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Submission to the House of Representatives Standing Committee on Social Policy and Legal Affairs: Inquiry into Fetal Alcohol Spectrum Disorders

Public Health Association
AUSTRALIA

fare
Foundation for Alcohol
Research & Education

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ABOUT THE FOUNDATION FOR ALCOHOL RESEARCH AND EDUCATION

The Foundation for Alcohol Research and Education (FARE) is an independent charitable organisation working to prevent the harmful use of alcohol in Australia. Our mission is to help Australia change the way it drinks by:

- helping communities to prevent and reduce alcohol-related harms;
- building the case for alcohol policy reform; and
- engaging Australians in conversations about our drinking culture.

Over the last ten years FARE has invested more than $115 million, helped 750 organisations and funded over 1,400 projects addressing the harms caused by alcohol misuse. FARE is guided by the *World Health Organisation's Global Strategy to Reduce the Harmful Use of Alcohol*[1] for addressing alcohol-related harms through population-based strategies, problem-directed policies, and direct interventions.

For more information visit: www.fare.org.au

ABOUT THE PUBLIC HEALTH ASSOCIATION OF AUSTRALIA

In Australia, the Public Health Association of Australia Inc (PHAA) provides a forum for the exchange of ideas, knowledge and information on public health. The Association is also involved in advocacy for public health policy, development, research and training.

PHAA has Branches in every state and territory. Membership of around 1500 individuals spans the health spectrum and over 40 public health related occupations are represented. PHAA has thirteen Special Interest Groups for members to meet with those who have similar interests and passions, to exchange information and to develop policy positions and papers.

For more information visit: www.phaa.net.au

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FARE'S ROLE IN FUNDING PROJECTS AND RESEARCH ON FETAL ALCOHOL SPECTRUM DISORDERS

Since 2001, FARE has invested over $2 million into the prevention and treatment of Fetal Alcohol Spectrum Disorders (FASD) in Australia. This wide body of work has included supporting the professional development of FASD researchers, commissioning research, raising awareness of FASD, and developing resources and programs for health professionals.

In 2011, FARE announced a $500,000 select tender to fund research and projects to address gaps in FASD work in Australia. This funding has been provided to seven projects which will develop tools to equip health professionals to diagnose and refer cases of FASD, and to educate women and the community about the harmful effects of drinking alcohol during pregnancy and breastfeeding.

Examples of these projects include:

- the Children's Hospital at Westmead, New South Wales, will develop Australia's first screening and diagnostic service for FASD;
- the National Drug and Alcohol Research Centre, New South Wales, will undertake research aimed at improving services for pregnant women dependent on alcohol, and another study to help improve services to families affected by FASD;
- the Telethon Institute for Child Health Research, Western Australia, will undertake an Australian-first study into how young people with FASD are treated by the criminal justice system; and research into the screening and diagnosis of children with FASD in state care; and
- the George Institute for Global Health will produce a feature documentary about the life of an Aboriginal child living with FASD; and an educational film about the broader issue of FASD.

This work complements the Government's study into assessing the prevalence of FASD and its impact on the health service needs of children and their families in Fitzroy Valley, Western Australia.

SUMMARY OF RECOMMENDATIONS

1. Strategies to address FASD should be implemented in conjunction with a range of other evidence-based measures, to reduce alcohol related harms.

2. Produce a National FASD Plan that specifies the Commonwealth, State and Territory Government's responsibilities in addressing FASD and includes actions, targets and outcomes.

Prevention strategies

Raising awareness of the National Health and Medical Research Council Australian Guidelines to Reduce Health Risks from Drinking Alcohol (NHMRC Guidelines)

3. Develop and fund an ongoing national public education campaign that promotes the NHMRC Guidelines, with a particular focus on guideline four on maternal alcohol consumption. The campaign should use a broad range of media and ensure that there are specific messages that target:

    - the general public;
    - women;
    - their partners; and
    - people in the community identified as being at risk.

4. The public education campaign should be appropriately resourced and developed by the Department of Health and Ageing (DoHA) and the Australian National Preventive Health Agency (ANPHA), with local organisations working to promote the campaign at the community level, including Medicare Locals.

Alcohol health warning labels

5. Introduce a mandatory health warning label regime for alcohol products sold in Australia, including a message about the risks of consuming alcohol while pregnant. The health warning labels should:

    - be mandatory so the label appears on all products;
    - be applied consistently across all products so they are visible and recognisable;
    - include a number of rotating messages focussing on different social and health harms;
    - be developed by health behaviour and public health experts;
    - be regulated and enforced by government; and
    - be accompanied by a national public education campaign.

Influencing cultural change about alcohol

6. Implement evidence-based policies that contribute to affecting broader cultural change about alcohol use and reduce harmful consumption, including:

    - a stepped approach to pricing alcohol based on its pure alcohol content and propensity to cause harm;
    - reducing the availability of alcohol;
    - regulating the promotion of alcohol; and
    - encouraging brief interventions to be routinely implemented by health professionals.

Intervention needs

Prevalence of FASD

7. Fund a large-scale FASD prevalence study in Australia and use this data to better inform programs, policy and service delivery for the prevention, intervention and management of FASD.

Screening for FASD

8. Raise awareness among health professionals of FASD and the risks of consuming alcohol during pregnancy by:

- embedding information about FASD and the NHMRC Guidelines into the curricula of health and medical university courses; and
- funding the establishment of continuing professional development modules for health professionals about the NHMRC Guidelines, and delivering messages consistent with the NHMRC Guidelines, including the maternal alcohol consumption guideline.

9. Develop programs for health professionals to routinely ask all women, including younger women about their alcohol consumption, along with other lifestyle questions.

10. Improve access to antenatal and maternity services for people in the community who are marginalised or geographically isolated.

Diagnosing FASD

11. Build on existing efforts to establish a national standardised diagnostic tool for FASD and ensure that training on its use is provided to a range of health professionals (including paediatricians, general practitioners, health workers, maternal and child health nurses, midwives, psychologists and psychiatrists).

12. Allocate funding, education and support to existing interdisciplinary health teams (such as in antenatal clinics and children's hospitals), to improve their ability to diagnose conditions within FASD.

13. Improve data collection on FASD and data linkage ability between various sectors by:

- encouraging health professionals to collect standardised data on FASD;
- providing secure processes that allow health information to be shared between relevant health professionals;
- developing a national data repository for information on FASD; and
- making anonymous population data publicly available through Australian health publications.

