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CPS Education Department
Tel.: 613-526-9397, ext 263
education@cps.ca

Kurongkurl Katitjin
Edith Cowan University

AUSTRALIA ECU EDITH COWAN UNIVERSITY

THE UNIVERSITY OF MELBOURNE

The KIDS RESEARCH INSTITUTE AUSTRALIA

Maladjiny
RESEARCH CENTRE

“Our babies is our gold”

Aboriginal Kinship Carer & PHC workers views on Disability

Faculty/Presenter Disclosure

- I have no financial relationships with the manufacturer(s) of any commercial product(s) and/or provider(s) of commercial services discussed in this CME activity.

- I do not intend to discuss an unapproved/investigative use of a commercial product/device in my presentation.

Learning Objectives

- Objective 1: Gain an in-depth understanding of how Aboriginal and Torres Strait Islander children with disabilities are uniquely affected within the child welfare system.
- Objective 2: Identify the main barriers that prevent effective support and early intervention for Aboriginal and Torres Islander children with disability in out of home care.
- Objective 3: Equip participants with knowledge and tools to advocate for policy changes that will improve the child protection system for Aboriginal and Torres Strail Islander children and families.

Research Collaboration between: University of Melbourne, Curtin University, & Kids Institute

Research team

Chief Investigators:

- Professor Sandra Eades
- Dr Bridgette McNamara
- Dr Melissa O'Donnell
- Dr Jocelyn Jones
- Dr Lina Gudhaju
- Dr Koen Simons
- Professor Richard Chenhall

Associate Investigators:

- Professor Dan McAullay
- Dr Robyn Williams
- Professor Emily Banks
- Dr Kathleen Falster
- Dr Francine Eades

Project co-Ordinator:
Alison Gibberd

Project team:
Dr Robyn Williams
Cathy Garlett
Juliet Brook
Katiska Davis
Sasha Moodie

Acknowledge the Aboriginal kinship carers and primary health care workers who have taken the time to participate in the project and share their stories

Acknowledge the passing of Ellen Corbett
a member of our Aboriginal Community Advisory group during the course of this project

Acknowledgement of country

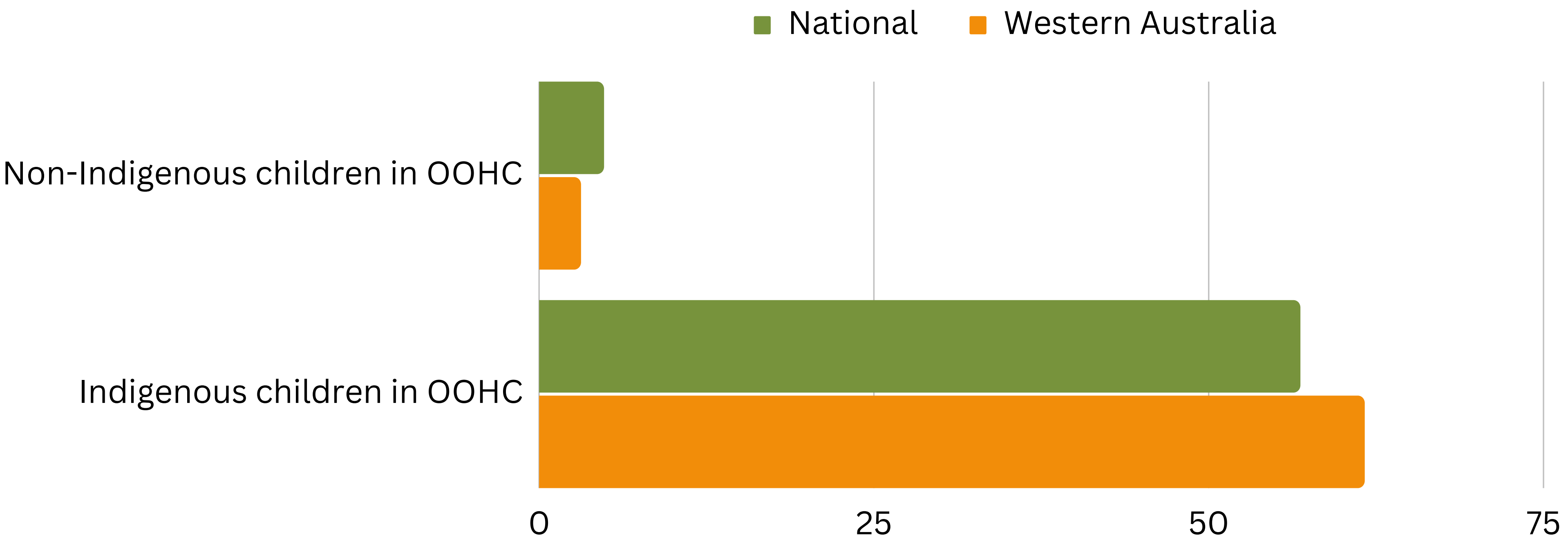
I would like to acknowledge that we are in Treaty 1 territory and that the land on which we gather is the traditional territory of Anishinaabeg, Cree, Oji-Cree, Dakota, and Dene Peoples, and on the homeland of the Métis Nation.

