



Department of Health Submission

**Legislative Assembly of the Northern Territory
Select Committee on Action to Prevent Fetal Alcohol Spectrum Disorders**

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BACKGROUND

Alcohol risk and the Australian alcohol guidelines

The harmful use of alcohol¹ is a well-recognised risk factor for negative health and social outcomes, for the individual drinker, those around them and the community more broadly (Laslett et al 2010; World Health Organisation (WHO), 2010). At harmful levels alcohol consumption is directly linked with risk of injury through motor vehicle crashes and interpersonal violence, neuropsychiatric disorders and other non-communicable diseases such as cirrhosis of the liver, cardiovascular disease, pancreatitis, diabetes, epilepsy and various cancers (Babor et al 2010; WHO 2010).

The 2009 National Health and Medical Research Council (NHMRC) guidelines to reduce health risks from drinking alcohol propose that 'for healthy men and women, drinking no more than two standard drinks on any day reduces the lifetime risk of harm from alcohol-related disease or injury' (NHMRC 2009: p.67). The guidelines also propose that for low risk of alcohol related injury on a single drinking occasion no more than four standard drinks should be consumed per day by healthy men and women (NHMRC 2009: p.39).

In relation to pregnancy and breastfeeding, the NHMRC guidelines state that 'maternal alcohol consumption can harm the developing foetus or breastfeeding baby'. Due to uncertainty as to the threshold for harm to occur, a precautionary approach is taken with the following recommendations. 'A: For women who are pregnant or planning a pregnancy, not drinking is the safest option. B: For women who are breastfeeding, not drinking is the safest option' (NHMRC 2009: p.67). There is reassurance that the risk is 'likely to be low if a woman has consumed only small amounts of alcohol (such as one or two drinks per week) before she knew she was pregnant or during pregnancy' and that the level of risk to the fetus or baby is 'individually variable as it is influenced by a wide range of maternal and fetal characteristics' (NHMRC 2009).

Fetal Alcohol Spectrum Disorders (FASD)

Intrauterine alcohol exposure is associated with a spectrum of physical, cognitive, behavioural and developmental effects referred to as *Fetal Alcohol Spectrum Disorders* (FASD). Although the teratogenic effect of alcohol upon the embryo and fetus² was first formally articulated as Fetal Alcohol Syndrome (FAS) over 40 years ago (Jones and Streissguth, 2010), the concept of FASD has been more clearly and formally defined since 2004 (Warren et al 2011; The University of Dakota 2013).

FASD is a non-diagnostic descriptive umbrella term encompassing fetal alcohol syndrome (FAS³) at the most severe and disabling end of the spectrum, partial FAS (pFAS), alcohol related birth defects (ARBD) and alcohol related neurodevelopmental disorders (ARND) (Warren et al 2011; Burns et al 2013). Multiple factors determine the severity of disabilities associated with prenatal alcohol consumption, such as genetic factors, timing and level of prenatal

¹ "the concept of harmful use of alcohol is broad and encompasses the drinking that causes detrimental health and social consequences for the drinker, the people around the drinker and society at large, as well as the patterns of drinking that are associated with increased risk of adverse health outcomes" (WHO, 2010)

² See Attachment A 'Pathophysiology of alcohol as a teratogen (toxin) upon the fetus and FASD' with thanks to Dr Jennifer Delima, Addiction Medicine Physician, Alice Springs Hospital.

³ The full presentation of FAS is the only outcome of in utero alcohol exposure widely accepted as a specific diagnosis. A diagnosis of full FAS is made if three primary defining features are present: (1) documentation of characteristic facial abnormalities (smooth philtrum, thin vermilion border, and short palpebral fissures); (2) prenatal and postnatal growth deficits; (3) central nervous system (CNS) abnormalities (i.e. structural, neurological, or behavioural, or a combination thereof) (Warren et al 2011). Those with FASD may display varying degrees of the latter two features but not necessarily the facial abnormalities.

alcohol exposure and nutritional status (Warren et al 2011). Further, the scope and severity of characteristics, developmental difficulties, emotional difficulties, and behaviours seen across the spectrum is vast and varied. FASD are lifelong conditions and can result in significant adverse educational, social, health and legal outcomes for those exposed to alcohol in utero, their families and communities.

FASD are considered the leading, preventable cause of non-genetic, developmental and cognitive disability in the United States (Bailey & Sokol 2008) and Australia (O’Leary 2002; FARE 2013; AIHW 2010). As an entirely preventable spectrum of disabilities, population based and targeted health promotion and prevention measures are crucial to reduce the incidence and burden of FASD, with early identification and ongoing, appropriate support measures required to improve outcomes for those with FASD, their families and communities.

Declaring FASD a disability

It has been proposed that FASD be declared a disability to enable access to services. Declaring FASD a disability is confounded by the difficulty of attributing accurately the causes of any individual case of intellectual, behavioural, physical, mental and or emotional difficulties or disability. Disability is a relative term dependent on the level of impairment and the impact of that impairment not necessarily on one particular syndrome or diagnosis. It remains unclear how it will be decided that in-utero exposure of the foetus to alcohol is the actual cause rather than other well defined causes of disability. In addition, labelling FAS or FASD as a disability could raise serious ethical issues for treatment such as children and adults with similar problems not deemed to have been caused by in-utero exposure to alcohol may not be able to access any ‘FASD-specific’ support services.

Recent national FASD activity

FASD has received significant national attention in recent years, although a coordinated approach to the prevention, intervention and management of FASD is yet to be established in Australia. Released first in 2010 then updated in 2012, the Intergovernmental Committee on Drugs (IGCD)⁴ FASD Monograph (Burns et al 2012), was the outcome of an IGCD FASD Working Party established in 2006 to advise on the developments in Australia and overseas regarding FASD and to identify best practice approaches to reduce the incidence of FASD, particularly in Indigenous communities. The Monograph examined the current state of research, policy and practice regarding alcohol use in pregnancy in Australia, particularly in relation to FASD, noting areas where additional attention is required and enhancements to existing practices are needed to improve the current situation with regard to prevention, early intervention and long term management of FASD.

