



Education and Health Standing Committee

**Foetal Alcohol Spectrum Disorder:
the invisible disability**

**Report No. 15
September 2012**

Legislative Assembly
Parliament of Western Australia

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Published by the Parliament of Western Australia, Perth.

September 2012.

ISBN: 978-1-921865-58-9

(Series: Western Australia. Parliament. Legislative Assembly. Committees.
Education and Health Standing Committee. Report 15)

328.365

Education and Health Standing Committee

Foetal Alcohol Spectrum Disorder: the invisible disability



Report No. 15

Presented by

Dr Janet Woollard MLA

Laid on the Table of the Legislative Assembly on 20 September 2012

Chair's Foreword

In 2009, the National Health and Medical Research Council (NHMRC) published the "Australian Guidelines to Reduce Health Risks from Drinking Alcohol".

Guideline 4 for Pregnancy and breastfeeding:

Maternal alcohol consumption can harm the developing foetus or breastfeeding baby.

A For women who are pregnant or planning a pregnancy, not drinking is the safest option.

B For women who are breastfeeding, not drinking is the safest option.¹

The safest way for a mother to ensure there is no harm to her unborn child from her alcohol consumption is not to drink alcohol during pregnancy. This is a difficult task for mothers as research shows 50% of pregnancies are unplanned and so the mother may be drinking for a while before she becomes aware she is pregnant.

Alcohol is a teratogen to an unborn child

For the unborn child, alcohol is a teratogen. A teratogen is an agent which can cross the placenta and interfere with the normal development of the embryo or foetus. Alcohol can cause a wide range of birth defects which come under the umbrella term of Foetal Alcohol Spectrum Disorder (FASD). These birth defects last a lifetime and have major social, behavioural and financial implications for the child born with FASD, their family and the community.

A teratogen is something that a mother has been exposed to or which she exposes herself to during her pregnancy. Known teratogens include diseases such as rubella and medications such as thalidomide.

As a teratogen, alcohol can harm an unborn baby at any time during a pregnancy. The harm done to the baby is influenced by the stage of growth of the embryo or foetus

¹ National Health and Medical Research Council "Australian Guidelines to Reduce Health Risks from Drinking Alcohol" Commonwealth of Australia 2009.

when the alcohol was consumed, how much alcohol was consumed, and the pattern of the mother's drinking. The mother's social, behavioural and economic status may influence, when, how much and the effect of the alcohol on the mother and child.

The harm done by alcohol to the unborn child may not be evident at birth but is life-long. There is no safe amount of alcohol intake. FASD is completely preventable if no alcohol is consumed during pregnancy.

During pregnancy, alcohol passes from the mother's blood stream to the unborn baby's blood stream. The alcohol may stay longer in the unborn baby's blood stream as the baby's liver may metabolise the alcohol more slowly. Alcohol can damage and affect the growth of the unborn baby's cells. Alcohol can cause miscarriage, stillbirth, brain damage or many other problems which will affect the child after it is born. Alcohol destroys the developing brain cells. The damage caused can be mild or severe. A child born with FASD has a lifelong condition which affects their lifestyle, the life of their family, their friends and the community in which they live.

Cognitive impairment (CI) is caused by the dysfunction or developmental delay from the damage or deterioration of the developing brain caused by alcohol. Cognitive impairment is as an ongoing impairment in comprehension, reason, judgment, learning or memory. A child with CI may have developmental delays, difficulty hearing, problems with vision, learning problems, language and speech deficits, impulsiveness, a short attention span, and difficulties getting along with others. They may be hyperactive, which is why they may be diagnosed as having hyperactivity (ADHD), and have problems controlling their behaviour.

Inappropriate behaviour by a person who has FASD is often because of the underlying brain dysfunction. Children and people with FASD often do not make rational decisions or choices. Their inappropriate behaviour may causes problems at school and after school, as they have difficulty finding and maintaining employment. Inappropriate behaviour may include inappropriate sexual behaviours. Related to their FASD is the greater likelihood for them to develop other conditions including alcohol and drug addiction or mental illness.

Some mothers may drink alcohol to deal with stress, despair or abuse. The higher the mother's alcohol intake, the more risk there is of damage to the unborn child. Some women are affected more than others, possibly due to other factors in their lifestyle such as their living conditions, their diet, and their use of other drugs, including tobacco. These women may have more than one child affected by FASD. Sadly, we are now hearing of children born with FASD whose mother and grandmother may also have FASD.

Drinking alcohol during pregnancy has been described, by Dr Stone in the Commonwealth Parliament, as “gambling with the welfare of your unborn child”.² Dr Stone said “we need to move away from the nonsense about a little bit will not hurt and have women and their partners understand that for nine months, at least, it is important not to gamble with the future, the lifetime of your child”.³ Further she went on to add “in order to change the rights of a child to be born without a preventable disability we have to make sure there is no misinformation in the community”.⁴

The pressure on the families of children and adults with FASD is high as they try to access care, special education programs, services and support. Non-government organisations such as the National Organisation for Foetal Alcohol Syndrome And Related Disorders (NOFASARD), have been developed to represent the interests of parents, carers and others interested in or affected by FASD.

Medicine is evidence based: there is a need for screening, diagnosis, data collection and prevention.

To decrease the prevalence of FASD in WA the government must provide funding for:

- Screening;
- Diagnosis;
- The collection of prevalence data; and
- Prevention.

Screening

Screening to prevent FASD should commence ante-natally by general practitioners and midwives. Other health professionals should also screen girls or women of child bearing age who they have as clients who have drug or alcohol problems.

In Western Australia, the general practitioner, the child health nurse or the school health nurse will, at different times, undertake infant and early childhood screening which may identify early cognitive or behavioural developmental delays. As well as routine screening, targeted screening should occur for newborns and children at risk of FASD.

There are a number of scheduled opportunities for such checks. In the case of Child Health Nurses, checks are meant to occur at birth, 6-8 weeks, 3-4 months, 8 months, 18 months, and at 3 years. In addition a school entry assessment is performed by school health nurses. School Health Nurses collect this data using the Parents Evaluation of

2 Dr Stone., Commonwealth House of Representatives, Hansard p141 22/8/11.

3 Ibid p142.

4 Ibid p142.

Developmental Status (PEDS) questions. Depending on the outcome of this assessment the school health nurse might then ask parents to complete an “Ages and Stages” questionnaire or might organise a referral to specialist services.

Such screening supports the early development of intervention and management strategies for affected families. Current shortfalls in both Child and School Health Nurses will impact the effectiveness of such screening.

Diagnosis

A diagnostic tool will enable the Government to determine the prevalence of FASD in WA and Australia. Diagnosis of FASD requires a multidisciplinary approach from paediatricians, general practitioners, nurses, social workers, psychologists, speech and language therapists. In the United States it has been estimated that one out of every 100 babies are born with FASD.⁵

The Committee was told that 30% or higher of the population in some remote Aboriginal communities may have FASD. We were also told that in WA children are being born who are 2nd or 3rd generation children with FASD. This means children born with FASD may have parents and grandparents who have FASD.

The reason children with FASD have not been diagnosed at birth is because these children do not look different from other children. The damage done to their brain during embryonic and foetal growth leads to cognitive impairment causing developmental delays that last a lifetime.

Given that FASD is diagnosed in other countries it is unacceptable that West Australians, and Australians, are still waiting for the government to sign off on an agreed diagnostic tool for FASD.

Other countries that have FASD diagnostic tools for young children are now developing tools to help diagnose older children, teenagers and adults with FASD. Often these older children, teenagers or adults present as clients in the juvenile and criminal justice system. This is sadly because the inappropriate behaviour of these individuals often sees them come into contact with these services.

Prevalence

Without screening and diagnosis we do not know how prevalent FASD is in the community. It has been referred to as the “invisible disability”.⁶ Once we have data on the prevalence of FASD, disability services can be given the responsibility to ensure

5 Chudley AE, Conry J, Cook JL, Looock C, Rosales T, LeBlanc N, et al. Fetal alcohol spectrum disorder; Canadian guidelines for diagnosis. CMAJ Canadian Medical Association Journal 2005; 172 (5 Suppl): S1-S21.

6 Carolyn Hartness, US Educator speaking to health professionals in Broome 2011.

children and adults with FASD are given the additional care and resources to enable them to live at their highest possible level of functioning and behaviour. Government services such as juvenile justice, criminal justice, foster care, child safety, mental health and social services will need additional funding to fund care and develop processes to assist children or adults with FASD. In other countries the additional cost of caring for each baby born with FASD is high, with different adjusted lifetime costs quoted between US\$1.1 million⁷ and US\$2 million.⁸

Prevention

The Role of Health Professionals

Diagnosis of FASD will enable health professionals to assist in parenting, and to assist in identification and treatment of developmental and behavioural problems as children with FASD grow older.

Health professionals should be educated and skilled to routinely ask all girls and women of childbearing age about their alcohol use. For those who are pregnant or trying to have a baby, advice should be given about alcohol consumption and the unborn child. Brief interventions by health professionals may decrease the incidence of FASD.

Girls or women with an alcohol dependency or who are living in high risk situations should be offered additional assistance. This might be at home or in a shelter for pregnant girls or women who would like to stop drinking alcohol to protect their unborn child.

Health professionals are ideally suited to run public or school based education programs to improve the awareness within the community of the effect of alcohol on the unborn child.

The treatment of FASD occurs across multiple government departments. There should be a dedicated FASD health professional to work with a number of clients with FASD. This professional could ensure children are not lost in the complexity of the referral and treatment pathways. They can ensure children engage with the specialist educational, behavioural and support services they require to maximise the child's potential.

7 Institute of Health Economics, Edmonton, Alberta, *COSTS OF FETAL ALCOHOL SPECTRUM DISORDER IN ALBERTA, CANADA*, 2008 (?), p1. Available at: <http://www.ncbi.nlm.nih.gov/pubmed/21515625>. Accessed on 8 May 2012.

8 Lupton C, Burd L & Harwood R (2004) Cost of fetal alcohol spectrum disorders. *American Journal of Medical Genetics* 127C 42-50.

The family and the community role to protect the unborn child

Fathers and those people who are close to a pregnant woman can have an important role in supporting a mother to stop or reduce their alcohol intake during pregnancy.

The community can help prevent FASD by encouraging young girls or women who are pregnant or want to get pregnant not to drink alcohol during their pregnancy.

Medicare Locals can play a role in promoting the NHMRC guidelines.

Stopping drinking at any time during a pregnancy will reduce the risk of damage by alcohol to an unborn child. Parents-to-be can be reminded that no alcohol is the safest choice. They can be offered non-alcoholic drinks and encouraged to drink less. Others can support parents by drinking less or not drinking when socialising with them as a measure of support for their unborn child.

Alcohol the debate, the fourth A: Advertising; Affordability; Access and AWARENESS

The three As are the three main factors which influence the sale and consumption of alcohol and were listed in our previous report on alcohol. These were the advertising of alcohol, the affordability of alcohol, and the access to purchase alcohol.

Advertising - the Federal Government is to be congratulated on plans to introduce warning labels on alcohol to assist in ensuring that every girl and woman who drinks alcohol is an informed consumer and knows there is no safe amount of alcohol for an unborn child. Liquor outlets could be proactive and ensure that any bags or boxes used for customers to carry their alcohol have warnings on the packaging. Both the State and Federal Governments could progressively eliminate alcohol advertising, particularly in areas like sport and television where young and teenage children are most susceptible.

Affordability – the Federal Government could increase the price of alcohol so that there is a minimum price per standard drink. This may prevent some of the preloading which occurs by teenagers and young adults. It may help in the culture shift required to stop young people drinking to get drunk.

Access - in WA the Minister for Liquor Licensing has stated in Parliament that he will review the *WA Liquor Control Act 1988*. It is hoped this review will ensure there is greater attention placed on the public health impact of alcohol sales. With this review, the Government is able to help prevent the sale and provision of alcohol to minors by ensuring parental consent is required before alcohol is given to minors. The review could amend the Act to allow the police to perform controlled purchasing operations to prevent liquor being sold to minors.

The Government has an opportunity through this review to amend the Act to ensure:

liquor license holders serve alcohol in a responsible manner, and the harm from alcohol consumption caused by high outlet density and long trading hours is reduced.

Awareness of FASD - this inquiry highlights the fourth A, the Awareness of FASD. The 2010 National Drug Strategy Household Survey found that 51.1 % of Australian women continued to consume alcohol while pregnant.⁹

The Commonwealth Department of Health and Ageing (DoHA) is responsible for promoting the NHMRC Guidelines. The State and Federal Governments have a responsibility to the community and to future generations to ensure that every child and woman of childbearing age has knowledge that alcohol, like measles and the drug thalidomide, is a teratogen. As discussed, alcohol, the teratogen to the unborn child, can cause lifelong birth defects. These may not become apparent until a child is 5 or 6 years old. These defects cannot be cured. Instead they will stay with the child for the rest of his or her life. Resources and strategies can only be implemented for the child or adult with FASD to deal with the social and behavioural problems resulting from their condition.

I commend this report to the Government and ask that the Premier consider appointing a Minister who will have responsibility for the collaborative approach to the prevention, treatment and management of children and adults with FASD in WA.

Acknowledgements and Thanks

I would like to thank the many people who made submissions or attended hearings for this important inquiry. I would like to thank the Telethon Institute for Child Health Research for their submission and their work in FASD.

I would like to acknowledge the work of the House of Representatives Standing Committee on Social and Legal Affairs which is currently conducting an inquiry into FASD, looking in particular at prevention strategies, intervention needs, and management issues. I would like to thank the Foundation for Alcohol Research and Education for their investment into research on FASD to contribute to the evidence we have to address FASD in Australia.

I would particularly like to congratulate June Oscar and Emily Carter, two wonderful Indigenous women who in 2007 showed leadership in Fitzroy Crossing in tackling the problems of alcohol and FASD. June Oscar and Emily Carter working with Professor Elizabeth Elliot, Dr James Fitzpatrick, and Associate Professor Jane Latimer saw the birth of "*Marulu: The Lilliwun Project*" meaning "all the little ones" in the Fitzroy Valley. This project was Australia's first ever prevalence study of FASD. It is hoped this project

⁹ Australian Institute of Health and Welfare (AIHW) (2011). 2010 National Drug Strategy Household Survey report. Drug statistics series no.25. Cat. No. PHE 145. AIHW, Canberra.

will not only determine the prevalence of FASD but will ensure support is provided to affected children and their families, and will inform future community diagnosis and community education programs.

I would like to thank all Committee members for their dedication to this inquiry, Mr Peter Abetz, Ms Lisa Baker, Dr Graham Jacobs and Mr Peter Watson (Deputy Chair). Finally I would like to thank our dedicated secretariat, Brian Gordon and Lucy Roberts. They have worked hard researching, organising hearings and trips and preparing this report. Their approach is always professional and supportive and we value the expertise they bring to the Committee.

Janet Woollard

DR JANET WOOLLARD MLA

CHAIR

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Executive Summary

This is the fourth Report of the Education and Health Standing Committee's Inquiry into Improving Educational Outcomes for Western Australians of All Ages. It has as its focus Foetal Alcohol Spectrum Disorder (FASD). FASD is an important moral, social, ethical and public health issue. Sufferers experience learning and behavioural difficulties with lifelong consequences.

Alcohol use during pregnancy has been associated with a number of adverse pregnancy outcomes. Current National Health and Medical Research Council (NHMRC) guidelines recommend that not drinking is the safest option for women who are pregnant or planning a pregnancy.

FASD is a serious condition that is totally preventable. FASD is caused by a mother drinking alcohol during pregnancy at levels which harm her unborn child.

As the name suggests, the disorder arises from the damaging impact of embryonic (up to 8 weeks) and foetal (8 weeks plus) exposure to alcohol. In the womb, alcohol freely crosses the placenta to the unborn child; it is metabolised more slowly after it has crossed the placenta, and the blood alcohol in an embryo or foetus can be higher than the mother's blood alcohol concentration.

While the evidence of the damaging impact of the exposure of alcohol to the embryo or foetus is clear, it is still unclear on the relative significance of:

- the impact of drinking in the three pregnancy trimesters;
- the quantities of alcohol that will negatively affect each embryo or foetus; and
- how other environmental and genetic factors combine with alcohol to result in Foetal Alcohol Syndrome (FAS) or FASD.

The consumption of alcohol during pregnancy can lead to irreversible brain damage in the unborn child. Alcohol consumption by the mother can cause damage to the frontal lobe of the foetal brain, or central nervous system (CNS). One of the consequences of this may be deficits in 'executive function'. Some researchers use the mnemonic ALARM as a summary of the core impairments that may result from damage to the CNS.

This mnemonic refers to:

- A**daptive behaviour;
- L**anguage;
- A**ttention,

**Reasoning; and
Memory.¹⁰**

Difficulty with abstract reasoning is often demonstrated in children and adults with FASD by a failure to learn from experience and difficulty in understanding the consequences of actions (to either themselves or to others). Children and adults with FASD can have problems understanding time and sequence, and can be highly suggestible.

Without adequate intervention and management strategies there are a broad range of secondary disabilities commonly identified with FASD, such as school absenteeism, inappropriate sexual behaviour and unemployment. At highly disproportionate rates secondary disabilities include:

- Fatigue, tantrums;
- Irritability, frustration, anger and aggression;
- Fear, anxiety, avoidance and withdrawal;
- Shut down, lying, running away;
- Trouble at home, school and community;
- Interaction with the justice system;
- Drug / Alcohol abuse;
- Homelessness; and
- Mental health problems (depression, self-injury, suicidal tendencies).¹¹

FASD is the leading cause of non-genetic, intellectual disability in Australia and the Western World. Data reflects an incidence rate of FASD greater than that of Down's Syndrome. When including a cost to the community of FASD, where there has been some contact with the criminal justice system, it may cost up to \$25,000 each year averaged across every year of an affected person's life. Thus, by the time a person with FASD is 40 years of age they will have cost the community up to \$1,000,000.

The two countries that lead the world in diagnosis, data collection, treating and resourcing the prevention of FASD are Canada and the United States. These countries are developing tools to identify FASD in childhood, in youth and in the adult population. Canada is currently preparing additional questions for their Early Development Instrument (EDI), (the counterpart and forerunner of the Australian Early Development Index (AEDI)), to help identify children who may have FASD.

In Australia there is an increasing level of awareness of FASD but as yet no agreed diagnostic tool. Without a diagnostic tool, data cannot be collected on the prevalence

10 Diane Fast and Julianne Conry, 'The Challenge of Fetal Alcohol Syndrome in the Criminal Legal System' (2004) *Addiction Biology* 161, 162; & Diane Fast and Julianne Conry 'Fetal Alcohol Spectrum Disorders and the Criminal Justice System' (2009) 15 *Developmental Disabilities Research Reviews* 250, 252.

11 Submission No. 22 from The Russell Family Fetal Alcohol Disorders Association, May 2012, p2.

and incidence of FASD from which current and future resourcing implications can be determined. As a matter of urgency, the Federal Government should support the adoption of a FASD Diagnostic tool and should classify FASD as a disability.

The WA Register of Developmental Anomalies suggests that FAS is under-reported and alcohol-related neurodevelopmental disorder is not reported at all.

FASD is significantly under reported in Australia due to a lack of screening, a lack of a nationally accepted diagnosis and a lack of sufficient data. Children with FASD may receive no or inappropriate treatment. The lack of diagnosis and prevalence data makes seeking additional funding for prevention very difficult.

Western Australia has been the focus of much of the research undertaken into FASD in Australia. This research has been attempting to determine the prevalence, treatment, and support for children with FASD, and factors to help prevent FASD.

In addition, the WA Child and Youth Health Network, which included representation from state government agencies, health services and research organisations has developed the FASD Model of Care. The model promotes a multi-agency approach in to the prevention, diagnosis, treatment and management of FASD.¹² Western Australia has become the first state to introduce a model of care in a response to FASD. (The model is described in greater detail in Chapter 11). The Model is a first for Australia.

The Committee was surprised that, to date, the State Government has not given additional funding to the Model of Care. Currently, the 'model' relies on the enthusiasm of agency staff using existing funds from other areas. The only new money being expended in this state in connection with FASD is Federal funding for the *Strong Spirit Strong Future* social marketing strategy.

The family and community consequences of the past and current failure to prevent, diagnose and treat FASD are having a negative effect on our community. The Committee was told that there are now children being born who have FASD parents and grandparents. Sadly FASD will continue to affect future generations until the community and the government place greater importance on the safety and care of the unborn child.

Funding is desperately needed to treat and care for children and adults who currently have FASD. Screening should occur for children considered at risk of FASD or involved with child protection, and for all juveniles involved in the juvenile justice system. Additional support should be given to a drug dependent pregnant woman who is any obstetric unit.

¹² Submission No. 12 from Department of Health, December 2012, p5.

WA needs a Minister with portfolio responsibility for FASD at cabinet level to ensure there is effective collaboration and liaison between government departments caring for children and adults with FASD.

Ministerial Response

In accordance with Standing Order 277(1) of the Standing Orders of the Legislative Assembly, the Education and Health Standing Committee directs that the Premier, the Minister for Health, the Attorney General, the Minister for Disability Services, and the Minister for Racing and Gaming report to the Assembly as to the action, if any, proposed to be taken by the Government with respect to the recommendations of the Committee.

Findings and Recommendations

Recommendation 1

Page 23

The Western Australian government encourages the Federal Government to support the adoption of a FASD Diagnostic tool and the classification of FASD as a disability by June 2013.

Finding 1

Page 28

Screening of alcohol consumption by pregnant women should occur at each antenatal visit with a general practitioner, nurse or midwife. Screening should occur post-natally for alcohol consumption as part of each universal child health check or general practitioner appointment until a child is four years of age.

Recommendation 2

Page 28

The Committee recommends to the Minister for Health that by June 2013 all pregnant and post-partum women are screened for alcohol use with validated screening tools by relevant health care providers. Women at risk for heavy alcohol use should receive early brief intervention (i.e. counselling).

Recommendation 3

Page 28

To protect the unborn child, the Committee recommends to the Minister for Health that the Government prepares guidelines for all health care professionals by June 2013, which should encourage all pregnant women or women attempting to become pregnant to abstain from alcohol.

Recommendation 4

Page 28

The Committee recommends to the Minister for Health that he direct the Department of Health to review and report back to Parliament by June 2013 on the ethical considerations involved in the analysis of meconium for pregnancy cases where there is a strong suspicion of significant alcohol consumption during pregnancy.

Finding 2

Page 30

There is broad acknowledgement in many parts of the health sector that a significant improvement in data collection is needed to understand the true extent of FASD in the Australian community. In particular, there is a need to standardise data on alcohol consumption during pregnancy and to collect and collate data once a FASD diagnosis has been made.

Recommendation 5

Page 31

The Committee recommends that the Government support the following WA FASD Model of Care recommendations:

- a. There should be a collection of data on alcohol use during pregnancy. Use can be made of existing tools such as the midwife notification form to include documentation of the presence or absence of alcohol consumption in pregnancy.
- b. Data linkage ability between sectors to be established to enable the monitoring, sharing and evaluation of data between relevant health professionals and services.

The Government reports back to Parliament on a bi-annual basis on the results of this data collection.

Recommendation 6

Page 31

In the 2013 budget the Government funds bi-monthly appointments by child health nurses for pregnant women and mothers with children under the age of 4 years who are thought to be drinking alcohol at harmful levels. These child health nurses will provide, at a minimum, a 6 monthly review of these families to the Department of Health. The Government will then report back to Parliament on a bi-annual basis on the effects of these additional appointments.

Finding 3

Page 34

An early diagnosis of FASD would enable access to interventions and resources. These may mitigate the development of subsequent secondary disabilities such as mental health problems, trouble with the law, inappropriate sexual behaviour, absenteeism and disrupted school experience, and unemployment.

Finding 4

Page 36

There is no current diagnostic tool for FASD in Australia. The Federal Government has awarded a tender for its development and a draft diagnostic instrument is under consideration by the Federal Government.

Finding 5

Page 37

Less than half of the people who have FASD are thought to have an IQ of less than 70 and some research indicates that the proportion may be as little as 25%. However, all people with FASD have varying expressions of neurocognitive damage that inhibit executive functioning, decision making, emotional and behavioural regulation, learning, memory, sensory processing, and adaptive behaviour.

Finding 6

Page 39

FASD requires a coordinated multidisciplinary diagnostic service.

Recommendation 7

Page 39

The Minister for Health allocates additional funding in the 2013 budget to existing interdisciplinary health teams (such as in antenatal clinics, children's hospitals and child

development centres), to improve their ability to diagnose and treat children with FASD and support education and awareness strategies.

Finding 7

Page 42

Most individuals with FASD have an IQ within the normal range and so are ineligible for the Disability Support pension and collateral benefits.

Recommendation 8

Page 43

The Committee recommends that the Government and the Minister for Disability Services support changes to commonwealth and state legislation to better accommodate children and adults with FASD. In particular any reference to disability or intellectual disability to be broadened to include a definition of cognitive impairment as an ongoing impairment in comprehension, reason, judgment, learning or memory, that is the result of any damage to or dysfunction, developmental delay, or deterioration of the brain or mind.

Finding 8

Page 50

The annual direct healthcare cost of FASD is 45% of the direct healthcare cost of cancer in Canada.

Finding 9

Page 53

FASD results in a significant direct and indirect cost to the community. While no studies have been carried out in Australia, overseas studies indicate that these costs are high. Understanding the economic impact of FASD to individual government and non-government agencies as well as the broader community is valuable in arguing the economic case for prevention services and adequate health resources.

Recommendation 9

Page 53

In recognising the negative human and economic impacts of FASD, the Committee recommends that commencing in 2013 the State Government undertakes tri-annual economic modelling of the cost of FAS and FASD in WA.

Recommendation 10

Page 65

The Committee recommends that funding be allocated in the 2013 budget for the development of culturally specific prevention, intervention and management strategies for Aboriginal and Torres Strait Islander people who have FASD similar to the current 'Marulu Strategy' in Western Australia.

Finding 10

Page 72

The issues faced by children with Autism Spectrum Disorder highlight the likelihood that acknowledgement of a disorder does not necessarily provide a solution without a considerable investment of resources into the community.

Finding 11**Page 82**

There is a lack of screening (and diagnostic) services for people with FASD in the regions. This impacts the way in which they are handled through the judicial system.

Finding 12**Page 82**

The endemic nature of certain FASD traits make community based orders, and suspended prison terms problematical when sentencing sufferers.

Finding 13**Page 82**

A person with FASD is more likely to:

- commit offences and be apprehended;
- be refused bail;
- be unresponsive to authority;
- be undeterred from reoffending through punishment
- be convicted; and, if convicted, be sentenced to a term of imprisonment, which they are likely to 'do harder' than other prisoners because of their –
 - High levels of suggestibility;
 - Memory deficits;
 - Possible hearing deficits;
 - Difficulty in understanding sarcasm, idiom or metaphor;
 - Lack of apparent empathy

Recommendation 11**Page 87**

The Committee recommends that the Attorney General make available additional funding in the 2013 budget for justice and corrective services to enable:

- a. The identification of people with FAS / FASD or who have a cognitive impairment.
- b. Additional programs to be developed to assist people with FAS / FASD or a cognitive impairment during their pre-sentence period, incarceration and following discharge to help them function in society.

Finding 14**Page 90**

A partner's drinking is a factor in maternal alcohol consumption. Seventy-five per cent of children with FASD have biological fathers who are heavy drinkers and often have extended families with heavy alcohol consumption.

Recommendation 12**Page 97**

The Committee recommends the government invest additional funds in the 2013 budget into FASD prevention campaigns that seek to:

1. Raise public awareness in the general population through campaigns highlighting harmful alcohol use as it relates to the unborn child, and the general health of girls and women;
2. Conduct targeted education for high risk groups through health and community services.

Recommendation 13

Page 97

While acknowledging that the Australia and New Zealand Standards Code, which includes labelling requirements, is administered by the federal regulatory body Food Standards Australia and New Zealand, the Committee recommends that the Minister for Racing and Gaming amend the *Liquor Control Act 1988* by December 2013 introducing a mandatory health warning label regime for alcohol products sold in Western Australia, including a message about the risks of consuming alcohol while pregnant. Similar legislative amendments were adopted in South Australia in relation to the mandatory labelling of beverage containers.

The health warning labels should be:

- mandatory so the label appears on all products;
- applied consistently across all products so they are visible and recognisable;
- include a number of rotating messages focussing on different social and health harms;
- developed by health behaviour and public health experts;
- regulated and enforced by government; and
- accompanied by a public education campaign.

Finding 15

Page 99

An estimated 50% of all pregnancies are unplanned. Consequently, many pregnancies may be exposed to alcohol before women realise they are pregnant. Therefore, the issue of promoting effective contraception is seen as a key strategy by many.

Recommendation 14

Page 99

The Committee recommends that the Government supports the following WA FASD Model of Care recommendations to reduce unplanned pregnancy:

1. Develop strategies to promote the use of contraception and to improve the consistency of contraceptive use, including contraception prior to discharge from hospital post-natally;
2. Educate men and enlist them as partners in family planning;
3. Develop strategies to promote communication between partners about the use of contraception;

4. Introduce evidence based primary and secondary school drug and sex education.

Recommendation 15

Page 99

The Government introduces or amends legislation in 2013 to ensure that the following NHMRC guidelines statements are printed outside and inside all pregnancy kits sold in WA after June 2015, namely:

- “Maternal alcohol consumption can harm the developing foetus or breastfeeding baby” and
- “For women who are planning a pregnancy, not drinking is the safest option”

Finding 16

Page 100

Education of women through the provision of screening and advice is effective in changing drinking habits.

Finding 17

Page 100

Raising awareness of the harmful effects of alcohol including FASD to health care professionals, through the provision of educative materials, increases their readiness to provide advice to women on the risks of drinking while pregnant.

Finding 18

Page 101

Women who knowingly continue to drink at risky levels while pregnant experience a number of other difficulties in their lives. These may include relationship problems, domestic violence, other substance use and mental health problems. Additional support services and interventions should be made available for these women.

Finding 19

Page 102

Postpartum support for mothers who were not able to make significant changes in their substance use during pregnancy is vital. This may include the provision of supported accommodation, including partial hospitalisation.

Recommendation 16

Page 102

The Government makes funding available in the 2013 budget for shelters in areas where there are high levels of alcohol consumption or children, or adults, with FASD. These shelters are to be available for women who have a problem managing their alcohol intake or whose families are restricting their ability to manage their alcohol intake.

Recommendation 17

Page 102

The Committee recommends the Government provide additional funding in the 2013 budget to support multidisciplinary and culturally appropriate strategies to address the often complex needs of alcohol dependent mothers and their families.

Finding 20**Page 107**

There are a number of identified concerns raised by health professionals that contribute to their reluctance to address the issue of alcohol consumption during pregnancy with their patients.

Finding 21**Page 108**

Mentoring is a relatively low cost relational strategy that, in both Canada and the United States, is seen to be an effective preventative strategy. Several evaluations of different mentoring programs have been undertaken which demonstrate their efficacy.

Recommendation 18**Page 108**

The Western Australian Government pilots a mentoring strategy in a high risk community. This strategy should be based on the Parent Child Assistance Program (PCAP) that was developed in Seattle in the 1990s. The government report to Parliament on the outcome of this trial by June 2015.

Finding 22**Page 113**

There is currently a lack of knowledge of FASD amongst health professionals in different disciplines. Training health professionals is important if Western Australia is to achieve stronger prevention and intervention outcomes for FASD. Some steps have been taken to raise awareness by relevant government departments. In addition to training there are a range of barriers to be overcome that will require organisational change.

Finding 23**Page 115**

The recently released and adopted Foetal Alcohol Spectrum Disorder Model of Care is focussed on prevention. However, it remains unfunded and is being implemented out of existing resources, by way of the enthusiasm and goodwill of existing agency staff who believe in its importance.

Finding 24**Page 119**

The road to preventing alcohol use in pregnancy starts long before a woman thinks about getting pregnant. Contributing factors to alcohol use may include trauma, poor education, lack of access to services, low family income, a lack of resources and opportunities. Prevention strategies are required where women live, learn, work and socialise.

Finding 25**Page 119**

The lack of services in some regional/remote areas contributes to poor social determinants of health which, in turn, are significant contributing factors to alcohol consumption during pregnancy.

There are indicatively a disproportionate number of people with FASD in the Justice system from some of these communities.

Recommendation 19

Page 119

The Committee recommends the Government fund in the 2013 budget, the 2010 'Making prisons work' report recommendation to pilot an evidence based, collaborative 'Justice Reinvestment' strategy in a regional 'high stakes' community.

This pilot study should measure the effectiveness of individual agencies as well as specific outcomes relating to interagency collaboration.

Finding 26

Page 123

There is a demonstrated need for evidence based screening, assessment and intervention services. This response would necessitate partnerships between all government and non-government health and education providers.

Recommendation 20

Page 129

The Committee recommends the Government develop a range of holistic community, education, employment and health services to support individuals and families who are affected by FASD with the Department of Health as the lead agency and report back to Parliament on these by December 2013.

Recommendation 21

Page 129

The Committee recommends the Minister(s) support a family case management approach to prevent alcohol abuse in persons and families where there are positive indicators that FASD is present or there are risk factors for FASD. The Government to report back to Parliament on this approach by December 2013.

Recommendation 22

Page 130

The Committee recommends that by December 2012 the Premier appoint a Minister, to have responsibility for a collaborative intergovernmental approach to the prevention, treatment and management of children and adults with FASD in WA.

The Committee recommends that by December 2012 the Premier appoint a Minister, to have responsibility for a collaborative intergovernmental approach to the prevention, treatment and management of children and adults with FASD in WA.

Chapter 1

What is FASD?

Drinking alcohol during pregnancy can result in premature births, brain damage, birth defects, growth retardation, developmental delay and cognitive, social, emotional and behavioural deficits.

What is foetal alcohol spectrum disorder?

Foetal Alcohol Spectrum Disorder (FASD) is an umbrella term referring to the lifelong disability resulting from an unborn child's pre-natal exposure to alcohol drunk by their mother during her pregnancy. It is the leading preventable cause of non-genetic, intellectual disability in Australia.

Like many other disabilities, people who are born with FASD have the condition for life, and the implications are far-reaching. For the person with FASD, their every-day life is affected as they struggle with relationships and encounter difficulties at school and work. For birth mothers and carers of people with FASD, there are life-long caring implications and ongoing financial commitments. In addition there is a range of social and emotional impacts associated with the stigma that comes with a FASD diagnosis.¹³

The conditions that fall within FASD include:

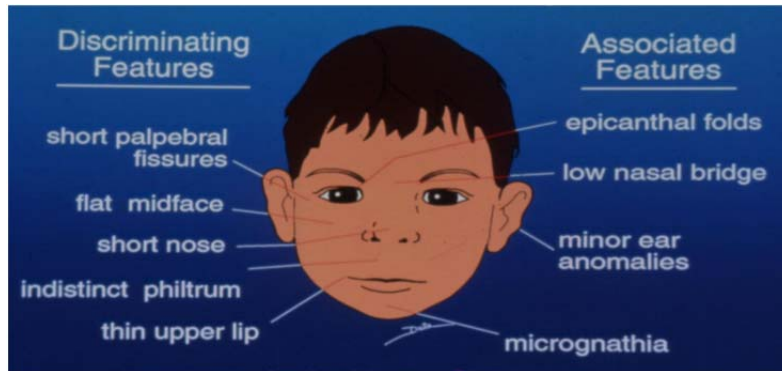
Foetal Alcohol Syndrome (FAS): The most clinically recognisable manifestation of FASD. FAS is characterised by facial anomalies, growth deficits and neuro-behavioural problems. The facial features are illustrated below.

