

Fostering children with disability in Victoria

Who are the children and what are the experience of their foster carers?

May 2024



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Acknowledgements

Acknowledgement of Country

The Centre respectfully acknowledges Victorian Traditional Owners and Custodians of the lands and waterways where we live and work and recognises that our work is delivered on many lands across the Kulin Nations.

We are proud that First Nations cultures continue to enrich the lives of us all through the sharing of values, places, resources and stories. We pay our respect to ancestors of this Country and Elders, knowledge holders and leaders – past, present and future. Through our leadership, we collaborate closely with First Nations organisations to ensure they have a say in the decisions that affect their children, families and communities.

At the Centre, we acknowledge the grief and loss that First Nations peoples have endured, and we celebrate their survival and resilience. We stand in solidarity now and always, acknowledging that First Nations peoples have never ceded sovereignty in Australia. Always was, always will be.

About the Centre For Excellence in Child and Family Welfare

The Centre for Excellence in Child and Family Welfare (the Centre) is the peak body for child and family services in Victoria. For over 100 years, we have advocated for the rights of children and young people to be heard, to be safe, to access education and to remain connected to family, community, and culture. We represent over 150 community service organisations, students and individuals throughout Victoria working across the continuum of child and family services, from prevention and early intervention to the provision of out-of-home care.

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Finally, we acknowledge the contribution and dedication of Victorian foster carers, who go above and beyond in caring for children who need it the most.

1. Foreword

Information on the changing needs of children in out of home care is a vital part of the work the Centre for Excellence in Child and Family Welfare does to support member agencies and carers in Victoria and build the evidence base for this sector.

To create change and improve the lives of children and young people in care we need data to understand their needs and how to best support them and their carers.

Data for the Fostering children with a disability report was collected prior to the NDIS Review released in December 2023, but used the same social model of disability definition. The proposed NDIS changes mean those with less severe disabilities, would be transitioned from the NDIS scheme to community support.

We now have a snapshot of this moment in time for children with disability in care along with valuable insights into the needs of carers supporting them.

Fostering children with a disability is a rewarding opportunity and throughout the report carers relay positive stories of the benefits for themselves and the young people in their care.

The NDIS Review recommendations signal the need for a new model of community care. This is an incredible opportunity for our sector to support children and families who do not qualify for NDIS support.

With the NDIS changes in hand, we see need for even better information on disability in care aligned to these new NDIS requirements. This data will define the scale, funding needs and supports. The Centre is excited to work with Government and our members as we develop these new service models.

This report gives us a baseline for disability in care in Victoria. We know that many children are entering care without a diagnosis and often that process is happening in care. For foster carers the challenges of accessing specialists and NDIS plans if appropriate, are compounded when coordinating between the carers, Child Protection, agency support, and the NDIS.

Foster carers spoke of the privilege of being part of the lives of children with complex needs, but also of their frustrations. Many said they were unaware of the additional and complex needs of children with undiagnosed disability and felt unprepared and unsupported.

This report provides immediate direction to expand existing programs and guide training and specialist advice and support services within the sector to help carers and their case workers.

As Victoria faces a shortage of carers, we have begun to target our foster care recruitment through Fostering Connections toward groups with skills and willingness to support children with disability.

Longer term we see opportunities to guide systemic review of out of home care with a lens on disability services that better reflect the realities of fostering children with complex needs and ensuring disability is embedded in all stages of the recruitment and accreditation process.

The data also drives our national advocacy for dedicated support within the NDIS for children and young people in care to navigate this system and to be defined as a distinct equity group with additional needs within the NDIS.

With awareness of disability front of mind, this is an incredibly exciting time for the child and family services to have valuable impact and create change in the communities that we work.

Deb Tsorbaris
CEO at the Centre for Excellence in Child and Family Welfare



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3. Glossary

Foster care

Foster carer is the temporary care of children and young people by trained and accredited members of the community.

Out-of-home care

Out-of-home care is the temporary care of children and young people who cannot live in their family home. Children and young people enter out-of-home care either after an investigation by Child Protection regarding protective concerns and subsequent removal from the family home, or when birth parents are unable to care for their child and voluntarily approach the Department of Families, Fairness and Housing (hereafter the Department) or a CSO or ACCO for support. Out-of-home care includes residential care, foster care, kinship care and permanent care.

Step by Step

Step by Step is the mandatory foster care assessment tool used to assess foster carer applicants in Victoria.

Shared Lives Victoria

Shared Lives Victoria is the mandatory foundational training package delivered to prospective foster carers by Community Service Organisation foster care agencies. This makes up part of the Step by Step package.

Our Carers for Our Kids

Our Carers for Our Kids is the foundational training package delivered to prospective foster carers by Aboriginal Community Controlled Organisation foster care agencies. This makes up part of the Step by Step package.



4. Executive Summary

In 2023, the Fostering Connections program at the Centre conducted a Victorian first-of-its-kind research initiative into the prevalence and characteristics of children with disability in foster care and the experience of their foster carers. This research was intended to contribute to the evidence base relating to improving the recruitment and retention of foster carers for children with disability.

The Child Protection system in Victoria continues to experience strong demand. Over the past decade, there has been an 89 per cent increase in children entering out-of-home care, and foster carers have emerged as invaluable contributors to the Victorian community¹. A 2021 report on the economic value of foster care to Victoria estimated that in 2020–21 foster carers generated \$80 million in providing approximately 2.9 million hours of active caregiving and \$453 million in avoided costs of placing children in alternative forms of care.² Despite this demand and value, the foster care system has not kept pace, evidenced by a concerning 26 per cent drop in new carer accreditations from 2022 to 2023.³ This decline, influenced by cost-of-living pressures, demographic shifts and societal changes, has contributed to stagnation in Victoria's home-based care system.

Prior to this research, there had been no dedicated effort to accurately capture the prevalence and characteristics of children with disability in foster care, nor the experience of their carers. This research draws on data from 23 out of 24 foster care agencies as of 31 March 2023, representing 1480 out of an estimated daily average of 1526 children in foster care.⁴ Analysis of this data revealed that around 41 per cent of children in foster care have disability, with 31 per cent of this group being Aboriginal and/or Torres Strait Islander children. This data also revealed that no more than 53 per cent of children with disability in foster care have a National Disability Insurance Scheme (NDIS) plan. It is important to note that this research was conducted prior to the release of the 2023 NDIS review findings.

This research also conducted a survey of 52 foster carers who have cared for children with disability to better understand their experiences. We also conducted a survey of 26 foster care recruitment workers and 30 case workers to understand their experiences and insights in recruiting and supporting carers.

Our research uncovered a range of key findings in relation to the prevalence of disability among children in care and the pivotal role that foster carers play in supporting them. Based on this research, the Centre and its members who provide foster care services call for actionable steps to address identified challenges. We have also identified potential future research areas to develop a more comprehensive understanding of the experiences and needs of children with disability in Victoria's foster care system.

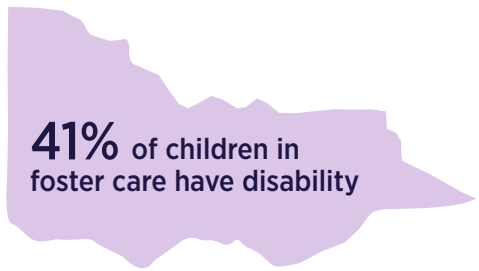
- 1 DFFH (2023). *2022-23 Child Protection and Family Services performance for selected measures - Quarter 3*
- 2 The Cube Group (2023). *Valuing Something That Really Matters: The Economic Value of Foster Care in Victoria* (unpublished)
- 3 CFECFW 2023 report (unpublished)
- 4 State of Victoria, (Department of Families, Fairness and Housing) (2023). *Annual Report, Child protection and family services, 2022-23 additional service delivery data*, pg 2. Retrieved from: <https://www.dffh.vic.gov.au/publications/annual-report>

Our research found that:

Children with disability are over-represented in foster care.

Of Victorian children in foster care, approximately 41 per cent have disability. Of those, 31 per cent are Aboriginal and/or Torres Strait Islander children.

The most common types of disability were developmental disorder, developmental delay and intellectual disabilities. Given the prevalence of disability, it is likely that all foster carers will foster a child with disability in their fostering journey. No more than 53 per cent of children with disability in foster care have an NDIS plan.



41% of children in foster care have disability

Fostering children with disability is a rewarding but a challenging experience.

Foster carers are highly motivated volunteers, and many bring valuable, relevant professional or life experience. Approximately 75 per cent of foster carer survey respondents reported that fostering children with disability had positively or very positively affected their sense of purpose and 77 per cent reported that fostering children with disability had positively or very positively affected their sense of contributing to their community.

“It’s challenging, it’s rewarding, it’s hard work, it’s an emotional roller coaster, it’s the best thing you’ll ever do!”

– Foster carer

However, 67 per cent of respondents strongly agreed that fostering a child with disability is challenging. Access to diagnoses and services, a lack of respite care, financial hardship and navigating Child Protection processes alongside the NDIS all impact carers’ wellbeing and capacity to continue fostering.

Foster carers play a role in caring for children with disability that goes above and beyond typical parenting. Many foster carers who care for children with disability face significant financial strain due to the cost associated with caring and necessity of taking time off work. The expectation that foster carers can maintain full-time employment while caring for a child with disability or complex needs is unrealistic. Our survey revealed that 60 per cent of respondents reported fostering a child with disability had negatively or very negatively impacted their employment and 54 per cent reported it had negatively or very negatively impacted their financial situation. Additionally, 62 per cent of respondents agreed or strongly agreed they had to reduce their work hours to properly care for a child with disability.

Although caring for a child with disability is not dissimilar to the experience of biological families, the complexities of caring for a child of whom you are not the guardian add another layer of challenges. This impacts a carer’s ability to make decisions, provide consent and to access timely support and services. Agencies also report an increasing trend of children entering care with increasingly complex needs; for example, disability, trauma, mental illness or challenging behaviours.

Prospective foster carers are not always adequately prepared to care for children with disability.

Despite the prevalence of disability among children in foster care, there is no dedicated space in the Step by Step package to explore disability in the context of foster care or the role that foster carers play in supporting a child with disability.

Only 17 per cent of foster carers surveyed agreed that the training and accreditation process prepared them to care for a child with disability and only 16 per cent of community services organisation (CSO) recruitment workers surveyed agreed or strongly agreed that the Shared Lives training within the Step by Step package is suitable for preparing foster carers to care for children with disability (Fig. 11).

“I’d call that a limitation of the training. There’s no specific place to think about the types of disabilities that the children might present with in care.”

– Foster carer assessor

Children’s disability status is often not known upon entering care.

Several foster carers noted that they had become ‘accidental disability carers’ because the disability status of the child upon entering care was unknown. This has implications for the commitment that these carers have made; for example, the capacity they have to provide such a level of care. Of the foster carer survey respondents, approximately 13 per cent said they were not necessarily motivated to foster a child with disability but had found out the child had a disability after the placement had begun.

“The child presented as autistic but did not have a diagnosis and no information was provided to us in advance about this little boy’s communication style, rigidity or sensory preferences.

He was a gorgeous kid and we figured it out as we went along, but it goes to show how likely it is that carers may end up with a child with disability without knowing it.”

– Foster carer

Foster carers play a significant role in identifying if a child in their care has a disability and advocating for assessment, diagnosis and support.

As a result of children’s disability status often being unknown by the Department, agencies and carers upon entering care, foster carers then play a significant role in identifying signs of disability and advocating for assessment and diagnosis. Among surveyed foster carers, 75 per cent reported they had fostered a child who they suspected had a disability but did not yet have a diagnosis. Moreover, 62 per cent of foster carers surveyed reported they had supported a child in their care through the process of obtaining a diagnosis. One foster carer shared that, in her 17 years of fostering, she had supported 50 children to obtain a diagnosis. The intersection between trauma and disability increases the challenge in determining diagnosis, with carers suggesting that signs or symptoms of disability may be downplayed as trauma or vice versa.

“I don’t even know where to start. My child with FS1 [Feingold Syndrome 1] clearly had GM (gross motor) difficulties, and no one listened until he finally had an MRI to reveal he had a stroke.”

