

# Protection from and predictors of mental illness in a cohort of young Aboriginal people with Fetal Alcohol Spectrum Disorder living in very remote communities: The Bigiswun Kid (adolescent) Project



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# Aboriginal-led research and advocacy

- **2008:** community in crisis; alcohol restrictions
- **2009:** Lililwan Project (FASD prevalence). Invited USyd to partner.
  - 95% children Fitzroy Valley (7-9 years, born 2002-3)
  - 55% prenatal alcohol exposure; **19% FASD**
  - >400 referrals to health, mental health services
- **2017:** Aboriginal women concerned Lililwan cohort were struggling in adolescence.
- USyd invited to partner to conduct follow-up at 10y (17-19y)



# Bigiswun Kid Project: Aims



## Overall aim:

- identify health/mental health needs of adolescents to inform development/enhancement of services to improve health & well-being.

## Specific aims

- Establish rates of ***adverse childhood experiences; self-reported symptoms of mental ill-health and wellbeing*** (psychological distress and thriving); ***diagnosed mental illness in youth with/without FASD***
- ***Predictors of and protective factors*** for mental illness

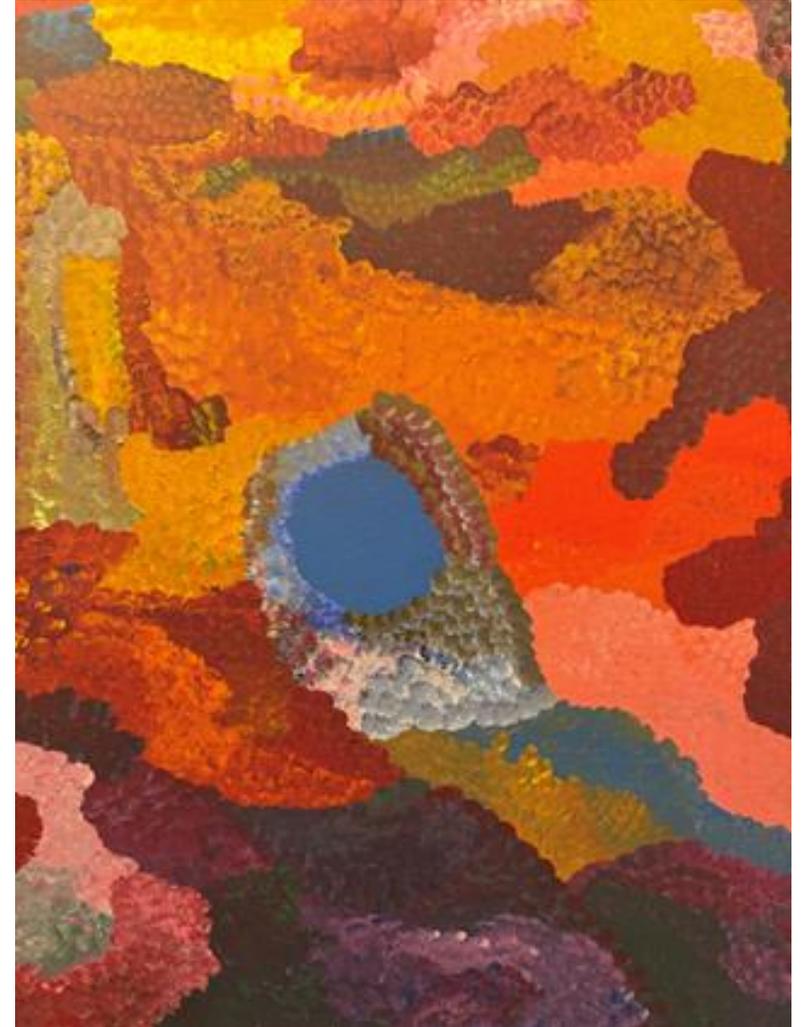
FASD associated with mental illness in children and adults including ND disorders, self-harm, suicide, substance use (*Wilson, Streissguth*)

? *Brain injury ?epigenetic ?secondary to impairments ?Adverse Child Experiences*

# Bigiswun Kid Project: Methods

## Aboriginal Participatory Action Research (APAR)

- Aboriginal leadership, co-design
- Action – translation during data collection
- Community, parent, and adolescent consultation and consent
- Interviews with adolescents
- Interviews with parents
- Qualitative, quantitative analysis, data linkage