FASD: The Hidden Harm. Inquiry into the prevention, diagnosis and management of Fetal Alcohol Spectrum Disorders, prepared by the House of Representatives Standing Committee on Social Policy and Legal Affairs under the previous Australian Government, was tabled in the Commonwealth House of Representatives in late 2012. The report contains a series of 19 recommendations which outline a cross-sectoral national strategy to prevent, identify and manage FASD in Australia.

In August 2013 the previous Government responded to the House of Representatives Inquiry with a *Commonwealth Action Plan to reduce the impact of FASD for the period of 2013-14 to 2016-17* (Australian Government, 2013) that

⁴ The Intergovernmental Committee on Drugs (IGCD) manages the ongoing work of the National Drug Strategy. <http://www.nationaldrugstrategy.gov.au/internet/drugstrategy/publishing.nsf/Content/igcd-lp>

acknowledged a whole of government response is needed to address FASD. The Plan committed \$20 million across five key priority areas⁵:

1. Enhancing efforts to prevent FASD in the community;
2. Secondary prevention targeting women with alcohol dependency;
3. Better diagnosis and management of FASD;
4. Targeted measures to prevent and manage FASD within Indigenous communities and families in areas of social disadvantage; and
5. National coordination, research and workforce support.

Northern Territory Department of Health initiatives ⁶

Whilst the Northern Territory (NT) Government does not currently have a whole of Government framework for preventing and responding to FASD, some current activity in the Department of Health (DoH) includes work completed by the Remote Health teams, where health checks and brief assessments for alcohol consumption during pregnancy and referral pathways are in place. The risks associated with alcohol consumption during pregnancy are part of training packages, such as those delivered by the Alcohol and Other Drugs Services (AODS) to AOD workers and by Remote Health to Aboriginal Health Practitioners. AODS 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.

Antenatal (prenatal) care across the Top End and Central Australia Hospitals (public and private) involves collection of self-reported alcohol use data where possible during the first visit and at approximately 36 weeks gestation. If a woman admits to drinking alcohol at either of these 2 visits she is recommended to discontinue alcohol use while pregnant and if high alcohol use is present, referral to drug and alcohol services is recommended (O’Kearney et al 2013).

The ‘Strong Women’s, Strong Babies, Strong Culture’ program is a bi-cultural, community development program that respects and supports the Aboriginal way of promoting good health in women and babies during pregnancy and early parenting. Aboriginal women deliver the program to Aboriginal women, combining traditional Aboriginal and current Western knowledge. This includes the provision of pregnancy, women’s health and child health education to pregnant women and mothers of infants and young children, including health issues such as FASD.

The Office of Disability (OOD) provides a range of services to support children and adults with a range of disabilities based on an assessment of functional impairment and associated needs rather than a specific diagnosis e.g. of FASD. Services currently provided for children include multidisciplinary allied health⁷ assessment and intervention (mostly focused on parent/school training) based on identified needs. While these assessments are not designed to inform any diagnosis in particular, they are completed to assist further development and may be used by medical practitioners such as paediatricians to inform a diagnosis. Funded services for children include respite based on assessed support needs, relating to the level of functional impairment and family coping.

⁵ <http://www.health.gov.au/internet/publications/publishing.nsf/Content/response-fasd~action-plan>

⁶ This is not an exhaustive description of the work being done across the Department of Health or Top End/Central Australia Health Services to address alcohol consumption and/or misuse, in particular maternal alcohol consumption during pregnancy.

⁷ e.g. speech pathology, occupational therapy, physiotherapy

OOD services for adults also include multidisciplinary allied health⁸ assessment and intervention based on identified needs. Intervention focuses on positive behaviour support, life skills training and social/communication skills training. Case coordination (routine service needs) or case management (intensive or complex service needs) is also provided. Funded services for adults include in-home accommodation support; community access and respite based on assessed support needs, relating to the level of functional impairment.

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 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-Room, 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.

In 2011 a time-limited, inter-agency NT FASD Working Group was formed. This was initially led by the former Department of Health and Families, then later by the Department of Children and Families (DCF). The direction of this group was informed by the IGCD FASD Monograph; recommendations from a DHF funded Alice Springs FASD Forum in 2010, as well as other relevant research and projects. Its purpose was to support and develop a framework for a coordinated and informed approach to FASD in the NT. The working group completed a discussion paper and action plan as planned by August 2011.

PREVALANCE IN THE NORTHERN TERRITORY OF FASD

In its final report, the 2012 House of Representatives Standing Committee on Social Policy and Legal Affairs found that:

“Australia currently lags behind other countries in recognising the prevalence of FASD and the impact on the individual as well as social and economic impact on families and society. It is clear that urgent measures must be taken to reduce the incidence of FASD and to better manage those diagnosed with FASD.” (House of Representatives Standing Committee on Social Policy and Legal Affairs 2012: p.3).

Estimating the prevalence of FASD in the Northern Territory

Estimating the prevalence of FASD in Australia has been difficult. A range of challenges exist in determining population-based FASD prevalence, such as limitations in prenatal alcohol screening, varied data collection methods and incomplete data collections (Burns et al 2013).

In 2000, a Western Australian study found a prevalence of 0.02 per 1000 births for non-Indigenous children and 2.76 per 1000 births for Indigenous children (Bower et al 2000). This study used data from both the Birth Defects Registry and Rural Paediatric service database and found a 38 per cent increase in prevalence estimates compared to previous estimates derived from the Birth Defects Registry alone, highlighting the importance of using multiple data sources to increase ascertainment (Burns et al 2013). In 2008, the first Australia-wide prognostic survey by the Australian Paediatric Surveillance Unit (APSU) estimated the prevalence at a mere 0.58 per 100,000 live births (Elliot et al 2008).

