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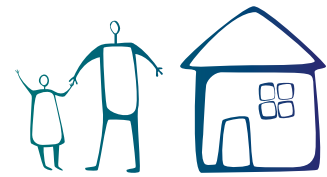
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Résumé de l'article

Children and youth with fetal alcohol spectrum disorder (FASD) have limited access to assessment, diagnostic, and treatment resources – a distinct disadvantage in meeting their care needs in Australia. Limited knowledge exists on the intersection of FASD, Indigeneity, racism, trauma, and child welfare involvement. Notably, the lack of support for children with FASD increases the risk of adverse outcomes, including incarceration, homelessness, mental health problems, and early mortality. Children with FASD are often cared for in the child protection system by kinship carers, many without a diagnosis or the benefits of FASD informed care. Rarely considered is the Australian response to FASD or the Aboriginal worldview on disability. Qualitative research was utilized to conduct semi-structured interviews with six carers of Indigenous children with FASD—three foster carers and three relative or kinship carers. Seven core themes identified by carers included: FASD awareness, caregiver health, advocacy for the child, mothers of the children with FASD, loss and grief experienced by the carer, social costs, and children in child protection care. Carers identified that limited resources existed to address the disabilities and care needs of children, including training and respite. Financial disparity exists with relative carers receiving less income than foster carers. Carers demonstrated advocacy, resiliency, and resourcefulness in providing care. A lack of knowledge of FASD and core resources in child welfare services were identified as major challenges in providing care. This research examined the caregiving experiences of foster and Aboriginal kinship carers, caring for children with FASD in child protection.



Aboriginal Kinship Carers and Children with Fetal Alcohol Spectrum Disorder in Western Australia: Advancing Knowledge from an Indigenous and Disability Lens

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Abstract

Children and youth with fetal alcohol spectrum disorder (FASD) have limited access to assessment, diagnostic, and treatment resources – a distinct disadvantage in meeting their care needs in Australia. Limited knowledge exists on the intersection of FASD, Indigeneity, racism, trauma, and child welfare involvement. Notably, the lack of support for children with FASD increases the risk of adverse outcomes, including incarceration, homelessness, mental health problems, and early mortality. Children with FASD are often cared for in the child protection system by kinship carers, many without a diagnosis or the benefits of FASD informed care. Rarely considered is the Australian response to FASD or the Aboriginal worldview on disability. Qualitative research was utilized to conduct semi-structured interviews with six carers of Indigenous children with FASD—three foster carers and three relative or kinship carers. Seven core themes identified by carers included: FASD awareness, caregiver health, advocacy for the child, mothers of the children with FASD, loss and grief experienced by the carer, social costs, and children in child protection care. Carers identified that limited resources existed to address the disabilities and care needs of children, including training and respite. Financial disparity exists with relative carers receiving less income than foster carers. Carers demonstrated advocacy, resiliency, and resourcefulness in providing care. A lack of knowledge of FASD and core resources in child welfare services were identified as major challenges in providing care. This research examined the caregiving experiences of foster and Aboriginal kinship carers, caring for children with FASD in child protection.

Keywords: FASD, child welfare, Australia, foster care, Indigenous, Aboriginal, kinship care, colonization, disability

Introduction

Indigenous people experience rates of disabilities at 2.7 times higher than non-Indigenous Australians and are more likely to experience higher rates of informal caring due to family and cultural obligations (Fitts & Soldatic, 2020). This is an important premise to explore the challenges of fetal alcohol spectrum disorder (FASD) within the Aboriginal and Torres Strait Islander community in Australia. This research provides a contextual framework for the Australian Indigenous experience of FASD and the positioning of Aboriginal kinship carers (also known as relative carers) raising children with FASD in Western Australia, who are the focus of this research. There is limited research on Aboriginal kinship carers in Australia, and their systemic challenges in raising children with neurodevelopmental conditions such as FASD (McRae et al., 2019; Williams & Badry, 2020). The history of colonization and the removal of children through the Stolen Generations has deeply contributed to the disparities experienced by Aboriginal and Torres Strait Islander children and their families. Similar parallels exist between Canada and the Residential Schools, and Australia and the Stolen Generations—historically both governments engaged in the systematic removal of Indigenous children from their families. In contemporary times, the removal of Indigenous children from their families continues and as noted by Blackstock (2007), has morphed into the child protection system. The Australian response to FASD in contrast to Canada is still relatively new, and notably limited resources and infrastructure exist to respond to the needs of children and families engaged with the child welfare system (Reid, 2018).

