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RESEARCH ARTICLE



## Kinship care and Aboriginal children with disabilities in out-of-home care: “My boy, I was his voice”

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### ABSTRACT

**Background:** Aboriginal and Torres Strait Islander children with a disability are over-represented in child welfare systems worldwide. Despite this, little is known about their involvement with the Australian child protection system or their lived experiences.

**Method:** Led by Indigenous researchers and methodologies, qualitative findings from yarning sessions with 46 kinship carers across Western Australia informed this research. This research is part of the Indigenous Child Removals WA (I-CaRe WA) project.

**Results:** Difficulty accessing disability assessments and diagnoses for children resulted in a lack of access to disability support services and missed opportunities for early intervention. Priority areas for improvement included appropriate and accessible training for carers and practice support.

**Conclusion:** Urgent reform to account for the needs of Aboriginal kinship carers and children with disabilities in their care is required to improve their health and wellbeing.

### ARTICLE HISTORY

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### KEYWORDS

Aboriginal and Torres Strait Islander children; Kinship care; Out-of-home care (OOHC); disability; Neurodevelopmental disorders; Early intervention and culturally safety

Aboriginal and Torres Strait Islander children are over-represented at all stages of the Australian child protection system. The continuing effects of colonisation, historical and current experiences of systemic racism, socioeconomic disadvantage, and intergenerational trauma contribute to disproportionate child removals in Aboriginal and Torres Strait Islander families (respectfully, referred to as Aboriginal people hereafter, unless referring to specific principles or statistical information) (Munns et al., 2018; O'Donnell et al., 2019). For Aboriginal children with disabilities in out-of-home care (OOHC), data are severely lacking. Aboriginal children in care experience significant barriers to identification and diagnosis of disabilities (Secretariat of National Aboriginal and Islander Child Care, 2023). Without access to early intervention (including diagnosis), Aboriginal children with disabilities in OOHC are at an increased risk of not having their needs met and experiencing poor health and wellbeing outcomes (Secretariat of National Aboriginal and Islander Child Care, 2023).

### Out-of-home care (OOHC)

OOHC can be defined as “overnight care for children under 18 who are unable to live with their families due to child safety concerns” (Australian Institute of Health and Welfare, 2022). Between 2021 and 2022, approximately 4,100 Aboriginal children entered OOHC nationally, with the highest admission rates among children younger than 1-year-old (Australian Institute of Health and Welfare, 2024b). Nationally, Aboriginal children enter OOHC at 12 times the rate of non-Aboriginal children (Australian Institute of Health and Welfare, 2024b). In Western Australia (WA), Aboriginal children enter OOHC at 20 times that of non-Aboriginal children (Australian Institute of Health and Welfare, 2024b). As of June 2022, almost 20,000 Aboriginal children were in OOHC (Australian Institute of Health and Welfare, 2024b). These consistent trends in the data are deeply concerning and continue to worsen despite national commitments to curb the rate of Aboriginal children entering OOHC (Commonwealth of Australia, n.d.).

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Kinship care is recognised as the preferred OOH placement option when an Aboriginal child is unable to live with their parents (Krakouer et al., 2018; Secretariat of National Aboriginal and Islander Child Care, 2017). For Aboriginal people, kinship care can be defined as “another Indigenous person who is a member of their (a child’s) community, a compatible community, or from the same language group” (Australian Institute of Health and Welfare, 2021). Kinship care may be formal (government child protection order) or informal (not formally acknowledged in the OOH system). Despite it being recognised by all Australian jurisdictions as the preferred OOH option for Aboriginal children, just over half (54%) of Aboriginal children are placed in kinship care arrangements (Australian Institute of Health and Welfare, 2024b). Consequently, Aboriginal children continue to be placed in other arrangements, such as foster care and residential care, at high rates. Considering connection to culture, family, community and country is instrumental to an Aboriginal child’s upbringing (Krakouer et al., 2018; Williams & Badry, 2023), and despite recognition of kinship care’s importance, evidence suggests kinship carers are undervalued and unsupported (Fernandes et al., 2021; McPherson et al., 2022; Moodie et al., 2024).

### ***The role of Aboriginal community controlled health organisations***

Aboriginal Community Controlled Health Organisations (ACCHOs) are not-for-profit services governed and controlled by Aboriginal people (Department of Communities, 2022). ACCHOs are recognised as best placed to deliver services to Aboriginal people, providing culturally appropriate, holistic, comprehensive, and culturally safe social and healthcare services for Aboriginal people and communities in their local community (Pearson et al., 2020), (Panaretto et al., 2014). This includes supporting children and kinship carers involved with child protection and disability support, including the National Disability Insurance Scheme (NDIS). The ATSICPP stipulates that ACCHOs should have greater involvement in all child protection matters (Secretariat of National Aboriginal and Islander Child Care, 2017).

