



Submission from the Russell Family Fetal Alcohol Disorders Association [rffada]

Standing Committee on Social Policy and Legal Affairs
INQUIRY INTO FETAL ALCOHOL SPECTRUM DISORDER [FASD]

BACKGROUND

The Standing Committee on Social Policy and Legal Affairs is to inquire into and report on developing a national approach to the prevention, intervention and management of FASD in Australia, with particular reference to:

- **Prevention strategies** – including education campaigns and consideration of options such as product warnings and other mechanisms to raise awareness of the harmful nature of alcohol assumption during pregnancy,
- **Intervention needs** – including FASD diagnostic tools for health and other professionals, and the early intervention therapies aimed at minimising the impact of FASD on affected individuals, and
- **Management issues** – including access to appropriate community care and support services across education, health, community services, employment and criminal justice sectors for the communities, families and individuals affected by FASD

rffada SUBMISSION

INTRODUCTION

In 2005, the founder of the Russell Family Fetal Alcohol Disorders Association (rffada) Elizabeth Russell published a book called *Alcohol and Pregnancy – A Mother's Responsible Disturbance*. In this book, now a free download on <http://rffada.org>, are recommendations which remain valid today - some of which are outlined below.

PREVENTION STRATEGIES:

Education campaigns

In Australia there still appears to be a range of advice, a lack of public education and a considerable level of confusion about alcohol use in pregnancy.

There is a wealth of emerging research in North America that demonstrates that the moderate use of alcohol (ie one to two units per day) has no place in pregnancy. Until recently the (Australian) National Health and Medical Research Council had the view that two units of alcohol per day can be safely consumed during pregnancy.¹ Thankfully it is now recommended that no alcohol is the safest message.

¹ <http://www.nhmrc.gov.au>

Anecdotal evidence suggests that in their efforts to avoid causing anxiety or guilt, many physicians counsel “moderation” thus giving mixed messages about alcohol. The prudent approach, given what is now scientifically known about alcohol’s fetal impacts, must surely be to recommend no alcohol is consumed when pregnant in order for babies to have as healthy a start to life as possible.

The rffada has had cause to change the wording of much of the information written about alcohol and pregnancy before on-forwarding or incorporating it in presentations or documents because we (researchers and workers in FASD) have not yet identified the correct word usage.

For instance in many research and other articles and documents it is said, “When women drink alcohol while pregnant, they are in danger of damaging their unborn baby” when we could equally accurately say, “When alcohol is consumed while pregnant it is possible that it can damage the fetus (or ‘baby’)”. It is just as easy to say but it takes the blame away from the mother. This is a key issue when media education begins and the rffada recommends that a parent advocate is on any committee or steering group related to education, advertising or media statements.

In the same manner as sexual abuse, domestic violence and other previously ‘hushed up’ conditions, we need to identify and use the correct language at the start so that it will be understood and used in time by the general public. As an active presenter on this topic I have had many queries relating to blame and shame and understand that not only do we need to offer education about alcohol and pregnancy and FASD, but also educate on the most inoffensive terminology to use. The public needs to be encouraged towards the understanding that there are always reasons alcohol is consumed during pregnancy and only rarely is it deliberate. Even in cases of purposeful abortion it must be understood that the internal and external circumstances for the mother must be unbearable.

Without the change in terminology occurring it is possible that women will not ‘come out’ and freely discuss this condition and it is crucial that as many women as possible do so. Hundreds of books, tens of thousands of research (projects) and scholarly articles and untold public health reports have been generated in the last thirty years. Yet one voice has been mostly silent, the voice of the birth mothers themselves¹.

When discussing pregnant women and alcohol consumption the most appropriate language is that which takes the blame from pregnant women and places it on alcohol.

For example language which states, “When a pregnant woman consumes alcohol”, places a measure of blame on the pregnant woman. If we use language which focuses the listener or reader on the alcohol, “when alcohol is consumed while pregnant” we will have more acceptance of the fact that mothers and fathers are not to be blamed or shamed should they deliver a child or children with FASD.

If we take steps to reduce the blame now, more birth mothers will feel confident in speaking up about the condition.

The rffada encourages the use of these terms to all who have cause to discuss this condition and its implications.

