Addressing FASD in Remote and Urban Indigenous Communities: Rewards and Challenges

8th International Conference on Fetal Alcohol Spectrum Disorder, Vancouver 6-9 March 2019. Research Results and Relevance
Addressing FASD in Remote and Urban Indigenous Communities: Rewards and Challenges

FACILITATORS
Elizabeth Elliott MD
Professor, University of Sydney
Christine Loock MD
Associate Professor, University of British Columbia, Social Pediatrics
RICHER Initiative

INDIGENOUS FACILITATORS
Marilyn Van Bibber
Kent Danielson
Jenelle McMillan
Wanda Pelletier
Grace Tait
Richard Willier

MODERATOR
Lori Cox PhD, Eastern Door, New Brunswick, Canada
Agenda

1. Welcome to workshop and introductions of moderators and elders – all (5 mins)
2. Acknowledgement of traditional people and welcome to Canada – Richard (5 mins)
3. Greetings from Australia – Gurrumul (5 mins)
4. Workshop objectives and principles of ethical research – Elizabeth (5 minute)
5. Case study: research in urban Vancouver (Christine 10 mins)
6. Yarning circle 1. FASD diagnosis in community context (10 min)
7. Impact of PAE and FASD in remote Australia. Jadnah (5 mins)
8. Case study: FASD research in remote Australia (10 mins)
9. Yarning circle 2. Discuss challenges/rewards of research in your community (10 min)
10. Yarning circle 3. Panel of urban Indigenous community partners on research process and partnerships (all) 15 min
11. Joining the circles (Lori and Marilyn) 5 mins
Acknowledgment of traditional people and welcome to Canada: Richard Willier
Geoffrey Gurrumul Yunupinga
Greetings from Australia:
Wiyathul, My fathers country
Workshop Objectives

1. Review and discuss epidemiology related to non-Indigenous & Indigenous populations, urban & remote:
   - Review varying patterns of reported FASD & alcohol use in pregnancy (Pre-Conference & Participant Survey)
   - Discuss risk & protective factors effecting occurrence & recurrence of FASD

2. Review processes of developing a shared vision for research and consent: community priority, consultation, engagement, partnerships, trust, empowerment, training

3. Share the challenges and rewards of research with Indigenous communities
Ethical conduct in research with Aboriginal and Torres Strait Islander Peoples and communities
In Loving Memory Of

June 16, 1962 - February 8, 2019
Urban Case Study Vancouver, Canada 1989-2019

1. Setting: Downtown Eastside ‘DTES’ Inner City population area with 8.5% (~10,000) of Vancouver’s children and youth, including indigenous & new immigrant families.

2. Pediatric specialty services are only 7 km away, but access and outcomes were ‘inequitable’.

3. Local primary care and pediatric services were fragmented.

4. High rates of low birth weight, maternal child separations, substance use, homelessness, HIV, and violence against women (MMW).

Loock & Lynam, 2017

- 1988 1st UBC International FAS Conference, Vancouver – Govt announces 8 BC Pregnancy Outreach Programs (POP) to address low birth weight and prevent FASD
- 1989: Vancouver refused funding for services (high quality tertiary services”) but not accessible to pregnant women
- 1990-1992: UBC FA/NAS Research initiated to justify need in urban Vancouver
  - 8% (False Creek/Granville Is.) vs. 47% (DTES) prenatal alcohol (+ other drugs) in vital stats and hospital liaison discharge records, suspected 1:5 FAS/FAE rates
  - Marked difference in social determinants
  - Many children taken into foster care
- 1993 Children’s Hospital Partnership funds development of harm reduction pregnancy outreach ‘Sheway’ + Rotary Kids Outreach; FASD Provincial Coordinators
- 2002-2005 IAPH CIHR Healthy Communities Mothers Children Research Project: to prevent recurrence FASD (1 urban+ 3 land-based communities and 3 Universities)
  - Identified barriers to health care access
  - Long waitlists for ECD services, low rates graduation, overwhelmed teachers
  - Strengths: YWCA, Sheway, Native Health Society, RayCam Cooperative, Schools, Street nurses, FASD Keyworker
Adverse Childhood Experiences: ACEs

**ABUSE**
- Physical
- Emotional
- Sexual

**NEGLECT**
- Physical
- Emotional

**HOUSEHOLD DYSFUNCTION**
- Mental Illness
- Mother treated violently
- Divorce
- Substance Abuse
- Incarcerated Relative

