



Public Health Association
AUSTRALIA

Public Health Association of Australia submission on effective approaches to prevention, diagnosis and support for Fetal Alcohol Spectrum Disorder

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Preamble

The Public Health Association of Australia

The Public Health Association of Australia (PHAA) is recognised as the principal non-government organisation for public health in Australia working to promote the health and well-being of all Australians. It is the pre-eminent voice for the public's health in Australia.

The PHAA works to ensure that the public's health is improved through sustained and determined efforts of the Board, the National Office, the State and Territory Branches, the Special Interest Groups and members.

The efforts of the PHAA are enhanced by our vision for a healthy Australia and by engaging with like-minded stakeholders in order to build coalitions of interest that influence public opinion, the media, political parties and governments.

Health is a human right, a vital resource for everyday life, and key factor in sustainability. Health equity and inequity do not exist in isolation from the conditions that underpin people's health. The health status of all people is impacted by the social, cultural, political, environmental and economic determinants of health. Specific focus on these determinants is necessary to reduce the unfair and unjust effects of conditions of living that cause poor health and disease. These determinants underpin the strategic direction of the Association.

All members of the Association are committed to better health outcomes based on these principles.

Vision for a healthy population

A healthy region, a healthy nation, healthy people: living in an equitable society underpinned by a well-functioning ecosystem and a healthy environment, improving and promoting health for all.

The reduction of social and health inequities should be an over-arching goal of national policy and recognised as a key measure of our progress as a society. All public health activities and related government policy should be directed towards reducing social and health inequity nationally and, where possible, internationally.

Mission for the Public Health Association of Australia

As the leading national peak body for public health representation and advocacy, to drive better health outcomes through increased knowledge, better access and equity, evidence informed policy and effective population-based practice in public health.



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Introduction

PHAA welcomes the opportunity to provide input to the Committee Inquiry into effective approaches to prevention, diagnosis and support for Fetal Alcohol Spectrum Disorder (FASD). FASD occurs in all parts of Australian society where alcohol is consumed, and is not only a medical condition, but also a social issue with lifelong consequences for the child, mother and their family. Myths and misconceptions about FASD are common, exacerbating the challenges involved.

PHAA Response to the Inquiry Terms of Reference

(a) The level of community awareness of risks of alcohol consumption during pregnancy

Current levels of awareness

The level of community awareness of the effects of alcohol consumption during pregnancy appears to be low and this is a public health concern. Various campaigns with the aim to promote the message of limiting alcohol during pregnancy and breastfeeding including *Women Want To Know* and *Pregnant Pause* are not well-established in the Australian media or online platforms.

With one in four women in Australia consuming alcohol after knowing they were pregnant,¹ community awareness that no level of alcohol exposure has been established as 'safe' for the developing fetus is clearly inadequate. Myths such as that it's OK to drink alcohol after the first trimester; 1 or 2 drinks a week is OK; the placenta filters out harmful substances so no alcohol reaches the fetus; and it depends what type of alcohol you are drinking; only the children of alcoholics get FASD – remain within the Australian population.² Similarly, there are a number of online forums where women are questioning whether it is suitable to consume alcohol cooked in foods. These forums have seemingly confusing messages for expectant mothers and the online information for this topic is unclear, the internet being a commonplace for women to go for information. With alcohol taking up to 3 hours of cooking time to be completely removed from food,³ clarity of information is essential.

PHAA supports ongoing investment in building and maintaining high levels of community awareness of the risks of alcohol use during pregnancy. Approaches to raising community awareness must recognise that this is a whole-of-community issue and not just a women's issue; the responsibility for healthy pregnancies is shared across the community. Partners have a key role in supporting pregnant women to abstain.

PHAA recommends the Australian Government funds research into alcohol consumption during pregnancy, to better monitor the scope of the problem and the effectiveness of raising community awareness.

Medical sources of information for pregnant women

When a woman discovers she is pregnant, her General Practitioner (GP) is responsible for providing the right level of information to the expectant mother of her risk to several conditions including FASD. This information, however, is dependent on the individual GP's level of awareness and effectiveness in promoting the message. The *Women Want To Know* campaign encourages health professionals to speak with patients about alcohol and pregnancy as a matter of routine, in and amongst the other information the GP is to provide.

