

FASD Research Australia

IMPACT REPORT

2016–2020

Results that change lives

ACKNOWLEDGEMENTS

FASD Research Australia, the National Health and Medical Research Council (NHMRC) Centre of Research Excellence (FASD Research Australia) acknowledges the Traditional Owners of country throughout Australia and recognises their continuing connection to land, waters and culture. We pay our respects to their elders past, present and emerging. We acknowledge their wisdom, advice and guidance in our work with partner organisations and communities across Australia.

FASD Research Australia Investigators and Team Members have had the privilege of working with many researchers, stakeholders, government and non-government organisations, support groups, Steering/Advisory Group members, navigators, consultants and members of communities across Australia. We are grateful for their expertise, contributions and support.

We acknowledge the huge contribution families and individuals have made to our research. They have shared their stories, provided the lived experience, told us what matters to them, and helped identify priorities for research.

We particularly acknowledge Senior Aboriginal women who have worked with FASD Research Australia and led community action and research relating to Fetal Alcohol Spectrum Disorder (FASD) across the country, including Dr Lorian Hayes (traditional connections to the Bidjara people and Wadja from central western Queensland), June Oscar AO (a Bunuba woman from Fitzroy Crossing in the East Kimberley region of Western Australia), Emily Carter (a Gooniyandi and Kija woman from the Kimberley region in Western Australia), Maureen Carter (a Gooniyandi and Kija woman from the Kimberley region in Western Australia), Marmingee Hand (a Walmatjarri woman from the Kimberley region in Western Australia) and Heather D'Antoine (a Bardi woman from the West Kimberley region in Western Australia). We are proud to see passionate young Aboriginal women emerging to continue in the footsteps of their elders.



Bower C, Elliott E, on behalf of the FASD Research Australia Centre of Research Excellence Investigators (2020). FASD Research Australia Impact Report 2016-2020: Results that change lives. ISBN: 978-0-6481297-5-2

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DIRECTORS' MESSAGE

Our aim, when applying for the NHMRC grant to establish this Centre of Research Excellence, was to turbo-boost FASD research in Australia. Our work over the last five years has laid a solid foundation for a bright future in FASD research and research translation.

We have established a strong and enduring national and international network of researchers and collaborators, built capacity in junior researchers, successfully sought research funding, and published new information that has influenced clinical practice and policy.

Most importantly, we have involved consumers in every aspect of the planning, conduct, interpretation, reporting and translation of our research. We highly value this engagement and regard it as essential in helping to prioritise future research.

Our achievements include:

- improved identification and management of alcohol use in pregnancy
- training health professionals across Australia in the use of the Australian Guide to the diagnosis of FASD (Australian Guide)
- novel work in 3D facial imaging and epigenetics that we hope will improve diagnosis
- showing the benefit of parenting support for families with children with FASD in Aboriginal communities and the need to develop flexible models of care, including telecare
- quantifying, from our national surveillance and register, the challenge of FASD for the paediatric workforce
- highlighting the urgent need for assessment of young people in the

justice system, developing and evaluating training for justice personnel, and ongoing advocacy for an increase in the age of criminal responsibility in Australia

- advocating for the long awaited, evidence-based, mandatory pregnancy warning labels on alcohol products in Australia and New Zealand

Our research has also influenced the national agenda, including through the Australasian FASD Conference, National FASD Strategic Action Plan 2018-2028, national FASD Advisory Group, 2020 Senate inquiry and the funding that followed. We are proud of our contribution to the establishment and continuation of the FASD Hub - a rich and accessible resource for health professionals, researchers, policy makers and the public which provides an enduring international platform to showcase Australian research.

Undertaking this work has only been possible with the help of our Investigators and Committees, including our Community Reference Group. We particularly thank our dedicated FASD Research Australia team and our partners at affiliated universities and research institutes, the National Organisation for FASD Australia (NOFASD) and the Foundation for Alcohol Research and Education (FARE).

We are grateful for funding provided by the NHMRC, Australian Government and philanthropic sources. In this report we showcase some of our research achievements and invite you to [visit our website](#) to find out more.



It has been an honour to lead this Centre of Research Excellence and we look forward to the ongoing development and future success of our talented students and researchers throughout Australia and on the international stage. Their participation in research and other endeavours will cultivate a depth of understanding that will change the lives of people with FASD.

PROF CAROL BOWER &
PROF ELIZABETH ELLIOTT AM

ABOUT US

The FASD Research Australia NHMRC Centre of Research Excellence (FASD Research Australia) is a partnership between Telethon Kids Institute, the University of Sydney, Murdoch Children’s Research Institute (MCRI), Menzies School of Health Research, the George Institute, the University of Queensland, the National Organisation for Fetal Alcohol Spectrum Disorders Australia (NOFASD) and Marninwarntikura Women’s Resource Centre.

FASD Centre of
Research Research
Australia Excellence

FUNDED BY



Australian Government
National Health and
Medical Research Council

NHMRC



Research centres

There are research centres based in Perth and Sydney led by the FASD Research Australia’s Directors Professor Carol Bower (Telethon Kids Institute) and Professor Elizabeth Elliott (University of Sydney).

Objectives

FASD Research Australia has the overarching objective of reducing the effects of antenatal alcohol on child health through prevention, diagnosis and therapy interventions.

We aim to do this by:

- ✓ Generating new knowledge and integrating it with existing evidence to develop and test models of prevention, diagnosis and interventions for FASD
- ✓ Harnessing the extensive skills and expertise of Australian researchers
- ✓ Involving the community in research projects and the overall direction of the centre
- ✓ Building on strong partnerships with Government, non-government, academic, human rights and community stakeholders
- ✓ Developing pathways for translating successful models into policy and practice nationally, through engagement with stakeholders and the wider community



THE UNIVERSITY OF
SYDNEY



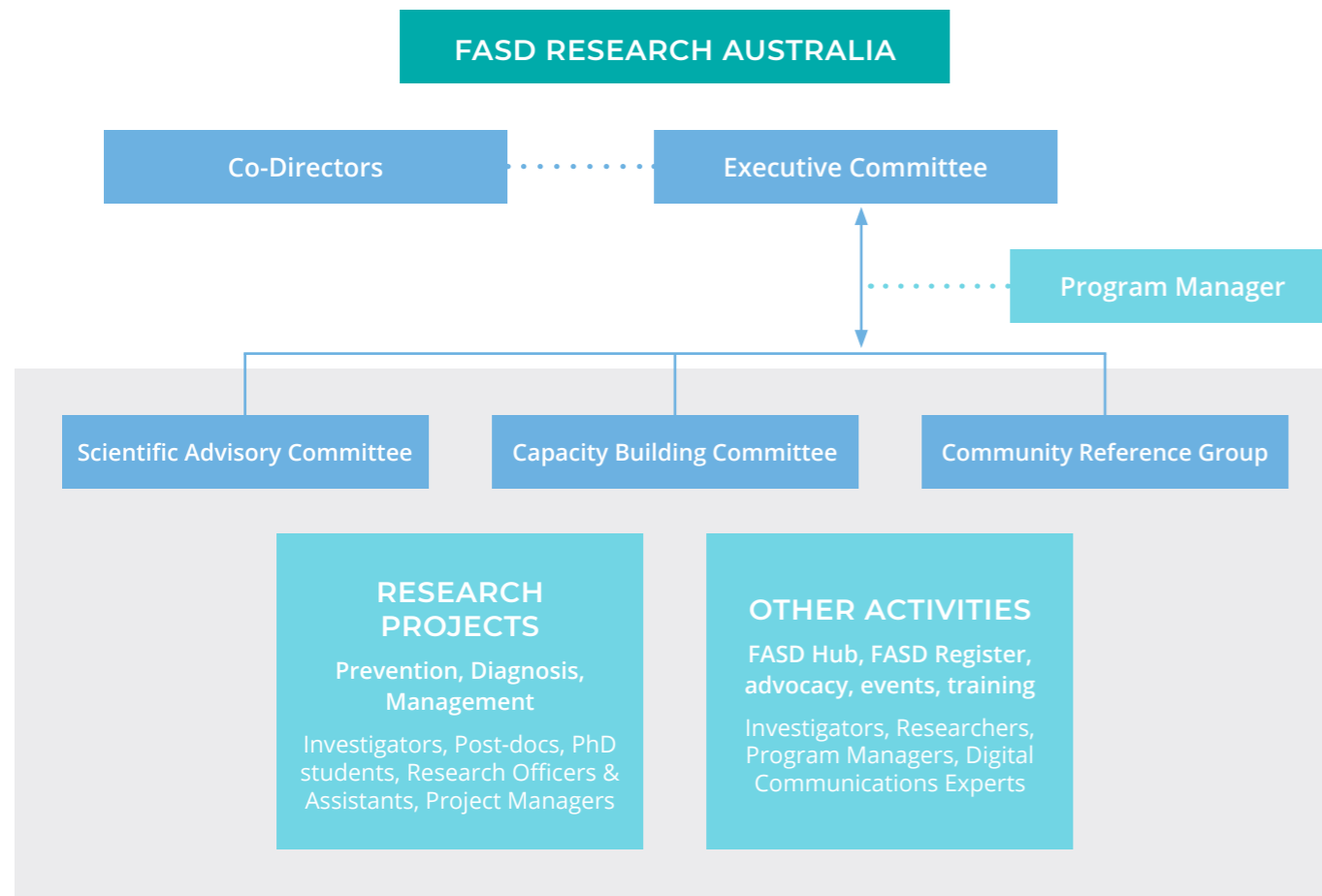
National
Organisation
for Fetal Alcohol
Spectrum Disorders





Governance

The Executive Committee provides oversight through effective leadership, good communication and timely reporting to ensure the outcomes of FASD Research Australia are met.



OUR CHALLENGES

While there have been many positive changes, there are still many challenges in Australia...



WORKING TOWARDS A SOLUTION

Adoption of the Australian Guide to the diagnosis of FASD

1,000 people accessed the eLearning modules; Australian Guide most accessed page on the FASD Hub with over 34,475 views; 689 confirmed cases of FASD reported to the Australian FASD Register using the Australian Guide criteria

Increased awareness of FASD activities

Creation of FASD Hub; presentations at conferences; researcher networks; reports; publications; social media

Increased community knowledge about alcohol use in pregnancy

Working with communities in the Kimberley and Pilbara has shown a reduction in the number of women drinking alcohol during pregnancy

Evidence base for prevention programs

Work in Alice Springs has shown that talking about grog is tough but the community is significantly invested in the campaign. In Newcastle people said the core messages in the campaign were clear and reliable

Increased workforce training

Hosted and conducted over 50 seminars and workshops; 75 clinical workshops or training sessions for clinicians on the use of the Australian Guide, 21 Reframe Training program workshops for justice professionals

Advocacy for legislation and policy change

Provided the evidence base for new labelling on alcohol packaging; introduction of alcohol use on midwives notification reports

Working in partnership with community and other organisations

Active Community Reference Group; Government departments such as justice, police, education; Non-government organisations such as Women's Health and Family Services; Aboriginal Community Controlled Health Organisations; health professionals; NOFASD Australia

Support for a national coordinated approach to reducing alcohol use in pregnancy

Worked with NOFASD Australia, FARE and health professionals on awareness of the risks of drinking alcohol during pregnancy (mass media, targeted health promotion, workforce upskilling)

OUR STRATEGY

FASD Research Australia aimed to:



Prevent alcohol use in pregnancy and its effects on child health



Decrease the incidence of FASD



Improve national FASD diagnostic capacity and management through effective interventions



INVESTIGATORS

Chief Investigators



Prof Carol Bower

Senior Principal Research Fellow, Telethon Kids Institute and Adjunct Professor Faculty of Health and Medical Sciences, Centre for Child Health Research, The University of Western Australia



Prof Elizabeth Elliott AM

Distinguished Professor in Paediatrics & Child Health, The University of Sydney and Consultant Paediatrician Sydney Children's Hospital Network; NHMRC Practitioner Fellow



Dr James Fitzpatrick

Clinical Research Fellow, Telethon Kids Institute and Adjunct Professor Faculty of Science, School of Psychological Science, The University of Western Australia



Dr Rochelle Watkins

Senior Research Fellow, Telethon Kids Institute



Ms Heather D'Antoine

Associate Director Aboriginal Programs & Division Leader Education & Research Support, Menzies School of Health Research 2016–2019



Ms June Oscar AO

CEO Marninwarntikura Women's Resource Centre. From 2017 Aboriginal & Torres Strait Islander Social Justice Commissioner



Dr Roslyn Giglia

Research Fellow, Telethon Kids Institute 2016–2018 and from 2019 Honorary Research Fellow Telethon Kids Institute



Prof Steve Zubrick

Senior Principal Research Fellow, Telethon Kids Institute and Professor Faculty of Health and Medical Sciences, Centre for Child Health Research, The University of Western Australia



Prof Jonathan Carapetis AM

Executive Director, Telethon Kids Institute and Professor Faculty of Health and Medical Sciences, Centre for Child Health Research, The University of Western Australia



INVESTIGATORS

Associate Investigators



Ms Catherine Crawford

Magistrate Perth Children's Court



Prof Jane Halliday

Group Leader of Public Health Genetics, Principal Research Fellow Murdoch Children's Research Institute



Dr Lorian Hayes

Researcher, Centre for Chronic Disease, School of Medicine, Faculty of Medicine, University of Queensland



Prof Jane Latimer

Professor & ARC Future Fellow, The George Institute for Global Health. From 2017 Professor School of Public Health, Faculty of Medicine and Health, The University of Sydney



Dr Raewyn Mutch

Honorary Research Fellow, Telethon Kids Institute & Clinical Associate Professor, School of Health and Medical Sciences, Paediatrics, The University of Western Australia



Mr Glenn Pearson

Deputy Director Aboriginal Health, Telethon Kids Institute



Assoc Prof Tracy Reibel

Senior Research Fellow, Telethon Kids Institute. From 2019 Associate Professor & Principal Research Fellow Ngangk Yira Research Centre for Aboriginal Health & Social Equality, Murdoch University



Ms Vicki Russell

CEO NOFASD Australia (2016)



Prof Sven Silburn

Director Centre for Child Development & Education, Menzies School of Health Research & Professorial Fellow Telethon Kids Institute (2016-2018)



COMMITTEES

Community Reference Group



Ms Astrid Chapman
Co-Chair
WA

I have a desire to increase awareness of FASD, and ultimately see the incidence of FASD reduced.



Mr Neil Reynolds
Co-Chair
WA

I am passionate about assisting my kids with FASD and all children and parents travelling a similar journey by learning, sharing and spreading as much positive information about FASD that is available.



Ms Bridgette Birda
QLD

I'm passionate about young people, they are our future.



Ms Christine Brooks
VICT (2020)

I am passionate about educating the educators.