This presentation contains sensitive information

Lack of investment in prevention

- The Family Matters Report 2022 shows that Western Australia, in comparison with other states and territories, has:
  - The highest over-representation of Aboriginal children in out-of-home care (OOHC)
  - The lowest proportion of expenditure on family support and intensive family support (5.6%), with high proportion of expenditure to ACCOs (21.1%)
  - Only one ACCO in WA is providing OOHC services
  - Aboriginal Family-led Decision Making pilot continues in 2 locations, but is not legislated
    - ➢ No clear commitment to broader roll-out

Aboriginal Children and the Child Protection System



- National rate of removal of Aboriginal children is almost 12 times higher than non-Aboriginal children (AIHW, 2022)
- WA has one of the highest rates of Indigenous children in out-of-home care at 20 times the rate of non-Aboriginal children (AIHW, 2022)
- The continuing rise in the number of children in out-of-home care in WA has partly been attributed to children entering care at earlier ages and staying in care for longer (Bilson et al. 2017)

Gaps in Child Protection Disability Data

- Data on disability status was only available for two-thirds of children in OOHC (Aboriginal and Torres Strait Islander and non-Indigenous)
    - Of these, about 30% were reported as having a disability (AIHW, 2022)

- Lack of accurate and consistent nationwide data on the prevalence of disability in Aboriginal and Torres Strait Islander children in OOHC
    - Variable estimates across states ranging from 14% to 40% (Family Matters, 2021)

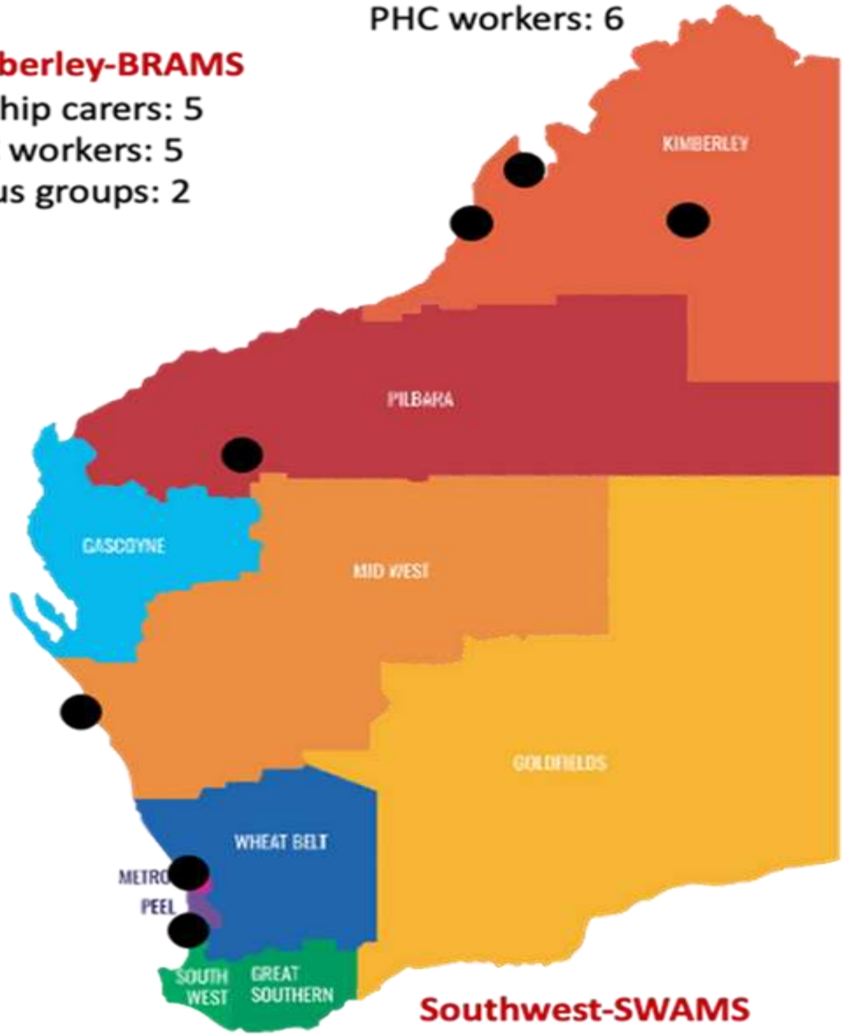
- Child protection authorities do not apply a uniform definition of disability and do not routinely capture information about a child's experience of disability within data collection frameworks (Snow, Mendes and O'Donoghue 2014)

