



**Northern Territory Council of Social Service Inc.**  
*'Growing the NT fairly'*

**NTCOSS Submission to the Legislative Assembly of the  
Northern Territory Government**

**Select Committee on Action to Prevent Fetal Alcohol  
Spectrum Disorder.**

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## **Introduction**

The Northern Territory of Social Services (NTCOSS) welcomes the opportunity to provide input to the Legislative Assembly of the Northern Territory Select Committee on Action to Prevent Foetal Alcohol Spectrum Disorder.

NTCOSS is a peak body for the community sector in the NT and is a voice for people affected by social and economic disadvantage and inequality. The community sector in the NT is made up of community managed, non-government, not for profit organisations who work in social and community service delivery, sector development and advocacy. The community sector plays a vital role in creating social wellbeing for all Territorians and in building safe and healthy communities by providing services that enable people to access and participate in health services, education, employment, economic development, and family and community life.

## **Scope of the Submission**

NTCOSS welcomes the opportunity to contribute to a discussion about best responses to FASD in the NT. Fetal<sup>1</sup> Alcohol Spectrum Disorders (FASD) are a set of potentially devastating lifelong conditions, which are poorly recognised and understood in Australia.

Terms of reference of the Inquiry are:

1. The prevalence in the Northern Territory of Foetal Alcohol Spectrum Disorder (FASD);
2. The nature of the injuries and effects of FASD on its sufferers; and
3. Actions the Government can take to reduce FASD based on evidence and consultation.

FASD has a significant impact on children, families, young people and adults in the Northern Territory. Although the data indicates Aboriginal children are at higher risk, the culture of alcohol consumption in the Northern Territory means many families are at risk of a pregnancy affected by alcohol. Aboriginal children are however particularly vulnerable to the negative consequences of FASD as they are already developmentally vulnerable.

NTCOSS represents a service sector with a high level of contact with affected individuals and their families. This submission will address:

### **1. A Coordinated and Culturally Safe Response to FASD across the NT**

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<sup>1</sup> This submission uses the spelling “Fetal” which is consistent with that used by the National Health and Medical Research Council. Most Australian FASD researchers are now using this spelling.

- Engagement with Aboriginal communities is critical to effective prevention and intervention with affected individuals and their families.

## **2. Prevention**

- NTCOSS recommends development of a preventative strategy informed by an understanding of the complexity of reasons why women consume alcohol in pregnancy
- Prevention strategy needs to target support for high-risk women based on international best practice.

## **3. Diagnosis**

- There are no diagnostic services for FASD in the NT, which means the majority of affected children, young people and adults are undiagnosed.
- The need for FASD to be recognised as a Disability in order to develop recognition of the disorder within the service system and improve access to supports.

## **4. Support for carers and family members affected by FASD**

- Carers have difficulty accessing supports and resources around FASD and need access to information and resources and to support workers who are trained and educated about FASD.

## **5. Resourcing of the service sector to better respond to the needs of individuals with FASD**

- Many services and agencies lack information and resources about FASD and therefore sector knowledge in many areas is very limited. Staff need to be knowledgeable about FASD to incorporate appropriate interventions into existing programs and services.

## **6. Implementation of best practice FASD prevention and intervention models informed by current research**

- We can learn from evaluated models of intervention which have been developed in the NT and WA with similar communities.
- While FASD responses can be integrated into the service system in many respects, there is a need for dedicated local FASD projects to raise awareness of the issue, develop local prevention strategies and educate the community, professionals and key stakeholders.

## **List of Recommendations:**

### **1.1 Establishment of cross-government FASD Working Group with key stakeholders from Health, DCF, Aboriginal health services,**

A FASD Working Group should include the following:

- a) Development of a Northern Territory-wide FASD prevention strategy
- b) Development of targeted FASD prevention interventions with high risk communities
- c) A consultative framework with a diverse range of Aboriginal people and organisations to develop and implement culturally appropriate, local strategies to prevent FASD.
- d) Promote community ownership in FASD prevention to ensure that communities are invested in FASD prevention strategies.
- e) Develop a strategy for supporting individuals with FASD, including resourcing existing services to better meet the needs of this group.
- f) Establishment of an FASD advisory committee comprising experts in the field to ensure that FASD interventions are consistent with national and international research, knowledge and practice.

### **2.1 That the Northern Territory Government commit to a FASD prevention strategy which includes:**

- a) Population wide messages about the risks of alcohol in pregnancy including alcohol labelling
- b) Guidelines for health professionals about messages relating to alcohol in pregnancy
- c) Specialised supports for women who have children with FASD and are at risk of further births
- d) Services to women who use alcohol in pregnancy should be supportive and recognise the complex issues relating to alcohol use in pregnancy
- e) Follow up support for at risk mothers after the birth of a child to reduce the risk of harm in future pregnancies
- f) Services for Aboriginal women should be non-judgmental, recognise impact of trauma, and be culturally safe.

### **2.2. NTCOSS does not support any form of punitive measures for pregnant women as research indicates this to be counter-productive.**

3.1 That FASD diagnostic teams be established in the NT

3.2 That FASD be identified as a disability in the NT

3.3 That individuals with FASD be able to access Disability Services

- 3.4 That Disability Services workers be trained in FASD
4. Development of training and FASD specific resources to enhance the skill and knowledge base for those caring for or supporting individuals with FASD.
  - 5.1 Improved data collection in relation to alcohol in pregnancy
  - 5.2 Development of procedures to ensure all pregnant women receive appropriate screening for alcohol use and training for practitioners to ensure this occurs.
  - 5.3 Resources for health practitioners to develop sensitive and culturally safe strategies for assessing alcohol use in pregnancy and providing education to mothers.
  - 5.4 Community consultation about appropriate service models to assist pregnant women with alcohol dependence access treatment.
  - 5.5 Further training of health providers in identification and diagnosis of FAS and FASD
  - 5.6 That the NT government produces resources for health providers on FASD, diagnosis and screening, effects of FASD and intervention strategies.
  - 5.7 That procedures be put in place to ensure that children with Fetal Alcohol Exposure are flagged for regular developmental screens
  - 5.8 That Fetal Alcohol exposure be recorded on medical files to enable future diagnosis when available
  - 5.9 That the NT government ensure that all agencies working with infants, children or families have access to accurate, up to date information about alcohol consumption in pregnancy and the impact of FASD.
  - 5.10 That the NT government provides FASD screening guidelines to professionals working with vulnerable infants and children.
  - 5.11 That culturally appropriate information is sourced from relevant successful FASD Projects in Australia and adapted where necessary to the NT setting.
  - 5.12 That the NT government explore screening of children at preschool for FASD in order to refer for diagnosis and early intervention services.
  - 5.13 That staff of early childcare services are provided with education and training in FASD

5.14 That successful interventions for children with FASD in preschool years are promoted.

5.15 That FASD training be included in professional development for all teachers in the NT.

5.16 That DET develop resources on classroom management strategies and individual learning plans that reflect best current international practice.

5.17 That Department of Children and Families identify and implement best practice models to assess and support children with FASD.

5.18 That workers with vulnerable young people be provided with access to resources and training to assist them in developing more appropriate service responses to young people with FASD.

5.19 That international best practice service models for supporting young people with FASD be explored and features of these models be incorporated into existing service design.

5.20 That services providing support to vulnerable adults are provided with resources about effective interventions with adults with FASD based on best practice Internationally.

