

Submission to the Legislative Assembly of the Northern Territory Government
Select Committee on Action to Prevent Fetal Alcohol Spectrum Disorder.

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Reducing the harms of FASD in the Northern Territory
through prevention and intervention.

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fetal alcohol spectrum disorder

TRAINING AND CONSULTING

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About the Author

Prue Walker (BA Hons, MA (Soc Pol), BSW) undertook a Churchill Fellowship in 2009 when she travelled to Canada and the United States to explore models of care for children with FASD. She presented her findings at the APCCAN Asia Pacific Conference on Child Abuse and Neglect in Perth 2009, and since that time has convened workshops and delivered training for health and child protection workers in the Northern Territory in relation to FASD, including assessment, prevention and case management.

In 2010 Prue collaborated with Alcohol and Other Drugs and other agencies to run a 3-day symposium on FASD in Alice Springs, which attracted expertise in the field including Professor Elizabeth Elliott from Sydney, Vicki Russell from Tasmania and speakers from the Fitzroy Crossing Lililwan Project and the Ord Valley FASD project in WA. Prue also spoke at a NAPCAN forum to mark International FASD Awareness Day in Darwin in 2011.

Prue has been employed for 15 years in child protection in both Victoria and the Northern Territory, most recently as Practice Leader, Department of Human Services (DHS), Victoria and earlier worked for 10 years in non-government homelessness services. Prue was employed by the NT Department of Children and Families (DCF) between 2006 and 2011 as a Child Protection Manager in both Alice Springs and East Arnhem where she was responsible for case management of a number of children with FASD. Since 2012 she has delivered FASD training for DCF which has become a regular part of the training calendar.

In 2013 Prue completed a FASD research project in conjunction with Menzies Institute of Health Research and the Department of Children and Families (DCF) exploring the prevalence of children at risk of FASD within the child protection system. The report is in the final editing stages prior to publication. Prue presented her findings at the Australasian Fetal Alcohol Spectrum Disorders Conference in Brisbane in September 2013 and at the Australian Association of Social Workers conference in Darwin in March 2014. In 2014 Prue established a

consultancy specializing in education and training for professionals and carers in FASD.

1. Summary and Recommendations

Alcohol has a devastating impact on family and community life across the Northern Territory. Aboriginal communities are particularly vulnerable to the impacts of alcohol including violence, assaults, alcohol related injuries, deaths, suicides, motor vehicle accidents and exposure of children to abuse and neglect, which is sometimes fatal.

The National Indigenous Drug and Alcohol Committee Strategic Plan 2012-14 states:

Patterns of alcohol, tobacco and other drug use among Indigenous Australians have been shaped by history. With the effects of dispossession, alienation, trauma and loss recognized as contributing factors to the lower health and socio-economic status that Indigenous Australians continue to experience today, the use of alcohol, tobacco and other drugs have consequently become the cause and effect of much suffering in Indigenous communities.¹

Fetal Alcohol Spectrum Disorder (FASD) represents one of the least recognised causes of alcohol related harm, with an enormous impact on individuals and families. FASD is a lifelong condition that is rarely diagnosed in Australia, despite affecting as many as 1:100 people in the population. FASD is more likely to be concentrated in areas where there is a high level of alcohol abuse, and there are vulnerable populations and communities across the NT. In Aboriginal communities FASD can have devastating consequences, where oral traditions rely on memory and where community development depends on growing children into strong future leaders. Children with FASD have a range of impairments, which require ongoing support. They may not be able to take their place as community leaders.

The Marulu Project in Fitzroy Crossing, Western Australia, was developed in response to this very need:

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 started²

The impact of FASD is long term, and it is suspected that many individuals in prison are there due to a brain injury caused by fetal alcohol exposure. It is possible to divert individuals from the correctional system if appropriate interventions are put in place, but these need to commence with early identification, diagnosis and assessment in childhood. For some adults it may be too late to change the course of their lives but we have the capacity to do things differently for children in the Northern Territory.

The Northern Territory has an opportunity to look at what other jurisdictions are doing in relation to FASD both in Australia and Internationally. We can learn from effective programs through which FASD is routinely diagnosed and treated as a lifelong condition, and many of the negative consequences can be significantly reduced through effective service delivery. There is an extraordinary level of interest in the area of FASD in the Northern Territory at present, and many health and drug and alcohol workers do as much as possible to raise awareness of FASD using existing resources and within existing program design. However we lack specific services funded to work with affected individuals, diagnostic teams and an NT-wide prevention strategy.

The Northern Territory has potential to be a leader in this field. Investment is required in a cross-government approach to FASD as a unique disorder affecting many children and adults. Investment in this area will save money in the long term by preventing further births of children with FASD, assisting those living with FASD to have productive lives and remain out of the justice system, and reduce the health burden by ensuring the community is aware of the risks of alcohol in pregnancy.

Recommendations to Reduce the Harms of FASD in the Northern Territory through Prevention and Intervention:

1. Reducing the harm of FASD through Diagnosis

- That FASD be declared a Disability
- That Disability support services be resourced to provide support services to individuals and families affected by FASD.

2. Reducing the harm of FASD through Prevention

- Establishment of a cross-government response to FASD
- Implementation of population-based prevention programs to address the risks of alcohol in pregnancy
- Implementation of targeted prevention programs based on those developed in Aboriginal communities in Australia to reduce the prevalence of FASD in those communities
- Implementation of indicated prevention targeting women most at risk of an alcohol-affected pregnancy including implementation of a prevention program based on a model such as the Parent-Child Assistance Program.