The lead author presents this research from an insider perspective as a Noongar woman from Western Australia, with a lived family experience of the Stolen Generations on the maternal side of the family, and the experience of supporting family members with FASD (Williams, 2018). The Noongar nation consist of 14 clans and the country of the Noongar people includes the city of Perth and the South West region in Western Australia. Noongar nation includes approximately 30,000 members and is the biggest Aboriginal nation in Australia (Scrine et al., 2020). Despite the onslaught of colonization, Aboriginal culture and Aboriginal families have survived and play a fundamental role in continuing to protect, nurture, and support vulnerable family members with diagnosed and undiagnosed disabilities in the family, albeit, with none to limited access to relevant services (Luke et al., 2022). The findings of this study reflect research completed on FASD in an urban setting in Western Australia.

The catalyst for this study was a community request made to the lead researcher by an Aboriginal family and Aunty who agreed to take on the care of her two nephews, both with undiagnosed and unrecognized FASD. The family requested this research be undertaken to explore the experience of caring for children with prenatal alcohol exposure. This request by one Aunty marked the beginning point of our journey into FASD in Western Australia in Noongar country. The core question driving this research was: *What are the experiences of caregivers of Aboriginal children with FASD in Western Australia?* Fetal alcohol spectrum disorder (FASD) refers to a range of disabling

conditions that affect individuals over their lifespan as a result of prenatal alcohol exposure. FASD is the leading cause of developmental disability in Canada and is a lifelong neurodevelopmental disability which includes a range of cognitive and developmental disabilities, behavioural challenges, learning problems, and the risk of being placed in child protective services care (Canada FASD Research Network, n.d.; Flannigan et al., 2022). According to the Foundation for Alcohol Research & Education, FASD is a leading cause of non-genetic disabilities in Australia (FARE, 2022). The focus of this research is on the experiences of Aboriginal kinship carers and foster carers looking after Aboriginal children with FASD in Western Australia in child welfare care. In particular, this paper will discuss some of the systemic disparities impacting on Aboriginal kinship carers. As authors we assert that FASD is certainly not only an Indigenous issue, but an issue across all populations. It is important to note that FASD is a complex issue, and it is the voice of participants in this research who raised concerns about inequities in the care and support of Aboriginal children with this disability involved in the child welfare system. The experience of an ongoing lack of resources and appropriate services including FASD-informed care are deeply related to colonization.

The term Aboriginal is commonly used to refer to Indigenous people in Australia, but at times the terms Aboriginal and Indigenous are used interchangeably in this paper and respectfully includes Torres Strait Islander children.

Australian Context

It is important to situate this research in the broader context of the experiences of individuals with FASD in relation to key systems including child welfare and justice. The Coroner's Court of Western Australia conducted an inquest to review the deaths of 13 Aboriginal youth suicide victims in the Kimberly Region from 2012-2015 (Fogliani, 2019). It was noted that while none of the young people had a diagnosis of FASD, it was considered to be a serious concern given "almost all the children and young persons grew up in homes marred by the effects of high levels of alcohol abuse" (p. 9). Further, FASD was identified on 42 pages of the report, primarily by key expert witnesses. In fact, the first recommendation in the report calls for universal screening for FASD "during infant health assessments and upon entering into the child protection system or justice system for the first time" (p. 268) and the first six of 42 recommendations focus on FASD due to the identified significance of alcohol harms. The Banksia Hill Detention Centre study of 99 incarcerated youth in Western Australia identified a prevalence rate of 36% who had FASD, of which 47% or 34 youth were Aboriginal, identifying "the highest reported prevalence of FASD in a youth justice setting worldwide" (Bower et al., p. 7). Fitts and Soldatic (2020) report that Indigenous populations have higher rates of disability in comparison to the general population in settler colonial countries including Canada, New Zealand, Australia and the United States and that Australian Indigenous populations report the highest rates of disabilities amongst these countries (United Nations Department of Economic and Social Affairs, 2015).

