

**SUBMISSION TO THE HOUSE OF REPRESENTATIVES
STANDING COMMITTEE ON SOCIAL POLICY AND LEGAL
AFFAIRS**

INQUIRY INTO FOETAL ALCOHOL SPECTRUM DISORDER

SOUTH AUSTRALIAN GOVERNMENT

January 2012

Introduction

The South Australian Government welcomes the opportunity to make the following submission to the Inquiry into Foetal Alcohol Spectrum Disorder (FASD).

On 8 November 2011, Hon Jenny Macklin MP, Minister for Families, Community Services and Indigenous Affairs and Hon Nicola Roxon MP, former Minister for Health and Ageing asked the House of Representatives' Standing Committee on Social Policy and Legal Affairs (Standing Committee on Social Policy and Legal Affairs) to inquire into and report on the incidence and prevention of FASD.

Terms of Reference

FASD is an overarching term used to describe a range of cognitive, physical, mental, behavioural, learning and developmental disorders that result from foetal exposure to alcohol.

The Standing Committee on Social Policy and Legal Affairs is to inquire into and report on developing a national approach to the prevention, intervention and management of FASD in Australia, with particular reference to:

- **Prevention strategies** – including education campaigns and consideration of options, such as product warnings and other mechanisms, to raise awareness of the harmful nature of alcohol consumption during pregnancy.
- **Intervention needs** – including FASD diagnostic tools for health and other professionals and the early intervention therapies aimed at minimising the impact of FASD on affected individuals.
- **Management issues** – including 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.

The South Australian Government wishes to make comment on the Terms of Reference.

Key Messages

1. Prevention of FASD is the highest priority, requiring a coordinated, whole-of-government approach across the population and for at risk population groups.
2. Narrowly focused, time limited programs that solely focus on FASD are unlikely to be successful in decreasing the incidence or improving outcomes. Policy and service approaches that are more likely to succeed need to be broad in scope, flexible in delivery, family-focused and be population-based, as well as providing individual support.

3. In addition to lost potential and the effects on quality of life for individuals and their families, FASD affects the use of resources in terms of treatments, lost productivity, social services and education.
4. The Indigenous Chronic Disease Package, established as part of the Council of Australian Governments' National Partnership on Closing the Gap in Indigenous Health Outcomes, and any future Commonwealth Government funding opportunities should consider and support the initiation and expansion of prevention programs for Aboriginal and Torres Strait Islander communities.
5. An evaluation is required on the efficacy of the alcohol industry voluntary codes of practice and other commitments in relation to alcohol advertising, especially in relation to alcohol consumption in pregnancy both in general population and at risk population groups.
6. There is a need for a national audit across vulnerable population groups, such as the prison population or the extent to which persons with FASD are clients within the disability sector, to determine the number with a diagnosis of FASD which are consequently receiving services and supports.
7. A coordinated whole-of-government approach to the provision of programs and services for individuals with FASD and their families is required to effect improved treatment and importantly, mitigate the impact of secondary personal and social problems arising from FASD. Appropriately resourced, the disability support sector would be well placed to lead the development and management of cross-agency services.
8. The recommendations from the Commonwealth Government's Monograph, *Foetal Alcohol Spectrum Disorders in Australia: An Update (2009)*¹, are also supported since they provide a broad, high-level response to the range of FASD related problems relevant to the deliberations of the Standing Committee on Social Policy and Legal Affairs. These recommendations include supporting:
 - Development of nationally agreed methods for asking about and recording alcohol use in pregnancy in clinical practice.
 - Nationally agreed criteria for diagnosing FASD be developed in order to ensure consistent and effective assessment and diagnosis to assist in determining prevalence in Australia.
 - Research on the relationship between alcohol use in pregnancy and the moderating factors that contribute to FASD is commissioned.
 - Programs, which aim to prevent alcohol use and foetal harm during pregnancy at both the population and targeted at risk population groups, are reviewed for their reach and effectiveness.
 - Community education strategies to raise awareness about alcohol use in pregnancy are developed.
 - A review of the evidence for effective interventions is undertaken and that guidelines are developed for early intervention with FASD.
 - A national coordinated screening, diagnostic and assessment FASD service be established and linked to a range of State based services that can offer early intervention, management and support to individuals affected by FASD and their families.

