

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

MODERATOR

Lori Cox PhD, Eastern Door, New
Brunswick, Canada

INDIGENOUS FACILITATORS

Marilyn Van Bibber

Kent Danielson

Jenelle McMillan

Wanda Pelletier

Grace Tait

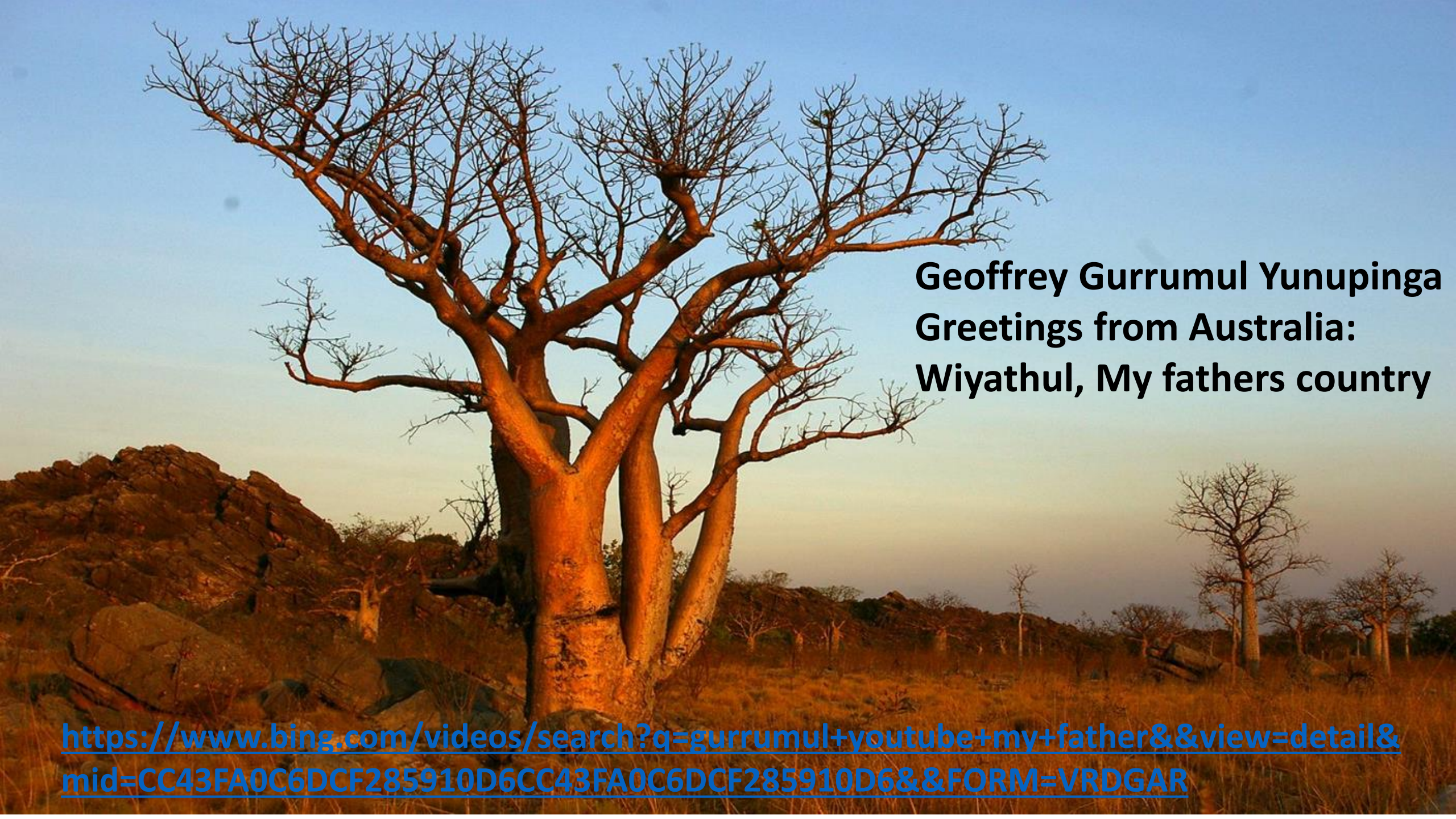
Richard Willier

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

A large, leafless tree with a thick, gnarled trunk and many bare branches stands in a dry, rocky landscape. The ground is covered with sparse, dry grass and scattered rocks. In the background, there are more trees and a clear sky. The lighting suggests it might be late afternoon or early morning.

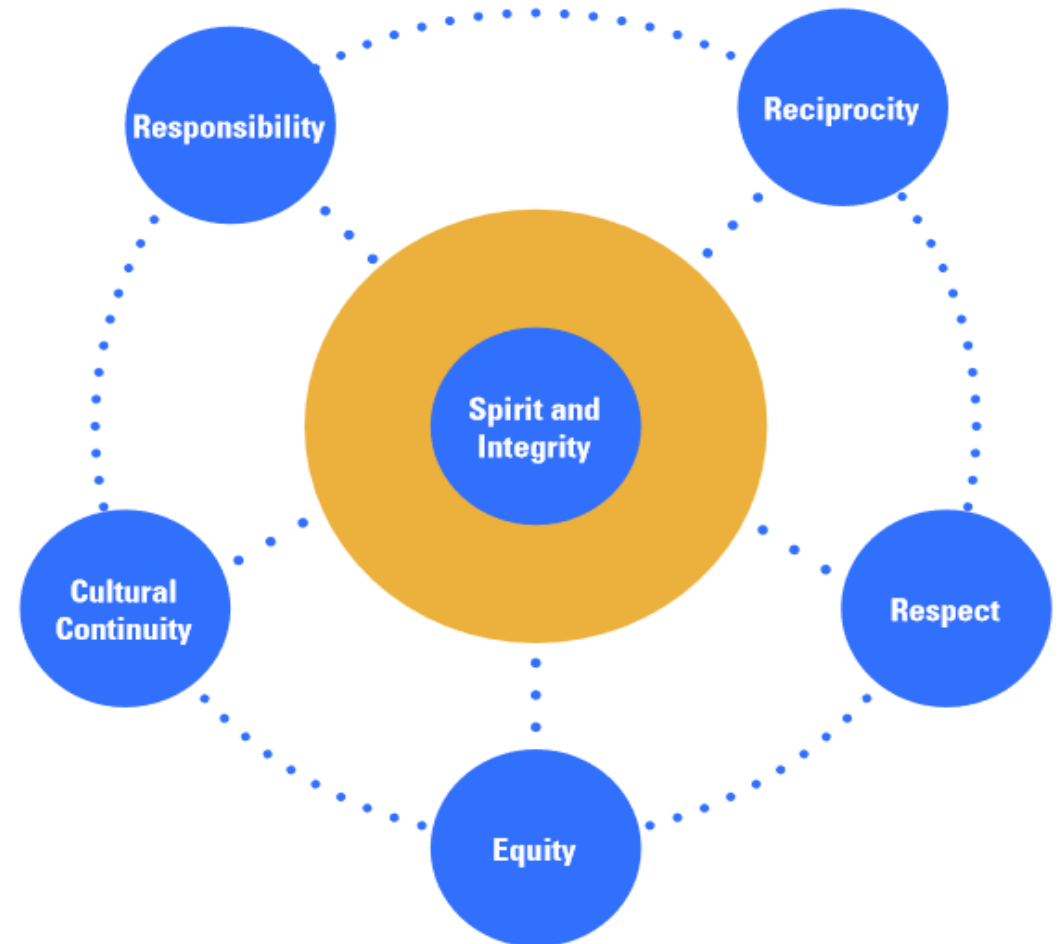
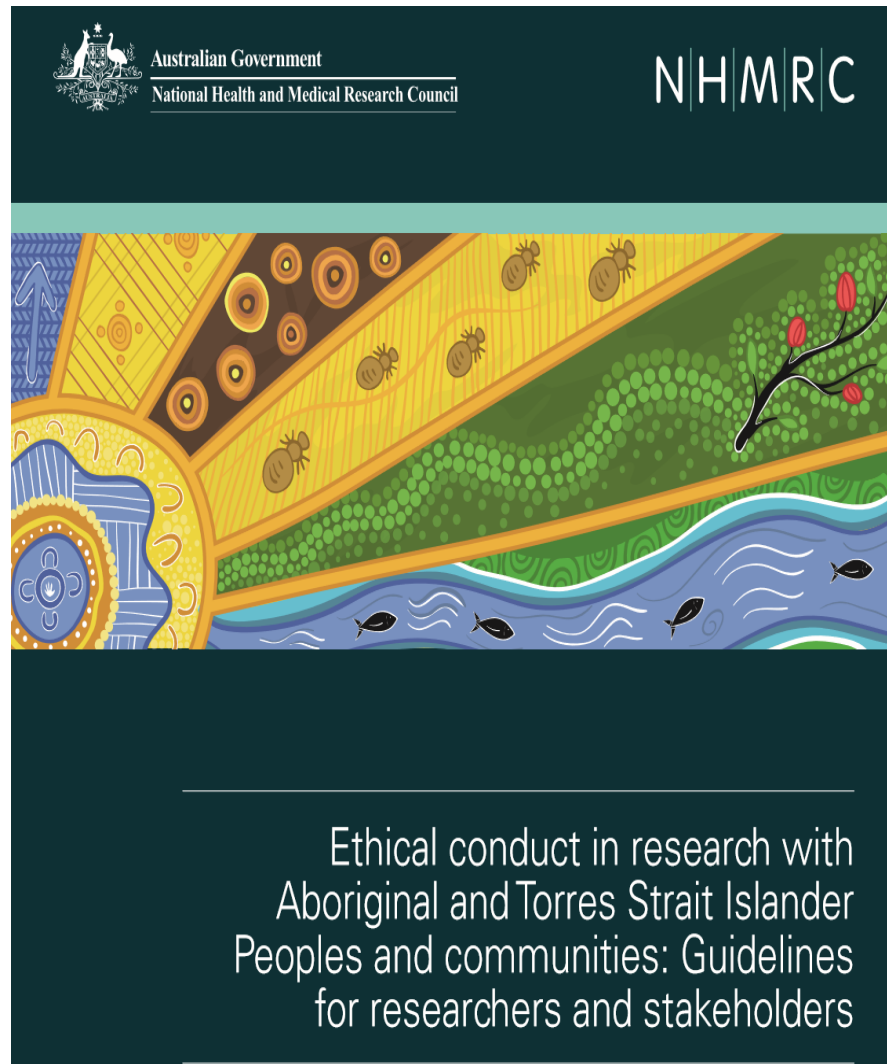
**Geoffrey Gurrumul Yunupinga
Greetings from Australia:
Wiyathul, My fathers country**

<https://www.bing.com/videos/search?q=gurrumul+youtube+my+father&&view=detail&mid=CC43FA0C6DCF285910D6CC43FA0C6DCF285910D6&&FORM=VRDGAR>

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





“No data, no problem, no action”

Research data allows communities to take control.