Management of FASD

Supporting people with FASD and their families and carers

14. Recognise FASD as a disability and modify eligibility criteria for disability services to support people with a FASD condition, their families and their carers.

15. Ensure that all people diagnosed with FASD are provided with a treatment and management plan, and recognise that a 'one size fits all' approach will not work for all people with FASD.

16. Allocate funding to support groups that assist people with FASD, their families and carers.

17. When developing management and care systems for people with FASD, their families and carers, ensure that equitable life-long services are provided and that transitions from child to adult services are pre-planned and coordinated to ensure that people do not “fall between the cracks”.

18. Develop processes to ensure that people who are considered to be at-risk of having FASD are screened when they come into contact with government services including the criminal justice system, foster care system, child safety system and child and family centres.

19. Examine sentencing options for people identified as having a FASD condition who come into contact with the criminal justice system, similar to options provided to other people who have cognitive functioning disabilities.

20. Fund further research into:

- education initiatives that support school staff to reduce the development of secondary disabilities among people with FASD;
- employment and training opportunities for people with FASD and ways that current systems can be enhanced to support people with FASD; and
- identifying and providing support to people with FASD who have come into contact with the criminal justice system.

Addressing the high prevalence of FASD among Aboriginal and Torres Strait Islander peoples

21. Develop culturally specific prevention, intervention and management strategies for Aboriginal and Torres Strait Islander peoples that are supported and managed by local communities. These strategies should be based on current good practice examples such as the *‘Marulu Strategy’* in Western Australia.

22. Provide resources to enable Aboriginal and Torres Strait Islander communities to develop community-driven solutions that address alcohol misuse. These should be comprehensive and include strategies to:

- prevent or minimise the harmful use of alcohol;
- provide safe acute care for those who are intoxicated;
- provide treatment for people who are dependent; and
- support people who are affected by FASD or whose harmful alcohol use has left them disabled or cognitively impaired.

INTRODUCTION

FARE welcomes the opportunity to prepare a submission to the *Inquiry into Fetal Alcohol Spectrum Disorders (FASD)*. This Inquiry provides an historic opportunity for governments to develop a long term strategy for the prevention of FASD, and to make a significant difference in the lives of people with FASD, their families and their carers.

FASD is the leading preventable cause of non-genetic, intellectual disability in Australia[2]. Like many other disabilities, people who are born with FASD have the condition for life, and the implications are far-reaching. For the person with FASD, their every-day life is affected as they struggle with relationships and encounter difficulties at school and work. For birth mothers and carers of people with FASD, there are life-long caring implications and ongoing financial commitments. In addition there is a range of social and emotional impacts associated with the stigma that comes with a FASD diagnosis.

Despite the severe and far-reaching consequences of FASD, it has not yet received enough attention from governments in Australia. When FASD specific programs have been developed, they have often been ad hoc and inconsistently applied across states and territories. At the Commonwealth Government level, there is currently no public education campaign about FASD or the risks of consuming alcohol while pregnant. There is also no formal diagnostic tool for FASD and there are very few targeted support options for people with FASD and their carers.

The insufficient allocation of funding and resources for addressing FASD in Australia has resulted in a low awareness of the potential harms of consuming alcohol while pregnant among the general population and health professionals. There is also no clear indication of the prevalence of FASD in Australia. Recent research estimates that the prevalence of Fetal Alcohol Syndrome (FAS), one of the conditions within the spectrum, to be between 0.06 and 0.68 per 1,000 live births[3]; however, experts believe this to be a significant underestimate.

While there is no cure for FASD, there are strategies that can be implemented to prevent FASD, and to lessen the impact of the condition on people with FASD. This can occur if governments demonstrate strong leadership in the prevention, early intervention, and management of FASD. The impact of strong government leadership on improving health and social outcomes for people with a disability can be demonstrated through Australia's experience with Autism Spectrum Disorders. Changes in diagnostic practices, referral patterns, availability of services, age at diagnosis and greater public awareness of autism has led to dramatically increased prevalence rates since the 1990s[4] .

A 2007 report by the Australian Advisory Board on Autism Spectrum Disorders recognised the following four areas that needed concerted effort nationally:

- access to timely and affordable diagnosis with a wait time of no longer than three months for diagnosis and assessment by multidisciplinary teams;
- early intervention services to allow for better outcomes for children;
- specific educational services to assist children to transition to mainstream schools; and
- improved data collection to help future research into causes, diagnostic pathways, effective interventions and outcomes[5].

As with Autism Spectrum Disorders, access to diagnosis, early intervention, specialised services and improved data collection of FASD are all areas which need further attention. However, FASD has not received the same attention, support or public recognition in Australia.

The response to FASD needs strong and ongoing Commonwealth Government leadership in order to address the serious health, social and economic impacts of FASD. This Inquiry presents an opportunity for the Government to develop a comprehensive long term plan for Australia that aims to support people with FASD and prevent future generations from being affected by these conditions.

Recommendation

1. Strategies to address FASD should be implemented in conjunction with a range of other evidence-based measures, to reduce alcohol related harms.

2. Produce a National FASD Action Plan that specifies the Commonwealth, State and Territory Government's responsibilities in addressing FASD and includes actions, targets and outcomes.

Structure of this submission

This submission includes a brief background on FASD, and addresses each of the Terms of Reference of the Inquiry: prevention strategies, intervention needs and management issues for FASD. The last section focuses on the higher prevalence rates of FASD among Aboriginal and Torres Strait Islander peoples.

BACKGROUND

Definition of Fetal Alcohol Spectrum Disorder

FASD is a non-diagnostic umbrella term for the range of disabilities that result from prenatal alcohol exposure[6]. The conditions that fall within FASD include[7]:

- Fetal Alcohol Syndrome (FAS): The most clinically recognisable manifestation of FASD, FAS is characterised by facial anomalies, growth deficits and neuro-behavioural problems;
- Partial Fetal Alcohol Syndrome (pFAS): Individuals with pFAS have most but not all the features of FAS;
- Alcohol-Related Neurodevelopmental Disorder (ARND): Individuals with ARND may present with many alcohol-related brain and behavioural abnormalities; however, they may not display any of the characteristic facial anomalies required for a FAS diagnosis; and
- Alcohol-Related Birth Defects (ARBD): Individuals with ARBD exhibit congenital birth defects related to confirmed prenatal alcohol exposure, although there may not be any neurological abnormalities.

