GAPS IN POST-CARE SUPPORT FOR YOUNG PEOPLE WITH DISABILITIES AGEING OUT OF THE CHILD PROTECTION SYSTEM

Submission No.3 of Advocacy for Disability Access and Inclusion Inc. SA to the Royal Commission into violence, abuse, neglect, and exploitation of people with disability

December 2022

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ABOUT ADAI

Advocacy for Disability Access and Inclusion Inc. SA (ADAI) are an advocacy organisation based in North Adelaide, South Australia.

ADAI was born as Parent Advocacy in 1986 after a group of parents acted as advisors to the then State Government in starting new and different disability services and to establish the Intellectually Disabled Persons' Services Act, 1986. At that time funds were provided by both the State and Federal Governments to establish Parent Advocacy. In 2006 Parent Advocacy changed its name to Family Advocacy Incorporated (FAI) and to Advocacy for Disability Access and Inclusion in 2015.

Today, ADAI is funded by the Department of Social Services (DSS) primarily through the National Disability Advocacy Program to provide independent advocacy to any person living with disability and or the family that supports them. ADAI has also been funded by DSS to provide advocacy and support to persons participating in the DRC. ADAI has assisted over 160 people to gather information about the Royal Commission, make a submission or assist someone to make a submission. ADAI is also funded to provided advocacy to people making an appeal to a NDIS decision through the NDIS AAT Appeals Program. The South Australian State Government does not currently provide funding for ADAI to provide advocacy.

ADAI welcomes the opportunity to make a submission to the Royal Commission into violence, abuse, neglect, and exploitation of people with disability.

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ADAI RECOMMENDATIONS

1. The Department for Child Protection must proactively engage with young people with disabilities well before they turn 18 to ensure there is a clear and positive pathway forward for them.
2. Review funding agreements and support services for foster carers who commit to continuing to care for young people in their homes after the advent of adulthood.
3. Increase funding to post-care service providers to ensure that services are accessible to care leavers with disabilities.
4. Post-care workers and the Department of Child Protection workers are provided specific training in the NDIS application and review process.
5. Ensure all children and young people in care have access to high quality health and medical care and ensure any disabilities are accurately identified and diagnosed. and
6. Ensure all children and young people with disability in care have the opportunity to access appropriate and consistent therapies.
7. Care leavers be supported up to age 25 within the Department for Child Protection and then transitioned to support to another more appropriate agency if required.
8. Review, with the aim to improve, communication pathways between all relevant Departments, such as the Department for Education and the Department for Child Protection.

PART 1: OUTLINE

A. INTRODUCTION

Advocacy for Disability Access and Inclusion Inc. SA (ADAI) hold serious concerns about the gaps in post-care support for young people with disabilities transitioning out of the Department for Child Protection (DCP) system. Many of these young people are especially vulnerable and the legislative and systemic social support frameworks are not adequately protecting them from harm.

This submission provides a discussion of issues identified by ADAI while working with clients navigating the out-of-home care sector. This submission will discuss the experience of children and young people with disabilities while noting the disproportionate number of parents with disabilities whose children are removed. For further consideration of a wider range of issues within the Child Protection system see ADAI's Submission no.6 to the Royal Commission: The importance of advocacy in the reduction of violence, abuse, neglect and exploitation of people with disability.

Children living with disability are over-represented in the out of home care sector. The supports provided to young people ageing out of the care systems are under-funded and there is a lack of clear referral processes from DCP to post-care services. Young people with disabilities who are ageing out of the foster, kinship or residential care system are at greater risk of disadvantage due to the intersecting factors of marginalisation. This disadvantage is further increased for young people from Aboriginal and Torres Strait Islander groups as well as those from cultural and linguistically diverse communities.

While the *National Framework for Protecting Australia's Children 2021–2031* (the Framework) notes that:

> ‘*young people leaving out-of-home care can face greater vulnerability as they move to independent living. This can be caused by traditional support such as family, friendship circles and communities being fractured. This limits the social support individuals can rely on to break the cycle of disadvantage, which can span several generations. Young people who have been in out-of-home care are 3 times more likely to receive income support in young adulthood as the general*

Australian population of the same age. Additionally, they are less likely to remain on student payment and more likely to remain on unemployment payments.[1]

ADAI do not see positive systemic change being implemented to support the objectives of the Framework to ensure that young people have adequate assistance to either transition into independent living, or continue with support on their journey into healthy adulthood. ADAI see many barriers to young people leaving out-of-home care living free from violence, abuse, neglect and exploitation.

The term 'Aboriginal' is used respectfully in this submission to refer to all people of Aboriginal and Torres Strait Islander descent who are living in South Australia. ADAI acknowledges and respects Aboriginal peoples as the state's First Peoples and nations and recognises Aboriginal peoples as Traditional Owners and occupants of lands and waters in South Australia.

The report uses the terminology 'people with disabilities' to refer to the disability community. ADAI acknowledges and respects that there is a range of views about language and celebrates the right of all people to identify as they see fit.

Note: all persons referred to in this submission have been de-identified.

Royal Commission Terms of Reference

This submission considers the experiences of young people leaving out-of-home care and the vulnerabilities they face. It recommends greater support for care-leavers and changes to the way paid supports can be administered under the NDIA.

The Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability (Royal Commission) terms of reference ask us to examine what should be done to promote a more inclusive society that supports the independence of people with disability and their right to live free from violence, abuse, neglect and exploitation

The Royal Commission is investigating how to:

a. prevent and better protect people with disability from experiencing violence, abuse, neglect and exploitation;
b. achieve best practice in reporting, investigating and responding to violence, abuse, neglect and exploitation of people with disability

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[1] Commonwealth of Australia Department of Social Services, *National Framework for Protecting Australia's Children 2021–2031* (Framework, 2021) p35.

c. promote a more inclusive society that supports people with disability to be independent and live free from violence, abuse, neglect and exploitation.[2]

This submission links to the terms of reference of the Royal Commission in that it explores:

> *(a) what governments, institutions and the community should do to prevent, and better protect, people with disability from experiencing violence, abuse, neglect and exploitation, having regard to the extent of violence, abuse, neglect and exploitation experienced by people with disability in all settings and contexts;*
>
> *(b) what governments, institutions and the community should do to achieve best practice to encourage reporting of, and effective investigations of and responses to, violence against, and abuse, neglect and exploitation of, people with disability, including addressing failures in, and impediments to, reporting, investigating and responding to such conduct;*
>
> *(c) what should be done to promote a more inclusive society that supports the independence of people with disability and their right to live free from violence, abuse, neglect and exploitation; and*
>
> *(d) any matter reasonably incidental to a matter referenced to in paragraphs (a) to (c)*[3]

This submission will examine the gaps in care for young people with disability who leave the child protection system and how these gaps put young people at risk of violence, abuse, neglect and exploitation.

Note: all persons referred to in this submission have been de-identified.

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[2] Commonwealth Letters Patent Constituting the Disability Royal Commission, issued on 4 April 2019.

[3] Ibid.

B. LEGISLATIVE AND POLICY BACKGROUND

The legislation that covers much of the regulation of child protection in South Australia is the *Children and Young People's Safety Act 2017* (SA) (CYPS Act).

The CYPS Act defines an eligible care leaver as a young person between the ages of 16 and 26 who has been under the guardianship of the Chief Executive (DCP) for a period of 6 months or longer. [4]

Under the current legislation the Minister *must* provide assistance to each eligible care leaver, as the Minister thinks appropriate.[5] Under the Act the type of assistance that can be provided includes:

> *(a) the provision of information about Government and other resources and services available to the eligible care leaver;*
>
> *(b) the provision of education and training services;*
>
> *(c) assistance in finding accommodation;*
>
> *(d) assistance in finding employment;*
>
> *(e) assistance in accessing legal advice and health services;*
>
> *(f) counselling and support services.*[6]

A review of the CYPS Act is currently being undertaken in South Australia with the final report expected to be tabled in Parliament in March 2023.

In ADAI's experience the above assistance the Minister must provide can be interpreted to be merely the provision of information about finding accommodation, rather than assistance to find accommodation.

Much of the legislation in this area is underpinned by the United Nations Convention on the Rights of Persons with Disability 2006 (UNCRPD) and the United Nations Convention on the Rights of the Child 1989 (UNCRC). Australia has obligations under these conventions to protect and promote the rights of children with disability.

The first General Principle of the UNCRPD is:

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[4] *Children and Young People's Safety Act 2017* (SA) s112(6).

[5] Ibid s112(1).

[6] Ibid s112(2).

1. *Respect for inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of persons.*[7]

The *National Framework for Protecting Australia's Children 2021–2031* is a federal Framework developed by the Australian Government to reduce child abuse and neglect and its intergenerational impacts.[8] It is focused on the best interests of the child, and aims to:

- provide protection for vulnerable and disadvantaged children in line with their needs; and
- help children express their views in developing and implementing activities.

These aims are consistent with the United Nations Convention on the Rights of the Child (UNCRC) and its 4 core principles of non-discrimination; the right to life; survival and development; respect for the views of the child and devotion to the best interest of the child.[9] The Framework aims 'to keep children safe and to achieve the best outcomes for vulnerable children and those experiencing disadvantage.'[10]

Australia also has a National Disability Strategy which was developed by the Commonwealth and state and territory governments under the auspices of the Council of Australian Governments (COAG). The Strategy was intended to support Australia's compliance with the CRPD after its ratification in 2008. The ten-year plan is currently up for review sets out six priority areas for action: inclusive and accessible communities; rights protection; economic security; personal and community support; learning and skills; and health and wellbeing.

South Australia has a variety of strong legislative and policy supports to look to and enable a healthy and proactive child protection system which provides excellent supports to children and young people with disability. Unfortunately, ADAI considers that it is not meeting its aims.

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[7] UN General Assembly, *Convention on the Rights of Persons with Disabilities*: resolution / adopted by the General Assembly, 24 January 2007, A/RES/61/106, Article 1.

[8] Commonwealth of Australia Department of Social Services, *National Framework for Protecting Australia's Children 2021–2031* (Framework, 2021) p6.

[9] Ibid p14.

[10] Ibid p2.

PART 2: DISCUSSION

ADAI provides advocacy assistance to clients navigating the child protection system, including young people transitioning out-of-home care, their families, and parents with children in care. This advocacy can take many forms including by assisting clients to link in with appropriate services to build their capacity, ensuring their needs are being heard and considered at meetings with DCP staff, supporting them to understand their legal rights and being a supportive ally. Many of ADAI's clients who are navigating the child protection system have complex issues, and can be in crisis.

Much of our work in this area is reactive, in that a referral has been made to us after a concerning event has occurred, and not before. Many clients state that they have never heard of advocacy and didn't know what an advocate could support them with before their referral to our service. ADAI would prefer to be able to support clients in a proactive manner within the child protection system, preventing harm, rather than responding to it. To enable advocacy organisations to be able to act in a more proactive manner, they need increased funding and support. This submission will outline the work of advocates while supporting clients leaving out-of-home care.

