Australian Government

Australian National Preventive Health Agency

Australian National Preventive Health Agency (ANPHA) submission:

The House of Representatives Standing Committee on Social Policy and Legal Affairs, Inquiry into Foetal Alcohol Spectrum Disorder (FASD)

January 2012

Contents

The Australian National Preventive Health Agency (ANPHA) welcomes the Inquiry into Foetal Alcohol Spectrum Disorder (FASD) by the House of Representatives Standing Committee on Social Policy and Legal Affairs, and acknowledges the need to develop a national approach to the prevention, intervention and management of FASD in Australia.

ANPHA also notes reports previously tabled by the Senate's Select Committee on Regional and Remote Indigenous Communities[1] that highlight the Committee's deep concern about the reported prevalence of foetal alcohol spectrum disorders in regional and remote (and many other) communities; and express the need for governments across Australia to give greater recognition to the issue of FASD in the formulation of health, education and justice policies[2].

Whilst the current Inquiry's terms of reference cover prevention strategies, intervention needs and management issues, in its submission to the Committee, ANPHA will address the issue of FASD prevention.

1. ANPHA's role in preventive health

The Australian National Preventive Health Agency (ANPHA) was established on 1 January 2011 to strengthen Australia's investment in preventive health, following the commencement of the *Australian National Preventive Health Agency Act 2010.*

The Council of Australian Governments (COAG) agreed to establish ANPHA in November 2008, as part of the *National Partnership Agreement on Preventive Health*[3]. The creation of a national preventive health agency was also recommended in the National Health and Hospitals Reform Commission's Report (released in July 2009) and in the final report of the National Preventative Health Taskforce (released in September 2009).

ANPHA contributes to improving health outcomes for Australians by helping to reverse the rising prevalence of preventable chronic diseases. ANPHA supports all Australian Health Ministers in managing the complex challenges of preventable chronic diseases. ANPHA supports the development and implementation of evidence-based approaches to preventive health initiatives and has been charged with focussing its initial efforts on the risks and burdens of disease associated with obesity, tobacco and harmful alcohol use.

2. Estimating the incidence of FASD in Australia

Foetal alcohol spectrum disorders (FASD) is a general term used to describe a range of adverse outcomes caused by exposure to alcohol during pregnancy. FASD encompasses a range of clinically significant effects; some of which include growth retardation, facial anomalies and developmental abnormalities of the central nervous system. FASD is not a diagnostic term; rather, it represents a spectrum of disorders, including the diagnostic terms of foetal alcohol syndrome (which sits at the severe end of the spectrum), alcohol-related birth defects and alcohol-related neuro-developmental disorder[4].

---

[1] Commonwealth of Australia 2008, The Senate Select Committee on Regional and Remote Indigenous Communities *First Report 2008, Third Report 2009* & *Final Report 2010*. Available at http://www.aph.gov.au/Senate/committee/indig_ctte/index.htm. Accessed on 12 December 2011.

[2] Commonwealth of Australia 2010, The Senate Select Committee on Regional and Remote Indigenous Communities *Final Report 2010*. Available at http://www.aph.gov.au/Senate/committee/indig_ctte/index.htm . Accessed on 12 December 2011.

[3] COAG 2008. *National Partnership Agreement on Preventive Health*. Available at http://www.federalfinancialrelations.gov.au/content/national_partnership_agreements/HE004/Preventive_Health.pdf

[4] 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.

Accurate diagnosis of FASD is difficult due to a wide range of factors. These include a lack of full agreement on the definition and scope of FASD, complexity of diagnostic tests, variability in health professionals' understanding of and ability to diagnose FASD, and a reluctance to diagnose due to the social stigma associated with this condition.

There is currently no objective laboratory diagnostic test for FASD. Instead, diagnosis relies on identification of a pattern of abnormalities that make up the syndrome and reports (generally self-reports) of alcohol use/misuse by the mother during pregnancy and around the time of conception[5]. As a result, there is a paucity of data in Australia on the incidence and prevalence of FASD as well as its associated burden on society.

The incidence of FASD is observed across the Australian community. However, several Australian studies indicate that FASD is almost certainly under-diagnosed and under-reported and that little is known about Australian health professionals' knowledge, attitudes and practices in regard to FASD and alcohol use in pregnancy[6].

