

ANNUAL REPORT 2017

Alcohol and Pregnancy & FASD Research Team

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OUR RESEARCH

WHAT IS FASD

Fetal Alcohol Spectrum Disorder (FASD) is a diagnostic term for severe neurodevelopmental impairments which may be seen as difficulties with physical activities, language, memory, learning and behaviour and is the result of brain damage caused by alcohol exposure before birth.

Fetal Alcohol Spectrum Disorder (FASD) occurs in all parts of Australian society where alcohol is consumed. No level of maternal alcohol consumption at any time during pregnancy can be guaranteed to be completely 'safe' or 'no risk' for the developing fetus. Our research raises awareness of FASD across different regions and sections of society. As a lead partner of the *FASD Research Australia Centre of Research Excellence*, we also build much needed research capacity in this area across Australia.

To reduce the rates of women drinking alcohol during pregnancy and while breastfeeding, we work with health professionals to raise awareness of the [Australian Guidelines to Reduce Health Risks from Drinking Alcohol](#) and the importance of asking women about their alcohol use.

We promote the [Australian Guide to the Diagnosis of FASD](#) with the aim of improving how FASD is diagnosed in Australia and the early implementation of evidence based support and therapy programs.

The team works closely with Government agencies to improve the lives of young people in youth justice by understanding how many are living with FASD. Related to this is the development of new resources for justice professionals to enable them to appropriately engage with these young people.

A strong focus of our research is building the capacity of other professionals such as those in the education sector. We are seeking to understand the needs of all teachers and support staff via national surveys while also implementing and evaluating self-regulation programs in rural and remote schools of WA.

NO ALCOHOL WHEN PLANNING A PREGNANCY, DURING PREGNANCY OR WHILE BREASTFEEDING IS THE SAFEST OPTION

Our goals

We work in partnership with researchers from other teams at the Telethon Kids Institute and other organisations, communities and stakeholders to provide evidence for prevention, assessment and diagnosis, therapy and support. Our goals are to:

- prevent alcohol use in pregnancy and its effects on child health
- decrease the incidence of FASD
- support prevention and management of FASD within Indigenous communities
- improve the diagnostic capacity of health professionals
- improve management of children and young people with a FASD through effective interventions
- improve the management of young people with FASD in contact with the justice system
- work with stakeholder and community partners to implement and measure the impact of our research
- work with partners to develop workforce strategies within the health, education and justice sectors
- empower local people and provide locally relevant solutions while building community and workforce capacity for FASD prevention
- increase capacity of Aboriginal Community Controlled Health Organisations (ACCHOs) to implement and evaluate evidence-based population health programs

Our team values and behaviours

Integrity is the overarching value of the team. It represents the spirit of who we are and pride in what we do and guides us to be ethical, authentic, honest, humble and professional, always.



Integrity
Compassion
Accountability and Quality
Respect and Relationships
Empowerment

Team Leadership

Dr James Fitzpatrick was the Head of the Alcohol and Pregnancy & FASD Research Team from 2016 until November 2017 when he stepped down to focus on leading the various research projects on which he is the Chief Investigator, and advocacy roles that require focus outside of the Institute. Dr Roslyn Giglia took over the role as Head of the Team.

OUR DEDICATED RESEARCHERS

Through dedication and high quality research, leadership and service, our researchers strive to deliver high impact and translational research to improve the lives of children and young people living with FASD and their families.

Awards



Professor Carol Bower

Inducted into the Australian Academy of Health and Medical Sciences Fellowship



Banksia Hill FASD Project Team

Policy and Research Translation Award, Public Health Association Australia WA Branch



Adrian Clinch

- Scholar of the Year, Port Hedland NAIDOC Week Awards
- Foundation for Alcohol Research and Education (FARE) Scholarship to attend the 2017 Global Alcohol Policy Conference in Melbourne



Sue Cherel

Semi-finalist for Western Australian Regional Achievement and Community Award



James Fitzpatrick

2017 Western Australian of the Year Professionals Award



Narelle Mullan and Amy Finlay-Jones

Telethon Kids Institute Emerging Leaders Program

Awards



Amy Finlay-Jones

- Women in Leadership Australia, Accelerated Program Scholarship
- Women in Leadership Australia, Accelerated Program, Telethon Kids Institute Top Up Funding
- Health Policy Research Scholarship, Deeble Institute
- Golden Key Society Invitation, Deakin University (Outstanding Academic Achievement)
- Aspire Conference Award (Finalist), City of Perth
- Startup Challenge Top 10 Finalist, West Tech Fest
- SPARK Co-Lab Award and Telethon Kids Institute Scholarship, Western Australia
- Biodesign Course Pitch Winner, Spark Co-Lab
- Innovation Award (Finalist), WA Association of Mental Health



Sharynne Hamilton

Peter and Anne Hector Award: Translational Research in Aboriginal Health



Natalie Kippin

PhD Scholarship, FASD Research Australia Centre of Research Excellence



Hayley Passmore

- Stan and Jean Perron Postgraduate Award for Excellence
- Best Abstract, Telethon Kids Institute Student Circle Symposium
- Runner up 8-minute Presentation, Telethon Kids Institute Student Circle Symposium



Bernadette Safe & Hayley Passmore

Australian Student Award for Best Abstract, Australian and New Zealand Society of Criminology Conference

Awards



Rebecca Pedrucci

Friends of the Institute Sabbatical Award to work in collaboration with Maastricht University in the Netherlands on best practice FASD prevention