A. FORMS OF CARE

Out-of-home care comprises of three primary arrangements. These are kinship care, foster care and residential care.

Kinship care is where a child is removed from their birth family and placed with a member of their extended family. This is particularly common with Aboriginal and Torres Strait Islander families as a means of keeping children connected to culture.

Residential care is an arrangement where children are placed in a residential home with up to three other children. These homes are staffed by paid carers and volunteers on a 24-hour roster system. Residential care can be short or long term and is generally for children aged between 10 and 17 years old with complex needs.

Foster care ranges from short term and long term care, as well as respite foster care. In a foster care arrangement, a child is placed with a foster carer and lives with them in a family type arrangement.

- In long term foster care, the child may end up staying with the foster carer until they are 18 years of age, or until their birth family circumstances improve.
- Short term foster care might be utilized if a child's birth family is experiencing crisis.
- Emergency care is for a period ranging between one night up to two weeks.
- Respite care is provided for long term foster carers to have some downtime and give the children an opportunity to build relationships beyond the foster family.
- Specialist foster carers are people who have undergone specific training to care for children with complex needs including trauma and disability.[11]

B. CHILDREN AND YOUNG PEOPLE WITH DISABILITY WITHIN THE STATE CARE SYSTEM

Children with disabilities are estimated to make up at least 40% of the population of children in out-of-home care.[12] Many of these children have disabilities such as speech and language delays, intellectual disabilities and autism spectrum disorder (ASD).[13] Often children with disabilities are relinquished to the care of the Minister due to a lack of resources and support available to the parents to meet the specific needs of their child.[14]

As of June 2020, there were 6,424 children with a disability in out-of-home care, or 15.3% of all children.[15] As stated in the Royal Commission's Interim Report, on average, 12% of children in out-of-home care were reported as having a disability.[16] This contradicts the findings by the Office of the Guardian for Children and Young People cited above and highlights the lack of consistent data. In ADAI's experience the number of children in care with disability is significantly higher. Several of our clients were not provided with adequate health and medical support as children and young people, and therefore did not have their disabilities diagnosed until they were adults. While directly comparable data is not available, the rate of disability in children and young

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[11] Government of South Australia Department for Child Protection, 'Types of foster care' (Information Guide, undated) <https://www.childprotection.sa.gov.au/children-care/become-foster-carer/types-of-foster-care>.

[12] Richards S, *InDaily*, 'Disability rate among children in care a travesty' (Article, 25 June 2019) <https://indaily.com.au/news/2019/06/25/disability-rate-among-children-in-care-a-travesty/>.

[13] Ibid.

[14] Nankervis N, Rosewarne A & M Vassos, 'Why do families relinquish care? An investigation of the factors that lead to relinquishment into out-of-home respite care', *Journal of Intellectual Disability Research,* Vol 55 Part 4 pp 422–433, April 2011, p.428.

[15] Commonwealth of Australia Department of Social Services, *National Framework for Protecting Australia's Children 2021–2031* (Framework, 2021) p22-23.

[16] Disability Royal Commission Interim Report cited in Commonwealth of Australia Department of Social Services, *National Framework for Protecting Australia's Children 2021–2031* (Framework, 2021) p23.

people in the general population was 7.7% for the 0–14 age group and 9.3% for the 15–24 age group.[17]

Early experience of trauma is also a factor in the prevalence of disability among children in care. Without early intervention, these experiences can manifest as long-term mental health issues. These issues impact learning and can be prohibitive to children meeting developmental milestones at the same time as other children.[18]

'Beyond 18: The Longitudinal Study on Leaving Care', commissioned by the Victorian Department of Health and Human Services, found that for children in care '37% of those with a physical disability or chronic health issue and 57% of those with an intellectual disability or learning difficulty reporting that they had little or no support in living with these health issues'.[19]

C. AGEING OUT OF THE CARE SYSTEM

There is very little support for young people with disability ageing out of the care system making them especially vulnerable to harm, abuse, violence and exploitation.

At the age of 18, young people transition from a child to an adult within the Australian legal system. For most, this significant milestone is a cause for celebration. For young people within the care system, transitioning to adulthood is not necessarily something to celebrate. Research by the CREATE Foundation has found that around 30% of young people experience homelessness within a year of leaving state care.[20] Having a disability is another risk factor for homelessness. The Australian Institute of Health and Wellbeing cite lack of income, community supports and access to the labor market as reasons that people living with disability are at greater risk of homelessness.[21] Given these two intersecting determinants of homelessness, it is essential that support is established early on to improve outcomes for this vulnerable cohort of young people.

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[17] Commonwealth of Australia Department of Social Services, *National Framework for Protecting Australia's Children 2021–2031* (Framework, 2021).

[18] Richards S, *InDaily*, 'Disability rate among children in care a travesty' (Article, 25 June 2019) <https://indaily.com.au/news/2019/06/25/disability-rate-among-children-in-care-a-travesty/>.

[19] Muir, Purtell, Hand, & Carroll, Beyond 18: The Longitudinal Study on Leaving Care, 2019, accessed at https://aifs.gov.au/research/research-reports/beyond-18-longitudinal-study-leaving-care-wave-3-researchreport Cited in Child and Family Focus SA Submission to the CYP Review, p.54

[20] McDowall, J.J. (2018). Out-of-home care in Australia: Children and Young Peoples views after five years of National Standards. CREATE Foundation.