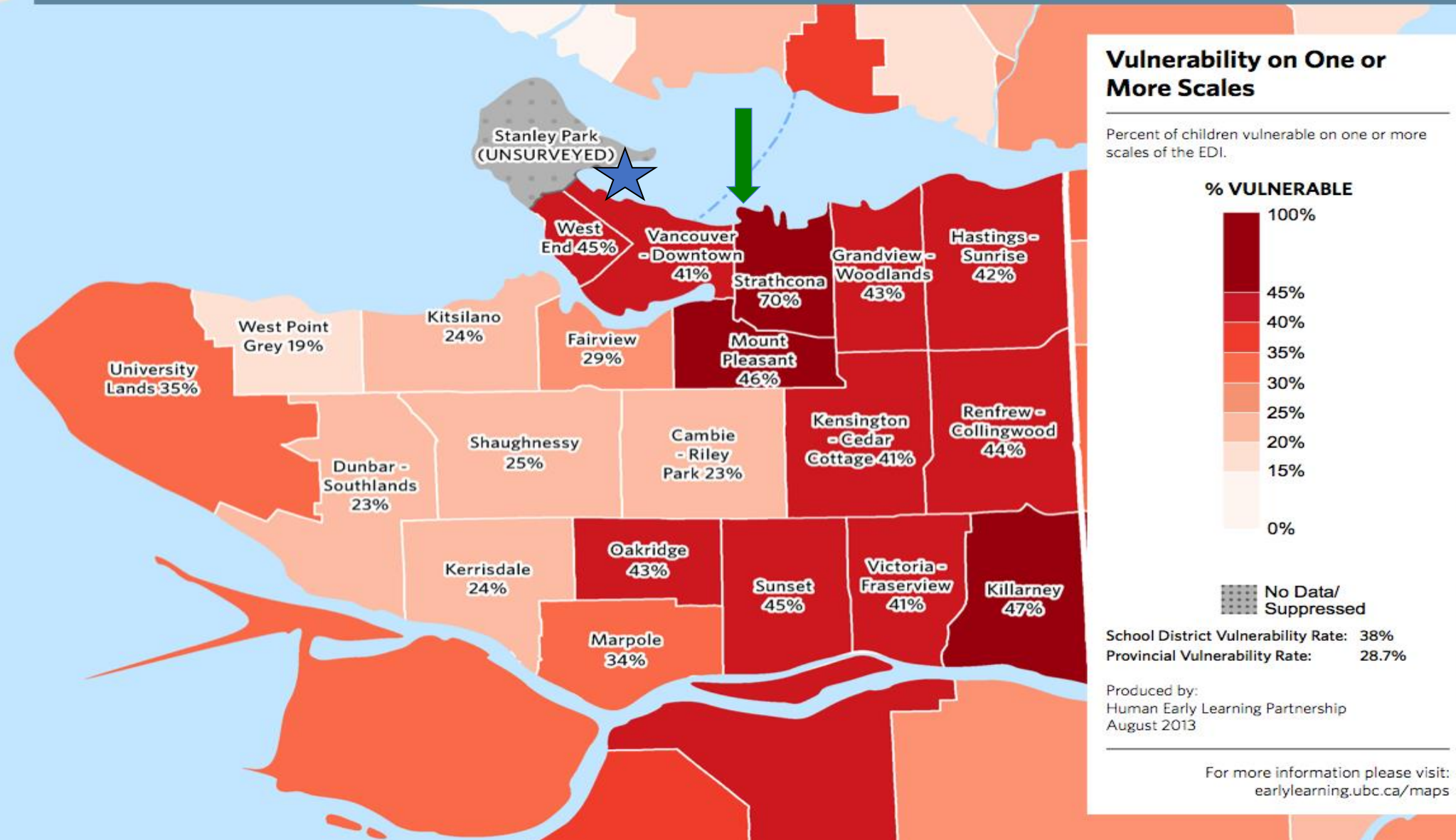
Urban Case Study Vancouver, Canada 1989-2019

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).

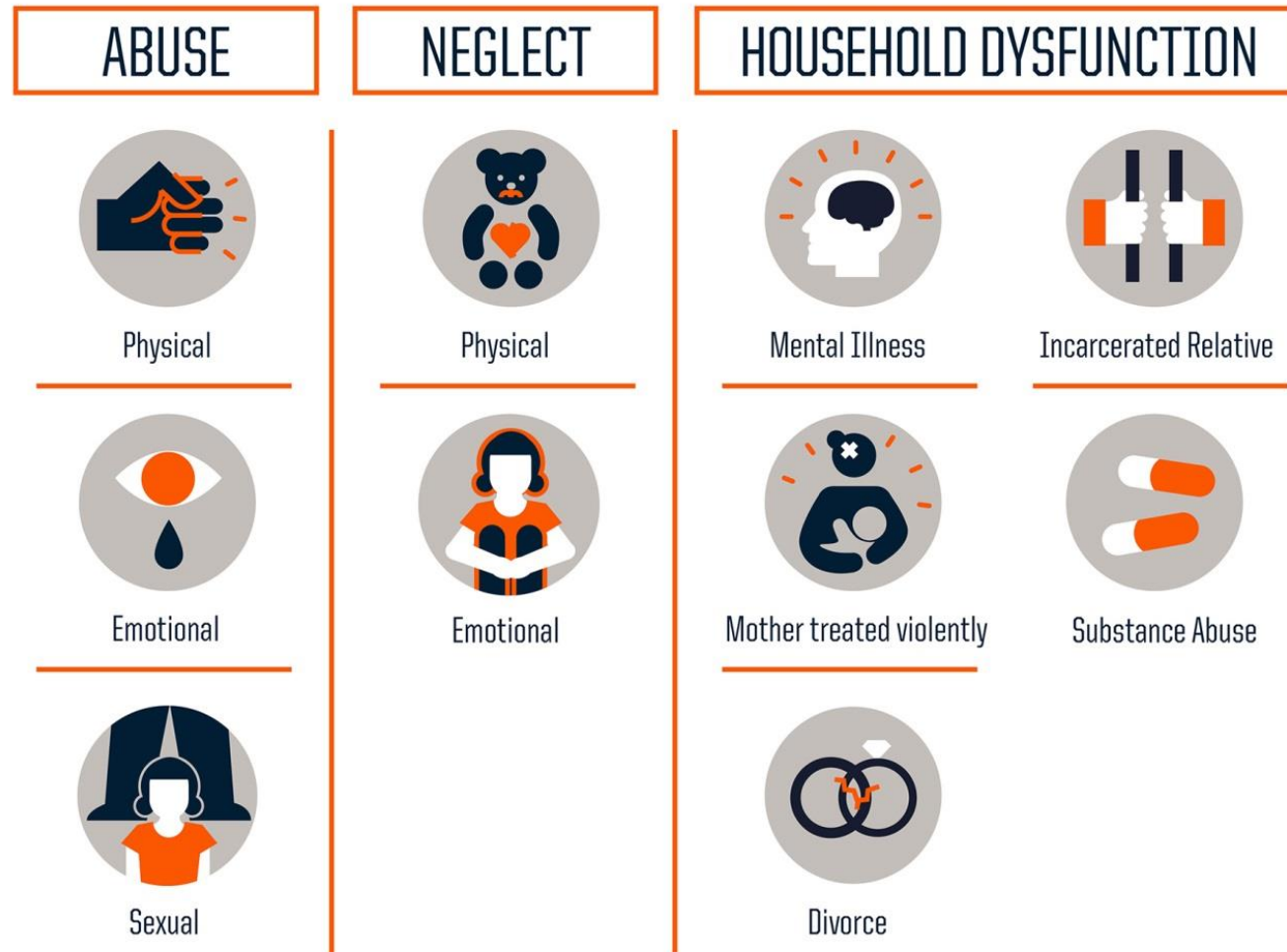
Urban Canada Case Study- Part 1 (1989-2005)

- 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

EDI Wave 3 SD 39 Vancouver



Adverse Childhood Experiences: ACEs

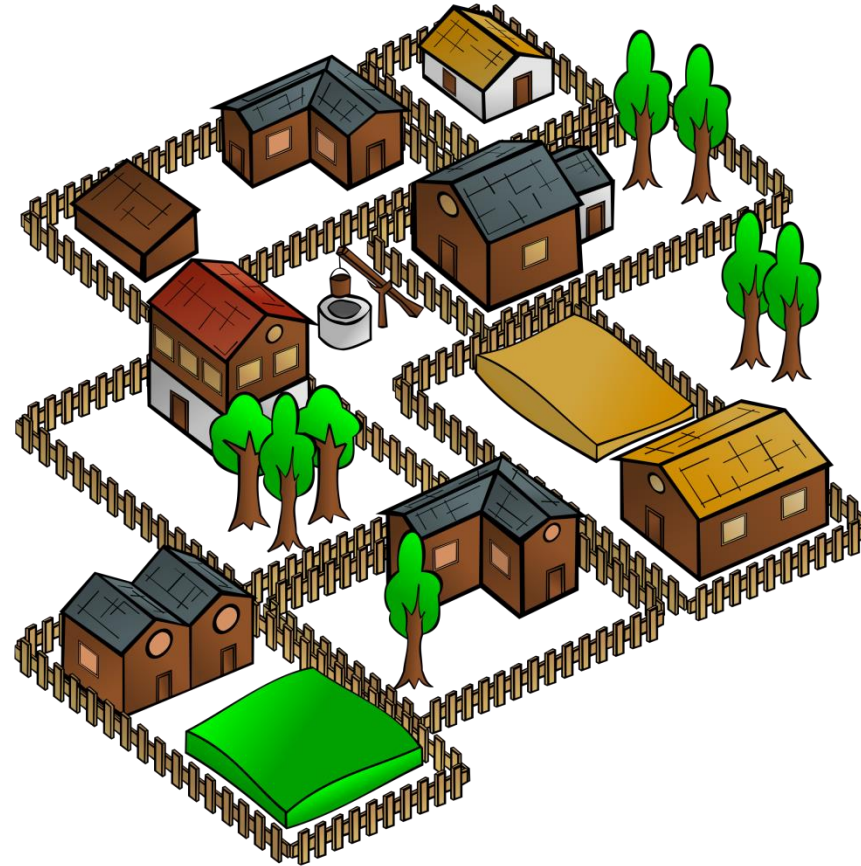


Urban Canada Case Study- Part 2 (2006-2019)