Aboriginal Worldview of Disability

Whilst there is limited literature on Indigenous experiences of disability, the key threads emerging include connections to colonization, racism, contrasting worldviews on disability, and the low engagement in services (Eades, 2018; Ferdinand, et al, 2021; Ravindran et al., 2016). Colonization has contributed to increased rates of disability amongst Aboriginal people (Collings et al., 2018). Prior to colonization, Australian Indigenous people, similar to Indigenous peoples in the United States, had no word in their language for the term disability (Lovern & Locust, 2013; Ferdinand et al., 2021). The Indigenous worldview of disability is about acceptance of diversity and embracing the whole person, recognizing the strengths that difference brings to the community (Ravindran et al., 2016; Lovern & Locust, 2013). Western disability definitions are typically based on the medical model of disability that is generally void of understanding relevant factors including culture, history, power relationships, and socioeconomic status (Ariotti, 1999). FASD is a critical topic that requires a more nuanced and broader conversation in the interest of decolonizing FASD as a disability. There is disparity in access to support services experienced by all Indigenous populations across the lifespan (DiGiacomo, 2017) and low engagement of Aboriginal people with disability services is reflective of the lack of culturally safe supports and services (Ferdinand et al., 2021; Green et al., 2018; Ravindran et al., 2016;). Ferdinand et al. (2021) also note that disability prevalence tends to be higher for Indigenous people in Australia, Canada, and New Zealand, and recognizes the Indigenous worldview, which is vastly different from a western paradigm, is often not incorporated into service delivery. The experiences of Indigenous people with disabilities have been largely neglected by disability studies (King et al., 2014), emphasizing the urgency in decolonizing disability.

Aboriginal Kinship Carers

To date there has been limited research on Aboriginal kinship care in Australia (Kiraly et al., 2014; Kiraly & Humphreys, 2013). Qu et al. (2016) report that major differences exist in socio-demographic characteristics of foster and relative/kinship carers. It is noted that approximately one fifth of relative/kinship carers were 65 years or older, more likely to be Aboriginal or Torres Strait Islander, and often were grandparents. Other characteristics noted were that relative/kinships carers faced financial hardships and 28% reported as having low household income (less than \$30,000). Most relative/kinship carers were asked to care for children by child welfare and reported receiving limited information about the child prior to placement. Foster carers tended to access support services for children at a much higher rate than relative/kinship cares (70% vs. 40%), and kinship carers had lower rates of access to respite care, disability support, transport and after-hours emergency/crisis services and less contact with the support worker on a regular basis (Qu et al., 2018). Green et al. (2018) report in qualitative research with 19 relative carers of Aboriginal children with disabilities that carers experience lower socioeconomic status, face discrimination, and are mostly female.

The Victoria Auditor General's Office (VAGO) released an audit on Kinship Care in June 2022 that highlights systemic failures in the child protection system in supporting kinship or relative carers.

It was found that 96% of Aboriginal kinship carers in comparison to foster carers had received the lowest level of care allowance whilst raising Aboriginal children (p. 35). Notably, most kinship carers were great-grandmothers and grandmothers whose average age was 54 years (VAGO, 2022). The key role of the auditor general is to act as independent office of the Victorian, Australian parliament and conducts both financial and performance audits to review compliance with public legislation. In this case VAGO audited compliance in the Kinship Care system (VAGO, n.d.) The gap widens and the disparities are amplified when Indigenous children who are already over-represented in child protection do not receive services to effectively support their disability and financial supports for their families. The lack of recognition of FASD for children in care contributes to the stacking on of disparities for Aboriginal children. Examples provided by participants in this research included a lack of support, funding, and disability-informed care (Williams, 2018).