⁸ e.g. behaviour education, speech pathology, occupational therapy

A passive surveillance⁹ study conducted in 2003 in the Top End of the NT showed the prevalence of FAS and pFAS/ARND to be 0.68 and 1.87 per 1000 births in non-Indigenous and Indigenous Australians respectively (Harris and Bucens 2003). This study involved a retrospective review of medical charts for all children seen at the Royal Darwin Hospital over the ten year period 1990-2000 to identify children with FAS and pFAS/ARND and all children identified with FAS or pFAS/ARND were Indigenous.

There are several factors that may explain these low figures which fall short of the international rate of 0.5–3 per 1000 live births in the general population and rise to as many as 9.1 per 1000 live births among high-risk populations (Stratton et al 1996).

Reasons for FASD underreporting include the following:

- Diagnosis of FASD related disabilities is a complex process, requiring a comprehensive history and physical and neurobehavioural assessments in the context of a multidisciplinary approach (Chudley et al 2005; Burns et al 2013);
- Maternal alcohol use during pregnancy is not consistently assessed and recorded (Payne et al 2005; Elliott et al 2006) making it difficult for medical and other health professionals to confidently provide a diagnosis;
- Surveys have shown that knowledge, awareness and understanding of FASD among health and medical professionals are limited, as is the confidence to manage patients with FASD (Payne et al 2005; Elliott et al 2006);
- There may be reluctance among health care practitioners to provide a child and family with a ‘stigmatising’ diagnosis (Payne et al 2005);
- Australia currently has no screening and diagnostic instrument for FASD, with various overseas diagnostic guidelines available for use e.g. Chudley et al 2005 (Canada) and Bertrand et al 2005 (USA). Some work is being completed in Western Australia and New South Wales (Fitzpatrick et al 2013 (WA); Bower et al¹⁰) to develop reliable Australian instruments;
- Standard features of FASD can be associated with standard alcohol consumption patterns, making diagnosis difficult. In the NT alcohol consumption patterns are materially different to other locations, therefore features of FASD in the NT may be different, and may take longer to establish and identify, from a diagnostic viewpoint.
- Diagnosis of adolescents and adults is more difficult as maternal history may be difficult to access, facial anomalies are more difficult to detect, and behaviours may be multifactorial in aetiology;
- Overlap with other behavioural, developmental, educational or social problems with well documented determinants may confound diagnoses; and
- Access to specifically FASD trained health professionals (paediatricians, psychologists, speech therapists, occupational therapists, addiction medicine physicians, psychiatrists etc.) is limited in the NT.

A recent NT passive surveillance study (Walker 2013) commissioned by the NT DCF examined the files of 230 children involved with the child protection system in the NT over 2011-12 in order to identify the proportion of children affected by prenatal alcohol exposure and to identify the prevalence of indicators of FASD within this cohort. The study found that prenatal alcohol exposure was associated with those children entering care, with 1 in 5 (21 per cent)

⁹ ‘Passive surveillance systems use existing record or data collections in a particular geographical area for a particular timeframe’ e.g. birth records, medical charts of hospitals and physicians (Burns et al 2013)

¹⁰ [http://telethonkids.org.au/our-research/projects-index/d/development-of-a-diagnostic-instrument-for-fetal-alcohol-spectrum-disorders-in-australia-\(fasd-project\)/](http://telethonkids.org.au/our-research/projects-index/d/development-of-a-diagnostic-instrument-for-fetal-alcohol-spectrum-disorders-in-australia-(fasd-project)/)

children in the study having experienced prenatal alcohol exposure. For children on protection orders, that figure rose to 2 in 5 (40 per cent).

Whilst data suggests a higher prevalence FAS/FASD among ATSI Australians, care must be taken if extrapolating from these data, notwithstanding data reported below relating to maternal alcohol consumption among ATSI women. A range of issues that may be attributed to suspected in utero alcohol exposure may be at least in part caused by other social and environmental conditions, with remoteness an additional factor to consider in relation to health outcomes¹¹ (e.g. learning difficulties, deficits in school performance, poor impulse control, problems in social perception, deficits in higher level receptive and expressive language, poor capacity for abstraction or metacognition, specific deficits in mathematical skills, or problems in memory, attention or judgement). Indeed the broad social determinants of health are essential to consider in relation to the health and wellbeing of all children, the drivers of alcohol consumption and aetiology of FASD regardless of geographical location (Carson et al 2007; WHO¹²).

Alcohol consumption – an indicator of alcohol related harm in the community

Where reliable prevalence estimates of FASD are not available for the NT, alcohol consumption is an important indicator of the burden of alcohol related disease and injury for the population ('alcohol related harm') (Norström & Ramstedt 2005; Babor et al 2010).

Pre-pregnancy alcohol consumption is reported to be one of the main predictors of prenatal alcohol use (Anderson et al 2013). This study, including 1,969 women from the Australian Longitudinal Study on Women's Health (ALSWH), aimed to gauge the predictors of antenatal alcohol use, among women who usually consume alcohol, to identify those most at risk of an alcohol-exposed pregnancy. 82 per cent of the sample reported consuming some alcohol during pregnancy, although most reported low alcohol usage with 77 per cent of these women consuming one or two drinks per drinking day and 90 per cent drinking no more than once or twice a week. Women who drank weekly prior to pregnancy were 50 per cent more likely to continue to drink during pregnancy, compared to those who drank less than weekly. Women who reported prior binge drinking behaviour were more than twice as likely to continue to consume alcohol during pregnancy.

Population level information on alcohol consumption can be estimated using both indirect and direct measurements. An example of an indirect measure is Per Capita pure Alcohol Consumption (PCAC) estimated from alcohol sales, while population surveys provide a direct, self-reported measure of alcohol consumption.