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A woman will see many health professionals throughout her pregnancy, and it is reliant upon these contact points for her to become aware that her behaviours are impacting the health of the fetus.

A qualitative study found women felt that midwives assumed they did not drink, and that midwives felt ill-equipped to explain the risks involved.⁴ With the key role of midwives in supporting women throughout pregnancy and childbirth, this is an area which should be explored further in future research.

Government information for consumers

It is important that information for consumers is clear, consistent and evidence-based. Health information should be provided by governments and health agencies, to ensure that it is evidence-based. Information provided by alcohol-industry funded bodies (such as DrinkWise) has been found to be significantly less likely to include important information, and more likely to emphasise uncertainties, use ambiguous language, and to provide misinformation which may actually increase risk.⁵

The National Health and Medical Research Centre's (NHMRC) Australian Guidelines to Reduce Health Risks from Drinking Alcohol,⁶ are currently being reviewed and updated, and this review should include the guidelines around pregnancy and alcohol. *Guideline 4* states that the level of risk is "likely to be low if a woman has consumed only small amounts of alcohol" and fails to use effective language to represent a strong message on the risk of alcohol consumption during pregnancy. The emphasis of alcohol consumption being 'frequent and heavy' such as is found in the messaging on one state government website in Australia,⁷ is an ineffective way to communicate the message that no alcohol should be consumed during pregnancy. The NHMRC guideline currently states that for pregnant and breastfeeding women: "Not drinking is the safest option".⁶ Following the outcome of the current review, the updated Guidelines should be implemented consistently across all Australian and State and Territory government information sources, to ensure consistent messaging that no level of alcohol consumption is safe for pregnancy.

Within a comprehensive approach to raising awareness across the community, the PHAA strongly supports the transition from voluntary to mandatory health warnings regarding the risks of consuming alcohol while pregnant. During the consultation about the development of the mandatory warning labels, we have been keen to ensure that the labels are designed and implemented with a view to optimise the attention they receive. In our submission to FSANZ regarding mandatory pregnancy warning labels on packaged alcoholic products (P1050), we emphasised that:

- The size of the font and overall warning label should be large enough to be easily noticed and read;
- The selection of the warning statement should be informed by the consumer testing results;
- The transition time to implement the mandatory labels should be minimised to 12 months, in recognition of the extensive delays to date in enacting mandatory labels;
- The warning label should appear on products containing >0.5% ABV, consistent with the requirements for standard drink labelling;
- Monitoring and evaluation of the labels will be important as part of their successful implementation;
- The warning labels should form part of a broader suite of awareness-raising measures funded by government.

The Australian Government should also provide greater publicly available resources - such as recipes - for women who have historically cooked with alcohol so they can be properly informed about their choices and alternatives.

Information provided must also be appropriate for different audiences including different cultural backgrounds, languages, and levels of literacy.

(b) The adequacy of the health advice provided to women planning a pregnancy, pregnant women and women who are breastfeeding, about the risks of alcohol consumption

The National Drug Strategy Household Survey is the main national source of data for this and shows that while the proportion abstaining is increasing, in 2016, 25% of pregnant women continued to drink alcohol after finding out they were pregnant.¹

(c) Barriers that may prevent women receiving accurate, timely and culturally/ethnically appropriate information and advice on alcohol and pregnancy

A qualitative study found women felt that midwives assumed they did not drink, and that midwives felt ill-equipped to explain the risks involved.⁴

One barrier which is difficult to overcome is that more than one quarter of pregnancies in Australia may be unplanned.⁸ For this reason, it is important that prevention messaging is provided to the whole community, not just pregnant women.

(d) Provision of diagnostic services in Australia including capacity, training, integration and diagnostic models in current use

Diagnostic multidisciplinary assessment for FASD is time-consuming and costly – even the current clinics have limited resources to cope with demand and have long waiting lists. Access for women in regional and remote areas is even more difficult. Clinic funding is varied (philanthropic, state and commonwealth, grants, and user-pays) and usually short-term. A nationally coordinated strategy for transparent, equitable, sustainable funding of FASD diagnostic services is needed to ensure timely and comprehensive assessments for all young people at risk of FASD, at no or low cost to the family.