Martyn Symons

Funding from Kids Brain Health Network to travel to Canada to train on the use of an eye tracking machine and foster collaborations with Telethon Kids Institute



Bree Wagner

Collaboration Awards Program, Friends of the Institute Travel Awards



Tess Fletcher

PhD Scholarship, FASD Research Australia Centre of Research Excellence



Celebrating our achievements in 2017

- National Consortium (Telethon Kids Institute, Central Australian Aboriginal Congress Aboriginal Corporation and Mercy Services) awarded a contract by the Australian Government Department of Health, to provide the prevention component of the Fetal Alcohol Spectrum Disorder (FASD) Diagnostic Services and Models of Care.
- An alliance of organisations (Telethon Kids Institute, the University of Sydney, NOFASD Australian, Menzies School of Health Research and the Australian FASD Clinical Network) received a grant from the Australian Government Department of Health to develop a national FASD Hub website, the first of its kind internationally.
- Amy Finlay-Jones, Martyn Symons, Carol Bower and Narelle Mullan were part of a cross Telethon Kids Institute team which received Think Big Funding to develop Precision pathways for young children at risk of Neurodevelopmental Disorders: Early identification and adaptive intervention starting from the prenatal period.
- Narelle Mullan, Amy Finlay-Jones, and James Fitzpatrick were part of a team that was awarded a Telethon Kids Institute Competitive Working Group Project Grant for a project Working Towards a Shared Framework in the Diagnosis of Neurodevelopmental Disorders in Australia: A Gap Analysis.
- The Alert Program® introduced into 4 schools in the Pilbara and data on the outcomes from the 9 schools who participated in the Alert Program® in the Kimberley over the past 3 years finalised.
- 2 Community researchers working on the Alert Program® completed their TAFE Certificate II in Community Services and 4 more will complete the course in 2018.
- The Pilbara project team had the privilege of visiting Parnngurr community during the Western Desert Football Carnival. During this trip, the team were able to get to know community members and service providers from the Western Desert, as well as travel to Punmu.
- Completion of the assessment of young people sentenced to detention in Banksia Hill Detention Centre and presentation of the results and recommendations to government and non-government stakeholders.
- Acknowledgement by maternal health professionals that alcohol and breastfeeding is something they would like to include on their agenda going forward.

New Resources

- **6 videos** developed with the local Aboriginal Community researchers and community members. A particular highlight was being able to share Tracy's story. She was diagnosed with FASD as a young person and made the decision not to drink alcohol while she was pregnant with her daughter Amy. Tracy is a member of the Hedland Community Reference Group. Videos can be accessed [here](#).
- **6 videos** were produced as part of the 3M FASD Prevention Strategy, to provide insights into children and their families living with FASD and broader information about FASD for health professionals, and the impact on communities. Videos can be accessed [here](#).
- **8 videos** were produced by FASD Hub Australia in partnership with parent and carers and health professionals. These videos focus on strengths, challenges and hopes of children with FASD, and information for health and other professionals involved in diagnosis and management. Videos can be accessed [here](#).

Other achievements

Submissions

- Review of the Young Offenders Act 1994
- Royal Commission into the Protection and Detention of Children in the Northern Territory
- Australian Law Reform Incarceration Rates of Aboriginal and Torres Strait Islander Peoples
- Global Alcohol Strategy
- National Breastfeeding Strategy 2017 and Beyond
- Development of the Australian Government National FASD Strategy
- Chief Health Officer's Submission to the licensing authority in respect to the extent of alcohol related harm being experienced in Hedland and surrounds

TELLING PEOPLE ABOUT OUR RESEARCH

Discover Day

Telethon Kids Institute Discover Day is a free family fun day to find out what we do at the Institute, allow kids to conduct experiments and talk to the researchers. In 2017 almost 1000 people attended the day. Our team provided a lounge area for pregnant and breastfeeding women.



During the day we invited visitors to our lounge area to do the following:

- pin up ideas for supporting pregnant women on a message board
 - vote for ideas to support pregnant women to not drink alcohol during pregnancy
 - see a demonstration of the Feedsafe app
- Provide an exciting range of non-alcoholic drink at social events.
 - Arrange to meet for breakfast instead of dinner and drinks.
 - Go alcohol free in the company of a pregnant person.
 - Abstinence from alcohol during pregnancy is the safest option for mum and baby.
 - When you feel like having a drink, do something else that you really enjoy instead
 - Make sure your family and friends support your choice to not drink.
 - Don't drink and smoke during your pregnancy for a healthy and strong future.
 - The wellbeing of your future child is worth the current restraint not to drink for '9 months' vs 'a lifetime.' Doesn't compare really!
 - Remember strong baby, strong mind.
 - Increase positive awareness through mass media and GP education antenatal classes.
 - Be positive and think wisely.
 - Align yourself with people that will support your breastfeeding journey when times get tough because breastfeeding is the most rewarding experience of your life.

What did people say?