Ms Helen Donnelly
WA

I'm passionate about empowering new mums to make the right decisions.



Ms Leia Earnshaw
ACT

I want to see more investment in health promotion about the risks of drinking during pregnancy.



Ms Deanne Fleay
WA

I want to see consistent messages given by health professionals.



Ms Kellie Hammerstein
VIC

I am passionate about equality, helping those with FASD live a full, rich and self-determined life.



Dr Tracey Harbour
QLD

I want to help other families living in rural communities with useful strategies.



Ms Judith King
WA (2017-2019)

I am passionate about building successful relationships between schools and families to benefit all children.



Ms Diane Mayers
NT

I am passionate about raising awareness of the effects of using alcohol and drugs in my community in the Northern Territory.



Ms Sue Miers AM
SA (2016-2019)

My focus has always been about advocating for, and supporting people living with FASD, and their families through the challenges across the lifespan.



Ms Amanda Mulligan
NSW

I am passionate about increasing awareness of this disability and connecting carers to each other.



Ms Sam Pinnell
QLD

I want to build community support for families and advocate for their support needs.



Ms Anne Russell
QLD

I want to help parents navigate the health system.



Ms Paula Sargent
ACT

I'm passionate about informing young women about the risks of drinking alcohol during pregnancy.

Executive Committee

Prof Carol Bower
Prof Elizabeth Elliott AM
Dr Tracey Tsang
Dr Rochelle Watkins
Ms Heather D'Antoine
Dr James Fitzpatrick (2016-2018)
Ms Louise Gray (2017-2020)
Ms Narelle Mullan (Program Manager)

Scientific Committee

Prof Elizabeth Elliott AM (Chair)
Dr Tracey Tsang
Dr Rochelle Watkins
Prof Steve Zubrick
Prof Jane Halliday
Prof Jane Latimer
Mr Glenn Pearson
Magistrate Catherine Crawford
Prof Sven Silburn (2016-2018)
Dr Lorian Hayes (2016-2018)
Ms Narelle Mullan (Program Manager)

Capacity Building Committee

Prof Carol Bower (Chair)
Prof Steve Zubrick
Dr Roslyn Giglia (2016-2018)
Ms Heather D'Antoine
Assoc Prof Tracy Reibel
Dr James Fitzpatrick (2016-2017)
Ms Vicki Russell (2016)
Dr Raewyn Mutch
Ms Narelle Mullan (Program Manager)
Ms Kerry Salter (2016-2018)
Dr Fiona Crawford-Williams (2016-2018)

THE TEAM

Team Members funded by FASD Research Australia



DR AMY FINLAY-JONES

Starlight Research Fellow, Telethon Kids Institute

I am motivated to find new ways to promote optimal developmental outcomes for vulnerable families and address health disparities.



DR MARTYN SYMONS

Post-doctoral Researcher, Telethon Kids Institute

I want to find out how we can help people across prevention and diagnosis and by applying novel data analysis techniques such as machine learning.



DR HAYLEY PASSMORE

Post-doctoral Researcher 2020 (PhD Candidate & Research Assistant 2016-2019)

I strive to improve the health and wellbeing of some of our most vulnerable young people – those who are involved in the justice system and who have neurodisabilities like FASD.



DR TRACEY TSANG

Snr Research Fellow, The University of Sydney

I have an overarching desire to help those in need by exploring ways to improve diagnosis & management of comorbidities; long term outcomes for youth from remote Aboriginal communities; and understand why some women consume alcohol.



DR LAUREN RICE

Research Fellow, Brain & Mind Centre, The University of Sydney

I am passionate about improving the lives of people with developmental disabilities and people living in remote Aboriginal Communities.



DR YI HUEY LIM

Research Officer, Telethon Kids Institute

I aim to identify the strengths and weaknesses of individuals with FASD as well as to analyse the resources available to support them. My hope is that one day there will be no lack of resources to support these individuals through different stages of life.



LISA CANNON

Research Assistant, Telethon Kids Institute

I provide insight into the experience of students with FASD within an educational setting, and the knowledge, attitudes, and training practices of school staff within Australian schools.



NATALIE KIPPIN

FASD Research Australia PhD Candidate, Telethon Kids Institute

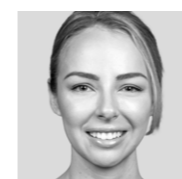
I value working in a multidisciplinary clinical and research team, and I am hopeful that our justice-related research will improve the personal, educational and health outcomes of young people.



TESS FLETCHER

FASD Research Australia PhD Candidate, Telethon Kids Institute

I aim to support women to make healthy choices about alcohol use during pregnancy.



CANDICE BROWNE

Project Co-ordinator, Telethon Kids Institute

I am passionate about engaging with communities and relevant stakeholders to create better health and wellbeing outcomes for all Australian families.



NARELLE MULLAN

FASD Research Australia CRE Program Manager, Telethon Kids Institute

I enjoy bringing people together to partner and collaborate for great outcomes.



HEATHER JONES

Snr Manager FASD Projects & Manager FASD Hub, Telethon Kids Institute

I learn from listening to individuals and their families and strive to provide information and resources that are useful and accessible for everyone.



KATE HARFORD

Digital Communications Specialist FASD Hub, Telethon Kids Institute

I aim to ensure women and their friends and families have access to the tools and resources to support them make the decision not to drink when trying for a baby, pregnant or breastfeeding.

PREVIOUS TEAM MEMBERS

ELISSA STRUMPHER

*Research Assistant
Telethon Kids Institute*

PETER O'MALLEY

*Digital Marketing FASD Hub
The University of Sydney*

DR ANNE MORRIS

*Australian Guide to
the diagnosis of FASD
Dissemination Project
The University of Sydney*

THE FASD HUB


Improving access to the evidence base for Fetal Alcohol Spectrum Disorder

The internet and social media allow us to find answers to our questions big or small, easy or complex, within seconds. But the wealth of information available makes it hard to separate fact from fiction, misinformation from research evidence.

For anyone looking to learn more about FASD, the **FASD Hub** offers a trustworthy, one-stop destination, bringing together all the latest resources. We cater to a range of stakeholders including health and other professionals, researchers, policy makers, people living with FASD and their families. Our goal is to provide the most comprehensive resources, tools, videos and stories to build awareness and understanding of FASD.

Chair of the FASD Hub Advisory Group and FASD Research Australia Co-Director Professor Elizabeth Elliott, commented *“Creation of the FASD Hub has been critical. Before it was established, there was no single destination for credible, evidence-based resources about FASD for clinicians, researchers and the general public. Many resources were available only in hard copy, were from overseas, and were limited to certain jurisdictions – meaning different people had access to different information. The FASD Hub set out to change this – and to showcase Australian data for the local context.”*

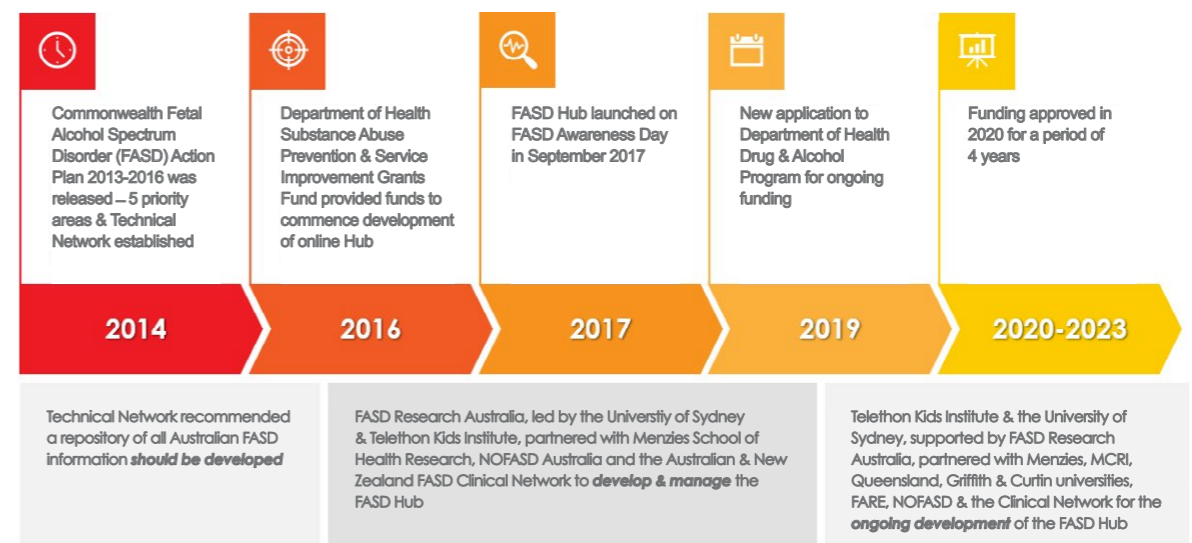
Following significant community and stakeholder consultation, the FASD Hub was launched in September 2017. Now, just three years on from its launch, the wide-ranging impact of the FASD Hub is evident.




FASD Hub Australia

Find information on Fetal Alcohol Spectrum Disorder (FASD) for Australian health professionals, teachers, justice professionals, service providers, researchers or parents and carers.


[Watch video: FASD in Australia ▶](#)




1 SEPTEMBER 2017 - 1 NOVEMBER 2020



94,160
USERS



455,516
PAGEVIEWS



37%
BOUNCE RATE

This is considered excellent. This means that 63% of people who found the website engaged with it.

76%
FEMALE

24%
MALE

DEMOGRAPHICS

TOP PAGES

Homepage	39,607
Guide to diagnosis	37,475
What is FASD	18,816
Understanding FASD	14,998
What can teachers do?	14,548

After the homepage the most popular page is the Australian Guide to the diagnosis of FASD, which was created to assist clinicians in the diagnosis, referral and management of FASD.

SESSIONS PER CHANNEL

Organic search	62,481
Direct search	26,047
Referral	14,729
Social media	4,775
Email	85

As well as collating and providing access to established resources, the FASD Hub has created:

New resources and tools based on feedback from users and under the leadership and expertise of a cross-discipline Advisory Group and Subject Matter Editorial Panels.

Australia's first language guide (adapted the Canadian Language Guide 'Promoting Dignity for those impacted by FASD) to assist people to talk about FASD in a sensitive and appropriate manner. We have commissioned a range of videos telling personal stories to educate and empowering professionals, people with FASD and their families.

Recorded and uploaded educational webinars and workshops.

Tip sheets to assist clinicians in dealing with challenges associated with FAS.

A directory of FASD-informed services and providers.

List of Australian research projects.

The Australian Guide to Diagnosis and associated e-learning modules are highly accessed. With a focus on the Australian context we have also collected local research projects and publications, policy initiatives, and news items. Following consumer input, we have tagged relevant content for Aboriginal Torres Strait Islanders.



Professor Carol Bower, Co-Director of FASD Research Australia said that to make the FASD Hub available to all those who needed it, it was important that it was designed in a way that reflected the varying needs of a range of stakeholders from both a content and accessibility point of view.

"From day one we have wanted the FASD Hub to be accessible to everyone. That's why we have ensured the site meets international Web Content Accessibility Guidelines, has achieved Health on the Net accreditation, and provides access to the National Telephone Interpreter Service."

"We take feedback from our users very seriously and strive to make the FASD Hub a place not only where they can find the information that they need, but where they can feel part of a broader community of people working to improve the lives of those living with FASD."

Combined with a growing social media network and database, the FASD Hub continues to play a key role in both providing information for professionals and being a platform for people living with FASD and their families to share their stories with, and hence improve knowledge and understanding of these professionals.

Our next chapter is to focus on increasing community knowledge and understanding of the harms of alcohol use in pregnancy and the lifelong consequences of FASD through FASD Hub networks and our social media, and promoting and supporting evidence based state and national initiatives.

THE BIGISWUN KID PROJECT

Community-led translational research in remote Aboriginal Communities built on trust, cultural understanding and mutual respect

In the *Bigiswun Kid* (adolescent) Project we are following-up young people who participated in the *Lililwan* (all the little children) Project in very remote Aboriginal communities of the Fitzroy Valley, Western Australia in 2010-2012. The *Lililwan* project remains Australia's only population-based prevalence study of alcohol use in pregnancy, FASD and early life trauma (ELT). In the *Bigiswun Kid* Project we will evaluate youth health and wellbeing and listen to the voices of young people with FASD to identify their needs. The long-term goal is to bring government services and Aboriginal-controlled Organisations together to develop sustainable youth mental health and disability services.

Following the *Lililwan* Project, *Marninwarntikura Women's Resource Centre* (MWRC) set up the *Marulu* Unit (a Bunuba word meaning precious, worth nurturing) to provide ongoing support to families affected by FASD and ELT. The *Marulu* Team has led the community response for the past eight years, including an NHMRC-funded trial of a community-modified, Indigenous, positive parenting program to address challenging behaviour in FASD, called *Jandu Yani U* (for all the family). They also formed a partnership with Royal Far West to deliver FASD and trauma-informed healthcare using novel models including telehealth (the NHMRC *Marurra-U* project).

KEY ISSUE

Although the *Lililwan* Project raised national awareness about FASD, resulted in local programs to reduce PAE, built capacity, supported continuation of community-led alcohol restrictions, and provided families with support, the community is aware that some of the *Lililwan* cohort are struggling in adolescence. They want to know **which prenatal and early childhood factors predict positive and adverse adolescent outcomes and when and how to intervene early in childhood to promote a trajectory to a happy and healthy adolescence**. Thus, the *Marulu* Team partnered with University of Sydney researchers to follow-up the *Lililwan* cohort at age 17-19 years, ten years after the *Lililwan* Project. In the *Bigiswun Kid* Project, we will conduct psychological assessments and interviews with youth from the *Lililwan* cohort and interviews with their parent or caregiver and teachers. We will also collect linked WA health, education, justice, and child protection data.



COMMUNITY-LED RESEARCH AND STRONG PARTNERSHIPS

The high participation rate in the *Lililwan* Project (95%) reflects that local Aboriginal women (Ms June Oscar, Ms Maureen Carter, Ms Emily Carter, Ms Marmingee Hand and Ms Jadnah Davies) initiated and led the research and worked hard to gain community support. Local lead of the *Bigiswun Kid* Project, Emily Carter, is CEO of MWRC, a local Aboriginal-Controlled Organisation, which was established by the community to act as women's voice and advocate. All work conducted in remote Aboriginal communities must be done in partnership with Aboriginal Organisations and local people. Professor Elliott and the University of Sydney have had a long and productive relationship with *Marninwarntikura* and the *Marulu* Team. In the *Bigiswun Kid* Project we have built on this trust and mutual respect.

We have confirmed poor health and educational attainment, and high rates of self-harm, suicidal ideation and contact with juvenile justice in youth in the *Bigiswun Kid* Project, but we have also seen resilience, initiative, and success. We have partnered with key government organisations to ensure services are working together to address adolescent needs and promote wellbeing.

