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Submission to the House Standing Committee on Social Policy and Legal Affairs

Developing a national approach to the prevention, intervention and management of Foetal Alcohol Spectrum Disorder in Australia

9 January 2012

This Submission is based on the views of the National Rural Health Alliance but may not reflect the full or particular views of all of its Member Bodies.

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Developing a national approach to the prevention, intervention[1] and management of Foetal Alcohol Spectrum Disorder in Australia

Executive summary

Foetal Alcohol Spectrum Disorders are 100 per cent preventable: if alcohol is not consumed during pregnancy, the baby will not have FASD.[2]

Australia should set in place a national strategy, agreed and prosecuted by all health jurisdictions, to prevent children from being affected by Foetal Alcohol Spectrum Disorder (FASD). The focus of such a strategy will be women who are considering becoming pregnant, those who are already pregnant, and the men and other family members and friends in such women's close networks. To be effective the strategy will need a whole-of-government focus.

The strategy will pursue prevention along two lines. First, women who have the capacity to stop (or reduce) their consumption of alcohol will be encouraged and/or assisted to do so before becoming pregnant. This type of prevention will focus on women who are trying to become pregnant or at significant risk of an unplanned pregnancy. Second, women who are currently alcohol-dependant should be encouraged and assisted to not become pregnant unless and until their alcoholism is under control. For them, contraception is more likely to be an effective FASD prevention strategy than even the best public health campaign relating to alcohol.

Men have been 'let off the hook' for too long in the FASD story. Their understanding, support and assistance can be very valuable in the prevention, identification and management of FASD. It is critical not to see FASD as a 'women's issue'.

The prognosis for the success of a national strategy to prevent FASD is sound because of the natural predisposition of those closely involved: no parent wants to have a child whose chances for a full and satisfying life are compromised from the start. No parent wants to commit to a much harder parenting experience than normal. The FASD prevention strategy will therefore have, at its core, helping parents get what they already want for their child and for themselves. This also means that prevention work can and should start with parents who have a child with FASD, as a way of preventing future affected births.

After prevention, the next most important imperative is early identification of those people with FASD. This paves the way for early intervention and meaningful management of this permanent condition. Even though there are no interventions that will cure a child with FASD, early identification is the precursor to good management as early as possible in the child's life: to improve quality of life, to assist family and teachers to appropriately manage behaviour and developmental issues, as well as reducing the chances of misdiagnoses and misunderstandings that will compound the difficulties the child will experience. While there is no treatment, the essence of management is to set in place appropriate care and to meet the child's need for continuous support (as an 'external brain', as it is sometimes called).

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[1] For reasons outlined later in this submission, in the context of this issue we prefer the word 'identification' to 'intervention'. To reflect the Inquiry's Terms of Reference, we have generally adopted the practice of using both words together.

[2] http://www.nofas.org/

At the heart of the national strategy will be better data on FASD, national action on alcohol use and misuse generally, and targeted programs for women planning pregnancies and at special risk where alcohol is concerned. The Alliance's particular interest is to see that action on these fronts in rural and remote areas takes account of the particular characteristics of those places and the at-risk groups who live in them.

Introduction

The Alliance is comprised of 32 Member Bodies, each a national body in its own right, representing rural and remote health professionals, service providers, consumers, educators, researchers and Indigenous health organisations (see Attachment). The vision of the National Rural Health Alliance is good health and wellbeing in rural and remote Australia, and it has the particular goal of equal health for all Australians by 2020. Underlying the Alliance's work is a belief in the importance of person-centred care.

Defining Foetal Alcohol Spectrum Disorder

> The Inquiry's Terms of Reference describe Foetal Alcohol Spectrum Disorder (FASD) as "an overarching term used to describe a range of cognitive, physical, mental, behavioural, learning and developmental disorders that result from foetal exposure to alcohol".

Foetal alcohol syndrome (FAS) is a congenital abnormality caused through alcohol consumption during pregnancy and is diagnosed in the presence of four criteria: confirmed maternal consumption of alcohol, a distinctive pattern of facial characteristics, growth deficiency, and a characteristic pattern of diffuse brain damage.

Foetal Alcohol Spectrum Disorder (FASD) is not a diagnostic term; it is an umbrella term to describe four diagnostic categories: Foetal Alcohol Syndrome (FAS); partial FAS (pFAS), alcohol-related neuro-developmental disorders (ARND); and alcohol-related birth defects (ARBD).

Alcohol use in pregnancy can cause a wide variety of problems for the developing foetus: organ damage, growth deficiency and various types of damage to all parts of the brain. Brain damage includes structural deficits as well as functional deficits. In more extreme cases, it can cause death.

Alcohol is a teratogen: an agent that can disturb the normal development of an embryo or foetus. Alcohol crosses from the maternal circulation to the baby's circulation and directly attacks cell development, making cells smaller and malformed. Other damage can be caused by a by-product of alcohol metabolism (called a CL aldehyde). Thirdly alcohol can affect oxygen balance across the placenta and an oxygen deficit will lead to brain damage in the foetus.

Functional brain injury is often difficult to diagnose, and can involve a team of professionals to do the necessary testing. The functions affected in children who are alcohol-exposed include: attention; learning; adaptation or life skills; the reasoning which also relates to

intellectual functioning; memory; motor functioning; executive functioning; regulation of state; and speech and language.

Children with FASD often display a variety of learning disabilities and behavioural problems. These are primarily the result of impairment of the brain's 'executive functions', including the ability to plan, learn from experience and control impulses. Children affected might be regarded as being wilful or undisciplined when in fact they have little control over their behaviour. Most often, FASD is an invisible birth defect.

FASD and organic brain damage can come with a host of other problems called secondary disabilities. Mental health problems are the most common but addictions are also seen. Children tend to start with having attention and anxiety problems, then move on to depression in adolescence and adulthood. There is also an increased risk for suicide.

