants to work together to regulate the use of alcohol in the Northern Territory and minimise alcohol-related harm to individuals and the community.⁴⁹⁸

9.17 The Framework identified seven mechanisms for achieving its aims:

- A coordinated whole of government approach to alcohol;
- Effective engagement with the community and business;
- Support for local and regional action on alcohol;
- Promotion of a culture of responsible alcohol use;
- Enhanced access to treatment and other forms of intervention;
- An effective system for control of the supply of alcohol; and

⁴⁹⁶ D'Abbs, 'Alignment of the policy planets', p. 55.

⁴⁹⁷ D'Abbs, 'Alignment of the policy planets', p. 57.

⁴⁹⁸ Parliament of Australia, *Bills Digest no. 28, 2007-08 – Northern Territory Emergency Response Bill 2007*, <http://www.aph.gov.au/Parliamentary_Business/Bills_Legislation/bd/bd0708/08bd028>

- Support for the liquor and hospitality industry to contribute to the aims of the Framework.

9.18 As outlined in Chapter 6, the emphasis of the Government's current action to address alcohol consumption is through the development of AMPs for individual communities, and mandatory interventions for nuisance drinkers through AMT and APO. These programs appear to be having some success in bringing down the rate of harmful consumption.

9.19 The Committee is concerned, however, at the lack of an overarching alcohol management framework to guide policy decisions and evaluate the effectiveness of existing programs. The Committee notes that the Department of Business' 2013-14 Corporate Plan has as a strategy "Develop and implement an Alcohol Policy..."⁴⁹⁹. However, its 2013-14 Annual Report indicates no progress in this area.⁵⁰⁰ While progress is being made through a range of individual initiatives, alcohol management is too great an issue for the Northern Territory to not have a high level whole of government coordination.

9.20 The Committee received a substantial amount of evidence identifying the importance of adopting a policy approach that incorporates the characteristics summarised in Table 12 below. These would provide a useful starting point for discussion in the event that a decision is made to develop an Alcohol Policy Framework.

Table 12: Key Components of an Alcohol Policy Framework

- | |
|---|
| <ul style="list-style-type: none">➤ A multi-faceted strategy rather than a series of isolated initiatives;➤ Coordinated action at national, jurisdictional and local levels;➤ Community and local government driven alcohol policy;➤ Take into account the social determinants of risky alcohol use when developing both individual and population level initiatives;➤ Use evidence based social marketing strategies;➤ Compulsory standards for alcohol promotion rather than a self-regulated model of alcohol promotion;➤ Develop specific prevention strategies for targeting to groups with different risk levels; and➤ Evaluate initiatives and interventions. |
|---|

9.21 There was a general consensus that a multi-faceted strategy should incorporate supply, demand and harm reduction strategies, with specific examples of the types of initiatives to be included under these domains set out below.

⁴⁹⁹ Department of Business, *Corporate Plan 2013-14*, p. 3.

⁵⁰⁰ Department of Business, *Annual Report 2013-14*, pp. 36-37.

- Supply reduction measures:
 - Minimum floor price;
 - TBLs;
 - Photo ID scanning at point of sale;
 - Reduction in trading hours; and
 - Reduction in number of liquor outlets.
- Demand reduction measures:
 - Targeted interventions, including voluntary and mandatory alcohol treatment;
 - Specialised drug and alcohol treatment services; and
 - Early childhood programs to support healthy development.
- Harm reduction measures:
 - Social marketing;
 - School education;
 - Brief interventions in primary and allied health settings;
 - Health warning labels on alcohol products ;
 - Regulation of alcohol advertising;
 - Sobering up shelters; and
 - Night patrols.

9.22 While the Committee notes that the complexity of alcohol abuse requires a wide range of responses, supply reduction measures have proven to provide the greatest benefits and the Committee considers that supply reduction should be the focus of attention.

Recommendation 15

The Committee recommends that the Government build on the Northern Territory's experience in tackling harmful alcohol consumption by developing an alcohol strategic framework that:

- a) Sets targets for reducing alcohol related harm;**
- b) Provides a mechanism for regular publication of performance data in meeting those targets;**
- c) Includes governance structures to ensure high level agency coordination and effective stakeholder engagement; and**
- d) Provides mechanisms for review of alcohol management programs in light of their performance.**

- 9.23 The Committee considers that the Assembly should also strengthen its role promoting greater alcohol management in the Northern Territory and scrutinising the performance of harm reduction measures.
- 9.24 Alcohol and other substance abuse is a major issue for the Northern Territory, and measures to address this issue have a significant impact across the community. It therefore merits the ongoing close attention of the Territory's elected representatives.
- 9.25 The Legislative Assembly previously had a committee to address alcohol abuse from 1989 until 2008. Establishing such a committee again would provide a public forum for the evaluation of alcohol control measures and consideration of what measures would best meet community expectations.

Recommendation 16

The Committee recommends that the Legislative Assembly establish a Standing Committee on Alcohol and other Substance Abuse to monitor alcohol management and supply programs and to inquire into strategies to reduce substance abuse.

Supply Reduction Strategies

Alcohol Management Plans

- 9.26 AMPs provide local communities with a mechanism through which they can tailor alcohol management strategies to their particular needs. They also provide an opportunity for government to work with local communities and develop local leadership potential.
- 9.27 Evaluations of AMPs report mixed results as to their effectiveness.⁵⁰¹ As noted in Chapter 7, a key factor for success is the level of community involvement in the development and management of the plan, with AMPs that have a relatively high level of community involvement demonstrating 'stronger and more sustainable outcomes than those developed and managed through a more 'top down' approach'.⁵⁰² The impact of AMPs is also likely to be enhanced where the full suite of supply, demand and harm reduction strategies are implemented rather than the more narrow focus on supply reduction.
- 9.28 Research suggests that if the full potential of AMPs is to be realised it will be necessary to address the following factors:
- Facilitate a 'bottom up' rather than a 'top down' approach;
 - Ensure that community involvement represents a wide range of interests including individuals, non-government organisations, the business sector and the alcohol industry;

⁵⁰¹ Smith et al, 'Alcohol management plans and related alcohol reforms', pp. 5-6.

⁵⁰² Smith et al, 'Alcohol management plans and related alcohol reforms', p. 6.

- Facilitate the implementation, not just the planning, of the full suite of supply, demand and harm reduction strategies;
- Ensure that the respective roles and responsibilities of government and the community are clearly set out; and
- Support the nurturing of local leadership in community members committed to dealing with alcohol related problems.

