



Submission to House Standing Committee on Social Policy and Legal Affairs Inquiry into Foetal Alcohol Spectrum Disorder

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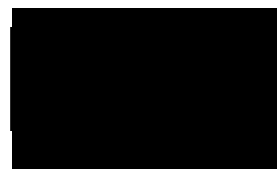
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The Telethon Institute for Child Health Research (the Institute) welcomes the opportunity to provide a submission to the House Standing Committee on Social Policy and Legal Affairs into Foetal Alcohol Spectrum Disorders.

The Institute 'Alcohol and Pregnancy Research Program' commenced in 2001 when we identified there was little information available from Australia on which to base public health practice. This is the first comprehensive, multi-centre program of research in Australia addressing prenatal alcohol exposure. Over the past 10 years Institute researchers have led and/or contributed to 19 alcohol, pregnancy and Fetal Alcohol Spectrum Disorders (FASD) research projects. As an Institute actively researching alcohol, pregnancy and FASD, we recognise the importance of prevention and early diagnosis.

Institute researchers would welcome the opportunity to meet with members of the House Standing Committee and contribute to public hearings. I will be on leave from 9 December 2011 until 9 January 2012. In my absence please contact Heather Jones on [REDACTED] [REDACTED] to discuss this submission or potential dates for the public hearings.



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Background

Exposure to alcohol in pregnancy may cause irreversible damage to the brain of the unborn child, with devastating life-long consequences. Although alcohol avoidance will prevent fetal damage, alcohol is still frequently used by Australian women in pregnancy. In Australia, a large proportion of women of child-bearing age consume alcohol and often at high levels. Results from a Western Australian study indicated that 59% of women drank alcohol in at least one trimester of pregnancy (Colvin et al., 2007). This study also revealed that 47% of women did not plan their pregnancy. In a more recent study (Peadon et al., 2011) 34% of Australian women reported drinking in their last pregnancy.

Research also shows that health professionals infrequently ask about alcohol use in pregnancy and most feel ill-equipped to advise women about alcohol use in pregnancy or its potential adverse effects. In a 2007 survey, just over half of Western Australian health professionals who cared for pregnant women routinely asked women about alcohol consumption in pregnancy and only 33% routinely provided information to pregnant women about the effects of alcohol use in pregnancy (Payne et al., 2011b). Only 18% of West Australian health professionals knew the four essential criteria for the diagnosis of Fetal Alcohol Syndrome (FAS), 67% were concerned about stigmatising the child or the family with a diagnosis of FAS and only 6% felt very prepared to deal with FAS (Payne et al., 2011a). Similar findings applied to studies of Australian paediatricians (Payne et al., 2011a).

There is good evidence however that FASD are poorly recognised in Australia and that the diagnoses are often missed or delayed. Under-diagnosis may be related to health professionals' reluctance to ask about alcohol use and lack of knowledge about FASD. Early recognition of alcohol-exposed infants and early diagnosis of Fetal Alcohol Spectrum Disorders (FASD) are crucial to allow early intervention and improve long term outcomes for children, to help treat vulnerable women and families, and prevent harm in future pregnancies.

There are no sustainable services specifically for the screening or diagnosis for FASD in Australia, no national guidelines for the diagnosis and management of FASD and no nationally accepted diagnostic or screening instrument. These barriers to diagnosis are accentuated in rural, remote and Indigenous communities where access to health services is limited. Lack of identification of FASD means we are unable to quantify the problem and thus lack evidence to advocate for much needed health professional training and diagnostic services.

The possible effects of drinking alcohol during pregnancy are brain damage, birth defects, poor growth, social and behavioural problems, delayed development and low IQ. The complex learning and behavioural difficulties observed in people with FASD may result in problems at school; with the criminal justice system; drug and alcohol misuse and addiction and mental health problems. It is critical that FASD is not considered only as a health issue. A co-ordinated and integrated approach between Commonwealth and State/Territory governments; and health, education, police, justice, child protection, drug and alcohol and mental health departments and organisations for prevention, treatment and support for children and families is essential.

FASD can directly impact on a student's ability to achieve success at school. Training and support for teachers is important to enable them to understand the different approaches required to aid a child with a FASD through school. The behavioural difficulties observed in people with FASD can also increase their risk of undertaking or being guided into criminal behaviour. A Canadian study (Conry et al 1999) found that 23% of youth remanded to an inpatient assessment unit over a one-year period received a diagnosis within FASD while another study (Streissguth et al 2004) reported that between 23% and 60% of those with a FASD will come into conflict with the law.

Support for the child diagnosed with a FASD and their family is crucial to improve their quality of life. Many children with a FASD do not live with their birth parents (Elliott, 2008) and foster/kinship carers also require help and assistance to improve the functioning of the child diagnosed with a FASD. However it is also important that there is understanding for the birth mother who may not have been aware of the harm that could be caused by consuming alcohol during pregnancy and did not intentionally try to harm the baby. It is also important to provide comprehensive services for birth mothers in order to prevent future alcohol exposed pregnancies.

