

Submission to: Education and Health Standing Committee - Inquiry into the Adequacy and Appropriateness of Prevention and Treatment Services for Alcohol and Illicit Drug Problems in WA

By: Alcohol and Pregnancy Research Group, Telethon Institute for Child Health Research

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This submission relates to the effects of exposure of the unborn child to alcohol.

Of note:

- Prenatal alcohol exposure can cause an array of adverse effects such as birth defects, neurobehavioural problems and poor growth. These effects are often grouped under the umbrella term Fetal Alcohol Spectrum Disorders (FASD), and Fetal Alcohol Syndrome (FAS) is the most well-recognised of these disorders. These problems frequently have lifelong health, educational and social consequences for the individual exposed.
- There is limited information on how common Fetal Alcohol Syndrome is in Australia and it is known to be under-diagnosed and under-reported. There are no Australian data on the prevalence of FASD.
- Few health professionals in Western Australia are familiar with the clinical features of FAS, and few routinely ask women about alcohol use in pregnancy.

Attached is a summary of the research we have undertaken, much of which relates directly to the Standing Committee:

Term of Reference (b): *Projects 8 and 10.*

Project 8 is an audit of international practice for the diagnosis of Fetal Alcohol Spectrum Disorder (FASD), which found that almost all clinics take a multidisciplinary approach to diagnosis and have at least one team member with specialist training in assessment of FASD. There are only two paediatricians in Australia with such specialist training (one in WA) and only one such clinic in Australia (also in WA) that is just being set up.

Project 10 was a systematic review of interventions for FASD world-wide. There are very few well-evaluated studies of the management of children with FASD, highlighting the need for well-designed and evaluated studies that address the specific physical and developmental strengths and weaknesses of children with FASD.

Term of Reference (c): *Projects 2, 4 and 11.*

We have surveyed health professionals in WA about their knowledge, attitudes and practice in relation to FASD and the use of alcohol in pregnancy. Based on the findings, we developed, distributed and evaluated educational resources for health professionals in WA. The resources are available on www.ichr.uwa.edu.au/alcoholandpregnancy.

We are available to provide further information to assist the Standing Committee if requested.

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Research projects from the Alcohol and Pregnancy Research Group, Telethon Institute for Child Health Research

The Alcohol and Pregnancy Research Group is a collaborative team of researchers from the following participating organisations: Telethon Institute for Child Health Research, Centre for Child Health Research, The University of Western Australia; University of Sydney, New South Wales; Edith Cowan University, Western Australia; Curtin University of Technology; The WA Drug and Alcohol Office; The Australian Paediatric Surveillance Unit; and the Western Australian Birth Defects Registry. Our research began in 2001 when we identified that there was little information available from Australia about alcohol in pregnancy on which to base public health practice. This research has been supported by grants and fellowships from Healthway and NHMRC.

In addition to the research listed below, members of the Group have provided expert advice to federal and state government agencies about alcohol and pregnancy, including contributing to the development of the recent NHMRC Australian Guidelines to reduce health risks from drinking alcohol and serving on the Intergovernmental Committee of Drugs Working Party on FASD and contributing to the Monograph about to be published by the IGCD Working Party. The Monograph contains information that may also be useful to your Committee, particularly on current education and training and the need for routine data collection on alcohol exposure in pregnancy and diagnostic and management capacities for FASD.

1. National surveillance of Fetal Alcohol Syndrome (FAS) through the Australian Paediatric Surveillance Unit (2001-2004)

Contribution: This is the only prospective national (or international) study of FAS. The findings highlight the ongoing severity, complexity and impact of FAS in Australia: (86% had nervous system dysfunction, 65% low birth weight, 36% were preterm, 25% had birth defects and all were high users of health, community and education services) and groups at most risk (65% of affected children were Indigenous, 60% did not live with a biological parent, and 51% had siblings who also had FAS, indicating missed opportunities for prevention). Few were diagnosed at birth (mean age 3.3 years) and most (78%) were also exposed to illicit drugs. Practical value: Demonstrated the importance of early diagnosis, referral and multi-disciplinary, cross-portfolio approach to care of children with FAS and the need for accurate national data to inform intervention and prevention strategies.

