

ALCOHOL & PREGNANCY & FASD RESEARCH PROGRAM ANNUAL REPORT 2014



**FOR WOMEN WHO ARE PREGNANT, PLANNING A PREGNANCY
OR BREASTFEEDING NOT DRINKING IS THE SAFEST
OPTION**



Alcohol & Pregnancy & FASD Research Program 2014

Head of Alcohol & Pregnancy & FASD Research Group

Professor Carol Bower

Senior Principal Research Fellow, Telethon Kids Institute

Professor, Centre for Child Health, The University of Western Australia

Leadership Group

Dr James Fitzpatrick

McCusker Clinical Research Fellow in Aboriginal Child Health, Telethon Kids Institute

Dr Rochelle Watkins (on leave)

Senior Research Fellow, Telethon Kids Institute

Dr Roslyn Giglia

Senior Research Fellow, Telethon Kids Institute

Advanced Practicing Dietitian

Group Members

Kaashifah Bruce – Marulu FASD Prevention Strategy Coordinator

Juanita Doorey – Senior Research Officer

Heather Jones – Manager FASD Projects

Associate Professor Raewyn Mutch – Clinical Research Fellow

Dr Jan Payne – Research Program Manager

Candice Rainsford – Project Officer

Dr Tracy Reibel – Senior Research Fellow

Gayle Segar – Patches Fitzroy Valley Paediatric Clinic Coordinator

Dr Martyn Symons – Senior Research Fellow

Bree Wagner – Alert Program Coordinator

*Dr Amanda Wilkins – Honorary Clinical Research Fellow

Telethon Kids Institute staff collaborating on Alcohol & Pregnancy & FASD Research

Glenn Pearson – Manager Aboriginal Health Research

Kristen White – Program Manager Aboriginal Health Research

Associate Professor Roz Walker – Centre for Research Excellence in Aboriginal Health and Wellbeing

Tanyana Jackiewicz – Program Manager Centre for Research and Evaluation

Dr Paula Wyndow – Senior Research Officer Centre for Research and Evaluation

Angela Dudley – Research Assistant Centre for Research and Evaluation

Contact us

Email: fasd@telethonkids.org.au

Phone: +61 8 9489 7724

Mail: PO Box 855 WEST PERTH WA 6872

Website: <http://alcoholpregnancy.telethonkids.org.au/>

Overview

Fetal Alcohol Spectrum Disorders (FASD) are preventable and our research will reduce the risks and effects of prenatal alcohol on child health through prevention, diagnosis and therapy interventions. FASD are characterised by brain damage from prenatal alcohol exposure and the effects are lifelong. Resultant neurodevelopmental disabilities include developmental delay, poor executive functioning, and problems with learning, behaviour, and social and adaptive functioning. These can lead to secondary outcomes such as poor school performance, unemployment, substance abuse, mental health problems and justice system engagement. Without intervention this may lead to a cycle of welfare dependency and privation which has significant intergenerational social and economic impact. For example, Fetal Alcohol Syndrome has been calculated at \$USD5bn per annum, with a lifetime cost for individuals ranging from \$USD1.6m to \$2.5m.

The Alcohol & Pregnancy & FASD Research Group has led research and policy development in the area of FASD for over a decade, has influenced policy and practice across a range of health professions and has engaged with consumers in the research process. Together with inquiries and plans calling for action, there is strong support from advocacy groups and professions in health, justice and education for implementation of strategies for prevention and for managing children and young people with FASD. Aboriginal communities have been at the forefront of these calls and have been proactive in seeking strategies to address educational and employment potential, and cultural integrity which is threatened by the learning and behavioural consequences of FASD.

Our program of research in 2014 included the following projects:

Epidemiology of FASD in WA – prevalence rates using data from the WA Register of Developmental Anomalies

Investigators: Raewyn Mutch¹, Rochelle Watkins¹, Carol Bower¹

¹Telethon Kids Institute, The University of Western Australia, Perth, Australia

Data on notified cases of FASD born in Western Australia 1980 – 2010 were identified from the WA Register of Developmental Anomalies. Tabulated denominator data were obtained from the Midwives Notification System. Prevalence rates per 1000 births were calculated by demographic variables. Prevalence ratios (PRs) and 95% confidence intervals (Cis) of Aboriginal compared with non-Aboriginal prevalence rates were calculated. PRs were also calculated to compare rates for births 2000 – 2010 with 1980 – 1989.

