



**Advocacy** for  
**Disability**  
**Access** and  
**Inclusion** Inc.

# THE IMPORTANCE OF ADVOCACY IN THE REDUCTION OF VIOLENCE, ABUSE, NEGLECT AND EXPLOITATION OF PEOPLE WITH DISABILITY

Submission No.5 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

Authored by Senior Advocate Alexandra Turnbull and the ADAI Royal Commission Advocacy  
Team

47 Tynte Street North Adelaide, South Australia, SA 5006 Phone (08) 8340 4450  
Country Callers 1800 856 464 [www.advocacyfordisability.org.au](http://www.advocacyfordisability.org.au)  
[admin@advocacyfordisability.org.au](mailto:admin@advocacyfordisability.org.au) ABN 14 743 342 196

## ABOUT ADAI

Advocacy for Disability Access and Inclusion (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 Royal Commission. 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.

**Address:** 47 Tynte Street  
North Adelaide, South  
Australia, SA 5006

**Phone:** (08) 8340 4450

**Country Callers:** 1800 856 464

**Website:**  
[www.advocacyfordisability.org](http://www.advocacyfordisability.org.au)  
[.au](http://www.advocacyfordisability.org.au)

**Email:**  
admin@advocacyfordisability.  
org.au

**ABN:** 14 743 342 196

## Contents

ABOUT ADAI .....	1
INTRODUCTION.....	3
ADAI RECOMMENDATIONS.....	6
GENERAL RECOMMENDATIONS .....	6
ADAI RECOMMENDATIONS – FROM SUBMISSION NO.2 EDUCATION: SYSTEMIC NEGLECT OF STUDENTS WITH DISABILITY .....	11
ADAI RECOMMENDATIONS – FROM SUBMISSION NO.3 GAPS IN POST-CARE SUPPORT FOR YOUNG PEOPLE WITH DISABILITIES AGEING OUT OF THE CHILD PROTECTION SYSTEM .....	13
ADAI RECOMMENDATIONS - FROM SUBMISSION NO.4 CAPABILITY AND CULTURE OF THE NDIA .....	14
THE LEGAL AND POLICY FRAMEWORK OF ADVOCACY .....	16
PART 1: PREVENTING AND PROTECTING - Advocacy and Improved Outcomes for clients.....	18
A. WHAT IS ADVOCACY AND HOW IS IT FUNDED? .....	18
B. HOW DOES ADVOCACY PREVENT AND PROTECT PEOPLE FROM HARM? .....	20
I. Advocacy through Education and Awareness.....	22
II. By Building Confidence and Capacity.....	23
III. By Identifying and Reporting Risks.....	24
IV. By Advocating for Inclusivity and Accessibility .....	26
PART 2: ACCESSING, NAVIGATING, REPORTING .....	27
Storytelling and complaint mechanisms.....	28
A. Advocating across Departments and State and Federal Systems.....	29
B. Advocating in private systems .....	30
C. Advocating through Public Systems.....	33
I. Education .....	34
II. Child Protection .....	35
III. The National Disability Insurance Scheme.....	39
IV. Centrelink and the Disability Support Pension .....	48
V. Housing .....	50
VI. Guardianship and Public Administration .....	55
VII. Health.....	58
VIII. Justice.....	60
PART 4: REMOVE THE BARRIERS.....	63
A. Increase Access to Supported Decision Making .....	63
B. More Advocacy for Rural and Regional South Australia .....	65
C. Increase Funding for Legal Services.....	69
PART 5: CONCLUSION – Clients in crisis and advocacy at capacity.....	71
A. People with disabilities in poverty.....	71
B. Increasingly complex issues and clients in crisis.....	72

## INTRODUCTION

The Advocacy for Disability Access and Inclusion Inc. SA (ADAI) submission to the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability (the Royal Commission) is focused on the provision of advocacy to uphold the rights and ensure the safety of people with disabilities. This submission has been informed by the knowledge and experience of ADAI advocates.

The focus of this submission is on the provision of advocacy to people with disability and its role in the prevention and protection of people with disabilities from experiencing violence, abuse, neglect and exploitation. This submission provides a small snapshot of the work undertaken by ADAI advocates and outlines some of the issues advocates have identified.

The 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; and
- b. Achieve best practice in reporting, investigating and responding to violence, abuse, neglect and exploitation of people with disability; and
- c. Promote a more inclusive society that supports people with disability to be independent and live free from violence, abuse, neglect and exploitation.<sup>1</sup>

This submission discusses some of the issues advocates manage as relating to the terms of reference of the Royal Commission.

We have focused on three areas of discussion. This submission outlines the important work of advocates in:

1. Preventing and protecting people with disability from experiencing violence, abuse, neglect and exploitation; and
2. Assisting people with disabilities to access and navigate services and utilise complaint mechanisms to report abuse, neglect, violence and exploitation ensuring these reports are investigated and responded to; and
3. Promoting a more inclusive society.

---

<sup>1</sup> Commonwealth Letters Patent constituting the Disability Royal Commission, issued on 4 April 2019.

This report acknowledges that not all people with disability are at a greater risk of harm, but that having a disability can be a risk factor to experiencing harm. This report also acknowledges that some particularly marginalised groups in the community are known to be at higher risk of violence, abuse, neglect and exploitation, and face additional barriers to accessing services.<sup>2</sup>

These include:

- people with intellectual disability;
- people with complex communication support needs;
- women;
- Aboriginal and Torres Strait Islander people;
- people from culturally and linguistically diverse (CALD) communities;
- LGBTQIA+ people;
- children and young people;
- people with disability with no informal support networks; and
- people in closed settings (segregated environments, prison, family or other domestic contexts and residential arrangements).

ADAI have seen a recent steady increase in the demand for advocacy, the complexity of client needs and the heightened risks of violence, abuse, neglect and exploitation. This submission calls for more funding for independent advocacy and for federal, state and territory governments to work collaboratively to establish comprehensive and consistent funding and reporting arrangements. ADAI call for all Australians with disability to have access to independent advocacy to eliminate their risks of violence, abuse, neglect and exploitation.

This submission includes several de-identified case studies which elucidate the discussion of the below issues. The aim of this submission is to provide evidence for the highly necessary work of advocacy to ensure its continued funding.

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.

---

<sup>2</sup> Multiple sources as cited in Disability Advocacy Network Australia, Submission to the Disability Royal Commission into Violence, Abuse, Neglect and Exploitation: Independent Disability Advocacy, *Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability* (December 2022).

*Note: all persons and identifying details referred to in this submission have been de-identified.*

ADAI has prepared the following submission to the Royal Commission into violence, abuse, neglect, and exploitation of people with disability which can be read in conjunction with this report. They are:

**Submission No.1**

*The Guardianship and Administration Act 1993: The case for free legal representation*

**Submission No. 2**

*Education: Systemic neglect of students with disability*

**Submission No. 2a**

*Education: Restricted Submission*

**Submission No.3**

*Gaps in post-care support for young people with disabilities ageing out of the child protection system*

**Submission No.4**

*Culture and Capability of the NDIA*

## ADAI RECOMMENDATIONS

### GENERAL RECOMMENDATIONS

1. Increase funding for independent advocacy.
2. Require the South Australian Government to fund independent advocacy.
3. Require federal, state and territory governments to work collaboratively to establish comprehensive and consistent funding and reporting arrangements for independent advocacy.
4. Ensure funding for independent advocacy is provided in minimum three-year funding cycles
5. Ensure all people with disabilities have access to independent advocacy.
6. Increase funding for systemic advocacy.

### Rights Awareness

7. The Disability Discrimination Commissioner must prepare and promote own Annual Report.

### Complaint Mechanisms

8. Implement a single door model for complaint reporting.
9. Duplicate the Care Finder model for vulnerable people with disabilities.
10. Fund independent advocates to provide ongoing support for storytelling.

### Child Protection

11. Ensure all parents and young people within the Child Protection system have access to early intervention supports.
12. Ensure all parents, children and young people are made aware of advocacy services.
13. Provide supported decision making for all young people and end the assumption that young people in care lack capacity.

#### National Disability Insurance Scheme

14. Require the NDIA to recognise the need for 'respite' and the importance of supporting a family unit.
15. Require the NDIA to ask for the specific evidence they require from a health professional preparing a report for the NDIA.
16. Improve the NDIA's regulation of health professionals who prepare fee-for-service NDIS reports.

#### Disability Support Pension (DSP)

17. Remove the barriers to access the DSP, especially for clients with psychosocial disabilities.
18. Implement a universal DSP access evidence form for use by General Practitioners and health professionals.

#### Housing

19. The South Australian Housing Authority (SAHA) must include a response to the measurable targets in the *Disability Inclusion Action Plan* in their Annual Report.



20. Increase substantive professional development for all SAHA staff to gain more awareness and understanding of disability.
21. Require SAHA to publish clear and accessible policies and procedures.
22. Review and re-draft the South Australian Civil & Administrative Tribunal Act 2013 to ensure its aims can be fulfilled.

### Guardianship and Public Administration

23. Ensure that for all Office of the Public Advocate (OPA) clients, where the OPA has decision making power regarding their NDIS Plan, the Plan must be made in collaboration with the client.
24. Require the OPA and the Public Trustee to have:
  - a. a positive duty to act in the best interests of their client, and when that duty is failed; and
  - b. ensure there is a clear pathway to ensure the accountability of the OPA and Public Trustee actions and clear complaint mechanisms.
25. Require the OPA and the Public Trustee to meet with and communicate with every client.
26. Ensure there is a positive duty for public authorities to seek supported decision-making for their clients where necessary.
27. Free legal representation is available as of right to persons facing applications for a Guardianship Order and/or an Administration Order
28. Section 65 of the *Guardianship and Administration Act 1993* should be amended to read:

*(1) Where in any proceedings before the Tribunal commenced under this Act a person in respect of whom a guardianship or administration order is in force or a person in respect of whom an application is made chooses to be represented pursuant to this section, he or she is entitled to be represented by a legal practitioner provided pursuant to a scheme established by the Minister for the purposes of this section, being a legal practitioner*

## Health

29. Ensure Universities take responsibility for relevant and appropriate training to enable newly qualified doctors and other health staff to have an excellent understanding of the diversity of people with disability.
30. Recognise and address the power imbalance within the health system that can lead to poor health outcomes and misdiagnosis.

## Justice

31. Fund and promote advocacy services to ensure people with disabilities can seek support when they are required to go to a SAPOL station, and assist them to communicate with police officers.
32. Increase substantive professional development and training for all SAPOL staff to gain better awareness and understanding of disability.

## Rural and Regional

33. Fund independent advocacy to provide high quality advocacy services in rural and regional areas, on par with metropolitan services.

## Supporting Vulnerable Clients

34. Recognise and rectify the gendered care load in all disability related systems and provide further support for women.

35. Increase funding for community legal services.
36. Lift the JobSeeker and Disability Support Pension (DSP) payment amounts so no people with disabilities are living in poverty.
37. Governments must identify gaps in disability service provision and provide resources to close those gaps.

## ADAI RECOMMENDATIONS – FROM SUBMISSION NO.2 EDUCATION: SYSTEMIC NEGLECT OF STUDENTS WITH DISABILITY

1. Increase professional development for all school staff to gain more awareness and understanding of disability.
2. Develop best practice strategies to deal with behavioural complexities that can present in students with disability, especially autism.
3. All universities must take responsibility for relevant and appropriate training to enable newly qualified teachers to be able to provide a good understanding of the diverse levels of abilities in the classroom.
4. Abolition of external suspensions and expulsions.
5. Require schools to provide meaningful and appropriate learning supports and education whilst a student is on suspension or exclusion from school.
6. The Department for Education appropriately investigate complaints made by guardians, parents and students regarding suspensions, exclusions and exemptions in a serious manner and must not revert to the school investigating themselves.
7. One Plans to be implemented within the first four weeks of a new school year and reviewed each term.
8. All One Plans to be created using the partnership approach.
9. Increase the use of Transition Plans and include teacher change overs, new school years, primary to high school and new school transfers.
10. Improved collaboration and accountability of the school when a child is enrolled at the school and is participating in Flexible Learning Options (FLO).
11. Department for Education oversight when a school is using suspensions and expulsions to manage the behaviors of students with disabilities.
12. Inclusive Education Support program (IESP) (disability funding for students and children) applications to take less time to process. For example, the IESP Panel meeting more often.

13. Advocate services are made known to parents and carers for advocacy support when a child is suspended or excluded from school.
14. Capture data regarding students with disabilities and the number of suspensions, expulsions, and school withdrawals.
15. Enable all schools to value the contribution and diversity that students with disability bring.
16. Capture and consider data with common themes, for example where multiple complaints have been made about a single school/member of staff.
17. Listen to and value the voice of the child.

## ADAI RECOMMENDATIONS – FROM SUBMISSION NO.3 GAPS IN POST-CARE SUPPORT FOR YOUNG PEOPLE WITH DISABILITIES AGEING OUT OF THE CHILD PROTECTION SYSTEM

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.

## ADAI RECOMMENDATIONS - FROM SUBMISSION NO.4 CAPABILITY AND CULTURE OF THE NDIA

1. Enable Local Area Coordinators to provide more extensive and personalised assistance.
2. Increase funding to ensure LACs are available in all rural and remote regions to enable adequate service provision.
3. Ensure all NDIA procedures and policies promote a client focussed scheme.
4. Require mandatory involvement of participants in all decisions related to planning.
5. Increase funding for legal advice and representation for NDIS Appeals applicants within the AAT.
6. Increase funding for advocacy for applicants in the AAT.
7. Implement mandatory training for NDIA staff and legal representatives specifically focusing on appropriate interaction with unrepresented litigants and their advocates.
8. Implement a requirement that all NDIA staff and consultants must have experience working with people with disability, or have lived experience of disability, or have the ability to gain the knowledge and competence required to work with people with disability.
9. Implement procedures that enable the NDIA Community Engagement Team to resolve local complaints.
10. Lengthen the period Complaints Officers can have complaints open for.
11. Enable Complaints Officers to address systemic issues that arise within individual complaints.

12. MOUs or other documentation to provide clarification regarding what supports each Department will fund.
  
13. Amend the delegations of NDIA Officers to enable decisions on client plans to be made by the case manager if within NDIA regulations.



## THE LEGAL AND POLICY FRAMEWORK OF ADVOCACY

Australia is a signatory to the United Nations, Convention on the Rights of Persons with Disabilities 2006 (UNCRPD) which prohibits discrimination against people with disability and describes the rights of persons with disabilities and the expectations to achieve and maintain these rights.<sup>3</sup> By ratifying the UNCRPD Australia has an obligation to protect, ensure and promote these rights.<sup>4</sup> Specifically, Article 16 of the UNCRPD, requires Australia as a signatory to ‘take all appropriate measures to prevent all forms of exploitation, violence and abuse’ against people with disability.<sup>5</sup> Australia must implement these obligations through legislation, policy and programs.

Australia has implemented the *Disability Discrimination Act 1992* (Cth) which aims to eliminate, as far as possible, discrimination against persons on the grounds of disability.<sup>6</sup> The Act also aims to ‘ensure, as far as practicable, that persons with disabilities have the same rights to equality before the law as the rest of the community’.<sup>7</sup> Unfortunately, the Object of the Act is limiting by the addition of ‘as far as possible’, and ‘as far as practicable’, which weakens any implementation of the legislation.

The Australian Human Rights Commission is an independent statutory organisation, established by an act of Federal Parliament. The Commission protects and promotes human rights and investigates and resolves complaints of discrimination and breaches of human rights. The Commission is a collegiate body made up of a President and seven Commissioners, including a Disability Discrimination Commissioner. The Disability Discrimination Commissioner also leads the implementation of the *Disability Discrimination Act 1992* (Cth).

The Commission prepares an Annual Report which sets out the performance of the Australian Human Rights Commission in each financial year. The Disability Discrimination Commissioner contributes to this report but does not produce their own report. Many of ADAI’s clients do not understand the role of the Commission or the Commissioner and ADAI rarely assist people to make complaints to the Commission. There is significant work the Commission and the Commissioner can do to make their work more widely known and accessible.

In South Australia the *Equal Opportunity Act 1984* (SA) prohibits discrimination on the grounds of disability and aims to ‘promote equality of opportunity between the citizens of

---

<sup>3</sup> UN General Assembly, *Convention on the Rights of Persons with Disabilities*, adopted by the General Assembly, 24 January 2007, A/RES/61/106 Preamble.

<sup>4</sup> *Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability* (Interim Report, October 2020) p 44.

<sup>5</sup> UN General Assembly, *Convention on the Rights of Persons with Disabilities*, adopted by the General Assembly, 24 January 2007, A/RES/61/106. Article 16.