- 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*

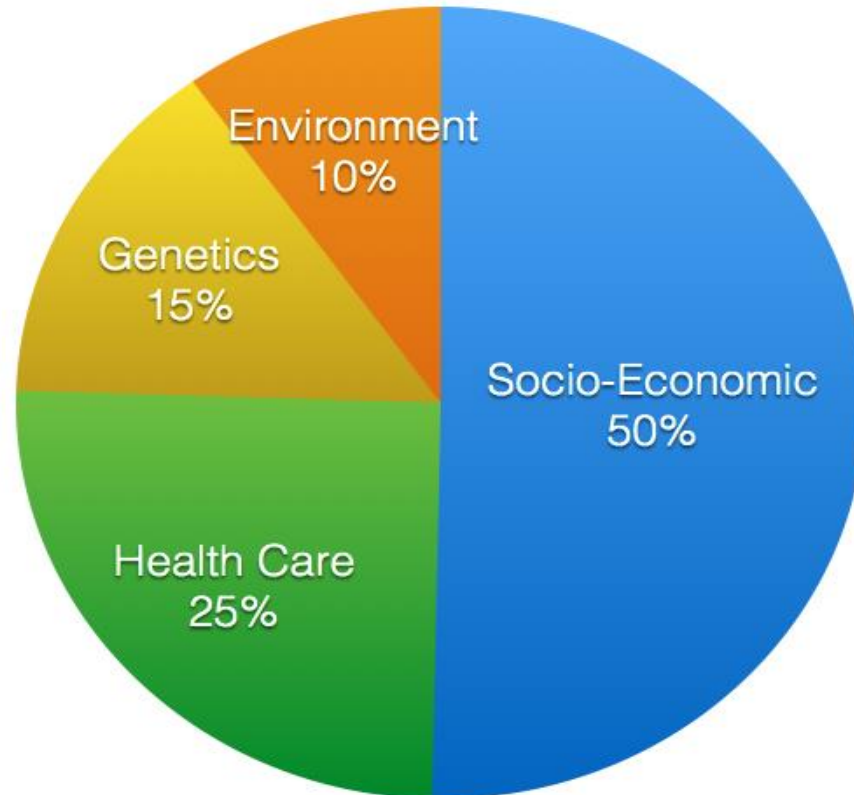
1. Horizontal Partnerships
2. Bridging Trust
3. Knowledge Support
4. Empowerment



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

Demi-regularities: semi-predictable patterns where outcomes are linked to context through mechanisms

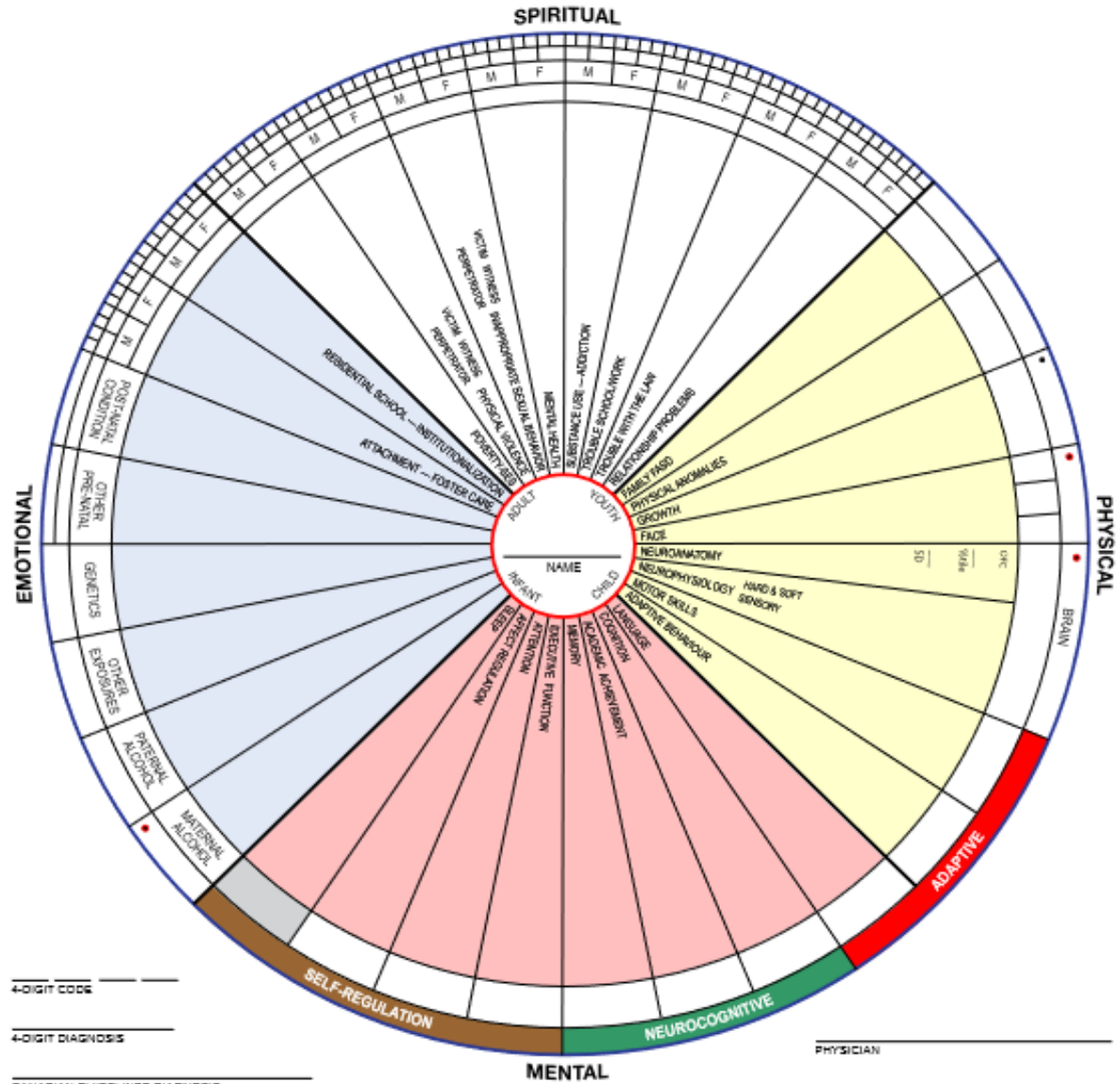
Social Determinants & Health Equity



- 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

Marmot & Allen, 2014
Canadian Institute of Health Research, 2012

Loock & Lynam, 2017



Encircling Our FASD Diagnostic Systems: Medicine Wheel

“Two Eyed Seeing”

4-DIGIT CODE _____
 4-DIGIT DIAGNOSIS _____
 CANADIAN GUIDELINES DIAGNOSIS _____
 DSM-5 DIAGNOSIS _____
 OTHER DIAGNOSIS _____



PHYSICIAN _____
 SIGNATURE _____
 DATE _____

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

<https://canfasd.ca/wp-content/uploads/sites/35/2017/06/Consensus-Statement-Eight-Tenets-June-1.pdf>

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?

