



Foundation for Alcohol Research & Education

25 June 2021

Standing Committee on Health and Community Wellbeing  
ACT Legislative Assembly  
GPO Box 1020, Canberra ACT 2601  
[LACommitteeHCW@parliament.act.gov.au](mailto:LACommitteeHCW@parliament.act.gov.au)

### **Re: Review of ACT Health programs for children and young people**

Thank you for the opportunity to provide a written submission to the above Inquiry.

The Foundation for Alcohol Research and Education (FARE) is a not-for-profit organisation working towards an Australia that is free from alcohol harm. We approach this through developing evidence-informed policy, enabling people-powered advocacy and delivering health promotion programs. Working with local communities, values-aligned organisations, health professionals and researchers across the country, we strive to improve the health and wellbeing of everyone in Australia.

This submission responds to Items 1) b) and c) of the Inquiry's Terms of Reference:

- 1) *Inquire into programs in place in the ACT providing for children and young people to-assess the adequacy, availability, and implementation of the following:*
  - b) *identify and review in particular all aspects of current preventative programs and associated programs for screening, diagnosis, assessment and treatment in the ACT for Fetal Alcohol Spectrum Disorder (FASD); and*
  - c) *Identify and review current programs in the ACT providing services that address support, treatment and assessment arising from diagnosis of anything requiring treatment in b).*

### **Fetal Alcohol Spectrum Disorder (FASD)**

Alcohol consumption in pregnancy increases the risk of children being born with FASD.<sup>i</sup> Alcohol passes across the placenta during pregnancy and the fetus has minimal ability to metabolise it due to its size and development. There is no safe time, no safe amount, and no safe type of alcohol that can be consumed during pregnancy. Other risks of alcohol consumption in pregnancy include miscarriage, stillbirth, low birth weight and pre-term birth.<sup>ii,iii,iv</sup>

FASD is a diagnostic term describing a range of neurodevelopmental impairments<sup>v</sup>. It describes impacts on the brain and body of individuals prenatally exposed to alcohol. FASD is a lifelong disability. People with FASD experience challenges in their daily living and need support with motor skills, physical health, learning, memory, attention, communication, emotional regulation, and social skills to reach their full potential. Each person with FASD is unique and has areas of both strengths and challenges.<sup>vi</sup>



Foundation for Alcohol Research & Education

FASD is the leading cause of preventable developmental disability in Australia. Due to inadequate FASD screening and diagnosis the prevalence of FASD is not known. However, estimates suggest that FASD affects between two to nine per cent of babies born each year.<sup>vii</sup> Aboriginal and Torres Strait Islander communities are disproportionately affected by FASD, with a rate of up to 12 per cent of births in some remote communities.<sup>viii</sup> Furthermore, a recent study screened young people in detention in Western Australia and found that at least 36 per cent had a confirmed diagnosis of FASD.<sup>ix</sup>

Without diagnosis and appropriate intervention, people with FASD have a higher likelihood of secondary disabilities such as requiring greater education, health and mental health support, problems with parenting and employment, homelessness, and problematic alcohol and other drug use.<sup>x</sup> With the many co-morbid conditions people with FASD experience,<sup>xi</sup> the medical and social costs are great. In Australia, the annual cost of FASD in 2018 was estimated at \$1.18 billion.<sup>xii</sup>

Australia has comparatively high rates of alcohol consumption during pregnancy.<sup>xiii</sup> There are three key factors contributing to high rates of prenatal alcohol use:

1. lack of awareness of the National Alcohol Guidelines and awareness of risk,
2. limited use of screening and brief interventions in antenatal care, and
3. lack of standardised data collection and monitoring.

However, wider socio-cultural factors play a part and the social environment around women who are pregnant is important, as are her own attitudes and beliefs.<sup>xiv</sup> Research has also shown that levels of alcohol use prior to the pregnancy and experience of intimate partner violence increase the likelihood of women using alcohol during pregnancy.<sup>xv</sup>

The underlying causes of FASD, therefore, are complex and prevention initiatives require a range of efforts to inform and support women who are pregnant to stop or reduce their alcohol intake. The World Health Organization *Global Strategy to reduce the harmful use of alcohol* acknowledges that whole of population approaches to alcohol policy, targeting the screening and treatment, price, promotion and physical availability of alcohol, are the best policy approaches to reduce overall population use and alcohol harm, including FASD.<sup>xvi</sup>

## Recommended areas for action

FARE has identified five areas where the ACT Government could take action to improve the prevention, screening, diagnosis and support of FASD.

### 1. Implement recommendations 12, 23, 24 and 27 of the Senate Inquiry into *Effective approaches to prevention, diagnosis and support for FASD*, that reported in March 2021.