• 2006: 70% were not ready for kindergarten at 5 years (EDI data)
• 2007: Youth high self-harm, suicide pacts (See RCY Paige report)
• CIHR/MSF RICHER Social paediatric research to practice developed with community:
  • Primary to Specialist Care: wrap-around services across the lifespan
  • Pre-Kindergarten screening & K readiness - significant improvement, EDI 50%
  • Youth Matters, Grad Strategy, OUR PLACE, ALIVE,...
  • Increase referrals for ASD & FASD; FASD community conference
  • Daycare, elder talking circles, violence prevention programs, employment (YWCA).
  • Medical Legal Community Partnership & “Circle of the Child” Montreal Partners

• Research allowed community to be part of the solution, not the problem
• Engagement, partnerships, trusted relationships, funding and services
• Improved outcomes for individuals and community.
• Community empowerment and increased agency and capacity
• 2014-2016 CIHR REALIST SYNTHESIS Study
It Takes a Village: Social Pediatric Mechanisms*

1. Horizontal Partnerships
2. Bridging Trust
3. Knowledge Support
4. Empowerment

*Realist Synthesis Research of Social Pediatrics Programs (Tyler et al 2018)

Demi-regularities: semi-predictable patterns where outcomes are linked to context through mechanisms
Social Determinants & Health Equity

Healthy Public Policy:
(1) Best start (0-6 years)
(2) Maximize potential (youth)
(3) Strengthen public health - obesity, smoking, alcohol
(4) Good work for all
(5) Healthy standard of living
(6) Sustainable communities
Encircling Our FASD Diagnostic Systems: Medicine Wheel

“Two Eyed Seeing”
Eight Tenets for Enacting TRC Call to Action #33

1. Centering Prevention around Indigenous Knowledge and Wellness
2. Using a Social and Structural Determinants of Health Lens ...
3. Highlighting Relationships ...(e.g. supporting Indigenous worldviews of child rearing)
4. Community Based, Community Driven Research and prevention
5. Provision of Wraparound Support and Holistic Services
6. Adopting a Life Course Approach For FASD prevention
7. Models Supporting Resiliency for Women, Families, and Communities
8. Ensuring Long-Term Sustainable Funding and Research

Canada FASD Research Network, Centre of Excellence for Women’s Health, Thunderbird Partnership Foundation, Canadian Institutes for Health Research and Health Canada’s First Nations and Inuit Health Branch
YESTERDAY’S ‘PRE-CON’ YARNING CIRCLE
Needs Assessment Survey
Epidemiology, Diagnosis, Prevention, Intervention

1. In my area of work, how prevalent [common] is FASD?
2. Does your community track alcohol use in pregnancy?
3. In your community, are there prevention services for alcohol use in pregnancy?
4. Does your community track prevalence of FASD?
5. In your community, is the diagnosis of FASD made?
6. If the diagnoses is made in your community, are there diagnostic services for FASD?
7. In your community, are there intervention services for individuals with FASD?
Pooled prevalence of FAS and FASD among special sub-populations (25 studies in total, representing 5 countries)

Popova et al., Addiction, 2019
FASD and Social Determinants of Health

8. In my community, FASD has been identified more frequently in populations who have experienced historical trauma or continue to experience adverse Social Determinants of Health?

1. Never
2. Sometimes
3. Often

ELLIOTT & LOOCK 2019
How often is FASD associated with historical or continued adverse Social Determinants of Health?

- Often: 64%
- Sometimes: 18%
- Never: 0%
YARNING CIRCLES
YARNING CIRCLE 1.
FASD diagnosis in community context

• Answer the following question and discuss the approaches to a FASD diagnosis in your community.

• Discuss the TES (Two-Eyed Seeing) neurodevelopmental diagnostic wheel and its applicability in your community?
YC 1. Diagnosis in community context

In your community, have you imbedded the diagnosis of FASD into historical contexts and identified SDOH and root causes to prevent occurrence & recurrence of intergeneration trauma.