### ***Aboriginal and Torres Strait Islander children with disabilities***

The 2018 Survey of Disability, Aging and Carers (SDAC) found almost a quarter of Aboriginal and Torres Strait Islander people living in households experienced a disability, with similar prevalence

among males (23.7%) and females (24.3%) (Australian Bureau of Statistics, 2018). Of children aged 0–14 years, 16.3% had a disability, an increase from 2015 (13.9%) (Australian Bureau of Statistics, 2018). Unlike the SDAC, the National Aboriginal and Torres Strait Islander Health Survey (NATSIHS) includes populations living in remote areas and discrete communities (Australian Institute of Health and Welfare, 2023). The 2018–19 NATSIHS found that 38% of Aboriginal and Torres Strait Islander people reported they had a disability, with 8% of people reporting they had a severe or profound disability (Australian Bureau of Statistics, 2019). The 2021 National Census of Population and Housing showed that 2.7% of Aboriginal and Torres Strait Islander children aged 0–4 years required assistance with core activities due to a severe or profound disability, with this increasing to 8.5% among children aged 5–9 years and 8.8% among children aged 10–14 years (Australian Institute of Health and Welfare, 2024a). The lack of consistent and detailed population level data concerning Aboriginal children means the prevalence estimates should be considered with caution.

Despite various studies highlighting the significant issue of undiagnosed disabilities among Indigenous children globally, there is limited evidence concerning Indigenous children in OOH (Di Pietro & Illes, 2016; Lau et al., 2024; Lindblom, 2014; Williams & Badry, 2023). Cross-jurisdictional inconsistencies make it difficult to collect accurate data for disability prevalence among Aboriginal children in OOH (Commission for Children and Young People, 2016). This has contributed to these children being a relatively “hidden” population resulting in Aboriginal children with disabilities and their kinship carers (who frequently care for more than one child) being at increased risk of not having their needs met.

### ***Disability and child protection***

Children and young people with disabilities are at an increased risk of child maltreatment and contact with the child protection system more broadly (Maclean et al., 2017; Stalker & McArthur, 2012). In WA, children with disabilities comprise 10.4% of the population, but represent 29% of substantiated maltreatment allegations (Maclean et al., 2017). Children with intellectual disabilities and mental/behavioural problems are most at-risk of substantiated allegations (Maclean et al., 2017).

Several studies have highlighted the evidence gaps in relation to this population’s health and wellbeing needs and discussed the extent to which their needs are unmet (Creamer et al., 2022; Hamilton et al., 2020). A recent data linkage study found Aboriginal children born in

WA with a placement in OOHC were three times more likely to have neurodevelopmental and mental health conditions compared to Aboriginal children never placed in OOHC (Harrap et al., 2024). Study authors emphasised the need for better resourcing of service delivery, including support and training for carers to ensure children are better able to have their needs met. A 2019 study in the United States found the prevalence of foetal alcohol spectrum disorder (FASD) among children in OOHC was 32 times higher than in the general population (Popova et al., 2019). For Aboriginal children in WA, the prevalence was 11 times higher for Aboriginal children in OOHC compared to Aboriginal children not in OOHC (Harrap et al., 2024). Children with FASD in care are vulnerable to a range of poor outcomes (Popova et al., 2019). A 2022 study exploring adverse childhood experiences among children and youth with FASD in WA found that 70% of participants had been involved with the child protection system and 40% with the justice system (Tan et al., 2022). Of the 199 mostly male (72%) study participants, 77% identified as Aboriginal and/or Torres Strait Islander. Early identification and intervention are critical to maximise the development and wellbeing of Aboriginal children with FASD across the lifespan (Reid et al., 2015).

Accurate prevalence data for Aboriginal children with FASD in Australia is lacking. Fitzpatrick et al.'s (2017) study found the rate of FASD prevalence among school-aged children in a remote WA community to be 19.4%. In a WA youth justice setting, Bower et al. (2018) found that 36% of predominantly young Aboriginal males had FASD, and the comprehensive assessment the participants received was their first, despite prior engagement with the child protection system (Bower et al., 2018).

### **Identification and diagnosis of disabilities in OOHC**

In 2021, the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability (hereafter the Royal Commission into Violence) held a public hearing on the experiences of Aboriginal and Torres Strait Islander children with disabilities in OOHC (Royal Commission into Violence, 2021). The public hearing examined several issues, relating to departmental policies and practices around: disability identification and diagnosis; support services; secure care environments; patterns, trends, experiences and negative outcomes for Aboriginal children in OOHC; and solutions to address systemic problems experienced by this cohort (Royal Commission into Violence, 2021).