African Region

South-East Asia Region

Eastern Mediterranean Region

Region of the Americas

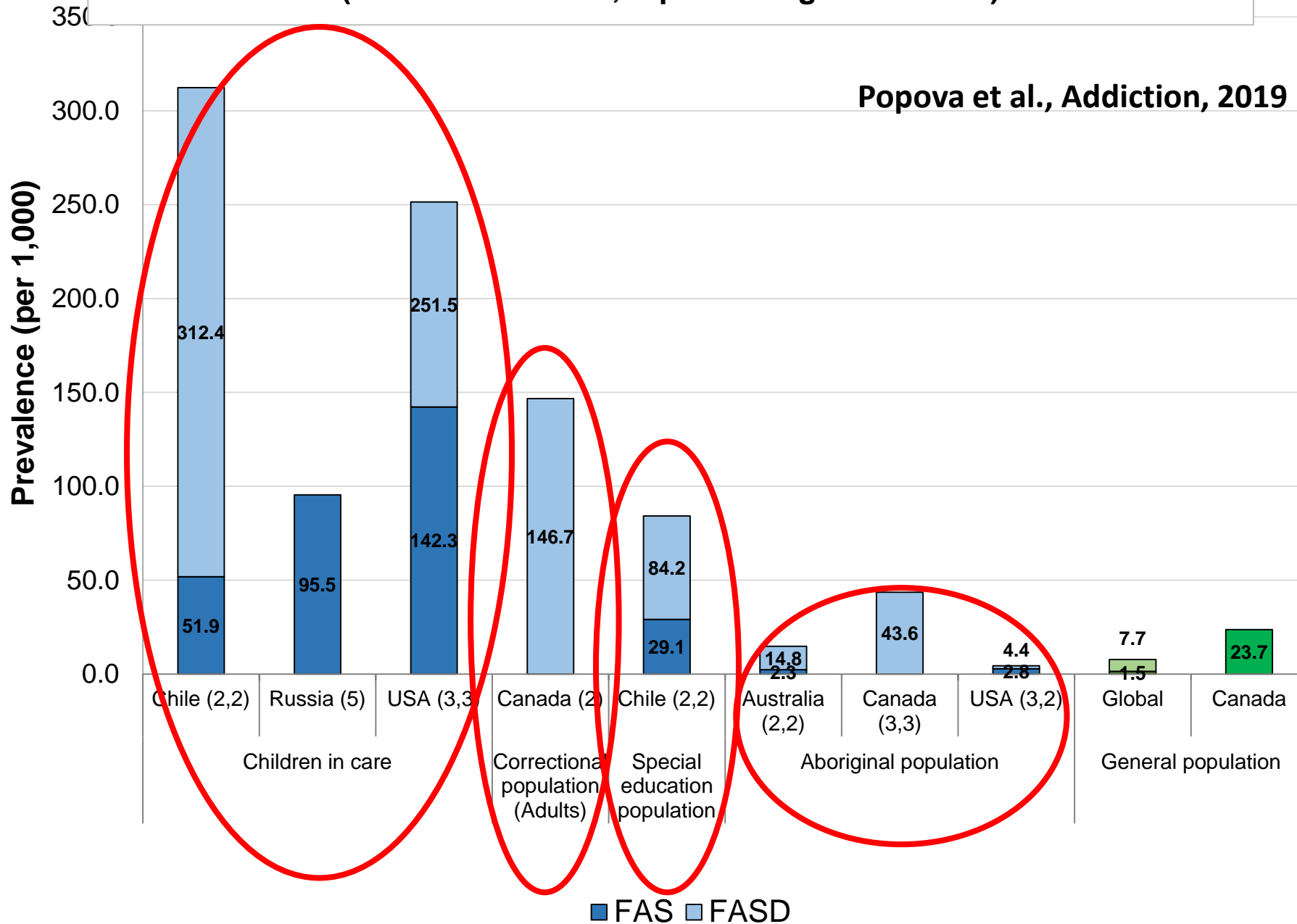
European Region

Western Pacific Region

ELLIOTT & LOOCK 2019

Pooled prevalence of FAS and FASD among special sub-populations (25 studies in total, representing 5 countries)

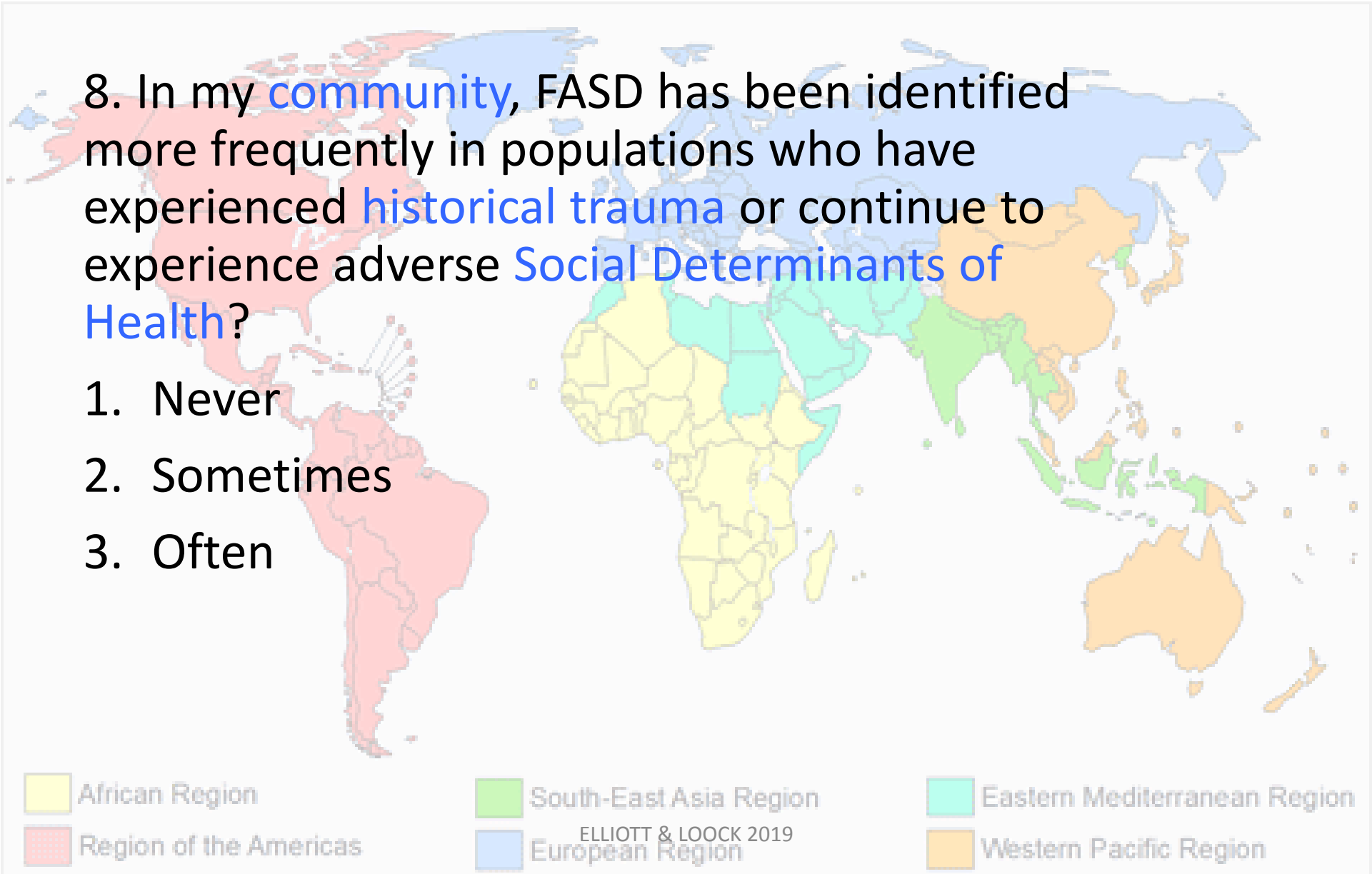
Popova et al., *Addiction*, 2019



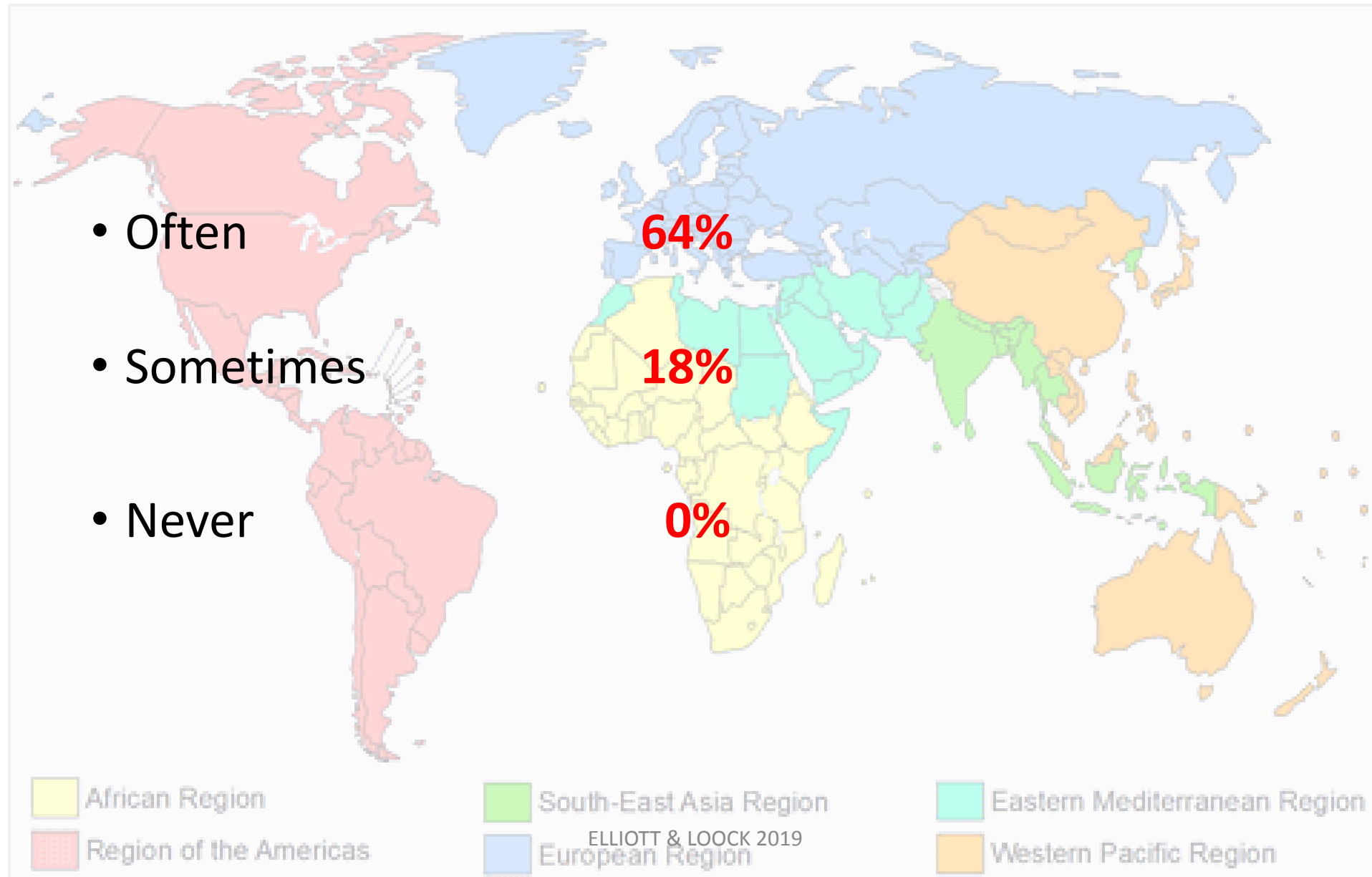
FASD and Social Determinants of Health

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



How often is FASD associated with historical or continued adverse Social Determinants of Health?



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.



