
The Parliament of the Commonwealth of Australia

FASD: The Hidden Harm

**Inquiry into the prevention, diagnosis and
management of Fetal Alcohol Spectrum Disorders**

House of Representatives
Standing Committee on Social Policy and Legal Affairs

November 2012
Canberra

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Foreword

Children are our hope distilled. At birth they are a launching pad for all of society's dreams and aspirations. They personify humanity's unlimited potential. Yet tragically, for too many babies in Australia, their opportunities and circumstances are severely diminished even before they draw their first breath.

The harm caused by Fetal Alcohol Spectrum Disorders (FASD) is hidden in the damaged brain. It may masquerade as naughty behaviour, poor parenting, lack of discipline, or simple-mindedness. However, it is none of these things.

FASD is an entirely preventable but incurable condition caused by a baby's exposure to alcohol in the womb. The consequences are expressed along a spectrum of disabilities including: physical, cognitive, intellectual, learning, behavioural, social and executive functioning abnormalities and problems with communication, motor skills, attention and memory.

While the risk of FASD increases with the quantity of alcohol a pregnant woman consumes, what is not widely understood is that even small amounts of alcohol, at critical times, can result in irrevocable damage to the developing fetus. In many cases, the damage is not physically apparent but can manifest itself in lifelong learning difficulties and cognitive impairment.

Awareness of FASD is increasing in Australia, but much work needs to be done. The series of recommendations made by the Committee outline a national strategy to prevent, identify and manage FASD in Australia. This national strategy can spearhead progress in all sectors – health, education, criminal justice, social support – toward understanding, treating and most importantly eliminating FASD.

The Committee is grateful for the unstinting work of individuals and organisations that have contributed to increasing awareness and knowledge of FASD and its prevalence in Australia and have lobbied for action, often without recognition or remuneration. These efforts have been the catalyst for this parliamentary inquiry and the actions that will follow.


Time and again during the inquiry, the Committee heard about the devastation that can be caused by prenatal alcohol exposure. Foster carers spoke about children in their care and the enormous challenges they face. Paediatricians spoke about the lack of awareness and lack of diagnostic resources for FASD. Indigenous community leaders spoke about communities and culture in crisis due to FASD. Women spoke about the conflicting health messages given and the desperate need for clear advice from health professionals.

Amidst all these voices, the most moving was that of Tristan, a young man affected by FASD. Tristan says:

I wish I can be a policeman just when I grow up ... Nah ... I just want to be normal first. I just want to be normal.

We owe it to Tristan, and to every child and every woman and every family in Australia, to bring to light the risk of FASD. We cannot keep hidden the devastating harms being caused by prenatal alcohol exposure.

Mr Graham Perrett MP
Chair



Membership of the Committee

Chair Mr Graham Perrett MP

Deputy Chair Hon. Judi Moylan MP

Members Mr Shayne Neumann MP

Ms Michelle Rowland MP
(to 07 February 2012)

Ms Laura Smyth MP


Hon. Dr Sharman Stone MP

Mr Mike Symon MP
(from 07 February 2012)

Mr Ross Vasta MP

Committee Secretariat

Secretary	Dr Anna Dacre
Inquiry Secretary	Ms Natalya Wells Ms Pauline Cullen
Administrative Officers	Katrina Gillogly Rebeka Mills



Terms of reference

Fetal Alcohol Spectrum Disorder (FASD) is an overarching term used to describe a range of cognitive, physical, mental, behavioural, learning and developmental disorders that result from fetal exposure to alcohol.

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 consumption 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



List of abbreviations and acronyms

ACCG	Australian Children's Commissioners and Guardians
ADCA	Alcohol and other Drugs Council of Australia
ADJC	Aboriginal Disability Justice Campaign
AHAWA	Australian Hotels Association Western Australia
AHRC	Australian Human Rights Commission
AIHW	Australian Institute of Health and Welfare
AMA	Australian Medical Association
ANPHA	Australian National Preventive Health Agency
ANZPAA	Australia and New Zealand Policing Advisory Agency
APONT	Aboriginal Peak Organisations Northern Territory
ARBD	Alcohol-Related Birth Defects
ARND	Alcohol-Related Neurodevelopmental Disorders
ASD	Autism Spectrum Disorders
Better Start	Better Start for Children with a Disability Initiative
DEEWR	Commonwealth Department of Education, Employment and Workplace Relations
DHHS	Department of Health and Human Services, Tasmania

