

# NOFASD Australia's Submission to the Inquiry into the Health Impacts of Alcohol and Other Drugs in Australia

NOFASD Australia Pty Ltd. 27/11/2024

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# Submission by NOFASD Australia to the House of Representatives Standing Committee on Health, Aged Care and Sport

Inquiry into the Health Impacts of Alcohol and Other Drugs in Australia

### **About Us**

NOFASD Australia, the national peak body for individuals and families living with Fetal Alcohol Spectrum Disorder (FASD), appreciates the opportunity to contribute to the Inquiry into the health impacts of alcohol and other drugs (AOD) in Australia. With over two decades of advocacy for FASD prevention, NOFASD brings extensive experience to this submission.

As the trusted voice for FASD, NOFASD has supported over 22,000 individuals and families through its advocacy and services, empowering communities across Australia. Our national helpline experienced a remarkable 74% increase in enquiries between 2019 and 2024, reflecting our growing impact and reach.

Our resources, including the widely recognised Parent-Carer Toolkit and Sensory Flyer, have been downloaded over 13,000 times in the past year alone. This year, our website welcomed 60,000 visitors—part of a total of 250,000 visitors over the past five years—seeking support, information, and guidance.

NOFASD's commitment to education and training is unwavering, with more than 5,000 participants registering for our Foundations in FASD Online Course in the past three years. We've delivered specialised training to community and custodial staff in NSW, Victoria, and the Northern Territory, ensuring FASD awareness reaches diverse sectors.

Our support extends beyond resources and training: since 2021, we have directly supported over 2,000 families and 600 professionals navigating the complexities of FASD. This submission highlights two key issues:

 the need to integrate and embed PAE awareness and FASD prevention into the broader AOD strategy.



 and the importance of recognising FASD within AOD services, as failure to address FASD in treatment programs leads to ineffective interventions and continued substance misuse.

NOFASD Australia remains dedicated to amplifying the voices of individuals and families impacted by FASD, creating a future where every Australian can thrive without the burden of prenatal alcohol exposure.

# **Summary of Recommendations**

- 1. Enhance FASD awareness and prevention training for AOD Services
- 2. Increase Funding for FASD Prevention
- 3. Integrate harms of PAE and FASD awareness into National Campaigns
- 4. Move Toward FASD-Informed Care
- 5. Integrate Culturally Safe Practices
- 6. Call for Integrated and Coordinated Health Services
- 7. Intersectional Collaboration
- 8. Enhanced Training Programs
- 9. FASD Education in Schools
- 10. Drawing from Domestic Best Practices
- 11. Sustaining Success for Domestic Approaches
- 12. Best Practices in qualitative systematic research
- 13. Adopt International Best Practices
- 14. Universal Screening for Alcohol Use During Pregnancy
- 15. Policy Integration:

#### **Terms of Reference**

# a) Assessing the Equity, Value for Money, and Outcomes of Current Services

NOFASD Australia Ltd. recognises the developments made by the current AOD services in reducing alcohol and drug-related harms. Initiatives by NOFASD and organisations such as The Foundation for Alcohol Research and Education (FARE), The Aboriginal Drug and Alcohol Council (ADAC), and The National Aboriginal Community Controlled Health Organisation (NACCHO), have been instrumental in promoting harm reduction. Despite these efforts, several key challenges remain, in



particular the lack of public awareness of the risks associated with PAE and the prevention, recognition and diagnosis of FASD.

## **Key Issues:**

- Cost: Addressing alcohol-related harms, including PAE, imposes a significant economic burden. Beyond immediate healthcare costs, the long-term impacts on education, social services, and the economy are substantial. Children with FASD often require ongoing medical care, educational support, and social services due to cognitive, medical, and behavioural challenges, leading to a persistent financial strain on public systems. Preventing FASD through informed care and early intervention not only improves health outcomes but also offers substantial cost savings. Educating pregnant women and communities about the risks of alcohol use and providing timely support can reduce PAE incidence, decreasing future demand for costly services and generating significant economic benefits.
- Stigma: Stigma surrounding alcohol consumption during pregnancy significantly hinders women from seeking help or openly disclosing their drinking habits. This fear of judgment or blame often leads to underreporting of alcohol use, making it difficult for healthcare providers to offer the necessary support and interventions. As a result, many women do not receive the guidance or care they need to reduce the risks associated with PAE. Reducing this stigma is essential to encourage open conversations, enabling women to access the help they need without fear of judgment, leading to better health outcomes for both mothers and their children.
- Limited PAE-Informed Clinicians: There is a shortage of clinicians who are well-informed about the risks of PAE and who consistently ask pregnant women about alcohol consumption. Many healthcare providers lack the necessary training, with only a third having completed training on alcohol and pregnancy in the last five years (FARE, 2021). Most rely on outdated knowledge, and training is often limited to specific jurisdictions, contributing to fragmented care. Barriers include a lack of awareness of training opportunities, perceived irrelevance, and the assumption that existing knowledge is sufficient. To



address this, accessible and comprehensive training linked to Continuing Professional Development (CPD) is urgently needed. Without coordinated training, opportunities for PAE prevention and early FASD diagnosis are often missed, leading to inconsistent care.

