

***Predictors and opportunities for prevention of mental health disorders in adolescents with FASD living in very remote Australian communities:  
The Bigiswun Kid Project***



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# Aboriginal-led research and advocacy

- **2008:** FV 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
- **2019:** Aboriginal women concerned Lililwan cohort were struggling in adolescence.
- USyd was invited to partner to conduct follow-up at 10y (17-19y)



# Bigiswun Kid Project: Aims



**FASD associated with mental illness in children/adults**

*(Wilson, Streissguth)*

## **Overall aim:**

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

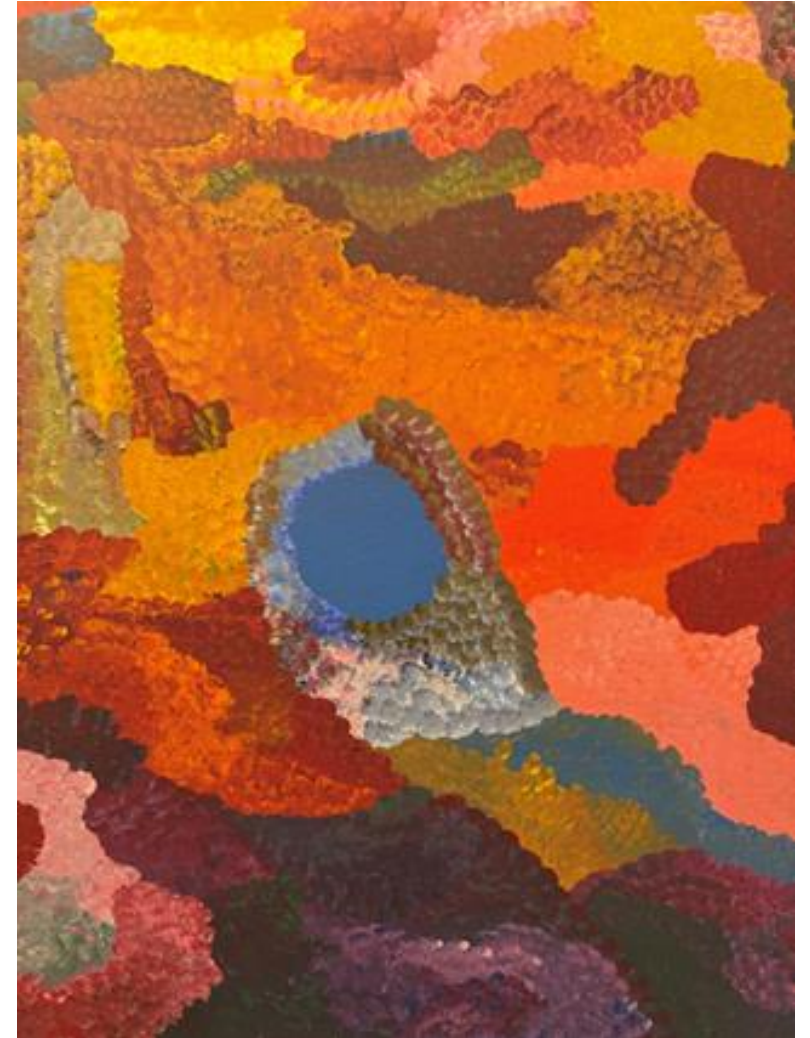
## **Specific aims**

- 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***
- ***Early childhood indicators and adolescent risk and protective factors*** for mental illness

# Bigiswun Kid Project: Methods

## Aboriginal Participatory Action Research (APAR)

- Aboriginal leadership, co-design
- Community, parent, and adolescent consultation and consent
- Interviews with adolescents
- Interviews with parents
- Qualitative, quantitative analysis, data linkage
- Research translation - action for immediate benefits  
e.g. access health and mental health services



**Purlta Maryanne Downs**



# Bigiswun Kid Project: Methods

- **Demographics**
- **Prenatal Alcohol Exposure (55%):** *AUDIT-C, interview, records*
- **FASD Diagnosis age 7-9y (19%):** MDT – Canadian criteria
- **Adverse Childhood Experiences:** Original & 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

\* Omitted question on sexual abuse; \*\* Designed validated for Aboriginal people



# Bigiswun Kid Project: Methods

- **PTSD:** DSM-5 PTSD Screener
- **Adolescent characteristics**  
Home, education, employment HEEADSSS  
Activities/relationships/media,  
drugs/alcohol, sexuality/gender,  
suicide/self-harm, safety/spirituality
- **MH diagnosis:** Psychiatrist/Paediatrician/GP
- **Peer/family relationships**  
Trust//closeness Body-self relations Q
- **Behaviour, internalising/  
externalising problems:** CBCL/PRF & TRF

