“Not just using the words”

Cultural factors and behavioural diagnoses

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Acknowledgement of Country

We acknowledge the Cadigal, Wangal and Bediagal people as the traditional owners and custodians of the land on which this work takes place.

We pay respect to Elders past, present and emerging, who hold the memories, traditions, cultures and hopes of Aboriginal and Torres Strait Islander peoples.

We recognise that their story began long before ours, and we thank them for generously sharing their lands, culture and knowledge with us.

The voices in this talk

UT

Uncle Terry Denzil

Community Elder

AD

Aunty Deb Daley

Aboriginal Education Officer

VE

Vanessa Edwige

Senior School Psychologist

UD

Uncle Des Barton

AECG

"We accept that it is our responsibility to ensure that their voices are heard."

Rungan, Denzil, Daley & Edwige, Journal of Paediatrics and Child Health, 2022

Today's talk

1. **Culture and behavioural diagnoses** — The yarn · History · Diagnoses today
2. **School-based integrated care** — The ask · The model · Results · Scale-up
3. **The journey forward**

PART 1

Culture and behavioural diagnoses

What does ‘childhood behavioural disorders’ mean in the context of Aboriginal culture?

Having a yarn: family, community and responsibility

Facilitator

"Growing up, what was childhood like for you?"

A yarn with Aboriginal community leaders about what behavioural problems mean to them

AD **Aunty Deb**

"Well, we all had a job to do. You know, when you're all in the family, you always had a job to do."

UT **Uncle Terry**

"We relied on family."

UT **Uncle Terry**

"...with colonisation and things like that, the actual fact of what Aboriginal people did with their families and their communities has changed a hell of a lot."

Trauma can look like ADHD

> *…the trauma symptoms look very similar to the symptoms that meets the diagnostic criteria for ADHD. So, I think a lot of that gets misdiagnosed.*

VE **Vanessa**

"…one of the first things they should ask the parent is, can you give us a bit of a history about the family life."

UT **Uncle Terry**

"…time and time again, the child is looked at, a diagnosis is made but there's no looking into the past of what's happened to that child."

UT **Uncle Terry**

Ask for the family's story first

A deficit lens misses how Aboriginal children learn

What classrooms expect

- Sit down, learn your times tables
- Sit still, hold a pencil
- A desk and the right equipment at home

How children have been brought up

- An exploratory style of learning
- Being in the context of the community
- Free to run around, knowing the community is looking after you

"...we're always looking at the deficit, isn't it? Your kid can't sit still, your kid can't hold a pencil. I mean, it's about what the family values, isn't it?"

VE **Vanessa**

Labels carry blame, and unlock funding

Blame

"...the problem with diagnoses is that there tends a bit of blame attached to it."

VE **Vanessa**

"...take the blame off the parent and centring the parent as the expert in the child's life..."

VE **Vanessa**

The funding gateway

"...in our system, the only way to get a child funding is if you've got a diagnosis."

VE **Vanessa**

"Now, have we met his needs? No, we haven't. We've already labelled him."

AD **Aunty Deb**

Western ideas of childhood are recent

Middle Ages	17th century	18th century	19th century	1913	1960s–70s
Children seen as small adults who work and have responsibilities	Child and adult become distinct: innocence versus experience	Family life turns insular; behaviour outside the norm blamed on parenting	Compulsory schooling; truancy officers; “gutter children”	First specialised school for behavioural issues in Australia	Family and community ties disrupted; parents turn to professionals

Expectations of children are a product of their time. What becomes of children who do not conform?

Diagnostic manuals evolved, and have limits

1853	First classification system: a list of causes of death
1952	First DSM published by the American Psychiatric Association
1968–69	Conduct disorders appear as subcategories (DSM-II, ICD-8)
1977–80	‘Conduct Disorder’ introduced (ICD-9, DSM-III)
2013	DSM-5 adds ‘Culture-Related Diagnostic Issues’
2022	ICD-11 aims for flexibility across cultural contexts

34× variation in the prevalence of anxiety disorders across countries using DSM-IV criteria

- Categories overlap; cut-offs are semi-arbitrary
- Comorbidity is the norm, not the outlier
- Definitions shift, so people move in and out
- Funding rules reward strict criteria

Two ways of seeing childhood collide

	WESTERN FRAMING	ABORIGINAL LIFE-WAYS
Health	Compartmentalised: mental or physical	**Holistic: body, mind, spirit, culture and country**
Family	Insular nuclear family	**Extended family; a shared approach to raising children**
The child	Protected from the adult world	**A valued member with responsibilities and autonomy**
Learning	Instruction and schooling	**Exploring and experiencing the world**
Guidance	Professionals	**Elders, grandparents and community**