Research Aims

To explore the views and narratives from Aboriginal kinship carers about positive and negative experiences of providing out-of-home care to Aboriginal children and their perceptions on how they can be better supported

To explore the views and narratives from Aboriginal primary health care staff about how services can be strengthened to support families at risk of having their children removed, and to better support kinship carers

Overview of Data Collection



Kimberley-DAHS
Kinship carers: 4
PHC workers: 6

Kimberley-BRAMS
Kinship carers: 5
PHC workers: 5
Focus groups: 2

Kimberley-YYMS
Kinship carers: 8
PHC workers: 9

Pilbara-PAMS
Kinship carers: 9
PHC workers: 9

Gascoyne-GRAMS
Kinship carers: 6
PHC workers: 11

Metro-DYHS
Kinship carers: 6
PHC workers: 1
Focus Groups: 1

Southwest-SWAMS
Kinship carers: 8
PHC workers: 14
Focus Group: 1

Kinship carers	46
PHC workers	55
Focus groups	4

Kinship Carer Characteristics

Age	**n (%)**
[redacted]	[redacted]
30 - 39	4 (8)
40 - 49	6 (13)
50 - 59	19 (42)
60 - 69	8 (18)
70 - 79	2 (4)
80 - 89	2 (4)
Gender	
Female	37 (82)
Male	6 (13)
Marital Status	
Single	15 (33)
Married or De facto	25 (56)
Other	1 (2)

Kinship Carer Relationships

Child Relationship to Kinship Carer	n=99 (%)
Biological Step Other	96 (97) 1 (1) 2 (2)
If biological, what family relationship	
Grandparent (2 x males) Aunt or Uncle Other	78 (79) 19 (19) 2 (2)
Kinship carer arrangement	
Formal Informal	53 (54) 46 (46)

Children’s Characteristics

Number of children	n (%)
Gender	
Male	52 (53%)
Female	47 (47%)
Age group	
<1	1 (1)
1-4	12 (12)
5-9	34 (34)
10-14	40 (40)
15+	12 (12)
Total	99

Diagnosed Children's Health and Development Conditions

Health or disability	
Neurodevelopmental	20
Trauma and mental health	14
Speech and hearing	16
Asthma	5
Epilepsy	2
Other	7
Total with any health issue or disability	48

Neurodevelopmental Disability

Disability	**Number of children diagnosed**
ADHD	10
Global Developmental Delay Intellectual Disability Cognitive impairment	5
FASD	4
Autism	4
Any neurodevelopmental disability	20 (20% of all children)

- Several children had multiple diagnoses e.g., ADHD and Global Developmental Delay or ADHD and Autism
- An additional 10 children are undiagnosed with behavioural or neurodevelopmental concerns and pending assessment, half with suspected FASD

Most Common Developmental Issues Reported

- Emotion regulation, hyperactivity and behavioural challenges
  - Impact on schooling highlighted
  - Some aggressive or sexualised behaviour

- Developmental delay, speech and hearing issues

- Problems with bladder and bowel control

- Eating/feeding difficulties
  - Selective eating patterns
  - Lack of appetite or interest in food, resulting in child being undernourished

Prenatal Alcohol and Other Drug Issues and Child Development

- High levels of alcohol & drug use in pregnancy were reported by a number of carers of children with neurodevelopmental concerns

- Although less common than alcohol-related neurodevelopmental issues, some carers perceived drug use in pregnancy to be a contributing factors:

    - Predominantly opioids and amphetamines
    - Usually learning disability and/or issues with sleep and emotion regulation

Prenatal Drug Use and Disability

"He doesn't sleep. So [boy's name] is nearly four. He'll wake up during the night, he'll cry for hours on end. Like hours. When it comes to bed and sleep time – he head-bangs as well… I know in my heart that it's the drugs from when he was in his mum's womb, and she was a big user. Like daily. Every day. I think that it's affected his brain development."

