

Fetal Alcohol Spectrum Disorder: Public health case study

Fetal Alcohol Spectrum Disorder (FASD) is a lifelong condition characterised by severe neurodevelopmental impairments (with/without physical impairments) that results from prenatal alcohol exposure. Research by Telethon Kids Institute (Telethon Kids), The University of Sydney and others established FASD as a significant public health issue. The results of this research led to funding for a Centre of Research Excellence which has contributed to capacity building, best practice in diagnosis and management, and public health initiatives for education and prevention.



Origin

Epidemiological studies in Australia in the 1980s and 90s provided evidence for researchers, clinicians and community members that alcohol use in pregnancy and FASD were problems in Australia.

Early research focused on identifying what women and clinicians knew about alcohol, pregnancy and FASD, and on developing educational resources to meet their needs.

In 1980, Professors Carol Bower and Fiona Stanley established Australia's first register of birth defects—now the WA Register of Developmental Anomalies (WARDA). Data from the register were the starting point for FASD research by Telethon Kids.

In 1993, Professor Elizabeth Elliott founded the Australian Paediatric Surveillance Unit (APSU) to study rare childhood diseases. In 2001, APSU undertook collection of national surveillance data for FASD. Dr Janet Payne was integral to early research with clinicians and women, WARDA and the APSU.

Professor Fiona Stanley AC, Patron of Telethon Kids:

"I am a researcher who has used data collected on individuals in WA for over 40 years. We have used data linkage to identify for the first time, the population effects of prenatal alcohol exposure on a number of important pregnancy and childhood outcomes, such as preterm birth, perinatal and infant mortality and cerebral palsy."

Grants and Investments

Key funding sources for FASD research at Telethon Kids and The University of Sydney include:

NHMRC

- Program Grants: 1996, 2000 and 2005
- Project Grants: 2012, 2015 and 2016
- Targeted Call for Research into FASD Grants: 2014 (three grants)
- Centre of Research Excellence (CRE) Grant: 2015
- Partnership Project Grants: 2015 and 2019
- Research Fellowships: Bower, 2001, 2005 and 2010
- Practitioner Fellowships: Elliott, 2007 and 2012
- Career Development Fellowship: Adjunct Professor James Fitzpatrick, 2017.

Other government grants and investment

- Department of Health (DoH): 2010, 2015 and 2018
- Department of Families, Housing, Community Services and Indigenous Affairs (FaHCSIA): 2010
- Australian Research Council: 2014
- Medical Research Future Fund (MRFF) Next Generation Clinical Researchers Practitioner Fellowship: Elliott, 2018
- NSW Government: 2012
- WA Government: 2014 and 2015.

Corporate, non-government and philanthropic investment

The following have contributed funding:

Ashurst, Australian Rotary Health, BHP, CAGES Foundation, Foundation for Alcohol Research and Education, McCusker Foundation, Poche Sydney, Presidents of Medical Colleges Rural Health Continuing Education Program, Save the Children, The University of Sydney Medical Foundation, Yajilarra Trust.

Collaborations

Collaborations have been important in building partnerships, conducting research and disseminating findings. Involving community members has been critical to research success. For example, initiatives by women in Kimberley communities, led by June Oscar, Maureen Carter, Jahnah Davies and Emily Carter, resulted in understanding the prevalence of FASD, strategies for prevention and support for caregivers to manage children with FASD.

Clinicians, parents and carers were involved in the development of a diagnostic tool for FASD, piloting and implementing the Australian Guide to Diagnosis of FASD (the Guide), and providing training for clinicians across Australia. NOFASD Australia, which offers parent support and advocacy, partners in many projects. The NHMRC FASD Research Australia CRE also collaborates with University of Newcastle and researchers at the George Institute, Menzies School of Health Research (NT) and Murdoch Children's Research Institute, and internationally with Canada (CanFASD and others), USA (National Institute on Alcohol Abuse and Alcoholism) and UK. This has helped link researchers and identify key priorities for future research.

Telethon Kids, The University of Sydney, the CRE and collaborators have made submissions and given evidence to a number of government and coronial inquiries and Royal Commissions relating to alcohol and FASD.

Collaboration between Telethon Kids and WA Department of Justice has also built significant capacity and raised awareness of FASD among justice professionals.

Research and Translation

FASD research champions have used data to advocate for research funding, diagnostic services, treatment, and prevention programs in Australia and have led policy and clinical practice change.

Key projects

- Surveys of clinicians and women found only 12% of health professionals could identify FASD and only 2% felt equipped to deal with it. This led to consultation and literature reviews to develop best practice in diagnosis of FASD, the Guide and other resources.
- Data linkage confirmed adverse outcomes following prenatal alcohol exposure in the WA population.
- Interdisciplinary assessment of children in high risk communities:
 - Data from the Lillilwan Project in the Fitzroy Valley, WA, led to awareness and parenting programs, services, and community-led prevention strategies to reduce alcohol use in pregnancy.
 - The Banksia Hill Detention Centre Project uncovered that 36% of young people in the WA justice system had FASD and 89% had neurodevelopmental impairments. A training program was developed for custodial staff and is now being adapted and rolled out to other front line staff.
- Pregnancy cohort studies revealed poor documentation of prenatal alcohol exposure and the need for pre-pregnancy education for women and training for clinicians.

