



National Centre for
Disability Advocacy

Systemic Advocacy Insight Report No. 1

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Abbreviations

Abbreviation	Definition
AAT	Administrative Appeals Tribunal
AWPR	Activity Work Plan Report
CALD	culturally and linguistically diverse
DANA	Disability Advocacy Network Australia
DRAS	Disability Rights Advocacy Service
DRC	Disability Royal Commission
DRO	Disability Representative Organisations
DSS	Department of Social Services
IER	Independent Expert Review
ILC	Information, Linkages and Capacity Building
NCDA	National Centre for Disability Advocacy
NCF	National Coordination Function
NDAP	National Disability Advocacy Program
NDIA	National Disability Insurance Agency
NDIS	National Disability Insurance Scheme
PITC	Partners in the Community
QAI	Queensland Advocacy for Inclusion
QIDAN	Queensland Independent Disability Advocacy Network
SDM	Supported Decision Making
SCIA	Spinal Cord Injury Australia
SDA	Specialist Disability Accommodation
SIL	Supported Independent Living
TTSS	Taxi Transport Subsidy Scheme
VALID	Victorian Advocacy League for Individuals with Disability
VMIAAC	Victorian Mental Illness Awareness Council Inc
WAT	wheelchair accessible taxi

Note: The purpose of this report is to identify and elevate the systemic work undertaken by Independent Disability Advocacy Organisations across Australia. Names of organisations who deliver independent advocacy have been styled in bold text at first mention within the body of this report.

Executive summary

The National Centre for Disability Advocacy (NCDA) has been established to improve access to, and quality of, disability advocacy services. One of the core functions of the NCDA is to identify and elevate systemic issues being addressed by independent disability advocacy organisations across Australia and bring these to the attention of government agencies, Disability Representative Organisations (DROs) and broader civil society.

It is not the role of the NCDA to coordinate or undertake systemic advocacy activities, but to collect information and analyse emerging issues that are informed by the disability advocacy sector. This includes organisations funded through the National Disability Advocacy Program (NDAP) and similar state-funded organisations that predominantly deliver individual advocacy but undertake some systemic advocacy when they have capacity.

Many NDAP organisations have cited concerns regarding limited capacity and resources for undertaking systemic advocacy. An NDAP standard funding agreement through the Australian Government Department of Social Services (DSS) will only permit a maximum of 10% of funding to be used for systemic work. Organisations claim this limits their ability to undertake systemic work for the most disadvantaged people with disability. Some organisations use this portion of funding to participate in state-based or regional networks. Others use the funding to identify trends from their individual advocacy work, write case studies and send these on to DROs in the hope it will contribute to a campaign or submission the DRO is developing.

Information for this report has been collected from January to December 2023 a . Key issues identified include:

- the NDIS (p 10)
- Housing and accommodation (p 14)
- Education (p 20)
- Transport (p 21)
- Accessible communities and facilities (p 24)

The NCDA used several methods to collect data, including:

- attending state-based advocacy networks
- meeting with individual organisations
- facilitating the online National Systemic Advocacy Forum for independent disability advocacy organisations.

During this process, advocates discussed the need for a systemic advocacy framework. The framework would contain clear information on systemic advocacy, including defining systemic work and activities. This framework may also give suggestions on the best pathways to escalate systemic issues and trends. This would ensure a greater shared understanding on systemic work

without being prescriptive. This is something the NCDA could co-design with the advocacy sector in future work programs.

Systemic advocacy is diverse and can include work undertaken at a local, state, or national level. Activities can include attending meetings with local Members of Parliament, media interviews, providing feedback on government reports, writing case studies, or contributing to submissions. There are no prescribed activities, only that policies, procedures, laws, or community is altered in a way that creates a more inclusive and equitable society for people with disability.

This report looks at emerging issues in 2023 as informed by advocacy organisations. It demonstrates a sector doing significant work to improve the outcomes for people with disability through various approaches. Overall, it identifies a sector that achieves its best systemic outcomes when working in collaboration with other like-minded organisations, including peak bodies, DROs, and networks.