[21] Australian Institute of Health and Wellbeing, People with disability in Australia, (Web Report, 2022)

Even though there has been recent small grant funding for supports for young people up to 21, currently, most of the funded supports are provided to agencies servicing clients under 18 in the out-of-home care system.[22] The cessation of most supports at 18 is of great concern to ADAI.

In 2018 Deloitte Access Economics undertook a federal and state cost benefit analysis of extending the leaving care age to 21 years and found that the benefit to cost ratio was 2.0, indicating that every $1 spent on the program of supporting young people between the ages of 18 to 21 years would generate a return of $2.[23] It is not only our right and obligation to support children and young people transition from out-of-home care effectively, it is good economic policy.

In November 2022 the Office of the Guardian for Children and Young People released the report 'Lived experience voices: insights into young people's transition from the child protection and youth justice system in South Australia and the intersections with homelessness' written by the Constellation project.[24] The report echoes ADAI's findings, that 'many young people do not feel prepared or ready to transition from care or youth justice to independent living on the mandated date (their 18th birthday)' and that a lack of basic independent living skills (such as budgeting, looking after a home and cooking), support, housing availability and awareness of accessible services were key concerns'.[25]

Some young people with disability will need extra support when transitioning from out-of-home care, and the lack of support can make them vulnerable to abuse, neglect, violence and exploitation.

Leaving Care Plan

The DCP is meant to ensure that young people are supported to plan their preparations to leave care from the age of 15.[26] This process can be assisted by the use of a Leaving Care Plan. The CREATE Foundation has developed a Leaving Care Plan, or 'Go Your Own Way kit' for young

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[22] Child and Family Focus SA, *Submission to the 2022 Review of the Children and Young People (Safety) Act 2017*, November 2022, p55.

[23] Deloitte Access Economics, 'A federal and state cost benefit analysis: Extending care to 21 years', Home Stretch Campaign, Anglicare Victoria (2018).

[24] The Constellation Project, Lived experience voices: insights into young people's transition from the child protection and youth justice system in South Australia and the intersections with homelessness, November 2022.

[25] Office of the Guardian for Children and Young People, 'Young people want more support when transitioning from care and youth justice' (Media Release, December 7 2022) <https://gcyp.sa.gov.au/2022/12/07/young-people-want-more-support-when-transitioning-from-care-and-youth-justice/>.

[26] Government of South Australia Department for Child Protection, 'Leaving Care' (Information Guide, Undated) <https://www.childprotection.sa.gov.au/children-care/support-children-care/leaving-care>.

people as a planning tool and resources folder to help them prepare for their transition from care to independent living.[27] Alarmingly, 67% of children in care over the age of 15 are unaware of a leaving care plan.[28] ADAI rarely see clients with a leaving care plan. When asked, clients are unsure of what this document is. This oversight could be in part due to the high turnover of case workers within the Department, however, this cannot be used as an excuse. McDowall (2020) states that 35% of children in care have more than five case workers across the time that they are in care.[29] This lack of consistency among case workers could well be contributing to the gaps in procedures.

In addition to housing and accommodation issues, some care-leavers living with disability have the added complication of navigating the NDIS. While researching this submission, ADAI spoke with post-care providers, employees of DCP and the Office of the Guardian of Young People. Every organisation stated that the standard practice of DCP and post-care service providers is to refer care-leavers with disabilities to the NDIS. It is unclear what this referral process is, it could be merely the provision of information about the benefits of applying for the NDIS. While some clients come to ADAI with NDIS plans, they are rarely adequate and most often the client does not understand what their Plan is for or how to use it. An advocate will work with them to build their awareness and capacity to use their Plan.

Accessing the NDIS has become increasingly difficult with applicants required to provide extensive evidence of their disability and how it impacts their day-to-day living. Getting the required evidence requires doctors' appointments, referrals and often a lot of back and forth with doctors and specialists. This is not only time-consuming but potentially very costly.

While children are in care, there is often a lack of support to access appropriate and consistent therapeutic support. This consistency is required for building a base of evidence to submit for a claim. Many of the required therapeutic support providers have long wait lists, creating a further barrier to access.

Unfortunately, due to inconsistent placements and a lack of communication between departments, especially Education, NDIA, and DCP, ADAI see some young people who have been undiagnosed when they have left care, with their disability requiring intensive supports, often in a crisis situation.

Going through the transition of care to independent living creates additional stress. This stress is increased exponentially if the NDIS Access application is denied and becomes subject to a

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[27] Leaving Care' <https://www.childprotection.sa.gov.au/children-care/support-children-care/leaving-care>. Undated

[28] McDowall, J.J. (2018). Out-of-home care in Australia: Children and Young Peoples views after five years of National Standards. CREATE Foundation.

[29] Ibid.

Tribunal appeal process. The legalistic and bureaucratic process of the Administrative Appeals Tribunal is exhausting, time-consuming and intimidating as acknowledged by ADAI clients.

For young people leaving care, this stress is compounded by the intersection of disability and a history of being under guardianship. The attached case study, "Sally" provides a stark example of the way that the NDIS can present as a hostile opponent, as opposed to a supportive body.

What is missing from Sally's experience is communication between the Department for Education, the Department for Child Protection, and the NDIA to ensure that Sally had spoken to a support person about her plans post-school, and to ensure that funded supports for Sally would be available once she finished school. Sally did not have these supports, and now at 19 she is still without a job, even though she wants to work.