<sup>6</sup> *Disability Discrimination Act 1992* (Cth) s3.

<sup>7</sup> *Ibid* s3(b).

this State; to prevent certain kinds of discrimination based on sex, race, disability, age or various other grounds; to facilitate the participation of citizens in the economic and social life of the community; and to deal with other related matters.<sup>8</sup>

Making a complaint under state or federal anti-discrimination law is complex and often requires a lawyer to make an assessment about which Act is best for the person to make a complaint under, based on the individual circumstances. ADAI advocates rarely assist clients to make complaints under either legislation as it is unnecessarily complex.

In South Australia the Office of the Commissioner for Equal Opportunity (OCEO) operates the Anti-Discrimination Register. When an individual makes a complaint through the register it sends an email directly to the business owner or operator, and reminds them of their obligations under the Equal Opportunity Act.<sup>9</sup>

Unfortunately, much of ADAI's experience in the area of anti-discrimination law in Australia has been centred around the gaps and involves clients deciding not to pursue anti-discrimination pathways or not being able to access legal funding to pursue these actions further.

---

<sup>8</sup> *Equal Opportunity Act 1984 (SA)* s66.

<sup>9</sup> Government of South Australia, *Equal Opportunity, 'Anti-Discrimination Register'* (Information Guide, 2021) <<https://www.equalopportunity.sa.gov.au/rights/anti-discrimination-register>>.

## PART 1: PREVENTING AND PROTECTING - Advocacy and Improved Outcomes for clients

Advocacy is a crucial safeguarding mechanism that reduces the risk of harm to people with disabilities. This submission will focus on the importance of independent advocacy, as undertaken by paid advocates. This form of advocacy is provided by Advocacy for Disability Access and Inclusion (ADAI). As a priority we must ensure access to advocacy is available for all those who need it. Without access to advocacy people with disabilities are at greater risk of violence, abuse, neglect and exploitation. Effective disability advocacy promotes and protects the 'rights, interests and wellbeing of people with disability'.<sup>10</sup> Advocacy can do this in many ways, including by:

- Increasing the knowledge of the client; and
- Increasing the self-advocacy skills and confidence of the client to self-advocate; and
- Identifying risks and following pathways to ensure the vulnerable person is safe from harm.

It is well established, although not widely acknowledged, that advocacy acts as a safeguarding mechanism and results in improved outcomes for clients.

### A. WHAT IS ADVOCACY AND HOW IS IT FUNDED?

There is no set definition within the disability community for what an advocate or advocacy is. The *National Disability Insurance Scheme Act 2013* (Cth) (the NDIS Act) defines independent advocacy as a person who:

*(a) is independent of the Agency, the Commission and any NDIS providers providing supports or services to the person with disability; and*

*(b) provides independent advocacy for the person with disability, to assist the person with disability to exercise choice and control and to have their voice heard in matters that affect them; and*

*(c) acts at the direction of the person with disability, reflecting the person with disability's expressed wishes, will, preferences and rights; and*

*(d) is free of relevant conflicts of interest.<sup>11</sup>*

---

<sup>10</sup> Disability Advocacy Network Australia, 'Submission on the Draft National Disability Advocacy Framework', *National Disability Advocacy Framework 2022-2025 Consultation* (July 2022) p6.

<sup>11</sup> *National Disability Insurance Scheme Act 2013* (Cth) s9.

Advocacy is generally understood to be the promotion, protection and support of a person or group of person's full and equal human rights. Advocates work with or on behalf of a person with disability to help them to speak out and defend their rights and interests.<sup>12</sup> Advocates also work with families and support people with the informed consent of the person with disability.

A high proportion of ADAI clients and primary contacts for clients under 18 are women, often mothers. These women are either supporting their child or navigating their own matter. This is especially true in the area of education. ADAI recognise that women overwhelmingly bear the work of advocating and systems navigation. The gendered care load in all disability related systems is high. This must be addressed and rectified.

The ADAI advocacy model is underpinned by a human rights model. ADAI aims to walk alongside our clients and ensure their voices are heard. ADAI helps individuals and families to be involved in decision-making, and to collaborate with services to ensure people with disabilities attain their rights and secure opportunities to participate in all aspects of life.

There are six main models of advocacy. These include individual advocacy, citizen advocacy, legal advocacy, self-advocacy, family advocacy, and systemic advocacy.

ADAI provides:

1. Individual advocacy where the person with the issue is the client; and
2. Self-advocacy, where we support and mentor a client to advocate for themselves; and
3. Family advocacy where we work with the family to advocate for the family member; and
4. Systemic advocacy where we tackle issues that affect large populations of people.

ADAI are funded to provide individual advocacy (must be 90% of clients) and systemic advocacy (10% of issues) under the National Disability Advocacy Program through the Department of Social Services. This funding has historically been provided in single year funding cycles, limiting the provision of advocacy and restricting any long-term planning. ADAI are also funded to provide NDIS Appeals Advocacy for people appealing NDIS Plans through the Administrative Appeals Tribunal (AAT) and advocacy for clients engaging with the Royal Commission. This Royal Commission funding will end in June 2023.

The South Australian Government does not provide any funding for general advocacy. The previous Liberal governed State Government funded one project for legal support and advocacy for people to navigate the NDIS and appeal NDIS plans. This Uniting Communities Law Centre were successful in applying for this funding and received \$400,000 a year for three

---

<sup>12</sup> Disability Advocacy Network Australia, 'How to Advocate', (Information Guide, Undated) <<https://www.dana.org.au/how-to-advocate/>>.

years. The project started in December 2020. As of December 2022 ADAI have yet to have a single client referred into the program. They are constantly at capacity. The demand for NDIS Appeals advocacy has since increased from 55 clients in 2020 to 134 in 2022. The current state Labor Government have not announced any further funding for advocacy for South Australians.

Funding for disability advocacy is fragmented, inadequate and inconsistent and has not kept pace with increased demand, making advocacy organisations inadequately resourced to respond to all requests for advocacy.<sup>13</sup> Short funding cycles make it impossible for advocacy agencies to undertake long term strategic planning and develop effective organisational systems and supports. ADAI support Disability Advocacy Network of Australia's (DANA) argument that 'the current funding structure does not reflect the level and complexity of needs of individuals with disability nor requirements for advocacy organisation sustainability and efficiency'.<sup>14</sup>

The South Australian state government needs to fund advocacy for their local communities and coordinate with the federal government to streamline that funding.

## B. HOW DOES ADVOCACY PREVENT AND PROTECT PEOPLE FROM HARM?

Advocacy acts as a safeguarding mechanism. Effective independent advocacy helps to prevent and protect people with disability from experiencing violence, abuse, neglect and exploitation. Advocacy can also assist people with disabilities to report abuse, violence, neglect and exploitation. Systemic advocacy protects by leading change to ensure that populations of people are not at risk of abuse, violence, neglect and exploitation. Advocacy includes both preventative and protective functions.

The Royal Commission accepts that people with disabilities are at higher risk of harm.<sup>15</sup> A person is not at risk of harm just because they have a disability but having a disability can be a risk factor to experiencing harm.

---

<sup>13</sup> Disability Advocacy Network Australia, Submission to the Disability Royal Commission into Violence, Abuse, Neglect and Exploitation: Independent Disability Advocacy, *Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability* (December 2022) p12.

<sup>14</sup> Ibid p13.

<sup>15</sup> *Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability* (Interim Report, October 2020) p6.

Only when people with disabilities experience ‘full and effective participation and inclusion in society’<sup>16</sup> will Australia then fully achieve the goal of an inclusive society that supports the independence of people with disability and their right to live free from violence, abuse, neglect and exploitation.<sup>17</sup> In Australia, almost two-thirds of people with disability have experienced violence in their lifetime, and people with disability are twice as likely as people without disability to experience violence in a 12-month period.<sup>18</sup>

Advocacy acts as a safeguarding measure to protect people from harm. Safeguarding measures which can be undertaken by advocates include:

- Educating and spreading awareness to help people understand their rights.
- Improving the confidence and capacity of a person, increasing their ability to self-advocate.
- Identifying risks using their knowledge and understanding of the systems and drawing upon their experience to can make appropriate referrals and stop harm from occurring.
- Reporting risks of harm and actual harm.
- Identifying and driving systemic change.

The general principles guiding actions under the *National Disability Insurance Scheme Act 2013* state that:

*‘The role of advocacy in representing the interests of people with disability is to be acknowledged and respected, recognising that advocacy supports people with disability by:*

- (a) promoting their independence and social and economic participation; and*
- (b) promoting choice and control in the pursuit of their goals and the planning and delivery of their supports; and*
- (c) maximising independent lifestyles of people with disability and their full inclusion in the community’.*<sup>19</sup>

To adequately safeguard against harm people with disability must have access to free, accessible, independent advocacy. Advocacy has a high cost-benefit. For every dollar invested in independent advocacy agencies return \$3.50 in benefits.<sup>20</sup> Further funding for advocacy

---

<sup>16</sup> United Nations, *Convention on the Rights of Persons with Disabilities*, , opened for signature 30 March 2007, 999 UNTS 3 (entered into force 3 May 2008), art 3 (c).

<sup>17</sup> *Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability* (Interim Report, October 2020) pp xxi.

<sup>18</sup> Buckmaster L and Clark S, ‘The National Disability Insurance Scheme: a quick guide’, *Parliament of Australia, Department of Parliamentary Services*, (Research paper, 8 May 2019) pp1–2.

<sup>19</sup> *National Disability Insurance Scheme Act 2013* (Cth), s4(13).

<sup>20</sup> Daly A, Barrett G and Williams R, ‘A Cost Benefit Analysis of Australian independent disability advocacy agencies’ *Report commissioned by Disability Advocacy Network Australia* (August 2017).

services is required to ensure that advocates can maintain and increase their safeguarding supports. Advocates assist people to identify risks, eliminate harm, report abuse and build safe pathways away from exploitation. At ADAI our advocates walk alongside our clients to amplify their voices, assist them to navigate systems and access safe services.

## I. Advocacy through Education and Awareness

One barrier to the full and equal achievement of human rights is knowing what those rights are. Advocates assist through educating and generating awareness. They work with clients to ensure they understand what they are entitled to. The UNCPRD has placed an obligation on Australia to undertake awareness raising activities.

Article 8 of the UNCPRD states:

*1. States Parties undertake to adopt immediate, effective and appropriate measures:*

*a) To raise awareness throughout society, including at the family level, regarding persons with disabilities, and to foster respect for the rights and dignity of persons with disabilities;*

*AND*

*d) Promoting awareness-training programmes regarding persons with disabilities and the rights of persons with disabilities.* <sup>21</sup>

Increased education leads to an increased capacity to self-advocate. Self-advocacy is when people living with disability having the skills, opportunities and necessary supports to make decisions about their own lives.

A lack of awareness and information about the rights of people with disability can leave people more exposed to abuse and exploitation, and it is also a major barrier to people making a complaint or asserting their rights in other ways.<sup>22</sup> Article 8 of the UNCPRD requires the Government to ‘immediately’ adopt disability rights awareness measures that are ‘effective’.<sup>23</sup> Advocacy works to encourage people to understand their rights and teaches them how to realise them.

---

<sup>21</sup> UN General Assembly, *Convention on the Rights of Persons with Disabilities*, adopted by the General Assembly, 24 January 2007, A/RES/61/106, Article 8.

<sup>22</sup> The United Nations Human Rights Council quoted in PWDA, *Safeguards help marginalised people with disability*, ‘Submission to Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability’ (February 2021) p9.

<sup>23</sup> PWDA, *Safeguards help marginalised people with disability*, ‘Submission to Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability’ (February 2021) p8.

### CASE STUDY: MARK – ELIGIBILITY FOR THE DISABILITY SUPPORT PENSION

Mark was injured in a work accident ten years ago and has struggled to find consistent work since. He struggles to pay his bills and can't afford the physiotherapy he needs to manage his pain. He is thinking of applying for the Disability Support Pension but doesn't know if he is eligible. Mark meets with an ADAI advocate and brings in his medical reports for her to review. They discuss Mark's experiences and the advocate steps him through the criteria for the Disability Support Pension. She believes he is eligible, so she draws up a step-by-step plan for him to work through to build his application. Mark learns about the application process and understands how he falls within the access criteria. Mark takes the advocate's advice and gathers his reports and evidence and submits his application on his own.

## II. By Building Confidence and Capacity

Capacity building involves helping people build up their capacity to ensure they are safe.<sup>24</sup> Capacity building can reduce the risk of people with disability being exposed to violence, abuse, neglect and exploitation in the first instance and increases rights-awareness. Capacity building empowers people to feel confident by identifying and reporting risks and asserting their rights.

A barrier to the full and equal participation in society is not having the ability to ask for those rights to be upheld. Advocates work with clients to amplify their voices and to make them feel confident in their ability to self-advocate. An advocate might work with a client to put together a plan of action and practice with the client until they feel comfortable self-advocating.

People with Disabilities Australia (PWDA) describes the building of confidence and capacity as a developmental safeguard called personal capacity.<sup>25</sup> Extending personal capital can include boosting 'self-esteem, confidence, cognitive and intuitive capacity, the ability to self-advocate and be present, and inner strength and resilience'.<sup>26</sup> Building capacity enables people to achieve outcomes that promote their rights, health, safety and wellbeing.

With increased confidence people feel more capable of self-advocating. One of the ways advocates make people feel confident is by listening to them. With confidence people can navigate and access services and supports more independently and safely. People with

---

<sup>24</sup> PWDA, *Safeguards help marginalised people with disability*, 'Submission to the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability' (February 2021) p6.

<sup>25</sup> Ibid p7.

<sup>26</sup> Ibid.



Disabilities Western Australia surveyed their clients and when asked how people can maintain choice and control if safeguards are needed, respondents ‘overwhelmingly stated the importance of listening to the person with a disability and ensuring adequate independent supports such as advocacy are available’.<sup>27</sup>

One of the most common comments clients make to advocates is ‘this is the first time someone has taken the time to listen to me and believe me’. Clients feel reassured that their concerns are real. Feeling heard gives the confidence that if something happens again to them, or someone they know, they feel that they will be taken seriously when making a complaint.

Many clients of the Royal Commission advocacy team have reported feeling huge relief at being listened to when telling their stories. Listening to people makes systems feel more accessible, which makes them accessible. It breaks down the us/them barrier.

#### **CASE STUDY: ADAI CLIENTS - THANK YOU FOR LISTENING**

Glenda could not express more how grateful she was in finding ADAI services saying, ‘thank you for listening and supporting me. I don’t think I would be able to have done this on my own’.

Tina thanked the advocate for listening, the advocate recalled that Tina went away feeling more confident with her next steps.

Erin thanked the advocate for always listening to her.

Victor thanked the intake officer for listening after she heard his story and provided relevant referrals.

### **III. By Identifying and Reporting Risks**

Trained independent advocates can identify risks and escalate reports to any complaint mechanism. Advocates can identify signs of abuse and support clients in crisis. Advocates are trained to ask probing questions in safe and effective ways to identify underlying issues and determine whether a client may be at risk. When a prospective client or their support person contacts ADAI an Intake Officer will complete a Client Referral Form with them. This document will assist a Senior Advocate to determine whether a client has urgent needs. ADAI

---

<sup>27</sup> People with Disabilities WA, *Issues paper: Safeguards and quality*, ‘Submission to the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability’, (undated) p10.

utilises a Triage Procedure to determine whether a client requires more urgent advocacy assistance.

In most circumstances an advocate will meet with a client face to face for their first appointment and make a further assessment of their needs. This enables the advocate to see the client and allows a further assessment based on their presentation. Sometimes this means that the matter the client has requested advocacy for is no longer considered the primary concern. For example, an advocate may meet with a client who wants to apply for the Disability Support Pension and during their meeting when they are confirming the client's details on their Client Referral Form they discover that even though the client is living in rental accommodation they are not on the lease, but are instead sleeping on a couch at their friend's rental unit. This would provoke the advocate do a warm referral to *Homeless Connect SA* who can put the client in contact with a homelessness service. Other times a client may present with poor self-care and hygiene. An advocate can ask them what supports they are receiving and can recommend an application to increase their NDIS Plan funding, or connect them with local health services. An advocate will support a client through this process. Advocates can identify risks using their extensive system knowledge and make appropriate referrals. They can also assist clients to utilise complaint mechanisms and follow up reports.