## **Recommendations:**

## NOFASD's recommends:

- 1. Enhance FASD awareness and prevention training for AOD Services: AOD services must provide mandatory, comprehensive training on the risks of PAE that address more than basic awareness. Healthcare providers need the skills to effectively discuss alcohol consumption with pregnant women, addressing both medical risks and social factors. This training should be integrated into ongoing professional development to ensure clinicians stay updated on the latest research and culturally sensitive practices. Continuous education will enable providers to offer tailored, empathetic support, fostering open dialogue and promoting healthy pregnancies; ultimately reducing incidence of FASD..
- 2. Increase Funding for FASD Prevention: Expanding training programs for clinicians is essential to ensure healthcare professionals are equipped to meet the needs of pregnant women in the AOD sector. Resources should support both broader training and targeted interventions addressing the unique challenges of this population, including specialised support services for medical and social factors influencing alcohol use during pregnancy. Additionally, funding should be allocated to public awareness campaigns focused on PAE risks, promoting early intervention and prevention. Investing in these areas will reduce PAE and FASD, resulting in long-term health savings and improved outcomes for mothers and children.

## b) Examining the Effectiveness of Current Programs and Initiatives

We acknowledge the effectiveness of current AOD programs in reducing alcohol consumption and related harms. However, these programs often fail to address the specific risks of FASD adequately, contributing to ongoing public health challenges.



## **Key Issues:**

- Low Public Awareness: Despite ongoing efforts, significant gaps in public knowledge about the risks of alcohol consumption during pregnancy persist. The Australian Institute of Health and Welfare (AIHW) reported that 77% of Australians aged 14 and over consumed alcohol in 2022-23, and approximately 25% of women continued drinking after learning they were pregnant. A 2021 poll by the Foundation for Alcohol Research and Education (FARE) found 30% of Australians are unaware that alcohol use during pregnancy can cause FASD. Awareness is particularly low amongst men (63%) compared to women (77%), and nearly 23% of Australians mistakenly believe that some alcohol consumption during pregnancy is safe.
- Fragmented Service Delivery: The lack of coordination across AOD services leads to inconsistent prevention of prenatal alcohol exposure. National gaps in routine screening and intervention persist. Only 46% of health professionals routinely ask about alcohol use during pregnancy, and just 32% discuss the risks. Furthermore, 70% of mothers with children diagnosed with FASD do not have alcohol use recorded during pregnancy. Screening gaps also remain, with only 64% of midwives and 22% of paediatricians addressing PAE risks. These inconsistencies highlight the urgent need for a unified, comprehensive approach to AOD services nationwide.
- existing clients of the AOD Sector with FASD: Nearly 80% of individuals diagnosed with Fetal Alcohol Spectrum Disorder (FASD) also have a co-occurring substance use disorder, yet many remain unrecognised within the alcohol and other drugs (AOD) sector. While not every person in treatment has FASD, a significant, overlooked population struggles with repeated treatment attempts due to the unrecognised effects of FASD. This group requires tailored support that addresses both substance use, and the cognitive and behavioural challenges associated with FASD. Without proper identification and targeted interventions, these individuals will continue to face barriers to effective treatment. The AOD sector must prioritise screening, awareness, and the integration of FASD-informed care into programs to provide comprehensive support.



• Education: There is a need for more focused education on FASD and PAE. The pervasiveness of alcohol consumption in Australia exacerbates the risks, making it crucial to integrate PAE prevention into educational curricula and public health strategies. According to the 2021 FARE poll, awareness of the risks of alcohol consumption during pregnancy varies significantly across states and territories, further reflecting the fragmented delivery of education and services. For example, while 77% of people in Western Australia were aware of the risks, awareness was lower in Victoria (67%).

