Empowering Remote Communities to Address Fetal Alcohol Spectrum Disorder (FASD): An Effectiveness-Implementation Study Protocol

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Funding

Expansion of FASD Services in Queensland Establishing Diagnostic Services in Remote Communities. Australian Government Department of Health: Drug and Alcohol Prevention and Early Intervention: Fetal Alcohol Spectrum Disorder Diagnostic Services and Models of Care Grant (H1617G038)

JAMA | Original Investigation

Prevalence of Fetal Alcohol Spectrum Disorders in 4 US Communities

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- 1.13 – 5% - conservative estimate
- 3.11 – 9.85% - less conservative estimate
- 0.01% previously identified

MAIN OUTCOMES AND MEASURES Prevalence of fetal alcohol spectrum disorders in the 4 communities was the main outcome. Conservative estimates for the prevalence of the disorder and 95% CIs were calculated using the eligible first-grade population as the denominator. Weighted prevalences and 95% CIs were also estimated, accounting for the sampling schemes and using data restricted to children who received a full evaluation.

RESULTS A total of 6639 children were selected for participation from a population of 13 146 first-graders (boys, 51.9%; mean age, 6.7 years [SD, 0.41] and white maternal race, 79.3%). A total of 222 cases of fetal alcohol spectrum disorders were identified. The conservative prevalence estimates for fetal alcohol spectrum disorders ranged from 11.3 (95% CI, 7.8-15.8) to 50.0 (95% CI, 39.9-61.7) per 1000 children. The weighted prevalence estimates for fetal alcohol spectrum disorders ranged from 31.1 (95% CI, 16.1-54.0) to 98.5 (95% CI, 57.5-139.5) per 1000 children.

CONCLUSIONS AND RELEVANCE Estimated prevalence of fetal alcohol spectrum disorders among first-graders in 4 US communities ranged from 1.1% to 5.0% using a conservative approach. These findings may represent more accurate US prevalence estimates than previous studies but may not be generalizable to all communities.

Getting FASD into routine care

- In Queensland, FASD assessment and diagnosis currently undertaken in specialist FASD clinics
  - Time intensive
  - Long waitlists
- Estimated that 3 357 multidisciplinary diagnostic clinics are required – just to assess new cases ~ Prof Larry Burd, International FASD Conference, 2017
- Often seen as too complex to be diagnosed by General Practitioners
- We are working towards enabling primary care practitioners to take part in FASD assessments
- Particularly in remote areas without access to specialist services

Northwest Queensland Communities

- Population is approximately 32 621
- 23.1% - 94% of people identify as First Nations (compared to 3.1% for QLD)
- Half of the population is in the lowest category for socioeconomic disadvantage
- More than 85% in some areas the most disadvantaged category