5.21 That staff working with adults who may have fetal alcohol exposure be educated and trained about the disorder

5.22 That staff working with adults ask about maternal alcohol consumption in pregnancy as part of their assessment.

6.1 That the NT FASD Working group examine good practice models of FASD prevention and intervention both from Australia and Internationally with a view to implementation in selected sites in the NT.

## **Fetal Alcohol Spectrum Disorders – Defining the problem**

Fetal Alcohol Spectrum Disorders (FASD) represent:

...a group of permanent disorders caused by exposure of the unborn child to alcohol consumed by the mother during pregnancy... Babies exposed to alcohol *in utero* may be born with deformities of the brain, nervous system, kidneys, heart, lungs, eyes, ears; may have growth problems; and may display a series of specific facial characteristics. Developmental, behavioural and learning problems are common. What is most devastating about this condition is that it is 100% preventable (Latimer et al 2010).

For those who don't have physical features or access to diagnosis, FASD is a largely invisible condition. Most people living with FASD in Australia don't know they have the condition. Children may be diagnosed with other disorders.

Primary conditions common to FASD include:

- learning difficulties
- impulsiveness
- difficulty relating actions to consequences
- social relationships
- attention/hyperactivity
- memory
- developmental delays

Over time these conditions lead to other secondary effects including:

- Difficulty with peer relationships
- Behavioural problems
- Aggression
- Easily frustrated
- Anxiety

Without support, long-term outcomes for individuals can include:

- Poverty and homelessness
- Involvement in the criminal justice system
- Substance abuse
- Mental health issues
- Victimization
- Suicidality
- Difficulty parenting and involvement with child protection services.

Individuals with FASD have particularly poor outcomes when their condition is not diagnosed. These adults experience many difficulties coping with the expectations of adult life, and no allowances are made for them on the basis of their disability. These adults have frequent contact with the social service system and the justice system, yet find it difficult to access services that meet their needs. Their presenting issues

may include mental illness or drug and alcohol issues, but these mask a brain-based disability of which neither they nor the agency is aware.

The most severe form of FASD is Fetal Alcohol Syndrome (FAS), a term which was coined in 1973 by Drs Jones and Smith from the University of Washington. The diagnostic criteria for FAS were established as:

1. Growth deficit
2. A set of distinctive facial features
3. Evidence of central nervous system damage
4. A confirmed history of maternal alcohol exposure.

These criteria have not changed since the paper was published. In Australia the diagnosis is made by a paediatrician.

Over time it became apparent that many individuals experienced some but not all of the criteria for FAS. In 2004, the term Fetal Alcohol Spectrum Disorders was agreed upon as an umbrella term for the range of possible effects of alcohol exposure. There are several diagnostic guidelines used in the US and Canada, but Australia does not have current FASD diagnostic guidelines.

Researchers from the Telethon institute in WA are currently finalizing a diagnostic instrument for FASD in Australia. Researchers have indicated that the criteria will include Partial Fetal Alcohol Syndrome (PFAS) where some but not all of the facial features are present, and Neurodevelopmental Disorder – Alcohol Exposed (ND-AE), which includes individuals who have none of the facial features and no growth deficit, but do have evidence of central nervous system damage, and a history of maternal alcohol exposure.

### **Prevalence of FASD in the NT**

Internationally, FAS is estimated to affect between 2.8/1000 and 4.8/1000 births, and FASD 9.1/1000 births (Sampson et al 1997).<sup>2</sup>

There is very little data about FASD in the Northern Territory. In 2003 Harris and Bucens conducted a prevalence study of FAS among children in the Top End of NT. They reviewed medical records children seen by paediatricians at Darwin Hospital between 1990-2000 and found that estimated rates of FAS of:

- 0.68/1000 live births
- 1.87/1000 live births for Aboriginal children

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<sup>2</sup> Sampson PD, Streissguth AP, Bookstein FL, et al. (1997) *Incidence of fetal alcohol syndrome and prevalence of alcohol-related neurodevelopmental disorder*. *Teratology* 1997; 56:317-26.

When other conditions on the FASD spectrum were included, the rates were 1.7:1000 live births and 4.7:1000 for Aboriginal children (Harris and Bucens 2003).<sup>3</sup> The results were considered to be an under-estimation due to the fact that many children are not brought in to see paediatricians in Darwin due to distance.

A study of births in WA found a rate of FAS at

- 0.02/1000 live births non Aboriginal children
- 2.76/ 1000 live births Aboriginal children (Bower et al 2000).

Peadon et al (2008) estimate that the rate of FASD among the Indigenous community is between 2.76 and 4.7/1000 live births. Others suggest the rates may be significantly higher, with a study in far north Queensland estimating FASD at 15/1000 births and one Cape York Community reporting a prevalence of 26/1000 births (Wise 2013)

The over-representation of Aboriginal children among children diagnosed with FASD is of great concern and indicates the need to actively and assertively address this issue among the Northern Territory population. Aboriginal children are already disadvantaged in relation to health outcomes and life expectancy, and brain-injury as a result of fetal alcohol exposure must be actively prevented.

### **Alcohol Use in the NT**

The prevalence of alcohol related harms in the Northern Territory are well documented. Each person in the NT consumes an average of 15 litres of alcohol per year, compared to an average of 10 litres per person across Australia. The National Drug Strategy Household Survey of 2007 found that 17.2% of non-Indigenous adults in the NT consumed alcohol at a level consistent with a risk to health in the long term, compared to the national average of 10.6%. Rates among Aboriginal adults are higher, with 30.1% of Aboriginal adults consuming alcohol at a high-risk level. Of those seeking assistance for drug or alcohol issues in the Northern Territory, alcohol is the most common substance representing 69% of treatment episodes (AIHW 2011).

Alcohol use in pregnancy is also at concerning levels. Around 50% of pregnancies are unplanned, so there is a risk with high levels of alcohol consumption across the population, that women consuming alcohol in pregnancy will often do so inadvertently.

Across Australia, 1 in 5 Indigenous mothers with children aged 0-3 reported drinking in pregnancy in 2008 (ABS 2012). Between 2003-2006, it was reported that one in eight Indigenous pregnant women and one in 12 non-Indigenous pregnant women in

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<sup>3</sup> Harris, KR and Bucens, IK. (2003) *Prevalance of fetal alcohol syndrome in the Top End of the Northern Territory*, Journal of Paediatric and Child Health Vol 39 pp 528-533.

the NT were consuming alcohol at the first antenatal visit. Between 8-8.7% of Indigenous women and 3.6-4.7% of non-Indigenous women were still consuming alcohol at 36 weeks (HGPIS 2010).

A recent Australian analysis of alcohol use in pregnancy indicate that while women's consumption of alcohol in pregnancy has declined in recent years, those who use alcohol either weekly or those who engage in binge drinking are less likely to change their pattern of use in pregnancy. 46% of women in the study continued risky drinking patterns in pregnancy (Anderson et al 2014).

### **Recent and Current Government initiatives**

In November 2012 the Commonwealth Parliamentary Inquiry into Fetal Alcohol Spectrum Disorders tabled its report entitled *FASD: The Hidden Harm*. The report included a number of recommendations including:

- A National Plan of Action for prevention, diagnosis and management of FASD including a range of strategies detailed below
- Training to ensure that all health professionals promote a clear message that not drinking while pregnant is safest
- Data collection on drinking in pregnancy
- Warning labels on alcoholic beverages
- A study of the impact of pricing and availability of alcohol including strategies marketing alcohol to young people
- Public awareness campaign on the risks of alcohol in pregnancy
- Working with the States and Territories to develop strategies to assist Aboriginal communities to reduce the impact of alcohol and assist in community-led initiatives to reduce high-risk consumption patterns and the impact of alcohol
- A national diagnostic and management strategy including awareness of health providers; a model of diagnostic services covering regional and metropolitan areas, and identification of best practice for management of FASD.
- Raising awareness of FASD including among teachers, parents, foster carers, youth workers, drug and alcohol workers, and corrections workers.
- That FASD be recognised as a disability.