FASD Awareness Day 2017

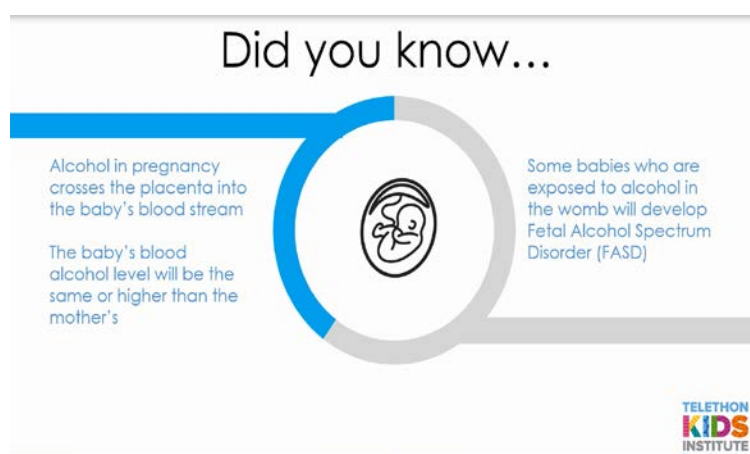


Members of the team wore red shoes on FASD Awareness Day 9 September. The **RED SHOES ROCK** campaign was initiated by the group 'Families affected by Fetal Alcohol Spectrum Disorder' in 2014 in the USA.

A short video was also released on FASD Awareness Day

The purpose was to raise awareness of alcohol and pregnancy targeted at women child bearing age.

[Watch the video](#)



The Pilbara FASD team attended the International FASD Awareness Day 2017 community event held at the South Hedland Town Square on Friday 8 September. Co-hosted by Wirraka Maya Health Service and the Telethon Kids Institute, the day also featured stalls and activities by South Hedland Aboriginal Family Law Services, South Hedland Child and Parent Centre and the KindiLink Program among others. The day was the perfect opportunity to unveil three new FASD Prevention videos, which featured local Pilbara people sharing their FASD experiences. Tracy Kynaston, a Hedland Community Reference Group member shared her personal experiences of living with FASD, and her decision not to drink while pregnant with her daughter, Amy.



Presentations at conferences, seminars & workshops



- 27 Western Australia
- 10 National
- 12 International

Publications

- 12 publications in national and international journals
- All publications authored by members of the Alcohol and Pregnancy & FASD Team at Telethon Kids Institute can be found in the [publications section of our website](#)

Media

Making FASD History: A multi-site prevention program

National Indigenous Radio Service, (2017, October 4). *FASD Program to be Rolled Out in Alice Springs, Newcastle*. National Indigenous Radio Service. <http://news.nirs.org.au/71735-2/>

Page, D. (2017, October 3). *\$2.7m for Newcastle and Alice Springs to fight the impact of alcohol on the*. Herald Sun. <http://www.theherald.com.au/story/4962794/newcastle-to-lead-fight-against-drinking-mothers/>

Sarv, T. (2017, October 3). *FASD Prevention Program Underway in Newcastle*. NBNNEWS. <http://www.nbnnews.com.au/2017/10/03/fasd-prevention-program-underway-in-newcastle/>
<http://www.abc.net.au/news/2017-10-03/project-underway-to-prevent-fetal-alcohol-spectrum-disorder/9001350>

Virtue, R. (2017, October 3). *Fetal Alcohol Spectrum Disorder prevention project underway in regional cities*. ABC Newcastle. <http://www.abc.net.au/news/2017-10-03/project-underway-to-prevent-fetal-alcohol-spectrum-disorder/9001350>

Website and social media

Visit our [Alcohol and Pregnancy and FASD website](#) to find out more information about our research, find resources, publications and news



@NoAlcohol4Mum

@MakeFASDHistory

Members of our team are also involved in the FASD Research Australia Centre of Research Excellence and FASD Hub Australia that also have websites.

[FASD Research Australia](#)

[FASD Hub Australia](#)

Providing our expertise



Our Aboriginal Community Researchers provide cultural knowledge and language expertise to project team members to ensure research is undertaken in a culturally and contextually sensitive way.

Members of our team provide their expertise to the following organisations/groups:

- Australian Association for Research in Education
- Australian Indigenous Alcohol and Other Drugs Knowledge Centre
- Australian Government Department of Health Breastfeeding Expert Reference Group
- Australian National Advisory Council on Alcohol and Drugs
- Australian Paediatric Surveillance Unit Scientific Review Panel
- Australian Society for Medical Research
- Drug and Alcohol Review Editorial Board
- FASD Hub Australia Advisory Group
- Indigenous Advisory Group for the Centre of Research Excellence in Indigenous Health and Alcohol
- Indigenous Advisory Group for the Positive Choices Indigenous portal
- National FASD Technical Network
- National Indigenous Drug and Alcohol Conference Organising Committee
- National Perinatal Epidemiology Statistics Unit Steering Committee for Congenital Anomalies
- Palmerston Association Board
- Public Health Association of Australia
- Queensland Government Department of Justice and the Attorney General Youth Justice Speech Pathology Advisory Group
- UWA Law School Aboriginal and Torres Strait Islander Community Justice Reference Group
- WA Department of Health Child & Youth Health Network Expert Advisory Group
- WA Department of Health Child and Youth Health Networks Youth Health Policy Working Group
- WA Key Stakeholders Breastfeeding Group