#### **CASE STUDY: KATY – RISK ASSESSMENT AND GIVING A YOUNG WOMAN A VOICE**

Katy is a 16-year-old young person living in a small regional town in South Australia. She has foetal alcohol syndrome and has recently been absconding from her home. Katy's Local Area Coordinator (LAC) asked her support coordinator to refer her for advocacy assistance. They held concerns about Katy's education and housing situation. They were considering a request that she be placed under guardianship. Two advocates organised to meet with Katy and her father and step-mother in their home. The advocates drove down and met with the family and discussed with them separately and as a family what their plans and wishes were for Katy's future. The advocates used their informal and formal risk assessment tools and drafted a report for the support coordinator to share with any interested parties. The advocates put forward Katy's wishes and the wishes of her family, which were to stay together as a family unit and to receive more formal support and respite to ensure this occurs. They identified that recent acute issues had occurred due to a lack of formal support for the family unit and a need for more paid support workers as Katy's family were experiencing carer burnout. The advocates considered that Katy would be at a higher risk of harm if she was moved to independent living before she was supported to develop independent living skills. They did not consider that Katy being placed under guardianship was necessary. People had been making decisions for Katy and she appreciated being given an opportunity to be asked what she wanted and to give some reasons why. This report was considered when drafting her next NDIS plan and Katy's school and support coordinator sought out more specific supports for her.

#### IV. By Advocating for Inclusivity and Accessibility

Independent individual advocacy plays an important role both in both protecting the rights of individuals and ensuring systemic improvement. DANA's submission argues that:

*'By scrutinising and challenging the disability service system, advocacy adds to its accountability. Access to independent advocacy fosters greater wellbeing, autonomy and community participation of people with disability, and thereby strengthens safeguards against abuse, violence and exploitation.'*<sup>28</sup>

While advocates assist people to access services, and advocate for their individual inclusion disability advocacy is also about protecting and preventing through systemic advocacy, by ensuring that government policy and practice supports, benefits, and includes people with disabilities.

ADAI undertakes systemic advocacy, arguing for changes to systems, frameworks, legislation, and policy. By advocating for inclusion advocates are assisting in the creation of a society which fosters a culture of inclusion in 'which people with disability experience safety and fulfilment in their lives'.<sup>29</sup> Improving systemic inclusion operates as an early intervention and safeguarding mechanism particularly in respect of those people with disabilities who are at most risk of harm.<sup>30</sup>

The underlying aim of advocacy is enabling people with disability to 'take control of the direction and form of their lives to the same extent as is available to the general population'.<sup>31</sup> Improving inclusivity and accessibility benefits everyone.

When services are overstretched there is limited capacity to work towards identification and analysis of the systemic issues that impact people with disability and to take action to address these in coalition with others.<sup>32</sup> Further funding for systemic advocacy is required to address and resolve widespread systemic issues that affect people with disabilities.

---

<sup>28</sup> Disability Advocacy Network Australia, 'Submission on the Draft National Disability Advocacy Framework', *National Disability Advocacy Framework 2022-2025 Consultation* (July 2022) p5.

<sup>29</sup> Disability Advocacy Network Australia, Submission to the Disability Royal Commission into Violence, Abuse, Neglect and Exploitation: Independent Disability Advocacy, *Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability* (December 2022) p7.

<sup>30</sup> Faulkner A and Sweeney A, *Social Care Institute of Excellence*, 'Report 41: Prevention in Adult Safeguarding' (2011) <[scie.org.uk/publications/reports/report41/index.asp](http://scie.org.uk/publications/reports/report41/index.asp)>.

<sup>31</sup> Disability Advocacy Network Australia, 'Submission on the Draft National Disability Advocacy Framework', *National Disability Advocacy Framework 2022-2025 Consultation* (July 2022).

<sup>32</sup> Disability Advocacy Network Australia, Submission to the Disability Royal Commission into Violence, Abuse, Neglect and Exploitation: Independent Disability Advocacy, *Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability* (December 2022) p16.

## PART 2: ACCESSING, NAVIGATING, REPORTING

Advocates assist clients by helping them to navigate inaccessible systems. Advocates can report and address risks and hold systems accountable to ensure they provide a quality service. Everyone, including people with disability require these systems to function effectively and efficiently. Accessibility is central to promoting inclusion.

If these systems are not effective and accessible, advocates can assist clients utilise the complaint mechanisms within these systems or find external complaint systems that are more suitable.

Unfortunately, the quality and accessibility of complaint mechanisms vary and there is no central body for people to report abuse, violence, neglect and exploitation. ADAI recommend instituting a single door model for people with disability and vulnerable people to make complaints, so they don't have to tell their story more than once. This would also allow people to navigate issues that are intersectional. Even though the introduction of anti-discrimination legislation 'provides people with disability a framework for protecting their rights, including through the making of complaints about unlawful discrimination,'<sup>33</sup> ADAI rarely support people to make a complaint to either state or federal anti-discrimination bodies. This is possibly due to the process of making a complaint being stressful, confronting, and difficult.

ADAI recommend that the Australian government implement a program such as Care Finder to assist people with disability to access specialised supports. The Care Finder program provides 'specialist and intensive assistance to help people within the care finder target population to understand and access aged care and connect with other relevant supports in the community'.<sup>34</sup> ADAI consider that this program should be duplicated to provide assistance for people with disability.

### Increasing complexity of matters

ADAI is not alone in recognising a recent (since approximately 2020) increasing complexity of client presentation and the complexity of issues that arise. Independent advocates are generally involved 'when the issues are complicated, where the systems or services are intransigent to people's wishes or needs, where the person with disability is at risk of violence, neglect or another form of harm, where the person does not have family or friends able to assist them or where a supporter has competing personal or organisational interests'.<sup>35</sup> ADAI

---

<sup>33</sup> *Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability*, Interim Report (30 October 2020) p55.

<sup>34</sup> Australian Government Department of Health, 'Care finder policy guidance' (1 April 2022) p4.

<sup>35</sup> Disability Advocacy Network Australia, 'Submission on the Draft National Disability Advocacy Framework', *National Disability Advocacy Framework 2022-2025 Consultation* (July 2022) p9.

has noticed a complexity of matters above and beyond the usual expected issues. This increasing complexity stretches advocacy organisations beyond the limits of their resource capabilities as this then carries a proportionate need for increased access to advocacy support.<sup>36</sup>

Public systems are becoming increasingly difficult to navigate, especially for people with psychosocial disabilities. ADAI has noticed an increase in clients with psychosocial disabilities requiring advocacy assistance. Of the 250 NDAP clients in January to November 30 2022, 73 of those listed a psychosocial disability as their primary disability. The majority of these clients had sought assistance to navigate a government administrative system, whether it was the Department for Child Protection, the South Australian Civil and Administrative Tribunal (SACAT), the NDIS or Services Australia. Many of these systems are largely inaccessible for people with psychosocial disabilities. ADAI suggest an investigation to determine why this has occurred, and implement changes to rectify this issue.

### Storytelling and complaint mechanisms

Many of ADAI's clients who have told their story for the Royal Commission report afterwards that they have then felt a strong sense of ownership over their experiences. Many of them have thanked advocates for listening to them and believing them. Almost all have taken a printed copy home to file away, as evidence of their story.

As outlined in the Royal Commission Interim Report:

*...stories show the effects of negative and positive attitudes and help other people understand why attitudes make a difference. Applying human rights concepts, such as fairness, equity and equality, to people's personal stories creates a resonance between the words used by communities and the government.<sup>37</sup>*

Storytelling can be a powerful facet of complaint mechanisms, if used centrally and in a single door model. The end of the Royal Commission should not be the end of funded support for story telling for people with disabilities. Advocacy should continue to be funded to provide this type of service. Storytelling allows people to take control of their narrative. Advocates recall many clients knowing something wrong happened to them, but they don't have the language to point to exactly what it was. By telling their story to an experienced advocate it

---

<sup>36</sup> Disability Advocacy Network Australia, Submission to the Disability Royal Commission into Violence, Abuse, Neglect and Exploitation: Independent Disability Advocacy, *Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability* (December 2022) p.8.

<sup>37</sup> *Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability*, Interim Report (30 October 2020) p55.

can be delved into and pulled apart to identify certain systemic failures and harms. Advocates can ask pointed questions and help a client develop their story into any format. An advocate can also identify common themes and feed that information up through any complaint mechanism. Storytelling should be an integral aspect of complaint mechanisms.

**CASE STUDY: JENNY - ‘TELLING THIS STORY GIVES SOME PURPOSE TO MY TERRIBLE EXPERIENCES AND TREATMENT’**

Jenny, a woman now in her 50s, has severe autism. For most of her life her autism was undiagnosed and she was managed in the mental health system. Her behaviour was treated with antipsychotic drugs. When the drugs did not achieve the desired result, she was given stronger drugs. She remained in the mental health system for 25 years, being heavily medicated and, at various times, detained in psychiatric wards. In the mental health system, she also suffered much abuse, including sexual abuse. Eventually her autism was diagnosed and she was moved into disability services. As a consequence of years of inappropriate medication, she has a range of serious physical health issues affecting her heart, lungs, liver and kidneys. She also now suffers from PTSD. Jenny wants autism to be diagnosed, understood and responded to in ways that enable people to live a good life. She regards telling her story to the Royal Commission as the thing that gives some purpose to her terrible experiences and treatment.

**A. Advocating across Departments and State and Federal Systems**

Navigating across state and federal departments or systems can be difficult. Many of ADAI’s clients come to us with issues that involve both federal and state departments or systems. For example, this could be an issue that needs to be resolved through both the NDIS and the Education system, or NDIS and Health etc. Without advocating across multiple systems the client is unlikely to resolve the matter. These matters are almost always complex. As outlined above, ADAI have noted a recent trend towards clients presenting with more complex matters across a dynamic range of systems.

Most often these issues are intertwined with the NDIS, as the primary funding body for disability support services. DANA have reported on the increasing complexity of advocacy issues, and the increased demand since the introduction of the NDIS.<sup>38</sup>

---

<sup>38</sup> Disability Advocacy Network Australia, Submission to the Disability Royal Commission into Violence, Abuse, Neglect and Exploitation: Independent Disability Advocacy, *Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability* (December 2022) p5.

State based advocacy organisations in South Australia are federally funded. ADAI receive no funding for general advocacy provision from the Government of South Australia even though local knowledge is essential for effective advocacy provision. Local services are also constantly changing. New projects start, staff leave, and funding is discontinued. Effective advocates will have an excellent understanding of the local disability sector, be able to navigate it and provide appropriate referrals. Local advocates are valuable due to their detailed local knowledge and referral networks.

#### **CASE STUDY: JEREMY – HEALTH, NDIA, AND NDIS QUALITY AND SAFEGUARDS COMMISSION**

Jeremy was living in a supported living facility when he had a medical episode and had to be transported to hospital. While there the staff assessed him further and determined that his needs had escalated and therefore his current NDIS was not viable. Due to his presentation the hospital staff also believed that he had been neglected at his living facility. Staff encouraged Jeremy's family to contact an advocate. An advocate met with Jeremy and discussed his complaint and his pathway out of hospital. The hospital were ready to discharge him but Jeremy and his family refused to have him return to his living facility. The advocate had to apply for a Change of Circumstances with the NDIA to ensure Jeremy's plan was adequate, and assisted them with a complaint to the NDIS Quality and Safeguards Commission, and negotiated his extended stay with the hospital.

For further discussion on the need for cross-department advocacy and communication see **ADAI's Submission No. 3 to the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability 'Gaps in post-care support for young people with disabilities ageing out of the child protection system'**.

## **B. Advocating in private systems**

Many private systems are not structured for accessibility. Capitalism is not designed to be an inclusive system.<sup>39</sup> There is often an overreliance on cheaper forms of customer service, like online message services. Clients who are illiterate or do not use a computer struggle to resolve issues and require advocacy assistance.

Advocates can help clients navigate this system and make recommendations to improve services. Unfortunately, the drive for competitiveness has led to economic concentration and

---

<sup>39</sup> Susan K. Sell, 'What COVID-19 Reveals About Twenty-First Century Capitalism: Adversity and Opportunity', *Development* 63, 150–156 (2020).



a reduction in competition.<sup>40</sup> Companies are not trying to out-do each other to become more accessible. This is very clearly demonstrated in Australia’s telecommunication market.

In the case study below Dawn tried to report an issue with her telecommunication system but was not communicated with effectively to resolve it. Telstra kept trying to call her, even though she had reported that the Teletypewriter (TTY) device she relied upon was not working. The reporting system to make a complaint was poor and the technical assistance tracking system would not allow a staff member to make a note that Dawn was deaf and preferred written notes to communicate. Dawn also required an advocate there whenever a technician was entering her home for safety purposes, but there was no way to alert the technician that the advocate had to be called 30 minutes prior to the appointment. This was a complex issue to resolve and the complaint mechanism was ineffective. The system needs to be redesigned to enable Dawn to use it independently.

#### **CASE STUDY: ‘DAWN’ – GOING AROUND IN CIRCLES WITH TELSTRA**

Dawn has had a hearing impairment for most of her life and has lived with profound deafness since she was about 40. She is now in her 80s. Dawn uses a teletypewriter (TTY) device and has used one for decades. In October 2019 the then federal government announced the Relay Service and the TTY backend systems would be subject to a new tender. This was won by Concentrix. There was a changeover around this time. Dawn’s phone service was provided by Telstra.

Dawn relies upon her TTY to make doctors’ appointments, speak to family members, communicate with the hospital etc. It was very unsafe for her to be without a communication device. Dawn is also a carer for her adult son.

From October 2019 the TTY service that Dawn used started to deteriorate to the point where the device became unusable as a TTY. It could still be used for regular landline calls and Dawn sometimes had her adult son use it for her, but his disability impacted his ability to communicate with people he didn’t know.

The advocate lodged a complaint with the Telecommunications Ombudsman in January 2021. After six months of being unresolved the case manager at the Ombudsman’s office said it was the most unnecessarily complex file they had ever had. The Ombudsman’s office was unable to provide much practical assistance.

Telstra sent out many technicians to test the lines and found no faults. The ADAI advocate repeatedly asked for a TTY specialist to discuss the problems with Dawn instead, as she was

---

<sup>40</sup> Susan K. Sell, ‘What COVID-19 Reveals About Twenty-First Century Capitalism: Adversity and Opportunity’, *Development* 63, 150–156 (2020).



able to specify what the problems were using the coding language the device relies on. The ADAI advocate was told such a specialist does not exist. Telstra sent more technicians to check the wiring.

It was eventually identified that Concentrix run the backend system, separate from Telstra's physical line management. Neither organisation was talking to each other. Both organisations kept saying it was the other's fault and they couldn't determine the problem. This continued for months.

The advocate contacted the Department of Infrastructure, Transport, Regional Development and Communication. This matter was then coordinated by a department official who ran a conference call meeting with the parties, excluding Dawn and the advocate. It was identified that there was both a data package problem and a line problem and that Dawn's understanding of the issue she raised originally was correct. Both were eventually fixed, but due to reduced funding to the TTY system they never worked at the same level as before the contract changeover.

This took 8 months for the advocate and Dawn to achieve. During this time Dawn did not have a functioning telephone. Dawn had not had a functioning telephone for around 22 months. The advocate had to negotiate for Dawn to receive a credit on the usage of the device which she had still been paying for while it was not working.

### Issues

When booking an appointment with a technician through Telstra's booking service there is no way of alerting a technician to a client's communication needs. Technicians were knocking on her door, instead of using the flashing doorbell, and leaving when she didn't hear them. There was no TTY specialist who could understand the issue or Dawn's feedback. The ADAI advocate repeatedly advocated for such a position to exist, and Telstra eventually created one and upskilled an existing technician. At the conference call meeting which was held at Dawn's house, no one spoke to Dawn or tried to communicate with her, even though she remained the expert on the device. She was constantly talked down to and treated poorly. There was no prior open communication between Telstra and Concentrix. If the advocate had not intervened Dawn's TTY would still be malfunctioning and Telstra would still be charging her upwards of \$1000 for a service she could not use.

The constant advocating and support provided by the advocate ensured that the companies involved took this seriously and worked to resolve the issue. This matter involved over 100 hours of advocacy support. It is still not working to the level which Dawn is used to and this appears to be because (according to employees at Concentrix) the system is old and staff are new and still learning the technology.

### **CASE STUDY: GIOVANNA – DISCRIMINATORY INSURANCE PRACTICES**

Giovanna first contacted a large Australian insurance company in 2001 about changing her home and contents insurance. She informed them that she was a wheelchair user with cerebral palsy and relied upon support workers daily. They provided her with an insurance option that they thought would work best for her and she signed up. In early 2021 about \$17,000 of Giovanna’s jewellery was stolen. She believed it was one of her support workers. A very short police investigation was inconclusive. When Giovanna tried to claim against her insurance, they were initially receptive, until she received a letter informing her that ‘as she had invited the thief into her home she was not eligible to claim’. Under the Product Statement theft by paid support workers was not covered. This was never explained to Giovanna when she purchased the product. She came to ADAI for assistance to write a complaint and to communicate with the insurance company. As Giovanna has cerebral palsy, she finds it easier to text or email but the company kept ringing to speak with her and hanging up when they couldn’t understand her. An advocate helped her write a letter to the company in her words and requested they communicate to her in her preferred way. After some advice from a community legal service Giovanna was successful in her claim. Giovanna wants all insurance companies to be change their policies and to hold all insurance agencies accountable for their discriminatory products.