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EDUCATION

The rffada recommends that the government provide and/or support initiatives that enable the implementation of Public Awareness Campaigns for the prevention of FASD disorders that include:

- Long-term sustainable strategies to enhance primary, secondary and tertiary prevention efforts within a community development approach across all states and territories to raise the awareness of the risk of alcohol use during pregnancy
- Primary prevention strategies that involve school-based educational programs; early recognition; treatment of at-risk women; and community-sponsored, culturally appropriate programs
- Resources that provide a clear and consistent message about alcohol use during pregnancy in line with NHMRC and World Health Organisation guidelines for a healthy pregnancy
- Programs aimed at surveillance of pregnancy exposures to alcohol and their outcomes in order to capture the true incidence of FASD and enable targeting and evaluation of prevention efforts. NB There has only been one surveillance program by the Telethon Institute for Child Health Research² and the results have been cited by those who established the program as clearly being under-ascertained. There is a program currently in the Fitzroy Valley in Western Australia called the Liliwan Project³ - the first population based study on FASD in Australia however this is focusing solely on the Indigenous communities of Fitzroy Crossing and Halls Creek and will not be representative of the general Australian population base.
- The labelling of alcoholic beverages and warning posters in hotels with a message such as “Alcohol may harm the unborn child – No alcohol is the safest choice for a healthy pregnancy.” The Russell Family Fetal Alcohol Disorders Association has designed and printed posters for free download⁴ and distribution. The Foundation for Alcohol Rehabilitation and Education (FARE) has developed submitted images and wording for the labelling of alcohol⁵ and warning posters
- The Australian Medical Association acknowledge and accept that FASD is a major health concern and take action to update their Clinical Practice Guidelines in relation to the diagnosis of FASD (The Telethon Institute for Child Health Research in Western Australia surveyed all medical practitioners in Western Australia⁶ and found that only 2% felt prepared to deal with patients or carers in the area of fetal alcohol syndrome)

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² [<http://www.apsu.org.au/index.cfm?objectid=D7C9C8A7-919E-08F5-B051C757D74FDD9B>]

³ [www.ichr.uwa.edu.au/fasdproject]

⁴ [<http://rffada.org/fasd/brochures-forms/>]

⁵ [<http://www.fare.org.au/wp-content/uploads/2011/11/MEDIA-RELEASE-November-9-FARE-Feedback.pdf?9d7bd4>]

⁶ Health professionals knowledge practice and opinions about

Payne J, Elliott E, D'Antoine H, O'Leary C, Mahony A, et al. (2005) Australian and New Zealand Journal of Public Health;29(6):558-564

- That the Australian Medical Association implement education programs for its members to bring them up to date with all aspects of this disability eg:
 - Becoming familiar with the screening tools that are available to diagnose the condition in children at various ages
 - Understanding the importance of early intervention should behavioural or physical abnormalities consistent with FASD be identified
 - Recognising the crucial role they can play in prevention by asking women about their drinking habits, whether or not they are pregnant
 - Ensuring that any parent who brings his or her child for a consultation regarding FASD, obtains suitable and appropriate options during consultation and for referral.
- As the FASD Collaboration headed by the Telethon Institute for Child Health Research (a member of the rffada was the consumer representative for this collaboration) has concluded their protocol for the screening and diagnosis of FASD, there will be an urgent need for diagnostic clinics in each capital city in Australia. While Perth and the Westmead Hospital in Sydney are preparing to establish a FASD clinic there needs to be a clinic at least in each major city.

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- There is an urgent need for the development of FASD treatment services. Current services would be sufficient if staff were adequately trained in the delivery of FASD related services (the rffada has collaborated with a registered training organisation Training Connections Australia⁷ to develop and deliver the first publicly available FASD training in Australia).

INTERVENTION:

The Better Start initiative⁸ also appears to be appropriate for children with FASD as early intervention is one of the key strategies in ensuring the child and family have appropriate support, intervention strategies, expectations and knowledge. This understanding and knowledge can also be passed on to teachers, parents, friends and family. The rffada prepared a submission to have children with FASD included in this initiative however that does not appear to have occurred. Children with FASD require:

- up to \$12,000 in funding for early intervention services and treatments
- additional assistance for children who live in outer-regional, rural or remote locations to help with the costs of accessing services
- a Medicare item for the development of a treatment and management plan up to the age of 13

⁷ WWW.TRAININGCA.COM.AU

⁸http://www.fahcsia.gov.au/sa/disability/progserv/people/betterstart/Pages/better_start_early_intervention.aspx

- Medicare items for up to four allied health diagnostic services, the results of which contribute to the development of the treatment and management plan, and
- Medicare items for up to 20 relevant allied health services in total for each eligible child up to the age of 15 provided the treatment and management plan is in place before the age of 13.