Figure 1.1: The outward appearance of Foetal Alcohol Syndrome in a young child.¹⁴

¹³ Submission No. 21 from Foundation for Alcohol Research and Education, April 2012, p8.

¹⁴ Ann Striessguth, University of Washington Medical School, *Prenatal Alcohol Exposure and the Developing Fetus: Links to Developmental Disabilities* 2007, Available at:

Chapter 1



The diagnostic criteria for FAS anomalies are outlined in the following table

Table 1.1: Institute of Medicine diagnostic criteria for FAS¹⁵

| Institute of Medicine Diagnostic Criteria for FAS | |
|---|--|
| Growth Retardation | |
| <ul style="list-style-type: none"> • Pre-natal growth deficiency – decreased birth weight for gestational age; • Postnatal growth deficiency – lack of catch up growth in spite of adequate nutrition; and • Low weight to height ratio. | |
| Characteristic facial features | |
| <ul style="list-style-type: none"> • Short palpebral fissures • Thin upper lip • Flattened philtrum (an absent or elongated groove between the upper lip and the nose); and • Maxillary hypoplasia, epicanthal folds and ptosis may occur | |
| Central nervous system anomalies or dysfunction | |
| <ul style="list-style-type: none"> • Decreased cranial size at birth; • Structural brain abnormalities including microcephaly; and • Abnormal neurologic hard or soft signs such as impaired fine or gross motor skills. | |

Partial Foetal Alcohol Syndrome (pFAS): Individuals with pFAS have most but not all the features of FAS;

Alcohol-Related Neurodevelopmental Disorder (ARND): Individuals with ARND may present with many alcohol-related brain and behavioural abnormalities. However, they may not display any of the characteristic facial anomalies required for a FAS diagnosis; and

[http://aaid.org/ehi/media/Streisguth%20PP%203%209%2007%20\(2\).pdf](http://aaid.org/ehi/media/Streisguth%20PP%203%209%2007%20(2).pdf). Accessed on 3 May 2012.

15 Stratton, K. et al *Fetal Alcohol Syndrome, Diagnosis, Epidemiology, Prevention and Treatment*. Washington DC: National Academy Press, 1996.

Alcohol-Related Birth Defects (ARBD): Individuals with ARBD exhibit congenital birth defects related to confirmed prenatal alcohol exposure, although there may not be any neurological abnormalities.

Figure 1.2: Diagnostic criteria FAS, pFAS, ARND¹⁶

| Foetal Alcohol Syndrome (FAS) | Partial Foetal Alcohol Syndrome (pFAS) | Alcohol Related Neuro-developmental Disorder (ARND) |
|---|--|---|
| <p>Physical indicators</p> <p>small for age distinctive facial appearance: - small eyes - smooth philtrum (area between the nose and upper lip) - thin upper lip</p> <p>abnormal brain function</p> | <p>Physical indicators</p> <p>some, but not all, of the physical signs of FAS</p> <p>abnormal brain function</p> | <p>Physical indicators</p> <p>no identifiable physical features specific to ARND</p> <p>abnormal brain function</p> |
| <p>Abnormal brain function, evident throughout the spectrum, includes impairment in at least three of the following areas:</p> <ul style="list-style-type: none"> • hard and soft neurological signs (including sensory-motor) • brain structure (head circumference or size, magnetic resonance imaging) • cognition (IQ) • communication (both receptive and expressive) • academic achievement • memory • executive functioning (common sense) and abstract reasoning • attention deficit/ hyperactivity • adaptive behaviour, social skills, social communication <p><i>Confirmation of maternal prenatal alcohol exposure is required for a diagnosis of FAS, pFAS and ARND. There is a diagnostic category “FAS without maternal confirmation of alcohol exposure”.</i></p> | | |

‘Age-appropriate’ behavioural expectations and development gaps associated with ‘foetal alcohol and neuro-behavioural’ (FA&NB) conditions

Behaviours of children, adolescents and adults with FA&NB are often seen as ‘inappropriate for their age,’ but may actually be appropriate for their *developmental age*.

The values and expectations of parents and professionals are for children to ‘act their (chronological) age,’ and be ‘age-appropriate.’

¹⁶ Healthy Child Manitoba, *What Educators Need to Know about FASD, Working Together to Educate Children in Manitoba with Fetal Alcohol Spectrum Disorder*, 2009, p5. Available at: http://www.gov.mb.ca/healthychild/fasd/fasdeducators_en.pdf. Accessed on 12 April 2012.

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Interventions to correct ‘inappropriate’ (developmentally younger) behaviours often inadvertently become the source of frustration for people with FA&NB conditions. It takes people with FA&NB longer to grow up.¹⁷

When support to children and adults with FA&NB is developmentally appropriate, frustration can often be prevented. The following list compares behavioural expectations based on chronological age and contrasts them with *actual* developmental abilities.¹⁸

Figure 1.3: *Age appropriate behavioural expectations and development gaps associated with foetal alcohol and neuro-behavioural (FA&NB) conditions*¹⁹

| Chronological age-appropriate expectations | Developmental age-appropriate expectations |
|--|--|
| 5 years old | 5 years... 2 years developmentally |
| Go to school Follow three instructions Sit still for 20 minutes Interactive, cooperative play, share Take turns | Take naps Follow one instruction, help mummy Acting, sit still for 5-10 minutes Parallel play My way or no way |
| 6 years old | 6 years.... 3 years developmentally |
| Listen, pay attention for an hour Read and write Line up on their own Wait their turn Remember events and requests | Pay attention for about ten minutes Scribble Need to be shown and reminded Don't wait gracefully, act impulsively Adults remind about tasks |
| 10 years old | 10 years.... 6 years developmentally |
| Read books without pictures Learn from worksheets Answer abstract questions Structure their own recess Get along and solve problems Learn inferentially, academic and social Know right from wrong Physical stamina | Beginning to read, with pictures Learn experientially Mirror and echo words, behaviours Supervised play, structured play Learn from modelled problem-solving Learn by doing, experiential Developing sense of fairness Easily fatigued by mental work |
| 13 years old | 13 years.... 8 years developmentally |

17 Malbin, D., *Fetal Alcohol/Neurobehavioural conditions*, FASCETS, Oregon, 2011, p6.

18 Malbin, D., *Fetal Alcohol/Neurobehavioural conditions*, FASCETS, Oregon, 2011, p6.

19 Malbin, D., *Fetal Alcohol/Neurobehavioural conditions*, FASCETS, Oregon, 2011, p6.

| | |
|--|---|
| Be responsible Organize themselves: plan ahead, follow through Meet deadlines after being told once Initiate, follow through Appropriate social boundaries Body Space Establish and maintain friendships | Need reminding Need visual cues, modelling Need simple expectations Need prompting Kinesthetic, tactile, lots of touching In your space Early friendships |
| 18 years old | 18 years..... 9 years developmentally |
| Be independent Maintain a job and graduate from school Have plans for their life Relationships, safe sexual behaviour Budget their money Organise: accomplish tasks at home, school, job. | Need structure and guidance Limited choices of activities In the now – little projection Easy friendship/ Buddies – curiosity and frustration Gets an allowance Need organisational help from adults |

Information Processing Differences

A brain that has been prenatally exposed to harm from alcohol which causes Foetal Alcohol Related Conditions can mean a child or adult has difficulty with the following:

- Input, or taking in of information;
- Integration of new information with previous learning;
- Memory, especially short-term memory; and
- Output, or ability to use information

Children and adolescents pre-natally exposed to alcohol have difficulty with:

- Abstract Reasoning – Abstract concepts are the invisible foundation that structures our world.
- Cause and Effect Reasoning – Imagination. People with Foetal Alcohol Related Conditions often can't imagine something they haven't experienced.
- Generalisation – People with FASD have difficulties in their thinking process; so, when you change a piece of a routine for the child, you create an entirely new routine.
- Time – Telling time, feeling the passage of time, associating specific activities to numbers on a clock, cyclical nature of events.

Chapter 1

- Memory – Especially short-term memory.²⁰

Can FASD be cured?

*Unfortunately, **FASD cannot be cured**. People live with FASD for their entire life. However, people with FASD can still do very well with helpful supports and services. Some examples include special education, vocational programs, tutors, structured environments, and lifelong care. They can find paid work or go to school if given special assistance.*²¹

What causes foetal alcohol spectrum disorder (FASD)?

As outlined in Appendix 1, the dangers of drinking alcohol during pregnancy have been known for many years. The risks are mentioned in differing contexts throughout history. The initial medical reports on FASD were published in France in 1968 and North America in 1973.

The conditions of FAS, Partial FAS (pFAS) or Alcohol Related Neuro Developmental Disorder (ARND) all have in common ‘a confirmed history of prenatal exposure to alcohol and evidence of organic brain damage by objective testing.’²² Alcohol can have a direct and indirect effect. It can directly damage the developing cells and organs of a foetus. It can affect the function of the placenta which provides the nutrients to the developing foetus.²³

Fifty per cent of pregnancies are reported to be unplanned. A young girl or woman who is aware of the risks of alcohol consumption during pregnancy may not want to drink during pregnancy. However, she may find out she is pregnant at six, eight, maybe even 10 or later weeks into her pregnancy, by which time the baby may have been inadvertently exposed to alcohol.²⁴

Around 50 per cent of Australian women report that they actually drink during pregnancy, and some papers say it is slightly higher and some slightly lower, perhaps 35 per cent. But it is still a very big

20 Fasstar.com, *Ain't misbehavin*, Available at: <http://www.fasstar.com/InternetGuide.htm>. Accessed on 2 July 2012.

21 Public Health Agency of Canada, *Fetal Alcohol Spectrum Disorder (FASD)*, 2012.

22 Andrew, G., 'What is Fetal Alcohol Spectrum Disorder and how is it diagnosed', Jonsson, E., Dennett, L., & Littlejohn, J-, (ed.), IHE Consensus Development Conference 2009, Institute of Health Economics, Canada, 2009, p6.

23 Andrew, G., 'What is Fetal Alcohol Spectrum Disorder and how is it diagnosed', Jonsson, E., Dennett, L., & Littlejohn, J-, (ed.), IHE Consensus Development Conference 2009, Institute of Health Economics, Canada, 2009, p6.

24 Dr Colleen O'Leary, Epidemiologist–Alcohol and Pregnancy Researcher, Curtin Health Innovation Research Institute, *Transcript of Evidence*, 28 March 2012, p5.

*proportion. Of particular concern is binge drinking, which ranges from four per cent through to 20 per cent of women reporting that they have been binge drinking during pregnancy at some stage, and usually earlier on, and they reduce it later on. Around 22 per cent of Aboriginal women say that they binge drink during pregnancy.*²⁵



Alcohol is a teratogen

A teratogen is an agent which can cause a birth defect.

Alcohol is the most commonly used teratogen in the western world.

A teratogen is usually something in the environment that the mother may be exposed to during her pregnancy. It could be a prescribed medication, a street drug, alcohol use, or a disease present in the mother which could increase the chance for the baby to be born with a birth defect.

Forty years ago alcohol was not commonly recognised as a teratogen. However, the ensuing years has seen the development of a better understanding of the consequences of prenatal alcohol exposure.

Many of the effects of pre-natal alcohol on the foetus are well established. The higher the dose of alcohol, the more pronounced the effects. **There is no known low dose that appears to be safe for every pregnancy.**²⁶

25 Dr Colleen O'Leary, Epidemiologist–Alcohol and Pregnancy Researcher, Curtin Health Innovation Research Institute, *Transcript of Evidence*, 28 March 2012, p5.

26 Helen M. Barr and Ann P. Streissguth, 'Identifying Maternal Self-Reported Alcohol Use Associated With Fetal Alcohol Spectrum Disorders', *ALCOHOLISM: CLINICAL AND EXPERIMENTAL RESEARCH*, vol. 25, no. 2, February 2001, p1.

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Alcohol exerts multiple actions on the developing embryo and foetus; it induces damage via many mechanisms. Developmental alcohol exposure alters gene expression.

Alcohol freely crosses the placenta to the foetus (unborn baby). Because the foetus metabolises alcohol more slowly than an adult does, the blood alcohol concentrations can be higher than the mothers.

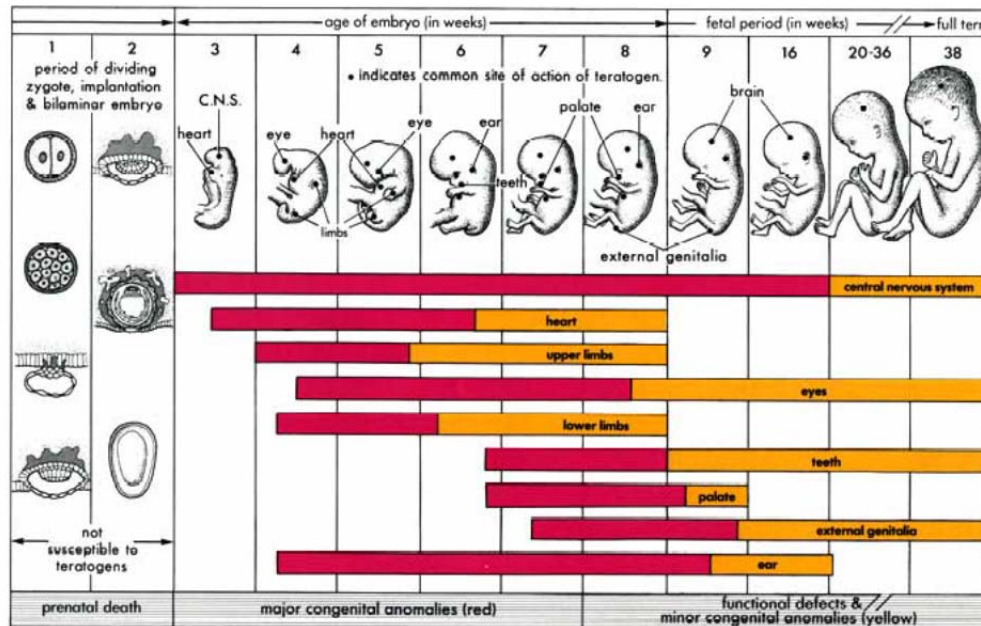


*Researchers use the term teratogen when referring to alcohol. A teratogen is a drug, chemical or even infection that interrupts or alters the normal development of a foetus, including development of the brain or other major organs. Other examples of teratogens include **Rubella, radiation, mercury and thalidomide.**²⁷*

²⁷ Telethon Institute of Child Health research, *Alcohol pregnancy and FASD*, 2012,. Available at: <http://alcoholpregnancy.childhealthresearch.org.au/about/alcohol-and-pregnancy.aspx>. Accessed on 9 March 2012. (emphasis added)

Effects of FASD

Figure 1.4: Effect of Exposure to Alcohol During Specific Periods of Pregnancy²⁸



The possible effects of embryonic and foetal alcohol exposure include:

- Brain damage;
- Birth defects;
- Poor growth;
- Social and behavioural problems;
- Delayed development; and
- Low IQ.²⁹

While alcohol exposure presents a physical risk to the embryo and foetus, as a teratogen it is in the area of behaviour that alcohol seems to do the most long-term damage.

The brain injury resulting from alcohol intake during pregnancy, results in an information processing deficit, an inability to reason in the way that others do, and an alarming inability to fit in with the rules and behaviours required by society because of the damage to the corpus callosum. (Refer chapter two).

²⁸ Model of Care

²⁹ Telethon Institute of Child Health research, Alcohol pregnancy and FASD, 2012,. Available at: <http://alcoholpregnancy.childhealthresearch.org.au/about/alcohol-and-pregnancy.aspx>. Accessed on 9 March 2012.

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Individuals affected by FASD can be seen as lazy, unmotivated, disorganised, in denial, or dishonest.³⁰

Primary FASD Disabilities

Irreversible brain damage is the primary FASD disability. The behaviours exhibited by people with FASD are often symptoms of the brain damage and are not made through rational decision making or choice.³¹

These include:

- difficulty in planning and following through on goals;
- poor memory or short-term memory lapses, where the person will quickly forget information or instructions;
- difficulties with abstract concepts;
- impaired language and communication skills;
- poor impulse control; and
- mental, social and emotional delays.³²

Additionally:

- people with FASD may have trouble setting personal boundaries and observing other people's boundaries;
- they often have emotional problems, and can be impulsive;
- they may not be able to sustain relationships;
- they often cannot anticipate consequences;
- they have difficulty paying attention;
- they have poor organisational skills; and
- they have trouble completing tasks.

When primary disabilities are not recognised, or insufficiently understood and or managed with appropriate strategies and interventions, secondary disabilities which could have been prevented can occur.

Secondary FASD disabilities

These include:

- mental health issues;
- alcohol and drug problems;

30 Submission No. 22 from The Russell Family Fetal Alcohol Disorders Association, May 2012, p2.

31 Submission No. 21 from Foundation for Alcohol Research and Education, April 2012, p8.

32 Communities for Children; Stronger Families and Communities Strategy, Drug Education Network Inc. (2011). Living with foetal alcohol spectrum disorder: A guide for parents and caregivers. <http://www.den.org.au/wp-content/uploads/2011/08/Living-with-FASD.2011.pdf>.

- trouble with the law;
- disrupted school experience; and
- inappropriate sexual behaviours.

For people living with FASD, much of their outward behaviour may appear to others as delinquent and/or antisocial. This often results in judgments being made about the nature of the person as well as criticism of their parents or carers.³³

Additionally, individuals with FASD tend to have difficulties coping with day-to-day living, such as managing money and sustaining regular employment. As a result, many adults with FASD may not be able to live independently.

In a study from the University of Washington, life history interviews of 415 individuals with FASD using 450 questions found:

- 94% of people diagnosed with FASD experienced mental health problems – which was the most prevalent secondary disability;
- 43% of people of school age experienced disrupted school experience (suspension, expulsion or drop out);
- 42% of people and 60% aged 12 and over had been in trouble with the law (involvement with authorities, charged or convicted of crime);
- 60% had been confined (inpatient treatment for mental health, alcohol/drug problems, or incarceration for crime);
- 45% aged 12 and over were reported to have exhibited inappropriate sexual behaviour;
- 30% of people over the age of 12 experienced alcohol and drug problems;
- Problems with employment were indicated in 80% of adults with FASD;
- Problems parenting: of the 100 females of childbearing age, 30 had given birth; 40% drank during pregnancy, more than half no longer had the child in their care - of their children, 30% have been diagnosed with, or were suspected of having, FASD.³⁴

In broad terms, when presented with social dilemmas, children with FASD demonstrate a deficiency in social problem solving. This difficulty may underlie their social and behaviour problems outlined above.³⁵

33 Submission No. 21 from Foundation for Alcohol Research and Education, April 2012, p8.

34 Submission No. 22 from The Russell Family Fetal Alcohol Disorders Association, May 2012, p2.

35 Stevens, S., 'Social problem solving in children with fetal alcohol spectrum disorder', *J Popul Ther Clin Pharmacol* Vol 19(1):e99-e110; April 19, 2012.

Chapter 2

Evidence and prevalence of FASD

There is no safe amount of alcohol during pregnancy.

There is no safe time to drink alcohol during pregnancy.

The evidence for FASD

There is a steadily growing body of evidence confirming the damaging impact of embryonic and foetal exposure to alcohol. A number of adult pathological conditions resulting from alcohol exposure in utero have been reported in cross sectional studies, including:³⁶

- Greater academic and cognitive deficits than would be expected on the basis of IQ alone;
- Attention problems, including auditory and visual inattention;
- A high prevalence of mental illness;
- Alcohol, drug or nicotine dependence;
- Suicidal tendency; and
- Abnormality on functional magnetic resonance imaging (MRI) and magnetic spectroscopic imaging.³⁷

A meta-analytical review conducted by Testa and colleagues investigated the effects of prenatal alcohol exposure on child development. These authors examined infants at:

- six months,
- 12-13 months and again at
- 18-26 months.

The findings indicated a consistent negative impact on development in children when the mother had consumed an average of two or more drinks a day.

However, while the evidence of the damaging impact of foetal exposure to alcohol is clear, the jury is still out on the relative significance of:

36 The Intergovernmental Committee on Drugs, *Monograph of the Intergovernmental Working Party on Fetal Alcohol Spectrum Disorders*, report prepared by Lucy Burns, Emma Black and Elizabeth Elliott, June 2012, p38.

37 The Intergovernmental Committee on Drugs, *Monograph of the Intergovernmental Working Party on Fetal Alcohol Spectrum Disorders*, report prepared by Lucy Burns, Emma Black and Elizabeth Elliott, June 2012, p38.

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- The impact of drinking in the three trimesters;
- the quantities of alcohol that will negatively affect the foetus; and
- how other environmental and genetic factors combine with alcohol to result in FAS/FASD.

Nonetheless, the underlying premise of ‘*don’t drink while pregnant*’ is one that has been adopted in many countries. As outlined in the previous chapter, alcohol is a teratogen that interrupts or alters the normal development of a foetus and, in particular, affects behaviour in the child and adult.

The Public Health Agency of Canada unequivocally states in its literature:

*There is no safe amount of alcohol during pregnancy. There is also no safe time to drink alcohol during pregnancy.*³⁸

As one senior paediatrician put it, ‘This is a moral issue. It’s a public health issue, regardless of the fine tuning of evidence. It’s about changing a culture. The issue is beyond public health.’³⁹

Numerous mechanisms, or social determinants of health, are likely contributors to the damaging effects of prenatal alcohol exposure on the developing foetus. This is of particular concern in respect to the developing central nervous system (CNS). The coexistence of such social determinants of health that may act simultaneously or consecutively, while differing in effect among various cell types, poses particular challenges to researchers.⁴⁰

To study alcohol’s effects on the embryo and foetus more easily, investigators have used animal models and tissue-culture experiments.⁴¹ Many animal studies have shown the physical teratogenic effects of alcohol on mouse and other models, with the facial features resembling those seen in humans (namely, the narrow eye openings, smooth philtrum and thin upper lip).⁴²

The evidentiary difficulties have been highlighted in recent months with some media publicity and debate following the release of a Danish study which stated that ‘low to moderate drinking is not associated with adverse effects on children under age five.

38 The Public Health Agency of Canada, *Fetal Alcohol Spectrum Disorder (FASD)*, information brochure – publication number 4200, Canada, p5.

39 Briefing March 2012 Broome.

40 Goodlett, C.R. and Horn, K.H. (2001). Mechanisms of alcohol-induced damage to the developing nervous system. *Alcohol Research & Health*, 25(3), 175-184.

41 Goodlett, C.R. and Horn, K.H. (2001). Mechanisms of alcohol-induced damage to the developing nervous system. *Alcohol Research & Health*, 25(3), 175-184.

42 Dr James Fitzpatrick, Electronic Mail, 22 March 2012, p1.

However despite these findings, additional large scale studies should be undertaken to investigate the possible effects'.⁴³

The media's interpretation of the study was that it suggested, contrary to all other research, that moderate alcohol drinking was safe for pregnant women. In investigating the study, the National Health Service in the UK found that the study was flawed in a number of respects and that '**Daily drinking in pregnancy is 'not safe'**'.⁴⁴ The Russell Family Foetal Alcohol Disorders Association advised that there were two critical factors that affected the study's conclusion, namely:

- The study only looked at children up to the age of 5 and a large percentage of children don't start to show the signs of alcohol harm until age 7. In fact the UK FASD Clinic established by Dr Raja Mukherjee won't accept a child for diagnosis for behaviour difficulties etc., until age 6; and
- The study was specifically for motor skills and not for the whole spectrum of learning and behaviour Alcohol Related Neurodevelopmental Disorders.⁴⁵

The Russell Family Foetal Alcohol Disorders Association added that:

*A 5-year-old's brain is not developed enough to perform complex tasks like following multiple instructions, writing a report or multiplying numbers. Decades of research on foetal alcohol syndrome confirms that alcohol has its greatest impact on complex brain functions. This is why children damaged by prenatal alcohol look deceptively good in the preschool years. The full impact of their exposure will not be evident until their adolescent years.*⁴⁶

The Telethon Institute of Child Health Research advised the Committee that in relation to this study:

This BBC report is based on a well-designed and conducted study from Denmark, assessing alcohol exposure during pregnancy (rather than asking women after pregnancy about their drinking habits during pregnancy) and assessing the children at 5yoa for a range of

43 BJOG: An International Journal of Obstetrics and Gynaecology, *Danish studies suggest low and moderate drinking in early pregnancy has no adverse effects on children aged five*, June 2012, Available at:

http://www.bjog.org/details/news/2085661/Danish_studies_suggest_low_and_moderate_drinking_in_early_pregnancy_has_no_adver.html. Accessed on 23 August 2012.

44 NHS Choice, *Daily drinking in pregnancy 'not safe'*, June 2012, Available at: <http://www.nhs.uk/news/2012/06june/Pages/daily-drinking-pregnancy-risk-not-safe.aspx>. Accessed on 22 June 2012.

45 Anne Russell, The Russell Family Fetal Alcohol Disorders Association, Electronic Mail, 22 June 2012.

46 *The Australian Fetal Alcohol Spectrum Disorder Newsletter*, July 2012, p1.

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neurodevelopmental outcomes. There are a number of limitations to the study, which are discussed in the paper. Unlike most of the media coverage of these papers, the authors of the papers were considered and measured in their conclusions.

They state "To date, the scientific literature, including the present study, does not establish a safe level of alcohol consumption during pregnancy. As alcohol is a known teratogen, it remains the most conservative advice for women to abstain from alcohol during pregnancy.

However, small quantities consumed occasionally in pregnancy do not appear to pose serious issues for these three areas of neurodevelopment."⁴⁷

Effects of pre-natal alcohol exposure

The fact that alcohol adversely affects the embryo and foetus is well established. In one example, in a review of the effects of pre-natal alcohol exposure, researchers at Wayne State University reported alcohol's effect on intellectual and socio-emotional functioning in respect to the brain as follows:

In respect to intellectual and socio emotional functioning

In summary, these data indicate that prenatal alcohol exposure is associated with a distinctive pattern of intellectual deficits, particularly in arithmetic and certain aspects of attention, including planning, cognitive flexibility, and the utilization of feedback to modify a previously learned response. With respect to learning, the acquisition of new information is more likely to be impaired than retention and retrieval of previously learned information. As alcohol-exposed children grow older, deficits in socioemotional function become increasingly salient, particularly with regard to social judgment, interpersonal skills, and antisocial behaviour. Although these deficits are most severe and have been documented most extensively in children with FAS, children prenatally exposed to lower levels of alcohol frequently exhibit similar problems.⁴⁸

47 Winthrop Research Professor Carol Bower, Telethon Institute for Child Health Research Centre for Child Health Research, The University of Western Australia, Electronic Mail, 24 June 2012.

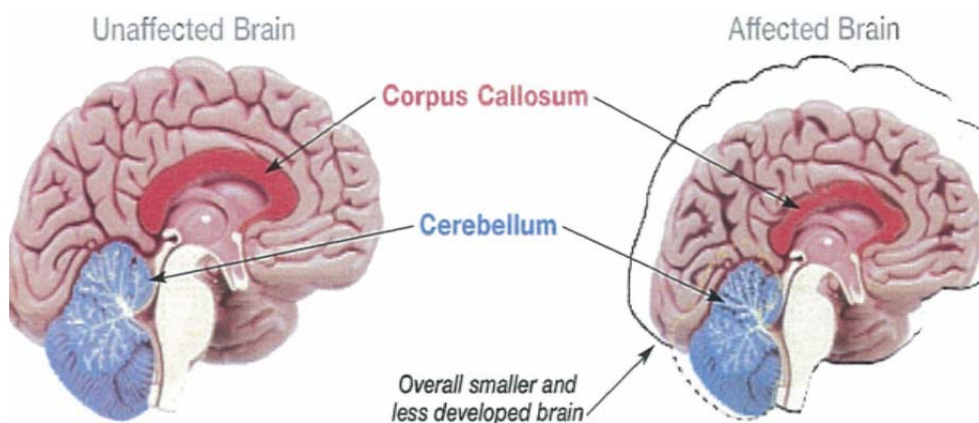
48 Joseph L. Jacobson, Ph.D., and Sandra W. Jacobson, Ph.D., *Effects of Prenatal Alcohol Exposure on Child Development*, 2003,. Available at: <http://pubs.niaaa.nih.gov/publications/arh26-4/282-286.htm>. Accessed on 3 May 2012.

Alcohol and the brain

Several recent studies using magnetic resonance imaging have shown damage to the **corpus callosum, a band of nerve fibers that connects the left and right sides of the brain**. A report published in 2002 compared the brain scans of adults and children who had severe or mild alcohol-related disabilities with the scans of healthy counterparts. The researchers found that the **corpus callosa were abnormally shaped in 80 per cent of those who had been exposed to alcohol in utero**.

Another study found that the corpus callosum was smaller and shifted forward in children and young adults with the syndrome. Using a technique known as diffusion tensor imaging to look closer at the corpus callosum, researchers at Emory University have seen abnormalities in the myelin, the substance that insulates nerve cells.⁴⁹

Figure 2.1: Brain Structures most sensitive to prenatal alcohol exposure⁵⁰



49 Joseph L. Jacobson, Ph.D., and Sandra W. Jacobson, Ph.D., *Effects of Prenatal Alcohol Exposure on Child Development*, 2003,. Available at: <http://pubs.niaaa.nih.gov/publications/arh26-4/282-286.htm>. Accessed on 3 May 2012.

50 National Organisation on Fetal Alcohol Syndrome , *Brain Structures most sensitive to prenatal alcohol exposure*, Available at: <http://www.nofas.org/healthcare/>. Accessed on 3 May 2012.

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| Brain Structure | Function | Prenatal alcohol exposure may result in problems with: |
|-----------------|--|--|
| Corpus Callosum | Communicates motor, sensory and cognitive information between the two hemispheres of the brain | Storing and retrieving information, problem solving, attention and verbal memory |
| Cerebellum | Processes input from other areas of the brain to coordinate motor and cognitive skills | Controlling movements, maintaining balance and fine motor skills |

‘When the myelin is damaged, signals do not carry as crisply through the cells’, said Dr Claire D. Coles, Director of the Foetal Alcohol Center at the Marcus Institute and a professor of psychiatry and behavioural sciences at Emory.

Another study published in 2002 found that frontal lobe structures were smaller in teenagers and young adults who had been exposed to alcohol prenatally.⁵¹

Under-identification of FASD

Foetal Alcohol Syndrome (FAS) is regarded as the leading cause of intellectual and developmental disability in the western world. This is an especially significant statement because of the fact that under-identification or diagnosis of FAS, FASD and FA&NB is still common.⁵²

The incidence of FASD varies markedly from study to study for a number of reasons including:

- worldwide, there are few comprehensive prevalence studies;
- there are differences in definition and diagnostic measures of FASD symptoms, where diagnostic measures exist at all;
- in many countries there is a lack of awareness of FASD; and

51 Fetal Brains Suffer Badly From Effects of Alcohol, 2003,. Available at: <http://www.come-over.to/FAS/Research.htm>. Accessed on 3 May 2012.

52 Mablín, D., 'Fetal Alcohol Spectrum Disorder (FA/NB) and the role of family court judges in improving outcomes for children and families', *Juvenile and Family Court Journal*, vol. 55, no. 2, 2004, p53-63.

- there are significant difficulties in diagnosing FASD. In Australia, for example, there is still no diagnostic tool.⁵³

This has led some researchers to believe that the actual incidence of FASD may be much higher than currently estimated in the literature.

The worldwide incidence rates of FAS have been estimated at 1.9 per 1000 live births while that of FASD is not known with any level of exactitude.⁵⁴ The fact that FASD is under-diagnosed around the world is widely acknowledged and there are no prevalence benchmarks currently set that serve as a valid starting point.⁵⁵

In Australia, in the absence of a diagnostic tool, the prevalence of FASD is totally unknown. There is only one FASD diagnostic clinic, which is based in Sydney, and, more generally, many health professionals do not routinely ask about alcohol use during pregnancy. The committee heard that in Western Australia fewer than 50% of health professionals routinely ask about alcohol use during pregnancy and only between 12% and 16% know the four diagnostic features of FAS.^{56 57}

In respect to the more readily diagnosable and physiologically visible FAS there is evidence that there has been significant under-reporting of the syndrome, as recounted to the Committee.⁵⁸

*The issues that contribute to the lack of prevalence are that the diagnosis of foetal alcohol syndrome, FAS, is difficult. There is a lack of recognition of FAS by health professionals in Western Australia. Research here has shown that only 16 per cent of health professionals know the four diagnostic features that are a part of the foetal alcohol syndrome. Only seven per cent have actually diagnosed a child with FAS.*⁵⁹

53 Blake Dawson, Submission 49, Submission to the Standing Committee on Social Policy and Legal Affairs, 2012, p6.

54 Institute of Health Economics, Edmonton, Alberta, *COSTS OF FETAL ALCOHOL SPECTRUM DISORDER IN ALBERTA, CANADA*, 2008), p1. Available at: <http://www.ncbi.nlm.nih.gov/pubmed/21515625>. Accessed on 8 May 2012.

55 Dr Linda Burnside, *Prevalence of Fetal Alcohol Spectrum Disorder: A Literature Review*, Tri-Province FASD Project, 2011, p7,8.

56 Dr Colleen O'Leary, Epidemiologist–Alcohol and Pregnancy Researcher, Curtin Health Innovation Research Institute, *Transcript of Evidence*, 28 March 2012, p2.

57 Lililwan Project Study protocol paper V23

58 Dr Rochelle Watkins, Research Fellow, Telethon Institute of Child Health Research, *Transcript of Evidence*, 16 May 2012, p3.

59 Dr Colleen O'Leary, Epidemiologist–Alcohol and Pregnancy Researcher, Curtin Health Innovation Research Institute, *Transcript of Evidence*, 28 March 2012, p2.

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Others have suggested that under-reporting of FAS by health professionals is due to several factors, including:

- difficulty in making, or lack of skills to make, a diagnosis;
- lack of awareness and recognition by physicians in considering the diagnosis;
- lack of availability of specialists in high risk and remote areas; and
- paediatricians not being prepared to deal with a FAS diagnosis.⁶⁰

Overseas where FAS and FASD may be diagnosed, the problem of under-reporting of FASD is compounded by misdiagnosis. In Canada, as an example, it was found that non-aboriginal children with FASD are often misdiagnosed and that a lot of children are diagnosed with ADD, ADHD, conduct disorder, and mild autism when their primary problem is FASD.⁶¹

There is no reason to suppose that the situation is different in Australia, particularly in the absence of a diagnostic tool.

There is an anecdotal belief that FASD is a problem that is largely confined to Aboriginal communities to the exclusion of other ethnic and socio economic status (SES) groups.⁶² The Committee was told FASD is not just an 'aboriginal problem' in Western Australia. Contrary to some commonly held views, FASD potentially affects all children whose mothers drank alcohol at harmful levels while pregnant.

The point that Fiona Stanley made on Sunday at the launch of our campaign was that this perception that it is more of an Indigenous Aboriginal issue than a non-Aboriginal issue is not the case.