- Foster carer

The findings of this research raise important questions as to what extent the current model of foster care in Victoria takes into account the prevalence of disability and therefore the role that foster carers play.



5. Methods

The key research question was ‘What are the opportunities and barriers in recruiting and retaining foster carers for children with disability in Victoria?’ To answer this question, the Centre collected qualitative and quantitative data from a range of sources, including from foster care agencies, surveys and interviews with foster carers and workers.

Definition of disability

For the purposes of this research, the social model of disability has been used in line with Victorian Government’s State Disability Plan (2022–2026) and the United Nations Convention on the Rights of Persons with Disabilities (2007)^{5,6}. This is also consistent with the 2023 NDIS review⁷.

The social model of disability recognises that a disability occurs when a long-term impairment in interaction with various attitudinal, environmental and societal barriers impacts a person’s ability to participate in society on an equal basis with others. These restrictions may be physical, developmental, sensory, intellectual, neurological or psycho-social or a combination. The definition recognises that society, rather than disability, places limitations on a person.

Working Group

The Centre set up a Working Group of six foster care agencies to provide support, guidance and advice for this project. Feedback and insights from the Working Group informed the development of the surveys and interview questions.

Data collection

The Centre analysed data from 23 of Victoria’s 24 foster care agencies to provide a snapshot as of 31 March 2023. The purpose of this data collection was to understand the prevalence rate of disability among children in foster care and the characteristics of these children.

Surveys and interviews

Carer survey

The Centre conducted a survey among Victorian foster carers who have cared for children with disability to understand their experiences and motivations. The survey was disseminated through foster care agencies and received 52 responses in the period 1 May to 31 August 2023

Of the respondents:

- 28 were from metropolitan Melbourne and 24 were from regional Victoria;
- 47 respondents were female and five were male;
- 15 respondents identified as being from a culturally or linguistically diverse background; and
- one respondent was an Aboriginal and/or Torres Strait Islander person.

5 State of Victoria (2022). *Victorian Government’s State Disability Plan 2022-2026*

6 UN General Assembly, *Convention on the Rights of Persons with Disabilities*, 13 December 2006, A/RES/61/106, Annex I,

7 Commonwealth of Australia (2023). *Working together to deliver the NDIS - Independent Review into the National Disability Insurance Scheme: Final Report*

Worker surveys

The Centre conducted two worker surveys, one with Victorian foster care recruitment workers and one with Victorian case workers. The purpose of these surveys was to better understand the experiences and perceptions of foster care workers in relation to fostering children with disability. The surveys were disseminated through foster care agencies and received 30 case worker responses and 26 recruitment worker responses. Survey responses were collected between 1 May to 31 August 2023. Of the recruitment worker responses, 40 per cent were from metropolitan Melbourne and 60 per cent were from regional Victoria. Of the case worker responses, half were from metropolitan Melbourne and half were from regional Victoria.

Interviews

Between April and September 2023, the Centre conducted eight 1-hour online interviews with foster carers who care for children with disability and six 1-hour interviews with workers. The purpose of these interviews was to provide:

- in-depth and nuanced understanding of the experience of carers and workers; and
- contextual information and case studies that could not otherwise be captured by the surveys.

Limitations

Data collection from agencies

The records for children in foster care held by foster care agencies are likely to be the most up-to-date and reliable source of data about these children. However, this dataset has limitations.

Foster care agencies were asked to provide data on the number of children with disability, with guidance around defining disability using the social model. It is not clear how each agency collected data or how consistently disability was defined or interpreted by the agency.

Aboriginal perspectives

Given that only one worker from an Aboriginal Community Controlled Organisation (ACCO) and one Aboriginal foster carer responded to the surveys, it was not possible to directly measure carer or worker perceptions in relation to the suitability of the Our Carers for Our Kids training package.

6. Background

About out-of-home care

Out-of-home care is the temporary care of children and young people who cannot live in their family home. Children and young people enter out-of-home care either after an investigation by Child Protection regarding protective concerns and subsequent removal from the family home, or when birth parents are unable to care for their child and voluntarily approach the Department of Families, Fairness and Housing or a CSO or ACCO for support.

When a child enters out-of-home care, an appropriate care arrangement might be sought with extended family members, known as kinship care. If this is not possible, then a child will generally be placed into foster care. Residential care is typically provided for young people aged 12 to 17 years where home-based care is not considered appropriate or where a foster care placement cannot be sourced.

In Victoria, foster care is the temporary care of children aged 0 to 17 years provided by trained and accredited foster carers. The goal of foster care is to reunify children with their family when and if it is safe to do so. People become foster carers by applying through a foster care agency who then place children into their care. Foster care agencies work alongside Child Protection to meet the protection needs of children in care.

Prevalence of disability among children in out-of-home care

In Victoria, 7.7 per cent of children under age 15 have disability and nationwide 8.2 per cent of children have disability.^{8,9} Estimates of the prevalence rates of disability among children in out-of-home care vary and should be treated with caution; however, in all available estimates, children with disability are over-represented in out-of-home care.

Australian Institute of Health and Welfare (AIHW) figures indicate that in Victoria, at 30 June 2021, approximately 13.1 per cent of children in out-of-home care were recorded as having a disability, 68.8 per cent were recorded as having no disability, and 18.1 per cent were recorded as 'not stated'.¹⁰ In 2020, the Commission for Children and Young People (CCYP) in Victoria reported that of the 166 children in out-of-home care whose files they examined, 36 per cent had a disability.¹¹ A 2012 study conducted by OzChild, which collected data from six of its child and family services programs, found that of the 475 children receiving these services, 200 (42%) had a disability.¹² Data made available to the Victorian Equal Opportunity and Human Rights Commission suggest that as of June 2011, of the 4064 children living in out-of-home care in Victoria, 579 (14%) had a disability. Twenty-two per cent of children in residential care

8 Australian Bureau of Statistics (2018). *Disability, Ageing and Carers, Australia: Summary of Findings*. Retrieved from: <https://www.abs.gov.au/statistics/health/disability/disability-ageing-and-carers-australia-summary-findings/latest-release>

9 Commonwealth of Australia (2023). *Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability: Final Report*

10 Australian Institute of Health and Welfare (2021). *Child Protection Australia 2020–2021*, Table S5.8. Children in out-of-home care by disability status and state or territory.

11 Commission for Children and Young People (2020) *Keep Caring: Systemic inquiry into services for young people transitioning from out-of-home care*

12 Mitchell, G. (2013). *Children with Disabilities using Child and Family Welfare Services*, Melbourne, OzChild

were identified as having a disability.¹³ More recently, anecdotal evidence from our members suggests this percentage is much higher.¹⁴

A 2018 survey of 2205 foster and kinship carers in Australia conducted by the Australian Institute of Family Studies reported that approximately 35 per cent of carers had a child in their care who had been diagnosed with at least one type of developmental condition, intellectual disability, a physical disability, diagnosed behavioural problem, or diagnosed mental health conditions.¹⁵

The over-representation of disability among children in care can be attributed to a range of reasons. Children with disability under age 15 are more than twice as likely to experience physical or sexual abuse (23 per cent) than those without disability (11 per cent).¹⁶ The development of a child's disability may also be a direct result of maltreatment or neglect.¹⁷ The over-representation of children with disability in out-of-home care may also be in part due to the difficult decision made by parents or families to voluntarily relinquish care of their child with disability because they are not adequately supported to care for their child in the home. A 2011 report by the Victorian Equal Opportunity and Human Rights Commission found that at least 50 families of children with disability annually are making the difficult decision to relinquish care, with some of these children entering out-of-home care.¹⁸

13 Victorian Equal Opportunity and Human Rights Commission (2012). *Desperate Measures: The relinquishment of children with disability into state care in Victoria*

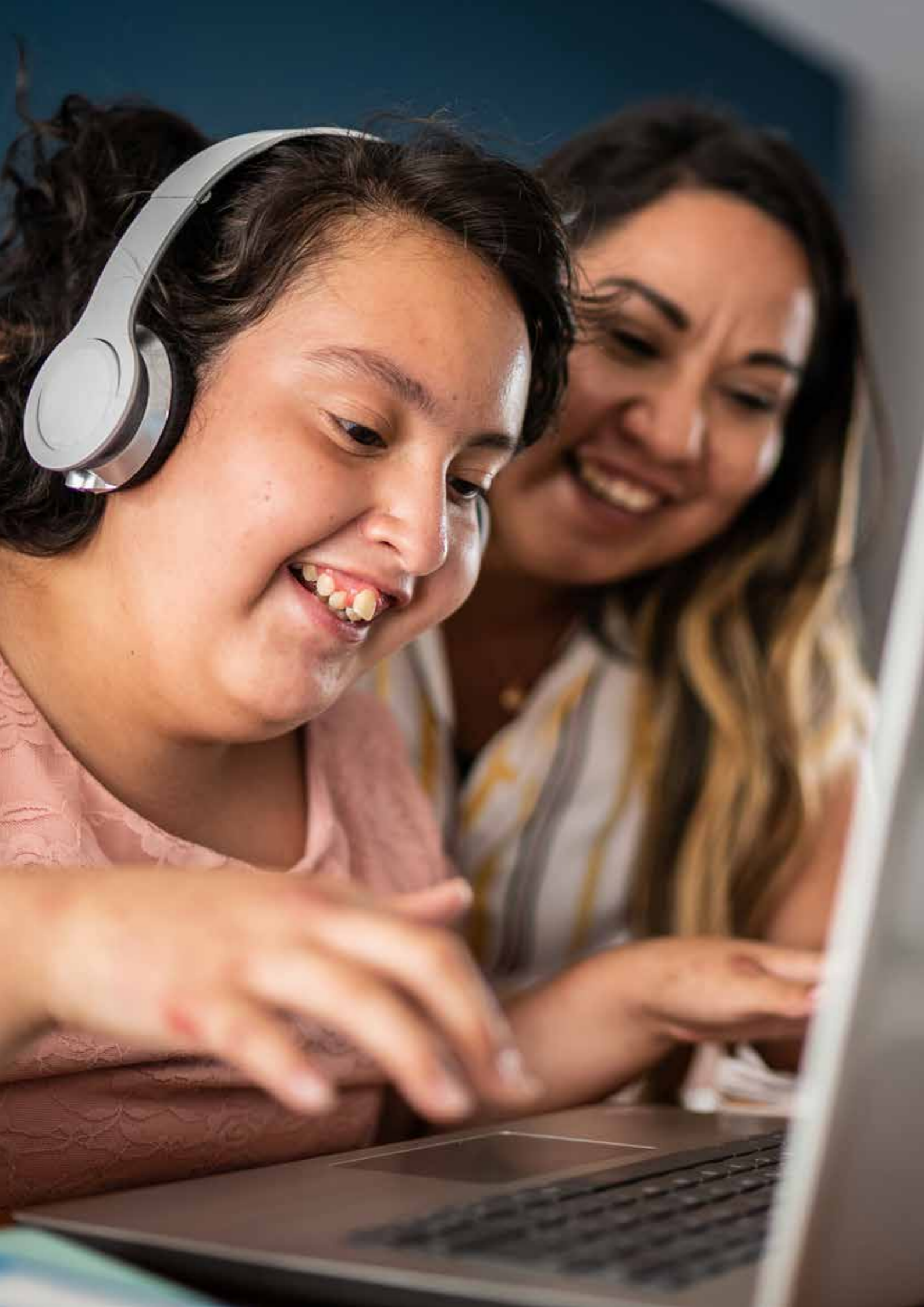
14 Centre for Excellence in Child and Family Welfare (2023). *NDIS review: Children in out-of-home care*. Unpublished submission to the NDIS Review

15 Qu, L., Lahausse, J. & Carson, R. (2018). *Working Together to Care for Kids: A survey of foster and relative/kinship carers*. (Research Report). Melbourne: Australian Institute of Family Studies

16 Commonwealth of Australia (2023). *Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability: Final Report*

17 Bruhn, C. M. (2004). Children with Disabilities: Abuse, Neglect, and the Child Welfare System. *Journal of Aggression, Maltreatment & Trauma*, vol. 8 (1–2), p 173–203. https://doi.org/10.1300/J146v08n01_07

18 Victorian Equal Opportunity and Human Rights Commission (2012). *Desperate Measures: The relinquishment of children with disability into state care in Victoria*. Retrieved from: <https://www.humanrights.vic.gov.au/resources/desperate-measures-the-relinquishment-of-children-with-disability-into-state-care-in-victoria-may-2012/>



7. Characteristics of children with disability

7.1 Prevalence of disability

Our research gathered existing agency data on the prevalence rate of disability among children in foster care placements, along with these children’s characteristics, as of 31 March 2023. Of 24 agencies at this time, 23 provided data, equivalent to 1480 children in foster care. The daily average number of children in foster care as of 31 March 2023 was 1526.¹⁹ This data indicates that around 41 per cent of children in foster care, or 602 out of 1480, have disability (Table 1). Agencies were asked to consider the social model of disability when collecting and sharing data; however, it was up to the discretion of agencies to provide data based on their own data collection methods.