OUR PROJECTS



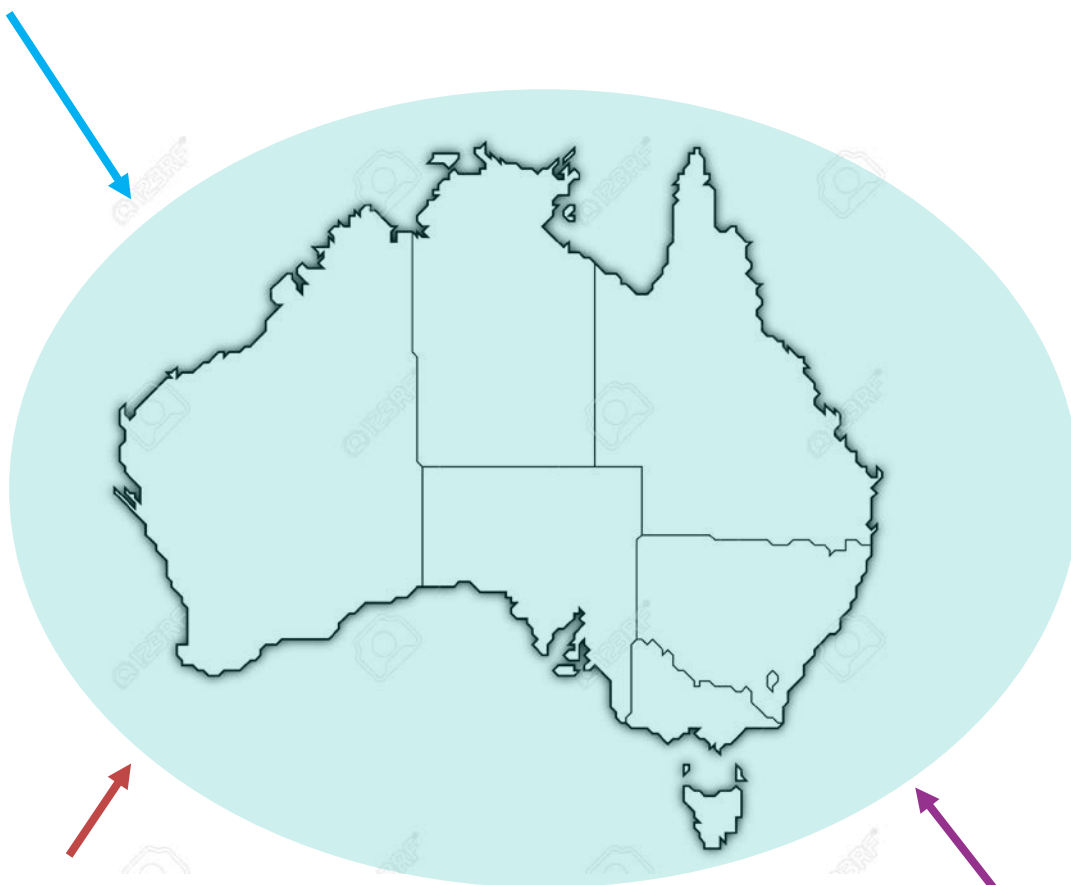
OUR NATIONAL ACTIVITIES & PROJECTS

FASD Research Australia Centre of Research Excellence

Co-Directors based in Perth and Sydney

Researchers, consumer & community representatives, health and other professionals participate in activities & projects across Australia

- FASD in the Australian Education System: Knowledge, attitudes, needs, and practices
- Normative Eye-tracking Data for Australian Children on Four Tasks
- Precision pathways for young children at risk of Neurodevelopmental Disorders: Early identification and adaptive intervention starting from the prenatal period
- Working Towards a Shared Framework in the Diagnosis of Neurodevelopmental Disorders in Australia: A Gap Analysis
- FASD Community Priority Setting Partnership for Research
- Using a participatory design to create impactful health promotion messages regarding alcohol use in pregnancy
- Communication, fetal alcohol spectrum disorder, and youth justice



FASD Hub Australia

Advisory Group members from across Australia and project staff based in Sydney and Perth

Consultations with parents and carers, health and other professionals, researchers and policy makers from all states and territories

NHMRC alcohol and breastfeeding guidelines, clinician application and maternal uptake

Consultations with health professionals and women across Australia

Hedland FASD Project

Warajanga Marnti Warrarnja – Together we walk on country

This project is working with existing Hedland, Warralong and Yandeyarra services, networks and communities to:

- identify rates of alcohol use in pregnancy using data routinely collected by midwives during antenatal care
- reduce the rates of alcohol use in pregnancy among local Aboriginal women
- increase the capacity of the local community and services to care for and support individuals and families affected by FASD

OUTPUTS & IMPACT

Prevention

- Mainstream mass media campaign delivered
- 3 FASD Promotional videos developed and launched at International FASD Awareness Day community event - [watch the videos](#)
- Over 400 community Knowledge, Attitudes and Practices surveys completed

Therapy and Support

- Alert Program delivered in four schools
- Commencement of Carer Support Program qualitative research interviews

Diagnosis

- 4 FASD diagnostic clinics conducted

Community Engagement and Capacity Building

- Regular Community Reference Group and FASD Network meetings conducted



This project is funded
by BHP



[Read more about this project](#)

Pilbara FASD Project

The Pilbara FASD Prevention Project seeks to enable the development and dissemination of a reproducible process to enable an evidence-based model of FASD prevention to be embedded in health policy and practices servicing all women in Australia. The results from data collection will inform and underpin the development of a culturally appropriate prevention intervention model for Aboriginal women in the Pilbara region.

OUTPUTS & IMPACT

- Improve the health, quality of life and social and economic potential of the next generation of children living in the Pilbara.
- Empower local people and provide local solutions while building community and workforce capacity for FASD prevention.
- Facilitate a context within the Pilbara that is receptive to healthy public policy and supports community-driven alcohol restrictions and other legislative change with regard to alcohol availability, access and promotion.
- Enhance the health workforce through embedding screening processes to track alcohol use before and during pregnancy in the Pilbara using AUDIT C, and trigger brief intervention and support of women at high risk of drinking in pregnancy.
- Increased capacity of Aboriginal Community Controlled Health Organisations (ACCHOs) to implement and evaluate evidence based population health programs.