JADNAH

https://www.dropbox.com/s/bgw3wd8e9uodcxk/4_Making%20FASD%20History%20Marulu%20FASD%20Prevention%20Strategy%20at%20WA%27s%20Fitzroy%20Crossing.mp4?dl=0

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

THE  TIMES
Life

The women who saved their town from alcoholism



Anne Barrowclough, Fitzroy Crossing Exclusive digital content
Last updated at 12:01AM, June 29 2012

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

◀ ▶ 1 of 10

June Oscar and Emily Carter of the Fitzroy Women's Resource Centre Andy Tyndall/NewsPix

Fetal Alcohol Spectrum Disorder

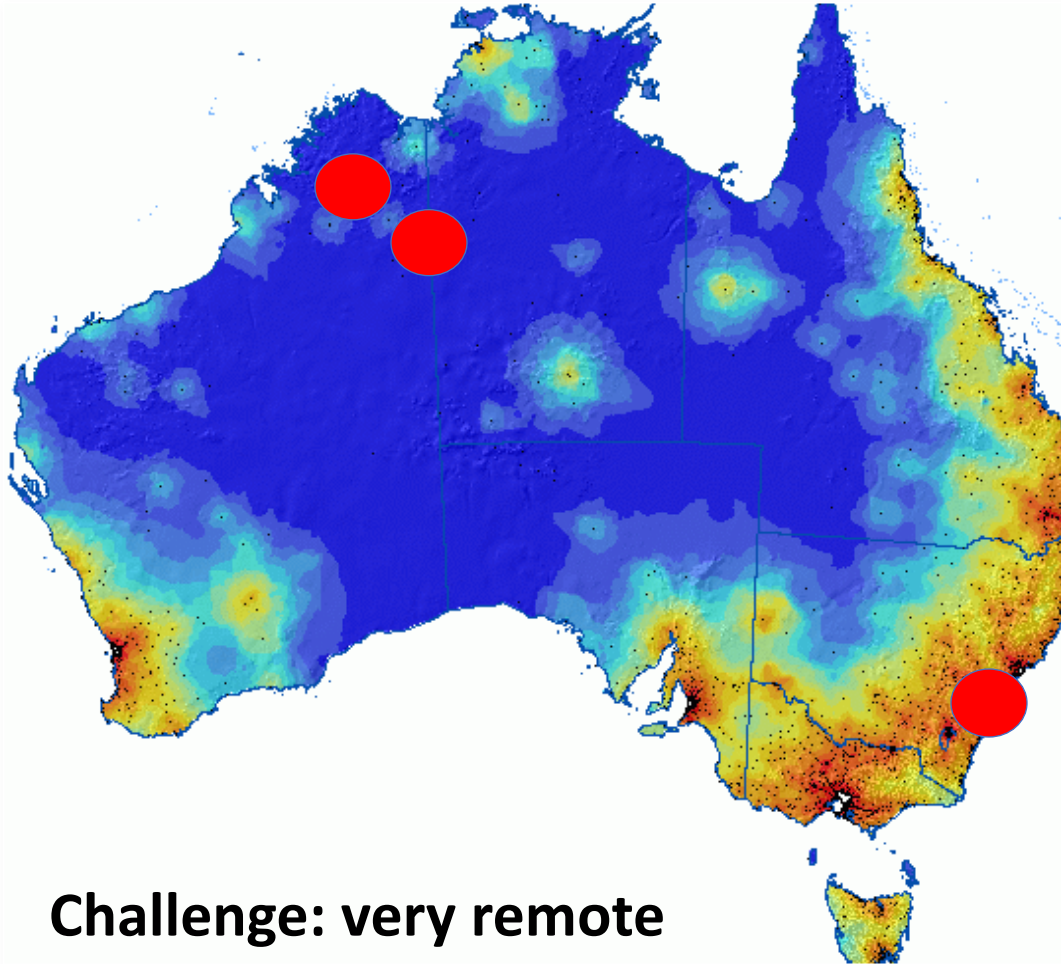
FASD is a tragedy that somehow transcends other aspects of grief and trauma. Here is innocent young life; the future of our people and all that goes with it – our culture, our language, knowledge about the magic creation and laws of our country – being born into this world with brains and nervous systems 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



MARULU The Lililwan Project



**Fetal Alcohol Spectrum Disorders (FASD)
Prevalence Study in the Fitzroy Valley:
A Community Consultation**



*A/Prof Jana Letimer
Prof Elisabeth Elliott, AM
Maureen Carter
Aine Oscar
Dr James Fitzpatrick
Dr Manuela Ferreira
Meredith Kefford
Administrative support:
Juliette O'Brien*



Challenges: Understanding the impact of FASD

Fading Image



Don't let our dreamtime stories disappear.

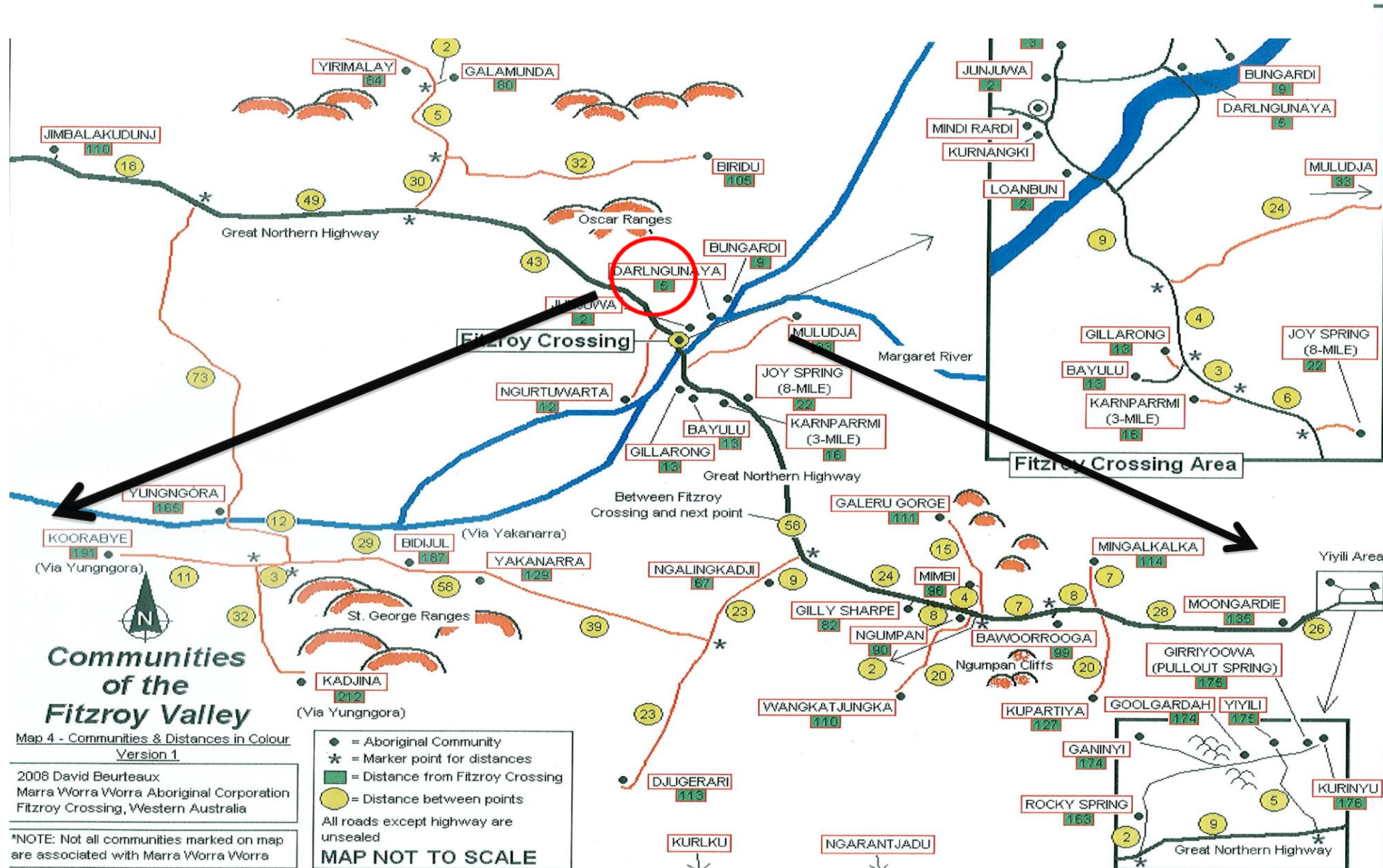


Don't let our dreamtime stories disappear.



Don't let our dreamtime stories disappear.

Challenges: Geographic



Challenges: accommodation, venomous snakes (spiders, scorpion, crocodiles)