The Importance of Connection to Culture for Aboriginal Children

In Australia, the Aboriginal kinship system is based on an extended family structure and is one of the fundamental strengths of Aboriginal culture that includes the cultural obligations of caring for family members (Williams & Badry, 2020). As such, Indigenous children will likely have attachment bonds with more than one adult (Krakouer et al., 2018; Secretariat of National Aboriginal and Islander Child Care [SNAICC], 2011). The extended family structure includes aunts, uncles, grandparents, as well as older brothers, sisters, and cousins who collectively contribute to the raising of Aboriginal children (Dudgeon et al., 2017). A recent qualitative study in Noongar country involving over 51 Elders described the multiple strengths of the extended family structure and the principle of having additional family members to provide guidance and support during childhood (Scrine et al., 2020). Connection to culture, kinship, identity, and land is the basis for positive emotional and social well-being for Aboriginal children (Dudgeon et al., 2017). The mental and physical health of Indigenous people is enhanced when they maintain connections to culture (Dockery, 2010). Krakouer et al. (2018) assert that whilst placement stability is important for Aboriginal children, equally is the connection to culture. A large longitudinal study of over 1,687 Indigenous children and families found connection to healthy and successful development of Aboriginal children must be grounded in their own culture (Colquhoun & Dockery, 2012). They noted that knowledge of kinship relationships, family stories, and protocols are identified as important rites of passage for the transition into adulthood for Aboriginal adolescents.

Despite attempted cultural genocide, the kinship structure adapted during the decades of the Stolen Generations and Aboriginal children who were not blood related were “adopted” into the kinship system (Williams, 2018; Maushart, 1993). Maushart (1993) describes in her interviews with survivors of the infamous Moore River Settlement the rich stories of survival and cultural adaptation; including culture going underground to survive and the adoption of non-blood Aboriginal children. In a similar fashion, through oral storytelling, the lead author William’s own mother, who was removed as a child in the 1950s and placed in the Carnarvon Mission, would fondly recall her bonds

and relationships with her childhood mission brothers and sisters that would last her lifetime (M. Williams, personal communication, March 2017). The past decade has also seen the emerging evidence of culture as intervention and is an important contribution to psychosocial interventions for Aboriginal children and adults (Gatwiri et al., 2021; Scrine et al., 2020; Williams & Badry, 2020).

Intersection of FASD and Systematic Racism for Indigenous Kinship Carers and Families

The intersection of FASD, Indigeneity, racism, trauma, and child welfare is rarely considered despite the over representation of Indigenous children in child protection (Lewis et al, 2019; Tilbury, 2009) and justice settings (Bower et al. 2018; Williams & Badry, 2020). Indigenous Australians experience higher rates of remand in prisons in comparison to non-Indigenous people and it is well documented that the criminal justice system is not therapeutic for people with disabilities (Baldry, 2018; Hollinsworth, 2013; Kairuz et al., 2021). In the past decade, Australian research has identified the often-tragic consequences of criminalization of people with mental and cognitive disabilities who are overrepresented in the incarceration system (Sotiri, McGee & Baldry 2012). Gatwiri et al., (2021) assert the over representation of Aboriginal children in care is not accidental and is the result of ongoing historical and contemporary structural inequities. The lack of political will in Australia to change this trajectory has contributed to ongoing structural inequalities impacting on the Aboriginal community (Gatwiri et al., 2021). In a similar fashion, de Finney et al. (2011) argue that the “problematizing” of minority groups is required to understand the over representation of Aboriginal children.

Aboriginal people with FASD face unparalleled levels of stigma, poverty, discrimination and racism (Hollinsworth, 2013). The linkage between colonization and the disproportionate access to disability services has been reported by Hollinsworth (2013). Luke et al. (2022) identify that Indigenous people receive less access to services than non-Indigenous populations. Notably, there is lower engagement in mainstream services by Aboriginal women, and Aboriginal people with disabilities avoid mainstream services due to feeling judged and reported racist treatment (Eades et al., 2020). King et al. (2014) state: “The interplay between Indigeneity, disability, and colonisation [sic] is complex and multifaceted and is constantly evolving” (p. 748). The intersection of racism, poverty, and intergenerational trauma adds complexity to the experience of Aboriginal people with FASD in Australia (Hollinsworth, 2013; Luke et al., 2022; Williams & Badry, 2020). Under the legacy of mistrust and the fear of child apprehension, many Aboriginal women often attend prenatal services late in pregnancy and are likely placing at risk their health and the health of their unborn child (Gibberd et al., 2019; Simpson et al., 2020). While countries such as Canada and the USA have recognized the importance of long-term mother mentoring relationships to address complex trauma and maternal health concerns related to substance use disorders, similar initiatives do not exist in Australia (Reid, 2018).