## **C. Advocating through Public Systems**

ADAI assists clients to navigate through all public systems. Access to well-functioning social services and supports reduces the risk of abuse, violence, neglect and exploitation for people with disability. Public systems should act as preventative safeguards, with a focus on service design and cultures to prevent abuse and neglect, and actively address risks for individuals.<sup>41</sup> Public systems should work as safeguarding mechanisms for the most vulnerable of our society.

Inclusion is linked to the accessibility of systems and even with the improvements linked to the NDIS, ‘exclusionary practices are still very much evident today, covering every aspect of civil, political, economic, social and cultural rights including education, health, housing, transport, family life, culture, and leisure, justice, political participation and the exercise of legal capacity’.<sup>42</sup>

<sup>41</sup> PWDA, Safeguards help marginalised people with disability, ‘Submission to the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability’ (February 2021) p11.

<sup>42</sup> Kayess, R and Sands, ‘Convention on the Rights of Persons with Disabilities: Shining a light on Social Transformation’, *Sydney: UNSW Social Policy Research Centre*, (2020) pp.21. cited in Queensland Advocacy for

People with disability often face challenges when trying to report violence, abuse, neglect and exploitation within these systems. Their complaints may be minimised, ignored or go unrecorded. Advocates assist people with disabilities to access, navigate and report issues within these systems. Poorly functioning systems with inadequate reporting systems enable violence, abuse, neglect and exploitation.

This section will outline some examples of advocacy where it was required to navigate through the systems of:

- Education
- Child Protection
- The National Disability Insurance Scheme
- Centrelink, the Disability Support Pension and other social support payments
- Housing
- Guardianship and Public Administration
- Health
- Justice

Many clients require assistance to navigate multiple systems at once. ADAI advocates have noticed an increasing complexity to client issues, with clients presenting with multiple concerns across several systems, matters that are in crisis and clients with acute comorbidities.

## I. Education

Advocacy for Disability Access and Inclusion (ADAI) have a long history of advocating for families and children in the education system.

**For further analysis ADAI has prepared Submission No.2 of *Advocacy for Disability Access and Inclusion Inc. SA to the Royal Commission into violence, abuse, neglect, and exploitation of people with disability – ‘Education: Systemic neglect of students with disability’*; and Submission No.2a ‘Education: Restricted Submission’.**

From 1 July 2019 – 30 June 2020 ADAI had 62 clients seeking advocacy assistance for an issue regarding education. This area was ADAI’s third most common request for assistance for

---

Inclusion, ‘Submission: Systems and Individual Advocacy for Vulnerable People with Disability’ (December 2021), pp. 4.

people, after questions about NDIS Internal Reviews (101 files) and general NDIS Access/Planning queries (63 files).

In the period from 1 July 2020 – 30 June 2021 education issues were the main concern for 54 clients, the fourth most common query after requests for assistance to access the NDIS (86 files), assistance with a NDIS Internal Review (57 files) and queries about Government Payments (55 files requesting support with Disability Support Pension, Carers Payments etc.).

In the period from 1 July 2021 – 30 June 2022, out of 381 clients, 58 of those were seeking assistance with an education issue, again the third most common request for assistance after NDIS Access/Planning advice (79 files), and assistance with an issue with a Government Payment (73 files).

#### **CASE STUDY: MAXINE AND JAMIE – NO MORE ACCOMMODATIONS FOR YEAR 12**

Maxine rang ADAI on the way to a meeting with Jamie’s school. Jamie is 17 and attends a small metropolitan catholic high school. For the last three years he has had accommodations at school to allow him to manage the impact of his disability. Jamie has been managing well with these accommodations, but the school has informed Maxine that they will not be continuing into his final year. The school told Maxine that this was the way things were done and that they expect every one of their students to complete the same work in the same timeframe in year 12. The advocate listened to Maxine and gave her some advice about what Jamie’s rights were and some practical tips for getting a good outcome at a school meeting. Maxine was able to advocate for Jamie on her own and rang back to let the advocate know that the school had a plan moving forward that took Jamie’s needs into account and thanked the advocate for listening to her and reassuring her that she was right to be concerned with the school’s initial approach.

## **II. Child Protection**

Children living with disability are over-represented in the out-of-home care sector. Many of these children, young people and their families are vulnerable, and the legislative and systemic social support frameworks are not adequately protecting them from harm.

**For an in-depth examination of ADAI’s concerns for children and young people transitioning from out-of-home care please see ADAI’s Submission No. 3: Gaps in post-care support for young people with disabilities ageing out of the child protection system.**

As of 30 September 2022, there were 4806 children under 18 in care.<sup>43</sup> In September of 2022 alone 55 children were placed under a new Order and 409 children had their orders reviewed or were placed under a new Order.<sup>44</sup>

A joint report released by the Office of the Guardian for Children and Young People and the Training Centre Visitor Program notes that ‘almost one quarter of children and young people who are detained in the Adelaide Youth Training Centre are under the legal guardianship of the state and are likely to be living in large residential care homes’.<sup>45</sup> Data such as this suggests the state’s child protection system is struggling to keep children and young people safe.

ADAI provide advocacy to clients navigating the Child Protection system by:

- Supporting clients in meetings, making them feel more confident and ensuring their voice is heard.
- Educating them about their legal rights.
- Connecting them with legal services.
- Listening to their story and making referrals to required services.
- Advocating to support organisations for immediate intervention and services for clients at risk.
- Supporting clients in Court and ensuring they understand everything that is happening.

Much of ADAI’s advocacy within the child protection system is reactive. Most of our clients have been referred for services after their children have been removed, or after the young people have experienced harm. There is a clear need for advocacy for parents and children prior to child removals, and while children and young people are in the child protection system. ADAI have heard from a number of young people who report harm they experienced in the out-of-home care system. Advocacy should be resourced effectively to be both proactive and reactive and be expanded to be readily available to young persons in care.

**CASE STUDY: ANNE – WITHOUT ADVOCACY SHE WOULD HAVE HAD HER CHILD REMOVED FROM HER CARE**

Anne is a 27-year-old aboriginal woman who has an intellectual disability that has a mild impact on her functional capacity. She was also under Guardianship of the Minister (GOM) as a child herself and has experienced trauma and violence in her life. She has three children who were all removed and placed under GOM18 orders. The reasons for these orders were

<sup>43</sup> Government of South Australia Department for Child Protection ‘Reporting and statistics’ (Information, 2022) <<https://www.childprotection.sa.gov.au/departement/reporting-and-statistics>>.

<sup>44</sup> Ibid.

<sup>45</sup> Office of the Guardian for Children and Young People and the Training Centre Visitor, ‘A Perfect Storm? Dual status children and young people in South Australia’s child protection and youth justice systems’ (Report 1, November 2019) p3.

listed as being due to Domestic Violence, drug and alcohol abuse and minor criminal activity. Two of these children are living in Adelaide in a Kinship Care arrangement and Anne has maintained regular contact. Her family have been supportive, and keen to keep her regular involvement in their lives. Anne has one child in Victoria with who she has no regular contact as there has been little if no communication with The Victoria Department of Families, Fairness and Housing (DFFH) and Department of Child Protection (DCP). It is not clear when Anne can have FaceTime calls with her child and the foster carer often changes times /dates/days etc. Anne is currently pregnant with her fourth child with her new partner.

Anne attended ADAI for assistance in gaining identification documents as she lost everything when she left Victoria due to Domestic Violence. She also required assistance to find stable housing. An ADAI advocate assisted her to gain identification documents, and referred Anne to Housing providers for a Housing case manager. Anne was triaged quickly as the advocate had worked with the Housing Case Manager before.

Anne has now changed her life, she left her previous DV partner, left Victoria, was homeless and was couch surfing for 10 months. She stopped taking drugs, started a new healthy relationship and fell pregnant. She now has a very supportive extended family through her new partner and a supportive, although complex, relationship with her sisters in Adelaide.

When Anne was home with her eldest children she received no in-home care. She had no NDIS plan and no support. The Victorian DFFH and the local hospital were aware that she had a disability. Rather than providing her with support and assistance they allowed Anne to struggle to the point that her children were removed. This was an entirely reactive process.

Anne's advocate was contacted by DCP Adelaide High Risk Infant team regarding the new baby, and the advocate attended a conference as DCP Adelaide were going to remove Anne's new baby at birth. They had not undertaken any recent assessments of Anne and her partner, and instead were basing their decision on her history. The advocate was involved in a DCP Birthing Safely planning meeting and advocated for DCP and services to work with Anne to enable her to keep this new baby. Anne was willing to work with DCP and any other useful services to enable her to keep this baby. DCP appeared reluctant and the advocate had to voice Anne's needs and wishes strongly. At the Discharge Safety Planning meeting further supports were put into place to assist Anne in maintaining her and baby's health and retaining baby.

DCP had been sending Anne letters, knowing she was illiterate and not making any attempts to ensure she understood the information that was provided to her. They set meetings for her, which she didn't attend as she didn't know what they were for. DCP considered this a reckless act which led them to believe she undertook 'risky behaviour'. Anne had had her third child removed in traumatic circumstances where DFFH Victoria told her she was going

home with the baby, and never told her it was being removed. They arranged for Anne to leave the hospital in a taxi and as Anne was in the taxi with her newborn and her gifts and balloons, 32 hours after giving birth, the baby was taken from her arms and she had the taxi door closed on her. She has not seen that baby in person again. After this experience Anne does not trust hospitals and was reluctant to attend her pre-natal appointments. After her advocate agreed to go with her and help her communicate with staff she attended.

ADAI see DCP working solely reactively and removing children while not supplying support for reunification of families. When parents completely change their lives, DCP do not acknowledge this.

DCP would have removed this new baby at birth without giving the new parents a chance. By Anne actively engaging with advocate and building a transparent and respectful working relationship, the advocate was better able to advocate on Anne's behalf for a successful outcome for all involved.

Anne is still working on reunification with her eldest three children.

#### **CASE STUDY: DECLAN - DCP AND GUARDIANSHIP**

Declan, aged seventeen, has a mild cognitive disability. He was under the guardianship of the Chief Executive of the Department for Child Protection (DCP). As he was about to turn eighteen the Department decided to apply to SACAT for an Administration Order and Guardianship Order that would come into effect when he turned eighteen. This was on the basis that they considered that he lacked capacity to make decisions about his finances and make 'life-decisions.' The DCP asserted that the orders should be made to protect his wellbeing but they had little evidence to demonstrate that it was needed, other than his diagnosis. They had not discussed with Declan what his wishes were and considered any other pathways. Seeing that these orders would have huge consequences for this young person, the DCP had the foresight to pay for him to have a legal representative. It is rare that this occurs. The final hearing was contested, the lawyer ensured that Declan also had the support of a professional communication partner. The lawyer made legal submissions and the applications were dismissed. Rather than do any proactive case management and work with Declan to ensure he had the skills and capacity to thrive when he turned 18, DCP worked in an entirely reactive way. Luckily for Declan they allowed him funded representation.

#### **DCP: CHARLIE – NO SUPPORT FROM DCP FOR FOSTER FAMILY**

Charlie is a young aboriginal boy aged 10 who has been placed in a Kinship Care arrangement. Charlie's foster parents contacted ADAI as they need more support to care for Charlie. Charlie has been working with an occupational therapist on 'supporting relationships' but has not

undergone an Occupational Therapy assessment. He has no formal diagnosis, but his language is delayed and his behaviour at home has been challenging. Charlie's family report that DCP have provided no practical support and will not pay for an assessment. DCP will not help the family apply for NDIS. ADAI advised that they should make an Access Request application to the NDIS and request an assessment as part of this process. The family feels like they will give up care for Charlie as they don't want to have to continue to engage with DCP in this way with such little support.

### III. The National Disability Insurance Scheme

ADAI assists NDIS participants, their families and their support people in many stages of the NDIS. ADAI also assist clients to access the NDIS and become participants. For further analysis of the NDIS see **Submission No.4 of Advocacy for Disability Access and Inclusion Inc. SA to the Royal Commission into violence, abuse, neglect, and exploitation of people with disability: Capability and Culture of the NDIA.**

#### Stages of Advocacy in the NDIS

1. Access to the NDIS scheme and services funded by the NDIS.
2. Prior to and during a plan review, to assist participants to gather evidence for a plan review that clearly outlines what assistance they need. ADAI assists participants to advocate for their needs and communicate with the Agency and the Planners.
3. During an internal review process when a participant deems the assistance with daily life supports to be inadequate.
4. During an external review through the Administrative Appeals Tribunal.
5. When making a complaint about service provision.

The *National Disability Insurance Scheme Act 2013* provides for the NDIS and among other obligations, aims to give effect to Australia's obligations under the UN Convention on the Rights of Persons with Disabilities.<sup>46</sup>

---

<sup>46</sup> *National Disability Insurance Scheme Act 2013*, Part 2, s3(a)(b).



Advocacy is accepted as an important external function to the NDIS that promotes the interests of individuals within the NDIS while systemic advocacy pushes for broad policy change.<sup>47</sup>

The NDIS has a complaint mechanism, the NDIS Quality and Safeguarding Commission, whose primary function is the regulation of service providers and those employed or engaged by those service providers. It does not regulate the NDIA or have any role in the approval or funding of supports and services received by participants.<sup>48</sup>

### The NDIS over-relies on and undervalues unpaid family supports

ADAI support the Royal Commission terms of reference that recognise that families, carers and supporters can play a critical role ‘in providing care and support to people with disability.’<sup>49</sup> Unfortunately, in the NDIS the role of families, carers and supporters is often misunderstood and undervalued. Unpaid supports are also over-relied upon to the point of carer burnout.

ADAI argue that where a family member has been providing unpaid care to a participant, that when this care arrangement changes the NDIA does not effectively understand how to transfer supports. The structure of the NDIA system makes it difficult to quantify unpaid family care. ADAI have heard reports that when care supports are transferred from unpaid family carers to NDIS funded supports, much of the quality of care is lost. ADAI have seen matters where the NDIA has determined that to provide an equal quality of care, equal when family members were providing unpaid care, is ‘unreasonable’ and ‘does not represent value for money’. This is despite the NDIA’s obligations under the UNCPRD to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity.<sup>50</sup>

The preference of the NDIA to consider professional therapist reports as evidence over the experience the person with disability and their families also devalues their experience and expertise. Rather than NDIA planners sitting down with the participant and their family, the NDIA prefers clients purchase reports, especially one off Occupational Therapy reports, where

---

<sup>47</sup> Productivity Commission Inquiry Report, Disability Care and Support, Volume 1, No. 54, 31 July 2011, page 26

<sup>48</sup> The Hon. Alan Robertson SC, Independent review of the adequacy of the regulation of the supports and services provided to Ms Ann-Marie Smith, an NDIS participant, who died on 6 April 2020, (Report to the Commissioner of the NDIS Quality and Safeguards Commission, 31 August 2020) p4.

<sup>49</sup> *Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability*, Interim Report (30 October 2020) p378.

<sup>50</sup> UN General Assembly, *Convention on the Rights of Persons with Disabilities*, adopted by the General Assembly, 24 January 2007, A/RES/61/106, Article 1.

they explain what supports the family had been providing. ADAI have seen many of these reports which families have paid upwards of \$6000 for that may not provide any useful information for the NDIA. This is especially the case for Access Request Evidence Reports where a prospective participant may only meet with the therapist once.

NDIA is often wary of family evidence and does not value the lengthy history of care knowledge a family has obtained. ADAI has been told by NDIA Lawyers that family evidence will be “taken with a grain of salt”. ADAI understands the need for independent evidence, but the preference for paid reports over personal and family Lived Experience reports or a letter from a client’s General Practitioner is a concern.

Many participants, especially those with intellectual disabilities, have been supported by their families most of their lives. These clients often do not have long term occupational therapists who would know their detailed history. The NDIA should be able to recognise the wealth of experience of families, carers and supporters and value their worth within the NDIS.