The behaviours associated with FASD are disruptive of the lives of many people, not just the parents of children affected. Many of the children act in ways that also endanger their own health and wellbeing.

> "By 'unmanageable' I mean I had no control over him. If he wanted to go out at night he would go out. I could tell him he wasn't allowed to go out at night, I locked the doors, I put security screening on his windows but still he went out whenever he wanted. I spent many nights awake, waiting for him to come home. Don and I explained the rules to him over and over, without seeing any change in his behaviour.
>
> He could also become very angry and violent. If he didn't want to go to school in the morning he wouldn't. I could wake him up, I could put his school clothes out, I could cajole, scream, cry, yell, bribe, threaten and plead – all to no avail. Later, though, bribery became an excellent method of getting him to do things that were essential to his health but which he refused to do.
>
> Getting him to go to a doctor's appointment was not something I could assume would simply occur because it was important. He could not see that going to the doctor was crucial to his physical and mental health. I would sacrifice everything that I knew was proper and correct as a mother by telling him that I would buy him a packet of cigarettes after he had been to the doctor. There was another stipulation – he had to cooperate – that is – in order to get the cigarettes; he had to answer the doctor's questions and not be aggressive."
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> *Elizabeth Russell (Paper to 11th National Rural Health Conference, Perth, 2011)*[3]

Risk factors for FASD

The biggest risk factor associated with an increased risk of FASD is the amount of alcohol ingested and how frequently it is consumed throughout the pregnancy. Frequent binge drinking is associated with especially high risks.

[3] See also *Russell Family Fetal Alcohol Disorders Association*, www.rffada.org

The Victorian Government's *Better Health* website lists the other major risk factors for FASD as:

- **an older mother (advanced maternal age)** – women over the age of 30 years who drink moderate to heavy amounts during pregnancy are more likely to have babies affected by FASD than younger women who drink the same amount when pregnant.
- **poverty** – alcohol consumption is higher in low socioeconomic groups[4]. Poor nutrition is also a factor.
- **genetic susceptibility** – while FASD seems to be related to the amount of alcohol consumed, not all babies are affected in the same way by alcohol. Not every baby exposed to alcohol in the uterus develops FASD, but the reason for this is unknown. Researchers believe that some babies are more sensitive to the effects of alcohol than others because of genetic differences.
- **other drugs** – drugs taken during pregnancy (including tobacco, prescription drugs, illegal drugs and caffeine) may increase the effects of alcohol on the foetus.
- **lack of knowledge** – research shows that most Australian women are unaware that alcohol consumed during pregnancy can harm the baby. In one Western Australian study, only 22 per cent of women knew about FASD and about one-third thought it was safe to drink moderate amounts of alcohol during pregnancy.
- **lack of medical advice** – about two-thirds of pregnant women are not given medical advice on drinking alcohol during pregnancy or they may not know about the guidelines relating to alcohol consumption in pregnancy.

Babies severely affected by FASD are at risk of dying before they are born. Current knowledge suggests there is no safe level of alcohol consumption during pregnancy, but there is no convincing evidence that a small intake is harmful[5]. Heavy alcohol consumption in the early months of pregnancy is regarded as particularly dangerous[6].

Prevalence and incidence

International and Australian attention to FASD has been increasing and the current Inquiry will play a useful role in that. Overall, however, there has to date been limited research and 'knowledge transfer' on the topic.

The Telethon Institute for Child Health Research[7] has reported the following:

> The Australian Paediatric Surveillance Unit in 2001-2004 estimated the birth prevalence of FAS to be 0.06 per 1000 live births. There was a significant increase each year in the number of children with FAS reported by paediatricians in each year of the study (from 2001-2004). In Western Australia, the prevalence of FAS for

[4] There are also a good number of children with FASD born to middle or upper class parents who have the wherewithal to hide behaviours associated with this condition.
[5] Even without such categorical evidence, it can be argued that alcohol should be avoided entirely because it is a teratogen. Other teratogens are toluene, thalidomide, Agent Orange and Mercury – and no mother would expose her baby to those. Also, there are studies which show that any amount of alcohol causes damage at a cellular level.
[6] http://www.betterhealth.vic.gov.au/bhcv2/bhcarticles.nsf/pages/Fetal_alcohol_spectrum_disorder?open
[7] Alcohol and Pregnancy Project. Alcohol and Pregnancy and Fetal Alcohol Spectrum Disorder: a Resource for Health Professionals (1st revision). Perth: Telethon Institute for Child Health Research; 2009. http://www.ichr.uwa.edu.au/files/user5/2009_Revised_Core_web.pdf

births from 1980-1997 was estimated to be 0.18 per 1000 births, with 0.02 per 1000 for non-Aboriginal infants and 2.76 per 1000 for Aboriginal infants. Since this time, there has been increased research and clinical attention on FAS in Western Australia and the prevalence has increased to 0.5 per 1000 for births from 2000-2004.[8] This latter figure is also likely to underestimate the true prevalence. In the United States, the prevalence of FAS is 1-3 per 1000 live births.

The identification of FASD at birth and in infancy is hindered because many health professionals lack knowledge and familiarity with FASD. A survey of Western Australian health professionals, for example, showed that only 12 per cent could identify all four of the essential diagnostic features of FAS (confirmed alcohol exposure in pregnancy, characteristic facial features, growth restriction and central nervous system abnormalities).

Alcohol is the most widely used drug in Australia, consumed by more than 80 per cent of people aged 14 years and older (AIHW 2011). In 2010, about 20 per cent of Australians drank at levels that put them at risk of harm over their lifetime and 28 per cent drank at least once a month at levels that put them at risk of accident or injury (AIHW 2011).[9]

In 2007, 60 per cent of women consumed alcohol during pregnancy, with most of them reducing their alcohol consumption because of their pregnancy[10].

