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House Standing Committee on Social Policy and Legal Affairs

Fetal Alcohol Spectrum Disorder in the Child Protection System: Opportunities for Prevention and Intervention.

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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 has convened and presented workshops and delivered training for health and child protection workers in the Northern Territory in relation to FASD, including identification, prevention and case management.

Prue has been employed by the NT Department of Children and Families between 2006 and 2011 as a Child Protection Manager in both Alice Springs and Nhulunbuy.

Summary

- FASD is a significant issue for the Child Protection system.
- Children in care are 10-15 times more likely to have FASD than other children.
- Children with FASD stay in care longer than other children.
- Children with FASD place significant demand on the care system due to their high needs, which are usually undiagnosed.
- Children with FASD have very poor long term outcomes, which are worse for children who are not diagnosed, as they grow into adults who have complex needs and require multi-agency support.
- Children of parents with FASD are more likely to be involved in the child protection system.
- Mothers of infants with FASD who enter care are at very high risk of giving birth to further alcohol-exposed children.
- The child protection system has an opportunity to make a difference through:
    - Education and training for workers, carers and birth families
    - Improved referrals and early intervention for developmental and learning problems in children in care who have FASD
    - Case management guidelines for working with adults and children with FASD
    - Early identification of women at risk of further alcohol affected births.
- FASD identification and intervention needs to be embedded in practice.

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.

1. Background to the Submission.

In 2009 I visited Canada and the United States to explore models of care for children with FASD. My interest in this topic derived from my experience working with children in care in Alice Springs where a number of children had been diagnosed with Foetal Alcohol Syndrome (FAS). In attempting to identify models of best practice with this group, I learned about Foetal Alcohol Spectrum Disorder and realised that it was highly likely that many more children who had been placed in Out Of Home Care (OOHC) might meet the criteria for this diagnosis.

I was particularly concerned about the case management of children in care with FASD as it was not easy to find any local resources, either from the NT or Australia, to provide information on this condition to assist health and welfare professionals or families in providing care.

2. Prevalence of 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.[1]

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 1000[2], and the estimate by Professor Marcia Langton that FASD affects 1:40 indigenous children.

International research suggests that actual rates of FASD may be higher than those previously estimated. Philip A. May, author of the study above, in his Keynote Address to the 4th International Conference on FASD in Vancouver in 2011, estimated FASD at between 20 to 50 per 1000 in a comparison of results from primary school based screening programs in Italy, South Africa and the United States. May argued that the majority of cases of FASD are unlikely to be identified without active screening.[3]

3. Prevalence of FASD in the Northern Territory

The Northern Territory Government Fact Sheet – *Alcohol use in the Northern Territory* (October 2010) documents the higher than average alcohol consumption among residents in the NT, and the associated risks:

- Average alcohol consumption in the NT per capita is 15 litres per year, compared to 10 litres average in Australia
- 17.2% of non-Indigenous adults consumed alcohol at risky levels, compared to the national average of 10.6%.
- 24.8% of women aged 35-44 consumed alcohol at risky levels
- 21.4% of indigenous women consumed alcohol at risky levels
- Approximately 1:8 indigenous women and 1:12 non-indigenous women reported consuming alcohol at their first antenatal visit.
- At 36 weeks pregnancy, this had fallen to 8.0 – 8.7% of indigenous women and 3.6 – 4.7% of non-indigenous women who continued to consume alcohol.

- Overall alcohol consumption by indigenous people in the NT is much higher than the national average for indigenous people[4].

The Menzies School of Health Research commissioned a report which estimated the cost of alcohol-related harms in the NT as four times greater than the national level. Hospital admissions due to FAS were included but numbers were low, suggesting that FASD is not a primary reason given for a hospital presentation. Infants and children with FASD are likely to be admitted to hospital due to prematurity, poor growth, or birth defects requiring intervention.

The study does not attempt to measure the annual cost of raising children with FASD, including the costs of foster care, speech and language support, developmental services, education support, and management of birth defects. In affected adults, FASD contributes to admission to mental health facilities, drug and alcohol treatment, incarceration, homelessness and involvement with the child protection system. When these costs are included, the cost of FASD to society rises.

Economic modelling undertaken in Canada in 2009 identified the average cost of health care for a person with FASD as $25 000 per annum. FASD was compared to other health conditions and its annual cost was significant.