#### Recommendations:

- 3. Integrate harms of PAE and FASD awareness into National Campaigns: Broaden the scope of existing AOD public health campaigns to include specific messaging about the risks. This should be integrated with the broader National Alcohol Strategy, ensuring that PAE and FASD awareness becomes a standard part of public health messaging.
- 4. Move Toward FASD-Informed Care: AOD services should adopt a care model that is informed by the risks and impacts of prenatal alcohol exposure (PAE), ensuring that all aspects of treatment and support address the potential effects of alcohol consumption during pregnancy. This approach should include the integration of PAE prevention strategies into routine healthcare practices, with a focus on early identification, education, and tailored interventions to improve outcomes for individuals at risk of or affected by FASD.
- 5. Recommendation for Culturally Safe Practices: The inquiry should consider the importance of culturally safe practices in health service delivery. Aboriginal Community Controlled Health Organisations (ACCHOs) have demonstrated success in providing culturally appropriate care, particularly during the COVID-19 pandemic. This model could be expanded to improve FASD prevention. (Brett, Katie et al., 2024).
- 6. Call for Integrated and Coordinated Health Services: The fragmented nature of mainstream health services often leads to inequitable outcomes for Indigenous Australians. The inquiry should advocate for a more integrated



approach to AOD service delivery that considers the specific cultural, social, and health needs of Indigenous populations (Brett, Katie et al., 2024).

# c) Engaging Sectors Beyond Health

To effectively address the challenges posed by PAE and FASD in the AOD sector, it is essential to engage sectors beyond health, such as education, justice, addiction treatment services and housing. These sectors play a critical role in prevention and early intervention efforts.

# **Key Issues:**

- Education Challenges: There is a significant gap in early and middle years' education, where health classes often fail to address the risks and consequences of PAE. As a result, young people remain uninformed about the importance of abstaining from alcohol during pregnancy or when planning pregnancy. A 2021 FARE poll found that young adults aged 18-34 had the lowest awareness of PAE risks, with 37% unaware that alcohol use during pregnancy can cause FASD. Additionally, 32% of this age group incorrectly believed that some alcohol consumption is safe during pregnancy.
- Justice System: Individuals with FASD are significantly overrepresented in the criminal justice system, with rates up to 30 times higher than the general population (McLachlan, K., et al., 2014). Cognitive and behavioural challenges associated with PAE, such as impulse control issues and difficulty understanding consequences, contribute to higher offending rates. Despite this, there is a lack of understanding and specialised training within the justice system to address their needs. Many individuals with FASD do not receive appropriate assessments or accommodations during legal proceedings, leading to unjust outcomes. The absence of tailored rehabilitation programs further exacerbates their challenges, often resulting in a cycle of incarceration. To break this cycle, the justice system must implement training to recognize FASD, integrate FASD-specific assessments, and provide appropriate support, leading to fairer outcomes and improved rehabilitation.
- Housing and Social Services: Vulnerable populations, particularly those experiencing unstable housing or significant social challenges, are at an



elevated risk of alcohol misuse during pregnancy or may have undiagnosed FASD. The stressors associated with homelessness, poverty, and social isolation can exacerbate substance use as a coping mechanism, increasing the likelihood of PAE. These individuals often lack access to consistent healthcare, support networks, and educational resources about the risks of alcohol during pregnancy, making them more vulnerable to its harmful effects. They are also more likely to have unrecognised FASD which impairs their capacity to access relevant support services.

PAE and FASD contribute directly to increasing housing and social services costs.

#### Recommendations:

- 7. Intersectional Collaboration: Promote collaboration between the health, education, justice, and housing sectors to create a comprehensive approach to FASD prevention and interventions where FASD is present or possibly present. This should include the development of cross-sectoral policies and programs relevant to FASD.
- 8. Enhanced Training Programs: Implement targeted training for educators, social workers, and justice system personnel to improve their understanding of the risks and effects of FASD to advocate for alcohol free pregnancies, as well as help those affected.
- 9. FASD Education in Schools: Integrate FASD education into school health curricula to ensure early intervention and prevention, equipping young people with the knowledge to make informed decisions in the future. From analysing the Australian Curriculum review F-10 (acara), it is evident that the Health and Physical Education curriculum provides the basis for developing knowledge, understanding and skills for students to lead healthy, safe and active lives. It is imperative that FASD and knowledge of PAE risk is embedded in the Australian curriculum. Alcohol and drug harms should never be discussed without ensuring that pregnancy risks and the lifetime harm of FASD are included in content.

## d) Drawing on Domestic and International Best Practices



There are several successful domestic and international models that Australia can adopt to improve FASD prevention and awareness.

# **Key Issues:**

Lack of Awareness: Despite various efforts and high prevalence, awareness
of FASD remains low, both domestically and internationally. There is a need to
learn from best practices and adapt them to the Australian context.