A significant number of pregnancies are unplanned. In a random sample of non-Aboriginal women in Western Australia, 47 per cent reported that their pregnancy was unplanned. Additionally most pregnancies are not confirmed until some time after conception. During this early phase before a pregnancy is known, a foetus may inadvertently be exposed to alcohol

This is a particular concern since women in Australia are drinking more and consuming alcohol in more harmful ways than in the past. Given that many pregnancies are unplanned, or unknown in the early stages, it would be advisable for health professionals to ask women about their alcohol use as part of a health history, which often occurs at a first visit, and then to re-assess this periodically. All women of child-bearing age should be advised of the consequences of alcohol exposure during pregnancy.

In general, women who drink alcohol during pregnancy do not want to hurt their unborn child and are unaware that they are putting the foetus at risk. Drinking alcohol is a social norm for many people, and there are a number of reasons why a woman might drink while she is pregnant:

- she may not be aware she is pregnant;
- she may find it helps her to cope with life's problems; and/or
- she may not be aware of the consequences of alcohol exposure to the foetus.

[8] We take this to mean that additional research led to better identification of the condition, rather than that the prevalence of the condition increased during that particular period.

[9] Alcohol misuse is estimated to cost $36 billion annually in terms of productivity losses and healthcare, crime and child protection costs and, overall, is responsible for 3.2 per cent of the total burden of disease and injury in Australia.

[10] http://aihw.gov.au/publication-detail/?id=6442468252&libID=6442468250&tab=2 Australian Institute of Health and Welfare 2009. A picture of Australia's children 2009. Cat. no. PHE 112. Canberra: AIHW.

The estimated cost of foetal alcohol spectrum disorders in USA has been estimated at $500,000 per individual over a 20-year period[11]. The costs are largely borne by families and public health budgets. The price of prevention is small by comparison, and the cost-savings significant. Early identification and intervention would save public funds and enhance the wellbeing of affected children, teenagers and adults.

Rural/Indigenous prevalence

About one-third of the Australian population (or 7.5 million people) live in rural and remote areas. In those areas, alcohol consumption and its associated harms are consistently higher than in urban areas.

Results from the 2007 National Drug Strategy Household Survey show a greater availability of alcohol in remote areas, with 44 per cent of those living in remote areas reporting fairly or very easy access to alcohol, compared with 29 per cent for the general population. The 2010 National Drug Strategy Household Survey shows that the proportion of those drinking at risky levels increases with increasing remoteness.

Prevalence rates of risky alcohol consumption (AIHW 2011)

Proportion of population who drink at risky levels	**Major cities**	**Inner regional**	**Outer regional**	**Remote/ Very remote**
... for lifetime harm	19%	22%	25%	31%
... for single-occasion harm	15%	17%	19%	26%

Figures from the latest National Health Survey indicate that, compared with residents of major cities, those who live in rural and remote areas are 32 per cent more likely to drink at levels that risk causing lifetime harm and 24 per cent more likely to drink at levels that are at risk of resulting in single-occasion harm. This makes national action to prevent FASD and to identify its presence as early as possible a critical issue for health services and practitioners in rural and remote areas.

Studies conducted in rural Australia suggest there is a lack of knowledge of alcohol guidelines and alcohol-related harms among rural residents. They also report a low level of awareness of alcohol as a local problem and of what existing alcohol interventions were available in the community.

There is relatively poor data on the prevalence of FASD in Australia, so it is not possible to be sure of its prevalence in particular areas or populations. It is known, however, that FASD is much more common in Indigenous children[12].

The Telethon Institute for Child Health Research reports that a smaller proportion of Aboriginal and Torres Strait Islander women drink alcohol compared with non-Aboriginal women, but those who *do* drink are more likely to use amounts of alcohol that are harmful for the short and long-term. The higher rates of FASD in Aboriginal populations reflect the

[11] Klug MG, Burd L. Foetal alcohol syndrome prevention: annual and cumulative cost savings. *Neurotoxicol Teratol* 2001;25: 763-5.

[12] Fetal alcohol syndrome: a prospective national surveillance study. E J Elliott, J Payne, A Morris, E Haan, C Bower *Arch Dis Child* 2008;**93**:732-737 doi:10.1136/adc.2007.120220 http://adc.bmj.com/content/93/9/732.abstract

greater presence of risk factors, such as low socio-economic status and poor nutrition, the pattern of drinking and the greater amounts of alcohol being consumed by those who do drink.

Similarly, given the relatively higher incidence of harmful levels of drinking in rural and remote areas (as compared with cities), it would be expected that FASD is proportionately more common in rural and remote areas. The higher proportion of Aboriginal and Torres Strait Islander people in remote areas and the higher proportion who drink at dangerous levels mean that FASD is a significant issue for remote Indigenous communities.

Indigenous women identify many reasons for the stress that they feel contributes to alcohol use during pregnancy. These include unemployment, lack of knowledge of the adverse effects of alcohol on the foetus, domestic violence, having a partner or friend who drinks, and the need to travel long distances to deliver their babies, which necessitates separation from family and community support; as well as the legacy of loss of traditional land and culture, and the impacts of the 'stolen' generation. [13] In order to develop culturally-sensitive and effective, public health and education programs it is important to better document the extent to which Aboriginal and Torres Strait Islander women use alcohol during pregnancy, and to better understand the reasons for its use in Aboriginal communities.

However, the phenomenon has not been and still is by no means restricted to remote Indigenous communities.