9.29 AMPs have the potential to be a valuable tool for combatting alcohol related problems due to their ability to tailor strategies to the specific needs of a community. However, the Committee notes that it will be important to take into account the factors identified above if their effectiveness is to be maximised.

Recommendation 17

The Committee recommends that the Government continue to support the development and implementation of Alcohol Management Plans and that these be evaluated on a regular basis to ensure their ongoing effectiveness.

Taxation Strategies and Minimum Floor Price

9.30 Chapter 7 reviewed several pricing mechanisms for reducing alcohol related harm. The Committee considers that a volumetric tax in conjunction with a minimum floor price would be the most effective pricing mechanism to use to reduce supply as it would prevent the effect of such a tax from being undermined by retailers through heavy discounting and product bundling. However, as only the Federal Government can institute a volumetric tax, the Committee encourages the Northern Territory Government to request the Federal Government to introduce such a tax.

9.31 The Committee found that a minimum floor price by itself would have a significant impact on the amount of alcohol consumed, particularly by those in high risk groups.

9.32 Evidence to the Committee, from both peak and individual non-government organisations, indicated that there is strong organisational support in the Northern Territory for a minimum floor price, particularly in the absence of other options such as a volumetric tax. One benefit of a minimum floor price is that it can be used to shift the preferences of risky drinkers from high alcohol content beverages to those which have a lower alcohol content. Research has also found that women reduce their alcohol consumption in response to price increases more than men, with this further suggesting its utility as a policy for reducing FASD.⁵⁰³ In their presentation to the Committee, the People's Alcohol Coalition noted:

if you make wine more expensive - at the moment, wine can be bought in Alice Springs, in some cases, for about 80¢ a standard drink. If you raise the price of each standard drink of wine by 50¢, up to \$1.30 which is what it costs to buy beer, people will switch to drinking beer. They will still spend every cent on

⁵⁰³ CA Dell & G Roberts, *Alcohol use and pregnancy: an important Canadian public health and social issue*, Public Health Agency of Canada, 2005.

beer, but they will be absorbing about 30% less ethanol into their bodies, so it will do some less harm.⁵⁰⁴

9.33 A minimum floor price would be relatively simple to implement, as Mr Goldflam from the People's Alcohol Coalition noted:

The Northern Territory could certainly lead the country by introducing a floor price – a simple amendment to the *Liquor Act* ... If you could not purchase a standard drink for less than \$1.30, we would reduce harms very substantially – just like that.⁵⁰⁵

9.34 The NT Branch of the Australian Hotels Association also considered that a minimum floor price had merit in the Northern Territory:

from a Territory perspective, which is not necessarily reflected from a national perspective, we do not have any issue with a floor price. When I go back to those people who just wake up to get drunk, one of the problems with that is they are going to go for the best bang for buck they can get. If they can get 10 standard drinks for the price of three standard drinks, they are going to buy the 10 standard drinks. That is what they are going to buy. To that end, we actually did a presentation a few years ago in Alice Springs. We, as an industry, are not against floor pricing.

That is certainly not the position in the national office, but they do not have our Territory issues, and we represent where we live. We represent our people and our community. We are members of the community before we are members of the liquor industry.⁵⁰⁶

Recommendation 18

The Committee recommends that the *Liquor Act* be amended to implement a minimum floor price ensuring that a standard drink would cost, at a minimum, \$1.30.

Limiting Trading Hours

9.35 In addition to the above, there was also strong support for strategies that limit trading times. The following view expressed by CAACAC was not uncommon:

The key to prevention of FASD are population level interventions that reduce heavy alcohol consumption amongst all men and women. These interventions include: an alcohol floor price of the price of beer; restrictions on takeaway trading hours, including a takeaway-free day linked to Centrelink payments; photo licensing at the point of sale with a Banned Drinker Register; and the restriction on late night trading through nightclubs.⁵⁰⁷

9.36 Targeted restrictions on trading times have proved to be very effective in a range of contexts and have been used in AMPs to prevent the sale of alcohol at strategic times.

⁵⁰⁴ Committee Transcript, 1 August 2014, p. 14.

⁵⁰⁵ Committee Transcript, 1 August 2014, p. 14.

⁵⁰⁶ Committee Transcript, 12 August 2014, p. 78.

⁵⁰⁷ Committee Transcript, 1 August 2014, p. 85.

Recommendation 19

The Committee recommends that the Government restrict the trading of alcohol at times when the greatest harm from alcohol consumption occurs.

Temporary Beat Locations

9.37 The Committee heard substantial evidence indicating the effectiveness of both the BDL, which has now ceased, and TBLs. Anecdotal evidence and early data regarding TBLs suggest that it is effective in reducing alcohol related harm and improving public amenity and safety.

9.38 The evidence obtained by the Committee suggests that TBLs are making a significant contribution to reducing harm from alcohol. Mr Eade, speaking for the Alice Springs Chamber of Commerce noted:

The TBLs, although they were not welcomed to start with - people found it an invasion of their privacy or their human rights. A lot of people say it is a racial act. In the scheme of things now, with the town the way it is, there is less violence, less domestic violence, it is a good move, especially with businesses because they are not being targeted for acts of vandalism etcetera. We were going through stages here where there were about six or seven businesses with their windows smashed every night. Now it is just about nil. It is very rare now, so that is a welcome change. It is good for tourism, it is good for everything else. People are accepting it. Some of the licensees still do not like it, but they can see the reasoning behind it.⁵⁰⁸

9.39 Similar views were expressed by CAACAC:

It is also worth noting at this point that the impact of the recent TBL strategy in Alice Springs has been very marked, and it is very likely this approach to supply reduction is having a major impact on reducing FASD. There are, however, concerns with this strategy, but it does have to be acknowledged that it is effective.⁵⁰⁹

9.40 CAACAC outlined further evidence for the effectiveness of TBLs:

We were looking at the impact that - what we have in Alice Springs now is a very effective supply reduction measure, which is the temporary beat locations, with police at takeaway outlets. There are concerns about that but it has been in full force since the end of February and we have seen publicly-reported data from police and from the hospital about a 50 percent reduction in assaults.

When you look at the data from our Safe and Sober program, at any one time it is treating around 200-plus people with an alcohol problem. One of the tools they look to use to measure consumption is a thing called time-line follow-back. For every client they see they ask how many standard drinks they had the week prior. I want to show you what we did. ... This is one graph where we analysed the data for the five months, March through to July this year, which is after temporary beat locations started, and looked at the same five months in 2013. What that graph shows is that in 2013, there were 80 clients who were drinking 50 or more standard drinks a week. In 2014, there are 30 clients drinking 50 or more standard drinks a week, at a population level. That is matched. This one looks at all clients in the previous week. You can see,

⁵⁰⁸ Committee Transcript, 1 August 2014, pp. 13-14.