Introduction

The National Centre for Disability Advocacy (NCDA) is a project delivered by Disability Advocacy Network Australia (DANA) with funding provided by the Australian Government Department of Social Services (DSS). The NCDA aims to improve access to, and quality of, independent disability advocacy services as part of Australia's Disability Strategy 2021-2031.¹ The NCDA does this by executing 3 main functions, which are:

- capacity building²
- identifying and addressing unmet demand and unmet need
- identifying and elevating systemic advocacy issues.

This report focuses on the third function of the NCDA, which is “identifying and elevating systemic advocacy issues” being undertaken by organisations providing independent disability advocacy, including National Disability Advocacy Program (NDAP) organisations and similar state-funded organisations across Australia. The report aims to bring these issues to the attention of key stakeholders, including:

- DANA, which delivers systemic advocacy on behalf of DANA members and works with other national Disability Representative Organisations (DROs). DANA's Advocacy and Policy Team is also tasked with the:
 - National Coordination Function (NCF), which coordinates systemic advocacy activities for DROs
 - National Disability Insurance Agency (NDIA) Disability Representative and Carer Organisations Secretariat, which provides support for these national organisations to engage with the NDIA
- the disability advocacy sector
- federal and state/territory governments and their associated agencies, including the DSS and state and territory departments tasked with disability and other relevant portfolios
- wider civil society, including peak bodies, such as Australian Council for Social Services, National Shelter, Homelessness Australia and National Disability Services.

Use of the report is likely to be varied. It may be used to inform individuals and organisations of current campaigns and actions being taken to address systemic

¹ Department of Social Services (DSS), 3 February 2022, [Australia's Disability Strategy 2021-2031](#).

² These activities include both capacity and capability building. According to the sector, “capability” refers to having a workforce, including the skills and experience, to do the work, whereas “capacity” refers to having the time to do the work. Capacity building will be used in this report as it is consistent with the aim of the centre, which is to deliver resources to the sector to build their capacity to deliver more services to clients.

issues. It may also provide examples of good practice approaches related to systemic work, as well as facilitate information sharing and collaboration across organisations and jurisdictions to encourage national campaigns where appropriate. According to the National Disability Advocacy Framework 2023–2025:³

“Systemic advocacy involves working for long-term social change to ensure the collective rights and interests of people with disability are served through legislation, policies and practices.”

Activities deemed systemic advocacy are varied. It can be a submission to government on the impact a proposed bill will have on a particular cohort, a campaign highlighting issues with event registration for another cohort, or maybe a meeting with a local council to highlight an accessibility issue in a Local Government Area. Systemic advocacy can occur in many forms and at many levels. It relies on the trends identified by individual advocacy activities to ensure systemic efforts are effective and have the most beneficial outcomes.

It is not intended that the NCDCA undertake or coordinate systemic advocacy activities. Its role is to develop and implement a methodology to identify, monitor, and elevate systemic issues identified by advocacy organisations and facilitate opportunities for collaboration within the sector.

The NCDCA will provide a channel for individual advocacy organisations to report emerging systemic issues identified during individual advocacy work with clients. A significant portion of the initial NCDCA consultation process focused on the benefit and the value all levels of government place on systemic advocacy regardless of the size of the organisation.

This report highlights resource-stretched individual organisations contributing to larger bodies of systemic work. It will demonstrate the diversity of activities the advocacy sector has been involved with during 2023. Examples:

- Providing case studies from individual advocacy work to demonstrate emerging systemic issues. This allows people to understand the context and humanity of a situation within a wider systemic issue. The NCDCA is aware of many deidentified case studies being provided from individual advocacy organisations to larger systemic campaigns. One example focused on an entire family at imminent risk of eviction due to an incremental rental increase; the story discussed the effects this would have on the family's employment, service provision, and schooling if they were to be evicted. This case study was used in a recent housing and homelessness inquiry to demonstrate the current frailties of the housing market for people with disability.
- Individual organisations being part of a collaborative state or regional network. In WA, an organisation raised concerns that Metronet's Morley- Ellenbrook Line project, currently under construction, may not be

³ DSS, no date, [National Disability Advocacy Framework 2023–2025](#), p. 3.

accessible. As a result of this concern, advocacy organisations joined community advisory groups that were established by Metronet for each station along the route. The WA Advocacy Collective then coordinated its efforts to ensure a member organisation attended each advisory group so that access issues were prioritised and addressed.