3. Reducing the impact of FASD through treatment and support of affected individuals

- That FASD Multidisciplinary Diagnostic Teams be established in the Northern Territory

- That training and education be provided to improve the capacity of generic social and health services to respond to individuals and families affected by FASD
- That specialist services be developed to provide expert services to individuals and families affected by FASD.

4 Reducing the harm of alcohol on children in the child protection system:

- That Child Protection services work closely with Alcohol and Other Drug Services to ensure that family assessments and interventions incorporate evidence based practice from both sectors, and that interventions include longer-term monitoring where there is evidence of long term alcohol use.
- That specialist child protection assessment and planning occur for infants of mothers who are consuming alcohol to a concerning degree
- That children with FASD have access to specialist assessment, diagnosis and intervention planning
- That foster carers and kinship carers receive specialist training and support to manage the care of children with FASD
- That Child Protection services develop a model of best practice for supporting children with FASD who are at risk of abuse and neglect.

2. Background to the Submission

In 2011 I prepared a written submission to the House of Representatives Standing Committee on Social Policy and Legal Affairs Inquiry into Fetal Alcohol Spectrum Disorders. My submission was quoted extensively in the Final Report of the Inquiry in *Chapter 5: Management Needs*.

I have included relevant sections from this submission where appropriate. Many of my observations and recommendations were based on my experience working in the Northern Territory (NT) Child Protection system, where Aboriginal families are over-represented. Therefore many of my comments about the impact of FASD and alcohol-related harms in families involved with the Child Protection system apply equally to the Aboriginal population.

My comments in this paper relate specifically to Aboriginal communities in the NT where I worked in Child Protection services between 2006-2011 and where I currently provide FASD training and education.

In this submission I will be addressing the Terms of Reference, specifically:

- 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. Fetal Alcohol Spectrum Disorder (FASD)

Fetal Alcohol Spectrum Disorder (FASD) is an umbrella term for the range of effects of fetal exposure to alcohol. In its most severe form, Fetal Alcohol Syndrome (FAS), children have distinctive facial features, impaired growth and central nervous system damage. In less severe cases, there are no visible signs and the main impairment is a brain injury which can be identified through a range of assessments of different domains of functioning – memory, cognition, learning, speech and language processing, motor skills and others. However many

individuals with FASD have an IQ in the normal range, and therefore their disability is difficult for a single medical practitioner to assess.

FASD is a lifelong condition and its impact varies across the lifespan. Some infants are particularly affected and have significant health conditions or birth defects. Others present as healthy and their care is straightforward, until some of the brain dysfunctions become evident in childhood, usually in the primary school years. Adults with unrecognised FASD can have particularly poor long-term outcomes as detailed below.

Paediatricians in Australia can diagnose individuals with FAS, although not all are confident in making the diagnosis. Broadly speaking, as there are variations between different states and territories, a preschool aged child diagnosed with FAS will be able to access specialist services for children with developmental delays, and a school aged child will be able to access disability supports, as long as their IQ score is below 70 or they have another diagnosis which allows for support funding such as ADHD/ADD. If a diagnosis is not made in childhood, it may not be made at all. The facial features of FASD can be assessed in adults by FASD clinics in the US and Canada but are generally considered to be within the domain of paediatricians in Australia.

Children with FASD who do not meet the diagnostic criteria for FAS are rarely diagnosed in Australia. FASD screening in Australia exists in only a few locations (Fitzroy Valley in WA, the Gold Coast children's developmental clinic) and national guidelines for assessment and diagnosis have not yet been agreed upon. As a result individuals with FASD are rarely identified and therefore go through life with a range of specific impairments but no diagnosis. While many professionals working with children and families are interesting in identification and screening of children for FASD, particularly in the NT, the disorder also affects adults, but these adults have no access to diagnostic services and therefore their disability is invisible, but very real.

Some of the functional impairments associated with FASD lead to social and behavioural problems, as the parts of the brain associated with impulse control, emotional regulation, understanding cause and effect and moderating behaviours to be socially acceptable can be impaired. The brain injury, combined with the lack of understanding by those around them, can lead to a range of long-term impacts for individuals including:

- Difficulty staying in school
- Difficulty managing housing or paying bills
- Difficulty getting or maintaining employment
- Difficulty managing social relationships
- Vulnerability and risk of exploitation by others
- Difficulty managing the tasks of parenting.

The problem is compounded by the fact that FASD is not recognised as a disability and currently not diagnosed in Australia, therefore there are no support designed to meet the needs of individuals with FASD. When the individual does not have their needs identified and met through appropriate support services, the consequences can include:

- Substance abuse
- Mental illness, particularly anxiety and depression
- School exclusion
- Criminal behaviour
- Living in a violent or unsafe environment, or homelessness
- Involvement with the Child Protection system as parents.

One of the challenges of FASD is that there is enormous variety of presentation within the spectrum. Some individual have a normal IQ, others have a significant intellectual disability. Some individuals have clear neurological signs and delayed development; while others only display difficulties when more advanced cognitive functions are required – such as making good social choices.

Barriers to identification of FASD in adults include:

- While evidence indicates facial features can be diagnosed at any age, there is reluctance to make diagnosis in newborns, adolescents or adults
- Growth deficiencies are no longer evident in adolescents
- Lack of reliable sources for personal history other than self-reporting
- Diagnosis often requires a social worker acting as a detective seeking out personal history details
- Few diagnostic options for adult diagnosis (in countries where diagnostic teams exist).³

4. Prevalence of FAS and FASD

International estimates of FAS and FASD are generally in the range of 0.5-2.0 births per 1000 for FAS, and 10 per 1000 births for FASD. Estimates vary based on the diagnostic criteria used.⁴

In the NT Harris and Bucens (2003) identified a rate of FAS of 0.68 per 1000 live births and 1.87 per 1000 live births in the Aboriginal population. A Western Australian study identified a rate of FAS of 0.02 per 1000 non-Aboriginal children and 2.76 per 1000 Aboriginal children. Due to lack of diagnosis for FASD in Australia there is little data, however there is consistent evidence that Aboriginal children are overrepresented among children with FASD.