⁵⁰⁹ Committee Transcript, 1 August 2014, p. 47.

again, between the two periods there is a massive shift to the left so that, in 2013, there many bits in the blue - there are many more clients have many more standard drinks in the previous week ...⁵¹⁰

- 9.41 The Committee also notes that in centres where TBLs have been introduced there has been a significant reduction in alcohol related violence, with police statistics showing a reduction in the 12 month period to September 2014 compared to the previous 12 months in the number of alcohol related assault of 21.9 percent in Alice Springs, 35.1 percent in Tennant Creek and 21.8 percent in Katherine. This contrasts to centres where TBLs have not been implemented, with a rise of 4.9 percent in Darwin, 8.7 percent in Palmerston and 36.9 percent in Nhulunbuy.⁵¹¹ This suggests that TBLs have been key to recent reductions in alcohol related harms, and without TBLs the Territory may have seen an increase in alcohol related violence.
- 9.42 The primary purpose of both the BDR and TBLs is the identification of individuals who attempt to buy alcohol while legally banned from doing so, either because they require a permit to drink and do not have one or because they are on the BDR or an APO, or, in the case of TBLs, they intend to drink the alcohol in a restricted area.
- 9.43 As highlighted in Chapter 7, the fundamental difference between the two mechanisms is the means used to make this identification. Disadvantages associated with the BDR include (a) the requirement that all people purchasing alcohol from take-away outlets had to present ID; and (b) that owners of take-away outlets were required to implement the program. Disadvantages associated with TBLs include (a) a perception that it is racially based; (b) issues with sustainability in the long term; and (c) lack of coverage across the whole of the Territory.
- 9.44 As with other alcohol management innovations implemented in the Territory, the maximum benefit can be obtained by identifying those elements found to be most effective and adapting them to contemporary and situational needs. The evidence presented to the Committee regarding the effectiveness of TBLs in reducing alcohol related crime in both Tennant Creek and Alice Springs make a compelling case that restricting who can purchase alcohol at the point of sale can be a highly effective measure.
- 9.45 Enforcement of point of sale restrictions will always come at some cost, whether that be borne by police (and passed on to taxpayers) or traders (and passed on to consumers). The challenge is to maximise the harm reduction (including social and economic cost) such measures can provide while minimising the cost of enforcement.
- 9.46 While TBLs appear to be providing significant benefits in places such as Tennant Creek and Alice Springs where there have been acute problems with harmful alcohol consumption, such a resource intensive approach would not be viable across the Territory. Further evidence is required on the effectiveness of point of

⁵¹⁰ Committee Transcript, 1 August 2014, p. 49.

⁵¹¹ Northern Territory Crime Statistics, < <http://www.pfes.nt.gov.au/Police/Community-safety/Northern-Territory-crime-statistics.aspx>>.

sale restrictions in areas with less acute problems and further development of options for reducing the cost of enforcement.

Recommendation 20

The Committee recommends that the Government:

- a) Conduct further analysis of the effectiveness of personal point of sale restrictions on purchasing alcohol such as the Temporary Beat Locations and the former Banned Drinker Register;**
- b) Develop options for reducing the cost of enforcement of such restrictions, such as only considering sales over a certain value; and**
- c) Implement personal point of sale restrictions where it is cost effective to do so.**

Alcohol Protection Orders

9.47 APOs play an important role in reducing alcohol related harm by prohibiting the consumption and possession of alcohol by people believed to have committed an alcohol related crime. However, they have been criticised for criminalising alcohol dependency rather than treating it as a medical condition. Questions have also been raised as to their efficacy, as individuals who breach an APO are not directed into treatment but can instead be charged and sentenced to imprisonment for up to three months. Responsibility for compliance with an APO is primarily placed on the individual and, to a limited extent, on police stationed at TBLs. Self-compliance is perceived as problematic as many people placed on an APO are likely to be alcohol dependent and have great difficulties controlling their drinking.

Demand and Harm Reduction

9.48 A key principle in best practice demand and harm reduction strategies is the implementation of policies that address the underlying social factors which predispose individuals to harmful use, as a clear link has been identified 'between socioeconomic deprivation and risk of dependence on alcohol, nicotine and other drugs'.⁵¹² This is particularly relevant to Indigenous Australians who experience significantly greater disadvantage than non-Indigenous Australians. In addition, service delivery to Indigenous Australians should be: culturally appropriate; tailored to local community needs; adequately and appropriately resourced; and include a high proportion of Indigenous staff. It is also important to deploy a wide range of demand and harm reduction strategies with key examples including: early intervention (eg early childhood programs); education and social marketing; treatment and rehabilitation; ongoing care; sobering up shelters; and night patrols.

⁵¹² Wilkinson and Marmot 2003 cited in Gray & Wilkes, 'Reducing alcohol and other drug related harm', p. 3.

Residential Treatment

9.49 The term 'treatment' covers a range of interventions such as screening, brief interventions, detoxification, and counselling approaches and can be carried out in either a residential or community setting.⁵¹³ PAAC noted that best practice treatments in the primary health care setting should include three key components:

medical care (including the use of pharmacotherapies), psychological care (including structured therapies such as Cognitive Behaviour Therapy) and social and cultural support (to help the client change the social context which is part of the reason that addiction occurs and is maintained).⁵¹⁴

The evidence also suggests that motivational interviewing techniques are effective in reducing risky alcohol consumption and increasing contraception.⁵¹⁵

9.50 Generally, non-residential treatment is more effective than residential treatment, except for clients with severe deterioration, social instability, and a high risk of relapse.⁵¹⁶ As Gray and Wilkes note, these characteristics are often found among Indigenous clients and therefore residential treatment may be the best option for this particular group. Residential treatment can be voluntary, part of a diversion program, or take place under the AMT legislation.

