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Midwives and AUDIT-C Intervention

Investigators/Researchers: Tracy Reibel, Roslyn Giglia & Carol Bower

Funder: WA Dept of Health

Project Summary:

Development, implementation and evaluation of a learning package for midwives to use during antenatal care, to promote routine use of AUDIT-C screening tool and brief interventions.

Consumer & Community Involvement:

The first part of the project involved focus groups with women in the community who had current or recent experience of pregnancy care, and their recollections regarding being assessed/screened for alcohol use in pregnancy or while breastfeeding and/or provided with brief intervention (education) about the possible effects of alcohol on the developing/breastfeeding baby.

A consumer representative was included in the Expert Group which provided review and feedback on the draft package prior to its implementation.

Current Status:

- Planned
- In Progress (likely end date February 2017)

Coverage:

- Community or Regional in: Armadale Health Service as a trial site with State-wide rollout planned during 2017.
- State-wide in _____
- National
- International

Outputs (e.g. publications, tools, guidelines):

Learning Package for midwives (provided to the WA DoH for distribution across all public maternity services in WA)

Two journal articles planned: 1] developmental work, results and outcomes; 2] impact evaluation results.

Fetal Alcohol Spectrum Disorder Prevention and Health Promotion Resources

Investigators/Researchers: Professor Sven Silburn, Nicole Hewlett, Heather D’Antoine, Dr Frances Cunningham, Marita Hefler, Dr Christine Armit, Hayley Williams, Rahni Cassad

Funder: Australian Government, Department of Health

Project Summary:

The Australian Government, Department of Health has contracted Menzies to develop and implement a flexible, modular package of FASD Prevention and Health Promotion Resources (FPHPR) to reduce the impacts of FASD on Aboriginal and Torres Strait Islander population. In partnership with National Aboriginal Community Controlled Health Organisation and Telethon Kids Institute, Menzies are using a ‘train-the-trainer’ approach to enable services to make the self-assessments needed in tailoring the resources for local circumstances, particularly community needs and local workforce capacity.

The project expects to achieve the following outcomes:

FASD prevention and health promotion resources are available for NDMBS services developing and implementing community-driven strategies and solutions

Education materials targeting clinicians, families and communities on alcohol, smoking & other causes of adverse pregnancy outcomes are more widely available.

A survey measure is developed for monitoring service provider’s knowledge, awareness and practice regarding risks to pregnancy. This includes women who drink alcohol, and/or smoke, who are either pregnant, of child bearing age, are planning a pregnancy, or sexually active and not using contraception

NDMBSs are able to establish information systems to measure the impact of brief antenatal care interventions for at-risk women undertaken in consultation with organizations engaged by the Department of Health for monitoring Primary Health Care program effectiveness

Partners:

- NACCHO
- Telethon Kids Institute

Consumer & Community Involvement:

Current Status:

- Planned
- In Progress

Coverage:

- Community or Regional in _____
- State-wide in _____
- National
- International

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

Investigators/Researchers: James Fitzpatrick, Maureen Carter, June Oscar, Rochelle Watkins, Carol Bower, Glenn Pearson, Jonathan Carapetis, Mike Daube, Kaashifah Bruce

Funder:

Government of Western Australia Department of Health

Government of Western Australia Department of Asboriginal Affairs

Project Summary:

This program has three initiatives responding to high FASD prevalence rates in the Fitzroy Valley through a whole of community prevention strategy:

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

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

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

Project aims

The objective of the FASD Prevention Strategy is to implement and evaluate a community designed FASD prevention strategy for the Fitzroy Valley and surrounding communities that, if effective, can be translated to other settings in Western Australia.

Consumer & Community Involvement:

- Quarterly meetings with Marulu Leadership Team which includes CEOs from Marninwarntikura Women's Resource Centre, Nindilingarri Cultural Health Service, Kimberley Education Regional Office and Telethon Kids Institute to provide updates on the project and to steer/direct the conduct of the research.
- Initial focus groups in 2015 were held with community members to determine needs and priorities in the area of FASD Prevention and alcohol use in pregnancy, which helped shape the KAP surveys.
- Community researchers and key stakeholders are continually involved with shaping, adapting and translating all project materials including information and consent forms, feedback reports, data collection instruments including KAP surveys and focus group questions. Community researchers and key stakeholders also advise researchers of best times to visit communities and culturally appropriate processes. Examples of this include times when there is 'sorry business' and community are away; a male Senior Research Officer from Telethon Kids was employed for KAP survey data collection to speak with male community members while the female project manager engaged with female community members for the KAP surveys. This was based on cultural advice from the Project Manager's mentor who is a member of the Marulu Leadership Team.
- Community researchers work in a two-way partnership with researchers to connect to community members to the visiting researchers, explain the research to community, gain consent

and translate survey questions to ensure the research is conducted in a culturally appropriate manner while maintaining the scientific rigour of data collected.

Current Status:

- Planned
- In Progress

Coverage:

- Community or Regional in _____
- State-wide in _____
- National
- International

Outputs (e.g. publications, tools, guidelines):

Making FASD history across the Pilbara: An evidence-based prevention intervention

Investigators/Researchers: Dr James Fitzpatrick, Associate Professor Roz Walker, Professor Rhonda Marriott, Mr Glenn Pearson, Professor Sven Silburn, Professor Mike Daube, Gary Kirby, Heather D'Antoine, Nancy Poole, Margaret Abernathy, Martyn Symons

Funder: National Health and Medical Research Council

Project Summary:

Alcohol use in pregnancy has been identified as a major priority by current Australian state and federal governments, health and social services and is an objective of the Pilbara Aboriginal Health Plan 2012-2015. The Pilbara Aboriginal Health Planning Forum have prioritised FASD as an urgent area for action. Prenatal alcohol exposure can cause permanent brain damage, resulting in conditions known as Fetal Alcohol Spectrum Disorders (FASD). Rates of FASD in remote WA Aboriginal communities are among the highest worldwide with as many as one in five children affected.

