



# Children with disability in out-of-home care – summary of the literature

## Overview of the research

Children and young people with disability in the child protection and out-of-home care (OOHC) system are a highly vulnerable group and evidence about prevalence, needs, and experiences is under-developed. At present there is no nationally consistent definition of disability in Australia and no prevalence data available to identify how many children in care have a disability.

In 2021 disability status was only available for 57% of children in OOHC in Australia. Based on the available data, 15.3% of children in out-of-home care were reported as having a disability. (AIHW, 2021)

Similarly, there is no national prevalence data on the number of indigenous children in OOHC care with disabilities (Davis, 2019). According to the Bringing Them Home Report, just over half of the children in care in the Northern Territory were Indigenous and almost half had disabilities (Human Rights and Equal Opportunity Commission, 1997).

The complex intersections between OOHC and disability have implications for policy and practice. However, despite the overrepresentation of children with disability in OOHC there has been limited attention to this group in research, policy or practice. At present, there remains significant gaps and a lack of collaboration between disability services such as the National Disability Insurance Scheme (NDIS) and child welfare services supporting children and young people with disability in OOHC and transitioning out of care (Elisha, 2022).

## Literature Review

This literature review explored international research on young people with disability in OOHC. The main areas of research are: leaving care; prevalence; voluntary out-of-home care placement; placement stability; health and education outcomes; support services; and family preservation.

Findings of studies consistently highlight that young people with disability experience greater risk of entry into care and more negative outcomes in care and transitioning from care. Limitations in effective service provision and collaboration between child welfare and disability services have also been highlighted as a significant gap within the sector, increasing vulnerability of children with disability to negative outcomes.

## What do we know about children with a disability in OOHC?

- Children and young people with disability are at an increased risk of maltreatment compared to children without disability (Bruhn, 2004; Hill & Lightfoot, 2018; Jones et al., 2012).
- Children with disability are at greater risk of abuse when parents are not adequately supported to deal with care responsibilities and stress associated with caring for a child with disability (Jordan & Sketchley, 2009).
- Some disabilities are directly linked to early experiences of physical or psychological maltreatment and trauma (Bruhn, 2004; Perry & Szalavitz, 2017).
- Children with disability are at risk of being relinquished by their parents, which can itself lead to trauma due to separation from, and rejection by, family (Hill & Lightfoot 2018; Llewellyn et al., 2005; Vassos et al., 2019).
- Children with disability who are placed in out-of-home care often experience longer stays in care and are more likely to be placed in institutional settings than other children. (Hill & Lightfoot, 2018).
- Further research is needed to understand the prevalence of disability in OOHC and improve outcomes for these children and young people.

A total of 53 studies were identified through the literature search that related to children and young people with disability in OOHC. Relevant studies implemented a wide range of methods including 27 quantitative studies, 19 qualitative studies, 3 mixed method studies and 4 literature reviews.

## What is disability?

Disability is an umbrella term that encompasses the interaction between a person's impairment and factors within their environment (World Health Organisation, 2002).

The social model of disability explains that disability is created by society not by impairment. It is the failure to take account of the needs of people with impairments that disables them. Equality for all depends on the removal of **institutional, attitudinal, and environmental** barriers (AFDO, n.d.).

Developmental disabilities are **conditions** that occur at birth or emerge during childhood **due to physical, learning, language, and/or behaviour** impairment.

The **classification of disability** types varies according to purpose and context. For example, in Australian context, the Australian Bureau of Statistics uses six main disability classifications, National Disability Services uses ten and the National Disability Insurance Scheme uses seventeen. This variability hampers consistency and quality of data collection and outcome monitoring.

## Evidence on children with disability in out-of-home care

### Leaving care

Young people with disability transitioning from out-of-home care are at increased vulnerability to negative outcomes compared to young people exiting care without disability.

- Young people with disability are more likely to exit into inappropriate forms of accommodation such as aged care facilities, returning to family of origin, boarding houses, becoming homeless and inappropriate residential facilities (Broadley, 2015; McCauley, 2022; Mendes & Snow, 2014; Snow et al., 2016).
- Young people with disability in OOHC are at higher risk of mental health issues (Lee et al, 2018).
- Young people transitioning from care with social/emotional disabilities are at higher risk of poor outcomes including unsafe housing, low education attainment, unemployment, and incarceration, compared to their peers with other types of disabilities (Cheatham et al., 2020; Kang-Yi & Adams, 2017; Lee et al., 2022; McCauley, 2021; McCauley, 2022; Mendes & Snow, 2014; Snow et al., 2016).
- Young people with intellectual disability have increased risk of unsuitable housing or homelessness, restrictive placements in residential facilities, unemployment, and lower levels of education (MacDonald et al., 2016; Mendes & Snow, 2014; Schmidt et al., 2013; Snow et al., 2016).