9.51 The Committee heard that while residential treatment has the potential to be effective over the long term, many clients find it difficult to access such treatment due to a lack of available facilities and other barriers. This is particularly likely to be the case for women with families. For example, Barkly Region Alcohol and Drug Abuse Advisory Group (BRADAAG) has only six beds for women and only one out of five houses is used for a family program, with this accommodating either one family or two single women with their children. Ms Bracken from Tennant Creek Women's Refuge spoke strongly on the need for more family rehabilitation facilities, as women who would voluntarily go into rehabilitation are discouraged from doing so because they do not want to leave their family with dysfunctional family members. Ms Bracken noted that:

It is often a barrier to a woman going into rehab that there is not the appropriate supportive facilities for pregnant women, for women with young children. They just do not want to abandon the children in order to go into rehab.⁵¹⁷

9.52 A further barrier for some women, particularly those who have been involved in alcohol abuse and violence over a long period, is the accumulation of a criminal history, which effectively debar a woman from participating in a family rehabilitation program.⁵¹⁸

9.53 There are sound reasons for enhancing the availability of family rehabilitation programs, with BRADAAG noting (a) that clients in family programs are more likely to complete a program than clients in individual programs and (b) that evidence

⁵¹³ Gray & Wilkes, 'Reducing alcohol and other drug related harm', p. 7.

⁵¹⁴ PAAC, Submission No. 23, p. 15.

⁵¹⁵ PAAC, Submission No. 23, p. 15-16.

⁵¹⁶ Shand et al 2003 cited in Gray & Wilkes, 'Reducing alcohol and other drug related harm', p. 7.

⁵¹⁷ Committee Transcript, 31 July 2014, p. 43.

⁵¹⁸ Ms Bracken, Committee Transcript, 31 July 2014, p. 43.

suggests these programs also 'reduce the long-term harmful effects for children when they are in their teens and twenties'.⁵¹⁹

- 9.54 Mr Casey Bishop, the manager of Venndale Rehabilitation, also noted the importance of having options for assisting families:

A conglomerate program, a comprehensive program, where it was family treated - I think CAAPS is the only one in the Territory. I believe they are successful in that – if you put aside FASD for a second, when dad gets out he is walking straight back into an atmosphere where he is just going to drink again, because nine times out of 10 where he is walking into is saying, 'Here you go, you can have one with us'. If mum and dad both know how to help each other then, obviously, you limit your chance of relapse.

If your children are a part of it as well - and for lack of better terms - monkey see, monkey do is eliminated as well. So, you are helping the adults to support each other, but you are also showing the kids that is not normal behaviour. From what we have seen and what our clients say to us, is they want to change their ways so their kids do not think what they do is appropriate, normal, or acceptable. I guess, without a doubt, combining and having a family approach is going to fit.⁵²⁰

Recommendation 21

The Committee recommends that the Government conducts a needs assessment for family rehabilitation facilities.

- 9.55 Evidence from witnesses suggests that the effectiveness of residential treatment is influenced by a range of factors apart from the client's readiness, including: length of time in treatment; the quality of transitional or after care; and location of the treatment facility.
- 9.56 Although some organisations may offer shorter or longer programs, most residential rehabilitation program last for three months. However, the time needed for the program to be effective often varies with the individual⁵²¹ and, as one witness noted, clients who have been caught up in an alcohol dependency cycle for a long period of time often require, and desire, a much longer program.⁵²² At the very least, such clients would require a lengthy period of support after the program has finished. Equally important is the need to assist those who have completed a program, into a more stable lifestyle and social context, one that will facilitate abstinence rather than relapse. Particularly important in this respect is the availability of alcohol free housing, the provision of employment assistance and social and cultural support. As Ms Bracken noted:

People are asking for a year and ongoing support after that. If you can put someone through rehab, whether they are pregnant or not pregnant, to spit them out at the end of the three months back into the same situation of a lack of housing, a lack of job etcetera, etcetera - it is asking them to fail. The peer pressure there is just extraordinary to drink and if you are not employed and you

⁵¹⁹ Committee Transcript, 31 July 2014, p. 28.

⁵²⁰ Committee Transcript, 29 July 2014, pp. 60-61.

⁵²¹ CAAPU, Committee Transcript, 1 August 2014, p. 106.

⁵²² Ms Bracken, Committee Transcript, 31 July 2014, p. 43.

are living with 15 other people who are drinking that is what happens. People get bored, they get disheartened and slip back into the same old cycle.⁵²³

Alcohol dependency is a chronic relapsing condition and the risk of relapse is heightened where adequate ongoing or follow-up care is not provided, with Gray and colleagues noting that there 'is a lack of such services for Indigenous Australians'.⁵²⁴

9.57 The location of rehabilitation facilities has also been identified as important. Several witnesses expressed a preference for rural rather than urban locations⁵²⁵ partly because of the access they provide to a natural healthy environment and partly because it physically separates those in treatment from an urban based lifestyle that is associated with alcohol consumption. Mr Scholz from BRADAAG commented that:

I think the best residential facilities are not based in the suburbs like we have, they are half way to a town camp. We get people going past our facility, and it is quite distracting for people who are in there seeing intoxicated people go past,
...⁵²⁶

and

places like CAAAPU in Alice Springs they have more land, more geographic land and that does help for making clients feel at ease, more-so.⁵²⁷

These observations about location also resonate with comments made by Mr James and Mr Curtis regarding the need for Indigenous people to 'get back to country' as discussed in 5.35.

Initiatives targeting FASD

Raising public awareness of risks of alcohol and pregnancy

9.58 Public awareness of the risks of alcohol and pregnancy is vital for prevention. Women need information on the risks so they can make informed choices about alcohol use when pregnant or at risk of getting pregnant. General awareness also increases the social pressure to avoid alcohol while pregnant and reduces the social pressure to drink.

9.59 There have been a range of national, territory and regional campaigns raising awareness of the dangers of alcohol during pregnancy, encouraging pregnant women not to drink, and encouraging men to support their pregnant partners in keeping off alcohol. For example, a number of witnesses comment on effectiveness of Anyinginyi's 'FASD puppets' advertisements in raising awareness of the dangers of alcohol.

⁵²³ Committee Transcript, 31 July 2014, p. 43.

⁵²⁴ Gray et al 2010 cited in Gray and Wilkes, 'Reducing alcohol and other drug related harm', p. 7.

⁵²⁵ Venndale Rehabilitation Centre, Committee Transcript, 29 July 2014, p. 66; BRADAAG, Committee Transcript, 31 July 2014, pp. 25-26.

⁵²⁶ Committee Transcript, 31 July 2014, p. 25.

⁵²⁷ Committee Transcript, 31 July 2014, p. 26.

- 9.60 For the observant, many alcohol containers are labelled with symbols or messages discouraging pregnant women from drinking, although many witnesses doubted the efficacy of this labelling due to its small size.
- 9.61 It is evident that public awareness of the risk of drinking alcohol while pregnant has increased over recent years, and this is reflected in a decline in the proportion of pregnant women who drink alcohol, although this decline has been much less in Indigenous populations. However, greater awareness is still required.

