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MENZIES SCHOOL OF HEALTH RESEARCH SUBMISSION TO THE SELECT COMMITTEE ON ACTION TO PREVENT FOETAL ALCOHOL SPECTRUM DISORDER

Menzies School of Health Research (Menzies) wishes to make a submission to this important inquiry on action to prevent foetal alcohol spectrum disorder (FASD). The purpose of our submission is two-fold. Firstly, to summarise relevant literature regarding the prevalence, burden, prevention, diagnosis and management of FASD. Secondly, we wish to highlight the potentially important role for research, evaluation, surveillance and monitoring in addressing FASD

INTRODUCTION

It was in 1968 that Paul LeMoine, a French pediatrician, provided the first description of dysmorphic facial features and growth delays that were similar in infants born to mothers who drank alcohol during their pregnancies (1). Five years later, the term Fetal Alcohol Syndrome (FAS) appeared in two papers by a team of clinicians from Seattle in Washington State University (2, 3). This team described characteristics in eight unrelated infants from three different ethnic backgrounds born to mothers who were chronic alcoholics. These children showed a similar pattern of craniofacial, limb and cardiovascular defects associated with prenatal-onset growth deficiency and developmental delay.

Since then, research conducted on the effects of prenatal alcohol exposure has shown that FAS is part of a spectrum of disorders. The term Foetal Alcohol Spectrum Disorder (FASD) was adopted as an umbrella term to cover the range of outcomes associated with all levels of prenatal alcohol exposure (4). (See Attachment 1 for the diagnostic categories for FASD in the Australian guidelines.)

PREVALENCE OF FOETAL ALCOHOL SPECTRUM DISORDERS

Establishing population-based prevalence of FAS and FASD is challenging. Few studies of population prevalence have been conducted and study methodology has varied, therefore limiting the generalisability of research findings (5). Furthermore, diagnostic criteria for each of the conditions under the umbrella of FASD are non-specific, with a great degree of overlap. Hence, most studies report on the rates of FAS and not the full spectrum of disorders which includes FAS,

Partial FAS and Neurodevelopmental Disorder – Alcohol Exposed (ND-AE). Other related diagnoses including Fetal Alcohol Effects (FAE) and Alcohol Related Birth Defect (ARBD) are less frequently used in Australia.

Prevalence studies have been conducted in Australia that are relevant to this inquiry. Importantly, a study on the prevalence of FASD in the Top End of the Northern Territory was conducted by reviewing medical records over a ten years from 1990 to 2000 (6). Seventeen children were identified with definite FAS and 26 with partial FAS or ND-AE. The prevalence of FAS for the total population in the Top End was 0.68 per 1,000 live births and a rate of 1.87 per 1,000 live births in the Indigenous population was reported. The authors stated that these rates are almost certainly underestimates of the true prevalence, as the facial features were not necessarily documented in the medical records.

A three year national surveillance of FAS in Australia reported a rate of FAS at 0.06 per 1,000 live births (7) and a Western Australian (WA) study using the birth defects registry reported a rate of FAS at 0.18 per 1,000 live births (8). Both these studies have shown that Aboriginal children with FAS are over-represented. The national study reported that 65% of the children diagnosed with FAS were recorded as Indigenous. The WA study reported the rate of FAS of 2.76 per 1,000 live births for Aboriginal children in WA — more than ten times higher than the reported rate of FAS in other Australian children (8).

Both the Top End study and the national study reported a recurrence of FAS within families. In the Top End study, there were four mothers in the study group who each had more than one child with FAS and there was one mother who had three children with FAS. The national study reported that up to 51 per cent of children with FAS may have a sibling with FAS (7).

It is believed that FAS is under-diagnosed (7) and under-reported, resulting in the under-estimation of FAS in Australia (9). Furthermore, different types of studies have been conducted to measure FASD in a given population (10). The Top End and WA studies used a passive record review system to estimate FAS and the national surveillance used a clinic-based study to estimate FAS. Active case ascertainment, which systematically assesses a population of children, typically reports a higher rate of FASD. In the Kimberley, researchers working with a community in the Fitzroy Valley have recently completed an active case ascertainment study (11). However, the results are not yet publicly available.