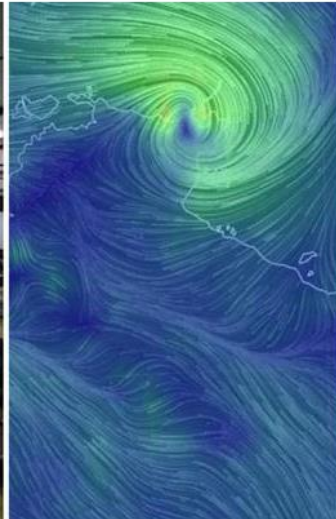


Challenges: Climatic

WESTERN AUSTRALIA

7:50pm February 21, 2015

Flood warning issued for WA's Kimberley region



February 21st, 2015

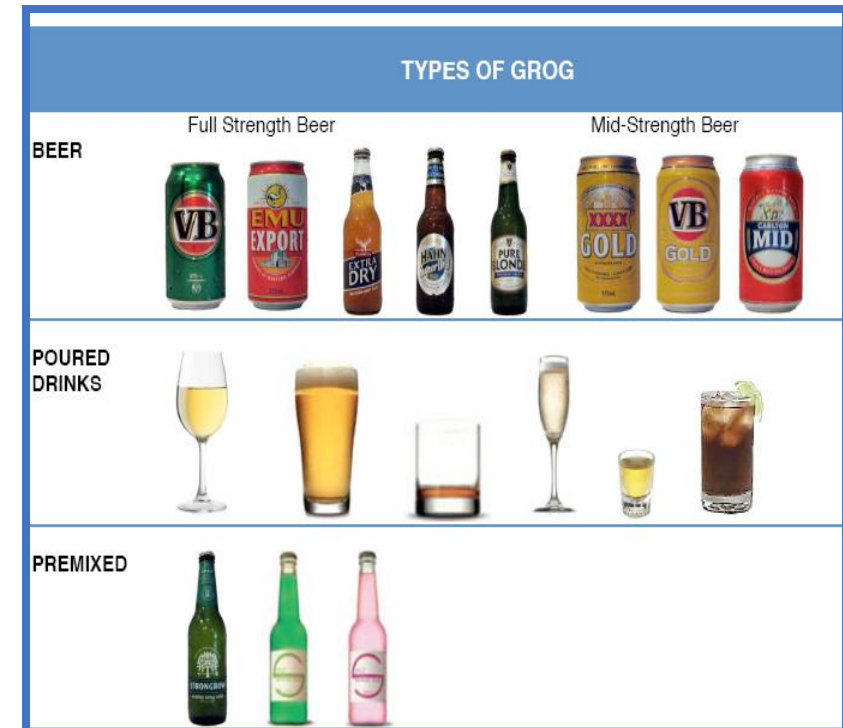
Ex-tropical Cyclone Lam

120 mm rain

Challenges: language, staff , training, cultural protocol, funding



Community Navigators



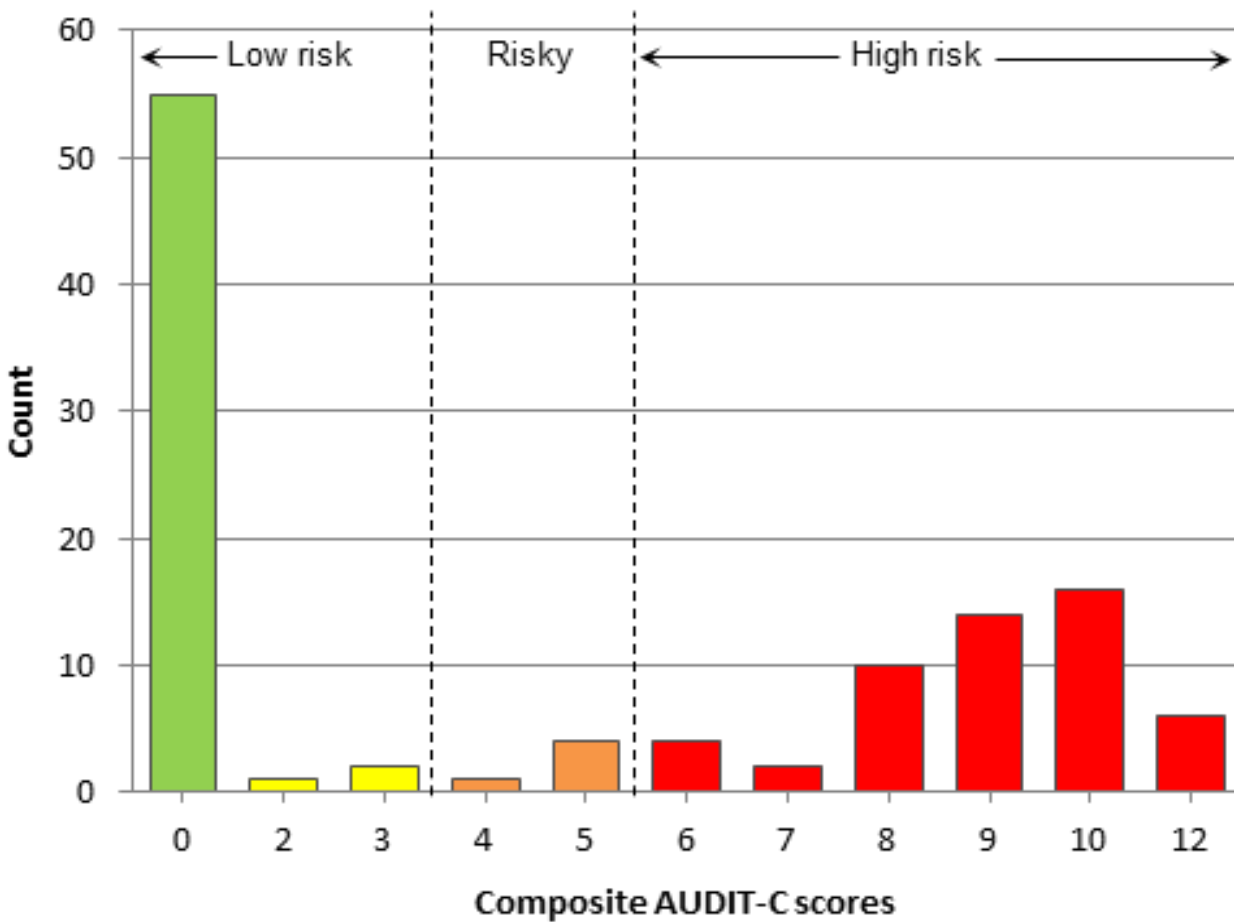
**Pictorial aids –
type, amount of grog**

Challenge: Multi-disciplinary assessment



Rewards: Data on PAE and FASD

Fitzpatrick et al.



n = 115
55% drank
93% high risk
Most throughout pregnancy

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

Rewards : Understanding about why indigenous women drink in pregnancy?

*Stress underlies drinking.
No shame, no blame...*



D'Antoine et al.

The Lililwan study: population-based n=108, mean 8.7y, 7.4-9.6

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



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'



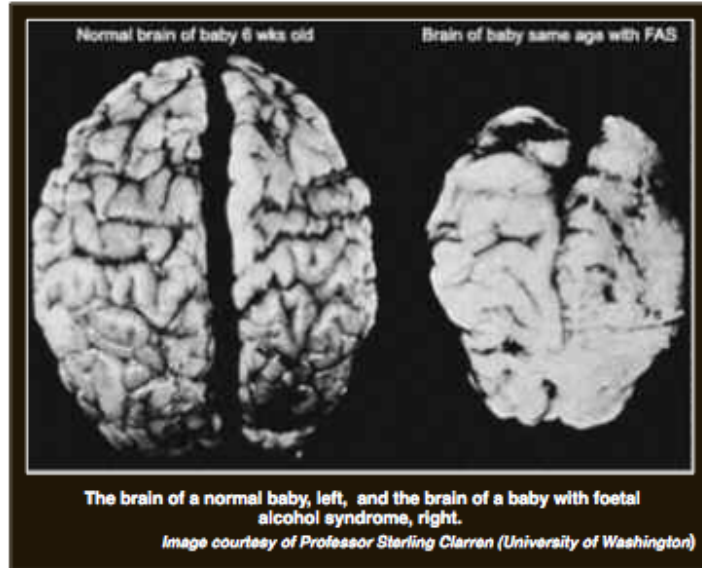
THE Fitzroy Valley community in Western Australia's Kimberley region has been called 'courageous and clever' for tackling Foetal Alcohol Spectrum Disorder (FASD) through the Liliwan Project, which started in April.

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

Liliwan means 'all the little ones' in Kriol and the project is a collaboration between the Nindilingarri Cultural Health Service, the University of Sydney and the George Institute for International Health.

Project manager Dr James Fitzpatrick



and song, FASD is even more concerning because children who can't learn well, who have poor memories, are not able to pass on their cultural stories."

Dr Fitzpatrick said the good news was that FASD was 100 per cent preventable.

"The community have been both courageous and clever in tackling FASD," he said.

The Liliwan Project involves a prevention strategy to educate community members, health, justice and education professionals, and alcohol outlets about FASD.

Dr Fitzpatrick said it also involved the first high-quality Australian prevalence study, a community-led research project that would measure exactly how many children have FASD so that health and education support could be planned.

The third component of the project would look at supporting individuals and their families who are living with FASD, so that the children can achieve their maximum potential at school and in the home.

Finally, he said the project team was advocating for greater recognition of FASD as an important disability in Australia and for more support for children and carers.

"(This) is a ground-breaking approach to high quality research that has immediate

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 led 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 in Indigenous communities."





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***

Don't stigmatise Aboriginals

SBS

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7 NOV 2014 - 7:44PM

Indigenous Elders urge caution as FASD reaches 'crisis levels'



SHARE



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 Lillilwan Project, a research collaboration between Maminwarntikura Women's Resource Centre and Nindilingarri 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.

Maminwarntikura Women's Resource Centre and Nindilingarri Cultural Health Services present a film by Melanie Hogan

Directed and Edited by [Melanie Hogan](#)
Producers [Jane Latimer](#), [Melanie Hogan](#)
Narration [Tristan McCarthy](#)
Cinematography [Carolyn Constantine](#)
Sound Design [Sam Petty](#)
Music [David Page](#), [Ranahl Skeen](#), [Troy Laurel](#),
[Leah Flanigan](#), [Stephen Pigram](#), [Patrick Davies](#)

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

TRISTAN

HOPES, DREAMS AND CHALLENGES
OF A YOUNG BOY LIVING WITH FASD



TRISTAN

HOPES, DREAMS AND CHALLENGES OF A YOUNG BOY LIVING WITH FASD



Images by E Elliott and C Constantine

United Nations 11th permanent forum on Indigenous Issues, NY, 2012



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



JANDU YANI U

For all the Family



Positive Parenting Program
Triple P International

40 accredited Parent Coaches, 34 Aboriginal, 10 organisations



Research Article

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](#) 

First published: 13 December 2016 | <https://doi.org/10.1111/1440-1630.12352> | Cited by: 1

Open Access

Protocol

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 Jirikowic,⁵ Donna Cross,⁶ Edie Wright,⁷
Emma Adams,¹ Maureen Carter,⁸ Kaashifah Bruce,¹ Jane Latimer⁹

Community – led alcohol restrictions



February 19, 2015[Print](#) [Email](#) [Facebook](#) [Twitter](#) [More](#)

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 —



On SBS Tuesdays 8:30pm
Repeated Wednesday 1:00pm

Follow us on Twitter  

Home Past Episode Archive Featured Sex Addiction Previously Strokes

Drinking When Pregnant

Tuesday, 15 Oct 13



Claire, 22

Claire's anger can be u
off. I get sensory overlo
pregnancy with Claire a
consequences and wa