The first attempt to estimate birth prevalence of FASD in Australia was published in 2000, by Bower et al. who found, using two data sources, a rate of 0.02 per 1,000 non indigenous live births and 2.76 per 1,000 Indigenous live births in Western Australia[7]. Subsequent studies in the Northern Territory and nationally through the Australian Paediatric Surveillance Unit (APSU) found similar or lower rates but all authors acknowledge under-ascertainment is likely. This is most likely due to the complexity of achieving a definite diagnosis[8]- both in the general population and in Indigenous communities, lack of access to paediatricians in regional and remote areas, and failure by paediatricians to report a diagnosis for reasons including; failure to ask about alcohol use in pregnancy, lack of knowledge about the essential diagnostic features and management of FASD, and a fear of stigmatising the child and family. Furthermore, a 2002-2003 survey of 1,143 WA health professionals, including Aboriginal health workers, allied health professionals, community nurses, general practitioners and obstetricians, found that only 12 percent of respondents could identify the four essential diagnostic features for FASD and only 2 percent felt they had the necessary knowledge and skills to deal with it[9].

Before accurate prevalence rates of FASD can be estimated in Australia, routine assessment and recording of maternal alcohol use during pregnancy, education about diagnosis of FASD, and methods for collecting national data would need to be established.

FASD symptoms in infants and children include developmental delay, low IQ, behavioural problems and learning difficulties. The severity of the condition and associated symptoms varies, but overall there is a poor prognosis and limited treatment therapies. The impact of some symptoms can be partially remediated through early intervention. In later life FASD can be associated with reduced social and economic participation. FASD can impact on families in a number of ways, through stigma of both parent and child, and can place additional pressure on parents and other siblings.

---

[5] O'Leary CM 2004, Fetal alcohol syndrome: Diagnosis, epidemiology, and developmental outcomes. *J Paediatr Child Health* 40: 2-7.

[6] Payne J, Elliott E, D'Antoine H, O'Leary C, Mahony A, Haan E and Bower C 2005, Health professionals' knowledge, practice and opinions about fetal alcohol syndrome and alcohol consumption during pregnancy. *Aust NZ J of Public Health* 29 (6): 558-564; Elliot E, Payne J, Morris A, Haan E and Bower C 2008, Fetal alcohol syndrome: a prospective national surveillance study. *Arch. Dis. Child. 93: 732-737.*

[7] Bower C, Silva D, Henderson TR, Ryan A, and Rudy E 2000, Ascertainment of birth defects: The effect on completeness of adding a new source of data. *J. Paediatr. Child Health* 2000; 36: 574-6.

[8] Elliot et al 2008, Fetal alcohol syndrome: a prospective national surveillance study. *Arch. Dis. Child. 93: 732-737*.

[9] Payne et al 2005, Health professionals' knowledge, practice and opinions about fetal alcohol syndrome and alcohol consumption during pregnancy. *Australian and New Zealand Journal of Public Health* 29 (6): 558-564.

3. Current Australian approaches to FASD prevention

Prevention of FASD is simple in theory, in that it is 100 percent preventable if women do not drink alcohol during pregnancy. In practice however, FASD prevention is highly complex requiring a range of interventions across numerous sectors that can address the issues relating to harmful alcohol consumption. As more is understood about the complex challenges of FASD prevention, it becomes clear that to assign pregnant women with the sole responsibility for FASD prevention is not only misguided, but ineffective and punitive[10].

The National Health and Medical Research Council's 2009 *Australian Guidelines to Reduce Health Risks from Drinking Alcohol* (NHMRC guidelines) recommend that for women who are pregnant or planning a pregnancy, not drinking is the safest option. Currently, a range of materials setting out the NHMRC guidelines' messages are available for order at www.alcohol.gov.au; however, no further national measures are in place to promote the Guidelines.

The *National Alcohol Strategy 2006-2011*, which sits under the policy framework of the National Drug Strategy, aims to prevent and minimise alcohol-related harm to individuals, families and communities in the context of developing safer drinking cultures in Australia. While this Strategy does not specifically address the issue of FASD, the Intergovernmental Committee on Drugs (IGCD), which oversees the implementation of the Strategy, convened a Working Party on FASD from 2006 – 2009.