MANAGEMENT ISSUES:

There only 2 active not for profit organisations in Australia which work specifically to support those parents, carers and individuals living with FASD. Funding must be available to develop and deliver services which support people with this condition in much the same way as Autism organisations have done.

There needs to be an overarching proactive government funded organisation overseeing a network of similar organisations in each state. The Russell Family Fetal Alcohol Disorders Association has been provided with a great deal of in-kind corporate sponsorship from Training Connections Australia and its sister companies ITEC Employment and Enterprise Management Group and from the Commonwealth Bank of Australia as a result of the founder being a finalist in the Australian of the Year Awards. However funding needs to be available for training and for staffing this organisation as it currently operates with support from volunteers and the work; presentation requests; enquiries (often from people in distress); keeping up with Facebook contacts and comments; administration and information dissemination is too much for the volunteers we have.

Funding from the government to continue the work that has been started would mean that the rffada, with input from the corporate organisations mentioned above, could very quickly develop support structures Australia-wide to support families once the diagnostic protocol developed by the FASD Collaboration becomes public.

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Elizabeth Russell

Russell Family Fetal Alcohol Disorders Association (rffada)

Member FASD Scientific Network - University of Queensland – Members' details and affiliations set out below

16 November 2011

Members of the FASD Scientific Network

Professor Paul Colditz, Director of Perinatal Research Centre, UQCCR. Prof Colditz is a neonatal clinician with research activity and contributions in neonatal intensive care, brain development, perinatal brain injury, plasticity, protection and repair. He has expertise in randomised clinical trials, brain imaging and neurodevelopmental outcomes which will be useful as components of a multidisciplinary approach to prevention, diagnosis and interventions in FASD.

Professor Wendy Hoy, Director of Centre for Chronic Diseases, University of Queensland, is a medical doctor with extensive experience in chronic disease risk factors, consequences and mitigation and especially in Indigenous populations. Professor Hoy has pioneered the demonstration of the influence of early life events on adult health in that environment.

Professor Emma Whitelaw, Australian Fellow, Chair of Genetics and Population Health Division & Head of Epigenetics Laboratory, QIMR. Recipient of the International Union of Biochemistry and Molecular Biology (IUBMB) Jubilee Medal, Professor Whitelaw's laboratory has developed an animal model of fetal alcohol syndrome.

Professor Wayne Hall, Ethicist and Addiction Specialist, UQCCR, Team member on FARE sponsored project, "FASD in the criminal justice system". Professor Hall is currently researching the ethical and public policy implications of research on the genetics and neurobiology of addiction and drug-related harm. He has worked with Dr Ernest Hunter and others on the effects of alcohol use on Indigenous health in the Kimberley region of Western Australia and Far North Queensland.

Professor David Pow, Senior Research Fellow, Neuroscience, UQCCR

A/Professor Glenda Gobe, Molecular & Cellular Pathology, UQCCR

A/Professor Stephen Rose, Principal Research Fellow, Biomedical Engineer, UQ Centre for Advanced Imaging. Dr Rose's research interests are towards the development of novel imaging technology to improve understanding of brain injury and mechanisms of recovery. An example would be linking neuroimaging biomarkers with genetic and clinical patient phenotypes to generate innovative strategies for measuring the efficacy of new therapies.

Mrs Anne Russell, Director, Russell Family Foundation for Fetal Alcohol Disorders, FASD Educator and Advocate, team member on FARE sponsored project, "FASD in the criminal justice system". Anne has written three books on FASD and produced videos to assist parents and carers of children and adults with FASD.

Professor Noel Hayman, UQ School of Medicine, Clinical Director/Physician, Inala Indigenous Health Service - Professor Hayman is widely acclaimed for adapting the mainstream primary health care model to better service the needs of urban Aboriginal populations.

A/Professor Gail Garvey, Menzies School of Health Research, Division Leader, Epidemiology and Health Systems, Indigenous Researcher, Carer of Aboriginal child with FASD.

Dr James Scott is a child and adolescent psychiatrist with a PhD in epidemiology. Dr Scott's clinical work is treating children in care who have experienced abuse and neglect as well as treating children and

adolescents with developmental disorders and psychosis. He continues to undertake research in child psychiatry with the Queensland Centre for Mental Health Research (QCMHR) and UQCCR.