The prevalence rate of disability at the individual agency level varies. One small regional agency reported that all four children in their foster care placements had a disability at that time. The lowest rate was 24 per cent (4 out of 17) for one larger agency. This variation in prevalence rate among individual agencies can be attributed partly to the availability of carers who are willing to foster a child with disability within a specific organisation and/or the methods used by individual agencies to capture data on disability status.

Regional breakdown

There was no significant difference between the prevalence rate of disability among children in foster care in metropolitan Melbourne compared with those in regional Victoria; however, the total number of children with disability in foster care was higher in regional Victoria (318 children) than in metropolitan Melbourne (284 children), despite people living in metropolitan Melbourne representing approximately 75 per cent of the Victorian population. Findings also show that at this time, there were also more children in foster care in regional Victoria than in metropolitan Melbourne.

Table 1: Prevalence rate of disability by region

Region	Number of children in foster care	Number of children in foster care with disability
Victoria-wide	1480	602
Metropolitan Melbourne	701	284
Regional Victoria	779	318
Regional breakdown		
Barwon	106	38
Central Highlands	114	30
Goulburn	77	19
Inner Gippsland	163	64
Loddon Campaspe	77	36
Mallee	35	17
Ovens Murray	55	35
Outer Gippsland	56	23
Western District	91	54

¹⁹ State of Victoria, (Department of Families, Fairness and Housing) (2023). *Annual Report, Child protection and family services, 2022-23 additional service delivery data*, pg 2. Retrieved from: <https://www.dffh.vic.gov.au/publications/annual-report>

Aboriginal and/or Torres Strait Islander children with disability

Many of the impacts experienced by children in out-of-home care are disproportionately experienced by Aboriginal and Torres Strait Islander children as a result of the lasting impact of Australia's history of colonisation. Of the children in out-of-home care in Victoria at 30 June 2021, approximately 40 per cent were Aboriginal, despite representing one per cent of the Victorian population.²⁰

Data collected through our research indicates that around 31 per cent of children with disability in foster care are Aboriginal and/or Torres Strait Islander, representing 184 out of 602 children. The prevalence rate was relatively similar between metropolitan Melbourne and regional Victoria, however there were more Aboriginal and/or Torres Strait Islander children with disability in regional Victoria than in metropolitan Melbourne. Of the foster carer survey respondents, 65 per cent reported they had fostered an Aboriginal or Torres Strait Islander child with disability.

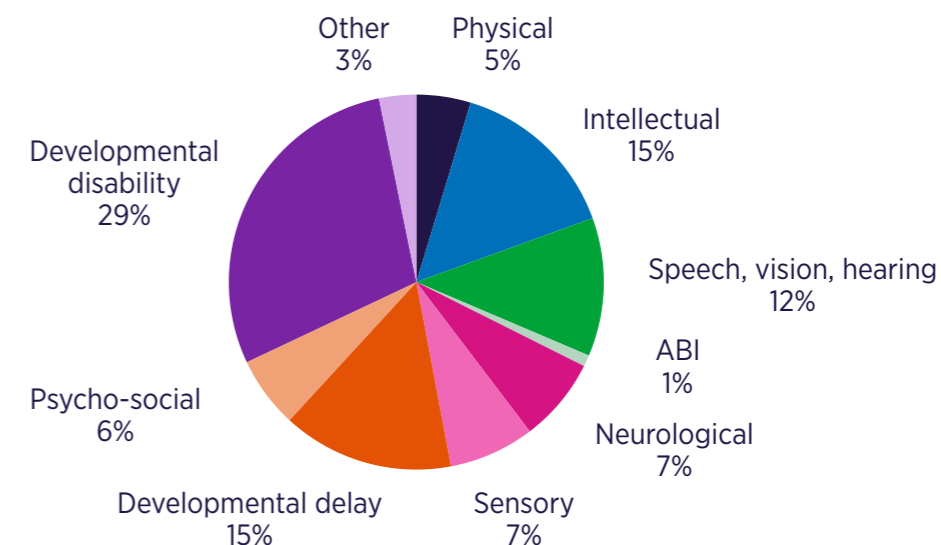
Culturally and linguistically diverse children with disability

Data collected through our research indicates that 9 per cent of children with disability in foster care, (56 out of 602) were from a culturally and linguistically diverse background. Of these, 16 per cent were living in metropolitan Melbourne and 3 per cent were living in regional Victoria. The total number of children in foster care from a culturally or linguistically diverse background is not known.

7.2 Types of disability

Data collected through our research on disability type represented 814 individual disability diagnoses (out of 602 children with disability), therefore representing multiple diagnoses for some children. Data on disability type was not available for all agencies there the total number of individual disability types is likely higher. The most common types of disabilities among children in foster care were developmental disability (29 per cent), developmental delay (15 per cent) and intellectual disability (15 per cent) (Fig. 1).

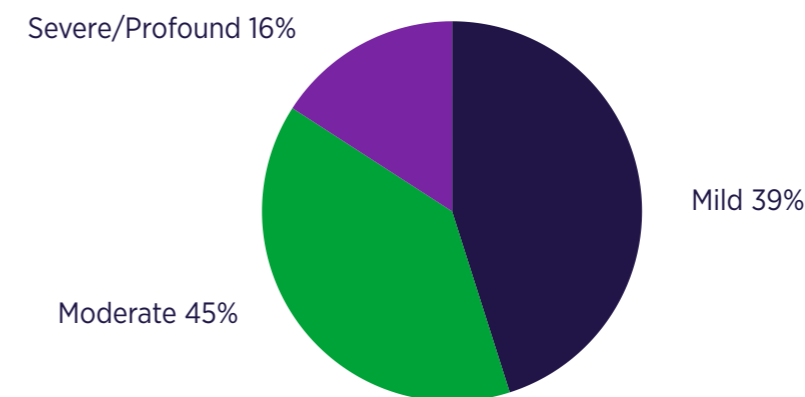
Figure 1: Types of disability among children in foster care



Severity

Data on the severity of disability was available for 398 of 602 children. This data indicates that 16 per cent or 63 children had severe or profound disability, 45 per cent or 180 children had a moderate disability and 39 per cent or 155 children had a mild disability (Fig. 2). Based on this data, it is possible to conclude that approximately 25 per cent of children in foster care have moderate to profound disability.

Figure 2: Severity of disability among children in foster care



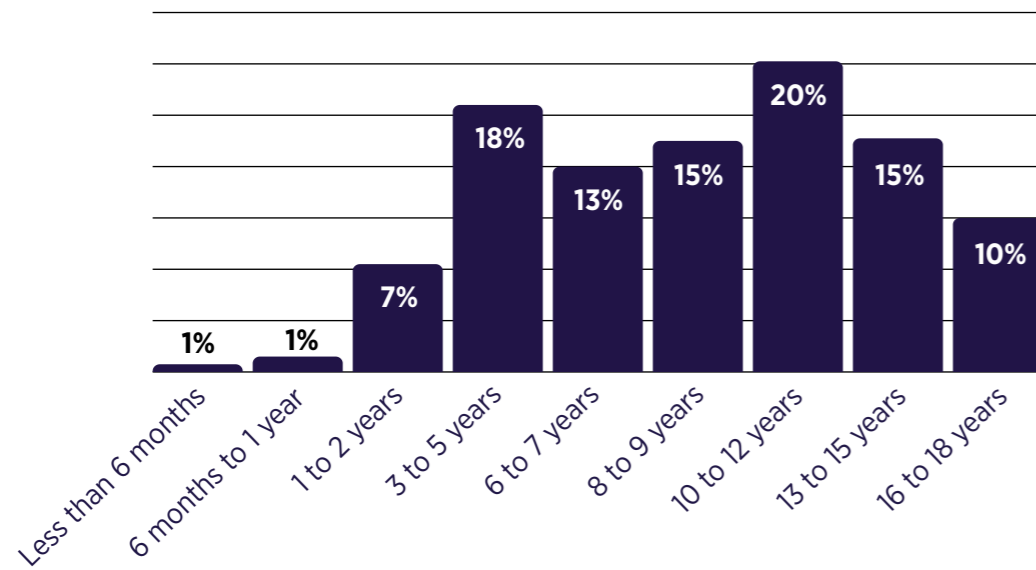
20 Australian Institute of Health and Welfare (2022). *Child protection Australia 2020-21*, AIHW, Australian Government, Table S5.5: Children in out-of-home care, by age group, Indigenous status and state or territory, 30 June 2021

7.3 Characteristics of children with disability

Age

Data on age was available for 597 out of 602 children with disability (Fig. 3).

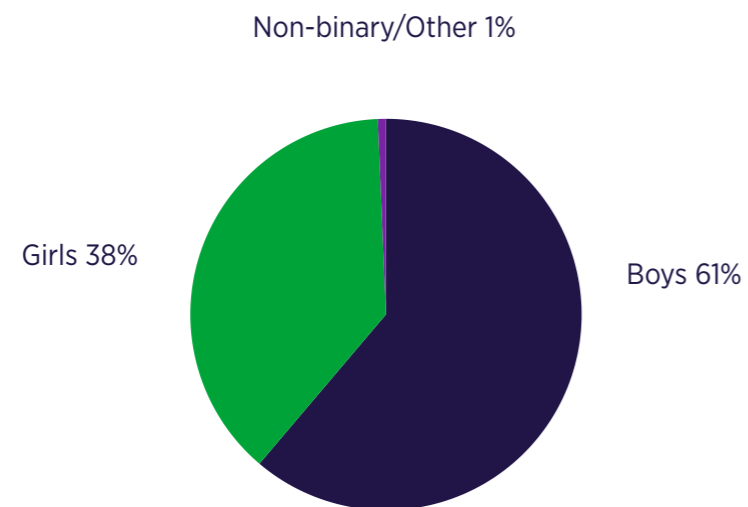
Figure 3: Age of children with disability in foster care



Gender

Data on gender was available for 598 out of 602 children with disability. This data indicates that boys were more likely to have disability (61 per cent) than girls (38 per cent) or non-binary children (1 per cent) (Fig. 4). This is consistent with findings from the 2018 ABS Survey of Disability, Ageing and Carers.²¹

Figure 4: Gender of children with disability in foster care

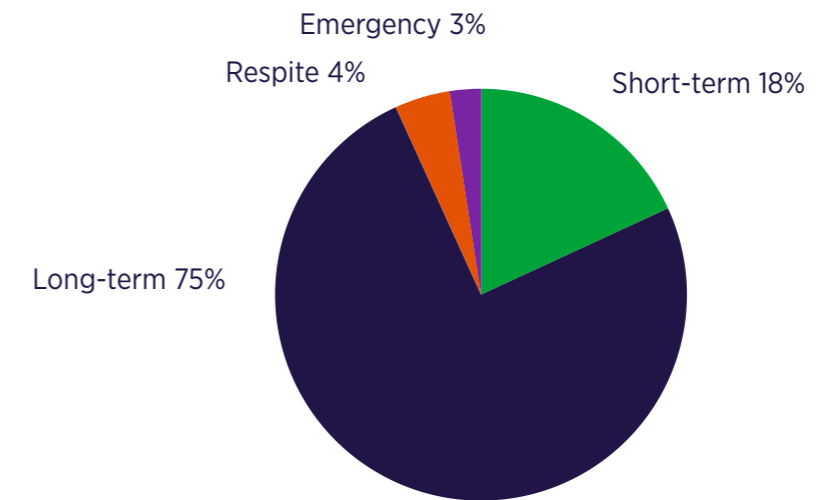


²¹ Australian Bureau of Statistics (2018). *Disability, Ageing and Carers, Australia: Summary of Findings*. Canberra: ABS

Placement type

Data was available on placement type for 575 out of 602 children with disability in foster care. Of those 575 children, 75 per cent were in a long-term placement, 18 per cent were in a short-term placement, 4 per cent were in a respite placement and 3 per cent were in an emergency placement (Fig. 5).