In August 2013 the Australian Government responded through the Australian Government Action Plan to reduce the impact of FASD 2013-14 to 2016-17. The plan includes:

- Improving the diagnosis of FASD by utilising the Medicare Local network to reduce and prevent substance misuse
- Finalising the development of a FASD diagnostic tool

- Development of guidelines to support diagnosis and early management of FASD
- Strengthening existing efforts to prevent FASD and reduce its impact on remote Indigenous communities through alcohol management plans and other measures including the New Directions Mother and Babies Services
- Raising awareness across relevant Government service providers including establishment of a collaborative network of FASD experts to improve information exchange.

The status of this Action Plan and the financial commitments is on hold since the Federal election in September 2013 and it is still unclear whether any of the commitments will proceed.

Three research projects have been funded under the NHMRC targeted call for research on FASD in Indigenous communities:

- Behaviour support training for FASD – University of Sydney
- FASD prevalence study at Cherbourg, Qld – University of Sydney
- Improving management of young people with FASD within the justice system – Western Australia.

### **FASD initiatives in Australia**

There have been a number of FASD initiatives in Australia:

- Development of a Diagnostic Instrument for FASD in Australia – funded by DoHA.
- The Liliwan project in Fitzroy Crossing, Western Australia which has screened all children born in 2002 and 2003 in the Fitzroy Valley for FASD.
- Anyinginyi Health FASD project, Tennant Creek, which raised awareness of FASD within the Barkly region, conducted FASD training, and produced several FASD prevention videos. This project was originally funded by FaHCSIA for two years.
- Ord Valley Aboriginal Health Service FASD Prevention Program provides community education to individuals and community groups. This project has developed innovative resources using an all of community approach to FASD education. This project was initially funded by the WA government but is now funded by DoHA through the New Directions Mothers and Babies program.
- Strong Spirits Strong Futures – promoting healthy women and pregnancy project, WA Drug and Alcohol Office. This initiative is funded under Closing the Gap until June 2014.
- The Telethon Institute in Perth has a Alcohol and Pregnancy and FASD Research Program which includes a focus on Aboriginal communities, and on translating research into practice.
- The Foundation for Alcohol Research and Education (FARE) has funded a number of small community grants for FASD prevention and education. FARE

also developed a fully-costed FASD Action Plan 2013-2016 with an estimated cost of \$37m to address gaps in the prevention and management of FASD. The plan recommended a broad-based population approach to addressing FASD including a public education campaign and three FASD diagnostic clinics across Australia.

In relation to population-wide prevention measures, while brochures are available from the Department of Health, there have been no recent education campaigns aimed at raising awareness within the community of the significant risks posed by fetal alcohol exposure.

In November 2013 an Australian conference on FASD was held in Brisbane. Delegates including community agencies, parents and carers, researchers and health professionals released a Call to Action urging “health professionals, service providers, governments and the community to work together to reduce the prevalence of FASD and improve the quality of life of individuals and families living with FASD.”

Key points included:

- The need for plans of action to address gaps in the prevention, diagnosis and management of FASD
- Comprehensive population-wide public education campaigns focusing on the risks of alcohol consumption in pregnancy
- Specialist services for pregnant women and research on effective treatments for women with alcohol use disorders
- Promotion of evidence-based screening and brief intervention among health professionals working with women who consume alcohol in pregnancy
- Recognition of FASD as a disability and access to a range of services to support individuals with the disorder across the lifespan
- A whole of government response with FASD systematically integrated into service development and policy
- A commitment by Government, providers and communities to address FASD through culturally secure strategies in partnership with Indigenous people
- Continuing research on FASD
- Prevention of FASD needs to be non-judgemental, sensitive and cognisant of the potential for stigma
- Training is required by those working in education, justice and care.

## **NTCOSS Recommendations:**

### **1. A Coordinated and culturally safe approach to FASD across the NT**

Fetal alcohol exposure is a significant risk to Indigenous children in the Northern Territory and compounds other well-documented inequities between Aboriginal and non-Aboriginal children and families. Risk factors for Aboriginal children compared to non-Aboriginal children include:

- Greater risk of low birth weight and prematurity
- Greater risk of exposure to smoking and alcohol in pregnancy
- More frequent hospitalisations for infections
- Higher death rates
- Skin infections leading to renal failure
- Impaired hearing.
- Higher risk of child protection involvement and entering care
- Higher exposure to family risk factors
- Higher risk of emotional or behavioural difficulties
- Greater risk of being developmentally vulnerable on the Australian Early Development Index. (Wise 2013, Bowes and Grace 2014).

Aboriginal children are overrepresented among individuals with FASD, with rates estimated as high as 100 times that of the non-Aboriginal population (Bower et al 2000).

It is essential that responses to FASD in the Northern Territory engage Aboriginal services in all respects, from engagement, definition of the problem, exploration of best practice models, development of strategies appropriate to the NT, and implementation and evaluation.

Strategies also need to be integrated with other early childhood services, but it is important that the FASD prevention message is not lost in amongst other issues such as smoking, nutrition and hygiene. When the impact of alcohol is presented alongside a long list of health messages, the important message about damage caused by alcohol in pregnancy can be lost.

Burton (2012) identified that two key ways to increase access to and engagement with children and family services for Aboriginal and Torres Strait Islander peoples are: (i) working within a cultural competence framework; and (ii) engaging in effective partnerships with Aboriginal and Torres Strait Islander communities and organisations.

Hunt (2013) reviewed the evidence for programs reducing Aboriginal disadvantage, and identified factors which contributed to positive engagement with Aboriginal communities, including:

- Services aligned with community needs

- Building trust through tangible benefits and implementing an empowering process through community development
- Partnerships that allowed for training of Aboriginal staff
- Participatory processes with Aboriginal research assistants, focus groups, consultation and feedback processes with Aboriginal communities and health services
- Extensive community consultation using existing community organisations/structures, Aboriginal Elders and Aboriginal health workers

### **Recommendations:**

#### **1.1 Establishment of cross-government FASD Working Group with key stakeholders from health, DCF, Aboriginal health services,**

A FASD Working Group should include the following:

- g) Development of a Northern Territory-wide FASD prevention strategy
- h) Development of targeted FASD prevention interventions with high risk communities
- i) A consultative framework with a diverse range of Aboriginal people and organisations to develop and implement culturally appropriate, local strategies to prevent FASD.
- j) Promote community ownership in FASD prevention to ensure that communities are invested in FASD prevention strategies.
- k) Develop a strategy for supporting individuals with FASD, including resourcing existing services to better meet the needs of this group.
- l) Establishment of an FASD advisory committee comprising experts in the field to ensure that FASD interventions are consistent with national and international research, knowledge and practice.

## 2. Prevention

In May 2014 NTCOSS hosted a FASD prevention workshop in Alice Springs presented by Nancy Poole, Director of the British Columbia Center of Excellence for Women's health Vancouver and the Lead researcher on the Prevention Team, Canada FASD Research Network.

