



Australian Government

Department of Health

Senate Community Affairs References Committee

**Inquiry into the effective approaches to prevention, diagnosis and support
for Fetal Alcohol Spectrum Disorder**

Submission

Australian Government Department of Health

November 2019

The Department of Health welcomes the opportunity to make this submission in response to an invitation extended to Ms Glenys Beauchamp, Secretary, Department of Health.

1. Policy and program context

Australia's National Drug Strategy 2017-2026ⁱ (NDS) provides a national framework which identifies national priorities relating to alcohol, tobacco and other drugs. It guides action by governments in partnership with service providers and the community, and outlines a national commitment to harm minimisation.

The NDS and its sub-strategies are the shared responsibility of the health and justice/law enforcement Ministers from all jurisdictions, with reporting to the Ministerial Drug and Alcohol Forum (MDAF).

Alcohol is listed as a priority substance in the NDS and the National Alcohol Strategy 2019-2028 (NAS) was endorsed by MDAF in November 2019. The NAS provides a guide for governments, communities, organisations and industry for reducing the harms of alcohol on the Australian community.

In November 2018, the Hon Greg Hunt, Minister for Health, launched the National FASD Strategic Action Plan 2018-2028ⁱⁱ on behalf of the Ministerial Drug and Alcohol Forum. The Fetal Alcohol Spectrum Disorder (FASD) Strategic Action Plan is a sub-strategy of the NAS.

The Australian Government is committed to reducing alcohol related harms including FASD. FASD is a diagnostic term for the range of physical, cognitive, behavioural and neurodevelopmental abnormalities which can result from maternal drinking during pregnancy.

In Australia, alcohol contributes to the burden of 30 diseases and injuriesⁱⁱⁱ. Recent data shows that Australia's per capita alcohol consumption has remained relatively stable over the last decade^{iv} and alcohol use among pregnant women in Australia remains common. The 2016 National Drug Strategy Household Survey^v reports that around 1 in 4 women continue to drink once becoming aware they are pregnant.

FASD affects many communities. It is not isolated to a specific region or population group. Australia does not have national FASD prevalence data, and it is widely considered that rates are underestimated. A recent study which estimated global prevalence of alcohol use during pregnancy and FASD estimated that 1 in every 67 women who consumed alcohol during pregnancy would deliver a child with some form of FASD^{vi}.

The current *Australian guidelines to reduce health risks from drinking alcohol* (2009)^{vii} recommend: For women who are pregnant or planning a pregnancy, not drinking is the safest option. This is based on the assessment of the evidence concerning the potential harms of alcohol for the developing fetus including FASD, and is aimed at women who are pregnant or planning a pregnancy.

The National Health and Medical Research Council (NHMRC) is updating the 2009 guidelines, and these are expected to be released for public consultation late in 2019. The purpose of the guidelines is to inform Australians of the health risks of drinking alcohol and to provide recommendations to reduce these risks to a low level. The revised guidelines will

continue to recommend that pregnant women don't drink alcohol to prevent harm to the developing fetus.

Following the release of the House of Representatives Standing Committee on Social Policy and Legal Affairs Report on *The hidden harm - Inquiry into prevention, diagnosis and management of Fetal Alcohol Spectrum Disorder*^{viii} in November 2012, the Australian Government made significant progress with endeavours to reduce the prevalence and impacts of FASD and address the recommendations provided in the report.

Department of Health Programs

Since 2014 the Australian Government has invested over \$27m towards FASD prevention and awareness programs and diagnostic services.

The Department has responsibility for managing the following Australian Government FASD Programs:

- FASD Action Plan (2013-14 to 2016-17)
- Taking More Action on FASD (2016-17 to 2019-20)
- Fetal Alcohol Spectrum Disorder Strategic Action Plan (2018-19 to 2021-22)

Additional detail on the activities within each Program is included below.

2. FASD Action Plan (2013-14 to 2016-17). Program Funding - \$9.2m over four years

On 25 June 2014 the Australian Government announced the FASD Action Plan (Action Plan) which committed funding of \$9.2m over four years (2013-14 to 2016-17). The Action Plan was announced in response to the 2012 House of Representatives Standing Committee on Social Policy and Legal Affairs Inquiry into FASD: *The Hidden Harm*.