Child Protection

Australia has a dark history in the treatment of Aboriginal children and families, resulting in the crisis of over-representation of Aboriginal children in care (Krakouer et al., 2018). Child protection legislation is the responsibility of each state and territory in Australia (Krakouer et al., 2018). The 1950s saw the commencement of Aboriginal children being placed with non-Aboriginal families (Choo, 2016; Haebich, 2000) It is only from the 1970s that Aboriginal family placements were even considered for Aboriginal children in care. Another recent development was the implementation of the Aboriginal child placement principle to support placement within the extended family and connection to their cultural identity (Krakouer et al., 2018). However, there is little monitoring and compliance of this principle in most jurisdictions, except for Queensland (McDowall, 2016). The lack of compliance by child protection is disturbingly high, with the rate of Aboriginal children not being placed within kinship placements as high as 65% in the Northern Territory (McDowall, 2016).

Western Australia has the highest rates of Aboriginal children in out of home care, a figure that has tripled in the past decade contributing to chronic under detection and under estimation of the number of Aboriginal children with disabilities in care (Davis, 2019). Another crucial gap in child protection in Australia for all children with FASD is the lack of FASD-informed case management for children and families in relation to best practice and interventions. Running parallel is the under resourcing of intensive family interventions and support for Aboriginal children with undiagnosed disabilities. In a recent study of 103 Aboriginal children in care in Victoria, 46% of children were identified with developmental delay, including 36% with speech delay (Shmerling et al., 2020). The study further highlighted the need for the Aboriginal Community Controlled Organizations to be adequately resourced to provide services for Aboriginal children and families. Burd (2016) indicates that the risk of mortality in FASD is higher for children with FASD, their siblings, and a marker for increased risk of death to the mother.

Barriers to early intervention support includes lack of adequate resourcing and lack of service availability, particularly Aboriginal designed and led services. Gatwiri et al. (2021) assert that the under resourcing for Aboriginal families is intentional. Western Australia lags behind all other states in Australia and has provided the lowest allocation towards intensive family support services (Lewis et al., 2019). “In 2017-18 only 17% of overall child protection funding was invested in support services for children and their families, while 83% was invested in child protection services” (Family Matters, 2019, p. 3). In Western Australia, the Family Matters Report (Hunter et al. 2020) warns that without culturally secure intervention programmes and intensive case management support led by Aboriginal agencies, the rates of Aboriginal children in care are likely to double by 2029. Aboriginal Community Controlled Organization agencies are best placed to work with Aboriginal families at risk (Shmerling et al., 2020). Led by the Aboriginal Community Controlled Organizations sector, Aboriginal communities continue to show leadership in the protection of our children and the response to FASD, as demonstrated by our Aboriginal elders, including Dr. Lorian Hayes and the late Dr. Jan Hammill; Fitzroy Crossing Community and the Derbarl Yerrigan Health Service in Western Australia (Williams, 2018).

Rationale for the Research

This research was driven by concerns of the Aboriginal community in Western Australia regarding the needs of children living with prenatal alcohol exposure. This research was one facet of a mixed methods study in Western Australia that included 180 Aboriginal participants who completed detailed surveys that explored awareness, knowledge, and critical issues about FASD (Williams, 2018). In the qualitative aspect of this research, interviews were conducted and took place in an urban setting with six families providing care to children with FASD, whose narratives are the focus of this paper. Children removed from parental care are generally placed in either foster care or often in relative care situations, which is particularly true for Aboriginal children (Libesman, 2014). All children in this study were in the care of the child protection system, and the majority came into care as infants.

Methods

Interviews were conducted with six participants who were recruited through purposeful and snowball sampling. This research was underpinned by Indigenous methodology and cultural protocols were observed for conducting research with Aboriginal families in Australia. Qualitative interviews were analyzed using NVivo computer software and themes were generated using thematic analysis (Braun & Clarke, 2006; 2020). This study purposefully selected three foster carers and three relative carers, to explore any differences between the groups. It is the narratives of the six families who participated in this research that have contributed to a deeper understanding of the care and support needs of children and youth with FASD in Western Australia. Interviews were conducted using semi-structured questions and yarning. Yarning is recognized as a culturally appropriate and safe research method in working with Aboriginal families (Bessarab & Ng'andu, 2010).

