

# Submission to the Australian Senate Inquiry into: Effective Approaches to Prevention, Diagnosis and Support for Foetal Alcohol Spectrum Disorder.

The <u>Alcohol Policy Coalition</u> (APC) is a collaboration of health and allied agencies that share concerns about the harmful impacts of the alcohol industry and its products in Victoria. The Alcohol Policy Coalition campaigns for regulation of the alcohol industry to protect the community from the harm it causes, and to provide balance to the industry's aggressive marketing and normalisation of alcoholic products.

The members of the Alcohol Policy Coalition are:

Australasian College of Emergency Medicine Royal Australasian College of Surgeons

Alcohol and Drug Foundation St Vincent's Health Australia

Cancer Council Victoria The Salvation Army

Centre for Alcohol Policy Research (CAPR), Turning Point

La Trobe University

Foundation for Alcohol Research and Education

Victorian Alcohol and Drug Association

Violence Prevention Group, School of

Jewish Community Council of Victoria Psychology, Deakin University

Public Health Association of Australia (Victoria) Uniting Church in Australia, Synod of Victoria

and Tasmania

### **Background**

Foetal alcohol spectrum disorder (FASD) is a serious health and social problem, which adversely impacts individuals, families, and communities worldwide. FASD is caused by alcohol consumption during pregnancy—no known amount of alcohol is safe for a growing foetus. Although early intervention can improve outcomes for individuals with FASD, the associated cognitive, behavioural, and physical impairments can have devastating implications for the individual, family, and the community.

Although maternal alcohol consumption during pregnancy is the direct cause of FASD, many underlying causes exist for consuming alcohol during planning of a pregnancy, during pregnancy or breastfeeding. These are: having little information about the risks of consuming alcohol while planning a pregnancy, while pregnant or breastfeeding, consuming alcohol before pregnancy is recognised, untreated mental health illness and social and cultural pressures to consume alcohol.

In 2012, the Australian House of Representatives Standing Committee on Social and Policy and Legal Affairs (2012 FASD Inquiry) noted in its report that although awareness of FASD is increasing in Australia, much work needs to be done in relation to the diagnosis, prevention and treatment of FASD. In 2019, improvement still needs to be made in these areas and more effective responses are needed to address the adverse relationship between maternal alcohol consumption and FASD.

APC welcomes the opportunity to make a submission into the Australian Senate Inquiry into Effective Approaches to Prevention, Diagnosis and Support for Foetal Alcohol Spectrum Disorder (Senate Inquiry). APC has responded to the terms of reference: (a), (b), (c), (f), (j), (m), (n) and (o).

## APC responses to terms of reference

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

APC is aware that there has been a lack of public information regarding alcohol consumption and FASD. APC highlights the importance of improving community awareness around the risk of consuming alcohol during planning pregnancy and during pregnancy and breastfeeding and the relationship between alcohol consumption and FASD. In support of this, the 2012 FASD Inquiry stated that, "FASD cannot be managed adequately without awareness of the risks of alcohol consumption during pregnancy and understanding among teachers, parents and carers, judicial officers, police and youth workers." 1

Data in a recent survey indicates a low level of community awareness of the risks of alcohol consumption during pregnancy. For example, FARE's *Annual alcohol poll 2018: Attitudes and behaviours* found that 78 per cent of Australian women surveyed who drank alcohol before becoming pregnant reported that they stopped consuming alcohol while pregnant, indicating that nearly one in four of these women continued to drink while pregnant.<sup>2</sup> The data shows that while a large percentage of women stopped consuming alcohol while pregnant, there is still a large section of the Australian community (1 in four) who continue to consume alcohol and are unaware of the dangers of consuming alcohol while pregnant.

APC is also aware that at a clinical level, there is an alarming lack of community awareness of the risks of alcohol consumption during pregnancy. Studies by leading researchers in Australia, including paediatrician and CRE Director Professor Elizabeth Elliott, found that 60 per cent of women drink at any time in pregnancy and 40 per cent are unaware that alcohol could harm the foetus. <sup>3</sup>

<sup>&</sup>lt;sup>1</sup> House of Representatives Standing Committee on Social Policy and Legal Affairs, FASD: the Hidden Harm, Inquiry into the prevention, diagnosis and management of foetal alcohol spectrum disorders, November 2012.

<sup>&</sup>lt;sup>2</sup> Foundation for Alcohol Research and Education (2018). *Annual Alcohol Poll 2018: Attitudes and Behaviours*. Canberra: Foundation for Alcohol Research and Education. <a href="http://fare.org.au/wp-content/uploads/FARE-Annual-Alcohol-Poll-2018-web.pdf">http://fare.org.au/wp-content/uploads/FARE-Annual-Alcohol-Poll-2018-web.pdf</a>.