1. Yes
   If yes, what responses do you consider
   1. Truth & Reconciliation Processes (eg TRC in Canada)
   2. Jordan’s Principle
   3. Elder engagement
   4. Empowerment to decrease domestic violence
   5. Supporting/reconnecting families to decrease in foster placements
   6. Advocacy/tools for persons in trouble with the law
   7. Access to services for children and youth with special needs
   8. Other

2. No
   1. If no, what are the barriers.
Aboriginal leadership in tackling fetal Alcohol Spectrum Disorder: from grass roots communities to the United Nations

Prof Elizabeth Elliott, Prof Jane Latimer Faculty of Medicine & Health Sciences on behalf of June Oscar, Maureen Carter, Emily Carter, Dr James Fitzpatrick and the Fitzroy Valley Communities.
Alcohol Restrictions

2006 - community in crisis

2007 - women decided “enough was enough”

2008 - WA liquor-licensing authority to impose restrictions
Life

The women who saved their town from alcoholism

When drink-related violence and murder threatened a remote Australian town, local Aboriginal women led the fightback
Fetal Alcohol Spectrum Disorder

FASD is a tragedy that somehow transcends other aspects of grief and trauma. Here is innocent young life; the future of our people and all that goes with it – our culture, our language, knowledge about the magic creation and laws of our county – being born into this world with brains and nervous systems that are so impaired that life for that person from birth to death is cruelly diminished.

June Oscar, Address to Parliament, Canberra, August 2009
Case study Fitzroy Crossing (Elizabeth Elliott)
Challenges and rewards of FASD research with Indigenous communities

Challenge: very remote location

Partnership: Marninwarntikura Women’s Resource Centre, Nindilingarri Cultural Health Services, University Sydney Dept Paediatrics and George Institute for Global Health. MOU
Challenges: Consultation and Community consent
Challenges: Understanding the impact of FASD
Challenges: Geographic
Challenges: accommodation, venomous snakes (spiders, scorpion, crocodiles)
Challenges: Climatic

Flood warning issued for WA's Kimberley region

February 21st, 2015
Ex-tropical Cyclone Lam
120 mm rain
Challenges: language, staff, training, cultural protocol, funding

Community Navigators

Pictorial aids – type, amount of grog
Challenge: Multi-disciplinary assessment
Rewards: Data on PAE and FASD
Fitzpatrick et al.

High rates of
- FASD 1 in 5 (19%)
- FAS/pFAS (12%)
- ND-AE (7%)
- Physical problems
- Growth
- Behavioural problems**
- Mental health
- IQ
- Memory
- Academic achievement
- Executive function
- Speech and language
- Motor skills
- Mental health

n = 115
55% drank
93% high risk
Most throughout pregnancy
Stress underlies drinking.

No shame, no blame…

D’Antoine et al.
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Early life trauma (FASD > no FASD)  
90% ELT, 50% ≥ 2 stresses; 20% DCP

1. Death close family member making child sad  45%  
2. Food insecurity  42%  
3. Money worries  38%  
4. Adults/parents fight too much  36%  
5. Too many people in house  34%  
6. Close family member in prison  33%  
7. Grog/drugs: children feel unsafe/sleep  30%  
8. Child protection/welfare involvement  20%  
9. Drug/alcohol used daily in home  14%  
10. Person in home with mental ill-health  13%  
11. Welfare taken child to live elsewhere  9%
Benefits for kids and families

- Health, hearing, eye checks
- Treatment (ears/skin/chest/head)
- Diagnosis of FASD and management plan
- Referral to child health, allied health, dentist, CAMHS, ear and eye doctor (>400)
- Help at school
- Support for families
Benefits for the community

- Awareness
- Education, training
- Support caregivers
- Employment
- Diagnostic, screening tool FASD
Community praised for FASD ‘courage’

The Fitzroy Valley community in Western Australia’s Kimberley region has been called ‘courageous and clever’ for tackling Foetal Alcohol Spectrum Disorder (FASD) through the Liliana Project, which started in April.

Stage one of the project, which was funded by an anonymous donor, involved collecting information about pregnancy, birth and early childhood of parents and caregivers of children born in 2002 and 2003. It has also resulted in community education around foetal alcohol and childhood and FASD.

Stage two will start later this year and has just received a $1 million grant from the Federal Government. It will involve a full health assessment of the children born in 2002 and 2003 by a team of health professionals, and those children found to have health or developmental problems will be given treatment and ongoing support.

Liliana means ‘all the little ones’ in Kriol and the project is a collaboration between the Nindigully Cultural Health Service, the University of Sydney and the George Institute for International Health.

Project manager Dr James Fitzpatrick.

Foetal Alcohol Spectrum Disorder study

From FaHCSIA

The first Australian study into the prevalence and impact of Foetal Alcohol Spectrum Disorder on Indigenous children will be undertaken in Fitzroy Valley, Western Australia, with the support of a $1 million Gillard Government grant.

