

# ACM SUBMISSION

## *Senate Inquiry: Effective approaches to prevention, diagnosis and support for Fetal Alcohol Spectrum Disorder*

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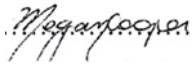
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### Cover Sheet

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<b>Is this submission being made on behalf of an organisation? (Y/N)</b>					Yes
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#### **(a) the level of community awareness of risks of alcohol consumption during pregnancy;**

Anecdotally, community awareness of fetal alcohol spectrum disorder (FASD) is limited. While women are likely aware that they should refrain from drinking alcohol during pregnancy, the rationale for this is arguably not well understood.

Women sometimes present for their first booking visit post the confirmation of pregnancy and disclose to the care provider that they had engaged in an episode of binge drinking prior to realising that they were pregnant. This is often associated with a level of guilt and concern for their baby's wellbeing. This suggests that women understand, at least to some degree, the implications of drinking alcohol in excess but what is not known is whether they understand that alcohol can be associated with both physical and psychological consequences for their unborn child, particularly when they are exposed to alcohol in the embryonic phase. This suggests that community knowledge and understanding is insufficient given that women within their social circles and communities, are unlikely to understand the implications. Further, whilst many recognise that alcohol is unsafe in excessive amounts they will not associate the occasional consumption with any adverse effect to their unborn child and as such, may continue to engage in social drinking.

Messaging around the implications of consuming alcohol during pregnancy are often confusing, unclear and inconsistent as is the information that is shared both professionally and socially. For example, labelling on alcoholic beverages has been effective to some degree, but has not yet been complemented by a campaign to reflect the associated rationale behind the messaging. Nor has the extent to which alcohol can affect the unborn child been widely disseminated. Labelling may prompt consideration from the woman or others about the effects of alcohol but may not specifically change their behaviour and so we are pleased to have been engaged in the current work by FSANZ on pregnancy warning labels for alcoholic beverages. However, without the supporting campaign, understanding of the implications, and particularly of FASD, will remain low and information shared among the community will not result in changed behaviours.

#### **(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;**

While we believe that women have a general understanding of the risks related to consumption of alcohol, our view is that there is insufficient and inconsistent advice with respect to what is appropriate in terms of quantity. We believe that there is even less understanding about the potential implications of alcohol consumption at all stages, whether that be while a woman is planning a pregnancy, is pregnant or during breastfeeding. In 2015, a sample of Australian women aged between 18-45 were asked about their alcohol consumption and their knowledge of alcohol with respect to pregnancy. Of the women included, 89.4% had consumed alcohol in the year prior, 50% had heard of FASD while 39% were unaware that alcohol could cause harm to the fetus (Elliot, 2015). In another Australian study, 58.7% of women who were surveyed suggested that they had consumed alcohol during the first trimester of their pregnancy. This study also concluded that there has been no change in the percentage of women who engage in high-risk drinking when compared with figures in 2007 and 2011 (Reid, Gamble, Creedy & Finlay-Jones, 2019). This reflects that there is unlikely to be sufficient health advice provided to women with this supported by Reid (2018) who suggests that caregivers of children with FASD commonly indicating that they were not provided with sufficient information from health professionals.

Prior to pregnancy, women may be exposed to messaging that provides them with an understanding that they should work towards risk minimisation and therefore, refrain from the consumption of alcohol and other drugs. However, we would argue that this messaging is limited in its efficacy and more, that there is little emphasis on the potential implications of exposing the embryo to any level of alcohol during the first trimester and indeed, the fetus throughout the second and third trimester.

Around 50% of pregnancies are unplanned and therefore, women may be consuming alcohol without an understanding that they are pregnant. In such situations, women may be unaware of pregnancy and therefore continue their patterns of alcohol consumption without an understanding of the potential impact it could have on their unborn child. This suggests that more information needs to be available in the public domain to ensure that women are not only aware of the fact that there is no safe level of alcohol consumption throughout pregnancy but that this is specifically pertinent to the early weeks of pregnancy.

Women who present for their first appointment during pregnancy, will be asked about their alcohol consumption as part of gathering a health history. At this appointment, there may be a discussion about ceasing or reducing alcohol consumption throughout pregnancy and there is generally the provision of written information. Often this is given with a multitude of other information. Post this first appointment, there may be very little follow up with respect to the woman's alcohol use unless it is raised by the woman herself, or the care provider suspects high-risk drinking. Occasional episodes of drinking may go undiscussed possibly due to the inconsistent messaging that means that women do not recognise the effects that drinking can have on their baby. Furthermore, a study revealed that the health care professionals relaxed attitude to alcohol consumption led women to believe that drinking was unlikely to be harmful (Meurk, Broom, Adams, Hall & Lucke 2014).