The report of the House Standing Committee on Aboriginal and Torres Strait Islander Affairs, *Doing Time –Time for Doing: Indigenous Youth in the criminal justice system* identifies the difficulty of obtaining accurate prevalence data for FASD in Australia. 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 1000⁵, and the estimate by Professor Marcia Langton that FASD affects 1:40 indigenous children.

5. FASD as a factor in children being placed in out of home care

Until very recently, FASD has received little attention in Australia as either

- a contributing factor to children entering care
- a complicating factor in working with families where parents have addictions, and
- a syndrome requiring significant case management resources for children in care.

Studies focusing on the needs of children whose parents abuse alcohol tend to focus on factors such as: the effect on parenting capacity; risks of abuse or neglect due to alcohol related harms such as violence; health issues of parents; and financial stressors due to addiction. Long-term harms to children are often identified as behavioural issues due to parenting deficits. However the issue of harm to the child's health and development through exposure to alcohol in-utero is not given sufficient prominence or attention.

- A literature review entitled *Parental alcohol misuse and the impact on children* published by the NSW Department of Community Services in 2006 makes only passing mention of Fetal Alcohol Syndrome and quotes only one reference.
- A practice paper produced by Queensland Government Department of Child Safety in 2007 entitled *Parental substance misuse and child protection: intervention strategies* makes no reference to FAS/FASD or pregnancy.
- A report on *Child Protection and Mothers in Substance Abuse Treatment* produced for the National Drug and Alcohol Research Centre, University of NSW in November 2011 makes no mention of FAS/FASD, although a proportion of mothers sought treatment due to pregnancy. Mothers were in treatment for opioid addiction but 21% had had an alcohol problem in the last 12 months.
- The paper, *Issues for the safety and wellbeing of children in families with*

multiple and complex problems: the co-occurrence of domestic violence, parental substance misuse, and mental health problems, published by the National Child Protection Clearinghouse in 2010, mentions the negative impact of alcohol in conjunction with diet, drug use, stress and violence in pregnancy. However there is no reference to FAS/FASD. 

Examples of resources where FASD is recognised include the Victorian DHS Specialist Assessment Guide for Assessing Parental Substance Use, 2000. This guide includes prompts around identification of FAS and states:

- *Newborn Infants diagnosed with fetal alcohol substance abuse symptoms are one of the highest protective risk categories for short and long term damage to their physical, social and emotional health and well being.*
- *The World Health Organisation estimates over 90% of pregnant women use some sort of drug during their pregnancy and that 2%-3% of all birth defects are due to drug use.*
- *The immediate and unique needs of these infants require parental care and skills not usually evident in substance abusing parents.*
- *These children are likely to require ongoing medical, community health and welfare services to overcome the damage cause to them prior to birth.* 

More recent documents from Victoria, such as the DHS guide entitled *Infants and their Families: Best interests case practice model* (2010), reference FAS as a possible factor in assessments but miss an opportunity to provide child protection workers with a more detailed understanding of FASD and the complexities of assessment and case management.  Western Australia has become a leader in FASD research and the WA Department of Communities is the only statutory agency which includes a webpage on FASD and Fetal Alcohol Spectrum Disorder in the Child Protection System: Opportunities for Prevention and Intervention and an information brochure on FASD which outlines the signs and ways to support affected children. A Fostering Fact Sheet is also available outlining some of the issues involved in fostering children with FASD.

These limited references are reflective of the under-recognition of the prevalence and impact of FASD in Australia, particularly its impact within families that come to attention of child protection services. Behavioural issues that can be explained as the result of abuse, neglect, exposure to parental alcohol or drug abuse, and consequent parenting deficits may in fact be due to a brain-based disorder that is going unrecognised.

Literature on the issue of child abuse and neglect in families where carers misuse alcohol tends to focus on the impact of impaired parenting, exposure to violence and other consequences, and if FASD is referenced it is generally as a condition affecting infants. However little attention has been paid to the combination of a child with FASD and a parent whose capacity is impaired by alcohol or other drugs. These children are some of the most vulnerable as their disability is unrecognized, their carers may not be attuned to their specific needs and they are not likely to receive the stability, quality care or services required to reduce the risk of secondary disabilities.

6. Children with FASD in the Child Protection System

Infants with FASD may present with growth difficulties, and may come to the attention of child protection services due to concerns related to parental alcohol use. Child protection interventions may focus on assisting the parents to address substance abuse while working to protect the child's safety and address their immediate health concerns.

If questions are raised at this stage about possible fetal alcohol exposure, there is unlikely to be a clear pathway into and through the service system. Child protection workers may not have information or resources to allow them to predict that the child may also experience speech and language problems or other developmental delays. The child may be slow to reach milestones but this may be attributed to a poor start in life, exposure to violence, and/or and early neglect or deprivation.

If the infant is placed in foster care, it may be some time before the carer can

identify that the infant is not meeting developmental milestones. Allied health services may have waiting lists, and other factors such as family access may also be involved. If the infant is placed with in a kinship placement, carers may not have sufficient experience to identify delays and it may be more difficult for the family to seek help. A carer or family member who suspects FASD may not be confident to raise the issue as they may consider it too sensitive.