- Contributing to submissions that peak bodies and DROs are preparing, through provision of advocacy data or individual case studies, or other forms of input such as sharing insights through discussion forums. Organisations providing information to DANA that can be used in a submission to the National Disability Insurance Scheme (NDIS) Review is an example.

This insight report presents information that has been collected by the NCDA and highlights emerging systemic trends informed by the work disability advocacy organisations are undertaking nationally. Over time, these insight reports will demonstrate the valuable systemic contribution being performed to support positive outcomes for people with disability.

Methodology

Five main methods were used to collect the information in this report:

1. State-based network attendance and documentation
2. National Systemic Advocacy Forum
3. Individual engagement with advocacy organisations
4. Activity Work Plan collection
5. Organisational sector survey.

1) State-based network attendance and documentation

Most states and territories have a network for independent advocacy organisations. The purpose of these networks is to foster collaboration and raise awareness of relevant issues for organisations within the jurisdiction. These networks involve organisations meeting regularly to discuss advocacy. Meetings may also include guest speakers, discussion on practice, updates on funding, and opportunities for organisations to share news of their current work.

A key component of these networks is the space for collaboration. When organisations share, emerging issues are often discussed leading to opportunities to partner with others to create campaigns to address systemic issues.

During 2023, each state and territory network has cited various issues seen as priority areas for their network; these have informed the findings of this report.

While each state and territory is unique in its approach to networking, a common theme is joint concern for the current funding model and its limitations in providing adequate resources to ensure the best outcomes for people with disability through formal advocacy.

Between March and November 2023, the NCDA team attended 17 formal meetings involving state-based networks.

2) National Systemic Advocacy Forum

In September 2023, the NCDA hosted an online forum on systemic advocacy in partnership with DANA. The forum was advertised through the NCDA and DANA mailing lists, and people were directed to register online. As part of the registration process, attendees were asked to identify their top 5 systemic issues for the past year.

45 people attended from the sector, as well as 7 DANA/NCDA staff members. The agenda involved introducing the roles of the NCDA and DANA in systemic work. This included DANA outlining its role with the NCF as well as introducing the policy team and raising awareness of its function in partnering with members in lodging submissions.

The forum then progressed into creating opportunities for collaboration. This involved break-out rooms for smaller group discussion to enable participants to explore their top 5 issues in more detail as well as any systemic advocacy activities they were involved in to address these issues.

Dialogue between organisations focused on identifying systemic advocacy issues. The forum also allowed for an analysis of the current state of systemic work in the sector. In time, a greater focus will be placed on facilitating opportunities for sharing and collaboration.

3) Individual engagement with advocacy organisations

Over the year, the NCDA formally met with over 15 NDAP organisations on a one-on-one basis. These meetings were a chance for both parties to build a purposeful relationship and understand how each other operates. They occurred with either an entire advocacy team or a key team contact. Meetings were designed to encourage dialogue and collect information on how the organisation does its work, including discussing intake processes and waiting lists, and giving an overview of any systemic work the organisation has been involved with. The issues raised by organisations in these meetings were noted and have informed the content of this report.

4) Activity Work Plan collection

During August of each year, NDAP organisations are required to provide the DSS with an Activity Work Plan Report (AWPR). This report outlines the work the organisation has been doing over the previous financial year. One portion of this report is dedicated to identifying systemic issues and associated activities. Organisations must also provide case studies that demonstrate the type of individual advocacy work they have been engaged with. While these reports are effective at keeping the DSS updated on organisational activities, the NCDA believes the sector would benefit from the in-depth analysis they provide.

During regular meetings, the NCDA has requested the DSS communicate to their Funding Arrangement Managers that NDAP organisations be allowed to

copy the systemic and case study components of their AWPR to the NCDA, to provide another avenue of data collection and collation.

The NCDA then publicised this request via the monthly newsletter. While the response was limited, the detail gained from this method was significant and included submissions to governing bodies, as well as summaries of meetings with local, state, and federal representatives.