No comprehensive evidence-based prevention intervention has before been implemented to address alcohol use in pregnancy amongst Aboriginal people in the Pilbara. This project will be the first in Australia to systematically implement and evaluate the evidence-based, holistic and woman-centered 'Four Part Model of Prevention' framework. Systematic reporting of alcohol use in pregnancy is not yet occurring in the Pilbara region and as such the extent of the issue, and prevalence of FASD is not known. However, research shows that the West Pilbara region has a per capita alcohol consumption that is more than twice that of the state average.

Other 'societal risk factors' are evident in the region, including its geographic remoteness, high-risk drinking patterns, and a high proportion of Indigenous people living with the legacy and secondary effects of social deprivation, subjugation and forced removal. Anecdotal evidence suggests that the impacts of FASD are now widespread in the Pilbara and there is an urgent need for a comprehensive prevention intervention that works and prevents more children being born affected. This project will enable the development and dissemination of a reproducible process to enable an evidence-based model of FASD prevention to be embedded in health policy and practices servicing all women in Australia.

Consumer & Community Involvement:

A community-based participatory action research methodology (CPAR) is being employed in the project to:

- empower community partners, leaders and community members in designing, implementing and evaluating the intervention.
- provide a framework for engaging and working with community and service providers and through existing community networks and processes.
- prioritise Indigenous knowledge through partnerships with Aboriginal-led and focused health organisations.
- ensure that Aboriginal participants, including women and families and communities impacted by FASD are engaged in all phases of the research
- build the capacity of Aboriginal Medical Service's staff to deliver culturally responsive services to maximise community engagement.

Community Reference Groups

These CRGs and existing stakeholders are also involved in designing, implementing and evaluating the local-based interventions, and will play a critical role in engaging with community members in the three sites and surrounding (remote) communities.

A Community Reference Group (CRG) has already been established in Hedland and has developed terms of reference to reflect the values and ethics of the NHMRC, Keeping Research on Track which provide clear guidelines for involving Aboriginal community members and organisations in health research.

Community Reference groups are also being established in Roebourne and Newman, with the membership building on previous research studies.

Current Status:

- Planned
- In Progress

Coverage:

- Community or Regional in _____
- State-wide in _____
- National
- International

Outputs (e.g. publications, tools, guidelines):

Hedland FASD Project

Investigators/Researchers: Glenn Pearson, James Fitzpatrick, Roz Walker

Funder: BHP Billiton

Project Summary:

This 5-year project is the first of a twenty year research program aimed at reducing the prevalence and impact of FASD in the Pilbara taking a regional approach but focusing in particular on Port Hedland, Warralong and Yandeyarra. The work will be structured to intentionally foster genuine community leadership (particularly women's leadership) and ownership of issues related to alcohol and substance use in pregnancy and increase the resilience and empowerment of local families.

Following on from Telethon Kids Institute's previous work and recognising ongoing local action, the Hedland FASD Project will work with Wirraka Maya and the Hedland FASD Network and others to support local efforts in prevention, diagnosis, treatment, family support, capacity building and policy advocacy through identifying needs, evidence-based practices, and evaluating specific strategies, programs and activities.

Critical focus will also be on supporting and measuring the effectiveness of programs that build the knowledge and capacity of families with children with FASD, and increasing their confidence in engaging with services and establishing/determining their own initiatives.

Consumer & Community Involvement:

A community-based participatory action research methodology (CPAR) is being employed in the project to:

- empower community partners, leaders and community members in designing, implementing and evaluating the intervention.
- provide a framework for engaging and working with community and service providers and through existing community networks and processes.
- prioritise Indigenous knowledge through partnerships with Aboriginal-led and focused health organisations.
- ensure that Aboriginal participants, including women and families and communities impacted by FASD are engaged in all phases of the research
- build the capacity of Aboriginal Medical Service's staff to deliver culturally responsive services to maximise community engagement.

Current Status:

- Planned
- In Progress

Coverage:

- Community or Regional in _____
- State-wide in _____
- National
- International

Asking QUestions about Alcohol in pregnancy (AQUA): a longitudinal cohort study of fetal effects of low to moderate alcohol exposure

Investigators/Researchers

Chief Investigators

Prof Jane Halliday- NHMRC Senior Research Fellow, Public Health Genetics, Murdoch Childrens Research Institute

Dr Colleen O'Leary- NHMRC Postdoctoral Research Fellow, National Drug Research Institute, Curtin University, Perth

Prof Della Forster- Research Fellow, Mother and Child Health Research, La Trobe University, Melbourne

A/Prof Susan Donath- Research Fellow, Clinical Epidemiology & Biostatistics Unit, Murdoch Childrens Research Institute

Prof Peter Anderson- NHMRC Senior Research Fellow, Vic. Infant Brain Studies (ViBeS), Murdoch Childrens Research Institute

Dr Sharon Lewis- Senior Research Officer, Public Health Genetics, Murdoch Childrens Research Institute

Prof Elizabeth Elliott- Consultant Paediatrician, The Children's Hospital at Westmead, Sydney

A/Prof Cate Nagle- Senior Lecturer, Faculty of Health, Medicine, Nursing & Behaviour, Deakin University, Geelong

A/Prof Jeffrey Craig- Group Leader, Developmental Epigenetics, Murdoch Childrens Research Institute

Ms Evi Muggli- Senior Research Officer, Public Health Genetics, Murdoch Childrens Research Institute

Associate Investigators

Prof Tony Penington- Jigsaw Foundation Chair, Dept of Plastic & Maxillofacial Surgery, University of Melbourne Academic Centre, Incorporating Department of Paediatrics

Dr Justine Ellis- Research Fellow, Environmental & Genetic Epidemiology Research, Murdoch Childrens Research Institute

Ms Joyce Cleary- Manager, Outcomes for Children and Young People, Department of Education and Early Childhood Development

Dr Susan White- Clinical Geneticist, Genetic Health Services Victoria, Melbourne

Dr Richard Saffery- Group Leader, Cancer & Disease Epigenetics, Murdoch Childrens Research Institute

Funder

NHMRC funded research project (2011-2014)

Other funding received from: VicHealth, McCusker Charitable Foundation, Financial Markets for Children Foundation, Murdoch Childrens Research Institute

Project Summary

The research collected detailed information about alcohol consumption in pregnancy from 1570 pregnant women from low risk antenatal clinics (2011-2012) to assess the effect of different doses of alcohol and other associated influences on the unborn child.