This project is funded by the NHMRC (Project ID #APP1105000)



[Read more about this project](#)

Alert Program®

While lots of children going to school in the Fitzroy Valley do well, some kids find school hard.

They may have problems:

- following instructions
- paying attention
- solving problems
- remembering things

This can cause problems for kids with their learning and behaviour.

To help all kids do their best at school, we would like to find out if teaching the Alert Program® in class helps primary school aged children learn more easily. We are also interested to find out if the program works well for kids with FASD.

OUTPUTS & IMPACT

- **4** Fitzroy Valley schools and **11** communities welcomed us throughout the project over 8 separate visits from Perth.
- **46** teachers, school leaders, school support and ancillary staff received training in Alert Program® and self-regulation concepts.
- **15** classrooms across 4 Fitzroy Valley schools delivered the Alert Program® curriculum.
- Approx. **145** students and their families participated in the research project.
- **7** Aboriginal community researchers worked in two-way teams with Perth based staff to deliver the research project.
- **6** community researchers undertook a Certificate II in Community Services and **5** flew to Perth to visit and share their expertise with Telethon Kids Institute staff.



This project is funded by
the NHMRC (Project ID
#APP1086145 & 100
Women

[Read more about this project](#)

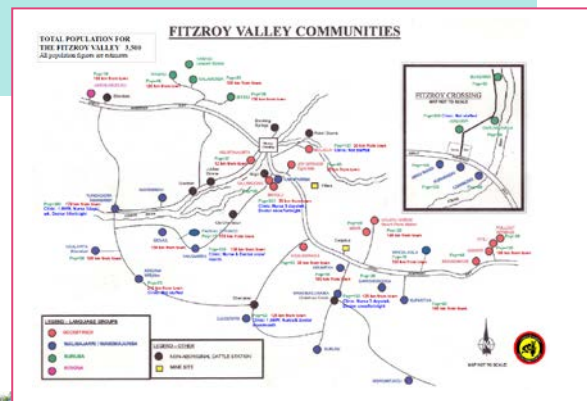
3M FASD Prevention Strategy: Marulu, Mass Media and Midwives

This project has three parts:

1. **Marulu:** development of prevention strategies to reduce the number of women drinking alcohol during pregnancy
2. **Midwives:** improve their capacity to talk to women about their alcohol use during pregnancy, and provide guidance to them about the effects of alcohol use on the developing baby
3. **Mass media:** provision of the message 'not drinking alcohol during pregnancy is the safest option' through television and radio advertisements

OUTPUTS & IMPACT

- Project completed 30 June 2017
- 6 FASD Awareness Promotional videos developed – [watch the videos](#)
- Final report submitted to WA Department of Health
- 4 papers in progress



This project is funded by the Government of Western Australia – Departments of Health & Aboriginal Affairs

[Read more about this project](#)

Midwives and Women AUDIT-C Intervention Project




This project was designed to improve the capacity of midwives working in antenatal settings to use the pregnancy specific AUDIT-C alcohol risk screening tool with pregnant women, and provide guidance to them about the effects of alcohol use on the developing baby. The project also developed a Learning Package for midwives and a comprehensive list of relevant professional educational resources.

OUTPUTS & IMPACT

- The AUDIT-C Learning Guide is a required component of hospital and other health services induction processes, for all health professional staff likely to provide care to pregnant women.
- Provides midwives with clear guidance about routine screening for alcohol use in pregnancy and associated education for women to alert them to the harmful effects of alcohol use.
- Is also relevant for other health professionals who have contact with pregnant women, including general practitioners, obstetricians, nurses, and Aboriginal Health Workers.

This project is funded by the Government of Western Australia – Departments of Health & Aboriginal Affairs & Telethon Kids Institute





Government of Western Australia
Department of Health

YOUNG MOTHER

"A friend of mine, she fell pregnant quite young. So she was maybe 19, and her doctor said there was no reason for her to stop drinking. I think that's the first thing I kind of threw into my mind. Is it alright to continue drinking a little bit? I didn't. But is it ok? A little bit ok? Or is it none?"

MIDWIFE

"They usually do disclose it, because they are worried about the baby. They genuinely want to do the right thing by their baby. So they will usually slide a question in somehow that makes you think 'oh!'"

[Read more about this project](#)

Making FASD History: A multi-site prevention program

The focus of this program is building capacity in local health services so that communities can own and continue to lead FASD prevention activity after the research is finished. The program aims to support communities to use consistent information and messages about drinking in pregnancy and FASD utilising existing national and regional FASD prevention resources.

This project received funding in 2017 and work commenced in 2018 with partners Central Australian Aboriginal Congress (NT) and Mercy Services (NSW).

FUTURE OUTPUTS & IMPACT

Community health promotion

- Increased awareness of prenatal alcohol exposure and FASD prevention messages.

Workforce education

- Health system changes, specifically improved data capturing mechanisms, standardised in line with the National FASD Action Plan (use of AUDIT-C).
- Enhanced workforce capacity through improved health professional knowledge of prenatal alcohol exposure, FASD prevention and local referral pathways for people living with FASD.

This project is funded by the Australian Government Department of Health

[Read more about this project](#)

Banksia Hill Detention Centre Project

The aim of this study was to evaluate the feasibility of screening, diagnosis and workforce development to best work with, and support young people living with FASD in the justice system.