The *Lililwan* Project was initiated and led by Aboriginal leaders of the Fitzroy Valley in partnership with The University of Sydney and the George Institute. We found:

55%
of children born in 2002 or 2003 and living in the Fitzroy Valley at age 7-9 years **had PAE**, usually at high-risk levels.

19%
met criteria for FASD - amongst the highest rate worldwide.

ELT
was almost universal. An individualised Management Plan was provided for all children. However, we were concerned about the capacity of health and education.

Translating data into policy

We have presented data from the *Bigiswun Kid* Project to:

- Minister for Indigenous Australians, Ken Wyatt
- Representatives of the WA Government Department of Premier and Cabinet
- National Indigenous Australian Agency
- Director General of the WA Government Department of Communities
- WA Mental Health Commissioner
- Drug and Alcohol Strategic Senior Officer Group, which includes senior representatives from each of the government service who are working together to respond to FASD and youth suicide

These connections will allow us to provide our research findings directly and rapidly to policymakers to inform planning for future services and community resources.



BIGISWUN TEAM: Sue Thomas, Laurena Shaw, Samantha Marr, Cheyenne Carter, Nikkita May, Lauren Rice
(Not in the photo: Elizabeth Elliott, Tracey Tsang, Lisa Cannon, Jadhav Davies, Emily Carter)

Supports for young people

During our consultation, the key message from the Fitzroy Valley community was that the *Bigiswun* research must provide direct and immediate benefits to families. Based on this feedback we decided the project needed two arms:

1. Focus on research aims
2. Ensure supports were available to the young people and their family during data collection

Below are the ways we are supporting young people throughout the data collection

YOUTH SUPPORT OFFICERS: The *Marulu* team has employed a local Aboriginal man and woman as youth support officers to train to assist young people during the project. They will connect young people to local health and mental health services, TAFE, and employment opportunities; run workshops to provide positive experiences for young people; and run yarning sessions about key concerns identified by families, including mental health and sexual health.

DISABILITY SUPPORT: None of the 21 participants from the *Lililwan* cohort known for the past 10 years to have a disability has received disability support. The NDIS is an exciting opportunity to address this issue. The *Marulu* and research teams will support individuals to apply for NDIS funding and will evaluate the application process. The *Marulu* and research team have been invited to partner with the NDIA to co-design a sustainable implementation model for the NDIS for the region.

JANDU YANI U PARENTING PROGRAMS: Some of the *Lililwan* cohort now have children of their own. We will invite these families to participate in the parenting program developed during *Jandu-Yani-U*.

The *Bigiswun Kid* Project is funded by grants received from Australian Rotary Health, The Ian Potter Foundation, Healthway, the University of Sydney, the Kimberley Brain and Mind Foundation and the FASD Research Australia, the NHMRC Centre of Research Excellence.



THE VALUE OF INVESTING IN OUR PHD STUDENTS AND EARLY CAREER RESEARCHERS

Their ability to influence future research and practice

BACKGROUND

The Banksia Hill Study was the first study in Australia to assess and diagnose young people in a youth custodial setting for FASD, and found the highest known prevalence of FASD in a justice setting worldwide. More than one third (36%) of young people assessed by the team had FASD. However, it was the devastating finding that almost all young people (89%) in detention had at least one severe neurodevelopmental impairment that has become the catalyst for change in the way authorities manage and support young people within the justice system. These impairments existed across a number of skills, including memory, attention, communication, cognition, executive functioning and motor skills.

Three early career researchers, Dr Sharynne Hamilton, Natalie Kippin and Dr Hayley Passmore, played critical roles in the Banksia Hill Study whilst also undertaking their PhD.



DR SHARYNNE HAMILTON

Yarning with and hearing the views of the young people and their caregivers

Dr Hamilton's research was the first international qualitative study to be undertaken with youth in detention undergoing assessment for FASD.

Due to the high number of Aboriginal participants involved in the Banksia Hill Study, Dr Hamilton, an Aboriginal researcher, used Indigenous methodologies to guide the qualitative research aspect of the study in its planning and design, data collection and research translation. Using social yarning and research-topic yarning data collection methods, she was able to capture the experiences of young people undergoing assessments and receiving a diagnosis for FASD, offering valuable information for future FASD research and its translation in Aboriginal communities.

Dr Hamilton's research highlighted that what is meaningful and valued by Aboriginal and non-Aboriginal participants can be different, offering new and unique insights into the cultural differences of understanding health and illness and what it means to receive a diagnosis or diagnostic resources.

Her research also emphasised the delicate balance that can exist between medical authority and receiving a diagnosis – particularly when the participants are young, and the health issue being investigated is one where the potential for diagnostic harm and stigma is high. Additionally, Dr Hamilton's work offers valuable strategies for researchers undertaking interviews with young people with FASD, and their caregivers, to reduce the potential for harm from research involving children and young people with neurodevelopmental disability.

Dr Hamilton's research also offered critical insights from the non-custodial staff about their need for training and resources about FASD and the need for system improvement – which are already proving beneficial to the youth justice system.

The combination of this range of diverse views has shown that having information about a young person's strengths, challenges and hopes is critical to effective interventions. It has also shown that for justice-involved youth, there is a significant need for earlier access to routine, affordable multi-disciplinary assessments which are strength-based, and neurodevelopmentally and culturally responsive.

Dr Hamilton was awarded an Honourable mention on the Dean's List by the members of the Board of the Graduate Research School at the University of Western Australia (UWA). This is a rare award made to only a fraction of these classified as 'Passed' by UWA.



Dr Hamilton was awarded the Shell Aboriginal STEM Student of the Year at the Premiers Science Awards 2019

NATALIE KIPPIN
Communication skills, FASD and youth justice

Many young people who come into contact with the youth justice system face problems with effective two-way communication. To better understand the communication profiles of young people in the Western Australian youth justice context, Natalie Kippin, a certified practising speech pathologist, undertook a PhD with FASD Research Australia looking at 'Communication, FASD and Youth Justice'.

Natalie's research highlights the need for the WA youth justice system to consider the communication skills of young people as well as the language and communication demands of forensic contexts, such as police interviews and rehabilitation programs. Natalie explained that, "to answer questions, follow orders, and to learn, two-way communication skills are required". However, the results of Natalie's research revealed that two-way communication may be difficult for many of the young people in youth detention. Firstly, eight different first-languages were spoken by the young people in youth detention, and secondly, nearly half of the young people had developmental problems with their communication skills. Natalie's findings emphasise the importance of taking account of a young person's first (or 'home') language, as well as understanding a young person's skills in comprehension, verbal expression, as well as reading and writing.

Natalie's research is the first in Australia to identify the co-occurrence of FASD and language disorder in a youth justice sample (69%). Her work points to the importance of prevention and early identification of prenatal alcohol exposure and FASD, as well as speech pathology assessment for young people involved with youth justice.

Being awarded a PhD scholarship with FASD Research Australia meant that funding was available to help Natalie complete her PhD and disseminate her research findings. "I've been able to share this research at local forums, interstate conferences, and through publications", explained Natalie. She is excited to see change happening at the Banksia Hill Detention Centre school. "The principal and teachers are so proactive; they have implemented evidence-based reading and spelling approaches with the young people, and they're seeing improvements," Natalie reported.

Natalie has contributed to the Speech Pathology Australia: Justice Clinical Guideline, an important resource to inform speech pathology service provision in justice settings. Along with Aboriginal Interpreting WA, Natalie was also invited to help inform a potential intermediary service for WA; this would see allied health professionals working in specialty communication assistant roles in police and court settings to help facilitate two-way communication. With her clinical background, Natalie has also been involved in advisory groups, providing input to FASD-related research and educational resources.

DR HAYLEY PASSMORE
Informing the training of staff working with young people

Dr Passmore's research used mixed methods to determine the current knowledge and practices relating to FASD and other neurodevelopmental impairments among the Western Australian youth justice workforce. These data informed the development of Reframe Training, which aims to build capacity among the frontline staff to support and manage young people with neurodevelopmental impairments including FASD.

Given the difficulties that individuals with FASD may have in discerning right from wrong, learning from past experiences, and adhering to social rules and expectations, they are likely to experience a greater number of challenges when engaged with the justice system at all stages in comparison to their peers who do not have neurodevelopmental impairment. If frontline staff engaging with affected individuals are not aware of their needs, they may misinterpret behaviours as wilful noncompliance, rather than as symptoms of permanent, organic brain damage. Prior to Dr Passmore's research, there had 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 had there been published interventions aiming to develop environments appropriate for those with FASD in detention.

In response to her findings, Hayley implemented and evaluated Reframe Training. To date, she has individually implemented Reframe to over 350 justice and community service professionals across WA. Multiple sectors across WA have requested access to the training, including the police, justice, child protection, education and health sectors, and as a result, Telethon Kids and the WA State Government have partnered to ensure Reframe Training can be implemented more widely across the state.

Hayley's research has received interest and support from researchers, service-providers and government agencies nationally and internationally, and has the potential to create pivotal policy and practice change across Australia regarding the management and support of young people with FASD and other neurodevelopmental impairments. Over 50 agencies nationally and internationally (justice, police, child protection, education, employment, health and community services) have expressed interest in Reframe Training.

Most recently, Dr Passmore was awarded a 2020 Churchill Fellowship, which will see her travelling internationally to explore how other countries are supporting young people with neurodisabilities who are in youth detention or other secure care facilities. Hayley hopes to use this knowledge to continue informing the models of care used in the Australia youth justice system, to help ensure that all young people with neurodisabilities have the opportunity to be appropriately supported and cared for.



Dr Hayley Passmore and Natalie Kippin visiting colleagues at a Victorian youth justice centre and learning about the education and speech pathology programs they provide to young people.

COMMUNITY INVOLVEMENT: A TWO-WAY STREET

It works for both researchers & community members because it is a relationship

As a National Health and Medical Research Council (NHMRC) funded Centre of Research Excellence, FASD Research Australia supports the joint NHMRC and Consumers Health Forum of Australia's 'Statement on consumer and community involvement in health and medical research', which involves supporting, facilitating and valuing the contributions of community members to research.

FASD Research Australia has had a strong commitment to community involvement from the very beginning, building on an existing relationship with NOFASD Australia, who committed to a five-year partnership with research organisations in the centre. They provided strategic guidance as a member of the Executive Committee and strong links to their extensive network across the country.

In addition, a Community Reference Group (CRG) was established in 2016 specifically for the centre. The role of the CRG was to sit alongside the Executive Committee and other Steering Groups to oversee the strategic direction of the Centre including setting priorities, reviewing research proposals, and contributing to strategic initiatives such as government submissions.

Researchers have immensely valued and benefited from the advice and guidance provided by the community members, and in turn, researchers have been able to provide community members with information on new evidence and current research.

These interactions have been multidimensional

and multifaceted for the benefit of both groups, and are ultimately, empowering women to abstain from alcohol when planning a pregnancy or while pregnant, and helping families who are supporting people living with FASD to reach their full potential.

Setting priorities for research was a key piece of work for the CRG, with the group highlighting the need to change societal views and beliefs about alcohol use during pregnancy through a national public health campaign and education as the most urgent priority. Information about the priorities for research was included in lobbying and advocacy to government, which together with strong lobbying from our colleagues at FARE and NOFASD Australia, has resulted in funding for a national campaign due to commence in 2021.

CRG members were also active in supporting researchers to require mandatory 'no alcohol during pregnancy' warning labels on packaged alcohol drinks. This strong advocacy was sustained over a number of years, with a final decision by the Food Standards Ministers made in favour of compulsory labelling in 2020.

Members of the CRG were also invited to join other research steering groups and committees and extend their connections across the country.

Each member of the CRG brought a different perspective, outlook and advice to the group and their contributions have been respected and valued. Some of their motivations for being involved are highlighted here.

"I am passionate about educating the educators. When teachers and staff at schools are FASD informed, there is a positive shift in the learning environment. Research influences policy and strengthens practice which leads to an increased understanding of FASD and the strategies needed to support students living with Fetal Alcohol Spectrum Disorder"

Christine Brooks, Educator & foster carer

"I have enjoyed being part of this research group and having a chance to produce a video-story about my family. The different formats for sharing information has meant that I can easily share with those in my community network, including the 960 members of the Facebook support group I run. FASD is my life now and I want to stay close to the research and new ideas"

Sam Pinnell, Parent and carer of adult & young person with FASD and founder of QLD FASD

"Being involved in the Community Reference Group has provided me with an opportunity to have improve the integration of the research into the community and the benefit to the individual"

Elizabeth (Anne) Russell Parent & Founder of the Russell Family Fetal Alcohol Disorders Association



"The Community Reference Group has been a great way to meet others passionate about preventing alcohol use in pregnancy, and understanding more about the condition. Through my role with the CRG I have been exposed to other projects and agencies, resulting in invitations to present to clinicians and be part of other committees. I am now a community representative on the National FASD Strategic Action Community"

Tracey Harbour, Parent of adult child with suspected FASD

"Being involved with the Community Reference Group through the CRE has given me and many others the opportunity to give input into that process and gain valuable knowledge towards those goals, while at the same time putting like-minded people in touch with each other and the ability to support and learn from each other"

Neil Reynolds, Foster carer for two children with FASD and other complex issues

"Being involved in the Community Reference Group has afforded me connection and information"