Activities under this Action Plan aimed to provide better diagnosis and management, development of best practice interventions and services to support high-risk women. Activities included:

2.1. Women Want to Know (WWTK)

The WWTK activity launched on 1 July 2014 and received additional funding in 2015-16 and 2017-18. The WWTK activity aims to improve access to FASD information and resources to support health professionals in initiating conversations about alcohol consumption with pregnant women and the broader workforce, and to disseminate information on alcohol consumption and pregnancy to increase awareness and prevent harmful consequences including FASD.

2.2. Pregnant Pause

Pregnant Pause is an activity funded by the Australian Government which aims to raise the awareness of drinking alcohol during pregnancy, while breastfeeding or when planning a pregnancy. The activity recognises that it can take a lot of support for women to abstain from drinking alcohol for some time and encourages friends and family to pledge to go alcohol free as well to support the women in their lives who are trying to stay alcohol free during pregnancy, while breastfeeding and when planning a pregnancy.

2.3. Indigenous Activities

Activities to enhance the capacity of maternal and child health services in Indigenous communities to prevent and manage FASD included:

- The development and implementation of FASD Prevention and Health Promotion Resources (FPHPR), by Menzies School of Health Research, in partnership with NACCHO and the Telethon Kids Institute. This project is now complete and a web accessible version of the resources is available on the FASD Hub.
- The development of FASD awareness messages, translated into 6 languages and broadcast through the National Indigenous Radio Service for 3 months during the AFL season.
- FASD specific grant rounds through the NHMRC's Partnership Projects program. These grants were aimed to support collaboration between policy makers, program managers, service providers and researchers with experience or interest in Aboriginal and Torres Strait Islander Health.

2.4. Funding to the National Organisation for FASD (NOFASD) Australia

In 2017 NOFASD Australia received activity funding to deliver a social media awareness raising campaign that aimed to increase awareness of FASD at the grass roots level in the Australian community using social media platforms.

2.5. The FASD Hub Australia

The FASD Hub was established in 2017 and is a central repository for information and resources on FASD for both clinicians and members of the public seeking information on a range of topics associated with FASD. The Hub was created with four key target audiences:

- Health professionals;
- Other professionals involved in care of people potentially with FASD;
- Parents and carers; and,
- Policy makers and government.

The Hub provides a services directory where health professionals or clinics can register to be included on the Hub's Australian service directory. It also includes information on the latest training and support resources available as well as research and publications.

Adults, children and families affected by FASD can access support services according to the type and severity of their disability. Support is not dependent on a diagnosis, or the name of the condition, rather the level of functional impact the condition has on their lives.

2.6. Data collection of maternal alcohol consumption in pregnancy

Under the 2013-14 budget measure the Australian Government contributed funding to the National Maternity Data Development activity (NMDDP). The purpose of this activity was to continue the development of nationally consistent maternal and perinatal data collection. The Data development of alcohol consumption during pregnancy for inclusion in the Perinatal National Best Endeavours Data Set NBEDS, contributed to the establishment of one of the NMDDP data priority items in the national Perinatal Data Collection.

This activity has been completed and is now live. Data to capture alcohol consumption in the first 20 weeks and second 20 weeks into the National Perinatal Best Endeavours Data Set (NBEDS) began collection on 1 July 2019.

2.7. An Australian FASD Register.

The Australian Government funded the FASD Australian Register (FASDAR) to improve Australia's ability to monitor FASD prevalence trends over time, which has been a long acknowledged gap needing to be addressed. The information collected as part of the FASDAR will allow for research including longitudinal studies to determine the prognosis of FASD and its impacts on affected individuals across the lifespan and families. The FASDAR complements the FASD Diagnostic tool which was publically released in 2016 (refer to item 4.3).

2.8. Funding to assist the development of the National FASD Strategic Action Plan.

In November 2018 the Hon Greg Hunt, Minister for Health, launched the National FASD Strategic Action Plan (the Plan) on behalf of the Ministerial Drug and Alcohol Forum. The Plan provides a cohesive, evidence based strategy that addresses the whole of life, whole-of-population and collaborative cross-sectoral approaches required to prevent FASD, and to support those living with and affected by FASD.

The Plan provides a clear pathway of priorities and opportunities to improve the prevention, diagnosis, support and management of FASD in Australia. The aim of the Plan is to reduce the prevalence of FASD and the impact it has on individuals, families, carers and communities. In November 2018 the Australian Government announced an additional \$7.2m in funding to support activities that align with the Plan.