- *"Their mum had a sniffing and any cheap drug that she could get. But [girl's name], I don't think - she just had learning disabilities…"*

- *"They were born - the father and mother both on drugs or whatever, and they were born* with learning disabilities."

Suspected and Undiagnosed FASD

- In addition to the 4 children diagnosed with FASD, carers believed another 5 had FASD (who were undiagnosed or diagnosed with another NDD)
- A number of carers highlighted the frequency of prenatal alcohol exposure and subsequent developmental issues, despite an absence of diagnoses

(Williams & Badry, 2023)

Voices of Kinship Carers

Oh, she's undiagnosed at the moment with FASD. But she shows all the signs and symptoms of it. I know that Mum was drinking with her when she was pregnant with her."

"I think they've all got a - probably a little touch of alcohol foetal or something like that because they've all been exposed to in pregnancy. They all have."

Barriers to Early Intervention

- Lack of timely support from the department and resources to obtain disability assessments
- High caseload and frequent turnover of caseworkers
- Lack of information, guidance and training provided to carers

> *"So, it's taken about - well, we've had her for six months, and I was told we were wait another six months. Nothing's been done from DCP. The whole time they've had her, since she was a child."*

Lack of Support from the Department

- Carers advocating tirelessly to caseworkers to get the child the right diagnosis in a timely manner
- After significant delays (six months to several years), some carers forced to coordinate their own assessments or seek external assistance

Lack of Support from Department

"We would have IEP meetings regularly with our caseworkers, and we would be screaming at them, almost saying, you've got to get him assessed, for whatever it might be. We didn't know what it was… My boy, I was his voice. He was unable to articulate what was going on [in him], and I had to skill myself up, by myself. Nothing prepared me for what I experienced… [Kulin Mort] are the ones right, who helped me so much in getting [son] diagnosed. I got sick and tired of DCP not doing anything… They did the actual testing just before he ran away [at twelve years old], and then the results came in after. Too late. Well, I was actually after them from the time he was eight. He was putting holes in the walls at home at eight."

High Caseworker Turnover

- Lack of continuity in case management due to high turnovers of caseworkers was a widely reported barrier to early intervention

> *"We had him for eight, nine months, that caseworker but now we've got no caseworker. We was in and out, a lot of caseworkers. We wasn't stable in one. So, we had one was a pretty good Aboriginal worker. She helped. But then get another case worker…"*

Implications of Delayed Intervention

- Carer desperate for child to be assessed and supported, but is told by the specialist to delay diagnosis until school, missing out on opportunity for early intervention.
- Carer believes that child is up to fail by being placed in an environment that is unequipped to meet their needs, which can be traumatic and exacerbate behavioural issues.

“[The paediatrician] said, that he has to start school because they can't really do a diagnosis until the little ones are older. I said to – because I really don’t feel that he’s ready for kindy this year. So I said, well, should I hold – should I keep him back a year? They said, no, the best thing for him is to start kindy this year and – because teachers can tell them a lot about their behaviour as well so they can have a lot of input. To me it just felt as though they didn’t believe me. But I know that in my heart that he’ll probably struggle with school because of his behaviour. But I – and it’s not his fault.”

Implications of Delayed Intervention

- Carers reported ineffective and harmful management of challenging or inappropriate behaviour in class related to children's undiagnosed disability.

- Can contribute to child's long-term disengagement from schooling, increasing their risk of contact with justice.

- Several children finally received their diagnosis while in juvenile detention.

"Suspended him instead of helping him….So, I said, well, okay. When he went into Banksia Hill, that's when they did the test. Yeah… Then when we found out, I told the teacher about it, and they said, oh now we understand why [child] has been like this."

Ineffective Assessment and Potential Misdiagnosis

- Some carers who had children with were either diagnosed with Intellectual Disability, Autism or ADHD (as well as those waiting to be assessed) noted the child's prenatal alcohol and other drug exposure, and felt that FASD better explained the full picture of the child's history and needs.

- After caseworker organised screening for the child through a specialist diagnostics service provider, a carer felt that the diagnosis was inaccurate.

"People started explaining to me about mum's drug use, and alcohol use when she was pregnant… I wanted him tested for FASD… He has definitely got the classic signs of FASD. He had 70 per cent cognition – that's what they diagnosed him with, which is quite severe. I still believe he's got FASD."