Kellie Hammerstein, Carer of two children with FASD

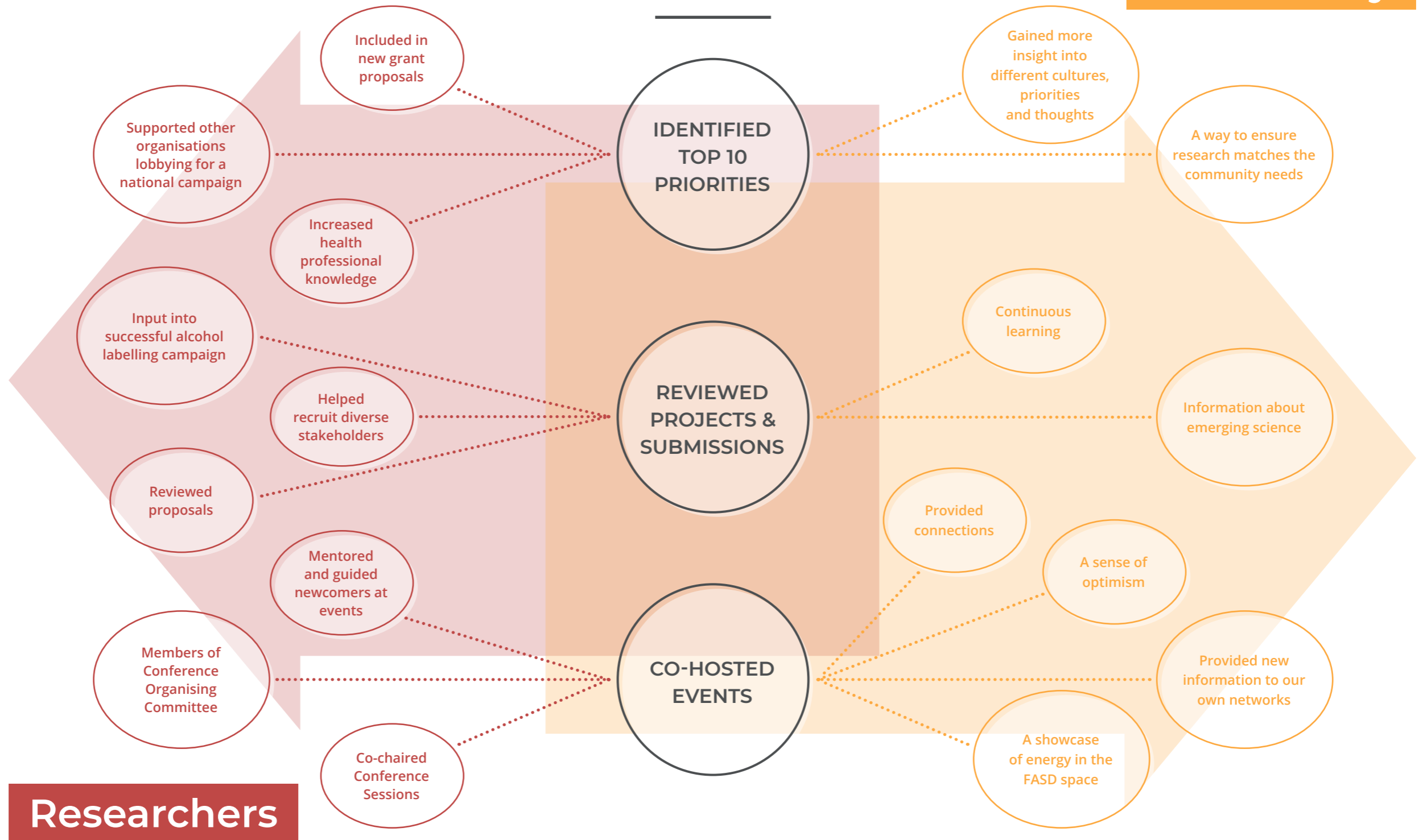
"It has enabled me to gather more tools for my toolbox for life"

Bridgette Birda, Foster carer of two children who have FASD

The Consumer Reference Group has facilitated an important two-way relationship between researchers and community members in a number of ways, as demonstrated in this graphic.

THE TWO-WAY STREET

FASD Research Australia Community Reference Group Activities



IMPROVEMENT IN HEALTH PROFESSIONAL KNOWLEDGE

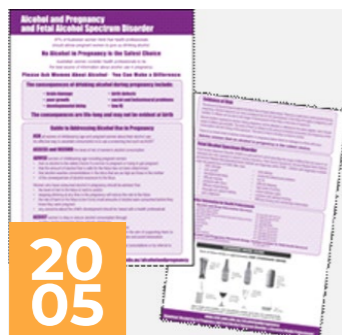
and use of the Australian Guide to the diagnosis of FASD

In Australia FASD is under-recognised and often goes undiagnosed, such that it has been described as a ‘hidden harm’ or ‘invisible disability’.

In the early 2000s, many health professionals were unaware of the diagnostic criteria, lacked confidence in making a diagnosis of FASD and did not know where to refer for diagnosis or treatment. Many had not read the NHMRC national guidelines to reduce health risks from drinking alcohol and few routinely asked pregnant women about alcohol use in pregnancy. Some were concerned about stigmatising families through making a FASD diagnosis. Limited training opportunities for health professionals, the lack of a nationally adopted diagnostic instrument, confusion about diagnostic criteria and perceived lack of evidence-based treatments were persisting barriers to early diagnosis, appropriate management and prevention of FASD.

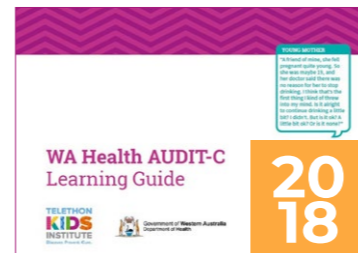
Research with health professionals

Research & surveys with health professionals about knowledge & practice 2005-2011. Developed resources & evaluated.



Research with midwives

Research & surveys of midwives on knowledge, attitudes & practice 2014-2018. AUDIT-C Learning Guide developed.



Research with health professionals

Health professional's knowledge of existing FASD guidelines.



Recording alcohol use in pregnancy

Addition of alcohol to Midwives Notification Form in WA 2018.



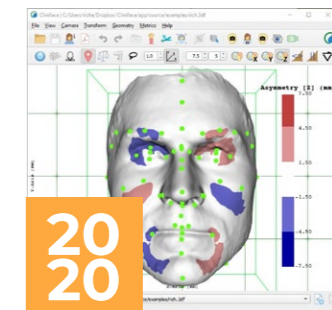
National Perinatal Data Collection

Addition of alcohol consumption in first 20 weeks of pregnancy & after 20 weeks.



New approaches to diagnosis

3D & 2D imaging, eye tracking, epigenetics.

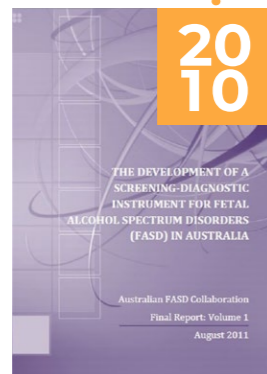


HEALTH PROFESSIONAL KNOWLEDGE AND THE JOURNEY TO AN AUSTRALIAN GUIDE

2010

Development of a diagnostic instrument for FASD

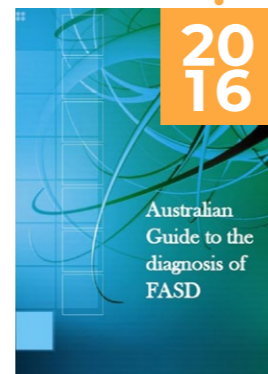
Research conducted with health professionals to develop a diagnostic instrument with a final report provided to the Australian Government Department of Health in 2012.



2016

Australian Guide to the diagnosis of FASD & eLearning modules

Published in 2016, followed by work to implement & disseminate. Clinical workshops, training & presentations provided across Australia 2017-2020.



2020

Review of the Australian Guide

Consideration of new international guidelines & new evidence – to be finalised in 2022.



2010

We successfully tendered for funding from the (then) Australian Department of Health and Ageing to develop a FASD diagnostic instrument for Australia and a guide to its use. These were developed following a systematic literature review, evaluation of existing diagnostic guidelines, a consultative process with experts in the field, and consultation with community and advocacy groups.

2015

The instrument was trialled in clinical practices around Australia and deemed to be informative, useful and flexible. However, just as the Australian instrument was finalised, a revised Canadian guide on the diagnosis of FASD was published and the Steering Group and Expert Panel recommended that the draft instrument be reviewed.

2016

We adopted the Canadian concept that Fetal Alcohol Spectrum Disorder be used as a diagnostic rather than an umbrella term. For a diagnosis of FASD, an individual must have severe neurodevelopmental impairment in at least three of ten specified domains of central nervous system structure or function and (with exceptions) prenatal alcohol exposure. The overarching diagnostic term of FASD simplifies the terminology and emphasises the primary importance of the severe neurodevelopmental impairment that results from an acquired brain injury caused by prenatal alcohol exposure.

Within FASD are two sub-categories: FASD with three sentinel facial features (similar to the previous diagnostic category of Fetal Alcohol Syndrome); and FASD with less than 3 sentinel facial features (which encompasses the previous diagnostic categories of Partial Fetal Alcohol Syndrome and Neurodevelopmental Disorder-Alcohol Exposed). The [Australian Guide to the diagnosis of FASD](#) was published in May 2016 and updated in February 2020.

E-Learning modules for health professionals, aligned with the Guide were developed and promoted at workshops and conferences and made available on the [FASD Hub](#).

2018-2020

Guide dissemination and training of health professionals was undertaken through clinical workshops and conferences.

"Speakers were all excellent, very knowledgeable, good interprofessional perspective. The courage and knowledge of Sue and April in sharing their stories was very powerful and I am grateful to them for doing that" - Health professional at Clinical workshop Adelaide

"Actually the whole diagnostic theme was about coming out of the dark into the light. You and the team have just contributed mightily to that end! Thank you and please thank all unsung heroes for me" - Participant at Webinar, 8 September

A FASD Clinical Workshop Facilitator Manual was developed to assist organisations to conduct clinical workshops. This manual can be accessed from the [FASD Hub](#).



Presenters at the Adelaide Clinical Workshop:
April Wilson, Sue Miers, Dr Andi Crawford, Dr Vanessa Spiller, Professor Elizabeth Elliott, Dr Doug Shelton

How will the increased knowledge of health professionals and use of the Australian Guide benefit Australians?

The Guide is the most often viewed (37,475) and downloaded page on the FASD Hub and is widely used and valued by clinicians nationally.

Diagnostic criteria are consistent with those used in Canada, New Zealand and the United Kingdom. The Guide gives clinicians the confidence to consider a diagnosis of FASD; the knowledge and tools to make or exclude the diagnosis; the information they need to manage an individual or refer them for treatment; and the capacity to support families and take steps to prevent FASD.

"The Guide has become invaluable for clinicians. It provides a framework to diagnosis and contains useful resources and we use it daily in our clinic."

The Guide is currently undergoing review and update with input from FASD Research Australia Investigators.

We are also engaged in research aimed at new approaches to diagnosis, including:

- 3D facial imaging
- Eye tracking
- 2D facial imaging
- Epigenetics

GETTING FASD ON THE AGENDA

Cross-agency Partnerships

The National FASD Strategic Action Plan 2018-2028 includes calls for jurisdictions and communities to collaborate to ensure the implementation of evidence-based initiatives.

A whole of government approach could see various sectors pooling their resources to look after the 'whole person', which would ensure better outcomes for people living with FASD and their families. For example, we know that putting money into early assessment and diagnosis, as well as support services for the child and their family, could reduce costs later in the lifespan.

FASD Research Australia has initiated new services with non-health agencies, built trans-diagnostic research partnerships and been invited to upskill frontline service providers - here are some examples of this work.



One of the aims of FASD Research Australia has been to advocate for policy and practice change through engagement with government at all levels and across multiple sectors.

HOLISTIC PARENTING SUPPORT



The Nurturing Families program is based on the Parent-Child Assistance Program (PCAP) and was established in response to research on the effects of prenatal alcohol and other drugs exposure on infants and young children, and poor treatment engagement and outcomes among mothers with intergenerational addiction issues.

The program's value is its holistic nature. It allows the time for case workers to assist women who have experienced significant trauma, disadvantage, abuse, alcohol and drug issues, mental health issues, contact with the justice system, and adverse childhood experiences, to achieve significant change in their lives. A pilot study led by Dr Martyn Symons in partnership with the Women's Health and Family Services, which worked with eight families, showed they made significant gains across many areas of their lives within one year. These improvements were statistically equivalent to changes seen in research evaluations in the US over three-year periods, and included:

- Attendance at alcohol/drug treatment programs
- Abstinence or reduction, non-use or harm minimisation surrounding alcohol and other drugs (AOD) use
- Addressing health, mental health & well-being of the client and their children
- Effective family planning methods to decrease AOD impacted pregnancies

Below are some of the quotes from participants who took part in the study:

"It is an awesome program that I would recommend to anyone. Without them I wouldn't know who to turn to."

"My case-manager is a kind of hero. I have had so many counsellors but they didn't help but she did. She never judged, was always calm and patient. Can tell her anything because she understands."

The team at Women's Health and Family Services have since committed to expanding the program and continuing the research partnership to evaluate and improve the service.



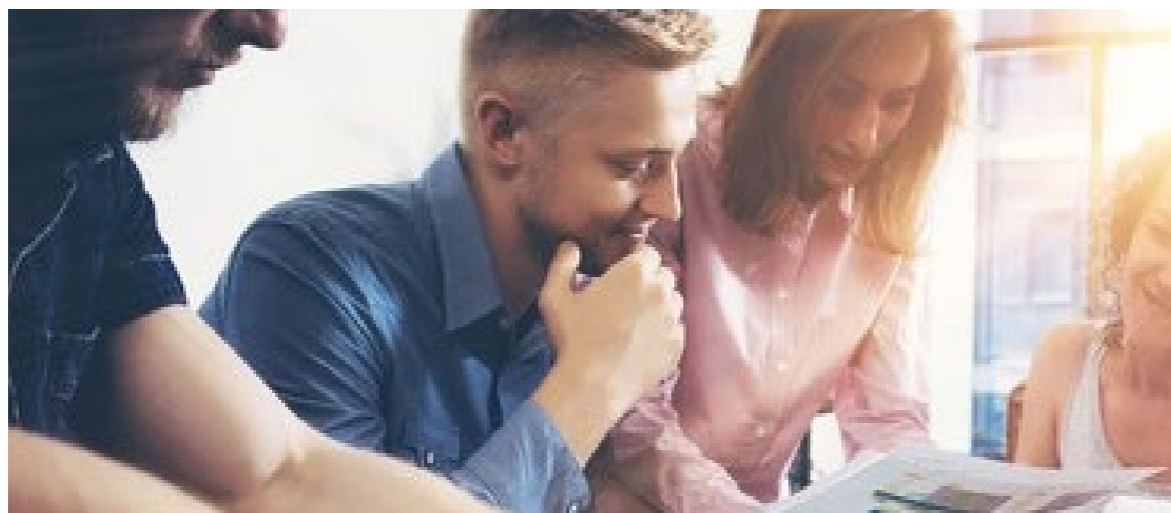
WHAT DO TEACHERS KNOW, AND CHILDREN NEED?

Students with FASD are most likely placed within mainstream classrooms, and it is therefore important that school staff have some knowledge and understanding of FASD, the possible needs of students with FASD, and effective strategies to implement within the classroom and school-wide setting. Researchers from FASD Research Australia have raised awareness with educators through:

- Presentations at education conferences (by invitation)
- The trial and evaluation of the Alert Program© by Dr James Fitzpatrick and Dr Bree Wagner
- The creation of the first online survey to assess knowledge, attitudes, needs and practices relating to FASD in Australian schools, created by Dr Amy Finlay-Jones
- Scoping reviews of Australian and international resources relating to FASD and education by Dr Amy Finlay-Jones and Lisa Cannon
- Systematic reviews of the oral and written communication outcomes (which includes literacy) among adolescents with prenatal alcohol exposure, completed by PhD candidate Natalie Kippin

In 2019, the WA Government Department of Education invited FASD Research Australia researchers to contribute to FASD professional development resources for teachers, which have since been made into an online module.