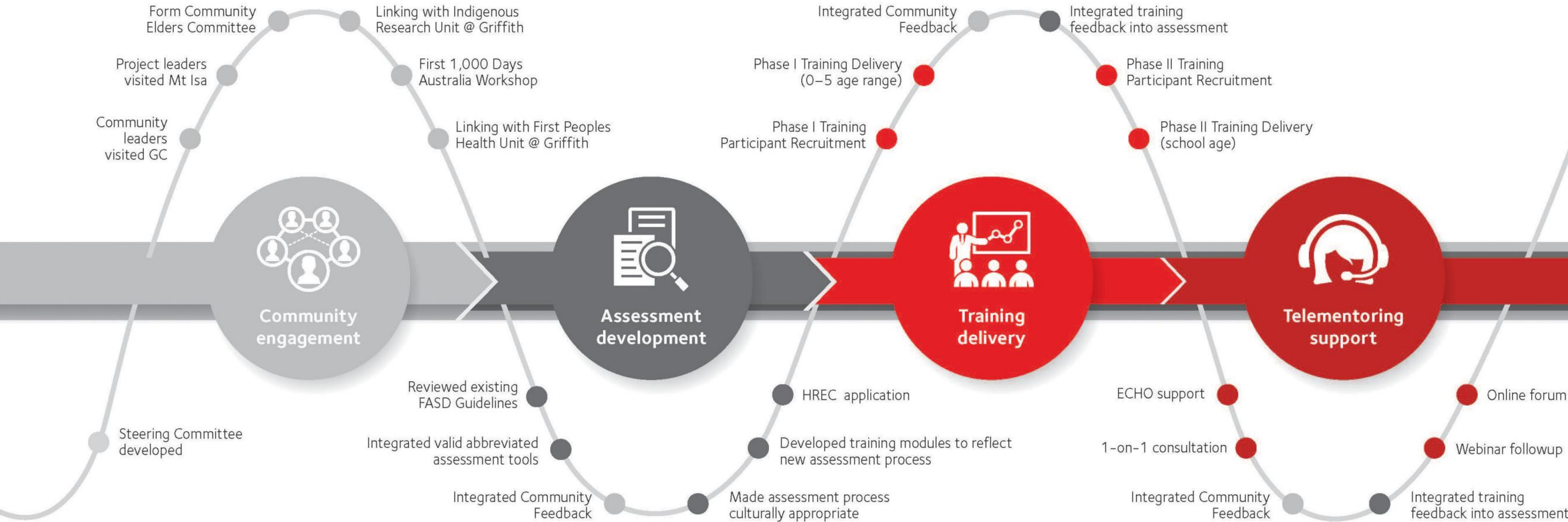
Project Objectives

1. Co-create an FASD model of care that integrates seamlessly with established community practices

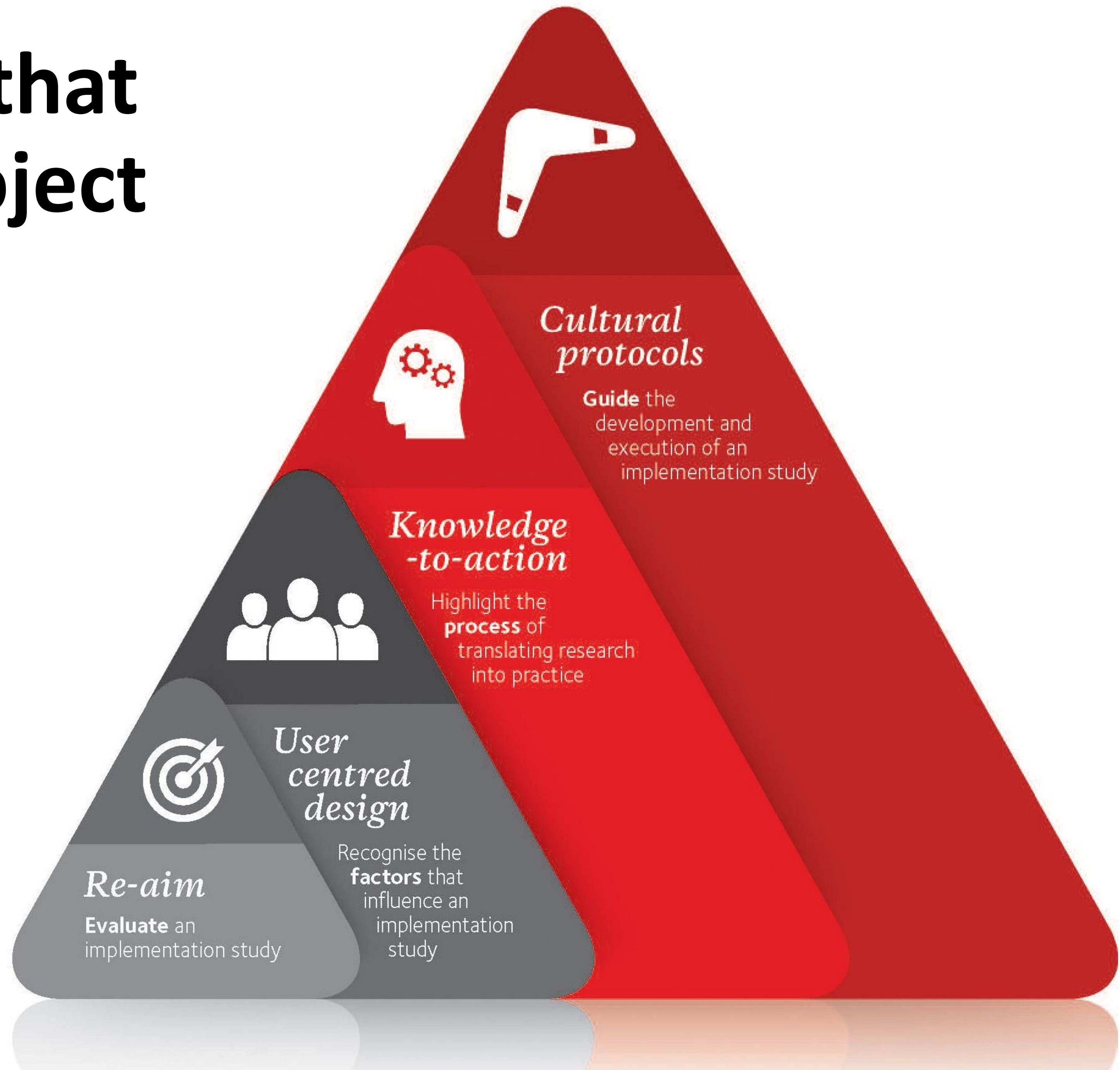
2. Train remote practitioners with varying levels of experience in the diagnosis and management of neurodevelopmental disorders, specifically FASD