The primary disabilities associated with FASD are directly linked to underlying brain damage. These include difficulty in planning and following through on goals, poor memory, difficulties with abstract concepts, impaired language and communication skills, poor impulse control, and mental, social and emotional delays[8]. This can lead to short-term memory lapses, where the person will quickly forget information or instructions. Behaviours exhibited by people with FASD are often symptoms of underlying brain dysfunction, and are not made through rational decision making or choice.

When primary disabilities are insufficiently understood and managed, secondary disabilities can occur. Secondary disabilities include mental health issues, alcohol and drug problems, trouble with the law, disrupted school experience and inappropriate sexual behaviours. Additionally, individuals with FASD tend to have difficulties coping with day-to-day living, such as managing money and sustaining regular employment. As a result, the majority of adults with FASD may not be able to live independently[9].

For people living with FASD, much of their outward behaviour may appear to others as delinquent and/or antisocial[10]. This often results in judgments being made about the nature of the person as well as criticism of their parents or carers.

A number of protective factors have been identified in successfully reducing and preventing secondary disabilities, including:

- early diagnosis;
- eligibility for disability services, support services and allowances;
- living in stable home with nurturing parents/carers with minimal changes in household structure; and
- protection from violence including witnessing or being a victim of violence[9].

These factors should be acknowledged in the development of policies to assist people with FASD manage their condition.

Alcohol exposure, maternal alcohol consumption and FASD

The disabilities that result from FASD are related to the amount of alcohol consumed during pregnancy, frequency of alcohol consumption, and timing of exposure (stage of pregnancy). For example, exposure to alcohol in early pregnancy may lead to structural brain abnormalities and other birth defects, while exposure later in pregnancy may result in defects in growth and neurological development[11].

The risk of FASD is highest if alcohol is consumed frequently, and at high levels during the first trimester of pregnancy. However, alcohol exposure at any time of the pregnancy (including before the pregnancy is confirmed) can have negative consequences for fetal brain development[12]. The evidence regarding a 'safe' threshold of alcohol consumption is unclear[12]. As a result of this, the NHMRC has recommended that for women who are 'pregnant or planning pregnancy not drinking is the safest option'.

There are a range of factors that can influence alcohol consumption during pregnancy. These include being unaware of the pregnancy, having a dependence on alcohol and/or being unaware of the consequences of alcohol exposure to the fetus[13]. A partner's drinking is also a factor in maternal alcohol consumption. Seventy-five percent of children with FASD have biological fathers who are heavy drinkers and often have extended families with heavy alcohol consumption[14]. Other risk factors that influence and perpetuate alcohol consumption during pregnancy include concurrent drug use, physical and sexual violence, fewer economic resources and opportunities[14].

An Australian study confirmed that women experiencing significant disadvantage were also those most likely to be using substances, including alcohol[15]. As a result, FASD is overrepresented among people experiencing disadvantage, with factors such as lower socioeconomic status, malnutrition, higher age of mother, loss of traditional culture and level of education all contributing to higher rates of FASD[2].

The stigma experienced by mothers caring for a child with FASD continues after pregnancy. Women often feel shame, embarrassment, guilt, grief, anger, regret and fear of being judged by others[13]. These feelings can limit women from seeking assistance and/or fully disclosing levels of alcohol consumption during pregnancy to health professionals[6]. Alcohol consumption cannot be seen in isolation as the only cause of FASD, and governments' approach to preventing FASD should be holistic in addressing culture, health, psychosocial and economic factors[16].

These factors, along with the limited options to access treatment, can hinder a woman's ability to reduce or stop her alcohol consumption during pregnancy. FASD, therefore, should not just be viewed as an issue of individual responsibility, but within a social determinants framework that acknowledges the broader factors in people's lives that contribute to their awareness of health harms, access to services and support options.

PREVENTION STRATEGIES

The prevention of FASD requires considerable investment by government. Prevention activities need to be targeted at a range of specific audiences, and should promote evidence-based messages about the harms associated with alcohol consumption during pregnancy. Prevention activities need to target the broader population to raise awareness of the potential risks associated with alcohol consumption during pregnancy. There should also be a focus on specific groups within the population that require tailored messages; including women of child-bearing ages and their partners.

Despite 30 years of research demonstrating that alcohol consumption during pregnancy can harm the fetus, there has been no concerted and comprehensive effort by the Commonwealth Government to raise awareness of these potential harms. This is reflected in the low awareness of the NHMRC Guidelines among the general population, with a 2011 FARE survey finding that only 12 percent of Australian adults were familiar with the content of the NHMRC Guidelines[17].

Alcohol product warning labels and a national public education campaign are required to raise awareness of the harms of alcohol use during pregnancy. In addition to the promotion of messages regarding alcohol consumption during pregnancy, there is also a need to address alcohol consumption among the broader population. This is because other people's alcohol consumption is also a factor in the prevalence of FASD.

This section examines the need to raise awareness of the NHMRC Guidelines, implement alcohol product warning labels and develop broader policies to affect change in Australia's drinking culture.

Raising awareness of the NHMRC Australian Guidelines to Reduce Health Risks from Drinking Alcohol (NHMRC Guidelines)

The 2009 NHRMC Guidelines contain four evidence-based guidelines to reduce the health risks from drinking alcohol[12]. Guideline four focuses on maternal alcohol consumption and states that 'Maternal alcohol consumption can harm the developing fetus or breastfeeding baby' and 'for women who are pregnant or planning a pregnancy, not drinking is the safest option'[18].

Despite the revised NHMRC Guidelines being in place for almost three years, people's awareness of these Guidelines is low. A recent Government-funded evaluation of the promotion of the NHMRC Guidelines, carried out by Horizon Research, reported a low level of awareness of the NHMRC Guidelines, with messages considered 'unrealistic and confusing'[19].

The low level of awareness of the NHMRC Guidelines is also reflected in the proportion of women who consume alcohol during pregnancy. The *2010 National Drug Strategy Household Survey* found that 51.1 per cent of Australian women continued to consume alcohol while pregnant, with 2.5 per cent of women reporting that they consumed either the same or more alcohol than they did before they were pregnant[20],[21].