### Don’t Say Respite

ADAI have had a recent increase in parents looking for support to gain funding for respite care for their children. The NDIA is rarely willing to fund respite care, and do not look positively upon the term ‘respite’. There is no recognition of the importance of carer health and the need to offset carer burnout, as related to the health and wellbeing of the participant. ADAI has been told by senior staff of the NDIA to never refer to respite as ‘respite’ and only as ‘overnight weekend support’, and to ensure it is referred to only as a support the participant requires, ignoring the needs of their parent or guardian. The NDIA must recognise the need for ‘respite’ and support the family as a unit to ensure the ongoing health and safety of the participant. If a carer becomes unwell and burns out this can put the person with disability at risk of harm. Sometimes the needs of the family unit need to be considered alongside and in conjunction with the needs of the individual.

### **CASE STUDY: LISA AND BOB – PERSON CENTRED CAN BE FAMILY CENTERED**

Lisa is 50 and has been diagnosed as having an intellectual disability, bilateral profound hearing loss (supported by bilateral cochlear implants), Autism Spectrum Disorder and language impairment disorder. Her brother Chris is 48 and has an intellectual disability and Autism Spectrum Disorder. They have both lived at home with their parents, Bob (80) and Mary (78) until recently. Bob and Mary are deeply concerned for the future of their children and they have purchased with their own funds, a modified home for Chris and Lisa to move into. Bob and Mary now need to secure sufficient NDIS funds necessary to enable them to live independently and continue to receive the level of support their parents have provided Chris

and Lisa over the years but are no longer able to, including 24-hour support, and Onsite Overnight Assistance.

Initially, Bob and Mary managed to navigate the NDIS process themselves. Chris and Lisa require differing levels of support. Lisa, having more complexities, was allocated a planner from the Complex Needs Unit, and Chris a General NDIS planner. The initial NDIS plans complemented each other because the two planners from the NDIS had come together and understood both Chris and Lisa's needs. The following year the NDIA plans were completed separately and there was a significant reduction of funds in both their plans. Bob and Mary submitted a RoRD for both Chris and Lisa. The complex needs unit reviewed Lisa's plan and a new favourable plan was developed but Chris's plan was reviewed at a later stage, despite Bob and Mary stating it was important for both Chris's and Lisa's plans to be considered together.

The review for Chris still did not provide the funding he needed to remain safe in the home. An advocate then assisted Bob and Mary to make an application to the AAT and for Legal Services Commission funding (LSC). The LSC funding was granted, and the AAT processes followed. Prior to the first AAT conference a meeting with the Early Resolution team took place and after much deliberation it was determined by the advocate that there had been a miscalculation (a NDIA administrative error). The advocate then liaised with LSC, and it was agreed with the early resolution team to ask for the plan to be recalculated and for the additional support hours to be included. The plan was recalculated from \$43,000 to \$153,000.

#### **CASE STUDY: MARLENE AND HER PARENTS WALTER AND NOLENE – NO RESPITE FOR ELDERLY PARENTS**

Marlene is a woman in her late 50s who lives with and is cared for by her parents Walter and Nolene. Her parents are in their 70s and still undertake all daily assistance tasks for Marlene. In 2021 Marlene had a plan review and the NDIA cut the funding for Marlene's day program. Marlene had no other social and community activities. This meant that Marlene was home all day with her parents who would now have to provide all support with meals and toileting during the weekdays, with little respite. Marlene was upset that she was no longer allowed to go to her day program and began to be violent towards her parents. To rectify this lack of funding Nolene began to ring the NDIA and ask questions about how to resolve the issue. The NDIA told her to 'stop ringing'.

Nolene and Walter are not computer literate. Three months after putting in a request to review the decision Nolene received a phone call from the NDIA to tell her they needed further evidence and that they were removing Marlene's respite funding as well because "Marlene didn't need it", as Nolene and Walter had not been utilising it fully. They were not

sure how to. During this process a NDIS Review Officer rang Marlene's Support Coordinator and told her that NDIS plans reduce every year, as an excuse for the reduced funding. When questioned about this the NDIA employee hung up.

Nolene and Walter were becoming increasingly stressed and exhausted and began recognising the strain on their bodies from the increased care load. Nolene had injured her shoulder. Marlene was having more health issues due to her lack of activity. Marlene was also losing her social skills due to the isolation and was experiencing more falls from the decreased exercise and movement. ADAI believe that the NDIS assumed that Marlene's parents would shoulder the ongoing and increased unpaid care load.

There was no discussion in the planning stage with the family about future planning or increasing respite to enable Walter and Nolene to maintain their caring roles for a longer period of time, or discussions about how to support the family unit. Risks to Nolene and Walter were not considered in this plan even with the increased reliance on their support roles. There was no choice and control exercised by the family in this plan. The matter went to the AAT and the family secured legal services funding as the NDIA were still challenging the need for respite and social and community activity funding.

ADAI have recently seen an increase in NDIA's reliance on unpaid carers, especially parents, who care for adult children in their home. There is an expectation that as the adult with the disability lives at home the parent will provide all assistance with daily activities support unpaid.

*See also 'Case study #2: Elliot and Charlene - Completely Fed Up with the System' from Submission No.4 of Advocacy for Disability Access and Inclusion Inc. SA to the Royal Commission into violence, abuse, neglect, and exploitation of people with disability: Capability and Culture of the NDIA for a further example of a family in need of funded weekend supports or 'respite'.*

### The NDIS and Neglect

There are few clear assessment tools that are readily used to identify risk of neglect. Most of these tools are created for use when working with children or used to identify elder abuse. ADAI are concerned about the lack of readily available tools and the lack of clarity regarding neglect.

ADAI are concerned that there is an increasing number of decisions made by the NDIA to refuse funding for self-care activities which could constitute neglect. There is a clear emphasis

on 'value for money' when approving funded supports and the rejection of funding for activities such as:

- support to maintain continence
- dental hygiene
- healthy eating
- exercise
- support to develop independent meal preparation skills
- daily preparation of nutritious and fresh meals

The NDIA also does not appear to value issues such as hygiene and healthy eating, preferring to have participants rely on continence products and bulk prepared meals and frozen foods. ADAI has heard participants be told by NDIA Technical Advisors that "most people use their supports to prepare their meals in bulk", and "the NDIA would only be prepared to offer 2-3 hours a week for this support". Many people are unwilling to eat frozen pre-prepared lasagne weekly and NDIS participants should not be expected to.

The NDIA do not value the nutritional benefits of freshly prepared food and are unwilling to fund this support, even with extensive independent evidence that a participant needs support in this area. ADAI are concerned that if a family decided to rely solely on pre-prepared frozen food for a person with disability that could be considered an act of neglect, but if the NDIA determine this is adequate that is 'value for money'. Family supports and NDIA funded supports are held to different standards.

ADAI understand that the NDIA are unwilling to provide support for participants to exercise and participate in sporting events to the extent that they would wish to, and to the extent that any non-disabled person would have access to.

ADAI was supporting a young man appeal his NDIS plan as he required a higher number of support person hours. We were advised by the NDIA lawyer not to tell the NDIA Case Manager that the young man wanted to attend the gym every day and use supports to do this. We were advised to ensure that the supports were used for a variety of experiences. The NDIA did not consider that attending the gym multiple days a week would be value for money, even though this young man was staying healthy and forming social relationships at the gym. The NDIA has a paternalistic expectation of what is a 'reasonable' amount of exercise a person can be 'allowed' to access funding for.

ADAI supported another young man in his appeal of his NDIS plan as he was given funding to attend one blind cricket match a week, but no support to attend training. After many conferences and significant support from an advocate he was successful in appealing his plan. After receiving it he realised the NDIA had not provided for him to receive any support at weekend rates, even though they were aware that this was when matches occurred. The

advocate went back to the NDIA lawyer and asked for this to be fixed, as it was clearly agreed to in the final conference that he would be able to attend cricket on the weekend. The NDIA lawyer said the Terms of Agreement didn't clearly state that and his notes did not reflect that agreement. Even though the advocate had reviewed the Terms of Agreement they were not a lawyer and did not see the difference in the terms. The NDIA had made no attempt to ensure the young man was communicated with accurately and never spoke to him directly, only sending emails which he had his wife read to him.

#### **CASE STUDY: ANDY – NDIS PREFERS TO FUND CONTINENCE AIDS THAN SUPPORT CLIENTS TO SELF-CARE**

Andy is 47 and lives by himself in a small private rental in regional South Australia. He works in supported employment and has an intellectual disability. Andy's job is very important to him and he has worked there since he was 18. Andy requires support with all self-care activities, support to prepare and eat healthy meals, assistance with domestic tasks and support to access the community. Andy needs support with all areas of continence, and support in the home to ensure he is safe. He requires prompting to toilet effectively. Andy is supported by his sister Michelle and her husband Tom. Michelle has been providing Andy with unpaid assistance with daily life over the past 25 years and is his guardian and administrator. Andy was previously funded by Disability SA who knew his history and needs. Recently Tom was diagnosed with a degenerative condition and requires Michelle's assistance more. As Michelle can no longer provide Andy with the same level of support going forward, she alerted the planner that Andy will need a higher level of paid supports.

The NDIA declined to fund further paid supports, and instead cut his existing supports. The NDIA's argument was that to provide the level of assistance with daily care that Michelle was requesting, being the level of care she used to provide, it would not be value for money. The NDIA did not consider Andy's assistance with continence as important. They considered the sole use of continence products, rather than personal prompting and assistance from a support worker, to be reasonable.

The family approached ADAI for assistance and an advocate helped the family to advocate for a new plan with a higher level of support. This plan was eventually received by Andy, and he was able to gain the supports he needed. In the next plan review process Andy's funding was again cut. This resulted in another review process and an AAT application. After a long AAT Appeal, the family accepted a lower support level than what was previously requested, because they were so worn down and burnt out by the process. This included about 3 hours of daily care assistance a weekday, not enough to support Andy with his continence and hygiene. If Andy was being provided with care from family, and those family members decided it would be easier for him to wear continence products then support him with regular

toileting, it is possible the NDIA and SACAT would consider that neglect and make an Order for Public Guardianship.

### 'Cut and paste' supports

ADAI is concerned that the NDIA is not looking at individual participant needs and is applying a "cut and paste" amount of assistance with daily supports as being three hours a day, regardless of a client's disability or needs. ADAI advocates have noticed a trend of agencies offering a limit of three hours of daily support each weekday and commonly two hours on a weekend. This offer has been made regardless of a person's disability whether it was schizophrenia or juvenile arthritis. In two recent final conferences ADAI advocates and their clients were told during negotiations by the case managers that they (the case managers) had been given authority to offer three hours only and no more and if the client needed further support they would have to take the matter to a hearing. The case manager then explained how difficult a hearing can be and warned the client against pursuing this option. Often at this point of the process it has been around a year since the client put in their NDIS Appeal and they are unable or unwilling to wait another three to five months for a hearing date. In one instance a client had been recommended for 16 hours a day of personal support by the Occupational Therapist and the NDIA was only willing to offer three hours.

In one pre-conference negotiation advocates asked the NDIA Technical Advisor in attendance why only three hours was being offered, as the OT report clearly stated the client needed two and a half hours support in the morning and two hours in the evening for personal self-care support. The Technical Advisor responded by explaining that 'we believe it is reasonable and necessary that people have three hours a day for personal tasks' and that it is generally understood by the NDIA that 'most people only need three hours a day' for personal daily supports. This is in direct opposition to the aims of the scheme as supporting the needs of individuals.

### Lack of clear instructions for the required evidence within reports

The NDIA do not provide clear instructions for therapists who are writing reports for clients. ADAI advocates are often required to assist therapists who do not know what information will be required by the NDIA for the plan review, as there is no clear direction from the Agency. Often a therapist will have to re-draft a report at a further cost to the client. ADAI advocates have reviewed reports from Occupational Therapists (OTs) which do not provide any of the information required by the NDIA to determine the need for support, or whether a client meets the Access Requirements. A higher level of regulation is required in this area. Some clients pay over \$5000 for OT reports which ADAI do not deem useful for a plan review or access process. These reports may not reflect the client's needs or wishes, and they may have



incorrect information about the client's functional capacity. This has been identified in numerous reports prepared for people with intellectual disabilities or with cognitive impairments. Often it is clear the OT is inexperienced, as the OT has asked the client direct closed questions in areas where open questions would provide better evidence. This often leads to the client overstating their abilities. For example, 'Do you make your own breakfast? Client replies yes'. Better regulation is required.

**NDIS: All clients are assumed to 'improve' every year, because disability is something to 'overcome'**

NDIS policy appears to be that clients must achieve their 'goals' for the year, which will lead to them 'improving their functional capacity' and a subsequent 'scaffolding down of support'. This is a harmful and reductive way of considering disability.

Some clients of the NDIS will not make 'significant' gains or continue to improve to the point where they will require much less support. For clients such as Dave below they will continue to need intensive therapies and services to enable them to live healthy, fulfilling lives. These services will be required in an ongoing manner. ADAI see many client NDIS Plans where supports have been reduced yearly, despite all the evidence that has been submitted. NDIS policy appears to be that clients are expected to scaffold their services down every year. This approach will not be appropriate for many clients and puts them at risk of harm.

#### **CASE STUDY: DAVE – NDIA: WE EXPECT HIM TO IMPROVE WITH THIS LEVEL OF FUNDING**

Dave is a 23 year old man with complex disabilities. He requires 1:1 support when at home in his rental unit which is funded through Supported Independent Living. He also works in supported employment. During the plan review process Dave's psychiatrist provided an update on his function and the medications he was on. At this time Dave was just leaving school. In this letter the psychiatrist wrote that "Dave may make gains" when addressing his functional capacity. The NDIA took this sentence as evidence that he no longer needed 1:1 support and took this evidence over the four other reports from therapists (including the rest of the evidence from the psychiatrist) which outlined the need for 1:1 support. The NDIA confirmed that this was their reasoning in a conciliation through the AAT process.

A plan with a lower amount of support was provided, and the family went through the review process. During this process Dave's mental health declined significantly along with his cognitive capacity due to the stress of living with another participant and the sudden change in his environment. Dave became so upset he harmed himself, requiring leave from his employment. After over a year of negotiations the NDIA agreed to fund Dave at 1:1 for his daily assistance needs again. Dave then required extensive support to recover from this process and has existing trauma from this period of time. He is unlikely to live with another



participant again and every review process is highly stressful for him as he is concerned the NDIA will suddenly cut his funding every year.

Dave has a Complex Needs Planner, but this has not avoided the need for further external plan reviews, as there has been one every year since due to inconsistencies in the Plan and the NDIA's continued insistence to reduce funding. The NDIA advisors have pointed to the fact that Dave works as supposed evidence for reducing his supports. Dave is heavily supported in his employment to ensure he can maintain this job. Only through lengthy conversations about Dave's disabilities and life experience (as provided by his family) have the Agency and their lawyers been able to understand Dave's support needs. It appears that this history is then lost every year as a new plan review is undertaken. Best practice file noting, consistent case managers and practitioners with knowledge about lived experience is crucial and often missing.

With yearlong plan periods Dave and his family spend about 6-12 months in plan review processes for every plan since the beginning of the NDIS. An AAT Appeal was finalised 18 months after it was submitted, with each support Dave requested in the s100 review eventually being confirmed. The advocate was also able to secure a 24-month plan so Dave and his family don't have to go through this process for another 18 months until they will have to prepare for the next review. The NDIA lawyer informed Dave's mother that the NDIA expected that with this 'high' level of support Dave would be making 'gains' throughout the year and that his plan next year will be scaffolded down. Dave's mother has tried to argue that Dave will most-likely need this level of support forever to ensure he remains out of the justice system and avoids institutionalisation.

#### IV. Centrelink and the Disability Support Pension

ADAI regularly receives requests for assistance from clients seeking access to the Disability Support Pension (DSP). From 1 January to December 2022, we had 73 clients requesting assistance with a DSP issue, with approximately 90% of those enquires were regarding an application for DSP with the other 10% requesting assistance to resolve an issue they were experiencing with their current DSP. Requests for assistance with the DSP is one of the top three categories annually in which ADAI provide advice and assistance. Of these ADAI clients who are seeking assistance with an application for the DSP, 27 out of 73 named a psychosocial disability as their primary disability. ADAI would consider that access to the DSP for people with a psychosocial disability is unnecessarily difficult, and there are numerous and unnecessary barriers to access.

ADAI often assist General Practitioners (GPs) to write reports which clearly demonstrate that the client meets the criteria to access the DSP. ADAI recommend there a standard universal DSP access form be available for use by GPs. ADAI advocates see many clients who are eligible for the DSP, but who are instead receiving the JobSeeker Payments. Many clients report that they would rather stay on the Jobseeker payments than undertake the onerous process of applying for the DSP. Many of them have been rejected before and may not understand why. ADAI see many DSP access rejections where Centrelink has requested further information on top of the numerous documents the client has already provided and the client has given up. This is not an accessible system and is forcing people with disabilities into poverty.