# Bigiswun Kid Project: Results

We located and interviewed:

- 94 (83%) of the Lililwan cohort at age 17-19 years
- 101 (89%) of their parents

FASD 21/94 (**22%**)

Diagnosed MH disorder 12/94 (**13%**) vs. 14% gen. pop. *Lawrence et al, 2016*

The **two** most requested supports (100% of parents, young people)

- Culturally appropriate **social and emotional wellbeing (mental health) service**
- Opportunities to participate in **on-country and cultural activities**

\* No comparative data in Australian Aboriginal population

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

- ACE score  $\geq 1$  (**97%** vs. 60%)  
ACE score  $\geq 4$  (**61%** vs. 15%)  
SR 206 studies (>0.5m mill. Adults in general population)\* *Madigan 2023*
- FASD mean score 4.79 vs non-FASD 3.79 (P>0.05)
- Adverse Childhood Experiences almost universal with ***no difference*** in mean ACE scores in adolescents with/without FASD

Univariable linear regression analyses were used to examine the difference in ACEs

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

- No difference in self-reported anxiety, depression, PTSD, suicidal ideation between groups ( $P > 0.05$ )

## A diagnosis of FASD was associated with

- Less resilience: Mean Difference -2.43 (95% CI -0.47, -0.11)  
P=0.04
- Higher self esteem: Mean Difference 2.04 (95% CI 0.10, 3.98)  
P=0.04

Univariable linear regression analyses were used to examine the difference in self-reported symptoms of wellbeing

# Is a diagnosis of FASD (versus no FASD) associated with clinician-diagnosed MH\* disorder? (n=94)

Adolescents with a FASD diagnosis had a 5x higher rate of mental health disorders than adolescents without FASD

FASD: OR 5.00 (95% CI 1.39, 20.06)  $P \leq 0.01$

PAE: OR 5.68 (95% CI 1.25, 54.32)  $p = 0.02$

\* Psychiatrist, Paediatrician or GP; MH diagnoses DSM-5 criteria included: PTSD, Anxiety Disorder, Reactive Attachment Disorder, Oppositional defiant disorder

# Early childhood indicators for diagnosed mental health disorder in adolescents

Predictor*	OR (95% CI) P value
Parent-rated Total Behavioural Problem Score (n=70)	1.07 (1.03, 1.12) P ≤0.01
Teacher-rated TBPS (n=78)	1.04, (1.02, 1.06) P ≤0.01
Parent-rated externalizing behaviour (n=70)	1.18 (1.07, 1.33) P ≤0.01
Teacher-rated externalizing behaviour (n=78)	1.10 (1.04, 1.17) P ≤0.01
Parent-reported internalising behaviour (n=70)	1.18 (1.03, 1.12) P ≤0.01

\*\* Child Behaviour Check List - Teacher and Parent Report Form, age 7-9 years

**Firth's Logistic Regression** used to identify early childhood indicators and protective/risk factors for mental illness

# Protective factors for a diagnosed mental health disorder?

## Significantly decreased risk of MH disorder

- Strong parent attachment (trust) OR 0.78 (95% CI 0.62, 0.93)  $P \leq 0.01$
- Close to family/household members OR 0.07 (95% CI 0.01, 0.34)  $P \leq 0.01$
- Adolescent raised by a birth parent OR 0.15 (95% CI 0.04, 0.54)  $P \leq 0.01$

**Firth's Logistic Regression** used to identify early childhood indicators and protective and risk factors for mental illness

# In adolescents the following factors had no significant impact on risk of a diagnosed mental health disorder

- ACE score
- Active hours sleep past week
- Alcohol or Ganja use
- Death, suicide of someone close
- Hearing loss
- Microcephaly
- Number of homes lived in
- School connectedness
- Self-esteem

**Firth's Logistic Regression** used to identify early childhood indicators and protective/risk factors for mental illness

## Adolescents with FASD

- 5 times higher rate MH diagnosis
- Similar ACE scores to those without FASD
- Similar self-reported MH symptoms
- Decreased resilience