Internationally, public education campaigns have been shown to increase awareness of FASD and the risks of consuming alcohol during pregnancy. In Canada, public education campaigns about FASD have been in place since 1999. An example of this is the 'Born Free' campaign developed by Alberta Children Services, which was carried out from 1999-2000. The campaign involved disseminating information at the point of sale, as well as the promotion of key messages through television, radio and print media[22]. The evaluation of 'Born Free' found that there was a statistically significant increase in public recall of the message 'When you are pregnant, NO alcohol is best'. The effectiveness of the Canadian efforts to raise awareness of FASD and the harms associated with consuming alcohol while pregnant is reflected in their prenatal alcohol consumption rates, which are less than 15 per cent[23].

In Australia, the Commonwealth Department of Health and Ageing (DoHA) is responsible for promoting the NHRMC Guidelines. While the Commonwealth Government has developed printed materials about the NHMRC Guidelines, there has not been a concerted effort to develop a comprehensive population-wide public education campaign. This is reflected in the recent Horizon Research evaluation of the promotion of the NHMRC Guidelines which stated that: 'the guidelines will not engage the community nor influence attitudes towards the consumption of alcohol merely by virtue of their existence or being the official recommendations' and 'a `low key' approach is unlikely to have a significant impact'[24].

A national, comprehensive and ongoing public education campaign about the NHMRC Guidelines is required to raise awareness among the general community about the potential harms associated with consuming alcohol while pregnant. The campaign should include targeted messages that are specifically tailored to women, and groups of people within the community that are identified as having a higher prevalence of FASD, including Aboriginal and Torres Strait Islander peoples[16]. The messages should be easy to understand and be based on the current evidence-base regarding alcohol use during pregnancy.

DoHA and the Australian National Preventive Health Agency (ANPHA) have a role to play on raising awareness of the risks about consuming alcohol while pregnant. ANPHA was established in January 2011 and one of its key roles is to "lead a national approach to social marketing for prevention and health promotion programs"[25]. While this should not abrogate responsibility from DoHA to promote the NHMRC Guidelines, ANPHA could provide support in this role by consulting with relevant stakeholders, including consumer and carer groups, on message development for a nation-wide prevention campaign.

At a community level, Medicare Locals have a role to play in reinforcing campaign messages and could also contribute to the communication of targeted messages for specific communities or regions. Because of their strong connection with primary care providers, Medicare Locals are an ideal vehicle to promote educational campaigns about alcohol consumption during pregnancy and FASD.

Recommendations

3. Develop and fund an ongoing national public education campaign that promotes the NHMRC Guidelines, with a particular focus on guideline four on maternal alcohol consumption. The campaign should use a broad range of media and ensure that there are specific messages that target:

    - the general public;
    - women;
    - their partners; and
    - people in the community identified as being at risk.

4. The public education campaign should be appropriately resourced and developed by the Department of Health and Ageing (DoHA) and the Australian National Preventive Health Agency (ANPHA), with local organisations working to promote the campaign at the community level, including Medicare Locals.

Alcohol health warning labels

Applying health warning labels to alcohol products is a low-cost awareness raising strategy which targets communication to the drinker at the vital points of sale and consumption. Internationally, at least eighteen countries or territories have introduced laws requiring the compulsory use of health warning labels on alcohol products. These countries include France, South Africa, Brazil, Costa Rica, Ecuador, Honduras, Mexico, South Korea and the United States of America[26,27,28].

Internationally, pregnancy warning labels on alcohol products have demonstrated the capacity to raise awareness as well as modify behaviours. In America, all alcohol products contain the message 'According to the Surgeon General, women should not drink alcoholic beverages during pregnancy because of the risk of birth defects'. The message is not applied consistently across all products and has remained unchanged since 1989[29]. Nonetheless, the message has been shown to be effective in communicating the harms of prenatal alcohol exposure, as well as initiating discussions of the issue among pregnant women. Message exposure has also resulted in decreased alcohol consumption in pregnant women who were normally light drinkers[30].

In France, pregnancy warning labels have also been shown to affect social norms about drinking during pregnancy. In 2007 a warning label was introduced consisting of either a silhouette of a pregnant woman drinking, or the message 'Drinking alcoholic beverages during pregnancy even in small quantities can have grave/serious consequences for the health of the baby'. Similar to the American experience, the label is applied inconsistently and often takes up only a small portion of the label. Despite this, viewing the label was associated with a decrease in the social acceptability of drinking during pregnancy[26].

Further evidence of the effectiveness of health warning labels can be derived from the tobacco warning label experience. Tobacco warning labels are mandatorily applied to all tobacco products in Australia with specifications on the size, application and location of the label on the product. Evaluations of Australian tobacco warning labels have shown that 45 per cent of smokers believed that even the plain text labels helped them to quit smoking[31]. This demonstrates that with proper development and implementation, warning messages can also change behaviour.

In December 2011, the Australia New Zealand Ministerial Council on Food Regulation (Ministerial Council) made a decision to support a mandated pregnancy warning label on alcohol products within two years, and to further examine 'the efficacy of generic alcohol warnings'[32]. Before mandating for a pregnancy warning label, the Government made a decision to allow the alcohol industry two years to implement their voluntary DrinkWise developed labels. These labels consist of a choice between a text warning 'It is safest not to drink while pregnant' or a silhouette of a woman drinking alcohol with a line through it[33].

The DrinkWise developed labels have been heavily criticised by public health organisations for a range of reasons. Firstly, the labels are not warnings, as they do not describe the potential harms that can result from alcohol misuse, nor do they provide information on how to avoid these harms. The labels are also ambiguous, contain weak message, are small in size and are difficult to locate on the alcohol product. Furthermore because they are being applied voluntarily, there is no certainty that all alcohol producers will adopt these labels.

The Ministerial Council's decision to allow the alcohol industry to apply these labels voluntarily for two years before moving to regulate is of significant concern because the industry may then argue against the implementation of a more evidence-based label because they will have already changed their processes to adopt the DrinkWise label.

A voluntary approach to alcohol warning labels is grossly inadequate. If warning labels are to be effective, they need to be government regulated and enforced, with instruction on the wording of the message, the size of the warning, and the application of the label to products and other materials. Alcohol warning labels should be evidence-based and developed in consultation with health behaviour experts.