The Royal Commission found there were significant barriers to disability identification, diagnosis and management, including high workloads of case workers, lack of continuity of care, unreliable medical histories, and low engagement with support services (Royal Commission into Violence, 2021; Secretariat of National Aboriginal and Islander Child Care, 2023). Addressing barriers experienced by Aboriginal children with disabilities in OOHC will inform progress with all four focus areas outlined in the National Child Protection Framework, in particular focus area one, “a national approach to early intervention and targeted support for children and families experiencing vulnerability or disadvantage” (Commonwealth of Australia, 2021).

### **Current study**

This study was part of the Indigenous Child Removals Western Australia (I-CaRe WA) project, which aimed to predict and prevent child removals and strengthen the child protection system to improve outcomes for Aboriginal children, kinship carers and at-risk families, through an analysis of linked administrative data and qualitative interviews with Aboriginal primary health care staff and kinship carers. This article draws on the qualitative component of the project, which aimed 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 how they can be better supported. Drawing on the qualitative data (from the I-CaRe WA project), this study aimed to explore the experiences of WA Aboriginal kinship carers of Aboriginal children with disabilities to better understand: (i) the needs of kinship carers, and (ii) the needs of children in their care.

## **Method**

### **Research design**

The project was conducted with an Aboriginal cultural lens and Indigenous methodology, including in its design, implementation, and interpretation of results. This ensured that it was culturally respectful, and considered the cultural values, beliefs, and diversity of Aboriginal communities in WA.

### **Aboriginal community advisory group**

A Community Advisory Group (CAG), comprising delegates from the participating ACCHOs, Aboriginal kinship carers from each region, and Elders provided guidance in the implementation of the project and

dissemination of findings. Elders provided local community leadership, cultural advice and connected the research team to the community.

### Study setting

Qualitative data were collected between 2020 and 2022, in partnership with seven ACCHOs across metropolitan, regional and remote WA, including the Kimberley, Pilbara, Gascoyne, Southwest and Perth. Qualitative data were collected by three experienced Aboriginal researchers and one Aboriginal research assistant.

### Recruitment

Two of the chief investigators, SE and JJ, made initial contact with the Chief Executive Officers (CEOs) of the ACCHOs at the Aboriginal Health Council of Western Australia (AHCWA) CEO annual gathering, after they were invited to present the study and obtain their agreement to be involved as partners in the research. Once the research team was ready to commence data collection, the CEO or relevant contact person for each participating ACCHO was contacted to organise a suitable time to recruit staff and kinship carers in their area. Participants were recruited using purposive and snowball sampling methods, consistent with the broader I-CaRe WA study design. The purposive approach ensured that recruitment focused on Aboriginal kinship carers and primary healthcare workers with direct experience supporting Aboriginal children with disabilities. ACCHOs across metropolitan and regional WA facilitated recruitment through their existing community networks and relationships with kinship carers and service providers.

Following initial referrals through participating ACCHOs, snowball sampling was used to reach additional participants. Several carers and healthcare workers referred others within their family, professional, or community networks who met the inclusion criteria and expressed interest in participating. This combination of recruitment strategies enabled the research team to engage participants with diverse experiences across both community and service contexts.

### Consent

Once a participant agreed to be involved, they received an information sheet detailing the study's purpose and terms of participation. This included a chance to ask questions before providing written consent. Additionally, participants were informed that they could opt out of answering specific questions and terminate the

interview at any point without having to provide an explanation. They were advised they could withdraw any data already collected if the data were still identifiable. Participants were asked if they wanted a copy of their transcript to review.

### Data collection

Qualitative data were collected from 46 Aboriginal kinship carers who participated in yarning circles and one-on-one yarning sessions. Kinship carers were interviewed at their local ACCHO, at home or at another venue where they felt comfortable and which offered privacy. Yarning is a culturally grounded method that privileges Aboriginal ways of sharing knowledge, relationship building, and storytelling (Bessarab & Ng'andu, 2010). It creates a democratic space where everyone has an equal voice, it encourages deep listening and mutual respect for diverse perspectives, experiences and stories, rather than focusing on problem solving or critical perspectives (Bessarab & Ng'andu, 2010; Kennedy et al., 2022). Participants nominated if they preferred to participate in a one-on-one yarn or a yarning circle. After participants were introduced to the yarning sessions, the researchers went through the information and consent process.