The specific aim of this project is to:

- Examine the effects of dose, pattern and timing of prenatal alcohol on specific physical and neurobehavioural outcomes in infants and young children, taking into account pertinent influences that may help understand the heterogeneous nature of pregnancy alcohol exposure.

Specifically, a key objective has been to investigate whether maternal DNA variations, psychosocial, demographic, specific dietary factors or other lifestyle and environmental influences can affect the impact of low to moderate quantities of alcohol in pregnancy.

Consumer & Community Involvement

Only as participants

Current Status:

- Planned
- In Progress

Coverage:

- Community or Regional in ___metropolitan antenatal clinics_____
- State-wide in ___Victoria___
- National
- International

Outputs (e.g. publications, tools, guidelines):

"Did you ever drink more?" A detailed description of pregnant women's drinking patterns. Muggli E, O'Leary C, Donath S, Orsini F, Forster D, Anderson PJ, et al. BMC Public Health. 2016;16:683.

Spatially dense morphometrics of craniofacial sexual dimorphism in 1-year-olds. Matthews H, Penington T, Saey I, Halliday J, Muggli E, Claes P. J Anat. 2016.

Study protocol: Asking QUestions about Alcohol in pregnancy (AQUA): a longitudinal cohort study of fetal effects of low to moderate alcohol exposure. Muggli E, O'Leary C, Forster D, Anderson P, Lewis S, Nagle C, Craig JM, Donath S, Elliott E, Halliday J. BMC Pregnancy Childbirth. 2014 Sep 3;14:302. doi: 10.1186/1471-2393-14-302.

Increasing accurate self-report in surveys of pregnancy alcohol use. Muggli E, Cook B, O'Leary C, Forster D, Halliday J. Midwifery. 2015 Mar;31(3):e23-8. doi: 10.1016/j.midw.2014.11.003. Epub 2014 Nov 13.

Preventing harm from alcohol: Asking questions about alcohol in pregnancy (AQUA study). A VicHealth Fact sheet. Published Jan 2012 <https://www.vichealth.vic.gov.au/media-and-resources/publications/asking-questions-about-alcohol-in-pregnancy>

Alcohol in pregnancy: What questions should we be asking? A report to the Commonwealth Department of Health and Ageing. Published March 2010
<http://webarchive.nla.gov.au/gov/20140802013746/http://www.alcohol.gov.au/internet/alcohol/publishing.nsf/Content/alc-preg-qu-doc>

Antenatal Care Addressing Maternal Alcohol Consumption During Pregnancy

Investigators/Researchers: Wiggers J, Elliott E, Dunlop A

Funder: NHMRC Partnership Grant # ; Hunter New England Local Health District; Foundation for Alcohol Research and Education

Project Summary:

Objective: To determine the effectiveness of a practice change intervention in increasing the provision of recommended antenatal care regarding maternal alcohol consumption during pregnancy (Assess, Brief Advice, Refer)

Method: Randomised stepped-wedge controlled trial with intervention delivered in random sequence to 3 public antenatal services in Hunter New England Local Health District (Greater Newcastle, Lower Mid-North Coast and Peel Sectors)

Primary outcome: Provision of care consistent with recommended care at 3 time periods (booking in visit, 28 weeks and 36 weeks) as indicated by pregnant women who attend the services. Repeated, cross-sectional measurement of the outcome measure will occur pre-intervention and at these time points over a 30 month period using a CATI survey in a random sample of women.

Secondary outcomes: Clinician knowledge, skills, practice regarding asking and advising about alcohol, recording data, providing advice and referring to specialist services.

Rationale:

- No known safe level of alcohol consumption at any time in pregnancy (NHMRC guidelines)
- Adverse outcomes for the fetus include FASD, premature birth, low birth weight, birth defects, developmental problems, long-term impacts on adult health/wellbeing
- 28%-72% of Australian women report consuming alcohol during pregnancy (47%, NDSHS 2013)
- 4%-18% pregnant women report consuming alcohol at risky levels
- International/national/state clinical guidelines recommend health professionals: assess alcohol consumption of all pregnant women; provide care as appropriate; provide brief interventions aimed at reducing low alcohol consumption; more intensive counselling/treatment for women with risky drinking behaviours/alcohol use disorders

Context

National

- Commonwealth Govt. FASD strategy and program funding
- FARE 'Women Want to Know' resources and professional training

NSW Ministry of Health

- Funding for Drug and Alcohol services including additional support for pregnant women
- Get Healthy (Alcohol) Telephone counselling service
- E-Maternity replacing Obstetrix by end 2016
- NSW Health resources for Aboriginal clients/services

Implementation Sites

- All antenatal services operating in the Greater Newcastle Sector (John Hunter Hospital, Belmont Hospital, Outreach Clinics and Birra Li Aboriginal Medical Health Service)

- Lower Mid North Coast Sector (Manning Hospital, Forster Outreach Clinic and AMIHS)
- Peel Sector (including Tamworth Hospital, Tamworth AMIHS, Gunnedah Hospital, Gunnedah AMIHS, Quirindi AMIHS)

Quality Improvement Approach

1. *Standardised Model of care*
2. *Evidence-based practice change strategies*
 - engage clinical leaders/networks
 - engage of antenatal staff
 - enable systems to prompt assessment, brief advice and referral (eMaternity)
 - develop clinician training/resources
 - monitor care delivery and feedback
 - Clinical Midwife Educator to support implementation of model of care

Evaluation

- *Design*: practice change delivered in a random sequence across 3 sites
- *Primary outcome*: provision of care consistent with recommended care at 3 time periods (booking in visit, 28 weeks and 36 weeks gestation)
- *Secondary outcomes*: alcohol consumption, acceptability of care to women/providers