When a child with FASD enters the care system, their care is likely to be complex. Typically, children with FASD require:

- Stable, safe environments
- Structure and routine
- Repetition and predictability
- Consistency
- Reward and redirection rather than punishment
- Close supervision
- Role modelling^[L SEP].

Children in care can experience changes and instability that is particularly ^[L SEP]difficulty for children with FASD to process. These include:

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

These children already have a background of abuse, neglect and/or trauma, which will have a significant impact on their emotional and social development, and they are likely to have a range of behavioural issues that may overlap with behaviours associated with FASD. ^[L SEP]

While visiting services as a part of my Churchill Fellowship I attempted to grapple with some of these disparities in assessing what is the best model of care for children with FASD. The issues are very complex.

A child with FASD in foster care who is receiving good quality care and support and is able to access a range of services and interventions to assist in their development and behavioural will benefit in some areas. Access to speech and language and other therapies and access to specialist support in the school setting are beneficial. Children with FASD in foster care also experience many behavioural issues that put strain on the placement. They can be subject to poor long-term outcomes and placement breakdown. The success of the placement is largely dependent on the level of training provided to the carer, other supports such as respite, and access to workers knowledgeable about FASD.

Another factor is the regular access between children in care and their family members. It is not uncommon for foster care placements to break down after periods of contact with family members, which the foster carer may feel destabilizes the child for whom routines have been established in placement that reduce the child's behavioural issues. Transitions are difficult for all children in care but those with FASD often cope with change poorly. However the access is necessary to provide the child with the emotional and cultural connections to family that will endure beyond the life of the placement.

There is also the likelihood that Aboriginal children raised in care will seek out their family of origin when they leave care. Growing up in a non-Indigenous environment may make it difficult for the young person to fit in with their family after leaving care, and negative outcomes such as mental health issues, isolation or homelessness may result.

The same child raised by extended family in an environment will benefit from strong emotional connections and a sense of belonging, which fosters emotional well being which may protect them from some of the negative long-term impacts of FASD. Their behavioural issues may be less of a concern if living in communities with less restrictive boundaries and expectations than a non-Indigenous foster carer. However the family may not be able to access the allied health services and developmental supports the child requires. They may also be living in overcrowded homes with poor food security and hygiene issues, cared for by over-stretched family members. Family members are unlikely to have

access to FASD diagnosis and support and may not understand some of the behavioural issues.

Care for children with FASD will be improved if both the foster care sector and kinship carers are resourced and educated about FASD. Aboriginal children with FASD may benefit from placement with Aboriginal families who have more in common with their family environment. At the same time I have had contact with non-Aboriginal carers who have provided excellent care for children with FASD and have gone out of their way to develop relationships with family and bridge the gap between the two cultures. There is no one-size-fits all in this area. Decisions need to be made by skilled Child Protection practitioners, in consultation with family members, and these enormously complex issues resolved on a case-by-case basis.

Education and training on FASD for child protection services, carers and family members is essential to improve service delivery to this group of vulnerable children. Case management of children in care needs to be informed by international best practice in FASD.

7. Findings of the study: Fetal Alcohol Exposure among Children in the Child Protection System in the NT

In 2014 I authored a study of fetal alcohol exposure among children in the Child Protection system in the NT. The project report is currently being finalised by the Department of Children and Families and will be provided to this Committee when completed. Findings reported to date are as follows.

The study involved 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.

7.1. Concerning alcohol use by parents

In the absence of information about the levels of alcohol consumption by parents, which would allow a level of "risky" alcohol consumption to be identified, the study identified "concerning" alcohol use by parents, which was recorded where:

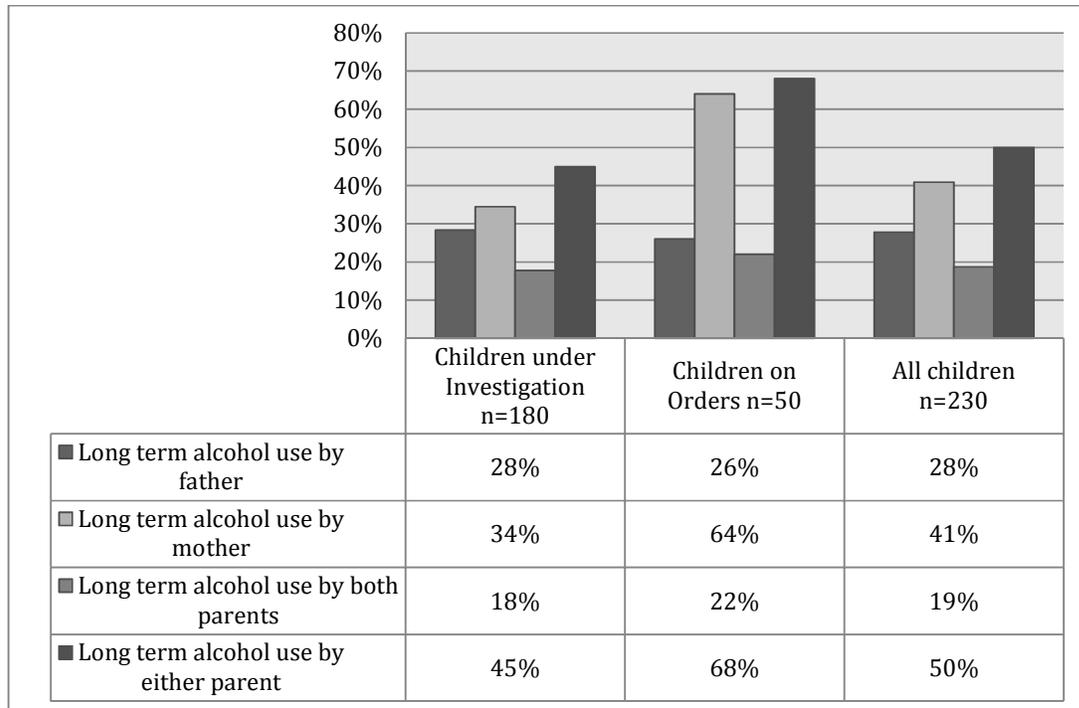
- Parental alcohol use was reported as a concern to Child Protection or identified as a concern by family members or professionals;
- Parents had a criminal history including alcohol-related offences;
- Alcohol use was identified in the report as impacting on parenting capacity (neglect, lack of supervision, lack of food, or medical neglect);
- Children were placed at risk due to parental alcohol use (exposure to alcohol-related domestic violence, car accidents, being dropped, exposed to the elements, or physically harmed);
- Children were residing with other family members due to parental alcohol use.