### Recommendations:

#### 10. Domestic Best Practices

- Every Moment Matters: The "Every Moment Matters" campaign, led by the Foundation for Alcohol Research and Education (FARE), is a domestic best practice initiative aimed at raising awareness about the harms of PAE and FASD. It provides educational materials, videos, and public health messaging to communicate these risks. The campaign encourages healthcare professionals to engage in non-judgmental, supportive discussions about alcohol use with their patients, reinforcing the message that "every moment matters" for the health of both mother and baby. By fostering stigma-free conversations and providing clear, evidence-based information, the campaign seeks to reduce alcohol-exposed pregnancies and improve long-term health outcomes.
- Strong Born: The "Strong Born" campaign by the National Aboriginal Community Controlled Health Organisation (NACCHO) is a culturally centred initiative aimed at preventing FASD in Aboriginal and Torres Strait Islander communities. It promotes awareness of the risks of alcohol during pregnancy and emphasises having healthy babies free from the effects of PAE. "Strong Born" provides culturally appropriate resources, including educational materials, videos, and community events, to empower women and families to make healthy choices. By fostering open conversations, reducing stigma, and integrating cultural values, the campaign seeks to reduce FASD and improve the health and well-being of Indigenous children.
- Alcohol Think Again: Spearheaded by the Government of Western Australia, the "Alcohol. Think Again" campaign raises awareness about



the risks of alcohol consumption, particularly during pregnancy, promoting the message that no amount of alcohol is safe. The campaign provides resources such as educational materials, videos, and advertisements to inform the public about alcohol-related health risks and encourage informed, healthier choices. It plays a key role in reducing alcohol-related harm by fostering public awareness and changing attitudes toward alcohol use.

- One Drink: Part of the "Alcohol. Think Again" initiative, the "One Drink" campaign by the Government of Western Australia highlights the risks of alcohol consumption during pregnancy, delivering the clear message that no amount of alcohol is safe. The campaign used powerful imagery in posters and TV ads. These visuals have increased public awareness about abstaining from alcohol during pregnancy and have made "One Drink" a key public health effort in reducing FASD incidence.
- Foundations in FASD & Workshops: NOFASD Australia offers a range of FASD education and training workshops aimed at increasing awareness and understanding of FASD These workshops, designed for healthcare professionals, educators, and community workers, provide practical strategies for supporting individuals and families impacted by FASD. The Foundations in FASD training program equips participants with essential knowledge about the risks of PAE the lifelong impact of FASD, and the importance of early intervention. By incorporating these workshops into ongoing professional development, NOFASD plays a vital role in building capacity for FASD-informed care across sectors.
- 365-Day FASD Helpline: NOFASD also provides 365-day Helpline and related services to offer support and guidance to families, individuals, and professionals navigating FASD-related challenges. This national helpline ensures immediate access to expert advice and referral services, helping callers connect to the appropriate resources and support systems year-round. NOFASD's helpline is a critical resource for those seeking real-time assistance and information on FASD.
- 11. **Sustaining Success for Domestic Approaches:** Ensuring the continued success of campaigns like "Every Moment Matters" and "One Drink" requires



long-term strategies, including ongoing public education, targeted interventions, and continuous evaluation. Expanding collaborations with healthcare providers, regular clinician training on discussing alcohol use during pregnancy, and maintaining culturally appropriate messaging will amplify their impact. Securing consistent funding and integrating these efforts into broader public health policies will further solidify their effectiveness, contributing to a lasting reduction in PAE and improved maternal and child health outcomes across Australia.

# 12. Best Practices in qualitative systematic research

- Gender-Informed and Inclusive Awareness: Building awareness that reaches women, their partners, and the broader public is crucial. This includes gender-informed approaches that consider the roles and responsibilities of both men and women in promoting healthy pregnancies (Lyall et al., 2021).
- Trauma-Informed, Gender-Inclusive Care: Providing care that is sensitive to trauma, gender, violence, and cultural factors. This involves understanding the broader context of a woman's life and the factors that may contribute to alcohol use during pregnancy (Lyall et al., 2021).
- Non-Judgmental, Relationship-Based Support: Emphasising the importance of non-judgmental, compassionate care from healthcare providers. Building trust and maintaining supportive relationships are critical in helping women reduce or abstain from alcohol use during pregnancy (Lyall et al., 2021).
- Access to Holistic and Integrated Services: Offering integrated support services that address a wide range of needs, including healthcare, mental health, social services, and substance use treatment. These services should be accessible, wraparound, and tailored to the specific needs of pregnant women (Lyall et al., 2021).
- Collaborative Models of Care: Promoting collaboration across various sectors, such as healthcare, social services, and community organisations, to provide comprehensive support to pregnant women.