Recommendation 22

The Committee recommends that the Government support further campaigns raising awareness of the dangers of drinking alcohol while pregnant, particularly culturally appropriate campaigns for Aboriginal communities.

Women of childbearing age awareness of reproductive health, alcohol and contraception

- 9.62 Ensuring women of childbearing age have a working understanding of reproductive health, alcohol and contraception is key to preventing FASD. It is therefore important that accessible and culturally appropriate information is provided at key times, in particular, when girls are approaching childbearing age and when women are, or are seeking to be, pregnant.
- 9.63 The Yirrkala Indigenous Engagement Officer, Ms Djapirri Mununggirritj, told the Committee of the importance of programs such as Core of Life in teaching young Yolngu women about reproductive health:

To my perspective there is very little ... knowledge of what alcohol does to each child inside the mother's womb. Because of the old ways - it is still there, but the younger generation has forgotten who to go to in our culture, where they think everything is okay without even realising what the parent takes affects the child inside. I think there should be more resources put into the community.

One of the good things I have seen is the antenatal program the Core of Life. The Core of Life is the central contact point in the community of Yirrkala. Because I was very much involved from the very beginning of when Core of Life came to this community, we enable the Yolngu people to train up in the field - also going to schools talking with those age groups from 19 down. Also, taking the program itself to the homelands and the school but connecting the culture [and] what we know and of the western world...⁵²⁸

- 9.64 Participants at a public forum in Nhulunbuy also talked about the contribution made by the Adolescent Sexual Education Program in raising awareness of reproductive health and the dangers of alcohol. DoH outlined that program in its submission:

The NT Adolescent Sexuality Education Program (ASEP) delivered by the Department's Centre for Disease Control trains local people in communities across the NT to become trainers of the community health education packages (CHEP) developed and owned by Alice Springs-based Central Australian Aboriginal Congress. The CHEP package is a culturally appropriate holistic

⁵²⁸ Committee Transcript, 7 November 2014, p. 25.

health education program, addressing sexual and reproductive health, healthy relationships as well as AOD, including the risks associated with alcohol consumption during pregnancy. The program is delivered through an interactive, participatory approach using picture cards, CD-ROM, activities and discussion. Participants are educated about alcohol and its effects on the individual, child, family and community, different types of alcoholic drinks and safe drinking practices. It explores the choices young people make in relation to sex, AOD and the consequences of both positive and negative choices. This is a good preventive measure for reducing the incidence of FASD.⁵²⁹

- 9.65 Both Professor Silburn and Dr Schultz spoke of the importance of conducting sexuality and contraception education at an early age, prior to, or at the time teenagers are becoming sexually active, with Dr Schultz noting that:

By the time kids are 15 or 16 it is way too late, but in the pre-adolescent phase - nine and 10 year olds - teaching them about sexuality is absolutely effective. ...if you make them aware of contraception and better availability of contraception and no shame to access it, that is one way we can prevent pregnancy as a whole, prevent all unwanted births and thereby also prevent unwanted births that might be alcohol exposed.⁵³⁰

Recommendation 23

The Committee recommends that the Government ensure that all children receive a culturally appropriate sexual health awareness program, such as the Adolescent Sexual Education Program and Core of Life.

- 9.66 Another key point for raising awareness of reproductive health and alcohol is when a woman contacts the health system due to a pregnancy. This is an important opportunity to both ensure the woman is aware of the dangers of drinking alcohol while pregnant and to determine whether the woman requires any assistance with issues relating to alcohol.
- 9.67 To enable this to occur, the relevant health practitioner should discuss the dangers of drinking alcohol while pregnant and ask about any alcohol consumption. This requires awareness of the practitioner of the risks of alcohol and a culturally appropriate means of asking the question. Barriers to this occurring include embarrassment regarding alcohol consumption and gender and cultural sensitivities in talking about reproductive issues. While many witnesses told the committee that such conversations would normally occur, the Committee also received evidence that this was not always the case.

Recommendation 24

The Committee recommends that the Department of Health ensures that all training of health professionals includes information on FASD and the risks of drinking while pregnant, and that protocols for antenatal visits include discussion of the risks of alcohol and whether the woman is consuming alcohol.

⁵²⁹ DoH, Submission No 9, 2014, p 5.

⁵³⁰ Committee Transcript, 1 August 2014, p. 31.

- 9.68 A key factor constraining the prevention of FASD is the high proportion of unplanned pregnancies. One witness commented that 47 percent of pregnancies were unplanned and consequently were exposed to the potential for alcohol related harm from conception.⁵³¹
- 9.69 Evidence to the Committee from both witnesses and submissions pointed to contraception as a key strategy for preventing FASD, first because it enables pregnancies to be planned and alcohol exposure to be avoided, and second, because it helps to delay the age of childbearing, with this reducing the likelihood of exposure to both alcohol and tobacco during the pregnancy.
- 9.70 Professor Silburn spoke of the efficacy of long term contraception:

There is a very good example in Maningrida where they have been very proactive in reaching out to young women and seeing they have access to Implanon. Since they have done that - this is long-term contraception - there has been quite a significant reduction in the number of pregnancies among school-aged girls. That bodes well because we know as the age of childbearing is delayed there is much less likelihood of there being issues with alcohol and pregnancy, and also there are generally better pregnancy outcomes for older women.⁵³²

Recommendation 25

The Committee recommends that the Department of Health implement programs to improve the awareness regarding, and availability of, contraception options.

Targeting women with alcohol dependency

- 9.71 Professor Burns highlighted to the Committee the importance of targeting alcohol dependent women:

Foetal alcohol spectrum is most common in women who are dependent on alcohol. To prevent Foetal Alcohol Spectrum Disorder, it is imperative that effective education and treatment is given to women who are alcohol dependent, both prior to conception and during pregnancy. A common indicator, or the most common indicator of the presence of a foetus exposed to alcohol is the presence of a prior child to that mother who already has Foetal Alcohol Spectrum Disorder.

Campaigns should be developed to identify, screen and treat at risk women and babies. There are pharmacotherapies available, and programs include things such as detoxification, adequate nutrition and support. Therefore procedures must be put in place for women who are drinking heavily, pregnant or not, in order to provide a backup to any screening that finds positive traits in these women.⁵³³

- 9.72 Professor Burns further argued that the greatest gains in reducing FASD would be achieved by targeting alcohol dependent women:

⁵³¹ Central Australian Health Services, Committee Transcript, 1 August 2014, p. 38.

⁵³² Committee Transcript, 29 May 2014, p.19.