The study found that:

- 63% of children in the study had been exposed to concerning alcohol use by one or both parents;
- 86% of children in care had been exposed to concerning alcohol use by one or both parents;
- 76% of those in care were exposed to concerning maternal alcohol use, and;
- 50% of those in care had been exposed to concerning paternal alcohol use.

Maternal alcohol use was most prevalent, affecting 34% of children under investigation and 64% of children in care.

Figure 2: Long Term alcohol use by parents



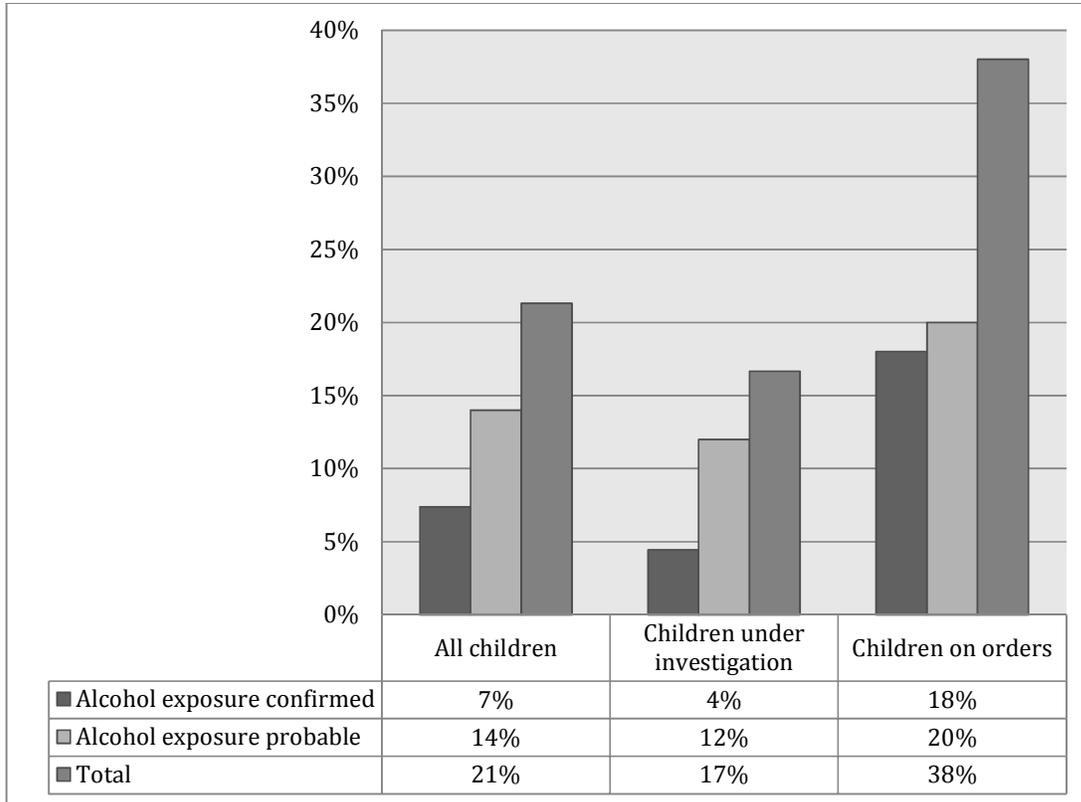
7.2. Fetal Alcohol Exposure

The study identified through case file reviews whether there was evidence of maternal alcohol consumption during pregnancy. In many cases there was no available data, such as in cases where the child was the oldest in the family and the family therefore had no child protection involvement during the pregnancy. The most accurate data was obtained in cases where DCF was involved with older siblings during the period of a subsequent pregnancy.

Fetal alcohol exposure could be confirmed in cases where there was direct evidence, such as a mother being admitted to hospital for alcohol related causes while pregnant, or police involvement for an alcohol related offence during pregnancy. In these cases, fetal alcohol exposure was **confirmed**. In other cases there was no contemporaneous evidence of alcohol consumption during the pregnancy but there was evidence suggestive of alcohol consumption, for example, evidence of alcohol consumption just prior to the start of pregnancy combined with alcohol consumption immediately after the birth. These cases were recorded as **probable**.

21% of all children were recorded as having been exposed to fetal alcohol consumption, with 7% of those cases confirmed and 14% probable. This rose to 38% of all children in care, with 18% confirmed and 20% probable.

Figure 3: Fetal exposure to alcohol for children under investigation and children in care.



7.3. Presence of FASD Indicators

The study looked at whether FASD indicators could be identified for children who had been fetally exposed to alcohol.