210 cases of FASD were identified: a birth prevalence of 0.26/1000 births (95% CI 0.23-0.30). The majority of cases reported were Aboriginal (89.5%), a rate of 4.08/1,000, compared with 0.03/1,000 in notified non-Aboriginal cases, giving a PR of 139 (95% CI 89-215). The prevalence of FASD in 2000 – 2010 was over twice that in 1980 – 1989 for both Aboriginal (PR 2.37, CI 1.60-3.51) and non-Aboriginal (PR 2.13, CI 0.68-6.69) children. Population surveillance data such as these are valuable in advocating for and monitoring the effectiveness of preventive activities and diagnostic and management services.

Findings from this study have been published in: Mutch RC, Watkins R, Bower C. Fetal alcohol spectrum disorders: Notifications to the Western Australian Register of Developmental Anomalies. *Journal of Paediatrics and Child Health*. 2014. doi:10.1111/jpc.12746

Funding: This project was supported by the NHMRC Program Grant 572742 and Research Fellowship 634341

Health and adverse life outcomes among individuals notified with FAS in Western Australia: implications for policy, service delivery and prevention

Investigators: Rochelle Watkins¹, Carol Bower¹

¹Telethon Kids Institute, The University of Western Australia, Perth, Australia

A retrospective population-based study of FAS diagnoses in WA will be conducted to describe health and adverse life outcomes, and health service use, among notified Fetal Alcohol Syndrome (FAS) cases, including emergency department encounters, hospital admissions, intellectual disability, contact with mental health services, school performance, and interactions with the WA criminal justice system. Health and adverse life outcomes among individuals with FAS will be compared with a population based comparison group. Comparative analysis of outcomes among individuals with FAS and those in the comparison group will enable identification of the population-level attributable risk for adverse life outcomes associated with FAS. A health economic analysis will also be undertaken.

Funding: Foundation for Alcohol Research and Education

Prenatal alcohol use & educational outcomes

Investigators: Carol Bower¹, Steve Zubrick¹

Project staff: Kirsten Hancock¹, Nadia Cunningham¹

¹Telethon Kids Institute, The University of Western Australia, Perth, Australia

In this project, we are using linked data to examine the educational outcomes for children of women with a record of an alcohol-related condition in the hospital morbidity data system, compared with the educational outcomes of children of women with no such record.

Funding: ARC Grant DP140101573 and Research Fellowship 634341

Alcohol and pregnancy and fetal alcohol spectrum disorder: Midwives' knowledge, attitudes and practice

Investigators: Jan Payne¹, Rochelle Watkins¹, Heather Jones¹, Tracy Reibel¹, Raewyn Mutch^{1,2}, Amanda Wilkins^{1,2}, Julie Whitlock¹, Carol Bower¹

¹Telethon Kids Institute, The University of Western Australia, Perth, Australia

²WA Government Department of Health, Child and Adolescent Health Services, Perth, Australia

This cross sectional study was conducted at 19 maternity sites across the seven health regions of WA. A questionnaire was designed following a review of the literature and other relevant surveys. Midwifery managers of the maternity sites distributed the questionnaires to all midwives working in their line of management. A total of 334 midwives were invited to participate in the research and 73.4% of these were eligible.

The response rate was 67.8%. Nearly all the midwives (93.2%) asked pregnant women about their alcohol consumption during pregnancy and 99.4% offered advice about alcohol consumption in accordance with the Australian Alcohol Guideline, which states "For women who are pregnant or planning a pregnancy, not drinking is the safest option." While informing women about the effects of alcohol consumption in pregnancy (64.2%), they did not always use the recommended AUDIT screening tool (47.5%) or conduct brief interventions when indicated (70.4%). Most midwives endorsed professional development about screening tools (93.5%) and brief interventions (92.9%). These findings support the need for further professional development and support for midwives.