In August 2011, FARE released a position on alcohol product labelling which outlined the requirements for an effective warning label regime. These requirements include that the labels should[34]:

- be mandatory so the label appears on all products;
- be applied consistently across all products so they are visible and recognisable;
- be developed by health behaviour and public health experts;
- include the text 'HEALTH WARNING';
- involve rotating messages on a range of harms, including during pregnancy; and
- be accompanied by a national public education campaign.

FARE has also developed a model set of messages for alcohol health warning labels, which includes a pregnancy warning label and complies with the current evidence-base on effective health warning labels. A recent Galaxy Research poll asking people to compare the DrinkWise pregnancy label with the FARE pregnancy pictogram, found that the majority of respondents (around 85 per cent) perceived the FARE label to be superior on all assessed dimensions. This includes raising awareness of the harms, prompting conversations regarding the message, and reducing alcohol consumption in pregnant women[35].

Recommendations

5. Introduce a mandatory health warning label regime for alcohol products sold in Australia, including a message about the risks of consuming alcohol while pregnant. The health warning labels should:

    - be mandatory so the label appears on all products;
    - be applied consistently across all products so they are visible and recognisable;
    - include a number of rotating messages focussing on different social and health harms;
    - be developed by health behaviour and public health experts;
    - be regulated and enforced by government; and
    - be accompanied by a national public education campaign.

Influencing cultural change about alcohol

Fundamental to the success of reducing the occurrence of prenatal alcohol exposure, is reducing the harmful consumption of alcohol in the general population. Alcohol is a major cause of preventable death, illness, injury and hospitalisation, which costs the Australian economy $36 billion annually[36]. There is a causal relationship between alcohol and 60 types of disease and injury, including road fatalities, stroke, coronary heart disease, high blood pressure, some cancers and pancreatitis[1]. Alcohol accounts for 3.2 per cent of the total burden of disease and injury, 3,340 deaths annually and a loss of 83,435 disability adjusted life years[37].

A comprehensive and complementary set of policy changes relating to alcohol consumption among the general population is essential, not only in reducing harmful alcohol consumption in the general population, but also in promoting positive cultural shifts around alcohol.

The most effective measures to reduce alcohol related harms are population-based strategies that seek to address the price, promotion and availability of alcohol. Studies have consistently found that these measures are the most cost-effective, and countless reviews including the Preventative Health Taskforce have recommended such measures[38,39]. Routine screening and brief interventions of individuals about their alcohol consumption have also been found to be both time and cost effective. Questions about alcohol consumption should be asked along with other lifestyle questions about diet, exercise and whether the person smokes or not. These answers can give a better understanding of a person's health and allow for education on the risks associated with alcohol to take place in a non-judgemental manner[40,41].

If preventing FASD is a priority for the Commonwealth Government, then broader cultural change around harmful alcohol consumption is needed. The best way to target this consumption practices is through proven and evidence-based measures that target the price, availability and promotion of alcohol. These measures should also be examined as part of this Inquiry.

Recommendations

6. Implement evidence-based policies that contribute to affecting broader cultural change about alcohol use and reduce harmful consumption, including:

    - a stepped approach to pricing alcohol based on its pure alcohol content and propensity to cause harm;
    - reducing the availability of alcohol;
    - regulating the promotion of alcohol; and
    - encouraging brief interventions to be routinely implemented by health professionals.

INTERVENTION NEEDS

While the prevalence of FASD in Australia is largely unknown, data suggest that prevalence rates for FAS (one of the conditions within the spectrum) are between 0.06 and 0.68 per 1,000 live births in the general population. Among Indigenous Australians, FAS is estimated to be 2.76 and 4.7 per 1,000 births[3].

The prevalence rates for FAS are believed to be significantly underestimated in Australia, due in part to the lack of routine screening of women about their alcohol use during pregnancy. Many health professionals are reluctant to take an alcohol history due to time pressures, discomfort, and fear of repercussions[10]. Adding to this is the social stigma associated with alcohol consumption during pregnancy and reluctance to report alcohol consumption is high due to embarrassment, guilt, and fear of being judged by others[13].

Furthermore, there are no national guidelines for the screening and diagnosis of FASD conditions. While some work is being done to develop a national diagnostic tool, further resources are required to ensure that when the tool is completed it is supported by health professionals and implemented consistently across the country. Training health professionals on how to use the diagnostic tool is of equal importance.

While the prevalence rate for FASD in Australia is largely unknown, international studies estimate FASD prevalence rates in populations among younger school children in America (with FAS prevalence between 0.5 to 2.0 per 1,000 live births) and Western European Countries to be as high as 2 to 5 per cent[42].

This section examines the prevalence of FASD in Australia, as well as screening practises and diagnosis of FASD.

Prevalence of FASD

There is a paucity of FASD prevalence information in Australia, making it difficult to know the extent to which it affects the population. The lack of prevalence data is due in-part to an absence of agreed clinical guidelines for FASD and a lack of understanding among the medical profession and the general population about the risks of consuming alcohol during pregnancy. Obtaining prevalence data is the vital to being able to better determine the extent of FASD in Australia and develop programs to support people with FASD.

Researchers have found one of the most successful ways to ascertain prevalence rates of FASD in a population has been through ‘active case ascertainment’ studies. These studies, predominantly carried out in America, have aimed to actively seek and recruit children who may have FASD within a given area[43]. For these studies, children and women are recruited from the entire community to ensure wide representation. This method has produced the most comprehensive assessment of FASD prevalence within the population. It has also allowed researchers to diagnose and help support individuals with FASD[43].

While the prevalence of FASD in Australia is largely unknown, there is some work underway by leading child and maternal health researchers to better understand the extent of FASD in Australia among specific populations.

Current FASD prevalence activities in Australia

Current activities to ascertain prevalence rates in Australia include:

- The *Liliwan Project*, based in the Fitzroy Valley in Western Australia, is the first study to undertake a comprehensive assessment of the extent of FASD in an Australian community. This study is part of a broader community strategy *'Marulu: Overcoming FASD and Early Life Trauma in the Fitzroy Valley,'* which was initiated by the community in response to the harms experienced due to alcohol misuse.

The first stage of the project (2009-11) includes the development and use of a medical history checklist to obtain information about antenatal exposure, early life trauma, and health and development from parents and carers of all children born in 2002 or 2003. The second stage involves multi-disciplinary assessment of the health and development of these children. The research includes a partnership of experts in local Aboriginal culture, Indigenous health, child health, research, epidemiology and human rights[44].