3. Sustainably support the new service delivery model by providing ongoing tele-mentoring support from neuro-developmental experts

The journey of empowering remote communities to address FASD



Frameworks that Guide the Project



Community Context

- Limited services, no local FASD specialists; 2 year waitlist at closest FASD specialist clinic (5 hr travel time)
  - Psychologists, Speech pathologists, OTs, Physios not always available
- Conducted a recent FASD training day in the region
  - 90 practitioners across 32 organisations
  - enthusiasm to contribute to assessments in the local area
  - Importance of a culturally appropriate assessment process
    - Framework for explaining the assessment process
    - Culturally sensitive informed consent
    - Soft-entry to the assessment process
    - Indigenous Health Worker (Elder) coordinating client care

Co-creating a Tiered Assessment Process (TAB)

- Break the assessment process into manageable chunks
- Dreamtime story supports the assessment process
- Health workers or educators as well as Allied Health Practitioners, nurses, GPs and other primary care providers collect information
- Valid and reliable measures of brain domains completed in the child's daily living environment
- Diagnostic decision making conducted by GPs, Psychologists or Paediatricians available in the community
- Outlines clear decision support tools for referral to specialist
- Flexibly yet consistently apply the Australian FASD guidelines for diagnosis

Tiered Assessment Overview

Tier 1: Collecting consent and sharing the dreamtime story

- Principle: Informed consent and understanding the assessment journey is integral

Tier 2: Developmental interview and facial features

- Principle: Understand the child's context and background

Tiered Assessment Overview

Tier 3: Rapid Neurodevelopmental Assessment

- Principle: Learn about the child's abilities and skills
  - A snake with great reflexes (reflexes).
  - A goanna running up and down the river (gross motor).
  - A koala drawing a picture while looking at the tree (fine motor).
  - An owl with big eyes (vision).
  - A bird listening to the sounds of the winds and water (hearing).
  - A Kookaburra yapping away (speech).
  - A wombat thinking very deeply (cognition).
  - A crocodile in the river looking at everyone's behavior (behavior).
  - And a Kangaroo jumping up and down making the ground shake (seizures).

Tier 4: Adaptive, Attention, Executive Functioning, Affect and Academic Assessments

- Principle: gather more information to further inform diagnosis and support for the child and family

