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**RACP Submission to the Australian  
Senate's Inquiry into Effective approaches  
to prevention, diagnosis and support for  
Fetal Alcohol Spectrum Disorder**

**December 2019**

## **About the Royal Australasian College of Physicians (RACP)**

The RACP trains, educates and advocates on behalf of over 17,000 physicians and 8,000 trainee physicians, across Australia and New Zealand. The College represents a broad range of medical specialties including general medicine, paediatrics and child health, neurology, addiction medicine, public health medicine, cardiology, respiratory medicine, oncology, occupational and environmental medicine, palliative medicine, sexual health medicine, rehabilitation medicine and geriatric medicine. Beyond its drive for medical excellence, the RACP is committed to developing health and social policies which bring vital improvements to the wellbeing of patients.

## Introduction

The Royal Australasian College of Physicians provided a [submission](#) to the House Standing Committee on Social Policy and Legal Affairs' Inquiry into Fetal Alcohol Spectrum Disorders (FASD) in 2011. We regret to say that after eight years of government inaction on this leading cause of mental, psychological and physical developmental disabilities, little progress has been made in the national approach on this matter.

## Comments

Without restating the points the RACP and other health and social policy bodies have consistently made about the urgent need to tackle FASD over the last decade, the RACP feels it is imperative to emphasise the following key facts about the matter:

### **The findings of the previous inquiry have been largely ignored.**

The Foundation of Alcohol Research and Education (FARE) has reviewed the recommendations delivered by the House of Representatives Standing Committee on Social Policy and Legal Affairs, tabled on 29 November 2012. FARE found that out of the 19 recommendations made by the inquiry, 3 have been implemented, 4 have been partially implemented and 12 have not been implemented at all.<sup>1</sup> We are now involved in another inquiry that, while needed, could have been avoided by actioning the recommendations that were made to the Parliament nearly a decade ago.

The evidence of the harm caused by alcohol in pregnancy is clear.<sup>2</sup> The estimates of the children and adults affected by FASD around the world are both scarce and variable, largely a result of varying patterns in maternal drinking behaviour and public awareness of harm as well as differences in the diagnostic criteria and assessment techniques, methods of surveillance and varying demographics of the studied populations.<sup>3</sup>

Australia lacks national standardised data collection and monitoring of alcohol consumption across pregnancy and of the diagnosis and recording of people with FASD; as such national prevalence data have not been established to date. However, State- and Territory-based studies have reported birth prevalence rates of FAS – the least prevalent but most severe form of FASD - of between 0.01 and 0.68 per 1000 live births.<sup>4</sup> Between two and five percent of births are estimated to be affected by FASD in America.<sup>5</sup> Inferring from existing evidence, over the last decade a considerable number of babies and families have been harmed because of government inaction on FASD.

### **The alcohol industry does not belong in the health policy making space.**

The alcohol industry has no role in policy making regarding alcohol consumption, taxation and harm prevention in Australia. It has a substantial conflict of interest and cannot be expected to act in any interest other than its own. While alcohol is a legal commodity in this country and numerous adults consume alcohol in a responsible manner, alcohol has been identified as the greatest substance-related contributor to our ill health, congenital malformation, mental illness and distress, as well as a cause of significant costs to the social and human services and criminal justice systems.<sup>6</sup>

The RACP appreciates the recent release of the National Alcohol Strategy 2019-26 which states that “the alcohol manufacturing industry, wider retail and hospitality industries, advertising, broadcasting and sporting industries play a significant role in Australia’s economy and social fabric. (...) These industries, which benefit from revenue through alcohol sales, have a responsibility in supporting and taking appropriate action to

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1 FARE Submission into the Senate Inquiry into FASD 2019

2 McLean S, McDougall S. Fetal Alcohol Spectrum Disorders: Current issues in awareness, prevention and intervention. Australian Institute of Family Studies. 2014

3 Popova S, Lange S, Burd L, Rehm J. Burden and Social Cost of Fetal Alcohol Spectrum Disorders. Oxford Books Online. Sep 2016

4 Burns L, Breen, C, Bower C et al. Counting fetal alcohol spectrum disorder in Australia: the evidence and the challenges. Drug Alcohol Rev. Sept 2013

5 <https://ama.com.au/position-statement/fetal-alcohol-spectrum-disorder-fasd-2016>

6 Bonomo, Y, Norman A et al. The Australian drug harms ranking study. J Psychopharmacol. Jul 2019

prevent and minimise alcohol-related harms through the lawful, responsible supply of alcohol and their ability to influence drinking behaviours.”