Findings from this study have been published in: Payne JM, Watkins RE, Jones HM, Reibel T, Mutch R, Wilkins A, Whitlock J, Bower C. Midwives' knowledge, attitudes and practice about alcohol exposure and at risk of fetal alcohol spectrum disorder. *BMC Pregnancy and Childbirth* 2014, 14:377

Funding: This project was supported by the NHMRC Program Grant 572742 and Research Fellowship 634341

3M FASD Prevention Project: Marulu, Mass Media, Midwives

Investigators: James Fitzpatrick¹, Rochelle Watkins¹, Carol Bower¹, Glenn Pearson¹, Jonathan Carapetis¹, Mike Daube², Kaashifah Bruce¹, Elizabeth Chester¹

Project staff: Kaashifah Bruce¹, Martyn Symons¹, Tracy Reibel¹

¹Telethon Kids Institute, The University of Western Australia, Perth, Australia,

² McCusker Centre for Action on Alcohol and Youth, Curtin University, Perth, Australia.

The objective of the 3M FASD Prevention Strategy is to implement and evaluate a community designed FASD prevention strategy for the Fitzroy Valley and surrounding communities that if effective can be translated to other settings in Western Australia. This overarching Strategy comprises three distinct but interrelated initiatives responding to high FASD prevalence rates in Western Australia through a whole of community prevention strategy: Marulu, Midwives and Mass Media.

Marulu: An exemplar high-impact FASD prevention strategy in the communities of the Fitzroy Valley, where high FASD prevalence has been documented;

Midwives: A workforce intervention up-skilling midwives in the documentation and brief intervention around alcohol use in pregnancy, to reinforce the community-wide interventions; and

Mass Media: A mass media strategy targeting regional and remote communities throughout the Kimberley and Pilbara, with a further aim of ensuring state-wide impact for the program and its messages.

Local impacts among the Fitzroy Valley communities include an increased knowledge of the harms of drinking while pregnant, altered social norms about the acceptability of drinking while pregnant, and reduced rates of alcohol use in pregnancy and FASD. The social, health and justice system benefits for the Fitzroy Valley communities will be significant and enduring. Documenting the Marulu strategy as an exemplar of a community-initiated response to a significant public health issue will enable this approach to be adopted in other communities in Western Australia where high-risk drinking is prevalent.

At the regional level across the Kimberley and Pilbara, the media campaigns will raise awareness of the NHMRC guidelines relating to alcohol use in pregnancy. Complementary communication strategies will seek to ensure a further state-wide impact. Additionally, health workforce benefits will be significant in that the AUDIT-C (a screening tool for alcohol use in pregnancy) intervention will have been developed. Training resources will be developed for the implementation of this intervention throughout other communities in regional and metropolitan Western Australia.

Funding: WA Department of Health

Marulu FASD Prevention Strategy

Investigators: James Fitzpatrick¹, Maureen Carter², June Oscar³, Glenn Pearson¹, Jonathan Carapetis¹, Carol Bower¹, Rochelle Watkins¹, Kaashifah Bruce¹

Project staff: Kaashifah Bruce¹, Martyn Symons¹

¹Telethon Kids Institute, The University of Western Australia, Perth, Australia

²Nindilingarri Cultural Health Services, Fitzroy Crossing, Australia

³Marninwarantikura Fitzroy Women's Resource Centre, Fitzroy Crossing, Australia

There is a humanitarian crisis in the Fitzroy Valley region of remote North-western Australia, which has amongst the highest rates of Fetal Alcohol Spectrum Disorders (FASD) in the world. However, Fitzroy Valley communities have shown strong leadership and commitment to tackling FASD through the initiation of a comprehensive and multifaceted program: the Marulu FASD Strategy that has the bold goal to "Make FASD History" by driving down rates of drinking in pregnancy.

'Marulu', meaning 'precious, worth nurturing' in the Bunuba language, has three priorities: to prevent FASD, to diagnose FASD and to support affected families. The initial phase of the Marulu FASD Strategy (2008-2013), saw the establishment of a locally-led governance structure, the successful implementation of alcohol restrictions (University of Notre Dame, 2010), and the collection of FASD prevalence data through the Lililwan Study (Fitzpatrick et al. 2012).

Now, the Telethon Kids Institute has been invited by the communities in the Fitzroy Valley to partner with them in developing, implementing and evaluating a prevention arm of the Marulu FASD Strategy.

Aim:

To develop, implement and evaluate The Marulu FASD Prevention Strategy to increase the proportion of women abstaining from alcohol while pregnant in the Fitzroy Valley.

Objectives:

To work with local health promotion organisations (Nindilingarri Cultural Health Services) to develop and implement a model for Fetal Alcohol Spectrum Disorder prevention that:

1. Works in the Fitzroy Valley.
2. Can be adapted for FASD prevention in other communities.

This project will develop a model for FASD prevention that can be transferred to other sites. The development of transferable interventions and strategies is also a priority for the community.