Overview of the tiered assessment process

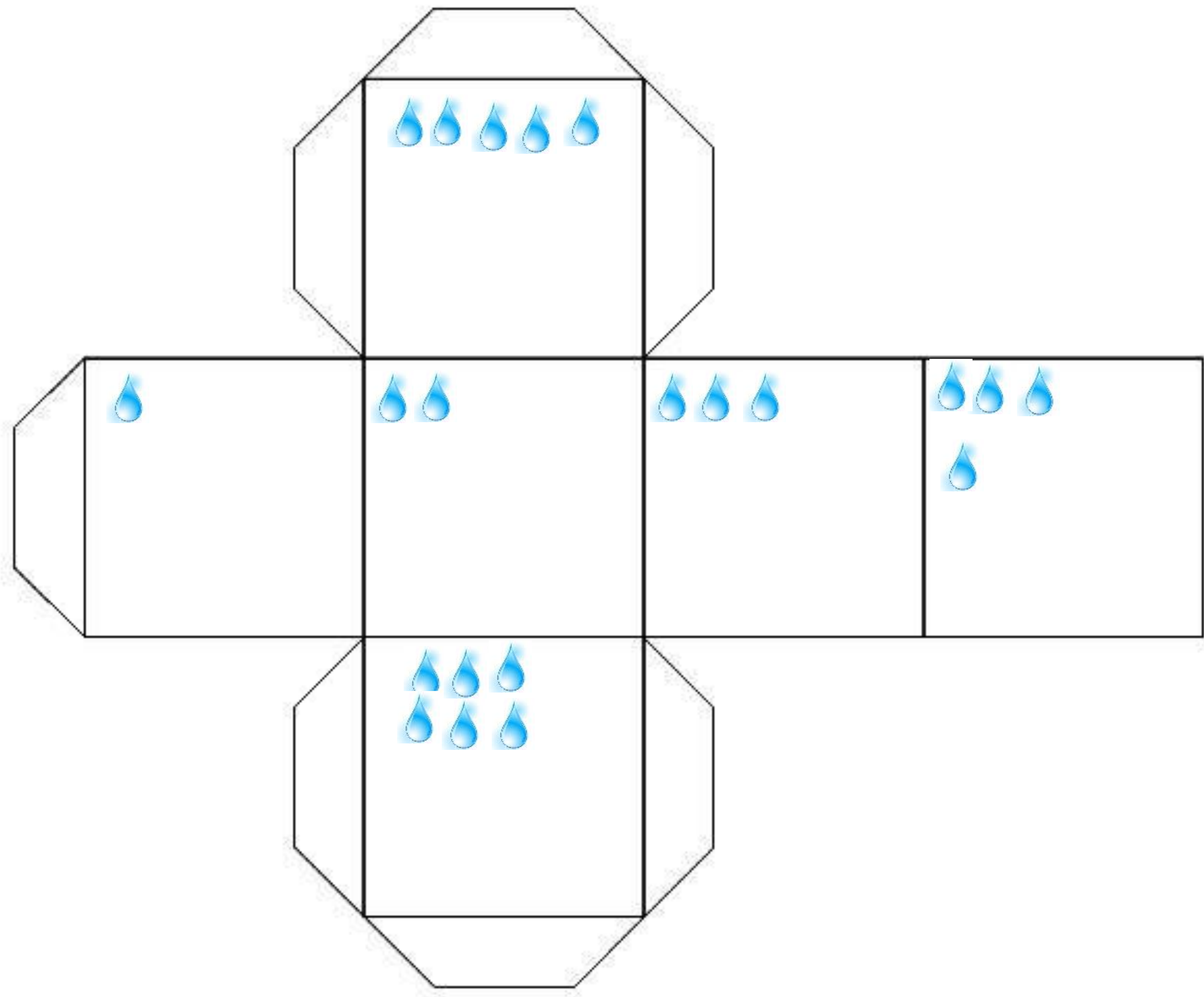
Tier 5: Feedback and strategies

- Principle: Build a positive self-identity, changing the environment to meet the child where they are at, changing our expectations of successes and failures.
- Principle: Build strong relationships, enhance child development (play, read, diet)

Tier 6: Further specialist assessments and/or case conference

- Principle: More detailed information may be needed in any of the 10 neurodevelopmental domains

Dreamtime story: By Marjad Page



Tier 1

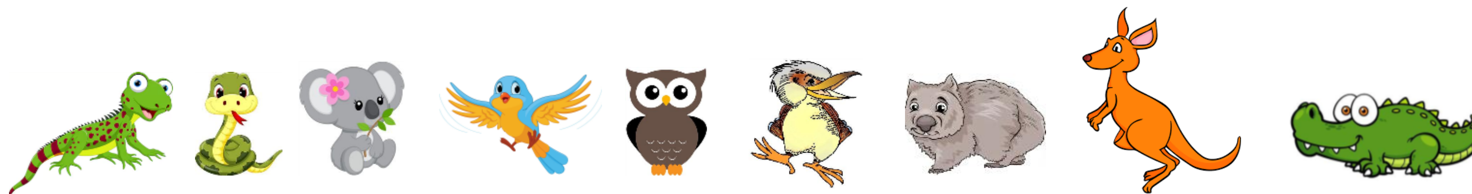
- No matter what you think, feel and do, you are mine and I will be with you.
- No matter how you move, hear and see, you are mine and will be MY CALM BABY.
- So let's discover ourselves on this journey, together as a family.