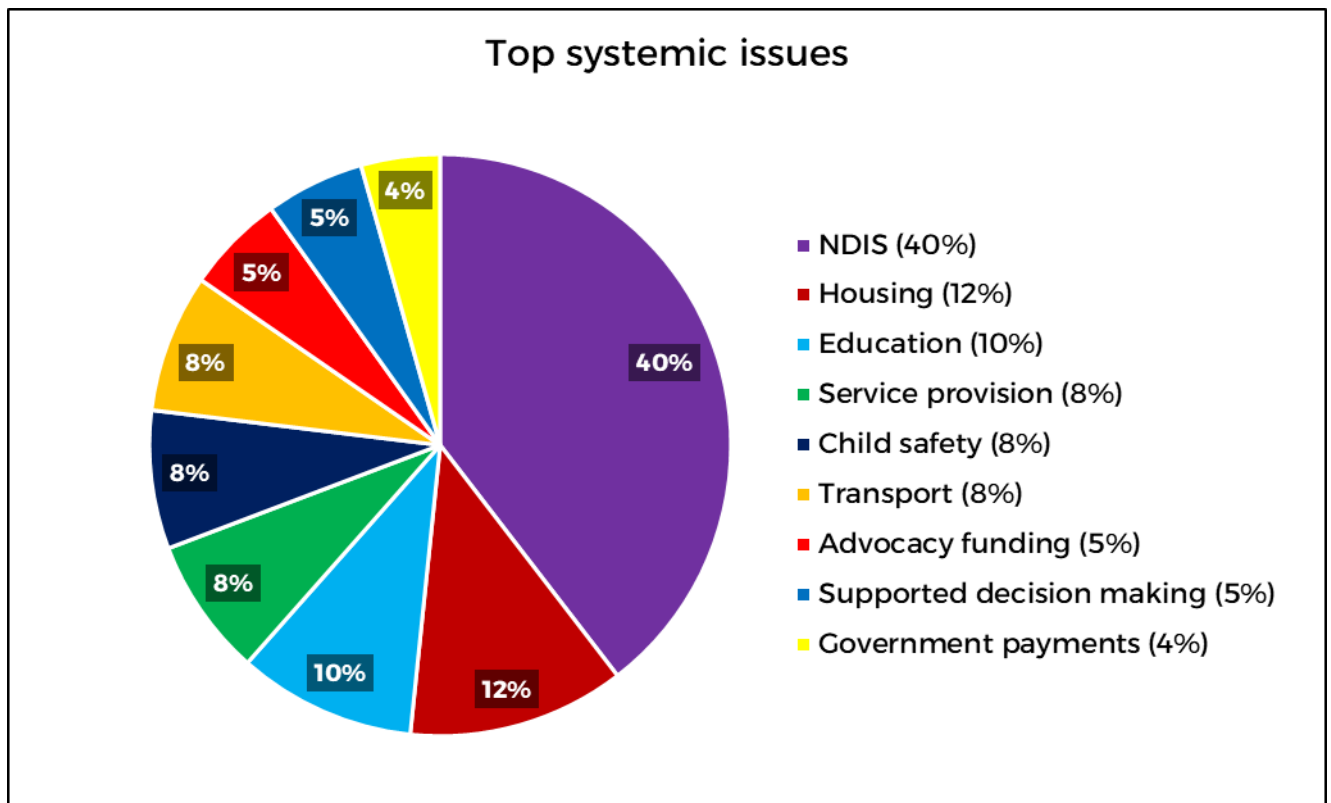
5) Organisational sector survey

In November 2023, the NCDA sent out a sector-wide survey to 80 disability advocacy organisations in Australia, including state and NDAP organisations. Each organisation was asked to give one response to the survey to avoid duplication. The survey comprised a range of questions, including the current capacity and capability of the organisations within the advocacy sector. One portion of the survey involved highlighting each respondent's top systemic issues. While state- and territory-funded organisations were asked, responses were not always received.

The survey had a 50% organisational completion rate on most of the questions and will play a significant role in identifying grassroots systemic issues around Australia through the work of individual advocacy organisations in the future.

Overview of identified systemic issues

The following chart shows identified issues highlighted by advocacy organisations in 2023.



Insight summary

This section gives an overview of the issues identified by the sector using the above methodologies. This is not a comprehensive list, but a snapshot of the systemic issues as informed by disability advocacy organisations. It should be noted there are many systemic activities undertaken by advocacy organisations that have not been included in this report. If a significant piece of work has been missed, the NCDA welcomes the feedback so that it can be included in future reports.