Prevalence studies on FAS and FASD have been conducted in a number of countries. In the United States, it is estimated that the population prevalence of FAS is 2 to 7 per 1,000 births (5). Studies conducted in the United States using active case ascertainment have reported rates ranging from 1.8 to 9.8 per 1,000 births (5).

In-school studies, which have been rare until recently, are more likely to be representative of the local population (10). A study of first grade children in schools near Rome, using active case ascertainment, estimated the rate of FAS to be between 4 to 12 per 1,000 children and the rate of FASD to be between 23.1 and 62.6 per 1,000 children (12). Recently, a very high rate of FASD has been reported in a South African population —135 to 207 per 1,000, or up to one-in-five, children enrolled in first-grade (13).

BURDEN OF FETAL ALCOHOL SPECTRUM DISORDERS

The societal costs of alcohol misuse in Australia in 2010 was estimated to be over $14 billion, with 11.7% representing costs to the health system (14). This however, did not include the cost of FASD. A 2004 paper in the US estimated the lifetime costs for a person with FAS may reach $US2 million (15). The adjusted average annual cost per child with FAS and Fetal Alcohol Effects (not a criterion used in Australia) aged one to 21 years in Canada was $14,342 and the cost of FASD annually to Canada for that age group was $344 million (16). The estimated costs are based on a prevalence rate of FAS/FAE of approximately 3 per 1,000 people (16). No cost of illness studies on FASD have been conducted in Australia.

Effect of Prenatal Alcohol Exposure

The most profound effect of prenatal alcohol exposure is on brain development which results in cognitive and behavioral difficulties (17). O'Malley provides a description of how this affects the individual: "the developmental disability of FASD is a complex learning disorder affecting multiple domains of functioning including working memory, attention, impulsivity, learning, interpersonal relatedness, social skills and language development" (18) (page 5). Comorbidity is the rule rather than the exception in people with FASD, beginning with infancy and continuing through the lifespan (18).

A prospective Australian study of 92 children notified to the Australian Paediatric Surveillance Unit reported that children with FAS are likely to be born preterm (35 per cent), be of low birth weight (65 per cent), have growth deficiency (56 per cent), have microcephaly (an abnormally small head) (53 per cent), have additional birth defects (24 per cent), have speech/language disorder (60 per cent), have sensorineural hearing loss (5 per cent) and visual impairment (4.3 per cent). Fewer than half (40 per cent) were in the care of a biological parent (7).

A study in WA reported that maternal alcohol-related diagnosis was the leading known cause of intellectual disability with no identified genetic origin (19). Cessation of maternal alcohol use could potentially prevent 1.3 per cent of intellectual disability in non-Aboriginal children and 15.6 per cent of intellectual disability in Aboriginal children (19).

A long term follow-up of people with FAS and Fetal Alcohol Effects (not a criterion used in Australia) in the USA reported a number of adverse outcomes. Inappropriate sexual behavior — including inappropriate sexual advances, promiscuity, exposing and voyeuristic behaviour — was the most frequent adverse outcome across the lifespan (20). Among adolescents and adults, 35 per cent were incarcerated for a crime, 23 per cent hospitalised for a psychiatric problem and 15 per cent had been hospitalised for alcohol and drug treatment. This study reported that one of the strongest correlates of adverse outcomes was the lack of early diagnosis (before 12 years of age). The authors acknowledged that these findings were from a clinical sample, therefore limiting their generalisability (20).

Impact of Fetal Alcohol Spectrum Disorders on Families and Individuals

Despite the documented importance of the quality and stability of the home environment (20), little is known about families with FASD (21). Research from the United States reported feelings of loss, guilt, shame and blame amongst parents of children with FASD (22). A systematic review of the limited body of research found that having a child/ children with FASD was associated with financial strain, frustration with the lack of knowledgeable professionals, stress related to the judicial system and multiple time demands (21).