⁵³³ Committee Transcript, 29 May 2014, p. 50.

It is not equally spread across the population. There has been within the media and I think within a lot of the research community, promotion of a population level approach, targeting all women, but that is not where the disability lies. The difficulty lies with women who are alcohol-dependent and usually have at least one other child with Foetal Alcohol Spectrum Disorder. So if it was serious, if this was to really look at how to reduce those problems, it would be to provide a new model of service that would ensure those women were treated, hopefully prior to having a baby, because you could in fact prevent that problem occurring at all.⁵³⁴

9.73 This view was supported by Dr Breen:

The greatest burden is among those women that are high risk. They are the ones most likely to have a child affected by FASD. The population messages of just saying no or stopping drinking during pregnancy will not work for them. They need to be supported and the issues associated with the alcohol dependence, mental health issues and domestic violence need to be addressed.

It is harder to do, but that is where the greatest burden is.⁵³⁵

9.74 Services that assist alcohol dependent women who are or may become pregnant can therefore greatly assist in preventing FASD. As discussed above, some witnesses highlighted the need for rehabilitation facilities that women could attend with their families and housing for pregnant women who needed a safe and alcohol free environment.

9.75 A number of witnesses also noted that interventions may come too late to avoid harm to an alcohol dependant pregnant woman by the time they are engaging the health service, but intervention was nevertheless critical to reduce the risk of harm to future children. Dr Skov noted that:

if you can work with young families – because you might not prevent something in the child that is born now but the woman might have another two or three babies. If you are able to support that woman and that family in the first instance with her first child you might have a better chance stopping her drinking as much as she might have done for the first pregnancy, in subsequent pregnancies.⁵³⁶

9.76 Dr Wright reinforced this point:

It is very difficult to get to the first pregnancy, in general, for a whole range of reasons, in the Northern Territory; not the least is that we have quite young women, teenagers, becoming pregnant on a regular basis. More than 20 percent of pregnancies in Indigenous women are less than 20 years of age.

The measures that actually promote sexual health education and contraception, if well developed, will also be effective in helping to reduce the harms associated with exposure to tobacco and alcohol during pregnancy, and so really ramped up measures along those lines are of great benefit. When combined with the enhanced community visiting program Steven was just talking about, they do provide the opportunity for interventions at both primary, as in the first baby, and subsequent babies level, because you can establish the

⁵³⁴ Committee Transcript, 29 May 2014, p. 51.

⁵³⁵ Committee Transcript, 29 May 2014, p. 53.

⁵³⁶ Committee Transcript, 29 May 2014, p. 80.

relationship with the mother and the child with the visiting program and much better link them in for subsequent pregnancies.⁵³⁷

- 9.77 The Committee has previously noted the need for sexual health education, contraception, antenatal and postnatal support programs, and children and family friendly rehabilitation programs. The Committee also considers that better access is required for rehabilitation and support services for alcohol dependent women who are or may become pregnant.

Recommendation 26

The Committee recommends that the Department of Health assess the need for intervention and support services for alcohol dependent pregnant women, having particular regard to rehabilitation services that provide for families and children, and alcohol free, safe accommodation.

Criminal penalties

- 9.78 Women who persist in drinking at dangerous levels while pregnant present a difficult challenge to policy makers and legislators due to the moral imperative to protect an unborn child from preventable harm. This is a complex question on which the Committee heard a range of views, with some witnesses considering that improved access to treatment options was the best solution and others believing that mandatory treatment and coercive action to prevent the consumption of alcohol being warranted. The Committee also noted that some states in the USA had criminalised the dangerous consumption of alcohol by pregnant women and that a civil action was being brought on behalf of a child against its mother in the United Kingdom for harm done by the consumption of alcohol.
- 9.79 The Committee considers that, regardless of views of the rights or humanity of a foetus, the Government has a responsibility to protect future children from harm as far as is possible. A key question is therefore what is in the best interest of the future child? Two elements of this question are: what will reduce the risk of harm to the foetus, and what will increase the chance of a nurturing childhood?
- 9.80 A number of witnesses in effect argued that the best interest of future children was secured by their mothers accessing effective treatment programs. Coercive treatment, or criminalisation of consuming alcohol while pregnant, would increase the stigma of alcohol dependency and be a major disincentive to pregnant women revealing their alcohol consumption or seeking help. This would lead to continued alcohol consumption by many pregnant women and greater harm to future children. Consequently, even if the interests of the future child were seen to come before all other rights and interests, coercive treatment or criminalisation of pregnant women consuming dangerous quantities of alcohol should not be pursued.
- 9.81 This view was taken by FARE:

⁵³⁷ Committee Transcript, 29 May 2014, p. 80.

The government recently indicated that it was exploring the antenatal rights of the unborn child, including options such as prosecute or alternatively restrain women who are drinking through pregnancy from engaging in conduct which harms their unborn child.

...

This is not a policy response that we would support. It does nothing but stigmatise women and prevent them from seeking the services they require and flies in the face of all the available evidence of what works and what does not. It is also counter World Health Organisation guidelines for the identification and management of substance use and substance use disorder in pregnancy, which states that prevention and treatment interventions should be provided to pregnant and breastfeeding women in a way that will prevent stigmatisation, discrimination and marginalisation and promote family, community and social support, as well as social inclusion, by fostering strong links with available childcare, employment, education, housing and other services.⁵³⁸

9.82 FARE also noted the complexity of issues that may be leading to a woman's consumption of alcohol:

I think the other thing as well is that we need to look at what else is going on in the woman's life, so for women that are alcohol dependent or who are very heavy drinkers and they are pregnant it is rarely a single issue that is taking place in their life. They are often survivors of violence or they are current victims of violence, domestic violence. There was a study in America of 80 mothers who had had children with FASD; 95 percent of them had been sexually, physically or verbally abused in their lives and 72 percent of them were in current abusive relationships and felt unable to stop drinking because it was not safe for them to stop drinking. So it is usually a very complex issue.

In Canada there was a program called She Way which basically worked with women and they tried to identify them early in their pregnancy and then worked with them to put in place things such as housing and support and education and jobs. If they were in domestic violence relationships they tried to support them to get out of those domestic violence relationships and they put in place a whole range of support really early on in the pregnancy so that they could help the woman stop her drinking and they had remarkable reductions in alcohol consumption. Not all of the women did become completely alcohol-free, but the alcohol consumption did come down greatly and therefore the harm is mitigated to some degree. Again, I think we should look to what happened internationally and what we can learn from those programs. It is really about trying to put those supports in place early and trying to support those women, rather than necessarily confining them or locking them up. They might go on to have a subsequent pregnancy and it might be the same situation again and again.⁵³⁹

9.83 There was a clear lack of support from the community for criminalising women who drink while pregnant, with arguments put to the Committee including:⁵⁴⁰

- There is no evidence to suggest that there is a correlation between deterrence and criminalisation;
- Criminalisation is likely to decrease the likelihood that women with substance abuse will access health services;

⁵³⁸ FARE, Committee Transcript, 29 May 2014, pp. 56-57.