Partners

- HNELHD Clinical Services Nursing & Midwifery
- NSW Office of Preventive Health
- HNELHD Drug & Alcohol Services
- HNELHD Population Health
- FARE
- NHRMC

Consumer & Community Involvement:

Current Status:

- Planned
- In Progress

Coverage:

- Community or Regional in _____
- State-wide in _____
- National
- International

Health and Pregnancy Survey

Investigators/Researchers: P Wyndow, Tanyana Jackiewicz, Ali Radomiljac, Carol Molster, Ali C Bower

Funder: WA Department of Health

Project Summary: The aims were to test the feasibility of establishing routine surveillance to fill gaps in routinely available information on pregnancy risk factors such as folate intake and prenatal alcohol exposure. Between August- October, 2015, 1268 women aged over 15 years, who had given birth in the preceding April- June participated in this survey. The sample was drawn from the State's Birth Notifications Dataset. Questions on alcohol use before and in early pregnancy were asked using AUDIT-C.

Consumer & Community Involvement: consumer involvement in design and development.

Current Status:

- Planned
- In Progress -Data collection and initial analyses completed; paper writing in progress.

Coverage:

- Community or Regional in _____
- State-wide in WA
- National
- International

Outputs (e.g. publications, tools, guidelines):

Report

Paper in preparation on alcohol use before and in early pregnancy.

The challenge of seeking national data on fetal alcohol spectrum disorder in Australia: prospective national case identification through The Australian Paediatric Surveillance Unit.

Investigators/Researchers: Zimmet M ^{1,2} Phu A ² Zurynski Y ^{1,2} Watkins R ³ Bower C ³ Elliott E ^{1,2} APSU Project Reference Group (K. Edwards, A. Wilkins, Sheldon D, Fitzpatrick J)

Funder: Australian Government Department of Health

Project Summary:

Background: The national incidence and epidemiology of Fetal Alcohol Spectrum Disorders (FASD) in Australia is unknown.

Method: Prospective active national case-finding of children under 15 years from December 2014, with monthly reporting of newly diagnosed cases by paediatricians reporting according to Australian diagnostic criteria¹.

Results: Surveillance is ongoing. Between December 2014 and August 2016 there were 97 notifications to the APSU for which 66 questionnaires were returned. Of these 9 were errors (did not fulfil case definition) and 9 were duplicate reports). Of the 48 incident cases for whom information was available 70% were classified as Fetal Alcohol Syndrome (FAS) or partial FAS (PFAS), and 30% Neurodevelopmental Disorder-Alcohol Exposed (ND-AE). The other cases are not yet classified. Of the confirmed cases 75% were male and most had psychology or speech pathology assessments. Nearly as many children were first suspected of having a FASD by their parent or caregiver as their paediatrician, suggesting increasing community awareness. 00% of children came from FASD clinics in NSW and Queensland.

Compared to case surveillance for FAS/PFAS in 2001-2004², the recently reported FASD cases were diagnosed later (mean age 6 vs 3 years), were more likely to be in foster or adoptive care (63% vs 38%) than with their biological parents and were predominantly of Caucasian (58%) rather than Indigenous heritage (37%).

Conclusion: Under-ascertainment is likely for some states/territories. The predominance of FAS and PFAS versus ND-AE may reflect limited awareness of Australian of the full spectrum of FASD and the prior absence of diagnostic guidelines rather than being a true representation of their differing incidence. Ongoing case surveillance over the next two years using modified FASD criteria and the recently published Australian Guide to the Diagnosis of FASD should provide a more accurate picture of FASD nationally.

Partners

1Discipline of Paediatrics & Child Health, Sydney Medical School, The University of Sydney c/o the *Lililwan Project*, The Children's Hospital at Westmead, NSW 2145, Australia;

2The George Institute for Global Health, Sydney Medical School, The University of Sydney, Sydney, NSW 2050, Australia;

3Department of Psychiatry & Behavioral Sciences, University of Washington School of Medicine, Seattle Children's Research Institute, Seattle, WA 98121, USA;

4 Telethon Kids Institute, Perth, WA 6008, Australia;

5Fitzroy Valley District High School, Fitzroy Crossing, WA 6765, Australia;

6Marninwarntikura Women's Resource Centre, Fitzroy Crossing, WA 6765, Australia;

7Nindilingarri Cultural Health Services, Fitzroy Crossing, WA 6765, Australia;

8The Sydney Children’s Hospital Networks (Westmead), Westmead NSW 2145, Australia;
9The Australian Paediatric Surveillance Unit, Kids’ Research Institute, Westmead NSW 2145, Australia.

Consumer & Community Involvement:

Current Status:

- Planned
- In Progress

Coverage:

- Community or Regional in _____
- State-wide in _____
- National
- International

Outputs (e.g. publications, tools, guidelines):

A feasibility study of screening, diagnosis and workforce development to improve management of FASD within the WA criminal justice system

Investigators/Researchers: CIs: Carol Bower, Rochelle Watkins, Raewyn Mutch, Rhonda Marriott; research team: Noni Walker, Jacinta Freeman, Natalie Kippin, Bernadette Safe, Carmela Pestell, Carmen Condon; and other CRE investigators-Jonathan Carapetis, James Fitzpatrick, Roslyn Giglia, Steve Zubrick

Funder: NHMRC

Project Summary: Young people 10-17 yoa and sentenced at Banksia Hill Detention Centre (the only juvenile detention facility in WA) are invited to participate in the study. Those assenting and with consent of their guardian, undergo clinical assessment with a paediatrician, neuropsychologist, occupational therapist and speech pathologist. Feedback is provided to the young person and guardian and a report outlining strengths and difficulties and a management is provided to the guardian. Assessments will conclude at the end of 2016. In parallel, staff and young people at the Centre are participating in surveys to assist in production of resources for workforce development. At the request of the Department of Corrective Services, the Department of Child Protection and Family Services and the Police Department, the surveys and development of resources will be extended to relevant staff in their organisations.