> "When I was pregnant with my children I was living in rural mining towns. Alcohol and one-upmanship were the key links between many of the people in these towns. … I drank no more or less than other young women my age, pregnant or not. I now have two children with FASD.
>
> Doctors in rural or remote settings have a far greater responsibility to their patients. While a single discussion about alcohol and pregnancy can filter through a rural or a remote town in a heartbeat, so can advising one woman that it is okay to have a few drinks while pregnant. The former can produce healthy children and the latter can cause no end of pain and suffering over a lifetime."
>
> *Elizabeth Russell*

According to the 2007 National Drug Strategy Household Survey, women in regional and remote areas were more likely than women in Major Cities *not* to drink alcohol in pregnancy (47 per cent compared with 37 per cent) but were less likely than women in Major Cities to *reduce* their alcohol consumption due to pregnancy (48 per cent compared with 61 per cent)[14].

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[13] Elizabeth Elliott, *Alcohol use in pregnancy in remote Australia: the Lililwan Project*, (The George Institute for International Health); paper to 11th National Rural Health Conference, Perth, 2011.

[14] http://aihw.gov.au/publication-detail/?id=6442468252&libID=6442468250&tab=2 Australian Institute of Health and Welfare 2009. A picture of Australia's children 2009. Cat. no. PHE 112. Canberra: AIHW.

The NHMRC's *Australian guidelines to reduce health risks from drinking alcohol* (2009) include the following:

"Australian studies indicate:

- continuing occurrence of FAS, with many children in foster care and many with an affected sibling suggesting missed opportunities for prevention (Elliott & Bower 2004; Elliott et al 2007);
- a likely under-ascertainment of FAS due to a lack of knowledge among health professionals of the condition and criteria for its diagnosis (Payne et al 2005; Elliott et al 2006);
- higher rates of FAS in some Indigenous communities compared with non-Indigenous communities (Bower et al 2000; Harris & Bucens 2003; Elliott et al 2007);
- an identified need for research into the association between low to moderate alcohol consumption and fetal harm (O'Leary et al 2007);
- a lack of data on rates of, and need for research on, alcohol-related birth defects and alcohol-related neurodevelopmental disorders in Australia."

Prevention

Foetal Alcohol Spectrum Disorders are 100 per cent preventable: if alcohol is not consumed, the baby will not have FASD. And yet, even with increased knowledge about the condition and its causes, there are still children being born who are alcohol-affected. The condition has immense consequences for families and society, as well as for affected individuals.

The main thrust of this Submission is that the Committee should propose a national strategy, to be agreed and prosecuted by all health jurisdictions, to prevent children from being affected by FASD. If successful, the strategy will effect a cultural shift in overall attitudes towards pregnancy and alcohol, and in the role of partners and fathers as active agents of support for healthy pregnancies. The strategy will accommodate the particular characteristics of rural and remote areas, in which there is a significant prevalence of FASD. It will target effective measures for early identification and ongoing management to selected population groups, including pregnant women, women of child-bearing age generally, 'at risk' groups such as young people, women with an alcohol dependency and the male partners of women in these groups. This targeting will be undertaken through a range of measures, including generic health promotion and information within the community, training and support for clinicians, and whole-of-government work to improve the determinants of health and wellbeing.

Much could be achieved through greater knowledge of and adherence to guidelines on the consumption of alcohol. The NHMRC guidelines contain the following advice for women who are pregnant or breastfeeding:

"Guideline 4: Pregnancy and Breastfeeding

Maternal alcohol consumption can harm the developing fetus 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."

As well as having accurate and appropriate content, it is also important for guidelines such as these to convey their messages in a non-judgemental, supportive way that gives a person hope for the possibility of change.

Further, the NHMRC gives the following advice to women who are pregnant or planning a pregnancy.

- Not drinking alcohol is the safest option.
- The risk of harm to the foetus is highest when there is high, frequent, maternal alcohol intake.
- The risk of harm to the foetus is likely to be low if a woman has consumed only small amounts of alcohol before she knew she was pregnant or during pregnancy.
- The level of risk to the individual foetus is influenced by maternal and foetal characteristics and is hard to predict.

WA Health has published a blueprint, *Model of Care*, to help prevent and address Foetal Alcohol Spectrum Disorder. It points out that, while no amount of alcohol can be considered to be safe during pregnancy, even if alcohol has already been consumed while pregnant, stopping alcohol use will decrease the risks associated with FASD. It also notes that for pregnant women with an alcohol dependency there is a significant risk in suddenly stopping alcohol use; expert supervision and support by medical practitioners is necessary. WA also has a 24-hour helpline for people wanting information and support for alcohol and drug related issues – 1800 190 024.

An Australian research project funded by Healthway in Western Australia targeted a broad range of health professionals, including Aboriginal health workers, various allied health professionals, community nurses and midwives, remote area nurses, GPs and obstetricians. With regard to asking patients about alcohol use in pregnancy, 12 per cent of the health professionals said they did not ask, and 45 per cent that they did routinely ask. In terms of how prepared the professionals were to deal with FASD, 2 per cent felt very prepared, 8 per cent felt fairly prepared, 23 per cent felt somewhat prepared, and 66 per cent felt not prepared at all. 84 per cent felt it would be useful to have materials addressing the issue; 79 per cent felt that there needed to be more information for actual clients; 64 per cent thought a FAS diagnostic check list would be useful as well as information about the referral sources, a registry of specialists, an alcohol history check list and training in alcohol assessment.

The Telethon Institute for Child Health Research has produced a range of resources for health professionals, including an Information booklet, *Alcohol and Pregnancy and Fetal Alcohol Spectrum Disorder* and a fact sheet containing a summary of relevant information and guidelines for alcohol usage. The Russell Family Fetal Alcohol Disorders Association (rffada) has prepared posters and flyers specifically for parents and carers, parents considering pregnancy and those people living with FASD[15].