1. NDIS – general

As indicated in the chart above, concerns about the NDIS were identified as the most common issue advocacy organisations dealt with. Advocates participating in forums said they had too many issues with the NDIS to list. The issues involved all aspects of the NDIS from people gaining access to the scheme, participant choice and control, provider and workforce issues, and the review and appeals process. These concerns have been communicated consistently by the advocacy sector for many years, and many organisations have written submissions to inquiries.

In October 2022, the Minister for the NDIS announced a review. Its purpose was to “restore trust, confidence and pride in the Scheme”.⁴ This review gave stakeholders an opportunity to submit their concerns regarding the current state of the NDIS. DANA was funded by the Australian Government, through DSS, to engage with the disability advocacy sector, people with disability, and disability policy experts. This project became known as the NDIS Review: Engagement and Solution Project.⁵ The project ran from May 2023 to August 2023 but was also informed by previous years of engagement, data, and knowledge of the advocacy sector regarding known issues and gaps within the NDIS.

DANA hosted online forums with 74 attendees, including 58 advocates from 38 organisations. The forums allowed a space for formal discussion on the identified issues, and these discussions were then compiled into reports and submitted to the NDIS Review. Advocates reported they appreciated the opportunity to be involved in the process and found it beneficial.

Many of the issues advocates raised about the NDIS are captured in issues and summary papers, which can be found on the [DANA website](#).

Issues raised by advocates featured strongly in the final NDIS Review report, including the adoption of several of the recommendations, such as increasing

⁴ Australian Government, 2023, [NDIS Review](#).

⁵ Disability Advocacy Network Australia (DANA) produced summary reports for the NDIS Review on 4 topics: a) Floods, Fires and COVID-19, b) Quality and Safety, c) Mainstream and Tier 2, d) Supported Decision Making. See [Engagement and Solution Project](#) for summary reports and discussion papers.

advocacy funding, support for decision making, and stronger safeguarding measures.

A number of disability advocacy organisations also provided their own submissions directly to the NDIS Review. Examples:

- Advocacy WA asked for a review of the roles and responsibilities of participants' nominees to ensure they have the capacity to act with the will, preferences, and safeguards of participants. It discussed the significant decisions nominees are asked to make on behalf of participants, often without appropriate training, information, or a general understanding of supported decision making.⁶
- Disability Rights Advocacy Service (DRAS) described ways in which the access request process can be confusing, onerous, and stressful for applicants and medical professionals. DRAS also noted that although there have been improvements in the review and appeals process, there is still room for improvement. It notes that many issues would be resolved if there was improved communication between NDIA planners and advocates.⁷
- Citizen Advocacy: Sunbury and Districts highlighted its experience with Information, Linkages and Capacity Building (ILC) funding. Although successful in 2 grant rounds – including peer networks – the funding cannot be used to deliver essential core services such as advocacy to vulnerable people with disability, including those without NDIS plans. The submission also noted that ILC grants are short term, so there is no guarantee of ongoing funding.⁸

The NDIS Review will lead to the next generation of reforms in the scheme, with a large part of the evidence base being provided by those in the advocacy sector. Advocates believe these reforms will only be successful if changes are made in partnership with NDIS participants and their advocates. This can be achieved through the establishment of a Disability Reform Implementation Council led by people with disability and their representative organisations to oversee changes flowing from both the NDIS Review and the Disability Royal Commission.⁹

Listed below are more NDIS-specific issues and activities addressing these.

⁶ Advocacy WA, 2023, [Submission: NDIS Review – Participant Safeguarding](#).

⁷ Disability Rights Advocacy Service (DRAS), 2023, [Submission to the NDIS Review](#).

⁸ Citizen Advocacy: Sunbury and Districts, 2023, [Submission SUB-J7T8-001843](#).