DoHA	Commonwealth Department of Health and Ageing
DSICA	Distilled Spirits Industry Council of Australia
FAE	Fetal Alcohol Effects
FaHCSIA	Commonwealth Department of Families, Housing, Community Services and Indigenous Affairs
FARE	Foundation for Alcohol Research and Education
FAS	Fetal Alcohol Syndrome
FASD	Fetal Alcohol Spectrum Disorders
FPDN	First Peoples Disability Network
GP	general practitioner
KPHU	Kimberley Population Health Unit
McCusker Centre	McCusker Centre for Action on Alcohol and Youth
NAAA	National Alliance for Action on Alcohol
NCID	National Council on Intellectual Disability
NDIS	National Disability Insurance Scheme
NHMRC	National Health and Medical Research Council
NOFASARD	National Organisation for Fetal Alcohol Syndrome and Related Disorders
NRHA	National Rural Health Alliance
pFAS	Partial Fetal Alcohol Syndrome
PHAA	Public Health Association of Australia
RACP	Royal Australasian College of Physicians
RFFADA	The Russell Family Fetal Alcohol Disorders Association
Telethon Institute	Telethon Institute for Child Health Research
the Blewett Report	<i>Labelling Logic: Review of Food Labelling Law and Policy</i>

(2011)

the Collaboration	The Australian FASD Collaboration
the Forum	The Legislative and Governance Forum on Food Regulation
the Guidelines	Australian Guidelines to Reduce Health Risks from Drinking Alcohol
WANADA	Western Australian Network of Alcohol and other Drug Agencies
WFA	Winemakers' Federation of Australia
WHO	World Health Organization



List of recommendations

1 Introduction

Recommendation 1

The actions set out in this report should constitute the Commonwealth Government's National Plan of Action for the prevention, diagnosis and management of Fetal Alcohol Spectrum Disorders (FASD). This FASD National Plan of Action should be publicly released by 1 June 2013.

Recommendation 2

The Committee recommends that the Commonwealth Government immediately establish an ongoing Fetal Alcohol Spectrum Disorders (FASD) Reference Group reporting to the relevant Commonwealth Government Ministers, consisting of a select group of appointed practitioners, professionals and stakeholders who are experts in the field of prevention and management of FASD.

The role of the FASD reference group would be to oversee and advise on the FASD National Plan of Action.

Recommendation 3

The Committee recommends that the Commonwealth Government publicly report:

- within 12 months on the progress of the implementation of a national Fetal Alcohol Spectrum Disorders (FASD) diagnostic and management services strategy, a critical element of the FASD National Plan of Action, and
- within five years on the progress towards eliminating FASD in Australia.

3 FASD awareness and prevention

Recommendation 4

The Committee recommends that the Commonwealth Government work with the National Health and Medical Research Council and professional peak bodies to ensure that all health professionals are:

- fully aware of the National Health and Medical Research Council Guidelines that advise women not to drink while pregnant;
- have alcohol consumption impacts on pregnancy and the developing fetus incorporated into all general practice and midwifery training;
- trained in discussing the National Health and Medical Research Council Guidelines and alcohol consumption with women; and
- skilled in asking women about alcohol consumption and recognising and responding to women at risk.

By 1 January 2014, all health professionals, including sexual health advisors, midwives, general practitioners and obstetric professionals should be promoting the consistent message that not drinking while pregnant is the safest option, in line with the National Health and Medical Research Council Guidelines.

Recommendation 5

The Committee recommends that the Commonwealth Government establish mechanisms for health professionals to record women's alcohol consumption during pregnancy, or at the time of birth for women who have not presented for prenatal care, and to ensure such information is recorded in midwives data collections or notifications across Australia.

Recommendation 6

The Committee recommends that the Commonwealth Government implement a general public awareness campaign which promotes not drinking alcohol when pregnant or when planning a pregnancy as the safest option, consistent with the National Health and Medical Research Council Guidelines.

Specific awareness campaigns should be developed to target youth and Indigenous communities.

Nationwide campaigns should be started no later than 1 July 2013.