Poole identified barriers to FASD prevention including:

- women report guilt and shame prevent them from reporting their alcohol use in pregnancy
- women are fearful their child will be removed from their care if they disclose alcohol use in pregnancy.
- Doctors and health providers do not feel fully prepared to discuss substance use with women
- Problem alcohol use in women is often not recognised or treated.

Poole argues that maternal alcohol use needs to be viewed in a context, both of the mother's health, access to antenatal care, stress and nutrition, and within a broader context of her age, genetics, resilience, isolation, exposure to violence and poverty.

FASD prevention needs to be underpinned by an understanding of why women drink in pregnancy. Factors identified include:

- being unaware they are pregnant
- being unaware of the extent of possible damage to the fetus
- underestimating the harms because they know other women who drank during pregnancy and their children appear healthy
- Alcohol use is the norm in their social group and abstaining is difficult
- Using alcohol to cope with difficult life situations including poverty, depression, violence or isolation.
- Addiction (Cismaru et al 2010).

Poole identifies four levels of FASD prevention which are required to effectively address the issue.

1. Broad awareness building and health promotion efforts encompassing:
  - Development of health promotion materials
  - Awareness campaigns
  - Alcohol consumption guidelines
  - Warning labels
  - Materials for group work facilitators

Important features of effective prevention campaigns include engaging the whole family or community rather than focussing on individual women. However education campaigns are most likely to influence low risk drinkers and have little effect on high risk or binge drinkers.

2. Discussion of alcohol by and with professionals including:
  - Education about drink size
  - Routine screening
  - Screening for poly drug use
  - Medical school training and continuing education.

Brief interventions by health professionals can assist in identifying women who require further supports. It is important that screening feels safe for women who are concerned about losing custody of their children. Health professionals need good resources to help them have supportive, non-judgmental discussions with women about alcohol use. Discussion about the reasons for the current guidelines (that there is no safe level of alcohol that can be consumed in pregnancy) can assist women. Motivational interviewing is considered the most effective technique as it can assist in resolving ambivalence and strengthen individual's motivation for change.

3. Holistic Care and Advocacy including:
  - Specialized support for women who have children with FASD

Women who have children with FASD are at very high risk of negative life outcomes. In a study of mothers of 257 children with FASD, only 80 mothers could be interviewed. 42% of birth mothers could not be located, and 11% were deceased at the time of the follow up.

Of these women:

- 100% had been seriously sexually, physically or emotionally assaulted
- 80% had a major mental illness
- 80% lived with men who did not want them to stop drinking
- 24% had been in foster care
- 35% had been in juvenile detention
- 80% had child protection involvement with their children (Astley et al 2000a).

The study also identified that 46% of the mothers interviewed were still at risk for alcohol-exposed pregnancies. Thirty five of the mothers had given birth to children since their older child was diagnosed with FAS, and 75% of these subsequent births were alcohol affected. The authors argue that it is unethical not to reach out to these women and offer them access to prevention services (Astley et al 2000b).

Sheway is a pregnancy outreach program operating in Vancouver, Canada. It provides a drop-in service to women who are pregnant or have infants and who have drug or alcohol issues. The program aims to assist women to have healthy pregnancies through provision of alcohol and drug counseling, social work, nutrition support, paediatricians and allied health providers, Aboriginal community workers

and a range of other services. Meals are provided and a range of other practical supports. The program is linked to a mother-baby unit where at risk mothers can stay for 10 days post birth with their babies, to promote attachment and bonding and to reduce the likelihood that children are taken into care.

The program aims to engage women in accessing prenatal care and a range of other supports during pregnancy through reducing risk, providing a positive experience, supporting mothers' health, and reducing harm of substance abuse in pregnancy and numbers of children born with FASD (Poole 2000). More than half the clients are Aboriginal. Staffing is provided by a consortium including Aboriginal and mainstream health services, child protection services, and housing services.

Outcomes of the program include:

- Early engagement of pregnant women affects a range of outcomes in relation to maternal and fetal health
- Women who participate in the program were more likely to retain custody of their child
- Children who are involved in a comprehensive program of support have enhanced developmental outcomes.

4. Postpartum initiatives and support for new parents, including:

- Home visitation by nurses
- Mentoring programs
- Key worker and parent support services.

The Olds program of nurse home visitation operates in selected Aboriginal Controlled Community Health services. This model is highly regarded and evaluation has indicated many positive outcomes for infants in the program, including reduction in maternal smoking, reducing infants emotional vulnerability, fewer language delays, and improved mental developmental (Olds et al 2002). However there was no significant effect of home visiting on mothers' substance use (Olds et al 2004). Addictions can also contribute to mothers being excluded from the program (Sivak et al 2008).

Astley et al recommend services such as the Parent Child Assistance Program a model developed in the United States, which offers a 3 year mentoring program to women, and aims to reduce alcohol use and improve contraception to reduce the risk of further alcohol exposed pregnancies. This program has been evaluated as highly successful and targets only women who are drinking in pregnancy at risky levels, or who have just had a child with FASD. It focuses on reducing the risk in future pregnancies. It has been estimated that the cost of raising a child with FAS is approximately 30 times the cost of a targeted prevention program (Astley et al 2002b).

Models of FASD prevention involving incarceration of pregnant women or other punitive measures have been raised from time to time by governments and have

been implemented at different times internationally, with minimal success. A review of 413 cases of women who had been deprived of liberty due to pregnancy in the United States between 1973-2004 found that:

- Overwhelmingly, women were economically disadvantaged
- 59% were women of colour
- in most cases there was no evidence of harm to the fetus
- actions were contrary to the consensus by public health organisations, medical groups and experts that such actions undermine rather than further maternal and fetal health
- Some women had been charged with murder following the death of a fetus
- Deprivations of liberty often occurred despite the fact there was a lack of legislative authority. Many charges against pregnant women were overturned on appeal to higher courts. Most of the legal arguments were based on the argument that the fetus is legally separate from a pregnant woman, which is not the case in US law.

Concerns regarding any form of punitive measure against pregnant women include the likelihood of women terminating pregnancies rather than being incarcerated or charged. It is also of concern that for every woman who is placed in a locked facility, on a treatment order or under some form of legal control during pregnancy, many other women will avoid disclosing their drug or alcohol use for fear of the consequences. Women will be less likely to seek help for their alcohol use in pregnancy, and they won't have access to preventative programs that support the health of the woman and her unborn child.

Research into Aboriginal women's experience of recovery from substance use in Canada identified key principles for treatment providers to understand:

- Empathy
- Being non-judgmental
- Providing inspiration
- Recognising the impact of trauma and colonialism
- Open communication
- Showing care
- Link to spirituality
- Helping women move toward the future (Dell 2013).

### **Recommendations:**

#### **2.1 That the Northern Territory Government commit to a FASD prevention strategy which includes:**

- g) Population wide messages about the risks of alcohol in pregnancy including alcohol labelling

- h) Guidelines for health professionals about messages relating to alcohol in pregnancy
- i) Specialised supports for women who have children with FASD and are at risk of further births
- j) Services to women who use alcohol in pregnancy should be supportive and recognise the complex issues relating to alcohol use in pregnancy
- k) Follow up support for at risk mothers after the birth of a child to reduce the risk of harm in future pregnancies
- l) Services for Aboriginal women should be non-judgmental, recognise impact of trauma, and be culturally safe.