Consumer & Community Involvement: Active Consumer and Community Reference Group

Current Status:

- Planned
- In Progress

Coverage:

- Community or Regional in _____
- State-wide in WA
- National
- International

Outputs (e.g. publications, tools, guidelines):

Protocol paper published. Passmore H et al. Study protocol for screening and diagnosis of fetal alcohol spectrum disorders (FASD) among young people sentenced to detention in Western Australia. *BMJ Open* 2016;6:e012184 doi:10.1136/bmjopen-2016-012184.

Behaviour in children with FASD in Remote Australian Communities.

Investigators/Researchers: Tracey W Tsang; Heather Carmichael Olson; Jane Latimer; James Fitzpatrick; Marmingee Hand; June Oscar; Maureen Carter; Elizabeth J Elliott.

Funder: NHMRC; Project Grant #:1024474); the Australian Government Department of Health and Ageing; the Australian Government Department of Families, Housing, Community Services and Indigenous Affairs

Project Summary:

OBJECTIVES: To document behaviour in children residing in very remote Western Australian communities as rated by parent/caregivers and teachers. We hypothesized that children with fetal alcohol spectrum disorders (FASD) would have higher rates of problematic behaviour than children without FASD.

METHODS: The Child Behaviour Checklist (CBCL; n=97), and Teacher Report Form (TRF; n=106) were used in this population-based study. Raw scores, proportions scoring within "Normal/Borderline/Clinical" ranges and frequencies of Critical items were determined. Mann-Whitney U and Chi-square tests were used for between-group comparisons.

RESULTS: Children were aged 7.5-9.6 years and 19% had a FASD. Academic performance was commonly rated in the "Borderline/Clinical" range (73%). Teacher-rated scores were poorer in the FASD group on 15 scales encompassing Total and Internalizing problems, Adaptive function, Academic performance, Attention, Withdrawn/depressed, Social problems, Post-traumatic stress, Thought problems, and Sluggish cognitive tempo ($p<0.05$). More children in the FASD group had scores in the "Borderline/Clinical" range on 11 TRF scales ($p<0.05$). "Attacks others" was the most prevalent Critical item endorsed by teachers for the total cohort (22%). "Speaking about suicide" was endorsed by teachers more often in the FASD group (14%) than the Non-FASD group (1%; $p=0.03$). There were no significant differences between groups in parent-reported CBCL scores after adjustment for multiple comparison testing.

CONCLUSIONS: Children with FASD had more teacher-reported behavioral impairment. In remote Australian communities, academic performance is poor. Support is urgently needed to help teachers and parents manage behavioral challenges, as is access to adequate mental health services.

1Discipline of Paediatrics & Child Health, Sydney Medical School, The University of Sydney c/o the *Lililwan Project*, The Children's Hospital at Westmead, NSW 2145, Australia;

2The George Institute for Global Health, Sydney Medical School, The University of Sydney, Sydney, NSW 2050, Australia;

3Department of Psychiatry & Behavioral Sciences, University of Washington School of Medicine, Seattle Children's Research Institute, Seattle, WA 98121, USA;

4 Telethon Kids Institute, Perth, WA 6008, Australia;

5Fitzroy Valley District High School, Fitzroy Crossing, WA 6765, Australia;

6Marninwarntikura Women's Resource Centre, Fitzroy Crossing, WA 6765, Australia;

7Nindilingarri Cultural Health Services, Fitzroy Crossing, WA 6765, Australia;

8The Sydney Children's Hospital Networks (Westmead), Westmead NSW 2145, Australia;

9The Australian Paediatric Surveillance Unit, Kids' Research Institute, Westmead NSW 2145, Australia.

Current Status:

- Planned
- In Progress

Coverage:

- Community or Regional in _____
- State-wide in _____
- National
- International

Outputs (e.g. publications, tools, guidelines):

Building capacity for FASD screening and diagnosis through a prevalence study: The Cherbourg project.

Investigators/Researchers: Elliott, E., Hayes, L, Barrett, J., Stewart, C., Fisher, T., & Andersson E.

Funder: Australian Government Department of Health (National Health and Medical Research Council)

Project Summary

Background: The Aboriginal leaders in Queensland's Cherbourg community have been long concerned with the adverse effects of alcohol in their community and identified Fetal Alcohol Spectrum Disorders as a priority area. They invited researchers from Sydney to initiate a capacity building, screening and prevalence project.

The project aims to (i) increase the community's awareness and education about the risks of alcohol use during pregnancy, (ii) develop a screening tool for FASD identification, facilitating early intervention and management of affected children; and (iii) compile population prevalence data to further inform the development and improvement of health services and prevention programs.

Method: The Cherbourg project has two primary components: i) to improve capacity for screening and management of FASD and ii) improve community awareness iii) population-based active case ascertainment study of the prevalence of FASD

Community capacity building will be achieved through education and training workshops for health professionals and teachers in combination with the development and implementation of community awareness campaigns through local radio and print materials.

Screening will take place in two phases: Phase I involves screening children aged seven to nine years (estimated 150 children) for physical features (growth deficits, microcephaly, facial features), neurobehavioral problems and mothers' alcohol use during pregnancy. In phase II those children who screened positive in phase I, will undergo an assessment by a psychologist and if required referred to establish a diagnosis of FASD.

Finally, population data of children born between 2006 and 2008 (inclusive) will be analysed to ascertain the prevalence alcohol use during pregnancy and birth outcomes.

Results: Screening and capacity building is ongoing. The data of 158 births in the Cherbourg community, for years February 2006 and December 2008, have been collected. Within this cohort 14% of mothers reported using alcohol while pregnant, 17% of the babies were born preterm and, 15% were classified as having a low birth weight.

Conclusion: For the community, the ongoing project will provide culturally-relevant tools, skills and knowledge to screen, diagnose and manage FASD. Further this study will provide population-based data on the prevalence and epidemiology of FASD to help inform the development of prevention programs, improved health services and raise community awareness of the potential harms of alcohol use during pregnancy.