In 2019-21, the Senate held an inquiry into *Effective approaches to prevention, diagnosis and support for FASD* (Senate FASD Inquiry). The final report,<sup>xvii</sup> released in March 2021, made 32 recommendations, some of which relate to areas where states and territories could make improvements. These recommendations should be implemented by the ACT Government to improve the prevention of FASD, data collection and supports for people with FASD. The relevant recommendations that engage State and Territory Governments are outlined below.

**“Recommendation 12.** The committee recommends that the Australian Government fund a National Prevention Strategy to be developed and delivered in collaboration with State and Territory Governments.” (p. 64)

Section 2 below elaborates further on this.

**“Recommendation 23.** The committee recommends that the Australian Government work with State and Territory Governments to provide all educators with professional development training in the awareness, understanding and management of FASD.” (p. 111)

More specifically, FARE recommended:

- That all health professionals (GPs, midwives, obstetrics, Aboriginal health workers) are educated on alcohol harms during pregnancy.
- That all university medical education includes curriculum on FASD and alcohol use during pregnancy.
- That support and training to health professionals is provided to increase skills in asking women about alcohol use, providing advice consistent with Alcohol Guidelines, recognising and responding to women at risk.
- That approaches to prevention and care for women who are pregnant are trauma-informed and conducted in a way aimed at reducing stigma.

**“Recommendation 24.** The committee recommends that the Australian Government work with State and Territory Governments to ensure all schools can deploy and resource FASD-specific strategies and assistance to support educators and to support students with FASD and suspected FASD, irrespective of IQ level.” (p. 111)

**“Recommendation 27.** The committee recommends that the Australian Government, in partnership with State and Territory Governments, develop and trial protocols for screening children and young people within child protection and youth justice systems for FASD.” (p. 112)

Section 5 below elaborates further on this.

## 2. Support the national campaign on alcohol, pregnancy and breastfeeding and find opportunities to promote and implement the campaign across the ACT.

FARE congratulates the ACT Government for their ongoing support of the Pregnant Pause health promotion campaign. The Pregnant Pause campaign has been funded by ACT Health since 2015. One of the main goals of this program has been to raise awareness of the current alcohol and pregnancy guidelines and to reduce the FASD within the Territory, supporting mums-to-be in going alcohol-free. This program has helped shift community sentiment and build understanding that no amount of alcohol is safe during pregnancy.

The ACT Government’s support for the successful Pregnant Pause campaign through the Health Promotion Grants Program, set the foundation for seeking funding for a national campaign on alcohol, pregnancy and breastfeeding. The national campaign has four streams, targeting the general



Foundation for Alcohol Research & Education

public, health professionals, women who are most at risk and Aboriginal and Torres Strait Islander peoples.

In December the National Health and Medical Research Council (NHMRC) released updated guidelines on alcohol. The *Australian guidelines to reduce health risks from drinking alcohol*<sup>[xviii]</sup> include "Guideline 3: To prevent harm from alcohol to their unborn child, women who are pregnant or planning a pregnancy should not drink alcohol". However, there is low awareness of the Alcohol Guidelines:

- In study of Australian women aged 18 to 45 years, the majority reported negative attitudes about alcohol in pregnancy, however one in three women did not know that alcohol use in pregnancy could cause adverse impacts<sup>xix</sup>.
- Research of Australian women who were pregnant, planning a pregnancy, or who had recently had a baby found that while women were aware that alcohol consumption during pregnancy was "probably unsafe," they didn't have information about the actual risks of alcohol consumption during pregnancy for the developing child<sup>xx, xxi</sup> and did not view 'moderate' alcohol consumption or having an 'occasional' drink as being at odds with messages regarding alcohol abstinence<sup>xxii</sup>.

FARE looks forward to engaging with the ACT Government on the upcoming National on alcohol, pregnancy and breastfeeding to support its implementation where possible, including the localising and sharing of resources and information.

### 3. Improve data collection to better inform policy and program development.

As acknowledged by the Senate FASD Inquiry, data collection relating to FASD is inadequate. The ACT has an opportunity to implement an effective diagnosis regime that can collate data and provide health practitioners and researchers with more information to inform treatments. There is currently no regular, consistent data collected within the ACT from women who are pregnant, from their doctor, midwife or gynaecologist, on the occurrence and frequency of drinking during pregnancy.

Maternal perinatal data collection of births in ACT hospitals and home births, currently covers such topics as mother's demographics, type of induction, method of birth, malformations, and apgar scores at birth<sup>xxiii</sup>. It should also collect information about alcohol consumption, in an informed, supportive, confidential and voluntary manner. This should then be matched with children who are found to have impairments at early health screening. (Full FASD diagnosis relies on confirming alcohol exposure during pregnancy.)