This research was one facet of a mixed methods study in Western Australia that included 180 Aboriginal participants who completed a survey with the interviewer. This is considered to be the largest consultation with Aboriginal people on FASD (Williams, 2018). In adhering to Indigenous methodology, protocols in Noongar country included getting permission from a respected Aboriginal elder at each site prior to commencing research. The researcher was also guided by local Aboriginal community members to ensure cultural safety for participants in the research process (Williams, 2018). This research was also conducted in partnership with Derbarl Yerrigan Health Service (DYHS), a leading Aboriginal health service, located in Perth, Western Australia. As part of reciprocity, FASD training was provided at each of the sites of DYHS; attended by both clinical and allied health staff. Key principles underpinning this research included Indigenous methodology, a commitment to community-based research, the adherence to Indigenous protocols, and honouring the principle of reciprocity (Wilson, 2001; 2008).

Introducing the Participants

The participants included families located in Western Australia, primarily in Perth and a rural town in the South West region. Three of the families were Aboriginal relative carers and three were foster carers (non-Aboriginal) for the Department of Child Protection. In total, the families cared for nine Aboriginal children, eight males and one female child. Three of the families were raising siblings with FASD. None of the nine children were raised by their biological parents with seven of the children apprehended from their parent at birth and placed in both foster and relative care. Two of the children had serious health problems including heart conditions and severe cognitive impairments impacting the behaviours of the children and requiring intensive support by the caregivers. All carers were of a mature age and had extensive experience in raising children. However, for all families this was their first experience in raising children with FASD. All carers raised their children without the benefit of FASD-informed services, interventions, or support.

Aboriginal Kinship Carers in This Study

All kinship carers were related to the children they were raising, including aunts, uncles and grandparents. Two of the kinship carers were asked to take on the care of their children as infants. Two kinship carers were single parents and the last was a two-parent home. All kinship carers were either themselves part of the Stolen Generations or was a direct descendant of the Stolen Generations. Two of the kinship carers homes had at least one member of the household who had serious pre-existing chronic health conditions. All homes were impacted by early mortality of key family members, further limiting their support within extended family structures. Kinship carers advised their chronic health conditions escalated during the years of caring for their children; caring in one placement ended abruptly due to the deteriorating health of both carers. Indigenous people from colonized countries experience worse health outcomes and shorter life expectancy than the non-Indigenous population (Harfield et al., 2015).

Aboriginal kinship carers experienced further loss and grief with the early deaths of key family members, highlighting the poor social health determinants impacting on Aboriginal families. The impact of FASD on the health of caregivers is identified as a key concern in this research. One of the Aboriginal grandfathers who had raised two grandsons from birth with FASD, passed away in his early 50s, leaving his wife and family to raise two young brothers. In another family, two closely related uncles to another child passed away at a similar age. The early deaths of close family members coincided with their children entering early adolescence and had a traumatic impact on the children and their families. Generationally, cultural obligations and protocols exist within Aboriginal families who often extend the natural level of caring to grandchildren and children within their extended family, and increasingly on a full-time basis. Hamill (2001) aptly identified this phenomenon within the Aboriginal community as “Granny Burnout”.

Findings

Interviews were conducted with six families and using thematic analysis (Braun & Clarke, 2006), several core themes were identified that are reported in this paper. Interviews were analyzed using NVivo qualitative software and codes generated. The core themes identified included FASD awareness, caregiver health, advocacy for the child, mothers of the child, loss and grief experienced by the caregiver and the social costs of FASD. Pseudonyms are used in the reporting of the results. It was noted that there was considerable burden on Aboriginal kinship carers who faced many challenges raising children with disabilities that were often undiagnosed.

Themes

FASD Awareness

It was recognized by carers that trying to access services in relation to assessment and diagnosis and trying to find support was a major challenge. In the voice of one carer trying to find a path to getting a diagnosis it was stated:

They didn't even know it was called FASD at the time... they realized that there was some problem with the child's development inside the womb because she was consuming alcohol... The wait time, we got a referral sent off, to the only pediatrician in Perth, which was a year and a half wait time. It was very much [about] us opening up Pandora's box, people weren't prepared to talk about it, they weren't prepared to name it up. (Kinship carer)

Caregiver Health

Caring for the children had a profound impact on the health of carers, including neglecting their own health. Early mortality of key family members also had a devastating impact on two of the relative carer families. In the voice of one carer:

I had them for four and a half years, so they left halfway through 2011. I got sick, seriously and honestly, you have to put this in, that I got burnt out, the impact on my family and my health, everything else. I hit brick walls everywhere; nobody wanted to talk to me, no doctors, and no services no anybody. (Kinship carer)

I think my raising Gary, my health is really my stress, because I just keep on going, I don't have time to go to the doctors, but I think it's just my own mental wellbeing with Gary, it's just stress. (Kinship carer)

Advocacy for the Child

All carers shared the importance of the need for constant advocacy their child, as this was often the only way to gain access to support and interventions for their child. Carers stated:

I would be saying jump up and down as loud as you can for the child. (Foster carer)

Get onto every single service that you can, that's Aboriginal and non-Aboriginal, especially the ones that claim to help people with disabilities, because this is a real disability, no matter what anybody says, no matter what box you try and put it into. (Foster carer)

Mothers of the Children with FASD

Carers expressed empathy and concern for the biological mothers and shared that the lives of these mothers had been marked by violence, homelessness, alcoholism, and undiagnosed mental health conditions; several mothers were suspected to have undiagnosed FASD. The birth mothers included both Aboriginal and non-Aboriginal women. The Aboriginal women had been removed as part of the Stolen Generations. Carers stated:

Because his mum had FASD as well, we told him when his mum used to come over to our house, she'd only have two or three cans and she'd be charged up. That's why we say to him don't drink more than two cans, you don't even need to drink, but he does because everybody else is. (Kinship carer)

She had three of them. There was Gary, John, and Rose... Aunty Joan got John, and little Rose who has got fetal alcohol and she's in care as well. We used to beg her not to drink when she was pregnant, but she didn't understand what we were saying. (Kinship carer)

Mum is really not well at the moment as she is doing herself damage with drugs and alcohol. Mum is supposed to take medication, and sometimes she goes off, she is really not good. (Foster carer)

Loss and Grief Experienced by the Caregiver

The carers shared feelings of loss and grief in relation to the daily adversity confronting the children, particularly as they became older and realized their own struggles in comparison to other children. Loss and grief were further compounded by the lack of services for their children and the early deaths of key family members. Carers stated:

This younger one would say I'm not good at anything, what am I good at, what are my qualities Aunty? (Kinship carer)

The agreement was that when Gary was 12 or 13, his Uncles take him on, and could look after their nephew, my two cousins passed away, so I was left with raising Gary. (Kinship carer)

Social Costs of FASD

The social costs of FASD were identified by the carers and offered insight into the ongoing social and financial costs made by the carers and also to the wider community when children with FASD are not supported. In the voice of one carer:

People with disabilities, why do these kids not get those same entitlements? Why are they forced onto families who can't cope? Why have they not been made a part of a disability safety net? That catches them, and looks after them, and cares for them. (Foster carer)

Children in Care – Department of Child Protection (DCP)

All the children in this study were in the care system and the majority came into care as infants. Both foster carers and kinship carers shared the challenges of trying to navigate the child protection system, particularly as they had no awareness of FASD at the time of placement. Nor were the carers provided with FASD training during the placement. This likely placed the child and all carers at a disadvantage from the start in terms of accessing ongoing support for their child, and most of the families were not provided with access to respite care. A core protective factor for children with FASD includes having a stable placement (Streissguth & Kanter, 1997). In the voice of one carer:

I got Gary when he was six months old, and when he was two and a half, I got a guardianship order on him. So therefore, the department stepped out, and I've had him by myself since then. I wouldn't have applied for a guardianship order, they talked me into doing it because he was such a sick baby and they thought he was going to die. (Kinship carer)

In the current study, remarkably seven of the nine children remained in the one home from birth. These seven children did not develop adverse challenges of early onset of mental health or engagement in the criminal justice system, highlighting the benefits of stable care. In contrast, the two siblings who had not experienced stable placements experienced adverse challenges in early adolescence including mental distress and were self-harming, began using alcohol, and had contact with the criminal justice system.