Three yarning circles were conducted with primary health care staff (one metropolitan and two regional), and one yarning circle was conducted with Aboriginal kinship carers. Additional one-on-one yarns were undertaken with participants who preferred to share their experiences privately. The discussions followed a semi-structured guide developed collaboratively with the I-CaRe Aboriginal Advisory Group and focused on participants' experiences of supporting Aboriginal children with disabilities, service access, and culturally safe care. The interview guide included the following areas for discussion with extensive prompts:

1. Before we talk about your experience as a kinship carer, could you tell me a little about yourself and your background? (prompts for age, language group, marital status, housing, employment etc)
2. Can you tell me a bit about the child/ren you are caring for? (prompts around health information, assessment, history of child under care)
3. Tell me about your experiences of being a carer (prompts around becoming a carer, describing their role, help and assistance received, impact on their health)
4. Can you tell me about your relationship with the Department? (prompt communication with Department, relationship with caseworker, support etc)



5. Do you believe that the cultural needs of the children in your care are being met? (prompt for contact with parents, cultural support plans, support, etc.)
6. Can you tell me about your experiences with the Department in regard to training, support services, and financial support? (prompt for type of support, services received, barriers, access to information, financial support)
7. Do you know what the plans are for the future of the child/children in your care? (prompt for reunification plan)
8. How have the child/ren changed since being with you? (prompt for changes in physical and emotional health)
9. Opportunity for debriefing.

All sessions were audio recorded with participant consent and transcribed verbatim by an independent transcription service. Transcripts were de-identified prior to analysis. Participants were offered debriefing opportunities and ongoing access to culturally appropriate support services. Data collection occurred between 2018 and 2021.

### Data analysis

Transcriptions from the one-on-one yarning sessions and yarning circles were imported into NVivo 12 software for data analysis. The authors used principles of reflexive thematic analysis (RSA) when coding the data into broader themes (Braun & Clarke, 2019). RTA is an approach to qualitative data analysis that considers participant views, experiences, and perceptions when undertaking a study on a particular phenomenon (Braun & Clarke, 2019). This approach to data analysis allowed the researchers to centre the voices of participants at all stages of the research (Braun & Clarke, 2019; Chun Tie et al., 2019; Mills et al., 2006).

Inter-coder reliability is a crucial aspect of qualitative data analysis, particularly when dealing with sensitive and culturally nuanced data (O'Connor & Joffe, 2020). The primary purposes of establishing inter-coder reliability are to ensure consistency in the interpretation and coding of data across multiple coders, minimise individual bias, enhance the credibility of the findings, validate the coding scheme and its applicability to the data set, and identify areas of ambiguity or complexity in the data that may require further discussion or refinement. In this study, the implementation of inter-coder reliability was particularly significant due to the cultural complexity and sensitivity of the subject matter. The coding team consisted of three Indigenous coders, each bringing their own cultural knowledge and

**Table 1.** The characteristics of children in kinship care.

| Children's characteristics                           | n (%)    |
|------------------------------------------------------|----------|
| Total                                                | 99 (100) |
| <b>Gender</b>                                        |          |
| Male                                                 | 52 (53)  |
| Female                                               | 47 (47)  |
| <b>Age (years)</b>                                   |          |
| 0–4                                                  | 13 (13)  |
| 5–9                                                  | 34 (34)  |
| 10–14                                                | 40 (40)  |
| 15–17                                                | 12 (12)  |
| <b>Children's health and developmental issues</b>    |          |
| Neurodevelopmental/neurological                      | 20 (20)  |
| Attention deficit hyperactivity disorder (ADHD)      | 10 (10)  |
| Global developmental delay and learning disabilities | 5 (5)    |
| Foetal alcohol spectrum disorder (FASD)              | 4 (4)    |
| Autism spectrum disorder (ASD)                       | 4 (4)    |
| Epilepsy                                             | 2 (2)    |
| Speech and hearing                                   | 14 (14)  |
| Mental health/trauma                                 | 12 (12)  |
| Asthma                                               | 5 (5)    |
| Other                                                | 8 (8)    |

Note. It is important to note that these conditions were identified by carers and we did not have the children's medical records. 48 of the 99 children were diagnosed with any health or developmental condition. However, nine children were described as having multiple diagnoses spanning one or more categories and were therefore represented in more than one row. There were 5 children with 2 neurodevelopmental/neurological conditions. Most carers did not explicitly list intellectual disability as a diagnosis, and this table represents the conditions that were meaningful to carers rather than an objective list of all conditions. For example, one carer indicated that their child had an intellectual disability; however, they believed FASD better explained their condition and care needs.

experiences to the analysis process. The inter-coding process began with each coder independently analysing a subset of the interviews. Following this, the team met to compare their coding and discuss any discrepancies. Based on these discussions, the coding scheme was refined to better reflect Indigenous perspectives and cultural nuances.

