

Department of Health and Ageing

**Department of Families, Housing,
Community Services and Indigenous
Affairs**

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

**Inquiry into
Foetal Alcohol Spectrum Disorder**

May 2012

INTRODUCTION

Alcohol consumption during pregnancy can cause a range of abnormalities in the unborn child which are included under the umbrella term Foetal Alcohol Spectrum Disorder (FASD). FASD, which is completely preventable, is not a clinical diagnosis in itself but represents a range of diagnoses that fall under the spectrum. These include, at the severe end of the spectrum, Foetal Alcohol Syndrome (FAS), as well as Alcohol Related Birth Defects (ARBD) and Alcohol Related Neurodevelopmental Disorders (ARND).

People affected by FASD experience a range of difficulties including low IQ, learning difficulties, developmental delays and behavioural problems. Secondary outcomes may include: mental health problems; drug and alcohol issues; poor social, educational and employment outcomes; and a high level of contact with the criminal justice system.

The level of prenatal alcohol exposure that can cause foetal harm is uncertain as a range of moderating factors impact on whether and what type of harm will occur. The 2009 National Health and Medical Research Council (NHMRC) Australian Guidelines to Reduce Health Risks from Drinking Alcohol (Guidelines) recommend that, for pregnant women, '*not drinking alcohol is the safest option*'. The Guidelines state that the potential risk of harm is higher with high alcohol intake, including episodic intoxication; and appears to be low with low level intake but it is impossible to determine how maternal and foetal factors will alter risk in the individual.

At present, there are no accurate data on the prevalence or incidence of FASD in Australia. A number of studies have estimated the birth prevalence of FAS. Current birth prevalence data for FAS ranges from between 0.06 to 0.68 per 1,000 live births¹. The known birth prevalence of FAS for Aboriginal children is considerably higher, being 2.76 per 1,000 live births in Western Australia² and 4.7 per 1,000 live births in the Northern Territory³.

The primary and secondary impact of FASD on individuals, their families and the community is wide ranging and crosses many portfolio areas such as physical and mental health, early childhood, education, disability, family and community services (including child protection), employment, housing and the criminal justice sector.

Clearly, given the association with the potential harms of alcohol consumption for the developing foetus during pregnancy, prevention of FASD is a significant priority. More consistent and timely diagnosis, evidence based early intervention and a broad range of health, social and disability support services are also appropriate particularly for children at the more severe end of the spectrum.

This submission focuses on outlining current efforts within the Department of Health and Ageing and the Department of Families, Housing, Community Services and Indigenous Affairs relevant to this Inquiry.

¹ Harris KR, Bucens IK. *Prevalence of fetal alcohol syndrome in the top end of the Northern Territory*. J Paediatr Child Health 2003;39:528–33.

² Bower C, Silva D, Henderson TR, Ryan A, Rudy E. *Ascertainment of birth defects: the effect on completeness of adding a new source of data*. J Paediatr Child Health 2000;36:574–6.

³ IBID Harris et. al.

ROLE OF THE DEPARTMENT OF HEALTH AND AGEING AND THE DEPARTMENT OF FAMILIES, HOUSING, COMMUNITY SERVICES AND INDIGENOUS AFFAIRS

The Department of Health and Ageing (DoHA) and the Department of Families, Housing, Community Services and Indigenous Affairs (FaHCSIA) consider that in planning for future activity, FASD should be managed as a whole of population issue, with targeted approaches for at risk populations, and coordinated whole of government responses. Targeted, culturally appropriate activities are required for at risk populations such as Indigenous people, alcohol dependent women and people from low socioeconomic backgrounds.

Further research is required in order to strengthen the evidence base on FASD, in particular to determine the prevalence of FASD in Australia and the effectiveness of specific interventions.

In summary, DoHA's role has included:

- Supporting prevention of FASD at a broad population level, by promoting evidence based information to support women and communities about the risk of consuming alcohol during pregnancy, and providing tools for primary care clinicians to support screening and management of alcohol misuse during pregnancy;
- Targeted prevention efforts through developing communication resources and 'train the trainer' activities aimed at preventing and raising awareness of FASD in Indigenous communities;
- Funding for the development of a diagnostic tool, promoting early and accurate diagnosis; and
- Provision of drug and alcohol treatment services which give priority for alcohol dependent women with or planning families.

Refer to **Attachment A** for detail on specific FASD activities.

FaHCSIA works in partnership with other government and non-government organisations to manage a diverse range of programs and services designed to support and improve the lives of Australians. A central part of FaHCSIA's work is to foster the development, wellbeing and safety of families and children, and to help support people with disability and their carers, including children and families affected by FASD. As the department responsible for Indigenous affairs, FaHCSIA is working to better integrate efforts at all levels of government to improve safety and wellbeing, and to reduce alcohol-related harm among Indigenous Australians.

More detail on these activities follow.