Dr Stephen Stathis, Associate Prof Stephen Stathis has a dual fellowship in paediatrics and psychiatry. He has treated young people in the Brisbane Youth Detention Centre for over 10 years and has expertise in adolescent forensic psychiatry. His research interest in FASD includes its impact on young people within the juvenile justice system.

Dr Tom Burne Behavioural Neuroscientist, Queensland Brain Institute - Dr Burne examines neurodevelopmental animal models of early life exposures and their impact on brain development and behaviour. He has expertise in areas covering behavioural phenol-typing, psychopharmacology and structural imaging of rodent (rat and mouse) models.

Dr Suyinn Chong Postdoctoral Fellow in Genetics, QIMR - Dr Chong and her colleagues have established a new mouse model of prenatal alcohol exposure that reproduces several of the diagnostic features of foetal alcohol syndrome (FAS), including growth restriction, craniofacial dysmorphism and central nervous system defects. This model system will be used to investigate the underlying causes of FAS, focusing on epigenetics.

Dr Leith Moxon-Lester, member Perinatal Research Group, UQCCR. Her main interest is exploring how impaired one carbon metabolism caused by alcohol and other environmental and genetic factors impacts on foetal and postnatal brain development. Nutritional supplements to correct metabolic dysfunction before and during pregnancy and in early childhood could potentially reduce the severity of FASD.

Dr Rosa Alati, NHMRC Postdoc Research Fellow, QADREC, UQ School Pop Health - Dr Alati's expertise is in the early origin of alcohol problems. She has published on the effects of in-utero alcohol exposure with adverse outcomes in adolescents and adults. She has evaluated a range of Indigenous drug and alcohol problems and worked with Indigenous people in Victoria, Northern Territory and Western Australia.

A/Prof Karen Moritz, NHMRC Senior Research Fellow, UQ School of Biomedical Sciences: We are using rodent models to investigate the long term effects of prenatal ethanol exposure on outcomes such as blood pressure, renal function and metabolic function.

Professor Heather Douglas, TC Bierne School of Law, University of Queensland, Team leader of FARE sponsored project, "FASD in the criminal justice system". Dr Douglas' focus is on criminal law with particular interests in sentencing, criminal responsibility and the way the criminal justice process impacts on Indigenous people.

Dr Margo Pritchard, Epidemiologist, Perinatal Researcher, University of Queensland CCR & RBWH. Dr Pritchard's research and clinical focus is in high-risk child and family surveillance and intervention. She has provided incremental evidence (population studies, RCTs) to support high risk primary health programs to optimise long-term neurobehavioral/development militating against attenuation of early intervention effect.

Ms Megan Williams, Indigenous PhD Candidate, UQ School of Population Health. Megan is currently establishing a research higher degree program focusing on alcohol and drug use post-prison release by

Aboriginal and Torres Strait Islanders. She is also evaluating the Lotus Glen Indigenous Peer Education Project funded by Queensland Corrective Services and Queensland Health.

Dr Peter Nixon, Honorary Reader, School of Chemistry & Molecular Sciences, UQ - Dr Nixon's interest is in establishing whether a single, acute alcohol dose given to a pregnant, experimental animal, opens the blood-CSF barrier at the choroid plexus which then grossly alters the CSF chemistry, particularly by a large increase in the CSF concentration of excitotoxic glutamate.

Dr Tracey Björkman, LMRF Senior Research Fellow, PRC, UQCCR: Understanding the role of excitotoxic mechanisms of alcoholic brain injury in the developing brain.

Dr Simon Finnigan, Senior Research Fellow (NHMRC Career Development Awardee), UQCCR - Dr Finnigan is a neurophysiologist with substantial expertise in the detection and monitoring of abnormal brain function in various clinical populations; including stroke patients, newborn babies suffering from asphyxiation at birth, and premature babies. A primary theme and objective of Dr Finnigan's work is to deliver novel insights into brain dysfunction which can uniquely inform clinical management (eg. diagnoses, prognoses and/or interventions).

Ms Lorian Hayes, Indigenous PhD Candidate, Director of National Indigenous Australian Fetal Alcohol Network (NIAFASEN), with qualifications in epidemiology and diagnostic training and assessment of FASD - Lorian has lead awareness and education on FASD across Australia and is internationally recognised for her effort.

Dr Janet Hammill, Indigenous Ethnographer, Coordinator of FASD Research Network, member of Perinatal Research Group UQCCR, Team Member on FARE sponsored project, "FASD in the criminal justice system". Dr Hammill's interests are in trans-generational experiences of stress alcohol use that can result in poor neurodevelopmental outcomes.