Per Capita pure Alcohol Consumption (PCAC)

Estimated per capita pure alcohol consumption (PCAC)¹³ in the Northern Territory was 12.84 litres per person for the 2012-13 financial year, representing a four per cent drop from the previous year (Department of Business, NT Government 2013). This is the lowest estimated consumption value recorded for the NT since prior to 2001-02, which is the first period for which PCAC has been estimated. The latest value continues the decrease observed in estimated consumption seen in the Territory since 2004-05 and yet is substantially higher than the national PCAC average for 2012-13 of 9.88 litres per person (ABS 2013a).

¹¹ <http://ruralhealth.org.au/advocacy/current-focus-areas/social-determinants-health>

¹² http://www.who.int/social_determinants/en/

¹³ PCAC for the NT is calculated by dividing the quantity of pure alcohol available for consumption by the estimated resident population, with an adjustment for the estimated number of visitors aged 15 years and over (Department of Business, NT Government, 2013)

Population survey findings

The 2010 National Drug Strategy Household Survey (NDSHS) (AIHW 2011) reported that of all the states and territories, those living in the NT (both women and men) were more likely to drink alcohol at quantities that placed them at risk of lifetime harm (29.4 per cent). People in the NT were also more likely to drink alcohol at levels that placed them at risk of an alcohol-related injury from a single occasion of drinking. Specifically, the proportions of male and female risky drinkers were highest in the NT (59.4 per cent for males and 41.5 per cent for females).

Non-indigenous NT women¹⁴

Data from the NDSHS (AIHW 2013) indicated that over half (54.9 per cent) NT non-Indigenous women aged between 18-24 years drank at least weekly. Over 40 per cent of women in this age group drank at levels putting them at risk of alcohol related harm in the short term at least monthly. Nearly 1 in 5 (18.9 per cent) NT non-Indigenous women aged between 25-34 years reported drinking alcohol at risky or high risk levels for long term alcohol related harm, which was greater than any other age group.

Indigenous NT women

A far smaller proportion of Indigenous women in the NT consume alcohol (40 per cent) than non-Indigenous women, but among those who are regular drinkers, a greater proportion drink at harmful levels (ABS 2013b). Risk of harm associated with a single occasion of drinking or 'binge drinking' is particularly high among young Indigenous women; 60 per cent of women aged 18-24 and 80 per cent of women aged 25-34 who do drink do so at harmful levels. It is worth noting this group accounts for only 14 per cent of NT Indigenous women aged between 18-34 (ABS 2013b). Indigenous women living remotely are considerably less likely to drink than women in non-remote areas (32 per cent and 74.2 per cent respectively).

Antenatal alcohol consumption data - Northern Territory Midwives' Collection, Mothers and Babies 2011

The 2011 DoH Northern Territory Midwives' Collection Mothers and Babies report found that at first antenatal visit, 6.3 per cent of all NT mothers reported drinking alcohol during pregnancy, although quantity, type and frequency of alcohol consumed weren't reported. The prevalence of alcohol consumption was found to be higher in Indigenous mothers (12.5 per cent at the first visit and 7 cent at 36 weeks gestation) than non-Indigenous mothers (3 per cent and 1 per cent, respectively) (Thompson 2014). Where alcohol consumption data was missing for the first and second antenatal visits (not asked, not reported, missing for no identified reason), missing data was more prevalent among the records of Indigenous mothers than non-Indigenous mothers. Exploration of the confidence of health professionals in asking about alcohol consumption during pregnancy is warranted.

Missing data for Indigenous mothers correlates with the finding that Indigenous mothers were more likely to attend their first antenatal visit later in the pregnancy than non-Indigenous mothers. Among those mothers who attended at least one antenatal visit and had a record of the time of their first visit, 82 per cent of non-Indigenous mothers attended their first visit during the first trimester of pregnancy. This proportion was much less for Indigenous mothers (50 per cent). The proportion of Indigenous women attending a first antenatal visit in the first trimester was higher in

¹⁴ Recent population surveys with self-reported alcohol intake for the NT population include the 2011-12 Australian Health Survey (AHS), 2012-2013 Australian Aboriginal Torres Strait Islander Health Survey (ATSIHS) and 2010 National Drug Strategy Household Survey (NDSHS). Due to inadequate samples from remote NT areas in the AHS and NDSHS these surveys do not reliably represent just over 20% of the population living remotely who are primarily Indigenous. Alcohol consumption rates for *non-Indigenous* women are thus drawn from the 2010 NDSHS and the 2012-2013 AATSIHS for *Indigenous women*.

urban areas than in rural-remote (56 per cent and 46 per cent respectively). Among non-Indigenous women, the proportion attending an antenatal visit in the first trimester was slightly higher in urban areas compared with remote (82% and 79% respectively).

The proportion of non-Indigenous pregnant women who consumed alcohol during pregnancy has steadily declined since 2003, whereas alcohol consumption among Indigenous pregnant women has remained relatively stable (see Table 1). This suggests a widening gap between the prevalence of drinking in pregnancy between non-indigenous and Indigenous mothers, although care is required when interpreting this data given missing data.

Table 1. Proportion of pregnant women reporting alcohol consumption at first antenatal visit and at 36 weeks gestation, Northern Territory, 2003-2011

	2003 ¹	2004 ²	2005 ³	2006 ⁴	2007 ⁵	2008 ⁶	2009 ⁷	2010 ⁸	2011 ⁹
% 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
NT 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
NT 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: (Zhang, Dempsey et al. 2009, Zhang, Dempsey et al. 2013, Thompson 2014).

THE NATURE OF THE INJURIES AND EFFECTS OF FASD ON ITS SUFFERERS

FASD has been shown to have profound and varying consequences for individuals, families and carers, the community and service providers.