As a sub-strategy of the National Alcohol Strategy the Plan is formally overseen by the Ministerial Drug and Alcohol Forum (MDAF) which is supported by the National Drug Strategy Committee (NDSC). Monitoring the implementation of the Plan is not solely the responsibility of government bodies. As such, the NDSC have established an ongoing FASD Advisory Group to monitor the implementation progress of the Plan.

3. Taking More Action on FASD (2016-17 – 2019-20). Program Funding - \$10.5m over four years

In the 2016-17 budget, The Australian Government committed a further \$10.5m over four years from 2016-17 to 2019-20 to build on the achievements of the Action Plan (2013-14 to 2016-17). The budget measure provided funding for additional prevention activities as well as the provision of on the ground FASD diagnostic services in communities of high need. Funded activities included:

3.1. Diagnostic Services (DS) and Models of Care (MoC) projects

The objectives of this activity are to:

- Deliver FASD diagnostic services in a flexible and consistent manner using the Australian Diagnostic Tool and Referral Guidelines;
- Capture FASD diagnostic data for the purpose of building knowledge and an understanding of the prevalence and incidence of FASD in Australia;
- Provide education, information and resources to communities at high risk of FASD with a view to preventing FASD in the Australian community;
- Provide appropriate referral services to those diagnosed with FASD and their families.

In addition to increasing diagnostic capacity the DS and MoC activities are delivering education programs which encourage and support women to abstain from alcohol in pregnancy and their communities to support them to abstain, leading to a reduction in the incidence of FASD births.

3.2. NOFASD telephone and online counselling activity

NOFASD have been funded to provide support for individuals and families affected by FASD through the provision of online and telephone support information services which includes dissemination of information, assistance with referral process and delivery of education and training workshops.

3.3. Support for parents and caregivers

The Australian Government also funds the Russell Family Fetal Alcohol Disorders Association (RFFADA) to deliver a range of support for parents and caregivers through support groups delivered by other parents and carers with lived experience of FASD. This activity aims to improve the quality of life for individuals with FASD and their families by providing on the ground support from other parents and carers in similar situations.

4. National FASD Strategic Action Plan. Program Funding - \$7.2m over four years.

The Strategic Action Plan proposed that a National FASD Advisory Group (FASD Advisory Group) be created to monitor and report on the implementation progress of the Strategic Action Plan.

The FASD Advisory Group has been established and consists of representatives from clinical, research, policy and parent/carer sectors and will provide advice to the NDSC on emerging issues, trends, opportunities and gaps that may exist across the domains of the Plan.

Activities approved for funding under the \$7.2m 2018-19 MYEFO measure include the 12 activities described below:

4.1. 2019 FASD Australian Register

The Australian Government has committed additional funding from 2019-20 to 2022-23 for the continuation and ongoing maintenance of the FASD Australian Register.

4.2. 2019 FASD Resource Hub

The Australian Government has committed additional funding from 2019-20 to 2022-23 for the continuation of the FASD Hub Australia.

4.3. Review and dissemination of diagnostic tool

The Australian Government has allocated funding to undertake a comprehensive review and update of the FASD Diagnostic Tool. This activity intends to review and update the Australian tool, and to conduct dissemination activities for the updated version of the tool. The FASD Diagnostic Tool currently serves to provide Australian health professionals with standardised diagnostic resources on FASD. The FASD Diagnostic Tool facilitates the diagnosis of FASD, and rates the level of impairment and functional impact on an individual. A review will ensure that the tool aligns with international and clinical best practice for the diagnosis of FASD.

4.4. Consumer resources

The Australian Government has allocated funding to the development of FASD consumer resources with the intention to increase general awareness of FASD, contribute to the prevention of FASD, and outline the potential consequences of drinking while pregnant. FASD consumer resources developed under this grant may include resources targeted toward women in high-risk groups, as well as resources for the partners and families of women who are pregnant or planning a pregnancy.

4.5. Awareness day

The Australian Government has allocated funding for the promotion of International FASD Awareness Day, held on 9 September each year. Through the development of a national awareness campaign promoting International FASD Awareness Day, it is expected that this grant will provide information about the risks of alcohol consumption during pregnancy, and encourage open and informed conversations about consumption risks.