Pre-conception health of the mother and father is a crucial factor influencing the wellbeing, behaviour, learning and life choices of their children. It is better if problem drinking is treated and controlled before conception occurs. Pre-pregnancy alcohol consumption and methylation stress can affect the imprinting of genes in sperm and alter the environment

[15] available at http://rffada.org

within the oocyte which can reduce fertility, fecundity, and increase the risk of low birth weight and abnormal foetal development.[16]

Young women should be encouraged to ask their GPs to measure their red cell folate, homocysteine and Vitamin B12 before they become pregnant. Folate concentrations greater than 900nM/L are required to avoid neural tube defects but a large number of women (~ 40%) have folate concentrations below this.

For prevention strategies to be effective it is necessary for both long-serving and newly trained practitioners to be provided with updated information. It is important that people in rural and remote communities and their health professionals get information early because the problem is worse in rural and remote communities and therefore the potential benefit is greater.

It is critical for information to reach Indigenous communities and the people who serve them, because so many in those communities are affected. Others who will be disproportionately affected include inner city people who are homeless.[17] Given such target groups as these, it cannot be left to mainstream city health professionals to do all that is necessary to prevent the occurrence of FASD.

> "Mick was born in 1981. Smith and Jones had published their observations about FAS in 1973 eight years prior to his birth, but I was not screened for substance abuse nor was alcohol mentioned or discussed at any time by my obstetrician until I had an amniocentesis. Then I was directed to go to the pub and have a few drinks to stave off labour. Twenty four years later – thirty two years after Smith and Jones published - doctors in Australia were *still* not giving a consistent message about alcohol and pregnancy.
>
> Doctors must discuss alcohol with pregnant women and with mothers whose children exhibit the signs and symptoms of this condition.
>
> Doctors will need to be well prepared because it simply will not be easy to discuss this with a mother who may have been drinking alcohol prior to knowledge of her pregnancy or because she may not have realised the potential for damage. She may well become anxious and distressed but so will the patient when he is told he has cancer. In both cases hard facts will hurt, but in both cases they must be said."
>
> *Elizabeth Russell*

There are good programs for helping pregnant women who are heroin addicts to go on to methadone and reduce the amount of substance that will affect their baby. Such programs are likely to have useful lessons for targeted work related to pregnancy and alcohol.

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[16] Leith Moxon-Lester, Research Fellow, University of Queensland Centre for Clinical Research.

[17] Many people affected by FASD are homeless as it renders them unable to plan, organise and put into place what is required to satisfy the rules of housing authorities or private rental agencies. Also FASD creates problems in employment and while it is possible for a person with FASD to gain employment because of their good verbal ability it is almost impossible for them to maintain employment.

Frequently the pregnant women who are 'at risk' of misusing alcohol are actually addicted to it and are driven by things underneath the surface in their lives that are not always recognised, nor easily 'curable'.

Screening needs to start early and be pursued proactively, especially for at-risk adolescent populations. There is a critical role for GPs who need to be engaged in broad-based screening. The social risks that accompany foetal alcohol spectrum disorders and the broader help required need to be better understood and there needs to be a more creative approach to our community supports for women who need help to cease or reduce drinking during pregnancy.

> "There are social factors that influence women to drink and any preventive measures would need to examine these. Pregnant women and mothers need support. And those most susceptible to excessive drinking during pregnancy are often young. They're often displaced and disconnected from their family or community. They often have a lot of tragedy in their life, often losses. They may have lost babies; they've lost important people in their lives. They're often victims of either domestic violence or of abuse and this is rarely talked about. They're often not there when people start to talk about their baby being less than perfect and they're not able to defend themselves. Frequently, the men who come through their lives are not functional. Alcohol is one of the factors that contribute to dysfunctional patterns of behaviour in these young men, and many of them have never seen a good functional man to be their role model. An unsettled childhood, compounded by being fostered by numerous families during their childhood, is also not unusual."
>
> *Rural paediatrician*

The Western Australian FASD Model of Care recommends that prevention strategies be embedded into broader alcohol harm reduction strategies and include the following key areas of focus:

- public education programs and support of community action to reduce alcohol-related problems;
- school-based education programs;
- supporting legislation and enforcement;
- routine screening of women of child bearing age and provision of appropriate information to all pregnant women and their families about substance use and the risks associated with alcohol use during pregnancy;
- support of pregnant women with an alcohol dependency to manage withdrawal;
- provide post-natal support to women with an alcohol dependency to improve parenting and child and family wellbeing;
- use of brief interventions by health professionals;
- reduction of unplanned pregnancy;
- improving the quality, availability and cultural appropriateness of maternity services; and
- increasing collaboration between health professionals and health services.

The Strong Women, Strong Babies Program in Indigenous communities

The *Strong Women, Strong Babies* program is a Northern Territory program with a primary focus to support grandmother's law and to support families to care for women during pregnancy, to help women care for themselves during pregnancy and to assist women care for babies and young children. It is a community-based program which is controlled by the *Strong Women* workers who operate in each community. This means the activities that people are engaged in and the focus that they have is directed by the local women. Every year the *Strong Women* workers run workshops and the content of those workshops is determined by them.

Although it is not a program about alcohol, the *Strong Women* workers are able to use the opportunities it provides for alcohol education and in some communities *Strong Women* workers have used their educational flick charts to talk about the impact of alcohol use. The received message was largely related to low birth weight and the statement that, "If you drink and smoke, your baby drinks and smokes".

When dealing with this issue, context is important. The context is wider than just a woman's use of alcohol in pregnancy and it is important to look at her in the world in which she lives. It is important for practitioners to understand that, for many women, drinking during their pregnancy occurs in a context where they do not feel safe.

The women were clear that assistance for women to stop drinking during pregnancy may well need to include help with other issues affecting their wellbeing. Their partners may also need to be encouraged to be supportive, even if this means to stop drinking themselves.