Figure 5: Placement type of children with disability in foster care



7.4 National Disability Insurance Scheme (NDIS)

In Victoria, there were 78,602 active participants in the NDIS under the age of 18 as of 31 March 2023. The most common primary disability for all Victorian NDIS participants was autism (34 per cent), intellectual disability (16 per cent), developmental delay (14 per cent) and psychosocial disability (13 per cent).²²

Data collect through our research indicates that 322 children in foster care had an NDIS plan as of 31 March 2023. With a total number of 602 children with disability in foster care (Table 2) we can conclude that no more than 53 per cent of children with disability in foster care have an NDIS plan as the total number of children with an NDIS plan may include a number of children under 7 involved in the NDIS through the early childhood approach which does not require a diagnosed disability to access. It is important that not all children with disability may be eligible for the NDIS.

Children in regional Victoria were less likely to have an NDIS plan (49 per cent) compared with those in metropolitan Melbourne (58 per cent).

Table 2: Number of children in foster care with an NDIS plan

	Number of children in foster care	Number of children in foster care with disability	Number of children in foster care with an NDIS plan
Victoria-wide	1,480	602	322
Metropolitan Melbourne	701	284	165
Regional Victoria	779	318	157
Regional breakdown			
Barwon	106	38	21
Central Highlands	114	30	10
Goulburn	77	19	10
Inner Gippsland	163	64	23
Loddon Campapse	77	36	24
Mallee	35	17	9
Outer Gippsland	59	23	14
Ovens Murray	55	35	18
Western District	91	54	27

²² National Disability Insurance Scheme (2023). *Participant Data Q3 22-23*. Retrieved from: <https://data.ndis.gov.au/explore-data>



8. The experiences of foster carers and agencies

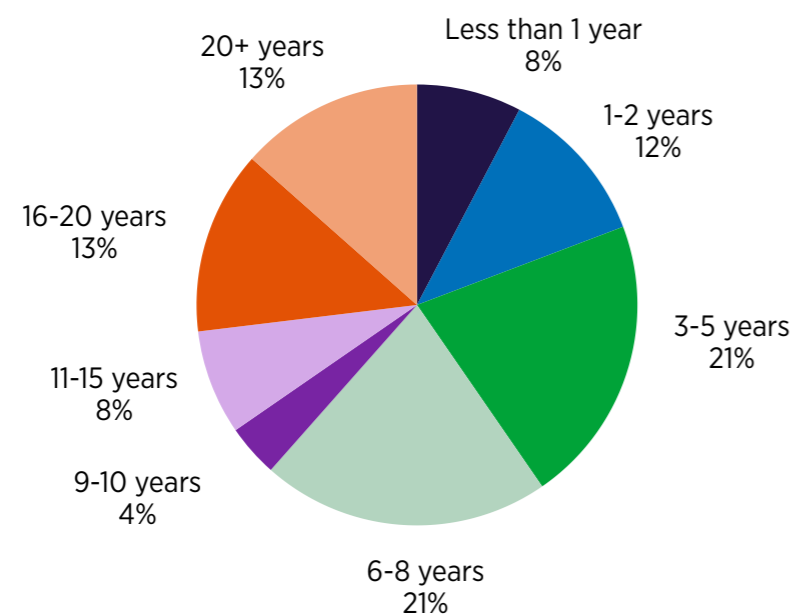
8.1 Profile of survey respondents

Survey respondents (foster carers, foster care recruitment workers and case workers) had the following demographic profile:

- The average age of respondents was 52.
- 90 per cent identified as female and 10 per cent identified as male.
- 60 per cent reported being married or in a de facto relationship and 40 per cent reported being single.
- Around 31 per cent worked full-time and 61 per cent of partners worked full-time.
- 29 per cent identified as coming from culturally or linguistically diverse backgrounds
- 8 per cent identified themselves as having a disability.
- The average number of foster care placements provided by respondents was 51.
- 34 per cent of respondents had been fostering for more than 10 years (Fig. 6).

These profiles should be considered when interpreting the survey results.

Figure 6: Time since becoming a foster carer



Results from in-depth carer and worker interviews and surveys uncovered a range of findings and themes about the experience of foster carers who care for children with disability.

8.2 Recruitment and accreditation

Fostering is a skilled and accredited voluntary role. The training and accreditation of prospective foster carers is a thorough process that typically takes 6 months, however in some cases up to 12 months or more. The accreditation process follows the Step by Step Victoria 2020 package, which requires applicants to demonstrate competencies in five domains and includes mandatory foundational foster carer training. For prospective foster carers engaged with a CSO, the prerequisite training is Shared Lives Victoria, delivered over 2 days. For prospective foster carers engaged with an ACCO, the prerequisite training is Our Carers for Our Kids, delivered over 3 days.

Almost half the survey respondents (48 per cent) reported fostering a child with disability in their first placement and twenty-three per cent reported fostering a child with disability within their first 6 months of fostering (Table 3). This reflects the high demand for foster carers to care for children with disability and has implications for the preparation that foster carers require early on in their journey.

Table 3: Time between becoming a foster carer and fostering a child with disability

Question: How long after becoming a foster carer did you first care for a child with disability?

Answer choices	% responses (%)	Number of responses (n = 52)
First placement	48.08%	25
Within first 6 months	23.08%	12
6 months - 1 year	13.46%	7
1-2 years	7.69%	4
3-5 years	3.85%	2
6-8 years	1.92%	1
9-10 years	0	0
11-15 years	1.92%	1
16-20 years	0	0
20+ years	0	0

Despite the prevalence rate of disability among children in foster care, there is no dedicated space to explore a foster carer's role in caring for a child with disability within the Step by Step package for either the Shared Lives and Our Carers for Our Kids training.

Around 58 per cent of survey respondents agreed or strongly agreed that they felt well prepared before becoming a foster carer for a child with disability; however, only 17 per cent of foster carers surveyed agreed or strongly agreed that the training and accreditation process prepared them to care for a child with disability (Table 4). This difference may suggest that a carer's sense of preparation was not a result of the accreditation and training package but may rather be a carer's own research, existing knowledge and/or supplementary support and advice provided by agencies. It is important to note that foster carers who responded to the survey had been fostering from 6 months to 20+ years, and that the most recent Step by Step accreditation package was implemented in 2020-21.

Table 4: Training and accreditation preparation

Question: To what extent do you agree or disagree with the following statements?

Responses (n=52)	Strongly disagree	Disagree	Neither disagree nor agree	Agree	Strongly agree	Don't know/Not applicable
The training and accreditation process prepared me for caring for a child with disability	13 (25%)	17 (32.69%)	12 (23.08%)	5 (9.62%)	4 (7.69%)	1 (1.92%)
I felt well prepared prior to/at the beginning of my role as a foster carer for children with disability	9 (17.31%)	6 (11.54%)	11 (21.15%)	19 (36.54%)	7 (13.46%)	0 (0%)
Caring for children with disability is what I expected	6 (11.54%)	9 (17.31%)	13 (25%)	15 (28.85%)	9 (17.31%)	0 (0%)

Around 46 per cent of respondents agreed or strongly agreed with the proposition that caring for a child with disability was what they expected, with 28 per cent disagreeing or strongly disagreeing with this statement (Table 4). Respondents who were motivated by relevant professional or volunteer experience (Table 8) were 10 per cent more likely to agree that caring for children with disability is what they expected (52 per cent agreed or strongly agreed compared with 42 per cent agreed or strongly agreed).

Survey respondents were also asked what they thought could have been done better to prepare them to care for children with disability.²³ The most common response was to have dedicated training on disability embedded throughout the training package or other opportunities for professional development relating to disability. One foster carer shared *“there was nothing specific in our initial training around caring for a disabled child. The emphasis was on trauma – what was it; how to understand behaviours because of it, etc. Another foster carer shared “I was unprepared for the extent of the impact caring for a child with a disability would have on my everyday life”.*

However, several carers and workers reflected on the reality of fostering children with disability and emphasised that ultimately nothing can truly prepare a person to care for a child with disability until they have that experience themselves, as indicated by this foster carer: *“I don’t think the recruitment process prepares you for a disability at all but I don’t think anything can really prepare you for a disability until you’ve got experience”.*

“We’ve got a beautiful older couple who have had a boy in their care for nearly 16 years with very high needs. They were not disability trained in any way shape or form when he came to them as a baby, and at first they just thought it was a little bit of developmental delay. I’ve asked them ‘is this what you signed up for?’ And they responded “no not even close. But what are we going to do he was a baby and nobody else would take him so we took him in” - Case worker

²³ Question: What more could be done to better prepare you to care for children with a disability?

The second most common response from foster carer survey respondents about what could have supported their preparation to care for children with disability was that agencies should enhance transparency during the accreditation process, specifically regarding the challenges of fostering children with disability and working within the Child Protection system. This includes providing clear information about available support, navigating both Child Protection and NDIS processes and the likelihood of a child in foster care having a disability, whether known or not known at the time of entering care.

Foster care recruitment workers were also asked about their perceptions of the Shared Lives training. Only 16 per cent (4 out of 25 CSO workers) agreed or strongly agreed that the training is suitable for preparing foster carers to care for children with disability (Table 5).

Table 5: Recruitment worker perception of the suitability of the Shared Lives training package

Question: To what extent do you agree or disagree with the following statements?

Responses (n=26)	Strongly disagree	Disagree	Neither disagree nor agree	Agree	Strongly agree	Don't know/Not applicable
The Shared Lives training package is suitable for preparing foster carers to care for children with disability	4 (15.38%)	10 (38.46%)	7 (26.92%)	3 (11.54%)	1 (3.85%)	1 (3.85%)

In the in-depth interviews, workers spoke of the limitations of the training for preparing foster carers to care for children with disability. One foster carer assessor stated *“I’d call that a limitation of the training. There’s no specific place to think about the types of disabilities that the children might present with in care”.*

Another foster carer recruiter and assessor suggested that *“there are sections in the Step by Step package that talk about providing day-to-day care but there are not specific examples around ‘what if a child had cerebral palsy’, ‘what if a child had cognitive delays or global developmental delays’... things like that”.* Workers also stated that a lack of data on the types of disability to date meant that workers were not always able to accurately prepare foster carers for the most common types of disabilities they might encounter.

Another worker reported that *“there needs to be more as part of the Shared Lives training that makes people feel like they can do it. When we ring about referrals, we’ll tell the carers what care the child needs and they say, ‘I don’t think I can/I haven’t got the skills’”.*

Any recruitment worker is permitted to facilitate the early phases of the foster care recruitment process, such as responding to enquiries; however, the training and assessment of foster carers must be facilitated by accredited Shared Lives trainers and Step by Step assessors. As part of the process, workers are encouraged to follow scripting and prompts laid out in the package tools in their conversations with carer applicants. As the scripting does not include comprehensive discussion prompts around caring for children with disability, agency workers reported supplementing their conversations to prepare carers and assess competence in this area. While this helps to better prepare foster carers, it means the training and assessment packages may be inconsistently applied across agencies.

Recruitment workers were asked about their confidence in their knowledge and comfort in discussing disability with prospective carers. Around 89 per cent of respondents agreed or strongly agreed that they feel comfortable in discussing disability with prospective carers; however, only 58 per cent agreed or strongly agreed that they felt confident in their knowledge about disability (Table 6).

Table 6: Recruitment worker knowledge and confidence

Question: To what extent do you agree or disagree with the following statements?