Other priorities under the Agenda are to strengthen police protection in remote communities, support community initiatives that heal trauma and change attitudes, and improve coordination of services to victims, especially children.

The Indigenous Family Safety Program is funded over four years.

While fewer Indigenous Australians drink alcohol than non-Indigenous Australians, alcohol abuse is a significant issue in Indigenous communities.

A recent study by the Australian Institute of Criminology found that “alcohol is now regarded as one, if not the primary risk factor for violence.”

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A recent study by the Australian Institute of Criminology found that “alcohol is now regarded as one, if not the primary risk factor for violence.”
This research is "a genuine partnership - one where research is done with the community and not just about the community," that it is "guided by a relationship underpinned by meaningful, respectful engagement and collaboration."

Mr Mick Gooda, ATSI Social Justice Commissioner
Australian Human Rights Commission
Indigenous Elders urge caution as FASD reaches 'crisis levels'
TRISTAN

Tristan tells the story of a 12-year-old boy born with one of the Fetal Alcohol Spectrum Disorders – the result of exposure to alcohol during pregnancy. The film is both confronting and courageous in its ability to transport the viewer to north-west Australia to experience the hopes, dreams and challenges facing Tristan. It has been produced as part of the LlWan Project, a research collaboration between Marnhwaantjula Women’s Resource Centre and Nind Lingan Cultural Health Services in Fitzroy Crossing; The George Institute for Global Health and Sydney Medical School at The University of Sydney.

The collaboration recognises the courage of Tristan and his family in sharing their story.

Marnhwaantjula Women’s Resource Centre and Nind Lingan Cultural Health Services present a film by Melanie Hogan

Directed and Edited by Melanie Hogan

Producers: Jane Lister, Melanie Hogan

Narration: Tristan McCrory

Cinematography: Carolyn Constantinou

Sound Design: Sam Petty

Music: David Page, Ranbir Sken, Troy Laurel, Leah Flannigan, Stephen Pigram, Patrick Davies

Funding for Tristan was provided by the Ngiyemp Trust; the Foundation for Alcohol Research and Education; and Astral Australia (formerly known as Blake Dawkins Lawyers), with advice from The Australian Human Rights Commission.

Images by E. Elliot and C. Constantinou
Baya Gawiy Children and Family Centre
Family Violence shelter and legal service
Royal Far West ELT-informed care
Alternative education pathways
Understanding and addressing the needs of children and young people living with Fetal Alcohol Spectrum Disorders (FASD)

A resource for teachers
For all the Family

Positive Parenting Program
Triple P International

40 accredited Parent Coaches, 34 Aboriginal, 10 organisations
The development of a culturally appropriate school based intervention for Australian Aboriginal children living in remote communities: A formative evaluation of the Alert Program® intervention

Bree Wagner BA (Ed)/BSocSc (HomeEc), James Fitzpatrick PhD, MBBS, BSc, Martyn Symons PhD, BA (Honours), BSc (Cognitive Science), ... See all authors


Open Access

BMJ Open

Study protocol for a self-controlled cluster randomised trial of the Alert Program to improve self-regulation and executive function in Australian Aboriginal children with fetal alcohol spectrum disorder

Bree Wagner,1 James P Fitzpatrick,1 Trevor G Mazzucchelli,2 Martyn Symons,3 Heather Carmichael Olson,4 Tracy Jirikovic,5 Donna Cross,6 Edie Wright,7 Emma Adams,4 Maureen Carter,6 Kaashifah Bruce,1 Jane Latimer9
Community – led alcohol restrictions
Girl, 11, killed after vehicle carrying seven children rolls near WA's Fitzroy Crossing

By Erin Parke
Updated 19 Feb 2015, 8:50pm

A young girl has died and six other children have been taken to hospital after a vehicle allegedly driven by a 15-year-old boy rolled over near Fitzroy Crossing in Western Australia's Kimberley.

The 11-year-old girl was killed when the four-wheel drive came off the road at about 5:00am, police said.

Officers alleged a 15-year-old boy was driving the car at the time and there were six passengers, two boys and four girls.

PHOTO: One of the children involved in the crash arrives at Broome airport. (ABC News)
Bigiswun project
Where are the Lililwan now?