Colonisation disrupted what protects children

Culture as protection

65,000 years

Connection to culture is a strength and a protective force for children and families

Colonisation

- Forced removal from country
- Kinship systems disrupted
- Languages suppressed
- Family life recast as deficit

The legacy today

- Intergenerational trauma
- Cultural disconnection
- Family disruption
- High levels of disadvantage

AD **Aunty Deb** *"...it all goes back to colonisation – it'll always go back to colonisation."*

VE **Vanessa** *"...those historical legacies live on, and they live well."*

Behavioural diagnoses among Aboriginal children

RISK OF HYPERACTIVITY PROBLEMS

15.8%

Aboriginal children

9.7%

non-Aboriginal children

WA Aboriginal Child Health Survey (Zubrick et al., 2004)

What sits behind the numbers

- Adverse childhood experiences
- The experience of racism
- Ongoing grief, loss and disadvantage from colonisation
- Higher reported prevalence, lower access to services
- The clinician both labels behaviour and is the gateway to resources

The impact of adversity is not set in stone

Protective factors

- Secure caregiver relationships
- Family encouragement to attend school
- Having someone to talk to
- Regular exercise
- Faith, hope and cultural traditions
- Self-efficacy and empowerment

How families see ADHD

- Hyperactivity seen as being mischievous, rather than a disorder
- Hesitant about medication
- Want support that involves the wider family unit

PART 2

School-based integrated care

From listening to doing: what community asked for, the model we built together, and what we are learning

What community asked for: a one-stop shop

Facilitator

"If you had a magic wand and you could have things exactly how you wanted it, what would you want?"

- Listen more, and hear what families are saying
- Face to face
- Support that stays for the long term
- Paediatricians and psychologists on site
- SEWB, housing and Centrelink workers
- More Aboriginal people as the face of schools

"...the concept of a one-stop shop is really important."

VE **Vanessa**

"That's what you call a community."

AD **Aunty Deb**

Schools are on the front line

1 in 5

children have a mental health, behavioural or developmental disorder

1 in 3

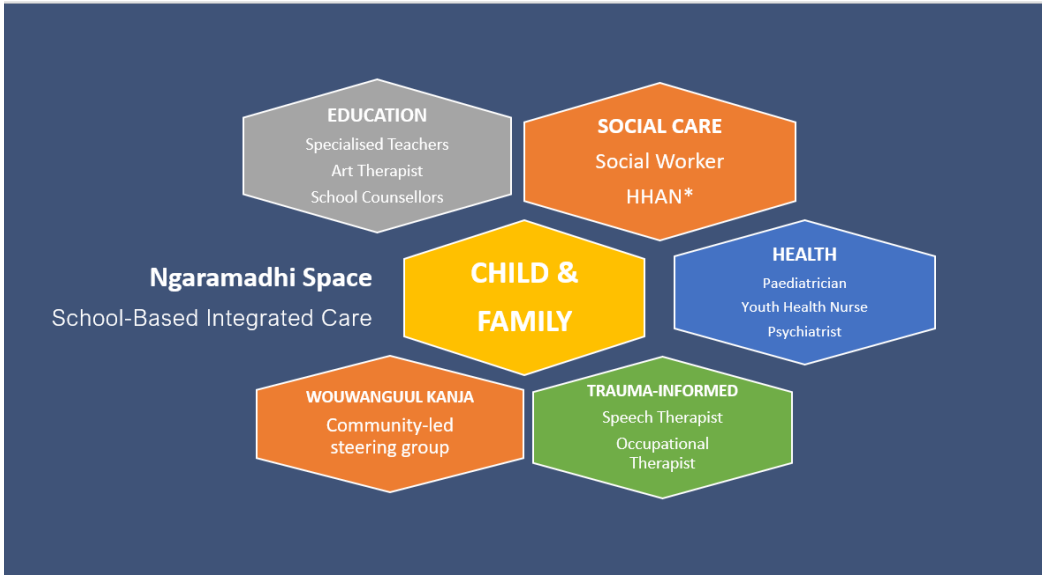
of those children access appropriate care

"[The] line of sight that the school has cannot be underestimated. They can anticipate months before [child protection services] that a child's wellbeing is on the downhill because of what's going on in their home."