The diagnosis of FASD is complex, and ideally requires a multidisciplinary team of clinicians to assess individuals for prenatal alcohol exposure, neurodevelopmental problems and general physical and health issues.

There are 5 multidisciplinary clinics in Australia – Child Development Service FASD Clinic (Gold Coast), Sunshine Coast Child Development Service FASD Clinic, CICADA Clinic Children's Hospital at Westmead, Developmental Paediatrics at Monash Children's Hospital, Patches Paediatrics which has a clinic in Perth and outreach services across WA, NT, SA, Victoria and Tasmania. Other child development services across Australia have received training on assessment and diagnosis for FASD. Individual health professionals have also participated in training programs and have registered their service (paediatrics, speech therapy, psychology services) on the FASD Hub Service Directory.

There are long wait times for children to access an initial assessment through child development services and subsequent referrals for other assessments. During this time a child's health and behavioural problems may escalate and result in problems at school and potentially contact with the justice system. The access to private clinics is limited due to location and the ability of families to pay for these services.

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In the lead up to publication of the Australian Guide to the diagnosis of FASD in May 2016, there had been extensive systematic review and consultation, and discussions with organisations responsible for international guidelines. The Australian Guidelines are harmonised with the Canadian Guidelines and include some aspects of the University of Washington Guidelines which are widely used in the USA. There have been projects to disseminate and provide training on the use of the Australian Guide to a range of health professionals, particularly paediatricians, psychologists, speech and language pathologists and occupational therapists. This work has been funded by the Australian Government Department of Health.

Based on the Guide, the diagnosis of FASD requires evidence of prenatal alcohol exposure and severe impairment in three or more domains of central nervous system structure or function. There are two sub-categories:

1. FASD with three sentinel facial features
2. FASD with less than three sentinel facial features

There has also been training undertaken by other groups, predominantly in Western Australia, Queensland and New South Wales. Some of this training has been funded by Commonwealth and State governments.

Health professionals who complete this training are encouraged to register their clinic or service on the FASD Hub Service Directory. The Service Directory can be searched by state/territory or type of health professional and provides the opportunity for referral from another health professional or parents trying to find a service as part of management or therapy strategies.

To remain current and evidence based, the Australian Guide, which has been in use since 2016, requires review and revision.

(f) International best practice in preventing, diagnosing and managing FASD

Ultimately, when we discuss the prevention of FASD, we are discussing how to prevent alcohol-exposed pregnancies. This includes the time before the woman is aware she is pregnant, and for the remainder of the pregnancy (and the period of breastfeeding). Therefore, it is appropriate to have a broad view that includes the evidence-based measures that can make the most difference in preventing and reducing the impacts of alcohol on individuals, families, and communities. The PHAA strongly supports governments taking steps to implement the policy interventions identified by the World Health Organization (WHO) as the 'best buys' to reduce harm from alcohol.⁹ These are:

- Increase excise taxes on alcoholic beverages;
- Enact and enforce bans or comprehensive restrictions on exposure to alcohol advertising; and
- Enact and enforce restrictions on the physical availability of retailed alcohol.

We briefly discuss each of these policy areas below.

Pricing

The current approach to alcohol taxation is flawed and inconsistent.¹⁰ Increasing the price of alcohol through taxation and minimum pricing policy are highly effective ways of reducing harm from alcohol.⁹ We support reforms to the alcohol taxation system that include removing the Wine Equalisation Tax (WET) and its associated rebate, and introducing volumetric taxation across all alcohol products, with tax increasing for products with higher alcohol volumes, complemented by a minimum floor price per standard drink.