¹ The South Australian Government is aware that the Commonwealth Government is currently funding the updating of the Monograph, *Foetal Alcohol Spectrum Disorders in Australia: An Update (2009)*, and that the updated version is due for release in the first half of 2012.

- Necessary workforce and organisational changes to support the implementation of prevention and intervention responses to FASD is undertaken.
- Whole-of-government programs and services are developed for individuals with FASD and their families. The disability sector should take the lead on this supported by additional resources from the Commonwealth Government.

Addressing the Terms of Reference

Prevention Strategies – including education campaigns and consideration of options such as product warnings and other mechanisms to raise awareness of the harmful nature of alcohol consumption during pregnancy.

While it is known that FASD is associated with heavy and chronic alcohol consumption during pregnancy, there is no known safe level of alcohol consumption during pregnancy because of a lack of certainty in knowledge about moderating risk factors. This means that there are women who are inadvertently exposing their unborn children to alcohol by drinking at risky levels before they know they are pregnant, as well as women in at risk populations who are unable or unwilling to moderate their alcohol intake even though they are pregnant.

Narrowly focused, time limited programs that focus solely on FASD are unlikely to be successful in decreasing the incidence or improving outcomes because of the social complexities surrounding alcohol consumption and the variation in health literacy generally and within population groups. Policy and service approaches that are more likely to succeed need to be broad in scope, flexible in delivery, family-focused and population-based, as well as providing individual support.

Therefore, the prevention of FASD will require strategies targeted at population and at risk population groups. Strategies should aim to reduce the overall risky alcohol consumption levels in Australia, as well as targeting women of child bearing age.

The South Australian whole-of-government *Alcohol and Other Drug Strategy 2011-2016* was recently released and reaffirms the South Australian Government's commitment to a number of priority actions to enhance the lives of South Australians by reducing the harms of alcohol and other drug misuse.

This plan sets priority activities under the following key objectives that are relevant to the Inquiry ie:

- reduce the rate of alcohol-related harm
- reduce harm from substance misuse among Aboriginal people
- improve the timeliness of monitoring systems in order that trends in alcohol and other drug misuse are detected as early as possible.

One of the key strategies is to implement comprehensive social marketing campaigns to increase the level of understanding in the community of the risks about excessive alcohol consumption and intoxication, particularly among young people.

Perinatal outcomes for Aboriginal women and infants in South Australia have been consistently much poorer than those for non-Indigenous women and infants. There are several successful models of maternal care operating in South Australia that have the potential to assist in preventing or reducing the incidence of FASD within indigenous populations.

One of these is the Family Anangu Bibi Birthing Program run in partnership with the Nunyara Wellbeing Centre (Whyalla) and Pika Wiya Health Service (Port Augusta) and Country Health SA.

The Program's success is based on:

- Aboriginal women being cared for by Aboriginal women
- consistency of known caregivers
- Aboriginal maternal and infant care workers working in partnership with midwives.

The Indigenous Chronic Disease Package, established as part of the Council of Australian Governments' National Partnership on Closing the Gap in Indigenous Health Outcomes, is well placed to support the initiation and expansion of prevention programs for Aboriginal and Torres Strait Islander communities.

There is also a need to better equip health professionals who provide services to women and their partners/families in terms of knowledge and skills in addressing FASD. Essential to this is the need for better information about the incidence of FASD in Australia and an understanding of the complex interaction between the biological, social, environmental and political risks factors that correlate with FASD. Especially for women in at risk populations, there needs to be a greater understanding of the cultural, sociological and economic context of their situations, and careful consideration of these contexts is needed when planning and evaluating prevention strategies developed for these populations.

The South Australian Government is aware that the Commonwealth Government is currently funding the updating of the Monograph, *Foetal Alcohol Spectrum Disorders in Australia (2009)*, and that the updated version should be available in the first half of 2012.

The South Australian Government supports the following recommendations based on the 2009 Monograph:

1. Methods for asking about and recording alcohol use in pregnancy and their introduction into clinical practice are developed and agreed upon nationally.
2. Nationally agreed criteria for diagnosing FASD be developed in order to ensure consistent and effective assessment and diagnosis to assist in determining prevalence in Australia.
3. Research on the relationship between alcohol use in pregnancy and the moderating factors that contribute to FASD is commissioned.
4. Programs, which aim to prevent alcohol use and foetal harm during pregnancy at both the population and targeted at risk population groups are, reviewed for their reach and effectiveness.
5. Community education strategies to raise awareness about alcohol use in pregnancy are developed.