Responses (n=26)	Strongly disagree	Disagree	Neither disagree nor agree	Agree	Strongly agree	Don't know/ Not applicable
I feel confident in my knowledge about disability	1 (3.85%)	4 (15.38%)	6 (23.08%)	10 (38.46%)	5 (19.23%)	0 (0%)
I feel comfortable in my ability to recruit foster carers for children with disability	1 (3.85%)	2 (7.69%)	6 (23.08%)	13 (50%)	4 (15.38%)	0 (0%)
I feel comfortable discussing children with disability with prospective foster carers	0 (0%)	1 (3.85%)	2 (7.69%)	10 (38.46%)	13 (50%)	0 (0%)

In the later stages of the accreditation process, foster carers are asked whether they would consider providing care for a child who has a physical disability and/or an intellectual disability, with an option to tick 'yes' or 'no'. Foster care recruitment workers expressed concern that this was limiting and lacked nuance. They suggested it served as a tick box exercise considering that disability is not brought up early, rather than an opportunity for education and conversation. Other concerns shared were that foster carers may feel obliged to select 'yes' in order to be accredited where instead they did not yet feel confident in fostering a child with disability, and that a 'yes' or 'no' option does not reflect the different disability types and or behaviours of children in care.

While a portion of prospective carers are specifically motivated to foster children with disability, fostering a child with disability is not front of mind for many prospective carers when they begin the journey. Agencies report that it is rare that a prospective foster carer will specifically enquire about or mention fostering a child with disability in the early stages of recruitment. One recruitment worker reported that prospective foster carers *"don't ask questions at all regarding this. When we raise the topic, the majority are not interested. Others are open to considering lower levels of disability"*.

Recruitment workers were asked about common misconceptions that prospective or new foster carers have about caring for children with disability. The most common misconceptions workers reported were that:

- prospective carers assumed the disability would be a physical disability,
- to foster children with disability they would need lots of experience, skills or qualifications,
- fostering children with disability was too hard, and
- the disabilities would be severe.

One worker suggested that *"there seems to be a real lack of understanding on just how many children in care will have delays or functioning challenges whether that's diagnosed as disability or not"*.

One agency worker reported that *"many potential carers are unsure of whether they would have the skills. Many have a limited understanding of disability i.e., if I ask if a person is willing to care for a child with a disability, a person often jumps to explaining whether or not they could care for a child in a wheelchair. Obviously, this is a limited view of disability"*.

Another worker stated that *"the minute you ask 'are you willing to care for a child with a disability', they immediately think of a child in a wheelchair, a child who needs a feeding tube, a child with really significant disabilities ... and we often have to break that down and say we're talking about developmental delay where a child who might be five is actually functioning at the age of a two or three year old"*.

If the topic of disability is broached by prospective carers during the accreditation process, the most commonly asked questions are around what support is available to them and whether they have the skills.

In one anomaly, a smaller agency reported that of the new foster carers they had accredited in 2021, all had expressed interest in fostering a child with disability. However, this was only in cases where the child's disability was considered mild, despite some of these carers having cared for family members with moderate to severe disability. Another agency worker indicated that *"we have not had any new carers who are equipped to cater to the needs for a child with disability. As soon as they hear the child has complex needs, they will not proceed with the placement"*.

Foster care recruitment workers were asked, in their experience, what are the most common reasons prospective foster carers give in deciding not to foster a child with disability. The most common responses were: lack of confidence in their knowledge/skills (89 per cent); not enough time (e.g., working full-time, other caring commitments; 77 per cent); lack of awareness (50 per cent); and physical/housing constraints (46 per cent) (Table 7). Interestingly, 'financial constraints' was not a primary reason and was equal to 'stigma/misconceptions about disability' (both 23 per cent). It is important to understand these reasons so they can potentially be addressed if the pool of foster carers willing to care for a child with disability is to be increased.

Table 7: Recruitment worker perceptions of barriers

Question: In your experience, what are the three main barriers that prospective carers describe to you in deciding not to care for children with disability?

Responses (n=26)	Responses
Lack of confidence in their knowledge/skills	23 (88.46%)
Not enough time e.g., working full-time, other caring commitments	20 (76.92%)
Lack of awareness	13 (50%)
Physical/housing constraints	12 (46.15%)
Stigma/misconceptions around disability	6 (23.07%)
Financial constraints	6 (23.07%)
Age	3 (11.53%)
Other	1 (3.84%)

Tapping community members on the shoulder

Agencies have reported approaching community members or people known to the child to step in and provide foster care. One regional foster carer reported they had been fast tracked through their accreditation process because they had been identified as having relevant skills and had been earmarked for a particular child with disability prior to completing the accreditation process. This demonstrates the demand for foster carers for children with disability. In another case, a regional agency reported that a person working at a specialist school became an accredited foster carer to provide respite care specifically for a child they worked with, based on their knowledge of the child's circumstance and needs; however, they only expressed interest in providing respite for that one child.

8.3 Motivations

“It’s challenging, it’s rewarding, it’s hard work, it’s an emotional roller coaster, it’s the best thing you’ll ever do!” - Foster carer

Foster carer survey respondents were asked their top three motivations for fostering a child with disability. The most common motivation for fostering children with disability was a desire to make an impact (88 per cent of respondents), not dissimilar to their motivation to become foster carers in general. In examples provided, carers emphasised that it was not necessarily an explicit choice, but rather a desire to foster any child who needed care. The second most common response was relevant work or volunteer experience (52 per cent of respondents). The third most common response was progression in their fostering journey; for example, an increased confidence in their skill and ability to provide care (31 per cent of respondents), followed by personal experience of disability (friend or family member) (29 per cent of respondents). Around 13 per cent of respondents reported that they did not choose to foster a child with disability and had only discovered that the child had a disability after the placement began, with implications for their preparedness. Several foster carers were identified through the interviews as having a motivation to exclusively foster children with disability, typically resulting from personal or professional experience of disability (Table 8).

Table 8: Motivation to foster children with disability

Question: What were your top three motivations in fostering children with disability?

Responses (n=52)	Responses
Personal experience of disability (myself)	1 (1.92%)
Personal experience of disability (friend or family member)	15 (28.84%)
Work or volunteer experience	27 (51.92%)
Desire to make an impact	46 (88.46%)
Progression in foster carer journey e.g., increased skill and confidence	16 (30.76%)
Did not choose/were not aware of child's disability	7 (13.46%)

Survey respondents were also asked how likely they were to continue fostering children with disability and how likely they were to encourage others to foster children with disability. Nearly three-quarters (73 per cent) of respondents agreed or strongly agreed that they would continue to foster children with disability. The limitation of this statement regarding likelihood to continue fostering is that it does not reflect the uniqueness of every child's disability and

that agreement to this statement would likely be dependent on the needs of the individual child, rather than disability status. Only 54 per cent agreed or strongly agreed that they would encourage other people to foster children with disability (Table 9).

Table 9: Likelihood of continuing and recommending fostering children with disability

Question: To what extent do you agree or disagree with the following statements?

Responses (n=52)	Strongly disagree	Disagree	Neither disagree nor agree	Agree	Strongly agree	Don't know/ Not applicable
I will continue to foster children with disability	3 (5.77%)	2 (3.85%)	5 (9.62%)	20 (38.46%)	18 (34.62%)	4 (7.69%)
I would encourage other people to become foster carers for children with disability	5 (9.62%)	5 (9.62%)	14 (26.92%)	19 (36.54%)	9 (17.31%)	0 (0%)

8.4 Skills, training and confidence

Development of skills

Foster carers are skilled volunteers who often bring relevant skills and professional experience to their role. Foster carers often come from relevant employment backgrounds such as education, community services and health care, which provides them with the knowledge and skills for caring for children.

Foster carers' overall confidence in their own ability to care for children with disability is high. Around 87 per cent of survey respondents agreed or strongly agreed that they feel confident in their ability to care for children with disability and 71 per cent agreed or strongly agreed that they feel confident in their ability to manage complex behaviours (Table 10). However, findings from the case worker survey found that the most common reason for placement breakdown was foster carers not being able to manage complex behaviours (Table 23). Around 67 per cent of respondents strongly agreed that fostering a child with disability is challenging (Table 11).

Table 10: Confidence in ability to care for children with disability

Question: To what extent do you agree or disagree with the following statements?

Responses (n=52)	Strongly disagree	Disagree	Neither disagree nor agree	Agree	Strongly agree	Don't know/Not applicable
I feel confident in my ability to care for children with disability	3 (5.77%)	0 (0%)	3 (5.77%)	23 (44.23%)	22 (42.31%)	1 (1.92%)
I feel confident in my ability to manage complex behaviours	2 (3.85%)	3 (5.77%)	10 (19.23%)	22 (42.31%)	15 (28.85%)	0 (0%)

Table 11: Fostering children with disability as a challenging experience

Question: To what extent do you agree or disagree with the following statements?

Responses (n=52)	Strongly disagree	Disagree	Neither disagree nor agree	Agree	Strongly agree	Don't know/ Not applicable
Being a foster carer for children with disability is challenging	2 (3.85%)	1 (1.92%)	0 (0%)	13 (25%)	35 (67.31%)	1 (1.92%)

Ongoing training and development for foster carers is vital to ensure they have the skills and knowledge to foster children with disability based on each child's individual needs. Carer training is provided through the Victorian-Government-funded Carer KaFÉ; however, specialised training may be provided upon request. Foster carers and agencies reported that their ability to access appropriate training for carers varies. Some foster carers reported being able to easily access specialised training, such as Auslan training, upon request and other foster carers reported requesting similar training and it was either declined by the Department.

Learning to become advocates for children and themselves

Foster carers, particularly those with 10 or more years' experience, spoke about building their confidence to advocate for themselves and for the children in their care, something they reported they did not have in the early stages of fostering. This confidence comes as a result of increasing confidence in their abilities but also knowledge and experience of the Child Protection system. One foster carer shared *“they're asking more and more and more of us as carers and lucky that I'm someone who will advocate until the cows come home, but if I wasn't one of those people it would be difficult and it would be exceptionally difficult with a child with a disability.”*

A foster carer's confidence in advocating for themselves also has implications for determining if a placement will be suitable. Foster carers report that, with more experience and confidence, they are able to ask the right questions when a referral is made to them, and gather more information to help make an informed decision as to whether they can accept a placement. *“When you get a call about getting a child with a disability you know what questions to ask”*, shared one experienced foster carer.

Attributes and strengths of foster carers

“Some of the most resilient carers have been those who have put their hand up to care for children with disabilities. They are lifelong carers who do incredible work and have excellent relationships with the agency. It is a tough job and they do it so, so well.” - Foster care worker

People with relevant experience, such as childcare workers, disability workers, medical staff, psychologists and experienced carers, can make great foster carers for a child with disability; however, any foster carer who is willing to learn and who can create a safe, consistent and supportive environment is encouraged to foster children with disability. Many of the attributes a person uses to support children without disability are the same for children with disability. This includes being patient, open-minded and empathetic. However, fostering children with

disability also requires the carer to have extra vigilance for safety, good communication skills and be able to offer and/or access specialist care.

Agency case workers were asked to describe the strengths of foster carers for children with disability. The most common attributes described were resilience, patience, commitment, advocacy, understanding, flexibility, willingness, compassion, knowledge and empathy.

8.5 Navigating the Child Protection systems

Foster carers encounter challenges while navigating the Child Protection system and its processes.^{24,25,26} Foster carer survey respondents were asked to what extent they agreed or disagreed with the level of difficulty in navigating Child Protection processes and accessing support. Only 13 per cent of respondents agreed or strongly agreed that navigating these systems was easy, while 19 per cent felt adequately supported by the Department to care for children with disability (Table 12).

Table 12: Foster carer experience of Child Protection processes and support

Question: To what extent do you agree or disagree with the following statements.

Responses (n=52)	Strongly disagree	Disagree	Neither disagree nor agree	Agree	Strongly agree	Don't know/ Not applicable
I find navigating child protection processes easy	25 (48.08%)	8 (15.38%)	9 (17.31%)	4 (7.69%)	3 (5.77%)	3 (5.77%)
I feel supported by DFFH to care for children with disability	18 (34.62%)	10 (19.23%)	12 (23.08%)	6 (11.54%)	4 (7.69%)	2 (3.85%)

Key challenges for foster carers that were identified by in-depth interviews include delays in consent and authorisation from the Department (for reimbursements, signing paperwork to attend schools and medical procedures etc.), a high turnover of Child Protection workers, inconsistently applied processes, and having to fight for the appropriate Care Allowance payment level and services for the child.