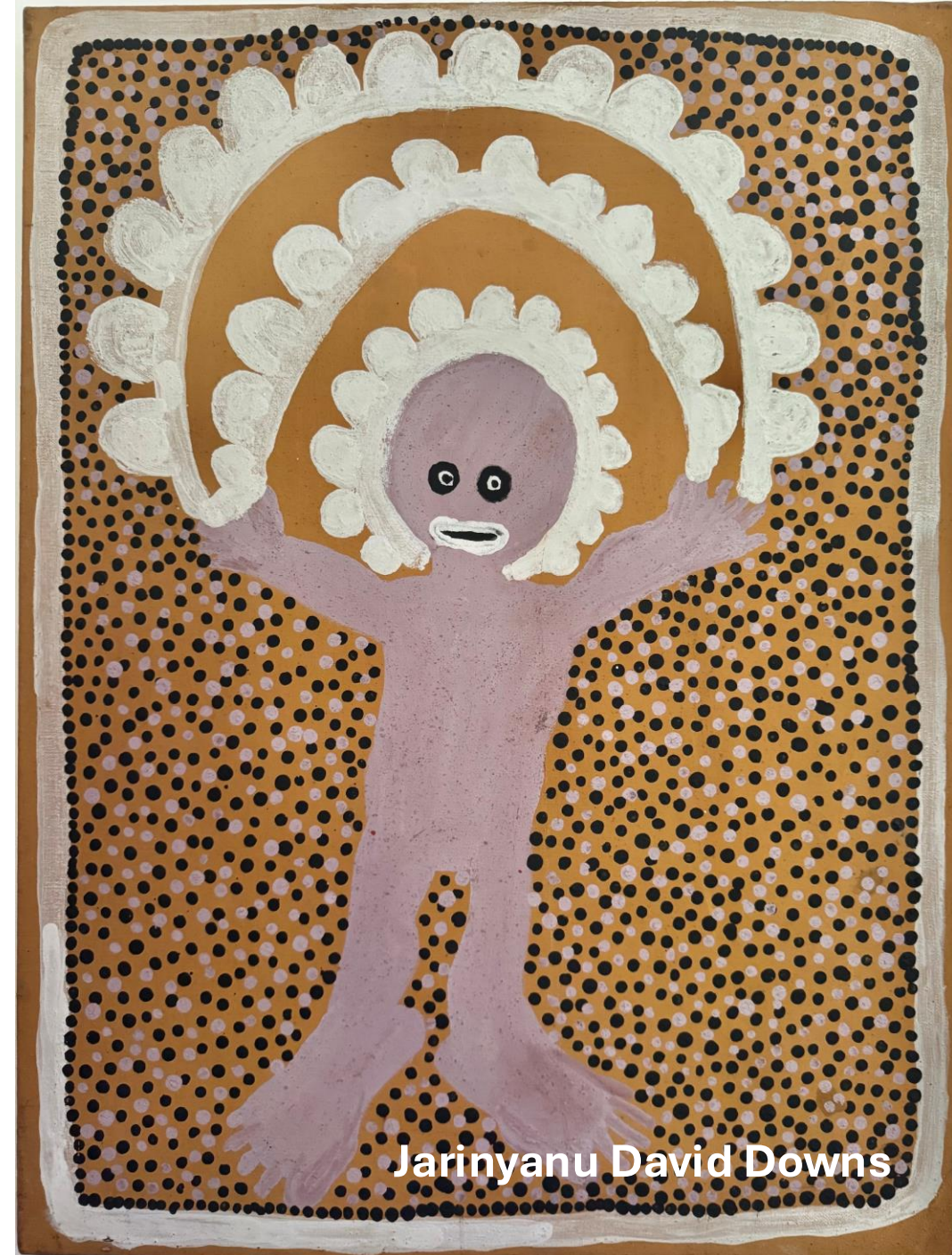
## In adolescents

### *Protective factors for MH disorders*

- Family (kinship) connection and support
- Parent attachment
- Raised by birth parent

### *Risk factors for MH disorders*

- Internalising and externalising behaviours &
- Total problem score 7-9y



Jarinyanu David Downs

# ***Rapid translation of research into action***

## ***- guided by the community***

- Mental health education and psychological support.  
*“Educate our people about having a healthy mind” and “who to talk to”*
- Workshops
  - Wellbeing (art, music, pampering, gardening)
  - Child development, parenting
  - Suicide-prevention, mental health first aid
- Support adolescents to navigate existing services
  - e.g. health services, obtaining a birth certificate, ID, driver’s license, employment, NDIS
- Youth mentor
  - Organized sport, traditional on-country activities (Rangers Camp).  
*“On-country is the best thing for our kids, spiritual healing, you don’t need words. Just being there makes you feel safe and happy inside.”*
- Supported work programs, tertiary education entry

# *Conclusions*

- Aboriginal participatory action research
  - embedded leadership and co-design
- Voices of adolescents and parents in very remote settings
- Rapid translation of research into action
- Influence government
  - Funding from MH Commission of WA for pilot Social Emotional Wellbeing Service
  - Funding for a Youth Night Hub in Fitzroy Crossing (30% decrease in police contact)



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