Foundation for Alcohol Research & Education

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Dear Dr Miller

SUBMISSION TO THE NATIONAL FASD STRATEGY 2018-2028

The Foundation for Alcohol Research and Education (FARE) welcomes the opportunity to make a submission to the development of the next *National Fetal Alcohol Spectrum Disorder (FASD) Strategy 2018-2028.*

FARE has been involved in advocacy and policy work on FASD for many years: this includes funding the first diagnostic clinic at Westmead Hospital in Sydney as well as publishing *The Australian FASD Action Plan 2013-2016* in 2012. The actions within this plan, as well as the recommendations made by FARE to the House of Representatives Parliamentary Inquiry into FASD in 2011-12, remain relevant.

I am pleased that the Australian Government is taking leadership to respond to FASD in Australia.

While admirable, the ambitions presented in the Discussion Paper released as part of the development of the next National FASD Strategy appear unclear on the strategic priorities, actions and targets. What FARE hopes to see is more clarity around the aspirations for the future, and a review of the effectiveness of the previous strategy.

The next National FASD Strategy has the potential to create a meaningful legacy and sustainable impact, and FARE appreciates the opportunity to make the following comments on the Discussion Paper.

This submission addresses each of the five areas within the Discussion Paper.

1. Purpose

The Discussion Paper notes that the strategy will be informed by evidence of what works.

As a first step, an in-depth assessment of the outcomes of the previous strategy should be undertaken. Evaluating the effectiveness of the previous strategy and the activities funded through it is important for understanding what needs to be done next.

2. Strategies to prevent FASD

Prevention activities need to target the whole population and raise awareness of harms of alcohol consumption during pregnancy. The *WHO Global Strategy to reduce harmful use of alcohol* acknowledges that price, promotion and availability of alcohol are the best policy buys in terms of reducing consumption and alcohol-related harm including FASD.[1] It is imperative that this policy frame forms the basis of Australia's efforts to stop alcohol harm. A greater commitment to these policies is critical to reducing FASD throughout Australia.

FARE's 2017 National Alcohol Poll shows that while 80 per cent of people are aware that pregnant women should not consume alcohol during pregnancy, 13 per cent believe that they can drink one or two drinks a day and two per cent believe they can drink three or more drinks.[2] This demonstrates ongoing confusion within the Australian community about whether alcohol consumption is safe during pregnancy.

In Australia, women continue to receive mixed messages from health professionals about alcohol consumption during pregnancy. The evaluation of FARE's Women Want to Know project in 2016 found that between 28 and 43 per cent of health professionals are unaware of the National Health and Medical Research Council's (NHMRC) *Australian Guidelines to Reduce Health Risks from Drinking Alcohol* (Alcohol Guidelines).[3]

The evaluation also revealed the failure of some health professionals to acknowledge the evidence that any level of alcohol consumption is harmful. Some health professionals expressed the view that small amounts of alcohol or occasional alcohol use were unlikely to cause harm, or stated that there was no evidence to contradict this. Health professionals need to be convinced about the importance and utility of undertaking training, especially as many feel that they have sufficient knowledge about alcohol and pregnancy.[4] Therefore, it is important that the Women Want to Know program continue to educate health professionals on this issue and ensure that women are receiving consistent and appropriate advice.

The prevention priority in the Discussion Paper is poorly worded, it does not indicate what needs to be achieved in the next ten years; and merely indicates that a list of prevention strategies will be outlined. This priority should identify the goal to be achieved. A possible goal could be to: "Prevent children in Australia being born with FASD and increase awareness of FASD within the community."

Prevention activities to be undertaken by governments need to range from whole of population measures to supporting women to have alcohol-free pregnancies. In particular, the following activities are required:

- Implement an ongoing national public education campaign about the risk of harm from alcohol consumption during pregnancy. The campaign should use a variety of mediums and ensure that there are specific messages which target:
  - the general public
  - women
  - groups in the community identified as being at risk
  - Public Health Networks (PHN) and health professional colleges to promote.
- Mandate health warning labels and messaging:
  - ensure warning labels and messaging have regulated text and symbols, size and position, with messages developed by health behaviour change experts, applied consistently on all alcohol products

- improve school based education to include the risks of alcohol consumption during pregnancy in subjects on the harms from alcohol and other drugs and sexual health
- ensure that contraception options are available to all women of child bearing age and that information is provided on alcohol consumption and pregnancy on pregnancy and ovulation testing kits.