A qualitative study of children living with FASD described how they understood the nature of the disability and how it affected their day-to-day lives (23):

> *Sometimes I have trouble concentrating. I am concentrating on one (activity), then I get distracted.*
>
> *Learning is hard. The teachers don't explain things (in a manner that allows her to understand).*

All children talked about how they tried to participate in normal activities despite their disability, but feeling different emerged as an overall construct (23).

ADDRESSING FASD

In 2010, the NT government formed a working group to address FASD. This was led by the Department of Child Protection. The working group provided a framework for how FASD could be addressed in the NT. At the time of writing this submission, the authors are not certain regarding to what extent recommendations from the working group have been implemented, what monitoring is being undertaken or whether performance indicators have been agreed.

Addressing FASD requires a comprehensive public policy approach, which would include addressing the social determinants of risk-taking behavior and should be based on sound evidence. Action will aim to prevent women drinking alcohol during pregnancy. However, any strategy would need to recognise that women's health behaviours are influenced by their family and community and a focus on pregnant women in isolation would be unsuccessful. Action will also aim to improve the diagnosis and management of FASD.

PRIMARY PREVENTION OF FASD

Understanding the environmental, social and economic determinants and patterns of alcohol consumption is crucial in preventing FASD. This essential information can be used to inform interventions to address alcohol and pregnancy. Australian studies illustrate that the reasons women drink alcohol during pregnancy are complex.

Australian Context for Alcohol Consumption in Pregnancy

Australian studies have reported rates of alcohol consumption in pregnancy ranging from 34 to 59 per cent (24, 25). A WA survey of non-Aboriginal women who had given birth between 1995 and 1997 found that 47 per cent had not planned their pregnancy (24) and a national survey of 1103 Australian women of child bearing age, conducted in 2006, reported that 32 per cent of women indicated that they would continue to drink alcohol if they were planning to become pregnant (25).

Drinking alcohol in the preceding pregnancy was a strong predictor of a woman's intention to drink alcohol if she were planning another pregnancy (25). Women reported that they would be less likely to drink alcohol if their partner encouraged them to stop or cut back (38 per cent), or if their partner stopped drinking alcohol during the pregnancy (31 per cent). Women with high levels of education and women who had given birth previously were more likely to drink alcohol in pregnancy (25).

In the Western Australian Aboriginal population, 23 per cent of a large representative sample of birth mothers of Aboriginal children surveyed in 2000 and 2001 reported having drunk alcohol in pregnancy (26). The most recent official NT data about alcohol consumption during pregnancy was reported this

year in the NT Midwives Collection: Mother and Babies 2011 Report (27). This report describes self-reported alcohol consumption during pregnancy at the first antenatal visit and again at around 36 weeks gestation. Of concern is the fact that the report notes that 8% of the maternal alcohol consumption data were missing at the first visit and 18% at 36 weeks. Missing data for maternal alcohol consumption was more prevalent among the antenatal records of Indigenous mothers than non-Indigenous mothers. After removal of the missing data, the reported prevalence of alcohol consumption at the first antenatal visit was 13% among Indigenous mothers and 7% at 36 weeks gestation. This compares with 3% and 1% respectively for non-Indigenous mothers. There are no published data on what proportion of Australian Aboriginal women plan their pregnancies, but a study conducted in a Native American population reported that Native American women were unlikely to plan a pregnancy (28).

Whilst the rates of reporting any level of alcohol consumption in pregnancy are higher for non-Aboriginal women, Aboriginal women are more likely to consume alcohol at harmful levels. A Western Australian (WA) study of women who had given birth over a 10-year period, found that Aboriginal women were 10 times more likely to have an alcohol diagnosis when compared with non-Aboriginal women — 23 per cent and 2.3 per cent respectively (29).