D. SUPPORTS AVAILABLE

There are very few supports available for young people leaving care, and the system is hard to navigate.

In 2016 the Nyland Report was published, which was the final report of the Child Protection Systems Royal Commission. The Child Protection Systems Royal Commission conducted a comprehensive investigation into the laws, policies, practices and structures in place for children at risk of harm, including those who were under guardianship of the minister.[30]

Chapter 14 of the Nyland Report[31] explores the experiences of young people leaving care and looks at the supports that have been provided for care leavers.

This Chapter of the Nyland Report explains the relationship between the Department of Child Protection (named as Families SA in the report) and Elm Place, an initiative of Relationships Australia SA (RASA), who are contracted by DCP to provide services to care leavers. This project as well as other services like it are desperately underfunded to support the needs of the young people who require the service.[32] Prior to undertaking research for this submission, ADAI staff

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[30] Department for Child Protection, 'Child Protection Systems (Information Guide, Undated) <https://www.childprotection.sa.gov.au/child-protection-initiatives/system-reform/child-protection-systems-royal-commission>.

[31] Commissioner Nyland, Child Protection Systems Royal Commission Report: The Life they Deserve (Report, 2016)

[32] Ibid

were unaware of this program due to lack of marketing and awareness. The referral process from DCP is also inconsistent and unclear.

The then South Australian Government released a report addressing the recommendations of the Nyland Report and made a number of commitments to uphold the recommendations around ongoing support for care leavers, including increasing the length of time that support is offered up to age 25, providing ongoing financial support to foster and kinship carers who offer continuity of care to young people after they turn 18, specifically if they are engaged in tertiary education or any post-school training as well as funding for Housing SA to develop specific housing models to support care leavers.[33] As helpful as these recommendations are for the broader cohort of young people leaving care, the recommendations and supports that specifically support care leavers with disability are lacking.

Unfortunately, despite the numerous recommendations within the Nyland report, many of them have not been implemented. The Minister for Child Protection has launched an independent investigation into these recommendations and the lack of implementation.[34]

As of 2022 the DCP have partnered with Centacare, Housing Choices SA and Aboriginal Sobriety Group to fund a pilot program called "Next Steps" which offers wrap around support for care leavers in residential care who have complex needs.[35] These complex needs are assessed using a standardised tool – The Complex Assessment Tool (CAT) and range between 1 (significant) and 4 (extreme).[36] Participants of the program need to sit at a level 3 or 4, to be considered for the program. While this program has great promise, unfortunately, it only has funding to support up to 20 young people. In addition, while the CAT may factor in disability as an element of complexity, the program isn't specifically designed to cater for young people with disabilities.

Within the Department for Education the National Disability Coordination Officer Program (NDCO) works strategically to assist people with disability to access and participate in tertiary education and subsequent employment' by providing funding to host provider organisations (universities, TAFEs, not-for-profit community organisations and employment and training service providers).[37] ADAI believe that the NDCO program could have space within it to advocate

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[33] Government of South Australia Attorney-General's Department, 'A fresh start: the Government of South Australia's Response to the Child Protection Systems Royal Commission Report, *The life they deserve*' (2016), p26.

[34] Richards S, *InDaily*, 'Disability rate among children in care a travesty' (Article, 25 June 2019) <https://indaily.com.au/news/2019/06/25/disability-rate-among-children-in-care-a-travesty/>.

[35] Department for Child Protection, Next Steps program receiving referrals (Media Release, 1 March 2022) <https://www.childprotection.sa.gov.au/service-providers/news-and-events/next-steps-program-receiving-referrals>.

[36] Ibid

[37] Department for Education, 'National Disability Coordination Officer Program' (Information Guide, 27 November 2020) <https://www.education.gov.au/access-and-participation/ndco>.

for the needs of students and young people who are transitioning from out-of-home care and need support to engage with further education, employment and training.

One safeguarding mechanism that is available to assess risks and gather the input of young people in their care arrangements is the Child and Young Person's Visitor. The Act states that the Minister 'may' establish a Child and Young Person's Visitor, ADAI recommend that this should be 'must establish' and 'must make available' a Child and Young Person's Visitor.[38]

After being unfunded for a period of nearly a year, ADAI are pleased to see that four years of funding has allocated to reinstate the Visitor role and scheme in August 2022. This scheme should be continued and expanded to ensure there is no unmet demand.

E. FAMILY BASED CARE TO INDIVIDUAL SUPPORTED LIVING ARRANGEMENTS

In or around early 2020 ADAI began to receive enquiries from long-term foster carers for adults and young people with disabilities who had been informed that they would no longer receive an allowance to cover the costs of the foster care arrangement. ADAI believe that around this time a revision of the funding arrangements was made and it was determined that under s29(5) of the Guardianship and Administration Act 1993 (Guardianship Act) that people who care for, and are guardians for, protected persons cannot be paid. This was interpreted as renumerated in any way, as a foster carer allowance is usually deemed a tax-free reimbursement for costs incurred. Families were told to choose, Guardianship or Allowance. A number of carers rang ADAI for advice and we referred them to the Legal Services Commission for legal advice.

Families have been told to choose either:

1. To provide unpaid care, or
2. Have the young person move to an independent living placement and become a paid support worker for them - but not if they maintain any supported or substituted decision making role including as guardian.