2. Understanding health professionals' knowledge, attitudes and practice about alcohol and pregnancy (2002-2004)

Contribution: These studies showed that only 12% of health professionals in Western Australia knew the diagnostic features of FAS and that 97% were not very prepared to deal with FAS. Less than half routinely asked pregnant clients about alcohol use in pregnancy or provided information to women about alcohol use or its consequences to the unborn child. Most health professionals requested educational materials for themselves and their clients

Practical value: Indicates that health professionals' lack of knowledge may contribute to under-diagnosis of FAS in Australia and the need for policy and educational materials to guide their clinical practice.

3. Alcohol consumption during pregnancy in Western Australian women (2004)

Contribution: From a study of a 10% random sample of births in Western Australia, 59% of women who had given birth had consumed alcohol during pregnancy and 4% had consumed five or more standard drinks on a typical occasion in at least one trimester of pregnancy. Nearly 50% of women did not plan their pregnancy.

Practical value: Highlights the importance of informing women before they become pregnant about the risks of drinking alcohol so they can make choices about alcohol consumption during pregnancy.

4. *Providing resources for health professionals about the prevention of prenatal alcohol exposure and Fetal Alcohol Spectrum Disorder (FASD) (2006-2008)*

Contribution: In response to the results of our health professional surveys we developed, distributed and evaluated four resources for health professionals: a 38 page booklet, an A4 fact sheet, wallet cards for health professionals to give to women to support their advice and a desk-top calendar. The resources are available on

www.ichr.uwa.edu.au/alcoholandpregnancy

Practical value: Over 3,500 Western Australian health professionals were mailed the resources and results of a subsequent survey show they use the resources and have changed their practice. The resources have been updated and are available to health professionals throughout Australia.

5. *Understanding Australian women's knowledge, attitudes and practice about alcohol and pregnancy (2006)*

Contribution: This survey of over 1,100 women of childbearing age in Australia indicated that over a third were unaware of the adverse effects of alcohol on the unborn child and that over 95% want and expect health professionals to ask and advise about alcohol use. This contrasts with responses from health professionals in the surveys described above, in which only 45% believed that women wanted to be given such advice by a health professional. It was also found that knowledge of the adverse effects of alcohol in pregnancy was influenced by women's level of educational attainment but that attitudes to alcohol use in pregnancy were not.

Practical value: It is important for health professionals to ask and advise women about alcohol consumption in pregnancy. The study identified the characteristics of women who intend to drink alcohol in future pregnancies, offering health promotion opportunities and highlights that changes in drinking behaviour depend on changing attitudes in addition to knowledge.

6. *Understanding Aboriginal women's knowledge, attitudes and practice about alcohol and pregnancy (2007)*

Contribution: This qualitative study of 61 Aboriginal women from Perth, the Goldfields and Fitzroy Crossing, showed that although some participants had not heard of FAS, they attributed some adverse birth outcomes and longer term outcomes to drinking alcohol in pregnancy. Many of the participants revealed a negative attitude towards women drinking in pregnancy, but some supported that it was the individual's choice. Multiple reasons were identified to explain why some Aboriginal women drink in pregnancy, including stress, role-modelling, intergenerational affects of alcohol consumption in pregnancy and the partner's behaviour. The participants identified several strategies to support Aboriginal women to refuse alcohol in pregnancy including education, counselling and addressing the partner's drinking behaviour. Women were supportive of health campaigns, labelling and signage, providing they included but did not focus on Aboriginal women.

Practical value: These findings provide insight into Aboriginal women's knowledge, attitudes and practice towards consuming alcohol in pregnancy in Perth, the Kimberley and Goldfields regions of Western Australia, which will inform development of education materials for Aboriginal women in these communities.

7. *Review of international policies on alcohol use in pregnancy (2007)*

In 2001 the National Health and Medical Research Council (NHMRC) published revised alcohol drinking guidelines replacing a recommendation of abstinence during pregnancy with advice that the consumption of 1-2 standard drinks per occasion and fewer than 7 standard drinks per week was 'low' risk. The 2001 Guidelines caused considerable controversy in Australia. This project reviewed alcohol and pregnancy guidelines across Australian jurisdictions and compared the NHMRC 2001 alcohol and pregnancy guideline for women who are pregnant or might soon become pregnant with policies existing in other English-speaking countries in 2006.

Practical value: The publication of the results of this study informed the development of the NHMRC 2009 alcohol guidelines and resulted in the generation of policies and/or guidelines in the small number of Australian jurisdictions that did not have these in place in 2006.