Funding: WA Department of Health WA, WA Department of Aboriginal Affairs, McCusker Charitable Foundation

Multidisciplinary Team (MDT) Evaluation: Evaluating multidisciplinary team-based early intervention for children with complex needs, in a remote community setting

Investigators: James Fitzpatrick¹, Maureen Carter², Catherine Elliot^{3,4}, Kaashifah Bruce¹

Project staff: Gayle Segar², Martyn Symons¹, Kaashifah Bruce¹

¹Telethon Kids Institute, The University of Western Australia, Perth, Australia

²Nindilingarri Cultural Health Services, Fitzroy Crossing, Australia

³Chair of Allied Health, Western Australian Child and Adolescent Health Services, WA Health, Perth, Australia

⁴Princess Margaret Hospital for Children Department of Paediatric Rehabilitation

This project aims to evaluate the effectiveness of a multi-disciplinary team (MDT) model in improving health and developmental outcomes in a cohort of children with complex health needs residing in the Fitzroy Valley, West Kimberley; and to document of the experience and perceptions of families who participate in the MDT model.

Objectives:

- The primary objective of this research project is to develop an effective model for delivering health care services to children with complex needs in remote Indigenous Australia.
- The secondary objective is to deliver the MDT model in a manner that engages local people and families in the health and education support networks established for the benefit of their children.
- The outcomes of this research will benefit the Fitzroy Valley communities by improving the effectiveness of health services to children in their region, and in the longer term, improving the health and education outcomes of these children. A more effective health service delivery model will be of value to families, by providing evidence-based therapy that is coordinated and outcome focused, relative to standard care currently available in the Fitzroy Valley. By including families in the MDT model, the treatment and language relating to their child's health will be de-mystified. This will build families' confidence to engage more proactively with the health and education services in the future.

Finally, the research will have national relevance by measuring and documenting a best practice approach to delivering child health services in remote Indigenous contexts.

Funding: CAGES Foundation, Royalties for Regions WA

Evaluating the evidence-practice gap between the NHMRC alcohol and breastfeeding guideline (2009), clinician application and maternal uptake

Investigator: Roslyn Giglia¹

¹Telethon Kids Institute, The University of Western Australia, Perth, Australia

Alcohol consumption is the cultural norm in Australia but alcohol in breast milk will disrupt the hormonal milieu required for successful lactation and result in a lower milk yield by the baby, a factor rarely considered in the early cessation of breastfeeding. In 2009 the NHMRC released the revised alcohol guidelines and a national first was the inclusion of a guideline exclusively for breastfeeding women (4B)(<http://www.nhmrc.gov.au/files/nhmrc/publications/attachments/ds10-alcohol.pdf>). With limited promotion of this guideline it is not known whether maternal health practitioners such as GPs and midwives, educate women on this guideline in their daily practice. It is also not known whether breastfeeding women are practising safe alcohol consumption during lactation. Given the proven, but not well-known negative impact of alcohol on breastfeeding, and the importance of extending the positive short (e.g. immunity) and long term effects (e.g. decrease in cancer, diabetes and adult obesity) of breastfeeding, it is important that the awareness and utilisation of this guideline be evaluated.

Dr Roslyn Giglia was successful in being awarded a Translational Research Into Practice (TRIP) Fellowship which will support her to conduct the evaluation of guideline 4B. Building on her PhD research, Dr Giglia has found that anecdotally there is little awareness of guideline 4B or of the adverse effect of alcohol on breastfeeding. The translation of the evaluation of guideline 4B into a practical and targeted awareness raising and education campaign for practitioners and women of child bearing age is not supported by the TRIP Fellowship. Potentially the promotion and uptake of this public policy guideline has the capacity to promote long term breastfeeding which in turn translates into a decrease in infant illness and the prevention of adult chronic diseases.