Partners

1. Discipline of Paediatrics & Child Health, Sydney Medical School, The University of Sydney, NSW, 2006, Australia
2. The Australian Paediatric Surveillance Unit, Kids' Research Institute, Westmead NSW 2145, Australia.
3. The Cherbourg Health Action Group, Cherbourg, QLD, 4605, Australia
4. The Cherbourg Aboriginal Shire Council, Cherbourg, QLD, 4605, Australia

Consumer & Community Involvement:

In 2013, the Cherbourg community identified FASD as a priority health area and initiated a partnership between the Cherbourg Community Council, Cherbourg Community Health Service (QLD), the Health Action group, Ms Lorian Hayes (an Aboriginal researcher with close ties to the Cherbourg community) and Professor Elliott. Extensive community involvement will help increase the longevity of the projects' benefits especially as it was initiated and will be driven by the Aboriginal people living in the Cherbourg community.

Current Status:

- Planned
- In Progress

Coverage:

- Community or Regional in: Cherbourg, Regional Queensland, Australia
- State-wide in _____
- National
- International

Outputs (e.g. publications, tools, guidelines):

The Alert Program® Study: an evidence based program to improve self-regulation and executive functioning in primary school aged children with and without FASD in the Fitzroy Valley

Investigators/Researchers: Dr James Fitzpatrick, Professor Karen Edmond, Professor Jane Latimer, Professor Branko Celler, Dr Trevor Mazzucchelli, Mr Glenn Pearson, Dr Heather Carmichael Olsen, Dr Rochelle Watkins, Professor John Boulton, Ms Maureen Carter

Funder: National Health and Medical Research Council

Project Summary

While lots of children going to school in the Fitzroy Valley do well, some kids find school hard. They may have problems controlling their actions and mood which can affect their ability to learn in the classroom. This can be a big problem for children who have FASD. Primary schools in the Fitzroy Valley are going to teach the Alert Program® in the classroom so students can learn to control their actions and mood. We call these skills "self-regulation".

We want to find out if teaching them the Alert Program® will help improve their learning and behaviour skills. This might help them to get better at remembering things, solving problems, paying attention, planning and organising themselves. These "executive functioning" skills are important for children to engage with the demands of school life.

The Alert Program® teaches kids that their body is like a car engine. It can go into high speed, it can go into low speed and it can go into just right speed. The program teaches kids different ways they can change their engine speeds (level of alertness) by using 'tools' for their mouth, body, ear, eyes and hands to help them self-regulate and therefore learn more easily in the classroom. For example, a student could be feeling hyped up when they enter the classroom after recess (high gear). The teacher or Aboriginal and Islander Education Officer might teach the student to do some chair push-ups (heavy work) to shift their engine (level of alertness) into just right gear so they can concentrate on their spelling task when sitting at their desk.

Consumer & Community Involvement:

The employment of Aboriginal community members as community researchers on this project has been fundamental to researchers and community members developing shared understanding and expectations for culturally and contextually sensitive research practices and processes. Locally employed community researchers have provided language and cultural support to both families participating in the research and to non-Aboriginal research staff. This two way research partnership has been central to the project being accepted by the community and to maximising participation from schools and families. Additional funding has been received to enable locally based Aboriginal research staff to complete a Certificate II in Community Health Research between 2016 and 2017. By doing so, community researchers working on this project will develop the research skills to complement their existing expertise and knowledge which will enable them to seek employment across other research projects taking place in the Fitzroy Valley. This has already occurred in 2015

whereby Alert Program® Community Researchers were able to be employed on the Fitzroy Valley FASD Prevention research project that is also taking place through the Telethon Kids Institute.

Current Status:

- Planned
- In Progress

Coverage:

- Community or Regional in: Cherbourg, Regional Queensland, Australia
- State-wide in _____
- National
- International

Outputs (e.g. publications, tools, guidelines):

The Picture Talk Project: Starting a Conversation with Community Leaders on Research with Remote Aboriginal Communities of Australia

Investigators: Fitzpatrick E^{1,2*}, Macdonald G³, Martiniuk A^{4,5,6}, D'Antoine H⁷, Oscar J^{8,9}, Carter M¹⁰, Lawford T¹¹, Elliott E^{1,2,4,5}

Funder: Avant; Drysdale Trust

Project Summary:

Introduction:

Researchers are required to seek consent from Indigenous communities prior to conducting research but there is inadequate information about how Indigenous people understand and become fully engaged with the consent process. Few studies have evaluated the preferences or understanding of the consent process for research with Indigenous populations. Lack of informed consent can impact on research projects and their findings.

Methods:

The Picture Talk Project was initiated with senior Aboriginal leaders of the Fitzroy Valley community of Western Australia. Aboriginal people were interviewed about their understanding and experiences of research and consent processes. Data were analysed using NVivo10 software using an integrated method of inductive and deductive coding and based in grounded theory. Local Aboriginal interpreters validated coding. Major themes were defined and supporting quotes sourced.

Results:

Interviews with Aboriginal leaders (n=20) were conducted by EF and facilitated by a local Aboriginal Community Navigator who could interpret if necessary and provide cultural guidance. Participants were from all five major local language groups of the Fitzroy Valley; aged 31 years and above; and half were male. Themes emerging from these discussions included Aboriginal peoples' Understanding of Research – finding knowledge; the need for Respect for Aboriginal people, including working on country and being flexible with time; the imperative to Working together with good communication; the value of Reciprocity – two-way learning; and Reaching consent.

Conclusion:

There is much to be learned about how research with remote Aboriginal communities should be conducted in a way that is culturally respectful and meaningful for participants. We identify Aboriginal leaders' understanding and experience of research and the elements that are important to Aboriginal people in the process of community consultation and seeking consent for research.