#### **CASE STUDY: EVA – ACCESS TO THE DSP**

Eva has a degenerative condition that causes her constant pain and impacts her ability to work. Eva loved her job, but as her condition worsened she was no longer able to continue. Eva has suffered from depression for most of her life and felt that a lot of her self worth was connected to her being able to work. Not being able to pay her bills was causing further stress. She was at risk of homelessness. Eva’s psychologist contacted ADAI for assistance for Eva to apply for the DSP. Even though Eva was had a high level of education, her disability impacted her ability to complete an application herself. She lives in a remote location and was able to make an appointment to see an advocate during an outreach visit. Eva’s GP had provided a very short letter to support her DSP application. The advocate worked extensively with the GP and Eva to draw out further evidence that Centrelink required and then assisted Eva and her GP to draft a more specific report for the DSP application. The GP took over a month to complete this report as she claimed she had no time to complete such reports. Once the advocate had assisted Eva to collect her documents the advocate booked in another appointment for the next outreach trip in six weeks’ time. The advocate sat with Eva and helped her upload every document and answer the questions in the online application. Eva would not have been able to do this on her own as she found the process overwhelming and it heightened her physical symptoms and escalated her depression. This appointment was over three hours long as the online application process for the DSP is onerous. Eva was successful in her application even though it took 10 months from the time of her initial contact to the acceptance of her application.

#### **CASE STUDY: ‘LACHLAN’ – NAVIGATING SERVICES AUSTRALIA WITH A PSYCHOSOCIAL DISABILITY**

Lachlan is a 45-year-old man with significant anxiety and depression who was seeking access to the Disability Support Pension (DSP). A DSP application was submitted in May 2019 with the assistance of an advocate. At this time Lachlan was suspended from their job network provider and in September 2019 his DSP application was rejected by Centrelink. In October 2019 the advocate and Lachlan requested a review of the decision. Lachlan became highly

anxious at this time because of the rejected DSP, and the advice that he had been deemed able to participate in a Job Network program. Lachlan’s anxiety escalated because any participation in the job network program may jeopardise the DSP review process. To elevate this issue he had submitted a sick certificate from his GP after their Job Network program exemption period had expired, which was rejected by Centrelink as they considered this to be the same condition had he had previously had an exemption for. As the wait for a specialist appointment with a public psychiatrist was to be 8-12 months Lachlan used all of his savings and paid \$2000 for a private psychiatrist report to support his application. Between January 2020 and May 2020 the advocate rang Centrelink multiple times asking about the status of the DSP review. In June 2020, an independent medical assessment was organised by Centrelink for the client to attend via Zoom (due to COVID19 restrictions). In August 2020, the client received a letter from Centrelink confirming DSP approval and back pay was granted from May 2019 because they considered an incorrect decision had been made to reject the Client’s DSP claim. This was a positive outcome, however the whole process and timeframe for this outcome took 15 months and contributed to significant anxiety for Lachlan.

## V. Housing

This section of ADAI’s submission will focus solely on public housing, as this is the main area of advocacy assistance we provide. In South Australia Public Housing is administrated and managed by the SA Housing Authority (SAHA), which is led by the South Australian Housing Trust Board. The South Australian Housing Trust Board is responsible to the Minister for Human Services who oversees the operations of the Authority. The Executive Team is led by the Chief Executive of SA Housing Authority. The SA Housing Authority have implemented the *Disability Access and Inclusion Plan 2020 – 2024*.

In South Australia the public housing model has been moving towards a community housing model, where tenants and properties are managed by Community Housing Providers who are grant funded and managed by the state government. The 2020-2021 SA Housing Authority Annual Report names the Trust has 46,977 social housing properties with 52,319 South Australians residing in public or state owned or managed indigenous housing (SOMIH) housing.<sup>51</sup> Within the most recent Annual Report there were only four references to disability.<sup>52</sup> Of concern to ADAI in the Annual Report is that 86% of tenants have an outstanding debt on a repayment arrangement. None of the measurable targets from the Disability Inclusion Action Plan are mentioned in the 2020-2021 Annual Report.

---

<sup>51</sup> 2020-2021 SA Housing Authority Annual Report (2021) p.27.

<sup>52</sup> Ibid.

ADAI find that SAHA employees have little experience supporting or communicating with people with disabilities, even though most of their tenants have a disability or are vulnerable people. SAHA policies and procedures are hard to access and their complaint mechanisms are inadequate. The case study below provides further discussion of these issues.

### **CASE STUDY: JIM – ABUSE FROM NEIGHBOURING SAHA TENANT NO SUPPORT FROM SAHA OR SACAT**

ADAI client Jim was a South Australian Housing Authority (SAHA) tenant who was being abused by his neighbour, also a SAHA tenant. Jim has a brain injury which affects his ability to communicate. The other tenant had caused harm to Jim in the past and he had a real fear they would do it again. The tenant was regularly coming onto Jim’s property and abusing and intimidating him.

SAHA’s considered that Jim’s neighbour’s behaviour was not meant with intention to intimidate or cause harm. The Tribunal found otherwise and considered that there was a real risk to our client.

SAHA saw Jim as a nuisance due to his repeated reporting of the tenant’s abusive behaviour. They did not understand the functional impact of his brain injury and his need to report each instance of abuse. By the time Jim began working with an advocate SAHA appeared to have lost most of its compassion for Jim.

#### Procedure

Jim requested assistance to apply to SACAT for an Order of the Tribunal against SAHA to control their tenant. The advocate also referred the client to Uniting Communities Law Centre who made a short phone call to the client and did not provide further support. The advocate and Jim applied for Legal Services Commission funding which was denied. The advocate assisted Jim to go to SAPOL to get an Intervention Order against the tenant, SAPOL declined to make one. The advocate found the client assistance from RentRight who attended on the hearing days to provide support from a legal officer. The advocate also coordinated a Communication Report from a speech therapist to be written and supplied to the Tribunal to assist all parties to communicate effectively. This report was especially effective in enabling the Tribunal Member to communicate in a way that Jim benefited from. SAHA’s legal representative did not read the provided report.

#### *Applying for an Order*

A SACAT employee advised Jim that he could apply for an Order against SAHA rather than the tenant under the legislation. This meant that SAHA would have responsibility to manage the tenant’s ongoing behaviour and would avoid any conflict in the Tribunal caused by the neighbour who our client feared. The neighbour would not have to appear. Jim had previously

made an application to SACAT against another tenant years ago and an acquaintance of that tenant intimidated Jim on the day of the tribunal and caused him to miss the hearing. Jim had a real fear of this happening again. Jim wanted SACAT to make an order requiring SAHA to control or evict their tenant.

An order was sought under - South Australian Civil & Administrative Tribunal Act 2013 section 65 – quiet enjoyment.

*(c) the landlord will take reasonable steps to prevent other tenants of the landlord in occupation of adjacent premises from causing or permitting interference with the reasonable peace, comfort or privacy of the tenant in the tenant's use of the premises.*

SAHA's attitude (conveyed by the Housing Manager) was that the issue was between the tenants and that our client was breaching his own lease agreement by photographing the other tenant when they abused the client. They were unaware that Jim had been instructed to do this by SAPOL to keep a record of any incidents.

It is our advocate's opinion that SA Housing staff had minimal understanding of how to communicate with people with brain injuries. The client kept receiving pro-forma SAHA letters. The client struggles to read and write. Even when supplied with a Communication Report it was not provided to any SAHA staff outside of the Tribunal forum.

SAHA offered to organise a meeting with the other tenant and Jim. SAHA wanted everyone in the room for the meeting, our client felt that this suggestion was unsafe. The advocate felt this suggestion showed a lack of understanding of violence and the pattern of intimidation that had been occurring. SAHA only offered this suggestion after the SACAT application had been made and had done very little to resolve the matter before then. ADAI's request to have Jim meet with the Regional Manager instead was declined. ADAI believed SAHA should not be facilitating their own meeting when our client's matter was against them as the respondent. This suggestion was also only made in the days leading up to the first hearing. It was not enough time for Jim as someone with a brain injury to prepare for such a meeting.

The Tribunal heard the matter and listened to the issues. The Member agreed that the other tenant's behaviour was something that SAHA needed to address. An Order was made for "SAHA to require its tenant NAME of ADDRESS to enter into an Acceptable Behaviour Contract".

*ADAI's advocate spoke to the Compliance Officer to discuss the Order*

SAHA asked the tenant if they would sign the contract and the tenant refused. ADAI's advocate asked what SAHA will do next and the Officer explained, nothing, the Regional Manager considered the matter closed.

The Compliance Officer divulged that the regional office investigated all the complaints (around 10 made by Jim) and only found only two substantiated. The attitude that was put forward was that Jim's claims were neither believed nor considered worthy of a lengthy investigation. The advocate reminded the Compliance officer that the tribunal also investigated and have 31 paragraphs of findings in the Order. When the advocate asked whether this could be used as evidence, they told no. SAHA chooses its own evidence, their process is to ask a tenant's neighbours if they saw the incidents. If they did not see the incidents SAHA consider there is no evidence they occurred. SAHA's policy regarding the investigation of complaints is difficult to find and is not transparent.

The advocate was then told by the Compliance Officer that SAHA believe the Order made by the Tribunal 'is an overreach anyway'. The Compliance Officer then tried to rescind the comment and told the Advocate they regretted saying this.

### *Second Hearing*

The Advocate asked the Tribunal whether they would re-list the matter on their own initiative. The advocate was told no, but the matter re-listed.

At the next Hearing Jim argued that this section of the Act requires the landlord (SAHA) take reasonable and positive steps to control their tenant. SAHA argued that their reasonable steps include only asking the tenant to sign a behaviour contract and if the tenant refuses they would do nothing further. Jim was unable to get a lawyer to represent them and argue that this failed the 'reasonable steps' test. He did not have the capacity to put this argument forward himself.

The matter was dismissed and the Tribunal member told Jim that he should ask for the matter to be re-listed with the neighbouring tenant as the respondent party. Jim has a real fear of violence from the tenant and fears that the abuse at home will escalate if he does this. He chose not to re-list the matter. Jim then felt defeated. He did not appeal the dismissal. ADAI has had little contact with Jim since this time. Jim is choosing to stay inside their home as they do not feel safe outside. He feels let down by SAHA, SACAT and the system that was meant to protect them. Jim was studying part-time, working towards a qualification that offered full time work. Due to the stress of this matter, he dropped a university subject during the Hearing process. The advocate is not sure if Jim has continued his studies this year.

It was very clear that the decisions about procedure were being made at the Regional Manager level. There was no way to escalate or challenge these decisions. ADAI were unable to meet with anyone who had any authority to do so. The Housing Officer was engaged but ultimately unhelpful. He explained to the advocate that the Regional Manager 'doesn't get involved in tenancy issues' even though the advocate was aware they were making decisions

about what actions SAHA would take to respond to the issues. ADAI tried to escalate this through the complaint mechanism pathways but was unsuccessful.

There is no transparency about SAHA's policies and procedures. We could not go to SACAT and demonstrate 'these are the steps SAHA should follow to investigate and resolve complaints'. There was a real disregard of Jim's experience and disability.

#### *SAHA's failure as a model litigant*

SAHA's Legal Representative at the Tribunal appeared to have no experience of disability, violence or any understanding of the behaviour patterns of perpetrators of violence. He acted in a way that actively negatively impacted our client's disability. He was argumentative, rude, and made suggestions such as, 'if (the client) isn't happy they can just terminate their lease and use the homelessness program'. Jim took this as a threat that SAHA were going to terminate his lease if he didn't comply. He was terrified. Comments such as that demonstrated the attitude of SAHA was that they had little interest in resolving the matter or assisting Jim, and would rather get rid of his tenancy as he was the 'troublemaker'. The Legal Representative had no suggestions to resolve the matter but came prepared to argue that SAHA had done nothing wrong and that they will do nothing to further to resolve the issues. Jim left each hearing severely impacted and the advocate was very worried for his health.

When the SAHA representative was asked by the Tribunal member whether they would do a full investigation into the tenant's behaviour the Representative responded immediately with the warning that 'I would have to investigate any reciprocal behaviour of JIM'.

Eventually the Representative asked the Tribunal to dismiss the application as "we (SAHA) feel like the matter is frivolous".

Jim's advocate had been in a number of Tribunal hearings and courtrooms in the past and was appalled at the language used by SAHA's representative and his behaviour at the Tribunal. The Representative had a long opening speech prepared which outlined why the matter should be dismissed because it wasn't technically 'domestic violence'. Whether the neighbour's behaviour was domestic violence wasn't at issue in the Tribunal.

Jim was pleased with the clear way the Tribunal Member managed the process, and the lengthy reasons provided in the Order that clearly set out why the Member believed Jim's claims of abuse and harassment. Jim felt happy that someone in power believed him. SAHA dismissed the findings in the Order and failed to support Jim, their own tenant and client. Eventually when the Tribunal dismissed the matter with no further Order Jim didn't understand how they could do that and was highly upset. It fell to the advocate to explain the legal technicality. It felt like a drawn out nine-month long process and the Tribunal had just said go back to step one and try again. It was wasted time. Jim couldn't believe he was initially



encouraged to apply for an Order with SAHA as the Respondent, but that eventually the Tribunal was unable to Order them to do anything in their role as landlord. The reason was that the Tribunal felt unable to ask SAHA to compel a third party, the tenant, to follow an Order. Even though this is exactly what this type of Order exists to do. The legislation needs to be rewritten to ensure its aims and objectives can be fulfilled. Jim felt that SAHA condoned the violence against him through this process.

## VI. Guardianship and Public Administration

Guardianship Orders in South Australia are imposed through the South Australian Civil and Administrative Tribunal (SACAT). SACAT can appoint a guardian to make decisions about where a person lives, the person's health needs and any necessary services including the NDIS.<sup>53</sup>

SACAT may also appoint a guardian of last resort, the Public Advocate from the Office of the Public Advocate (OPA). In South Australia Public Advocates are not the same as independent paid advocates, their role is very different. The Public Advocate can make decisions about a person's accommodation, health and lifestyle. SACAT can also appoint the Public Trustee to administer the personal financial affairs of people who are unable to manage their own affairs.<sup>54</sup>

ADAI assist clients to review, alter, remove and defend the application of guardianship and administration orders. ADAI clients navigating guardianship are often referred by family members and friends. Most often this is once the guardianship or administration order has been applied. ADAI rarely (if ever) have clients request advocacy services with the help of their public advocate.

When assisting clients navigate matters regarding guardianship and administration ADAI has identified the following concerns:

### Public Trustee – financial administration

- No effort being made to ensure that financial administration arrangements are only short term.
- No upskilling of clients to ensure they have the skills to manage their own finances in the future.
- No future or long-term planning.

<sup>53</sup> Government of South Australia Attorney-General's Department, 'Guardianship' (Information guide, undated) <<https://www.agd.sa.gov.au/legal-rights/guardianship>>.

<sup>54</sup> Ibid.



## Guardianship

- Clients who have never met their public advocate.
- Clients who have never communicated directly with their public advocate.
- Clients who don't understand what the role of their advocates is.
- People being placed under Guardianship without access to legal support.

There is a pressing need for people facing applications for a Guardianship Order and/or an Administration Order to be legally represented. Disability advocates are indispensable, but their role stops short and needs to be augmented with legal representatives. For an in-depth discussion of this issue see ***Submission No.1 of Advocacy for Disability Access and Inclusion Inc. SA to the Royal Commission into violence, abuse, neglect, and exploitation of people with disability: The Guardianship and Administration Act 1993: The case for free legal representation.***

### **CASE STUDY: WINNIE – HEIGHTENED RISK OF HARM THROUGH APPROVAL OF GUARDIANSHIP**

Winnie is a 22-year-old autistic woman with a severe intellectual disability. She lived with her father but had frequent access visits with her mother. The parents had a very acrimonious relationship and over the years there had been protracted proceedings in the Family Court. The father felt that the mother was neglectful and unstable, so he decided to stop all contact. He then filed an application to be appointed Winnie's Guardian which was granted. Amongst other matters, this enabled him to have unilateral control about how much contact Winnie had with her mother. At no time in the process was Winnie ever consulted about her wishes and feelings in relation to seeing her mother.

If there had been a legal representative acting on Winnie's behalf they could have taken steps to ensure that her wishes and feelings were explored; this might have added weight to an argument that her well-being would be best served by placing decisions about access in the hands of a neutral third party. It is common in cases of family conflict for the Office of the Public Advocate to be appointed to the role of Guardian. This decision put Winnie at an even higher risk of violence, abuse and exploitation by isolating her and placing a single self-interested person in charge of decisions about her accommodation, health and lifestyle.