Carer-reported health and developmental conditions were recorded verbatim during the interview and subsequently coded into broad categories (see Table 1). We did not access children's medical records or administer standardised cognitive assessments. Carers sometimes used different terms for overlapping concepts (e.g., "developmental delay," "learning disability," or specific diagnostic labels such as FASD or ASD). Where carers used synonymous or related phrasing we coded to the category that reflected the carer's own description. Because diagnoses were caregiver-reported and not clinically verified, explicit mentions of "intellectual disability" may be under-reported.

When inconsistencies in coding arose, they were not immediately viewed as errors but as opportunities for deeper cultural interpretation and understanding. The team adopted an approach that involved open dialogue, where coders engaged in respectful discussions about their interpretations, sharing their cultural insights and perspectives. In cases of significant disagreement,

the team consulted with community Elders for guidance and cultural context. Rather than forcing agreement, the team worked towards a consensus that honoured diverse interpretations while maintaining analytical rigour. This provided important opportunities for researcher reflexivity in the coding and subsequent interpretation of data. This iterative and collaborative process allowed codes and themes to emerge inductively from the data while ensuring Aboriginal worldviews and cultural understandings remained central. The team maintained reflexive journals and engaged in regular debriefing to uphold rigour and transparency. All data were securely stored on password-protected university drives accessible only to the research team.

### Debrief process

A vicarious trauma protocol was put in place to deal with potential psychological distress experienced by participants. After each one-on-one yarning session and circle, each individual was debriefed to support their wellbeing and safety. Participants were asked if they were upset or distressed, if they wanted the researcher to “check in” on them the next day or would like a referral to an appropriate counselling service. Arrangements were made with culturally safe services within each community prior to the commencement of the project to accept referrals. During the study period, one participant was referred to a counselling service.

### Results

There were 99 children in the care of this cohort of 46 kinship carers. Around half (47%) of the children were aged less than 10 years (Table 1). Six of the carers were from metropolitan areas of Perth (indicated as M in the results) and the remaining 40 were from regional areas across WA (indicated as R in the results). The health conditions and disabilities were self-reported by the kinship carers. Many of the children had health conditions, trauma, and/or disabilities, including a significant number with diagnosed or suspected neurodevelopmental disabilities, including attention deficit hyperactivity disorder (ADHD), global developmental delay (GDD) and FASD. Several children had multiple diagnoses, such as ADHD and GDD or ADHD and autism spectrum disorder (ASD).

In addition to the 20 children identified by their carers as having a neurodevelopmental disability, 10 children were waiting to be assessed for neurodevelopmental, emotional, or behavioural concerns. Of these, half were suspected by kinship carers as having FASD

( $n = 5$ ). A number of children were exhibiting developmental concerns and were currently undiagnosed, placing a significant burden on both the children and their carers. A larger proportion of children with suspected FASD were undiagnosed compared to other neurodevelopmental disabilities, which may reflect the heightened barriers towards obtaining a FASD assessment in under-resourced settings.

### Themes

#### Diagnosis of disability and support pathways

##### Underdiagnosis of FASD

Among the children waiting to be assessed, carers suspected that half had FASD. Carers explained that their suspicion was due to children in their care having neurodevelopmental and behavioural difficulties after known prenatal alcohol exposure. Several carers voiced this belief:

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

But foetal alcohol syndrome, them kids ... All of them. His mum was drinking, partying and ... I just see the alcohol syndrome there you know [R].

One carer believed the child in their care was misdiagnosed and that FASD better explained the child's history and signs. She expressed concerns about the effectiveness and accuracy of the specialist assessment coordinated by the Department of Communities (“the Department”), the agency responsible for child protection:

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 [M].

##### Pathways after diagnosis

Some kinship carers discussed their experiences navigating the system after receiving a diagnosis. Both formal and informal kinship carers often prefaced their views with a description of the length of time it took to receive a diagnosis. After receiving a diagnosis, carers described how determining next steps was a complex process with little guidance:

Then the waiting process to get that done because that nearly took a 12-month period to get her diagnosed. Then once the diagnosis came through, it was setting up the process of, okay this is what we're dealing

with, and this. Where do we go from here? What strategy is put in place? [R].

A number of kinship carers reported that the children in their care were NDIS recipients. Other kinship carers were unaware of the NDIS or had not been referred to it. One formal kinship carer highlighted the difficulties in receiving disability support through the NDIS when waiting lengthy periods of time for children in care to receive a diagnosis:

But – like with NDIS too – like we can't put NDIS – anything with NDIS in place until we have a diagnosis and that takes time (M).