The individual

The manifestations of FASD vary greatly between individuals. There is a constellation of physical, mental, behavioural and learning disabilities that may result from maternal alcohol consumption (see table 2 below), including:

- *Impulse control and behaviour*: emotional outbursts, inattention at school, rule breaking, stealing, inability of the individual to make a connection between their actions and consequences such as a punishment, or the impact on others (NOFASD 2013a).
- *Information processing*: poor language skills, difficulty in expressing themselves, an inability to connect information to actions, inability to remember information (NOFASD 2013b).
- *Memory*: difficulties with learning from their experiences (i.e. the consequences of breaking a rule), unpredictable performance when attempting the same task, even in a short time frame, continual need to relearn rules and concepts (i.e. rules of a sport, how to spell a word) (NOFASD 2013c).
- *Adaptive and executive functioning*: one of the most significant outcomes that may be associated with FASD is the lack of developing personal and social skills needed to live independently (Streissguth et al 2004).
- *Mental health*: high rates of mental health disorders have been found among FASD sufferers, with up to 87 per cent in one sample meeting criteria for a psychiatric disorder (O'Connor et al 2002), and depressive symptoms evident in FASD children as young as six years old (Rasmussen et al 2008). This may have significant

implications for NT mental health services in terms of delivering services but also in consideration of FASD as a potential underlying problem among their clients. Mental health issues are important for FASD sufferers because they may complicate treatment and contribute to other difficulties such as schooling outcomes and risk taking behaviour (e.g. substance misuse, sexual behaviour).

- In one longitudinal study (Streissguth et al 1996) on secondary disabilities among adolescents and adults with FASD found that:
 - 90 per cent had mental health problems;
 - Nearly half of the adolescents and adults demonstrated inappropriate sexual behaviour;
 - 60 per cent had disrupted school experience (suspension, expelled, dropping out);
 - 60 per cent had been in trouble with the law

Table 2: Summary of outcomes associated with antenatal alcohol exposure

Behavioural	Mental health	Adaptive and executive functioning
Antisocial behaviour Delinquent behaviour Classroom/school behaviours Learning behaviours Externalizing behaviour Aggressive behaviour Criminal activity Maladaptive behaviour Impulsivity <ul style="list-style-type: none"> • Teasing/bullying • Dishonesty • Avoiding work/school • Sexual inappropriateness • Self-injury • Alcohol/drug use 	Alcohol problems Mood disorder Bipolar disorder Depression Panic disorder Hyperkinetic disorders Emotional disorders Conduct disorders Sleep disorders Abnormal habits Stereotypical behaviour Other psychiatric disorders (post-traumatic stress disorder, obsessive-compulsive disorder and oppositional defiant disorder)	Socialization Employment difficulties Independent living difficulties Inhibitory control Cause and effect reasoning Planning and organizing Learning from mistakes

(Source: Rasmussen et al 2008)

It is challenging to clearly define the proportion of variance for each of the listed difficulties that is caused by in utero exposure to alcohol. As mentioned above, it is important not to overlook other proven determinants of adverse health outcomes for individuals and those around them, across both Indigenous and non-Indigenous populations, in addition to prenatal alcohol exposure.

It is worth noting, for instance, that the Wave 4 Report from the *Footprints in Time Longitudinal Study of Indigenous Children* (Australian Government Department of Social services 2013) provides significant detail about the actual and measured impact of various adverse life events on the development in the lives of Indigenous children. The three main risk factors found to have the greatest impact on these children’s social and emotional difficulties scores included:

- If a close family member had been arrested, been in jail or had problems with the police (experienced in two or three years);
- Children cared for by someone else for at least a week (over three or four years) as opposed to remaining constantly with their regular carers;
- Children scared by other people’s behaviour in three or four years.

This highlights the need to place an individual child or adult's health in the context of their overall environment and experiences.

The Family

Families are also affected by the serious disabilities and conditions common in FASD sufferers. Families experience much stress from the day-to-day challenges of the behavioural and cognitive problems. In particular, inability to retain information around rules and consequences create unique difficulties for parenting practices. Parents or caregivers need to adapt their parenting techniques and expectations. Family stress may result in breakdown in family relations, violence and involvement of child protective services. 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.

The Community

FASD can have a significant impact on the health care, social services, education, and the criminal justice system. Together this amounts to a considerable economic and resource burden.

Social services

An Australian prospective national surveillance study of FAS cases noted that only 40.2 per cent lived with a biological parent (Elliott et al 2008). It may be that FASD children are overrepresented in the child protection system in the NT. The ongoing behavioural, cognitive, and mental health issues would lead to many challenges for carers. As many individuals with FASD will not attain the skills to live independently, many require lifelong supported living arrangements. Capacity for full time employment similarly may not be feasible for many FASD individuals, depending on the severity of their disorder.

Education system

FASD manifests in a range of school domains including mathematical deficiency, difficulty with abstract concepts such as time and space, and inability to see the relationship between cause and effect, as well as comprehension and memory deficits. FASD causes learning difficulties not easily overcome with extra tutoring or support. Difficulties with comprehending and following rules would present many challenges and disruptions in the classroom setting.

There is limited data on FASD, primarily due to a limited capacity to diagnose students with FASD. The NT Department of Education is focused on building the capacity of schools and teachers to support students who display characteristics and behaviours consistent with FASD to ensure students remain engaged in the education system and achieve their best educational outcomes. As of March 2014, there were 27 students clinically diagnosed with FASD, however, anecdotal evidence coupled with the NT's high alcohol consumption rates, suggests there are many students in NT schools exhibiting FASD behaviours. Diagnosed FASD students are supported through the same model of care provided to students with disabilities. This involves education advisors facilitating program development support and educational adjustment plans.