Funding: NHMRC Translational Research Into Practice (TRIP) Fellowship

Development of a diagnostic instrument for FASD in Australia

Investigators: Carol Bower¹, Elizabeth Elliott^{2,3}, Rochelle Watkins¹, Jan Payne¹, Raewyn Mutch^{1,4}, Amanda Wilkins^{1,4}, James Fitzpatrick¹, Jane Latimer⁵, Sue Miers⁶, Elizabeth Peardon², Anne McKenzie¹, Heather D'Antoine⁷, Elizabeth Russell⁸, Colleen O'Leary⁹, Jane Halliday¹⁰, Lucinda Burns¹¹, Lorian Hayes¹², Maureen Carter¹³

Project staff: Heather Jones¹

¹Telethon Kids Institute, The University of Western Australia, Perth, Australia

² Discipline of Paediatrics and Child Health, Sydney Medical School, University of Sydney, Sydney Australia

³The Children's Hospital at Westmead, Sydney, Australia

⁴WA Government Department of Health, Child and Adolescent Health Services, Perth, Australia

⁵The George Institute for Global Health, Sydney Medical School, University of Sydney, Sydney, Australia

⁶National Organisation for Fetal Alcohol Spectrum Disorders, Australia

⁷Menzies School of Health Research, Charles Darwin University, Darwin, Australia

⁸Russell Family Fetal Alcohol Disorders Association, Australia

⁹Centre for Population Health Research, Curtin University, Perth, Australia

¹⁰Public Health Genetics, Genetic Disorders, Murdoch Children's Research Institute, Melbourne, Australia

¹⁰National Drug and Alcohol Research Centre, University of New South Wales, Sydney, Australia

¹¹Centre for Chronic Disease, School of Medicine, University of Queensland, Brisbane, Australia

¹²Nindilingarri Cultural Health Services, Fitzroy Crossing, Australia

The Australian FASD Diagnostic Instrument was developed to facilitate and standardise the identification of FASD in Australia. This guide provides clinicians with the background information needed to apply standard national diagnostic criteria for FASD in the Australian context. The recommended clinical diagnostic assessment methods are based on the University of Washington (UW) 4-Digit Diagnostic Code¹ method of interdisciplinary team assessment, and the Australian diagnostic categories and criteria combine elements of the UW and Canadian Guidelines for the diagnosis of FASD.² Although the actual 4-Digit Diagnostic Code does not need to be routinely derived during the diagnostic assessment, it can be derived from information recorded on the Australian FASD Diagnostic Assessment Form.

The diagnosis of FASD is complex, and ideally requires an interdisciplinary team of clinicians to evaluate individuals for a range of potential outcomes that are associated with, but not unique to, prenatal alcohol exposure. In addition, alternative diagnoses must be excluded and the potential influence of other adverse exposures assessed. Diagnostic criteria used internationally are based on criteria developed in North America. Research is required to ensure that diagnostic criteria and methods recommended for use in Australia are validated in the Australian context, and can be updated to include new diagnostic technologies or diagnostic classifications when appropriate.

As reported in previous Telethon Kids Institute Annual Report Scientific supplements, a Final Report was submitted to the Commonwealth Department of Health in 2012. Five papers were published in 2012 – 2013 and a final paper published in 2014. Watkins RE, Elliott EJ, Wilkins A, Latimer J, Halliday J, Fitzpatrick JP, Mutch RC, O'Leary CM, Burns L, McKenzie A, Jones HM, Payne JM, D'Antoine H, Miers S, Russell E, Hayes L, Carter M, Bower C. Fetal alcohol spectrum disorder: development of consensus referral criteria for specialist diagnostic assessment in Australia. *BMC Pediatrics* 2014, 14:178

Funding: Commonwealth Department of Health and Ageing

FASD Diagnostic Instrument for Australia Trial and Implementation

Investigators: Carol Bower¹, Elizabeth Elliott¹, Rochelle Watkins¹

Project staff: Juanita Doorey¹

¹Telethon Kids Institute, The University of Western Australia, Perth, Australia

² Discipline of Paediatrics and Child Health, Sydney Medical School, University of Sydney, Sydney Australia

The Telethon Kids Institute, in collaboration with the University of Sydney, developed a diagnostic instrument for FASD for use in Australia, on contract from the Commonwealth Department of Health and Ageing. Following its development, the Commonwealth Department of Health contracted the Telethon Kids Institute in 2014 to trial the implementation of the diagnostic instrument for FASD, again in collaboration with the University of Sydney.

The specific objectives of the project are to:

- Develop guidelines for health professionals on how to use the diagnostic instrument;
- Develop guidelines for support and referral pathways for families when a family member is diagnosed with FASD;
- Finalise the diagnostic instrument for release Australia-wide;
- Develop training resources for health professionals to support the national implementation; and,
- Establish a mechanism for the evaluation of the use of the diagnostic instrument.