**2.2. NTCOSS does not support any form of punitive measures for pregnant women as research indicates this to be counter-productive.**

### **3. Diagnosis of FASD**

Diagnosis of FASD is usually made by a multi-disciplinary team. These teams include a paediatrician, speech and language therapist, physiotherapist, occupational therapist, neuropsychologist or other psychologist and social worker. The diagnostic process includes:

- a history provided by the social worker
- psychological testing including the domains identified above.
- Speech and language testing
- Motor skills testing
- Facial measurements
- Review of growth charts
- Discussion of the individuals' test results and agreement on a diagnosis.
- Recommendations for future interventions to support the individual
- Feedback to the individual and family
- Follow up may be offered.

The diagnostic process is usually completed in a half-day session. There are no diagnostic clinics for FASD in the Northern Territory. Paediatricians in the NT will sometimes diagnose FASD depending on the confidence of the practitioner that the conditions are met.

Peadon (2007), a General Practitioner, provides a rationale for FASD diagnosis looking at both individual and social factors:

*For the child, accurate diagnosis informs and enables early intervention which leads to a 2–4 times reduction in the risk of secondary disabilities in adulthood (Streissguth et al 2004) For the family, diagnosis is important. It provides an explanation for the child's problems, leads to better understanding and more appropriate expectations of the child, and may improve access to educational and social services and government*

*allowances. Making the diagnosis of FAS, ARBD or ARND also provides an opportunity for prevention of damage to future children. At a public health level, diagnosis can improve reporting of incidence and prevalence and thus allows research, advocacy and planning for health, educational and social services. Potential negatives of making the diagnosis such as maternal guilt and blame always need to be addressed sensitively as part of assessment and management. (Peadon et al 2007)*

Early intervention is dependent on diagnosis. Diagnostic teams have been identified as a best practice model and have been operating in the United States for over 20 years. The model is effective and could be implemented in the NT using existing practitioners.

Recognition of FASD as a disability would open up further pathways into services for affected individuals. Access to assessment, case management services, specialist behavioural management services and housing would be of benefit, the disability workforce would need to be resourced around the unique nature of FASD and the range of variability in the condition.

**Recommendations:**

- 3.1 That FASD diagnostic teams be established in the NT**
- 3.2 That FASD be identified as a disability in the NT**
- 3.3 That individuals with FASD be able to access Disability Services**
- 3.4 That Disability Services workers be trained in FASD.**

#### **4. Support to Carers and Family Members**

Children with FASD in foster care are at greater risk of placement breakdown due to difficult behaviours. Foster carers often experience high levels of frustration at the challenges of managing children with FASD, and the lack of support provided by child protection workers and other agencies in relation to FASD, often due to the fact that workers do not have access to resources and training on this issue.

The National Organisation for FASD (NOFASD Australia) has conducted training with foster carers on an annual basis. Carers need resourcing around the needs of children with FASD and access to ongoing support from professionals who are knowledgeable about FASD management strategies.

More needs to be done to support children in care with FASD and to support carers. Accesses to services can be adhoc and carers may be required to advocate for the children in their care to get a diagnosis and support. A review of the needs of families affected by FASD in Australia found that carers wanted access to diagnosis, support and knowledgeable professionals. Key recommendations included:

- Biological mothers of affected children need support if FASD is to be prevented
- There is little recognition of the disorder or the burden associated with FASD
- Classification of FASD as a disability will improve services for those affected
- Carers need to be provided with information about FASD and strategies for dealing with the behaviour and health of children
- Out of home care placements need to be supported and sustained.
- Effective interventions for families caring for children with FASD should be piloted and evaluated (Breen et al 2012).

#### **Recommendations:**

- 4. Development of training and FASD specific resources to enhance the skill and knowledge base for those caring for or supporting individuals with FASD.**

## **5. Resourcing of the Service Sector to better respond to FASD**

### **Antenatal care**

Women are not always provided with clear, accurate information about the risks of drinking in pregnancy. An Australian study of paediatricians in Western Australia in 2006 found that only 43.9% of paediatricians believed women should abstain from using alcohol in pregnancy. Only 11.4% had read the current Australian guidelines and only 9.1% provided advice consistent with the guidelines (Elliott et al 2006).

When health providers were surveyed more broadly, it was identified that 45% of those caring for pregnant women routinely ask about alcohol in pregnancy, 25% routinely provide information on the consequences of alcohol in pregnancy and only 13% provide advice consistent with NHMRC guidelines (Payne et al 2005).

Women who are high risk of having a child with FASD may access services late in pregnancy. Women who have alcohol dependency may not access antenatal care at all. These women are highly vulnerable and may avoid services where they feel under pressure. Women consuming alcohol in pregnancy should be advised that it is never too late to stop consuming alcohol in a pregnancy. This education may also assist in future pregnancies. However women with alcohol dependence may not be able to stop using alcohol without specialist treatment. It can be difficult for women to enter alcohol treatment when they have other children at home, and when their partners consume alcohol. Community consultation about the best programs to assist pregnant women with alcohol dependence is required.

Limited data exists about the use of alcohol in pregnancy. The Australian Institute of Health and Welfare produces an annual report "Australia's Mothers and Babies". Data on smoking in pregnancy is collated but data on alcohol is under development. This is a significant gap.

### **Recommendations:**

#### **5.1 Improved data collection in relation to alcohol in pregnancy**

**5.2 Development of procedures to ensure all pregnant women receive appropriate screening for alcohol use and training for practitioners to ensure this occurs.**

**5.3 Resources for health practitioners to develop sensitive and culturally safe strategies for assessing alcohol use in pregnancy and providing education to mothers.**

**5.4 Community consultation about appropriate service models to assist pregnant women with alcohol dependence access treatment.**

## **Identification of Infants with Fetal Alcohol Exposure**

Infants born with FASD are usually not diagnosed until age 7 or 8 as the assessments require a certain level of brain development. Even infants with FAS are rarely identified at birth. A study of children diagnosed with FAS in Australia found that only 6.5% of children who met the criteria for Fetal Alcohol Syndrome were diagnosed at birth (Elliott xx). Health workers may suspect that an infant is affected but this may or may not be recorded in case notes due to lack of firm evidence.

Many doctors are reluctant to diagnose FASD because they fear it will stigmatise the child and the mother. Research has found that 69.6% of paediatricians and 53% of other health providers thought diagnosis would be stigmatizing (Elliott et al 2006). Only 2% of health providers felt equipped to deal with FAS (Payne et al 2005).

Only 18.9% of paediatricians could identify all four diagnostic features of FAS and only 23.3% routinely ask about alcohol in pregnancy when taking a child's history (Elliott et al 2006).

Nearly all the providers surveyed wanted more information about the effects of alcohol in pregnancy. Health providers in the NT need to source their own information about FASD as there is nothing produced locally. There are a number of online resources produced by agencies in the US and Canada, and a few Australian resources. The projects in Tennant Creek and Ord Valley (Kunnunurra) have produced high quality resources suitable for working with Aboriginal families, but these are not widely distributed.

The stigma associated with FASD needs to be overcome so that parents receive the information they need and so that affected children are diagnosed early and offered early intervention. Early intervention is the most effective way to assist children with FASD developing to the best of their abilities and to prevent development of secondary disabilities. Early diagnosis can also assist in educating parents to prevent further alcohol affected pregnancies.