PREVENTION STRATEGIES

- The National Partnership Agreement on Preventive Health (NPAPH), agreed by the Council of Australian Governments in 2008, represents a significant Australian Government commitment to the prevention of lifestyle related chronic disease. Under the Partnership, governments at all levels work with a range of stakeholders including industry, non-government and not-for profit groups to implement a range of preventive health activities focused on reducing rates of overweight and obesity, increasing levels of physical activity and intake of fruit and vegetables, reducing harmful levels of alcohol consumption and smoking cessation.

- DoHA has undertaken activities, including local community projects and the dissemination of brochures and posters, through initiatives, including programs such as the National Binge Drinking Strategy to promote the 2009 NHMRC Guidelines message that for women who are pregnant or breastfeeding, '*not drinking alcohol is the safest option*'. The *2010 National Drug Strategy Household Survey* report indicates that the proportion of pregnant women abstaining from alcohol during pregnancy increased from 40 per cent in 2007 to 52 per cent in 2010.
- In recognition of the higher rates of FASD in Indigenous communities, DoHA has funded the National Indigenous FASD Resource Project, which is developing culturally appropriate communication resources on FASD for Aboriginal and Torres Strait Islander peoples.
- An important part of improving prevention and diagnosis of FASD is screening for alcohol use during pregnancy. In 2010, DoHA funded the Murdoch Childrens Research Institute to examine and develop screening tools for alcohol use during pregnancy. The final report '*Alcohol in pregnancy: What questions should we be asking?*' can be downloaded from the website at www.alcohol.gov.au.
- The final report recommends the use of a clinical tool, the Alcohol and Pregnancy Lifescripts Kit (part of the Australian Government GP Lifescripts resources), which is informed by the 2009 NHMRC Guidelines and provides primary healthcare professionals with a practical resource to assist with assessment and management of alcohol consumption during pregnancy. The updated Lifescripts Kit should be available in May 2012.
- To help improve data on the prevalence of FASD, DoHA has funded the Australian Institute of Health and Welfare to undertake a scoping study on ways to improve data collection and reporting. This project is complete and the report is being finalised.
- As a result of the *Review of Food Labelling Law and Policy 2011*, and the decision on 9 December 2011 by the Legislative and Governance Forum on Food Regulation, DoHA is consulting with key stakeholders in regard to the implementation of warning messages on alcoholic beverages about the risks of consuming alcohol while pregnant, noting that the alcohol industry has been given an opportunity to introduce appropriate warning labels on alcohol products on a voluntary basis for a period of two years, before consideration of regulating for this change.
- DoHA anticipates funding activity in 2012-13 under the new Flexible Fund for Substance Prevention and Service Improvement to promote consistent evidence based messages about the harm of drinking alcohol during pregnancy, and to support networking between Indigenous organisations aimed at best practice models of prevention of substance misuse.
- In addition to the programs to address FASD, work is under way to reduce the devastation and community dysfunction driven by alcohol misuse in Indigenous communities. FaHCSIA is administering the *Breaking the Cycle of Alcohol and Substance Abuse* initiative to support community led solutions to address alcohol-related harm in Indigenous communities.

- Other national programs that aim to improve child and maternal care, which may impact on the amount of alcohol consumed during pregnancy, include:
 - the *Healthy for Life Program*, which provides support to deliver frontline maternal and child health services, men’s health services and chronic disease services for Indigenous Australians;
 - the *New Directions Mothers and Babies Services Program*, which provides greater access to child and maternal health services; and
 - the *Australian Nurse Family Partnership Program*, an intensive home visiting program to help women improve their health, and the health and development of their children before and after childbirth.

EARLY DIAGNOSIS AND INTERVENTION NEEDS

- Accurate and consistent diagnosis of FASD is important to ensure that people are connected to appropriate care and support. In addition, early diagnosis may prevent recurrence in later pregnancies. For this reason, DoHA has engaged the Telethon Institute for Child Health Research to research and report on development of a diagnostic instrument to assist clinicians in diagnosing babies and children affected by FASD. The report *'Development of a Diagnostic Instrument for Foetal Alcohol Spectrum Disorders (FASD) in Australia'* is being finalised.
- DoHA and FaHCSIA have jointly funded the George Institute for Global Health to conduct the Marulu: Lirilwan Project in the Fitzroy Valley, Western Australia. This is the first Australian study into the prevalence and impact of FASD in Indigenous children. The project will also provide support to affected children and families in Fitzroy Valley and help to inform diagnosis and community education strategies which may be transferrable regionally and nationally.
- FaHCSIA has funded a FASD program in the Barkly Region in the Northern Territory to raise awareness of FASD in the community, develop community solutions to dealing with FASD, and work with health and other professionals to support families living with the effects or potential effects of FASD.
- Under the Commonwealth *Indigenous Early Childhood Development National Partnership*, there are programs to raise awareness about the harm of alcohol consumption during pregnancy.