Regrettably, it is unlikely that the industry will influence drinking behaviours in a positive manner, unless mandated, regulated, overseen and, if necessary, sanctioned by our governments to do so. The Australian Government has the decisive role in minimising the harms of alcohol to everyone, including women and their children. The publication of another report or strategy such as the well-intentioned but underfunded National FASD Strategic Action Plan 2018-2028 will not solve the issue of fetal exposure to alcohol unless the Australian Government and other governments fully commit to doing so, including by tackling the alcohol industry’s influence over our political system and wider society.

*The College recommends that the Australian Government ensure the alcohol industry is not involved in the development and implementation of health policies, including policies in relation to alcohol-related harm.*

### **Evidence-based interventions remain underutilised and under-researched while children, families and society experience harm.**

Successive Australian governments have a record of underperformance at trialling and implementing effective measures to reduce alcohol-related harm. For instance, it has taken over 23 years since the first application for effective and mandatory alcohol pregnancy labelling in Australia for the issue to become subject to government regulation. This demonstrates that our governments have been deficient in their role as regulator and protector of our health and wellbeing.<sup>7</sup>

The cost associated with FASD, as calculated in Canada where the research on the spectrum is most advanced amongst the OECD countries, has been assessed at \$1.8 billion a year, most of it resulting from the productivity losses due to morbidity and premature mortality.<sup>8</sup> The cost of human potential in our own communities is likely to be similar and remains ongoing, as the generation of women born in the mid-nineties has continued to be exposed to misleading messages about the use of alcohol during pregnancy propagated by the alcohol industry with little oversight from regulators. While warning labels are not sufficient on their own to reduce alcohol consumption in pregnancy, they must be a key component in any national alcohol strategy and the current labelling does not accurately reflect the evidence for best practice warnings.<sup>9</sup>

The pattern, amount or critical period of prenatal alcohol exposure that is safe i.e. resulting in no structural and/or functional teratogenesis is not yet quantified, therefore women must be advised clearly and uniformly that it is in the best interest of themselves and their unborn babies not to drink. The industry, once again, must have no role in deciding what such warnings look like and how they are displayed. A range of other prevention strategies are essential to support labelling. These include active campaigns to reduce alcohol consumption across the whole population, including wider use of effective strategies such as minimum unit pricing and banning of advertising.

As with most issues related to FASD, there exist major evidence gaps related to the most effective and cost-effective measures to diagnose and manage the condition. *The RACP recommends that improved and standardised surveillance and data collection as well as a concerted and increased investment in evidence-based prevention measures become the top priorities for the Australian Government in tackling the condition.*

### **Treatment services must be better funded to deal with the crisis of alcohol and other drugs misuse.**

While it is in the best interest of society, families and babies that levels of prenatal alcohol exposure in the population are minimised, and while the most recent statistics from the National Drug Strategy Household Survey 2016 indicate that the rate of women abstaining while pregnant increased by 16 percent between 2007 and 2016, 44 percent of pregnant women still use alcohol.<sup>10</sup> While the exact causal patterns of alcohol-related teratogenesis are complex and remain the subject of research, it is clear that the amount and frequency of consumption are a major factor in the level of fetal toxicity and subsequent child impairment.

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7 <http://drinktank.org.au/2019/11/pregnancy-warning-labelling-our-best-opportunity-to-get-the-labels-correct/>

8 Popova S, Lange S, Burd L, Rehm J. Burden and Social Cost of Fetal Alcohol Spectrum Disorders. Oxford Books Online: Sep 2016

9 <http://fare.org.au/wp-content/uploads/FARE-Labelling-Market-Testing-Report.pdf>

10 National Drug Strategy Household Survey 2016 <https://www.aihw.gov.au/getmedia/15db8c15-7062-4cde-bfa4-3c2079f30af3/21028a.pdf.aspx?inline=true>

As such, it is extremely important not just to educate women about the dangers of drinking while pregnant, but to allow them easy, affordable, non-stigmatising access to medical services before, during and after pregnancy. Access to such services would greatly reduce the harm caused by in-utero exposure to alcohol to alcohol-dependant women's babies, subsequent affected children and their entire families. Importantly, this approach must include a routine screening of pregnant women for alcohol use in primary care. Such screening, when performed in a timely, non-judgmental, culturally sensitive manner is likely to result in a reduction of alcohol use and alcohol-related harm to mother and baby.