Given that there are significantly greater numbers in the non-Aboriginal population, when you apply these percentages to that population, the numbers of people potentially affected are significantly greater than they would be in the Aboriginal population.⁶³

The Department of Education, Employment and Workplace Relations (DEEWR) note, while FASD is not exclusively an issue for Indigenous communities, the prevalence of FASD is much higher among Indigenous children than non-Indigenous

60 Chudley, A.E., 'Fetal alcohol spectrum disorder: counting the invisible – mission impossible?', *Diseases*, 2008, 93(9), Arch Dis Child 721.

61 Dr Ted Rosales, *FASD not limited to aboriginals*, April 2005. Available at: <http://www.cbc.ca/news/canada/newfoundland-labrador/story/2005/04/21/nf-fasd-rosales-050421.html>. Accessed on 28 May 2012.

62 Dr Colleen O'Leary, Epidemiologist–Alcohol and Pregnancy Researcher, Curtin Health Innovation Research Institute, *Transcript of Evidence*, 28 March 2012, p2.

63 Mr Neil Guard, Executive Director, Drug and Alcohol Office, *Transcript of Evidence*, 20 June 2012, p2.

children. DEEWR also acknowledges that both diagnosis and measurement of FASD are difficult.⁶⁴

One expert witness to the Inquiry, commenting on the issue of prevalence, stated:

First of all, I am sure you are already aware that the prevalence of FAS in Western Australia is considerably lower than that recorded overseas. In Western Australia the prevalence for non-Aboriginal children is 0.02 per 1 000, which is very low. For Aboriginal children, it is about 100 times higher—2.76 per 1 000. The estimates from overseas range from two per 1 000 to seven per 1 000 for the general population, so you can see ours are much, much lower. For minority groups such as First Nations and, I think, the term in South Africa is the Coloured population, they are much higher. The highest are recorded in South Africa at 50 per 1 000, which is actually five per cent. Those studies are in-school studies, where they have looked to the children in school. It is well accepted by researchers and health professionals that the presence of FAS in Western Australia and Australia actually underrepresent the true prevalence.

But a major gap in our knowledge and a major gap that appears to me on the terms of the inquiry here is the local population best estimates of the prevalence of the broader Foetal Alcohol Spectrum Disorders. Foetal spectrum alcohol disorders is an umbrella term. Under these sit a number of diagnostic categories, of which foetal alcohol syndrome, FAS, is one of these. The children with FAS have a characteristic facial feature, which makes diagnosis a little bit easier. It is still hard, but it is easier. For children who have brain damage without the characteristic facial features, the diagnostic term is alcohol related neurodevelopmental disorder. These are very difficult to identify. There are a number of issues in WA that contribute to this lack.⁶⁵

In summary, it is believed that the prevalence of FASD in Australia is under-reported.

Factors why FASD is underreported include:

- lack of screening;
- lack of diagnosis; and

64 Department of Education and Employment and Workplace Relations, *Submission to the Standing Committee on Social Policy and Legal Affairs*, 2012, p4.

65 Dr Colleen O'Leary, Epidemiologist—Alcohol and Pregnancy Researcher, Curtin Health Innovation Research Institute, *Transcript of Evidence*, 28 March 2012, p2.

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- lack of sufficient data.⁶⁶

*Critically, when we do not know how many people are affected we are not able to consistently and accurately measure the extent of FASD in society. In particular, individuals with FASD remain undiagnosed, or misdiagnosed, and either do not receive the interventions that they need or receive interventions that are unfitting for their need.*⁶⁷

WA Register of Developmental Anomalies and FAS

In Western Australia there is a Register of Developmental Anomalies (sometimes referred to as WARDA or the Register). WARDA collects information to keep track of where and when developmental anomalies are occurring in Western Australia. This information guides research and helps to investigate causes, prevention and management of developmental anomalies.

The register is a statutory register. It receives notifications of all birth defects and cerebral palsy in children diagnosed up to the age of six years. With the increased encouragement to notify FAS has come an increased level of reporting, further supporting the likelihood of significant under-reporting.

*It is a bit of a problem [for FAS] because sometimes that diagnosis is later than that. The register largely accepts what is sent to us by the notifier. They are usually paediatricians who notify us. We do not check that they have covered all the features and that sort of thing. Since we have had an interest in foetal alcohol syndrome, we have sent out reminders and notification cards to the paediatricians and encouraged notification in general but with a particular focus on foetal alcohol syndrome. We have seen an increase in notification over that period. So that is another reason why we think there has been under-recognition and/or under-diagnosis and/or under-notification rather than an increase in the actual condition. We will register FASD if it is notified to us. We would include other anomalies within the spectrum but I do not think—I cannot say for sure—we have been notified of an alcohol-related neurodevelopmental disorder. I do not recall that coming in.*⁶⁸

66 Submission No. 12 from Department of Health, December 2012, Appendix A p5.

67 Dr Linda Burnside, *Prevalence of Fetal Alcohol Spectrum Disorder: A Literature Review*, Tri-Province FASD Project, 2011, p1,2.

68 Dr Rochelle Watkins, Research Fellow, Telethon Institute of Child Health Research, *Transcript of Evidence*, 16 May 2012, p9.

Australian Early Development Index

It has long been acknowledged that children who lack school-readiness at the age of five are much more likely to experience behavioural, social and academic difficulties in school and to drop-out before graduating.

One population measure, the Australian Early Development Index (AEDI), examines early childhood development across the whole community. It provides a snapshot of how children in any given local area have developed by the time they start school.

The AEDI results help governments and communities gain an understanding of what is working well and what needs to be improved or developed to better support children and their families within given communities. Together with other socio-demographic and community information, the AEDI results are seen as a powerful tool for influencing planning and policy around early childhood development.⁶⁹

In Canada, modifications to the equivalent development measure have been proposed to secure FASD recognition within the instrument. This is seen as a strategy to better map the incidence and prevalence of FASD across the community and so inform policy.

Such population specific modifications have a precedent in Australia. In acknowledging some of the cultural and ethno specific issues faced by indigenous communities, the AEDI was modified in 2011:

As informed by the consultations in Western Australia, a number of additional checklist items considered to be of particular relevance to Indigenous children, such as the identification of English as a Second Language (ESL) or special learning support needs, were included. These items included: reasons for days absent from school (e.g. for cultural reasons, for reasons of sickness, or for other reasons); proficiency in use of home (Indigenous) language; history of chronic illness (such as otitis media) or neurodevelopmental disorders (such as Foetal Alcohol Syndrome);⁷⁰

Recommendation 1

The Western Australian government encourages the Federal Government to support the adoption of a FASD Diagnostic tool and the classification of FASD as a disability by June 2013.

69 Royal Children's Hospital, *AEDI*, Available at: http://www.rch.org.au/aedi/faq.cfm?doc_id=13176. Accessed on 5 June 2012.

70 Silburn et al, *The Australian Early Development Index (AEDI) Indigenous Adaptation Study*, 2009, p5. Available at: http://www.rch.org.au/emplibrary/australianedi/AEDI_Indigenous_Adaptation_Study_Report_Nov_2009.pdf. Accessed on 16 May 2012.

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Screening

Early intervention begins with a rigorous approach to identifying women whose babies are at risk.

Types of screening

Screening should not be equated with diagnosis. Screening for FASD identifies populations at risk while a diagnostic test is a procedure that is performed to detect the presence of a specific disease. In this context, diagnosis describes the tests undertaken to identify FASD.

Early intervention begins with a rigorous approach to identifying women whose babies are at risk.⁷¹

FASD is an umbrella term describing the range of effects that can occur in a child or an adult who has prenatally been exposed to a harmful level of alcohol intake by their mother. These effects may include physical, mental, behavioural, and/or learning disabilities with possible lifelong implications.⁷²

One purpose of screening is to identify and refer pregnant women who may be at risk for an alcohol use disorder and who may place their child at risk of FASD.⁷³ Screening for FASD is both a secondary and tertiary prevention strategy – secondary because it allows intervention to prevent alcohol exposure for subsequent pregnancies, and tertiary because intervention may prevent disability or reduce other cognitive, social or behavioural problems in an identified child.

The two primary methods for screening for prenatal alcohol exposure are:

- Self-reporting; and
- Meconium screening.

The Royal Australasian College of Physicians (the RACP) recommends targeted screening be applied for some population groups, namely for:

71 Submission No. 25 from The Royal Australasian College of Physicians, June 2012, p3.
72 SAMHSA, 'FASD and the Justice system', Paper presented at the 5th National biennial Conference on Adults with Fetal Alcohol Spectrum Disorder, Vancouver, April 2012.
73 Chudley, A.E., et al. 'Fetal alcohol spectrum disorder: Canadian guidelines for diagnosis', Canadian Medical Association Journal, March 2005, p172.

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- all children discharged from a drug dependency service in any obstetric unit;
- all children apprehended into child protection; and
- all juveniles going through justice, into probation, community/first line sentencing.

This targeted approach to screening occurs in North America and should be applied in Australia. Screening families in this way has also reduced harmful exposures of alcohol in subsequent pregnancies. Many children diagnosed with FASD will go on to have younger siblings in whom FASD can be prevented if the diagnosis is timely and accurate. Screening needs to be supported by a validated diagnostic system (undertaken by multidisciplinary teams) and clinical pathways for following up children who screen positive.⁷⁴

Self-Reporting

Evidence suggests that women accurately and willingly describe their pre-natal substance use when asked, provided that safety is assured.⁷⁵ The issue that the Committee was made aware of during this inquiry is “whether women are asked in the first place”.

In a recent study by the Australian Paediatric Surveillance Unit it was found that women were not routinely advised about the risks of drinking alcohol in pregnancy, nor were they advised not to drink alcohol in pregnancy.⁷⁶

The Department of Health advised the Committee that, in its view:

Antenatal screening is really important, and so asking women the question about alcohol use pre-pregnancy through doctors when they come through and say, “I’m planning to get pregnant, I need testing for X, Y and Z.” The alcohol question needs to be asked there, and depending on what you get there, it would put you into a risk category. That would identify a targeted risk assessment, and those, through antenatal care, who are drinking through pregnancy. Again, asking the question in the antenatal period would solicit out your targeted response, and given there will always be fixed resources, we should target those most at risk.⁷⁷

Screening of alcohol consumption by pregnant women should occur at each antenatal visit. The fear of stigmatisation of the child or family and

74 Submission No. 25 from The Royal Australasian College of Physicians, June 2012, p3.

75 Clarren, S et al, *Prevention of fetal alcohol spectrum*, Wiley Blackwell Germany, 2011, p12.

76 Dr Carol Bower, Epidemiologist, Telethon Institute of Child Health Research, *Transcript of Evidence*, 16 May 2012, p1.

77 Mrs Kate Gatti, Clinical Lead, Child and Youth Health Network; Population Health Area Director, WA Country Health Service, *Transcript of Evidence*, 28 March 2012, p10.

*lack of knowledge about how to refer and manage children must also be addressed in health professional education. Suitable training must also be provided for health professionals in order that existing FASD educational resources are more extensively utilised. This is particularly the case in rural and remote settings where access to health services is limited and barriers to diagnosis are accentuated.*⁷⁸

It is acknowledged that adopting a universal approach to self-reporting will not identify all the women who drink while pregnant. This is because women who are most at risk of having an alcohol-exposed child often do not access prenatal care.⁷⁹

Meconium Screening

Meconium is a bio-marker. It can confirm the presence of ethanol in a system. Meconium is a dark, tarry material passed from the neonate's rectum in the first days after birth before a milk or formula-based stool appears. It is the best specimen for assessing *in utero* exposure of the newborn to maternal drug use.⁸⁰

Post-natally, meconium screening is effective in confirming an infant's exposure to alcohol during the last two trimesters of foetal development.⁸¹

Meconium begins to form during the 12th–16th week of gestation and is usually passed within first 3 days of birth. Passage may be delayed when the baby is exposed to opioids or with premature birth. However, it may be expelled *in utero* or during birth. Meconium is preferred over urine for testing of neonates. This is because urine testing indicates drug use only over the last 1–10 days, depending on the drug. Meconium documents drug use over an extended period of time, covering at least the last trimester of pregnancy.⁸²

However, meconium screening will not predict neurodevelopmental delays or any other negative effects from alcohol exposure.

The perceived ethical issue in undertaking meconium screening is that it is a test to determine what the mother already knows, and has chosen not to reveal voluntarily, nor necessarily given her consent to the test. This is different from most diagnostic

78 Australian National Preventive Health Agency, Submission to the Standing Committee on Social Policy and Legal Affairs, 2012, p8

79 Dr Linda Burnside, *Prevalence of Fetal Alcohol Spectrum Disorder: A Literature Review*, Tri-Province FASD Project, 2011, p5.

80 ARUP Consult, *Newborn Drug Screening - Meconium and Umbilical Cord*, 2012. Available at: <http://www.arupconsult.com/Topics/MeconiumandUmbilicalCord.html>. Accessed on 9 March 2012.

81 Clarren, S et al, *Prevention of fetal alcohol spectrum*, Wiley Blackwell Germany, 2011, p12.

82 ARUP Consult, *Newborn Drug Screening - Meconium and Umbilical Cord*, 2012. Available at: <http://www.arupconsult.com/Topics/MeconiumandUmbilicalCord.html>. Accessed on 9 March 2012.

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tests that reveal information that is not known. As a consequence the implementation of this test may inhibit high risk mothers from seeking obstetric care in case they are deemed an unfit mother and lose their child to foster care.⁸³

Finding 1

Screening of alcohol consumption by pregnant women should occur at each antenatal visit with a general practitioner, nurse or midwife. Screening should occur post-natally for alcohol consumption as part of each universal child health check or general practitioner appointment until a child is four years of age.

Recommendation 2

The Committee recommends to the Minister for Health that by June 2013 all pregnant and post-partum women are screened for alcohol use with validated screening tools by relevant health care providers. Women at risk for heavy alcohol use should receive early brief intervention (i.e. counselling).

Recommendation 3

To protect the unborn child, the Committee recommends to the Minister for Health that the Government prepares guidelines for all health care professionals by June 2013, which should encourage all pregnant women or women attempting to become pregnant to abstain from alcohol.

Recommendation 4

The Committee recommends to the Minister for Health that he direct the Department of Health to review and report back to Parliament by June 2013 on the ethical considerations involved in the analysis of meconium for pregnancy cases where there is a strong suspicion of significant alcohol consumption during pregnancy.

Data collection

Data collection on FASD is important. Governments, professional bodies and researchers need to better understand who and how many people are affected by FASD. The Government needs to estimate the current and future cost to health, education, social and community services, justice and child protection systems. FASD prevention and intervention programs should be developed and evaluated. Currently there is very limited data on FASD incidence and prevalence in Western Australia and Australia.

⁸³ Clarren, S et al, *Prevention of fetal alcohol spectrum*, Wiley Blackwell Germany, 2011, p12.

There are two parts to data collection:

- collection of data about alcohol consumption from pregnant women. This could potentially be done through the National Perinatal Minimum Data Set (similar to tobacco use); and
- collection of data about cases of FAS/FASD after birth. This could potentially be done through the Paediatric Surveillance Unit and/or the Australian Congenital Anomalies Monitoring System.

Currently, each state collects different information with no standardisation. In Western Australia, there is no standard routine data collection to prevent, monitor and evaluate maternal alcohol use in pregnancy and research into pregnancy, infant and child outcomes.⁸⁴

There is broad acknowledgement in many parts of the health sector that a significant improvement in data collection is needed to understand the true extent of FASD in the Australian community. In particular, there is a need to standardise data on alcohol consumption during pregnancy and on the collection and collation of data once a FASD diagnosis has been made.⁸⁵

As one witness put it:

I think there is a general acceptance, will and enthusiasm for having a collaborative approach to diagnoses, an Australian diagnostic instrument and the national collection of data. The National Perinatal Statistics and Epidemiology Unit, part of the Australian Institute of Health and Welfare, had a meeting last year to discuss having a national data collection for FASD. I think that is a really important thing.⁸⁶

84 Ms Kate Gatti, WA Child and youth Health Network, Fetal Alcohol Spectrum Disorder Model of Care Power point presentation 2012.

85 Foundation for Alcohol Research and Education, 'Changing the way we respond to Fetal Alcohol Spectrum Disorders', email 13 June 2012.

86 Dr Carol Bower, Epidemiologist, Telethon Institute of Child Health Research, *Transcript of Evidence*, 16 May 2012, p4.

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The Western Australian Model of Care recommends that:

- There should be a collection of data on alcohol use during pregnancy. Use can be made of existing tools such as the midwife notification form to include documentation of the presence or absence of alcohol consumption in pregnancy.
- There should be data linkage ability between government sectors. Such linkage should record, evaluate and share the health and other needs and service access of individuals with FASD.

To achieve this there would need to be approved channels of agreed and confidential communication between sectors.⁸⁷

This would represent a significant challenge as:

If you are inquiring about FASD and the youth, you are already on the back foot if you wanted to search data. If you have birth mothers or access to the records of the Department for Child Protection about what the world was like for that child, and you have a suspicion that there was alcohol exposure or proof that there was alcohol exposure, then they should be considered for a FASD diagnosis, and that is not happening at the moment.⁸⁸

Finding 2

There is broad acknowledgement in many parts of the health sector that a significant improvement in data collection is needed to understand the true extent of FASD in the Australian community. In particular, there is a need to standardise data on alcohol consumption during pregnancy and to collect and collate data once a FASD diagnosis has been made.

87 Ms Kate Gatti, WA Child and youth Health Network, Fetal Alcohol Spectrum Disorder Model of Care Power point presentation 2012.

88 Dr Raewyn Mutch, Paediatrician and Post-doctoral Fellow with the Alcohol and Pregnancy Research Group of the Telethon Institute for Child Health Research, *Transcript of Evidence*, 9 July 2012, p11.

Recommendation 5

The Committee recommends that the Government support the following WA FASD Model of Care recommendations:

- c. There should be a collection of data on alcohol use during pregnancy. Use can be made of existing tools such as the midwife notification form to include documentation of the presence or absence of alcohol consumption in pregnancy.
- d. Data linkage ability between sectors to be established to enable the monitoring, sharing and evaluation of data between relevant health professionals and services.

The Government reports back to Parliament on a bi-annual basis on the results of this data collection.

Recommendation 6

In the 2013 budget the Government funds bi-monthly appointments by child health nurses for pregnant women and mothers with children under the age of 4 years who are thought to be drinking alcohol at harmful levels. These child health nurses will provide, at a minimum, a 6 monthly review of these families to the Department of Health. The Government will then report back to Parliament on a bi-annual basis on the effects of these additional appointments.

Chapter 4

Diagnosing FASD

Early diagnosis is important to allow access to appropriate intervention, resources and support.

Diagnosis – why bother?

As an expert witness told the Committee, congenital anomalies such as FAS/FASD are worth bothering about — they affect around one in 20 births in Australia. For many congenital anomalies, early identification and diagnosis allows interventions to decrease the risk of secondary disabilities.⁸⁹

The early diagnosis of FASD is important because after FASD has been recognised by the Federal and State Government as a disability:

- An early diagnosis should enable access to interventions and resources that may mitigate the development of subsequent secondary disabilities (e.g., unemployment, mental health problems, trouble with the law, inappropriate sexual behaviour, and disrupted school experience).
- An early diagnosis should allow appropriate intervention, counselling and treatment for the mother and may prevent the birth of subsequent children who are affected with FASD.
- An early diagnosis may prompt caregivers to seek diagnosis and support for previously undiagnosed siblings.⁹⁰

As one witness to the Inquiry put it:

I have a strong belief in the importance of knowing about the problem because that will enable not only research on how we address it in our local context—when you do not have a good handle on what is going on, how big it is and what works and what doesn't, it is very difficult to argue for services and intervention. I see diagnoses as the first stage in

89 Bower, C et al., 'Congenital anomalies — why bother?', *Medical Journal of Australia*, Volume 192 Number 6, 15 March 2010, p300.

90 Chudley, A.E. et al, 'Fetal alcohol spectrum disorder: Canadian guidelines for diagnosis', *Canadian Medical Association Journal*, March 1, 2005 vol. 172 no. 5.

Chapter 4

*enabling prevention and in particular ... in targeting prevention to very high-risk individuals.*⁹¹

Finding 3

An early diagnosis of FASD would enable access to interventions and resources. These may mitigate the development of subsequent secondary disabilities such as mental health problems, trouble with the law, inappropriate sexual behaviour, absenteeism and disrupted school experience, and unemployment.

Background to screening and diagnosis

The Western Australian Department of Health acknowledges that in Western Australia, as in Australia more generally, there is no screening system in place for women of child-bearing age who are planning a pregnancy or are pregnant; nor is there a coordinated service to diagnose children with FASD or to provide ongoing services.⁹²

There are a number of barriers to effective diagnosis, which impact upon attempts to determine prevalence rates including:

- evidence of brain damage is often not evident until the child has reached the school-age years, making early diagnosis difficult. In addition, there are fewer diagnostic resources available for youth and adults, often leaving their functional challenges undiagnosed;
- the difficulty in confirming maternal alcohol use during pregnancy;
- reluctance to diagnose due to the stigmatisation of the condition;
- a lack of training in making FASD diagnoses;
- a belief that the condition can be treated effectively without the FASD label; and
- the lack of diagnostic services in general.⁹³

91 Dr Rochelle Watkins, Research Fellow, Telethon Institute of Child Health Research, *Transcript of Evidence*, 16 May 2012, p5.

92 Submission No. 12 from Department of Health, December 2011, p5.

93 Dr Linda Burnside, *Prevalence of Fetal Alcohol Spectrum Disorder: A Literature Review*, Tri-Province FASD Project, 2011, p1,2.

The psychological barriers to diagnosing FAS/FASD

In addition to a lack of awareness of the existence of FAS or the diagnostic approach to FAS or any other FASD syndrome, two psychological barriers have been put forward to securing a FASD diagnosis, namely:

- Many physicians believe that intervention programs are equally effective for individuals with any form of mental retardation or attention deficit disorder. In doing so they fail to recognize the more complex and subtle brain damage in alcohol affected individuals. Recognising a child with FASD may assist in future FASD prevention.
- Patients with FAS and FASD together with their families often need help with: foster or adoption support services; educational interventions; alcohol treatment; vocational rehabilitation; and/or the criminal justice system. Most physicians are not trained to lead intervention programs in these arenas. They may not have well-established referral linkages to professionals in these other fields. Further, many physicians may believe these issues are truly outside of the appropriate purview of paediatrics and 'healthcare'.⁹⁴

Diagnostic ability in WA

Currently there is limited diagnostic capacity in WA. In fact, there is no centralised diagnostic centre. The State Child Development Centre has the capacity, but they do not have the resources.⁹⁵

As mentioned earlier, Western Australian studies have shown that on average only about 12 per cent of health professional groups actually knew the four cardinal features of foetal alcohol syndrome (FAS), and so it is not well diagnosed.⁹⁶ FASD is even less well known.

Michelle Bishop, Inclusive Education Consultant with the Association of Independent Schools of WA (AISWA) similarly advised that there has historically been a difficulty in getting paediatricians to diagnose FAS/FASD on paper. She attributed this to their lack of clarity around the diagnostic factors.⁹⁷

94 Astley, S.J. et al., 'Fetal Alcohol Syndrome – primary prevention through diagnosis', *Alcohol & Alcoholism Vol. 35, No. 5, pp. 499-508, 2000.*

95 Dr Colleen O'Leary, Epidemiologist–Alcohol and Pregnancy Researcher, Curtin Health Innovation Research Institute, *Transcript of Evidence*, 28 March 2012, p2.

96 Dr Carol Bower, Epidemiologist, Telethon Institute of Child Health Research, *Transcript of Evidence*, 16 May 2012, p1.

97 Briefing Michelle Bishop, Inclusive Education Consultant with the Association of Independent Schools (WA) 30 May 2012.

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In order to address this issue, the Commonwealth put out a tender in 2010 for the development of a diagnostic instrument for Australia. In 2012, the Telethon Institute of Child Health Research advised that, ‘the final report is about to go back in [to the Commonwealth Government].’⁹⁸

The main aim of the project was to develop an instrument that could be used to improve the identification or diagnosis of FASD in Australia. It was run with a national collaboration of researchers from around the country.

*We were looking at multiple methods to capture as much evidence as is available. Our main findings are still with the department. As a result of the work we have produced a draft diagnostic instrument and resources that we hope to move forward with in future research.*⁹⁹

Finding 4

There is no current diagnostic tool for FASD in Australia. The Federal Government has awarded a tender for its development and a draft diagnostic instrument is under consideration by the Federal Government.

It’s not about the IQ – it’s about adaptive function

People who have FASD are sometimes described as ‘cognitively impaired.’ While IQ is a common measure of ‘cognition’, intelligence is more than a function of IQ. Intelligence involves risk awareness while intellectual disability involves risk unawareness.¹⁰⁰

Less than half of those with FASD are thought to have an IQ of less than 70 and some research indicates that the proportion may be as little as 25%.¹⁰¹ This, combined with an absence of overt physiological indicators, makes diagnosis more complex.

In the United States where there are a few diagnostic clinics, the great majority of children affected by prenatal alcohol exposure have normal IQs and normal physical features. But ‘although the children “look” normal, they all have varying neurocognitive damage that inhibits executive functioning, decision making, emotional and

98 Dr Carol Bower, Epidemiologist, Telethon Institute of Child Health Research, *Transcript of Evidence*, 16 May 2012, p2.

99 Dr Rochelle Watkins, Research Fellow, Telethon Institute of Child Health Research, *Transcript of Evidence*, 16 May 2012, p3.

100 Greenspan et al., ‘Implications of the theory of common sense’, Paper presented at the 5th Biennial Conference on Adolescents and Adults with fetal Alcohol Spectrum Disorder, Vancouver, April 2012.

101 Dr Heather Douglas, The TC Beirne School of Law, University of Queensland.

behavioural regulation, learning, memory, sensory processing, and adaptive behaviour.¹⁰²

Adaptive behaviour includes the age-appropriate behaviours necessary for people to live independently and to function safely and appropriately in daily life. Adaptive behaviours include real life skills such as grooming, dressing, safety, safe food handling, obeying school rules, ability to work, money management, cleaning, making friends, social skills, and personal responsibility.

As one witness put it:

Examining it from the diagnostic point of view, the IQ is really just one assessment of cognitive function. Pretty well the literature to date will identify three main areas of impairment that are associated with the damage due to alcohol. It is often not just in the IQ; you can actually have a high IQ—even into the 120s or higher—but in fact show deficits in adaptive functioning, in attention and in other areas of cognitive functioning like spatial awareness or motor function. That is one of the difficulties in diagnosis and one of the difficulties in creating a cut-off. My impression of what I have read is that you would not really capture it in just IQ, and that is why a lot of the diagnostic guides look at quite a comprehensive assessment based on what the patient or the parents or carers or educational professionals might identify as the issues, because in fact there can be some profound difficulties in adaptive functioning, everyday functioning and attention and behaviour that are not going to be reflected in IQ. It is about capturing the broad nature of damage that can have occurred.¹⁰³

Finding 5

Less than half of the people who have FASD are thought to have an IQ of less than 70 and some research indicates that the proportion may be as little as 25%. However, all people with FASD have varying expressions of neurocognitive damage that inhibit executive functioning, decision making, emotional and behavioural regulation, learning, memory, sensory processing, and adaptive behaviour.

102 Chasnoff, I., 'FASD as a Mitigating Factor in Juvenile Litigation and Sentencing', Paper presented at Paper presented at the 5th Biennial Conference on Adolescents and Adults with fetal Alcohol Spectrum Disorder, Vancouver, April 2012..

103 Dr Rochelle Watkins, Research Fellow, Telethon Institute of Child Health Research, *Transcript of Evidence*, 16 May 2012, p9,10.

Chapter 4

A multi-disciplinary approach to diagnosis is needed

The need for a multidisciplinary approach was highlighted by the Disability Services Commission in their submission to the Inquiry.¹⁰⁴ Another witness put it:

Because of the complexity, I am not sure that the instrument can just be pulled off the shelf and used. I think there will need to be some workforce development. There will need to be training. Most people around the world who are heavily into diagnoses of FASD make the point that there needs to be training of the workforce and that it needs to be done by a multidisciplinary team. One person cannot get the information that is needed for all aspects—in particular, with the neurodevelopmental assessment of children you need people whose particular field is to make those assessments.¹⁰⁵

The Foundation for Alcohol Research and Education similarly echoed the need for a multidisciplinary team. It noted the parallels with a 2007 report by the Australian Advisory Board on Autism Spectrum Disorders, which recognised the need for access to timely and affordable diagnosis with a wait time of no longer than three months for diagnosis and assessment by multidisciplinary teams.¹⁰⁶

In a similar vein, the Department of Health advised that: ‘Developmental delays or disorders can manifest as a single issue or as a cluster of issues requiring multidisciplinary services’.¹⁰⁷ Such a multidisciplinary service may require a combination of health and allied services including speech pathologists, physiotherapists, occupational therapists, clinical psychologists, social workers, dieticians, nurses, podiatrists, child care assistants, therapy assistants, audiologists, paediatricians and medical officers.

Overseas, the diagnostic approach is a multidisciplinary approach. In the United States, ‘97% of clinics took a multidisciplinary approach to diagnosis and 94% had at least one team member with specialist training in assessment of FASD.’¹⁰⁸

In a report developed by a Churchill Fellow, it was found that in Canada and the United States that ‘diagnosis for FASD requires a Multidisciplinary team of

104 Submission No. 4 from Disability Services Commission, December 2011, p5.

105 Dr Carol Bower, Epidemiologist, Telethon Institute of Child Health Research, *Transcript of Evidence*, 16 May 2012, p2.

106 Submission No. 21 from The Foundation for Alcohol Research and Education, 2012, p8.

107 Submission No. 12 from Western Australian Department of Health December 2011, p9.

108 Submission No. 14 from Clinical Professor Carol Bower, January 2012, p14.

specialists including a Paediatrician, Psychologist, Speech Therapist, Occupational Therapist, Social Worker, Support worker and a geneticist.¹⁰⁹

Finding 6

FASD requires a coordinated multidisciplinary diagnostic service.

Recommendation 7

The Minister for Health allocates additional funding in the 2013 budget to existing interdisciplinary health teams (such as in antenatal clinics, children's hospitals and child development centres), to improve their ability to diagnose and treat children with FASD and support education and awareness strategies.

Diagnostic and Statistical Manual of Mental Disorders-5

At the time of writing, FASD is not included in the Diagnostic and Statistical Manual of Mental Disorders (DSM). This is significant because:

*The DSM defines and classifies all mental illnesses and is widely used by practitioners and insurance companies to determine what conditions are considered abnormal, which treatments should be covered by insurance companies, and which warrant special educational services. Consequently, changes to the precise content of the DSM have major social implications.*¹¹⁰

The DSM is currently under review and FASD is being considered for inclusion in the next manual DSM-5. A group of FASD experts in Australia and overseas has been discussing the particulars before sending in their comments to the reviewers.¹¹¹ It is understood that FASD's inclusion has been recommended by a number of organisations, both in Australia and overseas including the US based National Organisation for Foetal Alcohol Syndrome and Related Disorders.¹¹²

At the time of writing the Committee understands that in the current version of the DSM-5, Neurobehavioral Disorder Associated with Prenatal Alcohol Exposure (ND-PAE), is only proposed for inclusion in section III - for conditions needing more research.

109 Report by June Councillor, The WA Department for Child Protection Churchill Fellowship to study: "Prenatal alcohol exposure and the impact on parenting affected children especially in Aboriginal communities" in Canada and the United States of America (USA) 2009, p25.

110 Maia Szalavitz, *DSM-5 Debate: Committee Backs Off Some Changes, Re-Opens Comments* Read more: <http://healthland.time.com/2012/05/03/dsm-5-debate-committee-backs-off-some-changes-re-opens-comments/#ixzz1wKzAnHHd>, May 2012. Available at: <http://healthland.time.com/2012/05/03/dsm-5-debate-committee-backs-off-some-changes-re-opens-comments/>. Accessed on 30 May 2012.

111 Dr James Fitzpatrick, Electronic Mail, 29 May 2012, p1.

112 Briefing Michelle Bishop, Inclusive Education Consultant with the Association of Independent Schools (WA) 30 May 2012.

Chapter 5

FASD: a disability

FASD is generally acknowledged as the most common preventable intellectual disability and yet does not have official recognition as a disability.

Defining FASD as a disability

FASD is generally acknowledged as the most common preventable intellectual disability. However it does not have official recognition as a disability and therefore 'attracts no funding and no support or assistance.'¹¹³ Because, as outlined in chapter four, at the time of writing, FASD is not included in the Diagnostic and Statistical Manual of Mental Disorders, individuals, families and carers are precluded from accessing government financial assistance.

This has broad ramifications because law and policy in the areas of welfare and criminal justice are developed largely with awareness of and in response to intellectual disability and mental illness.

Consequently, the determination as to whether a person is able to access government support or have their reduced culpability recognised and taken into account in the criminal law often depends on the person falling within the definitions of 'mental illness' or 'intellectual disability'.¹¹⁴

One of the key issues with determining an intellectual disability is the reliance on IQ as the measure of disability. This is because intelligence is seen as central to the definition of intellectual disability.

This is exemplified in the Impairment Tables for the Disability Support Pension under Table 9 –

Table 9 is to be used where the person has a permanent condition resulting in low intellectual function (IQ score of 70 to 85) resulting in functional impairment, which originated before the person turned 18 years of age.

113 O'Sullivan, M., 'The hurt inside', *About the House*, Issue 44, April 2012, p18.

114 Blake Dawson, Submission 49, Submission to the Standing Committee on Social Policy and Legal Affairs, 2012, p2.

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*A person with Autism Spectrum Disorder, Fragile X Syndrome or Foetal Alcohol Spectrum Disorder who also has a low IQ should be assessed under this Table.*¹¹⁵

We know from research that most individuals with FASD have an IQ within a normal range (75% of people prenatally exposed to alcohol will have a normal IQ) so they would be precluded from this table and FASD is not included in any other table.¹¹⁶ The Committee was advised that people with FASD would best fit under this table as they often have issues with executive functioning of the brain.

Finding 7

Most individuals with FASD have an IQ within the normal range and so are ineligible for the Disability Support pension and collateral benefits.

The international law firm, Blake Dawson, in its submission to the House of Representatives Standing Committee on Social Policy and Legal Affairs on the management of Foetal Alcohol Spectrum Disorder (FASD), argued that there is significant inconsistency in the use of terms to describe cognitive impairment in law and policy across Australia.

It proposed that a nationally consistent definition, which is not exhaustive but which provides strong guidance to those implementing the law and policy, would increase certainty for government and people with FASD about when particular laws and policies apply to people with FASD. This would assist to remove the barriers faced by people with FASD to the support and services they need.¹¹⁷

Currently, the Commonwealth provides disability support payments for those who qualify and their carers as follows:

- the Disability Support Pension;¹¹⁸
- the Youth Disability Supplement;¹¹⁹
- the Carer Payment;¹²⁰
- the Carer Allowance;¹²¹ and
- the Mobility Allowance.¹²²

115 *Social Security (Tables for the Assessment of Work-related Impairment for Disability Support Pension) Determination 2011*, . Available at: http://www.comlaw.gov.au/Details/F2011L02716/Html/Text#_Toc310259519. Accessed on 3 May 2012.