### **CASE STUDY: ANDREA – GUARDIANSHIP ORDER REPEALED, OPA NO SHOW**

Andrea and her sister contacted ADAI for assistance to remove the guardianship order under which Andrea had been placed. The advocate assisted Andrea to gather evidence for the SACAT hearing. No one from the Office of the Public Advocate (OPA) attended the hearing so the Tribunal Member repealed the Order.

If the OPA did not attend because they no longer believed that Andrea should have been under an order they should have proactively applied for its repeal much earlier.

#### **CASE STUDY: NEIL – BEST INTERESTS OF WHO?**

Neil is a 59-year-old man with early onset dementia. He had been under a joint Guardianship and Administration Order for six months before his niece contacts ADAI. Neil was the carer for both his wife and his son before his diagnosis. They now live in a separate residential care home to Neil which is a two-minute drive away. Since the OPA has been Neil's guardian and placed him in the residential care facility Neil has not seen his wife or his son. There is no reason why they couldn't all live in the same facility, and no reason why they can't visit each other. The OPA has not spoken to Neil about his wishes, nor made any proactive steps to enable him to spend time with his wife and son. Neil has a NDIS plan that was approved by the OPA, but it has no mention of his wishes to spend time with his wife and son. ADAI were not aware of any communication that had occurred between Neil and the OPA in the making of this plan.

#### **Holding the Public Trustee Accountable**

The Public Trustee is meant to act in the best interest of the trust and its beneficiaries,<sup>55</sup> but there is little policy regarding what is considered 'best interest'. In many matters that ADAI have been involved in there has been little if any communication between the administrator and the client, with the client's wishes not recorded or adhered to. ADAI consider that there is no possible way the Public Trustee can act in the best interests of their client if they have not discussed their needs with them.

Of concern to ADAI is that the Public Trustee does not appear to be proactive in its role, with little active debt recovery and no asset building, or asset protection. The Public Trustee must have transparent policies and procedures that outline how they consider and act in the best interests of their clients.

#### **CASE STUDY: TOM – HOLDING THE PUBLIC TRUSTEE ACCOUNTABLE**

Tom is a 52-year-old man. He is an amputee and lives with a psychosocial disability. He was under an administration and guardianship order, where the South Australian Public Trustee managed his finances and made decisions about his where he lived. He was living in his own home with his son and his son's girlfriend up until he became unwell and was hospitalised. While in the hospital his relationship with his son broke down and it was decided he would

---

<sup>55</sup> Government of South Australia Public Trustees, 'How Trusts Work' (Information Guide, 2021) <<https://www.publictrustee.sa.gov.au/wills-executors-trusts/trusts/how-trusts-work>>.

not move back home. Alternative accommodation was sought for him and he ended up moving to an aged care home after many months in hospital. He alerted the Public Trustees to this change in circumstances, but they continued to pay the bills for the family home for six months when Tom was not living there. The Public Trustees also paid every bill the Aged Care facility sent to them with Tom's small savings, even though 90% of these bills were to be funded through Tom's NDIS plan. Tom also received a bill from the hospital for his stay, even though he was forced to stay there while accommodation was found. The Public Trustees did not closely consider the bills when they were sent, they just paid them. Around a year later Tom received a new support coordinator who identified that he needed advocacy support for these debts and referred him to ADAI. An advocate contacted the Public Trustees and an 18-month negotiation process followed where the Public Trustees failed to rectify the mismanagement of Tom's finances as they considered too great a time had passed. The Public Trustees are not willing to speak to an advocate and kept communicating solely with Tom, but Tom found this too overwhelming. Tom eventually became burnt out with the process and withdrew his contact with the advocate.

#### **CASE STUDY: PATRICK – PUBLIC ADVOCATE NOT BEING PROACTIVE**

Patrick was injured in a car accident as a young teen and had an acquired brain injury. He was under both a guardianship order and an administration order as a young adult. Patrick had a lawyer who was being funded by his trust, managed by the Public Trustee. Seven years after the accident Patrick's settlement had not been finalised. The Public Advocate/Public Trustee had not followed up with his lawyer and no one was acting with any haste. This meant that Patrick still had this legal matter ongoing and was he unable to access any settlement monies which could have been used to improve his living situation and benefit him. When contacted, the Public Advocate did not know where the legal matter was up to. The Public Trustees were still managing Patrick's file in their Children's Trust unit. Neither were advocating for Patrick. A family friend contacted ADAI on his behalf and our advocates wrote to the Public Trustees and the Public Advocate to encourage them to act to ensure the matter was resolved. Patrick had been building up legal bills which the Public Trustees were paying as they arrived with no consideration that this matter had been drawn out for seven years and should have been resolved.

## VII. Health

Many people do not feel empowered to self-advocate when they are within the health system. Much of the work we do with clients in this area is enabling them to self-advocate by providing advice, information and acting as an ally. There appears to be efficient complaint

mechanisms within Health, as issues are often resolved after they are raised, but often they are difficult to use or access. Many people do not know about them. The most common complaint ADAI hear from clients about the health system is people in power not listening to them, not believing them, or misdiagnosing them.

Often a client will come to ADAI with another issue and report an incident that occurred within the health system many years ago. They often report that they were unwell at the time and were unable to make and resolve this complaint back then. Sometimes it is after gaining awareness and capacity that they consider that they experienced harm in the health system.

#### **CASE STUDY: SY AND BILLIE – AWARENESS AND EDUCATION ABOUT COMPLAINT MECHANISMS**

Billie rang our office line for some advice for their friend Sy. Sy lives with a chronic health condition and a psychosocial disability. Sy had that day been placed under an order through the Mental Health Act. Billie was concerned for Sy because when she had rung the hospital asking where to take Sy's medication the hospital employee had used Sy's incorrect pronouns and said Sy couldn't be able to have any medication until the psychiatrist had seen them next week (as this was close to 5pm on a Friday). Billie wanted some advice about what to do as she knew Sy's medication for their health condition could not be stopped suddenly and was concerned about the level of care they were receiving. The advocate directed Billie to the hospital's Consumer Experience Team and made other appropriate referrals. Billie felt confident to follow up herself.

#### **CASE STUDY: DON – NO DIALYSIS IN RURAL AREA**

Don was referred to ADAI by a family friend who was concerned that he was travelling to Flinders Hospital from Kangaroo Island every week for dialysis. Don was driving himself there and back, often sleeping in his car after treatment. Don's niece was hoping to apply for a carers payment so she could stop work and drive him there and back. The family didn't have the financial support to take time off work to drive him unless they could secure a support payment. Flinders Hospital were aware that Don was driving himself home but said they didn't have the resources to support him to stay locally, or to apply for any financial support to enable him to rest nearby after treatment. Don and his family weren't eligible for any immediate emergency financial assistance because Don's condition was not 'palliative enough'. Don's family were also frustrated that the local Kangaroo Island Health Service couldn't coordinate fast enough, and wasn't resourced enough, to enable Don to undertake dialysis at home. Unfortunately, while the carer's payment was still being considered for approval Don passed away.

### **CASE STUDY: BEVERLY – NO SERVICES IF YOU ARE DYING, BUT NOT FAST ENOUGH**

Beverly came to ADAI for assistance with her mental health worker. Beverly, 57, lives in a rural area of South Australia and her lung cancer had been classified as palliative. She also lives with a psychosocial disability. Beverly was getting funding from her local country hospital for a cleaner to come once a week to her home. This helped with the impact of her symptoms from the cancer and also helped with her mental health. This was only a six-week program post her exit from hospital. Beverly attempted to access the NDIS to try and get this service ongoing. After months of communication with the advocate and the NDIA Community Engagement Team it was determined that Beverly didn't meet the required visa requirements. Without the cleaning Beverly became ill again and was readmitted, then for six weeks after she could access home care and funding for cleaning. This cycle continued, which aggravated her symptoms until eventually Beverly's condition was classified as palliative-end of life, where she became eligible for further funding. Without a state funded or council funded program to assist Beverly she fell within the gap of NDIS provided services, and hospital health services.

## VIII. Justice

ADAI provide advocacy assistance for clients who need to communicate with the South Australian Police (SAPOL), or people who need to assistance from within a justice facility. Most often clients will divulge issues they have had with the justice system while seeking assistance for an alternative matter.

ADAI acknowledge the overrepresentation of people with disability in the criminal justice system. ADAI made a considered effort to promote our service within the South Australian justice facilities and assisted several clients to make a submission to the Royal Commission. ADAI have found that clients not currently within the justice system, but who have had poor interactions with the justice system, have been less interested in making a submission to the Royal Commission as they often hold concerns about privacy and further victimisation.

ADAI had multiple clients who wanted to make a submission about their experiences with the justice system, and SAPOL officers in particular. Advocates heard several stories from clients who had similar complaints. Often people would refer to SAPOL as 'corrupt', or as having 'tried to kill me', or being 'out to get me'. While making a submission to the Royal Commission an ADAI client stated that 'people don't want to believe corruption within institutions like the justice system because they rely on them to function properly'.

When an advocate has taken the time to listen to these complaints of corruption and asked further probing questions, they have found that multiple clients have experienced:

- Being cuffed and put in the back of a SAPOL wagon untethered.

- Having officers whisper to them something along the lines of ‘complain and I’ll make sure they get you’.
- After divulging a disability such as an anxiety disorder or a brain injury an officer has then tried to provoke the client into having an attack or a fit.
- Being arrested after they attended a police station to make a report because they became loud and frustrated when the officer won’t take the report.
- Asking to be communicated with in a certain way (e.g. email) and having that request ignored or not recorded.
- Officers seeing them act or move differently in public because of the impact of their disability and being asked questions and feeling harassed.
- Officers believing them to be drunk and treating them as though they were a nuisance because of the functional impact of their disability.

The majority of clients who recorded issues such as these above have cognitive disabilities. SAPOL must improve their training around communicating with people with disability, especially people with cognitive disabilities such as brain injuries.

ADAI clients commonly recall difficulty communicating with SAPOL and feel intimidated by the process. One of ADAI’s clients recommended that there be an advocacy service available for people to go to when they need to make a report or are required to go to a police station. He wanted someone there to help him communicate with the police, and an ally to enable him to exercise his rights. More people need to be aware of advocacy services that can assist with these matters, and they must be funded to be appropriately responsive.

#### **CASE STUDY: BRIAN - TRYING TO MAKE A REPORT TO POLICE**

Brian had been threatened by some people he knew and was feeling unsafe at home. He had been stalked home and abused. He wanted to make a report to the police, so he approached an advocate to get help making one. The advocate had heard of specialist police officers who were trained to work with vulnerable people. Brian and the advocate rang a local police station for advice. The advocate asked the person answering the phone if they had any specialist police officers working in the northern region. The person/police officer at the station asked what area they were looking into. The advocate responded with ‘Elizabeth Park’. The person/police officer on the phone answering by stating with clear frustration that ‘each Park did not have its own Police Officers’. The advocate had to explain that Elizabeth Park was the suburb name. The person/police officer on the phone continued to be rude and abrupt and Brian decided against making a report.

#### **CASE STUDY: ABBY – SAPOL ‘IT’S JUST A NEIGHBOUR DISPUTE’**

Abby came to ADAI for advocacy assistance with a Housing SA transfer. At the time she was living independently with minimal formal and no informal supports. Abby has an intellectual disability and wanted assistance to move away from an aggressive neighbour. During the period she was working with an advocate Abby experienced a major incident with the neighbour threatening her, knocking on her door all through the night and wielding a knife. She was unsure of what to do, so she waited in fear all night until she knew her advocate would be in the office in the morning. Abby called the office and the advocate informed her to contact the police and when she did so was advised by SAPOL that she needed to phone them at the time the threats were being made. The advocate then accompanied her to the police station to make a report that afternoon. Our advocate also contacted the local Mental Health Team, who were aware of the situation with Abby's neighbour as they were a client, and advised that a rapid response team would be attending soon.

When Abby and the Advocate returned to her house police were present and told Abby it was just a neighbour dispute and there was not much they could do. This was extremely intimidating and upsetting for Abby. The advocate needed to strongly advocate for Abby, informing the police that Abby's neighbour was having a mental health episode, that the Northern Mental Health Services Rapid response was aware of the situation and would be attending soon. The attitude of the police changed slightly and they were more understanding of Abby, and the risk to her safety but were essentially unhelpful.

## PART 4: REMOVE THE BARRIERS

To improve inclusion in society for people with disability we must break down the barriers to access. We must end ableism and change attitudes that influence negative behaviours which result in harmful acts towards people with disability. The below discussion is a short selection of barriers ADAI advocates have identified that could be overcome with further funding for advocacy and small changes to common systemic attitudes and procedures.

### A. Increase Access to Supported Decision Making

A safer system for people with disability requires the inclusion of every voice. While many people with disability can speak out for themselves when their care is unsatisfactory, and should be encouraged to do so, those who cannot are especially vulnerable. A robust system of advocacy is required to ensure that those who need support to speak up when something is not right are able to access that support.<sup>56</sup> Advocacy provides people with disability support and capacity to make and participate in decisions that impact their lives to ensure their rights are promoted and protected.<sup>57</sup>

The Convention on the Rights of People with Disabilities (UNCRPD) is the first international treaty to recognize that all people including those with disabilities should enjoy legal capacity on an equal basis in all areas of life. Article 12 affirms that ‘all persons with disabilities have full legal capacity’.<sup>58</sup> Article 12 requires States to support individuals who are in need of it and to safeguard against abuse within that support system.<sup>59</sup> This calls for a system of supported decision-making that could take many different forms including by having one trusted support person or a network of support people providing assistance on a one-time basis or consistently throughout an individual’s life.

The traditional approach has been to prioritise any perceived risks and appoint substituted decision makers. In one of our recent NDIS appeal cases the NDIA did not encourage supported decision making and declined funding for extra support worker hours on the basis that ‘increased support worker hours won’t decrease the risk to the client’. Instead, the NDIA increasingly focussed on implementing a substituted decision making. This argument showed a flawed understanding of supported decision making and the safeguarding benefits of

---

<sup>56</sup> Victorian Ombudsman (2015a) Reporting and investigation of allegations of abuse in the disability sector: Phase 1 – the effectiveness of statutory oversight, p 9.

<sup>57</sup> Disability Advocacy Network Australia, ‘Submission on the Draft National Disability Advocacy Framework’, *National Disability Advocacy Framework 2022-2025 Consultation* (July 2022) p3.

<sup>58</sup> UN General Assembly, *Convention on the Rights of Persons with Disabilities*, adopted by the General Assembly, 24 January 2007, A/RES/61/106. Article 12.

<sup>59</sup> Ibid Article 12 and 16.



support workers especially for people with cognitive or intellectual disabilities. In our view properly funded support people and advocates can play an important role in supported decision making by helping to balance the perceived risks with an individual's rights to control their lives. Supported decision making empowers the individual and should be considered ahead of the appointment of a substituted decision maker. Public agencies and bodies should encourage and assist with supported decision making where required.

Advocacy ensures that people with disability are included in all forms of decision making. ADAI support DANA's recommendation that we must 'strengthen the inclusion and involvement of people with disability in decision making, co-design and organisational governance.'<sup>60</sup> Inclusion and representation leads to co-designed products which ensure the needs of the people the program is for, are being met.

ADAI agree with People with Disabilities WA's findings that prevailing attitudes are paternalistic, in that there is an assumption that a person without a disability is better placed to make decisions in the best interest of the person with disability.<sup>61</sup> This often comes from the tension between dignity of risk and the duty of care of providers,<sup>62</sup> with providers preferring to mitigate their risk and liability, but in doing so remove the decision making from the person with disability, which is an act that can cause harm in itself.

The NDIA has produced a 'Support for Decision Making Consultation Summary Report' after undertaking a consultation process with the aim to produce a policy on supported decision making. This report was published in December 2021. As of December 2022 no policy has been produced, and ADAI understand the drafting of the policy has been set aside.

The Report found that:

*Overall, you told us that it is important that we have a policy about how we support people with disability to make decisions and that you want us to work with you and others to get this right.<sup>63</sup>*

*You told us that having people to help, who are working together with you, is one of the best supports for decision making.<sup>64</sup>*

---

<sup>60</sup> Disability Advocacy Network Australia, Submission to the Disability Royal Commission into Violence, Abuse, Neglect and Exploitation: Independent Disability Advocacy, *Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability* (December 2022).

<sup>61</sup> People with Disabilities WA, *Issues paper: Safeguards and quality*, 'Submission to the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability', (undated) p10.

<sup>62</sup> Ibid.

<sup>63</sup> National Disability Insurance Scheme, *Consultation summary: Supporting you to make your own decisions* (December 2021) p11.

<sup>64</sup> Ibid p14.

By delaying the policy NDIA have demonstrated that they believe that a Supported Decision Making Policy is not important right now.