<sup>&</sup>lt;sup>3</sup> Media Release: pressure's on to tackle invisible epidemic affecting generations of Australians, 1 August 2019.

The APC is also concerned that since the 2012 FASD Inquiry, there has *never* been a national awareness campaign in relation to FASD which is one of the most effective ways to prevent FASD from occurring. <sup>4</sup>

Further, the results of a study, recently presented at a recent Australian conference, confirm there is low community awareness in relation to current pregnancy advisory labels in Australia, likely because they are not mandatory and due to the variation in labelling formats used. <sup>5</sup>

#### APC recommendation:

That an effective national awareness communication campaign be implemented with two aims:

- 1. to inform the Australian community about the risks of alcohol consumption when planning a pregnancy, during pregnancy or breastfeeding; and
- 2. to promote not consuming alcohol when pregnant, during breastfeeding or when planning a pregnancy consistent with the 2009 National Health and Medical Research Council (NHMRC) Australian Guidelines to reduce health risks from drinking alcohol (the Alcohol Guidelines).
- (b) The adequacy of health advice provided to women planning a pregnancy, pregnant. women and women who are breastfeeding about the risks of alcohol consumption; and
- (c) Barriers that may prevent women receiving accurate, timely and culturally/ethically appropriate information and advice on alcohol and pregnancy.

APC is aware through the findings in the 'Women Want to Know' evaluation report there are a range of barriers experienced by health professionals when raising alcohol consumption with consumers generally and this is also true for pregnant women.<sup>6</sup>

These barriers include: a lack of awareness by medical practitioners and midwives about the existence of the Alcohol Guidelines,<sup>8</sup> an assumption that pregnant women already know the adverse effects of consuming alcohol while pregnant and a lack of training on how to sensitively communicate the risks of consuming alcohol while pregnant to women.

APC supports the recommendations in the evaluation report which aim to address these barriers. These recommendations include: that funding is provided (from the outset) for the ongoing promotion and evaluation of resources developed for medical practitioners and midwives to continue an awareness of the need to communicate the risk of consuming alcohol during pregnancy.

APC acknowledges the work by Food Standards Australia and New Zealand (FSANZ) to implement mandatory pregnancy warning labels on all alcoholic beverages. It is noted that this initiative is currently progressing.

<sup>&</sup>lt;sup>4</sup> Media Release: pressure's on to tackle invisible epidemic affecting generations of Australians, 1 August 2019.

<sup>&</sup>lt;sup>5</sup> Bastable A , Myers G , Sapountsis N, Dana L, Pettigrew S, Atkins J, Pratt S, McAleese A. *Attitudes and awareness to alcohol labelling in* Australia Melbourne Convention and Exhibition Centre. Session 2C, 12 May 2019. Link to abstract <a href="https://6fe441aa-8f79-436f-a97d-7d1c079009f3.filesusr.com/ugd/a52314\_247935f69fb44088baeccd3a5c9b45dc.pdf">https://6fe441aa-8f79-436f-a97d-7d1c079009f3.filesusr.com/ugd/a52314\_247935f69fb44088baeccd3a5c9b45dc.pdf</a>

<sup>&</sup>lt;sup>6</sup> Hall & Partners Open Mind. (2016). Women Want to Know project evaluation. Canberra: Foundation for Alcohol Research and Education (FARE).

<sup>&</sup>lt;sup>7</sup> In2014, an educational resource was published by the National Drug and Alcohol Research Centre and UNSW Australia, entitled, (Supporting pregnant women who use alcohol or other drugs: a review of the evidence) for clinicians was published to help identify, treat and refer substance (including alcohol) dependent pregnant women who present in primary care settings, however, there is no evidence to suggest that this resource is used by alcohol and other drug services or whether best practice interventions have been developed in response.

<sup>&</sup>lt;sup>8</sup> This is also supported by the Australian Medical Association (AMA) which has emphasised the need for increased awareness of FASD both among clinicians and also the general community.

APC also supports the recommendation that more practising health professionals should be encouraged to participate in training courses on the Alcohol Guidelines to ensure that their advice is consistent with those guidelines.

The recommendations also include that messaging on the risks of alcohol consumption in women planning pregnancy, during breastfeeding or in pregnant women should not be limited to written materials but also communicated at key events such as conferences were exposure to health professionals would be maximised.<sup>9</sup> APC also supports the view that future efforts to increase awareness and understanding of the Alcohol Guidelines among health professionals should ideally be accompanied by a wider awareness raising campaign targeted at the public generally.