Recommendation 7

The Committee recommends that the Commonwealth Government mandate a health advisory label advising women not to drink when pregnant or when planning a pregnancy to be included on the packaging of all pregnancy and ovulation testing kits. These labels should be in place by 1 October 2013.

Recommendation 8

The Committee recommends that the Commonwealth Government raise with the States and Territories the critical importance of strategies to assist Indigenous communities in managing issues of alcohol consumption and to assist community led initiatives to reduce high-risk consumption patterns and the impact of alcohol.

Recommendation 9

The Committee recommends that the Commonwealth Government work with State and Territory governments to identify and implement effective strategies for pregnant women with alcohol dependence or misuse.

Recommendation 10

The Committee recommends that the Commonwealth Government seek to include health warning labels for alcoholic beverages, including a warning label that advises women not to drink when pregnant or when planning a pregnancy, on the Legislative and Governance Forum on Food Regulation's December agenda.

The Commonwealth Government should determine the appropriate format and design of the labels by 1 March 2013, to assist the alcohol industry in adopting best practice principles and preparing for mandatory implementation.

Recommendation 11

The Committee recommends that the Commonwealth Government mandate the range of health warning labels for alcoholic beverages as decided by the Legislative and Governance Forum on Food Regulation.

- The warning labels should consist of text and a symbol and should be required to be displayed on all alcohol products, advertising and packaging by 1 January 2014;
- The minimum size, position and content of all health warning labels should be regulated; and
- The introduction of mandated warning labels should be accompanied by a comprehensive public awareness campaign.

Recommendation 12

The Committee recommends that the Commonwealth Government commission an independent study into the impacts of the pricing and availability of alcohol and the influence of these factors in the changing patterns of alcohol consumption across age groups and gender.

The study should be completed by 1 October 2013.

Recommendation 13

The Committee recommends that the Commonwealth Government commission an independent study into the impacts and appropriateness of current alcohol marketing strategies directed to young people. The study should have regard to these strategies and the volume and frequency of alcohol consumption amongst young people, the links being made between alcohol and sport, the efficacy of efforts to promote responsible drinking behaviours, and the adequacy of current regulations to respond to marketing through digital platforms such as the internet, social media and smartphones.

The study should be completed by 1 October 2013.

Recommendation 14

The Committee recommends that, following the completion of the study into the pricing and availability of alcohol and the study into alcohol marketing strategies, the Commonwealth Government develop a National Alcohol Sales Reform Plan aimed at reducing the harms caused by irresponsible alcohol consumption across Australia.

4 Diagnosis

Recommendation 15

The Committee recommends that the Commonwealth Government expedite the rollout of the Fetal Alcohol Spectrum Disorder (FASD) diagnostic instrument and the development of a training and user manual. These should be available for use by 1 October 2013.

Following the rollout, the Commonwealth Government should establish a mechanism to collect and monitor diagnostic data in order to assess the effectiveness of prevention strategies and patterns of FASD occurrence.

Recommendation 16

The Committee recommends that the Commonwealth Government develop and implement a national Fetal Alcohol Spectrum Disorders (FASD) diagnostic and management services strategy.

This strategy should be monitored and informed by the FASD Reference Group, and should establish capacity by 1 July 2014 for the following:

- awareness amongst all general practitioners and child and maternal health professionals of the causation and clinical features of FASD and the importance of early diagnosis and intervention;
- establishment of a model for diagnostic services such that regional as well as metropolitan areas are properly serviced; and
- identification of effective methodologies of management including international best practice.

5 Management needs

Recommendation 17

The Committee recommends that the Commonwealth Government develop educational material to raise awareness about Fetal Alcohol Spectrum Disorders (FASD). These materials should be monitored and informed by the FASD Reference Group.

In particular, targeted training and materials should be developed for:

- special education teacher aides and class teachers;
- parents, foster carers and foster care agencies;
- police and court officials;
- youth workers and drug and alcohol officers; and
- officers in correctional facilities and juvenile detention centres.

Recommendation 18

The Committee recommends that the Commonwealth Government include Fetal Alcohol Spectrum Disorders in the List of Recognised Disabilities and the Better Start for Children with a Disability Initiative.

Recommendation 19

The Committee recommends that the Commonwealth Government recognise that people with Fetal Alcohol Spectrum Disorders have, amongst other disabilities, a cognitive impairment and therefore amend the eligibility criteria to enable access to support services and diversionary laws.