Unfortunately, access to alcohol treatment services remains limited. The RACP, St Vincent's Australia and a number of other health policy bodies have estimated that the alcohol and other drug treatment system would need another billion dollars a year to be able to address the needs of people in need of treatment, a large percentage of whom would be women of child-bearing age.<sup>11</sup> The fact that the National FASD Strategic Action Plan so far committed \$7 million to dealing with this issue across the education, clinician awareness and treatment spectrums speaks to the inadequacy of governmental efforts in this space.

While educating women about the dangers of drinking while pregnant is a key aspect of FASD prevention, effective harm minimisation and treatment for women who are pregnant and drink, so that they desist or reduce the intake of alcohol, are equally important to the overall reduction of harm caused to babies, women and their families.

*The RACP recommends that the Government substantially increase its funding for alcohol and other drugs treatment services.*

### **Diagnosis and treatment of FASD and other neurodevelopmental conditions are similarly underfunded.**

Timely diagnosis of FASD or other neurodevelopmental conditions is of extreme importance because delays in diagnosis and provision of appropriate health and educational interventions increase the risk of adverse secondary outcomes. It is crucial to note that these developmental vulnerabilities are often multifactorial in origin, with the more proximal causal factors including lack of food security, undernutrition and chronic anaemia (both in utero and in early childhood); early childhood trauma; chronic and recurrent infections of the ears, chest, skin and gut; exposure to family domestic violence and community violence (both in utero and in early childhood); lack of financial security; social and economic deprivation; family breakdown with loss of attachment relationships; exposure to alcohol and other drugs in utero; and early childhood exposure to the family and community effects of alcohol and other drugs.

These more proximal factors ultimately stem from generations of trauma, poverty, and marginalisation. A comprehensive developmental assessment and neurodevelopmental diagnosis in this context should seek to accurately represent these multiple contributory factors.

One of the many barriers to better diagnosis of FASD and other neurodevelopmental conditions is the limited number of specially trained health professionals and specialist diagnostic clinics for FASD. The Australian assessment and diagnostic guidelines for FASD developed by Professors Bower and Elliot recommend the use of multidisciplinary teams of specially trained professionals who also take responsibility for training other health professionals<sup>12</sup>. Service models can be then adapted depending on the circumstances, for example by supplementing assessment services with telemedicine in rural and remote communities. Services should be underpinned by standardised, nationally agreed diagnostic criteria for FASD and appropriate protocols for assessment.

As with other clinical and social issues facing people with FASD and other neurodevelopmental conditions, the current funding and availability of diagnostic and treatment services, including wraparound medical, educational and social care, are unsatisfactory. *The RACP recommends that all children in Australia have access to a multidisciplinary development service with capacity for the diagnosis of a broad range of neurodevelopmental conditions, including, but not focussed primarily on FASD. Timely identification of and intervention in developmental difficulties must be prioritised.*

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11 <https://www.svha.org.au/newsroom/media/boost-needed-to-meet-demand-for-alcohol-and-other-drug>

12 Bower C, Elliott EJ 2016, on behalf of the Steering Group. Report to the Australian Government Department of Health: Australian Guide to the diagnosis of Fetal Alcohol Spectrum Disorder (FASD)

## **Anyone can be affected by FASD but vulnerable subpopulations do need additional support.**

As already noted, reliable prevalence data for FASD in Australia are limited, with the Australian Medical Association extrapolating from Northern American data and a few small local studies to estimate FASD to be present at about 2 to 5 percent of births<sup>13</sup>, with noted disparities between states and territories and various populations. Any pregnant woman who consumes alcohol at harmful levels is at risk of giving birth to a child with FASD. FASD is an issue that transcends social, racial and economic boundaries.