In 2013, the Department of Education employed two senior level officers, one based in Darwin and the other in Alice Springs, to work with NT Government agencies and other non-government organisations on FASD related issues. Their work mainly focuses on developing resources that target the needs of NT students displaying behaviours and characteristics consistent with FASD. The project is a pilot and will extend throughout 2014-15.

A key focus of the project has been working with Anyinginyi Health Aboriginal Corporation in Tennant Creek throughout 2013-14 to develop culturally appropriate FASD teaching resources, as well as to evaluate the integrated approach taken to FASD in the school and broader community to inform systemic policy development. The implementation focus for 2014-15 will include supporting schools to meet the needs of students diagnosed with or displaying characteristics and behaviours consistent with FASD. Further, there will be a focus on working with NT Government and other non-government agencies to promote prevention and early intervention programs. Evaluation of the approaches taken at community, school and student level will inform future opportunities for program expansion.

Criminal justice system

There is currently no estimate of the number of offenders in the Australian criminal justice system. Overseas studies of people with FASD demonstrate that adolescents and adults with FASD are at high risk of encounters with the criminal justice system, either as offenders or victims (Streissguth et al 2004; Popova et al 2011; Jonsson et al 2014). For instance Streissguth et al found that of individuals with FASD, 60 per cent had encountered the law and half had been subject to confinement e.g. detention, prison, psychiatric or AOD inpatient service (Streissguth et al 2004). A Canadian study indicated that youth with FASD in particular are disproportionately represented in the juvenile justice system (Cox et al 2008).

Two Australian studies have explored the knowledge, attitudes and practice of professionals in the Western Australian (WA) and Queensland justice systems (Mutch et al 2013; Douglas et al 2013). Overall, the studies found that justice system professionals (e.g. judicial officers, lawyers, corrections staff, police officers) are aware of FASD, although require additional information relating to how it affects individuals and how best to respond and support them; have observed suspected FASD among individuals they have dealt with, raising concerns about the management of these individuals within the justice system; support assessment and diagnosis of FASD to improve the possibilities of appropriate consequences for unacceptable behaviour; and support appropriate alternative or diversionary sentencing options for people with FASD.

Economic costs

The complex consequences of FASD place a significant financial burden on the community and government. A Canadian study examined key costs components associated with FASD to estimate the annual costs associated with FASD per person. Key cost components included direct costs such as medical, education, social services, and out-of-pocket expenses, as well as indirect costs such as productivity losses. The estimated annual costs were over \$21,000 per person (around \$20,000 AUD). Costs of FASD to the Canadian community from birth to 53 years old were estimated at \$5.3 billion Canadian (around \$5.04 billion AUD) each year.

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.

ACTIONS THE GOVERNMENT CAN TAKE TO REDUCE FASD

It is recommended that actions taken by the NT Government to address alcohol use in pregnancy are grounded in a set of broader guiding principles:

- Actions must be embedded in a population health framework (Robinson et al 2011), in recognition of the fact that alcohol consumption during pregnancy and FASD are part of a complex interplay of biological, social, psychological, environmental and economic factors;
- Addressing FASD adequately will require a Whole-of-Government approach and a range of prevention measures, including universal strategies aimed at the whole population as well as targeted strategies for specific groups, especially school-age children and adolescents, women of child-bearing age, pregnant women and high-risk women (Pyett 2008).

Primary, secondary and tertiary prevention strategies to decrease alcohol use in pregnancy and harm to the unborn child should be developed, delivered and evaluated. A successful prevention strategy must take a holistic approach, utilise the evidence base and be part of a broader action plan to reduce alcohol related harms in the NT community.

Recommended guiding principles for NTG action:

- Consistent, clear and simple messages
- Utilise evidence-based strategies
- Community driven and locally adapted strategies
- Long term commitment
- Broad based policy initiatives and actions at different levels
- Non-judgemental and non-stigmatising
- Measure the effectiveness (or not) of what is being implemented
- Strategies that fall across the continuum of health promotion practice, as per the NT Health Promotion Framework (DoH - in press). For example: community action, health information and social marketing, health education and skills development.

Primary Prevention

Primary prevention strategies aim to reduce the incidence of FASD and must focus on both women of child bearing age and general population.

Reducing alcohol consumption and addressing social norms

Any potential permanent brain damage caused by in-utero exposure of the developing foetus to alcohol can be prevented by the avoidance of consumption of alcohol during pregnancy. On an individual level, prevention of FASD relies on the willingness and ability of women to avoid alcohol in pregnancy. Education of women of child bearing age regarding potential harms of alcohol use in pregnancy and FASD is required but may not change behaviour. A range of prevention initiatives are thus required across society to change attitudes and behaviour in respect to alcohol use, including during pregnancy.

Overall alcohol consumption at the population level is a crucial driver of maternal alcohol consumption during pregnancy and thus FASD. Central to reducing alcohol related harms generally and the risk of FASD more specifically in Australia is addressing the issues of alcohol availability, affordability and the Australian drinking culture.

Relevant strategies include:

- Reducing availability / supply of alcohol (e.g. reviewing liquor outlet density, trading hours)
- Regulating price (e.g. volumetric tax)
- Regulating alcohol advertising (e.g. eliminating promotions that increase consumption)

- Health professional and community education e.g. Territory wide and targeted public health awareness campaigns
- Brief interventions in primary and allied health care settings
- Support for health warning labels on alcohol products

It is important that programs that address known key determinants of alcohol consumption and that have demonstrated measurable reductions in alcohol consumption are not overlooked. The crucial issue is that more effective approaches to reducing the consumption of alcohol during pregnancy in vulnerable communities need to be urgently established, trialled and then evaluated.