Early identification and intervention

In some contexts, the word 'intervention' carries with it connotations of treatment and/or cure which may raise expectations that FASD is curable or reversible through early action. Unfortunately this is not the case. However early identification is likely to lead sooner to better understanding and management of the condition, and care for the family, and therefore to improved outcomes.

Early and accurate diagnosis is therefore critical. A clinical diagnosis will require a multi-disciplinary health team who will also help to rule out other causes for a child not growing and developing, look fully at what the primary disabilities of the infant are, and recognise secondary problems, if there are any. Early diagnosis will lead to appropriate management and other interventions that are helpful for the family and the ongoing care of the child.

The distinctive facial features of FAS are caused by alcohol exposure on approximately the 19^{th} and 20^{th} day of pregnancy following conception, during a period of pregnancy called gastrulation. This feature will not help diagnose (or exclude) children who were prenatally exposed to alcohol after the first 20 days.

Life is complex and there can be many factors affecting how a child is on any particular day. When there is a foetal alcohol diagnosis, it is usually associated with a pregnancy that did not go well, with poor nutrition, alcohol, smoking marijuana excessively, a poor birthing experience compounded by often poor attachment and poor ability of parents to meet the needs of their children.

These human factors need to be accommodated within a national program. It must be sensible of the need for a non-judgmental, non-blaming approach to avoid further abuse of the women involved and for them to avoid further loss of self-esteem.

Program design should also address the barriers faced by rural residents and Aboriginal and Torres Strait Islander people in accessing treatment and care for alcohol problems. These barriers potentially include:

- lower socio-economic status, which could translate into lower health literacy and less ability to afford health-related expenses;
- stoic attitudes which may lead to a delay in seeking treatment;
- less access to healthcare professionals, including GPs and alcohol and other drugs specialists;
- less access to alcohol treatment and rehabilitation services, such as alcohol counselling ;
- issues of cultural safety, languages other than English, and appropriate communications;
- greater distances to health services and lack of public transport; and
- the real and perceived lack of confidentiality in rural and remote areas, because healthcare professionals are more likely to be personally known to the patient.

With limited resources in rural and remote areas, implementation of programs should ideally be in partnership with local organisations so as to share resources and skills. Possible local partners include local governments (such as town planners and transport authorities) and healthcare and community service organisations (including alcohol treatment services, social welfare, income support and job services, housing and homelessness services, mental health care providers, child and family services and national FASD-specific organisations such as the rffada). The newly-established Medicare Locals will also have a critical role.

Program managers will need to understand the underlying causes of alcohol misuse through consultation with the local community. Engaging the local community in program design will generate a program that meets local needs and foster greater community support and ownership. For example, the National Drug Research Institute reports a review of past and existing alcohol restrictions applied throughout Australia that suggests that alcohol restrictions in Indigenous communities are only effective where community consultation is undertaken.

WA Health's FASD Model of Care recognises that some rural and remote communities have a high prevalence of FASD and limited health and developmental services due to their remoteness, and that this offers a significant challenge to the provision of diagnostic and therapeutic services. The document suggests that models of service delivery to rural and remote areas could include the following.

- Workforce training and development in regional centres to provide a local service. This should be prioritised according to level of need, ie according to established or estimated prevalence of FASD in local communities.
- Scheduled rural visits by metropolitan-based teams with the opportunity of assessing whole subpopulations within a short time period and providing education and support

to local services. Involvement of the local health service providers in the visiting team's assessment process will enable building of local expertise.

- Telehealth models for individual assessment.

Management

Successful management of an infant with FASD will involve the patient, the mother, perhaps an adoptive or foster family, the school and the community. Longitudinal studies show that one of the universal protective factors for the prevention of secondary disabilities is diagnosis before the age of six and the implementation of appropriate interventions. Health professionals need to be made aware that typical behaviour modification programs do not work with these children.

Overseas studies are demonstrating that early identification and appropriate care and management lead to more positive life outcomes for the individuals involved. Families affected by FASD have the right to the same quality of care that is currently provided to those with other more visible and familiar disabilities – and this should be available irrespective of where they live.

> "Regardless of what we do as professionals it is important to acknowledge the fundamental importance of family. The children I see growing up need good, functional adults somewhere in their lives. Often they have such women; but many of the boys do not have men – whether it's a football coach or a good minister, or an uncle or a grandparent – a man who's prepared to step up and be there for a young man for a period of time. Family is the fundamental building block. Professionals only slightly value-add I think it would be fair to say."
>
> *Rural paediatrician*

Families are likely to need help to manage an affected child's behaviour, especially behaviour that places themselves or others at risk or is disruptive to community and family life.

The pattern of problems related to foetal alcohol harm are complex and the needs of affected children call for a variety of strategies, including school remedial programs and training for teachers in recommended management techniques.

With the exception of formal diagnosis of FAS, the identification and management of care for children and young people who have FASD are not roles limited to medical or other health professionals. Workers in the children's sector can play a critical role in FASD awareness. Initially this will be challenging because there is only an emerging body of experience and anecdotal evidence about 'how to tell' and 'what works'.

The most promising ways of helping people with FASD appear to be behavioural, environmental and relationship-driven interventions by educators, youth workers and other non-health children's sector staff. Building upon strengths and assets is proving to be a better approach than focusing solely on difficulties. Five evidence-based intervention strategies

have been shown to have positive results in the United States and funding should be made available to provide such programs in Australia.[18]

National goals for addressing FASD

To contribute effectively to prevention of foetal alcohol harm, it is important to reach prospective mothers and their partners earlier and more persuasively with accurate information. Another priority is additional research into the true costs and consequences of living with foetal alcohol harm, into effective treatment and management methods, and into the best means of targeting prevention. It is also important to identify those who have FASD as early as possible, so that treatment and management can start quickly.