116 Submission No. 22 from The Russell Family Fetal Alcohol Disorders Association, May 2012, p2.

117 Blake Dawson, Submission 49, Submission to the Standing Committee on Social Policy and Legal Affairs, 2012, p2.

118 Social Security Act 1991 (Cth) part 2.3, ss 94 -146Q.

119 Social Security Act 1991 (Cth) ss 1066A-C1, 1066B-C1, 1067G-D1, 1190.

120 Social Security Act 1991 (Cth) part 2.5, ss 197-246; part 2.5A, ss 247-276.

121 Social Security Act 1991 (Cth) part 2.19, ss 952-992M; part 2.19A, ss 992N-992W.

In similar fashion to the Commonwealth, in Western Australia under the *Disability Services Act 1993* disability means a disability —

(a) which is attributable to an intellectual, psychiatric, cognitive, neurological, sensory, or physical impairment or a combination of those impairments;

(b) which is permanent or likely to be permanent;

(c) which may or may not be of a chronic or episodic nature; and

(d) which results in —

(i) a substantially reduced capacity of the person for communication, social interaction, learning or mobility; and

(ii) a need for continuing support services.¹²³

As with the Commonwealth, in Western Australia intellectual disability or a profound and severe disability which impacts on function rather than cognitive impairment is the key if the individual or the carer is to receive support.¹²⁴

Changes to appropriate legislation enabling the recognition of FASD as a disability would potentially extend these benefits to FASD affected individuals and their carers.

Recommendation 8

The Committee recommends that the Government and the Minister for Disability Services support changes to commonwealth and state legislation to better accommodate children and adults with FASD. In particular any reference to disability or intellectual disability to be broadened to include a definition of cognitive impairment as an ongoing impairment in comprehension, reason, judgment, learning or memory, that is the result of any damage to or dysfunction, developmental delay, or deterioration of the brain or mind.

122 Social Security Act 1991 (Cth) part 2.21, ss 1035-1046.

123 Disability Services Act 1993, amended 2004, Available at:

[http://www.slp.wa.gov.au/pco/prod/FileStore.nsf/Documents/MRDocument:20585P/\\$FILE/DisabilityServAct1993_03-i0-00.pdf?OpenElement](http://www.slp.wa.gov.au/pco/prod/FileStore.nsf/Documents/MRDocument:20585P/$FILE/DisabilityServAct1993_03-i0-00.pdf?OpenElement). Accessed on 16 July 2012.

124 Submission No. 4 from The Disability Services Commission, December 2011, p5.

Chapter 6

The economic costs of FASD

Over 40 years the cost to the community of a person affected by FASD is \$1,000,000.

Background

FASD poses a serious social and health issue for children and adults, impacting on their lives and on the community around them. Understanding the economic impact of FASD to individual government (and non-government) agencies, as well as the larger community, is valuable in arguing the economic case for prevention services and adequate health resources.

In the absence of actual state or national prevalence data, (refer chapter two), measuring the economic impact of FASD in Australia is not possible. Therefore this chapter draws on overseas modelling where diagnostic tools are more established and there is a clearer understanding of prevalence. Such modelling is confined to the United States and Canada in the absence of data from other countries. In those two countries, most studies of the costs of FASD focus on the direct costs to government and few, if any, calculate productivity costs borne by the FASD individual.¹²⁵

Research reflects the fact that both the children in the FASD group and those affected by parental alcohol misuse, account for significantly higher utilisation costs in the health, education and justice sectors.¹²⁶ This is because, without the crucial support required, people affected by FASD are at a high risk of developing secondary disabilities related to mental health problems, trouble with the law, dropping out of school, becoming unemployed, becoming homeless and/or developing alcohol and other drug problems. This, in turn, produces tremendous costs to society.¹²⁷

125 The Intergovernmental Committee on Drugs, *Monograph of the Intergovernmental Working Party on Fetal Alcohol Spectrum Disorders*, report prepared by Lucy Burns, Emma Black and Elizabeth Elliott, June 2012, p29.

126 Fuchs, D. et al, *The economic impact of children in care with FASD and parental alcohol issues*, Public Health Agency of Canada, Canada, 2009, pvii.

127 Centre for Addiction and Mental Health, *Economic Impact of Fetal Alcohol Syndrome (FAS) and Fetal Alcohol Spectrum Disorder (FASD) a systematic literature review*, report prepared by Popova, S. et al., Canada, 2012, p7.

Chapter 6

The nature of costs

Direct Costs (actual use of goods and services):

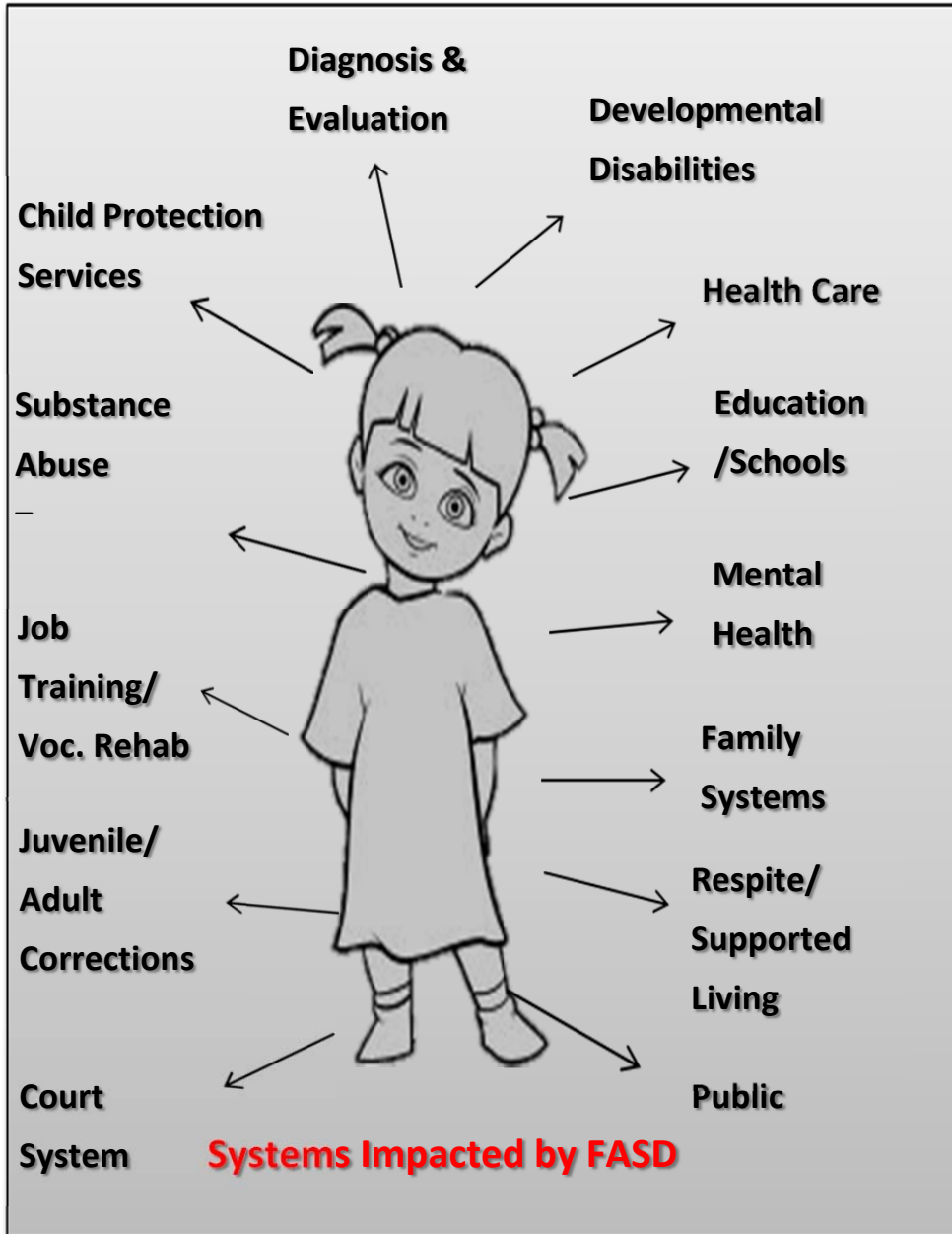
- Health system;
- Social system;
- Justice System.

Indirect Costs (foregone potential productivity)

- Mortality;
- Morbidity;
- Disability;
- Incarceration/crime;
- Career.

Schematically the areas of costs of FASD to our society are represented as follows:

Figure 6.1 Systems and services impacted by FASD¹²⁸



128 Adapted from a talk on FASD and criminal justice by Dr Heather Douglas, The TC Beirne School of Law, University of Queensland.

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The difficulty in calculating costs in Australia is clearly demonstrated when considering the interface of people with FASD within the justice system. Even though the prison population is readily accessible, because of the lack of screening and diagnostic tools in Australia to identify the numbers of affected persons within the justice system, the costs relative to justice are largely unknown.

In studies on the cost of people with FASD which have been undertaken in the USA and Canada, there are differences in the calculations because:

1. The selected point of view may be fiscal, individual, or societal;
2. Different age ranges are included in the studies. (The higher the range, the higher the cost);
3. Different cost drivers are included;
4. Co-morbidities are included differently in different studies;
5. Different assumptions are made in rates of service utilisation;
6. Use of differing costs of services;
7. The knowledge base for developing estimates rapidly increases over time;
and
8. Inflation occurs in intervening years between the different studies.^{129 130}

Additionally, while the Canadian and American researchers agree that the expenses associated with FASD, such as medical and educational costs, are not difficult to estimate, other cost drivers, such as those associated with the child welfare system and the criminal justice system, 'are challenging because of the lack of data.'¹³¹ As a consequence some studies omit the latter cost drivers all together.

129 Centre for Addiction and Mental Health, *Economic Impact of Fetal Alcohol Syndrome (FAS) and Fetal Alcohol Spectrum Disorder (FASD) a systematic literature review*, report prepared by Popova, S. et al., Canada, 2012, p7.

130 Fuchs, D. et al, 'The economic impact of children in care with FASD and parental alcohol issues.' 2009 p7.

131 Centre for Addiction and Mental Health, *Economic Impact of Fetal Alcohol Syndrome (FAS) and Fetal Alcohol Spectrum Disorder (FASD) a systematic literature review*, report prepared by Popova, S. et al., Canada, 2012, p7.

Two cost analyses from Canada are summarised as follows:

One study in Alberta, in 2008, found that the annual cost per child with FASD was \$15,812. Given the average age of death being 71.6 years, the lifetime cost of caring for each child born with FASD would be equal to \$15,812 x 71.6yrs ≈\$1.1 million.¹³²

In a broader and more recent study, outlined below, the cost per annum per person is estimated at \$25,000 if the justice system is factored in. On this basis the cost for each child born with FASD over the same period (71.6 years) would equal \$1,790,000.

Canadian cost analysis

*Annual cost per person aged 0-53 with FASD in Canada in 2009*¹³³

| Cost item | Canadian Dollars (CAD) |
|--|------------------------|
| Medical | \$6,860 |
| Education | \$5,443 |
| Social services | \$4,217 |
| Out of pocket | \$2,912 |
| Total direct costs | \$19,432 |
| Indirect costs | \$1,481 |
| Total direct and indirect costs | \$20,912 |
| Adjusted for severity of disability, & age | \$22,393 |
| Adjusted for estimated cost of correctional services | \$25,000 |

132 Institute of Health Economics, Edmonton, Alberta, *COSTS OF FETAL ALCOHOL SPECTRUM DISORDER IN ALBERTA, CANADA*, 2008 (?), p1. Available at: <http://www.ncbi.nlm.nih.gov/pubmed/21515625>. Accessed on 8 May 2012.

133 Clarren, S et al, *Prevention of fetal alcohol spectrum*, Wiley Blackwell Germany, 2011, p7.

Cost of FASD to the Canadian economy¹³⁴

| Cost of FASD to the Canadian economy | |
|--|-----------------|
| Total annual direct and indirect costs | CAD 7.6 billion |
| Total annual direct costs of healthcare, educational and social services but excluding cost of correctional services and ‘out of pockets’. | CAD 4.9 billion |
| Total annual direct cost of healthcare for people with FASD | CAD 2.1 billion |

Comparing costs with other common ailments.

To put this into perspective the economic magnitude of FASD is highlighted when compared to the annual costs of other selected diseases as follows:

Annual direct costs of selected diseases and FASD in CANADA 2009¹³⁵

| Cost item | Annual cost |
|--|-----------------|
| Direct healthcare costs of respiratory disease | CAD 4.8 billion |
| Direct healthcare costs of all forms of cancer | CAD 4.7 billion |
| Direct healthcare costs of FASD | CAD 2.1 billion |

These figures highlight the fact that the total direct healthcare cost of FASD is approximately 45% of those associated with cancer.

Finding 8

The annual direct healthcare cost of FASD is 45% of the direct healthcare cost of cancer in Canada.

Cost of inaction

Several witnesses suggested to the Committee that the single biggest issue after diagnosis is the question of the adequate resourcing of the services needed to address the treatment and management of FASD.^{136 137 138}

134 Clarren, S et al, *Prevention of fetal alcohol spectrum*, Wiley Blackwell Germany, 2011, p6.

135 Clarren, S et al, *Prevention of fetal alcohol spectrum*, Wiley Blackwell Germany, 2011, p7.

136 Briefing Dr Heather Douglas, Brisbane, July 2012.

137 Briefing March 2012 Broome,

This chapter argues that the economics of the cost of FASD to the community, demonstrates the benefits of the adequate resourcing of services to prevent and/or treat children, adults and families where FASD is present.

Currently there are no line items in the Western Australian state budget for prevention, intervention and management of FASD. Such funds as have been invested by different agencies in prevention strategies (refer chapter 11) have been a reallocation of monies from competing priorities.

The opportunity cost of preventing a single case of FASD and saving the direct costs is represented in the table below. The figures are calculated based on the lifetime incremental cost of FASD, which in Canada was \$749,000 in 2009. The incremental cost is the cost over and above the cost of services that would be incurred by the general population over the same lifetime.

Table 1. Opportunity cost of preventing one case of FASD in Canada in 2009¹³⁹

| Procedure | Average cost | Number of procedures that could be performed by preventing one case of FASD |
|------------------------------|--------------|---|
| Repair of inguinal hernia | CAD 4,938 | 150 |
| Appendectomy | CAD 5,505 | 135 |
| Caesarean section | CAD 5,303 | 140 |
| Hysterectomy | CAD 6,327 | 117 |
| Cholecystectomy | CAD 6,985 | 106 |
| Knee replacement | CAD 10,903 | 68 |
| Hip replacement | CAD 13,182 | 56 |
| Coronary artery bypass graft | CAD 24,966 | 30 |

In Australia, based on figures provided by Medicare the opportunity costs using the same incremental cost, \$749,000, as a baseline, are:¹⁴⁰

138 Dr Raewyn Mutch, Paediatrician and Post-doctoral Fellow with the Alcohol and Pregnancy Research Group of the Telethon Institute for Child Health Research, *Transcript of Evidence*, 9 July 2012, p8.

139 Clarren, S et al, *Prevention of fetal alcohol spectrum*, Wiley Blackwell Germany, 2011, p7.

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Figure: .Opportunity cost of preventing one case of FASD in Australia

| Procedure | Average Cost | Number of procedures that could be performed by preventing one case of FASD |
|---------------------------|--------------|---|
| Repair of inguinal hernia | \$608.72 | 1230 |
| Appendectomy | \$523.64 | 1430 |
| Caesarean section | \$2,081.42 | 360 |
| Hysterectomy | \$1,391.89 | 538 |
| Cholecystectomy | \$1,042.35 | 719 |
| Knee replacement | \$2,419.76 | 310 |
| Hip replacement | \$2,338.91 | 320 |

In the United States, the cost of Foetal Alcohol Syndrome (as opposed to FASD, a much larger group) was estimated at US \$5.4 billion in 2003 with a FAS birth carrying a lifetime health cost of \$860,000.¹⁴¹

A significant additional economic cost is the collateral effects of FASD. Canadian studies show that a disproportionate number of children with FASD are taken into care, with 50% of children in care in Alberta being diagnosed with FAS. In Manitoba, 17% of children in care were diagnosed or suspected of suffering from FASD.¹⁴²

Based on the few existing studies for Canada and the USA, it is clear that FASD is a **serious public health problem** and is associated with significant direct and indirect monetary costs. These costs place a burden on governments at both state and Federal level, as well as on society as a whole.

Because of the negative human and economic impacts of FASD, prevention is a good public investment.

140 Margaret Park, Medicare, Electronic Mail, 29 May 2012. Average cost of MBS procedures for WA from 01/04/2011 - 31/03/2012 (based on date of service).

141 The Lewin Group, Fairfax, Virginia, *Economic Costs of Fetal Alcohol Syndrome*, 2004. Available at: <http://fasdcenter.samhsa.gov/documents/RickHarwoodPresentation.pdf>. Accessed on 8 May 2012.

142 Fuchs, D. et al, 'The economic impact of children in care with FASD and parental alcohol issues.' 2009 p7.

Finding 9

FASD results in a significant direct and indirect cost to the community. While no studies have been carried out in Australia, overseas studies indicate that these costs are high. Understanding the economic impact of FASD to individual government and non-government agencies as well as the broader community is valuable in arguing the economic case for prevention services and adequate health resources.

Recommendation 9

In recognising the negative human and economic impacts of FASD, the Committee recommends that commencing in 2013 the State Government undertakes tri-annual economic modelling of the cost of FAS and FASD in WA.

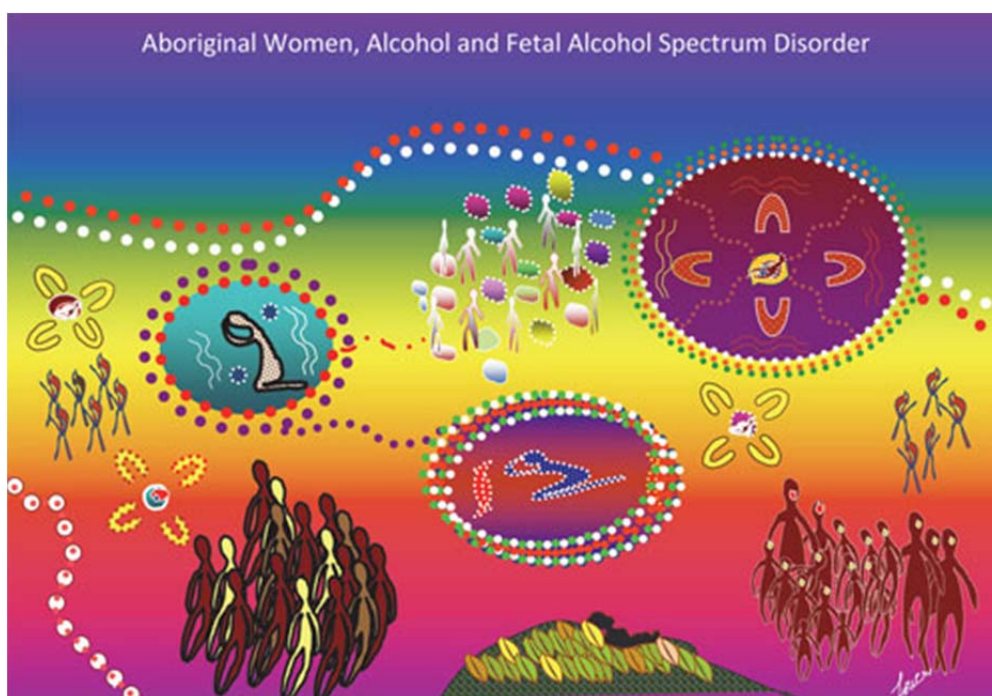
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FASD in Aboriginal communities

The impact of FASD is affected by the social and physical environment as well as access to alcohol.

Background

The girls don't drink much; 'bout the same as the fellas.¹⁴³



Compared to non-Indigenous Australians, Aboriginal and Torres Strait Islander peoples face considerably greater disadvantage and greater ill health. Indigenous Australians have poorer access to health care, are more likely to be hospitalised, to experience disability and to die at younger ages. Indigenous Australians suffer a higher burden of

143 The Medical Journal of Australia, *Aboriginal women, alcohol and the road to fetal alcohol spectrum disorder*, 2012; 197 (1): p21-23.. Available at: https://www.mja.com.au/journal/2012/197/1/aboriginal-women-alcohol-and-road-fetal-alcohol-spectrum-disorder?0=ip_login_no_cache%3D221fdc786f87f3a1962958ddedf8aa01. Accessed on 17 July 2012.

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emotional distress and mental illness than the wider community.^{144 145} One Aboriginal researcher writes:

The early years will shape the life's journey for many children who were not only exposed to alcohol in utero, but were also born into an environment that was awash with alcohol and violence. If basic human needs are met through nurturing and responsible care, children will develop hopefulness, cheerfulness, trust, confidence and security. If children do not have caring experiences, they will develop insecurity, a feeling of worthlessness and general mistrust.¹⁴⁶

These factors are some of the social determinants of health that underlie the abuse of alcohol in any community, whether indigenous or non-indigenous. However, the use and abuse of alcohol was never an intrinsic part of Aboriginal culture historically.

Alcohol as I learned from my own family and community was never a part of our Aboriginal culture; it was first introduced to Aboriginal people in our community in the 1960's when Aboriginal people were awarded Citizenship rights - giving Aboriginal people rights to enter hotels, to purchase and to consume alcohol – this also became the birth of many problems still suffered by our people and communities today.¹⁴⁷

Incidence of FASD in Aboriginal communities

The Committee was reminded by many witnesses to the inquiry that the impact of FASD is affected by the social and physical environment as well as access to alcohol.¹⁴⁸ For example 'factors, such as living with an alcoholic parent or being subjected to child abuse or neglect, or other adverse life conditions such as poverty. This is a particularly relevant point as it pertains to indigenous populations, who frequently are affected by

144 Australian Institute of Health and Welfare (2011). Indigenous Health webpage. <http://www.aihw.gov.au/indigenous-health/>

145 Submission No. 21 from Foundation for Alcohol Research and Education, April 2012, p25.

146 The Medical Journal of Australia, *Aboriginal women, alcohol and the road to fetal alcohol spectrum disorder*, 2012; 197 (1): p21-23.. Available at: https://www.mja.com.au/journal/2012/197/1/aboriginal-women-alcohol-and-road-fetal-alcohol-spectrum-disorder?0=ip_login_no_cache%3D221fdc786f87f3a1962958ddedf8aa01. Accessed on 17 July 2012.

147 Aboriginal Elder, Report by June Councillor, The WA Department for Child Protection Churchill Fellowship to study: "Prenatal alcohol exposure and the impact on parenting affected children especially in Aboriginal communities" in Canada and the United States of America (USA) 2009 p17.

148 Briefing Foundation for Alcohol Research and Education Canberra 6 July 2012.

low socioeconomic status and the drinking patterns that are associated with coping with impoverished living conditions.¹⁴⁹

No representative data is available on the prevalence of alcohol consumption prior to or during pregnancy among Indigenous women in Australia. Neither the National Aboriginal and Torres Strait Islander Social Survey nor the National Health Survey report measures related to alcohol consumption prior to or during pregnancy or breastfeeding.¹⁵⁰

There is no data on the prevalence of FASD among Aboriginal people. To some degree the findings on the Lililwan study (refer below), which are to be made public later in 2012, will provide some indicative data, although the level to which it could be generalised would be questionable.

Risk to culture

*Something not right with these little ones – something wrong, they can't listen!*¹⁵¹

Primary disabilities associated with FASD include poor memory and poor communication skills. This has particular implications for the continued loss of Aboriginal and Torres Strait Islander culture, which is based on oral story telling. For people with FASD who have difficulty in remembering and retaining information, this is a particularly devastating consequence.¹⁵²

Addressing FASD in Aboriginal communities

General strategies

The Cape York Institute for Policy and Leadership has suggested that strategies that tackle FASD in Aboriginal communities need to tackle the breakdown of social norms around alcohol consumption which is experienced by the whole family. This is because, although the pregnant woman needs to be supported, she is within a web of influence and behaviour that must also be addressed.

Such a program could be delivered through a family case management model. This model could guide engagement and support services between agencies and women of child-bearing age, particularly for at-risk women. This will require advocating for

149 Dr Linda Burnside, *Prevalence of Fetal Alcohol Spectrum Disorder: A Literature Review*, Tri-Province FASD Project, 2011, p1,2.

150 NIDAC FASD position paper 2012 p11

151 Aboriginal Elder, Report by June Councillor, The WA Department for Child Protection Churchill Fellowship to study: "Prenatal alcohol exposure and the impact on parenting affected children especially in Aboriginal communities" in Canada and the United States of America (USA) 2009 p5

152 Submission No. 21 from Foundation for Alcohol Research and Education, April 2012, p25.

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increased and better services for women of childbearing age that can provide intense support both pre-, during and post-pregnancy in a culturally appropriate manner.

In addition the Cape York Institute for Policy and Leadership made the following points:

- *Pre-pregnancy care is important as often FASD occurs in the first trimester before the woman may know she is pregnant.*
- *Tackling women in the 'pre-pregnancy' phase can be in the years before they fall pregnant.*
- *Having care around the entire pregnancy is not only important for preventing FASD but multiple other conditions that are linked with a poor pregnancy and outcomes such as low birth weight.*
- *Engagement of family members and the community is needed to help create accepted social patterns of behaviour around pregnant women, and the entire family.*¹⁵³

The Royal Australasian College of Physicians advised the Committee that in respect to Aboriginal people, holistically treating alcohol problems can help the drinker, the family and the entire community. 'In this case, Aboriginal-specific detox and rehabilitation services need greater improvement.'¹⁵⁴

Other barriers to services for Aboriginal people include:

- Transport, even in cities;
- Lack of family-friendly services and the need to care for the family;
- Cost of treatment;
- Language barriers, particularly if from a remote community; and
- General Practitioners are not always comfortable or willing to offer treatment.¹⁵⁵

Improving appropriate services for Aboriginal people includes the continued development of the Indigenous health workforce such as health education and leadership support.¹⁵⁶

153 Cape York Institute for Policy and Leadership, *Submission 68*, to the Standing Committee on Social Policy and Legal Affairs, 2012, p1.

154 Submission No. 25 from The Royal Australasian College of Physicians, June 2012, p4.

155 Submission No. 25 from The Royal Australasian College of Physicians, June 2012, p4.

156 Submission No. 25 from The Royal Australasian College of Physicians, June 2012, p4.

Social marketing: Strong Spirit Strong Future - Promoting Healthy Women and Pregnancies

The Western Australian Drug and Alcohol Office (DAO) has received COAG funding of \$2.23 million over four years, to develop a suite of state-wide Aboriginal FASD prevention initiatives. Using these funds it commenced the 'Strong Spirit Strong Future - Promoting Healthy Women and Pregnancies' project in 2010.¹⁵⁷

*This project targets Aboriginal women, families and communities. It aims to improve awareness among Aboriginal people, families and communities in metro, regional and remote Western Australia about the harms associated with alcohol use in pregnancy to prevent the occurrence of FASD. It includes the development of culturally secure resources, community awareness campaigns and activities, and workforce development activities. The development of the whole thing is being overseen and continues to be overseen by an Aboriginal advisory group and a patron who provide cultural knowledge and wisdom, content, expertise and community linkages, which is really important.*¹⁵⁸

In 2012, DAO spent approximately \$489,000 on the Strong Spirit Strong Future initiatives, and is 'hopeful to have at least that amount, if not a little bit more, in the next year to repeat and build on it.'¹⁵⁹

The campaign has three parts:

1. A media campaign that includes a television advertisement and three radio advertisements, featuring Mary G (Mary G of the Mary Gedarrdyu show). This is aired in metropolitan and regional areas of WA;
2. Small grants to regional areas to enable them to localise some of the resources and engage in community-based initiatives to support the campaign. Approximately \$150,000 in 2010–11 and nearly \$60 000 in 2011–12 was offered through those grants;
3. A workforce development component, which aims to provide health workers with skills in and knowledge of screenings, brief interventions and referral pathways. This is state-wide. Since January 2011, a total of 22 workforce development events were delivered to approximately 1,000 participants,

157 Western Australia Drug and Alcohol Office, *WA Fetal Alcohol Spectrum Disorder (FASD) Prevention Aboriginal Consultation Forum 2010*, Perth, 2012, p5.

158 Mr Neil Guard, Executive Director, Drug and Alcohol Office, *Transcript of Evidence*, 20 June 2012, p12.

159 Mr Neil Guard, Executive Director, Drug and Alcohol Office, *Transcript of Evidence*, 20 June 2012, p12.

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together with a presentation at the Aboriginal Maternal and Child Health Conference at the end of June.¹⁶⁰

The Western Australian Foetal Alcohol Spectrum Disorder (FASD) Prevention Aboriginal Consultation Forum 2010

In 2010, in developing the Strong Spirit – Strong Future initiative, WA hosted a Foetal Alcohol Spectrum Disorder (FASD) Prevention Aboriginal Consultation Forum. This was held ‘to seek the input and guidance of senior Aboriginal professionals, Aboriginal community members, and people who provide services to Aboriginal people. The forum considered early development, the consultation framework and the direction of the project.’¹⁶¹

Recommendations from the FASD Prevention Aboriginal Consultation Forum

The following recommendations arose out of the Western Australian Foetal Alcohol Spectrum Disorder (FASD) Prevention Aboriginal Consultation Forum 2010.

- Raise the level of awareness in the community of the potential impact on the foetus of prenatal alcohol exposure through a state-wide campaign that is then supported by the localisation of key messages and implemented through locally identified strategies.
- Develop a comprehensive approach which ensures a culturally secure, non-judgmental, prevention focussed message that aims to do no harm to Aboriginal women, children and their families. The message should be factual and promote strong families and strong children.
- Awareness messages must be adapted to have local relevance including:
 - Being delivered in plain or local language, which connects with the community.
 - Being delivered by credible spokespeople.
 - Using a range of mediums to get the message to different target groups (females, males and youth).
- A broad range of communication strategies should be used to reach different target groups. They may differ for metro, regional and remote areas.

160 Mr Neil Guard, Executive Director, Drug and Alcohol Office, *Transcript of Evidence*, 20 June 2012, p12,13.

161 Drug and Alcohol Office, (2011). *The Western Australian Fetal Alcohol Spectrum Disorder (FASD) Prevention Aboriginal Consultation Forum 2010: Strong Spirit Strong Future Promoting Healthy Women and Pregnancies*. Drug and Alcohol Office, Perth, Western Australia.

- Men should be targeted by education and FASD prevention messages. Their support is needed for women to be able to make and sustain the change to not drink alcohol during pre-conception and pregnancy.
- Youth should be targeted to address risky behaviour that results from alcohol consumption, including unplanned, unprotected sex, and unplanned pregnancy.
- Ensure that the project is linked to, and supported by State-wide, regional and local level alcohol management strategies and plans. This includes creating supportive environments to empower communities to make change.
- Increase awareness of where, and how, to access professional support to address alcohol use pre-conception and throughout pregnancy.¹⁶²

The Lililwan Project – a snapshot of FASD in the Kimberley

To find out how widespread FASD is in the communities of Fitzroy Valley, community leaders initiated a partnership to conduct Australia's first ever prevalence study of FASD, the Lililwan Project.¹⁶³

*The 'Lililwan Project' could assist in educating the whole of Australia on the impact of alcohol use in pregnancy.*¹⁶⁴

*Researchers have found one of the most successful ways to ascertain prevalence rates of FASD in a population has been through 'active case ascertainment' studies. These studies, predominantly carried out in America, have aimed to actively seek and recruit children who may have FASD within a given area. For these studies, children and women are recruited from the entire community to ensure wide representation. This method has produced the most comprehensive assessment of FASD prevalence within the population. It has also allowed researchers to diagnose and help support individuals with FASD.*¹⁶⁵

162 Drug and Alcohol Office, (2011). The Western Australian Fetal Alcohol Spectrum Disorder (FASD) Prevention Aboriginal Consultation Forum 2010: Strong Spirit Strong Future Promoting Healthy Women and Pregnancies. Drug and Alcohol Office, Perth, Western Australia.

163 The George Institute for Global Health, *Marulu- The Lililwan Project*, 2012, Available at: <http://www.facebook.com/media/set/?set=a.10150150987182658.334579.95985737657&type=3>. Accessed on 19 July 2012.

164 Submission No. 19 from Marninwarntikura Fitzroy Womens Resource Centre, March 2012, p31.

165 Submission No. 21 from Foundation for Alcohol Research and Education, April 2012, p17.

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Background

The Fitzroy Valley, where the Lililwan Project was undertaken, is 2,500 km north of Perth. It is 400 km east of Broome, in the remote West Kimberley region of Western Australia. Fitzroy Crossing town is at its centre. The Valley is home to approximately 4,500 people, 80% of whom are Aboriginal, belonging to 5 language groups (Bunuba, Walmajarri/ Wangkatjungka, Nyikina and Gooniyandi).

There are 45 distinct communities ranging from larger communities (300 people) in the Fitzroy Crossing town site, to small Aboriginal cattle station communities with as few as 10-20 people depending on the season.

Fitzroy Crossing is typical of many such communities, with a large Indigenous population (around 60%) across the north of Australia. For many years it has suffered from high rates of harmful alcohol use, and high rates of alcohol-related violence and crime.

A tipping point came in 2007 when there were 55 deaths in the community, 13 being suicides. Alcohol was a factor in most deaths. After much consultation, community elders took what at the time was unthinkable action: proposing that all stores selling take-away alcohol be restricted only to low-strength beverages, with a maximum of 2.5% alcohol by volume.¹⁶⁶

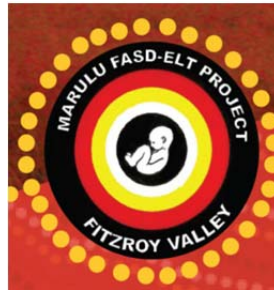
Subsequent to the introduction of alcohol restrictions, the community was still faced with dealing with the long-term effect of endemic alcohol abuse. One of the principal challenges was the fear that FASD was prevalent among the community's children.

In 2008, a FASD leadership team, including local organisations and service providers, formed to develop the Marulu strategy, which included the Lililwan project, to address FASD.

¹⁶⁶ The Lancet, *Blunting the legacy of alcohol abuse in Western Australia*, 2012, p217/8. Available at: <http://www.lancet.com/journals/lancet/article/>. Accessed on 10 May 2012.

The Lililwan Project

The word **Lililwan** is Kriol (Aboriginal) meaning 'all the little ones'.



The Lililwan Project was a prevalence study undertaken on Foetal Alcohol Spectrum Disorders (FASD) in the Fitzroy Valley. It was a partnership comprising:

- the Nindilingarri Cultural Health Services,
- Marninwarntikura Women's Resource Centre (MWRC),
- the George Institute for Global Health, Sydney, and
- the Discipline of Paediatrics and Child Health at the University of Sydney.

The Lililwan Project was conducted in two stages. The first stage, completed in 2010, involved the interviewing of parents or carers of all children born in 2002 and 2003 residing in the Fitzroy Valley. Information was gathered in relation to antenatal exposures, early life trauma, and the health and development of each child. There was a 95% participation rate in Stage 1 reflecting the fact that the community is leading this work.¹⁶⁷

Stage 2, which occurred in 2011 involved the multi-disciplinary assessment of the health and development of these children. A major aspect of this assessment was to establish the prevalence of FASD. A major outcome became the development of structured nurturing support for each child to help them become the best they can be.¹⁶⁸

The diagnostic criteria were based on the Canadian diagnostic guidelines, as outlined in Appendix six.