Women expect health professionals to ask about, and advise them on, alcohol use during pregnancy (25), however a survey of health professionals reported that most health professionals did not routinely ask pregnant women about their alcohol use or provide them with information about the effects of alcohol on the unborn baby (30). A qualitative study of health professionals revealed barriers in addressing alcohol use with pregnant women (31). The authors provided strategies for overcoming the barriers. For example, a barrier included the perception that most women do not drink much alcohol during pregnancy, yet Australian research has reported high rates of women drinking at least some alcohol during pregnancy. Rather than assume that pregnant women are not consuming alcohol, a critical strategy in addressing this is to encourage health professionals to routinely ask *all* women about their alcohol use (31).

A Framework for Prevention

Menzies hosted a 'Conversation on Alcohol and Pregnancy' forum on the 20th May 2014. The structure of this forum included two presentations followed by a 'Question and Answer' session with an expert panel. *Both presentations have been made available to this inquiry.*

One of the speakers, Nancy Poole, is the Director of the British Columbia Centre for Excellence for Women's Health Prevention and Team Leader for the Canada FASD Research Network. Her presentation was titled 'Effective FASD Prevention: What do we know'? Dr Poole spoke about the four levels of prevention, supported by a public policy framework seeking to reduce alcohol-related harm.

Level 1: Broad awareness building and health promotion efforts — Examples of this would include development of culturally appropriate health education materials, awareness campaigns and warning labels.

Level 2: Discussion of alcohol use and related risks with all women of child-bearing years and their support networks — An example would be health professionals providing brief interventions for women of child bearing age.

Level 3: Specialised, holistic support of pregnant women with alcohol and other health / social problems — An example would be enhanced case management of women with alcohol misuse.

Level 4: Postpartum support for new mothers and support for child assessment and development — An example would be a home visiting program.

An overarching and supportive alcohol policy is vital to the success of prevention of FASD. Some examples would include monitoring and containing the number of alcohol outlets, minimum pricing and community or local government driven alcohol policy.

DIAGNOSIS AND MANAGEMENT OF FASD

Diagnosis and management of FASD play important roles in both primary and secondary prevention, but they are not without their challenges.

Diagnosing Fetal Alcohol Spectrum Disorders

Early diagnosis and intervention may be beneficial to children with FASD (20). Further, a failure to diagnose FAS potentially places subsequent children of the same mother at greater risk of being affected (6).

However, the broad range of expression of dysfunction related to prenatal alcohol exposure makes the diagnoses of FASD, which relies on a clinical assessment and history taking (6), complex (32). Guidelines have been developed to assist health professionals in the assessment and diagnosis of FAS and FASD (32, 33). Some countries have established specialized diagnostic clinics, but these are concentrated in North America (29 of 34 clinics) with none in Australasia (34). Nearly all of those clinics (97 per cent) had a multidisciplinary team and, for 94 per cent of the clinics, at least one member of the team had specialist training in the assessment of FASD (34).

While it is recognised that diagnosing FASD is complex, in Australia it is further complicated as health professionals have limited knowledge of the diagnostic criteria for FAS (9, 30), when compared with health professionals in Canada (35). In addition, 52 per cent of health professionals (general practitioners, Aboriginal health

workers, allied health, community nurses and obstetricians) (30) and 70 per cent of paediatricians in Australia believed that making a diagnosis of FAS might stigmatise the child or family (9).

In regards to diagnostic guidelines for Australia, a Delphi survey of health professionals found general consensus and support for the accepted diagnostic criteria for FAS (36). (See Attachment 1) There was, however, lack of consensus regarding diagnostic criteria for Partial FAS and ND-AE (36). Australian guidelines, informed by international guidelines and the Delphi survey of health professionals, are now available (36). (Attachment 1 provides a summary of the Australian guidelines.)

There are resources within Australia that could be utilised to facilitate the diagnosis of FASD. In some areas, which face similar challenges in engaging and sustaining a skilled workforce to provide necessary treatment services as the NT, paediatricians have been active in diagnosing and managing children with FASD. The recent Liliwan project, conducted in the Fitzroy Valley, will provide much information that will be relevant to the Northern Territory.

MANAGEMENT OF FASD

The management of FASD poses significant challenges nationally and, specifically, in the NT context. Difficulties posed by lack of consensus regarding diagnosis have already been discussed in this submission. However, the specific need for further investment in training of NT health professionals and improvement in access to multidisciplinary assessment in the NT should be noted. In addition, a significant increase in capacity to provide therapeutic intervention for FASD is required across the whole of the NT.