- Educate all health professionals on alcohol harms during pregnancy and ensure that:
  - training is incorporated into all general practice, midwifery, obstetrics and Aboriginal Health Worker education on the impacts of alcohol consumption on pregnancy and the developing fetus
  - university medical courses (such as midwifery and medical degrees) include curricular on FASD and alcohol consumption during pregnancy
  - health professionals are skilled in asking women about alcohol consumption, provide advice that is consistent with the NHMRC Alcohol Guidelines and can recognise and respond to women at risk
  - continue to fund FARE's Women Want to Know project, ensuring there is continuity in promotion over time to train health professionals about the risks of alcohol consumption during pregnancy
  - all pregnant women are asked about their alcohol consumption during pregnancy and establish mechanisms for that data to be recorded in the pregnancy handheld records and perinatal minimum dataset
  - pregnant women with alcohol use disorders, including post-partum support are provided with specialist support services and have access to treatment services.

The impact of stigma on prevention efforts

The Discussion Paper notes that for some women prevention efforts through campaigns and other initiatives may bring up concerns about their own use of alcohol during their pregnancies. The inference is that these women may feel guilt or stigma around their alcohol consumption. However, this does not mean prevention activities should not be undertaken. Instead, prevention activities need to ensure that appropriate care is taken in message creation and in understanding why women consume alcohol during pregnancy.

A range of factors influence alcohol consumption during pregnancy, including:

- being unaware of the pregnancy
- being unaware of the extent and consequences of alcohol exposure on the fetus
- finding it difficult to abstain as alcohol consumption is normal within their social group
- using alcohol a way to cope with difficult life situations such as violence, depression, poverty and isolation
- having an alcohol use disorder
- having a partner who is drinking or not discouraging a women from drinking.[5,6,7]

Life circumstances also impact on women's use of alcohol during pregnancy. These include, but are not limited to poor mental health, high life stress, poverty, housing and legal issues, concurrent drug use and exposure to violence such as domestic and family violence and trauma.[8] A study of 80 birth mothers of children with FASD by the University of Washington, found that all women had alcohol use histories, and 63 had a parent with an alcohol problem. The study also found that 96 per cent of the mothers had mental health disorders, 95 per cent had been physically or sexually abused in their life, and 80 per cent lived with men who did not want them to stop drinking during pregnancy.[9]

Prevention activities need to ensure that women are supported during pregnancy and that responses are trauma informed. This means that an empathic approach is taken, moving from straight education (outlining the risks of alcohol consumption during pregnancy) to one that acknowledges that a woman's life circumstances (she may or may not know the risks, but may need strategies to assist her). The Centre for Excellence for Women's Health and the CanFASD Research Network have done work in this area and Australia can learn from this experience.[10]

3. Evidence-based screening and diagnosis

The Australia FASD Diagnostic instrument has been finalised, but diagnostic capacity remains extremely limited. This priority area in the Discussion Paper needs to outline how access to a FASD diagnosis will be improved. This includes how relevant health professionals being trained in the use of the diagnostic tool and how new FASD diagnostic services will be established and maintained.

This priority area in the Discussion Paper is poorly worded, as only screening and diagnosis that is evidence-based should be taking place. This priority should identify and work to achieve the goal: "Improving diagnostic capacity for FASD in Australia".

The following activities are required:

- establish a national FASD diagnostic service strategy to train health professionals (including paediatricians, general practitioners, health workers, maternal and child health nurses, midwives, psychologists and psychiatrists) on the Australian FASD diagnostic tool and understand the importance of early diagnosis and intervention
- fund a range of diagnostic service models across Australia
- ensure that interdisciplinary health teams that already exist (such as in child development services[*]) can undertake FASD diagnosis as part of the services they provide
- increase diagnostic capacity in rural and remote areas by implementing workforce training for people living and working in the area, and improve the use of telehealth to help undertake diagnosis
- improve data collection and linkage ability between sectors to record, evaluate and share the health information relevant to the needs of individuals with FASD
- ensure that FASD diagnosis are recorded in the national registry (or birth defects register) and ensure anonymised population data is available throughout Australia.