The APC recently made recommendations to the Food Standards Australia New Zealand P1050 Proposal 'Pregnancy warning labels on alcoholic beverages' consultation as to the most effective features of pregnancy warning labels on alcohol product. Our recommendations were for features that would maximise the impact of the labels and clearly communicate the message to consumers that no amount of alcohol is safe during planning pregnancy or during breastfeeding or pregnancy. The APC's view is that (based on research) pregnancy warning labels (pictogram and text) should:

- be positioned in a prominent location on the front of the bottle or package,
- be large in size and occupy a significant proportion of the label,
- use large, bold, legible text,
- use colour (for the pictogram and text) that increases noticeability of the label, and
- ensure a high level of contrast from the surrounding label and background packaging.

#### **APC** recommendation

1. The Australian Government should implement an awareness raising public campaign which also has the aim of increasing health professionals' awareness and understanding of the Alcohol Guidelines.

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

APC is aware of the following international resources that assist in the prevention and management of FASD:

# Publications/Guidelines

- World Health Organisation, Guidelines for the identification and management of substance use and substance use disorders in pregnancy (2014). These guidelines contain recommendations on the identification and management of substance use and substance use disorders for health care services which assist women who are pregnant, or have recently had a child, and who use alcohol or drugs or who have a substance use disorder. They have been developed in response to requests from organizations, institutions and individuals for technical guidance on the identification and management of alcohol and other substance use and substance use disorders in pregnant women, with the target of healthy outcomes for both pregnant and their foetus or infant;
- Lisa Scholin, The prevention of harm caused by alcohol exposure during pregnancy
   Copenhagen: WHO Regional Office for Europe, 2016;
   <a href="https://apps.who.int/iris/handle/10665/329491">https://apps.who.int/iris/handle/10665/329491</a> (2016), this report provides a literature

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<sup>&</sup>lt;sup>9</sup> Ibid.

review on interventions that prevent alcohol consumption that target both pregnant and non- pregnant women in the European Union and the European Region.

#### International Charter

• The Canadian International Charter on the prevention of FASD (https://www.thelancet.com/journals/langlo/article/PIIS2214-109X(13)70173-6/fulltext): In 2013, a conference was held in Edmonton, Canada which led to adoption of the international charter on the prevention of foetal alcohol spectrum disorder by more than 700 people from 35 countries worldwide, including senior government officials, scholars and policymakers, clinicians and other front-line service providers, parents, families, and indigenous people. It is presented to all concerned in the international community as a call for urgent action to prevent foetal alcohol spectrum disorder.

#### International networks

The Following international networks are also collaborating to address FASD:

 the International FASD prevention network; and
 the Canadian Northwest FASD Research network, which is a collaboration between researchers, clinicians, service providers and community members in Canada's north.

### International article

 Adebiyi, B.O., Mukumbang, F.C. & Beytell, A. A guideline for the prevention and management of Foetal Alcohol Spectrum Disorder in South Africa. BMC Health Serv Res 19, 809 (2019)-is an article which proposes developing a comprehensive and intersectoral policy to guide programmes and interventions for the prevention and management of FASD based on the WHO guidelines.

# (J) Outline the social and economic costs of FASD in Australia, including health, education, welfare and criminal justice.

The APC believes the following estimates of the economic cost of FASD, conducted in 2010 in Australia represent the best evidence available at the time of writing:

A 2010 cost-benefit analysis of FASD prevention activities conducted on behalf of Food Standards Australia New Zealand (as part of earlier work on alcohol pregnancy warning labels) found that international estimates of the prevalence of FASD (1 per cent of all pregnant women who deliver a child with FASD) translates to 2,599 children per year in Australia, and 581 children per year in New Zealand. Using conservative modelling, the economic costs were estimated as AU\$66 million in Australia and NZ\$16 million in New Zealand per annum.<sup>10</sup>

<sup>&</sup>lt;sup>10</sup> Health Technology Analysts Pty Ltd (2010). Foetal Alcohol Spectrum Disorder (FASD): Exploratory economic analysis of different prevention strategies in Australia and New Zealand. Food Standards Australia New Zealand.

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

APC is concerned that a majority of the recommendations made in the 2012 FASD Inquiry remain unimplemented. Further, only 3 recommendations were implemented, which include: the implementation of a national plan on FASD, establishing a FASD Reference Group (now no longer existing) and the development of a FASD diagnostic tool and training manual.

An audit undertaken by FARE in on the implementation of 19 recommendations made in the FASD report found:

- 12 of the recommendations were not implemented at all;
- 4 of the recommendations were partially implemented; and
- Recommendations 1, 2 and 15 (3 in total) were the only recommendations implemented in the FASD report. <sup>11</sup>

The APC understands that some work has commenced in implementing several of the recommendations made in the 2012 FASD Inquiry. However, it encourages a commitment to addressing national challenges posed by alcohol consumption and FASD by fully implementing those recommendations that were either partially implemented or not implemented at all.