**Purlta Maryanne Downs**



- **Demographics**
- **Prenatal Alcohol Exposure (55%):** *AUDIT-C, interview, records*
- **FASD Diagnosis age 7-9y (19%):** MDT - IOM criteria
- **Adverse Childhood Experiences:** Revised ACE scale
- **Self-reported symptoms psychological stress and wellbeing**
  - Depression, Anxiety, Suicidality: Strong Souls Inventory
  - Resilience: Strong Souls Inventory
  - Hopefulness and Despair: Hunter Opinion personal expectation Scale
- **PTSD:** DSM-5 PTSD Screener
  - Home, education, employment HEEADSSS
  - Activities/relationships/media, drugs/alcohol, sexuality/gender, suicide/self-harm, safety/spirituality
- **MH diagnosis:** Psychiatrist
- **Peer/family Trust/closeness** Body-self relations Qu
- **Behaviour, int/ext problems:** CBCL/TRF

## Results (n=94)

We found and interviewed:

94 (83%) of the Lililwan cohort) at age 17-19 years

101 (89%) of their parents

FASD (23%)

Psychiatrist-diagnosed mental health disorder (11%) vs 14% gen. pop.

The **two** most requested supports (requested by 100% of parents and young people) were:

Culturally appropriate **social and emotional wellbeing (mental health) service**

Opportunities to participate in **on-country and cultural activities**

## Have adolescents with a diagnosis of FASD experienced more Adverse Childhood Experiences (ACE) than those without FASD? (n=94)

- Adverse Childhood Experiences almost universal with ***no difference*** in mean ACE scores, or in the proportion with ACE scores >4 in adolescents with/without FASD ( $P>0.05$ )

## Is a diagnosis of FASD (versus no FASD) associated with differences in self-reported wellbeing or distress? (n=94)

- Higher self esteem OR 2.04 (95% CI 0.10, 3.98) P=0.04
- Less resilience OR -2.43 (95% CI -.47, -0.11) P=0.04
- No difference in self-reported anxiety, depression, PTSD, suicidal ideation between groups (P>0.05)

## Is a diagnosis of FASD associated with psychiatrist-diagnosed MH disorder? (n=94)

Adolescents with FASD diagnosis had a 5 times higher rate of psychiatrist-diagnosed mental health disorders than those without FASD

OR 5.33 (95% CI 1.32, 24.84) P=0.02

# In adolescents with FASD what predicted a psychiatrist-diagnosed mental health disorder?

## Significantly increased risk of diagnosed Mental Health disorder (P<0.05)

- No-one to go to when sad OR 4.85 (95% CI 1.004, 20.95)
- Total behaviour problems\* OR 1.04 (95% CI 1.01, 1.06)
- Externalising problems\* OR 1.09 (95% CI 1.03, 1.06)

\*Child Behaviour Check List, Teacher Report Form 7-9y.

# In adolescents with FASD what protected against a psychiatrist-diagnosed mental health disorder?

## Significantly decreased risk of MH disorder (P<0.05)

- Living >100km from town: OR 0.43 (95% CI 0.098, 0.54) P=0.04
- Strong parent attachment (trust): OR 0.75 (95% CI 0.59, 0.92) P=0.007
- Strong peer attachment (trust): OR 0.87 (95% CI 0.75, 0.99) P=0.033
- Close to family/household members OR 0.099 (95% CI 0.01, 0.49) p=0.003

# In adolescents with FASD what factors had no impact on psychiatrist-diagnosed mental health disorder?

**No significantly increased or decreased risk of MH disorder ( $P > 0.05$ )**

- Prenatal Alcohol Exposure (No FASD)
- Resilience
- Active hours sleep past week
- Exercise past week
- Alcohol or Ganja use
- Death or suicide of someone close
- Number of homes lived in
- Internalising problems at 7-9 years on CBCL-TRF
- Impairment in cognition, executive function or adaptive function