FARE believes that screening, such as the screening of pregnant women about the amount of alcohol being consumed during pregnancy, should be considered as a preventive health measure and be included in the previous priority.

4. Evidence-based treatment and care for individuals affected by FASD and approaches that support individuals, families and carers across health, education, criminal justice and other settings

For people with FASD, their parents and carers, having access to early intervention and support can vastly improve their life outcomes. Early diagnosis also positively affects the life of an individual as this enables access to early intervention and support.[11] People with FASD who are unable to receive a

[*] These services are known by different names in different states, for example South Australia they are called Early Childhood Intervention Program, and in Western Australia they are known as Child Development Centres. These teams are already multi-disciplinary and see a range of children for issues such as Autism, Attention Hyperactivity Disorder and speech delay.

diagnosis in childhood or early intervention programs are more likely to experience problems with mental health, alcohol and other drugs and incarceration.[12] They are vulnerable to exploitation, they are often guided into criminal behaviour or used as a scapegoat, and have been victimised or exposed to more serious criminal elements.[13,14]

The Government recognises the need to support children with disabilities through early intervention through two key programs: Helping Children with Autism and Better Start for Children with Disability.[15] Neither of these programs are available for those with FASD.

FASD should be considered in the same way as other disabilities, especially those that affect neurological development. There needs to be a 'no wrong door' approach to service delivery that recognises that disability is cross-sectoral and responses must be system-wide to be the most effective.

This priority area within the Discussion Paper needs to better reflect these issues. There is insufficient information about the programs listed in this priority to know which are effective or recommended (if any). Additionally, this priority needs to outline how people with FASD, their parents and carers can access support through the National Disability Insurance Scheme (NDIS) and other carer payments. Many disability payments in Australia still rely on an individual having a diagnosis of Fetal Alcohol Syndrome and lower IQ. However, around 75-80 percent of individuals with FASD have IQs within the normal range. This precludes them from accessing disability services and carers allowances.[16]

This priority area needs to articulate how early intervention will be improved as well as outline strategies for individuals already affected within the justice system, education and employment systems. The following activities are required:

Parents and carers

- allocate funding to support groups that assist people with FASD, their families and carers and ensure that this funding is ongoing
- ensure that support groups are established in alongside each diagnostic clinic to help support those who have recently received or are undergoing the diagnostic process.

Education, employment and the criminal justice system

- develop processes to ensure that people with FASD, or are 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
- examine court proceedings and sentencing options for people with FASD to ensure that proceedings are understood, and similar options are provided to those who have cognitive functioning disabilities
- develop education initiatives that support schools and teachers to understand FASD and create training materials on supporting children with FASD
- develop employment and training opportunities for people with FASD and ways that current systems can be enhanced to support people with FASD
- develop targeted training materials for:
  - parents, foster carers and foster care agencies
  - police and court officials
  - youth workers and drug and alcohol officers

- officers in correctional facilities and juvenile detention centres.

Disability sector

- improve the recognition of FASD as a disability within the National Disability Insurance Scheme and the National Disability Insurance Agency
- remove reference to lower IQ (under 70) from FASD being an eligible disability for support including Disability Support Pension, Youth Disability Allowance, Mobility Allowance, Carer Allowance and Carer Payments
- update diagnostic terminology and remove reference to Fetal Alcohol Syndrome and older diagnostic terms within disability support payments
- recognise the current difficulty in people being able to obtain a diagnosis for FASD, due to the lack of diagnostic capacity in Australia and the difficulty of people being able to satisfy the "treated and stabilised" criteria of these payments
- add FASD to the List of Recognised Disabilities and the Better Start for Children with a Disability Initiative
- ensure that all people diagnosed with FASD are provided with a treatment and management plan that outlines their strengths and weaknesses and where support is required.

5. Strategies to support professional education and training in FASD

It is unclear from the title of this priority area which professionals are being trained. The detail provided in this priority area focuses on health professionals and human services. FARE considers the training of health professionals in asking about alcohol consumption during pregnancy to be part of prevention activities and training on FASD diagnosis as part of improving diagnostic treatment services.