Each State and Territory Government also has its own drug and alcohol strategies and several states and territories have developed a range of FASD focused activities. For example in September 2011, the Government of Western Australia announced its 'No alcohol while pregnant' campaign launch. This campaign is aimed at sending the clear message that the safest option is to not drink alcohol during pregnancy, and when planning pregnancy and breastfeeding. Western Australia's Drug and Alcohol Office has also received funding to develop a suite of indigenous focused FASD prevention initiatives. Additionally, there is evidence of regionally-based programs that aim to reduce the incidence of FASD in local communities[11].

A range of online FASD resources do exist that address the issue of FASD prevention[12]. However, any potential impact is limited by access and distribution. Furthermore, as identified at a 2010 WA FASD Prevention Aboriginal Consultation Forum, there are limited training opportunities specific to FASD, limited availability of resources specific to regional and remote areas, and in many cases, resources are only applicable to maternal health settings.

In 2001 the Telethon Institute for Child Health Research commenced the 'Alcohol and Pregnancy Research Program'. This has led and contributed to multiple FASD research projects and promotes the importance of prevention and early diagnosis. The Institute was recently funded by the Department of Health and Ageing to undertake the *FASD Project*. This project included the development of an evidence-based screening and diagnostic tool planned for national use.

---

[10] Clarren S, Salmon A and Jonsson E (Eds) 2011, *Prevention of Fetal Alcohol Spectrum Disorder FASD: Who is responsible?*, Wiley-Blackwell, Weinham.

[11] For example, the Ord Valley Aboriginal Health Service's *Fetal alcohol spectrum disorders program* was developed and implemented in remote north Western Australia in order to put in place strategies aimed at preventing maternal alcohol use and in turn FASD in the local community.

[12] Some of these resources include: a *FASD Model of Care*, developed by the Government of WA; a *FASD guide for midwives*, and the resource: *Pregnancy and alcohol don't mix*, developed by the Government of SA; *National clinical guidelines for the management of drug use during pregnancy, birth and the early development of the newborn*, commissioned by the Ministerial Council on Drug Strategy under the Cost Shared Funding Model; and *Alcohol and Pregnancy and Fetal Alcohol Spectrum Disorder: a Resource for Health Professionals* with accompanying factsheets, developed by UWA's Telethon Institute for Child Health Research.

There is currently no Commonwealth policy strategy specifically dedicated to FASD prevention.

4. International approaches to FASD prevention

There are a limited number of published studies that have evaluated FASD prevention strategies; mostly with a focus on the USA and Canada.

In Canada, four public awareness campaigns and supporting resources specific to FASD were evaluated, including the campaigns: Born Free (Alberta), Mother Kangaroo (Saskatchewan), With Child/Without Alcohol (Manitoba), and Be Safe (Ontario). These involved the dissemination of information at point-of-sale, as well as the promotion of key messages through television, radio and print media. Restaurants also participated in providing free non-alcoholic beverages to pregnant customers. Data from the evaluation showed that whilst there was improved public awareness in the general population following campaign activity, campaign messages had often failed to reach high risk groups. The evaluation highlighted the importance of determining the target audiences and including them in the development phase[13].

A more recent comprehensive review of FASD prevention in Canada identifies similar challenges to Australia in terms of a lack of clarity on governance and leadership arrangements, and the difficulty of allocating portfolio responsibility for FASD at the national level[14].

5. The Australian preventive health context for FASD prevention

The National Preventative Health Taskforce's 2009 *Roadmap for Action*[15](Taskforce Report) recommended a number of measures to reduce the prevalence of short and long-term harmful and risky drinking for all Australians. A phased approach to these strategies is recommended, ranging from national consistency in, and improvements to, liquor licensing and enforcement, regulation of alcohol promotion, increasing public awareness, reform of alcohol taxing and pricing arrangements, and strengthening the evidence base including improved data collection systems regarding alcohol consumption. In addition there are recommendations related to action at the local level and through the primary health care system, including improved access to health services for indigenous Australians drinking, or at risk of drinking, at harmful levels. Some of these proposals need to be taken into account together with FASD-specific actions.