In 2020, Professor Elizabeth Elliott and Dr Lauren Rice, together with their colleague Sue Thomas, were invited to collaborate with the Matilda Institute and NOFASD to develop resources for the primary school and early childhood sectors.



EARLY IDENTIFICATION

Following the release of the WA Coroner's report on the inquest into the deaths of young persons in the Kimberley Region of Western Australia, a cross-department FASD Working Group was formed to consider what actions needed to be taken in each department. One of the recommendations was the introduction of universal screening for FASD at specific ages. Dr Amy Finlay-Jones and Dr

Rochelle Watkins were invited to conduct a short-term project, 'Screening for FASD in Western Australia: Policy and Practice Recommendations'. The team worked closely with a range of stakeholders to produce evidence-based recommendations, together with a summary of feasibility and costs for integrating screening tools into policy and practice.

Dr Finlay-Jones is also co-leading a program of work with Dr Jenny Downs titled the *Australian Collaboration to Enhance Neuro-Development* (ASCEND). Based at Telethon Kids and building on seed funding from the BHP sponsored *Think Big* initiative, ASCEND is working to build capacity for Australian researchers across a range of disciplines to conduct long-term research which will enable early identification of children at high risk of developing neurodevelopmental conditions; and allow early intervention (before the age of two) to enhance neurodevelopment.



UPSKILLING FRONTLINE STAFF

A prime example of how research can be translated into meaningful and sustainable training opportunities for frontline professionals is the Reframe Training program. Developed by Dr Hayley Passmore, in consultation with youth in detention and frontline justice professionals during the landmark Banksia Hill study, Reframe Training is an evidence-based training intervention which aims to build capacity among frontline professionals to understand and reframe the behaviours of young people with FASD and other neurodevelopmental impairments. Reframe Training incorporates a combination of face-to-face education, with short films and peer-to-peer learning. Requests to conduct this training are nationwide – from youth justice agencies, police, education, disability, child protection and community services.

Below is just one of the quotes from a recent participant in the Reframe Training program:

"[Because of this training I intend to] be more aware of the behaviours of the youth I work with in order to understand the best way to communicate with them, with the knowledge they may have a disability."

PREVENTION ACTIVITIES INFLUENCING POLICY & PRACTICE

Despite work to improve awareness within the wider community that the safest choice for a healthy pregnancy is to avoid alcohol, estimates suggest one in four Australian women continue to consume alcohol whilst pregnant, with many women unaware of, or underestimating, the severity of the risk.

Women have a right to know if a product can cause harm to their unborn child, and over the past five years, the FASD Australia CRE has focused on research and advocacy to educate and inform women, their partners and families about the importance of not drinking whilst trying for a baby, pregnant or breastfeeding. This work has been multi-faceted, consumer-driven, and successful.

Understanding decisions about alcohol use in pregnancy by Australian women

When incorporating health advice into decision making about health behaviours, an individual's beliefs about the behaviour play a large role. Women often receive conflicting advice about alcohol use during pregnancy from both health professionals and their own friends and family. Women also report different interpretations of the reference to there being 'no known safe amount' of alcohol, which can result in confusion.

To explore this further our FASD Research Australia PhD candidate Tess Fletcher, interviewed and surveyed women to gain insight into the relationship between women's beliefs about alcohol use during pregnancy and their own alcohol use behaviour.

IMPACT OF THIS RESEARCH

This evidence will be used to inform the development of health campaigns advocating for abstinence from alcohol during pregnancy. By using a bottom-up approach, it is possible to design health promotion messages that better address the needs of Australian women and the wider community.



Influencing decisions about alcohol use in pregnancy: Mandatory labelling for alcoholic beverages

Alcohol is a teratogen, known to cause damage to the developing fetus but, until 2011, alcohol products in Australia and New Zealand carried no warning about this risk. In 2011, the alcohol industry was given two years to voluntarily add their own pregnancy warning labels to their products. Evaluation of voluntary labelling showed low uptake, often inconspicuous labels, and unclear messages.

In response to this evaluation, Health & Food Safety Ministers allowed a further two years of voluntary labelling, which saw only modest increases in the uptake of labels, and similar unclear messages. Finally, in 2018, the Ministers asked Food Standards Australia New Zealand (FSANZ) to develop a best practice label as a priority.

IMPACT OF THIS RESEARCH & ADVOCACY

These strong advocacy efforts paid off, with health and food safety ministers from Australia and New Zealand approving the recommended version of a warning label designed to highlight the risks of consuming alcohol during pregnancy. This decision will see distinctive red, black and white labels become mandatory on all alcoholic beverages.

Professors Carol Bower and Elizabeth Elliott, Co-Directors of FASD Research Australia, noted that this was another important part of the strategy to reduce the harmful and lasting impacts of prenatal alcohol use.

The result (below), supported by research, was a clear label which included red writing to ensure maximum visibility.



The powerful alcohol industry lobbied to reject the colour red in the proposed label, despite evidence of its effectiveness in drawing attention to the warning.

In July 2020, the recommended red and black label became mandatory. It will now be seen on all alcoholic beverages by 2023.

Mandatory labelling is one part of the prevention strategy to change social norms and ultimately reduce the harmful and lasting impacts or prenatal alcohol use.

To ensure the best practice label became mandatory, FASD Research Australia researchers:

- Served on advisory groups for FSANZ
- Provided evidence of the problem
- Reviewed the proposed labels with respect to size, colour and message
- Joined with advocates from around Australia and New Zealand - led by FARE to actively campaign for adoption of the FSANZ-proposed label
- Provided briefings to Ministers

Influencing information about alcohol use in pregnancy provided to women by health professionals

General Practitioners (GPs) are often the first health professional a woman goes to when she is either planning a pregnancy or thinks she may be pregnant. Because of this, GPs have an important role in providing the most accurate information to help women have a healthy pregnancy and healthy baby. In 2018-2019, FASD Research Australia Investigators and team members, Associate Professor Tracy Reibel, Dr Roslyn Giglia, and Heather Jones undertook work to increase the levels of GP understanding and awareness of:

- the impact of prenatal alcohol exposure
- the importance of asking, assessing and advising women about alcohol and pregnancy
- the importance of using a standardised tool such as the *AUDIT-C tool* to record alcohol use

As well as GPs, involving midwives was critical due to their role in the provision of information

GPaskthequestion page on the FASD Hub includes a range of information for GPs

3 videos have been watched by 1,200 viewers

Promotional card distributed to GP practices and individual GPs in Western Australia

to pregnant women, and also in recording alcohol use in pregnancy.

Midwives are expected to routinely use screening tools to establish the presence of known pregnancy risk factors (alcohol, smoking, domestic violence, mental health). Previous research conducted with midwives in Western Australia indicated that while their awareness of the link between alcohol use in pregnancy and FASD was high, a lack of confidence with using alcohol-related risk assessment tools and providing advice to expectant mothers was reported.

GPs ask the question...

For all pregnant women and women planning a pregnancy:

Ask	about alcohol use
Assess	any alcohol use during pregnancy (AUDIT C)
Advise	'No safe amount of alcohol at any time during pregnancy'

Logos: WA Primary Health Alliance, phn, TELETHON KIDS INSTITUTE, #GPaskthequestion, www.GPaskthequestion.org.au

Led by FASD Research Australia Investigator Associate Professor Tracy Reibel, this research focused on providing midwives and other health professionals who have contact with pregnant women 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. The study used the *AUDIT-C screening tool*.

A self-directed *AUDIT-C Learning Guide* was developed to upskill and improve midwives' confidence with risk screening and application of the *AUDIT-C tool*, and provides information on FASD and brief interventions related to alcohol use. The *Learning Guide* can be accessed from the [FASD Hub](#).

FASD Research Australia researchers have championed for the inclusion of information on prenatal alcohol use in the statutory Midwives Notification System in WA, and have also argued for such information to be collected nationally. From 2019 information is required on self-reported alcohol use in the first 20 weeks of pregnancy and after 20 weeks. The frequency of drinking is recorded for each of these time periods, as well as the number of standard alcohol drinks consumed on a typical day.

You ask about smoking and diet, why not alcohol?

- 50% of pregnancies are unplanned- there is a link between unplanned pregnancy and binge drinking.
- 47% of Australian women surveyed said they had consumed alcohol before knowing they were pregnant.
- 26% of Australian women surveyed said they had consumed alcohol after knowing they were pregnant.

Fetal Alcohol Spectrum Disorder (FASD) is caused by exposure to alcohol during pregnancy.

This is why all health professionals who have contact with pregnant women or women of child bearing age need to advise 'No alcohol when planning a pregnancy, while pregnant and breastfeeding' is the safest option.

Pregnant women participating in the study confirmed the acceptability of the AUDIT-C screening process, and the screening questions as fair and reasonable.

The results contribute further evidence to dispel concerns midwives or other health professionals may have about using the AUDIT-C risk screening tool or discussing alcohol use with women.

MORE OF OUR STORY

Conferences
Networks
Collaborations



RESEARCH TRANSLATION
(as of November 2020)

200+
conference presentations

28
submissions to parliamentary inquiries and reviews

103
publications with FASD Research Australia Investigators / Team Members as authors

6
reports

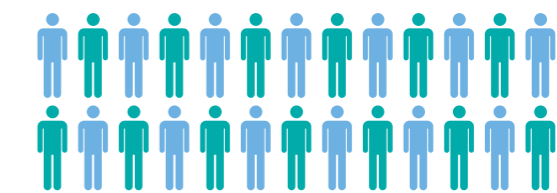
27
publications authored by affiliated researchers

171
publications 2016–2020
(130 publications 1978–2015)



RESEARCH CAPACITY STRENGTHS

13
PhD and Masters students supervised by a CRE Investigator or Team Member



26
affiliated researchers

2
capacity building seminars

27
publications which had a student supervised by a CRE Investigator or Team Member as lead author

SHARING OUR EXPERTISE

5 International **27** National **12** State/Territory
advisory groups & expert panels



GRANTS FUNDING
research projects & funding total



\$23,000,000

EVENTS, SYMPOSIUMS & CONFERENCES

2016 ● Advancing FASD Research Together Research Symposium, Perth

FUNDED | HOSTED | LEAD ROLE

2016 saw the beginning of a national coordinated approach to advancing FASD research capabilities in Australia. The inaugural Research Symposium for FASD Research Australia was held in Perth. The symposium was attended by 45 delegates. In addition to researchers, attendees included representatives from justice, education, disability, health, child protection sectors and NOFASD Australia. Numbers were limited to encourage open dialogue during the day and enable the whole group to participate. The program was a mix of short presentations and workshop activities, including ideas for future research. A summary report of the symposium issues and research ideas was published and circulated to all participants.

2017 ● International FASD Conference, Vancouver Canada

SPONSORED RESEARCHERS

- Sponsored 4 researchers to attend
- Keynote presentations by Prof Elizabeth Elliott and Dr James Fitzpatrick
- Presentations by 7 FASD Research Australia Investigators and Team Members
- Postdoc visits to Canadian, American, Scottish and Australian research institutes and universities
- Built stronger collaboration with Prof James Reynolds and Kids Brain Health Network

2017 ● Murdoch Children's Research Institute (MCRI) Seminar Series & Roundtable, Melbourne

SPONSORED

- FASD Workshop
- Keynote Presentation and MCRI Seminar Series by Prof Elliott
- Roundtable clinical discussion held at MCRI

2018 ● Victoria FASD Awareness Day, Melbourne

SPONSORED

This event was attended by over 250 people from a diverse range of disciplines, alongside parents and carers. Over 80 organisations were represented. The evaluation indicates a high level of satisfaction with the event. All respondents thought that the information provided will be useful in their work. There was strong positive feedback regarding all of the sessions, and especially the keynote and panel presentation, and the workshops. There was also positive feedback about the overall organisation of the event. The written comments demonstrated a desire for further FASD training and networking opportunities in Victoria. This feedback will help to inform the VIC FASD Special Interest Group (SIG)'s future directions and ongoing efforts to build capacity to respond to FASD in Victoria. The event was successful in reaching out to the wider public via the media, with an estimated cumulative audience reach exceeding 700,000.

Sponsored by FASD Research Australia, hosted by the [Victorian FASD SIG](#).

NOTE: Victoria SIG have been instrumental in advocating for FASD Diagnostic services and in 2019, Dr Katrina Harris was successful in applying for a Commonwealth grant for the Victorian Fetal Alcohol Service ([VicFAS](#)).



Dr Kerry Bagley, Chair VIC SIG

SPONSORED | HOSTED | LEAD ROLE



Hosted by FASD Research Australia, the two-day conference held in Perth, Western Australia on 21-22 November 2018 attracted over 370 participants including Australian and international researchers, health, justice and education professionals, as well as families, carers and advocates for people living with FASD.

Co-Chair of the conference Professor Carol Bower said the conference theme 'Our Science Our Stories' gave scientists, clinicians and community members equal billing, highlighting the strong partnership that exists between researchers, practitioners and families in the FASD field.

Event organisers received many positive comments and feedback:

Networking opportunities, participation of parents & carers, personal stories, strong plenary/keynote speakers, research

Quality of the presentations, speakers and the careful organisation to support the events

Wonderful atmosphere, a very diverse range of valuable attendees and a very inclusive approach - which is so beneficial to the FASD community

Liked seeing FASD from perspectives of carers, researchers & clinicians

Networking, met some awesome people, meeting people from diverse backgrounds

Finding out about the large number of research projects occurring within Australia

Watch videos of the plenary speakers and view some presentations from the conference on the [FASD Hub](#).

Two pre-conference workshops were held on 20 November.



WORKSHOP 1: FASD and Justice

This workshop was facilitated by Renu Burr and attended by over 80 participants including lawyers, judicial officers, staff within Commonwealth, State & Territory government departments, police, clinicians, staff working with young people and their families.

[Read the final communique from this workshop](#)

Key actions identified by attendees at this workshop included advocating for a whole of government plan to address FASD across the lifespan, further training of human service workforces, and support for early diagnosis. They also called for individualised plans that involved all relevant agencies in the spheres of Education, Child Protection, Juvenile Justice, Disability, Health and Mental Health and Police.



NOFASD Panel Voices of parents and carers for health professionals - how can we help each other? Facilitator Sophie Harrington Panel members Neroli Endacott, April Wilson, Cheryl Dedman, Neil Reynolds, Christine Brooks



WORKSHOP 2: FASD Clinical

This workshop was part of the dissemination and evaluation of the Australian Guide to the diagnosis of FASD project under the auspice of FASD Research Australia.

Invitations were extended to all health professionals involved in the assessment and diagnosis of FASD, and those interested in learning more about this process - paediatricians, psychiatrists, geneticists, psychologists, speech pathologists and occupational therapists. Over 40 people attended this workshop.