⁵³⁹ Committee Transcript, 29 May 2014, pp. 67-68.

⁵⁴⁰ TEWLS, Submission No. 20, 2014, p. 4; Chamber of Commerce, Committee Transcript, 12 August 2014, p. 4; NAAJA/CAALAS Submission No. 21, 2014, p. 5.

- Criminalisation is not effective as it will lead to increased rates of incarceration;
- Alcohol dependence is a mental illness and should be treated as such;
- Criminalising alcohol dependence or coercing women into treatment may have a 'net-widening' effect and result in women being mandated into treatment on a precautionary or preventative basis, thus further marginalising vulnerable women; and
- Such a law is difficult to implement at a population level:
 - Much damage could occur to the foetus prior to the woman knowing she was pregnant;
 - It is not realistic to expect owners and staff of businesses selling alcohol to refuse supply, as it would be difficult for them to establish whether or not a woman was pregnant; and
 - Equitable and consistent enforcement would be virtually impossible;

Mandatory treatment

9.84 Whether there might be benefit in mandatory treatment in extreme cases was seen as a more open question. Some witnesses considered there could be benefits in prohibiting pregnant women from consuming alcohol or placing persistent pregnant drinkers in mandatory treatment.⁵⁴¹ The President of the Barkly Regional Council and Chair of the Tennant Creek Alcohol Reference Group, Ms Barb Shaw, when asked if she was in favour of banning the serving of alcohol to pregnant women, and of making the consumption of alcohol by pregnant women illegal, made the following comments:

I personally would go that far. The problem that you would have with that then is how you control and monitor that, but the fact is while you may not be able to control and monitor it you have got the message there loud and clear saying you can't drink and there would be – and I have thought about this – there would be criticisms about the rights of an individual allowed to be doing whatever. But I think sometimes, again, when it particularly comes to Indigenous people, that becomes a block from Indigenous people making a difference for themselves and being accountable for themselves to make those changes.⁵⁴²

9.85 Ms Shaw felt that it was important to open up the debate with respect to mandatory rehabilitation for pregnant women who consumed alcohol, as this would facilitate an exploration of the most appropriate models to support pregnant women with alcohol problems:

I do not think, because it might be contentious, we have to stay away from having the conversation; it still needs to be had because if you allow the conversation to go ahead then you could look at models to deal with supporting

⁵⁴¹ See, for example, Committee Transcript, 29 July 2014, p. 44.

⁵⁴² Committee Transcript, 31 July 2014, p. 36.

the young person without it being set up as a big stick thing from government. We could have some really good discussions about how that can be modelled, but modelled on compassionate grounds. You would run a whole lot of education and family support. You would put in the Piliyintinji-Ki's Stronger Families program from Anyinginyi, which would work the way it is working with families. There has to be support from government.⁵⁴³

9.86 One of the themes that arose when the Committee asked witnesses about the Government's obligations to protect unborn children was the need for greater support options for alcohol dependent women:

Mr WOOD: ... if you believe that the government has a role to protect the unborn and a person has had every opportunity to stop drinking and it could be because they are addicted. The question I am putting to the government is, what is the priority, the rights of the woman or protecting the unborn? Once the unborn is born - if someone damaged that child they would be immediately charged with assault or hurting that child, - if someone is drinking and we know it is hurting that unborn child, what is the role of government in that?

Ms TURNER: The community has lobbied and dreamed of having a rehab place out bush on one of the homelands - we still lobby and advocate for that whenever we can.⁵⁴⁴

9.87 The Committee notes that key barriers to alcohol dependent pregnant women accessing services to help them keep off alcohol are fear of the stigma of alcohol consumption while pregnant and involuntary interventions, and a shortage of appropriate services. Coercive interventions or penalising the consumption of alcohol while pregnant could discourage alcohol dependent women from seeking medical assistance during their pregnancy, which could cause significant harm to both the woman and the foetus and any children she may have in future. The Committee notes the views of Miwatj Health that:

In the NT key to prevention of FASD is the trusting relationship between the newly pregnant woman and her midwife/Aboriginal Health Practitioner.⁵⁴⁵

9.88 The Committee also notes that any coercive intervention or penalty would come at a significant cost in administration, security and procedural fairness that in itself is of no or negative therapeutic value.

9.89 At the same time, the Committee was challenged by the question of how the Government should best discharge its duty to protect future children from harm when a pregnant woman continues to consume alcohol at dangerous levels even when appropriate advice and assistance is provided.

9.90 One member of the Committee considered that the Government should consider, as a last resort option, the mandated restriction of a pregnant woman from drinking alcohol through amendment of the *Alcohol Mandatory Treatment Act*. That Act provides for orders for treatment in a secure residential treatment service, treatment in a community residential treatment service, and other forms of community management.

⁵⁴³ Committee Transcript, 31 August 2014, pp. 36-37.

⁵⁴⁴ Committee Transcript, 31 July 2014, p. 9.

⁵⁴⁵ Miwatj Health Aboriginal Corporation, Submission No. 27, 2014, p 2.

- 9.91 The member also believed that the Government should consider whether the *Care and Protection of Children Act* should be applicable to the unborn. The Act deals with protecting children from harm, safeguarding the wellbeing of children, and obliging people to report cases of harm. Whilst the unborn may not legally be a child, it will be a child and the harm caused by alcohol is predictable harm to the child when born. This also raises the question of whether a Government could be legally liable for not intervening.
- 9.92 All Committee members agreed that the Government should discharge its duty to protect future children from harm by ensuring that there were adequate treatment options available for pregnant women to address problems with alcohol dependency. However, the majority of the Committee was not convinced that the benefits that a mandatory treatment regime might provide in some instances would outweigh the unwanted effects that such a regime may have overall. In particular, the majority were concerned about the potential for a mandatory regime to deter some women from freely accessing health services, and that greater harm reduction could be achieved by using the additional Government resources required for developing and implementing a mandatory treatment regime on improving the availability and accessibility of voluntary services.