Cost of FASD in Canada 2009

- Direct and indirect costs 7.6 billion
- Direct costs of FASD 4.9 billion
- Total cost health care only 2.1 billion

Compared to other diseases:

- Respiratory diseases 4.8 billion
- Cancers 4.7 billion
- FASD 2.1 billion[5]

High rates of alcohol consumption in the population, and particularly among women, place children in the NT at a greater risk of FASD than the Australian average.

4. Prevalence of FASD among the children involved with the statutory child protection system.

There is strong international evidence that children with FASD are over-represented in the child protection system, and that prenatal alcohol exposure greatly increases the risk of children entering care, including foster care, residential care, or family placements.

Children with FASD are at high risk of entering the care system due to:

- Abuse and neglect due to parental alcohol use;
- Risks to growth and development, including failure to thrive.

A range of international studies have indicated that children with FASD are more likely to be placed in care.

Susan Astley and colleagues conducted a study which screened all children entering foster care in Washington State and identified the rate of FAS as 10-15 per 1000, approximately 10 to 15 times greater than the estimated population rate of 1:1000. This study was conducted with high reliability.[6]

Other studies identifying over-representation of children with FASD among the in-care population include:

- A Washington state study of 415 individuals with FAS or Fetal Alcohol Effects (FAE) identified that only 20% had been raised by their biological mothers[7].
- A Manitoba study found that 11% of all children in care had a FASD diagnosis, representing one-third of all children in care with disabilities.[8]
- A Norwegian study which found 11% of children diagnosed with FAS or FASD had been removed from their mother soon after birth due to her alcohol use[9].
- In Saskatchewan, 72% of 207 individuals with FASD had resided in foster care for some period of their lives[10].
- A French study in 2010 found that 18% of babies born to mothers who had not modified their alcohol consumption when pregnant were placed in foster care.[11]
- A study of 250 individuals with FASD identified that the majority of infants under 1 year of age in the sample were residing in the care of a child protection service.[12]

Children entering care with FASD are also likely to remain in care for longer periods.

- A study of children in care in Illinois identified that only 14% of substance exposed infants who entered care in 1994 were reunited after seven years.[13]

Research into FASD in the population of children in OOHC is still at very early stages. In a 2005 evaluation of a FASD practice initiative among child protection services in Alberta, Canada, Dorothy Badry reported that a literature search combining the terms “fetal alcohol syndrome” and “foster care” yielded no results.[14]

Australian research is very limited. A review of children diagnosed with FAS between 2001-2004 in Australia revealed that 60% of children in the study were in care, 51% had a sibling with FAS, and 65% were indigenous.[15]

There is evidence that alcohol plays a major part in the numbers of child protection notifications each year in Australia. The Australian Education and Rehabilitation Foundation identified that 20,000 children across Australia would be the victim of substantiated alcohol-related child abuse each year. Using data from Victoria it was identified that 33% of all substantiated cases of child abuse recorded alcohol as a factor.[16]

A South Australian study found that substance abuse was a factor in approximately 70% of all cases of children entering care, with 77% of these cases involving alcohol.[17] This report identifies that 6% of children were known to be prenatally exposed to substances including alcohol.

A study of risk factors for behaviour problems among children with FASD identified that the length of time spent in residential care was associated with increased behaviour problems.[18]

5. Under-recognition of FASD within Child Protection Systems in Australia

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.
- A recent 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 foetal 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

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 brief references and omissions in other states and territories reflect the under-recognition of the prevalence and impact of FASD in Australia, particularly within families that come to attention of child protection services. Behavioural issues which 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 which is going unrecognised.

International research on FASD has identified that alcohol-exposed children have specific brain injuries which lead to problematic behaviour and which deserve increased recognition in order to provide more appropriate services to this group of children. Philip May (cited above) has highlighted that the majority of cases of FASD are not identified until screening occurs.

6. Impact of FASD on children

The impact of FASD in children is well documented and includes:

Infants:

- Low birth weight/poor growth
- Irritability
- Sensitivity to light, noises and/or touch
- Feeding problems
- Failure to thrive

Toddlers;

- Memory problems
- Hyperactivity
- Lack of fear
- Poor sense of boundaries
- Impairment of gross or fine motor skills

Children:

- Poor growth
- Developmental delay
- Problems with vision
- Memory problems
- Language and speech deficits
- Poor judgement
- Birth defects
- Improperly formed bodies and organs
- Social and behavioural problems
- Cognitive problems
- Sleeping difficulties
- Hyperactivity
- Impulsiveness
- Difficulty concentrating
- Problems with abstract thinking (time, money)
- Difficulty forming and maintaining relationships.[19]

7. Impact of FASD on children in care

Typically, children with FASD require:

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

Children in care can experience changes and instability which are particularly 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.