### ***Social and emotional wellbeing problems and trauma***

Several kinship carers discussed children's social and emotional wellbeing problems, often related to trauma and attachment (Bailey & Clark, 2024). Social and emotional wellbeing is a holistic, relational concept that encompasses the whole-of-life worldview of Aboriginal and Torres Strait Islander peoples, emphasising harmony and interconnectedness across various domains of life and community (Dudgeon et al., 2025). They discussed how support and counselling were not always being provided for children with trauma:

They're very traumatised children. They have their own needs ... Nothing has been put in place [by the Department]. Nothing at all [R].

A number of children were reported as having comorbid disabilities, trauma and attachment problems. Carers often described how the signs of trauma and/or attachment problems can intersect with the child's disability.

They've both suffered trauma. One has got a thing called RAD [reactive attachment disorder]. That's the one with the autism. With the RAD, well because she's got autism, we sort of blend it within that spectrum because it's kind of some of the symptoms are sort of related, so it's really hard to separate [R].

The experiences of these carers demonstrate the need for comprehensive support services to manage the intersecting and often complex needs of children in kinship care.

### ***Knowledge, training and support for kinship carers***

Carers described their experiences of navigating various issues associated with disabilities, trauma and/or attachment, including emotional and behavioural challenges,

developmental delays, issues with speech and hearing, bladder and bowel control and eating difficulties. Some carers reported they were struggling to manage children's behaviours and complex needs, particularly given the lack of information and guidance from the Department. As one formal kinship carer explained:

When I got them, I just knew their first name. I knew nothing about them, and I wasn't trained for six months about being a carer [M].

Participants expressed a desire for more information and training to improve their understanding of how to manage the needs of children with disabilities and trauma:

[the children under my care] are autistic, so I want to be able to understand their disabilities, you know, and teach my daughter with the boy [R].

Many carers were not aware of what support they were entitled to, and a number reported being offered no training to manage children's disabilities, behavioural challenges, and needs. Several carers noted that any knowledge they had was through their own employment:

I was just lucky to have my experience as an education assistant at school ... so I had worked with special needs kids and ... I had a good understanding of trauma and FASD and all of those special needs things already and how to communicate with kids ... but I did not get any training or offered any training at all ... and I asked for first aid for about 12 months, and I didn't get it. I still haven't got it [R].

Other carers highlighted issues accessing available training because of the time commitment of their employment. Some carers felt the training that was available was not culturally safe or delivered in an accessible way. One carer described this experience:

[The training is] very generic. You know they send you out the information about training sessions and stuff like that, a lot of that stuff is geared towards non-Indigenous carers, like how to deal with Aboriginal children ... Not only that, the hours for them doesn't work for someone that works [M].

### ***Barriers to early intervention and support***

#### ***Implications of delayed intervention***

Carers highlighted significant issues with delays in obtaining health checks and disability assessments, particularly for children with suspected FASD and other neurodevelopmental disabilities:

She's undiagnosed at the moment with FASD. She shows all the signs and symptoms of it. I know that



mum was drinking ... when she was pregnant ... we've had her for six months, and I was told we were to wait another six months. Nothing's been done from DCP. The whole time they've had her since she was a child [R].

One carer described encountering ongoing hurdles while trying to obtain trauma counselling for her kin child who required it urgently:

They've been requested – [laughs] thousands, hundreds of times by me and my mum and dad and family [for trauma counselling for the children] ... You email them or you ask them for it, or you want it to be in place and it doesn't happen. It's always an excuse ... They'll just say, well we've got to wait for this paperwork or that court date or this information or we're just holding off a bit [R].

High caseloads and a lack of continuity in case management due to high staff turnover were widely reported barriers to early intervention, with some carers resorting to coordinating health and disability assessments on their own:

He was deaf. So, the only thing he knew is this tablet. [Did DCP do a health assessment?] Not when I first got him ... I did these things myself ... we were getting caseworker after caseworker [R].

Carers were exasperated by the long delays in obtaining assessments and the missed opportunities for early intervention. One carer commented how she was instructed by a specialist to delay assessment until the child began school, despite her desperation to have him assessed for neurodevelopmental issues that were apparent from a very early age. She expressed her belief that this was setting him up to fail:

[The paediatrician] said that he has to start school because they can't really do a diagnosis until the little ones are older ... 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 ... and it's not his fault [M].

### *Long-term implications for children and need for advocacy in the system*

Many carers described the impact of a child's emotional and behavioural problems on their education. Children with trauma and/or undiagnosed neurodevelopmental disabilities often struggle with the school environment, and some are punished for challenging behaviours without receiving the support they need. Tragically, some children only finally receive their diagnosis upon entering the juvenile justice system:

They suspended him instead of helping him. So, I said, well, okay. When he went into Banksia Hill, that's when

they did the test ... Then when we found out [he has FASD], I told the teacher about it, and they said, oh now we understand why [he] has been like this [R].