Discussion

The findings and themes identified in this study provide insight into the experiences of both kinship and foster carers raising Aboriginal children with FASD. At the initial stage of the placement of children, all carers generally had no knowledge or awareness of FASD, placing them at a disadvantage in their initial dealings with the child protection system and the ability to advocate for the best therapeutic plan for their children. The lack of FASD awareness by health and social services heightened caring responsibilities of their child and resulted in under-resourced placements. Additionally, kinship carers are less likely to receive support from social services than non-relative carers (Mann-Johnson & Kikulwe, 2018). The lack of support from health and social services

heightened the stress of caregivers and at times contributed to experiences of trauma, loss, and grief for caregivers and for the child. It is well established that children with FASD are overrepresented in child protection and criminal justice system in Australia and globally (Blagg et al., 2020; Bower et al., 2018; Lewis et al., 2019; Tilbury, 2009; Williams & Badry, 2020;).

While considerable research on FASD has now been undertaken in Australia (Williams, 2018; Chamberlain et al., 2017; Bower et al., 2018; Symons et al., 2018; Elliott, 2015; Fitzpatrick et al., 2012) this has yet to translate into proper access to FASD diagnosis, interventions, and service delivery. The historical context of trauma, racism, and poor social health determinants requires that interventions on FASD for the Aboriginal community must be decolonized and led by the Aboriginal community (Gonzales et al., 2021). Further, Australian infrastructure to effectively address neurodevelopmental conditions such as FASD are basically non-existent. As Reid (2018) states, “FASD is not recognized as a disability within the current Australian health and education system, meaning that children and their families do not receive additional supports” (p. 829). In addition, Elliot (2015) asserts that the majority of children with FASD in Australia have a sibling with FASD, and that we continue to miss the chance of prevention of FASD within the same family. In the current research, three of the six families were caring for siblings with FASD. Watkins et al. (2013) and Shelton et al. (2018) identify the need to engage in prevention work and noted intervention is critical to prevent further cases of FASD in the same family. Researchers in Canada indicate there are maternal as well as societal factors that contribute to the risk of giving birth to a child with FASD and that alcohol use during pregnancy is related to complex psychosocial histories (Treit et al., 2016). Notably, there are limited supports for vulnerable women with complex early trauma histories who may themselves have a history of being raised in the child protection system.

Conclusion

In Australia, the failure to respond to FASD in a meaningful way underscores the gaps and disparities in responding to Aboriginal children living with a lifelong disability. FASD has been referred to as an invisible disability, however, in Australia it has become the most overlooked disability in child protection. A lack of diagnosis and FASD-informed case management in the child welfare system represents a distinct disadvantage to children, their families, and carers. Duty of care in relation to children with FASD in the child protection system would assume that children would receive timely access to assessment, diagnosis, intervention, and the provision of FASD-informed care. Whilst this study is based in Australia, the parallels of colonization are globally comparable for Indigenous communities and families. Colonization has contributed to the poor social and health determinants of Indigenous populations and the over representation of Indigenous children and adults in child protection and justice settings.

This paper presented key findings on the challenges experienced by both kinship and foster carers raising Aboriginal children with FASD in Western Australia. This study identified the essential need

to implement best practice across child protection settings in collaboration with health, criminal justice, and education. The needs emerging from this study include the urgency of addressing FASD within the Aboriginal community and the child protection system in Western Australia and all of Australia. This study supports the call to decolonize FASD interventions for Aboriginal families, and to engage in Aboriginal led approaches and solutions. This research further highlights the need to approach and consider FASD from a relational perspective that provides equitable resources to kinship carers. The disparity in service provision and supports to kinship carers as noted by VAGO (2022), underscores the findings of Williams (2018) in interviews with kinship and foster carers. Children with FASD have the right for their disability to be recognized, diagnosed, and to be provided with disability supports across the lifespan. The child protection system has a duty of care to ensure that all children in the system with disabilities receive supports and interventions appropriate to their developmental needs and disabilities. Creating infrastructure and models of service delivery to respond to FASD in key systems such as child protection and allied health care systems would provide a foundation for an Australian FASD model of care that includes children, families, communities, and the caregiver network.

Ethics

Ethical approval was received from the Western Australia Aboriginal Health Ethics Committee and Curtin University. Ethical consent was also obtained from the Department of Child Protection in Western Australia. As this research was undertaken in country towns in Western Australia, cultural protocols were observed and respected local elders were consulted. Each elder was provided information about the study and the opportunity to review survey and research questions.

Audience

The paper is intended for a wide audience of key human service sectors including child welfare, foster care, justice, health, education, Aboriginal health, and the overall community.

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