Because the incidence and prevalence of FASD is greater in rural and remote areas, and because the impacts of the condition are greater in those areas due to the fact that infrastructure, workforce and opportunity for effective treatment and management are more limited, it is important that national goals for addressing FASD and measures relating to prevention, identification and management are targeted specifically to at-risk populations in those areas.

The Russell Family Fetal Alcohol Disorders Association (RRFADA) has proposed five goals:

1. a national media awareness campaign for the prevention of FASD;
2. alcohol and pregnancy education in all high schools;
3. training for the employees of all services likely to be visited by a person with FASD;
4. early intervention funding similar in nature to the Better Start Initiative; and
5. ongoing government funding for the RRFADA strategic projects.

The Alliance commends these goals to the Committee's consideration.

Resources on FASD

Australian Indigenous Health Infonet

The Australian Indigenous Health Infonet is an impressive resource for information and resource materials about FASD, and provides access to many of the current research projects, programs, reports and resources that are listed below. www.healthinfonet.ecu.edu.au

National Indigenous foetal alcohol spectrum disorders (FASD) resource project

This two year project involves a National Aboriginal and Torres Strait Islander FASD Prevention Reference Group, the Western Australian Drug and Alcohol Office, and key stakeholders throughout Australia. It aims to develop templates that can be used in the production of culturally secure and appropriate resources to assist health professionals in Aboriginal and Torres Strait health care settings across Australia to address the issues of alcohol and pregnancy, and FASD.

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[18] Bertrand J; Interventions for Children with Fetal Alcohol Spectrum Disorders Research Consortium, *Interventions for children with fetal alcohol spectrum disorders (FASDs): overview of findings for five innovative research projects.* PubMed. http://www.ncbi.nlm.nih.gov/pubmed/19327965?log$=activity

Seven nationwide studies are being funded to address FASD in Australia. The Alcohol Education and Rehabilitation Foundation is funding studies to better diagnose and treat those affected by the disorder, which it refers to as 'Australia's hidden disability'. Additionally, the Westmead Children's Hospital in New South Wales is developing the first FASD screening and diagnostic service, and in Western Australia the Telethon Institute for Child Health research is studying how young people with the disorder are treated in state care.

Australian Human Rights Commission
The *Social justice report* is the primary responsibility of the Aboriginal and Torres Strait Islander Social Justice Commissioner. In the 2010 report the Commissioner reviews developments in the exercise of human rights by Aboriginal and Torres Strait Islander peoples in the year July 2009 to July 2010. Chapter 3 is a case study of recent successes in the Fitzroy Valley, including community-led alcohol restrictions, an innovation model of local governance and a local community project to address Foetal Alcohol Spectrum Disorders. It also considers how these successes in Fitzroy Valley can be applied to the wider delivery of government programs and services.

Ord Valley Aboriginal Health Service foetal alcohol spectrum disorders program
Launched in 2009 in response to the incidence of alcohol consumption during pregnancy by women in the Kimberley, this program specifically targets the population of Kununurra and has been funded by local Aboriginal people through the Miriuwung Gajerrong Ord Enhancement Scheme. It is delivered through the Ord Valley Aboriginal Health Service (OVAHS), an Aboriginal community controlled primary health care facility.

The **Lililwan project** is a community-led strategy developed to address FASD in the Fitzroy Valley of Western Australia. The first stage of the project was funded by a philanthropist, and included the development and use of a medical history checklist to obtain information about antenatal exposures, early life trauma, health and development from parents and carers of all children born in 2002 or 2003. Stage 2 will involve a multi-disciplinary assessment of the health and development of the children surveyed in Stage 1.

The **Russell Family Fetal Alcohol Disorders Association (**rffada) in conjunction with Training Connections Australia, a registered training organisation, has developed 10 modules of training in Foetal Alcohol Syndrome Disorder (FASD) - the first publicly available FASD training in Australia. Module 9 is for FASD for Indigenous Australians. The Russell Family Fetal Alcohol Disorders Association website is www.rffada.org

Foetal Alcohol Spectrum Disorder (2006) DVD
Produced by the Rural Health Education Foundation, this DVD discusses the prevention, diagnosis, early intervention and long-term management and support for sufferers of FASD and their families. Two location-based case studies illustrate the difficulties and responsibilities for a child with a diagnosis of FASD.

Children in Scotland has useful resource materials on the subject, including *Early Years Briefing 1: Fetal Alcohol Harm*, April 2011
http://www.childreninscotland.org.uk/docs/EYFbriefingsFetalAlcoholv6_000.pdf

A valuable new reference is http://www.fishpond.com.au/Books/Alcohol-Drugs-and-Medication-Pregnancy-Philip-M-Preece-Edited-by-Edward-P-Riley-Edited-by/9781898683889.

Parliamentarians for the Prevention of FASD is a multi-Party group of Members and Senators of the Federal Parliament and has the aim of eliminating FASD from Australia. The group aims to ensure that, in future, there are warnings on alcohol product labelling. The group is committed to acknowledging the issues associated with FASD, including:

- the need for a national diagnostic tool for the condition. This tool is currently under development;
- the need for better education for practising medical professionals, service providers and particularly police and those who work in the judiciary;
- the need to assist and support pregnant women who have alcohol dependency;
- the need to give FAS and FASD the status of recognised disabilities in Australia to facilitate better funding for the delivery of services; and
- the need to help families living with FASD.

RECOMMENDATIONS

1. It is vital that there are better data available on FASD so that women and families at risk can be effectively targeted for prevention, and those with the condition can be identified early and receive effective care and management, and so as to minimise harm in future generations. What is needed are data to show the incidence and prevalence in the nation as a whole, by rurality (ASGC-RA 1-5), and by Indigenous/non-Indigenous.