These children already have a background of abuse or neglect which impacts on their ability to cope with change.

For indigenous children in the NT in particular, these changes and transitions can be very challenging. Moving between family of origin, kinship care and foster care involves changes in culture, language and location. All of these are a challenge for a child with FASD to manage.

8. The experience of children in care with FASD

There has been relatively little research into the experience of children in care who also have FASD, and this area deserves greater attention, given the lifelong impact of FASD on the individual and their families.

In Australia, children with FAS can be identified early in life, if they are referred to a paediatrician who is confident to make a diagnosis. In these cases, facial features are always present. However children with FASD are more complex to diagnose in the absence of the distinctive facial features, and the absence of diagnostic guidelines. As infants they 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 foetal 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 an 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 extended family, their 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.

For those who come to the attention of child protection in childhood, there will be several possible explanations for any behaviour problems, learning difficulties or developmental delays which the child may experience. Intervention will be likely to focus on addressing parenting issues, obtaining behavioural support through the school system, and working with parents or carers to manage the child's behaviour.

Without information and training on FASD, child protection workers, health professionals, family members and carers are responding to each aspect of the child's behaviour and development without reference to the impact of prenatal alcohol exposure and the "syndrome" of effects which results.

Typically, carers will become very frustrated with children who, after several years of positive parenting, educational support and therapies are still not making progress. Diane Malbin coined the often-used expression "Trying differently, not harder". A FASD diagnosis can allow the carer, child protection worker and extended family to make sense of the child's behaviour and provides an organising framework for intervention.

A young person who does not receive appropriate interventions in childhood is likely to enter the care system as an angry, confused young adult who has had negative experiences at school, at home and among peers. Secondary disabilities emerge around this time and young people with FASD frequently experience mental health problems, addictions, or display behaviour which puts the safety of themselves and others at risk, including inappropriate sexual behaviours or involvement in criminal activities.

These young people are likely to become adults who are highly reliant on social services through life, even when positive interventions occur. Without an understanding of FASD, interventions are likely to be counter-productive as the young person engages in a service system which promotes a model of increasing self reliance and independence, a goal which is not often appropriate for a young person with a lifelong brain-based condition that impairs judgement and decision making.

9. Adults with FASD

There is also a need for greater recognition that parents involved with child protection who have complex issues, including substance abuse, mental health, criminal behaviour and homelessness, may themselves have an FASD, and that if this is the case, different approaches to intervention are required.

It is not surprising that FASD in adults is not recognised in Australia, given the following factors:

- Recent identification: FAS was identified in 1973, and the FASD 4-digit diagnostic code developed in 1997
- High alcohol use in Australia: Consumption of beer per capita in Australia peaked in 1974-75, and consumption of wine in 1985-86, both declining since this time.[20]
- Lack of information about risks of drinking in pregnancy: The first guidelines on alcohol consumption in pregnancy were developed in 1980s.

FASD is not a new condition, but diagnosis has been in early stages in the US and Canada, and has only recently been identified as an area requiring attention in

Australia. It is likely that a similar proportion of the adult population to the population of children, would meet the criteria for FASD.

A literature review on substance abusing women with FASD identified the following barriers to identification of FASD in adults:

- Facial features are most distinct between 2-11 years of age but become less pronounced with age
- 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 Canada)
- Costs of diagnosis.[21]

A linked qualitative study interviewed 13 women with FASD, of whom 12 were parents. All 12 of these women had had contact with child protection services.

There are a number of similarities in the characteristics of adults with FASD and those involved in the child protection system. The table below illustrates the overlap between these two groups.

Comparison between the Characteristics of Adults with FASD, and Adults involved with the Child Protection System.