#### **CASE STUDY: KIM – NDIA INSISTS ON USING OWN RISK MATRIX**

Kim is a young man with cerebral palsy who wants to move into his own unit. His family have used a community housing provider to find one that is suitable and will accommodate his lifting equipment. Kim's housing provider has completed their own risk assessment and Kim and the provider are both happy with the unit. The NDIA is unwilling to approve payment for the unit until it is able to undertake its own risk assessment. This would mean that Kim's family would have to pay the bond and sign the lease to enable the NDIA to do this. The NDIA have refused to conduct the risk assessment until this payment has been made. Kim and his family don't want to pay bond and sign the lease if there is a risk that the NDIA will not approve the property. The matter is currently before the AAT and at a recent conference the Tribunal member told the family they were 'being ridiculous' and 'holding up the process' and that she 'knew the case manager well and they should trust him'. The family was concerned the Tribunal member was not impartial. At this point the housing provider has kept the unit open and empty for a year waiting for the NDIA to overcome their own red tape. This demonstrates that the NDIA considers that Kim is not allowed to make his own decisions about where he lives.

## **B. More Advocacy for Rural and Regional South Australia**

ADAI provide a state-wide advocacy service and run a successful Outreach Program making regular visits to Kangaroo Island, Port Lincoln, Port Augusta, Yorke Peninsula and their surrounding areas. Outreach visits are limited by funding and availability of advocacy staff.

Approximately one third of the Australian population live outside of major cities. Those who live outside of major cities experience health disparities, higher levels of preventable deaths and a five-year mortality gap when compared to metropolitan dwelling persons.<sup>65</sup> Advocacy should be easily accessible to those who live in rural and regional South Australia to close these gaps.

---

<sup>65</sup> Waycott and Garad, 'The role of health literacy in reducing health disparities in rural CaLD communities', presented at the 13th National Rural Health Conference, (May 2015).

## Kangaroo Island Outreach Program

In 2019/2020 the Australian bushfire season severely impacted many communities, primarily in the country's southeast. People living with disabilities and their families were significantly impacted. In response ADAI created the Kangaroo Island Outreach Program.

### *Client numbers*

#### 1 July 2019 – 30 June 2020

*0 clients Kangaroo Island*

#### 1 July 2020 – 30 Sep 2021

*22 Clients*

*10 clients were vulnerable/isolated*

*20 Enquiries resolved*

#### 1 October 2021 – 31 December 2021

*10 clients*

*1 Education session – 9 participants*

*4 Enquiries resolved*

#### 1 January – 30 June 2022

*19 Clients*

#### 1 July – 31 December 2022

*12 Clients – 3 of those for NDIS Appeals*

ADAI initially linked in with the Bushfire Recovery Centre located in Parndana, Kangaroo Island, and provided advocacy services to residents. Many clients were referred by the centre for practical support with issues such as DSP applications, carer payment applications or advice about applying for the NDIS. Many clients had been living with disabilities or medical conditions and managing on their own for many years. It was only identified that they were eligible for more support when they came in for assistance with alternative, bushfire related, issues. After the funding for the Bushfire Recovery Centre ended and no alternative support was funded in that specific area ADAI received no further referrals from Parndana. ADAI are concerned that without the locally accessible service there is growing unmet need.

ADAI uses an intake form which records whether people self-identify as having a disability or medical condition. The percentage of clients who identified as having a disability or as needing support was very small. Despite this, during the intake process it was identified by staff that around a quarter of the clients (who were accessing services as carers or support people) had a disability or a medical condition.

ADAI found that people either did not identify as having a disability or a medical condition, were unwilling to discuss it, or lacked a diagnosis. One barrier may be a lack of awareness and information about disabilities and medical conditions. Sometimes the barrier to identifying as having a disability and accessing supports was the stoic nature of rural community members themselves.

One issue that was identified was that for the age group of clients who were 70 plus there was a strong emphasis on staying at the farm and a lack of formal or regular informal supports. Some discussions were had with clients about having carers in the home or applying for My Aged Care. ADAI flagged with clients that there are different options available for care in the home. Clients assured advocates that either that they had everything in hand, spouses had everything in hand, or that children would provide those services.

Staff identified that there was a reluctance to engage with services, and a reluctance to acknowledge there was a need. No clients wanted to take the step to apply for My Aged Care.

ADAI also saw clients who had managed by themselves for a long time, but were now in acute need of a higher level of care and were no longer managing at home on their own. Because they had limited prior experience with bureaucracy, it was much harder to keep these clients engaged and harder still to reduce their risk of harm by connecting them to support services.

Some clients presented as benefiting from some in-home assistance. ADAI staff knew of some services they could refer clients to but weren't sure of their availability or how to make a referral. It was hard to find information about availability, waitlists, and whether in home services are provided on Kangaroo Island. This is the same for many rural and remote areas. Health information is often not accessible. Referral pathways weren't clear, and who provided what service was also not clear. Often advocates will make positive connections with a local service provider, but then that employee will move on and the connection will be lost and referrals will stop.

The aged care services available on Kangaroo Island are at full capacity for both respite and residential aged care. State Government funding has recently been received for a new residential aged care service located near the current hospital. My Aged Care is also not very well publicised to residents. Many people don't know how to apply or what is available.

One issue ADAI have with referrals for rural and remote services is the disappearance of services. It is often unclear when a service would be in town next. In Kangaroo Island the Salvos and the Financial Counselling Service both stopped coming for a period of time and there was no communication about when they would return.

Recently ADAI have seen funding preferences for larger state-wide service providers, rather than small, localised services. Some funding is provided in rural and remote areas for project based work, but this type of funding enables inconsistency in service provision.

Some of the state-wide services that are on offer regionally do not offer the same level of service they can offer in the metropolitan area.

The most common question advocates heard on Kangaroo Island was ‘when are you returning?’. Clients were sceptical of fly-in-fly out services as they had experienced many start offering services only for them to never return to the Island. There is a strong demand for in person, face to face appointments. Initially ADAI had around 15% of clients disengage due to difficulties with the distance, lack of frequent meetings, or were frustrated by the time taken to resolve an issue.

Telecommunication services, especially phone reception can be poor on Kangaroo Island, and internet connections are not in many households. ADAI have had clients who have to drive to the end of their driveways to get reception because they have none around their home. We have also been referred to a number of clients who are vulnerable, but have declined to engage and due to the infrequency of our visits we have not been able to build up a strong rapport with them to provide advocacy.

If we do infrequent visits, don’t communicate with the community or are unable to provide the same level of service that we do to our metropolitan clients there is a risk that Outreach services will fail. Outreach advocacy needs to be funded further.

#### **CASE STUDY: WHERE ARE THE COUNSELLORS?**

Advocates met with the local Child and Family Health Services (CaFHS) nurse in a rural town of South Australia to share information about service provision and advocacy. Advocates were travelling with counsellors from Relationships Australia utilising the Royal Commission funding. The CaFHS nurse was especially interested in referring clients to family counselling, as she saw many families struggling who would benefit from proactive counselling. Unfortunately, the service provider who has the funding for relationships counselling in this regional area only offers zoom appointments, while you can make in-person appointments in the metropolitan area. The CaFHS nurse explained that zoom counselling is not good enough and that her clients need in-person counselling. For many parents with children with disabilities there is already a dearth of services in regional areas, a lack of counselling can exacerbate any other issues the families are dealing with. The advocate offered to contact the funding body on her behalf, but she didn’t feel comfortable putting her name to anything in writing and as the only CaFHS nurse in the region she would have been easily identified.

### C. Increase Funding for Legal Services

Many clients would benefit from some legal advice from a community or public legal service, but are unable to access any. Advocates are not meant to be providing legal advice but are often left to navigate legal systems due to a lack of other more appropriate supports. In South Australia region-specific legal services are funded to provide general legal advice. The Legal Services Commission provides a legal hotline and funds a small number of legal matters. For NDIS AAT Appeals matters you can get a single hour on the phone with a lawyer. The LSC also take on some clients for NDIS Appeals matters but the number of clients ADAI have been able to refer has decreased dramatically in the last 18 months. The Uniting Communities Law Centre is also funded to provide legal support for NDIS matters, although ADAI have not been able to make a successful referral into this program as it is constantly at capacity.

Although ADAI are unaware of any specific policies LSC utilise, the preference in South Australia appears to be that either the LSC take on a client's matter in its entirety, or they only provide one free long form phone call. Clients may ring up with short questions as well at any time through their advice line. Many of our clients would benefit from legal assistance, even in the form of a legal advice letter.

With access to legal advice many ADAI clients would be able to resolve matters quickly and more effectively. ADAI advocates are finding that they are being assumed to act as quasi-legal officers, especially provision of NDIS Appeals advocacy. Advocates have had to remind NDIA lawyers multiple times that advocates are not lawyers and their clients are actually unrepresented.

For further discussion of these issues please see

***Submission No.4 of Advocacy for Disability Access and Inclusion Inc. SA to the Royal Commission into violence, abuse, neglect, and exploitation of people with disability: Capability and Culture of the NDIA***

and

***Submission No.1 of Advocacy for Disability Access and Inclusion Inc. SA to the Royal Commission into violence, abuse, neglect, and exploitation of people with disability: The Guardianship and Administration Act 1993: The case for free legal representation.***

#### **CASE STUDY: 'RAELENE AND SHANE' – A CASE FOR SHORT FORM LEGAL SUPPORT**

Raelene is the primary carer for her 28-year-old son Shane. Shane has an intellectual disability and requires a lot of assistance and prompting so he can complete his day-to-day tasks. Raelene works in security in hospitality venues and primarily only has night shifts available to her. She wants to be able to work 25 hours a week not only to pay their bills, but for her own mental health. She told this to Shane's NDIA planner who reassured her Shane would receive a plan that worked for them. When the plan arrived Shane was funded for six hours a week

1:3 support. This would not allow Raelene to hire a support worker to come into their home and support Shane while she worked. She appealed Shane's plan and was told by the NDIA Lawyer that the NDIA do not fund 'respite services', but if Raelene wanted, they could look at funding Supported Independent Living for Shane. As the NDIA considered on the evidence available Shane that would only be eligible for 1:3 funding, it would have to be a group home. Shane had tried sharing a home with a housemate before and came home traumatised after being assaulted. The NDIA Lawyer did not have this information in the file. Raelene believed the NDIA were asking her to choose between work or institutionalising her son. She was a strong self-advocate but she didn't know the legislation to argue against the lawyer. She would have benefited from an hour of legal advice with a lawyer and a written letter of advice to give her some legal framework going forward. The advocate could not get a referral for Raelene as no community organisations were available to assist and the LSC was not funded to provide that support.

## PART 5: CONCLUSION – Clients in crisis and advocacy at capacity

ADAI is consistently at capacity with advocates managing a high case load and constantly navigating multiple issues. ADAI maintain a waitlist for services and demand is consistent. For the period from 1 January – 31 December 2022 the average time recorded spent working on a client file was approximately 10 hours, up from approximately 8 in 2021. Some client files have upwards of 50 hours recorded advocacy time and advocates are increasingly seeing NDIS Appeals files involving a minimum of 18 hours from start to resolution. Several NDAP/Appeals files have involved over 100 hours of advocacy. As of December 2022 ADAI had 86 clients on their waitlist with an average wait time of five months. Advocates are recognising an increasingly complexity of matters, and growing barriers to access and navigate systems. The advocacy sector needs to be funded appropriately to meet the growing demand for services.

### A. People with disabilities in poverty

ADAI are concerned about the number of clients living in poverty. Many are trying to navigate inaccessible systems, or are caring for children without appropriate financial support. Often advocates find that financial issues become a primary concern for clients, who might set aside their health needs to resolve those issues first, causing long-term harm. There is extensive anecdotal evidence about the increased risk of harm for people with disabilities living in poverty but more research needs to be undertaken.<sup>66</sup> ADAI argue that allowing people with disability to live in poverty is a policy choice.

ADAI provide advocacy clients with chronic health conditions who are not eligible for disability support, but who cannot afford specialised health care. There are few public services offered to people with disability or chronic health conditions who do not qualify for the NDIS. Other clients may be eligible for the NDIS but cannot afford expensive assessments to confirm their diagnosis, or are left on public waiting lists for an assessment for up to two years. ADAI support the recommendations in the Joint Submission from Disability Representative Organisations 'Identified gaps in the scope of work undertaken by the Disability Royal Commission as at November 2022', in that they have identified as a priority area the need for further examination of the intersection between disability and poverty and the need to

---

<sup>66</sup> Jericho, G 'The pandemic showed us that poverty is a policy choice – we must do better' *The Guardian* (News Article, 15 December 2022).



ensure that further research is commissioned to ‘examine and address the impact of structural, institutional economic neglect on people with disability’.<sup>67</sup>

In the Preamble of the UNCRPD the fact that ‘the majority of persons with disabilities live in conditions of poverty, and in this regard recognizing the critical need to address the negative impact of poverty on persons with disabilities’ is clearly stated.<sup>68</sup> Many ADAI clients are trying to navigate issues while living in poverty. The Disability Support Pension should ensure that any Australian experiencing impacts of a disability which prevent them from employment, has the means to live a dignified and contributing life in our community.<sup>69</sup>

### **CASE STUDY: DANIEL – POVERTY AND THE IMPACT ON HEALTH**

Daniel is a young man who lives in a rural area of South Australia. He lives with a form of epilepsy that is often triggered by stress, a lack of sleep or not eating the required nutrient rich foods. Work is not constant where Daniel lives so sometimes he gets one shift a week, other times he gets six. When Daniel doesn’t have many shifts he lives off toast and cup of soups, often having more seizures those weeks. Daniel came to ADAI for assistance to access the NDIS so he can get support for his epilepsy, but the advocate explained that he doesn’t fit the criteria. He tells the advocate he is sleeping on a friend’s couch and only has \$21 left for the week. The advocate asks Daniel to list his upcoming bills and assists him to delete some reoccurring payment subscription services he doesn’t need. The advocate helps him to book in an appointment with his GP to review his medication. Daniel is frustrated he can’t get NDIS support, but he tells the advocate he doesn’t feel like he is spiralling out of control anymore.

## **B. Increasingly complex issues and clients in crisis**

ADAI advocates are often prioritising crisis response work over other forms of general advocacy due to the increasing complexity of issues and the presentation of clients in crisis. ADAI are finding resources significantly stretched to meet the increasing demand for services. DANA, the peak body for advocacy agencies, has collected data that demonstrates a collective strain on advocacy services across Australia. They state that this has been caused by chronic

<sup>67</sup> Joint submission from Disability Representative Organisations, ‘Identified gaps in the scope of work undertaken by the Disability Royal Commission as at November 2022’ (Submission to the Royal Commission into violence, abuse, neglect, and exploitation of people with disability, 21 November 2022) p5.

<sup>68</sup> UN General Assembly, *Convention on the Rights of Persons with Disabilities*, adopted by the General Assembly, 24 January 2007, A/RES/61/106, Preamble.

<sup>69</sup> Mental Health Australia, ‘Institutional economic neglect in relation to the Disability Support Pension’ (submission to the Royal Commission), pp.8.

under-funding, exacerbated by the strains created by COVID-19 and other emergencies, and the ongoing high demand on NDIS Appeals advocacy.<sup>70</sup>

When advocacy agencies are increasingly forced to prioritise crisis response work for clients who are at risk of immediate harm, the important preventative and proactive advocacy work is set aside. Much of this preventative work is outlined in Part 1 of this submission, the awareness raising, rights education, systemic advocacy, capacity building and early-stage resolutions. Much of ADAI's advocacy work is forced to be reactive, in that clients seek out our services and apply for our waitlist after identifying an issue they need assistance with. Advocacy work needs the flexibility to be proactive, but ADAI is consistently at capacity and advocates do not have the time to undertake preventative advocacy. This also means that ADAI are unable to efficiently address our unmet need and seek out clients those hard-to-reach client who otherwise would not know about our services, such as people in institutional settings and closed supported living facilities.

If ADAI could make referrals to case managers for vulnerable people in crisis they would be able to return to their important early intervention advocacy work and reduce the unmet demand on advocacy services. ADAI recommend that case managers be funded through a central body, so they can work across departments and systems. They could be implemented into a Care Finder style model for people with disability.

There are many risks to the community if advocacy is not properly funded and resourced. ADAI hope the Royal Commission into violence, abuse, neglect, and exploitation of people with disability put forward for action the recommendations provided in this submission, to ensure that people with disabilities live free from violence, abuse, neglect and exploitation.

---

<sup>70</sup> Disability Advocacy Network Australia, 'Submission on the Draft National Disability Advocacy Framework', *National Disability Advocacy Framework 2022-2025 Consultation* (July 2022) p9.