### **Recommendations:**

**5.5 Further training of health providers in identification and diagnosis of FAS and FASD**

**5.6 That the NT government produce resources for health providers on FASD, diagnosis and screening, effects of FASD and intervention strategies.**

**5.7 That procedures be put in place to ensure that children with Fetal Alcohol Exposure are flagged for regular developmental screens**

**5.8 That Fetal Alcohol exposure be recorded on medical files to enable future diagnosis when available**

**Early Childhood and Allied Health Services**

Aboriginal children in the NT experience a range of developmental vulnerabilities due to factors including anemia, malnutrition, infections, and lack of access to quality child care. Their parenting may be compromised if parents have drug or alcohol issues, low educational attainment, live in violence or overcrowding, and experience other socio-economic factors. Developmental issues may be due to multiple causes and it is important that these issues are taken into account in assessing children.

With so many issues impacting on children, FASD is often invisible and when identified, not seen as a priority due to many other competing demands. Yet FASD is a predictor of poor long term outcomes. Early intervention with children at risk of FASD includes identifying areas in which the child is not meeting milestones and implementing aggressive early interventions. These include speech and language, gross motor and fine motor skills, and behavioural management where relevant. It also involves resourcing the parents or carers to understand the risks associated with fetal alcohol exposure so they can identify symptoms when they emerge.

Screening for FASD can identify children at risk of the disorder, and early interventions can be put in place based on the presenting issues of each child, even without diagnosis. There are a range of screening tools which have been developed in the US and Canada which could be adapted to the NT setting and while not providing an accurate diagnosis, help identify children who require interventions and further follow up.

**Recommendations:**

**5.9 That the NT government ensure that all agencies working with infants, children or families have access to accurate, up to date information about alcohol consumption in pregnancy and the impact of FASD.**

**5.10 That the NT government provide FASD screening guidelines to professionals working with vulnerable infants and children.**

**5.11 That culturally appropriate information is sourced from relevant successful FASD Projects in Australia and adapted where necessary to the NT setting.**

## **Childcare and Preschool services**

Children with FASD may be first identified at childcare or preschool, when their behaviours indicate that there may be developmental issues. Commonly children with FASD may struggle to understand social rules, may have trouble with boundaries and consequences, may have difficulty with peer relationships and may not cope with the stimulation of a busy childcare setting. This overstimulation can lead to aggression or withdrawal, which is subsequently identified as problematic behaviour.

Children may also struggle to learn, may repeat mistakes, or may learn something but appear to forget it the next day. Because children's performance can be very inconsistent, they are often labeled as non-compliant rather than having their disability recognised.

Behavioural issues such as tantrums and aggression can be linked to delayed speech development, and early intervention in this area can reduce the impact of FASD.<sup>4</sup> Where children do not have access to childcare, these behaviours may not be recognised until the child starts primary school, and an opportunity to intervene early may be lost.

Staff providing early intervention services such as allied health care or behavioural support, require education and training about FASD and successful approaches. Effective strategies include reducing stimulation, providing quiet spaces for a child to withdraw into, creating visual cues for routines and use of techniques such as positive rewards, skill rehearsal and catching the child 'being good' (Burd 2006).

### **Recommendations:**

**5.12 That the NT government explore screening of children at preschool for FASD in order to refer for diagnosis and early intervention services.**

**5.13 That staff of early childcare services are provided with education and training in FASD**

**5.14 That successful interventions for children with FASD in preschool years are promoted.**

### **Education**

Indigenous education in the Northern Territory has been explored in detail. Kronemann (2007) identified that challenges to education are complex and cannot be dealt with in isolation, and that success requires partnerships between communities, service providers and government.

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Within a context where significant work is being done to improve issues impacting on education of Aboriginal children in the NT, FASD can pose challenges for educators which they may not be trained and resourced to respond to.

Children with FASD in the education system are likely to have significant issues in the classroom. These children are likely to struggle with many aspects of learning, due to problems with memory, auditory processing issues, cognitive issues and difficulties with abstract concepts. Sensory issues associated with FASD also make it difficult for children to concentrate in a classroom environment. Lighting, noise, and a highly stimulating environment can overwhelm a child who has limited ability to process multiple stimuli.

A recent comprehensive review of Indigenous education in the Northern Territory identified a theme particularly in remote schools that student behaviour constitutes a barrier to effective teaching and learning. Factors identified included hearing loss, lack of sleep, FAS, hyperactivity and trauma-associated issues, mental health. There is not always capacity for staff to manage all these issues (Wilson 2013).

The NT has appointed a Senior FASD Consultant in Darwin and a Psychologist in Alice Springs to assist schools to better identify and meet the needs of children with FASD. The program will provide training to schools and assistance to plan classroom management strategies.

Children can be referred by a paediatrician to Disability Support Services. Anecdotal information suggests some children with FASD are successfully being referred for support services in the classroom. However the majority of children do not have access to 1:1 support. Generally when funding for inclusion support is provided, it is spread across the classroom to support all children in their learning. Yet children with FASD will often require 1:1 support to succeed in the classroom.

#### **Recommendations:**

**5.15 That FASD training be included in professional development for all teachers in the NT.**

**5.16 That DET develop resources on classroom management strategies and individual learning plans that reflect best current international practice.**

#### **Child Protection and foster care**

Children in care are a high-risk population for FASD (Astley et al 2002). A recent study of children in the Child Protection system in NT identified that 20% of children under investigation and 38% of children in care were subject to fetal alcohol exposure (Walker 2014). While not all children who have been exposed to alcohol will develop FASD, those who do will pose significant challenges for the care system.

Department of Children and Families has conducted FASD training for the past three years. There is little information readily available to child protection workers about successful models of intervention with this group and almost no research has been conducted in Australia on children with FASD in the child protection system. More work is needed to raise the profile of children with FASD to ensure that their needs can be better identified and addressed in the child protection system.

### **Recommendations:**

#### **5.17 That Department of Children and Families identify and implement best practice models to assess and support children with FASD.**

##### **Youth services**

By the time a young person with FASD reaches adolescence, they are likely to have been frustrated with school, have low self esteem and very few friends. These young people are often desperate to make friends, and with low impulse control, lack of ability to weigh up risks, and a poor understanding of the consequences of their behaviour, are vulnerable to others who may want to exploit them. People, who they consider as friends may abuse them financially, exploit them sexually or involve them in criminal activity and drug use.

Mental health issues are common as is suicidality. Mental health and drug and alcohol services are not always trained in working with the particular brain injury caused by alcohol – where young people appear verbally competent but don't always understand what is being said, and have impaired capacity to plan or evaluate different courses of action. Strategies which rely on memory, such as making agreements about seeking help if feeling suicidal or planning to reduce drug use, may be forgotten as soon as the young person leaves the room. It is important that all workers who have contact with young people with Fetal Alcohol exposure are aware of the nature and characteristics of FASD in order to identify when a young person may be affected and adapt service delivery to the needs of the individual.

Many of these young people will drift into the homelessness system, either after leaving care or as a result of family living circumstances. A longitudinal study of individuals with FASD found that of those aged 12 and over:

- 94% had mental health issues, usually depression or anxiety
- 60% of children had ADHD
- 70% had disrupted school experiences
- 60% had been in trouble with the law
- 60% had been incarcerated for criminal or treatment purposes
- 30% experienced substance abuse problems
- 80% of adults lived in dependent accommodation

Individuals who did not have the full Fetal Alcohol Syndrome had higher rates of secondary disabilities. Early diagnosis and access to services was a protective factor (Streissguth 1996).