4.6. Early childhood identification guide

The Australian Government has allocated funding to contribute to the development of a FASD identification guide for use in the early childhood setting. It is intended that this guide will provide information for people working in early childhood education settings to identify children who potentially meet the assessment criteria for FASD, and how to facilitate discussions with parents/carers on undertaking a formal FASD diagnostic assessment. The guide may also assist workers in early childhood education settings to provide support for children and their families.

4.7. Teacher and educational setting resources

The Australian Government has allocated funding to contribute to developing a suite of evidence-based resources with the intention of being able to provide resources for educators to draw on and assist in identifying and managing students with FASD. To inform the development of new resources, a thorough review of existing resources within the education sector to support students with FASD will be undertaken to determine current gaps, strengths and weaknesses in existing Australian and International materials. This grant opportunity will provide useful guidance materials, tools and templates to assist students with FASD. All resources developed to assist in identifying students with FASD will be aligned with the Australian Guide to the Diagnosis of FASD.

4.8. Justice and policing resources

The Australian Government has allocated funds with the intention of reviewing and adapting existing resources for a) recruitment and employment personnel, to guide them in understanding FASD and assisting people with FASD to obtain and retain employment, and for b) people working in the criminal justice system, to assist them in recognising people affected by FASD and improve their understanding of the implications of the disorder within the criminal justice system. The resources may also provide information on assessment processes and management strategies to improve the outcomes of people with FASD.

4.9. Best practice resources for priority groups

The Australian Government has allocated funding for the development of resources to support women at a higher risk of having a child with FASD. Resources may target high-risk population groups predisposed to FASD. Resources will be evidence based, and provide

tailored information for use by a range of health professionals in a variety of settings. The resources could include information outlining appropriate alcohol screening methods, and ways to support and educate people in high-risk groups on the harms associated with alcohol consumption during pregnancy.

4.10. Women Want to Know and Pregnant Pause programs

The Australian Government has allocated additional funds to provide continued support for the Women Want to Know and the Pregnant Pause health promotion campaigns.

4.11. DrinkWise FASD program

The Australian Government has allocated funds to potentially provide support to the DrinkWise FASD Prevention Program. It is intended that any support provided to DrinkWise will support a range of activities including health promotion activities in general practice settings, school-based settings, Indigenous medical services as well as point-of-sale initiatives to raise awareness of FASD and the risks associated with drinking alcohol whilst pregnant.

4.12. Translation and promotion of new NHMRC guidelines.

The Australian Government has allocated funding for activities associated with the promotion of the revised *Australian Guidelines to Reduce Health Risks from Drinking Alcohol*. The National Health and Medical Research Council is currently reviewing and revising the guidelines published in 2009; the revised guidelines are due to be released in the second quarter of 2020. This review will ensure that advice provided to health professionals, policy makers, and the public is up-to-date and reflective of recent and emerging evidence. This grant will promote the revised guidelines following their release, and translate and communicate messaging from the revised guidelines to the general public.

ⁱ <https://www.health.gov.au/resources/publications/national-drug-strategy-2017-2026>

ⁱⁱ <https://www.health.gov.au/resources/publications/national-fetal-alcohol-spectrum-disorder-fasd-strategic-action-plan-2018-2028>

ⁱⁱⁱ <https://www.aihw.gov.au/reports/burden-of-disease/burden-disease-study-illness-death-2015/contents/table-of-contents>

^{iv} <https://www.abs.gov.au/AUSSTATS/abs@.nsf/mf/4307.0.55.001/>

^v <https://www.aihw.gov.au/getmedia/15db8c15-7062-4cde-bfa4-3c2079f30af3/21028a.pdf.aspx?inline=true>

^{vi} [https://www.thelancet.com/journals/langlo/article/PIIS2214-109X\(17\)30021-9/fulltext#](https://www.thelancet.com/journals/langlo/article/PIIS2214-109X(17)30021-9/fulltext#)

^{vii} <https://www.nhmrc.gov.au/about-us/publications/australian-guidelines-reduce-health-risks-drinking-alcohol#block-views-block-file-attachments-content-block-1>

^{viii}

https://www.aph.gov.au/Parliamentary_Business/Committees/House_of_Representatives_Committees?url=spla/fasd/report.htm