The FASD Clinical Workshop focused on:

- Australian Guide to the diagnosis of FASD
- Asking about alcohol use in pregnancy and recording this information
- Understanding diagnostic and intervention pathways
- Parents perspective of the importance of diagnosis
- Interactive case studies (different age groups)

Presenters and panel members:

- Professor Elizabeth Elliott – paediatrician (Australia)
- Dr Doug Shelton – paediatrician (Australia)
- Dr Marcel Zimmet– paediatrician (Australia)
- Dr Amanda Wilkins – paediatrician (Australia)
- Dr Andi Crawford – clinical psychologist (New Zealand)
- Claire Gyde – parent and chair of FASD-Can (New Zealand)
- Dr Tracey Harbour – parent (Australia)

Access the Australian Guide on the [FASD Hub](#).

Information on training and workshops for health professionals can be found on the [FASD Hub](#).

2019

International FASD Conference, Vancouver Canada

SPONSORED RESEARCHERS

- Sponsored 2 researchers to attend
- Keynote speakers Professor Elizabeth Elliott, Dr James Fitzpatrick, Dr Raewyn Mutch and Dr Hayley Passmore
- Together with NOFASD Australia, promoted Australian research and resources and the FASD2020 conference through a trade display
- Meetings with CanFASD & Kids Brain Health Network
- PostDoc visits and meetings with Canadian and US researchers and collaborators

2019

Youth Justice & Health Forum, Perth

LEAD ROLE

A forum for front-line workers who provide support to and services for families involved with the Western Australia youth justice system was held on 13 November 2019. This event was conducted by Telethon Kids Institute in partnership with experts Dr Robyn Williams, Dr Jocelyn Jones, Justine Bennell, Dorinda Cox, Magistrate Catherine Crawford and Tanja Carson.

The purpose of the forum was to share information about the health of young people who are justice-involved, and to learn more about the experiences and needs of front-line workers. The forum sought to empower front-line workers as they continue to advocate for the needs of these children and young people, including their physical, social, emotional and educational needs associated with disabilities. [Read the Summary report.](#)

2019

Early & Mid-Career Researcher Workshop, Sydney

FUNDED | LEAD ROLE

Researchers from across Australia were invited to attend the 2-day workshop in Sydney. Facilitated by Nicole Velik from The Ideas Bodega, the objectives of the workshop were to:

- Hear from other researchers on their current projects
- Build connections
- Encourage research collaborations
- Inspire creative thinking
- Ideas for staying connected after 2020

Feedback - What participants enjoyed:

“ *Hearing what everyone else is doing and meeting new faces. I was also inspired by the creative thinking session and will try to apply this to future project concepts.*

The group work doing creative thinking on FASD research projects. So helpful using all experience at the table to imagine the ideal research project/intervention. Loved it. ”

Participants commented on what they would like to see at future events:

“ *Maybe add a more structured learning focus, e.g. knowledge translation of one's research findings. The creative thinking one was good, but very general.*

Getting people from different stages in their research career to share their experiences (how to succeed, how to avoid pitfalls).

More opportunities for general networking and collaboration building - could suggest that people come with a list of projects they could be interested in collaborating on with others and spend time together developing these together.

Opening up to clinicians involved in research, but are not researchers. Extra brain power and ideas in the room. ”



FUNDED | LEAD ROLE

With the cancellation of the 3rd Australasian FASD Conference due to the COVID pandemic, the FASD Research Australia Executive and Conference Organising Committee agreed to reach out to researchers, stakeholders and community members in Australia and New Zealand via a series of virtual events.



SEMINAR 1

Assessment and diagnosis: there's more than the test results

To coincide with International FASD Awareness month the first event was held on 8 September. This session included a series of videos providing real life stories of the impact of a FASD diagnosis for young people and adults, information from a Queensland clinic on feeding back the information following the assessment process, and a live Q&A session. With almost 100 people joining the seminar the feedback was very positive. You can watch the videos, listen to the recording and view the illustrations [here](#).

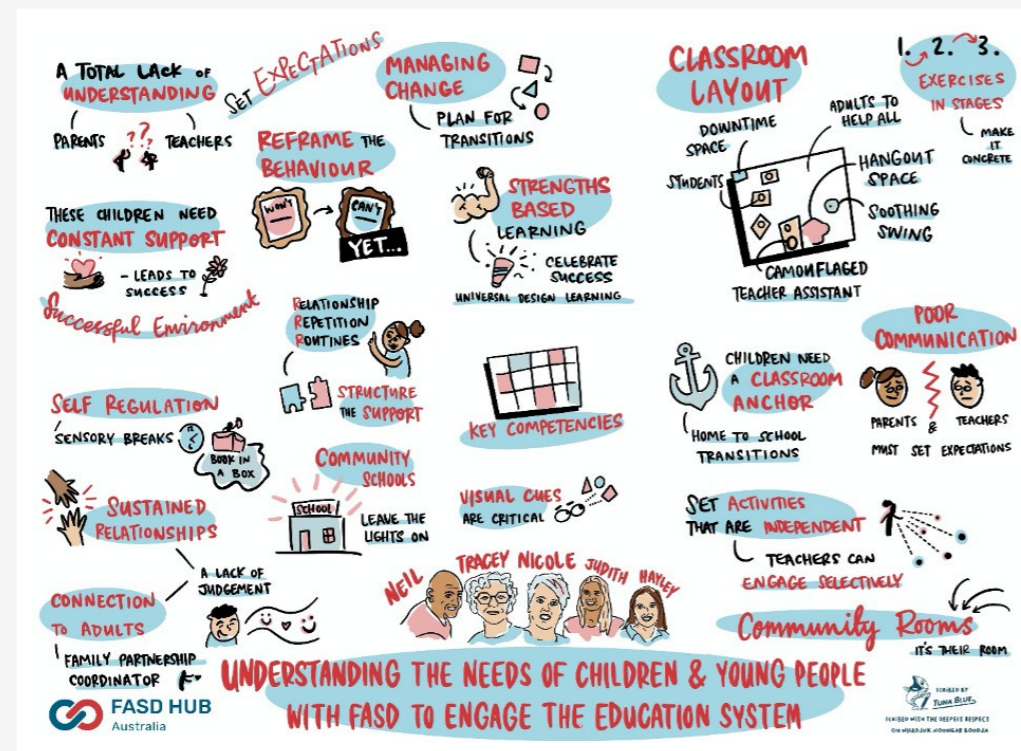




SEMINAR 2

Understanding the needs of children & young adults with FASD to effectively engage with the education system

This event held on 27 October focused on the lived experiences of the difficulties for a child/young person with FASD trying to meet the expectations of school, what makes a successful relationship between schools and families, and strategies for teachers. The presentations and panel discussions were followed by a live Q& A session. You can listen to the recording and see the illustrations [here](#).



VIRTUAL POSTERS

Prevention: Advocacy and action - how we can all contribute to preventing alcohol use in pregnancy

All posters were uploaded to the FASD Hub and promoted via Facebook, Twitter and email networks. A review panel of researchers and community members reviewed the posters and identified the best poster. The posters can be viewed [here](#).

VIDEOS

- A conversation with Professor Carol Bower: Shining a light on FASD
- Professor Carol Bower's Advice to Early Career Researchers

These videos can be watched [here](#).

SEMINAR 3

FASD Research Australia: Shining a light on FASD and Awards Ceremony

This seminar facilitated by Julie McCrossin, included an interview with the Co-Directors Professor Carol Bower and Professor Elizabeth Elliott highlighting achievements, policy changes over the five years of the centre 2016-2020, and priority goals for future research. This was followed by a panel discussion highlighting the involvement of the community and work of several FASD Research Australia researchers.

A virtual awards ceremony concluded this event. Information on the award recipients can be found on [pages 44-47](#).

You can read more about the awards [here](#).

VIRTUAL RESEARCH PRESENTATIONS

In early 2021 there will be a call for research presentations. This will be followed by a research focussed webinar. All presentations will be uploaded to the [FASD Hub](#).



WIDENING THE RESEARCH NETWORK



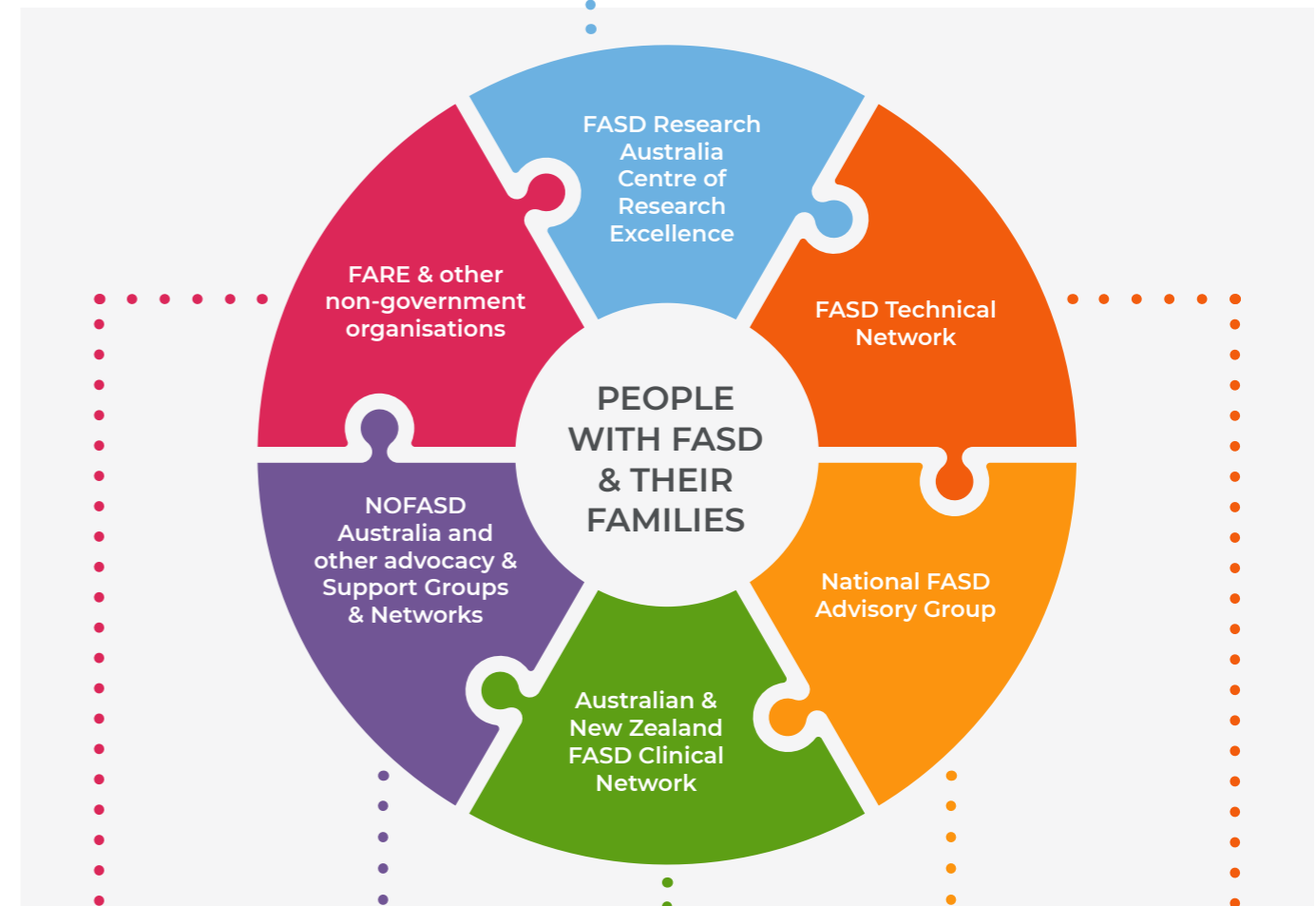
One of the key activities of FASD Research Australia was to build a network of researchers across Australia:

- ✓ We increased our researcher network through new affiliations and supporting students
- ✓ We strengthened connections to others by linking with groups such as the Australian & New Zealand FASD Clinical Network, NOFASD Australia and FARE

We have also increased our networks with international research organisations.

The fourth objective of a Centre of Research Excellence is to build on strong partnerships with Government, non-government, academic, human rights and community stakeholders.

Direct and Affiliated Research Projects: PREVENTION DIAGNOSIS THERAPY & MANAGEMENT JUSTICE	Provide a national platform of collaborative expertise to integrate FASD research, workforce development and dissemination and translation of research results into models and tools	Research Organisations • Telethon Kids Institute • University of Sydney • Menzies School of Health Research • Murdoch Children's Research Institute • George Institute for Global Health • University of Queensland • University of Western Australia • University of Newcastle • Curtin University • Griffith University • Murdoch University
FASD Research Australia Community Reference Group		



- Provide a strong and effective voice to raise community awareness of harm from alcohol use in pregnancy, policy and legislation
- Provide a strong and effective voice for individuals living with FASD and their families
- Coordinate, expand capacity and align clinical approaches to referral, assessment, diagnosis and intervention across Australia and NZ
- Report on the evaluation of the implementation of the National FASD Strategic Action Plan 2018-2028 and identification of emerging issues and gaps
- Provide advice to the Australian Government Department of Health on how to achieve a strategic coordinated approach to FASD

International

CanFASD

Canada - Australia FASD Research Network

To forge ongoing and strategic relationships between researchers in Australia and Canada and to explore issues of mutual interest, a Memorandum of Understanding (MOU) was signed between the Canada Fetal Alcohol Spectrum Disorder Research Network (CanFASD) and the FASD Research Australia Centre of Research Excellence in November 2018.

The purpose of this MOU is to formalise a cooperative effort between the two organisations to advance the knowledge and understanding of FASD and its link with alcohol use.

Specific activities and programs implemented under authority of this MOU shall be subject to availability of funds and the approval of each institution's authorized representatives, and may include:



The expansion and enrichment of both research networks



The promotion of academic research excellence in the area of alcohol use during pregnancy, FASD diagnosis and intervention



The promotion of knowledge mobilisation of FASD-related tools and resources to improve prevention, diagnosis and intervention



FASD Research
Australia
Centre of Research Excellence

CanFASD
CANADA FASD RESEARCH NETWORK

Ms Audrey McFarlane
Executive Director

Canada Fetal Alcohol Spectrum
Disorder Research Network

Prof Carol Bower
Co-Director

FASD Research Australia
Centre of Research Excellence

Prof Elizabeth Elliott AM
Co-Director

FASD Research Australia
Centre of Research Excellence

Research affiliates

Researchers working in alcohol use in pregnancy and/or FASD research, who were not FASD Research Australia Investigators or Team Members, were invited to become affiliated researchers. There has been significant contributions by affiliated researchers through research projects, publications and leadership/mentorship of early and mid-career researchers.