The detail for this priority area within the Discussion Paper appears to outline that there is a need for a similar campaign to Women Want to Know for human services professionals to educate them about FASD, the risks of alcohol consumption and pregnancy, and the options that are available for support.

In 2014 FARE funded National Organisation for Fetal Alcohol Spectrum Disorders (NOFASD) Australia to develop a FASD training program to building the capacity within Child Protection services to better support those caring for people with FASD. The outcome of this project was that service providers were better informed to support parents and carers. However, it was a small pilot and there were significant limitations in scale and time. This project could be scaled-up to a larger national project to educate human service sectors on FASD. This work is also supported by that of the Australian Institute of Family Studies which released practice principles on supporting children with FASD in 2014.[17]

The title of this priority area should reflect what is trying to be achieved. For example: Ensure that health and human service sectors are educated in FASD in order to support and advocate for people with FASD. The required actions within this priority area are to:

- undertake a baseline survey to establish knowledge of FASD among human service professionals across Australia
- work with state government human services to introduce an educational campaign for health and human service professionals covering:
  - causes and outcomes of FASD

- support options
- how to adapt services to accommodate people with FASD and others with brain-based difficulties
- how to reframe challenging behaviour and recognise the impact of FASD on the brain

- ensure that individuals with FASD receive specialist case management to coordinate relevant service, including face-to-face support

- increase awareness and advocate for the individual's needs amongst schools, doctors, family support workers, justice professionals.

6. Strategies to improve research, monitoring and evaluation

The prevalence of FASD in Australia continues to be unknown and FARE agrees with the Discussion Paper that more needs to be more to achieve this. However, several steps are required in order to achieve this (these are outlined below).

Two population studies on alcohol and drug use in pregnancy are occuring in Australia. These studies are the *Triple B: Bumps, babies and beyond* in New South Wales and the *Asking Questions about Alcohol in Pregnancy* (AQUA) study in Victoria. It is critical that funding for these studies continue, as they are likely to contribute new evidence on possible harms from alcohol at low-levels of consumption and the occasional consumption of alcohol during pregnancy.

It is unclear if this priority area within the Discussion Paper is monitoring and evaluating the strategy or monitoring the prevalence of FASD in Australia. These are separate points. It is important that the strategy is monitored and evaluated, and it is important that Australia achieve a better understanding on the extent of FASD in the country. This priority should outline the goal that is trying to be achieved. This goal could be to: Understand the extent of FASD in Australia by undertaking research and establishing data collection mechanisms to monitor prevalence.

Further, the 'research about medications' would be more appropriately situated under the 'evidence-based treatment and care and approaches that support individuals, families and carers' priority area. To understand the prevalence of FASD in Australia the following activities are required:

Prevalence of FASD

- routinely ask and record women's alcohol consumption during pregnancy by:
  - making AUDIT-C compulsory component of state Pregnancy Handheld records
  - asking AUDIT-C a minimum of three times throughout the pregnancy
  - ensuring data on alcohol consumption and AUDIT-C results are part of the National perinatal minimum dataset
  - ensuring that information on maternal alcohol consumption is part of the baby's records once born, this can be de-identified to protect patient confidentiality

- establish a FASD diagnostic register to ensure that once a diagnosis is made that this information is recorded

- update state congeniality anomalies registers to cover the same age ranges and ensure that the diagnosis of FASD is a notifiable condition.

Population studies

- Ensure funding continues for current population studies in Australia examining alcohol harms the Triple B: Bumps, Babies and Beyond and the Asking Questions about Alcohol in Pregnancy (AQUA).

Evaluation

- Ensure that a proportion of funding for actions and programs undertaken through the strategy is dedicated to evaluation.

I wish you well in coordinating the responses to the Discussion Paper and thank you for the opportunity to provide comment to the draft National FASD Strategy. If further information is required on the information outlined in this submission please contact Ms Sarah Ward, Senior Policy Officer, on 02 6122 8600 or sarah.ward@fare.org.au.

Yours sincerely

MICHAEL THORN
CHIEF EXECUTIVE

Cc: Mr David Laffan, Assistant Secretary, Drug Strategy Branch, Department of Health

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