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Marketing

Young people are heavily exposed to alcohol marketing in many different forms including television, radio, social media, online video channels, mobile phones, sponsorship of sporting and music events, and outdoor media.¹¹ There is compelling evidence that exposure to alcohol advertising influences young people's attitudes about drinking and increases the likelihood that adolescents will start to use alcohol and will drink more if they are already using alcohol.¹² Self-regulation of alcohol marketing by the alcohol and advertising industries has failed to protect young people and the general community, and should be replaced by independent regulation with sanctions for non-compliance.¹³ The ways in which alcohol brands and alcohol marketing are targeted to women is a particularly relevant issue in the context of the current inquiry; a recent report from the UK points to "a clear feminisation of alcohol products, drinking spaces and drinking culture", including via "lifestyle messages that appeal to gender stereotypes" and "messages of empowerment" that have been used to target the female market.¹⁴

Availability

Appropriate controls on the physical availability of alcohol are essential components of effectively preventing and reducing harm from alcohol.¹⁵⁻¹⁷ FASD is one of those potential harms, which, like violence, injuries and mental health issues, may see a reduction in risk where trading hours and outlet density are restricted. Restrictions also need to be comprehensive across geographical locations – without exemptions.

(g) Awareness of FASD in schools, and the effectiveness of systems to identify and support affected students

Education should emphasise a whole of community approach, and include the role of males and partners in prevention.

(h) The prevalence of, and approaches to, FASD in vulnerable populations, including children in foster and state care, migrant communities and Indigenous communities

The Legislative Assembly of the Northern Territory report from the Select Committee on Action to Prevent Foetal Alcohol Spectrum Disorder – The Preventable Disability – found that internationally, prevalence estimates vary from 1-3 per 1,000 live births in the general population to as high as 65-74 per 1,000 live births in high risk populations. This report noted that prevalence rates in Australia are likely to be underestimated.¹⁸

Aboriginal and Torres Strait Islander people

FASD is a sensitive issue within the Aboriginal and Torres Strait Islander community. PHAA affirms that work in Aboriginal and Torres Strait Islander health including FASD needs to be led by Aboriginal and Torres Strait Islander people. While affecting all sections of Australian society, there is a high incidence of FASD among Aboriginal and Torres Strait Islander people.^{19, 20} Aboriginal led research show there is much stigma around FASD for Aboriginal and Torres Strait Islander mothers, children and families.¹⁹

Alcohol, for some Aboriginal and Torres Strait Islander people is used as a way of coping with trauma and appropriate support services need to be in place. Any prevention and available support needs to be trauma informed, culturally appropriate and sensitive to the stigma. Therefore, to address, prevent, diagnose and support people with FASD and their families, solutions must be driven locally by Aboriginal and Torres Strait Islander people. Given the collective nature of many Aboriginal and Torres Strait Islander communities, FASD programs need to take a whole of community approach with specific resources for fathers and men.²¹

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FASD does not occur in isolation from other aspects of poor Aboriginal and Torres Strait Islander health. For example, a FASD child can also have hearing difficulty due to otitis media.¹⁹ This means Aboriginal and Torres Strait Islander families can be placed under greater stress as a result of FASD and comorbid health problems than other families.¹⁹ For many Aboriginal and Torres Strait Islander people with FASD, they have yet to be diagnosed, and if they do have a diagnosis, they do not receive the assistance they require, nor do their families.

FASD screening and diagnostic services for Aboriginal and Torres Strait Islander communities must be developed to incorporate the broader aspects of the social determinants of Indigenous health. A qualitative study with Aboriginal youth who undertook assessment and diagnostic screening in youth detention in Western Australia showed Aboriginal youth understood their diagnosis in the context of culture and community, and had particular special needs for understanding a FASD diagnosis.²⁰ Future initiatives for FASD screening and diagnosis should be community determined, led and driven. Access to FASD screening and diagnostic services, particularly in regional and remote communities, is limited, inconsistent and currently exist within the context of non-Indigenous mainstream services.

People with FASD have a reduced life expectancy at just 34 years. Suicide is the leading cause of death and more needs to be done to support adult cases of FASD.¹⁹

Indigenous-led research to develop culturally-informed screening tools which assist communities to identify children and young people who may be affected by FASD is required. Further, supporting communities in health promotion activities related to FASD prevention, and to identify strategies to manage the problems which can arise from FASD relevant to specific communities and their needs, is imperative.