By the time one carer's child had received a diagnosis, he had left her care, leading to a missed window of opportunity for intervention. This was following years of continually advocating to the Department to get him assessed, and the assessment only occurred after the carer sought external support to put pressure on the Department to coordinate the assessment.

We would have IEP [Individual Education Plan] 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 ... I got sick and tired of DCP not doing anything ... They did the actual testing just before he ran away [at 12 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 [M].

Overall, the experiences of kinship carers highlighted the difficulties of navigating the child protection system and accessing services for children with disabilities in their care. Participant experiences emphasised a significant lack of support and advocacy within the system. One participant explained that, because of this, they had to upskill themselves to be able to navigate the system:

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 [M].

## **Discussion**

### *Barriers to screening and accessing support*

The experiences of kinship carers involved in this qualitative study support the view that current prevalence data on the number of Aboriginal children with disabilities in OOHHC are underestimated (Secretariat of National Aboriginal and Islander Child Care, 2023; Williams & Badry, 2023). Of the 99 children cared for by interviewed kinship carers, 48 children were considered to have a disability or health condition. There was a strong theme of carers encountering seemingly insurmountable barriers to obtaining accurate and comprehensive assessments and diagnoses for their children, leading to frustration, exhaustion, and likely placing the kinship care placement at risk. Kinship carers frequently raised the issue of enduring long delays ranging from a few months to several years, often citing poor communication, a lack of follow-up, and high staff turnover of departmental staff. Some participants discussed

how these delays affected their ability to obtain support from the NDIS. The substantial delays in accessing assessments and supports reflect the lack of culturally appropriate support and the availability of specialists needed to conduct assessments, particularly in regional or remote areas (Blagg et al., 2020; Jones et al., 2023). These barriers to diagnosis and the consequent difficulty in accessing support and connection to services are echoed in the submission made by the AHCWA to the Inquiry into Child Development Services (Aboriginal Health Council of Western Australia, 2022). These barriers were also reported among formal kinship carers who were engaged with government child protection services.

Themes related to difficulties in obtaining diagnoses and accessing support are reflected in the findings from the recent hearings examining the experiences of Aboriginal children with disabilities in OOHC conducted by the Royal Commission into Violence. These hearings highlighted a number of barriers to the identification of disabilities and access to assessments amongst Aboriginal children in care, including a lack of continuity of care and high case worker workload, the lack of reliable health histories, and lower engagement with support services where disabilities may be identified (Royal Commission into Violence, 2021; Secretariat of National Aboriginal and Islander Child Care, 2023). The Royal Commission heard that health checks may not be an effective mechanism to identify certain disabilities, and there were concerns about whether currently available assessment and treatment planning is trauma-informed and culturally appropriate (Commission for Children and Young People, 2016; Royal Commission into Violence, 2021). Family Matters from WA has stated that often an assessment will only be conducted due to a child's contact with the justice system, pressure from a senior figure within the Department, or in high-profile cases (Blagg et al., 2020; Secretariat of National Aboriginal and Islander Child Care, 2023). They further stated that an Aboriginal child is unlikely to receive an assessment without "strong and sustained advocacy from family members, carers or other stakeholders" (Secretariat of National Aboriginal and Islander Child Care, 2023). Similar findings were reflected in the experiences of our kinship carers, highlighting the prevalence of these concerning issues.

### Importance of early intervention

Carers noted that delays in accessing assessments and support resulted in missed opportunities for early intervention, which contributed to poor outcomes for the children in their care, ranging from disruptions in

schooling to involvement with the juvenile justice system (Blagg et al., 2020; Bower et al., 2018; Jones et al., 2023). Many children struggled with the school environment, sometimes resulting in punishment for challenging behaviour despite a lack of support. At least two kinship carers reported that their child had entered the juvenile justice system. One of these children received a diagnosis of FASD upon entering juvenile detention. The other was diagnosed with an intellectual disability, however, his carer believed FASD better explained his behaviour and care needs. Carers felt that this trajectory could have been prevented through timely access to assessments and appropriate support and emphasised that the failure to support kinship carers and children results in cycles of disadvantage and trauma being perpetuated across generations (Jones et al., 2023).

Research has found that a lack of early intervention can contribute to criminalisation as "disability-related behaviour [is] reinscribed as offending behaviour" (McCausland & Dowse, 2022). This theme is reflected in findings from the Royal Commission into Violence that a lack of disability support for children in care can increase the instability of placements and risk of contact with the justice system (Royal Commission into Violence, 2021). An investigation of the cases of children with experience of both the child protection and justice system found that a substantial number of these "crossover" children had neurodevelopmental disabilities and that in most cases professionals had attributed criminalisation to the cumulative effects of trauma, attachment, emotional and behavioural challenges and disabilities (Baidawi & Sheehan, 2019).