Delays in paperwork being signed have been reported to impact accessing specialist schools and medical procedures. One foster carer shared that they submitted paperwork to the Department for a child in their care to attend specialist school 3 months prior to school starting. On the first day of term, the paperwork was still not signed; however, with some negotiation with the school (which was initially reluctant until receiving the paperwork), the child was able to attend on the first day. The signed paperwork came through days later. The carer reported frustration at having to fight for children to be able to attend school: *“I shouldn't have to do that. I shouldn't have to micromanage the Department to get her into a school”* she shared.

Foster carers spoke of the impact of a high turnover of Child Protection workers delaying signing off paperwork and therefore timely access to services. This impacts a carer's ability

24 McLean K et al. (2020). Foster and kinship carer experiences of accessing healthcare: A qualitative study of barriers, enablers and potential solutions, *Children and Youth Services Review*, Volume 113.
 25 Commonwealth of Australia (2023). *Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability: Final Report*
 26 Ernst & Young (2021). *Strong Carers, stronger children – Victorian Carer Strategy: Findings from the Home-Based Carer Census*, commissioned by DFFH

to follow up paperwork and reimbursements. One foster carer shared that a young girl in her care, who was 3 years old, had experienced many different workers in her life: “[She] alone had around 11 different agency workers herself. I don’t even know who her Department worker is now but she’s had at least five different Department workers and sometimes they change so quickly that I’m not even notified that they’ve changed.” This impacts a carer’s ability to follow up paperwork and reimbursements.

The processes for caring for multiple children in care, as well as a carer’s own biological children, adds additional complexity for carers. Carers must navigate attending medical appointments or long hospital stays while also caring for their other children, both biological and children in their care. Although they may be able to ask friends or family to care for their biological children, children in care are required to be cared for by people with prior background checks and approval from the Department. When a carer is single, or when their partner or household is not available, this stretches carers. A foster carer shared that while attending hospital with a sick child in her care, and with her partner away, the Department denied a request for a worker to relieve her so that she could return home to pick up her other children (who included her biological children and another child in her care) from school. She was eventually able to have a family friend pick up her biological children but the friend was not permitted to pick up her other child in foster care. “The Department wouldn’t let me leave the hospital, but they wouldn’t let anyone else pick up my other children”, she shared.

8.6 Obtaining an assessment and diagnosis

“We don’t like labelling but unfortunately we need to label to get support” - Foster carer

Our findings demonstrate that foster carers play a significant role in identifying the signs that a child in their care may have disability. Among the surveyed foster carers, 75 per cent reported they had fostered a child who they suspected had a disability but did not yet have a diagnosis and 62 per cent reported they had supported a child in their care through the process of obtaining a diagnosis.

“We try to be very reassuring during the recruitment phase that they will get the support but as we know the reality of that’s quite different when children come into a placement. It’s often the carers telling us what they’ve observed. We’re often relying on the carers to inform us and to make decisions around what support the child needs.” - Agency worker

Foster carers were asked about their experience accessing assessments for children in their care. Common challenges reported by foster carers included being believed by their agency or the Department, particularly where signs and symptoms might mimic trauma or vice versa, and long wait periods for obtaining an assessment, which were compounded by navigating Child Protection approval processes.

One foster carer shared “[Our] agency thought our foster child just had hydrocephalus and put all behaviour and delays down to trauma. I asked the neurosurgeon if the child had a traumatic brain injury and they confirmed the child had x 2 traumatic brain injuries.”

Another foster carer shared “I don’t even know where to start. My child with FS1 [Feingold Syndrome 1] clearly had GM [gross motor] difficulties, and no one listened until he finally had an MRI to reveal he had a stroke.”

One foster carer reported that it took four years to obtain a diagnosis for a child in their care: “I could see one child had FASD [Fetal Alcohol Spectrum Disorder] from facial features... getting the diagnosis took me four years, many multi-disciplinary testing days, 30 hours of answering questionnaires and a lot of advocating for the child.”

Another carer stated that the process is still ongoing after many years: “I have a child in my care who has no formal medical diagnosis as we keep on getting referred to different specialists who then tell us we don’t meet criteria for their [MEDICAL] care so once again we get referred to a different specialist. This has been going on for eight years now and we still haven’t got a diagnosis or a referral to a service who can help this child.”

Foster carers also report feeling as though they have to do the groundwork to identify the appropriate and available services for a child in their care. Suggestions from carers included having a centralised resource within the Department that retained knowledge of which specialists were suitable and available that agencies and carers could access. “I can’t be the first foster carer looking for a play therapist [for example] in my area. There has to be a way of carers accessing that information all in one place.”

Obtaining an assessment and diagnosis opens vital pathways for children to access services and to inform foster carers how to best parent and support children’s needs. One foster carer reported that “we noticed difficulties with learning and attention/hyperactivity in some siblings we cared for. We started the conversations with their care team about arranging assessments for the kids. Child Protection were hesitant to fund any assessments, so we arranged and paid for the assessments ourselves (later our agency agreed to reimburse us) which found that the children had learning disorders. Knowing this information was incredibly helpful in framing how we parented as well as how we supported the children’s learning.”

Extended waiting times for assessments pose a challenge across Victoria. However, children in out-of-home care face heightened impacts due to the unique nature of being in care. The intricate process of navigating Child Protection consent procedures, combined with the flux of children entering and exiting care or experiencing placement turnover, disrupts and extends the journey toward obtaining a diagnosis. At times, prolonged waitlists for specialists and delays in Child Protection approvals have led to situations where a child has transitioned to another placement or returned to their family’s care before attending specialist appointments. This disruption causes a loss of continuity and delays in receiving a diagnosis. One worker shared that “delays (within Child Protection and waiting lists for public system doctors and bulk billing GPs) in accessing specialists meant children moved on before appointments occurred.”

Unknown information upon entering care

When children first enter care, it is not uncommon that information about the child’s medical history is unknown. This is particularly so when a child enters foster care with short notice. In these cases, a foster carer might make the decision to care for a child without knowing whether the child has a disability and therefore whether they as carers have the capacity or skills required. One case worker reported that they were “working with a number of foster carers in

this situation. One of them took a newborn and four years on, now has an immensely challenging 4-year-old with a severe intellectual disability.”

One foster carer shared that in her 17 years of fostering, she had supported at least 50 children in her care to get a diagnosis.

One foster carer stated that “when you get emergency placements the Department don’t always know a lot about the children if it’s their first removal. It’s important to get them seen by a paediatrician early and link them with services and supports as soon as possible in order to get them the help and support they have probably needed for a long time but were not given in their home, hence the removal. Often the parents have a disability themselves and are just surviving as best they can.”

In one foster carer’s experience, “the child presented as autistic but did not have a diagnosis and no information was provided to us in advance about this little boy’s communication style, rigidity or sensory preferences. He was a gorgeous kid and we figured it out as we went along, but it goes to show how little Child Protection may know about emergency placements and how likely it is that carers may end up with a child with a disability without knowing it.”

8.7 Navigating the NDIS

“Foster care and NDIS are both difficult on their own; when you’ve got them at the same time with a child with disability it complicates everything even more.” - Foster carer

The NDIS can be a challenging system to navigate for parents and carers. Accessing the Scheme is made more difficult for foster carers because it requires integrating the Child Protection process and systems with those of the NDIS. Foster carers do their best, alongside their care team, to navigate this complicated system, taking children to various appointments to complete assessments and finding the right provider for them and their needs. Navigating consent from the Department and obtaining the relevant paperwork and medical histories reduces foster carers’ autonomy to make decisions quickly to respond to children’s needs: “It’s been really frustrating having to wait for the Department to do their bit to get NDIS funding. If it is a biological child, it only takes a month from start to finish. For my foster child it’s so far taken 3 months and still ongoing.”

Approximately 53 per cent of children with disability in care have an NDIS plan (Table 2). With many children being diagnosed with disability after entering care, it is likely a child will also access the NDIS for the first time after entering care, adding to the role that carers and agencies play: “[U]nless a foster carer already has knowledge or experience in the disability sector, the foster carers and the care team require training and upskilling in managing a whole other system on top of the Child Protection system that is already difficult to understand and work within.” It is important to note that not all children with disability are eligible for the NDIS.

There is variation in level of involvement in NDIS planning among foster carers. Some foster carers reported being very involved with their agency in the process and the value this had, while others said they were excluded from the process and were not aware of what the package included for children in their care. One foster carer shared that for 2 years, she was unaware that she was able to access in-home support through her child’s NDIS plan. This support had been vital, she reported, and had allowed her to continue with the placement.

Where NDIS and Child Protection are both involved, foster carers and agencies have reported there can be disputes between what the NDIS pays for versus what the Department pays for. A foster carer shared “Child Protection trying not to pay for anything NDIS will pay for, NDIS trying not to pay for anything Child Protection will pay for.”

Not having the available NDIS supports in place can result in placements breaking down because carers are not getting the support they need. One carer indicated that they “were never able to get any support for the child from NDIS despite them having funding. Because their case plan was not clear the NDIS supports weren’t prioritised. I had zero support despite having multiple kids in my care, one with a large NDIS package and another waiting to get onto NDIS. I could have continued caring for these children if the supports were in place. Unfortunately, months went by, with no support and I eventually had to say goodbye to the kids”.

8.8 Accessing respite care

Respite care is short-term or intermittent care provided to children in foster care who are living with full-time foster carers, and is designed to give carers a break. Respite care appeals to newly accredited foster carers because it provides them with an opportunity to experience fostering in a structured short-term way, where information about a child is already known. For this reason, foster care agencies have reported an abundance of new respite carers. In 2023, the Centre for Excellence in Child and Family Welfare surveyed 14 foster carer agencies to understand trends in recruitment and accreditation. Fifty-seven per cent of respondents reported they had observed a growing preference among new carers for providing respite care rather than long-term care.²⁷

Finding respite carers for children with complex needs is much more difficult than for children with less complex needs. Of the foster carer survey respondents where respite was applicable, 33 per cent agreed or strongly agreed that they had ready access to enough respite compared with 50 per cent who disagreed or strongly disagreed, excluding those where respite was not applicable (Table 13).

Table 13: Access to respite care

Question: To what extent do you agree or disagree with the following statements.

Responses (n=52)	Strongly disagree	Disagree	Neither disagree nor agree	Agree	Strongly agree	Don't know/ Not applicable
I easily have access to enough respite	14 (26.92%)	9 (17.31%)	8 (15.38%)	11 (21.15%)	4 (7.69%)	6 (11.54%)

For carers who were not able to access respite care, the impact and wait time was notable. In some cases, foster carers reported not being able to access respite from 12 month up to 6 years. Foster care agencies reported that a lack of respite care is the second most common cause of placement breakdown (Table 23).

Some foster carers reported initially feeling ‘too guilty’ to access respite in the early stages of their fostering journey, but eventually built up the confidence to make the request. A Melbourne foster carer stated that “the first probably 12 years that I was fostering I never wanted respite. I just felt like I was being selfish and I felt too guilty. But then the last eight, nine years I have been

²⁷ CFECFW report 2023 (unpublished)

having respite because I just felt like I think it's the best thing for my partner and I to maintain a good healthy relationship which is really important to me too."

Some foster carers report a desire to build an attachment with the child and develop a trusting relationship within the first 6 to 12 months of a placement before exploring respite care. Another carer commented "I don't have respite in the first six months of a placement. I rarely do that only because I need to have a relationship with a child before I can send them to respite." The carer reported she was able to access regular respite for children with less complex needs, but when it came to wanting to access respite care for a child with a severe mental illness, there was no carer willing or available to provide respite.

Other foster carers reported they did not feel it was appropriate given their commitment to the child. One foster carer shared "we were offered it but we thought if you're going to look after kids and give them unconditional love then you don't send them away for weekends, it's a bit of a contradiction".

A lack of appropriate respite care options to meet a child's needs can also result in a child returning home to their long-term carers dysregulated, regressing and with more challenging behaviours. This is not necessarily through fault of the respite carer but in some cases can simply be a result of the child being out of their routine, the respite carer having less experience with a certain type of disability or a respite care option that didn't meet the needs of the child. These findings demonstrate a need for more skilled and experienced respite carers who can provide care to children with complex needs or disabilities.