Prevention of FASD

2. Given their greater health needs overall, people in rural and remote Australia should be among the groups given priority in national strategies and programs to reduce alcohol misuse. The importance and urgency of such broad national action should be informed in part by its capacity to reduce, and potentially eliminate, the incidence of FASD.

3. This national action on alcohol misuse should include use of the 'big levers': alcohol pricing and taxation, alcohol marketing and promotion, and alcohol availability.

4. Education campaigns and product warnings can raise awareness of the harmful nature of alcohol consumption during pregnancy, with primary carers (GPs, Aboriginal Health Workers, remote area nurses) and role models (parents and siblings, sports personalities, community Elders) having great capacity to support such campaigns and influence behaviours. National awareness campaigns for prevention of FASD should target rural and (especially) remote areas using communication methods that are fit for purpose and of proven effectiveness for those populations, not 'off the shelf' urban means. Partnering the local community in program design will help ensure that the program meets needs and foster greater community support and ownership of the work.

5. Women and families in 'at risk' circumstances (the homeless; long-term unemployed; those with poor literacy skills) should be the focus of specific outreach activity by community services and health agencies that are provided with appropriate resources for such work. In rural and remote areas such preventive activity will necessarily involve major travel times, languages other than English, the need for culturally safe approaches, and good evidence. A significant reduction in the incidence of FASD can be secured through a combination of national information dissemination and targeted outreach activity.

6. In order to develop culturally-sensitive and effective public health and education programs, it is important to better document the extent to which Aboriginal and Torres Strait Islander women use alcohol during pregnancy, and to better understand the reasons for such use.

7. Community development activity controlled by local people, such as the *Strong Women, Strong Babies* program, can provide support to women and families wanting to reduce or stop their drinking. A range of innovative teaching and learning methods (sand drawing; theatre; art and song) can be used and should be eligible for support from 'mainstream' health bodies. The focus of such community activity will include improvements to the social determinants of health (education, employment, income) which are key facets of the action required to prevent FASD.

8. All high schools, including those in rural and (especially) remote areas, should provide education about the impacts of alcohol misuse, including during pregnancy. In areas where school attendance is poor, effective measures should be designed to reach teenagers who are not attending school.

9. Because of the low level of knowledge of the issue and the challenge of identifying mothers and children at risk, education and training for health professionals on FASD should be given higher priority than it currently has. It will need to be made available at multiple levels, including undergraduate, postgraduate and in-service training programs.

10. Given that many pregnancies are unplanned, or unknown in the early stages, it would be advisable for health professionals to ask women about their alcohol use as part of a health history, which often occurs at a first visit, and then re-assess this periodically. It is recommended that women and their partners be informed before pregnancy of the consequences of alcohol exposure during pregnancy.

11. In their capacity as both clinicians and mentors/leaders, health practitioners working in areas where there are at-risk women and families should be trained and supported in the various means by which consumption of alcohol can be minimised. Screening needs to start early and be pursued proactively, especially for at-risk adolescent populations.

Identification / intervention and FASD

12. Diagnostic tools should be available for use in rural and remote areas and should be compatible with the skills of those health professionals who are available locally.

13. Health professionals at all levels should have access to and knowledge of identification and early intervention therapies aimed at minimising the impact of FASD on affected individuals. Special professional development and support (eg translators) will be required when the health professional and affected family do not share fluency in the same language.

14. Funding for early identification and management should be provided to enable development of programs that will effectively serve women whose babies have been diagnosed with FASD, irrespective of where they live.

Management of FASD

15. Good management of those people living with FASD requires a whole-of-government approach, in which education, health, community services, employment and criminal justice sectors are all involved. The targets for good management include communities, families and individuals impacted by the various conditions associated with FASD.

16. Funding should be made available in Australia to provide intervention and management programs that have been found to have positive results overseas, for example in the United States.

Attachment

Member Bodies of the National Rural Health Alliance

ACHSM	Australasian College of Health Service Management
ACRRM	Australian College of Rural and Remote Medicine
AGPN	Australian General Practice Network
AHHA	Australian Healthcare & Hospitals Association
AHPARR	Allied Health Professions Australia Rural and Remote
AIDA	Australian Indigenous Doctors' Association
ANF	Australian Nursing Federation (rural members)
APA (RMN)	Australian Physiotherapy Association Rural Member Network
APS	Australian Paediatric Society
APS (RRIG)	Australian Psychological Society (Rural and Remote Interest Group)
ARHEN	Australian Rural Health Education Network Limited
CAA (RRG)	Council of Ambulance Authorities (Rural and Remote Group)
CHA	Catholic Health Australia (rural members)
CRANAplus	CRANAplus – the professional body for all remote health
CWAA	Country Women's Association of Australia
FS	Frontier Services of the Uniting Church in Australia
HCRRA	Health Consumers of Rural and Remote Australia
ICPA	Isolated Children's Parents' Association
NACCHO	National Aboriginal Community Controlled Health Organisation
NRHSN	National Rural Health Students' Network
PA (RRSIG)	Paramedics Australasia (Rural and Remote Special Interest Group
RACGP (NRF)	National Rural Faculty of the Royal Australian College of General Practitioners
RDAA	Rural Doctors Association of Australia
RDN of ADA	Rural Dentists' Network of the Australian Dental Association
RHW	Rural Health Workforce
RFDS	Royal Flying Doctor Service
RHEF	Rural Health Education Foundation
RIHG of CAA	Rural Indigenous and Health-interest Group of the Chiropractors' Association of Australia
RNMF of RCNA	Rural Nursing and Midwifery Faculty of the Royal College of Nursing Australia
ROG of OAA	Rural Optometry Group of the Australian Optometrists Association
RPA	Rural Pharmacists Australia—Rural Interest Group of the Pharmacy Guild of Australia and the Society of Hospital Pharmacists of Australia
SARRAH	Services for Australian Rural and Remote Allied Health