Appendix 1: Submissions Received

1. First Peoples Disability Network Australia
2. National Drug Research Institute
3. Anyinginyi Health Aboriginal Corporation
4. National Indigenous Drug and Alcohol Committee (NIDAC)
5. Danila Dilba Health Service
6. Northern Territory Legal Aid
7. Public Health Association Australia (PHAA)
8. Australian Institute of Health and Welfare
9. Department of Health
10. University of New South Wales
11. National Organisation for Foetal Alcohol Spectrum Disorder (NOFASD)
12. Foundation for Alcohol Research and Education
13. CatholicCare NT
14. Department of Children and Families
15. Menzies School of Health Research
16. Department of Education
17. Prue Walker
18. Northern Territory Council of Social Service
19. McCusker Centre for Action on Alcohol and Youth
20. Top End Women's Legal Service
21. North Australian Aboriginal Justice Agency / Central Australian Aboriginal Legal Aid Service
22. Office of the Children's Commissioner
23. People's Alcohol Action Coalition
24. Central Australian Aboriginal Congress Aboriginal Corporation
25. Association of Alcohol and Other Drug Agencies NT
26. Barkly Youth Services
27. Miwatj Health Aboriginal Corporation

Note: Copies of submissions are available at:

<http://www.nt.gov.au/lant/parliamentary-business/committees/fasd/Submissions.shtml>

Appendix 2: Hearings and Forums

Public Hearings

Darwin – 29 May 2014

1. Menzies Foundation
2. Aboriginal Peak Organisations Northern Territory (APONT)
3. National Organisation for Foetal Alcohol Syndrome and Related Disorders (NOFASD)
4. National Drug and Alcohol Research Centre
5. Foundation for Alcohol Research and Education
6. Telethon Institute for Child Health Research
7. Department of Health
8. Department of Children and Families
9. Department of Education
10. Australian FASD Association

Katherine – 29 July 2014

1. Wurli-Wurlinjang Health Service
2. Katherine Region Action Group (KRAG) and the Association of Alcohol and Other Drug Agencies NT, (AADANT)
3. Kintore Clinic
4. Sunrise Health Service
5. Chamber of Commerce
6. Venndale Rehabilitation and Withdrawal Centre
7. Top End Health Service
8. Katherine Health Centre and Hospital
9. Katherine West Health Board Aboriginal Corporation

Tennant Creek – 31 July 2014

1. Anyinginyi Health Aboriginal Corporation
2. Barkly Region Alcohol and Drug Abuse Advisory Group Inc (BRADAAG)
3. Tennant Creek Alcohol Reference Group
4. Tennant Creek Women's Refuge
5. The Patta Aboriginal Corporation
6. Julalikari Council Aboriginal Corporation
7. Central Australian Health Services
8. Tennant Creek Hospital

9. Tennant Creek Community Health Centre
10. Tennant Creek Liquor Accord
11. Mr Kevin Jones (Foster Parent)
12. Barkly Youth Services

Alice Springs – 1 August 2014

1. Chamber of Commerce NT
2. Australian Institute of Health and Welfare (AIHW)
3. CatholicCare NT
4. Danila Dilba Health Service
5. NT Council of Social Services (NTCOSS)
6. Top End Women's Legal Service Inc
7. First Peoples Disability Network
8. National Indigenous Drug and Alcohol Committee (NIDAC)
9. Australian Hotels Association (NT Branch)

Nhulunbuy – 7 November 2014

1. Miwatj Health Aboriginal Corporation
2. Anglicare
3. Nhulunbuy Alcohol and Other Drugs Rehabilitation Service
4. Djapirri Mumumgirtj and Dhangal Gurruwiwi

Public Forums

Katherine – 29 July 2014

1. Mr Geoff Lohmeyer, Sunrise Health
2. Ms Surinder Crichton, Department of Business
3. Ms Denese Woods, Katherine High School Ready
4. Ms Sally Pannifex, Katherine High Special Needs Unit
5. Ms Eugenie Collyer, Parent and Interpreter
6. Elaine Jaesohke, Office of Disability, Department of Health
7. Ms Kate Bishop, Good Beginnings
8. Ms Kylie Stothers, Flinders University Northern Territory
9. Ms Josephine Nicholson, Katherine Women's Crisis Centre
10. Ms Pascale Dettwilles, Flinders University Northern Territory
11. Ms Marion Scrymgour, Wurli-Wurlinjang
12. Mr Warwick Jack

Tennant Creek – 30 July 2014

1. Ms Pauline Davenport, Tennant Creek High School

2. Ms Victoria Davenport, Tennant Creek High School
3. Ms Eleanor Diph, Tennant Creek High School
4. Ms Jacqui Lyster, Tennant Creek Primary School
5. Ms Nicola Norman, National Disability Insurance Scheme
6. Ms Tracey Chaplin, National Disability Insurance Agency
7. Ms Carmel Edwards, Department of Prime Minister and Cabinet
8. Ms Neroli Raff, National Disability Insurance Agency
9. Ms Jennifer Kitching, Department of Health (Northern Territory)
10. Mr Paul Phillips, ARC
11. Ms Georgina Bracken, Tennant Creek Women's Refuge
12. Mr Ray Wallis,
13. Ms Lorraine Baer, ARRC
14. Pastor Mike Baker, Tennant Creek Christian Family
15. Ms Meg McGrath, Department of Business
16. Dr Stuart Philipet, Australia Red Cross
17. Ms Barb Shaw, Barkly Region Council
18. Mr Peter Cain, Barkly Youth Services
19. Ms Jenni Kennedy, Child and Family Health Nurse
20. Melanie Baldwin, Stronger Sisters, TCHS
21. Mr Eric Brace, Australian Literacy and Numeracy Foundation
22. Mr Tony Miles, Anyinginyi Health
23. Ms Valencia Pratt, BRADAAG
24. Ms Lyn Andrews, Tennant Creek Women's Refuge
25. Ms Kate Brookman, Midwife TCH/ASH
26. Ms Carol Enthoven, Foster Carers
27. Mr Kevin Jones, Foster Carers
28. Ms Wendy MacTaggant, Department of Health
29. Ms Ann Hallett, Midwifery Group
30. Ms Becky Hallett, Student/ Youth Parliament
31. Mr Martin Power, Tennant Creek High School
32. Ms Leanne Shaw, Anyinginyi Health
33. Ms Linda Turner, Anyinginyi Health
34. Ms Laura Wu, The Australian Literacy and Numeracy

Note: Copies of transcripts are available at:

<http://www.nt.gov.au/lant/parliamentary-business/committees/fasd/Inquiries.shtml>

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