Adults with FAS/FASD – Washington[22]	**Adults with FASD – British Columbia[23]**	**Substance abusing women with FASD[24]**	**Parents involved in child protection system in Queensland[25]**
	26% were parents 69% lived with a caregiver 56% of parents were still parenting	48% had been in foster care or involved with child protection 11% had FASD diagnosis	
94% mental health problems, most commonly depression	92% mental health diagnosis	80% had a history of depression 57% had been mental health outpatients	19% of primary parents had a diagnosed mental health condition.
70% disrupted school experience	61% disrupted school experience		
60% in trouble with the law	45% trouble with the law		21% of primary parents had a criminal history
60% confined for treatment of mental health, substance abuse or for criminal behaviour 40% of adults had been incarcerated	32% had been confined to a hospital or prison		
53% of men and 70% of women experienced substance abuse problems	22% had alcohol or drug problem	100% had had substance abuse problem	In 47% of households one or both parents have or had a substance abuse problem
80% problems with employment			
72% had been exposed to violence	77% had experienced violence	61% history of physical abuse 70% history of sexual abuse	35% of households had 2 or more incidents of domestic violence in the past year. 25% were abused or neglected as a child

10. Prevention

There are many FASD prevention strategies, ranging from broad community education campaigns, labelling of beverages, brief interventions in antenatal care, training and education for health providers, substance abuse treatment for pregnant women which can play a role in the prevention of FASD.

Some of the most promising practice has been evident in the state of Washington, which is a leader in FASD from the identification of FAS in 1973, the development of the FASD 4 Digit Diagnostic Tool, and the implementation of a range of preventative programs.

Strategies implemented within Washington State have included:

- mandatory warnings on alcohol
- ongoing surveillance of risk through the Pregnancy Risk Assessment Monitoring System
- establishment of a diagnostic clinic with a strong research focus which has developed the FASD 4-Digit Diagnostic Code, and FAS Facial Imagery
- the development of the First Steps Program assisting low income pregnant women to access health and social services
- Establishment of the Seattle Birth-3 program, (later the Parent-Child Assistance Program, discussed below),
- a three-fold increase in gender specific residential substance abuse treatment beds for pregnant and post-partum women
- FASD Education in schools
- A wide range of FASD training for professionals.[26]

The screening of children entering foster care in Washington State has identified a significant decline in FAS in children born between 1993 and 1998 (Astley 2004) and a corresponding decline in maternal consumption of alcohol in this same period[27]. (PRAMS 1999), suggesting that the prevention initiatives in the Washington are having a positive effect.

It has been estimated that the cost of treating FAS-related problems are about 100 times the cost of research necessary to develop early identification and prevention strategies.[28]

Australia has only recently seen the growth of interest in FASD. Programs currently underway in Australia, likely to be detailed in other submissions to this Inquiry, include:

- The Liliwan project in Fitzroy Valley, WA
- The Ord Valley Aboriginal Health Service FASD Project in Kununurra, WA
- Employment of FASD workers in the Aboriginal Health Service, Tennant Creek
- A perinatal FASD project at Ali Curung, NT.
- The Alcohol Education and Rehabilitation Foundation has funded a range of FASD projects including the development of diagnostic tools and a research study into the screening and diagnosis of children with FASD in state care in Western Australia.

It is anticipated that outcomes of these projects will point to future directions for prevention programs targeted to specific communities within Australia, particularly rural and remote communities.

The role of the Child Protection System in FASD Prevention.

Child Protection workers have contact with a cohort of women who are at very high risk of giving birth to a child with FASD. Unfortunately, these are women who have already given birth to an alcohol-exposed infant. These mothers may only seek health services late in pregnancy but are frequently notified to child protection services either in pregnancy or after delivery. They are likely to have had previous contact with drug and alcohol services, may have had involvement with police or emergency departments due to alcohol related violence or assault, or may be on the banned drinkers register in NT.

The pattern of help-seeking among this group is often in response to an emergency or health crisis, and contact with services may not be voluntary. This client group is unlikely to return for follow up appointments, but likely to present to emergency departments on a repeated basis. These clients may seek help from time to time but don't sustain their involvement in the service system. They may enter rehabilitation but fail to complete it, or may engage with child protection services, but are unable to complete the steps required to reach their goal.

As clients, these women are unlikely to benefit from general FASD community education programs or even those targeted at pregnant women. Identification of and intervention with women at the highest level of risk of alcohol exposed births is known as "indicated prevention".