It is also important to shift some of the focus in the clinical and cultural conversations about FASD away from women to men, whose drinking patterns often contribute to similar behaviour amongst their partners. Recent Australian research indicated that 75 percent of women who drank alcohol while pregnant drank with their partners at home.<sup>14</sup> Men's alcohol consumption has also been shown to have negative epigenetic effects on the developing fetus.<sup>15</sup>

While research from the Growing up in New Zealand Study identified varying patterns of alcohol use by pregnant women of different demographic and ethnic backgrounds, it also established that this is not just a problem affecting poorer or Indigenous women.<sup>16</sup> Erroneously painted as chiefly an Indigenous or low socio-economic level issue, FASD is overall more prevalent amongst women who are alcohol dependent, women with a child with FASD who continue to drink into their subsequent pregnancies and in some segments of high-risk Aboriginal and Torres Strait Islander communities.

While fewer Aboriginal women than non-Aboriginal women drink alcohol in general, some studies have found high rates of FASD in certain Indigenous communities. Indigenous women who do drink tend to drink at higher risk levels in comparison to non-Indigenous women (11.6% compared with 9.5%).<sup>17</sup> This is likely to be connected to the experience of colonisation, leading to high levels of disadvantage and intergenerational trauma that have persisted in some communities, as well as to the poor access to prevention and treatment services in many regional and remote areas, where large sections of these populations often live.

Of special importance in this context is the unacceptably high prevalence of FASD-affected youth incarcerated in the juvenile penal system that imposes draconian penalties on so affected youngsters, often targeting children under the age of 14. A recent study in Western Australia found that in Banksia Hill youth detention facility, 89 percent of inmates had at least one form of severe brain impairment and 36 percent had a diagnosis of FASD.<sup>18</sup> FASD is also overrepresented in out-of-home care, where the special needs of children with the disorder are often ignored for lack of awareness, screening protocols and appropriate resourcing for early intervention and symptom management.<sup>19</sup>

All these populations were identified as priority groups in the National FASD Strategic Action Plan 2018-28 that set out a strategic framework for prevention, screening and support and management of FASD-affected individuals in Australia. As in other areas of research related to FASD, evaluations of progress in these populations remain limited and funding and personnel shortages have been reported by physicians and paediatricians working with underserved populations with FASD.<sup>20</sup>

FASD tends to have life-long consequences which are of a varying nature and severity. Adults with FASD typically have more physical and mental health needs that persist over their lifetime and experience more socioeconomic disadvantage, social problems and discrimination. Adolescents and adults with FASD and their families need to be supported through wraparound health and social services that address their specific health and wellbeing needs, increasing the extent to which adults with FASD can live supported lives that provide

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13 <https://ama.com.au/position-statement/fetal-alcohol-spectrum-disorder-fasd-2016>

14 FASD Hub (2018) Assessing maternal alcohol use. <https://www.fasdhub.org.au/fasd-information/assessment-and-diagnosis-for-health-professionals/assessing-maternal-alcohol-use/>

15 Finegersh A, Rompala GR et al. Drinking beyond a lifetime: New and emerging insights into paternal alcohol exposure on subsequent generations. Alcohol Aug 2015

16 <https://www.nzma.org.nz/journal/read-the-journal/all-issues/2010-2019/2018/vol-131-no-147927-july-2018/7642>

17 Burns L, Breen, C, Bower C et al. Counting fetal alcohol spectrum disorder in Australia: the evidence and the challenges. Drug Alcohol Rev Sept 2013

18 Bower C, Watkins RE, et al. Fetal alcohol spectrum disorder and youth justice: a prevalence study among young people sentenced to detention in Western Australia. BMJ Open 2018

19 [https://www.racp.edu.au/docs/default-source/advocacy-library/racp-submission-to-the-victorian-department-of-health-and-human-services-consultation-into-looking-after-children-s-health-in-out-of-home-care.pdf?sfvrsn=cf3fe21a\\_4](https://www.racp.edu.au/docs/default-source/advocacy-library/racp-submission-to-the-victorian-department-of-health-and-human-services-consultation-into-looking-after-children-s-health-in-out-of-home-care.pdf?sfvrsn=cf3fe21a_4)

20 <https://www.abc.net.au/news/2018-09-13/fetal-alcohol-spectrum-disorder-obstacles-to-ndis-funding/10218842>

them with an appropriate level of independence and giving their families the aid and respite they often need.<sup>21</sup> According to a recent systematic study, very little is also known about the experiences and expectations of supportive interventions for individuals with FASD and their families.<sup>22</sup>