Researchers affiliated with FASD Research Australia

- **Ms Tiffany Allen**
University of Sydney
- **Ms Ellaina Andersson**
University of Sydney
- **Dr Kerryn Bagley**
LaTrobe University
- **Dr Melissa Cheung**
University of Sydney
- **Assoc Prof Jeff Craig**
Deakin University
- **Ms Phillipa Crooks**
University of Sydney
- **Dr Himanshu Gupta**
Menzies School of Health Research
- **Ms Olivia Hamilton**
Mercy Services
- **Dr Sharynne Hamilton**
Telethon Kids Institute
- **Assoc Prof Delyse Hutchinson**
Deakin University
- **Dr Erin Kelty**
University of Western Australia
- **Dr Melanie Kingsland**
University of Newcastle
- **Dr Barbara Lucas**
University of Sydney
- **Prof Alexandra Martiniuk**
University of Sydney
- **Dr Carlos Nunez Miranda**
University of Sydney
- **Dr Anne Morris**
University of Sydney
- **Prof Karen Moritz**
University of Queensland
- **Ms Evi Muggli**
Murdoch Children's Research Institute
- **Dr Sara McLean**
University of South Australia
- **Dr Rebecca Pedrucci**
Telethon Kids Institute
- **Dr Natasha Reid**
University of Queensland
- **Ms Kelly Skorka**
University of Queensland
- **Prof James Smith**
Menzies School of Health Research
- **Ms Annalee Stearne**
Curtin University
- **Ms Donna-Marie Stephens**
Menzies School of Health Research
- **Ms Sophie Young**
University of Queensland

Australia

Students

FASD Research Australia aimed to develop the capabilities and experiences of students undertaking a doctorate by offering mentorship, research skills and academic experiences. Two PhD scholarships were offered and Investigators and Team Members supervised candidates across a number of universities and institutes.

STUDENT	TITLE OF THESIS	SUPERVISORS	STATUS
PhD candidates funded by FASD Research Australia			
Natalie Kippin	Communication, fetal alcohol spectrum disorder, and youth justice	Assoc Prof Suze Leitao Dr Amy Finlay-Jones* Dr Rochelle Watkins*	Current
Tess Fletcher	The psychosocial determinants of alcohol use in pregnancy: Implications for health promotion messages in Western Australia	Dr Amy Finlay-Jones* Dr Barbara Mullan	Current
PhD candidates supervised by FASD Research Australia Investigators and Team Members*			
Barbara Lucas	Motor performance, prenatal alcohol exposure and fetal alcohol spectrum disorders in Aboriginal children in remote Australia	Prof Elizabeth Elliott* Prof Jane Latimer*	Passed 2016
Robyn Doney	Fetal Alcohol Spectrum Disorder and Fine Motor Skills: A population-based study of children in the Fitzroy Valley	Prof Peter Howat Dr Kay Sauer Dr Jonine Jancey Prof Elizabeth Elliott*	Passed 2018
Emily Fitzpatrick	The Picture Talk Project: Research Partnerships, Community Engagement and Reaching Consent for Research with Remote Aboriginal Communities in Australia	Prof Elizabeth Elliott* Prof Alexandra Martiniuk Dr Gaynor Macdonald	Passed 2019
Hayley Passmore	Improving the management of young people with Fetal Alcohol Spectrum Disorder in detention	Prof Carol Bower* Prof Jonathan Carapetis* Clinical Assoc Prof Raewyn Mutch* Assoc Prof Sharyn Burns Assoc Prof Guy Hall	Passed 2019

STUDENT	TITLE OF THESIS	SUPERVISORS	STATUS
Sharynne Hamilton	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	Prof Carol Bower* Dr Melissa O'Donnell Clinical Assoc Prof Raewyn Mutch* Assoc Prof Tracy Reibel* Prof Valerie Braithwaite	Passed 2020
Bree Wagner	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)	Dr James Fitzpatrick* Dr Martyn Symons* Prof Donna Cross	Passed 2020
Stewart McDougall	A neurodevelopmental focused screening tool for young children with Fetal Alcohol Spectrum Disorder (FASD)	Dr Amy Finlay-Jones* Prof Fiona Arney Dr Andrea Gordon	Passed 2020
Kuen Yee Tan	Diagnosing Fetal Alcohol Spectrum Disorder (FASD) in Western Australia: Investigating the characteristic profiles of children, adolescents and young adults	Dr Martyn Symons* Dr James Fitzpatrick*	Current
David Tucker	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	Dr Nyanda McBride Dr Martyn Symons* Assoc Prof Roz Walker	Current
Mitchell Bestry	The Epigenetic Origin of Alcohol Induced disorders: A Cross-Species Study	Dr Martyn Symons* Dr David Martino Prof Ryan Lister	Current
PhD candidate FASD Research Australia Investigator			
Lorian Hayes	An Aboriginal woman's historical and philosophical enquiry to identify the outcomes of prenatal alcohol exposure and early life trauma in Indigenous children who live in Aboriginal communities in Queensland	Prof Wendy Hoy Prof Paul Coldtz	Passed 2019
Masters candidate FASD Research Australia Team Member			
Dr Amy Finlay-Jones	Estimating the economic burden of fetal alcohol spectrum disorders in Australia	Assoc Prof Lisa Gold	Passed Masters of Health Economics 2019
Masters candidates supervised by FASD Research Australia Investigators and Team Members*			
Bernadette Safe	Young people in detention in Western Australia: An examination of motor skills and the effect of prenatal alcohol exposure	Dr Roslyn Giglia* Assoc Prof Annette Joosten	Passed Master of Child Health Research 2019

PROVIDING OUR ADVICE & EXPERTISE TO OTHERS

Advisory Groups and Expert Panels

International

1. Elliott EJ. Expert Advisory Committee, biannual International Conference on FASD, 2015-2020
2. Elliott EJ. Expert Advisory Committee, biannual International Conference on Adolescents and Adults with FASD, Vancouver, Canada, 2016-2020
3. Elliott E. Invited participant, Inaugural WHO Global Summit on Alcohol, Gambling and Drugs, Geneva, 2017
4. Fitzpatrick J. International FASD Prevention Network (includes the Netherlands, Canada, USA and Australia). 2017-2020
5. Elliott E. FASD Consensus Committee, National Institute on Alcohol Abuse and Alcoholism USA, 2019-2020

National

1. Elliott EJ. Director Australian Paediatric Surveillance Unit, 1993-2020
2. Bower C. Intellectual Disability (IDEA) Database Advisory Council Member 2002-2010; Chair 2011-2020
3. Bower C. National Perinatal Epidemiology Statistics Unit Steering Committee for Congenital Anomalies. 2012-2020
4. Bower C. Australian Paediatric Surveillance Unit Scientific Review Panel. 2012-2020
5. Elliott E. National Awareness Campaign Evaluation Steering Committee. Foundation for Alcohol Research and Education. 2014.
6. Elliott E (Chair), Bower C, Mutch R. National FASD Technical Network 2014-2017
7. Elliott EJ. Champion, Pregnant Pause Campaign, Foundation for Alcohol Research and Education, 2014-2017.
8. Bower C. Reference Group, Australian Indigenous Alcohol and Other Drugs Knowledge Centre 2014-2018
9. Fitzpatrick J. Australian National Advisory Council on Alcohol and Drugs. 2014-2020
10. Giglia R. Australian Government Department of Health Breastfeeding Expert Reference Group 2017
11. Elliott EJ. Review of National Alcohol Strategy: Round Table, Invited Participant, Australian Minister for Health, 2018
12. Elliott EJ. Invited reviewer, National Fetal Alcohol Spectrum Disorder Plan, Australian Department of Health, 2018
13. Elliott EJ. Specialist and Consultant Physician Clinical Committee, Medical Benefits Scheme Review, Australian Department of Health, 2018
14. Bower C, Elliott EJ. Co-Convenors, 2nd Australasian FASD Conference, Perth, 2018
15. Bower C. Australian Indigenous HealthInfoNet, Honorary Consultant 2018-2020
16. Elliott EJ. Board Member, National Organisation for Fetal Alcohol Spectrum Disorder, 2018-2020
17. Kippin N. Speech Pathology Australia, Justice Practice Document Working Party, Contributor 2018-2020
18. Kippin N. FASD Hub Subject Matter Editorial Panel Member 2018-2020

19. Elliott EJ. Food Standards Australia New Zealand Pregnancy Warning Labelling Targeted Consultation. June 2019.
20. Bower C. Food Standards Australia New Zealand public health consultation meeting, warning labels on alcoholic beverages. March, June 2019.
21. Elliott EJ. Board Member, Royal Far West, 2019-2020
22. Elliott EJ. Co-Chair (2020), Member (2019-2020) National FASD Advisory Group, Australian Department of Health
23. Bower C. (Co-Chair 2019-20) National FASD Advisory Group, Australian Department of Health
24. Bower C, Elliott EJ. Co-Convenors, FASD Australia Webinar Series on FASD, 2020
25. Elliott E. FASD Early Childhood Identification Guide Advisory Group. NOFASD Australia 2020
26. Elliott E. National Awareness Campaign Evaluation Steering Committee. Foundation for Alcohol Research and Education. 2020
27. Elliott E. FASD Early Childhood Identification Guide Advisory Group. NOFASD Australia 2020

State / Territory

1. Elliott E. Consultant, NSW Health Aboriginal Prenatal Alcohol and FASD Campaign, 2014-2018
2. Giglia R. WA Key Stakeholders Breastfeeding Group 2014-2020
3. Elliott E. Member, Advisory Group, Marulu FASD Strategy, Marninwarntikura Women's Resource Centre, Fitzroy Crossing, WA. 2015-2020
4. Jones H. WA Department of Health Child & Youth Health Network Expert Advisory Group 2015-2020
5. Elliott E. Head, NSW FASD Assessment Clinic, The Sydney Children's Hospitals Network, Westmead 2015-2020
6. Jones H. WA Department of Health Child and Youth Health Networks Youth Health Policy Working Group 2016-2017
7. Co-Director, NSW Health Centre for Care and Intervention for Children and Adolescents affected by Drugs and Alcohol (CICADA), The Sydney Children's Hospitals Network (Westmead), 2016-2020
8. Alcohol and Pregnancy Clinical Expert Group, NSW Ministry of Health Get Healthy Information and Coaching Service, 2016-2018
9. Kippin N. Youth Justice Speech Pathology Advisory Group, Department of Justice and the Attorney General, Queensland Government 2017-2019
10. Mutch R. UWA Law School Aboriginal and Torres Strait Islander Community Justice Reference Group
11. Bower C. Pharmaceutical Society WA JM O'Hara Research Fund Grants Committee, Chair 2018-2020
12. Kippin N, Passmore H, Cannon L, Finlay-Jones A, Mullan N, Jones H. Advice to Western Australian Department of Education on development of FASD in Schools project and online learning modules 2018-2020



AWARDS

Outstanding Contributions by our Investigators and Team Members

Many people have been acknowledged for their significant contributions to health and medical research, made sustained and significant contributions to the community, and been instrumental in advocating for policy and legislative changes.



Lifetime Achievement Award recipient, Sue Miers AM

2nd Australasian FASD Conference Perth | November 2018



LIFETIME ACHIEVEMENT AWARD

SUE MIERS AM

Sue is the founder and past Chair of the Board of the National Organisation for Fetal Alcohol Spectrum Disorders Australia (NOFASD Australia).

Sue lobbied extensively on both a state and national level to raise awareness about FASD and was an invited member of, and reported to, various national and state government agencies in Australia, as a recognised parent authority in this area. In this voluntary role, Sue also provided one-on-one support to many parents/carers and individuals living with FASD and also delivered FASD presentations/workshops to foster carers, teachers, drug and alcohol workers, disability workers, mental health workers, midwives and many other community organisations throughout Australia.

She has significant expertise and knowledge around the secondary conditions which develop for people affected by FASD.

Sue has been widely acknowledged as a significant contributor to knowledge and awareness of FASD in Australia. This has encouraged the development of clinical expertise and recognition at a national level that Australia requires a serious commitment to the prevention, diagnosis and development of effective interventions for FASD.

Sue retired from NOFASD Australia in an official capacity in 2015 but continues to provide voluntary support to the organisation in various roles. In addition, Sue's practice based wisdom as the Parent & Family Support Coordinator ensures that NOFASD is able to develop staff, support clients and upskill those working to enhance the lives of individuals and families affected by FASD.

<p>PEOPLE'S CHOICE AWARD CLAIRE GYDE for her inspiring presentation 'The Art of Living with Hope' Watch Claire's presentation</p>	<p>BEST STUDENT PRESENTATION ROBYN DONEY for her presentation 'Can informal assessments be used in FASD diagnosis? Graphomotor examples from the Lililwan Project'</p>	<p>BEST POSTER PRESENTATION DIANA BARNETT JESSICA HANNAN for their poster 'The role of Occupational Therapists in diagnosis, intervention and education of FASD on young people'</p>
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Virtual Awards Ceremony

12 November 2020

SUE MIERS LIFETIME ACHIEVEMENT AWARD

PROFESSOR CAROL BOWER



This prestigious Lifetime Achievement Award recognises and celebrates a person who has made an outstanding and sustained contribution to the field of Fetal Alcohol Spectrum Disorder and/or alcohol use in pregnancy on a local, national or international level.

Professor Bower is an internationally recognised public health researcher who has spent almost her entire research career working in birth defects and aiming to improve maternal and child health. She has qualifications in medicine, epidemiology and public health. She commenced her research career in 1980 and for the past 20 years has led a team of multidisciplinary researchers in studies on alcohol in pregnancy and FASD, successfully collaborating with relevant state, national and international colleagues, organisations and consumer and community members.

Professor Bower has been a generous participant in countless committees and has consistently involved consumers in community reference groups, steering groups, and as investigators. We are immensely proud of her achievements, not just of her contribution to health research, but her commitment to its translation into practical public health outcomes, and her passion for involving consumers and community members in the process. Throughout her career, Carol has supported

and developed the next generation of health and medical researchers in WA and has mentored/supervised more than 30 early career researchers, PhD candidates, Masters students and medical students. In each she has instilled her commitment to using scientific research for the benefit of the wider community. Many of those she has supervised and mentored have gone on to outstanding research careers and/or significant leadership positions.

This award was sponsored by FASD Research Australia.



Sue Miers Lifetime Achievement Award recipient, Prof Carol Bower

COMMUNITY AWARD

NEROLI ENDACOTT

This award recognises the voluntary achievements and contributions to the community, people living with FASD and their families and support networks by a person who has helped people and added value to their lives.