Outcomes and Impact

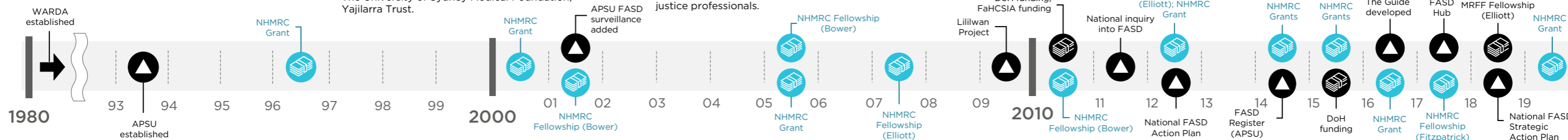
Methods developed by researchers for the diagnosis, management and prevention of FASD are now being implemented to address FASD and to support those living with the disorder.

Key impacts

- Investment by federal and state governments to increase FASD awareness, services and clinician training
- Development and dissemination of the Guide
- Establishment of FASD Hub Australia website
- National surveillance of FASD and disease register established by APSU
- Policy input into:
 - NHMRC Australian Guidelines to Reduce Health Risks from Drinking Alcohol
 - WHO Guidelines for identification and management of substance use in pregnancy
 - Pregnancy Care Guidelines and National guide to a preventive health assessment for Aboriginal and Torres Strait Islander people
 - National FASD Strategic Action Plan 2018-28
 - Warning labels on alcohol products for sale in Australia
 - Recording of prenatal alcohol exposure in pregnancy in relevant midwives' databases.

Family and Community Partnerships

Aboriginal leaders in the remote Fitzroy Valley in North Western Australia identified FASD as a community priority and initiated the Lillilwan Project in partnership with The University of Sydney and the George Institute. FASD Research Australia CRE has worked hard to build effective partnerships, consistently involving community members with lived experience and community organisations in their projects.



Professor Carol Bower

Professor Bower is a Senior Principal Research Fellow at Telethon Kids. She is an epidemiologist and public health physician who, over more than 30 years, has made a profound impact on the health of WA's children. Bower uncovered a link between low dietary folate consumption and the risk of neural tube defects (such as spina bifida), and instigated the world's first public health campaign to encourage folic acid supplement use. She is uniting scientific, justice, social services and health communities around Australia in order to tackle FASD. Bower was inducted into the Australian Academy of Health and Medical Sciences in 2017 and WA Science Hall of Fame in 2019. She has received several NHMRC Principal Research Fellowships and is Co-Director of the NHMRC FASD Research Australia CRE.

Professor Elizabeth Elliott AM

Professor Elliott is an MRFF Clinical Researchers Program Practitioner Fellow; Professor of Paediatrics and Child Health, The University of Sydney; Consultant Paediatrician and Head of the NSW FASD Assessment Service at the Children's Hospital Westmead, Sydney. She chaired the national committee to advise government on FASD strategy; led novel research on FASD prevalence in the Kimberley; and participates in cohort studies on epigenetic, neurodevelopmental and physical impacts of FASD. She is APSU Director and a Fellow of the Australian Academy of Health and Medical Sciences and Royal Society of NSW. She won the AMA Excellence in Healthcare Award in 2018. She is Co-Director of the NHMRC FASD Research Australia CRE.

Ms June Oscar AO

Ms June Oscar AO is a proud Bunuba woman from Fitzroy Crossing in WA's Kimberley region. Oscar successfully lobbied for alcohol restrictions in Fitzroy Crossing, initiated and was a chief investigator on the Lillilwan Project, and has worked tirelessly to prevent FASD. She is a chief investigator on the NHMRC FASD Research Australia CRE. Oscar has held many influential positions including Deputy Director of the Kimberley Land Council, and Chair of the Kimberley Language Resource Centre and the Kimberley Interpreting Service. She is currently Australia's Aboriginal and Torres Strait Islander Social Justice Commissioner at the Australian Human Rights Commission.

Ms Marmingee Hand

Ms Marmingee Hand lives in Fitzroy Crossing and belongs to the Walmajarri language group. She is a senior teacher and Co-ordinator of the Aboriginal language program at Fitzroy Valley High School. She was a Community Education Consultant on the Lillilwan FASD prevalence study and is on the advisory groups for the Jandu Yani U (positive parenting) and Bigiswun Kid (Lillilwan follow up) projects. She is Chairperson of Mariniwarntikura Women's Resource Centre and Yununijarra, the Native Title Prescribed Body Corporate that manages the Ngurrara (Great Sandy Desert) Healthy Country Program.

Other key FASD researchers

Dr Rochelle Watkins is a Senior Research Fellow at Telethon Kids and a chief investigator and Chair of the Scientific Committee for the NHMRC FASD Research Australia CRE.

Prof James Fitzpatrick is a researcher at UWA and Telethon Kids and is also a chief investigator on the NHMRC FASD Research Australia CRE. He was the inaugural Chair of the Australian FASD Clinical Network.

Dr Janet Payne was an inaugural member of the Alcohol and Pregnancy & FASD Research Program at Telethon Kids. She passed away in May 2019.