Partners:

1. Discipline of Paediatrics and Child Health, Sydney Medical School, University of Sydney, Sydney, NSW, Australia. 2. The Sydney Children's Hospital Network, Sydney, NSW, Australia

3. Department of Anthropology, University of Sydney, Sydney, NSW, Australia. 4. Sydney Medical School, University of Sydney, Sydney, NSW, Australia. 5. The George Institute for Global Health, Sydney, NSW, Australia. 6. Dalla Lana School of Public Health, University of Toronto, Toronto, Canada. 7. Menzies School of Health Research, Darwin, NT, Australia. 8. Marninwarntikura Women's Resource Centre, Fitzroy Crossing, WA, Australia; 9. Nulungu Research Institute, The University of Notre Dame, Broome, Australia. 10. Nindilingarri Cultural Health Services, Fitzroy Crossing, WA, Australia. 11. Kimberley Aboriginal Law and Culture Centre, Fitzroy Crossing, Australia

Digital assessment of the fetal alcohol syndrome facial phenotype: Reliability and agreement

Investigators/Researchers: Tracey W. Tsang^{1,2}, Zoe Laing-Aiken¹, Jane Latimer², James Fitzpatrick^{1,2,3}, June Oscar⁴, Maureen Carter⁵, Elizabeth J Elliot^{1,2,6,7}

Funder: NHMRC Project Grant #

Project Summary:

Background

Superior accuracy has been demonstrated in digital assessment of fetal alcohol syndrome (FAS) facial dysmorphology compared to direct measurements. Digital methods have not been investigated in Aboriginal cohorts, in which some have high levels of maternal alcohol use.

Objective To digitally analyse FAS facial features in an Aboriginal child cohort to assess the: i) intra- and inter-rater reliability; ii) agreement when different race charts were applied; and iii) agreement with clinician measures.

Methods Historical photographs and data were sourced from the *Lililwan Project* for 106 Aboriginal children (aged 7.4-9.6 years). Thirteen had a diagnosis of FAS/partial FAS and 58% were prenatally exposed to alcohol. Categorical palpebral fissure length, lip and philtrum ratings, and 4-Digit Diagnostic Code Rank for the face (Severity) were recorded. Intra- and inter-rater reliability of digital ratings was examined in two assessors; and agreement between African-American and Caucasian charts, and digital and clinician ratings was assessed using weighted kappa. Photographs were analysed using FAS Facial Photographic Analysis Software.

Results Reliability was substantial within (kappa range: 0.7-1.0) and between assessors (kappa range: 0.64-0.89). Application of different race charts yielded large differences in numbers having “Absent/Mild” (African-American: 67%; Caucasian: 100%) and “Moderate/Severe” (African-American: 33%; Caucasian: 0%) ratings of Severity (kappa: 0.15 [95%CI: 0.07-0.23]). Clinician and digital ratings showed only moderate agreement (kappa range: 0.47-0.58).

Conclusion The software demonstrated good reliability in our cohort. Further comparisons of available assessment methods and collation of Australian Aboriginal normative data are needed to ensure accurate diagnosis in this high-risk population.

Partners:

- 1) Discipline of Paediatrics and Child Health, Sydney Medical School, The University of Sydney c/o The *Lililwan Project*, The Children’s Hospital at Westmead, Westmead NSW 2145, Australia;
- 2) The George Institute for Global Health, Sydney Medical School, The University of Sydney, Sydney NSW 2050, Australia;
- 3) The Telethon Institute of Child Health Research, West Perth, WA 6872, Australia;
- 4) Marninwarntikura Women’s Resource Centre, Fitzroy Crossing, WA 6765, Australia;
- 5) Nindilingarri Cultural Health Services, Fitzroy Crossing, WA 6765, Australia;
- 6) The Sydney Children’s Hospital Networks (Westmead), Westmead, NSW 2145, Australia;

Consumer & Community Involvement:

Current Status:

- Planned
- In Progress

Perinatal maternal alcohol consumption and methylation of the dopamine receptor DRD4 in the offspring: the Triple B study

Investigators/Researchers: Peter D. Fransquet^{1,2}, Delyse Hutchinson^{1,2,3,4}, Craig A. Olsson^{1,2,4}, Judy Wilson³, Steve Allsop⁵, Jake Najman⁶, Elizabeth Elliott⁷, Richard P. Mattick³, Richard Saffery^{1,2}, *Joanne Ryan^{1,2,8,9} On behalf of the Triple B Research Consortium[†]

Funder: NHMRC; Project Grant #:)

Project Summary:

Background: Maternal alcohol use during the prenatal and perinatal periods is a major public health issue and may be associated with fetal alcohol spectrum disorder (FASD) and a range of adverse health outcomes in the progeny. The specific underlying molecular mechanisms associated with alcohol harm remain unknown but may include epigenetic disruption of gene activity during fetal development. It is known that alcohol directly activates the neurotransmitter dopamine, which plays an essential role in neurodevelopment.

Objective: To investigate whether antenatal and early postnatal alcohol consumption are associated with differential methylation in the dopamine receptor *DRD4* promoter in infants ($n=844$).

Method: Data were drawn from a large, population based pregnancy cohort (the Triple B study) which collected detailed information on maternal alcohol consumption in each trimester of pregnancy and in the early postpartum period. DNA was extracted from infant buccal swabs collected at 8-weeks of age. *DRD4* promoter DNA methylation was analysed by Sequenom MassARRAY.

Results: Of the 884 mothers, the mean age (SD) was 32.6(5) years; 55% were Australian born; 67% had completed tertiary education; 46% were employed full time; and 93% were living with their partner. Of mothers, 68.8% drank at any time during pregnancy; 62.1% during the first trimester; 30.9% in trimester two, 31.3% in trimester three and 61.7% at 8 weeks post-partum. After adjustment for confounding and for multiple testing, no strong evidence was found for an association between alcohol consumption during pregnancy and infant *DRD4* methylation at 8-weeks postpartum. However, maternal alcohol consumption assessed contemporaneously at 8-weeks postpartum was associated with increased methylation at 13 of the 19 CpG units examined ($p<0.05$). The largest difference ($\Delta+3.20\%$, 95% CI:1.66,4.75%, $p=0.0001$) was observed at CpG.6.

Conclusion: The association between methylation and alcohol use was strongest in women who breastfeed, suggesting the possibility of a direct effect of alcohol exposure via breast milk. The findings of this study could influence public health guidelines around alcohol consumption for breastfeeding mothers, however further research is required to confirm these novel findings.