- In 2011, FARE contributed $150,000 to fund a study to determine the prevalence of FASD within a cohort of children from birth to 12 years of age living in the Perth metropolitan area. This study will screen the population for developmental delays and learning difficulties and coordinate further assessment and therapeutic and educational interventions.

Recommendations

7. Fund a large-scale FASD prevalence study in Australia and use this data to better inform programs, policy and service delivery for the prevention, intervention and management of FASD.

Screening for FASD

Australian women consider health professionals to be the best source of information regarding their alcohol consumption during pregnancy; however, many women do not ask about alcohol consumption during pregnancy as they expect that all important issues will be raised by the health professionals[45]. At the same time, health professionals often don't discuss alcohol consumption with pregnant women due to time pressures, discomfort, or fear of upsetting the woman.

Recent national polling by FARE found that fewer than half of the women surveyed who have been pregnant or breastfed recall having had a healthcare professional raise with them the harms associated with drinking alcohol (42 per cent)[17]. A 2005 study of health professionals in Western Australia corroborates these findings. The study asked the 659 health professionals who had cared for pregnant women whether they routinely asked about alcohol consumption during pregnancy. Only 45 per cent had routinely asked about alcohol use during pregnancy, 25 per cent routinely provided information on the consequences of alcohol use during pregnancy, and only 13 per cent provided advice consistent with NHMRC Guidelines on alcohol consumption in pregnancy[46].

Many health professionals are reluctant to take alcohol history as a routine part of antenatal care. This may be because they are concerned about upsetting the woman, and possibly stigmatising the child and their families[10]. Furthermore, some health professionals make the assumption that women know about the need to minimise alcohol consumption during pregnancy and therefore do not ask women about their alcohol intake[47].

Health professionals should routinely screen for alcohol consumption during pregnancy as pregnancy is often seen by women as an opportunity for change. With the baby's health in mind, many women are often willing to make changes to their diet and reduce their alcohol consumption if advised to do so[45]. Each time a health professional sees a mother there is potential to intervene to prevent FASD. For some women it is particularly important to ask about their alcohol consumption either before or during their pregnancy. This includes:

- women with a history of risky drinking and who have had unplanned pregnancies;
- women who have already had a child with FASD; and
- women who have had FASD themselves[48].

Screening for alcohol consumption should not only focus on the pregnant woman, but should also involve their partner[49]. This is because the consumption of alcohol by other people in the woman's life, especially those close to her, can also have a strong influence on her drinking patterns[50]. Family members, particularly partners, can play an important role in supporting women to stop drinking or to reduce their alcohol consumption during pregnancy. Partners who drink can foster an environment where alcohol use is tolerated and encouraged[14]. As a prediction of behaviour, research has showed that 30.5 per cent of women would stop or reduce their drinking if their partner also stopped drinking for the duration of the pregnancy, and 38 per cent would drink less if their partner encouraged them to stop or cut back[51].

All health professionals should have sound knowledge of NHMRC Guidelines and be able to discuss this information with women. Additionally, all women of childbearing age should be routinely asked about their alcohol consumption in relation to their general health as well as in prevention of FASD[45]. Non-judgemental approaches by health professionals, use of effective screening tools and routine questioning of alcohol consumption among all consumers is important in preventing alcohol use during pregnancy[45].

Current FASD screening activities in Australia

Current activities for screening and supporting women in Australia include:

- The National Drug and Alcohol Research Centre (NDARC) is coordinating a longitudinal birth cohort study (funded by NHMRC) of 1,800-2,000 Australian families, called the *'Triple B Study: Bumps, Babies and Beyond'*. This study aims to identify substance misuse patterns among women who are pregnant and their partners. It will examine the effects of this substance misuse on the development of the infant and family functioning. This research follows on from a FARE funded study ($15,000), which examined 100 women and their alcohol and other drug consumption during pregnancy.

- FARE has recently commissioned NDARC (funded to $50,000) to study the improvement in treatment practices for women who are alcohol dependent during pregnancy. This study will examine ethnographic and social research on attitudes to FASD, problems in identification, diagnosis, and other barriers in accessing services. The project will also develop a resource for clinicians to improve practices in the management of alcohol dependence in pregnancy.

Recommendations

8. Raise awareness among health professionals of FASD and the risks of consuming alcohol during pregnancy by:

    - embedding information about FASD and the NHMRC Guidelines into the curricula of

health and medical university courses; and
- funding the establishment of continuing professional development modules for health professionals about the NHMRC Guidelines, and delivering messages consistent with the NHMRC Guidelines, including the maternal alcohol consumption guideline.

9. Develop programs for health professionals to routinely ask all women, including younger women about their alcohol consumption, along with other lifestyle questions.

10. Improve access to antenatal and maternity services for people in the community who are marginalised or geographically isolated.

Diagnosing FASD

Australia does not have diagnostic guidelines for FASD, resulting in there being no consistent approach to the diagnosis of these conditions. FASD is often described as an 'invisible' disability, because people with FASD may not have any or all of the physical traits characterised by the condition[52]. Even if people don't display the distinct physical traits of FAS, they may experience brain damage from prenatal alcohol exposure that results in problems in behaviour; difficulty with speech and language; impairment of vision and hearing; and difficulty with judgment and reasoning[53].

Conditions within FASD can be difficult to diagnose. FAS, which is at the most extreme end of the spectrum, is commonly associated with abnormal facial features including small eye openings, a thin upper lip, a flat mid-face and absence or elongated groove between the upper lip and nose. These facial features are not always easy to assess, particularly in newborns, and across different racial groups. There is also no biomarker for FAS, meaning that it cannot be determined by blood-test or urine sample.

A 2005 study of 1,143 health professionals in WA found that only 12 per cent correctly identified all four essential features of FAS, 95 per cent had never diagnosed FAS and only 2 per cent considered themselves properly skilled to manage an individual with FAS[46]. This research included Aboriginal Health Workers, allied health professionals, community nurses, GPs and obstetricians. When a similar study was conducted on paediatricians (n=132), it found that only 18.9 per cent identified all essential diagnostic features for FAS, 76.5 per cent had suspected but not diagnosed FAS and 12.1 per cent had been convinced of it but not recorded the diagnosis[54].

