

SUBMISSION

**To the House of Representative Standing Committee on Social Policy and Legal Affairs:
Inquiry into Fetal Alcohol Spectrum Disorder**

On behalf of the Fetal Alcohol Spectrum Disorder (FASD) Research Network¹

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The following submission will not outline a full profile of Fetal Alcohol Spectrum Disorders (FASD) as the topic was most capably presented to the House by Honourable Members, Drs Sharman Stone and Mal Washer, and Mr Sid Sidebottom² in August 2011. This submission proposes a TEN POINT PLAN OF ACTION to build national capacity to address FASD at every level of community, human service, policy and science. It proposes rigorous endeavours for early identification, diagnostic services, supportive interventions, prevention strategies and innovative research.

In closing the inaugural symposium of the Fetal Alcohol Spectrum Disorder Research Network (FASDRN) on 9th September 2011 at the Queensland Institute of Medical Research in Brisbane, those attending identified the most crucial element in creating a countrywide awareness of FASD was to educate the medical profession. This may clarify the inconsistent preventive messages about FASD being given to women about alcohol use during pregnancy despite the present National Guidelines, issued in 2009, recommending no alcohol use during pregnancy as the safest option.

As yet there are no credible statistics of prevalence in Australia. Other than a recently initiated prevalence study in the Fitzroy Valley³, there are a number of smaller national

¹ Attachment 1 – list of members

² Attachment 2 - Hansard House of Representatives Main Committee, Monday 22nd August 2011, pages 141-146.

³ Marulu, The Lilliwann Project, 'Fetal Alcohol Spectrum Disorders (FASD) Prevalence Study in the Fitzroy Valley: A Community Consultation' Eds: Latimer J, Elliott e, Fitzpatrick J, Ferreira M, Carter M, Oscar J, Kefford M, April 2010.

studies in progress which demonstrates increasing concerns about the damage caused by alcohol exposure before birth. There is good reason to suspect a high incidence of FASD in the mainstream population from data published in the Australian National Council on Drugs (ANCD) Report of 2007 when 451,000 Australian children from birth to 12 years were found to be living in binge drinking families. These statistics represent one child in every eight children.

Gleaning the best from forty years of North American research and incorporating lessons learned through the process we propose the following action plan.

1. Initiate a **national media awareness campaign** to educate all alcohol users, men and women, as a matter of urgency. This is a crucial element given that alcohol marketing continues to blanket the entire population. As the campaign progresses, higher risk populations can be identified for more specific interventions.
2. Recognise FASD as an **eligible diagnostic category for disability-related benefits** programs. Services should be available for those with developmental/ functioning irrespective of their IQ.
3. Embed **FASD training into curricula of all health disciplines** – medicine, nursing, social work, psychology, physiotherapy, occupational therapy, and others to assure diagnoses and treatment have fidelity with research evidence. Establish **community training** as inextricable from the diagnostic process to assure adequate capacity for implementation of neurobehaviorally-informed recommendations.
4. Improve **identification** by establishing neurobehavioral screening systems for FASD. These systems will also increase professional individual and multidisciplinary capacity in all geographic areas from metropolitan to rural and remote services and across all socioeconomic groups.
5. **Intensify research initiatives** and interagency coordination:
 - Systematically **evaluate the research evidence** for all FASD related activities and collaborations across tertiary institutions, non-profit organisations and stakeholders.
 - **Inject substantial funding** into essential collaborations.
 - Make it **mandatory that all research on child development** carry a compulsory requirement that parental alcohol use is ascertained as far as possible during the course of the study and that study design adequately represents latest research on FASD.
 - Fund studies that **map the full fetal alcohol spectrum** and identify causal mechanisms, biomarkers, paternal input, transgenerational transfer and other

possible contributors. Fund investigations into protective mechanisms, such as the role of micronutrients during pregnancy.

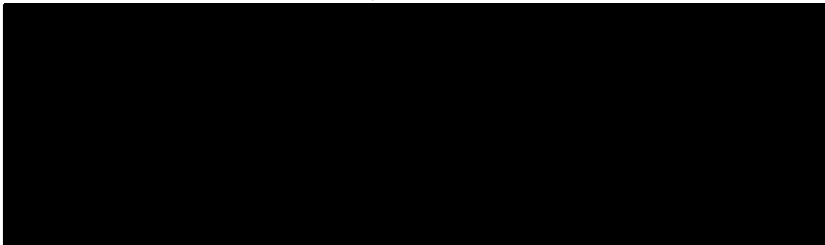
- **Initiate relevant longitudinal studies** of persons affected with FASD⁴ with parallel participatory action interventions across disciplines and customised for Australian systems.
6. **Legislate for obligatory warning labels** on alcohol beverage containers and fund prime time media advertisements promoting preparation for pregnancy by both partners and during pregnancy with a “no alcohol no risk” message. As an example, for each advertisement promoting alcohol on television, an equal time space must carry health warnings relevant to FASD.
 7. Promote comprehensive evidence, informed and accessible **continuum of care** for families raising infants, children and adolescents with FASD as well as youth, adults and older individuals living with FASDs.
 8. Implement universal and **on-going education about FASDs**, family planning and peer education with unfolding evaluation of knowledge gained and gaps remaining. These must be conducted across multiple service systems including criminal justice.
 9. Enhance strong, collaborative interagency and **carer/parent-driven leadership** at state and national levels to inform legislators, policymakers and public.
 10. Maintain a **national forum** in which parents, advocates, professional organisations and experts in the field of FASDs can advance essential services and advocate for research on individuals with FASDs and their families.
 - Focus on **grassroot areas** to recognise their support as powerful and efficient agents of change.
 - Establish effective **community interventions** using emerging best practices within a neurobehavioral framework that includes translation of science, practice and wisdom-based interventions and strategies.
 - Encourage **preparation for pregnancy** using multiple public health strategies that target males and females.
 - Supply **additional resources** to family planning and school nurses, and midwives to educate in managing lifestyle choices.

⁴ It should be possible to embed key questions about perinatal alcohol use by both parents into the existing Longitudinal Study on Australian Children (LSAC) and the Longitudinal Study on Indigenous Children (LSIC).

- Introduce **peer educators** under a career structure scheme.
- **Implement closely aligned programs** in jails, treatment centres, mental health and social services programs for both male and female clients.
- Develop and implement **training for all community sectors** with establishment of informed systems of care as evidenced by conceptual consistency and congruent application of neurobehavioral principles that are evidence-based.
- Improve the **quality and utilisation of interventions** in all service areas by evaluating policy, program and practice for relevance for people with FASD.
- Continually scan services to **identify missed opportunities** such as the inclusion of alcohol education into sexual health support services.

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