At present, there are no programs in Australia known to the writer which aim to deliver indicated prevention interventions for these mothers in order to reduce the very high risk of FASD in future pregnancies. Yet these women are almost certain, without intervention, to go on to have further unplanned, alcohol exposed pregnancies.

In any town or community in the NT, it is likely that child protection workers, midwives, emergency nurses, homeless shelters, drug and alcohol treatment providers, and child health nurses could identify without much difficulty the group of individuals at the highest risk of alcohol exposed pregnancy. Yet unless women seek help, they are unlikely to receive the combination of supports required to reduce their risk.

FASD Prevention with High Risk Mothers

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'.[29]

A highly effective program which was also 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.[30]

As part of the Churchill Fellowship 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.[31]

A review of the First Steps Program, modelled after PCAP in Alberta, Canada, found similarly that "at program exit, many participants were abstinent from alcohol and/or drugs and the majority did not experience a subsequent pregnancy."[32]

The evaluation of First Steps 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. [33]

Features important 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 does not rely on women maintaining a consistent address or turning up to appointments.
- A dual focus on reducing substance use and improving reliability of contraception.
- Feedback regularly provided to staff about client and program outcomes, which assists in staff satisfaction and retention.

The PCAP Program is also considered highly cost effective as a prevention program. There is potential for this successful program to be implemented in the Australian context.

> 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.**[34]

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.

A Finnish study 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.[35]

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.

Child protection services and health services need to develop a collaborative service response to prevent further FASD births among this group.

11. Conclusion

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 are uniquely positioned to take a lead in FASD prevention due to their high level of contact with these families. 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 where alcohol use is very high.

- Arranging screening for FASD for children entering care, where prenatal alcohol exposure is known or suspected
- Developing risk assessment and case management guidelines for case work with children with FASD and their families
- Incorporating the possibility of a FASD diagnosis into case planning with adults who are known to have been alcohol exposed
- Training for child protection workers, carers and family members who support or care for children with FASD
- Providing up-to-date, relevant information to carers
- Advocating for children in care who are affected by FASD within the broader service system.

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.

12. REFERENCES

[1] Philip A May, and J. Phillip Gossage (2001) Estimating the Prevalence of Fetal Alcohol Syndrome: A Summary, Alcohol Res Health 25(3):159-164

[2] Bower et al, (2000) Ascertainment of birth defects: the effect on completeness of adding a new source of data. Journal of Paediatrics and Child Health 36(6):574-6.

[3] Philip A. May, (2011) Geoffrey Robinson Keynote Address, 4th International Conference on FASD, Vancouver 2011.

[4] NT Government (2010) Alcohol use in the Northern Territory, factsheet.

[5] Jonsson, E. (2011) CEO *Economic Implications of FASD.*Conference paper, 4th International FASD Conference, Vancouver 2011, Institute of Health Economics, Alberta CA.

[6] Astley, S, Stachowiak, J, Clarren, S and Clausen, C. (2002) Application of the fetal alcohol syndrome facial photographic screening tool in a foster care population, Journal of Paediatrics, Vol 141 no 5.

[7] Streissguth, A et al. (2004) Risk Factors for Adverse Life Outcomes in Fetal Alcohol Syndrome and Fetal Alcohol Effects, Developmental and Behavioral Pediatrics, Vol 25, no 4,

[8] Fuchs, D., Burnside, L., Marchenski, S. and Mudry, A. (2005) Children with disabilities receiving services from child welfare agencies in Manitoba. Winnipeg, MB: Center of Excellence for Child Welfare.

[9] Elgen,I, Brauroy, S and Laegreid, LM. (2007) Lack of recognition and complexity of foetal alcohol neuroimpairments, Acta Paediatrica 2007:96, pp1-5.

[10] Habbick, BF et al. (1996) Foetal alcohol syndrome in Saskatchewan: unchanged incidence in a 20 year period, Can J Public Health, May-Jun;87(3):204-7.

[11] Toutain, S. et al. (2010) Consequences for the newborn of alcohol consumption during pregnancy, Arch Pediatr, 2010 Sep;17(9):1273-80.

[12] Slade, B. et al. (2009)The Burden of Prenatal Exposure to Alcohol – revised measure of cost. Can J Clin Pharmacol Vol 16(1) Winter 2009.

[13] Budde, S and Harden, (2003) A. Substance-exposed infants in Illinois 1988-2001: Trends in caseloads, placement and subsequent maltreatment, Report to te Children and Family Research Center at the University of Illinois at Urbana-Champaign.