Diagnosis at the lower end of the spectrum is even more difficult, and these conditions can often be misdiagnosed as Attention Deficit Hyperactivity Disorder or autism[55,10]. Additionally, there is a wide spectrum of behaviours that are defined with FASD and it is often necessary to wait until a child is older before neurological and cognitive impairments become apparent and a diagnosis can be made[56].

Final diagnosis of FASD often requires input from a range of specialists including doctors, psychologists, speech and language therapists and social workers. In America (Washington) a network of diagnostic clinics, made up of interdisciplinary teams, has existed since 1993[57]. These clinics have helped to raise awareness of FASD among health professionals and improve diagnosis, with 61 to 90 per cent of North American paediatricians being able to correctly identify the essential diagnostic features of FAS[54].

Early diagnosis of FASD conditions is vital to ensuring that people with FASD are provided with the best possible life outcomes. A national diagnostic tool for FASD is required and funding should be allocated to train health professionals working in multi-disciplinary teams to have the capacity to diagnose FASD. Some of this work is already underway in Australia, with the start of research into the establishment of a screening and diagnostic tool and multi-disciplinary teams working in Western Australia and NSW.

Current diagnosis activities for FASD in Australia

Current activities to develop diagnostic tools in Australia include:

- In 2010-11 DoHA commissioned a group of Australian FASD researchers to develop a Screening and Diagnostic Instrument for Australia. This collaborative group brought together clinicians, epidemiologists, policy makers, parents and carers, consumer advocates, researchers and public health personnel. A final report has been submitted to government, but the results have not yet been made public[58]. The collaboration is now seeking further funding to produce Australian guidelines on how to use the diagnostic instrument in a clinical setting. In addition to these guidelines health professionals will require a clinical checklist, and have the ability to take maternal history to support the diagnostic tool. The collaboration aims to publish information on what standardised data should be collected and how this should be submitted to a national depository.

- In 2010 the West Australian Government developed a Model of Care for FASD. Working groups have been established to develop an implementation plan for the Model[16].

- In 2011, FARE invested $108,000 to establish of the first FASD diagnostic service in Australia. Led by the Children's Hospital at Westmead, New South Wales, a key component of this project, will involve the testing and refining of a new diagnostic tool, and building consensus on nationally agreed clinical guidelines. As part of the evaluation for this project, the research team will estimate the costs of setting up and running a FASD assessment service to inform the development of screening and diagnostic services elsewhere in Australia.

Recommendations

11. Build on existing efforts to establish a national standardised diagnostic tool for FASD and ensure that training on its use is provided to a range of health professionals (including paediatricians, general practitioners, health workers, maternal and child health nurses, midwives, psychologists and psychiatrists).

12. Allocate funding, education and support to existing interdisciplinary health teams (such as in antenatal clinics and children's hospitals), to improve their ability to diagnose conditions within FASD.

13. Improve data collection on FASD and data linkage ability between various sectors by:

    - encouraging health professionals to collect standardised data on FASD;
    - providing secure processes that allow health information to be shared between relevant health professionals;
    - developing a national data repository for information on FASD; and
    - making anonymous population data publicly available through Australian health publications.

MANAGEMENT OF FASD

FASD is a lifelong condition, with significant impacts on individuals, their families and carers. People with FASD and their carers require extensive support over many years and often struggle to access assistance from social services, education and training, justice and health agencies.

However FASD is not recognised as a disability in Australia, which results in a lack of support options for people with FASD, their families and their carers. Government funded support services are often limited or non-existent. Consequently, people with FASD have difficulty acquiring an education, gaining and retaining employment and are often are overrepresented in the criminal justice system.

There is an urgent need to improve the management of FASD through more accurate diagnosis; better coordination of services, and adapting the societal systems such as the employment system to accommodate people with FASD throughout their life-span.

This section examines the support needed by individuals with FASD and their families, and carers and the changes that are required to the education, employment and criminal justice systems to better support people these people

Supporting people with FASD and their families

There is currently a lack of support options available from Australian governments for people with FASD, their families and carers[46]. People with FASD often experience difficulties in forming relationships, acquiring an education and gaining and maintaining employment. The families and carers of people with FASD often face considerable financial and emotional hardships.

Currently in Australia FASD is not recognised as a disability, and this precludes those with impaired mental functioning from receiving the help and support they require to manage their condition. One of the reasons for FASD not being classified as a disability is because recognition of mental disability status in Australia relies on IQ as a measurement. While FAS is associated with a lower IQ, 75 to 80 per cent of people with FASD have IQs within the normal range[59]. This precludes many people with FASD from accessing disability services and carers allowances.

The pressure on the families of people with FASD is immense and it is estimated that 85 per cent of children with FASD in Australia are in the care of grandparents and or other relatives/ foster parents or adoptive parents[52]. Primary carers often give up work to care for children with FASD and can spend a great deal of time navigating health, education and criminal justice systems in order to receive the correct level of care.

The impacts of FASD span throughout the lifespan. Adults with FASD have difficulties in maintaining employment, are believed to be overrepresented in the criminal justice system. They also often have alcohol, drug and mental health problems and difficulty raising children[10,59].

People with FASD and their carers require coordinated access to the differing parts of government systems including child welfare, education, mental health and the criminal justice sector. Particular attention is required on transition points, such as moving from child to adult services, so that people with FASD do not ‘fall through the cracks’ when trying to access appropriate services[10].

Current activities that support people with FASD, their families and carers in Australia

Current activities that support people with FASD, their families and their carers in Australia include:

- The *'Lililwan Project'* in the Fitzroy Valley of Western Australia, which includes a prevalence study, aims to give each child with FASD a personalised management plan involving their families, doctors and teachers. The project will also educate the communities about the risks of consuming alcohol during pregnancy and about the challenges faced by children with FASD and their families[60]. They are also developing a model of care called *'Circle of Community Care'* that aims to provide seamless assistance for the individual with FASD, as well as their families and carers[61].

- FARE provided $150,000 to the Telethon Institute for Child Health Research to examine the prevalence of FASD among a cohort of West Australian children up to twelve years of age who are placed in State care for one month or more. The results of the project will provide valuable data on the epidemiology of FASD and the healthcare needs of this population group. The project will take place in the Perth metropolitan region over a 12 month period, and involve inter-sectoral collaboration between health and welfare professionals and a model of care for children in State care. Screening upon entering State care will also improve the support for foster and kinship carers. The results of screening and assessment will be incorporated into a "Health Passport" which provides a document that children in State care can carry with them between care settings.

