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AMA submission to Senate Community Affairs References Committee – Inquiry into effective approaches to prevention, diagnosis and support for Fetal Alcohol Spectrum Disorder

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The Australian Medical Association (AMA) welcomes the opportunity to make a submission to this Inquiry into effective approaches to prevention, diagnosis and support for Fetal Alcohol Spectrum Disorder (FASD). The AMA's formal policy on FASD is outlined in the Position Statement *Fetal Alcohol Spectrum Disorder - 2016*. Due to the broad nature of the inquiry's Terms of Reference, the AMA's submission will provide a short covering letter to our existing Position Statement, which covers the areas of prevalence, prevention, diagnosis and treatment. The AMA's submission is relevant to Terms of Reference (a), (b), (d), (e), (i), (m) and (o).

AMA Policy on Fetal Alcohol Spectrum Disorder

The AMA's Position Statement *Fetal Alcohol Spectrum Disorder - 2016* makes a series of recommendations regarding the prevention, diagnosis and treatment of FASD, which remain pertinent for consideration by this Inquiry. The policy's key recommendations include:

- Measures to support health professionals to engage in conversations with their patients about alcohol consumption during pregnancy;
- Measures to increase health professionals' awareness of FASD diagnosis and management, including dissemination of the Australian Guide to the Diagnosis of FASD and information about specialist FASD diagnostic centres;
- A coordinated national approach to reducing FASD, including wider efforts to reduce the availability, affordability and accessibility of alcohol; and
- Collection of nationally consistent and representative FASD data.

In 2019, the AMA has updated its existing policy regarding the use of alcohol in pregnancy. The AMA Federal Council passed a motion in August 2019 "*That the AMA support NHMRC guidelines that clinicians should advise women who are pregnant or planning a pregnancy that the safest option is to avoid alcohol entirely, based on the information that prenatal alcohol exposure may harm the unborn child and that no safe level has been established for alcohol consumption in pregnancy*." This motion re-emphasises background information included in the 2016 Position

Statement that "*there is no safe level of alcohol consumption during pregnancy*". Medical practitioners fill a vital role in providing advice to women that are pregnant or planning a pregnancy about alcohol consumption. Medical practitioners must be appropriately supported to hold these conversations sensitively and productively, while maintaining the evidence-based advice that there is no safe level of alcohol consumption during pregnancy.

Relevant Issues for this Inquiry

The attached Position Statement provides the AMA's overarching policy and recommendations for FASD prevention, diagnosis and treatment. There are several issues that the AMA would like to specifically highlight to the committee given the current policy environment regarding FASD.

Funding for the collection and analysis of nationally representative data on FASD prevalence is vital for appropriate management and support as well as targeted prevention. The current lack of national prevalence data is highlighted in the AMA's Position Statement, in the 2012 Senate Inquiry report "FASD: The Hidden Harm", and in the National FASD Strategic Action Plan 2018-2028. This lack of broadscale data makes it very difficult to anticipate funding needs, areas for improvement and to measure the effectiveness of policy approaches. While "reducing the prevalence of FASD" is an admirable goal for the National FASD Strategic Action Plan, measuring progress will be difficult without a robust baseline estimate of prevalence. Despite progress in some areas of FASD policy since the 2012 inquiry, the AMA believes that data collection on national FASD prevalence is a pivotal area which has been largely overlooked.

A national prevalence estimate is also needed to dispel the idea that FASD is only a problem for Indigenous Australians. Much of the existing research on FASD prevalence in Australia is focussed on Indigenous populations. It is true that some Indigenous communities face a high burden of FASD and that this necessitates targeted, culturally safe responses. However, the lack of population-wide data perpetuates a narrative that FASD is not a problem in the non-Indigenous population, and may contribute to tolerant attitudes to alcohol consumption during pregnancy among the wider population[1]. Population-wide prevalence estimates are needed to develop appropriate and relevant responses regarding alcohol consumption during pregnancy.

The AMA welcomes recent progress made on the 2012 Inquiry's recommendation to mandate pregnancy warning labels on alcoholic beverages, although noting that seven years after this recommendation, the label is not yet operational. In order to prevent FASD, it is vital that clear health messages are conveyed to people who may be unaware of the consequences of drinking alcohol while pregnant. The AMA believes that warning labels must be located front-of-pack in order to adequately highlight the message that "any amount of alcohol can harm your baby".