Partners

1Murdoch Childrens Research Institute, Parkville, Australia.

2University of Melbourne, Department of Paediatrics, Royal Children's Hospital, Melbourne, Australia

3National Drug and Alcohol Research Centre, University of New South Wales, Sydney, Australia

4Deakin University, Centre for Social and Early Emotional Development, School of Psychology, Faculty of Health, Melbourne, Australia

5National Drug Research Institute, Curtin University, Perth, Australia

6Queensland Alcohol and Drug Research and Education Centre, Schools of Public Health and Social Science, University of Queensland, Australia

7Discipline of Paediatrics and Child Health, The University of Sydney, The Children's Hospital at Westmead, Sydney, Australia

8Inserm U1061, Montpellier, France

9Monash University, School of Public Health & Preventive Medicine, Prahran, Australia

Consumer & Community Involvement:

Current Status:

Planned

In Progress

Coverage:

Community or Regional in _____

State-wide in _____

National

International

Outputs (e.g. publications, tools, guidelines):

Jandu Yandi U “For All Families”: Empowering Aboriginal Families in the Fitzroy Valley in Positive Parenting

Investigators/Researchers: Elliott EJ, Oscar J, Carter E, Thomas S, Mc Ilduff C, Einfield S, Turner K

Funder: NHMRC Project Grant #

Project Summary:

Background: During the population-based (Lililwan) study of Fetal Alcohol Spectrum Disorder (FASD) prevalence in the remote communities of the Fitzroy Valley in Western Australia, families and teachers reported challenging child behaviours as a major problem for all children. In response, Marninwarntikura Women’s Resource Centre initiated a partnership with clinician-researchers to bring the Positive Parenting Program (Triple P) to the Valley. In other Australian Aboriginal communities Triple P has been found to be effective for increasing carer confidence and parenting skills resulting in improved child behaviour.

Methods:

Consultation: In October 2013 and April 2016, workshops were held in Broome and Fitzroy Crossing with the local Advisory Group to ensure community understanding and consent for the program. The group chose to implement Triple P level 4, small group training sessions which includes all 17 core parenting skills and an additional 7 skills relevant to children with complex needs. This was based on recognition of the complexities of family life in the Valley, similar to those in other remote communities.

Training and accreditation: With the imperative to building community capacity, 20 women (18 residents, 12 Aboriginal, from 10 local organizations) were trained over 4 days in July 2016 by an Aboriginal implementation consultant and a trainer with experience in diverse Aboriginal communities. Participants included school and pre-school teachers, psychologists and workers in domestic violence, women’s support, health and social services groups. Following the training weekly support, consultation and team-building with 18 local participants was provided by CMI, a behavioural psychologist who has used Triple-P in all Indigenous communities in Canada and Australia. After an additional 4 day’s training in August 2016, including Stepping Stones module for managing children with developmental problems, all participants were accredited as “Parent Coaches”. According to Triple-P this is the first time that all trainees in an Aboriginal program have achieved accreditation.

Evaluation: includes parenting skills, confidence; a measure of empowerment; attainment of behaviour goals

Training and accreditation provided a safe space for women to share past historical trauma and parenting experiences and reflect on how they have impacted their own parenting skills. Feedback from trainees is excellent. One Parent Coach wrote:

‘...I’m glad we’ve been taught the Positive Parenting Way; I can’t wait to tell my countrymen and hear what they got to say. I hope they feel like I do and practice it everyday; ‘Cause it makes you feel real deadly when bringing up kids this way....’

One employer of a Parent Coach acknowledged the program empowered women and built self-esteem, stating:

‘This training and support has been the making of her.’

Delivery of Triple P: Parent Coaches are very motivated to share their skills: 3 parent groups have commenced and 2 parents have completed the program.

The strategy of engagement through extensive consultation; gaining support of key Aboriginal community organisations; collaboration; and the provision of ongoing trainee support by an experienced Triple P Practitioner has been essential for the successful implementation of the

program. An approach that ensures that Aboriginal communities are equal partners in program delivery and evaluation is imperative for efficacy, engagement and sustainability of programs.

Partners: Marninwarntikura Women’s Resource Centre, Fitzroy Crossing; The University of Sydney (Discipline of Paediatrics and Child Health and Brain and Mind Institute); The University of Queensland.

Support Organisations in Fitzroy Crossing: Marninwarntikura Women’s Resource Centre; Fitzroy Valley High School; Nindilingarri Cultural Health Services; Marra Warra Warra; Kimberley Aboriginal Land Council; Karriyili Adult Education Centre; Prime Minister and Cabinet
Consumer & Community Involvement:

Current Status:

- Planned
- In Progress

Coverage:

- Community or Regional in _____
- State-wide in _____
- National
- International

Outputs (e.g. publications, tools, guidelines):

PhD Results: Understanding Fetal Alcohol Spectrum Disorder (FASD) through the stories of Nyoongar families and how may this inform policy and service delivery.

Objectives:

The aims were two fold; exploring FASD awareness within the Aboriginal community and recording the experiences of families caring for Aboriginal children with FASD.

Methods:

This study included a mixed methods approach of quantitative and qualitative. The study sites included Perth and several towns in the south west region, Western Australia. A survey tool on FASD was developed in consultation with the critical reference group. A total of 180 Aboriginal community members aged 16 years and upwards participated in this study. Six families were interviewed and included both relative carers and foster carers.

Results:

The majority of participants (61%) were aware of FASD, however only 10% indicated they had a good awareness on FASD. The preferred delivery for FASD information was both small groups (45%) and community forums (55%). Three of the families were caring for siblings with FASD. Themes emerging from family interviews included; behavioural challenges; trauma; financial challenges; health issues; stress; respite issues; and lack of FASD awareness by society.

Conclusion:

All children in this study remained in out of home care and the majority came into care as infants and young children. None of the carers had received FASD training and received little support from agencies. There was also a financial disparity between relative carers and foster carers.