Of the children fetally exposed to alcohol:

- 6% had a FAS diagnosis
- 8% had suspected FAS

- 10% experienced growth delay/prematurity/low birth weight
- 10% experienced speech or language delay
- 23% had behavioural problems

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

7.4. Conclusions of the study

The study identified that significant numbers of children had been fetally exposed to alcohol (38% of those in care) although not all children would be expected to go on to develop a FASD.

Recommendations of the study are being finalised at present and will be provided to the Inquiry when available.

8. FASD as a disability

FASD is unrecognized as a disability in Australia and there are many consequences including:

- lack of diagnostic services
- lack of access for children to classroom assistance and other supports

Children with FASD grow up unaware that they have a brain-based disability. These children grow up knowing that they don't fit in, particularly at school, but believe that they are stupid. Without a diagnosis they are denied the opportunity to understand their own condition and to begin to understand behavioural triggers and

Adults with FASD may be involved with the criminal system, homelessness services, domestic violence services, mental health and drug and alcohol services. They may seek care from hospital emergency departments, have children placed in care and have repeated episodes of incarceration – all at great cost. Recognition of FASD is the first step in allowing adults with FASD to understand

that they have a brain-based disability and to understand why they struggle with some of the tasks of daily living.

When I found out I had FASD, it was a big relief. Knowing it was a medical condition explained a lot to me. With help, I began to learn different ways to cope with my difficulties.⁶

Disability services are not well resourced to manage the number of affected individuals and are likely to require support, education and training to develop appropriate responses to this target group. However models of service delivery in the US and Canada demonstrate that FASD service provision can be integrated into the broader social service sector, and that it is not necessary to develop stand-alone services.

Recommendations:

- That the NT recognize FASD as a Disability
- That disability support services be resourced to provide support services to individuals and families affected by FASD.

9. Reducing the harm of FASD through Prevention

Prevention of FASD needs to occur at many levels. At the community level, information is required to education the population about the facts about alcohol in pregnancy. Communities with high levels of FASD require locally developed, owned and driven solutions which engage all parts of the community. Mothers who are at high risk of giving birth to a child with FASD require targetted intervention, based on an understanding of best practice with women with addictions and an acknowledgement of the complex factors contributing to alcohol use in pregnancy.

9.1. Community Prevention

The Northern Territory requires a wide-ranging strategy to educate the community about the harms of alcohol consumption in pregnancy. Australian culture is one in which alcohol holds a unique place, and in comparison to smoking, is heavily normalized. There has been recent media coverage suggesting that there is no harm in consuming low levels of alcohol in pregnancy. Data from the University of Washington FASD clinic indicated that one in every 14 children diagnosed with FAS (not FASD) was exposed to one drink of alcohol per day. One in every seven children diagnosed with FAS was exposed to between 1-8 drinks per week.⁷ This message is not reaching the Australian population who feel confused about medical guidelines for alcohol in pregnancy.⁸

Generic information strategies usually only change behaviours in individuals who take such messages on board. Attitudes to alcohol consumption are complex and information is only one part of the picture. Many women who consume alcohol in pregnancy do so due to confusion about guidelines, beliefs that alcohol has not harmed previous pregnancies, pressure from family members and addiction. Specific prevention strategies need to be targeted to groups with different risk levels. There are many excellent television advertisements produced in WA under Alcohol prevention programs and in Broome through Goolari Media. The NPY Women's Council has also developed prevention resources in Central Australia. Community-based FASD prevention programs have also developed a range of community education materials that could be used across the NT.

A FASD Strategy should be developed with input from all Government departments dealing with affected individuals including Health, Children and Families, Justice and Education. Involvement from the non-government sector, experts in the field and Aboriginal representation and consultation is essential to the success of any strategy.

9.2. Community-Based FASD Prevention Programs

Communities with high numbers of children at risk of FASD need specific strategies which are owned and controlled by community members in order to gain widespread acceptance and to be integrated into health service delivery for the future. There have been some short-term FASD prevention programs in Australia. The Ord River Aboriginal Health Service in Kununurra, WA, and Anyingini Health Aboriginal Corporation in Tennant Creek, NT, have both developed prevention programs targeting Aboriginal communities. The Liliwan project in the Fitzroy Valley, has raised awareness of FASD as part of a broader Marulu strategy to reduce the harm of alcohol.

Programs like those in Ord River and Tennant Creek are not expensive. The Ord River project initially received funding from local traditional owners but now continues under the New Directions Mothers and Babies program. However it would not have had the impact it has without community concern and ownership of the issue, rather than a directive being imposed from outside the community.

All of these agencies have produced some valuable resources but project funding means that the interventions are short term, and not replicated in other places.

9.3. FASD Prevention with High Risk Mothers

Effective prevention also requires targeted strategies for high-risk groups. The highest risk group, mothers who have already had an alcohol-exposed pregnancy, are almost certain to have further alcohol-affected pregnancies and therefore there is a unique opportunity to target individuals most at risk.

Women who give birth to children with FASD have extremely poor long term outcomes, including having multiple children placed in care and being at much greater risk of premature death. International FASD expert Professor Sterling Clarren reviewed a cohort of children who had been diagnosed with FAS and found that three years after a FAS diagnosis was made, 25% of birth mothers were missing or deceased.⁹ A study in Finland found that, 6 - 15 years after a

pregnancy complicated by alcohol or drugs, women were at 38 times greater risk of death than the rest of the population and 31 times more likely to have died from accidents or violence.¹⁰

The quality of life of women who have given birth to children with FASD is generally very poor and unlikely to improve, even with traditional interventions. A targeted response to this group is required.