Finally, FASD in Australia must not be separated from the wider issue of alcohol-related harm; including the social acceptability, and even expectation, of regular and heavy alcohol consumption. The AMA continues to be dismayed by the significant delay in the finalisation of the National Alcohol Strategy (NAS), the last version of which expired in 2011. A comprehensive NAS is urgently needed to address alcohol-related harm in Australia. The NAS should outline measures to reduce the availability, affordability and accessibility of alcohol; including education

[1] O'Keeffe et al. 2015. 'Prevalence and predictors of alcohol use during pregnancy: findings from international multicentre cohort studies'. *BMJ Open* 5(7): e006323.

and awareness campaigns on alcohol-related harms, increased treatment and prevention services including Indigenous-specific services, statutory regulation of alcohol marketing, and a review of alcohol taxation and pricing. Policy to address FASD prevention and treatment should not exist in isolation from these wider measures.

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Fetal Alcohol Spectrum Disorder (FASD)
2016

The AMA acknowledges that FASD occurs in Australia and recommends:

1. Measures to improve clinician awareness of alcohol harms to the fetus and increase the likelihood of health professionals engaging in conversations with their patients about alcohol consumption during pregnancy and providing advice consistent with the NHMRC *Australian Guidelines to Reduce Health Risks from Drinking Alcohol.*

2. Dissemination to, and use by, health professionals of the recently published *Australian Guide to the Diagnosis of FASD.* This should be complemented by efforts to increase awareness about specialist FASD diagnostic centres and services in Australia.

3. Ongoing education and training for clinicians to increase knowledge about populations at risk of FASD and increase early FASD diagnosis and management.

4. Investment to improve access to, and affordability of, specialist FASD diagnostic and treatment services and ensure that management is evidence-based.

5. Acknowledgement that culturally appropriate diagnostic and treatment approaches are required for at-risk populations.

6. Inclusion of FASD to the Australian Government Department of Social Services' List of Recognised Disabilities. This should be complemented by efforts to increase awareness and understanding of FASD among National Disability Insurance Scheme (NDIS) assessors to improve access to NDIS.

7. Implementation of strategies that identify and support people with FAS

8. D who come into contact with the education, criminal justice and child protection systems.

9. A coordinated national approach to reducing FASD, that is consistent with the broader campaign for combatting problem drinking in Australia, including efforts to reduce availability, affordability and accessibility of alcohol.

10. Mandatory, informative, front-of-pack warning labels on all alcohol products to inform the public about the harms of alcohol use in pregnancy and discourage pregnant women from drinking alcohol.

11. Funding to allow for the collection of nationally consistent and representative FASD data.

12. Government commitment to ongoing funding and support for the outcomes of the Commonwealth Action Plan, including: the National FASD Hub, National FASD Technical Network, National FASD Clinical Network, and National FASD Register; Implementation and Evaluation of the *Australian Guide to the Diagnosis of FASD*, and treatment services for alcohol misuse in pregnancy.

Background

Fetal alcohol spectrum disorder (FASD) is a diagnostic term used to describe the permanent, severe neurodevelopmental impairments that may occur as a result of maternal drinking during pregnancy. Globally, it is estimated that alcohol is the leading cause of preventable birth defects and intellectual disability[i], however, failure to identify children at risk or to consider a diagnosis of FASD means that many individuals with the disorder are not identified and do not receive appropriate support and early intervention. FASD is associated with a range of birth defects and the average life expectancy for a child with FASD is only 34 years of age.[ii] FASD is extremely costly to our health, education and justice systems, yet is potentially preventable.

There is emerging evidence that alcohol use around the time of conception and during pregnancy can also have epigenetic effects that may be transmitted to future generations.[iii]

Few data on FASD prevalence are available for Australia, however alcohol consumption statistics and epidemiological data on FASD prevalence from comparable countries suggest that FASD prevalence is higher than previously thought in Australia.[iv] Given the significant personal and community impacts of FASD, targeted and ongoing attention is warranted to alleviate its impact.

Australian and international guidelines advise that there is no safe level of alcohol consumption during pregnancy.[v] Alcohol crosses the placenta and the fetal liver cannot effectively metabolise it, meaning the fetus is vulnerable to any level of exposure at any stage of pregnancy.

Prevalence

FASD is an issue that is not confined to a particular community or demographic; it is a disorder that crosses socio-economic, racial and education boundaries. Few accurate data on the prevalence of FASD in Australia is available but it is estimated that FASD affects roughly between 2% and 5% of the population in the United States.[vi]

The prevalence may be as high as 12% in some high-risk Indigenous communities.[vii] It is important that culturally and linguistically appropriate diagnosis services are made available in communities with a high prevalence of FASD.

Whilst the high prevalence of FASD in some communities warrants targeted intervention, it is important to consider FASD in the context of a broader societal problem, and not one that only affects particular parts of the community.

Prevention

Because no safe level of maternal alcohol consumption has been established, current Australian guidelines recommend that women abstain from alcohol consumption when planning, and throughout, their pregnancy. Despite this it has been estimated that at least 38% of Australian women continue to drink while pregnant.[viii] The percentage of women drinking during pregnancy falls to about 7% after the first trimester[ix], indicating that many women cease consuming alcohol upon finding out that they are pregnant.