*The RACP recommends that the Partnership Agreement on Closing the Gap between a coalition of Peak Aboriginal and Torres Strait Islander organisations – also known as the Coalition of Peaks – and the COAG be used as a mechanism to progress the work on FASD in Indigenous communities.*

*The RACP further recommends that all developmental assessment and therapy services whose clients include a high proportion of Aboriginal and Torres Strait Islander families be able to demonstrate appropriate training in and implementation of principles of cultural safety, trauma-informed practice, and appropriate use of interpreter services.*

*We also recommend that all health promotion activities aiming to improve the developmental outcomes of Aboriginal and Torres Strait Islander children accurately represent the multifactorial origins of developmental vulnerabilities in these populations.*

*Future research into FASD should include investigations into the progress of the National Strategic Action Plan in respect to the priority populations; into the requirements and experiences of supportive services for children, adolescents and adults; as well as into the perspectives of people who live with FASD.*

### **NDIS must recognise FASD as a neurodevelopmental disability.**

Currently the National Disability Insurance Scheme only recognises Fetal Alcohol Spectrum under 'Congenital conditions - cases where malformations cannot be corrected by surgery or other treatment and result in permanent impairment.' Several submissions have been made to the National Disability Insurance Agency with respect to recognising FASD as a neurodevelopmental disability.

*In light of the constrained fiscal environment for treatment of FASD and other neurodevelopmental disabilities and the critical need for early diagnosis and intensive intervention for patients with these conditions, the RACP strongly supports this recommendation.*

However, specifically identifying FASD as a basis for funding support could create an unjust situation where two individuals with identical impairments would receive different levels of support on the basis of one having had a history of prenatal exposure to alcohol, and the other not. Explicitly linking funding to the diagnosis of FASD would also likely exacerbate the existing risk of over-diagnosis.<sup>23</sup>

*Accordingly, the RACP recommends that all disability funding across Australian governmental agencies be accessible based on the level of functional impairment rather than the cause of that impairment.*

### **FASD is a whole-of-society issue and must be addressed as such.**

The most significant and cost-effective interventions to address FASD will be made at a population level. In addition to the remarks made above, the RACP, per its [Alcohol Policy](#), recommends that the Government immediately:

- Introduce a volumetric taxation system for all alcohol products and abolish the Wine Equalisation Tax (WET) and rebate.
- Allocate a proportion of the increased revenue raised from volumetric taxation to funding alcohol and other drug treatment and prevention services as part of a coordinated national response to alcohol and other drug use disorders. Some of that funding must be committed specifically to FASD-related research, prevention and treatment; the funding should be

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21 Wolfson L, Poole N, Ninomiya M et al. Collaborative Action on Fetal Alcohol Spectrum Disorder Prevention. *Int J Environ Res Public Health*. May 2019

22 Domeij H, Fahlström G, Bertilsson G et al. Experiences of living with fetal alcohol spectrum disorders: a systematic review and synthesis of qualitative data. *Dev Med Child Neurol*. Aug 2018

23 Price KJ & Miskelly KJ. Why Ask Why? Logical Fallacies in the Diagnosis of Fetal Alcohol Spectrum Disorder. *Ethics Behav*. 2015

commensurable to the high cost FASD is likely to have to our children, society and community.

- Increase research and prevention efforts in relation to social determinants of drinking with a special focus on and collaboration with specific communities and populations. Focal points of such initiatives should be the social and health burdens of FASD on youth and young adults who live with FASD, women dependent on alcohol, affected Aboriginal and Torres Strait Islander communities as well as people in rural and remote settings.
- Substantially increase funding for alcohol and other drug treatment services, including for appropriate and multidisciplinary workforce development, capital works to improve the physical infrastructure and the development of appropriate needs-based planning models and suitable models of care to address unmet demand for treatment.
- Increase funding for prevention services to reduce the incidence of alcohol and other drug use disorders across the population.

FASD is a harmful and persisting health and social issue. The RACP asks that the Australian Government act now to prevent future harm related to this condition and remedy the damage that has already been done to our children and communities because of this problem. We do not have time to wait or resources to expend in waiting for another inquiry. The health of our future generations depends on action.