8.9 Carer health, well-being and sense of purpose

The health and wellbeing of foster carers is integral in carers' ability to effectively and sustainably care for children. The impact of fostering a child with disability on carers' mental health and overall wellbeing were considered through a range of statements (Table 14).

Around 48 per cent of survey respondents reported that fostering children with disability had negatively or very negatively affected their overall mental health and 46 per cent of survey respondents reported that fostering a child with disability had negatively or very negatively impacted their physical health.

Despite the impact on their mental and physical health, respondents reported their overall happiness, sense of purpose and sense of contributing to their community was higher. Nearly 60 per cent of respondents reported that fostering a child with disability has positively impacted their overall happiness, with 75 per cent of respondents reporting that fostering children with disability had positively or very positively affected their sense of purpose and 77 per cent reporting that fostering children with disability had positively or very positively affected their sense of contributing to their community.

Table 14: Carer health, wellbeing and sense of purpose

Question: To what extent have the following been positively, or negatively, affected as a result of caring for children with disability?

Responses (n=52)	Very negatively affected	Negatively affected	Neither	Positively affected	Very positively affected	Don't know/ Not applicable
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My overall happiness	2 (3.85%)	3 (5.77%)	14 (26.92%)	23 (44.23%)	8 (15.38%)	2 (3.85%)
My sense of contributing to my community	1 (1.92%)	2 (3.85%)	8 (15.38%)	21 (40.38%)	19 (36.54%)	1 (1.92%)
My sense of purpose	3 (5.77%)	2 (3.85%)	8 (15.38%)	22 (42.31%)	17 (32.69%)	0 (0%)
My physical health	6 (11.54%)	18 (34.62%)	21 (40.38%)	4 (7.69%)	1 (1.92%)	2 (3.85%)
My overall mental health	5 (9.62%)	20 (38.46%)	18 (34.62%)	4 (7.69%)	4 (7.69%)	1 (1.92%)

Of foster carers surveyed, 73 per cent agreed or strongly agreed that fostering children with disability is rewarding (Table 15). Foster carers were asked what the most rewarding thing about fostering children with disability was. One foster carer shared that their reward was "knowing that we helped another person have a good start to life, even if it was just a little while. I have satisfaction knowing that we kept them safe and helped them develop to their potential."

Another foster carer shared the rewards were "seeing the improvements and strides you can make in a child's life. Seeing a smile for hearing laughter from a child with a challenge greater than children experience brings such joy."

Table 15: Rewards of fostering children with disability

Question: To what extent do you agree or disagree with the following statements?

Responses (n=52)	Strongly disagree	Disagree	Neither disagree nor agree	Agree	Strongly agree	Don't know/ Not applicable
Being a foster carer for children with disability is rewarding	1 (1.92%)	2 (3.85%)	11 (21.15%)	17 (32.69%)	21 (40.38%)	0 (0%)

Value as a carer

Surveyed foster carers were asked about their sense of value in caring for children with disability: 46 per cent agreed or strongly agreed that they felt appreciated in their role as foster carers for children with disability, and 29 per cent disagreed or strongly disagreed (Table 16).

When asked what they would like to see improved about their experience, foster carers spoke of a desire to be recognised as an essential member of the care team. One foster carer shared their desire for increased "respect to foster carers as knowledgeable valued members of the care team not seen as a disposable babysitter."

Table 16: Value as a carer

Question: To what extent do you agree or disagree with the following statements?

Responses (n=52)	Strongly disagree	Disagree	Neither disagree nor agree	Agree	Strongly agree	Don't know/ Not applicable
I feel valued in my role as a foster carer for children with disability	5 (9.62%)	10 (19.23%)	12 (23.08%)	12 (23.08)	12 (23.08%)	1 (1.92%)

8.10 Carer families and relationships

When a child enters a foster care placement, all members of the family in the household are considered to ensure the placement is an appropriate match for both the child and the family. Many children in foster care benefit from being part of a family with other children and, for some children, a single carer is more suitable.

Foster carers were asked the extent to which fostering a child with disability had impacted their family and their relationship with a partner. For most, fostering a child with disability was more likely than not to positively impact a carer's family (45 per cent versus 31 per cent, respectively). Of foster carers in a relationship, positive versus negative impact was evenly split. Twenty three per cent of foster carers surveyed reported it had positively affected their relationship with a partner compared with 23 per cent of who reported it had negatively or very negatively affected their relationship.

Around 45 per cent of respondents reported fostering a child with disability had positively or very positively affected their family compared with 31 per cent who reported it had negatively or very negatively affected their family (Table 17).

Table 17: Impact on relationships and family

Question: To what extent have the following been positively, or negatively, affected as a result of caring for children with disability?

Responses (n=52)	Very negatively affected	Negatively affected	Neither	Positively affected	Very positively affected	Don't know/ Not applicable
My relationship with my partner	3 (5.77%)	9 (17.31%)	14 (26.92%)	11 (21.15%)	1 (1.92%)	14 (26.92%)
My family	5 (9.62%)	10 (19.23%)	12 (23.08%)	15 (28.85%)	7 (13.46%)	3 (5.77%)

8.11 Support from foster care agencies

Foster care agencies play an important role in supporting children in care and supporting foster carers through training, accreditation and placement. On 31 March 2023, there were 24 foster care agencies (six ACCOs and 18 CSOs). Foster care agencies are the primary point of contact for foster carers and play an important role in carer retention and wellbeing.

When foster carers were asked about the support they received from their agencies, 60 per cent responded that they feel supported (Table 18).

Table 18: Carer perception of support from foster care agency

Question: To what extent do you agree or disagree with the following statements in relation to your role as a foster carer?

Responses (n=52)	Strongly disagree	Disagree	Neither disagree nor agree	Agree	Strongly agree	Don't know/ Not applicable
I feel valued in my role as a foster carer for children with disability	5 (9.62%)	5 (9.62%)	10 (19.23%)	19	12 (23.08%)	1 (1.92%)

Foster carers report they feel supported, respected and listened to when they build a long-standing relationship with their case worker. This relationship also allows foster carers to build a sense that they are trusted. One foster carer shared, *"our relationship with the agency is a trusting one. We trust each other, they trust us with our [foster child] and we trust them to hear us."*

Case worker perspective

When case workers were asked what they need more of to support them in their role, the most common response was greater training for workers in relation to disability and the NDIS (50 per cent). This was followed by greater access to support services (23 per cent), support with navigating the NDIS (20 per cent), and smaller caseloads (13 per cent).

When asked about what they would like to see more of to improve retention of foster carers, the most common response was greater training for carers (43 per cent), followed by: greater financial support (37 per cent; e.g. increased Care Allowance, more efficient reimbursement processes, professionalisation of foster care and increasing funding for support); support with navigating the NDIS (23 per cent); more respite care (20 per cent); smaller caseloads (17 per cent); and access to services (13 per cent).

"My case load is more than 75 per cent [children with disability], 10 out of 13. Three of these are barely contained by their excellent and highly committed carers who are at their wits end", a case worker shared.

The prevalence rate of disability among children in foster care has implications for the role that case workers have in supporting children and carers and the skills they may require. Case workers reported high confidence in their own ability to provide support to carers of children with disability (77 per cent feel confident; Table 19).

However, a range of factors impacted case workers' capacity to provide this support. Only 43 per cent agreed or strongly agreed they are confident in knowledge about disability. Only 30 per cent agreed or strongly agreed they have enough time to support foster carers for children with disability and only 37 per cent agreed or strongly agreed that they are confident in their knowledge about disability support services available to carers (Table 19).

Table 19: Case worker confidence and capacity

Question: To what extent do you agree or disagree with the following statements?

Responses (n=30)	Strongly disagree	Disagree	Neither disagree nor agree	Agree	Strongly agree	Don't know/ Not applicable
I am confident in my ability to support foster carers for children with disability	1 (3.33%)	1 (3.33%)	5 (16.6%)	17 (56.7%)	6 (20%)	0 (0%)
I am confident in my knowledge about disability	2 (6.67%)	4 (13.33%)	11 (36.7%)	11 (36.7%)	2 (6.7%)	0 (0%)
I am confident in my knowledge of disability services to support foster carers of children with disability	1 (3.33%)	10 (34.5%)	7 (24.1%)	10 (35%)	1 (3.33%)	0

I have enough time available to best support foster carers of children with disability	5 (16.7%)	11 (36.7%)	5 (16.7%)	7 (24.1%)	2 (6.7%)	0
I have enough resources available to best support foster carers of children with disability	2 (6.7%)	15 (50%)	7 (23.33%)	6 (20%)	0 (0%)	0 (0%)

8.12 Financial support

In Victoria, home-based carers, including foster carers, receive a Care Allowance from the Department to cover the day-to-day costs associated with caring for children, with five different pay levels designed to reflect a child’s needs and age. Additional funding is also available through the Client Support Funding Framework for items or services that exceed the day-to-day costs covered by the Care Allowance or when high costs place an unreasonable financial burden on the carer.

A number of foster carers were adamant that financial gain should not be the motivator for people to foster children and that their contribution should be recognised for its altruistic intention; however, findings from this research make clear that foster carers are financially worse off as a result of fostering children with disability and that, in some cases, this had impacted foster carers’ ability to continue fostering.

Sixty-two per cent of foster carer respondents agreed or strongly agreed that the Care Allowance they receive is not adequate to support children with disability and 44 per cent of foster carers agreed or strongly agreed that cost of living pressures in the last 12 months have impacted their ability to foster children with disability (Table 20). There was no measurable difference between results for regional Victoria compared with metropolitan Melbourne.

One carer suggested *“you will always be out of pocket if you want your foster child to have the experiences that other children are having and sometimes a child with a disability may need more assistance to be able to have the same experience.”*

Table 20: Care Allowance and cost of living

Question: To what extent do you agree or disagree with the following statements?

Responses (n=52)	Strongly disagree	Disagree	Neither disagree nor agree	Agree	Strongly agree	Don't know/ Not applicable
The Care Allowance I receive to care for children with disability is adequate	21 (40.38%)	11 (21.15%)	8 (15.38%)	7 (13.46%)	3 (5.77%)	2 (3.85%)
Cost of living pressures (in the last 12 months) have impacted my ability to foster	4 (7.69%)	8 (15.38%)	14 (26.92%)	14 (26.92%)	9 (17.31%)	3 (5.77%)

When a child first enters out-of-home care, a needs-based assessment is made by the Department to determine the level of Care Allowance given to a foster carer. Foster carers caring for children with disability reported having to make a case for a higher level of Care Allowance that accurately reflects the costs associated with the greater level of care required. While the Care Allowance was reportedly a concern, carers elaborated about the negative impact of the lack of clarity and transparency in the reimbursement process through the Client

Support Funding Framework for cost recovery of services that are usually the responsibility of the Department. Foster carers reported that this process is difficult to navigate and that reimbursement processes are slow, resulting in foster carers experiencing financial hardship. Foster carers and agency workers reported that carers were covering costs that should have otherwise been covered by the Client Support Funding Framework. These expenses included medications that cost greater than \$100 per fortnight, functional assessments and medical procedures.

In one extreme example, a foster carer reported they were still following up reimbursements for medical expenses after a child in their care had passed away as a result of their disability. Despite being in care since birth, the child still did not have a concession card at the time they passed away. As a result, the child’s carers were following up reimbursements for associated medical costs at least 2 months after the child’s passing. During the 18 months that the child was in their care, they queried the Care Allowance but were told the child was on the correct payment, only to find out after his passing that they were eligible for a higher payment. The foster carers were then only reimbursed for 6 of the 18 months.

Delays in reimbursements also impinge access to specialists. Agencies report that, in some cases, it takes months for specialists to be reimbursed by the Department. Although agencies reported upfront payment is often denied by the Department, upfront payment for specialists would avoid agencies bearing the cost. Agencies also reported that these delays in payment result in specialists no longer being in a position to work with children in care.

“I’ve got no super left. I have spent so much money getting these kids the services they need because the Department won’t fund it.” - Foster carer

A Melbourne foster carer of 15+ years reported that they had spent all of their superannuation ensuring children in their care accessed services they needed as well as being able to afford time off work to take them to medical appointments.

“I’ve fostered more than 100 children. That’s a lot of diagnoses, a lot of medical appointments and I’ve used up all my super on that. It’s also the simple things, after that many children the lounges wear down, the beds break and need replacing” they shared.