NGO



Ngaramadhi Space: one team around child and family



- Developed in partnership with the Indigenous community, education and the social sector
- Piloted 2016–2019 at Yudi Gunyi School
- Holistic, multidisciplinary, child- and family-centred care
- Wouwanguul Kanja: a community-led steering group

What Elders, families and school staff told us

> *Gather everything that's needed in the one dilly bag – take it home, and keep it in the same spot so everyone has access.*

UD **Uncle Des Barton, AECG**

1	**Elder-identified need**	Culturally safe, holistic, accessible support in schools
2	**A co-located 'one-stop shop'**	Existing services work together around the whole child and family
3	**A trusted environment**	The school as a place families already know and trust
4	**One multidisciplinary team**	Paediatrician, nurse, social worker, counsellor, speech pathologist, OT and teachers
5	**Bridging systems, not silos**	Knowledge and policy brought together, kept simple
6	**Partnerships need resourcing**	Joint policy to support life beyond the school gate

What the evaluation found

79
students seen (mean age 12)

73%
known to child protection

50%
seeing a health professional

ACCESS

8%
failed to attend

8%
cancellations

Multiple
unmet health and social needs identified

Part of the school, not apart from it

1

Embedded, not bolted on

Woven into everyday school life, not a clinic that sits apart from it

2

Meets needs behind the behaviour

Addresses unmet health and social needs that surface as behaviour and learning difficulty

3

Eases pressure, doesn't add to it

Frees teachers to teach: support comes to the student, not the other way around

"I felt heard, and I'm thankful that I was listened to. Now I finally have answers."

Student

"You've got to make connection to the kids – it's just about having conversations and yarns."

Teacher

From one school to a statewide network

2016

Ngaramadhi Space

2019

Bridge Road School

2020

Alexandria Park Community School

Marrickville West Public School

Glebe Public School

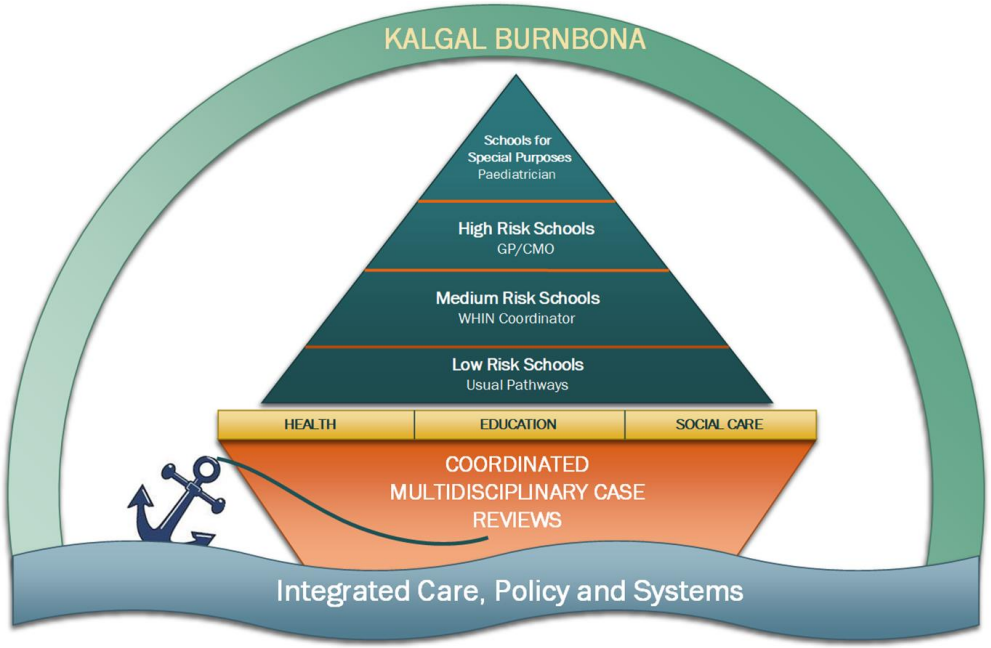
2024

Belmore South SBIC (4 schools)

Statewide Working Group

Includes 2 disability schools and 2 behavioural Schools for Specific Purposes, and an emerging interstate working group with Victoria and Western Australia