### Need for appropriate training

Kinship carers voiced their urgent need for appropriate training in the effective management of the needs and behaviours of children with challenges related to trauma and/or disabilities. The *Always was, always will be Koori children: Investigation into the circumstances of Aboriginal children and young people in out-of-home care in Victoria* report highlighted the need for carers to be trained and equipped with the right tools and knowledge to enable them to meet the needs of children in their care, since this can impact the stability of a child's placement and help prevent placement breakdown (Commission for Children and Young People, 2016; Snow et al., 2014).

### FASD in OOHC

The prevalence of FASD is disproportionately higher among children in OOHC and is likely underestimated

(Lange et al., 2013). Kinship carers with children without a confirmed diagnosis observed a link between prenatal alcohol exposure and subsequent developmental issues, and several believed that the child in their care may have FASD. The reported lack of support for kinship carers of children with a FASD diagnosis or suspected FASD has been found to increase stress levels and contribute to adverse health outcomes, particularly when carers are not able to prioritise their own health (Williams & Badry, 2023).

### Co-related trauma and disabilities

Children with disabilities often enter care with complex support needs and a history of adverse childhood experiences, both of which can result in emotional and behavioural problems that can impact placement stability and contribute to poor outcomes (McCausland & Dowse, 2022; Tan et al., 2022). More needs to be done to support Aboriginal kinship carers, who are best placed to care for these children by keeping them connected to their culture and community (Krakouer, 2023).

### Conclusion

While there is limited knowledge of the prevalence of disabilities among Aboriginal children in OOHC and little is known about their experiences, through our Aboriginal Community Advisory Group and analysis of in-depth interviews with kinship carers, our study has determined support for Aboriginal children with trauma and disabilities in OOHC to be an urgent priority for the government. Together with recent findings from the Royal Commission into Violence and the Inquiry into Child Development Services, the voices of our kinship carers and Community Advisory Group illustrate that the WA government is still failing to provide Aboriginal children in OOHC with timely access to appropriate and comprehensive assessments and support. This lack of access to tailored diagnostic and support services contributes to a breakdown in care arrangements, which can lead to serious detrimental outcomes for the child (Secretariat of National Aboriginal and Islander Child Care, 2023).

Urgent reform is needed to better support Aboriginal children with disabilities in the child protection system. Closing the Gap targets, specifically Target 12, include recommendations around improving multidisciplinary response programs (Measure 1), developing cultural competency and trauma responsive skills and capabilities of the child and family sector (Measure 2), alongside disability cross-cutting outcomes (Commonwealth of

Australia, n.d.). Our findings in this research show there is a critical need for significant investment into meeting these targets, working towards co-designed culturally safe support services to ensure the wellbeing of carers and children in OOHC with disabilities.

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### Author contributions

CRedit: **Jocelyn Jones:** Conceptualisation, Data curation, Formal analysis, Funding acquisition, Investigation, Methodology, Project administration, Software, Supervision, Validation, Writing – original draft, Writing – review & editing; **Juliet Brook:** Data curation, Writing – review & editing; **Sasha Moodie:** Formal analysis, Writing – original draft, Writing – review & editing; **Richard Chenhall:** Data curation, Formal analysis, Investigation, Methodology, Project administration, Writing – original draft, Writing – review & editing; **Robyn Williams:** Conceptualisation, Data curation, Formal analysis, Investigation, Methodology, Writing – review & editing; **Cathy Garlett:** Conceptualisation, Data curation, Formal analysis, Writing – review & editing; **Katiska Davis:** Investigation, Writing – review & editing; **Alison Gibberd:** Conceptualisation, Data curation, Formal analysis, Funding acquisition, Investigation, Project administration, Supervision, Writing – review & editing; **Ben Harrap:** Formal analysis, Writing – review & editing; **Bridgette McNamara:** Data curation, Formal analysis, Methodology, Writing – review & editing; **Melissa O'Donnell:** Conceptualisation, Investigation, Writing – review & editing; **Sandra Eades:** Conceptualisation, Data curation, Formal analysis, Funding acquisition, Investigation, Methodology, Project administration, Resources, Supervision, Validation, Writing – review & editing.

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### Data availability

The datasets used in this article are not publicly accessible, as they are restricted to the research team for analysis and publication purposes.

## Ethics statement

The study involving human participants received approval from the Western Australian Aboriginal Health Ethics Committee (HREC 919), Curtin University Human Research Ethics Committee (HREC 2020-0428), and the University of Melbourne Central Human Research Ethics Committee (HREC 1,956,013).

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