ONGOING MANAGEMENT AND SUPPORT ISSUES

- Support for people with FASD and their carers is available through a range of specialist disability services, which are provided by state and territory governments under the National Disability Agreement (the Agreement). From 1 January 2009 to 30 June 2015, the Government will be providing around \$7.6 billion to state and territory governments for increased and improved specialist disability services under the Agreement. People with FASD that require ongoing self-care, mobility or communication support may be eligible for support from these specialist disability support services.

- A National Disability Insurance Scheme will ensure that people with significant and permanent disability receive the care and support they need over their lifetimes, regardless of where they live or how they acquired their disability. On 8 May 2012 the Government announced \$1 billion to support the first stage of a National Disability Insurance Scheme, which will start from mid-2013.
- People with FASD who are over age 16 may qualify for Disability Support Pension if they have a physical, intellectual or psychiatric impairment (assessed at 20 points or more under the impairment tables*) that prevents them from working, or being re-skilled to work, for more than 15 hours a week at or above the relevant minimum wage, within the next two years.

* If at least 20 points are not allocated under a single impairment table, the person must have actively participated in a program of support.

- Carers of people with FASD may be able to access financial assistance in recognition of their caring role:
 - Carer Payment is paid to people who, because of the demands of their caring role, are unable to support themselves through substantial paid employment;
 - Carer Allowance is a non-income and assets tested income supplement available to people who provide daily care and can be paid in addition to Carer Payment; and
 - Carers receiving Carer Allowance may be eligible to receive a \$600 annual Carer Supplement for each person for whom they receive Carer Allowance. An additional \$600 Carer Supplement is also paid to eligible carers in receipt of Carer Payment.
- Some carers may also be entitled to receive the Child Disability Assistance Payment, which is a \$1,000 annual payment, available to a child with disability under 16 years who attracts a payment of Carer Allowance for their carer.
- People with FASD who have broader needs and co-morbidities may be eligible to access the following mainstream DoHA programs:
 - Health assessments for Indigenous people, children aged 3-5 years, people aged 45-49 years, people with intellectual disability, residents of aged care facilities and people aged 75 years and older, through the Medicare Benefits Schedule (MBS);
 - Access to allied health services for children with an eligible disability through the MBS; and
 - Mental health services including a new initiative under the Access to Allied Psychological Services (ATAPS) which targets children and Indigenous people.
- In addition, FaHCSIA funds a range of community based mental health services under the *Targeted Community Care (Mental Health) Program*. Access is based on an eligibility assessment. Depending on eligibility, people with FASD, their families and carers may be eligible to access the:
 - *Personal Helpers and Mentors Service*, which assists people with severe and debilitating mental illness to set and achieve personal goals such as finding employment, help with connecting to appropriate medical and health supports and improving relationships with family and friends;

- *Family Mental Health Support Services*, which provides a range of early intervention, prevention support and community education activities to assist vulnerable families with children and young people who are affected by or at risk of mental illness; and
- *Mental Health Respite: Carer Support Service*, which provides flexible support to meet the individual needs of carers and families of people with severe mental illness, autism or intellectual disability.

OTHER COMMONWEALTH AND NATIONAL ACTIVITIES ON FASD

FASD is an ongoing priority for the InterGovernmental Committee on Drugs (IGCD), which provides a partnership between health and law enforcement across jurisdictions to implement priority actions under the *National Drug Strategy 2010-2015*. The IGCD provides a forum through which government to government coordination of actions and strategies can take place.

In November 2009, a working party of the IGCD prepared a comprehensive report '*Foetal Alcohol Spectrum Disorder in Australia: an update*' (the FASD Monograph) at the request of the former Ministerial Council on Drugs Strategy.

The FASD Monograph covers research, policy and practice regarding FASD in Australia, illustrates the complex multi-faceted nature of FASD, and includes recommendations that identify potential actions in prevention, screening, diagnosis, models of care and workforce capabilities.

The FASD Monograph is being considered by Health Ministers and the final report is expected to be available by mid 2012. The FASD Monograph will be instrumental in informing future policy and planning in regard to FASD.

DoHA is also aware that FASD is an area that has been identified as part of the National Health and Medical Research Council (NHMRC) roadmap for targeted research. NHMRC is in the advanced stages of planning a Targeted Call for Research (TCR) into FASD. A total of \$2.5 million has been allocated for this TCR which will provide support for research grants up to 5 years duration. This could help to address the gap in knowledge about how best to prevent and reduce the impact of FASD.

There are a number of ways in which the coordination of FASD activities across government can be facilitated. For example, DoHA and FaHCSIA have recently set up, and are co-chairing, a working group with Australian Government agencies to focus on coordinated whole of government responses to FASD. An initial meeting of the chairs has been held to determine the parameters for the group, which will meet formally in May 2012.

DoHA and FaHCSIA jointly acknowledge that appropriate sharing of information should utilise existing communication channels, not duplicate or establish resource intensive and competing administrative structures. As FASD is a complex issue it is important that all government agencies, community organisations, stakeholders and the broader community work together to achieve meaningful outcomes.