FASD is not currently recognised as a disability in Australia. The move to introduce the Social Security and Other Legislation Amendment (Miscellaneous Measures) Bill 2011 to give FASD the status of a recognised disability in Australia, and the call for Parliament to continue to facilitate and support the development of a national screening and diagnostic instrument for FASD are strongly supported by the Institute.

Primary and secondary prevention strategies must involve a range of stakeholders, including researchers, health professionals, FASD support organisations and members of the community. Messages in a national campaign across a range of media and those being provided by health

professionals must be consistent with the National Health and Medical Research Council Australian Guidelines to Reduce Health Risks from Drinking Alcohol.

Consumer and community participation in the Institute 'Alcohol and Pregnancy Research Program' indicated strong support for a standard set of questions for all pregnant women. These questions should ask about diet, smoking, alcohol and other lifestyle issues. The use of a standard set of questions for all pregnant women increases the opportunity for all pregnant women to be asked about alcohol consumption in an empathetic manner. Participants in alcohol and pregnancy Community Conversations backed the call for mandatory labelling on alcoholic beverages and the need for a public campaign across a range of media to provide information for the whole community, not just women.

Recommendations to the House Standing Committee on Social Policy and Legal Affairs Inquiry into Foetal Alcohol Spectrum Disorders

Prevention strategies

- National campaign to increase public awareness and understanding of how the consumption of alcohol during pregnancy can affect the developing fetus
- Primary and secondary prevention strategies must involve a range of stakeholders, including researchers, health professionals, FASD support organisations and members of the community
- Messages in a national campaign across a range of media and those being provided by health professionals must be consistent with the National Health and Medical Research Council Australian Guidelines to Reduce Health Risks from Drinking Alcohol
- Easily accessible sources of information about alcohol, pregnancy and FASD for women and the community, that are visual rather than lengthy written descriptions, easy to understand, culturally relevant and available in different languages
- Health professional education on FASD as part of initial training and qualifications and subsequent continuing professional development
- Information on how the consumption of alcohol during pregnancy can affect the developing fetus to be included in the health education curriculum for primary and secondary school students
- Mandatory warning labels on alcoholic beverages

Intervention Needs

- Support the evaluation and implementation of the Australian Diagnostic Instrument for FASD developed by the Australian FASD Collaboration
- Develop population reference data for growth, head circumference and facial features in the Australian population
- Multidisciplinary diagnostic clinics be established in all states with outreach services available for regional areas

- Services be available to provide appropriate care and support to affected individuals and their families and carers once a diagnosis of a FASD has been made
- Provision of counselling for primary prevention in future pregnancies
- Health professional training and workforce development in diagnosis and subsequent management

Management Issues

- Support the Social Security and Other Legislation Amendment (Miscellaneous Measures) Bill 2011 to give FASD the status of a recognised disability in Australia
- Support the Australian FASD Collaboration to continue and expand their role to consolidate resources, skills and knowledge to extend the research into FASD to inform policy and practice on prevention, screening and diagnosis of FASD in Australia
- Establish national mandatory reporting for FASD diagnoses
- Mandatory recording of alcohol use in pregnancy in the minimum data set for the national perinatal data collection

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Summary of our Alcohol, Pregnancy and FASD Research

The contribution and practical value of the research conducted by Institute researchers and by our researchers in collaboration with researchers from other organisations and universities is presented below.

Current Projects

Interdisciplinary research on professional knowledge, attitude and practice of FASD in the criminal justice system in WA (2011-2012)

This project aims to:

- Find out what people within the justice sector know about FASD, their attitudes towards children and adolescents who may have a disorder in the spectrum, and their current practices in dealing with FASD.
- Identify the training and information needs relating to FASD within the justice system, so that people with FASD may receive appropriate consideration within the justice system and referral for appropriate services within and outside the justice system

This project is funded by the Foundation for Alcohol Research and Education (formerly Alcohol Education and Rehabilitation Foundation AERF).

Evaluation of information and support for parents and carers of children with a FASD (2011-2012)

This project aims to:

- To evaluate currently available Fetal Alcohol Spectrum Disorder (FASD) resources and information for parents and foster carers
- To evaluate currently available FASD resources and information for key government and non-government foster care and support agencies
- To investigate specific information needs of parents and foster carers of children with a FASD

This project is funded by the Foundation for Alcohol Research and Education (formerly Alcohol Education and Rehabilitation Foundation AERF).

Prevalence of Fetal Alcohol Syndrome in Western Australia (2011-2012)

This study will use un-named information on all cases of Fetal Alcohol Syndrome (FAS) notified to the Western Australian Register of Developmental Anomalies (WARDA), born in WA from 1980 to November 2010. Birth prevalence per 1000 births will be calculated by year of birth to examine trends over time. Prevalence ratios will be used to describe the demographic and clinical characteristics, such as maternal age, socio-economic status and place of residence, and age of the child when FAS was diagnosed. The project will be conducted at the Western Australian Register of Developmental Anomalies (WARDA) and the Telethon Institute for Child Health Research. This project is funded by NHMRC Program Grant (#572742).