Tristan, 14

Tristan lives in Fitzroy Valley, Western Australia, with his Aunt Marmingee and Uncle Geoff. His mother drunk heavily when she was pregnant. He struggles with reading and writing and has to be reminded to do basic things like shower. Geoff and Marmingee 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

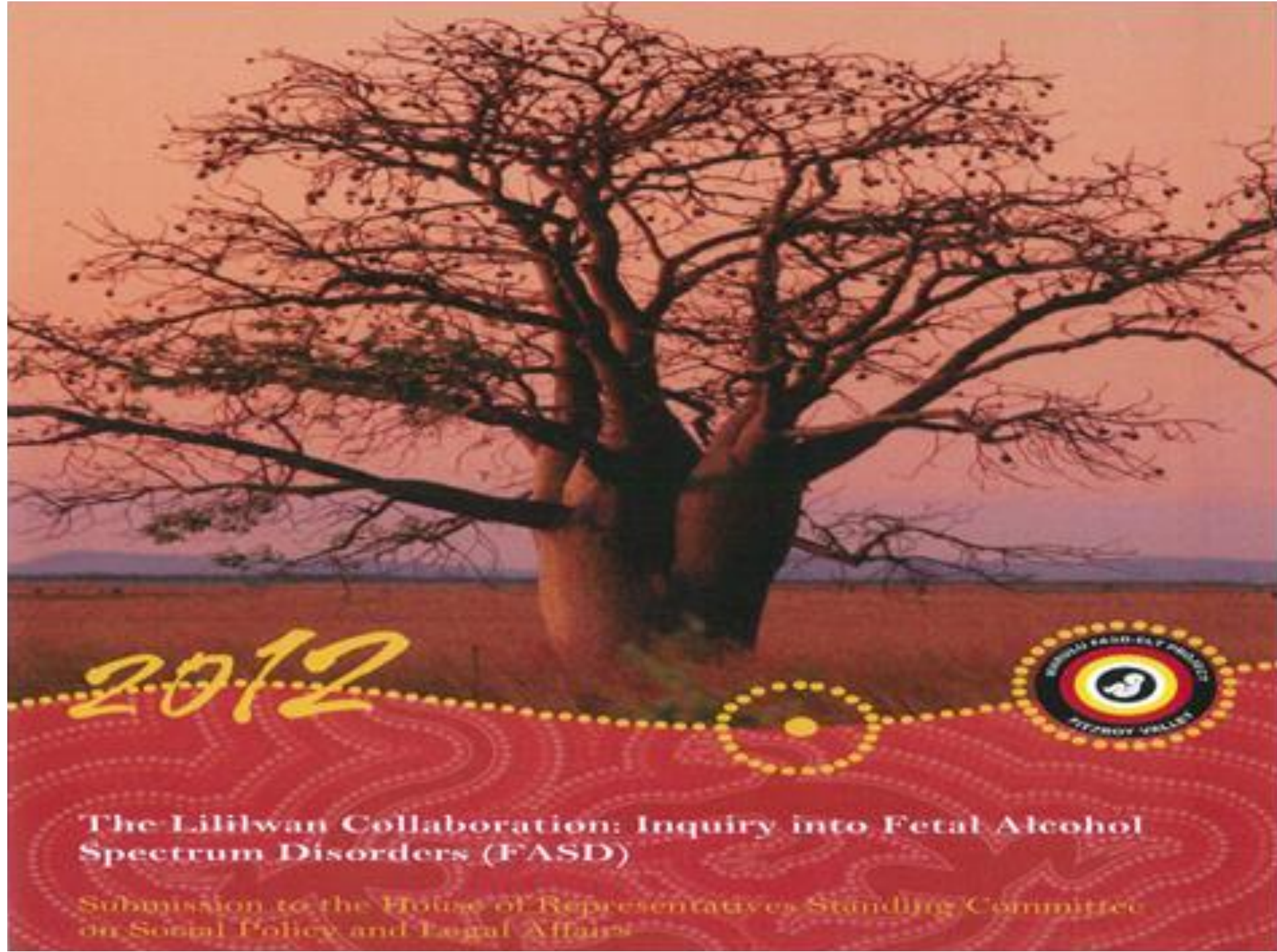
- Dr James Fitzpatrick PhD
- Barb Lucas PhD
- Dr Robyn Doney PhD
- Emily Fitzpatrick PhD
- Philippa Dossetor PhD
- Marmingee Hand MEd
- June Oscar PhD

Post Doctoral Fellows

- Dr Rochelle Watkins
- Dr Tracey Tsang
- Dr Kathryn Thorburn

Medical, Allied Health Students





2012



The Lilibwan Collaboration: Inquiry into Fetal Alcohol Spectrum Disorders (FASD)


Submission to the House of Representatives Standing Committee on Social Policy and Legal Affairs

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





Australian Guide to the diagnosis of FASD

10.jpg

<http://www.apsu.org.au/home/australian-fasd-diagnostic-guidelines/> e-modules, 2016

DOH Funding 2017, 2018



Help me choose

FASD Information

Services

Training & Support

More...



Welcome to FASD Hub Australia

Information on Fetal Alcohol Spectrum
Disorder (FASD) for Australian health



<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

NOFASD Australia

Find out more

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



menzies school of health research

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Fetal Alcohol Spectrum Disorder Preventi

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FETAL ALCOHOL SPECTRUM DISORDER PREVENTION AND HEALTH PROMOTION RESOURCES PACKAGE



The Fetal Alcohol Spectrum Disorder (FASD) Prevention and Health Promotion Resources Package – ‘the Package’ – is designed to equip Australian health professionals with the knowledge and skills needed to develop, implement and evaluate community-driven solutions to reduce alcohol consumption, tobacco smoking and substance misuse during pregnancy, and to cut down on the number of unplanned pregnancies in their communities. During 2015–17, the Package was delivered to staff from participating New Directions: Mothers and Babies Services (NDMBS), a national program to increase access to child and maternal health care for Aboriginal and Torres Strait Islander families.

When surveyed, most health professionals reported they did not ask their clients about alcohol use in pregnancy, or provide women with information about the effects of alcohol on the fetus.² Challenges included limited knowledge and resources among health professionals to tackle the issue, along with a lack of confidence in advising clients. As such, we determined that resourcing and educating health professionals were critical factors to implementing a whole-of-community approach to preventing FASD in Aboriginal and Torres Strait Islander communities.

WHY ARE THESE RESOURCES NEEDED?

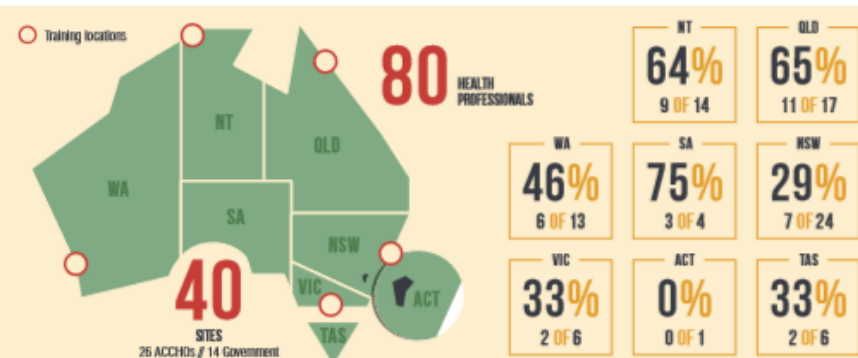
Although high rates of alcohol consumption have been reported across all Australian populations, research shows that Aboriginal and Torres Strait Islander women are more likely to consume alcohol at harmful levels during pregnancy, thereby greatly increasing the risk of stillbirths, infant mortality and infants born with an intellectual disability.³ Addressing the effects of alcohol consumption during pregnancy, and in particular FASD, requires both an understanding of how the cultural context, historical legacy and social determinants affect Aboriginal and Torres Strait Islander people, and the importance of working in partnership with communities and relevant organisations.

PILOTING THE PACKAGE

We piloted two days of training with 80 health professionals from 40 participating NDMBS sites, with the aim of increasing:

- 1 awareness and understanding of alcohol, tobacco and other substances use during pregnancy and of FASD
- 2 awareness of existing FASD health promotion resources and of how best to use these resources within primary health care services in line with their community needs
- 3 knowledge and skills to develop, implement and evaluate community-driven solutions to reduce alcohol consumption, tobacco smoking and substance misuse during pregnancy, and reduce unplanned pregnancies in their communities.

