



Preventing Foetal Alcohol Spectrum Disorder (FASD)

**A submission by the National Drug Research Institute to the
Legislative Assembly of the Northern Territory Select
Committee on Action to Prevent Foetal Alcohol Spectrum
Disorder (FASD)**

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INTRODUCTION

The National Drug Research Institute's (NDRI) mission is to conduct and disseminate high quality research that contributes to the primary prevention of harmful drug use and the reduction of drug related harm. The Institute has an internationally-recognised reputation for providing evidence-based research to inform policy and practice.

NDRI's research endeavours are determined by its eight research priorities, one of which is of direct relevance to this inquiry: primary prevention and early intervention. As part of this research priority, NDRI researchers are conducting research on the impact of alcohol during pregnancy and Fetal Alcohol Spectrum Disorder (FASD). For example, NDRI researchers are completing research projects that focus on:

- mothers with alcohol-related diagnoses and the long-term health of mother and child;
- knowledge and referral pathways for FASD in early childhood settings;
- building national resources to prevent and respond to FASD among Indigenous communities;
- interventions to reduce alcohol use during pregnancy - literature review; and
- Impact of parental substance use on infant development and family functioning.

Given this research focus, NDRI particularly welcomes the opportunity to put forward this submission and address the terms of reference of this inquiry.

Given that "product warnings" form part of those terms of reference, NDRI acknowledges that, in 2009, some of its researchers were involved in the preparation of two reports on the possible impact of alcohol warning labels for Food Standards Australia New Zealand. However those researchers were not involved in the preparation of this submission.

BACKGROUND INFORMATION

Alcohol exposure during pregnancy, which results in FASD, is the leading cause of environmental birth defects and mental retardation in the Western World (1). FAS is characterised by structural brain abnormalities, and deficits in growth and neurological development resulting in a range of life long disabilities. Although the outcomes of FASD often present as behavioural problems, these are secondary disabilities (2).

FASD is an umbrella term that refers to the range of harms caused by prenatal exposure to alcohol. FASD includes Fetal Alcohol Syndrome (FAS). Individuals with FASD may have reduced ability to function on a day-to-day basis, increased physical and mental concerns leading to disrupted schooling and employment, reduced ability to live independently, increased risk of involvement with the law, and a higher level of substance use, unintended pregnancy, sexually transmitted disease and injury. FASD has its primary origins in damage to the developing central nervous system and this structural damage is irreversible. When a pregnant women drinks alcohol, the concentration of alcohol that enters her blood system also enters the blood system of the developing fetus. Alcohol acts as a teratogen or poison on the developing brain, changing the way brain cells develop and multiply. Research also suggests that alcohol-related chromosomal damage can occur during preconception as the egg and sperm develop, and that alcohol can impact on infant brain development during breastfeeding.

Recognition of FAS as a public health problem in Australia is relatively new. Recent estimates of FAS prevalence in Australia are 0.06 per 1000 live births for the general population, and 8.11 per 1000 live births for the Indigenous population. Accurate prevalence rates however are not yet available in Australia as FAS is not systematically diagnosed or reported. Approximately 50% of pregnant women in Australia drink alcohol. This means that potentially 50% of all children born in Australia are at some risk of exposure to FASD.

Data from the US show that the cost of treatment of FAS is US\$2.9 million per case per lifetime, or an annual cost of US\$3.6 billion. This makes FAS one of the most expensive preventable birth defects for the community to treat.

PREVENTION STRATEGIES

Prevention strategies

Decisions about alcohol use during pregnancy are not the sole providence of women, but occur within the social context of Australian society. Australian per capita alcohol consumption is high by world standards (WHO, 2011) and is a behaviour that occurs and is often supported by complex social and cultural circumstances.

This, along with the evidence base around effective alcohol interventions, suggests that it is crucial that a wide range of strategies are implemented to reduce or eliminate alcohol intake during pregnancy, including controls on alcohol availability as the likely most effective strategy among high risk populations. It is also important that

measures focus on tackling drinking among the whole population, and the importance of supporting women in non-drinking decisions.

With specific reference to TOR1, the evidence indicates that mass education campaigns have in the past been ineffective (Elliot et al, 2008) and there is a limited body of evidence as to the efficacy of product warning labels on alcohol. However the body of evidence about effective alcohol interventions is comprehensive. This evidence has been summarised by various groups (e.g. Babor et al 2003; Loxley et al 2004, NDRI 2007) but briefly effective interventions include: controls on availability through price and tax; controls on physical access through hours of sale, number of outlets, and age restrictions; enforcement of liquor licence laws; ensuring low risk drinking contexts; interventions aimed at specific risks (e.g. random breath testing); and brief and more intensive treatment options.