In its 2009 Technical Report No 3, *Preventing alcohol-related harm in Australia: a window of opportunity*, the National Health Preventative Taskforce determined that warning labels on alcohol products 'while not required in Australia, have a high level of public support'. More recently, the issue of mandating product warning labels on alcohol and at point of sale was highlighted in the 2011 *Independent Review of Food Labelling Law and Policy*, with a recommendation:

'That a suitably worded warning message about the risks of consuming alcohol while pregnant be mandated on individual containers of alcoholic beverages and at the point of sale for unpackaged alcoholic beverages, as support for ongoing broader community education'².

While there is little evidence to support that mandating information on the harms of consuming alcohol during pregnancy influences knowledge and attitudes, there is strong evidence that warning labels have some effect (in the case of tobacco products). Notwithstanding the Commonwealth Government's preference to allow the industry to operate under a voluntary code of practice, an evaluation on the efficacy of this and other commitments in relation to alcohol advertising, especially in relation to alcohol consumption in pregnancy would be required to determine the merits of mandating product warning labels.

Intervention needs – including FASD diagnostic tools for health and other professionals, and the early intervention therapies aimed at minimising the impact of FASD on affected individuals.

At this stage, there is neither a specific diagnostic laboratory test available to detect adverse effects of alcohol consumption on the foetus, nor a specific diagnostic laboratory test for detecting FASD in babies.

Early diagnosis and intervention may substantially reduce the risk and impact of secondary social, emotional and behavioural problems in children, adolescents and adults affected by FASD. Early diagnosis of a child with FASD might also prevent alcohol exposure in future pregnancies.

Guidelines for assessing children suspected of having FASD have been published in North America and these recommend the establishment of multi-disciplinary teams that not only assess children exposed to alcohol in utero but also assess the abilities and needs of families to address the consequences of FASD on their children. Such specialised diagnostic and early intervention services are not currently available in Australia.

However, it needs to be acknowledged that there is a paucity of evidence about the efficacy of specific interventions for people with FASD.

The South Australian Government supports the following recommendations based on those of the 2009 Monograph:

1. A review of the evidence for effective interventions is undertaken and that guidelines are developed for early intervention with FASD.

² *Labelling Logic: Review of Food Labelling Law and Policy 2011*, Report to the Australia and New Zealand Food Regulation Ministerial Council

2. Agreement is reached on diagnostic criteria for FASD and that a national coordinated screening, diagnostic and assessment FASD service is established linked to a range of State based services that can offer early intervention, management and support to individuals affected by FASD and their families.
3. Necessary workforce and organisational changes to support the implementation of prevention and intervention responses to FASD is undertaken.

Management issues – including 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.

The problems associated with foetal exposure to alcohol are life-long. The management issues around people affected by FASD, together with assistance and support for their families, is an area which is best addressed by a cross portfolio approach.

There is a reasonable view that the number of people with FASD is under-diagnosed and may not as a consequence receive the support and services they need. Since it is not known what the actual prevalence of FASD is in the adult population, particularly in some at risk populations, such as the prison population or the extent to which persons with FASD are clients within the disability sector, the Standing Committee on Social Policy and Legal Affairs may wish to consider the need for a carefully conducted national research audit across such vulnerable population groups and sectors to determine the number with a diagnosis of FASD, which are consequently receiving services and supports.

In South Australia, a number of cross-agency services are provided for people with co-morbid mental health and disability or substance abuse issues by specialist Mental Health Services, Disability SA, the Exceptional Needs Unit, the Brain Injury Rehabilitation Unit and Disability, Ageing and Carers Branch of the Department for Communities and Social Inclusion.

These cross-agency services include assessment, intervention, individual and developmental support, assistance to access community services, as well as access to more intensive services where behavioural difficulties are extreme.

A coordinated nationally led approach across Governments for the provision of programs and services for individuals with FASD and their families is required to effect improved treatment and importantly, mitigate the impact of secondary personal and social problems arising from FASD. As part of this approach, appropriately resourced, the national disability support sector would be well placed to lead the development and management of cross-agency services.