The reasons that women continue to drink alcohol when pregnant are likely to be varied and complex. Identified risk factors include: having a tolerant attitude towards alcohol consumption during pregnancy, if their partner continues to drink throughout the pregnancy, and stressful living circumstances.[x] In a minority of cases it may be due to an underlying mental illness or addiction.

Recognising that half of all Australian women will experience an unplanned pregnancy[xi], it is important that messages regarding the harms of fetal alcohol exposure are emphasised in broader non-judgmental public health campaigns.

Research has shown that women will tend to avoid preventive health messages that they perceive as too alarmist or extreme.[xii] Balancing this with the need to provide consistent and unambiguous information about the risks of even minimal fetal alcohol exposure is challenging, and highlights a need for further research to establish the most appropriate prevention strategies. Once identified, these messages should be included in the alcohol-related education that occurs within school-based health and sexual education curricula.

Pre-pregnancy counselling presents an invaluable opportunity for physicians to discuss alcohol consumption with parents as part of a broader discussion around pre-pregnancy health. Physicians consulting their patients in the lead up to a pregnancy should be ensuring that both parents are physically healthy, and this should include discussions around nutrition, vaccination, mental health and alcohol consumption. Women with existing mental illness or addiction problems require increased support to reduce the risk of alcohol-related harm to the fetus.[xiii] Women at risk should be identified as early as possible and

information must be provided to GPs about the appropriate local referral pathways to specialised treatment and support services.

Diagnosis

A FASD diagnosis can be made at any time from infancy to adulthood, although it may be more difficult to establish neurodevelopmental impairments in infants and antenatal alcohol exposure in older patients.

Due to the perceived stigma about diagnosing FASD, there can be a reluctance by health professionals to engage in conversations regarding the possibility of fetal alcohol exposure. This commonly leads to a misdiagnoses including: Attention Deficit Hyperactivity Disorder, Autism Spectrum Disorder, or other behavioural or learning problems.[xiv] Antenatal consultations provide an opportunity to screen for fetal alcohol exposure, but to be effective, these conversations must be conducted with due sensitivity.

A diagnosis of FASD requires confirmation of antenatal alcohol exposure, and severe impairment of central nervous system function in several domains. Ideally, diagnostic assessments are carried out by specialist multi-disciplinary teams. As a means of bridging the gap between the availability and demand for these specialist assessment teams, alternative avenues of consultation should be explored including Child Development Units, developmental and general paediatricians. Initiatives including the use of technology-based consultations through which a patient in a remote area could be assessed by a specialist team through a secure videoconference connection should also be considered.[xv]

As part of the Commonwealth FASD Action Plan[xvi], the *Australian Guide to the diagnosis of FASD*[xvii] has been developed to educate clinicians, to standardise and streamline FASD diagnoses, and ensure that the Australian diagnostic framework is consistent with comparable countries. All doctors who consult with children and adolescents should be aware of this tool and be comfortable in making a referral for a diagnostic assessment of FASD. An e-learning package is available to complement the Guide.

Treatment/Support

International studies have identified a range of psychosocial and pharmacological treatment strategies to manage FASD, although few are evidence-based. Effective interventions included family, educational and parental support, increased social-skills education for FASD children, and prescription medications to help manage the attention deficit issues associated with FASD.[xviii]

Early intervention and support following timely diagnosis improves psychosocial and behavioural outcomes for those affected by FASD. At present, though, many people with FASD are not identified until relatively late in life, or not at all.[xix]

Newly diagnosed adult FASD patients may benefit greatly from increased support to assist them with financial management, employability, interpersonal relationships or legal situations as a result of their neurocognitive disability.[xx]

FASD is currently not recognised as a disability in Australia[xxi], and this restricts access to traditional disability support mechanisms. Although the National Disability Insurance Scheme does not require a specific diagnosis to receive funding for services, this lack of disability recognition drastically reduces the availability of cohesive and comprehensive support services for people with FASD.

Canadian research has found that people with FASD are approximately 19 times more likely to be arrested than their peers[xxii], significantly increasing the costs of both the adult and juvenile custodial systems.[xxiii] The impact of FASD on the criminal justice system is multifaceted in that it increases the likelihood of a person coming into contact with the system, and subsequently impairs their ability to navigate it effectively.[xxiv] Given this problem, an important aspect of early intervention is to provide skills that reduce the likelihood that an individual with FASD will come into contact with the criminal justice system.

Most children who enter the criminal justice system have previously been recognised by child protection authorities.[xxv] These families should be assessed for signs of FASD and, where appropriate, afforded the necessary treatment.

This position statement was developed by the AMA's FASD Working Group. The Working Group would like to acknowledge the contribution of Prof Elizabeth Elliott AM.

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