In 2009, the National Health and Medical Research Council (NHMRC) released the Australian Guidelines to Reduce Health Risks from Drinking. Included within this was guidance around the consumption of alcohol during lactation. This was the first time the effect of alcohol was nationally and internationally acknowledged with respect to breastfeeding however, there is suggestion that the adoption of such information has been limited in the clinical environment. However, a 2018 study reflected that there was only average uptake of the information by health care professionals (Giglia, Symons & Shaw 2019). With respect to breastfeeding, we would argue that there is a paucity of resources and guidance to assist women in their decision making and choices and therefore, this is an area of emphasis in any future plans to increase awareness and improve education.

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

Alcohol consumption is commonly aligned with social occasions and is arguably seen as less problematic or risky when compared with other recreational drugs and so awareness and uptake of messaging is likely to be influenced by these factors. There may be a level of complacency based on the belief that alcohol consumption in moderation is unlikely to result in any adverse effect to the baby in utero and indeed, after birth and through the lifespan.

Social conditioning is therefore likely to be quite a significant influence or barrier to women receiving accurate information particularly in situations where alcohol is accepted. There are cultural aspects that are also likely to play a factor particularly with the alcohol being synonymous with social and celebratory occasions.

Stigma surrounding the consumption of alcohol may also present a barrier, particularly if the woman has any level of dependence, where dependence is acknowledged as another barrier to women seeking appropriate information. While the woman may be aware of the reasons why it is in the best interests of both herself and her baby to limit or cease alcohol use, there may be barriers to seeking help where the woman fears being judged or ridiculed for her drinking behaviours. Without the necessary guidance and assistance, the woman may not have the strategies to overcome her dependence. Given this, the provision of accessible and approachable programs that support women without associated blame or shame are likely to be significant in any prevention strategy or approach.

This is particularly pertinent in the event that there are cultural considerations that may compound help seeking behaviour. Care provision and support services that are not culturally appropriate are likely to result in limited engagement and disclosure and therefore, present a significant barrier to improving awareness and prevention.

Personal experience of having consumed alcohol in prior pregnancies and/or the woman knowing someone who has done so, may also result in the belief that alcohol presents no harm to the unborn child. While there may be no obvious signs or symptoms which can be definitely aligned with the drinking of behaviours of women throughout pregnancy, it is important to note that FASD is both difficult to diagnose and often goes, undiagnosed. Without awareness, women may hold the belief that there is little to no detriment caused by alcohol consumption. Raising awareness of these impacts is therefore essential in order for women to understand that implications of consuming alcohol during pregnancy.

Lack of understanding is likely a result of insufficient messaging and the provision of limited information in easy to understand formats. It is also likely to be a result of limitations in health care provider knowledge and as such, a multifaceted approach to awareness is essential to overcome these barriers.

A lack of health care professional understanding and knowledge of referral, diagnosis and strategies to support women in their drinking behaviour is likely the most significant barrier to women receiving appropriate and timely information. Many studies have demonstrated that professionals have limited training and education with respect to the effects of alcohol and FASD with this extending to university curricula. Health care providers may presume that the woman has ceased drinking alcohol and therefore, may not ask the woman directly. This is supported by a study that found that only 45% of health professionals routinely asked about the woman's alcohol use while only 25% provided information about the implications of drinking alcohol and 13% provided advice in line with NHMRC guidelines (Jayne et al. 2019). As such, there is a pressing need for this to be addressed.

#### **(d) provision of diagnostic services in Australia including capacity, training, integration and diagnostic models in current use;**

The level of understanding of alcohol consumption and the associated effects in pregnancy are not well known and this greatly influences the provision of diagnostic services. Diagnosis is complex and requires a thorough understanding of both physical and cognitive factors. While the gold standard approach to involves 'multiple days of assessments, followed by a multidisciplinary case-conference' (Reid 2018) this is both time consuming and expensive particularly in areas where the incidence is likely to be high.

Given the geographical vastness of Australia, approaches to diagnosis should be flexible and draw on care providers who are most likely to have access to women before and during pregnancy and during breastfeeding.

#### **(e) the prevalence and nature of co-occurring conditions and of misdiagnosis of FASD;**

We believe that due to FASD being both difficult to diagnose and often being undiagnosed it is at this stage difficult to determine the prevalence and nature of co-occurring conditions or of misdiagnosis of FASD. However, we do understand that FASD is commonly associated with cognitive difficulties. Memory, attention and language are also commonly affected. These factors may contribute to difficulties with social interactions. Studies further suggest that FASD also increases the risk of other diseases such as arthritis and hypertension.