### Transition from care for young people with disability

#### Barriers:

- Mental health issues
- Placement instability
- Lack of high-quality independent living programs
- Lack of positive relationships
- Lack of highly skilled professionals.

#### Supports:

- Access to education and employment services for young people with disability.

### Recommendations

- Early identification and intervention of leaving care plans for young people with disability (Carrelas 2021; McCauley 2021; Mendes & Snow 2014)
- Improved interagency collaboration and networking to improve continuity of support between out-of-home and adult disability services (Broadley 2015; Harwick 2020; Kang-Yi 2017).

## Prevalence

Young people with disability are overrepresented in OOHC, at higher risk of abuse and poor outcomes than both their peers without disability in out-of-home care and with disability in the general population.

- Children with disability in out-of-home care are more likely to have significant needs, challenging behaviours, and placement in residential care (Baidawi & Piquero, 2021; McConkey et al., 2004; McCool & Stevens, 2011; Pilling et al., 2007; Vanderwerker et al., 2014).
- Children with intellectual disability or autism are more likely to enter care than children without these disabilities (Cidav et al., 2018; Simmel et al., 2016).
- Boys with disability are more likely than girls with disability to be in OOHC (Bilaver & Havlicek, 2013; McCool & Stevens, 2011; Pilling et al., 2007).

The relationship between disability and maltreatment is complex and bidirectional such that children with disability are not only more susceptible to abuse and neglect but maltreatment can itself increase a child's risk of acquiring disability.

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## Recommendations

- There should be enhanced disability screening and improved recording of disability status to ensure children are effectively identified and supported and to address Australia's current lack of consistent documentation of disability status of children in out-of-home care (McCool & Stevens, 2011).

## Voluntary out-of-home care placement

The issue of voluntary relinquishment of children to OOHC is identified in the literature as specific to children with disability. Research highlights that this group includes children whose parents are not otherwise known to child protection agencies and only come into contact with them in the context of a decision to relinquish their child to state care due to their disability.

- The decision to relinquish care commonly occurs when families are in a state of crisis (Ellem et al., 2016; Llewellyn et al., 2005; Nankervis et al., 2011; Nankervis et al., 2011).
- Caregivers identify a range of issues that influence their decision to relinquish care including challenging behaviour, lack of adequate support, family/marital problems, and parental ill health (Alborz, 2003; Ellem et al., 2016; Hostyn & Maes, 2007; Llewellyn et al., 2005; McConnell et al., 2015; Mirfin-Veitch et al., 2003; Nankervis et al., 2011; Nankervis et al., 2011).
- Children with intellectual disability, autism and significant challenging behaviours are at greatest risk of a voluntary out-of-home care placement (Alborz, 2003; Crettenden et al., 2014; Ellem et al., 2016; Llewellyn et al., 2005; Mirfin-Veitch et al., 2003; Nankervis et al., 2011; Roper & Jackson, 2007; Vassos et al., 2019).

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## Recommendations

- Better processes are needed to identify families at-risk of voluntary placement and more targeted and appropriate support for these families prior to relinquishment (Llewellyn 2005; Nankervis et al 2011).
- Active support and cognitive behavioural therapy can support families who are considering, or have previously relinquished, care of their child (K. Nankervis et al 2011).
- Importance of early identification of at-risk families is a key issue in preventing voluntary out-of-home care placements prior to families reaching a point of crisis (Llewellyn et al., 2005; Nankervis et al., 2011). Research related to vulnerable parent profiles and behaviours such as increased requests for respite could assist in early identification of at-risk families.

## Placement stability

Children with disability experience higher rates of placement disruptions and longer stays in care than children without disability.

- Children with disability are less likely to be reunified or placed in kinship care and more likely to be placed in specialised care settings (Baidawi & Piquero, 2021; Bilaver & Havlicek, 2013; Slayter, 2016; Welch et al., 2015).
- Boys with disability are more likely to be placed in specialised care settings such as residential settings, experience social isolation and have significant behavioural difficulties (Pilling et al., 2007).