In South Australia a program named 'Homelink program' is available through Uniting Communities and provides out-of-home based care for children, young people and adults with intellectual disabilities and autism spectrum disorders. Care is provided on a respite, shared care,

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[38] *Children and Young People's Safety Act 2017* (SA) s117.

or full-time basis. Due to the NDIA legislation and the current interpretation of the Guardianship Act, care providers through the Homelink Program are prevented from receiving payment for the support they provide.

The NDIA takes a similar view and will provide no funding to foster carers for people with disabilities who have maintained an out-of-home care relationship with their foster family. The NDIA has taken a strict 'conflict of interest' approach, but does not appear to have considered the wishes or best interests of the young person, and does not have any risk assessment protocols they can refer to determine what conflict exists and how to mitigate it to maintain the health and safety of the young person. The NDIA are concerned that there is a conflict of interest if in-home carers receive reimbursement. As the only aspect that has changed in the relationship between young and their foster carer/s is the young person's age, it is difficult to see the rush to exit the families from the formal care program and the allowances associated with that arrangement.

ADAI advocates have asked for what risk assessment or conflict of interest assessment tools the NDIA utilize, and have been told they do not exist. ADAI Advocates questioned NDIA Lawyers about this issue and asked whether there were any Risk Assessment documents the NDIA possessed that could be used by the NDIA in their assessments to ensure that there was no conflict, or to ensure the young person's wishes were being considered and were told there were no such documents. The NDIA is concerned about conflicts of interest but has no assessment documents to point to or procedures to conduct a risk assessment with.

Several of ADAI's clients are young people who feel safe and supported in their out-of-home care arrangement and want it to continue. Some of them have not yet developed the necessary independent living skills, or are unwilling to move out of their home yet. Some of them were not provided with opportunities to practice their independent living skills in previous placements and are just beginning to gain confidence and build allies.

Article 3 of the UNCPRD – General Principles – states that:

> *The principles of the present Convention shall be:*
>
> *Respect for inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of persons;*[39]

Young people with disability should be able to choose where they want to live, and have this choice respected and supported. The choice to stay in their out-of-home arrangement is viewed with skepticism by the NDIA, but there are no safeguarding measures or protocols to determine

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[39] UN General Assembly, *Convention on the Rights of Persons with Disabilities*: resolution / adopted by the General Assembly, 24 January 2007, A/RES/61/106, Article 3.

whether a young people is at risk of exploitation through the continuation of this arrangement. The NDIA is not respecting the wishes of these young people or providing a safe and effective pathway for them to follow. If the NDIA remains concerned about the conflict of interest and risks to the participant there are many supported decision-making tools available to utilize to ensure that the young person has their wishes and needs appropriately considered, and to make an assessment that this accommodation is safe.

ADAI look forward to the forthcoming 'Guidelines on Deinstitutionalization, including in emergencies', as issued by the *United Nations Committee on the Rights of Persons with Disabilities* which are currently in draft.[40] The Guideline is intended to guide and support States parties, 'in their efforts to realize the right of persons with disabilities to live independently and be included in the community, and to be the basis for planning deinstitutionalization processes and prevention of institutionalization'.[41] The Draft Guidelines provide 'clarification that the creation of new segregated services, such as small group homes or sheltered workshops, should be prevented during the deinstitutionalization process and that they do not constitute community-based services.'[42] ADAI support this move as it has concerns about NDIA's preference to fund supported independent living options for young people, but not out-of-home care. Many of ADAI's client who are currently preferring to live in out-of-home care, unfunded, would only be eligible under the NDIA's assessment guidelines for a shared living arrangement. ADAI look forward to the forthcoming Guidelines providing further support to end small group home arrangements.

Alternatives to the NDIA

ADAI understand that the NDIS is not meant to be the sole source of supports for people with disabilities. Previously in South Australia, people with disabilities in out-of-home foster placements were supported through Disability SA, which no longer exists in that form. Support for people with disabilities in South Australia is only provided through the now Department of Health Services to NDIS participants and pre-existing customers. Carers SA is funded to provide unpaid support to family or friends with disability, age-related frailty or chronic illness. This is mainly information, advice and resources. The South Australian government website provides three options for carers seeking financial support, a link to the Services SA website, an application

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[40] Committee on the Rights of Persons with Disabilities, 'CRPD/C/5: Guidelines on deinstitutionalization, including in emergencies (2022)', 9 September 2022, p1.

[41] Ibid.

[42] Queensland Advocacy for Inclusion and People with Disability Australia, 'Draft Guidelines on Deinstitutionalization', (4 July 2022) p1.

for a companion card, and information about financial counselling.[43] ADAI would welcome more state-based disability support and services to fill in the existing gaps.

F. PREFERENCE TOWARDS FORMAL STATE GUARDIANSHIP

ADAI find that many young people with cognitive and intellectual disabilities are expected to be placed under formal state guardianship once they turn 18. In ADAI's experience one or more of the Departments (DCP or NDIA) will suggest a Guardianship Order, regardless of the needs or wishes of the young person.

There appears to be a belief by bureaucrats and lawyers within the government that young people with cognitive disabilities are 'safer' with formal guardianship in place. Many of the concerns we hear from Department employees are around whether the young person can consent to a NDIS plan, and whether they are of 'sound mind' to make a decision. This reductive type of thinking ignores the capacity of the young person, and diminishes their voice. In ADAI's experience the NDIA is more concerned about whether they have 'consent', over than the wishes and needs of a participant. There is extensive reporting about the use of supported decision making, further addressed in ADAI's Royal Commission Submission No.5 THE IMPORTANCE OF ADVOCACY IN THE REDUCTION OF VIOLENCE, ABUSE, NEGLECT AND EXPLOITATION OF PEOPLE WITH DISABILITY. ADAI's position is that formal guardianship through the Office of the Public Advocate does not reduce the risk of harm to the participant. ADAI many people who were subjected to harm while under Guardianship.