#### **Recommendations:**

**5.18 That workers with vulnerable young people be provided with access to resources and training to assist them in developing more appropriate service responses to young people with FASD.**

**5.19 That international best practice service models for supporting young people with FASD be explored and features of these models be incorporated into existing service design.**

#### **Services for vulnerable adults**

As stated above, adults with FASD have particularly poor outcomes. FASD sets up a lifetime of difficulty in negotiating many of the tasks of daily living, including finding and maintaining accommodation, paying bills, keeping up to date with appointments, self care, and managing the care of children. Most adults with FASD will struggle with one or more of these areas over time, if not all. Combined with the effects of the secondary disabilities listed above, in particular drug and alcohol issues, mental health, involvement with the justice system and being a victim of violence, it is highly likely that adults with FASD will come into contact with a number of welfare and support services.

#### Homelessness services

Adults with FASD are likely to require support in independent living. They are likely to access homelessness services at some stage of life but may struggle with expectations such as rules, expectations, boundaries and appropriate behaviour. They are likely to have difficulty attending appointments, using public transport and adhering to plans and agreements. As a result they are likely to be excluded from services from time to time due to breaching the agreements made.

Adults also are likely to require ongoing support. Transitional services, which rely on the individual learning skills over time and then applying them independently, are likely to fail with adults with FASD. Traditional models of intervention involving teaching skills (ie bill paying), modeling, monitoring and then phasing out support are unlikely to be effective, as the adult with FASD will be able to learn skills, but may not be able to continue to apply them after support is withdrawn. The service system does not often support adults who need ongoing support unless they have been diagnosed with a disability.

## Disability services

A number of adults and children with FAS are cared for by the Disability Services system, where they meet criteria. The more affected the individual, the more likely that they will be eligible for Disability Services, usually due to their low level of independent functioning or their IQ being below the cut off of 70. Yet most individuals with FASD have IQs in the normal range and present well verbally, giving the impression that they do not have a disability.

FASD diagnosis will ensure that these individuals are eligible for Disability support services. However increased resourcing is required to meet these needs of this client group, and to educate and train workers in the Disability sector to adapt their practice to include FASD clients.

## Family violence services

Many adults with FASD are victims of violence and are vulnerable to exploitation in relationships. These adults may struggle with some of the expectations of services in relation to safety planning and following through on plans to leave the relationship, establish housing and parent children who have been exposed to violence. Family violence workers need education and training to identify adults who may have FASD and adapt their service model to the individual's abilities. Ongoing support services may be required for some individuals to establish themselves in an environment free of violence.

## Drug and alcohol services

A high proportion of adults with FASD have alcohol and drug issues. Often models of counseling are not designed for clients with impairments in the areas of memory, cognition, planning and evaluation of options. Reflecting on past drug use and planning to change future behaviours are not necessarily effective strategies with this group of clients. Successful strategies have been documented internationally and these need to be identified and adapted to the client group in the NT. For example, adults with FASD with addictions may reduce their alcohol or drug use by changing the environment rather than changing their thinking. An environment free of drugs and alcohol and positive role models and mentors are more effective strategies with this client group. Cognitive behavioural therapy is likely to be ineffective with this group.

## Mental health services

Similar issues exist with mental health services, particularly in the use of cognitive behavioural therapy which assumes a level of working memory. Suicidality is unlikely to be addressed effectively through making plans or agreements which rely on memory. Individuals with FASD who are suicidal may be unable to be an active player in their own safety plan and safety may need to come from external

monitoring. Again, changing the environment, mentoring and role modeling are the most effective strategies to address negative behaviour and thinking in individuals with FASD.

**Recommendations:**

**5.20 That services providing support to vulnerable adults are provided with resources about effective interventions with adults with FASD based on best practice Internationally.**

**5.21 That staff working with adults who may have fetal alcohol exposure be educated and trained about the disorder**

**5.22 That staff working with adults ask about maternal alcohol consumption in pregnancy as part of their assessment.**

## **6. Implementation of Good Practice FASD Prevention and Intervention models**

There are a number of good practice models for FASD prevention and intervention. The programs described here all have features that could work effectively in the NT context. These are a small sample of many programs which could deliver benefits for children, young people and families.

### **Australian Programs**

#### **OVAHS FASD project: A locally owned and driven project with community-wide prevention, and individual support for high risk families**

The Ord Valley Aboriginal Health Service (OVAHS) FASD Project was developed in response to local concerns about high levels of alcohol use, including during pregnancy, and suspected rates of FASD. The local traditional owners identified alcohol use in pregnancy and provided the initial funding for the project.

The first stage of the project was to develop an understanding of the problem locally, including drinking patterns among pregnant women. It aimed to identify the needs of women in the target group and deliver strategies to assist individuals and families to make informed choices about alcohol use in pregnancy.

The project developed a plan addressing the needs of 5 target groups.

1. All antenatal clients of OVAHS were provided with FASD education, AOD assessment and counseling. Interventions were extended to include partners and family members. Contraception advice was provided and follow up was extended post-birth.
2. Women of childbearing age (13-45) were provided with FASD and contraception education through local services including schools, local services and community events. A focus was placed on at-risk women who might not normally access services. Education for older women was also provided as a way of supporting younger women and promoting inter-generational knowledge about alcohol in pregnancy.
3. All staff of OVAHS were provided with training on alcohol awareness, FASD and contraception. Nursing and medical staff completed the FASD diagnostic course online through the University of Washington.
4. Local Aboriginal men were targeted as key players in supporting their partners to abstain from alcohol in pregnancy. Men were engaged around their fatherhood responsibilities and the need to pass on oral cultural knowledge, which is disrupted when young people suffer neurological damage.
5. Broad community consultation and development of connections with Aboriginal population, local organisations occurred to ensure that the local community was invested in the program. Relationships with national and international FASD networks were developed to ensure that the program was

informed by current research and knowledge.

Outcomes identified at the end of the first year included:

- FASD assessment and education through brief interventions has become a routine part of antenatal care.
- An antenatal survey has been developed which measures women's alcohol use, knowledge of FASD and knowledge of risks of alcohol in pregnancy. The questionnaire is delivered by an Aboriginal health worker. Follow up support in relation to reducing alcohol use where indicated is offered by the Social Support Unit.
- 84.7% of women identified alcohol use during pregnancy.
- After FASD education, 56.4% of women reported that they abstained from alcohol, 14.1% cut down and 1.2% continued to drink alcohol.
- The program has identified gaps in young women's knowledge about contraception. Health centre staff now routinely ask young women about contraception.
- There were challenges in educating women about the impact of FASD when many babies born had no visible signs of the disorder. Education has focused on the hidden nature of the disability and has used visual aids and audiovisual materials to convey the message.
- Women reported pressure from their partners to consume alcohol with their family, and that if they removed themselves from the 'drinking circle' that conflicts with their partner resulted. OVAHS had to overcome views that pregnancy was "women's business" and did so through engaging men who wanted FASD education and to participate in program design. Men were actively engaged in the program and were encouraged to take an active role supporting partners but cutting down or abstaining from alcohol themselves during the pregnancy.

The program was based on a foundation of community control, ownership and investment. Its development was a response to a need identified by community members and this has been critical to its success. The program is now embedded within the OVAHS as part of the New Directions Mothers and Babies program.

### **Anyinginyi Health Aboriginal Corporation FASD Project**

The Project mandate has been to raise awareness, educate, prevent and support. The initial focus has been two fold:

- To identify and partner/network with existing services and programs; and
- To develop a library of resources, which can continue to be used by the community beyond the lifetime of the Project.