Lililwan Project Study protocol paper V23

The Lililwan Project Study protocol paper V23 outlined the project as follows:

167 Submission No. 19 from Marninwarntikura Fitzroy Womens Resource Centre, March 2012, p31.

168 Submission No. 19 from Marninwarntikura Fitzroy Womens Resource Centre, March 2012, p31.

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Study aims

The aims of the Lililwan Project were to:

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

Additionally, the researchers undertook to:

- provide individual, multidisciplinary health management plans for each participant and
- deliver education and family support to increase the benefit of the study to participants and their communities.

The data will be used in service planning and prevention programs.¹⁶⁹

Study design

The Lililwan Project is a population based active case ascertainment study of the prevalence of FASD.¹⁷⁰

Outcomes

The Lililwan Project provides for:

- a model for effective community consultation.
- adaptation of clinical and research techniques to suit complex cultural and language conditions, and
- provision of short and long term benefit to communities that participate in clinical research.

Barriers

There are, a number of identified 'barriers' to achieving a multidisciplinary response to the health needs of the Kimberley including:

- Socio cultural: a predominantly non-Indigenous workforce working with predominantly Indigenous population, and a gradient between the health literacy of the practitioners and the clients;

169 Lililwan Project Study protocol paper V23.

170 Lililwan Project Study protocol paper V23.

- Resourcing: inadequate staff for the population, remoteness and prevalence of health problems;
- Population – it is hard to recruit and retain staff into remote positions, and those who work there often cover 0-99 year olds across vast geographical areas.
- Remoteness -it is more expensive and takes far longer to provide a service in remote areas. Staffing formulas do not always appear to take this into account.
- Prevalence of health problems – people out there generally have hugely complex health needs at rates far higher than in the city.
- Coordination - while within the Allied health team there is good co-ordination (except for psychology services that are delivered independently), there is often poor coordination with GP, paediatric and school services, thus reducing the overall management.
- Acute care focus - the main focus of the Western Australian Country Health Services (WACHS) funded positions is to provide acute care in the hospital setting. Preventative community based outreach is not often on the priority list, and does not get adequate attention.
- Data - databases and systems are currently inadequate. There are 3-4 data systems that a child in Derby / Fitzroy Crossing might be on including Communicare, Medical Director, MMeX, and Ferret.¹⁷¹

Recommendation 10

The Committee recommends that funding be allocated in the 2013 budget for the development of culturally specific prevention, intervention and management strategies for Aboriginal and Torres Strait Islander people who have FASD similar to the current 'Marulu Strategy' in Western Australia.

¹⁷¹ Dr James Fitzpatrick, Electronic Mail, 29 May 2012, p1.

Chapter 8

Lessons to be learned from Autism Spectrum Disorder

This chapter details some of the reported difficulties faced by those impacted directly or indirectly by the acknowledged disability of Autism Spectrum Disorder (ASD).

The chapter highlights the potential difficulties faced by families and carers in seeking diagnosis, support and early intervention for ASD. Children who are diagnosed with FASD will face similar difficulties when FASD is recognised as a disability.

Autism Spectrum Disorder (ASD)

The issues faced by those affected by ASD¹⁷² highlight the likelihood that acknowledgement of a disorder does not necessarily provide a solution without a considerable investment of resources into the community.

The Committee learned that, despite being recognised as a disability in Western Australia (WA), parents of children with an Autism Spectrum Disorder (ASD) face a range of difficulties in gaining appropriate assistance for their child. For health and education these include:

- Timely, accurate diagnosis.
- Timely, evidence-based, affordable and appropriate early intervention.
- Appropriate support and direction for home based education.
- Reliable, inclusive education based on best practice principles (especially in high schools).
- A separate school for children with ASD who do not have an accompanying intellectual disability (IQ 70 or under).

Prevalence

Prevalence rates for all forms of Autism Spectrum Disorders (ASDs) worldwide have risen dramatically since the mid-1960s. One in 88 U.S. children has an ASD, according to a new report from the 'Centers for Disease Control and Prevention'. This represents a

172 The WA government has been made aware of these ongoing difficulties for families and their children with an ASD since the late 1990s (Crosby, 1998) and subsequently by other recently conducted WA research (MacDermott, 2008; McDonald, 2010). However, little has changed for these families as evidenced by the parent testimonies circa May 2012 submitted by the Northern Suburbs Autism Mums' Group, Perth

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23 per cent increase in prevalence from the 2009 autism report, which estimated that autism affected one in 110 children.

One recent Australian report indicates that more than 1% of Australian school-age children have a confirmed diagnosis of Autistic Disorder or Asperger's Disorder.¹⁷³ As a consequence, the health, education and family support requirements of those affected by ASD need to be understood so that their potential and independence in life can be maximised.

It is commonly agreed that students with ASD experience a triad of impairments involving idiosyncratic difficulties with communication, socialisation and stereotyped behaviour.¹⁷⁴ Beyond the triad of impairments there are often more cognitive characteristics to consider and these involve deficits in theory of mind skills, difficulties with executive function, weak central coherence, sensory processing and motor functioning problems.

International, Australian and West Australian research continues to indicate that early and accurate diagnosis is imperative to maximise the individual educational potential of children with an ASD so that they may access appropriate evidence-based early intervention at the earliest time.¹⁷⁵

Diagnosis

For school age students with a suspected Autism Spectrum Disorder (ASD) to gain funded services in WA they must seek a diagnosis.

All states in Australia have different assessment and diagnostic practices for a diagnosis to be made of an ASD. To receive government funding in WA for early intervention and educational support, parents must first seek a diagnosis of an ASD or a Pervasive Developmental Disorder (PDD).

The Committee was advised that parents in WA have found over many years that gaining an accurate diagnosis of an ASD for their child is often a very expensive,

173 Buckley, B. (2009) Relating Autism spectrum prevalence and government policy. Paper presented at the Asia Pacific Autism Conference 2009, Sydney, Australia.

174 American Psychiatric Association 2000; Australian Autism Education and Training Consortium (AAETC) 2008.

175 Dissanayake, C. (2009). Promoting the early identification of infants and toddlers with an Autism Spectrum Disorder. Paper presented at the Asia Pacific Autism Conference 2009, Sydney, Australia, Granpeesheh, D., Dixon, D. R., Tarbox, J., Kaplan, A. M., & Wilke, A. E. (2009). Effects of Age and Treatment Intensity on Behavioral Intervention Outcomes for Children with Autism Spectrum Disorders. *Research in Autism Spectrum Disorders*, 3(4), 1014-1022

protracted and traumatic process where waiting lists are common. For some families this process can take many months or years.¹⁷⁶

To gain a diagnosis, parents or carers generally seek a referral from medical and allied health practitioners, school psychologists and/or other educators in both government and private sectors. The Disability Services Commission (DSC), Health Department and private practitioners receive the referral and organise an assessment.

Diagnosis for ASD involves a multi-disciplinary team made up of a paediatrician, psychologist and speech pathologist. This is conducted privately or through the health or disability sectors. A psychiatrist, social worker and occupational therapist may also be involved.

The multi-disciplinary team responsible for the diagnosis makes intervention referrals and recommendations. The client is referred to DSC for eligibility for the level and type of service determination.

Assessments conducted by government funded agencies usually have a diagnostic team which conduct the assessment in one place. These assessments have the longest waiting lists attached to them and parents become very frustrated waiting for an assessment and for appropriate therapy. Without the diagnosis, appropriate intervention cannot be sourced or funded.

The Committee is advised that parents out of desperation and at great financial cost seek a private assessment. Others commence therapy without an official diagnosis. Private assessments require parents to 'trek' from one member of an assessment team to another. This can delay timely diagnosis given how busy paediatricians, psychologists and speech therapists are in the WA health sector.¹⁷⁷

Intervention

Additionally, parents in WA routinely find it difficult to access and afford appropriate intensive, best practice early intervention in a timely manner for their child with an ASD.¹⁷⁸ The Federal Helping Children With Autism (HCWA) initiative currently provides

176 MacDermott, S. (2008). Can you Help Us to Help You? Autism School-age Family Needs Report. Perth: A Joint project by The State Child Development Centre, the Autism Association of Western Australia & Therapy Focus Inc., McDonald, J. (2010). Seeking Progressive Fit: A constructivist grounded theory and autoethnographic study investigating how parents deal with the education of their child with an Autism Spectrum Disorder (ASD) over time. Unpublished Doctor of Philosophy Thesis: The University of Western Australia, Perth.

177 Dr Jasmine McDonald, Electronic Mail, 21 June 2012,

178 MacDermott, S. (2008). Can you Help Us to Help You? Autism School-age Family Needs Report. Perth: A Joint project by The State Child Development Centre, the Autism Association of Western Australia & Therapy Focus Inc. & McDonald, J. (2010). Seeking Progressive Fit: A constructivist grounded theory and autoethnographic study investigating how parents deal with the education

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all children aged six and under who are diagnosed with an ASD and are not yet school-aged with funding of up to \$12,000 (up to \$6,000 per financial year) to assist with the financial cost of accessing early intervention services. This figure does not provide appropriate funding for the intensity of early intervention recommended by a Federal government review, which investigated current research regarding the most efficacious models of early intervention for children with an ASD.¹⁷⁹

The review recommended that best practice early intervention consisted of a model based on Applied Behaviour Analysis / Discrete Trial Training (ABA/DTT) methods. It recommended that the early intervention should 'be extensive and intensive' and be conducted for 'a minimum of 20 hours a week over two or more years'. This was recommended to support major gains in young children.

The Committee is advised that government funding for this model is still inadequate and does not cover the recommended intensity of intervention needed in best practice models. Most families continue to struggle to find up to \$60,000 per year, even with the HCWA package, to cover the intensive therapy needed to conduct this best practice model.

Education

Over the past two decades there has been an increasing development of inclusive practice regarding appropriate accommodation of students with an ASD in mainstream schooling sites.¹⁸⁰

This has been in response to powerful moral, social justice and political arguments. These arguments have asserted that positive attitudes towards individuals with disabilities are developed when children with disabilities interact with other children at school.

Recent international, Australian and WA research has shown that students with intellectual and cognitive disabilities, including ASD, often cannot access reliable and consistent mainstream inclusive practice that maximises their progress over time.¹⁸¹

of their child with an Autism Spectrum Disorder (ASD) over time. Unpublished Doctor of Philosophy Thesis: The University of Western Australia, Perth.

179 Submission No. 23 from Dr Jasmine McDonald, June 2012, and Roberts, J., & Prior, M. (2006). A Review of the Research to Identify the Most Effective Models of Practice in Early Intervention for Children with Autism Spectrum Disorders. Canberra: Australian Government Department of Health and Ageing

180 Frederickson, N., Jones, A.P. & Lang, J. (2010). Inclusive provision options for pupils on the autistic spectrum. *Journal of Research in Special Educational Needs*, 10, 63-73.

181 Humphrey, N. & Lewis. S. (2008a). 'Make me normal'. The views and experiences of pupils on the autistic spectrum in mainstream secondary schools. *Autism*, 12, 23-46. & Humphrey, N. & Lewis. S. (2008b). What does "inclusion" mean for pupils on the autistic spectrum in mainstream secondary schools? *Journal of Research in Special Education Needs*, 8, 132-140. & Humphrey, N. & Symes, W. (2010). Perceptions of social support and experience of bullying among pupils with

Concerns have been raised about the lack of appropriate, individualised attention and support available, the high attrition rates and the inordinate degree of bullying experienced by students with an ASD in mainstream settings.¹⁸² These students often experience social isolation, anxiety and sensory difficulties in mainstream settings. Their need for routine and predictability is often at odds with the chaotic, noisy happenings of mainstream school life, especially at the high school level.

Parental responses in WA to these ongoing difficulties in schooling for children with ASD include:

- a growing number of parents home educating their children.¹⁸³
- children being withdrawn from mainstream schools to enrol them in segregated schools designed to ensure an appropriate education.

WA families can only choose to home school a child with an ASD if their family circumstances can support such a decision. There is currently no government funding or appropriate formal expertise.

One option for these children is the Schools of Isolated and Distance Education (SIDE). The Committee was advised that families routinely find the entry requirements for SIDE particularly stringent. Parents must furnish proof in the form of documentation of diagnosis and the inability of the child with an ASD to attend mainstream school. Many parents are at crisis point when they make such a request because of ongoing difficulties gaining appropriate inclusive schooling. Additionally, SIDE routinely advises parents that there is an expectation that students will return to mainstream schooling as soon as possible.

The option of placing a child with an ASD into a segregated school site in WA is only available to families who have a child who has an intellectual disability (IQ of approximately 70 or below). Children with Asperger's Disorder or High Functioning Autistic Disorder are currently not eligible for enrolment at segregated school sites.¹⁸⁴

autistic spectrum disorders in mainstream secondary schools. *European Journal of Special Needs Education* 25 (1), 77-91.

182 MacDermott, S. (2008). *Can you Help Us to Help You? Autism School-age Family Needs Report*. Perth: A Joint project by The State Child Development Centre, the Autism Association of Western Australia & Therapy Focus Inc. & McDonald, J. (2010). *Seeking Progressive Fit: A constructivist grounded theory and autoethnographic study investigating how parents deal with the education of their child with an Autism Spectrum Disorder (ASD) over time*. Unpublished Doctor of Philosophy Thesis: The University of Western Australia, Perth.

183 Kidd, T. & Kaczmarek, E. (2010). The experiences of mothers home educating their children with autism spectrum disorder. *Issues in Educational Research* 20(3), 257-275

184 McDonald, J. (2010). *Seeking Progressive Fit: A constructivist grounded theory and autoethnographic study investigating how parents deal with the education of their child with an*

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It was suggested that a better solution to the educational difficulties faced by children with ASD would be for the Department of Education (DoE) to provide a number of Home Schooling Consultants (with experience of educational diversity). These consultants could offer appropriate support and advice to parents to enable them to make informed choices.¹⁸⁵

Summary

Improvements are required to enable early diagnosis and early intervention for children with ASD. Mainstream schools need support to become more inclusive for children with ASD or other disorders. In addition appropriate funding and support is required for alternative educational pathways (home schooling and segregated school sites).

Families who have a child with an ASD will continually be at increased risk of serious mental health issues and family breakdown.¹⁸⁶ Current research indicates that parents of children with an ASD are potentially at greater risk of mental health problems than most other parent groups who have a child with a disability.^{187 188}

The consequential risks from inadequate diagnosis, intervention and support relative to mental health problems for parents and primary carers of children with ASD would, in the Committee's view, be just as true for those with children affected by FASD.

Finding 10

The issues faced by children with Autism Spectrum Disorder highlight the likelihood that acknowledgement of a disorder does not necessarily provide a solution without a considerable investment of resources into the community.

Autism Spectrum Disorder (ASD) over time. Unpublished Doctor of Philosophy Thesis: The University of Western Australia, Perth.

185 Dr Jasmine McDonald, attachment to Electronic Mail, 20 June 2012,

186 Hartley, Sigan L.; Barker, Erin T.; Seltzer, Marsha Mailick; Floyd, Frank; Greenberg, Jan; Orsmond, Gael & Bolt, Daniel (2010) The relative risk and timing of divorce in families of children with an autism spectrum disorder. *Journal of Family Psychology*, 24(4), 449-457.

187 Benson, P. & Karlof, K. (2009). Anger, stress proliferation, and depressed mood among parents of children with ASD: A longitudinal replication. *Journal of Autism and Developmental Disorders*, 39, 350-362 & Tehee, E., R. Honan, and D. Hevey. 2009. Factors Contributing to Stress in Parents of Individuals with Autistic Spectrum Disorders. *Journal of Applied Research in Intellectual Disabilities* 22: 34-42.

188 Dr Jasmine McDonald Electronic Mail, 20 June 2012,

Chapter 9

The justice system and FASD



The position in Western Australia

On 20 June 2012 the Chief Justice Wayne Martin addressed the Committee and outlined in detail the issue of foetal alcohol spectrum disorder (FASD) as it relates to the justice system in Western Australia. This chapter is divided into two parts. Part one provides a record of the Chief Justice's comprehensive testimony (in italics). Part two discusses the experience and research in other jurisdictions.¹⁸⁹

Part 1: Chief Justice Wayne Martin, In an address to Committee 20 June 2012

As I have said many times since my appointment as Chief Justice, the overrepresentation of Aboriginal people in the criminal justice system of this state is probably the single biggest issue confronting that system. Tragically, foetal alcohol spectrum disorder is becoming an increasingly significant component for many interrelated issues that produce that overrepresentation of Aboriginal people in the criminal justice system.

In order to address the significance of the problem it is necessary to commence by looking at the evidence we have about the extent to which FASD occurs in the community. There has been a number of statistical studies which endeavour to place an estimate on the incidence of FASD, usually per 100, 000 live births. Those studies have come up with a spectrum of estimates of the incidence of FASD. The breadth of that spectrum is probably due to the many difficulties that are associated with diagnosis, including uncertainty with respect to the exact criteria for FASD, the variability of systems experienced by FASD sufferers and, in Western Australia, the lack of diagnostic facilities in the areas in which many FASD sufferers are born. It is also been suggested in

¹⁸⁹ Chief Justice Wayne Martin, Chief Justice of Western Australia, *Transcript of Evidence*, 20 June 2012.

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the literature that there may be some reluctance on behalf of the health professionals to diagnose FASD because of the stigma which attaches not only to the patient but of course also to the family of the patient and in particular the mother of the patient.

One estimate that I have seen suggests that FASD sufferers may comprise up to two per cent of the population. Whatever be the correct statistic, my discussions with health professionals, including paediatricians, and with magistrates in regional Western Australia lead me to the view that the incidence of FASD among Aboriginal people in regional and remote Western Australia is alarmingly high and increasing. The prevalence of FASD, I think, is likely to be compounded by the fact that while it was once thought that FASD was associated only with gross or chronic alcohol abuse during pregnancy, most recent studies, I think, suggest that even relatively moderate amounts of alcohol use during pregnancy can cause the condition, particularly if alcohol is imbibed at particularly sensitive stages of the pregnancy.

Prevalence in the justice system

Turning then to the connection between FASD and the courts, there have been studies attempting to assess the incidence ... of FASD sufferers coming before the courts. One study suggested that 60 per cent of those who suffer FASD have some intersection with the criminal justice system. I think there are good reasons to conclude that people with FASD are more likely to come before the courts, and I will address those shortly, but I think you need to be cautious before applying a statistic like that to conclude that there is a causal relationship between FASD and court representation. The reason for that is that the studies also show a clear correlation between the incidence of FASD and Aboriginality and low socioeconomic status. Aboriginality and low socioeconomic status are themselves predictors of likelihood of appearing before court, so you cannot conclude that merely because FASD sufferers appear before the court, that is the cause of them appearing before the court. But when you have regard to the symptoms commonly associated with FASD, I think it is very likely that there is in fact a causal connection.

FASD symptoms relative to criminal behaviour

Turning then to those symptoms, obviously, the committee would be better assisted by evidence from a clinician with respect to the range of symptoms associated with FASD than by the evidence from a judge. But I think it is vitally important for those involved in the criminal justice system, including police, prosecutors, defence lawyers, judges and magistrates and corrective services officers, to have an appreciation of the symptoms that are often associated with FASD in order to identify the problem and perhaps come out with an appropriate disposition. Some of the diagnostic features of FASD have little to do with criminal behaviour; they include reduced size and sometimes craniofacial abnormality. Other symptoms including attention deficit and difficulties in solving

problems and completing tasks are more likely to have an indirect rather than a direct effect upon criminal behaviour. But there are a number of symptoms commonly associated with FASD that are likely to have a direct effect on offending behaviour. They include the difficulty which FASD sufferers have in learning from experience and in understanding the consequences of their actions. Other features of personality often associated with FASD include:

- *lack of empathy;*
- *difficulty restraining impulses and in making judgements;*
- *[difficulty in] understanding time and sequence;*
- *Inappropriate sexual behaviour is another common feature of FASD.*

Fairly obviously, all of these symptoms are very likely to predispose a person to offending behaviour which is likely to result in them being brought before a criminal court.

There are a number of other conditions often associated with FASD which also are likely to have a criminogenic effect. As I have already indicated, FASD is often associated with low socioeconomic status and poor or unstable home environments, including poor parenting, substance abuse, domestic violence and poor nutrition. That kind of background is a characteristic of many offenders within the criminal population. In addition, FASD sufferers also have a very high incidence of diagnosis with other mental or psychiatric conditions, and studies have estimated that at 90 per cent—suffering some other mental or psychiatric condition, but very often conditions associated with substance abuse. Again, they are prevalent characteristics of the criminal population.

In summary, there are a number of symptoms of FASD that will almost certainly increase the likelihood of a person with that condition coming before a court. In addition, there are other health and environmental factors associated with FASD that are likely to produce precisely the same result.

FASD sufferers disadvantaged in the courts

There are also symptoms of FASD that will place a person at a significant disadvantage when they enter the criminal justice system. Those symptoms include high levels of suggestibility, which means that people with FASD are very likely to agree with propositions that are put to them by police in their interview. Other symptoms include memory deficit. That obviously is going to place a person at a disadvantage when trying to explain their behaviour to police or when giving instructions to defence lawyers or when giving evidence to a court in defence of a charge brought against them. FASD

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sufferers also have considerable difficulty understanding sarcasm, idiom or metaphor, and these are all common characteristics of language used in the courtroom process.

Hearing impediment is another feature of FASD. If you are going places, a person has a significant disadvantage in the court process. Those factors in combination, together with language difficulties and low socioeconomic status, almost inevitably place FASD sufferers at a very significant disadvantage in their dealings with police, in securing adequate legal representation, in comprehending the court process, deciding upon the strategy to be adopted in response to the charges that are laid and in either defending themselves or placing relevant material before the court in relation to a sentence to be imposed.

There are other aspects of the criminal justice system in which FASD sufferers are significantly disadvantaged. If bail is granted, it will almost inevitably be granted with conditions. The various symptoms to which I have referred and which are often associated with FASD make it quite likely, or certainly increase the likelihood, that an FASD sufferer will breach the conditions of bail. If that happens, bail is likely to be revoked. If bail has been revoked, it is likely that when that person is charged again, that bail will be refused because of previous breach of bail.

One of the symptoms often associated with FASD is lack of empathy. In the sentencing process there is little risk that that will be seen as a lack of remorse, with the result that a more significant sentence will be imposed. When consideration is given by a court to the question of whether a custodial or a non-custodial penalty should be imposed, previous failure to comply with the conditions attached to a non-custodial penalty will likely encourage the court to consider a custodial penalty more seriously.

FASD sufferers disadvantaged in prison

If a person with FASD is sentenced to a custodial penalty and imprisoned, they are likely to suffer significant disadvantages within the prison system. There are, of course, a number of rules and regulations imposed by prison authorities in relation to the behaviour of prisoners within the system. FASD sufferers are unlikely to be in a position to fully comply with those rules, with the result that they will find themselves in trouble with the authorities. And of course there are social hierarchies within prisons, which have their own rules. Again, FASD sufferers are at a disadvantage in complying with those social rules, with the result that they are very likely to find themselves in trouble with their fellow inmates.

So in summary, the various factors that I have referred to provide, I think, a coherent explanation for the significant overrepresentation of people suffering from FASD within our court system.

Not only are such people:

- *more likely to commit offences but they are also more likely to be apprehended;*
- *they are more likely to be refused bail;*
- *they are more likely to be convicted; and, if convicted, they are more likely to be sentenced to a term of imprisonment, which they are likely to do harder than other prisoners.*

Judicial awareness of FASD

Because of all those impacts for FASD within the court system, the next obvious question is: are the people involved in that system sufficiently aware of FASD and its consequences? In particular, are the people who work within the system, which includes police, prosecutors, defence lawyers, judges, magistrates and corrective service officers, aware of the condition and its consequences for appropriate disposition? My own view—it is very hard to get a scientific basis for an answer to that question—is that we still have a long way to go in Western Australia for levels of awareness to be as high as one would like. There was a study of judicial awareness and attitudes with respect to FASD conducted in Queensland which suggested that levels of awareness within that state are not as great as they were in relation to a similar study conducted among judicial officers in Canada. My research of literature suggests to me that Canada is significantly more enhanced than Australia in recognition and awareness of FASD and in program development for dealing with the problem.

I am not aware of any study on the subject of judicial awareness of FASD in Western Australia, so I am dependent upon anecdotal experience. My discussions with regional magistrates led me to conclude that they would almost certainly all be well aware of the condition and of its consequences. But the lack of diagnostic screening, the pressures of having to deal with a large number of cases at any one time, coupled with the lack of any relevant management or treatment programs, I think, have the consequence that, very often, even an awareness of FASD would not be acted upon or have any significant consequences in the way in which that person is dealt with through the system.

That is not, of course, to say that FASD is never taken into account; far from it. In Western Australia, the Sentencing Act provides any judge or magistrate with the power to order a pre-sentence report from a number of disciplines, including medical and psychiatric disciplines. So if FASD is suspected, that power can be exercised and a report obtained on whether or not the offender suffers the condition, and I am sure that that happens from time to time. But I would also be fairly confident that there would be a number of cases in which FASD was suspected but that power was not exercised.

There would be a number of reasons for that, I think.

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1. *The first is the very limited availability of medical and psychiatric resources in the regional and remote parts of our state where this condition seems to be most prevalent.*
2. *The second is the delay that is likely to be occasioned by the commissioning of a report in a certain situation in which the magistrate may not be scheduled to revisit that circuit location for quite some time, and so commissioning a report will inevitably delay the disposition of the case quite significantly.*
3. *Another factor discouraging inquiry into the condition is the fact that even if an offender is diagnosed, there simply are no programs or management plans to deal with that diagnosis. So it is useful information, but its utility is limited by that sad fact.*

I would also like to suggest that police and prosecutors and defence lawyers are much more likely to have access to the information that would create a prospect of an FASD diagnosis than judges or magistrates.

A judge or magistrate called upon to sentence an offender does not have a great deal of interaction with the offender before sentence is passed. Usually, they will simply see them sitting in the back of a court room; they will have little opportunity to observe their behaviour in such a way as to give rise to a suspicion of FASD. By contrast, police, prosecutors and defence lawyers have much greater interaction with the offender and would be in a better position to assess the possibility that FASD may be involved.

I do not for that reason mean to suggest that judicial awareness of FASD is unimportant, but what I do suggest is that if you are looking at improving awareness of the condition, training of police, prosecutors and defence lawyers is more likely to pay significant practical dividends than training of judges and magistrates.

Better still, of course, would be the provision of resources in terms of the skilled health professionals capable of undertaking diagnosis. That could be court based; even better still, in my view, a regionally based screening program applied in the regions where this condition appears to be most prevalent would, I think, be the ideal paradigm solution to these problems of diagnosis.

Sentencing of FASD sufferers

The last subject I would like to address is about FASD and sentencing, because FASD sufferers do pose some significant problems for courts in relation to sentence. I would like to address that in two ways:

1. *firstly, by looking at the principles that govern sentencing; and*

2. *secondly, by looking at the specific sentencing options that courts in Western Australia have.*

Dealing firstly with the principles, the primary principle of sentencing is, of course, that the court must impose a punishment which reflects the seriousness of the offence and the culpability of the offender. Related sentencing principles include the public denunciation of the offending behaviour and the exaction of retribution from the offender for the harm which they have caused to the victim and to the community.

In the case of FASD offenders, I think there is good reason for thinking that each of these factors should be given less weight. Dealing firstly with punishment, I think most reasonable people would agree with the proposition that the culpability of an offender suffering from FASD is less than an offender who commits a similar crime who is not suffering from the criminogenic conditions that are often associated with FASD.

Because the culpability of those offenders is lower, again I think most reasonable people would consider that the need to exact retribution from that offender is reduced, as is the need to denounce FASD suffers, particularly in a context in which if one were looking to denounce aspects of that offender's behaviour, one would really be denouncing the family background and the society that has allowed the offender to suffer from that condition.

Another very significant sentencing principle is, of course, that of deterrence, and that has two components—general deterrence, which is to deter people generally from offending, and specific deterrence, which is to deter the particular offender from reoffending. Again, I think with FASD sufferers, there is reason to think that this factor should be given less weight. General deterrence is unlikely to be significant because non-FASD sufferers are unlikely to be affected by the penalty imposed on somebody who is known to suffer FASD.

In the case of specific deterrence, that is discouraging reoffending by the particular offender, one of the tragic aspects of FASD is ... that many of the symptoms are not susceptible to treatment so that the prospect of deterring somebody from reoffending by punishment is reduced.

Rehabilitation

Rehabilitation is, of course, another very significant sentencing factor. In the case of FASD offenders, I have already mentioned the fact that some of the symptoms are not readily susceptible to treatment. I do not mean to suggest by that that we should throw our hands in the air in despair and not do anything about those offenders. In Canada, they have developed a program for FASD offenders, which in turn suggests that there are things that can be done to reduce the risks associated with the presence of those persons in the community. I think another aspect of the acknowledgement of the fact

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that these offenders are resistant to treatment is that, in terms of long-term management, probably the most effective way of diminishing the risk of reoffending is by providing a safe and stable environment in which these people can be managed within the community in a way that reduces the risk of offending behaviour. The problem at the moment is that there are simply very few options to judges and magistrates to produce a sentence that will encourage that sort of environment, unless either family members or community members come forward and offer to provide that sort of support, and unfortunately that does not happen very often at all.

Incapacitation

The final sentencing principle I will refer to is what is sometimes referred to as “incapacitation”, and that refers to the fact that while an offender is in prison, obviously they are prevented from committing offences against the community generally. But, of course, incapacitation only works for as long as the offender is in custody, so unless one is resigned to incarcerating a person effectively for the rest of their life, it is not a very effective means of reducing reoffending, and it is very expensive. Many FASD offenders commit offences at the lower end of the criminal spectrum, with the result that incarceration for lengthy periods of time is simply not justified by the seriousness of those offences. But for some of the FASD sufferers who commit serious sexual offences, prolonged incarceration is likely to be the only way of adequately protecting the community, unless some other alternative can be devised.

So those are the sentencing principles moving out of the types of sentences that courts have available to them in relation to FASD sufferers. There are, I think, problems with each of those, and I will deal with them, if you like, in increasing levels of severity. The sentence most commonly applied in Western Australia is that of a fine.

Fines

In relation to FASD sufferers, though, this penalty is often problematic. Often they will lack the capacity to pay, or even if they do have the capacity to pay, they will lack the wherewithal to make the arrangements to pay within the time stipulated by the court; the organisational skills necessary to actually organise payment are often beyond them.

Community-based orders

Moving up into community-based orders, there is a range of community-based orders available to courts under the Sentencing Act, almost all of which have conditions attached to them. Because of the symptoms I have already mentioned, imposing conditions that have to be complied with upon these offenders is often likely to lead to breach, with the result that they will be brought back before the court and sometimes with a more serious sentencing disposition arrived at.

Suspended prison term

Moving up the scale, the next sentence available to the court is that of a suspended prison term. Again, that is, of its nature, conditional; it is conditional upon the offender not reoffending during the period of suspension. Because of the various aspects of FASD to which I have referred, that type of sentence is very likely to be setting a person up to fail, because they will reoffend during the period of suspension and then they will be brought back before the court and the suspended prison term will be imposed, together with another penalty for the offence that they have committed to breach the suspended term.

Imprisonment

The most serious penalty we have available to us is, of course, imprisonment. For reasons I have already mentioned, it is very likely that FASD sufferers will do their time harder than other prisoners and, of course, because there are presently no management or treatment programs available for FASD sufferers within the prison system, there is unlikely to be anything done that will address their offending behaviour while they are in prison.

WA in summary

In summary, people who suffer from FASD are likely to be predisposed to offending behaviour, and they are likely to be significantly disadvantaged at virtually every point in the criminal justice system.

It is, I think, poignant to recall that people suffer from this condition through no fault of their own. There is, I think, room for the view that our current processes do not fairly and justly deal with people who suffer from this condition. Ways in which those processes could be improved include, in my view, greater awareness and training among police, prosecutors, defence lawyers, judicial officers—judges and magistrates—and Corrective Services officers. Better still would be improved diagnostic screening services provided by health professionals. One way would be to provide those through the court, so that when somebody comes before the court, they are screened. Better still, I think, would be a regionally based screening program that would cover all the people likely to be at risk in the regions of the state, where, we have reason to suspect, these conditions are more prevalent. I say that because such a program would, I think, produce information, particularly when a diagnosis was made, that would be very helpful to a range of agencies. Those agencies would include, obviously, Health, the Department for Child Protection, Education, the police and disability services, not just the courts. That is what I suggest that a broader-based screening program would be of great assistance.

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Within the court system, sentencing dispositions could, I think, be improved by the availability of a program specifically designed to reduce the risk of such offenders reoffending and by the provision of resources that would enable those offenders to be managed in a safe environment within the community, which would reduce the risk of them reoffending.

Finding 11

There is a lack of screening (and diagnostic) services for people with FASD in the regions. This impacts the way in which they are handled through the judicial system.

Finding 12

The endemic nature of certain FASD traits make community based orders, and suspended prison terms problematical when sentencing sufferers.

Finding 13

A person with FASD is more likely to:

- commit offences and be apprehended;
- be refused bail;
- be unresponsive to authority;
- be undeterred from reoffending through punishment
- be convicted; and, if convicted, be sentenced to a term of imprisonment, which they are likely to 'do harder' than other prisoners because of their –
 - High levels of suggestibility;
 - Memory deficits;
 - Possible hearing deficits;
 - Difficulty in understanding sarcasm, idiom or metaphor;
 - Lack of apparent empathy

Part 2: Justice and FASD outside of Western Australia

The Committee was told that in all Australian court jurisdictions, the issue of FASD is generally missed because those affected can usually talk normally. As a consequence it was suggested that a checklist should be prepared for those interacting with people who may have FASD.¹⁹⁰

In the courts it is problematic to get defence lawyers to put forward FASD as a defence, as people with FASD are impulsive and US studies show that they may be more likely to commit certain offences. As a consequence, identifying a defendant as potentially having FASD is seen to be flagging them as potentially more dangerous, to that individual's detriment. In Queensland this is compounded by the fact that magistrates will often wait on the defence lawyer to make a request for a pre-sentence report.¹⁹¹ An expert in the field suggested to the Committee:

- *Rather than jails, perhaps we should have places that provided structured environments. We have had this problem as a country since de-institutionalisation – there is an argument that the structural environment of prisons is helpful but the problem is that the other prisoners can scapegoat prisoners with FASD and they cannot be segregated.*
- *In all of Australia I have only found 6 or 7 judgements that recognise the condition;*
- *For FASD cases, the courts should be devoid of visitors; sentences should be repeated to them so that they are understood and forms should be simple with lots of white space;*
- *In the Canadian system it was found that the seeming lack of empathy for people with FASD led to heavier sentencing;*
- *Defence lawyers should also be prepared to talk to prosecutors about it.*¹⁹²

Prevalence of people with disabilities in the justice system

Since its identification in the 1970s, FASD is recognised as one of the two most common types of developmental disability. The correlation between learning disabilities and trouble with the law is well established with studies showing that between 10 and 25% of the Canadian national prison population is mentally

190 Briefing Dr Heather Douglas, Brisbane, July 2012.

191 Briefing Dr Heather Douglas, Brisbane, July 2012.

192 Briefing Dr Heather Douglas, Brisbane, July 2012

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handicapped compared to 2-3% of people in the general population.¹⁹³ There is no reason to believe that Australia would be different.

In the case of people with FASD, impulsive behaviour may lead to stealing things for immediate consumption or use, unplanned offending and offending behaviour precipitated by fright or noise. As a result of their suggestibility, people with FASD are a higher risk for criminal behaviour and may engage in secondary participation with more sophisticated offenders.