(i) The recognition of, and approaches to, FASD in the criminal justice system and adequacy of rehabilitation responses

A study at Banksia Hill, the only youth detention centre in WA, found a high prevalence of FASD (36%) and at least one severe neurodevelopmental impairment (89%), among the young people in the centre, most of which had not been previously recognised.²² As part of this study, training resources for corrections staff were developed, evaluated and found to improve knowledge and attitudes among staff regarding FASD, and increased intent to use appropriate management approaches with young people with FASD and neurodevelopmental impairment.²³

Further research is required in this area, to better identify the prevalence of FASD in the criminal justice system, both adult and youth, and develop appropriate responses to FASD, given the very high rates of Aboriginal and Torres Strait Islander people, particularly youth involved with the justice system.

(j) The social and economic costs of FASD in Australia, including health, education, welfare and criminal justice

The NT report also noted that the profound impacts, both social and economic, of FASD reach beyond the immediate individuals and families, with community-level burden. This includes from poor health outcomes; loss of productivity; reduced quality of life and longevity; increased need for government services including special education services, employment services, community services, income support services, child protection and justice services.¹⁸

With the high costs and consequences, and clear and effective prevention pathways, prevention of FASD must be a high priority.

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(m) Progress on outstanding recommendations of the House of Representatives Standing Committee on Social Policy and Legal Affairs report, FASD: The Hidden Harm, tabled on 29 November 2012

Several recommendations within the *FASD: The Hidden Harm* report continue to be relevant and relate to the content of this submission. While we are not fully informed of the extent to which the recommendations have been progressed, there are some areas that stand out as requiring ongoing attention, including:

- Recommendation 6 for public awareness campaigns implemented by the Commonwealth Government to promote the NHMRC guidelines.
- Recommendation 11 for mandated health warning labels for alcoholic products and a comprehensive public awareness campaign.
- Recommendation 12 for an independent study into the impacts of pricing and availability of alcohol and the influence of these factors in the changing patterns of alcohol use across age groups and gender.
- Recommendation 13 for an independent study into the impacts and appropriateness of current alcohol marketing strategies, including the adequacy of regulations to respond to marketing through digital platforms.

(n) The effectiveness of the National FASD Action Plan 2018-2028, including gaps in ensuring a nationally co-ordinated response and adequacy of funding

The PHAA strongly supports adequate funding and an ongoing government commitment to implement the National FASD Strategic Action Plan 2018-2028, including actions across the priority areas of prevention, screening and diagnosis, and support and management. We believe much greater investment is required to truly prevent and respond to FASD adequately, and we would welcome a commitment from the Australian Government to work with states and territories on implementation.

(o) The need for improved perinatal data collection and statistical reporting on FASD and maternal drinking

PHAA also notes the work done by the Australian Institute of Health and Welfare and the Murdoch Children's Research Institute towards the development of a nationally agreed, uniform method for measuring and recording alcohol use during pregnancy.

It is important that women are provided with the confidence in their health professional to admit to consuming alcohol during pregnancy. The current literature is limited to measuring those who are willing to admit their consumption of alcohol, given that admitting this can result in feelings of guilt and shame to the expectant mother.

Conclusion

PHAA supports the inquiry into FASD in Australia. We are particularly keen that the following points are highlighted:

- Awareness is currently low
- Information should be provided by the Government as a trusted sourced
- Health warnings on alcoholic beverages should be mandatory
- Diagnosis is complex and requires multidisciplinary teams – this needs a national strategy with funding, improvements to access to services across Australia, and updates to the Australian Guidelines
- WHO best buys regarding alcohol policy should be implemented
- All prevention, diagnosis and support offered for people with FASD and their families need to be trauma informed
- Screening and diagnostic services need to be accessible to Aboriginal and Torres Strait Islander people
- Develop Aboriginal and Torres Strait Islander specific health promotion materials on prevention, diagnosis, and support in collaboration with Aboriginal and Torres Strait Islander people
- Aboriginal Community Controlled Health Organisations should be funded to undertake FASD health promotion activities and to support people with FASD including adults
- All relevant clinical staff should receive FASD training which includes but is not limited to health promotion, diagnosis and best practice supports.

The PHAA appreciates the opportunity to make this submission and the opportunity to contribute to preventing FASD in Australia.

Please do not hesitate to contact me should you require additional information or have any queries in relation to this submission.

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