Activities of the program include:

- The development of Pregnancy Pamper Packs, currently being distributed via health professionals to all pregnant women with the aim of providing information and support to encourage them not to drink alcohol;
- The creation of a FASD Prevention hip hop song with local young people, called “Strong Baby, Strong Life!”
- The adoption of warning signage in local licensed premises;
- Various education and prevention sessions with different community groups; and,
- Ongoing collection of resources and research.

Staff of the program have presented at the International Conference on FASD in Canada in 2013.

In the second year of the project, despite funding being cut, the project aimed to consolidate and build on community knowledge and ownership of the FASD issues, as well as support of individuals, families and services dealing with FASD. A training package for teachers was developed, and rolled out as a multimedia package for use by teachers, health professionals, families and carers in the Barkly region. A second film was produced using puppets to tell the story of a child with FASD, with funding from the Foundation for Alcohol Research and Education (FARE). Puppets are used in many of the training workshops and have proven to be a very valuable resource for breaking down barriers in education.

**No Safe Amount – the Effects of Alcohol in Pregnancy Campaign – NPY Womens Council Aboriginal Corporation**

The *No safe amount - the effects of alcohol in pregnancy* campaign was created by the Ngaanyatjarra Pitjantjatjara Yankunytjatjara (NPY) Women's Council Aboriginal Corporation. The program is an early intervention and prevention campaign designed to raise awareness of the deleterious and permanent effects of using alcohol during pregnancy. This message is achieved through an education and advertising campaign, and a DVD resource that uses a combination of multimedia including animation and live action.

The campaign was developed in partnership with young people in the remote Aboriginal Community of Imanpa, including script development, pre and post production, and casting. The stories contained within the DVD have been role played by local community members who were actively engaged in the process. In 2010, the commercials produced as part of the campaign were aired on Imparja Television. The three 30 second broadcast quality commercials are in both Pitjantjatjara (the local language) and English, and comprise of:

- a. Ititjara (pregnancy)
- b. The growing brain
- c. Responsible fathers

The campaign won the Outstanding Achievement in Aboriginal and Torres Strait Islander Health Award at the Deadly Awards in 2011 (NPYWC.org.au). However, the screening of this valuable DVD is rather costly and NPY does not have the financial resources to have it screened on commercial TV. This would be a very good and excellent promotional resource, if it could attract further funding.

### **Marulu: The Liliwan project, Fitzroy Crossing**

Marulu: the Liliwan project is a community-led strategy developed to address Fetal alcohol spectrum disorder (FASD) in the Fitzroy Valley of Western Australia. A group of Aboriginal leaders have partnered with experts in Aboriginal health, paediatric medicine, human rights advocacy, child protection and a production company to progress the strategy. The project has three components:

- a. diagnosis and prevention of FASD
- b. support for parents and carers of children with FASD
- c. advocacy and awareness-raising about FASD.

To find out how widespread FASD is in the communities of Fitzroy Valley, community leaders initiated a partnership between Nindilingarri Cultural Health Services, Marninwarntikura Woman's Resource Centre, The George Institute for Global Health and the Discipline of Paediatrics and Child Health at The University of Sydney Medical School. This partnership is conducting Australia's first ever prevalence study of FASD, the Liliwan Project.

Each child diagnosed with FASD will be given a personalized FASD management plan involving their families, doctors and teachers. The project will also educate the communities about the risks of drinking alcohol during pregnancy and about the challenges faced by children with FASD and their families.

The project team has produced two films - a documentary and an educational film - to raise awareness of FASD and its impact on the lives of children, their families, carers and communities living in the Fitzroy Valley (The George Institute, <http://www.georgeinstitute.org.au/projects/marulu-overcoming-fetal-alcohol-spectrum-disorders-fasd>).

The Liliwan project is a large scale diagnostic program which has attracted considerable funding. While it would be difficult to replicate, the learnings of the project should inform NT policy and program development in this area. Health professionals in the NT would benefit from learning about the diagnostic strategies used, and the personalised FASD management plans would be highly relevant to the NT context, as they draw on the resources of a small community with visiting specialist services and share all the challenges of remote towns and Aboriginal communities in the NT.

## **International Programs**

### **The Parent Child Assistance Program – multiple sites in the United States and Canada.**

The Parent–Child Assistance Program (PCAP) began in 1991 at the University of Washington. It is an intensive three-year one-on-one mentoring program for women at high risk of having a child born with FASD.

The primary aim of the program is to prevent future alcohol and drug exposed pregnancies by encouraging the use of effective contraceptive use, by helping women abstain from or decrease their use of alcohol and drugs and by addressing the range of factors that contribute to women’s substance use, including poverty, isolation, and lack of parenting support. The program uses a home visiting/case management approach and is based on principles of harm reduction.

The model has been replicated and evaluated across North America and has been found to be effective in a number of ways. A number of programs have been implemented in First Nations communities and the model is considered very appropriate in working with Indigenous women.

A recent study conducted an economic evaluation of the PCAP program in Alberta. Between 2008 and 2011, 366 women participated in 25 P-CAP programs across the province.

The evaluation estimated that the program prevented approximately 31 (range 20–43) cases of FASD among the 366 clients in a 3-year period which resulted in a cost-benefit of approximately US\$22 million (*Girls, Women and Pregnancy, fasdprevention.wordpress*).

### **FASD Key Worker Program – Canada, multiple locations.**

The FASD Key Worker program provides support to families with children and young people with confirmed or suspected FASD. Parents may self refer for assessment and the child is not required to have a diagnosis.

Key workers assist families to understand FASD by providing education and information specific to the needs of the child and family. They assist families to locate appropriate resources, assist them to get support, health and education services and can act as an advocate for the family in the service system. They also provide emotional and practical support to families.

Key workers support family members to adapt the environment to better meet the child’s needs and assist the family to become advocates for the child. The role can include facilitating carer and parent groups, parent training and mentoring. In Canada these programs are often located in Aboriginal Health services or Family support services (Ministry for Children and Families, British Columbia, Canada [http://www.mcf.gov.bc.ca/fasd/kw\\_support.htm](http://www.mcf.gov.bc.ca/fasd/kw_support.htm)).

### **Through an Aboriginal Lens Project – British Columbia, Canada.**

This is a new project funded in 2014 to address a gap in services for Aboriginal youth referred for FASD assessment by Youth Probation Officers. The program aims to create culturally appropriate supports among Aboriginal family and community members and build the capacity of participating young people to help them transition from justice involvement to rehabilitation and reintegration into the community.

Two Aboriginal FASD Youth and Family Support Workers are employed to work with young people to assist them in understanding what living with an FASD diagnosis, co-existing substance abuse and other life harms means in relation to their conflict with the law. The goal is to help youth identify within themselves and their support systems both the assets and areas that need additional support in order to develop individual strategies that will ensure their successful navigation through the justice system and assessment process.

The Support Workers are responsible for providing basic counselling, guidance, support, community development, service networking, education and advocacy. The overall approach will be nonjudgmental, accepting each young person regardless of the number of offences committed, relapses, types of drugs or length of usage (Asante Centre, [asantecentre.org](http://asantecentre.org), 2014)

#### **Recommendation:**

**6.1 That the NT FASD Working group examine good practice models of FASD prevention and intervention both from Australia and Internationally with a view to implementation in selected sites in the NT.**

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