Neroli Endacott is a quiet achiever and has worked hard to raise awareness of FASD, support parents and carers, and promote promising and best practices for interventions and management. She was a founding member of the Board of NOFASD Australia and founder of the national helpline. She was another person who realised early on that many children in foster care were born with a disability which impacted on their potential, created challenges for healthy development of the individual and placed families trying to do their best under pressure.

Neroli has cared for over 100 children providing dedicated, patient and caring parenting. When she realised that health professionals did not understand FASD, she personally visited practices in her local area delivering some of the earliest alcohol and pregnancy advice flyers ever developed in

Australia. Neroli also conducted schools education on alcohol and pregnancy - again a pioneer in FASD awareness raising in Australia. For 30 years she has continued her mission and inspired many on the way.

This award was sponsored by Sue Miers.



Community Award recipient, Neroli Endacott (right) with Sue Miers

**YOU CAN WATCH A RECORDING
OF THIS EVENT AT
www.fasdhub.org.au**

EARLY CAREER RESEARCHER AWARD

DR NATASHA REID

This award recognises the outstanding contribution to the field of FASD and/or alcohol use and pregnancy in a researcher who is less than five years post PhD.

Dr Natasha Reid has a vision to raise awareness within society regarding FASD to prevent future children being affected. For those affected, her research aims to contribute to further evolving, implementing and evaluating effective assessment, diagnostic and intervention approaches, ensuring that children and families can have access to the appropriate services they need. In just over 3 years since obtaining her PhD (2017) she has published more than 25 papers, been involved in health professional training and caregiver workshops with more than 300 participants and been involved in many community awareness events.

Natasha is already recognised as a leader in the field, is the current co-chair of the Australian and New Zealand FASD Clinical Network and a member of the Organising and Scientific Committee for the 2020 FASD conference. She is passionate about training a broad range of students and health professionals, and supervising Master and PhD students.

This award was sponsored by Prof Carol Bower.

MID-CAREER RESEARCHER AWARD

DR KERRY N BAGLEY

This award recognises the outstanding contribution to the field of FASD and/or alcohol use and pregnancy in a researcher who is less than 10 years post PhD.

Dr Kerry N Bagley is a researcher and lecturer in Social Work, Social Policy and Rural Health at La Trobe University Australia. Her role has provided her with a platform to inform graduate social workers about FASD and the challenges families face over the life course.

She is also known for her research into health and human service sector responses to FASD, which stems from her extensive practice experience in child and adolescent mental health services with families affected by FASD. She has been engaged in FASD practice and research since 2008 and undertook her FASD diagnostic team training and evidence-based intervention training in the USA and Canada. Kerry's research has highlighted why a social work response to FASD is needed and explores social work frameworks and models that underpin current FASD-informed practice, and is informed from her time working in Canada, New Zealand and Australia.

Together with colleagues from these countries she has made submissions to many national inquiries. She was the inaugural co-chair of the Australian and New Zealand FASD clinical network and currently chairs the Victorian FASD Special Interest Group.

This award was sponsored by Prof Elizabeth Elliott.

BEST POSTER AWARD

AUTHORS:

DR REBECCA PEDRUZZI & ISABELLA PRUITI

Pre-Testie Bestie – a novel social media campaign highlighting the critical role of a friend in supporting safe choices about alcohol.

This poster features a pilot project to test if the highly successful Pre Testie Bestie campaign from New Zealand could address local intervention goals in Newcastle NSW. The campaign reached 91,264 women on average 26 times.

Women who saw the campaign thought that it was more relevant to a friend than to themselves and were more likely to endorse the message of waiting 3 weeks after unprotected sex to take a pregnancy test. Researchers aimed to understand the characteristics of the audience most influenced by the campaign.

This award was sponsored by the FASD Hub.





FASD Research Australia Investigators & Team Awards

Prof Carol Bower

- Inducted into WA Premier's Science Hall of Fame, 2019
- Public Health Association Australia Top 10 Public health successes over the last 20 years, Folate: we reduced neural tube defects, 2018
- Fellow Australian Academy of Health and Medical Sciences, 2017
- Finalist Scientist of the Year Premier's Science Award, 2016
- International Clearinghouse for Birth Defects Surveillance and Research - J David Erickson Scientific Lectureship, 2016

Prof Elizabeth Elliott AM

- Vernon Collins Medal and Oration, Royal Children's Hospital Melbourne, 2020
- Award for Child Protection, for Capacity Building and Strengthening with Vulnerable Families. CICADA Sydney Children's Hospital Network, 2020
- Starfish Award, 8th International Conference on FASD, 2019
- Honorary Fellowship, Royal College of Paediatrics and Child Health UK, 2019
- Elected Fellow, Royal Society of NSW, 2019
- Elected Member, Chief Executive Women Australia, 2019
- Excellence in Healthcare Award, Australian Medical Association, 2018
- Next Generation Fellowship, Medical Research Futures Fund, 2018
- Outstanding Asian Paediatrician Award, Asia Pacific Paediatric Association, 2018
- James Cook Medal, Royal Society of New South Wales, 2018
- Inaugural Fellow, Academy of Child and Adolescent Health, 2018
- 'Pioneer' in FASD, Red Shoes Rock: International Voice for Prenatal Alcohol Exposure, 2018
- Howard Williams Medal and Oration, Royal Australia College of Physicians, 2017
- Elected Fellow, Australian Academy of Health and Medical Science, 2016
- Alumnae Award, Women's College, University of Sydney, 2016
- Elected Member, International Society for the Study of Behavioural Phenotypes, 2016

June Oscar AO

- NAIDOC Person of the Year at the National NAIDOC Awards, 2018
- WA Local Hero, 2017 and finalist for Australian of the Year Award
- Recipient of the prestigious Desmond Tutu Reconciliation Fellowship 2016

Prof Jonathon Carapetis AM

- Western Australian of the Year Awards – Professional Award Finalist, 2018
- Order of Australia, 2018
- Australian Council for Educational Leaders (ACEL) Pre-Eminent Educational Leader Award, WA, 2016

Adjunct Prof James Fitzpatrick

- Finalist Early Career Scientist of the Year Premier's Science Award, 2016

Dr Lorian Hayes

- Aboriginal and Torres Strait Islander RHD Research Excellence Award 2019

Prof Steve Zubrick

- Finalist Scientist of the Year Premier's Science Award, 2018
- Fellow Australian Academy of Health and Medical Sciences, 2017



Prof Jane Halliday

- British Fertility Society Exchange Award – Geoffrey Driscoll Medal, 2018
- Selected as a "Brilliant Mind" for the 30 year anniversary of the Murdoch Children's Research Institute, 2016

Dr Tracey Tsang

- The Vice-Chancellor's Sponsorship Program, For Culturally and Linguistically Diverse Women, 2018

Natalie Kippin

- FASD Research Australia Centre of Research Excellence PhD Scholarship
- EMCR Best Poster Presentation Telethon Kids Institute, 2019

Dr Amy Finlay-Jones

- Golden Key Society Invitation, Deakin University (Outstanding Academic Achievement), 2019
- Health Policy Research Scholarship, Deeble Institute, 2018
- ASPIRE Conference Award, Perth Convention Bureau 2018
- Starlight Fellow 2018
- Women in Leadership Australia, Accelerated Program, Telethon Kids Institute Top-up Funding, 2017
- Women in Leadership Australia, Accelerated Program Scholarship, 2017
- Think Big Award, Telethon Kids Institute 2017
- Innovation Award (Finalist) WA Association of Mental Health, 2017
- Startup Challenge Innovation Central Prize West Tech Fest 2017
- Telethon Kids Institute Emerging Leaders Program
- SPARK Co-Lab Award Design Course Winning Team 2017

Dr Hayley Passmore

- Semi-Finalist, Western Australia Young Achiever Awards, Catholic Education Young Leadership Award, 2019
- Finalist, WA Premier's Science Awards, Exxonmobil Student Scientist of the Year Award, 2019
- Aspire Award, Telethon Kids Institute Professional Development Award, Perth Convention Bureau Aspire Awards, 2019
- PhD Student Paper Prize, Australian and New Zealand Society of Criminology Conference, Canberra, 2018
- Stan and Jean Perron Postgraduate Award for Excellence, 2017
- Best Abstract – Telethon Kids Institute Student Circle Symposium, 2017
- Runner up 8-minute Presentation – Telethon Kids Institute Student Circle Symposium, 2017
- Australian Student Award for Best Abstract, Australian and New Zealand Society of Criminology Conference, 2017
- Best 3 minute presentation. The 10th Annual student Circle Symposium, 2016

Narelle Mullan

- Travel Award, Peers & Partners, Telethon Kids Institute, 2019
- Telethon Kids Institute Emerging Leaders Program, 2018

Heather Jones

- Travel Award, Peers & Partners, Telethon Kids Institute, 2020

Dr Yi Huey Lim

- Curtin University Chancellor's Commendation for PhD thesis *The Postural Control System in Individuals with Autism Spectrum Disorder: Insights from Exploring the Effects of Visual Information on Postural Control* (Exceptional Higher Degree by Research Thesis), 2020



PUBLICATIONS, REPORTS & SUBMISSIONS

A total of

171

AUSTRALIAN PUBLICATIONS

on alcohol and pregnancy and FASD were published between

2016 & 2020

Of these

103 (60%)

ARTICLES

included FASD Research Australia Investigators and Team Members as authors and

27

PUBLICATIONS

included a student as the lead author. A further

29 (17%)

ARTICLES

were published by researchers associated with the CRE.

Publications

You can access the Impact Report Supplement Projects and Publications [here](#). The publications include articles and reports which include FASD Research Australia Investigators and Team Members as authors.

All Australian publications, including book chapters, reports and journal articles pertaining to alcohol and pregnancy & FASD can be found on the [FASD Hub](#). You can sort by year, author or topic. Lists of publications can also be printed.

Submissions and contributions to government inquiries and reviews

Our researchers influence and make a difference at all stages of the policy pipeline:

- Identifying critical problems
- Being trusted advisors
- Actively participating in the policy process
- Presenting benefits and harms of policy solutions
- Providing evidence for legislative change

1. **Bower C**, Walker N. Hamilton S. **Pearson G**. Part of the First Peoples Disability Network Australia submission to the Senate Inquiry into the indefinite detention of people with cognitive and psychiatric impairment in Australia. April 2016.
2. **Mutch R**. Walker N. Evidence to the Community Affairs Reference Committee hearing in Perth (Senate Inquiry into the indefinite detention of people with cognitive and psychiatric impairment in Australia). September 2016.
3. **Elliott E**, **Bower C**, **Fitzpatrick J**. Participation in the Australian Government FASD Roundtable, Canberra December 2016
4. **Fitzpatrick J**. Pestell C. NT Royal Commission into Youth in Detention. December 2016.
5. **Giglia R**. Contributed to the development of the Global Alcohol Strategy 2017
6. **Giglia R**. Contributed to the National Breastfeeding Strategy 2017 and Beyond 2017
7. Banksia Hill project team (including **Bower C**, **Passmore H**, **Mutch R**, **Kippin N**) contribution to Telethon Kids Institute submission, Review of the Young Offenders Act 1994, Department of Corrective Services, Feb 2017
8. Banksia Hill project team (including **Bower C**, **Passmore H**, **Mutch R**, **Kippin N**) contribution to Telethon Kids Institute submission, Response to, 'Royal Commission into the Protection and Detention of Children in the Northern Territory', August 2017
9. Banksia Hill project team (including **Bower C**, **Passmore H**, **Mutch R**, **Kippin N**) contribution to Telethon Kids Institute submission,, 'Terms of Reference for: Incarceration Rates of Aboriginal and Torres Strait Islander Peoples August 2017
10. **Halliday J**. Involved in face to face consultations held by Siggins Miller to inform the development of the National FASD Strategy. Melbourne. August 2017.
11. **Bower C**, **Fitzpatrick J**, **Giglia R**, **Jones H**. Involved in consultations to inform the development of the National FASD Strategy. August 2017.
12. **Elliott E**, **Bower C**, on behalf of the FASD Research Australia Centre of Research Excellence. Submission to Siggins Miller re the National FASD Strategy 2018 – 2028. September 2017
13. **Bower C**, **Fitzpatrick J**, **Giglia R**, **Jones H**. Involved in face to face consultations held by Siggins Miller to inform the development of the National FASD Strategy. Perth. August 2017.
14. **Elliott E**, Involved in face to face consultations held by Siggins Miller to inform the development of the National FASD Strategy. Sydney August 2017.
15. **Elliott E**, **Bower C**, on behalf of the FASD Research Australia Centre of Research Excellence. Letter of support for the inclusion of alcohol use in pregnancy to the Perinatal National Best Endeavours Data Set. November 2017
16. **Bower C**, **Elliott E**, **Jones H**. Australian Government Department of Health, submission relating to the Clinical Practice Guidelines - Pregnancy Care. 2018

17. **Elliott E, Bower C**, on behalf of the FASD Research Australia Centre of Research Excellence. Response to the Draft Australian Guidelines to reduce health risks from drinking alcohol. February 2018
18. **Bower C, Finlay-Jones A**, Hamilton S, **Kippin N, Mutch R**. Contribution to Telethon Kids Institute's Response to the Coroner's report on the Kimberley Youth Suicides, February 2019
19. **Elliott E, Bower C**, on behalf of the FASD Research Australia Centre of Research Excellence. Submission to the review by Food Standards Australia and New Zealand in relation to the requirements for pregnancy warning labels on all alcohol, 2019
20. **Elliott E, Bower C**, on behalf of the chief investigators and supporting partners of FASD Research Australia Centre of Research Excellence. Submission to the Australian Parliament Senate Inquiry into effective approaches to prevention, diagnosis and support for Fetal Alcohol Spectrum Disorder. 2019
21. **Mutch R, Passmore H**, Pestell C, ... Submission to the Council of Attorneys-General Age of Criminal Responsibility Working Group Review. ... 2020
22. **Bower C, Mutch R, Passmore H, Kippin N**, Hamilton S. Western Australian Supreme Court Equal Justice Bench Book revision, 2020.
23. Thompson A, O'Donnell M, **Kippin N**, & Burrow S. Response to: 'A Therapeutic Approach (Pilot Court) for Protection and Care in the Children's Court of WA, Discussion paper', Court and Tribunal Services, Department of Justice, March 2020.
24. **Halliday J**, Muggli E, **Elliott E, Bower C, Passmore H**. Senate Community Affairs References Committee Inquiry – effective approaches to prevention, diagnosis and support for FASD. Invitation to present at a Senate Hearing. 19 May 2020
25. **Gray L**. Senate Community Affairs References Committee Inquiry – effective approaches to prevention, diagnosis and support for FASD. Invitation to present at a Senate Hearing. 24 May 2020
26. **Mutch R**. Senate Community Affairs References Committee Inquiry – effective approaches to prevention, diagnosis and support for FASD. Invitation to present at a Senate Hearing. 25 May 2020





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