In May 2010, the Australian Government responded to the Taskforce Report in *Taking Preventative Action: A response to Australia: the healthiest country by 2020*[16], in which it reiterated its commitment to addressing a number of broad alcohol issues. These included:

- working with states and territories through COAG and Ministerial Council on Drug Strategy to strengthen liquor control legislation and regulations;
- supporting community-led initiatives under the National Binge Drinking Strategy to tackle the problem of binge drinking and alcohol-related violence;
- increasing public awareness and reshaping attitudes to promote a safer drinking culture through social marketing and public education, including widely distributing educational

[13] Saskatchewan Prevention Institute 2009. Creating effective primary prevention FASD resources: Evaluation processes in health promotion. Available at: http://www.preventioninstitute.sk.ca/uploads/FASD%20Resources%20Evaluation.pdf . Accessed on 4 January 2012.
[14] Clarren S, Salmon A and Jonsson E (Eds) 2011, *Prevention of Fetal Alcohol Spectrum Disorder FASD: Who is responsible?*, Wiley-Blackwell, Weinham.
[15] National Preventative Health Taskforce 2009. *Australia: The Healthiest Country by 2020 –National Preventative Health Taskforce - Roadmap for Action.*
[16]Commonwealth of Australia 2010. *Taking Preventative Action – A Response to Australia: The Healthiest Country by 2020 – The Report of the National Preventative Health Taskforce*. Available at: http://www.yourhealth.gov.au/internet/yourhealth/publishing.nsf/Content/take-prev-action-toc#.Tu_UWDXKmHc

materials about the updated NHMRC guidelines with a particular focus on pregnant and breastfeeding women, young people and parents;
- charging ANPHA with developing a public interest case for minimum pricing of alcohol for further consideration by Government;
- continuing to invest in the Aboriginal and Torres Strait Islander Substance Abuse Program and in alcohol and other drug services under COAG's 2007 Closing the Gap – Indigenous drug and alcohol services measure; and
- developing a range of materials aimed at parents to promote the NHMRC guidelines.

In a recent review of food labelling, *Labelling Logic: Review of Food Labelling Law and Policy (2011)* [17], four key recommendations were made to the Australian Government concerning alcoholic beverage labelling and packaging. This included the 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 for sale for unpackaged alcohol beverages, as support for ongoing broader community education."

On 9 December 2011 the Legislative and Governance Forum on Food Regulation (convening as the Australian and New Zealand Food Regulation Ministerial Council, hereafter referred to as FoFR) met and agreed its response to the 61 recommendations in *Labelling Logic.* In the 'Response to the Recommendations of *Labelling Logic: Review of Food Labelling Law and Policy (2011)*' report[18], the FoFR agreed that warnings about the risks of consuming alcohol while pregnant should be pursued. It noted the voluntary steps industry has already taken in this area and has suggested that industry is to be given the opportunity to introduce appropriate labelling on a voluntary basis for a period of two years before regulating for this change.

The effect of this labelling measure would be enhanced by its integration with other public health strategies, including broad public education and awareness campaigns.

6. Evidence for future strategies to prevent FASD in Australia

FASD prevention as a population health strategy is difficult in environments where there is access to cheap alcohol, high levels of alcohol promotion, and where the risk factors for harmful alcohol use, including social dislocation and unemployment in local communities, exist. In Australia, an approach to FASD prevention is required that addresses the underlying issues relating to harmful alcohol consumption, together with strategies that minimise the damage caused by prenatal alcohol exposure, through early diagnosis and intervention.

In the case of FASD, as is typical of many public health problems, a range of intervention strategies will be required in combination to achieve effective outcomes. These will include broad population-based approaches that reduce the average risk in the whole population from alcohol consumption, as well as approaches that aim to reduce alcohol consumption specifically among individual pregnant women or women of child-bearing age.

FASD prevention strategies must be both comprehensive and specifically address those already identified high risk groups, such as the socially and economically disadvantaged and Indigenous communities, where differences in the incidence of FASD have been reported[19].