The primary objective of this study was to:

- Establish the prevalence of FASD among youth in detention in Western Australia (WA)

Further objectives:

- Development and evaluation of a FASD screening tool for use among young people entering youth justice in Australia
- Development, implementation and evaluation of a workforce development intervention to support youth detention staff in their work with young people living with FASD
- Evaluation of the impact of the research project from individual through to system levels, employing qualitative research methodology

IMPACT

- Our research has received national and international recognition for identifying that 1 in 3 young people in youth detention in WA are living with FASD, the highest known estimate among justice-involved youth world-wide. Our study also revealed that 9 out of 10 young people in detention are living with at least one severe impairment in a neurodevelopmental domain.
- Young people valued the assessments, particularly receiving knowledge of their individual strengths which can be harnessed to help create pathways for positive futures. Assessment information has enriched management plans for while youth are involved in youth justice, and the study has enabled young people and their families to be linked to community and disability services. Staff training has been implemented across the detention centre workforce, upskilling staff on caring for young people with neurodevelopmental impairments. The training is currently under evaluation.
- Our team of researchers and clinicians continue to engage with government departments and other stakeholder groups, influencing policy and practice, and exploring how research can help to build capacity and facilitate the work they undertake with young people involved in the justice system.

**This project is funded by
the NHMRC (Project ID
#APP1072072)**



Artwork by 16-year-old Yamadji boy at BHDC. Permission to use

[Read more about this project](#)

Alcohol and Pregnancy & FASD Research Team PhD and Masters candidates

Sharynne Hamilton

PhD Title: *Talking, Hearing, Understanding, Knowing: A qualitative exploration of the experiences of justice-involved youth undergoing assessment for Fetal Alcohol Spectrum Disorder in a juvenile detention centre*

Summary

The proposed qualitative research aims to examine the views of young people and their families, non-custodial staff working in the detention centre, and youth justice service providers to explore their views and experiences of assessments for FASD or neuro-developmental disability which were undertaken as part of the Banksia Hill Detention Centre prevalence study. The thesis will be underpinned by two theoretical frameworks: 'Wicked Problems' and 'Hope'.

Examining and reporting on these experiences and understanding the effects of being diagnosed with FASD or a neurodevelopmental disability while engaged in the youth justice system will provide a unique insight into the challenges the young people have experienced in their lives and how they may be assisted. By gaining an in-depth understanding of the complex needs of young people in detention, the study aims to:

- Gain an in-depth understanding of the complex needs of young people in detention, including participation in FASD assessment process/outcomes.
- Identify intervention points which may assist young people in detention to find alternative life pathways which enable them to fulfil their hopes.
- Identify solutions which address the 'wickedness' of the problems associated with youth justice systems.
- Provide a unique contribution to evolving policy in Australian youth justice systems.

[Read more about this PhD](#)

Bree Wagner

PhD Title: *The Alert Program® Study: development and evaluation of an intervention to improve the self-regulation and executive functioning skills of Australian Aboriginal primary school children with a focus on fetal alcohol spectrum disorder (FASD)*

Summary

This project aims to:

1. Modify, implement and evaluate a school curriculum version of the Alert Program®.
2. Evaluate the effectiveness of an eight-week Alert Program® curriculum to improve the self-regulation and executive functioning skills of children attending primary school in the Fitzroy Valley.
3. Document a sustainable and culturally appropriate method of implementing the Alert Program® in Fitzroy Valley schools.

[Read more about this PhD](#)

Hayley Passmore

PhD Title: *Improving the management of young people with fetal alcohol spectrum disorder (FASD) in detention*

Summary

Health and justice professionals across Australia are urging for an increase in services to better support young people with fetal alcohol spectrum disorder (FASD) involved with the justice system. Knowledge of FASD among young people sentenced to a period of detention is increasing, with a prevalence study ascertaining that 36% of young people sentenced to detention have FASD, and 89% are severely impaired in at least one area of neurodevelopmental function. However, previously there has been little investigation into the capacity of custodial staff to identify and manage young people in Australian detention centres with FASD or similar impairments, nor have there been published interventions aiming to develop environments appropriate for those with FASD in detention.

Hayley's PhD research has used mixed methods to determine the current knowledge and practices relating to FASD and neurodevelopmental impairments among the custodial workforce at Banksia Hill Detention Centre, the only youth detention centre in Western Australia. These data informed the development and evaluation of training resources (a series of short, educational videos) which are currently being implemented to the custodial workforce at Banksia Hill Detention Centre, and evaluated using mixed methods. The aim of these resources, and the ultimate objective of Hayley's PhD research, is to build capacity among the custodial workforce regarding FASD and other neurodevelopmental impairments by upskilling them in the management strategies most appropriate for young people in detention with such impairments.

[Read more about this PhD](#)

Dave Tucker

PhD Title: *Determinants of prenatal alcohol exposure among Aboriginal women in the Pilbara: Developing a statistically validated model of prenatal alcohol consumption for evidence based intervention development*

Summary

The overarching aim of the proposed research is to identify the key psycho-social and contextual determinants of alcohol use during pregnancy in Aboriginal women of the Pilbara region of Western Australia.

[Read more about this PhD](#)

Bernadette Safe

Masters Title: Young people in detention in Western Australia: An examination of motor skills and the effect of prenatal alcohol exposure

Summary

The aims of this research were to review what is known about motor impairments in adolescents with FASD and Prenatal Alcohol Exposure (PAE). Following this, the research aimed to assess and characterise motor performance in young people in a Western Australian youth detention centre with a high level of FASD, and explore the relationship between motor skills, FASD and PAE.

This thesis is currently under examination.