# Adolescents with FASD

5 times higher rate MH diagnosis

Similar ACE

Decreased resilience

## In adolescents with FASD

*Protective factors for MH disorders*

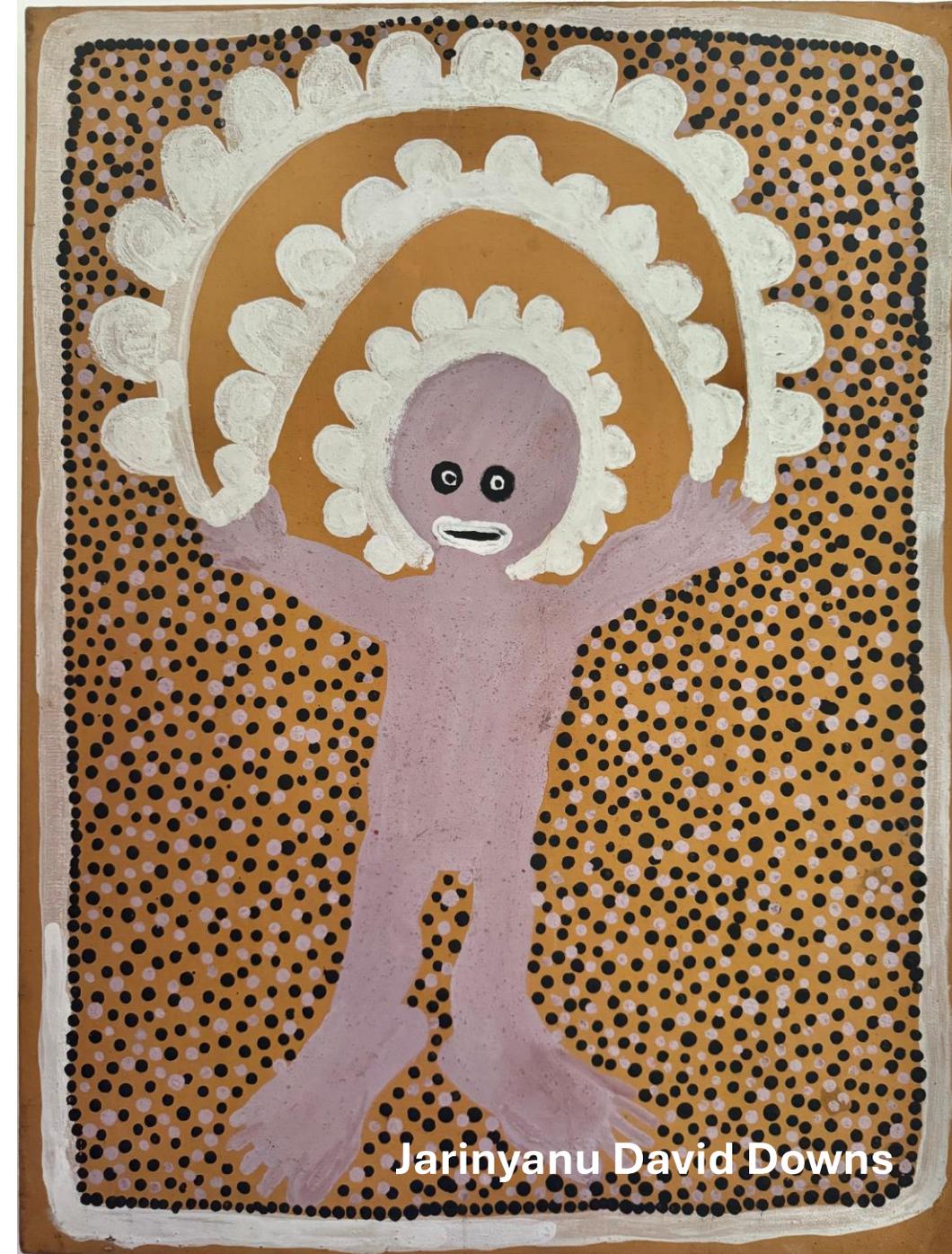
Peer and family connection and support

Living out of town, traditional practices

*Predictive factors for MH disorders*

Behavioural and externalizing problems 7-9y

No-one to talk to about worries



# Translating research into a culturally appropriate response

- ***Aboriginal participatory action research, embedded co-design and leadership, voices of adolescents and parents enabled research in action***
- Funding from MH Commission of WA for pilot SEWB service
- Mental health education and psychological support. *“Educate our people on mental health – about having a healthy mind and what makes your feel like that. Education and knowing who to talk to” – parent*
- Wellbeing workshops –activities (art, music, pampering, gardening)
- Workshops - child development, parenting, suicide-prevention, mental health fist aid
- Supported adolescents to navigate existing services (e.g., help navigating health services, obtaining a birth certificate, ID, driver’s license, employment, NDIS)
- Youth mentor/support – organized sport, on-country traditional activities (Rangers Camp, Men’s camps). *On-country is the best thing for our kids, spiritual healing when you don’t need words. Just being there makes you feel safe and happy inside.” - Parent*
- Youth night hub - Fitzroy Crossing
- Supported work programs, tertiary education entry



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