*A 1996 study found that 60% of those with FASD come into contact with the criminal justice system. Courts in Canada and the United States have acknowledged the particular vulnerability of those with FASD who are charged with offences or are witnesses in a criminal case. Canadian and United States courts have frequently stated that FASD merits consideration at both the guilt assessment stage and sentencing stage.*¹⁹⁴

A person with FASD who has a lack of memory, or is unable to understand cause and effect, may breach court orders, further enmeshing FASD sufferers in the justice system.¹⁹⁵

As discussed earlier in this report, children affected by FASD have their executive function damaged *in utero* by harmful alcohol exposure. The executive function describes a set of cognitive abilities that control and regulate other abilities and behaviours. Executive functions include the ability to initiate and stop actions and to monitor and change behaviour as needed.¹⁹⁶

While the courts in the USA and Canada have long been aware of the behavioural problems encountered in people with FASD, those in Australia are less so:

*I have surveyed the judiciary but the 50% of respondents were probably those who had heard of the condition and only two talked about it coming up in their courts.*¹⁹⁷

In 2011 Hennepin County Minnesota undertook to screen and diagnose youths in the justice system for FASD. Of the 166 youths screened for prenatal alcohol exposure, 74

193 Conry, J. & Fast, D.k., *Fetal alcohol syndrome and the justice system*, The Law Foundation of British Columbia, Canada, 2000, p23.

194 Douglas, H. et al., 'Judicial views of Foetal Alcohol Spectrum Disorder in Queensland's criminal justice system', *Journal of Judicial Administration*, vol. 21, 2012, p178.

195 Douglas, H., 'The sentencing response to defendants with foetal alcohol spectrum disorder', *Criminal Law Journal*, Vol. 34, pp. 221-239, 2010.

196 Encyclopaedia of mental disorders, *Executive Function*, 2012. Available at: <http://www.minddisorders.com/Del-Fi/Executive-function.html>. Accessed on 14 June 2012.

197 Briefing Dr Heather Douglas, Brisbane, July 2012.

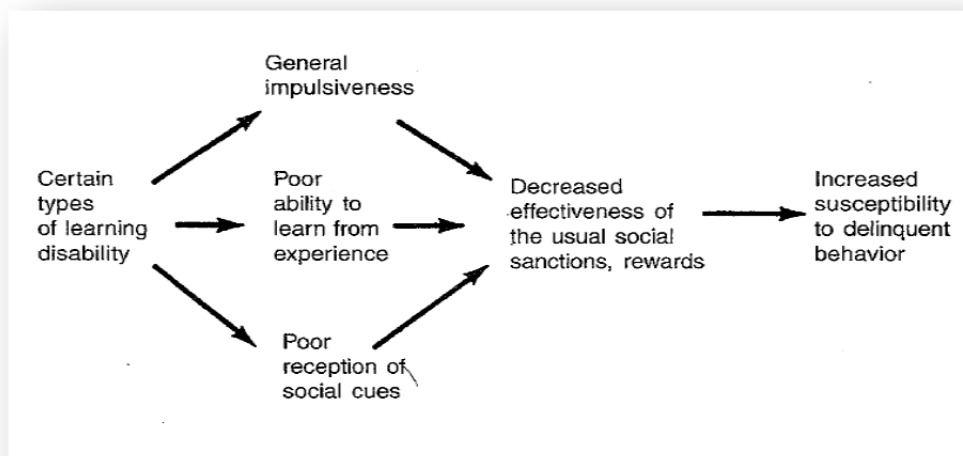
or 45% screened positive. Of the 64 that completed the FASD diagnostic evaluation process, 58 or 91% were diagnosed positive.¹⁹⁸

In another British Columbian study which examined 287 youths who had committed offenses and been referred for an in-patient psychological exam, 23.3% had a foetal alcohol related diagnosis.¹⁹⁹

Legal competence before the law

The susceptibility of individuals with learning disabilities, such as those exhibited in FASD to being involved in the justice system, is illustrated below:

Figure 9.1 Linking FASD Learning Disabilities and Delinquency²⁰⁰



Judicial referrals for FASD screening occur regularly at the Youth Justice Program in Manitoba. This program has identified a number of 'red flags' that trigger a referral for diagnosis of FASD by the judge or others in the criminal justice process. These red flags include:

- A repeated history of 'fail to comply';
- Lacking empathy, poor school experiences;
- Unable to connect actions with consequences;

198 Bisgard, E.B., Carls, S.S. & Louis, M., 'FASD in the juvenile court', Paper presented at the It's a Matter of Justice Conference, Vancouver, April 2012.

199 Bisgard, E.B., Carls, S.S. & Louis, M., 'FASD in the juvenile court', Paper presented at the It's a Matter of Justice Conference, Vancouver, April 2012.

200 Conry, J. & Fast, D.K., *Fetal alcohol syndrome and the justice system*, The Law Foundation of British Columbia, Canada, 2000, p23.

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- Does not seem to be affected by past punishments;
- Opportunity crimes rather than planned crimes;
- Crimes that involve risky behaviour for little gain/gang involvement; and
- Superficial relationships/friends.²⁰¹

In Queensland, one witness referred the Committee to the establishment of a 'special circumstances list'.²⁰²

Special circumstances list

This was established at the Brisbane Magistrates' Court in May 2006. Based on an existing Melbourne model, the list was aimed at finding an alternative way to deal with defendants charged with public order-type offences, who had impaired capacity at the time of the offence, as a result of mental illness or intellectual disability, and homelessness.

In Brisbane, a person is eligible to be dealt with under the special circumstances list if he or she is 17 years of age or older. They must be homeless, and appear to be suffering from impaired decision-making capacity as a result of either mental health issues, intellectual disability or brain/neurological disorder.

They must have been charged and pleaded guilty to an 'eligible offence'. An eligible offence arises from circumstances which have an aspect of 'public order'. These include procedural offences such as failing to appear, breach of bail, public nuisance, begging, public drunkenness and failing to properly dispose of a syringe.

Serious drug offences, sexual offences and serious offences of personal violence are disqualifying offences.

A 2007 evaluation found that:

The Brisbane special circumstances list is meeting the aims set for it. It is succeeding in ensuring that disadvantaged defendants who have committed public order offences are dealt with in a more appropriate manner. The rate of court supervision and referral to treatment and other social services is high, indicating a solid commitment to a case management approach, and a genuine

201 Douglas, H. et al., 'Judicial views of Foetal Alcohol Spectrum Disorder in Queensland's criminal justice system', *Journal of Judicial Administration*, vol. 21, 2012, p178.

202 Briefing Dr Heather Douglas, Brisbane, July 2012.

*attempt to address the underlying causes of defendants' offending behaviour.*²⁰³

Intellectual disability / Cognitive Impairment : A legal definition

Legal definitions of intellectual disability are being considered. In the NSW Law Reform Commission's Inquiry into the Bail Act it was recommended the adoption of the following definition of cognitive impairment, which would be used in decisions about bail, diversion and sentencing, for people with cognitive and mental health impairments.

Cognitive impairment is an ongoing impairment in comprehension, reason, judgment, learning or memory that is the result of any damage to or dysfunction, developmental delay, or deterioration of the brain or mind.

Such cognitive impairment may arise from, but is not limited to, the following:

- *Intellectual disability*
- *Borderline intellectual functioning*
- *Dementias*
- *Acquired brain injury*
- *Drug or alcohol related brain damage*
- *Autism spectrum disorders.*²⁰⁴

The term 'cognitive impairment' replaced the term 'intellectual disability' in the Bail Act 1978 (NSW).

Recommendation 11

The Committee recommends that the Attorney General make available additional funding in the 2013 budget for justice and corrective services to enable:

- c. The identification of people with FAS / FASD or who have a cognitive impairment.
- d. Additional programs to be developed to assist people with FAS / FASD or a cognitive impairment during their pre-sentence period, incarceration and following discharge to help them function in society.

203 Walsh, T. *The Queensland Special Circumstances Court Journal of Judicial Administration* 2007

204 New South Wales Law Reform Commission, *Bail Report 133*, NSW, April 2012, p175.

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Prevention: there is no cure

FASD prevention work is complex; it involves much more than providing information about the risks of alcohol use in pregnancy. Preventing risky alcohol use by pregnant women (and mothers before and after pregnancy) does not take place at any single point in time, nor does it occur through a single interaction with a care provider.

A background to prevention

FASD is a complex issue. Research confirms that women who give birth to children with FASD are those most likely to have their own health compromised by addictions, mental health problems, high stress levels, depression, anxiety, or extensive experiences of grief, trauma and loss.²⁰⁵ There is also widespread acknowledgement that a low socio-economic status (SES) is associated with both FAS and FASD with its linkages to poor nutrition and collateral social factors, including stress, physical abuse and sometimes a lack of social support.²⁰⁶

As the name suggests, FASD is directly attributable to alcohol consumption during pregnancy. However, these factors - the prevailing culture, health, psychosocial and economic factors - mean that alcohol cannot be viewed in isolation when considering any response.

*An Australian study confirmed that women experiencing significant disadvantage were also those most likely to be using substances, including alcohol. As a result, FASD is overrepresented among people experiencing disadvantage, with factors such as lower socioeconomic status, malnutrition, higher age of mother, loss of traditional culture and level of education all contributing to higher rates of FASD.*²⁰⁷

Because of the underlying determinants, prevention of FAS and FASD is complex.

FASD results from harmful levels of alcohol consumption during pregnancy. In Australia, alcohol is widely used and is very much a part of the social and cultural aspects of the Australian lifestyle. The National Drug Strategy Household Survey

205 Baydala, L. et al., 'Five perspectives on Prevention of FASD', in Clarren, S. (ed.), *Prevention of Fetal Alcohol Spectrum Disorder FASD*, Wiley-Blackwell, Germany, 2011, p351.

206 The Intergovernmental Committee on Drugs, *Monograph of the Intergovernmental Working Party on Fetal Alcohol Spectrum Disorders*, report prepared by Lucy Burns, Emma Black and Elizabeth Elliott, June 2012, p13.

207 Submission No. 21 from Foundation for Alcohol Research and Education, April 2012, p11.

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(NDSHS) in 2010 found that almost 17 per cent of Australians reported that they drink at risky levels; these are levels that place them at risk of harm.

The societal tolerance of drinking and binge drinking and to have drinking at risky levels is actually also found in women who are pregnant. Around 50 per cent of Australian women report that they actually drink during pregnancy, and some papers say it is slightly higher and some slightly lower, perhaps 35 per cent. But it is still a very big proportion. Of particular concern is binge drinking, which ranges from four per cent through to 20 per cent of women reporting that they have been binge drinking during pregnancy at some stage.²⁰⁸

There are a range of factors that can influence alcohol consumption during pregnancy. These include being unaware of the pregnancy, having a dependence on alcohol and/or being unaware of the consequences of alcohol exposure to the foetus. A partner's drinking is a factor in maternal alcohol consumption. Seventy-five per cent of children with FASD have biological fathers who are heavy drinkers and often have extended families with heavy alcohol consumption. Other risk factors that influence and perpetuate alcohol consumption during pregnancy include concurrent drug use, physical and sexual violence, fewer economic resources and opportunities.²⁰⁹

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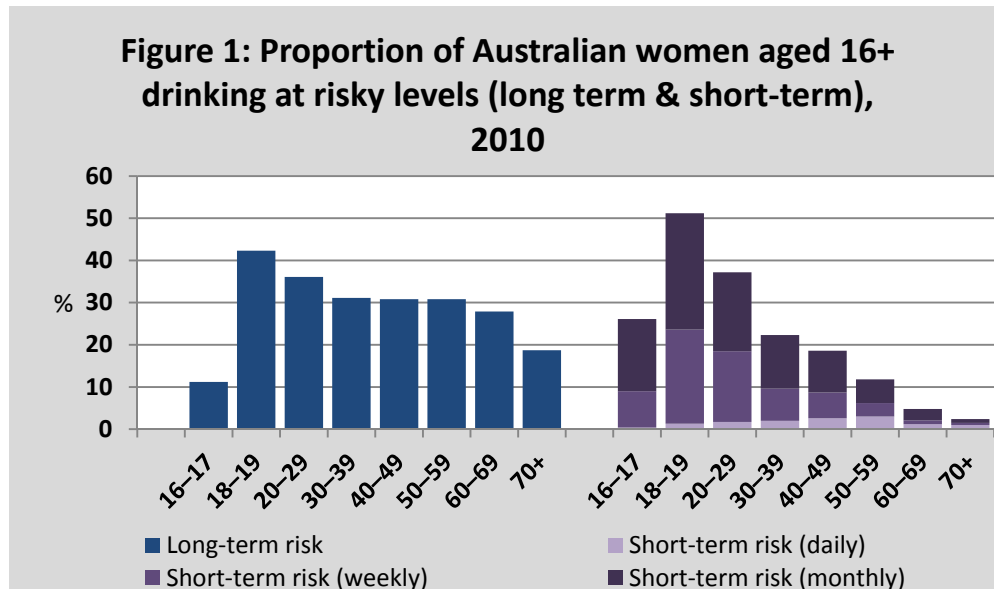
A partner's drinking is a factor in maternal alcohol consumption. Seventy-five per cent of children with FASD have biological fathers who are heavy drinkers and often have extended families with heavy alcohol consumption.

208 Dr Colleen O'Leary, Epidemiologist–Alcohol and Pregnancy Researcher, Curtin Health Innovation Research Institute, Transcript of Evidence, 28 March 2012, p5.

209 Submission No. 21 from Foundation for Alcohol Research and Education, April 2012, p11.

Figure 10.1 presents the proportion of Australian women who drink at risky and high risk levels of alcohol-related harm from the 2010 NDSHS.

Figure 10.1 Proportion of Australian women drinking at risky levels.²¹⁰



The series on the left (blue) is the proportion of women drinking at risky levels for alcohol-related harm in the long term. It shows that more than 30 per cent of Australian women of childbearing age drink at risky levels for long-term harm, peaking at over 40 per cent among 18-19 year olds.

The series on the right (purple) shows the proportion of women drinking at risky levels for harm in the short-term at least weekly or daily. This shows that young Australian women of childbearing age drink at risky levels more often than older women.²¹¹

In a study conducted by eight researchers, it was found that:

Results: The majority of women (89.4%) had consumed alcohol in the last 12 months. During their last pregnancy (n = 700), 34.1% drank alcohol. When asked what they would do if planning a pregnancy (n = 1103), 31.6% said they would consume alcohol and 4.8% would smoke. Intention to consume alcohol in a future pregnancy was associated with: alcohol use in the last pregnancy (adjusted OR (aOR) 43.9; 95% Confidence Interval (CI) 27.0 to 71.4); neutral or positive attitudes towards alcohol use in pregnancy (aOR 5.1; 95% CI 3.6 to 7.1); intention to smoke in a future pregnancy (aOR 4.7; 95% CI 2.5 to 9.0); and more frequent and higher current alcohol consumption.

210 NIDAC – FASD position paper 2012 p7

211 NIDAC – FASD position paper 2012 p7

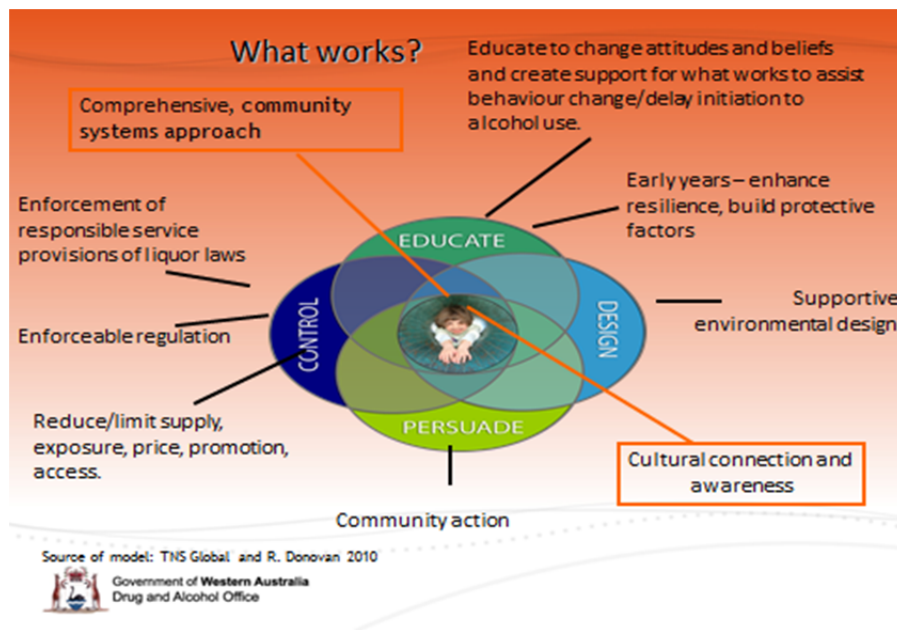
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*Conclusions: Women's past pregnancy and current drinking behaviour, and attitudes to alcohol use in pregnancy were the strongest predictors of alcohol consumption in pregnancy. Targeted interventions for women at higher risk of alcohol consumption in pregnancy are needed to change women's risk perception and behaviour.*²¹²

FASD prevention work is complex; it involves much more than providing information about the risks of alcohol use in pregnancy. Preventing risky alcohol use by pregnant women (and mothers before and after pregnancy) does not take place at any single point in time, nor does it occur through a single interaction with a care provider.

The figure below illustrates some of the protective factors in preventing alcohol abuse.

Figure 10.2 Prevention – what works?²¹³



Community development strategies are a key component of the first level of FASD prevention. This is about the need for people to work together to bring awareness to women's substance use and related health and social issues, and to link those working with children, youth and adults who are affected by FASD. Such strategies are about

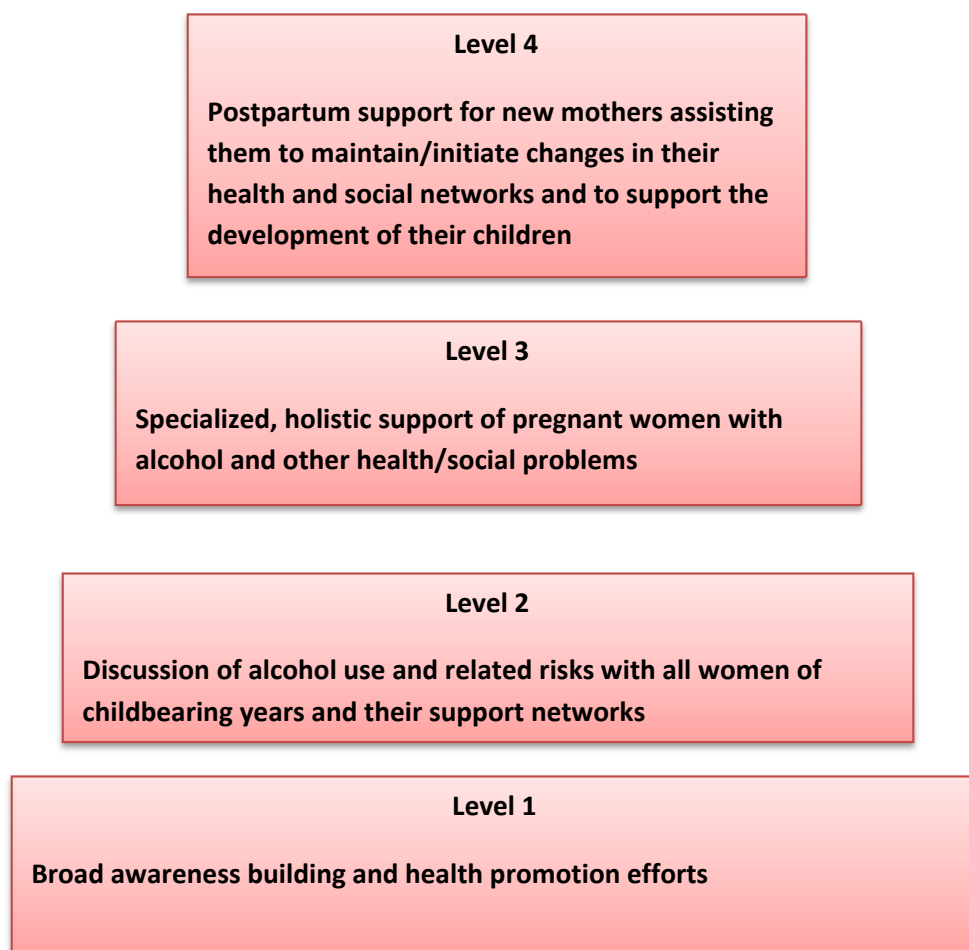
212 Elizabeth Peadon, Janet Payne, Nadine Henley, Heather D'Antoine, Anne Bartu, Colleen O'Leary, Carol Bower and Elizabeth J Elliott¹, 'Attitudes and behaviour predict women's intention to drink alcohol during pregnancy: the challenge for health professionals', *BMC Public Health* 2011, 11:584.

213 Drug and Alcohol Office of Western Australia

connecting the people in a position to contribute to awareness and action and involving them in working together on community and system-level changes.²¹⁴

Canadian prevention specialists have identified four mutually reinforcing prevention approaches as effective in delivering FASD prevention. These four levels of prevention span general and specific practices that assist women to improve their health and the health of their babies, with support from family, support networks, services and community. They are illustrated as follows:

Figure 10.3: The four part model of prevention



214 Public Health Agency of Canada, *Fetal Alcohol Spectrum Disorder (FASD) Prevention: Canadian Perspectives*, report prepared by, Canada, 2008.

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The first level of prevention – public awareness

The first level of prevention is raising public awareness through social marketing campaigns and other broad strategies.²¹⁵ These can include public policy and health promotion activities that are supportive of girls' and women's health. The engagement and involvement of a broad range of people at the community level is considered the 'key' to advancing social support and social change.

Primary prevention campaigns and awareness raising materials that target women, or those in a position to influence women, have been used extensively overseas and form the basis of the strategies embodied in the Western Australian Model of Care, (chapter 11). Such general campaigns are relatively inexpensive.

Some researchers suggest that 'remarkably few campaigns have been evaluated and therefore little is known about their impacts. Without serious and sustained efforts to understand this social marketing experiment, improvements will not be possible.'²¹⁶

However, the Foundation for Alcohol Research and Education highlighted to the Committee the perceived effectiveness of such campaigns. In their view these campaigns have often been poorly resourced and of a low standard. Yet, both the road safety and anti-tobacco social marketing strategies demonstrate the effectiveness of a well conducted, well-resourced campaign.²¹⁷

One campaign that has been evaluated was the health communication campaign '*Mummy Drinks Baby Drinks*', which aimed to raise awareness about the effects of drinking alcohol during pregnancy in the childbearing-aged population of the Local Health Authority of Treviso (Italy). The following health messages accompanied the image in communication materials:

'drinking alcohol during pregnancy and breast-feeding can damage the physical and mental development of your baby',

'avoid drinking during pregnancy, breastfeeding and while trying to conceive' and

*'your doctor, midwife and family members can help you remember'*²¹⁸

215 Social marketing seeks to influence social behaviours not to benefit the marketer, but to benefit the target audience and the general society

216 Clarren, S et al, *Prevention of fetal alcohol spectrum*, Wiley Blackwell Germany, 2011p11

217 Briefing by The Foundation for Alcohol Research and Education, Canberra, 6 July 2012

218 Bazzo, S. et al, ' Evaluation of the Impact of the Image Used in a Communication Campaign to Raise Awareness about the Effects of Alcohol Use During Pregnancy ', *Alcohol and Alcoholism Vol. 0, No. 0, pp. 1-6, 2012.*



Almost all respondents recalled the image (84%) and almost all respondents recalled the warning message conveyed by the image ('if a pregnant woman drinks alcoholic beverages, it can harm the baby').

When asked to focus on the feelings evoked by the picture, the number of caregivers who expressed distress emotions was approximately 50%, while only 13% were pleasantly affected by it.²¹⁹

Figure 10.4 Emotive responses to the 'Mummy Drinks Baby Drinks' campaign.²²⁰

| | Emotional reaction one year out: <i>How does the image seem to you?</i> | Feelings aroused: <i>What feelings does it arouse in you?</i> |
|-------------------|--|--|
| Distress | 265 (38.4%) | 342 (49.6%) |
| Indifference | 32 (4.6%) | 31 (4.5%) |
| Generic awareness | 52 (7.5%) | 98 (14.2%) |
| Liking | 273 (39.6%) | 90 (13.0%) |
| Unexpressed | 68 (9.9%) | 129 (18.7%) |
| Total | 690 (100.0%) | 690 (100.0%) |

219 Bazzo, S. et al, ' Evaluation of the Impact of the Image Used in a Communication Campaign to Raise Awareness about the Effects of Alcohol Use During Pregnancy ', *Alcohol and Alcoholism Vol. 0, No. 0, pp. 1-6, 2012*

220 Bazzo, S. et al, ' Evaluation of the Impact of the Image Used in a Communication Campaign to Raise Awareness about the Effects of Alcohol Use During Pregnancy ', *Alcohol and Alcoholism Vol. 0, No. 0, pp. 1-6, 2012*

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The Royal Australasian College of Physicians (RACP) has considered the benefits of such campaigns and strongly supports the need for a generalised prevention strategy together with a targeted strategy.

The RACP advised that knowledge of FASD has been shown to reduce the risk of pregnant women drinking.

*Evidence has shown that targeting drinking behaviours in the general population is associated with decreased occurrence of FASD. This includes current attitudes and behaviour in relation to alcohol. Prevention programs should therefore be targeted to the wider population on the risks of alcohol to the foetus.*²²¹

In addition, high risk groups, including women who have multiple births, young women and Indigenous women, should also be targeted.

*For example, young women, identified as “high-risk” and who are undergoing antenatal assessments could be educated on appropriate maternal nutrition, folate supplements as well as reducing alcohol, tobacco and illicit drug use in pregnancy. This has shown to have benefits for the unborn child and decreased the prevalence of some features of FASD.*²²²

Another recent New Zealand study of women who drank prior to learning of their pregnancy found that ‘a majority of women stop alcohol consumption on pregnancy recognition but prior to this, drink at levels posing a risk for the developing foetus.’²²³ Women most at risk for drinking and binge drinking in early pregnancy were younger in age and exhibited risky drinking behaviour prior to pregnancy. The study concluded that a targeted intervention to reduce the risk for an alcohol exposed pregnancy is warranted for sexually active younger women in New Zealand and elsewhere.

While acknowledging recent findings, the knowledge of adverse effects is not as strong a determinant of intention to drink as are tolerant attitudes towards alcohol use in pregnancy. Thus, simply educating women about potential adverse effects of prenatal alcohol exposure will be insufficient to induce behavioural change. Societal attitudes about alcohol use, particularly during pregnancy, must also be addressed.²²⁴

221 Submission No. 25 from The Royal Australasian College of Physicians, June 2012, p2.

222 Submission No. 25 from The Royal Australasian College of Physicians, June 2012, p2.

223 S. M. Parackal, M. K. Parackal and J. A. Harraway, 'Prevalence and Correlates of Drinking in Early Pregnancy Among Women who Stopped Drinking on Pregnancy Recognition', *Maternal and Child Health Journal, Online First™*, 4 May 2012

224 The Intergovernmental Committee on Drugs, *Monograph of the Intergovernmental Working Party on Fetal Alcohol Spectrum Disorders*, report prepared by Lucy Burns, Emma Black and Elizabeth Elliott, June 2012.

The Committee concludes that there is a substantiated need a general and a targeted campaign to raise awareness and to change risky behaviour.

Recommendation 12

The Committee recommends the government invest additional funds in the 2013 budget into FASD prevention campaigns that seek to:

1. Raise public awareness in the general population through campaigns highlighting harmful alcohol use as it relates to the unborn child, and the general health of girls and women;
2. Conduct targeted education for high risk groups through health and community services.

Recommendation 13

While acknowledging that the Australia and New Zealand Standards Code, which includes labelling requirements, is administered by the federal regulatory body Food Standards Australia and New Zealand, the Committee recommends that the Minister for Racing and Gaming amend the *Liquor Control Act 1988* by December 2013 introducing a mandatory health warning label regime for alcohol products sold in Western Australia, including a message about the risks of consuming alcohol while pregnant. Similar legislative amendments were adopted in South Australia in relation to the mandatory labelling of beverage containers.

The health warning labels should be:

- mandatory so the label appears on all products;
- applied consistently across all products so they are visible and recognisable;
- include a number of rotating messages focussing on different social and health harms;
- developed by health behaviour and public health experts;
- regulated and enforced by government; and
- accompanied by a public education campaign.

Chapter 10

The second level of prevention - education

The second level of prevention focuses on girls and women of childbearing years having the opportunity for safe discussion of pregnancy, alcohol use, and related issues, with their support networks and healthcare providers.

Contraception

An estimated 50% of all pregnancies are unplanned. Consequently, many women may be exposed to alcohol at harmful levels before they realise they are pregnant. The issue of promoting effective contraception is seen as a key strategy by many.²²⁵

The National Preventative Health Taskforce Report suggested the rates of FASD may be between three and seven times higher in the Indigenous population. It suggested that specific preventive health strategies are required to improve the health of Indigenous Australians. These include increasing access to health (contraceptive, antenatal and maternity) services for Indigenous people.²²⁶

The Western Australian 'Model of Care' supports the use of brief interventions by health professionals. Brief interventions would address high-risk alcohol use and promote consistent use of contraception in women of childbearing age. This is seen as particularly important for women with harmful patterns of drinking and alcohol dependence. The 'model' recommends that in order to reduce unplanned pregnancy:

- Strategies are developed to promote the use of contraception and to improve the consistency of contraceptive use, including contraception prior to discharge from hospital post-natally;
- Men are educated and enlisted partners in family planning;
- Strategies are developed to promote communication between partners about the use of contraception;
- Evidence based primary and secondary school drug and sex education is implemented;²²⁷

The Committee supports these recommendations.

225 Briefing by The Foundation for Alcohol Research and Education, Canberra, 6 July 2012

226 Submission No. 16 from Australian National Preventive Health Agency, January 2012, p7.

227 Department of Health, Western Australia. Fetal Alcohol Spectrum Disorder Model of Care. Perth: Health Networks Branch, Department of Health, Western Australia; 2010

Finding 15

An estimated 50% of all pregnancies are unplanned. Consequently, many pregnancies may be exposed to alcohol before women realise they are pregnant. Therefore, the issue of promoting effective contraception is seen as a key strategy by many.

Recommendation 14

The Committee recommends that the Government supports the following WA FASD Model of Care recommendations to reduce unplanned pregnancy:

5. Develop strategies to promote the use of contraception and to improve the consistency of contraceptive use, including contraception prior to discharge from hospital post-natally;
6. Educate men and enlist them as partners in family planning;
7. Develop strategies to promote communication between partners about the use of contraception;
8. Introduce evidence based primary and secondary school drug and sex education.

Recommendation 15

The Government introduces or amends legislation in 2013 to ensure that the following NHMRC guidelines statements are printed outside and inside all pregnancy kits sold in WA after June 2015, namely:

- “Maternal alcohol consumption can harm the developing foetus or breastfeeding baby” and
- “For women who are planning a pregnancy, not drinking is the safest option”

Screening for risky alcohol use

The issue of screening was canvassed in chapter three. In the context of this chapter:

Screening and intervention for risky alcohol use across the general population and alcohol use 'per se' for women of child bearing age in general practice; antenatal clinics and other primary healthcare settings is crucial for policy and practice to prevent FASD in Australia. There is much evidence to suggest that screening and advice, if delivered by credible health professionals, and in particular, medical

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*doctors, is effective in changing drinking habits. A national screening program for alcohol use is urgently needed.*²²⁸

Finding 16

Education of women through the provision of screening and advice is effective in changing drinking habits.

The Committee was repeatedly advised that education on FASD should be provided to all girls and women of child bearing years and to all health care professionals working with them, or with people who have FASD.

*There was a call from all those health professions—paediatricians, general practitioners, obstetricians, allied health professionals in the public sector, community and child health nurses and Aboriginal health workers—for more information for educational resources and so on.*²²⁹

The use of education materials in Western Australia has anecdotally led to health care professionals being increasingly likely to discuss the issue of the risks of drinking while pregnant with women, although the strategy did not result in much improvement in the recognition of the cardinal features of FAS.²³⁰

Finding 17

Raising awareness of the harmful effects of alcohol including FASD to health care professionals, through the provision of educative materials, increases their readiness to provide advice to women on the risks of drinking while pregnant.

The third level of prevention - recovery and support services

The third level of prevention is even more specific. It relates to the provision of recovery and support services that are specialised, culturally specific and accessible for women with alcohol problems and related mental health concerns. These services are needed not only for pregnant women, but before pregnancy and throughout the childbearing years.

From my reading of the evidence in other places—because I have not been involved in that research here and I am not aware that it happened—that really assumes that alcohol provides no other function for that person and that they can voluntarily choose to change their behaviours. There is evidence in the US that even mothers who are

228 Department of Health and Human Services Tasmania, *Submission 6, Submission to the Standing Committee on Social Policy and Legal Affairs, 2012*, p4.

229 Dr Carol Bower, Epidemiologist, Telethon Institute of Child Health Research, *Transcript of Evidence*, 16 May 2012, p3.

230 Dr Carol Bower, Epidemiologist, Telethon Institute of Child Health Research, *Transcript of Evidence*, 16 May 2012, p3.

*aware of that and clearly have an innate investment in protecting the health of their children were, for other reasons, not able to or did not have the support to change their behaviours. I feel that that is an important point.*²³¹

The Australian Intergovernmental Committee on Drugs, reports that many women who knowingly continue to drink at risky levels while pregnant experience a number of other difficulties in their lives. These include relationship problems, domestic violence, other substance use and mental health problems. Additional strategies which may be useful in treating these women should include the provision of appropriate support services and interventions.²³²

Finding 18

Women who knowingly continue to drink at risky levels while pregnant experience a number of other difficulties in their lives. These may include relationship problems, domestic violence, other substance use and mental health problems. Additional support services and interventions should be made available for these women.

The fourth level of prevention - Postpartum support

Finally, the fourth level of FASD prevention is focuses on supporting new mothers to maintain healthy changes made during pregnancy. Postpartum support for mothers who were not able to make significant changes in their substance use during pregnancy is vital. This will assist them to continue to improve their health and social support, as well as the health of their children. Early interventions for children who potentially have FASD are important at this stage.

The Intergovernmental Committee on Drugs recommends that:

If women are not dependent but wish to stop drinking, other settings are also appropriate and may include:

- *Partial hospitalisation;*
- *Residential treatment;*
- *Outpatient individual or group psychotherapy;*
- *Family or couples therapy and/or*

231 Dr Carol Bower, Epidemiologist, Telethon Institute of Child Health Research,, *Transcript of Evidence*, 16 May 2012, p5.

232 The Intergovernmental Committee on Drugs, *Monograph of the Intergovernmental Working Party on Fetal Alcohol Spectrum Disorders*, report prepared by Lucy Burns, Emma Black and Elizabeth Elliott, June 2012, p13.

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- *Involvement in self-help groups.*²³³

The Intergovernmental Committee on Drugs identified a number of components of successful programs that target the mother and her partner. These include positive parent role models, parent training, self-help groups, outreach, case management, life skills management, family support services, follow up referrals and support across a range of domains, mental health, educational vocational, legal and respite care.²³⁴

Finding 19

Postpartum support for mothers who were not able to make significant changes in their substance use during pregnancy is vital. This may include the provision of supported accommodation, including partial hospitalisation.