[17] The full report, presented to the Ministerial Council on 28 January 2011, is available on the Food and Labelling Review website at: www.foodlabellingreview.gov.au

[18] The full response is available on the Food Labelling Review Website

[19] During a public hearing for the Senate's Select Committee on Regional and Remote Indigenous Communities, a doctor from Halls Creek hospital informed the Committee that he believed around 30 percent of children in the region suffered from some symptoms of FASD, while 50 percent of the children he treated at the hospital had symptoms. (Commonwealth of Australia 2009, the Senate Select Committee on Regional and Remote Indigenous Communities

Targeted strategies must consider and adopt different approaches where required. The acceptance of alcohol use in Australia and the social contexts in which alcohol is consumed are also critical issues to consider, as are other perspectives such as education, justice and child protection. In some settings prevention and health promotion should involve contributing factors and risks to foetal and childhood development such as the mother's social and emotional wellbeing, education, unemployment, nutritional status, and tobacco and cannabis use that may enhance the teratogenic effects of alcohol[20]. Any targeted strategies will be further strengthened by ongoing measures to address broader community attitudes towards, and behaviours around, alcohol consumption. A reduction in harmful drinking in the broader community will have a flow-on reduction of the incidence of FASD.

Australian studies specifically indicate a need for further work in the following three areas:

1. Strengthening the evidence base

Effective preventive health policies and programs relating to FASD need to be informed by epidemiological data, as well as data on alcohol consumption and alcohol related harm in the Australian population[21]. Effective strategies for FASD prevention require:

- nationally agreed methods for asking about, and recording, alcohol use in pregnancy;
- a national surveillance system for FASD;
- a systematic review of prevention programs that have been adequately evaluated; and
- a commitment to evaluating and reporting on prevention strategies that are implemented.

There also remains a lack of data on rates of, and a need for continuing research on, alcohol-related birth defects and alcohol-related neuro-developmental disorders[22]. The NHMRC guidelines highlight the need for research on the association between low to moderate alcohol consumption and foetal harm.

In improving the health of Indigenous Australians, the National Preventative Taskforce Report highlights the importance of establishing a reliable, regular and sustained system for the collection and analysis of population statistics on alcohol and drug use among Indigenous people. Such data would assist in documenting groups at risk, co-morbidities, and health service and educational requirements.

2. Community attitudes, knowledge and awareness

A comprehensive approach to reduce harmful drinking across the population is required that includes a well-coordinated, evidence-based national campaign to increase public awareness of how alcohol consumption during pregnancy can affect the developing foetus. Activities need to be culturally-sensitive, consider and consult with the high-risk target audiences, and involve a variety of media, cultural mediums, and communication networks. Policy practices and programs, including appropriate labelling on alcoholic beverages, alcohol promotion and sponsorship, and

---

Third Report 2009. Available at http://www.aph.gov.au/Senate/committee/indig_ctte/index.htm). Differences in incidence of FASD have also been reported by O'Leary CM (2004) in Fetal alcohol syndrome: Diagnosis, epidemiology, and developmental outcomes. *J Paediatr Child Health* 40: 2-7.

[20] Elliot et al (2008) found that when studying the maternal and family characteristics of children born with FASD, almost 80 percent of children were found to have been exposed to one or more substances in addition to alcohol, commonly nicotine and marijuana.

[21] National Preventative Health Taskforce 2009. *Australia: The Healthiest Country by 2020 –National Preventative Health Taskforce - Roadmap for Action*.

[22] National Health and Medical Research Council (2009) *Australian guidelines to reduce health risks from drinking alcohol*. Commonwealth of Australia: Canberra.

alcohol pricing, are also required to influence the way that alcohol is portrayed and is made available.

As highlighted in the National Preventative Health Taskforce Report, specific preventive health strategies will be required to improve the health of Indigenous Australians, with rates of FASD estimated as being between three and seven times higher in the Indigenous population than in the non-Indigenous[23]. These strategies could include:

- increasing access to health (including contraceptive, antenatal and maternity) services for Indigenous people.
- easy access to culturally appropriate information;
- targeting women who have previously given birth to a baby with FASD; and
- supporting local initiatives in Indigenous communities that are aimed at improving social cohesion, education and employment, and drug and alcohol use.