After that one rain drop fell from the sky, and the river started to fill up.

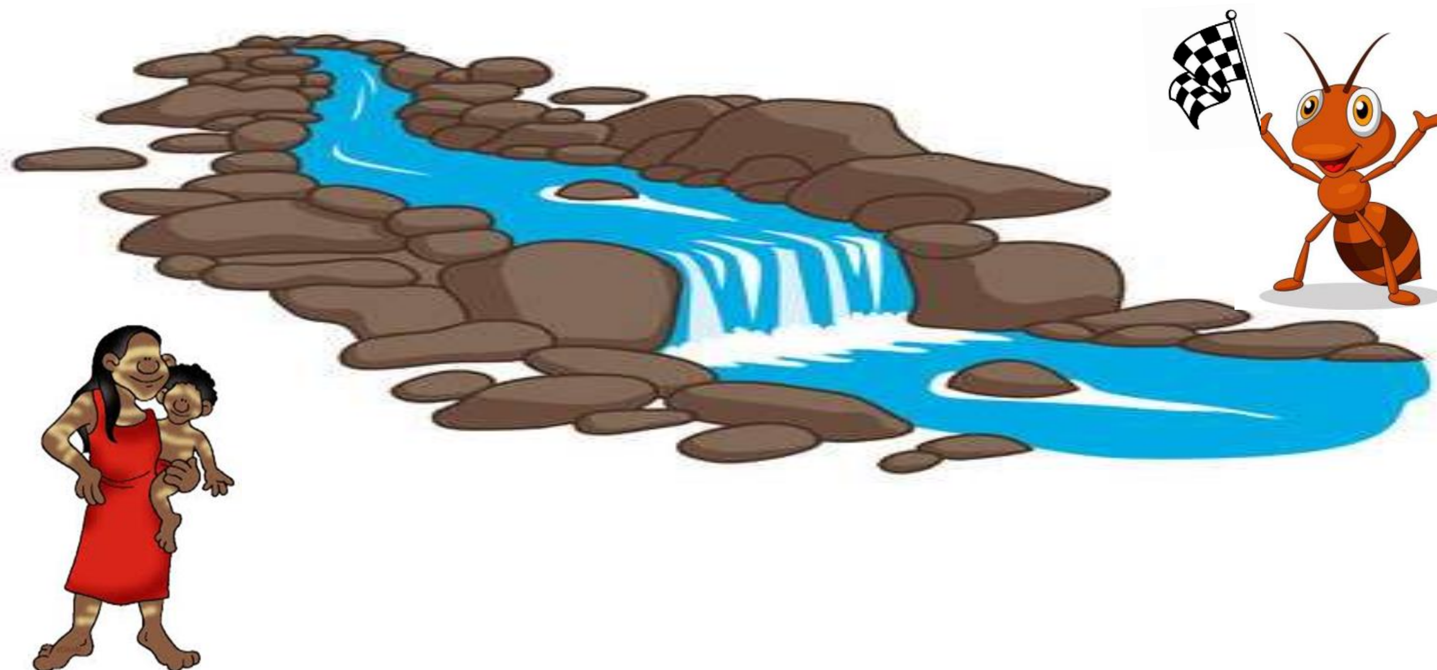
Tier 2

- No matter what you think, feel and do, you are mine and I will be with you.
- No matter how you move, hear and see, you are mine and will be MY CALM BABY.
- So let's discover ourselves on this journey, together as a family.

After that one rain drop fell from the sky, and the river started to fill up.



Tier 5



- You are you and that’s good enough. You are not a kangaroo, but you are tough. You are you and that’s what I need. You are not a koala, but you are a good seed. You are you and that’s what the world screams for. You are not a wombat, but you are Marjad and will continue to soar.
- Five rain drops fell from the sky, and the river started to flow.

Where we are headed

1. Does TAB produce the same outcomes as FAB?
2. Can primary care practitioners (GPs) play a larger role in the assessment process as part of routine practice?
2. Cost-effectiveness of the TAB process compared to the FAB process?
3. How generalizable is the TAB process to new communities?

THANK-YOU