Lack of appropriate training

- Many carers reported being offered no training to manage their child's behavioural challenges and needs associated with trauma, disability and other health issues
- Several carers noted that any training or knowledge they had was through their own employment
- Carers highlighted issues accessing available training due to employment

"No, no training at all. No, ***I was just lucky to have my experience as an education assistant at school****. That was my career before now and so I had worked with special needs kids and being in the school environments,* ***I had a good understanding of trauma and FASD*** *and all of those special needs things already and how to communicate with kids. So,* ***my background helped me, but I did not get any training or offered any training at all****."*

Areas of Highest Need

- Support in obtaining disability assessment in a timely manner.
- Training and ongoing support and guidance
    - Managing emotional and behavioural challenges associated with trauma and neurodevelopmental disability
    - Understanding trauma and disability
- Access to regular respite.

Stakeholder views on Disability

Stakeholder's Perspectives: Supporting Families and Children with Disability

Reaffirming carer's themes:

- High prevalence of FASD and other neurodevelopmental disability in children in OOHC.
- Lack of support from the department for managing children with disabilities and complex needs.

"Oh, at the moment we've got seven families here, just alone, the family care services or the children in care, and out of those seven families, every one of them have a disability, those children, or two of them… Most of these kids that Child Protection have and are under the care of the CEO, and what I've found is that they are probably all those kids with FASD and all those disabilities. For a family member to take that kid on, with not the proper support that they should have, you are setting them up to fail".

Stakeholder’s Role in Prevention

- Emphasised the need to ‘break the cycle’
- Importance of the role of ACCOs in FASD prevention, through providing woman-centred perinatal care and holistic support to families

“This is why I'm concentrating on health, because if we can [unclear] to that mother through pregnancy and look after her, make sure she – saying, don’t drink, eat properly, and all this and that, we won't have that problem in five years’ time that kid’s ready to go to school.”

“Go right to - back to that time of what caused that disability… we’re talking about prevention… So yeah, it just can’t go onto the next generation.”

Areas of Highest Need

Mothers with disability have a greater risk of child removals and face heightened barriers to reunification (relates to the theme of generational disability):

- Need for extra support throughout the perinatal period
- Need for advocates to support women with disability throughout contact with child protection

"So, I worked with this lady who has schizophrenia for 12 months and they took her three children, the younger ones, off her… the lawyer said to her, oh, you've got no chance of getting the kids. I said, hey, hang on, what are you talking about? What are you saying, she's got no chance? I don't know, he said, she's got schizophrenia. No, no, no, I said, no. I said, people with mental health issues, or disabilities, they have rights."

Supporting Parents with Disability

A number of stakeholders at ACCHOs highlighted the issue of generational disability, identifying that they needed additional guidance on how to support parents with FASD and other disabilities:

> *"I'm finding is that a lot of parents - I guess in our mob don't know how to care for somebody with a disability… A lot of people are struggling with kids with disability and mental health. . It's not just the children, it's the parents as well. The parent also has a disability, but they're not aware that they've actually got it. They don't know how to approach it. They don't know how to get a diagnosis and stuff like that. That's why I feel like they're struggling because they just turn to drugs and alcohol not knowing their diagnosis."*

"How do we support them? How do we genuinely support people who themselves might have FASD trying to parent a child and they've had no support or not been able to find support that *matches them."*

Recommendations

- Comprehensive and timely health and culturally safe screening and assessment for neurodevelopmental concerns for all children who enter care, as well as culturally appropriate training to equip carers to meet children's needs
- Develop and integrate culturally safe evidence-based protocols around disability with Aboriginal experts.
- FASD informed case management and mandatory training in FASD for relevant staff.
- The establishment of a culturally safe skilled disability support team for managing children with disability, to include positions for disability navigators.
- Structural reform within the department including a team which specialises in supporting children with disability and the establishment of an independent body (like VACCA in Victoria) to provide advocacy and support to Aboriginal families who are involved with child protection.

Recommendations cont.

- Need for investment in best practice evidence-based prevention and early intervention programs implemented by ACCOs like the Aboriginal Cradle to Kinder Program implemented by VACCA in Victoria which provides holistic support to vulnerable mothers from pregnancy to 5 years, involving advocacy, support accessing mental health care, AOD care etc.

- Better representation on peak state and national bodies (including Noongar representation on state bodies).

Acknowledgements

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Study & Aboriginal Community Leadership Group

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- PAMS-Robbie
- BRAMS-Cassie Atchison, Delia
- DAHS-Heather Taylor

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