

**Screening and diagnosis of FASD in children in State care. The evaluation of information resources on FASD and the information needs of foster carers.**

Telethon Institute for Child Health Research (WA)  
Lead Researcher: Dr Amanda Wilkins  
Budget: \$150,000

Overview

This project aims to examine the prevalence of FASD in a cohort of children up to twelve years of age who are placed in State care for 1 month or more, and will be the first prevalence study of FASD in a targeted urban population in Australia. The results of the project will provide valuable data on the epidemiology of FASD and the healthcare needs of this population.

The project will take place in the Perth metropolitan region over a 12 month period. As part of this process, the group of children will be screened for developmental delays and learning difficulties in order to coordinate further assessment and therapeutic and educational interventions. Current FASD information resources for parents and carers, available from a range of government departments, will also be evaluated in order to investigate the specific information needs of foster carers.

This study will provide an example of inter-sectoral collaboration between health and welfare professionals and a model of care for children in State care. Screening at a time of entering State care will also improve the support for foster and kinship carers. The results of screening and assessment will be incorporated into a "Health Passport" which provides a document that children in State care can carry with them between care settings.

**Interdisciplinary research on professional knowledge, attitudes and practice relating to FASD in the criminal justice sector.**

Telethon Institute for Child Health Research (WA)  
Lead Researcher: Dr Raewyn Mutch  
Budget: \$50,000

Overview

This project aims to identify what professionals working within the justice sector know about FASD, their attitudes towards children and adolescents who may have a disorder in the spectrum, and their current practices in dealing with FASD. The project will also identify the gaps in provision of training and information for workers within the criminal justice system.

Assessing knowledge, attitudes and practice in relation to FASD within the justice sector will offer the prospect for improving the outcome for affected individuals and their families, including identifying opportunities for intervention strategies. The information will be valuable in identifying the needs of judicial staff, and assist in developing educational and training materials so that they have a better understanding of how to manage young offenders with a FASD.

A range of stakeholders will be consulted, including the Family Law Practitioners' Association of WA, Criminal Lawyers Association of WA, The Law Society of Western Australia and WA Bar Association.

**The medical, developmental, educational and social consequences of FASD: A survey of the knowledge, attitudes, practices and training deficits within the Queensland criminal justice agencies in regard to FASD.**

The University of Queensland Centre for Clinical Research (Qld)  
Lead Researcher: Associate Professor Heather Douglas  
Budget: \$63,560

Overview

The aim of the project is to inform and provide the impetus to reform the policing, judicial and correctional systems while optimising effective service delivery, and contribute to the development of appropriate rehabilitation, support and management strategies for people with FASD and their families.

Researchers will survey the knowledge, attitudes, practices and training deficits within Queensland criminal justice agencies in regards to FASD. Survey data will be collected from representatives from probation and parole services, correctional services, the police service, lawyers, judiciary, defence counsel, legal aid and other staff as appropriate.

The survey results will inform recommendations for training across the Australian criminal justice sector.

**Development of the first screening and diagnostic service for FASD in Australia.**

The Children's Hospital at Westmead (NSW)  
Lead Researchers: Professor Elizabeth Elliott and Dr Elizabeth Peadon  
Budget: \$108,000

Overview

This project will establish the first diagnostic clinic for FASD in Australia, and is a collaboration of health professionals, researchers, community organisations and government. A key component of the project involves testing and refining a new diagnostic tool, and building consensus on nationally agreed clinical guidelines.

The project will inform evidence-based practice and provide training and education to more health professionals in the use of screening and diagnostic tools. The research team will collate prevalence data on FASD and also survey the impact of FASD on families, parents and carers, to enable the provision of more relevant and improved services.

As part of the project evaluation, the research team will estimate the costs of setting up and running a FASD assessment service to inform the development of screening and diagnostic services elsewhere in Australia.

## Improving services to families affected by FASD

The National Drug and Alcohol Research Centre (NSW)  
Lead Researcher: Dr Lucy Burns  
Budget: \$50,057

### Overview

This project seeks to establish a benchmark for service delivery for families affected by FASD. To date, there has been little systematic work undertaken with the families of children with FASD to determine their experiences and needs. This is of critical importance, given that FASD is a lifelong disability requiring constant care by parents and carers.

The range of secondary disabilities arising from FASD include mental health problems, disrupted school experience, trouble with the law, inappropriate sexual behaviour, alcohol and drug problems, dependent living and problems with employment and problems with parenting. For children with a FASD, early diagnosis and intervention may substantially reduce the risk of secondary social, emotional and behavioural problems. Diagnosis of an affected child also provides an opportunity for preventing alcohol exposure in future pregnancies.

Research will be undertaken with families to determine their experiences in raising children with FASD through both surveys and semi-structured interviews. The research results will be used to make recommendations for improvement in service delivery to families and their children, including health, financial, legal and educational support.

## Improving services for women who are pregnant and alcohol dependent

The National Drug and Alcohol Research Centre (NSW)  
Lead Researcher: Dr Lucy Burns  
Budget: \$50,057

### Overview

This project aims to improve treatment practices of chronic alcohol dependence in pregnancy. At present, only a small proportion of pregnant women who drink at high levels are identified and treated. There are a number of reasons for this, and to date barriers to treatment have been identified as including a fear of losing custody of their children, a lack of childcare if they were to go into treatment, a lack of access or priority for pregnant women and a lack of special services.

This study will examine ethnographic and social research on attitudes to FASD, problems in identification and diagnosis and other barriers in accessing services. In particular, this study will examine the role of gender stereotypes in the development of alcohol use problems in contemporary Australian society.

Through this project, a new resource will be produced for use by clinicians to improve practices in the management of alcohol dependence in pregnancy.

## Marulu Film Project

The George Institute for Global Health (NSW/WA)

Project Leaders: Associate Professor Jane Latimer and Professor Elizabeth Elliott

Budget: \$40,000

### Overview

A documentary and an educational film will be produced to raise awareness of FASD and their impact on children, their parents and carers, and whole communities.

A group of Indigenous leaders has partnered with experts in Indigenous health, paediatric medicine, human rights advocacy, child protection and a world-class production company to progress a community-led strategy developed to address FASD in the Fitzroy Valley of WA. The strategy, Marulu, has three components: diagnosis and prevention of FASD, support for parents and carers of children with FASD, and advocacy and awareness-raising about FASD. In line with the third component of the strategy the project team will produce two films to raise awareness of FASD and their impact on the lives of children living in the Fitzroy Valley.

The documentary film will be of 30 mins duration and will give a unique perspective on FAS by highlighting through the eyes of an 11 year old child living with FAS the challenges faced by both children with FAS or a FASD and also their families.

The educational film will be of 15 mins duration and will include more detailed information about the clinical, behavioural and psychosocial features of FASD and the evidence base for its diagnosis, management and prevention.