Kalgal Burnbona: support matched to need



Schools for Specific Purposes

Paediatrician

High-risk schools

GP / CMO

Medium-risk schools

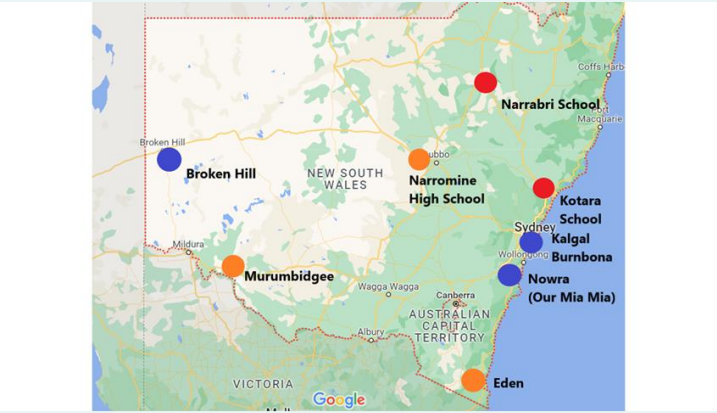
WHIN Coordinator

Low-risk schools

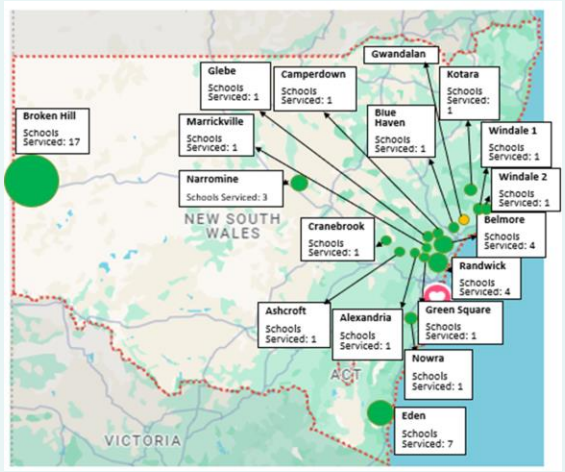
Usual pathways

From 8 sites to 54 in two years

2022 8 sites



2024 54 sites · 10,000 students



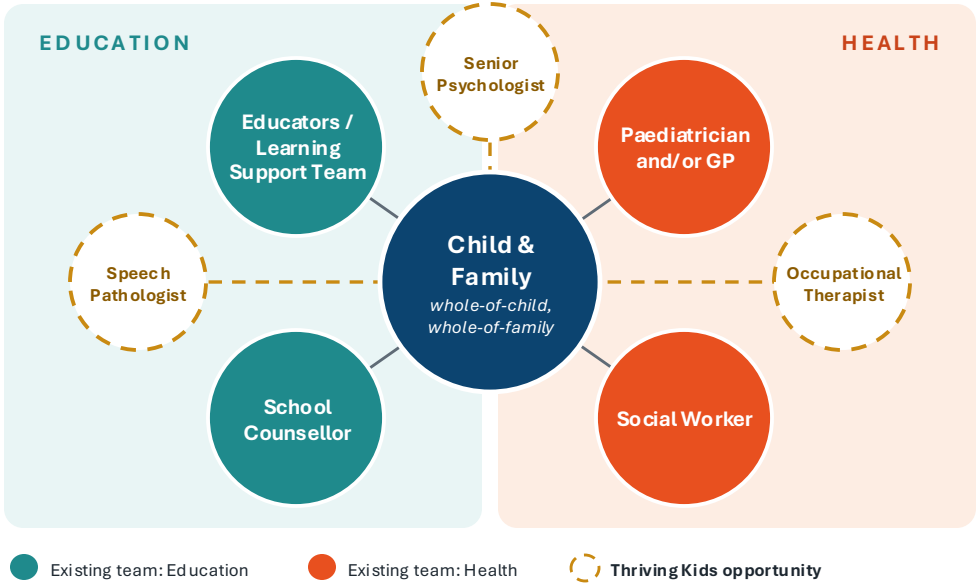
SBIC is a delivery mechanism for Thriving Kids

Thriving Kids reforms: implementation by January 2028

SBIC already operates the multisector, place-based architecture these reforms are designed to create

Allied health 'plug-in'

The SBIC model: a partnership between Health and Education



The journey forward: cultural medicines

> *Cultural wounds require cultural medicines*
>
> Chandler & Dunlop, 2015

- Self-determination: Aboriginal people in every aspect of design and delivery
- Build on existing strengths, culture and connections
- Respond to holistic needs, including finances and housing
- Validate assessment tools and treatments in Aboriginal populations
- Ongoing training and everyday culturally safe practice
- Build flexibility into diagnostic and funding rules

“Just change one thing…”

1. Definitions of childhood behavioural disorders have been shaped by history, society and medical classification systems

2. These definitions can collide with how childhood behaviour is viewed among Aboriginal people

3. Health professionals need to work in partnership with the Aboriginal community to address these issues

“…if you make one change… that’s one change you’ve made.”

UT **Uncle Terry**

“…it’s about the conversations that you have with other people… That’s how you bring about change.”

AD **Aunty Deb**

Thank you

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With thanks to Uncle Terry Denzil, Aunty Deb Daley, Vanessa Edwige and Uncle Des Barton

FURTHER READING

Rungan S, Denzil T, Daley D, Edwige V. What does the term childhood behavioural disorders mean in the context of Aboriginal culture within Australia? Part 1: 'Not just using the words'. J Paediatr Child Health 2022;58:1942–1945. doi:10.1111/jpc.16232

Rungan S, Liu HM, Edwige V, Smith-Merry J, Eastwood J. Part 2: Historical and social context. J Paediatr Child Health 2022;58:1946–1951. doi:10.1111/jpc.16219