[14] Badry, D, Pelech, W and Norman, D. Fetal Alcohol Spectrum Disorder Practice Standards Evaluation Report: Final Report, (2005) Prepared for Alberta Children's Services October.

[15] Elliot, E., Payne, J et al. (2007)Fetal alcohol syndrome: a prospective national surveillance study, Archives of Diseases in Childhood, 93:732-737.

[16] Laslett, A-M et al. (2010)The Range and Magnitude of Alcohol's Harm to Others, AER Centre for Alcohol Policy Research, Turning Point Alcohol and Drug Centre, Eastern Health.

[17] Jeffreys, H., Hirte, C., Rogers, N., and Wilson, R. (2009) Parental substance misuse and children's entry into Alternative Care in South Australia, Department for Families and Communities, Government of South Australia.

[18] Fagerlund, A, et al. (2011) Risk factors for behavioural problems in foetal alcohol spectrum disorders, Acta Paediatrica, 100(11) 1481-1488.

[19] WA Department for Communities (2010) Foetal Alcohol Spectrum Disorder: Information for people working with children and families.

[20] ABS: 4102.0 Australian Social Trends (1995) Health risk factors: Alcohol use.

[21] Gelb, K and Rutman, D. (2011) A Literature Review on Promising Approaches in Substance Use Treatment and Care for Women with FASD, School of Social Work, University of Victoria BC.

[22] Streissguth, A et al. (2004). Risk Factors for Adverse Life Outcomes in Fetal Alcohol Syndrome and Fetal Alcohol Effects, Developmental and Behavioral Pediatrics, Vol 25, no 4,

[23] Clark, e., Lutke, J., Minnes, P.,Ouellette-Kuntz, H. (2004) Secondary Disabilities among Adults with Fetal Alcohol Spectrum Disorder in British Columbia, J FAS Int;2e13 October 2004.

[24] Grant, T. Whitney, N., Huggins, J. and O'Malley, K. (2009). An Evidence-based Model for FASD Prevention: Effectiveness Among Women Who Were Themselves Prenatally Exposed to Alcohol, 3rd International FASD Conference on FASD, Victoria BC.

[25] Queensland Department of Child Safety, (2008) Characteristics of parents involved in the Queensland child protection system, report 2: Parental risk factors for child abuse and neglect.

[26] Fetal Alcohol Spectrum Disorders: Washington State History (1968-2004), www.depts.washington.edu//fasdpn/asdpm/htmls/evidence-success.htm

[27] Pregnancy Risk Assessment Monitoring System Surveillance Report (1999) Washington State Department of Health, p81.

[28] Abel, E.L., Sokol, R.J. Incidence of fetal alcohol syndrome and economic impact of FAS-related abnormalities. Drug Alcohl Depend, 1987, Jan; (19):51-70.

29 Burd L, Cotsonas-Hassler T, Martsolf J & Kerbeshian J (2003) Recognition and management of fetal alcohol syndrome. Neurotoxicology and Teratology 25:681–8.

[30] http://depts.washington.edu/chdd/ucedd/ctu_5/parentchildprog_5.html, retrieved 11.12.2011.

[31] Grant, T., Ernst, C., Streissguth, A., & Stark, K. (2005). Preventing alcohol and drug exposed births in Washington State: Intervention findings from three Parent-Child Assistance Program sites. American Journal of Drug and Alcohol Abuse, 31(3): 471-490.

[32] Rasmussen, C., Kully-Martens, K., Denys, K., Badry, D., Henneveld, D., Wyper, K., & Grant, T. (2010). The effectiveness of a community-based intervention program for women at risk for giving birth to a child with Fetal Alcohol Spectrum Disorder (FASD). Community Mental Health Journal, DOI: 10.1007/s10597-010-9342-0. Epub 2010 Aug 8.

[33] http://fasdprevention.wordpress.com/2011/04/page/2/ retrieved 13.12.11.

[34] http://fasdprevention.wordpress.com/2011/04/page/2/ retrieved 13.12.11.

[35] IAutti-Rämö, I (2011). Maternal Welfare, Morbidity and Mortality 6-15 Years After a Pregnancy Complicated by Alcohol and Substance Abuse, 4th International Conference on Fetal Alcohol Spectrum Disorder