Previous Projects

Development of a Screening and Diagnostic Instrument for FASD in Australia (2010-2011)

Contribution: Exposure to alcohol in pregnancy may cause irreversible damage to the brain of the unborn child, with devastating life-long consequences. An Australian FASD Collaboration, which included health professionals, researchers and consumer and community members conducted a literature review, Delphi survey of health professionals and a workshop to develop an instrument that could be used to diagnose FASD in Australia. Consumer and community participation in this project was achieved through membership on the Collaboration and Community Conversations.

Practical value: Early and accurate diagnosis will allow early intervention and improve long term outcomes for children, help treat vulnerable women and their families and help prevent the subsequent birth of affected children.

A final report was submitted to the Commonwealth Department of Health and Ageing in September 2011. While this report is being considered by the Department of Health and Ageing and the detailed conclusions are confidential, the Institute is strongly supportive of national guidelines for the diagnosis of FASD. We commend the recommendations/findings and conclusions of this project to the House Standing Committee.

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.

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

Contribution: 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. Four 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, (3) child behaviour problems and (4) birth defects in children. A fifth study compared the results of the studies using the new method of

classifying prenatal alcohol exposure with the results obtained using traditional methods of classification.

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.

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.

Systematic review of interventions for FASD (2007-2010)

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. This study is being updated in 2010 to incorporate the latest research and will be submitted to the Cochrane Library as two separate reviews on pharmacological and non-pharmacological interventions for FASD.

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.

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.

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 effects 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.

Providing educational 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 and a wallet cards for health professionals to give to women to support their advice.

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 on <http://www.dohpackcentre.com.au/DOH/Login.aspx>

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.

Alcohol consumption during pregnancy in Western Australian women (2007)

Contribution: From 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.

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: Indicated 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. Informed development of educational materials for health professionals.

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 severity, complexity and impact of FAS in Australia: (86% had central 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.

Contributions to policy and practice

Intergovernmental Committee on Drugs (IGCD) Working Party on FASD (2006-2009)

Contribution: Three members of the FASD Steering Group were members of the Working Party (Elliott (Deputy Chair and Editor of Monograph), Bower and Burns (Editor of Monograph)) that was convened by the Ministerial Council on Drugs Strategy. The Working Party initiated and supported research into FASD, including examination of the economic impact of FASD and services and

treatment for FASD. It compiled a log of FASD-related activities in Australia. The Working Party convened a multi-disciplinary National Conference on FASD, co-sponsored by the Commonwealth Department of Health and Ageing (DoHA) and Drug and Alcohol Services South Australia (DASSA) and wrote and edited a Monograph on FASD in Australia to be published by DoHA. One of the recommendations of this report was the development of a nationally agreed screening and diagnostic tool.

Practical value: This Working Party was highly productive in promoting research and education and allowing national collaboration between individuals working with FASD.

NHMRC Review of Australian Alcohol Guidelines Working Committee (2006-2009)

Professor Elliott was a member of the working committee that reviewed and revised the 2001 National Health and Medical Research Council Australian alcohol guidelines with respect to alcohol use during pregnancy. Members of the FASD Project Steering Group provided feedback on the guidelines during a process of community consultation.

Practical value: Produced the document NHMRC Australian Guidelines to reduce health risks from drinking alcohol, Commonwealth of Australia 2009. ISBN 1864963743.

Development of the WA Child and Youth Health Network FASD Model of Care Working Group (2008-2010)

Contribution: Three researchers from the Alcohol and Pregnancy research program were selected to participate on the WA Child and Youth Health Network FASD Model of Care Working Group. The researchers were involved in contributing to and/or writing a number of the chapters of the document including prevention, epidemiology, diagnosis, screening and early detection and monitoring and evaluation.

Practical value: The FASD Model of Care provides a wide range of information that will educate and enable health professionals to deal with children presenting with a FASD including early detection, diagnosis, and treatment. The document prioritises prevention strategies recognizing that FASD are potentially preventable and that there is no cure. It also recognizes the importance of supporting and treating mothers who are dependent on alcohol and provides guidelines to enable health professionals to manage their treatment. It is the first comprehensive document on FASD for health professionals in Australia.

Alcohol, Pregnancy and FASD Publications

2011

Peadon, E., Payne, J., Henley, N., D'Antoine, H., Bartu, A., O'Leary, C., Bower, C., & Elliott, E. J. Attitudes and behaviour predict women's intention to drink alcohol during pregnancy: the challenge for health professionals. *BMC Public Health*, 2011, 584. doi: 10.1186/1471-2458-11-584.

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