Recommendations

14. Recognise FASD as a disability and modify eligibility criteria for disability services to support people with FASD, their families and their carers.

15. Ensure that all people diagnosed with a FASD condition are provided with a treatment and management plan, and recognises that a 'one size fits all' approach will not work for all people with FASD.

16. Allocate funding to support groups that assist people with FASD, their families and carers.

17. When developing management and care systems for people with FASD, their families and carers, ensure that equitable life-long services are provided and that transitions from child to adult services are pre-planned and coordinated to ensure that people do not 'fall between the cracks'.

18. Develop processes to ensure that people who are considered to be at-risk of having FASD are screened when they come into contact with government services including the criminal justice system, foster care system, child safety system and child and family centres.

19. Examine sentencing options for people identified as having a FASD condition who come into contact with the criminal justice system, similar to options provided to other people who have cognitive functioning disabilities.

20. Fund further research into:

    - education initiatives that support school staff to reduce the development of secondary disabilities among people with FASD;

- employment and training opportunities for people with FASD and ways that current systems can be enhanced to support people with FASD; and
- identifying and providing support to people with FASD who have come into contact with the criminal justice system.

ADDRESSING THE HIGH PREVALENCE OF FASD AMONG ABORIGINAL AND TORRES STRAIT ISLANDER PEOPLES

Compared to non-Indigenous Australians, Aboriginal and Torres Strait Islander peoples face considerable disadvantage and greater ill health than the rest of the population. Indigenous Australians have poorer access to health care, are more likely to be hospitalised, to experience disability and to die at younger ages. Indigenous Australians also suffer a higher burden of emotional distress and mental illness than the wider community[62].

Among Aboriginal and Torres Strait Islander people, risky alcohol and other drug consumption is high, and the related harm is twice that compared to non-Indigenous Australians. These higher levels of harm are acknowledged to be both as a consequence of, and contribute to, the health and social gap between Indigenous and non-Indigenous Australians[63].

Aboriginal and Torres Strait Islander peoples are also disproportionately affected by FAS with an incidence of between 2.76 and 4.7 per 1,000 births compared to only 0.6 and 0.68 per 1,000 live births in the general population[3]. Anecdotal reports suggest that in certain communities where alcohol abuse is pervasive, the prevalence of FASD may be even higher. For instance, a director of a Queensland preschool and kindergarten reported to the House of Representatives Standing Committee on Aboriginal and Torres Strait Islander Affairs that around 80 per cent of the children at the school were showing symptoms of FASD[64].

Primary disabilities associated with FASD include poor memory, impaired language and poor communication skills. This has particular implications for the continued loss of Aboriginal and Torres Strait Islander culture, which is based on oral story telling. For people with FASD that have difficulty in remembering and retaining information, this is a particularly devastating consequence.

Approximately 26 per cent of Indigenous Australians live in remote or very remote areas of Australia, compared to 2 per cent of non-Indigenous Australians. These areas have acute shortages of health professionals and lack of accommodation to house locum health professionals[62]. In 2002 there were significant shortages of specialist clinicians in remote and very remote areas, with only 29 specialists per 100,000 people compared to 114 per 100,000 in major cities. Also 78 per cent of discrete Indigenous communities were located more than 50km from the nearest hospital, and 50 per cent were located more than 25km from the nearest community health centre[62].

Aboriginal and Torres Strait Islander peoples are disproportionally represented in the criminal justice system. The recent House of Representatives Standing Committee on Aboriginal and Torres Strait Islander Affairs concluded that the significant numbers of Indigenous people in detention or prison are there '...as a result of the failure of governments to identify FASD as an issue underpinning their offending behaviour. As a result, punitive rather than remedial responses have prevailed.[64]' The committee went on to recognise that as long as individuals with FASD are undetected and do not receive appropriate support, their chances of offending and re-offending are high[64].

Aboriginal and Torres Strait Islander peoples require culturally appropriate diagnostic and treatment services to assist them in detecting cases of FASD and in supporting people with the condition. The *'Marulu Strategy'* in the Fitzroy Valley of Western Australia may provide an example of community led approaches to care provision for individual with FASD, as well as their families and carers through their *'Collaborative Circle of Community Care'*[61].

Recommendations

21. Develop culturally specific prevention, intervention and management strategies for Aboriginal and Torres Strait Islander peoples that are supported and managed by local communities. These strategies should be based on current good practice examples such as the *'Marulu Strategy'* in Western Australia.

22. Provide resources to enable Aboriginal and Torres Strait Islander communities to develop community-driven solutions that address alcohol misuse. These should be comprehensive and include strategies to:

    - prevent or minimise the harmful use of alcohol;
    - provide safe acute care for those who are intoxicated;
    - provide treatment for people who are dependent; and
    - support people who are affected by FASD or whose harmful alcohol use has left them disabled or cognitively impaired.

CONCLUSION

This Inquiry presents an opportunity for the Commonwealth Government to demonstrate strong leadership in addressing FASD, through the development of a comprehensive plan that focuses on the prevention, intervention and management of FASD. Strategies to address FASD should be seen as part of an overall approach to reducing alcohol-related harms.

This submission demonstrates the breadth of work that still needs to be undertaken by governments in order to address the gaps in the prevention of FASD, research and service delivery. To ensure that the Commonwealth, state and territory Governments work collaboratively over the longer term to address these gaps, a comprehensive plan is required. The plan should demonstrate how government will support people with FASD, their families and carers. The strategy should also include actions and clearly defined targets.

The strategy should be informed by the *'Fetal Alcohol Spectrum Disorder in Australia'* Monograph, which was finalised in 2009 and updated in 2011 but is yet to be publically released by DoHA[65]. The Monograph contains evidence on the extent of alcohol use during pregnancy, FASD service availability and health professional knowledge and practice about FASD in Australia.

The Commonwealth Government now has an opportunity to lead action on the prevention of FASD in Australia. People with FASD also require immediate and appropriate services to manage their conditions and improve their quality of life. People with FASD, their families and their carers can no longer wait for governments to deliberate on the need to act. We urge this Inquiry to call for prompt and comprehensive action so that FASD is no longer the 'invisible disability'.

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