[Find out more about this Masters study](#)

Fetal Alcohol Spectrum Disorder in the Australian Education System: Knowledge, attitudes, needs, and practices

The primary aim of this study is to examine knowledge, attitudes, and practices related to Fetal Alcohol Spectrum Disorder (FASD) and its implications for the classroom, among primary and secondary school staff working in Catholic and Independent Schools in Western Australia. In addition, the aim of this research is to examine school staff perspectives of the needs of students with FASD, and to compare needs of students with FASD with the needs of students with Autism Spectrum Disorder (ASD).

These aims will be achieved by:

- conducting an online survey of staff in Catholic and Independent schools in Australia, using a random sample of schools drawn from a national sampling frame
- comparing outcomes with data collected in the Autism Cooperative Research Centre Education Needs Analysis survey

FUTURE OUTPUTS & IMPACT

- Provide insight into current knowledge and practices surrounding FASD in the classroom.
- A comprehensive snapshot of the social/emotional, behavioural, communication, and academic needs of students with FASD.
- Inform the development of FASD interventions and adaptation considerations for specific settings (e.g. justice).
- Determine the feasibility of transdiagnostic vs disorder-specific models of classroom intervention for ASD and FASD.
- Support the development of a network of educators and caregivers for dissemination of the resources and training.

**This project is funded by the
FASD Research Australia
Centre of Research Excellence
(Grant ID #APP1110341)**



[Read more about this project](#)

Normative Eye-tracking Data for Australian Children on Four Tasks

This research will replicate promising methods from Canada where eye-tracking coupled with advanced statistical models can screen children for FASD with 74.1% accuracy. Before we use this system to screen for FASD in Australia we need to know what is “normal” for eye-movements for both Aboriginal and non-Aboriginal children in Australia and check if this is the same as in Canada. To do this we will collect eye-tracking data for 100 children (50 non-Aboriginal and 50 Aboriginal, half male and half female) aged between 7-12 years old. Having this data will also allow us to make comparisons with children who have neurodevelopmental disorders in the future. The de-identified, aggregated data collected in this study will be used in future research to compare with data collected from children with neurodevelopment disorders, including FASD.

FUTURE OUTPUTS & IMPACT

- Taking the first steps to developing a quicker, cheaper screening tool for neurodiversity in children.
- Bringing new research and technology from the Kids Brain Health Network in Canada to Australia and fostering stronger collaboration.
- One of the first studies collecting eye-tracking data for Aboriginal children in Australia.

This project is funded by the
FASD Research Australia
Centre of Research Excellence
(Grant ID #APP1110341)



[Read more about this project](#)

Precision pathways for young children at risk of Neurodevelopmental Disorders: Early identification and adaptive intervention starting from the prenatal period

This project aims to improve the identification and treatment of children at risk of Neurodevelopmental disorders (NDDs). We aim to identify early (birth - 2 years) markers and risk profiles for neurodevelopmental impairment, and to develop and evaluate very early treatments that are personalised to individual strengths and difficulties. By doing this, we hope to promote positive developmental outcomes across the lifespan. Together with strategies that aim to engage optimally with at-risk families and translate screening and intervention principles into policy and practice, this program has the very real potential to revolutionize the clinical management of children at heightened risk of NDDs.

FUTURE OUTPUTS & IMPACT

- Improve the identification and treatment of children at risk of NDDs.
- Identify early (birth - 2 years) markers and risk profiles for neurodevelopmental impairment.
- Develop and evaluate very early treatments that are personalized to individual strengths and difficulties.
- Promote positive developmental outcomes across the lifespan.

**This project is funded by the
FASD Research Australia
Centre of Research Excellence
(Grant ID #APP1110341)**

[Read more about this project](#)

Working Towards a Shared Framework in the Diagnosis of Neurodevelopmental Disorders in Australia: A Gap Analysis

The short-term aim of this project is to understand how the current Australian clinical guidance documents for Neurodevelopmental disorders (NDDs) diagnosis work together, and to learn from clinicians and families how to better coordinate the process of diagnosis through a shared framework.

This project involves two parts and each part will be guided by a Steering Group of clinical experts and community members with lived experience:

1. Review of existing Australian and international clinical guidance documents for NDD diagnosis to explore similarities and differences between guidelines.
2. Online or workshop consultations with clinical experts and community members. The purpose of this consultation is to identify current gaps in knowledge about NDD diagnosis, as well as potential benefits and challenges which may come from having a shared framework to guide the process of diagnosing one or more NDDs in children.

FUTURE OUTPUTS & IMPACT

- To understand how the current Australian clinical guidance documents for the assessment and diagnosis of neurodevelopmental disorders work together.
- To learn from clinicians and families how to better coordinate the process of neurodevelopmental disorder diagnosis through a shared framework.
- The long-term aim is that the Australian clinical guidelines for neurodevelopmental disorders will be integrated, holistic and efficient.

**This project is funded by the
FASD Research Australia
Centre of Research Excellence
(Grant ID #APP1110341)**

[Read more about this project](#)

Fetal Alcohol Spectrum Disorder (FASD) Community Priority Setting Partnership for Research

Understanding the research priorities of different stakeholders in the area of Fetal Alcohol Spectrum Disorder will assist in informing future research and will ensure research undertaken is community relevant, which will in turn facilitate interventions and policies that are relevant, useful and effective.

OUTPUTS & IMPACT

The next stage in the process is to seek answers and actions for these top ten priorities and use the results to shape policy and practice. The FASD Research Australia Centre of Research Excellence will review their research strategy and continue to advocate for a national strategic approach to FASD research that includes the views and perspectives of the community.