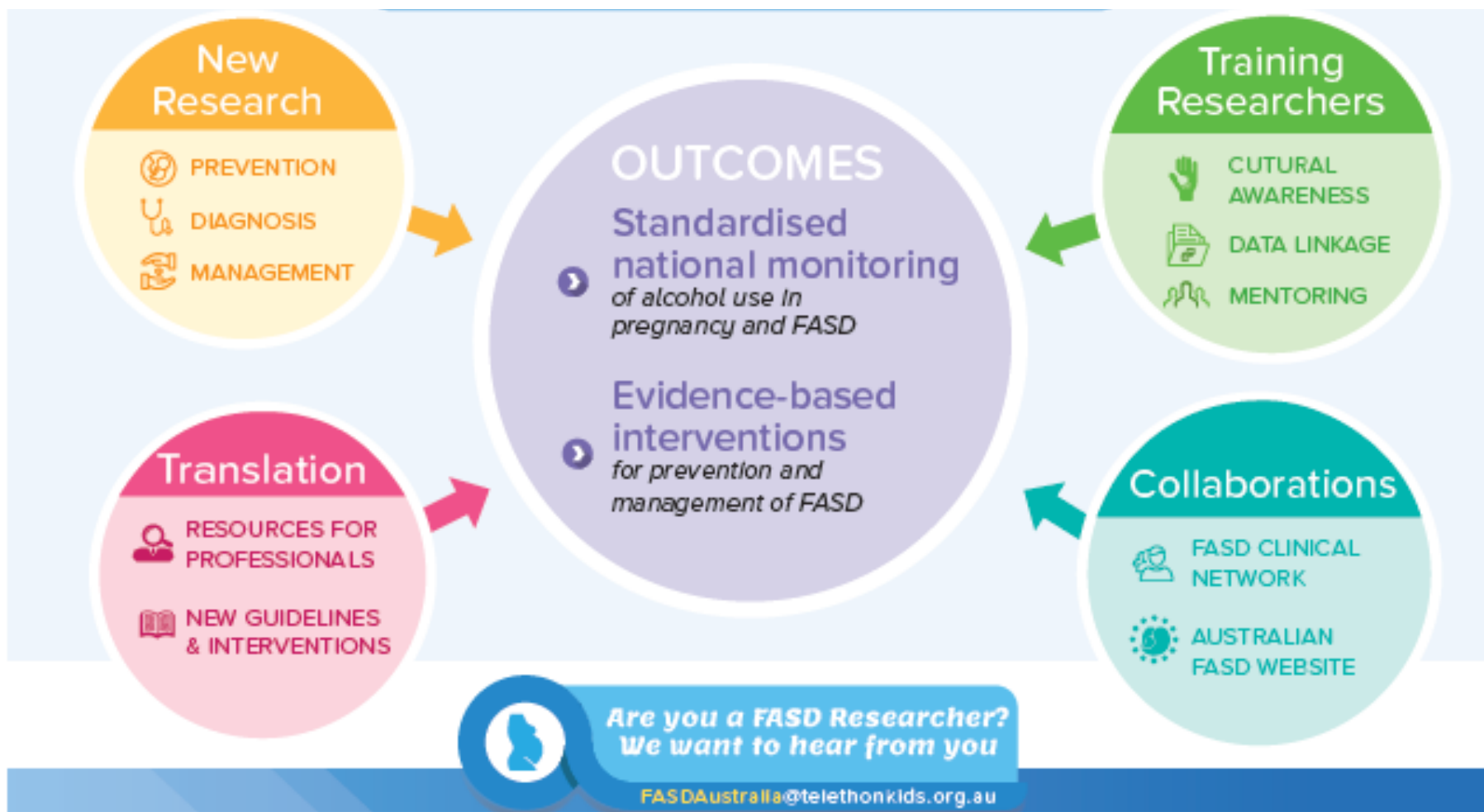
PARTICIPATING NDMBS SITES



FASD Research Australia

Centre of Research Excellence

Generating Knowledge Together



Baird pledges \$2.3 million to fight fetal alcohol spectrum disorder, new centre

March 16, 2015 ☆ Read later

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Sydney Morning Herald
March 16, 2015

*4 year funding
multi-disciplinary
training
education*

NSW Health Aboriginal Videos - women, men, health professionals, youth; storybook, pamphlets



Advocacy

Consultations

- National FASD strategy
- National Alcohol Strategy

Guidelines

- WHO, RACP, AMA

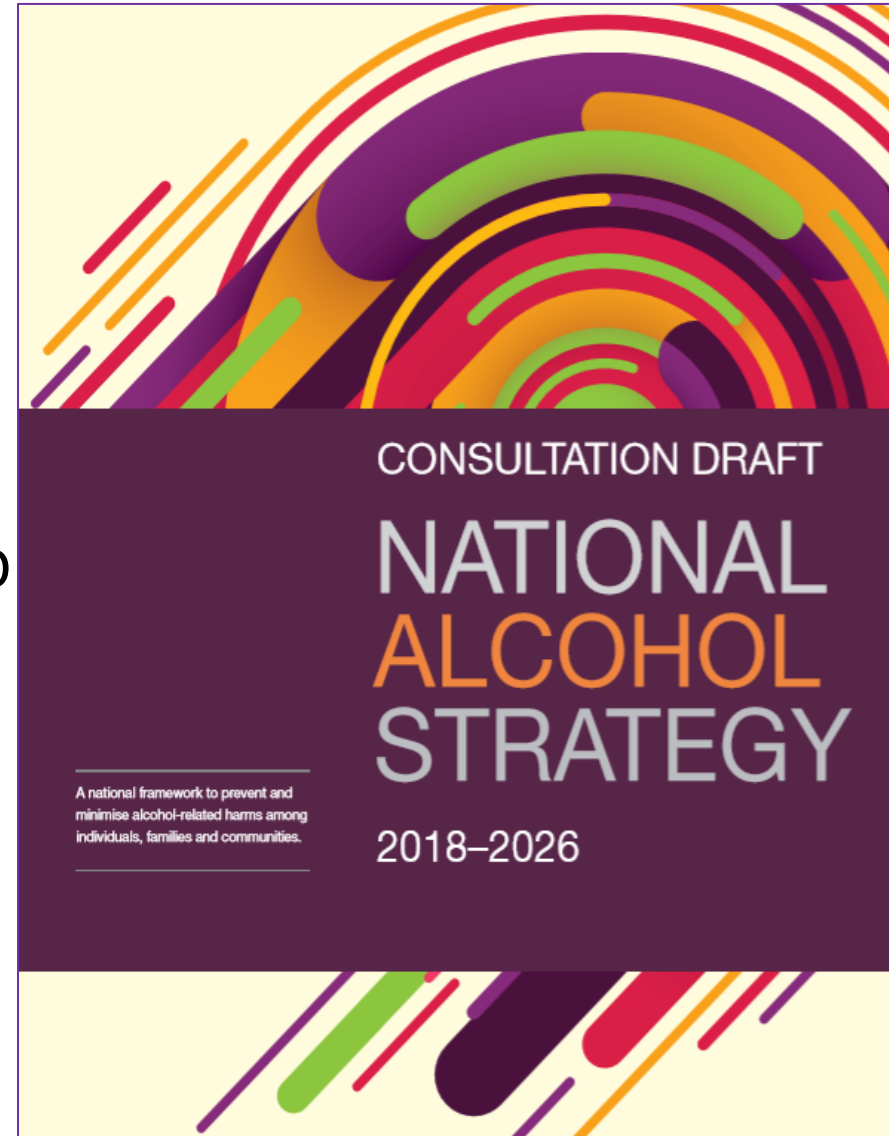
Policy change

- Gilbert and Tobin lawyers:
Advocacy for recognition of FASD
justice system
- Labelling

Inquiries

- Mental health, FASD NT, Alcohol

Media, Scientific meetings



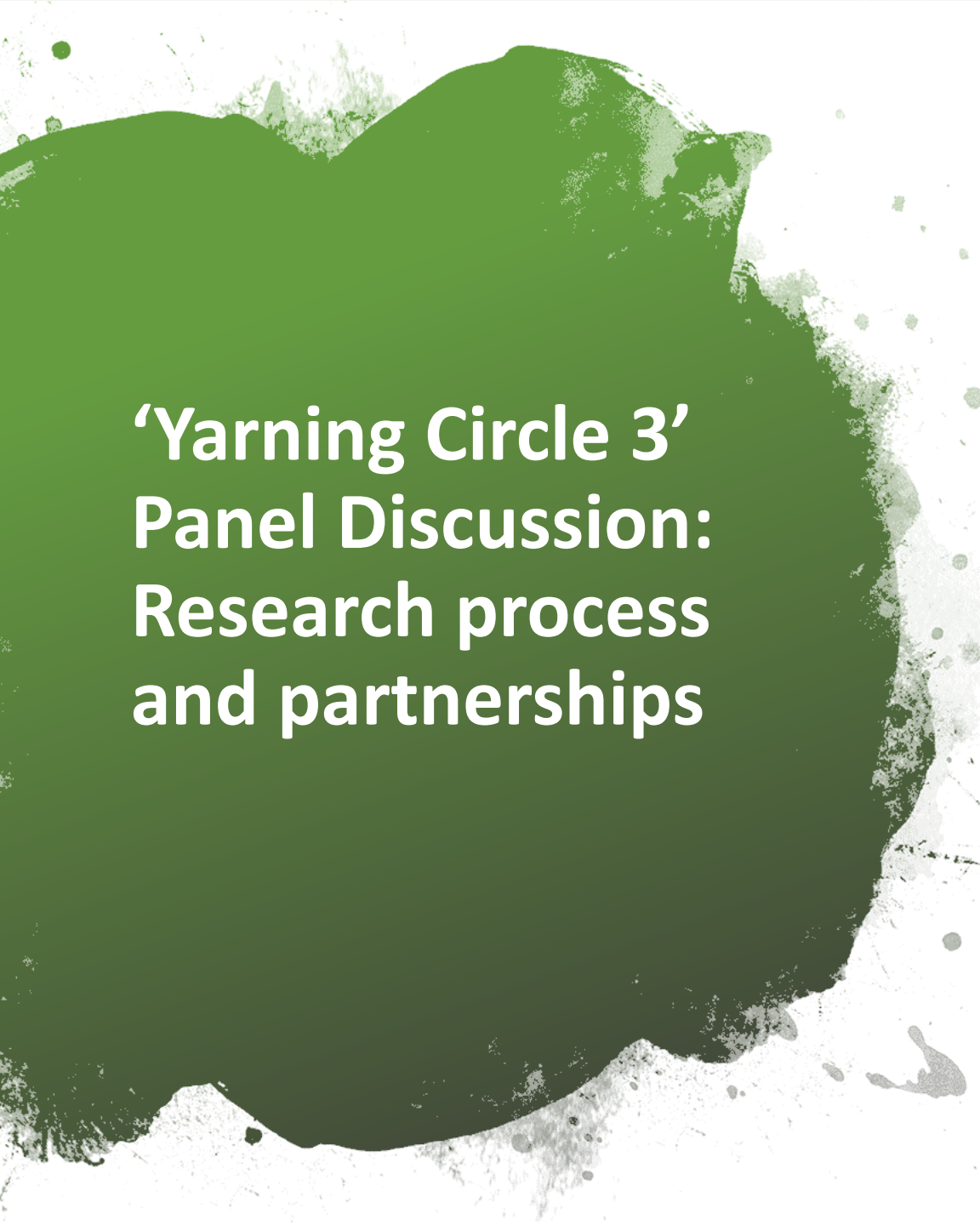
YARNING CIRCLES



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 diagnosis 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



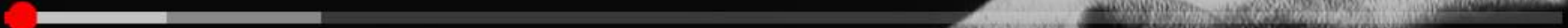
Geoffrey Gurrumul Yunupingu - History (I Was Born Blind)



Watch later



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Geoffrey Gurrumul Yunupingu - History (I Was Born Blind)

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