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## Recommendations

- Carers identified needing additional supports including provision of and advocacy for appropriate services, adequate financial support, specialised training, and enhanced collaboration with services involved in the care of children (Schormans et al., 2006).
- Need for targeted carer recruitment and provision of specialised training to carers of children and young people with disability (Welch et al., 2015).

## Health and Education Outcomes

Young people with disability in OOHC have poorer outcomes, lower quality of life and more restrictive placements than other young people in care and young people with disability who are not in care (Anctil et al., 2007; Geenen & Powers, 2006; Lee et al., 2018; Valicenti-McDermott & Demb, 2008; Welch et al., 2015).

- In a literature review of 90 empirical studies exploring permanency for children with disability, children who did not have a permanent placement were found to be more likely to have poor mental health, attachment disorders, developmental disorders, and compromised brain functioning (Welch et al., 2015).
- Young people in special education are vulnerable to a range of negative outcomes associated with lower quality of life, poor self-esteem, low educational attainment, frequent placement changes and more restrictive placements (Anctil et al., 2007; Geenen & Powers, 2006; Lee et al., 2018).
- Children in out-of-home care are more likely to be placed on medication than children with disability who are not in care (Rubin et al., 2009; Vanderwerker et al., 2014).

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## Recommendations

- Screening tools are needed to help identify and record disability status of children and young people in out-of-home care (McCool and Stevens 2011).
- Provision of targeted interventions and supports from child welfare and disability services are needed to improve the outcomes of children and young people with disability (Hodder et al 2020; Reid 2013).

## Support services

Young people with disability are more likely to receive additional support upon entering care in contrast to young people with disability who are not in care (Simmel et al., 2016).

- Most interventions targeted toward young people with disability in OOHC are focused on addressing challenging behaviour (Ingersoll et al., 2017; Ziviani et al., 2012).
- Capacity for interagency collaboration is identified as a key sector issue for effectively supporting young people with disability in out-of-home care (Ziviani et al., 2013).

### Collaboration between out-of-home and disability services

#### Barriers

- Lack of clarity around communication and responsibilities

#### Benefits

- Additional support for carers

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| <ul style="list-style-type: none"> <li>• Restrictions on information sharing</li> <li>• Organisational differences</li> <li>• High staff turnover</li> <li>• Geography difficulties in rural areas</li> </ul> | <ul style="list-style-type: none"> <li>• More comprehensive understanding of young person's situation</li> <li>• More effective provision of services</li> </ul> |
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## Recommendations

- There is a need for research evaluating the effectiveness of services for young people with disability in OOHC and their caregivers (Ziviani et al., 2012, 2013).
- Build on emerging evidence that interventions targeting challenging behaviours of young people with disability have had a positive effect improving social functioning and reducing difficult behaviours (Ingersoll et al 2017).

## Family Preservation

Intensive supports improve family quality of life and reduce the likelihood of voluntary relinquishment (Hodder et al., 2020; Reid et al., 2013).

A nationally representative survey of 538 primary parent-carers of children with disability in Canada found that the sustainability of daily routine was closely associated with likelihood of voluntary placement. Access to supports such as appropriate childcare and work flexibility reduced the likelihood of placements (McConnell et al., 2015).

## Recommendations

- The provision of additional and intensive support to at risk families can promote family preservation and prevent voluntary placements, however current evaluations include small qualitative samples and need to be evaluated through more robust methods (Hodder et al 2020; Reid 2013).

## DISCUSSION POINTS

- How do we improve identification and data recording of disability status for children in out-of-home care and what are the potential barriers?
- What factors need to be considered in defining disability in the out-of-home care sector?
- How does the overlap between trauma and disability impact practice across out-of-home and disability sectors?
- How can support be enhanced for families of children with disability?
- How can training and recruitment of carer for children with disability be enhanced?
- How can services work more effectively to support young people with disability transitioning from care to adult disability services?
- What are the issues that should be research priorities for young people with disability in out-of-home care?

## Acknowledgement of Country

The Research Centre for Children and Families acknowledges Aboriginal and Torres Strait Islander peoples as the First Australians, whose lands, winds and waters we now all share, and pays respect to their unique values, and their continuing and enduring cultures which deepen and enrich the life of our nation and communities.

### For more information

Research Centre for Children and Families

**e** [rccf.research@sydney.edu.au](mailto:rccf.research@sydney.edu.au)

**w** <https://www.sydney.edu.au/arts/our-research/centres-institutes-and-groups/research-centre-for-children-and-families.html>



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