A 2009 systematic review of interventions for children with FASD found limited high quality evidence for specific interventions for managing FASD (37). However, since that review, an overview of findings from five innovative research projects, conducted in the USA, has been reported (38). We have not included a description of these studies in this submission. However, this is one area where a rapid review could be undertaken by Menzies, including an assessment of the relevance of these intervention studies to the NT.

SURVEILLANCE AND MONITORING

Surveillance and Monitoring of Alcohol in Pregnancy
Addressing FASD requires surveillance and monitoring of alcohol consumption. The NT has resources in place that could be used to provide surveillance and monitoring of alcohol intake during pregnancy, which would directly inform strategies to address FASD.

Most pregnant women who present for antenatal care in the NT are asked about their alcohol use and this is recorded in a database. Although there are concerns regarding the level of completeness of this population dataset and rigor with which data are collected, this information could be used to provide surveillance across the whole of the NT regarding the frequency and pattern of use of alcohol during pregnancy. This information could also be used to evaluate interventions aimed at reducing the rates of alcohol consumption in pregnancy.

Surveillance and Monitoring of FASD
Developing a system for the surveillance and monitoring of FASD is much more challenging. The population prevalence of FASD in the NT has not been reliably established. Many children in the NT wait long periods of time for assessment and diagnosis of developmental, learning and behavioural problems. With FASD being one of a range of causes of developmental problems, these broader issues of the need to improve access to necessary specialist paediatric and allied health capacity impact directly on the ability to establish systems to enable population surveillance and monitoring. Developing and implementing such a system would require careful consideration, planning across government agencies and a considerable investment in health professional training and workforce.

ROLE OF RESEARCH

Policy and practice measures to reduce the incidence and consequences of FASD in the NT need to be based on sound local evidence. While international and other Australian studies have provided information relevant to advancing professional knowledge and public awareness of the issue, its true extent and the manner in which FASD manifests in the NT remain poorly understood.

Menzies recommends that following research priorities be considered to build the evidence-base for policy, prevention and interventions to better address the needs of children and families affected by FASD. We suggest, as an initial step, that a rapid review of the evidence regarding intervention strategies for the screening, diagnosis and management of FASD be undertaken, with a focus on assessment of the relevance of evidence to the local NT environment.

1. Improving surveillance and monitoring of alcohol in pregnancy

Since 2006, NT Department of Health practice guidelines have required pregnant women presenting for antenatal care to be routinely asked about their alcohol and tobacco use. This information is routinely recorded in their electronic health record. While it is understood that the completeness of this information has improved in recent years, there remains concern at the level of missing data – particularly for Indigenous women. It is vital that all antenatal care staff are adequately informed and supported in ensuring this information is sought from all pregnant women and that these data are entered into the electronic health record. Ensuring the completeness of these data is vital to the reliability of prevalence estimates, not only for purposes of monitoring progress in reducing the proportion of children at risk of FASD, but also for research into the developmental origins of a range of other longer-term diseases where foetal alcohol exposure is believed to play a role.

2. Improving prevalence estimates of FASD in the NT

The costs and complexity of a NT prevalence and validation study such as that recently carried out in the WA Fitzroy Valley are likely to be prohibitive (11). However, the research capability in data-linkage recently developed through the NT being a contributing partner to the SA NT Datalink Consortium provides a new means of investigating the variation between communities and regions in mother's self-reported alcohol consumption during pregnancy and its potential relation to a range of child outcomes in terms of their health, early child development and school learning. This is currently being investigated by a research partnership between the NT Government and Menzies, however the initial findings will only be available later this year.

