

20th May 2014

Russell Keith Secretary Select Committee on Action to Prevent FASD GPO Box 3721 DARWIN 0801

Dear Mr Keith.

## Action to Prevent Fetal Alcohol Spectrum Disorder

A significant burden of disease arises from alcohol use during pregnancy. There is strong evidence of a range of adverse maternal and neonatal outcomes as a result of alcohol exposure during pregnancy.

The term Fetal Alcohol Spectrum Disorders (FASD) was introduced as an umbrella term to describe the range of effects that can occur in an individual whose mother drank alcohol during pregnancy [1]. There are a number of diagnostic terms used to describe the range of fetal effects stemming from prenatal alcohol exposure including Fetal Alcohol Syndrome (FAS), Fetal Alcohol Effects (FAE), Alcohol Related Birth Defects (ARBD), and Alcohol Related Neurodevelopmental Disorders (ARND).

### Prevalence of FASD in the NT

Alcohol use is common among women of reproductive age in Australia, with rates of risky drinking in the NT the highest across the country [2]. Although many women abstain from alcohol use in pregnancy, substantial proportions continue to drink, including a minority at high risk levels.

There are difficulties of determining accurate prevalence estimates of FASD mainly due to inadequate data collected on alcohol use in pregnancy and problems with diagnoses [3]. State and Territory-based studies have reported birth prevalence rates of FAS of between 0.01 and 0.68 per 1,000 live births. Prevalence of the other disorders in the FASD spectrum have not been estimated in Australia [4].

A study estimating birth prevalence of FAS in the NT reviewed medical charts of all children born over a ten year period to identify children with FAS and partial FAS. All children identified were Indigenous. The estimated birth prevalence of FAS was 1.9 per 1000 Indigenous live births. The birth prevalence for the population overall was 0.68 per 1000 live births for FAS [5].

International and Australian data suggest higher prevalence rates of FAS among Indigenous populations [4].

### Nature of the injuries and effects of FASD on its sufferers

It is now well accepted that heavy alcohol consumption during pregnancy places the fetus at increased risk of negative pregnancy outcome including birth defects, growth impairment, developmental disabilities and neurodevelopmental dysfunction. A complex pattern of neurodevelopmental dysfunction that is unrelated to developmental maturity or to family or home environment has been identified. The central nervous system abnormalities include cognitive abnormalities, poor impulse control and problems in behaviour, mental health, social interactions, learning and school achievement [6].

Many of the adverse effects persist over time and result in significant challenges in adulthood. Prospective longitudinal studies have reported a range of adverse life outcomes including disrupted education and persistent behavioural and mental health problems [7-12]. Individuals with FASD are at increased risk of problems in adulthood classified as 'secondary disabilities' [8, 13, 14]. Adaptive functioning has been identified as a key predictor of the development of secondary disabilities with better outcomes for individuals with high adaptive functioning [13]. Risk factors for secondary disabilities include disrupted family life and exposure to violence, while living with a stable caregiver is a significant protective factor.

In addition to effects on individuals who have FASD, people who care for people with FASD require support given the ongoing nature of the disability and therefore carers responsibilities over time [15].

# Actions the Government can take to reduce FASD based on evidence and consultation

There is evidence for harm associated with moderate alcohol use and conflicting evidence regarding low alcohol consumption [16, 17]. The burden of harm is concentrated with heavy use and binge alcohol use. It is unlikely a safe level of alcohol consumption will ever be determine due to the complex association between dose, timing, frequency and individual maternal characteristics [18]. The NHMRC Australian Guidelines to Reduce Health Risks from Drinking Alcohol recommend abstinence and this message has been promoted through recent work.

• Population awareness regarding harmful effects of alcohol in pregnancy In recent years there has been a focus on increased awareness of the harmful effects of alcohol use in pregnancy, including the promotion of the NHMRC guidelines. There have been projects focussing on the development of culturally appropriate resources for Indigenous peoples including the Strong Spirit Strong Future campaign in WA [19] and the FASD Postmaker App developed at the National Drug Research Institute.

 Early identification of women that are at risk of exposed pregnancy and access to antenatal care

It is essential that the primary health carers are able to identify risks and respond appropriately to the needs of all women. This includes women at low risk for whom abstinence messages are likely to be successful and alcohol-dependent women who require referral to specialised drug and alcohol treatment services.

The primary health care workforce needs to have adequate education and support to screen all pregnant women for alcohol use, provide brief intervention where indicated, and refer for specialist treatment.

Strategies to engage women in antenatal care are required. Women with alcohol problems present later to antenatal care and it is known that women that earlier prenatal have better outcomes [20].

### Supportive treatment for women most at risk

Although there is evidence that increasing proportions of pregnant women are abstaining from alcohol, data from NSW and QLD found the number of women who drink at high risk levels has remained stable [21]. The abstinence messages are not adequate for women that are dependent on alcohol and at greatest risk of having a child affected by FASD. They cannot just stop drinking and need to be supported by effective interventions [22]. Specialist antenatal care should be provided to women at high risk and include access to appropriate detoxification if required.

The evidence suggests that treatment within a comprehensive, holistic framework has the best maternal and neonatal outcomes [23]. Treatments that address complex presentations including comorbid mental health, trauma histories including domestic violence and provide support with practical issues like child care are required.

### Workforce development

It is essential that professionals have the required skills to effectively implement evidence-based strategies and incorporate them into routine clinical practice. Screening for alcohol use requires a non-judgemental, empathetic approach which builds rapport and provides a safe environment for disclosure.

To facilitate access to treatment, it is critical that primary health care, specialist drug and alcohol services and other community service providers have the capacity to form strong collaborative relationships. Joint clarification of treatment pathways and referral processes would be of strong benefit.

NDARC is currently coordinating a national project that examines effective treatments for substance using pregnant women and also involves developing resource for primary health care professionals in Australia, to identify and

manage substance use in pregnancy including alcohol.

Please feel free to contact us if you would like to discuss any aspect of this submission.

Yours sincerely

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