### **(f) international best practice in preventing, diagnosing and managing FASD;**

Prevention is better than cure particularly given that FASD is 100% preventable. However, prevention must acknowledge that there is a complex interplay of factors that influence the likelihood of a woman of consuming alcohol during pregnancy; many of which have been discussed earlier in this submission. Further complicating this is the lack of data to suggest the prevalence of FASD in Australia.

Prevention strategies are most effective when they are approached from a collaborative, multifactorial, widespread approach that takes into consideration the various contributing factors. Such approaches must address:

- Legislative changes
- Access to alcohol
- Alcohol labelling
- Community awareness
- Women's awareness
- Health care provider knowledge and ability to diagnose
- Targeted education for high risk groups
- Flexible, evidence-based approaches to diagnosis
- Quality care throughout pregnancy

Access to alcohol can be reduced through a range of strategies such as pricing, limitations on sale, taxes and trading hours of retailers. While such preventative measures are likely to be met with opposition, such approaches are effective in deterring consumption. Improvements in messaging through the provision of labelling on alcoholic beverages (as being addressed by FSANZ P1050) and media campaigns are likely to raise community awareness but must take into consideration cultural factors. Legislative changes and public health policy are essential to ensure that these key factors are addressed.

Targeted education has been effective in reducing alcohol consumption in high risk groups and also has value in improving health care professional's knowledge which leads to better screening and support. Such education should also target undergraduate level curricula with the view of working towards better understanding of the multifactorial issues that surround alcohol consumption. Courses such as those offered by the Australian College of Midwives and FARE should be made more accessible and promoted more strongly to ensure that all professional who work alongside women are able to provide evidence-based information with respect to alcohol and pregnancy.

Support throughout pregnancy is a significant consideration in minimising the potential and likely rates of FASD. Pregnancy is an opportune time to educate women and therefore to promote healthy lifestyle changes that not only have the benefit of improving their own health but also that of their unborn baby in addition to the wider family unit. Women, by majority, are more likely to embrace change during this time in order to keep their baby safe. It is therefore important that maternity care providers such as midwives and obstetricians are well informed, as well as attentive to the implications of alcohol consumption and can draw on evidence-based approaches to assist women with risk minimisation and ultimately, cessation. This involves encouraging an atmosphere that is supportive, non-judgemental and facilitative of strategies that will achieve such an objective.

At present, there are no practice frameworks developed specifically for Australian maternity care. This is a limitation and could be addressed by drawing on the four-part framework from Canada. This framework takes into consideration the following foci:

1. Public awareness and health promotion
2. Conversations with and education of women of childbearing age including their social networks
3. Targeted support for women who are pregnant

#### 4. Postpartum support for new mothers and assessment of the child's development

Midwives and obstetricians are pivotal with respect to foci 2-4. The implementation of this framework in Western Australia, Northern Territory and New South Wales have demonstrated a reduction in drinking behaviours.

A therapeutic relationship is a prerequisite to ensuring an environment where women can be supported and care can be tailored to the individual. To achieve such an environment, Reid et al. (2019) argue that care should be underpinned by continuity of carer approach. Caseload midwifery, which is an approach to midwifery continuity of care, has the potential to facilitate such a relationship as well as provide opportunities to address the key areas outlined in this framework. Women have access to a known midwife who provides care throughout pregnancy, birth and up to six weeks postnatal. However, only 8% of women in Australia are able to access this model of care in Australia. As such, increasing equity of access to such care is one way of working towards these key factors in working towards reductions in FASD.

Support for individuals post diagnosis of FASD, is limited and carers have indicated that they are not always able to access the required and necessary services. To date FASD, is not recognised as a disability and as such, limited resources and funding have been allocated to supporting families. FASD is a multifaceted disorder that is commonly associated with intellectual disability. Many children will also be diagnosed with autism spectrum disorder and may as a result, receive support through NDIS. However, there is currently no additional support available for children diagnosed with FASD. Early intervention is associated with the best outcomes however, current programs need to take into consideration the complexities that children with FASD face. Further research and funding are required to inform and facilitate services that provide the required to multifaceted approach.

Subsequently, we echo calls for a comprehensive multifaceted public education/awareness campaign that has two components - a focus on women and the general public and a component focused on health professionals. For example, where a woman sees a bus stop poster with a clear message to not drink during pregnancy and that message is supported by the midwife/GP/Obstetrician and family and friends giving similar messages.

#### **(g) awareness of FASD in schools, and the effectiveness of systems to identify and support affected students;**

While we have limited insight into the wider context, anecdotally there appears to be little awareness or understanding of FASD and associated challenges in the school context especially with respect to the extent of the cognitive, social and physical needs of children with FASD.