Increasing public awareness of the harms associated with alcohol consumption during pregnancy

There are clear messages that can form the basis for action of the NTG:

1. For women who are pregnant or planning a pregnancy, not drinking is the safest option. This message is to be presented in a balanced and rational format (NHMRC 2009; Burns et al 2012).
2. Alcohol misuse and FASD are whole of population concerns, with high risk populations requiring more targeted interventions and support.
3. Preventing alcohol misuse and FASD is everybody's responsibility.

The 'Strong Women's, Strong Babies, Strong Culture' program provides one promising and culturally respectful avenue to educate Aboriginal women about the risks associated with drinking during pregnancy, such as FASD. However, broader health promotion and prevention efforts, with our target populations, are also required. The perception that FASD is affected only by a woman's choice is a major barrier to effective prevention efforts (Jonsson et al 2014) - prevention is a shared duty. Mothers, partners, families, communities, health professionals, service providers, the liquor industry, and Government each must take responsibility and take steps to prevent drinking in pregnancy.

Population wide health education and social marketing campaigns and community programs should utilise a clear, consistent message. While it is ultimately the mother whose drinking choices determine the risk of FASD, the role society can play in this 'choice' should be promoted in campaigns and programs, in particular the role of partners could be a focus.¹⁵ It is recommended that the NTG support urban and remote communities to develop and deliver these messages through increased investment in health promotion and public health efforts.

Routine screening of women of childbearing age for alcohol misuse in primary health care settings, with referral pathways in place if misuse is identified, is essential as an early prevention measure.

Sexual health education and contraception

Given that approximately half of all pregnancies are reported to be unplanned (Burns et al 2012), it is likely that many women inadvertently expose their unborn child to alcohol before they are aware of their pregnancy. Ensuring women of childbearing age have access to sexual health education and reliable, affordable contraceptive options is a practical and effective strategy to reducing the risk of exposing unborn infants to alcohol, in addition to working to reduce alcohol consumption by the broader population and during pregnancy.

¹⁵ <http://fasdprevention.files.wordpress.com/2014/02/what-men-can-do-final-feb-2014.pdf>, <http://pregnantpause.com.au/>

A coordinated intra and interagency approach to health and sexual health promotion is recommended (DoH Alcohol and Other Drugs Services and the Centre for Disease Control and DCF).

Secondary prevention

Secondary prevention strategies to reduce FASD aim to reduce the risk of alcohol related harm to the developing fetus.

Preventing or minimising alcohol consumption during pregnancy

Screening of alcohol consumption in women

It is important for maternal and fetal health for women to have their first antenatal visit within the first trimester of pregnancy. The World Health Organisation classifies less than four antenatal visits during the whole pregnancy to be insufficient (WHO 2007). Findings in the 2011 Mothers and Babies (Thompson 2014) regarding missing alcohol consumption data and delayed antenatal visits among Indigenous mothers indicates a need to ensure early engagement in both remote and urban communities to ensure optimal care for both mother and baby.

The NT has a strong network of antenatal services. 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 alcohol 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.

Addressing drivers of drinking during pregnancy

Many underlying causes exist for alcohol consumption during pregnancy and vary between individuals and population cohorts. These may include: social pressure to drink, lack of consistent information relating to the risks of drinking during pregnancy, drinking prior to the pregnancy being recognised and untreated mental health issues (Jonsson et al 2014). The complex biological and social determinants of health are also essential to consider e.g. genetics, remoteness, poverty, domestic violence, malnutrition, poor social support networks and personal autonomy, adverse life events, trauma, social isolation, stress (Jonsson et al 2014). A coordinated interagency approach (e.g. Education, Justice, Health, DCF) will be required to address these factors.

Treatment of alcohol use disorders for pregnant women

Women planning pregnancy and pregnant women who drink at levels considered to be risky should have access to support services and evidence based treatments. Information about the effectiveness of pharmacotherapies and psychosocial interventions for pregnant women who consume alcohol at risky levels is limited. There is a need for research on safe, ethical, effective and culturally responsive treatments for pregnant women with alcohol-use disorders and support for their families. The broader context in which women live also needs to be taken into account during treatment (see above drivers of drinking during pregnancy).

Screening for FASD / in utero alcohol exposure

Early identification of in utero alcohol exposure can enable early intervention to reduce the harms to the developing fetus or child, however there is currently no standardised FASD screening test in use in Australia and limited capacity of health professionals to confidently screen for FASD.

Screening needs to be based on an agreed standard set of criteria for referral that can be consistently used across the many likely settings where screening will take place. The pathway beyond screening similarly needs to be standardised and consistent and be navigable by NT families and service providers.

Population-based screening for FASD is not recommended as there are no validated population based screening tests available. Rather, screening could be undertaken in high-risk groups.

These groups may include:

- Infants with a maternal history (self-reported) of antenatal alcohol consumption
- infants discharged from a drug dependency service in obstetric units
- Children taken into child protection services
- Adolescents entering the justice system
- Adolescents receiving mental health services
- Children with profound learning and behavioural difficulties.

It is recommended that NTG conduct consultation with relevant stakeholders from these areas to decide on the feasibility, acceptability and effectiveness of potential screening in these settings.

Diagnosis of FASD

Diagnosing FASD is a complex proposition and process and there is no single internationally accepted instrument or classification system. As with any health condition, early diagnosis can enable timely and appropriate interventions to prevent or at least greatly minimise secondary disabilities associated with FASD (e.g. mental health issues, AOD misuse, and interaction with the criminal justice system). It is important however that NTG does not prematurely invest in costly diagnosis programs until more robust evidence emerges in support of FASD diagnostic tools, in particular those under development across Australia. Diagnostic tools will need to be safe, ethical and culturally responsive and take into account other social determinant of health.

An ethical approach to the 'diagnosis' would be for a continuation of the current criteria for disability diagnosis; people who have a neurodevelopmental, behavioural or cognitive disability, have access to services and are able to identify their disability as early as possible, whatever the presumed cause of that impairment, for any reversible cause of the disability to be identified and removed, then for appropriate professional support services provided to permit them to live their lives to the best of their capability, regardless of any hypothecated cause of that impairment.