### 4. Fill the gaps left by National Disability Insurance Scheme (NDIS) barriers to access and difficult eligibility through advocacy and policy actions.

The FASD Senate Inquiry<sup>xxiv</sup> noted that carers, families and individuals impacted by FASD face multiple barriers with the complex task of assessment, diagnosis and supports. People with FASD are further negatively impacted by issues within the NDIS, such as gaps in funding and support options and a lack of coordination between the health system and the NDIS. NDIS funding for support for people with FASD is possible, but the process is complex and fraught with barriers in relation to



Foundation for Alcohol Research & Education

language and the burden of proof for functional impairments.<sup>xxv</sup> Due to this difficulty many people with FASD do not gain NDIS support.

Another challenge with FASD and the NDIS is that there is a high prevalence of FASD in people detained in the criminal justice system, including children, who are excluded from the NDIS. The exclusion of people in prison who have a cognitive disability from the NDIS represents a substantial barrier to people with cognitive and mental health impairments getting adequate support, care and protection for their disability-related complex support needs.<sup>xxvi</sup>

In both cases, ACT Government intervention is critical as it may be the only pathway for some people towards gaining a FASD diagnosis and the needed supports. The ACT Government must advocate for improved access for people with FASD to the NDIS through the Disability Reform Ministers' Meetings.

## **5. Implement improved FASD screening, assessment and support in paediatric, youth justice, adult criminal justice and population-wide settings.**

ACT currently does not have FASD diagnostic services or support services for those living with FASD. Diagnosis is complex and expensive and so it becomes difficult to access and so many people miss out on the treatment and support that a diagnosis facilitates. As the FASD Senate Inquiry recommended, Governments should ensure all schools can deploy and resource FASD-specific strategies and assistance to support educators and to support students with FASD and suspected FASD, irrespective of IQ level.

Screening, diagnosis and treatment should be especially targeted towards those in the criminal justice system, including in Canberra's Bimberi Youth Justice Centre<sup>xxvii</sup>, but for both children and adults throughout the system. Research at the Banksia Hill Youth Detention Centre in Western Australia<sup>xxviii</sup> identified that more than a third of the screened young people in detention had confirmed FASD. Researchers suggested this may be an under-estimate due to, for example, the lack of confirmation of prenatal alcohol exposure, suspecting that almost half of these young people may have FASD.

Additional funding and resourcing are needed for screening, diagnosis, assessment and treatment. There is also an urgent and critical need to educate health practitioners as many are not aware of the signs or dismiss FASD prior to proper assessments being undertaken. This can include being misdiagnosed with Attention Deficit Hyperactivity Disorder (ADHD) or other disorders.<sup>xxix</sup>

FASD screening pathways through General Practitioners, paediatricians, educators and social service providers should be promoted to ensure children who would benefit from a diagnosis and relevant support are identified as early as possible. Given the high rates of FASD within youth justice settings, appropriate screening, diagnosis and ongoing support is critical to improving the lives of these children and establishing an ongoing pathway out of the criminal justice system.

Receiving a diagnosis is critical to people, both children and adults, understanding their disability is a result of FASD. This information allows them to be supported appropriately and take steps to manage their disability to get the most from their lives.





Foundation for Alcohol Research & Education

Thank you for the opportunity to provide a submission to this Inquiry and for including FASD in its terms of reference.

Yours sincerely,

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CHIEF EXECUTIVE OFFICER

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<sup>iv</sup> Jaddoe VVW, Bakker R, Hofman A, et al (2007) Moderate Alcohol Consumption During Pregnancy and the Risk of Low Birth Weight and Preterm Birth. The Generation R Study. *Annals of Epidemiology*, 17(10), 834-840.

<sup>v</sup> Bower C & Elliott EJ (2016) *Australian Guide to the diagnosis of FASD*.

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<sup>vi</sup> CanFASD (2018) *What is FASD?*, Canada FASD Research Network (CanFASD)

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<sup>vii</sup> Food Regulation Standing Committee (2018) *Decision Regulation Impact Statement: Pregnancy Warning Labels on Packaged Alcoholic Beverages*, October 2018, p. 26.

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<sup>viii</sup> Fitzpatrick JP, Latimer J, Carter M et al (2015) *Prevalence of fetal alcohol syndrome in a population-based sample of children living in remote Australia: The Lililwan Project*. Paediatrics and Child Health 51(4), 450-457.

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<sup>ix</sup> Bower C, Watkins RE, Mutch RC, et al (2018) *Fetal alcohol spectrum disorder and youth justice: a prevalence study among young people sentenced to detention in Western Australia*.

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Foundation for Alcohol Research & Education

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Foundation for Alcohol Research & Education

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