This includes co-located services that can offer a continuum of care and improve communication among service providers (Lyall et al., 2021).

- Patient-Oriented and Culturally Safe Interventions: Ensuring that interventions are patient-centred and culturally safe, particularly for Indigenous women and other marginalised groups. This includes respecting cultural practices and providing care that aligns with the values and needs of the community (Lyall et al., 2021).
- Public Awareness Campaigns: Implementing public health campaigns that effectively communicate the risks of alcohol use during pregnancy.
   These campaigns should aim to reduce stigma and provide clear, evidence-based information to the public (Lyall et al., 2021).
- Training for Health and Social Service Providers: Providing ongoing training for health and social service providers on how to discuss alcohol use with pregnant women. This includes equipping providers with the skills to offer brief interventions and support in a non-stigmatising way (Lyall et al., 2021).

# 13. Adopt International Best Practices:

- Public Health Campaigns
  - "Think FASD" by CanFASD:
  - with an aim to educate women of childbearing age about the risks of consuming alcohol during pregnancy. These campaigns include online resources, printed materials, and social media outreach to raise awareness on a national level.
  - The campaigns are evidence-based and tailored to reach diverse populations, including Indigenous communities and rural areas, where the risks may be less well known.
  - Ask About Alcohol" Campaign: Ireland has implemented the "Ask About Alcohol" campaign, which is a national public health initiative aimed at reducing alcohol-related harms, including those associated with PAE. This campaign includes specific messaging about the risks of drinking alcohol during pregnancy and



promotes the idea that no amount of alcohol is safe during pregnancy. The campaign uses a variety of media, including television, radio, online platforms, and printed materials, to reach a broad audience. It also provides resources for healthcare providers to facilitate conversations about alcohol use with pregnant women.

- Training for Healthcare Providers: The Health Service Executive (HSE) in Ireland has developed training programs for healthcare providers, including midwives and general practitioners, to ensure they are equipped to discuss alcohol use with pregnant women. This training is aimed at increasing awareness among healthcare providers about the importance of screening for alcohol use and providing appropriate guidance and support.
- The "#DRYMESTER" campaign in the UK raises awareness about the risks of alcohol consumption during pregnancy, promoting the message that no amount of alcohol is safe. It encourages women to stay alcohol-free to protect their baby's health, providing resources like informational materials, social media content, and community support. The campaign collaborates with partners and healthcare professionals to spread the message and support pregnant women. Known for its clear and impactful messaging, #DRYMESTER has fostered a supportive environment that helps prevent FASD and promote healthier pregnancies.

# 14. Universal Screening for Alcohol Use During Pregnancy

• The Centre for Addiction and Mental Health Canada has implemented universal screening for alcohol use in prenatal care settings. The CAMH Network advocates for the <u>routine screening</u> of ALL women of child-bearing age for alcohol use, from preconception, throughout pregnancy and during the postpartum period through validated tools such as the <u>TWEAK</u> and the <u>T-</u>



**ACE** questionnaire. This approach ensures that all women receive the same level of care and attention, helping to identify those who may need additional support early in their pregnancy.

15. **Policy Integration:** It is crucial that national policies on alcohol and drug use explicitly prioritise FASD prevention as a central focus. This can be achieved by incorporating proven best practices from both domestic initiatives, like "Every Moment Matters" and "One Drink," as well as international models such as "#DRYMESTER." Policies should mandate comprehensive education, public awareness campaigns, and clinical training focused on PAE prevention, ensuring that these efforts are embedded into existing alcohol and drug use frameworks. By doing so, FASD prevention will become a key component of broader public health strategies, promoting consistent messaging and effective interventions nationwide.

# Conclusion

NOFASD Australia strongly believes that addressing FASD must be a key part of Australia's national alcohol and drug strategy.

Despite progress in reducing alcohol-related harms, there is still a need to enhance public awareness, improve clinician training, and integrate PAE prevention and FASD-informed approaches across health, education, justice, and social services sectors. The economic and social burden of PAE affects not only individuals but also broader systems.

Investment in prevention, education, and support for those affected by FASD will reduce social and economic burdens while protecting future generations. NOFASD is ready to support the Committee in prioritising PAE and FASD prevention, promoting evidence-based practices, and ensuring equitable care for all Australians. We look forward to continued collaboration and lasting change in this critical public health area.



Yours Sincerely,

Sophie Harrington Chief Executive Officer (Interim) NOFASD Australia Pty Ltd.

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