3. Workforce development

Health professionals must be targeted to ensure that they are resourced to provide the best advice and education to women and their families. The NHMRC guidelines recommend that not drinking is the safest option for women who are pregnant or planning a pregnancy. Although an increasing proportion of pregnant Australian women do abstain, almost half (48 percent) still reported alcohol consumption[24].

Studies show that health professionals want educational resources for themselves and for women about alcohol and pregnancy. Strategies are required that improve health workforce awareness of the NHMRC guidelines, and screening of alcohol consumption by pregnant women should occur at each antenatal visit. The fear of stigmatisation of the child or family and lack of knowledge about how to refer and manage children must also be addressed in health professional education[25]. Suitable training must also be provided for health professionals in order that existing FASD educational resources are more extensively utilised. This is particularly the case in rural and remote settings where access to health services is limited and barriers to diagnosis are accentuated.

One of the most serious issues in Australia is the lack of consistent and reliable methods of ascertaining and recording both alcohol use in pregnancy and the diagnosis of FASD. Health professionals need an understanding of the clinical features of, and diagnostic criteria for, FASD. With the recent development of an Australian diagnostic instrument by the Telethon Institute for Child Health Research, a carefully planned implementation and evaluation strategy would complement prevention efforts. In using the instrument, health professionals would be able to target women who have a child with FASD as well as women and/or partners who have an alcohol dependency: allowing for prevention opportunities in subsequent pregnancies[26]. In the absence of nationally agreed, consistent, sensitive and specific criteria for diagnosing FASD prevention will remain compromised.

Conclusion

The harms and costs of FASD are significant and have been long recognised. They can be, and in the Australian context often are, concentrated in families and communities that have a myriad of

[23] National Preventative Health Taskforce 2009. *Australia: The Healthiest Country by 2020 –National Preventative Health Taskforce - Roadmap for Action.*

[24] Australian Institute of Health and Welfare 2011. 2010 National Drug Strategy Household Survey report. Drug statistics series no. 25. Cat. No. PHE 145. Canberra: AIHW.

[25] Elliot et al (2006) Diagnosis of foetal alcohol syndrome and alcohol use in pregnancy: A survey of paediatricians' knowledge, attitudes and practice. *J Paediatr Child Health* 42: 698-703.

[26]Mutch R, Peadon EM, Elliot EJ and Bower C 2009, Need to establish a national diagnostic capacity for foetal alcohol spectrum disorders. *J Paediatr Child Health* 45: 79-81.

risks and social challenges, all of which need to accommodated for in approaches to FASD prevention. Importantly, it must be recognised that an infant born with a FASD-related condition may also likely grow up in a family or community environment adversely affected by alcohol. Thus, many of the key social and physiological milestones expected through infancy and early childhood may also be detrimentally affected. Strategies and approaches must recognise and account for this and aim for a comprehensive proactive approach that seeks to improve outcomes for the foetus, infant and child.

Efforts to enhance and advance national efforts around FASD prevention should address the range of issues canvassed in Section 6 of this submission from a population focused approach, as well as by addressing diagnostic, treatment, referral and service delivery needs. Recognition of the extent of the problem as well as the development of evidence-based solutions could be achieved within the context of a national FASD strategy. Comprehensive and timely evaluation must also be explicitly tied to the development or implementation of activities in order to measure the effectiveness of FASD prevention initiatives.

There is a strong evidence base for national effort that can be used to inform population-level and other responses to FASD. Additional resourcing at national and jurisdiction levels may be required to coordinate, implement and evaluate a range of strategies and programs. This will involve identifying appropriate governance mechanisms, leadership roles and resourcing initiatives. Currently, there are a range of FASD focussed activities occurring in isolation in jurisdictions that could benefit from incorporation into a coordinated national strategic approach.

A whole of government coordinated approach is needed at the national level to manage a strategic focus for FASD across Australia and to ensure that jurisdictions are able to access the expertise and advice they require to establish sustainable systems around FASD prevention.

A national FASD prevention strategy could involve both a broad population-based approach to harmful alcohol consumption coordinated with specific FASD focussed prevention activities in particular areas or settings of high risk. Close collaboration is required between key government agencies, state, territory and local governments, Aboriginal health organisations, researchers, FASD support organisations and local communities. Such a strategy could be embedded within the next National Alcohol Strategy which is due for development.