- WELL-BEING
- QOL
- HEALTH
- MENTAL HEALTH
- EDUCATION
- JUSTICE
- CHILD PROTECTION
- COMMUNITY
- EMPLOYMENT

Service use, Community survey
Self-report
The Story of Alcohol

Indigenous Leadership and Fetal Alcohol Spectrum Disorders

2013
Claire, 22
Claire’s anger can be turned on quickly and is off. I get sensory overload from a pregnancy with Claire and the consequences and was

Tristan, 14
Tristan lives in Fitzroy Valley, Western Australia, with his Aunt Mamingee and Uncle Geoff. His mother drank heavily when she was pregnant. He struggles with reading and writing and has to be reminded to do basic things like shower. Geoff and Mamingee are worried about him getting into trouble as he gets older.

Elizabeth Elliott
Professor Elizabeth Elliott says there is no safe level of drinking in pregnancy because each woman metabolises alcohol differently. She says that alcohol can cause worse permanent damage to babies’ brains than heroin or crack cocaine. She runs a FASD clinic at The Children’s Hospital at Westmead. Professor Elliott says many doctors don’t have a good understanding of FASD and she’s worried women are getting mixed messages from doctors about drinking during pregnancy.
Post graduate students
• Dr James Fitzpatrick PhD
• Barb Lucas PhD
• Dr Robyn Doney PhD
• Emily Fitzpatrick PhD
• Philippa Dossetor PhD
• Marmingee Hand MEd
• June Oscar PhD

Post Doctoral Fellows
• Dr Rochelle Watkins
• Dr Tracey Tsang
• Dr Kathryn Thorburn

Medical, Allied Health Students
House of Representatives
Inquiry into the prevention, diagnosis and management of FASD, 2012

Federal Government
National Action Plan to reduce impact of FASD
$20 million, 2013-17

*Inquiries FASD in NT, Alcohol use ATSI, Advertising alcohol NSW
DOH Funding 2017, 2018

https://www.fasdhub.org.au/
Are you a parent or carer of a child with FASD?

NOFASD Australia provides a support service for individuals and families living with FASD.

Speak with someone 😊

Do you have questions about Fetal Alcohol Spectrum Disorder? Would you like to speak to someone confidentially?

1300 306 238  
Leave a Message

https://www.nofasd.org.au
Menzies School of Health Research: FASD Prevention and Health Promotion Resources. New Directions services for mothers & babies
FASD Research Australia
Centre of Research Excellence
Generating Knowledge Together

New Research
- Prevention
- Diagnosis
- Management

OUTCOMES
- Standardised national monitoring of alcohol use in pregnancy and FASD
- Evidence-based interventions for prevention and management of FASD

Training Researchers
- Cultural awareness
- Data linkage
- Mentoring

Translation
- Resources for professionals
- New guidelines & interventions

Collaborations
- FASD clinical network
- Australian FASD website

Are you a FASD Researcher? We want to hear from you
FASDAustralia@telethonkids.org.au
Baird pledges $2.3 million to fight fetal alcohol spectrum disorder, new centre

Sydney Morning Herald
March 16, 2015

4 year funding multi-disciplinary training education
NSW Health Aboriginal Videos - women, men, health professionals, youth; storybook, pamphlets
Consultations
• National FASD strategy
• National Alcohol Strategy

Guidelines
• WHO, RACP, AMA

Policy change
• Gilbert and Tobin lawyers: Advocacy for recognition of FASD justice system
• Labelling

Inquiries
• Mental health, FASD NT, Alcohol Media, Scientific meetings
YARNING CIRCLES
YARNING CIRCLE 2.
Discuss the challenges and rewards of research in your community

- Is research needed in your community?
- If so what do you want to know and who decides?
- How are partnerships developed and formalised?
- What consent processes should be used?
- Who owns the data and is responsible for reporting?
- Who is accountable and to whom?
Yarning Circle 3 Panel Discussion: Research process and partnerships

AIMS:
- Who decides what to study?

ETHICS:
- Who gives consent?
- Who ‘owns’ the data?

PROCESS:
- Who are the participants, partners, knowledge keepers, co-investigators?
- Developing an MOU
- Payment for time
- Resolving disagreements

REPORTING:
- Who is accountable and to whom?
YARNING PANEL
Epidemiology, Diagnosis, Prevention, Intervention

- Does your community track alcohol use in pregnancy?
- In your community, are there prevention services for alcohol use in pregnancy?
- In my area of work, how prevalent [common] is FASD?
- Does your community track prevalence of FASD?
- In your community, is the diagnosis of FASD made?
- If the diagnoses is made in your community, are there diagnostic services for FASD?
- In your community, are there intervention services for individuals with FASD?
New FASD International [Urban & Remote] Partners