In South Australia you can procure an administrative order for guardianship where the guardian is only making decisions about the participant's NDIS plan, but the South Australian Civil and Administrative Tribunal (SACAT) often views these types of orders as unnecessary, unless the participant themselves is seeking one.

The over-legalization of the NDIS process also diminishes the voice of the participant and advocates find themselves having to repeatedly tell NDIA Lawyers and Case Managers to contact the participants themselves, rather than going through advocates who are there for support and information. There appears to be a preference to talk to an advocate or support coordinator, or therapist about a participant, than speak to a participant themselves. This preference is coming from NDIA Lawyers who are trained to communicate with applicant lawyers, not applicants themselves. Many do not have the skills to communicate with unrepresented clients and

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[43] Government of South Australia, 'Money Matters' (Information Guide, 14 August 2019) <https://www.sa.gov.au/topics/care-and-support/carers/money-matters>.

advocates spend much of their time translating legalese back into plain English. ADAI believe that the appeal process of a NDIA plan would be more efficient and productive without the NDIA having legal representation.

The NDIA needs to recognize supported decision making as a legitimate and useful process, and make changes to their procedural documents to enable its consistent use.

CASE STUDIES

CASE STUDY #1: SARAH – NO NDIA RISK ASSESSMENT, NO FRAUD IDENTIFICATION MECHANISM

Sarah was turning 17 turning 18 when she was transitioned out of DCP supports. At the time she was living with a foster parent, Vanessa, who identified that Sarah had a disability and organized for her to be assessed and diagnosed. Vanessa also helped Sarah apply for access to the NDIS. Vanessa had been receiving foster carer payments for having Sarah in her care, and when she was no longer eligible for those payments Vanessa transitioned to being a paid support worker, receiving an hourly payment.

Sarah did not have an experienced, registered support coordinator at the time. Because DCP has transitioned Sarah from their care they provided no further support or oversight. They were happy to leave Sarah in Vanessa's care. Vanessa charged for her support hours as she pleased and received payment through Sarah's NDIS plan.

When Sarah's plan was exhausted eight months early Vanessa kicked Sarah out. There were no mechanisms in place to protect Sarah. Sarah ended up living into a motel and experienced violence and abuse. Eventually Sarah was connected to an advocate who assisted her to apply for a Change of Circumstances for her NDIS Plan, referred her to some new support coordinator options and reported Vanessa to the NDIA Quality and Safeguards Commission.

CASE STUDY #2: ‘VALERIE AND SUSIE - GUARDIANSHIP FAILING AS A PROTECTIVE MEASURE

Valerie came to ADAI with concerns about her granddaughter Susie. Susie had been in out-of-home care since she was 16 and was living with a cognitive disability. From when she was 16-18 Susie was living in her own unit with supported independent living funding. Valerie had always been close with Susie and saw her often, although her own disabilities prevented her from caring for Susie in her own home. When Susie was 18 she was placed with a family and moved further away from Valerie and into the care of couple Laurie and Gary. This decision was made by the Public Advocate as Susie was also under guardianship by the Office of the Public Advocate (OPA).

From that time Valerie found it hard to contact Susie and when she did manage to see her, she thought she was different, less bubbly, nervous and more tired than usual. After a few years of minimal contact and continuing concerns Valerie contacted Susie’s guardian and requested an assessment and review of Susie’s placement. The OPA’s investigation included meeting with Susie once and speaking only to Laurie and Gary. Valerie believed the OPA considered her a ‘meddler’ and she did not feel that they treated her concerns seriously.

Valerie procured the assistance of an advocate to look into applying for a guardianship order which would ensure she had contact with Susie consistently, but this process was too difficult for Valerie with her ongoing health issues. Around a year later Susie was suddenly removed from Laurie and Gary’s care. Someone else had alerted the OPA to ongoing abuse and it was revealed that Susie had been medically restrained to make her more subdued and her behaviours more ‘’manageable’’ for many years. Her carers were charged with misuse of funds and ill-treatment of a vulnerable person. Susie had to be weaned off the strong medication. She began to see Valerie more regularly and now they enjoy a close relationship again. Susie is back in her own unit with support and is re-learning her out-of-home living skills again.

CASE STUDY #3: PATRICK - NO SUPPORT FOR LONG-TERM PLACEMENTS AND THE ENCOURAGEMENT OF INSTITUTIONALISATION

Patrick is a young person in his early 20's who has been living with his foster parents since he was around nine years old. Patrick has cerebral palsy and an intellectual disability. Jane and Brett have been providing long-term out-of-home care. When Patrick was turning 18 his foster mum Jane applied and was successful in obtaining guardianship for Patrick because they were worried about the Office of the Public Advocate obtaining guardianship. They had heard some scary stories from other foster families. Before Patrick turned 18 Jane and Brett received a foster carer payment through the Department for Child Protection of around $1200 a fortnight to cover Patrick's expenses. They also used some of their own money to make adjustments to their home and to take Patrick on holidays with them. Jane only worked part-time to enable her to provide care for Patrick and limit the number of support workers cycling through their home. When Patrick turned 18 the DCP transitioned him from their care. Jane and Brett stopped receiving any payments and were no longer receiving any family support, for example to organise respite that they used to access.