Early childhood interventions

While there appears to be little or no significant research demonstrating that current support interventions for FASD can reverse the neurodevelopmental injury incurred by in-utero exposure of the developing foetus to alcohol, these interventions may provide much valued, and much needed, social and developmental supports for affected individuals and families where in utero alcohol exposure has been identified.

The extensive primary health care services provided by the NTG and Aboriginal community controlled health organisations are well placed to provide culturally appropriate early childhood interventions to Indigenous mothers and their children. In the urban centres, where the majority of non-Indigenous Territorians reside, NTG Community Health Services, Mental health services and non-government agencies are best placed to provide supports. DoH, DoE and DCF could work in partnership to ensure FASD is addressed through existing early childhood programs and support services.

Tertiary prevention

Health care services

Tertiary prevention strategies, generally delivered by health professionals, aim primarily to support women with an alcohol related dependency and / or women known to have a FASD child to prevent further future alcohol exposed pregnancies. Promoting the health and wellbeing of the mother and health, wellbeing and development of the child/person affected by alcohol in utero are the focus of these strategies.

DoH should ensure that health professionals who work in areas where they are likely to encounter individuals exposed to alcohol in utero are provided with training to tailor management plans and health promotion messages to the special needs of FASD individuals. There are significant cognitive, mental health and behavioural outcomes associated with FASD. These require the direct input and management from mental health, allied health and social and emotional wellbeing workers.

Interagency coordination and case management will optimise the outcomes for individuals, families and communities.

FASD in the education setting

FASD children will have widely differing educational needs. These need to be reflected in the planning of how, when, and what services are delivered. It is not the remit of the DoH to provide recommendations regarding education services, however program partnership and joint case management across health (including disability services) and schools is recommended.

Instead our recommendations are the need for services for FASD children to not be siloed into services under medical, education or mental health banners. FASD requires complex management.

Many individuals will never gain the life skills needed to live independently. Many will be at risk of victimisation. The NTG needs to ensure that planning and provision of supported accommodation options takes this population into consideration.

FASD in the criminal justice setting

Greater awareness of FASD, how it can affect individuals and how best to respond and provide support to them is required throughout the criminal justice continuum (e.g. police, lawyers, corrections).

FASD in the child protection setting

Research suggests that a significant proportion of FASD children will enter into child protection services. Case management and an intensive family support model should be considered to prevent the high proportion of FASD children entering into the child protection system.

NTG should ensure awareness and training for staff involved with child protection services in FASD. Resources and supports should be made available for carers who take over the care of FASD individuals. A partnership between DCF and DoH to ensure consistency of health promotion and prevention efforts tailored to at risk groups is recommended.

Optimising the environment

A Whole-of-Government approach is needed to prevent FASD including addressing the social determinants of health.

Healthy, stable home environments and infrequent changes in living arrangement are known protective factors for children with FASD.

We know that FASD children are at higher risk of harmful alcohol use themselves. Parents and close family members of FASD with alcohol and substance abuse issues could be prioritised and better targeted to receive support and education about the influence of their actions.

FASD individuals may also benefit from specific strategies regarding assisted employment or community service tasks.

Addressing our knowledge deficits

There are many areas where key information is lacking on the impact of FASD in the NT and what are the best methods of action the NTG can take to reduce this burden. However this should not delay action. Rather, strategies to fill these information gaps and build our own 'evidence bank' should be integrated from the outset in the NTG plan.

The NTG should seek to work in partnership with research institutes, Aboriginal community controlled organisations, and health and education professionals to develop reliable and practical methods to measure both the impact of FASD, and the effectiveness of interventions.

These should draw upon systems already in place wherever possible and reduce the need for duplicating work. Furthermore it is important to have strong support and guidance among those who this information affects to ensure that better diagnosis does not equate to labelling and stigmatising families, and that measuring effectiveness of a program takes into account the perceptions and values of those receiving the program.

Long-term follow up and support for FASD adults will be needed. Data linkage and share health records may offer opportunities to better elucidate the long-term consequences and needs of FASD individuals and their families in the Northern Territory.

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ATTACHMENT A

Pathophysiology of alcohol as a teratogen (toxin) upon the fetus and FASD

FASD describes the teratogenic effects of alcohol upon the embryo and fetus, which result from the toxic effect upon normally proliferating and migrating cells in the embryo, as well as disrupting normal electro physiologic and neurochemical development of brain tissue in the fetus.

Alcohol is classified as a teratogen upon the growing embryo (0-8 weeks gestation) and consequently upon the developing foetus (8-40 weeks). It inhibits cell proliferation and migration resulting in growth retardation of all structures. As the central nervous system (CNS) is continually developing, differentiating and growing throughout pregnancy, this tissue and structure is highly vulnerable to the effect of alcohol. During the latter trimesters of pregnancy, it is the electrophysiological and neuro-chemical brain development that is particularly affected, resulting in the well described neuro-behavioural and brain processing functional disabilities.

Alcohol is typically metabolised by the liver, however fetal hepatic (liver) function remains immature till well after birth. From around the tenth gestational week, hepatic enzymes to metabolise alcohol begin to activate, however remain at less than 10 per cent that of the mother.

The maternal blood alcohol transfers directly across the placenta and equilibrates with the fetus. Although the mother is able to metabolise her blood alcohol with her fully active level of hepatic enzymes, the fetus is only able to metabolise at a much reduced rate with un-metabolised alcohol remaining within its surround amniotic fluid for a prolonged period of time.

The diagram below illustrates the development periods for many organ systems. Vulnerability of the fetus to alcohol-related defects may occur during these periods.

Source: http://www.ias.org.uk/uploads/images/the-globe/gl200702-200701_p13s14.jpg

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