8. *International survey of diagnostic services for FASD (2007-2008)*

Contribution: This survey of specialist clinics for the assessment of fetal alcohol spectrum disorders (FASD) indicated that FASD clinics were concentrated in North America (there were none in Australasia and Asia). Many clinics, including four of the five outside North America, relied on research funding, thus their sustainability was questionable. Clinics used a variety of diagnostic criteria and one third used more than one set of criteria or an adaptation of published criteria. 97% of clinics took a multidisciplinary approach to diagnosis and 94% had at least one team member with specialist training in assessment of FASD.

Practical value: The information documented in this international study is informing development of diagnostic and management services for FASD in Australia. It emphasises the need for specific training for health professionals in diagnosis and management of FASD and the value of multi-disciplinary management.

9. *Population-based longitudinal cohort studies investigating the association between dose, pattern, and, timing of prenatal alcohol and fetal and child development (2007-2009)*

There is a lack of knowledge about the relationship between dose, pattern, and timing of prenatal alcohol exposure (PAE) and fetal and child outcomes. In particular, there is a lack of knowledge about the level of risk to the baby from low to moderate levels of PAE. This has generated considerable debate about the most appropriate advice to give women about alcohol consumption during pregnancy. A new classification system for maternal alcohol consumption was devised for this project. Three studies have been conducted investigating the association between dose, pattern, and timing of PAE using the new classification system and (1) fetal growth and preterm birth, (2) language delay in two-year old children, and (3) child behaviour problems in children.

Practical value: These studies have added new knowledge about the importance of dose, pattern, and timing of PAE and the need for researchers to account for each of these when examining the effect of PAE on the developing child. The results of these studies extend our knowledge of these issues and have the potential to inform the development of policies and guidelines for women and health professionals.

10. Systematic review of interventions for FASD (2007-2009)

Contribution: From over 5000 published papers on FASD only 12 intervention studies for children with FASD were identified. In these, methodological weaknesses were common, including: small sample sizes, inadequate study design and only short term follow up. Stimulant medications, evaluated in two randomised controlled trials were beneficial. Educational and learning strategies were evaluated in seven studies and there was some evidence that virtual reality training, cognitive control therapy, language and literacy therapy, mathematics intervention and rehearsal training for memory are beneficial. Skills training improves social skills and behaviour at home and Attention Process Training improves attention.

Practical value: This study provides a comprehensive review of interventions that have been evaluated for the management of children with FASD. It highlights the lack of good quality evidence to inform management and the need for well-designed, adequately sized studies to evaluate new treatments that address the specific physical and developmental strengths and weaknesses of children with FASD.

11. Enhancing capacity to diagnose FAS (2008-2009)

Contribution: We evaluated the current diagnostic capacity for FASD in child development services in Western Australia. We measured referral patterns to child development services and current clinical practice, knowledge and attitudes of all staff within those services regarding alcohol, smoking and other drug consumption. We also explored their perceptions of the need and ability to ask about alcohol and drug use. The results showed that referring health professionals do not routinely document prenatal consumption of alcohol and other drugs. Attitudes regarding questioning about alcohol and other drug use indicated a reticence to ask. Alcohol and other prenatal drug exposures were considered less important than factors such as place of birth. FASD was not considered within the differential diagnosis for any child assessed in these services. Our evaluation will be repeated following establishment of a diagnostic capacity for FASD to evaluate change in knowledge, attitudes and practice.

Practical value: This study demonstrates a systemic failure to record alcohol and drug use within the context of child development and a reticence by health workers in these services to ask women about alcohol and other drug consumption. There is a lack of importance attributed to alcohol and other drugs as causative agents in developmental disabilities through prenatal and postnatal exposures.

12. Informing women about the prevention of prenatal alcohol exposure through a communication campaign - formative research phase (2009-2010)

Contribution: Awareness and knowledge about the risks of prenatal alcohol exposure can assist women to make informed choices about their alcohol use during pregnancy. Alcohol use in pregnancy is a sensitive issue. Formative research is necessary to develop and test messages about alcohol and pregnancy, targeting women who are pregnant and planning a pregnancy. These health promotion messages will seek to promote healthy decisions and educate women about the risks to the fetus of prenatal alcohol exposure.

Practical value: Messages about alcohol and pregnancy that are suitable for a communication campaign will be developed and tested in women of childbearing age, including pregnant women and women planning a pregnancy.