Research indicates that interventions with those at risk of alcohol-exposed pregnancies should be non-stigmatising and broad-based, including 'enhancing a woman's diet, reducing physical and emotional abuse, and enhancing a woman's current living status'.¹¹

A highly effective evidence-based program that was developed in Seattle, Washington, is the Parent –Child Assistance Program (PCAP). The program website states:

The Parent-Child Assistance Program (PCAP) is a home visitation intervention program that works with women who abuse alcohol or drugs during pregnancy, with the aim of preventing future alcohol- and drug-exposed births among these mothers. PCAP supports mothers in achieving this goal by helping them complete substance abuse treatment and stay in recovery and by motivating them to choose effective family planning methods.

The goals of the program are to (1) assist mothers in obtaining treatment, maintaining recovery, and resolving the complex problems associated with their substance abuse; (2) guarantee that the children are in a safe environment and receiving appropriate health care; (3) effectively link families with community resources; and (4) demonstrate successful strategies for working with this population to prevent the risk of future drug- and alcohol- affected children.

PCAP provides trained and supervised case managers who work with a caseload of 16 mothers and their families for three years, beginning during pregnancy or

up to six months postpartum. The case managers offer regular home visitation and link women and their families with a comprehensive array of existing community resources to address health care, housing, child welfare, and other issues. Case managers help mothers identify personal goals and the steps necessary to achieve them; they monitor progress, facilitate case conferencing and integrated service delivery among providers, transport clients and children to important appointments, and work actively with the extended family.¹²

As part of my Churchill Fellowship in 2009 I visited a number of sites in the US and Canada where the PCAP model has been implemented. Evaluation indicates the program has demonstrated success in reduction of further alcohol-affected births among very high-risk women. An internal evaluation conducted in 2005 identified that after 3 years in the program, participants showed greater participation in substance treatment, improved contraception, and most were no longer at risk of a further alcohol or drug affected pregnancy.¹³

A review of a version of the program in Alberta, Canada, found that "at program exit, many participants were abstinent from alcohol and/or drugs and the majority did not experience a subsequent pregnancy."¹⁴

The evaluation of the Canadian program between 1999 and 2007 found:

- The mean age of participants was 26 years
- Most had had an unplanned pregnancy (88%), and after the birth of their child had an average of 2.6 children; 63% had custody of at least one child.
- Nearly half of the clients enrolled were of Aboriginal ethnicity (49%)
- Over the course of the program, regular use of a family planning method increased from 36% to 56%
- Welfare use decreased from 92% to 72%
- After the birth of their child (either before or shortly after program began), 71% did not have a subsequent pregnancy.
- In terms of substance use, 44% were abstinent from drugs and 35% were abstinent from alcohol at program exit.
- During their enrolment in the program, 93% of clients had been clean and sober (with no relapses) for at least one month.¹⁵

Features crucial to the success of PCAP include:

- Three-year duration, reflecting the time required for lasting changes to be made.
- A strong theoretical basis drawing on Relational Theory (the concept of the therapeutic alliance), Stages of Change Theory (involving motivational interviewing) and Harm Reduction theory.
- Assertive outreach, which acknowledges that women may not have a stable address or be able to attend appointments reliably.
- A two-pronged approach of reducing substance use and improving reliability of birth control.

Dr Therese Grant (2010) reports that PCAP costs approximately \$15,000 USD per client for the three-year program, including intervention, administration and evaluation. The estimated average lifetime cost for an individual with FASD is at least \$1.5 million.

If PCAP were to prevent a single new case of FASD, the estimated lifetime cost savings would be equivalent to the cost of the PCAP intervention for 102 women.¹⁶

There is potential for this successful program to be implemented in the Australian context and in the NT in particular. It would be an excellent complementary service to a home-visiting program such as the Family Partnership Program operating through Central Australian Aboriginal Congress, which provides home visiting for new mothers until the child's second birthday. High-risk women may be excluded from this program as engagement must commence in the second trimester of pregnancy, and many women who consume high levels of alcohol do not engage in antenatal care.

Recommendations:

- Establishment of a cross-government response to FASD
- Implementation of population-based prevention programs to address the risks of alcohol in pregnancy
- Implementation of targeted prevention programs based on those developed in Aboriginal communities in Australia to reduce the prevalence of FASD in those communities
- Implementation of indicated prevention targeting women most at risk of an alcohol-affected pregnancy including implementation of a prevention program based on the Parent-Child Assistance Program

10. Reducing the impact of FASD through treatment and support of affected individuals

The first step in recognising and treating FASD is diagnosis. Diagnostic teams are urgently required to provide multi-disciplinary diagnosis. The team models developed in the US and Canada, and implemented now in New Zealand, Fitzroy Crossing and the Gold Coast, are based on international best practice.

Because FASD is a complex brain based disability with varying presentations, diagnostic teams require a multidisciplinary approach to assess the individual across a number of domains – cognition, motor skills, speech and language, executive functioning, adaptive functioning, sensory processing and others. A team typically includes a paediatrician, psychologist, neuropsychologist where possible, physiotherapist, occupational therapist, social worker, and speech and language therapist.