Recommendation 16

The Government makes funding available in the 2013 budget for shelters in areas where there are high levels of alcohol consumption or children, or adults, with FASD. These shelters are to be available for women who have a problem managing their alcohol intake or whose families are restricting their ability to manage their alcohol intake.

Recommendation 17

The Committee recommends the Government provide additional funding in the 2013 budget to support multidisciplinary and culturally appropriate strategies to address the often complex needs of alcohol dependent mothers and their families.

Barriers to addressing alcohol use in pregnant women

In a 2010 paper, seven Western Australian researchers from a range of centres looked at the psychological barriers faced by health professionals when addressing alcohol use with pregnant women. These were grouped into five areas.²³⁵

1. How health professionals perceive their clients

Most women do not drink much alcohol during pregnancy. Some health professionals said that most of the pregnant women they cared for did not drink much alcohol during

233 The Intergovernmental Committee on Drugs, *Monograph of the Intergovernmental Working Party on Fetal Alcohol Spectrum Disorders*, report prepared by Lucy Burns, Emma Black and Elizabeth Elliott, June 2012, p29.

234 The Intergovernmental Committee on Drugs, *Monograph of the Intergovernmental Working Party on Fetal Alcohol Spectrum Disorders*, report prepared by Lucy Burns, Emma Black and Elizabeth Elliott, June 2012, p29.

235 France, K., et al 'Health Professionals Addressing Alcohol Use with Pregnant Women in Western Australia: Barriers and Strategies for Communication', *Substance Use & Misuse*, 45:1474–1490.

pregnancy and that alcohol was “a very small problem with (their) patients.” They seldom raised the subject of alcohol with their pregnant clients as they felt that it was not relevant to most of the women who attended their service.

Health professionals generally thought most pregnant women were ‘very switched on, health conscious, and want to do all they can to provide a better environment for their baby.’ In some cases, health professionals felt that this reflected the socio-economic demographics of women who attended their service.

Some health professionals noted that alcohol use was more of a concern for pregnant women living in particular areas, and particularly for groups such as aboriginal women and women who were poly-drug users.

2. Pregnant women know not to drink

Health professionals felt that most of their clients knew not to drink alcohol during pregnancy, or to drink only minimally, and that their choices about alcohol use during pregnancy reflected this knowledge. As a result, health professionals generally believed that they did not have a large role to play in advising women about alcohol use during pregnancy. However, some health professionals acknowledged that they were not directly asking their clients about their alcohol intake and hence were making an assumption that women knew to minimise alcohol consumption during pregnancy.

Women who drink at high-risk levels during pregnancy have other contextual issues that need to be addressed. Health professionals believed that they generally identified the minority of pregnant women who drank high levels of alcohol during pregnancy and whose pregnancies may be at risk of poor outcomes. They recognised that these women had a range of social and emotional factors that needed to be addressed, such as poly-drug use, homelessness, and abuse. Health professionals generally found it difficult to support these women as their needs were substantial and health professionals felt their ability to make a positive difference was limited.

The relatively short period of pregnancy, during which women were most likely to have some health professional care, restricted health professionals’ ability to establish adequate support to enable a woman to reduce or cease her alcohol consumption.

3. How health professionals prioritise their practice

Alcohol is not on the list of antenatal priorities for health care professionals. Health professionals identified other antenatal care issues, other than alcohol consumption, as having high priority including diet and tobacco use.

4. Concern for the client and the health professional/client relationship

It was considered that asking a woman about her alcohol intake during pregnancy could add to her anxiety or guilt. Health professionals did not want to add to any shame, anxiety or guilt already felt by women who had consumed alcohol during pregnancy. Furthermore, they did not want to alienate women from their care or exacerbate the issue by alarming clients with advice and information about the risks for the foetus.

Many of these points were summed up in a submission by the Health Department.

Health professionals may not ask women about alcohol use during pregnancy because they lack knowledge about the consequences of alcohol consumption during pregnancy. They also may have concerns about a woman's response when asked about alcohol use and assume that it is not relevant to the woman. Health professionals also are under considerable time constraints and may not be aware of effective screening tools and the effectiveness of brief intervention. They may also be unaware of the appropriate referral pathways and services, which are not always available in certain areas. For example, rural and remote areas have limited access to pregnancy and parenting substance use programs.²³⁶

5. Lack of skills and resources

For some health professionals a lack of skills and resources often prevented them from raising the subject of alcohol with pregnant women: “if I don’t have the skills and I know I can’t access a counsellor who can help me, then why would I ask the questions?”

In addition to the above listed psychological barriers, the Intergovernmental Committee on Drugs added that:

- women are more likely to attribute their problems to mental health rather than alcohol use and would therefore be more likely to be seen in mental health or general practice rather than substance abuse treatment centres; and
- there is a fear of losing custody of their children, lack of childcare and a lack of special services.²³⁷

236 Submission No. 12 from Department of Health, December 2012, p5.

237 The Intergovernmental Committee on Drugs, *Monograph of the Intergovernmental Working Party on Fetal Alcohol Spectrum Disorders*, report prepared by Lucy Burns, Emma Black and Elizabeth Elliott, June 2012, p29.

One submission highlighted the scarcity of appropriate primary health resources in the community:

When I was working in child and community health, in about 2003, I actually had discussions with some of the senior child and community health nurses about the possibility of having the children in the Perth centre screened by a child and community health nurse. But the resources in the suburb where the centre is located were really stretched and the nurses said that they just could not do it. I think that is, again, a missed opportunity for dealing with issues surrounding the mother, her behaviour and how that is impacting on the children.²³⁸

Figure 10.5: The Barriers and strategies for addressing alcohol use with pregnant women²³⁹

| Barriers | Strategies |
|--|---|
| <ul style="list-style-type: none"> • Perception that: <ul style="list-style-type: none"> ○ most women do not drink much alcohol during pregnancy ○ pregnant women know not to drink ○ women who drink at high-risk levels during pregnancy have other contextual issues that need to be addressed ○ asking about alcohol could add to a woman's anxiety or guilt ○ asking about alcohol could appear judgmental • Alcohol is not on the professionals' list of priorities in the antenatal consultation • The burden of consultation is huge • Lack of skills and resources to support women | <ul style="list-style-type: none"> • Ask about alcohol routinely • Include alcohol on a checklist of issues to address during antenatal care • Ask about alcohol within the context of health and everyday behaviour • When asking a woman about alcohol, assume that she does drink alcohol and seek to quantify the amount and frequency of consumption |

General barriers

Lack of community screening, knowledge and awareness regarding mental health/alcohol and other drug issues, and ambiguous early symptoms and stigma of

238 Dr Colleen O'Leary, Epidemiologist–Alcohol and Pregnancy Researcher, Curtin Health Innovation Research Institute, *Transcript of Evidence*, 28 March 2012, p5.

239 France, K., et al ' Health Professionals Addressing Alcohol Use with Pregnant Women in Western Australia: Barriers and Strategies for Communication', *Substance Use & Misuse*, 45:1474–1490.

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mental illness, contribute to the delay in appropriate services being offered and accepted. Early prevention and intervention is crucial.²⁴⁰

Stigmatising attitudes towards people with mental illness and alcohol and other drug issues are common in adolescents and are of major concern to those with these conditions. Such attitudes may act as barriers to seeking help, can interfere with treatment and adversely affect quality of life as they may cause a young person to feel abnormal, socially disconnected and dependent on others.²⁴¹

Who decides a pregnant woman can't drink anyway?

Figure 10.6 Pregnant pause. Is it right for others to dictate a pregnant woman's diet?

Photo: Simon Bosch



The sensitive nature of drinking alcohol during pregnancy is evidenced by a recent blog that went viral after reporting the story of a waiter who refused to serve the writer a glass of wine while she was pregnant.²⁴² The subsequent debate on the blog site reflected the diversity and strength of viewpoints that will be faced by any health professional in raising the issue.

240 Submission No. 11 from Department of Health South Metropolitan Area Health Service, December 2011, p3.

241 Submission No. 11 from Department of Health South Metropolitan Area Health Service, December 2011, p3.

242 WA today 'I can't serve you. You're pregnant', 11 July 2012, Available at: <http://www.watoday.com.au/lifestyle/diet-and-fitness/i-cant-serve-you-youre-pregnant-20120710-21sob.html#ixzz20HujyJah>. Accessed on 16 July 2012.

Finding 20

There are a number of identified concerns raised by health professionals that contribute to their reluctance to address the issue of alcohol consumption during pregnancy with their patients.

Mentor programs

FASD is considered to be a condition that can be prevented. Consequently, mentoring programs have been established in many communities in North Western Canada. This is in response to the need to more effectively engage women in recognising the dangers of prenatal alcohol exposure and in helping them to eliminate or reduce their use of alcohol use during pregnancy. Many such programs are based on the Parent Child Assistance Program (PCAP) that was developed in Seattle in the 1990s. Such programs have been running for up to ten years in some places.²⁴³

In Canada and the United States, mentoring is seen as effective; in part this is because women may face barriers in receiving care if they have substance misuse problems, and this can be especially true for those who are pregnant. 'High-risk women and families often remain completely outside service delivery systems because negotiating their way through multiple poorly coordinated agencies can be an overwhelming task for them.'^{244 245}

Mentoring is a relational strategy that recognises that, for women, positive relationships are very important for treatment and intervention strategies. In the context of working with pregnant and parenting women with addictions, interpersonal relationships are used to narrow the gap that frequently exists between high-risk women and the programs and services that they need.²⁴⁶

The emphasis that the mentoring program places on relationships is not limited to the relationship between a mentor and client, but extends to the relationships between mentors and service providers. Mentors act as case managers for their clients and work closely with clients and service providers to ensure that clients' needs were being met.

243 Canada Northwest FASD Research Network, *Network Action Team 4 - Evaluation of FASD Mentoring Programs*, report prepared by Burnside, L. et al, Canada, March 2011, p1.

244 Grant, T., Ernst, C. C., & Streissguth, A. P. (1999). Intervention with high-risk alcohol and drug-abusing mothers: I. Administrative strategies of the Seattle model of paraprofessional advocacy. *Journal of Community Psychology*, 27(1), 1-18.

245 Canada Northwest FASD Research Network, *Network Action Team 4 - Evaluation of FASD Mentoring Programs*, report prepared by Burnside, L. et al, Canada, March 2011, p1.

246 Canada Northwest FASD Research Network, *Network Action Team 4 - Evaluation of FASD Mentoring Programs*, report prepared by Burnside, L. et al, Canada, March 2011, p1.

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Evaluation of several mentoring programs demonstrated significant benefits over baseline scores. These included:

*participants in the programs being significantly more likely to have sought substance abuse treatment and abstained from using alcohol or drugs than individuals in the control group, and were more likely to be using birth control regularly. Greater positive outcomes were seen in terms of children's health, especially in their custody status. Finally, clients reported being better connected to service providers than individuals in the control group.*²⁴⁷

Mentors are chosen for non-judgmental empathy and are seen as paraprofessionals.

*[They] work with a caseload of 9-15 clients each, beginning with enrolment during pregnancy or up to six months after the birth of the index child and continuing for three years. Mentors do not provide services directly themselves, but instead help the substance-abusing mothers to address a wide range of problems by visiting them in their homes, connecting them with community services, coordinating the multidisciplinary service network, transporting them to appointments, assisting them in following through with service provider recommendations including obtaining substance abuse treatment, and making sure that the children are in safe home environments and receiving any treatments that they need. Uniquely, relapses are understood to be part of the recovery process and women are never asked to leave the program because of them. Mentors work with both the clients and their children, even if the children are not living with the clients because of child welfare involvement or other reasons.*²⁴⁸

Finding 21

Mentoring is a relatively low cost relational strategy that, in both Canada and the United States, is seen to be an effective preventative strategy. Several evaluations of different mentoring programs have been undertaken which demonstrate their efficacy.

Recommendation 18

The Western Australian Government pilots a mentoring strategy in a high risk community. This strategy should be based on the Parent Child Assistance Program

247 Canada Northwest FASD Research Network, *Network Action Team 4 - Evaluation of FASD Mentoring Programs*, report prepared by Burnside, L. et al, Canada, March 2011, p23.

248 Canada Northwest FASD Research Network, *Network Action Team 4 - Evaluation of FASD Mentoring Programs*, report prepared by Burnside, L. et al, Canada, March 2011, p27.

(PCAP) that was developed in Seattle in the 1990s. The government report to Parliament on the outcome of this trial by June 2015.

Health starts in the community: the social determinants of health

*The body of literature documenting the devastating impact of FASD as a result of the primary impact of alcohol as a teratogen on the developing foetus, and the secondary effects that are influenced by the interaction of environmental factors with the child's developmental disability, is building.*²⁴⁹

As outlined in this report, the single most important risk factor relative to FASD is related to high blood alcohol exposure in the embryo and the foetus. While there are no large-scale studies of additional risk factors the data suggest that risk factors for prenatal alcohol exposure more broadly include:

- *higher maternal age;*
- *lower education level;*
- *prenatal exposure to illicit drugs and smoking;*
- *custody changes;*
- *lower socioeconomic status;*
- *paternal drinking – while FASD can be caused only when a mother drinks alcohol during pregnancy it is known that women with partners who drink are more likely to drink themselves during pregnancy;*²⁵⁰
- *quality and adequacy of prenatal and postnatal care and services;*
- *inadequate nutrition; and*
- *a poor developmental environment (e.g., stress, abuse, neglect).*²⁵¹

In a Canadian 5-year follow-up study of birth mothers of children with FAS, it was found that these women came from diverse racial, educational and economic backgrounds. 'They were often challenged by untreated or under-treated mental health concerns, they were socially isolated, they were victims of abuse and they had histories of severe childhood sexual abuse.'²⁵²

FASD crosses the operating jurisdictions of many health professionals and there is no single mandate for responsibility.

Because of its causal complexity:

249 Dr Linda Burnside, *Prevalence of Fetal Alcohol Spectrum Disorder: A Literature Review*, Tri-Province FASD Project, 2011, p1,2.

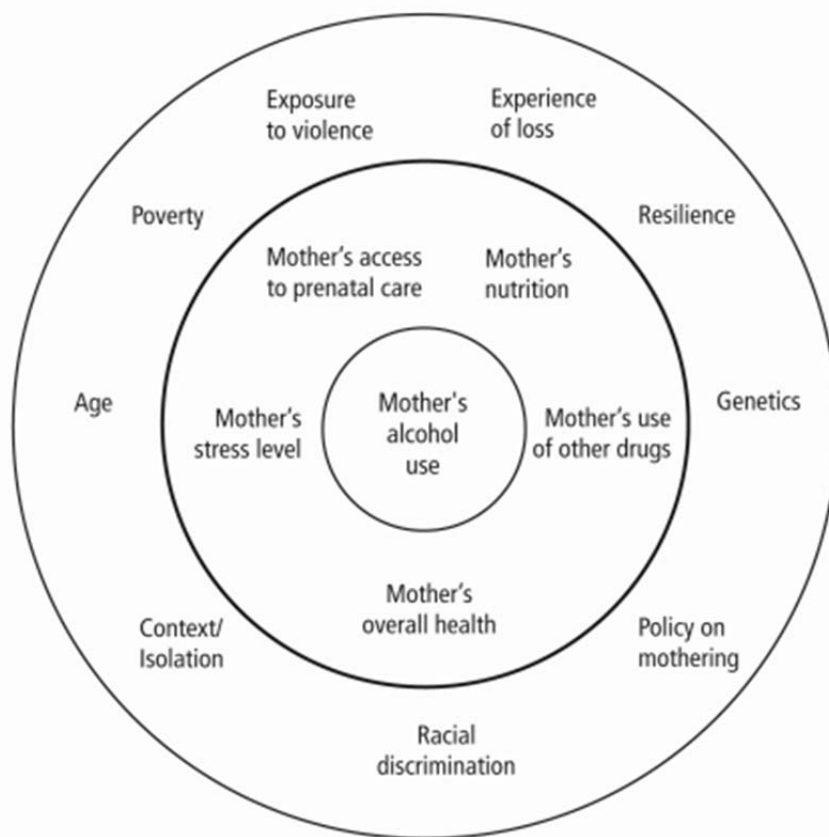
250 Public Health Agency of Canada, *Fetal Alcohol Spectrum Disorder (FASD)*, 2012.

251 Chudley, A.E., et al. 'Fetal alcohol spectrum disorder: Canadian guidelines for diagnosis', *Canadian Medical Association Journal*, March 2005, p172.

252 Chudley, A.E., et al. 'Fetal alcohol spectrum disorder: Canadian guidelines for diagnosis', *Canadian Medical Association Journal*, March 2005, p172.

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we need to move from a focus on women's alcohol use alone to increased understanding of related health and social problems experienced by women that contribute to FASD, and to provide a network of supports that directly address these contributing factors. Community health policy that addresses broader determinants of health is also foundational to successful FASD prevention.²⁵³



This means that effective prevention will need attention to the social determinants of health. This translates into expenditure. However, as chapter six outlines, the cost of inaction is greater than the social and economic cost of effective prevention, intervention and management.

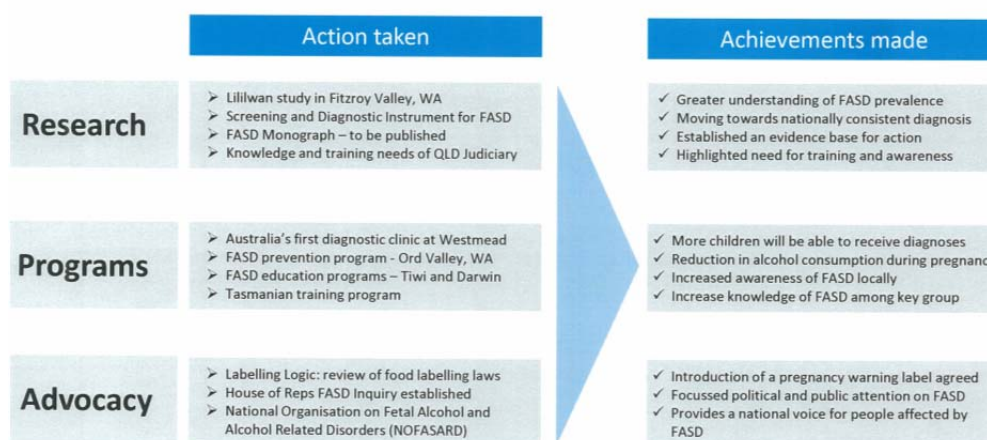
253 Poole, N. (2003). *Mother and Child Reunion: Preventing Fetal Alcohol Spectrum Disorder by Promoting Women's Health*. Vancouver, BC, p5

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Preventing FASD in WA in 2012

In Australia, when taken as a whole, there is an increasing level of awareness and consequent response to the issue of FASD.

Figure 11.1 Actions taken and achievements made²⁵⁴



However, much remains to be done.

Workforce training and development

The Royal Australasian College of Physicians advised the Committee that there is a need for formal training of a range of health professionals including community nurses, allied health professionals, general practitioners, paediatricians, physicians and psychiatrists to better identify and diagnose children and adults with FASD and to recognise the needs of the diagnosed individuals.²⁵⁵

A recent survey of 1,143 health care professionals throughout Western Australia found in relation to FAS that:

- *only 12% could identify all four FAS essential diagnostic features;*
- *most respondents had never diagnosed FAS;*
- *53% believed that diagnosing FAS might stigmatise a child or their family;*
- *4% were convinced of FAS but did not record it;*

²⁵⁴ Foundation for Alcohol Research and Education, 'Changing the way we respond to Fetal Alcohol Spectrum Disorders', email 13 June 2012.

²⁵⁵ Submission No. 25 from The Royal Australasian College of Physicians, June 2012, p3.

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- *less than half the health professionals caring for women said they routinely asked pregnant women about alcohol use in pregnancy; and*
- *less than one third of respondents advised pregnant women not to become intoxicated;*²⁵⁶

There is no comparable survey in relation to FASD.

The spectrum of health services that touch on FASD is broad. Health service involvement will often include vision and hearing services, psychiatric and psychological intervention, early childhood developmental intervention as well as monitoring of growth and specific organ abnormalities, for example, congenital heart disease. Additionally, teachers require special skills and training to educate children who suffer FAS/FASD.²⁵⁷

Training of health and education professionals who are likely to encounter FASD is considered a good starting point in the prevention, intervention and management of FASD. This is especially the case as FASD is a relatively recently acknowledged phenomenon.²⁵⁸ To date few professionals have received much training.

Barriers to changing professional practice

A number of factors have been identified in the recently published *Monograph of the Intergovernmental Working Party on Fetal Alcohol Spectrum Disorders*. The level at which these barriers to innovation and change work are listed as follows:

- Healthcare system – resources and policies;
- Political environment – ideology;
- Social environment - the needs of disadvantaged groups;
- Education environment – the curricula;
- Practice environment – time, resources, organisational structure;
- Practitioners – knowledge, beliefs and attitudes; and
- Patient client – demands and perceptions.²⁵⁹

Knowledge of FAS/FASD and the effects of alcohol in pregnancy is the key to early diagnosis and subsequent intervention and to minimising adverse outcomes.²⁶⁰

256 The Intergovernmental Committee on Drugs, *Monograph of the Intergovernmental Working Party on Fetal Alcohol Spectrum Disorders*, report prepared by Lucy Burns, Emma Black and Elizabeth Elliott, June 2012, p69.

257 Submission No. 25 from The Royal Australasian College of Physicians, June 2012, p3.

258 The Intergovernmental Committee on Drugs, *Monograph of the Intergovernmental Working Party on Fetal Alcohol Spectrum Disorders*, report prepared by Lucy Burns, Emma Black and Elizabeth Elliott, June 2012, p13.

259 The Intergovernmental Committee on Drugs, *Monograph of the Intergovernmental Working Party on Fetal Alcohol Spectrum Disorders*, report prepared by Lucy Burns, Emma Black and Elizabeth Elliott, June 2012, p69.

Some limited training of the Western Australian workforce has in fact been carried out over the past two to three years. Both the Minister for Community Service and the Minister for Energy, representing the Minister for Education, advised the Parliament of Western Australia in 2012 of some of the training initiatives currently being undertaken to raise awareness of FAS/FASD. These are detailed in Appendix six of this report.

The Committee acknowledges that change is complex and requires a multi-level approach that is not simply about 'the training of individuals. There is a need to implement a raft of broader systems changes that address both the barriers and the stigma associated with FASD.'²⁶¹

Finding 22

There is currently a lack of knowledge of FASD amongst health professionals in different disciplines. Training health professionals is important if Western Australia is to achieve stronger prevention and intervention outcomes for FASD. Some steps have been taken to raise awareness by relevant government departments. In addition to training there are a range of barriers to be overcome that will require organisational change.

The Foetal Alcohol Spectrum Disorder Model of Care

Western Australia has become the first state to introduce a model of care in a response to FASD.

It is known as the Foetal Alcohol Spectrum Disorder Model of Care, (Model of Care). In common with some other Health Department models of care, it promotes a multi-agency approach in its response to the issue. The multi-agency approach is supported by the fact that it is the product of a working group with diverse representation from various government and non-government agencies. The FASD Model of Care describes the continuum of care, including the prevention, diagnosis, and treatment and management of FASD.²⁶²

The Model of Care's history commenced when, in 2008, the Office of Aboriginal Health approached the Department of Health to consider developing a Foetal Alcohol Spectrum Disorder (FASD) model of care.²⁶³ Subsequently the FASD Model of Care was developed under the banner of the WA Child and Youth Health Network, which

260 The Intergovernmental Committee on Drugs, *Monograph of the Intergovernmental Working Party on Fetal Alcohol Spectrum Disorders*, report prepared by Lucy Burns, Emma Black and Elizabeth Elliott, June 2012, p76.

261 The Intergovernmental Committee on Drugs, *Monograph of the Intergovernmental Working Party on Fetal Alcohol Spectrum Disorders*, report prepared by Lucy Burns, Emma Black and Elizabeth Elliott, June 2012, p79.

262 Submission No. 12 from Department of Health, December 2012, p5.

263 Ms Kate Gatti, Clinical Lead, Child and Youth Health Network; Population Health Area Director, WA Country Health Service, *Transcript of Evidence*, 28 March 2012, p2.

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included representation from other government agencies, health services and research organisations. In 2010 the WA Child and Youth Health Network published the FASD Model of Care.²⁶⁴

The Model of Care priority is prevention

While including recommendations on screening and diagnosis the Model of Care's priorities lie in prevention. The goal of the model is to reduce 'the prevalence of FASD, recognising there is no cure for this avoidable condition.'²⁶⁵

Another reason for the focus on prevention rather than intervention is that, in the absence of diagnosis of FASD there is little knowledge of its prevalence. In the absence of knowing its prevalence there is no basis upon which it can be determined whether or not an intervention has made a difference or not.

*So you are caught in a catch 22 ... you do not get the literature or evidence being developed until you have some notion of how widespread the problem of focus is. Until such time as you get some notion of that, you have very little idea about how much difference you have made with regard to the outcome.*²⁶⁶

The model adopts an across-government and sector approach that focuses on primary, secondary and tertiary care and prevention.^{267,268}

No additional funding for the Model of Care

The current focus of the implementation of the Model of Care is confined to prevention. However, the Committee was advised that no additional funding has been attached to this or any other proposed strategy.

*No new money or project funding has been made available to develop and implement the state-wide implementation plan for the FASD MOC. Resources, in the form of staff time come from already current Departmental resources.*²⁶⁹

As one witness put it:

264 Submission No. 12 from Department of Health, December 2012, p5.

265 Submission No. 12 from Department of Health, December 2012, p5.

266 Mr Gary Kirby, Director, Prevention and Workforce Development, Drug and Alcohol Office, *Transcript of Evidence*, 20 June 2012, p4.

267 Mr Neil Guard, Executive Director, Drug and Alcohol Office, *Transcript of Evidence*, 20 June 2012, p3.

268 Submission No. 12 from Department of Health, December 2012, p5.

269 Ms Kate Gatti, Area Director, Population Health, WA Country Health Service, Electronic Mail, 10 May 2012.

*While there might not be any money attached to it, there is an awful lot of enthusiasm and a lot of goodwill and a lot of people putting time an effort into it, for no financial gain, because they think this is really important.*²⁷⁰

Finding 23

The recently released and adopted Foetal Alcohol Spectrum Disorder Model of Care is focussed on prevention. However, it remains unfunded and is being implemented out of existing resources, by way of the enthusiasm and goodwill of existing agency staff who believe in its importance.

The Model of Care aligns with national directions, including the recently released Intergovernmental Committee on Drugs (IGCD) monograph, and its multiple care recommendations are 'pretty consistent with the majority of the recommendations in the monograph.'²⁷¹

This Monograph on Foetal Alcohol Spectrum Disorders (FASD) was released on 28 June 2012, six years after its inception.

*The Monograph aimed to examine current research, policy and practice relating to FASD in Australia and was completed in 2009. The Monograph has had a long pregnancy; commissioned in 2006 by the Intergovernmental Committee on Drugs (IGCD) and prepared under the auspices of the Ministerial Council on Drug Strategy (MCDS) during 2008/09. Since its completion in 2009 the publication has slowly made its way through various Government committees including the Australian Health Ministers Conference and the Australian Population Health Development Principal Committee and most recently through the Standing Committee on Health.*²⁷²

Effective implementation of the Model of Care will require a coordinated interagency approach as the issues are broader than DOH. Endorsement and support for an across Government approach has been received from the Community Services Leadership Group (CSLG). The CSLG is made up of Directors General from all human and health services departments in WA. A Project Control Group has been established with key agencies including the Drug and Alcohol Office, Department of Education and

270 Dr Carol Bower, Epidemiologist, Telethon Institute of Child Health Research,, Transcript of Evidence, 16 May 2012, p8.

271 Mr Neil Guard, Executive Director, Drug and Alcohol Office, *Transcript of Evidence*, 20 June 2012, p3.

272 the Intergovernmental Committee on Drugs, Monograph of the Intergovernmental Working Party on Fetal Alcohol Spectrum Disorders, report prepared by Lucy Burns, Emma Black and Elizabeth Elliott, June 2012.

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Department for Communities to develop implementation plans as outlined in the FASD Model of Care recommendations.

Model of Care recommendations

The MOC includes 33 recommendations across the areas of prevention, screening, diagnosis, advocacy and partnerships, workforce and professional development and monitoring, evaluation and surveillance.

The MOC's Clinical based objectives include:

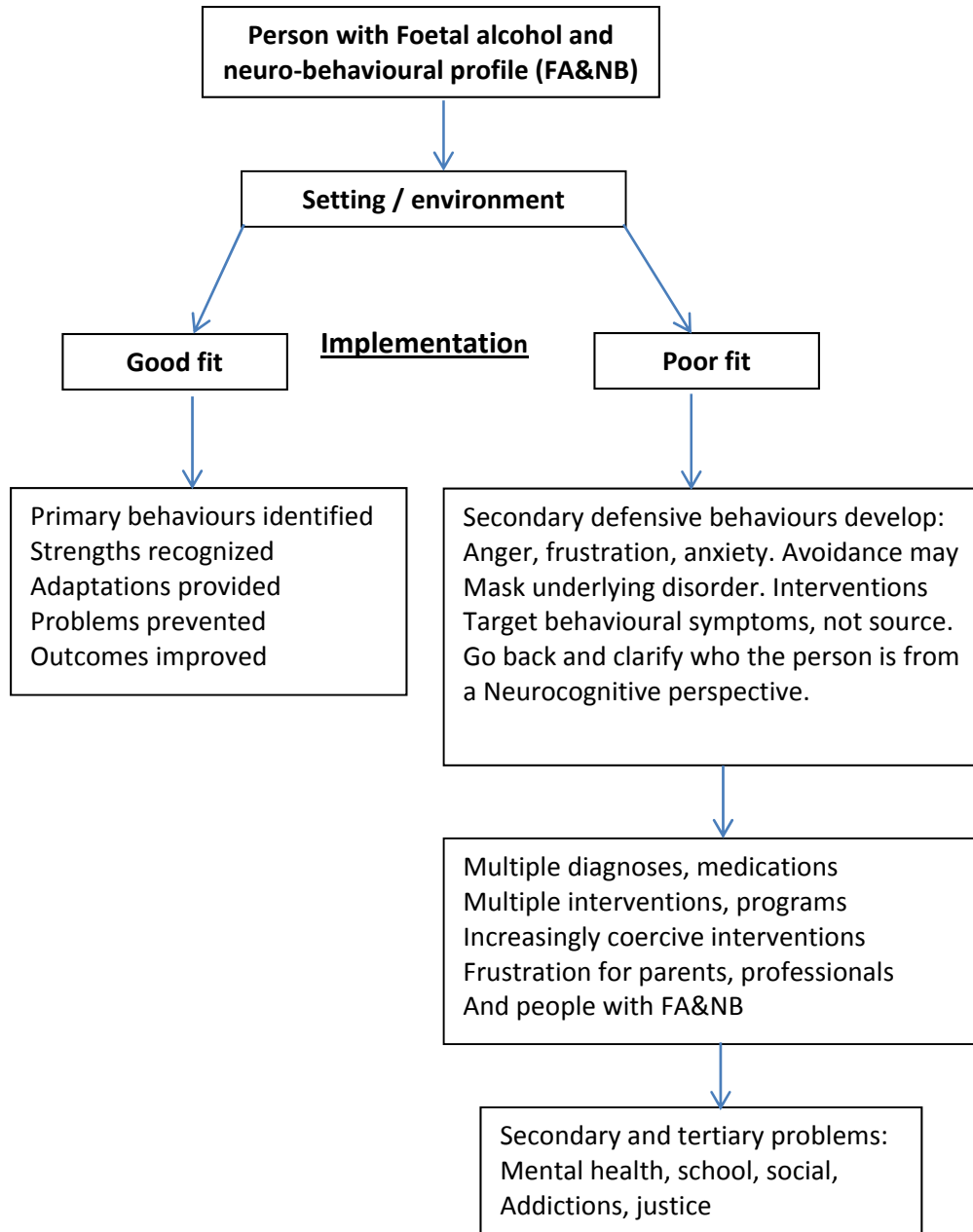
- Prioritise use of prevention strategies;
- Implement appropriate screening to prevent FASD; and
- Early intervention

The identified enablers to meeting the objectives, other than resources, include:

- An interagency approach –coordinated and collaborated services with effective cross-sector communication;
- Research and data linkage to develop evidence base;
- Training and education, workforce development; and
- Clinical pathways for cross sector assessment, diagnosis, treatment and management

The need for effective prevention/intervention and management decision-making strategies is illustrated in the following tree.

Environmental accommodations decision tree



Chapter 11

Justice Reinvestment

In considering the cost of the measures for the management of FASD, prevention strategies and addressing intervention needs, that cost may be offset at a later date in some communities, against savings in the criminal justice system.

Nationally, the average cost of keeping an adult in prison for a year, including capital costs, is approximately \$100,000. The cost of detaining a young person is higher. There is a strong evidentiary base for the proposition that early intervention can substantially reduce the risk of contact with the criminal justice system in adolescence and adulthood.

Justice reinvestment redirects money from the justice system into crime prevention and community services by investing in additional services to significantly improve the social determinants of health.

Justice Reinvestment recognises that most offenders come from a small number of disadvantaged communities with poor social determinants. As such it responds both to the individual and to the causes of crime through a less centralised more localised approach to reduce offending. Such approaches have met with demonstrable success in some jurisdictions.

The Commonwealth Senate Legal and Constitutional Affairs Reference Committee supported trialling justice reinvestment after further mapping. The Committee recommended in 2009 'that the federal, state and territory governments recognise the potential benefits of justice reinvestment, and develop and fund a justice reinvestment pilot program for the criminal justice system.'²⁷³

In November 2010 the Western Australian Community Development and Justice Standing Committee recommended a properly funded, evidence based, collaborative Justice Reinvestment strategy. A pilot evaluation was proposed for one metropolitan and one regional 'high stakes' community. The community selected would have been identified by the recommended mapping exercise. This pilot assessment would measure the effectiveness of the role of each of the individual participating agencies in addition to specific outcomes relating to the interagency collaboration on the ground.²⁷⁴ This Committee supports the evaluation of such a pilot program.

273 Senate Legal and Constitutional Affairs Reference Committee, *Alternative means of delivering justice*, 6.56. Available at: http://www.aph.gov.au/Parliamentary_Business/Committees/Senate_Committees?url=legcon_ctte/access_to_justice/report/c06.htm. Accessed on 23 July 2012.

274 Community Development and Justice Standing Committee, *Making our prisons work*, Perth, Western Australia, November 2010, p112.

Finding 24

The road to preventing alcohol use in pregnancy starts long before a woman thinks about getting pregnant. Contributing factors to alcohol use may include trauma, poor education, lack of access to services, low family income, a lack of resources and opportunities. Prevention strategies are required where women live, learn, work and socialise.

Finding 25

The lack of services in some regional/remote areas contributes to poor social determinants of health which, in turn, are significant contributing factors to alcohol consumption during pregnancy.

There are indicatively a disproportionate number of people with FASD in the Justice system from some of these communities.

Recommendation 19

The Committee recommends the Government fund in the 2013 budget, the 2010 'Making prisons work' report recommendation to pilot an evidence based, collaborative 'Justice Reinvestment' strategy in a regional 'high stakes' community.

This pilot study should measure the effectiveness of individual agencies as well as specific outcomes relating to interagency collaboration.

