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 (Tel keathon) 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.

Epidemiological studies in Australia in the 1980s and 1990s 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 Pape was integral in early research with clinicians and women, WARDA and the APSU.

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, Jadhav Davis and Emily Carter, resulted in understanding the prevalence of FASD, strategies for prevention and support for caregivers to manage children.

Collaborations have included:
- Professor Carol 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 contribution to understanding FASD in Australia. Bower uncovered a national problem with public health significance. Her research has led to changes in practice and policy, for example, the development of community-based services, the establishment of fetal alcohol syndrome clinics, the implementation of alcohol education sessions in schools, youth centres and childcare services, and the use of the Alberta FASD Action Plan.
- Professor Elizabeth Elliott AM is an NHMRC Career Development Fellow at Telethon Kids Institute. She is a medical doctor with expertise in maternal and child health, and her research has contributed to understanding the neurodevelopmental benefits of prenatal alcohol exposure on a range of outcomes, such as prematurity, perinatal mortality, and the development and health of children with FASD.
- Ms June Oscar AO is a researcher who has used data collected on Aboriginal children in two Far North Queensland communities to identify the effects of prenatal alcohol exposure on a range of outcomes, such as poor birth outcomes, mental and emotional health, and reduced school attendance.
- Ms Marmingee Hand is a Researcher and Aboriginal Community Health Worker in the Kimberley region. She was a Community Education Consultant on the Lililwan FASD prevalence study and is on the advisory group for the Kimberley FASD Prevention Action Plan.

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 Lililwan Project in the Fitzroy Valley, WA, led to the development of a referral program, training 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.
- Collaboration between Telethon Kids and WA Department of Justice has also significantly contributed to the community awareness and understanding of FASD among justice professionals.

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 burden 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 guidance to a preventive health assessment for Aboriginal and Torres Strait Islander people
- National FASD Strategic Action Plan
- Warnings labels on alcohol products for sale in Australia
- Recording of prenatal alcohol exposure in pregnancy in relevant midwives’ databases.

Other key FASD researchers
- Dr Rochelle Watkins is a Senior Research Fellow at Telethon Kids Institute and lead investigator on the NHMRC FASD Research Australia CRE. She was the inaugural Chair of the NHMRC Australian FASD and Alcohol Research Network.
- Dr Janet Pape was an inaugural member of the Alcohol and Pregnancy Prevention Program at Telethon Kids. She passed away in May 2019.

25 February 2020. All NHMRC case studies may be found at: https://www.nhmrc.gov.au/about-us/resources/impact-case-studies