One of the children in their care was recommended to undertake Dialectical behaviour therapy through Monash Health Stepping Stones for treatment for her Borderline Personality Disorder. The young person had recently had multiple hospital admissions for suicide attempts and was in inpatient care. The request for funding was declined by the Department and they suggested funding a basketball membership instead.

Without this treatment, the carer felt they were no longer able to provide the care the child needed. Reluctantly, the carer gave the Department an ultimatum and said she would be relinquishing care that day at 2 pm. At 2:20 pm, she received a call from the Department to say they had approved the funding for specialist care. While the carer was relieved, she reported feeling stressed and anxious about having to threaten relinquishing care to get a child the therapeutic support they needed.

“I am happy to fight for these kids, but I am frustrated that the Department don’t see the value of investing in these children” they shared.

Employment

Household structure and income is an important consideration for foster carers' capacity to foster children with disability. Agencies reported that the profile of foster carers has changed over the last couple of decades, from families where one parent was able to stay at home, the foster parents owned their own home and had multiple spare bedrooms, to households where both adults are required to work, or where they are a single-headed household.

Foster carers were asked to state their level of agreement with a range of statements about the financial impact of fostering children with disability, 60 per cent of survey respondents reported that fostering a child with disability had negatively or very negatively affected their employment and 54 per cent reported it had negatively or very negatively affected their financial situation (Table 21). Around 60 per cent of respondents agreed or strongly agreed that they had had to reduce the number of hours they worked to care for a child with disability (Table 22). These findings suggest it is unrealistic to expect a foster carer and/or foster carer household to foster a child with disability while working close to full-time hours.

Table 21: Employment and financial situation

Question: To what extent have the following been positively, or negatively, affected as a result of caring for children with disability?

Responses (n=52)	Very negatively affected	Negatively affected	Neither	Positively affected	Very positively affected	Don't know/ Not applicable
My employment	13 (25%)	18 (34.62%)	16 (30.77%)	0 (0%)	1 (1.92%)	4 (7.69%)
My financial situation	11 (21.15%)	17 (32.69%)	20 (38.46%)	2 (3.85%)	1 (1.92%)	1 (1.92%)

Table 22: Reduced hours of work

Question: To what extent do you agree or disagree with the following statements in relation to your role as a foster carer?

Responses (n=52)	Strongly disagree	Disagree	Neither disagree nor agree	Agree	Strongly agree	Don't know/ Not applicable
I have had to reduce the number of hours I work to care for children with a disability	3 (5.77%)	7 (13.46%)	7 (13.46%)	11 (21.15%)	20 (38.46%)	4 (7.69%)

While support from agencies is available to help children attend appointments, carers are typically expected to be available to take children to medical appointments or to be able to pick them up from school early if required. One carer reported needing to be 'on-call' for school-aged children with challenging behaviours because of the likelihood of the school ringing and asking for the child to be picked up and taken home. The carer suggested that *"it might be three times a week you get a call to say sorry you need to come and get him because of his behaviour or because he's not coping at school. It makes it hard as far work goes, if your work thinks that at any time you could have to leave."*

Despite the time burden, foster carers still want to be available to attend these appointments to ensure continuity of care and to receive all relevant information about the child's care, and to support the child through this process. Some foster carers have reported losing significant portions of their income because they needed to take time off work to support a child in need of medical care.

Foster carer lost \$6,000 of income in first three months of fostering a baby with complex medical needs

A Melbourne-based foster carer reported losing \$6,000 of income in the first 3 months of fostering a young baby with complex medical needs. The carer reported that they had agreed to have the child in their care because they were already caring for the child's sibling and did not want to separate the pair.

The young baby had come into their care shortly after birth with little pre-natal care and were not prepared for how unwell the child was when he came into their care.

For the first 10 months of the boy's life, the carer and her husband attended nearly daily GP appointments and, as a result, were unable to work. The carer was a support worker and lost clients permanently as a result of being unable to work for this period of time.

Foster carers have reported turning down placements that they would have otherwise accepted because they felt they were not able to give the child the support they needed while maintaining their working hours. One foster carer shared she was offered a placement for a 4-year-old with complex disabilities under the assumption the carer could work 3 days a week and care for the child; however, the foster carer declined because she felt that the child needed full-time care. *"It was expected that the child could go to childcare on those three days, but with the amount of care required and time needed to take them to their many medical appointments, but I knew that wouldn't be possible with my work commitments. If there was TFCO [Treatment Foster Care Oregon] for disability I would have been able to take on that placement"* she shared.

8.13 Placement breakdown and stability

Placement stability demonstrates the health of a care system and the appropriateness of a care model for meeting the needs of children in care. Studies have shown that children with disability are more likely to experience placement disruption and a higher number of placements than children without a disability.^{28,29,30} The 2021 Department of Families, Fairness and Housing (DFFH) Carer Census survey found that, of the foster carers who had stated a placement had broken down, 17 per cent cited behavioural and mental health issues as the cause.

28 Baidawi, S., Ball, R., Newitt, R., Turnbull, L., Kembhavi-Tam, G., Avery, S., & Sheehan, R. (2022). Research Report - Care Criminalisation of Children with Disability in Child Protection Systems. Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability.

29 Bilaver, A & Judy Havlicek, J (2013) Foster Children With Autism Spectrum Disorder: Prevalence, Length of Stay, and Placement Patterns, Journal of Public Child Welfare, Vol 7:5, p 496-519, DOI: 10.1080/15548732.2013.843496

30 Slayter, E (2016) Foster Care Outcomes for Children With Intellectual Disability Intellect Dev Disabil Vol 54 (5), p 299-315.

A higher number of placements and placement disruption have been shown to negatively impact a child’s attachment, developmental milestones, social and relational connections and their education outcomes, as well as increasing their likelihood for contact with the youth justice system.^{31,32,33,34}

Foster carers were surveyed to understand their experience of placement breakdown. Of the foster carers surveyed, 29 per cent reported they had ended a placement early for a child with disability in their care because the child required more care than they were able to provide. Some (31 per cent) survey respondents reported they had ended a placement early for a child with disability because it was having a negative impact on themselves and/or their family. This is despite a high number of foster carers feeling confident in their ability to manage complex behaviours (Table 19), demonstrating that it is likely a lack of support and capacity to care, rather than ability, that increases the likelihood of placement breakdown.

Foster carer case workers were also surveyed to understand their perceptions of the reasons why foster carers ended placements early. The top three reasons case workers stated that foster carers ended a placement early were being unable to manage complex behaviours (80 per cent) a lack of respite care options (63 per cent) and a lack of adequate support services (53 per cent) (Table 23).

Table 23: Agency worker perception of placement breakdown

Question: In your experience, what are the most common reasons foster carers prematurely end a placement for a child with disability (option of 3)?

Respondents (n=30)	% Responses	Number of responses
Unable to manage complex behaviours	80	24
Lack of respite care	63.33	19
Lack of adequate support services	53.33	16
Unable to meet needs of the child	46.67	14
Negative impact on family	36.67	11
Not enough financial support	26.67	8
Lack of time	26.67	8
Negative impact on mental health	23.33	7
Other	6.67	2

One foster carer reported that “the care system did not provide enough financial, emotional or practical support for us to continue caring full time for a young person with a disability. We were forced to end the placement because not enough support was provided for a 15-year-old in our care with a level 2 autism diagnosis. We received no extra training, only the basic carer’s payment, and set up the NDIS support ourselves. After over 1 year of advocacy from us with no change to circumstances or support, we ended the placement on a full-time basis and remain respite carers for the young person.”

Foster care workers reported children with disability as young as 5 years old entering residential care because of a lack of foster care options. These children were otherwise suitable for home-based care but were placed in residential care because of their disability. In some cases, foster care agencies reported that children might be placed with a kinship carer without the skills to manage the child, leading to burn-out and the child being relinquished back into foster care or residential care. In other cases, children with disability have needed to go into contingency units or placements or stay in hospital settings for extended periods of time because there were no placement options available.

“Without sufficient carers to care for children with a disability, we are either in a position where a child is placed with inexperienced carers, or the child does not have access to home based care and will not receive the family-based environment that every child should experience. Inexperienced foster carers will be more stressed, requiring more support from agencies and require more training than resources sometimes allow”, a foster care worker shared.

A lack of suitable foster care options can result in children being moved away from their local area, community and school. One case worker noted that “sometimes we read referrals for 12-18 months about the same young person who has a disability and needs care. They remain in unstable care environments which could end at any point or are cared for by staffing models because there is no suitable open”.

31 Elysia V. Clemens, Kristin Klopfenstein, Trent L. Lalonde, Matt Tis (2018). The effects of placement and school stability on academic growth trajectories of students in foster care, *Children and Youth Services Review*, Vol 87, p 86-94, <https://doi.org/10.1016/j.childyouth.2018.02.015>.

32 Stott, T. (2012). Placement instability and risky behaviors of youth aging out of foster care. *Child & Adolescent Social Work Journal*, 29(1), 61-83. <https://doi.org/10.1007/s10560-011-0247-8>

33 Ahn E, Gil Y, Putnam-Hornstein E. (2021). Predicting youth at high risk of aging out of foster care using machine learning methods. *Child Abuse Negl*. Vol 117:105059. doi: 10.1016/j.chiabu.2021.105059.

34 Goodkind, S., Shook, J. J., Kim, K. H., Pohlig, R. T., & Herring, D. J. (2013). From Child Welfare to Juvenile Justice: Race, Gender, and System Experiences, *Youth Violence and Juvenile Justice*, 11(3), 249-272. <https://doi.org/10.1177/1541204012463409>.



9. Conclusion

The results of this research provide, to date, the most accurate estimate of the prevalence rate of disability among children in foster care in Victoria. Disability is markedly over-represented for children in foster care (41 per cent compared with 7.7% in the general population of children under age 15) including from Aboriginal and Torres Strait Islander backgrounds (31 per cent).

Findings from carer surveys and interviews show that, while fostering children with disability is a rewarding experience, it is also a challenging experience. Factors that contribute to this are: a lack of adequate preparation, particularly where agency workers are limited to the scripted Step by Step package that does not reflect the realities of fostering children with disability; the challenges of navigating both Child Protection processes and the NDIS; and the significant financial and time burden that is required of carers of children with disability.

These research findings contribute to the evidence base relating to improving the recruitment and retention of foster carers for children with disability. The recruitment and retention of foster carers in Victoria is an important policy issue and there is great demand for more foster carers for children with disability. Without an adequate supply of skilled and motivated foster carers for children with disability, children in care may experience placements that are not suitable, a higher rate of placement disruption and, in some cases, placement in residential care instead of a home-based environment. These findings raise important questions about the extent to which the current model of foster care in Victoria takes into account the prevalence rate of disability and therefore the complexity of the role that foster carers play.



10. Recommendations for consideration

Recommendations include disability specific recommendations as well as broader service system recommendations that relate directly to the key findings of this report.

Recommendation 1: Examine the current model of foster care to ensure it is fit for purpose for a contemporary Victoria.

Recommendation 2: Include appropriate representation from the child and family services sector in policy discussions to inform service design decisions in relation to children with disability in foster care.

Recommendation 3: In consultation with the sector and ACCOs, examine the Step by Step package to make sure that information about the nature, challenges and rewards associated with caring for children with disability is embedded in all stages of the recruitment and accreditation process.

Recommendation 4: Support ongoing professional development and training for foster care workers and foster carers in disability, NDIS, and allied health, including provision for access to specialist services.

Recommendation 5: Support the Centre to systematically collect and report on data relating to the number of children and young people with disability in out-of-home care.

Recommendation 6: To support current foster carers in the interim by

- » Making sure agencies and carers can readily access specialist advice to navigate Child Protection, NDIS and allied health systems either through
 - » expanding the DFFH Disability Advisory team so that it is directly accessible for carers and agencies and/or
 - » funding a dedicated disability specialist role within agencies/regions to support carers and workers.
- » Establishing a dedicated fund to cover the assessment, medical and therapeutic care costs of individuals caring for children with disability.
- » Making sure that foster carers are receiving the correct Care Allowance payment level
- » Making sure that reimbursements for carers and medical specialist are timely and transparent.

11. References

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