Chapter 12

It takes a village - The need for collaboration

The impact of FAS/FASD is cross sectoral, and therefore the most cost effective intervention that the agencies can make to achieve an effective outcome is collaborative.

Why the need for collaboration?

While Foetal Alcohol Spectrum Disorder is a disability resulting from pre-natal exposure to alcohol, it does not occur in isolation. FASD results from a complex interplay of legal, biological, social, psychological, environmental and economic factors. The complexity of these co-factors demands a coordinated interagency response.

Figure 12.1 The background factors contributing to unsafe alcohol consumption²⁷⁵



The need for a multi-agency collaborative approach to FASD was highlighted by many witnesses to the Committee:

*[FASD] requires a multi-agency approach. Health cannot fix this, nor can any one person.... No one agency can own this.*²⁷⁶

275 Foundation for Alcohol Research and Education, 'Changing the way we respond to Fetal Alcohol Spectrum Disorders', email 13 June 2012.

276 Mrs Kate Gatti, Clinical Lead, Child and Youth Health Network; Population Health Area Director, WA Country Health Service, Transcript of Evidence, 28 March 2012, p.

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*People with FASD and their carers require extensive support over many years and often struggle to access assistance from social services, education and training, justice and health agencies.*²⁷⁷

*The National Surveillance of FAS through the Australian Paediatric Surveillance Unit demonstrated the importance of early diagnosis, referral and multi-disciplinary, cross-portfolio approach to care of children with FAS.*²⁷⁸

*There is broad consensus that the most effective means of delivering early childhood services, particularly for vulnerable children, is through a multi- agency or integrated systems approach.*²⁷⁹

As a disability, the impact of FAS/FASD is cross sectoral, and therefore the most cost effective intervention that the agencies can make to achieve an effective outcome is collaborative. In the context of the complexity of the issue, collaboration provides far greater flexibility to meet personal needs than a silo approach by departments. There needs to be an ability to connect resources and activities across entire systems of governance. In a service domain dominated by functional agencies, inter-agency effort can achieve better results for specific people, locations and issues.²⁸⁰

Another of the drivers for collaboration in this area is the need to reduce the number of 'doors a person has to knock on' in order to gain a diagnosis of FAS/FASD or secure access to an intervention program. Currently, there is evidence that the process of gaining assessment for a disability or cognitive impairment 'can take many, many months because you go to a physio one day, an OT the next, a paediatrician the next et cetera.'²⁸¹ This creates stress and increases the risk factors leading to alcohol abuse.

Whether it is a birth mother or a foster mother, if you have a prolonged period of time to complete the diagnostic measures for any child going through that process irrespective of what their final diagnosis is, it is very, very stressful. If you are dealing with a family who still have dependency issues, that stress is likely to make it more difficult for them to be restrained in their use of whatever substances

277 Submission No. 21 from Foundation for Alcohol Research and Education, April 2012, p22.

278 Submission No. 14 from Clinical Professor Carol Bower, Senior Principal Research Fellow, Telethon Institute for Child Health Research, January 2012, p15.

279 Department of Education and Employment and Workplace Relations, *Submission to the Standing Committee on Social Policy and Legal Affairs*, 2012, p4.

280 Tim Farland, Strategic Projects Division Dept. of Premier and Cabinet, NSW

281 Dr James Fitzpatrick, Paediatric Doctor, The George Institute for Global Health, *Transcript of Evidence*, 9 May 2012, p16.

*they are dependent on. You are adding to their stress irrespective of whether you are looking for FASD or anything else.*²⁸²

In one submission, the need for a systemic collaborative response to FAS/FASD was highlighted, to deliver evidence based screening, assessment and interventions. This response would see 'the formation of partnerships between health care and education providers, both government and non-government, primary, secondary and tertiary health and educational services.' It would require 'a continued and expanded provision of primary, secondary and tertiary health resources together with enhanced knowledge and competency for both health and education professionals.'²⁸³

In a similar vein, one witness highlighted the multidisciplinary approach adopted in the state of Washington:

*When I was in Washington, once you diagnosed the children and then you went out to the school and fed the information to the team about what these children's strengths are and what their limitations were, you knew you were feeding that information forward to a multidisciplinary team at the school.*²⁸⁴

A holistic, integrated approach supports the 'Connected approaches', the second key reform direction, of the 'Mental Health Commission, Mental Health 2020: Making it personal and everybody's business' publication.'²⁸⁵

Finding 26

There is a demonstrated need for evidence based screening, assessment and intervention services. This response would necessitate partnerships between all government and non-government health and education providers.

Prevention, early detection and appropriate intervention are integral to responding to FAS/FASD for reasons illustrated below.

282 Dr Raewyn Mutch, Paediatrician and Post-doctoral Fellow with the Alcohol and Pregnancy Research Group of the Telethon Institute for Child Health Research, Transcript of Evidence, 9 July 2012, p7.

283 Submission No. 11 from Peel and Rockingham Kwinana Mental Health Service Steering Committee, December 2011, covering letter.

284 Dr Raewyn Mutch, Paediatrician and Post-doctoral Fellow with the Alcohol and Pregnancy Research Group of the Telethon Institute for Child Health Research, *Transcript of Evidence*, 9 July 2012, p5.

285 Submission No. 11 from Peel and Rockingham Kwinana Mental Health Service Steering Committee, December 2011, covering letter.

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Figure 12.2 Prevention, early detection and appropriate intervention - the circle of need



It takes a village to address FAS/FASD

*The future of our country...
Does not only lie within our mothers' wombs...
But also in the supporting hands of many...
Mothers', Fathers', Families', Community Leaders'...
And yours...because in the end it takes a village to raise a child.²⁸⁶*

FAS/FASD, as outlined throughout this report, is a social, moral and ethical problem borne by all of us.

In the absence of identification, people with FASD often experience chronic frustration. Over time, patterns of defensive behaviours commonly develop, but these characteristics could be prevented with appropriate supports. As such these are generally known as 'preventable secondary characteristics'. As discussed earlier in this report they include:

- *Fatigue, tantrums*
- *Irritability, frustration, anger and aggression*
- *Fear, anxiety, avoidance and withdrawal*
- *Shut down, lying, running away*
- *Trouble at home, school and community*
- *Legal trouble*
- *Drug / Alcohol abuse*
- *Mental health problems (depression, self-injury, suicidal tendencies).²⁸⁷*

When left unmanaged, these secondary characteristics cause serious social and behaviour problems that impact the individual and the community.

Managing FASD must include ensuring access to appropriate community care and support services across education, health, community services, employment and criminal justice sectors for the communities, families and individuals impacted by FASD.²⁸⁸

Currently, different approaches may be taken by social services, education, health, the courts and the corrections system. The resulting fragmentation can be frustrating to people affected by FASD and expensive for tax payers. There should be 'no wrong doors' for people

286 FASfacts, *It takes village*, Available at: <http://fasfacts.org.za/fas-information/village>. Accessed on 2 July 2012.

287 Submission No. 22 from The Russell Family Fetal Alcohol Disorders Association, May 2012, p2.

288 Submission No. 25 from The Royal Australasian College of Physicians, June 2012, p3.

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*affected by FASD who need support; mechanisms need to be in place to ensure such support is seamless. Services should address cumulative risk, both environmental and biological, and not be based on silos of care.*²⁸⁹

The earlier management can be instituted, the better the outcomes for children and their families.²⁹⁰ A recommended strategy is the assessment of children at key developmental transition points, by multidisciplinary teams; for instance at ages 5 (entering school), 12 (starting high school) and 18 (leaving school) as well as at other transitions such as entering foster care or incarceration. In this way therapy could be tailored to ensure that children, youth and adults with FASD receive the most effective treatment.²⁹¹

The integrated response to preventable secondary characteristics

There are two existing agency models of integrated responses to service needs in Western Australia.

The Disabilities Service Commission (DSC).

*It is in the area of citizen centred services that the Commission has demonstrated success. In a range of initiatives the Disability Services Commission has been able to make significant progress in ensuring that the services delivered to individuals are those most needed (and desired) by the person and their family. It is through the development of these initiatives that the Commission has also been successful in developing links between itself and other agencies.*²⁹²

The Mental Health Commission whose Mental Health 2020 Strategic Policy proposed a whole of government and community approach to mental health, with three key directions for the future:

- person centred supports and services;
- connected approaches; and
- balanced investment.

289 Institute of Health Economics Consensus Statements, *Volume 4 – October 7 - 9, 2009*, p7. Available at: http://www.ihe.ca/documents/FinalWeb_FASDStatement.pdf. Accessed on 17 July 2012.

290 Dr Carol Bower, Epidemiologist, Telethon Institute of Child Health Research,, *Transcript of Evidence*, 16 May 2012, p5.

291 Submission No. 25 from The Royal Australasian College of Physicians, June 2012, p4.

²⁹² Submission No. 44 from Disability Services Commission, to the Community Development and Justice Standing Committee 31 March 2008, p3.

The Mental Health Commission suggests that such ‘person centred’ supports and services will help give people with mental health problems and/or mental illness increased choice, flexibility and control of the services they receive. More emphasis will be placed on the important role of family, carers and friends in supporting people.²⁹³

Additionally, better connections between public and private mental health services and the range of formal and informal supports, services, and community organisations will help ensure better support for people.²⁹⁴

The three key directions are similar to those proposed to the Committee for people with FASD and for their family or carers.

Who or which agency should take responsibility?

A whole of government response is needed to address the underlying contributory factors leading to alcohol use in pregnancy and therefore to FASD. The affected agency sectors include:

- Health;
- Employment;
- Education;
- Justice;
- Indigenous affairs;
- Community;
- Housing; and
- Liquor Licensing.

While there is no cure for FASD, there are strategies that can be implemented to prevent FASD, and to lessen the impact of the condition on people with FASD. This can occur if governments demonstrate strong leadership in the prevention, early intervention, and management of FASD. The impact of strong government leadership on improving health and social outcomes for people with a disability can be demonstrated through Australia’s experience with Autism Spectrum Disorders. Changes in diagnostic practices, referral patterns, availability of services, age at diagnosis and greater public

293 Mental Health Commission, *Mental Health 2020 Strategic Policy*, 2012 Available at: http://www.mentalhealth.wa.gov.au/about_mentalhealthcommission/Mental_Health2020_strategic_policy.aspx. Accessed on 7 May 2012.

294 Mental Health Commission, *Mental Health 2020 Strategic Policy*, 2012 Available at: http://www.mentalhealth.wa.gov.au/about_mentalhealthcommission/Mental_Health2020_strategic_policy.aspx. Accessed on 7 May 2012.

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*awareness of autism has led to dramatically increased prevalence rates since the 1990s.*²⁹⁵

As this report has highlighted, FASD is a broadly preventable and often devastating disability. Its implications not only impact the life of the child but its family and the community in which it lives. There are significant imposts on the health system, the education and justice system.

This report argues that any response to this lies across government and requires a whole of government response. In some sectors of government this is acknowledged.

*The network, of which I am lead, is now moving through a phase to implement the [FASD] model of care. It requires a multi-agency approach. Health cannot fix this, nor can any one person. Fundamentally, the problem is a cultural issue. We need to change our attitudes to alcohol generally, but in this case particularly around the intake of alcohol during pregnancy. ... We have developed a governance structure around who will own this. It is a multi-agency government structure. There are number of interested groups.*²⁹⁶

While the management of FASD can only follow on from diagnosis, there is little advantage to diagnosis without effective intervention and support services.

*Diagnosis is the first step – be prepared to organise everything that follows; – we should not diagnose unless we have something to offer.*²⁹⁷

The consequential outcome of effective FASD diagnosis will have a profound impact in many realms: program development, service delivery, policy creation, funding projections, staff training, and public awareness.

Currently, the Department of Health is making the running through the Drug and Alcohol Office in responding to FASD. It is considered that in many ways that Department would continue to be well placed to be the lead agency.

295 Submission No. 21 from Foundation for Alcohol Research and Education, April 2012, p8.

296 Mrs Kate Gatti, Clinical Lead, Child and Youth Health Network; Population Health Area Director, WA Country Health Service, *Transcript of Evidence*, 28 March 2012, p2.

297 Ilona Autti-Rämö, MD, Chief of Health Research; Research Professor, The Social Insurance Institution, Helsinki, Finland

Recommendation 20

The Committee recommends the Government develop a range of holistic community, education, employment and health services to support individuals and families who are affected by FASD with the Department of Health as the lead agency and report back to Parliament on these by December 2013.

Recommendation 21

The Committee recommends the Minister(s) support a family case management approach to prevent alcohol abuse in persons and families where there are positive indicators that FASD is present or there are risk factors for FASD. The Government to report back to Parliament on this approach by December 2013.

Conclusion

Western Australia (mainly through the Telethon Institute for Child Health Research) has conducted and published much of the research undertaken in this country on FASD. In addition, the uniquely designed and executed prevalence study, 'the Lirilwan project' has been undertaken in the Kimberley by the George Institute for Global Health, Sydney, and the Discipline of Paediatrics and Child Health at the University of Sydney.

The WA Child and Youth Health Network, which included representation from state government agencies, health services and research organisations has developed the FASD Model of Care. This is a first for Australia.

Given the relatively high profile the state has for its response to FASD, the Committee encourages the State government to invest in the prevalence and prevention of FASD.

The Committee was surprised to hear from witnesses that they believed there was minimal awareness at a Ministerial level of FASD. There was expressed concern that the government may delay responding to FASD because of the known costs of providing the resources required to address the problem.²⁹⁸

The Committee was advised that the State government has not provided additional funding to the implementation of the Model of Care which currently draws on the enthusiasm of agency staff utilising existing funds from other line items for its limited implementation. A strong interagency collaborative approach is required for the prevention, management and intervention of FAS/FASD.

298 Briefing Broome 14 March 2012.

Chapter 12

Leadership is required at a senior level to reduce the prevalence of FASD in Western Australia. The current efforts by middle management require higher level support to ensure continued successful collaboration and expansion of service delivery. The sustainability of projects becomes precarious when they rely on the enthusiasm and commitment of individuals.²⁹⁹ In the absence of real authority for implementation, anything that requires complex solutions tends not to happen.³⁰⁰ The strength of Ministerial/CEO advocacy for a project can be a critical factor; conversely the absence of a Ministerial champion may hamper the progress and success of a project.³⁰¹

The Committee believes that until FASD becomes the responsibility of an identified Minister at cabinet level, the preventable tragedy represented by FASD, will not only increase but that the family and community consequences of a failure to respond will be felt for generations to come.

Recommendation 22

The Committee recommends that by December 2012 the Premier appoint a Minister, to have responsibility for a collaborative intergovernmental approach to the prevention, treatment and management of children and adults with FASD in WA.

²⁹⁹ Submission No. 27 from the Commissioner for Children and Young People, to an Inquiry into Collaborative Approaches in Government – not tabled - 13 March 2008, p4.

³⁰⁰ Submission No. 25 from John Mant Consultant Urban Planner, to an Inquiry into Collaborative Approaches in Government – not tabled - 31 March 2008, p4.

³⁰¹ Submission No. 47 from Western Australia Police, to an Inquiry into Collaborative Approaches in Government – not tabled - 31 March 2008, Annexure A p3.

Appendix One

Historical references to alcohol consumption during pregnancy

Biblical "Behold, thou shalt conceive and bear a son: and now drink no wine or strong drinks. "Judges 13:7

Aristotle In *Problemata*, stated, "...foolish, drunken, or hair-brained women for the most part bring forth children like unto themselves, morose and languid." (Burton, 1621)

1700s In the early part of the century, England's relaxed traditional restrictions on distilling and selling gin, which hit London's slums especially hard. Within a few years of the "Gin epidemic" (in 1726), the Royal College of Physicians petitioned parliament of controls on liquor and called the gin "...the cause of weak, feeble and distempered children." (See Hogarth lithograph, "Gin Lane," 1751)

1857 Morel published this theory which stated that "...parental darkness produced depravity, alcoholic excess, and degeneration in the first generation of offspring and progressively more severe symptoms in their children, until the fourth generation developed sterility, which caused extinction of the line." (Rosett)

1800s Numerous reports in the U.S. and in Britain describing alcohol's harmful effects on the fetus.

1899 Sir Francis Galton noted that children born to mothers during sobriety were healthy; they were "neurotic" if born during a drinking period. He reasoned that the women's tissue must have been drenched with alcohol, the "...infant alcoholised through its existence." He also reasoned the mothers' milk would be of diminished quality and that alcohol would have a contributing effect on a bad home environment which would "... prejudice the health of growing child."

1899 W.C. Sullivan conducted the first "truly scientific" study of the teratogenicity of alcohol. He compared infants born of chronically alcoholic mothers in the Liverpool Jail: The death rate by age 2 of the children was 56% for firstborn (2.5x greater than that of a non-alcoholic relatives), and 76% among sixth born. He also observed that women who had previously given birth to impaired children gave birth to perfectly healthy infants when, due to the mothers' incarcerations they were forced to abstain from alcohol. (1899)

1901 Paul LaDrague, a French medical student wrote observed Fetal Alcohol Effects.

1923-30 Hanson reported no "...deleterious or beneficial effects (of alcohol) on the progeny." As result, the problem become uninteresting – there was nothing to look for. (Pauley, 1996)

1957 Jacqueline Rouquette described malformation patterns in 100 foundling home children.³⁰²

1965 Ashley Montague wrote in *Life Before Birth*, "...it can now be stated categorically, after hundreds of studies covering many years, that no matter how great the amounts of alcohol taken by the mother—or by the father, for that matter—neither the germ cells nor the development of the child will be affected.

1968 Dr. Lemoine in France described the strikingly similar pattern of facial malformations in children born of alcoholic mothers. This article did not initially appear in U.S. literature.

1970 Christy Ulleland, a paediatric resident, noted a group of "failure to thrive" infants who showed no improvements, despite special treatment. She discovered all of the infants shared one common variable: Maternal alcoholism.

1973 Diagnostic criteria for full Fetal Alcohol Syndrome were established. Within a few years, the term Fetal Alcohol Effects was being used where there was a history of prenatal alcohol exposure but the person did not meet the criteria for a diagnosis of FAS.

1970-1980 Over 2,000 articles written documenting the range of effects and implications. Significantly, the disseminations of this information has been slow; physicians continue to recommend drinking to provide "relaxation," and in some areas, La Leche League recommends drinking during nursing.

1983 Study confirmed measurable negative effects on foetuses of prenatal alcohol drips routinely used to arrest premature labour.

1996 Institute of Medicine introduced the term Alcohol-Related Neurodevelopmental Disorder (ARND) to replace more ambiguous term Fetal Alcohol Effects. Studies continued to clarify primary and secondary characteristics associated with FAS.

2004 Terminology continues to evolve; Fetal Alcohol Spectrum Disorders (FASD), a non-diagnostic descriptive umbrella term that captures FAS and the continuum of effects, is adopted. Disagreements on diagnostic criteria for the spectrum of effects continues; the 4-digit scale development by Clarren and Astley is widely used in Canada and now more commonly in the U.S.

302 Malbin, D., *Fetal Alcohol/Neurobehavioural conditions*, FASCETS, Oregon, 2011, p6.

2009 Continued research on pre- and post-natal events affecting brain function in addition to alcohol exposure broadens the umbrella to encompass the entire neurobehavioral spectrum which includes Fetal Alcohol / Neurobehavioral conditions and the acronym FA/NB.

Appendix Two

Functional neuro-behavioural assessment (FNA)

Examples of fit and accommodations for FA/NB

| Setting expectations | Brain tasks | Primary characteristics FA/NB | Secondary characteristics FA/NB | Strengths | Accommodations |
|---|---|---|--|--|---|
| School or employment | | | | | |
| Understand spoken instruction | Fast auditory pace | Slow auditory pace | Anxiety, frustration | Visual learner | Slow down, build on strengths |
| Be age-appropriate | Development on time | Dysmaturity | Isolation, bullied, teased | Willing, friendly, trusting | Adjust expectations; recognize developmental level of functioning |
| Work quickly | Fast cognitive pace | Slow cognitive pace | Fear, frustration, avoidance | Hands-on, experiential learner | Slow down, give more time |
| Concentrate for long periods | Cognitive stamina | Easily fatigued | Irritability, tantrums, avoidance | Hard worker | Adjust work load, give breaks, assure success |
| Learn quickly and remember | Strong memory | Memory storage and retrieval problems | Anger, frustration, anxiety, avoidance | Experiential learns by doing | Show, model, reteach, ask person for strategies |
| Mental health Addictions | | | | | |
| Cognitive behavioural techniques: Language-based programs | Ability to process language form associations, abstract | Concrete; difficulty with language; difficulty with abstraction | Seen as “noncompliant” treatment failure; escalating interventions | Artistic, musical, creative; learns through senses | Recognize brain function; build on strengths; avoid pathologizing |
| Apply new understanding in all environments | Ability to generalize | State-specific learning; difficulty generalizing | Increased frustration; experience of failure | Relational, experiential | Adapt programs; model; mentor to assure application in different settings |

Appendix Three

Diagnostic criteria based on Canadian Guidelines for the Diagnosis of FASD

| Diagnostic category | Fetal Alcohol Syndrome (FAS) | Partial Fetal Alcohol Syndrome (pFAS) | Neurodevelopmental Disorder-Alcohol Exposed (ND/AE) |
|----------------------------------|---|--|---|
| Diagnostic criteria | Requires all 4 criteria below to be met | Requires confirmed prenatal alcohol exposure, the presence of 2 of the 3 characteristic facial anomalies at any age, and CNS criteria to be met | Requires confirmed prenatal alcohol exposure and CNS criteria to be met |
| Prenatal alcohol exposure | Confirmed or unknown | Confirmed | Confirmed |
| Facial anomalies | Presence of all 3 of the following facial anomalies at any age: <ul style="list-style-type: none"> • Short palpebral fissure length (≤ 2 standard deviations below the mean using the Hall charts [43]) • Smooth philtrum (Rank 4 or 5 on the UW Lip-Philtrum Guide^a) • Thin upper lip (Rank 4 or 5 on the UW Lip-Philtrum Guide) | Presence of any 2 of the following facial anomalies at any age: <ul style="list-style-type: none"> • Short palpebral fissure length (≤ 2 standard deviations below the mean) • Smooth philtrum (Rank 4 or 5 on the UW Lip-Philtrum Guide) • Thin upper lip (Rank 4 or 5 on the UW Lip-Philtrum Guide) | No anomalies required |
| Growth deficit | Prenatal or postnatal growth deficit indicated by birth length or weight $\leq 10^{\text{th}}$ percentile adjusted for gestational age, or postnatal height or weight $\leq 10^{\text{th}}$ percentile | No deficit required | No deficit required |

| | |
|--|--|
| <p>Central Nervous System (CNS) abnormality</p> | <p>Significant CNS dysfunction (evidence of impairment in 3 or more of the following CNS domains):</p> <ul style="list-style-type: none"> • Hard and soft neurological signs; seizure disorder; gross and fine motor functioning; articulation, phonology and motor speech • Cognition (IQ or uneven cognitive profile) • Memory • Executive functioning and abstract reasoning • Communication (expressive and receptive language) • Attention deficit/hyperactivity and other behavioural problems; including sensory function • Visual motor integration • Adaptive behaviour/social skills/social communication • Academic achievement • CNS structure (including head circumference (HC) \leq 3rd percentile or other structural CNS abnormality) |
|--|--|

Appendix Four

Abbreviations

| | |
|-------|--|
| AEDI | the Australian Early Development Index |
| ARBD | Alcohol-related birth defects |
| ARND | Alcohol-related neurodevelopmental disorder |
| FA/NB | Foetal alcohol/Neuro-behavioural |
| FASD | Foetal Alcohol Spectrum Disorder |
| DEEWR | Department of Education and Employment and Workplace Relations |
| DSC | Disabilities Service Commission |
| DSM | Diagnostic and Statistical Manual of Mental Disorders. |
| FNA | Functional neuro-behavioural assessment |
| IGCD | Intergovernmental Committee on Drugs |
| PNA | Prenatal alcohol exposure |
| SES | Socio economic status |

Appendix Five

Glossary

| | |
|--------------------|---|
| Adaptive behaviour | Adaptive behaviour includes the age-appropriate behaviours necessary for people to live independently and to function safely and appropriately in daily life. Adaptive behaviours include real life skills such as grooming, dressing, safety, safe food handling, school rules, ability to work, money management, cleaning, making friends, social skills, and personal responsibility. |
| Binge drinking | Binge drinking is defined as consumption of alcohol that -brings blood alcohol concentration to about 0.08% or above. This corresponds to an average-size female consuming 4 or more drinks in about 2 hours. This definition is used in the annual Behaviour Risk Factor Surveillance Survey according to the Centres for Disease Control and Prevention |
| Model of Care | A "model of care" broadly defines the way health services are delivered. It outlines best practice care and services for a person or population group as they progress through the stages of a condition, injury or event. It aims to ensure people get the right care, at the right time, by the right team and in the right place. ³⁰³ |

³⁰³ Department of health, *Models of Care*, 2012,. Available at: <http://www.agedcare.health.wa.gov.au/home/moc.cfm>. Accessed on 28 June 2012.

| | |
|--------------------------------------|--|
| <p>Social Determinants of Health</p> | <p>Social determinants of health are non-medical factors that affect well-being. The health of any individual is a complex interaction between many factors. The National Collaborating Centre for Determinants of Health identifies the following as examples of determinants of health (National Collaborating Centre for Determinants of Health, 2007):</p> <ul style="list-style-type: none"> • Income and social status; • Social support networks • Education • Employment and working conditions • Social environments • Geography • Physical environments • Healthy child development • Health services • Gender • Culture` |
| <p>Teratogen</p> | <p>A teratogen is an agent, which can cause a birth defect. It is usually something in the environment that the mother may be exposed to during her pregnancy. It could be a prescribed medication, a street drug, alcohol use, or a disease present in the mother which could increase the chance for the baby to be born with a birth defect.³⁰⁴</p> |

304 Children’s Hospital of Wisconsin, *What is a teratogen*, Available at: <http://www.chw.org/display/PPF/DocID/22924/router.asp>. Accessed on 14 June 2012.

Appendix Six

WA training initiatives

Some limited training of the Western Australian workforce has been carried out over the past two to three years to raise awareness of FAS/FASD. These are detailed as follows.

(1) Staff from the Department for Communities respond to requests for advice and support about FASD from parents, carers and community services, and also distribute a booklet published by the department entitled Foetal Alcohol Spectrum Disorder — Information for people working with children and families.

(2) In June 2009, five officers attended a departmental four day training program and 23 officers attended a one day training forum. Since 2009, one officer has attended two FASD interagency planning forums with the Department for Health and three officers have attended forums and information sessions conducted by the Telethon Institute for Child Health Research and the Drug and Alcohol Office of WA.

(3) The in-house training program and forum in 2009 were provided by a departmental officer and Caroline Hartness, a visiting FASD expert from the United States.

(4) The training provided in 2009 included a four day intensive training course for five staff and a one day training forum for 23 staff.³⁰⁵

And

Professional learning in foetal alcohol spectrum disorder (FASD) conducted by the Department of Education commenced in 2009. This professional learning has focussed primarily on raising awareness of FASD.

Professional learning undertaken by school staff about FASD is often initiated by individual school principals. The Department does not maintain centralised records of professional learning arranged and conducted at the local level.

³⁰⁵ Hon Robyn McSweeney, Minister for Community Services, Western Australia, Legislative Council, *Parliamentary Debates* (Hansard), 12 June 2012, p5517.

From 2009–2011, an awareness raising session of 35–40 minutes on FASD was included in the professional learning sessions for the Indigenous Tutorial Assistance Scheme. Education staff who attended these sessions included teachers, administrators, Aboriginal and Islander Education Officers and Education Assistants.

Teachers who have students who require additional support, such as students with FASD, can seek information and advice through the Visiting Teacher Program managed by the Department's School of Special Education Needs: Disability.

In addition training has been delivered by three consultants from the Department of Education. Finally,

2009 Awareness raising sessions conducted for staff in Aboriginal Kindergartens (April–May 2009) Location where training was conducted
Aboriginal Kindergartens represented at the Professional Learning

Perth — Canning District: Hilton, West Northam, Tranby, Westminster, Brookman, Gwynne Park, Medina, Moorditj Kindergartens

Broome — Kimberley District Office: Halls Creek, Fitzroy Crossing, Broome, Cable Beach, Derby and Mowanjum Kindergartens

Bunbury — Bunbury District Office: Djidi Djidi, Katanning, Spencer Park and Dudley Park Kindergartens

Kalgoorlie — Goldfields District Office: East Kalgoorlie, Nulsen and Boulder Kindergartens

Geraldton — Midwest District Office: South Hedland, Beachlands, East Carnarvon and Meekatharra Kindergartens

In 2012, staff from the Department's School of Special Needs: Disability, facilitated an information session for 70 Education Assistants from schools in the Broome region.³⁰⁶ 2 In Western Australia, the state government has introduced a Model of Care (refer below) which prioritises the use of prevention strategies to reduce the prevalence of FASD.

306 Hon Peter Collier, the Minister for Energy representing the Minister for Education, Western Australia, Legislative Council, *Parliamentary Debates* (Hansard), 12 June 2012, p5520.

Raising awareness of options, to both health professionals and the public, is important in supporting women to access treatment and support. Public education and community action to support responses to alcohol related problems should include, alcohol and other drugs awareness in schools, family and community education, engaging community members as educators, and developing peer education support networks. This would include partnerships with the division of General Practitioners, maternity and newborn service providers, and alcohol and other drug service providers. Universal screening for alcohol use and offering referral options/pathways, resources and in service training is needed to achieve this.³⁰⁷

307 Submission No. 11 from Department of Health South Metropolitan Area Health Service, December 2011, p5.

Appendix Seven

Inquiry Terms of Reference

Inquiry Terms of Reference

1. Current and future resourcing of new methods and activities to improve educational outcomes such as e-learning and school partnerships;
2. Factors influencing positive or negative childhood development from birth to year 12;
3. Facilitating greater opportunities to engage all students in year 11 and 12;
4. Improving access and opportunities for adult learning in regional and remote WA; and
5. Foetal Alcohol Syndrome: prevalence, prevention, identification, funding and treatment to improve education, social and economic outcomes.

The Committee will report by 30 November 2012.

Appendix Eight

Committee's functions and powers

The functions of the Committee are to review and report to the Assembly on:

- (a) the outcomes and administration of the departments within the Committee's portfolio responsibilities;
 - (b) annual reports of government departments laid on the Table of the House;
 - (c) the adequacy of legislation and regulations within its jurisdiction; and
 - (d) any matters referred to it by the Assembly including a bill, motion, petition, vote or expenditure, other financial matter, report or paper.
- At the commencement of each Parliament and as often thereafter as the Speaker considers necessary, the Speaker will determine and table a schedule showing the portfolio responsibilities for each committee. Annual reports of government departments and authorities tabled in the Assembly will stand referred to the relevant committee for any inquiry the committee may make.
 - Whenever a committee receives or determines for itself fresh or amended terms of reference, the committee will forward them to each standing and select committee of the Assembly and Joint Committee of the Assembly and Council. The Speaker will announce them to the Assembly at the next opportunity and arrange for them to be placed on the notice boards of the Assembly.

Appendix Nine

Submissions received as they relate to this Report

| Organisation | Date |
|---|---------------|
| National Council of Women of WA Inc. | October 2012 |
| Disability Services Commission | December 2011 |
| Catholic Education Office of Western Australia | December 2011 |
| South Metropolitan Area Health Service | December 2011 |
| Department of Health | December 2011 |
| Department for Child Protection | January 2012 |
| Telethon Institute for Child Health Research | January 2012 |
| Australian National Preventive Health Agency | February 2012 |
| Marninwarntikura Fitzroy Women's Resource Centre | March 2012 |
| Professor John Boulton | March 2012 |
| Foundation for Alcohol Research and Education | April 2012 |
| Russell Family Fetal Alcohol Disorder Association | May 2012 |
| Dr Jasmine McDonald | June 2012 |
| The Royal Australasian College of Physicians | June 2012 |

Appendix Ten

Hearings and Briefings as they relate to this Report

Hearings

| Date | Name | Position | Organisation |
|-------------------|----------------------|--|---|
| 28 September 2011 | Dr Caroline Goossens | Child Psychiatrist | Faculty of Child Psychiatry |
| 23 November 2011 | Mr Terry Murphy | Director General | Department of Child Protection |
| 30 November 2011 | Mrs Kate Gatti | Area Director Public Health | WA Country Health Service |
| 28 March 2012 | Mrs Kate Gatti | Clinical Lead | Child and Youth Health Network |
| 28 March 2012 | Dr Colleen O'Leary | Epidemiologist | Curtin Health Innovation Research Institute |
| 28 March 2012 | Ms Sarah McKerracher | A/Development Officer | Child and Youth Health Network |
| 16 May 2012 | Dr Carol Bower | Epidemiologist | Telethon Institute of Child Health Research |
| 20 June 2012 | Mr Neil Guard | Executive Director | Drug and Alcohol Office |
| 20 June 2012 | Mr Gary Kirby | Director, Prevention and Workforce Development | Drug and Alcohol Office |
| 9 July 2012 | Dr Raewyn Mutch | Paediatrician | Telethon Institute of Child Health Research |

Briefings

| Date | Name | Position | Organisation |
|-----------------|----------------------|---|--|
| 11 October 2011 | Mrs Sue Miers | Chair | NOFASARD |
| 12 October 2011 | Hon Dr Sharman Stone | Parliamentary Liaison Group for the Prevention of Fetal Alcohol Spectrum Disorder (FASD)/ Fetal Alcohol Syndrome (FAS) (PFFASD/FAS) | Federal Member for Murray |
| 13 October 2011 | Dr Jenny Proimos | Paediatrician and Adolescent Health Consultant | Centre for Adolescent Health |
| 12 March 2012 | Ms Sue Cuneo | Regional Executive Director | the Pilbara Education Region |
| 12 March 2012 | Mr Daniel Brown | CEO | Mawarnkarra Health Service Aboriginal Corporation |
| 14 March 2012 | Ms Maureen Carter | CEO | Nindilingarri Cultural Health Services, |
| 14 March 2012 | Dr John Boulton | Senior Paediatrician | Country Health Services |
| 14 March 2012 | Tim O'Brien | Director | Kimberley Population Health |
| 15 March 2012 | Tracey Gillett | District Director | East Kimberley, Department of Child Protection |
| 15 March 2012 | Carol Ehlank | Director of Nursing | Fitzroy Valley Health Service |
| 16 April 2012 | Dr Jocelynn Cook | Executive Director | the Canada FASD Research Network |
| 16 April 2012 | Valerie Flynn | Manager | FASD Strategic Programming Unit, First Nations and Inuit Health. Branch, Health Canada |

| | | | |
|---------------|-------------------------|--|---|
| 16 April 2012 | Anne-Marie Bédard | A/Manager | Fetal Alcohol Spectrum Disorder Division of Childhood and Adolescence Division de l'enfance et de l'adolescence Public Health Agency of Canada |
| 17 April 2012 | Dr. David Butler-Jones, | Chief Public Health Officer | Canada |
| 5 July 2012 | Dr Heather Douglas, | Director of Postgraduate Research Programs | TC Beirne School of Law The University of Queensland |
| 6 July 2012 | Mr Michael Thorn | CEO | Foundation for Alcohol Research and Education |
| 6 July 2012 | Ms Sarah Ward | Senior Policy Officer | Foundation for Alcohol Research and Education |