3. Understanding the relation between NT community rates of alcohol consumption and maternal alcohol use in pregnancy

This relationship is important to understand in identifying communities and regions of the NT at higher risk for FASD. This is an issue which the above data-linkage study is seeking to investigate using methods of multi-level analysis. This is being done by investigating whether communities/regions with higher rates of maternal alcohol use in p[regency have higher levels of adverse child outcomes possibly indicative of FASD when potential confounding socio-demographic factors are taken into account. Child outcomes being examined include developmental vulnerability on the Australian Early Development Index (AEDI), NAPLAN literacy and numeracy, early school leaving and juvenile crime. It is hoped that these data may also enable health economic analysis of the current and longer-term costs to government of FASD and the potential savings which may arise from reductions in the proportion of pregnant women

who drink alcohol and/or increasing the proportion who benefit from early diagnosis and intervention.

4. Improving the knowledge, skills and practices of health care staff

Training manuals for Aboriginal Health Workers in the NT address issues around FASD. In better targeting training materials to be appropriate to the local context and improving the capacity of the NT health care work-force to address FASD, it could be useful to survey medical officers, nursing staff and Aboriginal Health Workers regarding their current awareness, knowledge and practice in screening, diagnosing and managing FASD and discussing related issues with patients. This could form a baseline for measuring progress in any future initiative aimed at improving professional skills and self-efficacy in this area.

5. Developmental screening of Indigenous children in remote areas

While developmental screening is recommended for all children as part of the NT's *Healthy Kids under Five* (HKu5) program, in many remote communities the medical, nursing and Aboriginal health worker staff have little or no formal training in the developmental assessment of children. A recent Menzies study has adapted and trialed a widely used developmental screening instrument, the *Ages and Stages Questionnaire* (ASQ) for culturally appropriate use with remote Indigenous children (39). Consideration should be given to evaluating its wider use in NT communities and the staff training needed for its effective routine use in enabling developmental assessments conducted through the HKu5 program. More effective developmental assessments will assist children with FASD and other developmental disorders being identified earlier and specialised assessment and early intervention occurring where this is indicated.

6. Community understanding of FASD and reducing reduce risk behavior

Evidence-based social-marketing and community education offers significant potential for changing community norms and reducing the population-level risk of alcohol consumption in pregnancy (40). For such initiatives to be effective, it is important that they are properly targeted; informed by understanding of the target audience's knowledge, attitudes and behaviour; utilize proven social-marketing methods; and they are evaluated to monitor outcomes.

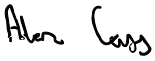
Thank you for considering this Menzies submission. Menzies is committed to engagement with NT communities, health services and government to address key issues in population health. We believe, even if accurate data regarding the population prevalence of FASD is not currently available, that addressing this problem is a high priority for researchers, providers and planning in the NT.

Yours sincerely,

Heather D'Antoine

Sven Silburn

Gurmeet Singh



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Attachment 1. Australian Guidelines - conditions under the FASD umbrella

(Bower C, Elliot E, Watkins R and Jones H, on behalf of the Australian FASD Collaboration, 2011. A report to the Commonwealth Department of Health and Ageing: 'The Development of a Screening Diagnostic Instrument for FASD in Australia'.)

	Diagnostic category		
Diagnostic criteria	Fetal Alcohol Syndrome	Partial Fetal Alcohol Syndrome	Neurodevelopmental Disorder-Alcohol Exposed (ND-AE)
Requirements for diagnosis	Requires all 4 of the following criteria to be met:	Requires confirmed prenatal alcohol exposure, the presence of 2 of the 3 characteristic of FAS facial anomalies at any age, and CN criteria to be met:	Requires confirmed prenatal alcohol exposure and CNS criteria to be met
Prenatal alcohol exposure	Confirmed or unknown	Confirmed	Confirmed
Facial anomalies	Presence of all 3 of the following facial anomalies at any age: • short palpebral fissure length • smooth philtrum • thin upper lip	Presence of any 2 of the following facial anomalies at any age: • short palpebral fissure length • smooth philtrum • thin upper lip	No anomalies required
Growth deficit	Prenatal or postnatal growth deficit	No deficit required	No deficit required
Central Nervous System (CNS) abnormality	At least 1 of the following: • clinically significant structural abnormality, or neurological abnormality; and /or • severe dysfunction		