

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

**Clinical Professor Carol Bower and Professor Elizabeth Elliott
On behalf of the Australian FASD Collaboration**

Contact Details

Heather Jones
Manager, FASD Projects

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The Australian FASD Collaboration welcomes the opportunity to provide a submission to the House Standing Committee on Social Policy and Legal Affairs into Foetal Alcohol Spectrum Disorders.

The Australian FASD Collaboration was established to guide the 'Development of a screening-diagnostic instrument for Fetal Alcohol Spectrum Disorders in Australia' (FASD Project). Led by Clinical Professor Carol Bower and Professor Elizabeth Elliott the Collaboration is a group of highly qualified and experienced health professionals, epidemiologists, researchers and consumer and community representatives dedicated to the prevention, diagnosis and care of individuals with FASD. A list of the members of the Australian FASD Collaboration can be found at Appendix 1.

To discuss this submission or for other enquiries please contact Heather Jones on

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Clinical Professor Carol Bower and Professor Elizabeth Elliott
Lead Investigators FASD Project
On behalf of the Australian FASD Collaboration

Submission from the Australian FASD Collaboration

- This submission is from the Australian FASD Collaboration, a national collaboration of experienced health professionals, epidemiologists, researchers and consumer and community representatives dedicated to the prevention, diagnosis and care of individuals with FASD.
- The Collaboration worked together on a Department of Health and Ageing contract to develop a screening-diagnostic instrument for FASD in Australia (the 'FASD Project').
- The contract was completed in September 2011, with the presentation of a report to the Department of Health and Ageing (the 'Report').
- The FASD Project involved a comprehensive review of the literature on FASD screening and diagnosis; consumer and community input into the design and implementation of screening and diagnosis for FASD in Australia; a Delphi survey of 103 health professionals with expertise and/or experience in screening and/or diagnosis of FASD; and a consensus development workshop with members of the Collaboration.
- Early diagnosis provides the best opportunity to reduce and manage the disabilities associated with FASD and to provide counselling for primary prevention in future pregnancies.
- It is essential that 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.
- The Collaboration is strongly supportive of primary preventive measures to reduce alcohol consumption in pregnancy, although this was not the brief of the Department of Health and Ageing contract.
- Whilst the Report is now being considered by the Department of Health and Ageing, and the detailed conclusions of the FASD Project are confidential, the Collaboration is strongly supportive of national guidelines for the diagnosis of FASD, preferably by a multidisciplinary team. A national implementation plan will be necessary and health professional training and workforce development in diagnosis and subsequent management is essential.
- When the Report is generally available, the Collaboration commends the recommendations/findings/conclusions to the Inquiry.

Australian FASD Collaboration

Lead Investigators

Clinical Professor Carol Bower MBBS, MSc, PhD, FAFPHM, DLSHTM, FFPHA

Senior Principal Research Fellow, Telethon Institute for Child Health Research; Clinical Professor, Centre for Child Health Research and School of Population Health, The University of Western Australia; Medical Specialist and Head, Western Australian Register of Developmental Anomalies, Women and Newborn Health Service

Professor Elizabeth Elliott MD, MPhil, MBBS, FRACP, FRCPCH, FRCP

Professor of Paediatrics and Child Health, University of Sydney; Consultant Paediatrician at the Children's Hospital at Westmead in Sydney; Director Australian Paediatric Surveillance Unit; NHMRC Practitioner Fellow; Honorary Professor The George Institute for Global Health

Senior Consultants

Dr Lucinda Burns RN, MPH, PhD, Grad Cert Health Policy

Senior Lecturer, National Drug and Alcohol Research Centre, New South Wales

Ms Heather D'Antoine SRN (WA), MHEcon (Aboriginal Health)

Associate Director Aboriginal Programs, Menzies School of Health Research, Northern Territory

Dr James Fitzpatrick BSc, MBBS

Discipline of Paediatrics and Child Health, George Institute for International Health, Sydney Medical School, University of Sydney, New South Wales

Assoc Prof Jane Halliday BSc, PhD

Public Health Genetics, Genetic Disorders, Murdoch Childrens Research Institute, and Department of Paediatrics, University of Melbourne, Victoria

Ms Lorian Hayes BAppSc (Hons), MSc(Epi)

Researcher with the School of Medicine, University of Queensland, Queensland

Assoc Prof Jane Latimer BAppSc(Phty), DipAppSc(Manip Phty), PhD

Senior Research Fellow and ARC Future Fellow, The George Institute for International Health, Sydney Medical School, New South Wales

Ms Anne McKenzie

Consumer Advocate, Telethon Institute for Child Health Research and School of Population Health, The University of Western Australia, Western Australia

Ms Sue Miers AM

Spokesperson, National Organisation of Fetal Alcohol Syndrome and Related Disorders (NOFASARD), South Australia

Dr Raewyn Mutch MBChB, DipRACOG, FRACP, PhD

Post-Doctoral Research Fellow, Telethon Institute for Child Health Research; Consultant Paediatrician, Refugee Health Service, Princess Margaret Hospital for Children, and State Child Development Service, WA Department of Health, Western Australia

Dr Colleen O'Leary BSc, MPH, PhD

NHMRC Post-Doctoral Fellow, National Drug Research Institute, Western Australia

Ms Jan Payne SRN (UKCC), Post Grad Dip (Health Admin), MSc (Public Health)

Senior Research Officer, Telethon Institute for Child Health Research, Western Australia

Dr Elizabeth Peadon MBBS, DCH, MPH, FRACP

Developmental Paediatrician, The Children's Hospital at Westmead and PhD Student, University of Sydney, New South Wales

Ms Elizabeth Russell

Executive Officer, Russell Family Fetal Alcohol Disorders Association, Queensland

Dr Amanda Wilkins MBBS, FRACP, MPH

Child Development Specialist, Koondoola Child Development Centre, WA Department of Health, Western Australia

Project Team

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Manager FASD Projects, Telethon Institute for Child Health Research, Western Australia

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Institute and Department of Paediatrics, University of Melbourne

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