Interventions are more effective when implemented as a part of multifaceted strategy, rather than as an isolated initiative. Strategies such as social marketing campaigns, school drug education, brief interventions and, in all likelihood, product warnings will be most effective when accompanied by other approaches that address the influence of factors such as alcohol availability, alcohol promotion, advice by primary health care staff, increased screening of alcohol use before and during pregnancy, family dynamics and parenting skills on people's drinking behaviour.

Well-designed prevention planning should include findings from evidence based reviews of the research literature. However, there is a dearth of evidence about what works in preventing and responding to FASD (Stade et al, 2009), and more limited information on the impact of larger scale community intervention such as warning labels and taxation on alcohol in relation to consumption by pregnant women. This suggests the need for more prevention and intervention effort that is carefully evaluated and researched.

Efforts in FASD should also focus on the early years (0-5) with settings such as playgroup, day care and pre-school providing opportunities to engage young mothers around prevention of FASD as well as the early detection of suspected FAS/FASD. This builds on opportunities to inform mothers before subsequent pregnancies as well as leveraging 'word of mouth' via infant health and other support networks for first-time mothers to disseminate FASD prevention messages.

NDRI also suggests consideration be given to utilising technological advances in message and intervention delivery. For example, social media channels or smartphone applications providing pre-conception information may be more effective at reaching the target demographic than more 'traditional' approaches.

Critical insights from the Indigenous area

The recently completed national FASD Resources project conducted 17 consultations with health professionals working in Aboriginal and Torres Strait Islander communities, and with community members across Australia. While no consultations were able to be undertaken in the Northern Territory for a number of reasons (see Roarty et al, 2013), the consultations provided some critical insights relevant to actions government can take to reduce FASD:

- health professionals and community members are looking for consistency in the messages received and given regarding issues around alcohol, pregnancy and FASD - for example, that **all** health professionals follow the practice of advising abstinence throughout pregnancy, when planning a pregnancy, or while breastfeeding;
- a recognition of the need for sensitivity in the provision of such information, but also of the need for messages that clearly and effectively demonstrate the dangers of drinking and pregnancy (that is to say, messages should be both direct and simple, and at the same time avoid any implication of blame or shame);
- the effectiveness of such messages will be enhanced when embedded within a holistic approach to combatting the normalisation of alcohol use more generally (separating alcohol promotion from sport and education venues, for example), and to the social circumstances existing in communities which negatively impact on the broader determinants of health;
- evidence-based information around alcohol, pregnancy and FASD will have its greatest effect when delivered to young people as part of a wider educational strategy around sex education and family planning issues;
- while 'traditional' resources (such as printed brochures) are welcomed, there is a real desire to use technology to gather and disperse information and education, both between and among health professionals, and out into communities (Roarty et al, 2013; also see Luxton et al, 2011; Okazaki, 2009);
- people want to have a choice of culturally safe, generally positive, evidence-based materials to draw on so they can develop their own locally relevant resources - that is to say, resources which use artwork, colours, forms of words and local contacts that are identifiable within the community; and,
- there must be a recognition that FASD is not a women's issue, but one that involves and affects everyone in the community.

In sum, there is a need and desire for uniformity in the education of health professionals at all levels around issues of alcohol, pregnancy and FASD, to ensure uniformity in the message conveyed to community. There is a need for community-wide education and the development and availability of educational tools with which to address issues of alcohol and pregnancy with both sexes and all age groups. People want access to locally relevant resources, which are evidence based but flexible to local need. Aboriginal and Torres Strait Islander people want to be involved and engaged in the development of these strategies and resources, with the ability to utilise local knowledge and content. New social media and technology has the potential to develop and disseminate resources to reach a wider audience than more traditional resources, particularly among young people.

For a copy of the full report please contact Dr Lynn Roarty at l.roarty@curtin.edu.au.

Roarty, L., Frances, K., Allsop, S., O'Leary, C., McBride, N. & Wilkes, T. (2013). *Alcohol, pregnancy and Fetal Alcohol Spectrum Disorders: resources for health professionals working in Aboriginal and Torres Strait Islander health care settings*. Perth: National Drug Research Institute.

INTERVENTION NEEDS

Effective interventions

Evidence suggests that effective interventions should:

- have the support of and be controlled by local communities;
- be designed for specific communities and sub-groups, such as Indigenous populations;
- be culturally sensitive and appropriate;
- provide aftercare;
- cater for complex presentations;
- be broad rather than a quick fix; and
- combine a range of harm minimisation strategies.

To develop effective intervention, it's important that there be a focus on research and evaluation of early intervention therapies, as few have been rigorously evaluated.