#### **APC Recommendation:**

- That the Australian Government take a proactive approach (in collaboration with key stakeholders) in implementing the remaining 12 recommendations in the 2012 FASD Inquiry and further progress the implementation of 4 recommendations which were partially implemented.
- (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 APC is aware that a national FASD Strategic Action Plan 2018-2028 (FASD Strategic Plan) was launched in November 2018 with allocated funding of only \$7 million and only \$1.47 million specifically targeted at FASD prevention initiatives.<sup>12</sup>

The APC believes that adequately funded targeted FASD prevention initiatives under the FSD Strategic Plan is critical in helping to address the adverse relationship between maternal alcohol consumption and FASD.

The APC suggests that a nationally co-ordinated approach among the states and territories should also be adopted when implementing the FASD Strategic Plan to ensure that its aims can be successfully achieved.

The APC also supports the development of a staged evaluation plan to assess whether the FASD Strategic Plan is successfully achieving its stated goals.

<sup>&</sup>lt;sup>11</sup> Email correspondence from FARE on 7 November 2019.

<sup>&</sup>lt;sup>12</sup> Media Release: Pressure's on to tackle invisible epidemic affecting generations of Australians, 1 August 2019.

## **APC** recommendation:

- The Australian Government should provide adequate funding to effectively implement policy aims in the FASD Strategic Plan that include targeted FASD prevention initiatives and ensure that a nationally co-ordinated approach is taken in implementing its policy goals; and
- The FASD Strategic Plan should be evaluated to measure whether its stated goals have been successfully achieved.

# (o) the need for improved perinatal data collection and statistical reporting of FASD and maternal drinking.

APC notes that the 2012 FASD Inquiry observed that there was a lack of FASD data in Australia. Specifically, that "Australia is lagging behind when it comes to standardised FASD diagnostic criteria and prevalence data." <sup>13</sup> APC also notes that in 2012 the FASD Reference Group recommended that consistent data on maternal alcohol consumption should be recorded. <sup>14</sup>

APC highlights the importance of collecting and maintaining nationally consistent data in respect of:1 rates of maternal alcohol consumption which will allow public health researchers to draw accurate conclusions about the relationship between maternal alcohol consumption and the health impacts; and 2. FASD diagnostic criteria and prevalence data.

The collection and evaluation of nationally consistent data can also be used to inform tailored prevention policy and program initiatives in relation to FASD at the national and at the state and territory level.

## **APC Recommendation:**

• That nationally consistent data should be collected in relation to the rates of maternal alcohol consumption, FASD diagnostic criteria and FASD prevalence data.

# **Conclusions**

The APC is concerned about the fact that 'Australia has among the highest rates of prenatal alcohol exposure in the world,' <sup>15</sup> despite the existence of Alcohol Guidelines which advise women that the safest option is to not consume alcohol when planning a pregnancy, during pregnancy and when breastfeeding.

APC believes that improved community awareness in the form of a national campaign around the risks of consuming alcohol when planning a pregnancy or when pregnant and the existence of the Alcohol Guidelines is critical in helping to prevent FASD.

Supporting the capacity of health professionals to provide accurate information to women consistent with the Alcohol Guidelines is important in addressing the adverse relationship between maternal consumption of alcohol and the prevalence of FASD.

<sup>&</sup>lt;sup>13</sup> House of Representatives Standing Committee on Social Policy and Legal Affairs, FASD: *The Hidden harm: Inquiry into the prevention, diagnosis and management of foetal alcohol spectrum disorders* (2012).

<sup>14</sup> Ibid.

<sup>&</sup>lt;sup>15</sup> n 12.

The APC believes that data on the prevalence of FASD diagnoses and the rates of maternal consumption of alcohol in Australia is important in informing a harm minimisation approach in relation to alcohol and FASD.

APC strongly supports a FASD Strategic Plan that is well resourced especially in relation to targeted FASD prevention initiatives and one that is co-ordinated at a national level. APC believes that the FASD Strategic Plan should be supported by a staged evaluation so that progress in the implementation of its goals can be effectively monitored.

APC also supports and encourages a continuing commitment to implementing the remaining recommendations in the 2012 FASD Inquiry (and those recommendations that have only been partially implemented) so that *real* progress can be made to prevent the adverse relationship between maternal alcohol consumption and FASD.

If you have any queries in relation to this submission please contact Liesl Oliver-Burger, Legal Policy Officer, Cancer Council Victoria