The diagnostic process is intensive but many children are already receiving assessments from multiple therapists and allied health services – just not in such a coordinated way. Diagnosis was first developed at the University of Washington clinic in Seattle and over 2500 individuals have been assessed in the past 20 years. Diagnosis at the clinic takes 4 hours, with the psychometric tests, interviews and carer checklists completed prior to the clinic. The individual has facial measurements and growth recorded, and the team assesses the results and provides feedback to the family. A key component of diagnosis is a list of recommendations for services and supports – which may include clinical or community based supports and therapeutic activities such as gymnastics, swimming or horseriding. The recommendations may include carer respite, sleep studies, school interventions, caregiver training or mentoring. Strategies to manage behaviours are included – such as wearing headphones to minimise sensory overload, or memory aids or checklists to assist in personal organisation. A review of outcomes for individuals following assessment found a high level of satisfaction by families, with 89% of families reporting that they were somewhat/very successful in accessing the recommended intervention services,

and 96% of those accessing services reporting that they met some/all of their needs.¹⁷

Training for staff dealing with individuals and families affected by FASD is also needed. FASD is a complex condition, and it takes time for individuals to fully understand the disorder beyond the symptoms on a checklist. There is enormous variability and no simple solutions. However with training, staff working with children, families, young people and adults can adapt their practice to make services inclusive of individuals with FASD.

Ideally a service system for those with FASD would include access to a diagnostic clinic and a FASD specialist service in each State and Territory, with those services having a role in training and resourcing agencies working with affected individuals to improve their capacity to respond effectively.

There are very few services for individuals with FASD currently operating in Australia and none in the NT. Support to carers may be provided by the peak body NOFASD Australia, the Russell Family Foundation, independent FASD consultants or Foster Care support groups.

Models of service delivery for individuals with FASD operating in the US and Canada include:

- The FASD Key Worker program, in which a designated worker within an agency resources and educates staff within the agency, and supports children and families referred in by other parts of the program. This is a cost-effective model, which allows larger agencies to be responsive to individuals in any area of service delivery. This program exists in many locations in the US and Canada and works effectively with First Nations people.
- Support services to families who have had a child diagnosed with FASD. These services provide support to the family to understand and cope with

the diagnosis, and advocate for the child within the broader service system (childcare, kindergarten, school and health services) to ensure that the child's specific needs are understood by all involved. These support services are often attached to diagnostic clinics.

- Behavioural management services to assist families and carers of children to manage behaviours of children with FASD. Often these children do not respond to traditional parenting interventions due to the distinct nature of the brain injury. Specialist behavioural management services can reduce the risk of placement breakdown and prevent carer burnout, keeping children out of the foster care system, or supporting those in care to maintain the placement.
- Youth outreach services targeting young people who have FASD. These young people are at risk of getting involved in crime, and dedicated services with staff that are knowledgeable about FASD can divert young people out of the criminal system.
- Services such as the PCAP model (above) also provide a service to adults with FASD as many mothers with FASD go on to have alcohol-affected pregnancies. These individuals struggle with parenting and the PCAP is inclusive of women with FASD. The program can assist in resolving child safety issues and improving quality of life for affected women.

Recommendations:

- That FASD Multidisciplinary Diagnostic Teams be implemented in the Northern Territory
- That training and education be provided to improve the capacity of generic social and health services to respond to individuals and families affected by FASD
- That specialist services be developed to provide expert services to individuals and families affected by FASD.

11. Reducing the harm of alcohol on children in the child protection system.

Themes emerging from the study *Fetal Alcohol Exposure among Children in the Child Protection System in the Northern Territory* include:

- Where parental alcohol use raises concerns for children's safety and wellbeing, interventions need to be longer term, with collaboration between services and close monitoring and evaluation. Short-term interventions are generally unsuccessful as they underestimate the severity and duration of the addiction.
- Child protection services need to work closely with alcohol and other drug services to develop a joint approach to assessment, treatment and intervention with families where parents are abusing alcohol using best practice approaches from both fields.

- Infants of mothers with alcohol issues are at extremely high risk, including risk of fatality, and they require specialist assessment and planning.
- Children who are likely to have FASD require specialist assessment, diagnosis and intervention planning. There are significant gaps in this area in the absence of FASD diagnosis or specialist support services.
- Carers for children with FASD require specialist training and support to manage the care of these vulnerable individuals and to minimise the likelihood of development of secondary disabilities.

Given the overrepresentation of Aboriginal children among those in care, and the higher rates of FASD among this population, it is important that strategies to address the issue are culturally appropriate and developed in consultation with Aboriginal workers and community members.

FASD is an under-recognised, preventable, life-long disability. Child Protection services have a responsibility for to be aware of the condition, given that FASD is diagnosed 10 to 15 times more frequently among children in care than in the rest of the population. These children have poor outcomes in care when they do not have access to early diagnosis, and require support from people who are knowledgeable about FASD.

Child protection services can make a difference to these children and families and FASD prevention needs to be embedded within child protection policy and practice across Australia, particularly in areas and among communities where alcohol use is very high.

Child protection services and health services need to develop a collaborative service response to prevent further FASD births among this group. New models of intervention are required to prevent further alcohol-affected pregnancies for women who have already given birth to a child with FASD. This is an area where indicated prevention can significantly reduce the risk of further alcohol-affected

births.  Child Protection services are a key player in identification and engagement of at-risk women.

Recommendations:

- That Child Protection services work closely with Alcohol and Other Drug Services to ensure that family assessments and interventions incorporate evidence based practice from both sectors, and that interventions include longer-term monitoring where there is evidence of long term alcohol use.
- That specialist child protection assessment and planning occur for infants of mothers who are consuming alcohol to a concerning degree
- That children with FASD have access to specialist assessment, diagnosis and intervention planning
- That foster carers and kinship carers receive specialist training and support to manage the care of children with FASD
- That Child Protection services develop a model of best practice for supporting children with FASD who are at risk of abuse and neglect
- That such a model is developed in consultation with Aboriginal workers and community members to ensure that the best interests of Aboriginal children in the care system are promoted.

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