An Expert Review Panel and project Steering Group have been established, recruitment of clinicians across Australia has commenced and ethics applications have been submitted.

Funding: Commonwealth Department of Health and Research Fellowship 634341

FASD in the juvenile justice system: a feasibility study of screening, diagnosis and workforce development

Investigators: Rochelle Watkins¹, Carol Bower¹, Raewyn Mutch¹, Rhonda Marriot², Steve Zubrick¹, Carmella Pestell³, James Fitzpatrick¹, Peter Collins⁴, Jonathan Carapetis¹

Project staff: Roslyn Giglia¹, Candice Rainsford¹, Jacinta Freeman¹, Natalie Kippin¹, Bernadette Safe¹

¹Telethon Kids Institute, The University of Western Australia, Perth, Australia

²Murdoch University, Perth, Australia

³University of Western Australia, Perth, Australia

⁴Aboriginal Legal Service, Perth, Australia

In 2013 the Alcohol and Pregnancy and FASD Research Group were successful in obtaining a \$1.4M grant from the National Health and Medical Research Council (NHMRC) to assess how many juvenile offenders in detention are affected by FASD. The aim of this research is to determine how common FASD are in young people in detention, develop a FASD screening tool appropriate for young people entering the juvenile justice system, and develop appropriate management strategies for these young people.

2014 saw the bulk of the foundation work for the implementation of the research project at Banksia Hill Detention Centre (Banksia Hill DC). Most often referred to as the 'Banksia Hill' project, work has progressed to include:

- The conferment of ethics from the WAAHEC and UWA HREC.
- The establishment and meeting of a Steering Group, and a Community and Consumer Representative Group.
- The advertising for the employment of a research officer, speech pathologist and occupational therapist who will be based at Banksia Hill DC as part of the diagnostic assessment team.
- The advertising for two research positions (PhD or Postdoc) supported by the project to investigate; 1) a qualitative case study of the entire research process, and 2) a workforce development project to provide staff with support in managing young people (detainees) with FASD.
- The enrolment of a neuropsychologist (PhD/Masters student with supervision) as part of the diagnostic assessment team.
- The engagement of Banksia Hill DC staff in the research program and the establishment of a dedicated work space at the centre.
- The development of a final research protocol for the Department of Corrective Services which when approved will allow the research pilot to take place.

In bedding down the research protocol there were many challenges which needed to be overcome to ensure project rigor, acceptance, and clear research outcomes articulated to all key stakeholders. 2015 will see the team move forward and build upon the strong foundation of collaboration and commitment that has been developed during 2014.

Funding: NHMRC Targeted Call for Research: Fetal Alcohol Spectrum Disorder among Aboriginal and Torres Strait Islander Peoples 1072072 and Research Fellowship 634341

Understanding FASD – a guide for justice professionals

Investigators: Heather Jones¹, Raewyn Mutch¹, Rochelle Watkins¹, Carol Bower¹

¹Telethon Kids Institute, The University of Western Australia, Perth, Australia

In 2011 and 2012 we conducted the '*Fetal Alcohol Spectrum Disorder: Knowledge, attitudes and practice within the Western Australian Justice System*' project with the aim of assessing justice professionals' (judicial officers, lawyers, corrections staff, police officers) awareness and knowledge of FASD, the perceived impact of FASD on practice within the justice system, and to identify the information needs relating to FASD for the justice system in WA. When asked if they would like more information about FASD 93% of judicial officers responded positively.

Our research on FASD knowledge, attitudes and practice of justice professionals in WA identified:

- what information is required by justice professionals; and
- how this information should be delivered

The purpose of this project is to translate this research into educational resources for justice professionals so that they can:

- recognise cognitive impairments and possible FASD in young people engaging with the criminal justice system whether as a victim, witness or offender; or otherwise engaged in, or the subject of legal proceedings
- identify legal implications
- consider referral for assessment if the disability is suspected
- consider decision making with respect to orders, sentencing and management

In 2014 a Steering Group with representation from the courts, legal organisations and the community was formed to provide high level advice and expertise into the development of FASD educational resources for justice professionals:

- 5 short videos for judicial officer (judges and magistrates) and lawyers
- On-line CPD module for lawyers
- Information on FASD for the WA Bench Book which is used by all judges and magistrates in WA
- Presentations at conferences and seminars + training and education sessions
- FASD and Justice section on the Alcohol and Pregnancy and FASD website

Funding: WA Department of the Attorney General Criminal Confiscation of Property Grants Program

The Alert ®Program: An evidence based treatment program for Aboriginal children living with FASD

Investigators: James Fitzpatrick¹, Karen Edmond², Jane Latimer³, Branko Celler⁴, Trevor Mazzucchelli⁵, Glenn Pearson¹, Heather Carmichael Olsen⁶, Rochelle Watkins¹, John Boulton⁷, Maureen Carter⁸
Project staff: Bree Wagner¹, Kaashifah Bruce¹, Martyn Symons¹

¹Telethon Kids Institute, The University of Western Australia, Perth, Australia

²Winthrop Professor of Aboriginal Clinical Child Health, The University of Western Australia, Perth, Australia

³ The George Institute for Global Health, University of Sydney, Sydney, Australia

⁴ Digital Productivity and Services Flagship, CSIRO, New South Wales, Australia

⁵Psychology and Speech Pathology, Curtin University, Perth, Australia

⁶Department of Psychiatry and Behavioral Sciences, University of Washington School of Medicine, Seattle, USA

⁷ Professor of Paediatrics, Kimberley Paediatric and Child Health Team

⁸Nindilingarri Cultural Health Services, Fitzroy Crossing, Australia

Children with FASD and early life trauma can experience difficulties with their self-regulation and executive functioning. This can impact on children's ability to plan, organise, maintain attention and choose an appropriate level of alertness to suit a particular task or situation. The Alert Program® is based on the analogy of the body being like a car engine to teach self-regulation and improve executive functioning. The body can run at different levels of alertness such as high, low or just right. Children are taught five ways to change their level of alertness through listening, moving, touching, looking or putting something in their mouth. The program also supports families, teachers and therapists to develop strategies to change or maintain states of alertness to optimise student functioning. Whilst initially designed for children with attention and learning disabilities, the program can be tailored to meet the needs of a specific population, such as children in the Fitzroy Valley, so that the concepts can be most effectively taught.

The goal of this research project is to develop, implement and evaluate the Alert Program® to improve self-regulation and executive functioning skills of primary school aged children in the Fitzroy Valley.

Alert Program® study objectives

- Establish a therapeutic program governance structure, representing community/families, schools, and child health services within the existing Marulu FASD Strategy Leadership Team.
- Identify children with impairments in self-regulation and executive functioning by screening and assessing school-aged children in the Fitzroy Valley, and accessing results of prior assessments (including those conducted during the Lililwan FASD prevalence study).
- Conduct consultation with community, schools, and child health services to tailor the Alert Program® and select measures of self-regulation and executive functioning to ensure cultural appropriateness and local relevance.
- Conduct training with teachers, Aboriginal school support staff and child health service providers in the delivery of the tailored Alert Program®.
- Determine the effectiveness of the tailored Alert Program® using a step wedged randomised controlled study design. This design introduces the Alert Program® to different schools at different times and compares outcomes for students before and after the program is implemented at each school. Quantitative data (numbers) will be collected to measure the effectiveness of the program at improving children's self-regulation and executive functioning. Qualitative (stories) data will determine provider/family satisfaction with the program.

- Provide parent/carer education and training to increase their knowledge of how strategies utilised in the tailored Alert Program® can assist children to self-regulate

Funding: NHMRC Program Grant 1086145

Fetal Alcohol Spectrum Disorders (FASD) in the National Disability Insurance Scheme (NDIS)

Investigators: James Fitzpatrick¹, Tanyana Jackiewicz¹, Carol Bower¹

Project staff: Angela Dudley¹

¹Telethon Kids Institute, The University of Western Australia, Perth, Australia

In 2014 we received funding to conduct a comprehensive review of the available information, both published and unpublished on services and supports for people living with FASD to inform the development of draft best practice guidelines for NDIA planners. The work which will commence in 2015 will:

- develop a draft functional severity index for people with FASD to assist planners in decision making around the level and type of services and supports required
- estimate service cost estimates including workforce requirements for evidence based and promising services and supports
- present these draft guidelines and functional severity index for assessment by the NDIA Expert Panel

Funding: National Disability Insurance Agency