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

A recent study in Western Australia found some of the highest rates of FASD in the world, with rates being highest in vulnerable and high-risk groups (Passmore et al. 2018). The rates were in the order of 194.4 per 1000 children. The rates are potentially an underestimate given that diagnosis is in itself, a challenge.

The points we have raised are systemic and social challenges that need to be addressed in order to reduce the incidence of FASD and alcohol consumption during pregnancy. However, consideration and attention are arguably more essential in supporting vulnerable populations both in terms of reducing behaviours that may lead to FASD and developing support services after a diagnosis. Both of these areas have to date, suffered from lack of funding and attention.

Timely and flexible approaches to diagnosis are essential as well as awareness and acknowledgement of the additional factors that surround the experience of children in vulnerable situations. This includes that provision of services that are attentive to the cultural needs of Indigenous and migrant communities. To date, there is very little in the way of service provision for FASD and even less for those who are a part of a minority group.

The provision of multifaceted services that speak to the complexities of FASD will allow caregivers the opportunity to better provide for and assist with their child's needs and more, provide opportunities for support which is significant for improving outcomes. Such approaches would assist children in state or foster care to receive the support they need with respect to their diagnosis and more, minimise the potential for breakdowns in both relationships and placements.

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

Due to the nature of the challenges related to and surrounding FASD, children and adolescents are more likely to be subjected to police interaction, incarceration and therefore, engagement with the criminal justice system. It is therefore essential that those involved in this space are not only aware of FASD and the associated challenges but are able to respond with an understanding of the multifaceted factors that are likely to be in play. This includes the vulnerability that a person with FASD may experience particularly due to the cognitive, social and mental factors that may inhibit the understanding and interpretation of information for the individual as well as their ability to express themselves. Individuals with FASD are also more susceptible to bullying and manipulation.

One study suggested that 53% of custodial officers were unsure and unaware of the link between FASD and brain damage and 57% were unaware that it was lifelong. However, almost all suggested that they were willing to engage in training to understand FASD.

Standardised approaches are therefore unlikely to be productive and only exacerbate the challenges that the individual is contending with. It is therefore essential that training is targeted at staff who are likely to engage with youth to ensure they are skilled and adaptive to the needs of the individual.

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

FASD is associated with significant social and economic burden with this including loss of productivity, disability and higher rates of premature death. The cost to the Australian health care and welfare systems is likely to be in the order of billions of dollars. This is supported by the fact that FASD is a lifelong condition associated with a multitude of comorbidities, many of which are known to increase a person's access to acute and chronic health care.

**(k) access, availability and adequacy of FASD support available through the National Disability Insurance Scheme, including access to effective and early intervention services for individuals diagnosed with FASD;**

While the National Disability Insurance Scheme currently provides support to individuals and families that are living with disabilities, there was little acknowledgement of FASD specifically at its inception. However, following lobbying and the Strategic Action Plan, Fetal Alcohol Spectrum Disorder is now recognised as a condition as opposed to being classified under 'Congenital conditions - cases where malformations cannot be corrected by surgery or other treatment and result in permanent impairment.'



While this is a positive step, access to the required diagnostic processes that satisfy the requirements of the NDIS are limited and therefore, individuals and families are unable to access the scheme due to these limitations. The provision of diagnostic services that specifically speak to the requirements of the NDIS are therefore essential to ensure that those who are most in need are able to access this financial support.

**(l) support for adults with FASD and for parents and carers of children with FASD;**

A recognised shortfall has been the availability and access to diagnostic services particularly for adults who are likely to be experience FASD. This is an area requiring urgent attention.

**(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;**

Nil comment.

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

While the action plan outlines a planned approach to FASD, the points raised above need to be coordinated to ensure that the strategies and goals are met. Of significance is the awareness and knowledge of the implications of consuming alcohol during pregnancy. A concerted effort to raise awareness is a priority. In order to achieve this, further funding must be committed to ensure a sustained and effective widespread public campaign.

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

Australia does not have sufficient data to reflect the true extent and prevalence of FASD. While there have been attempts to gather data, these are not likely to reflect the true extent. Without an understanding of the true prevalence, the costs both socially and financially are likely to continue being underestimated and even overlooked. A rigorous National approach to perinatal data collection is therefore essential. Not only will this assist in working towards a greater understanding of the magnitude of FASD but it will also support targeted approaches towards those areas and groups who are most affected. Consistent and standardised data collection that is both accessible and provides tangible information in order to inform service provision and strategies will result in reducing rates of FASD and minimising the challenges that individuals with FASD and their care providers experience.

**(p) any other related matters.**

Nil comments.

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