This project is funded by the
FASD Research Australia
Centre of Research Excellence
(Grant ID #APP1110341)



[Read more about the Top 10 priorities and this project](#)

Tess Fletcher

PhD Title: *Using a participatory design to create impactful health promotion messages regarding alcohol use in pregnancy*

Summary

The overarching aim of this proposed research is to explore the limitations of existing alcohol and pregnancy messages and to assess the effectiveness of targeted messages, developed using a participatory design approach, for changing attitudes and behaviours in target groups. Specific objectives are:

1. To identify and evaluate existing alcohol in pregnancy messages to determine the framing of the messages and the target audience;
2. To test existing messages with a community sample to determine the effectiveness for influencing attitudes and behaviour;
3. To use a participatory design process to tailor the health promotion message “No alcohol in pregnancy is the safest choice’ with and for up to four distinct groups not currently receiving effective messages about alcohol use in pregnancy;
4. Identify the specific themes that emerge from the participatory design process in regard to the different target groups’ understanding and attitudes about alcohol use in pregnancy and relevant outcomes;
5. Establish the extent to which messages created using participatory design improve the understanding and change the attitudes around alcohol use in pregnancy of the specific groups they were designed for;
6. Document a health promotion message participatory design process that may be replicated for other target groups and/or health promotion messages.

[Read more about this project](#)

Natalie Kippin

PhD Title: *Communication, fetal alcohol spectrum disorder, and youth justice*

Summary

Communication competency is of significant vulnerability for young people in youth justice, and youth people living with FASD. Difficulties with communication has important implications for a young person’s social, emotional, educational and occupational success. This research aims to examine the communication abilities of young people sentenced to detention in Western Australia (WA), where a high prevalence of FASD and neurodevelopmental disorder has been identified. Outcomes are anticipated to inform youth justice approaches for supporting young people in their care.

The four studies of this PhD include:

1. Reviewing what is already known about the communication profiles of adolescents with FASD?

2. Describing the oral and written narrative abilities of young people sentenced to detention in WA?
3. Identifying the overall communication profile of young people sentenced to detention in WA, including those living with FASD?
4. Exploring the implications and opportunities for education and youth justice services in working with and supporting youth with communication vulnerabilities, including those with FASD.

[Read more about this project](#)

Dr Amy Finlay-Jones

Masters Title: *Estimating the economic burden of fetal alcohol spectrum disorder in Australia*

Summary

This project aims to estimate the lifetime economic burden of fetal alcohol spectrum disorder (FASD) in Australia using economic modelling. FASD is a neurodevelopmental disorder caused by prenatal exposure to alcohol, and is the most common preventable cause of intellectual disability in high income countries. FASD can have profound effects on learning and behaviour and is associated with disengagement from school and vocational endeavours, and increased risk of contact with the justice system. Given the pervasive impact of alcohol on the developing fetus, individuals with FASD are also at risk of multiple comorbidities: a recent study found that FASD was associated with 428 comorbid conditions. Accordingly, the burden for individuals living with FASD and their families is immense. Previous work in the US, Canada, and New Zealand has identified substantial costs attributable to FASD, including the provision of special education, healthcare services, productivity losses, and justice-system costs. This will be the first study to model the costs attributable to FASD in Australia.

[Read more about this study](#)

FASD Hub Australia

Historically, on-line information focussing on different aspects of FASD was available on Australian websites, but it was a challenge to find current, reliable, locally relevant information. This project aimed to develop a 'one-stop shop' for information, resources, tools, services, research and publications about FASD in Australia.

OUTPUTS & IMPACT

- Improved access to high quality information and resources in one central location.
- Service Directory useful for people looking for FASD informed health professionals in their area.
- Evaluation survey respondents found the site easy or very easy to use, met their needs very well or extremely well, and was trustworthy and evidence-based.
- Videos offering insights to children living with FASD have been well received and people found them useful and more impactful than text information.

This project is funded by the
Australian Government
Department of Health



[Visit the FASD Hub website](#)

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

If there was a magic pill to grow the healthiest and smartest children, prevent them getting many childhood sicknesses such as ear infection, allergies and asthma; and stop them developing obesity and heart disease later in life then we would all be buying it for our kids. In fact, this magic pill is available to all new parents and is called breastfeeding. This research is all about encouraging women to start breastfeeding and to continue breastfeeding for as long as they want; hopefully for six months or more.

OUTPUTS & IMPACT

- The development of a large and supportive key stakeholder base around alcohol and breastfeeding, strategies to keep the hard to reach health professionals engaged in this topic area.
- Australian National Breastfeeding Strategy: 2018 and Beyond. This research has the capacity to influence T3 (the implementation and dissemination) of health professionals who interact with breastfeeding women to promote longer breastfeeding duration.
- Review of the NHMRC 2009 'Australian Alcohol Guidelines to Reduce Health Risks from Drinking' is currently underway and outcomes from this research will be able to advocate for the dissemination and implementation of the new guidelines.
- Two peer review publications and four stories in medical journals and media
- Five presentations



Guideline 4: Pregnancy and breastfeeding

GUIDELINE 4

Maternal alcohol consumption can harm the developing fetus or breastfeeding baby.

A For women who are pregnant or planning a pregnancy, not drinking is the safest option.

B For women who are breastfeeding, not drinking is the safest option.



**This project is funded by
the NHMRC (Project ID #**

[Read more about this project](#)

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