Jane tried to get information through the NDIA and she was told by a Local Area Coordinator (LAC) you can choose to be either his guardian or a paid carer, not both. This was even though Patrick's needs had not changed. Jane was now out of pocket for all of Patrick's from food, medical expenses and transport costs. Jane didn't want to take Patrick's Disability Support Pension because she considers that his money. She was unable to apply for Carers Payment through Services Australia as the family didn't meet the criteria. The LAC said they would be happy to help transition Patrick out of home and to an independent living facility and then Jane can register as a paid support worker. As Patrick was not eligible for 1:1 support due to his assessed needs this would be a shared living facility, which falls within the definition of an institution under the current CPRD. Jane was appalled by this suggestion and carers for Patrick in her home, with no reimbursement for her out of pocket costs.

CASE STUDY #4: SALLY – SPECIALIST SUPPORT ENDS AT 18

Sally is an 18-year-old woman who has an intellectual disability. She has been in the foster care system since she was a small child. In 2019, when Sally was 16, she was placed with Carolyn* as a specialist family based care placement through Life Without Barriers. Carolyn is an experienced specialist foster carer who also has another young adult with an intellectual disability living with her. After a few weeks, it was decided between Sally, Carolyn and LWB that Sally would stay in Carolyn's care permanently. Carolyn was funded to support Sally through the foster care wage system administrated by the DCP. Carolyn was reimbursed for the known day -to-day costs of caring for a child or young person.

As Sally approached her 18th birthday, the Department for Child Protection (DCP) suggested putting a guardianship order in place. As Sally had been under the guardianship of the department since early childhood, she refused this suggestion, citing that she wanted to be responsible for making her own choices in life. Sally is vehemently against this. The decision to apply to put Sally under guardianship appears to be procedural, rather than specific to her needs based on any assessment done by DCP.

Leading up to her 18th birthday, Sally's NDIS plan was reviewed, and included an assessment of her capacity for independent living. This assessment concluded that Sally didn't have the capacity for independent living and Carolyn agreed to continue caring for her. During this review, Carolyn and Sally requested independent living option (ILO) supports and supported employment funding to be included in the next NDIS plan. Both of these supports were refused. With Carolyn's assistance, Sally applied put in a request for review of the decision with the NDIA, however the decision remained and the supports were still denied.

When she turned 18, Sally and Carolyn described a sudden drop in any form of support from the Department of Child Protection. While the DCP has a process in place to identify and provide support to children with intellectual disability who are leaving care, this process relies on communication between multiple services, which in many cases, is not occurring (Caudrey, 2021). As Sally was exited from the DCP out-of-home care system Carolyn's foster carer payments were also stopped. She was told she would be able to now receive funding through the NDIS. This was not the case and while the costs for caring for Sally in her home have only increased, Carolyn is no longer funded. The DCP and NDIS have been quite happy to leave Sally to live at Carolyn's house while she is willing to stay there.

Day to day, Sally faces a number of challenges. She struggles to retain instructions, has low literacy and numeracy skills and struggles with judgement and emotional regulation. Sally relies on Carolyn for direction and reassurance throughout the day as well as overnight. Carolyn requires Sally to do household tasks, and works with her to build her capacity to be independent. Due to her intellectual disability and difficulty with judgement, Sally is extremely vulnerable to exploitation. There have been at least three incidents where Sally has had money, possessions and identifying documents (such as her bank cards and Medicare cards) stolen from her by people who have knowingly and maliciously taken advantage of her vulnerability. During the AAT period Sally experienced severe exploitation. She met a man online who befriended her. She left Carolyn's home and met up with him. Within a few days he had taken all of her possessions to Cash Converters and left with the money. The NDIA Lawyer informed advocate that this matter was better dealt through the health system than through NDIS and did not know how further supports could prevent her from being exploited again.

In light of this vulnerability, Carolyn and Sally have requested further support funding from NDIS to keep Sally safe as well as support her to have some employment with a specialist employer such as Bedford Group or Barkuma. The funding for her most recent NDIS plan was exhausted well before the review date, suggesting that the funding level was insufficient for Sally's needs, however the NDIA has disputed the requested support funding and Sally's NDIS plan is now being processed through the Administrative Appeals Tribunal. The Occupational Therapist's report suggest Sally needs 16 hours of support a day. In discussions with the advocate the NDIA's lawyer stressed that there was no way Sally would get this amount of support as he didn't understand how more support would keep her safer.

The advocate had to explain how having a support worker around will allow Sally support in her decision making and ensures that she is not alone with strangers when she is vulnerable. The NDIA lawyer did not know this was how a support worker could work.

The NDIA also wanted an enormous amount of information on top of what had already been provided to the Tribunal to justify four hours of support a day. The NDIA asked for each day of the week to be broken down into 15 minute intervals, detailing what Sally does every 15 minutes.

The NDIA is also suggesting that there is a conflict of interest as Carolyn is a registered NDIS provider and stands to gain financially from Sally's support being increased. NDIS have also made suggestions of a guardianship order. There has been no appreciation of the work Carolyn has done with Sally, or support from the DCP to allow her to stay in her home. The NDIA repeatedly refer to Carolyn as Sally's informal support, and emphasise the need for everyone to have unpaid, informal supports.

Sally and Carolyn both feel that DCP and the NDIS have let them down. They feel that the NDIS hasn't listened to and understood their needs. Carolyn is feeling burned out from providing full-time care for a young person who has very high needs, with absolutely no financial compensation or respite.