Early years interventions

As noted, international evidence indicates that 0-5 is the age group where antenatal care, child health and development, and school readiness can impact upon key

social determinants of problematic drug use in later life. Early years intervention in the 0-5 age group provides a significant opportunity to deliver information and interventions through such settings as playgroup, day care and pre-school. Such a focus on development in the early years provides opportunities for early detection of suspected FAS/FASD while engaging young mothers around prevention of FASD.

Screening tools and referral pathways

It is important that a focus on FASD prevention and intervention include support for and research on referral pathways for children with FAS/FASD at all ages. This ties in with a strong focus on training in FAS/FASD for all health, education and community workers in identifying and helping to address FAS and FASD.

With specific reference to screening, [Elliott et al](#) (2008) have reviewed screening tools and recommend T-ACE and TWEAK as most appropriate in clinical settings.

Paternal alcohol consumption during preconception

There is emerging evidence that paternal alcohol use contributes to DNA damage to sperm and fetus (low birthweight, congenital heart defects, reduced cognitive ability). Animal studies support impact of paternal alcohol consumption on fetus even in the absence of maternal alcohol exposure.

Male partners have an important impact on maternal consumption during pregnancy through social facilitation. A NDRI study showed that 75% of women who drank during pregnancy usually drank with their partner, with 40% noting that their partner usually initiated drinking occasions. International research notes that heavy drinking pregnant women are more likely to have partners who are heavy drinkers.

Research also suggests that specific risk factors may include recent maternal drug use (Accornero et al 2002), high life stress (Lynch et al 2003), maternal psychopathology (Sood et al, 2001), custodial changes, current drug use in home, and violence exposure (Delaney-Black et al 2000). Several of these factors have a level of partner involvement.

Preconception

Preconception is an important intervention point. In his study of epigenetics, Haycock (2009, 2011), suggests that there can be a timelag in alcohol's teratogenic effects on embryonic development. That is, there can be a delayed impact of alcohol on the developing embryo when alcohol use occurs prior to conception and pregnancy.

Often consumption occurs in the non-recognised phase of pregnancy. This demonstrates the need for intervention and prevention activity during preconception and child bearing years.

Choline supplementation

Choline supplementation has been shown to reduce learning deficits and spatial working memory during and after prenatal alcohol consumption in animal studies (Thomas, 2011).

'Risky' women

Another NDRI study showed that some 'risky' women were concerned about drinking during pregnancy, but less so than about their use of other drugs, particularly tobacco. Combined prevention efforts may therefore be an important consideration, as will be intensive individually targeted programs to assist in quitting multiple substances.

'Risky' women are less likely to have a planned pregnancy. Research suggests that unplanned pregnancies can result from ineffective contraception use often associated with the use of alcohol. The combination of drinking and ineffective contraception suggests that interventions with combined messages for women who drink to risky levels may be an important form of intervention.

MANAGEMENT ISSUES

Infants and children impacted upon by fetal alcohol effects are diagnosed under other disabilities and receive services under these alternative classifications. The aetiologies of disabilities are important as they can determine treatment protocols, and at a community level, can have an important impact on policy, funding and focus of prevention activity.

Participatory research with women who cease consumption once pregnancy is recognised could assist in the development of prevention programs.

A recent Canadian study reports that a higher proportion of the population is affected by less severe FASD outcomes than those affected by FAS, and this replicates the findings of a German study (Loser, 1999) which notes that the number of severe cases of FAS decreased between 1973 and 1999 but the number of mild cases increased. If this pattern also proves to be in play in Australia then it has implications for policy and funding recommendations as it introduces the issue of the prevention

paradox. That is, more harm may be prevented by targeting a larger although lower consuming proportion of the population (Hawks, 1989).

Calculating accurate economic costs for Australia will be an essential part of any future focus on FASD. Included in these costs, but often hidden from discussions about FASD, is the likelihood of FASD affected children and adults being overrepresented in the criminal justice system.

It is also imperative that there be a strong focus on training in FAS/FASD for all service workers in health, education and community services, including in such specific settings as prisons and the criminal justice sector.

CONCLUSION

FASD intervention and research is still in its early days in Australia. Therefore the National Drug Research Institute supports this inquiry into FASD prevention, intervention and management as a key and crucial step in addressing a significant but entirely preventable problem.

It is imperative that any measures focussing on FASD be introduced as part of a broader multi-faceted and supported strategy, following the evidence base where it exists. Where the evidence base is limited or lacking, significant investment should be made in conducting intervention and prevention research.

NDRI also believes that an evaluation component should be explicitly included as part of a comprehensive strategy focusing on interventions targeted at FASD. This will allow specific approaches to be modified in response to emerging issues and trends, while maximising the effectiveness of efforts to reduce and prevent the effects of FASD in Australia.