⁹ DANA, 2023, [Joint media statement: NDIS change must be led by people with disability](#); DANA, 2024, [Submission: The Australian Government response to the Disability Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability](#).

a) NDIS workforce

NDIS workforce issues were identified by several organisations, in particular, those working in regional, rural, and remote areas. The main issues identified concern the availability of direct disability support staff and allied health professionals, such as occupational and speech therapists. This workforce incurs additional travel expenses in remote settings, which results in limited provision of support available to people with disability. This, in turn, limits access to choice and control: “You do not have to live too far out of major regional centres to not be able to receive support from qualified workers”.¹⁰ Ben Foley, the Executive Officer of Regional Disability Advocacy Service (RDAS), echoed this in an interview with the ABC, stating “The thin markets start very close to the cities. Many organisations have wait lists because they do not have the workforce to support new participants”.¹¹

Another issue identified by organisations is the lack of expertise related to specific disabilities. This issue is prevalent, particularly with participants who have lived experience of mental health issues. When asked how important a lived experience workforce is in the Victorian Mental Health system, 84% of respondents stated that it was very important as “it gives people hope”.¹² Victorian Mental Illness Awareness Council Inc (VMIAC) has been proactive in encouraging more people with lived experience of mental health issues to work within the NDIS and associated sector’s “consumer workforce” project.¹³ This project offers training as well as an advisory group aimed at increasing the confidence of employers, the community, and potential workers. The purpose of this program is to increase the amount of workers with lived experience in the NDIS workforce. VMIAC has expressed concerns about NDIS providers’ hesitancy to include people with lived experience in employment.

b) NDIS Appeals Program

Advocates reported their frustrations with the NDIS appeals process. Issues identified include the length of time taken to work through the process, the communication from the NDIA, as well as the lack of transparency and accountability throughout the appeals process. Appeals advocates also expressed their disappointment that the Independent Expert Review (IER) program trial ended without giving it ample opportunity for success and appropriate implementation. The NCDA has been told by some advocates that they believe the IER process was beginning to show potential. Although participation rates were lower than anticipated for the IER, some advocates believe they were starting to see issues resolved quicker than the conventional

¹⁰ Discussion during the National Systemic Advocacy Forum, September 2023.

¹¹ Australian Broadcasting Corporation (ABC), 19 June 2023, [In-home care search difficult to navigate as people left to “mercy of the system”](#).

¹² Victorian Mental Illness Awareness Council Inc (VMIAC), 2024, [Consumer workforce - response to DRC recommendations](#).

¹³ VMIAC, 2024, [Consumer workforce - response to DRC recommendations](#).

Administrative Appeals Tribunal (AAT) pathway, while maintaining similar outcomes for participants.

Advocates identified a need to create a greater open dialogue between the advocacy sector, the NDIA appeals team, and the AAT (or soon-to-be-established Administrative Review Tribunal). As a result of this concern, the disability advocacy sector established the National Systemic Appeals Network. This network meets online regularly and invites guests from the AAT and the NDIA to meetings to discuss systemic issues associated with the appeals process for people with disability. This network is coordinated by the members with secretarial support provided by Rights Information and Advocacy Centre (RIAC).

c) NDIS access

One of the biggest issues associated with the NDIS is access. Advocates have cited an increased difficulty in accessing the scheme for particular cohorts, most notably, people with lived experience of mental health issues and people between the ages of 60 and 65. Advocates have cited evidence provided in prior years to support an application to the scheme resulted in individuals successfully gaining access, but the same evidence did not provide the same outcomes over the past year. The inconsistency in these decisions has individuals then progressing to the review and appeal stage or not believing the NDIS is intended to support their needs. This is causing further issues in other sectors (such as the health and housing sector), where support is not available to individuals to maintain tenancies, and health outcomes are being compromised.

Where access would previously be the role of the NDIS partners providing the local area coordinator contracts in various locations, advocates have explained access requests are being routinely referred to their organisation from local service providers, support coordinators and, at times, the local area coordinators themselves.

A continued discussion point within the sector is whether an initial access request should be an advocacy issue as there are funded services, such as NDIS Partners in the Community (PITC), who have been contracted to support applicants through the access process, and this must be recognised. A sizeable portion of advocates' time is spent identifying referral pathways for people who are making their first access request to the NDIS, as well as referring and then consulting with the NDIS PITC in their geographical area to ensure they follow up with the client to provide appropriate access support. It is acknowledged that advocates will continue to assist people with their initial access if this is a part of a broader issue they are working on with the client (e.g. housing or access to education) or it is evident that the client does not have the capacity to navigate access on their own.

2. Housing and accommodation

Housing has been identified as an emerging issue during 2023 with an increase in the number of people with disability reporting they are currently at risk of homelessness. This includes those sleeping rough or couch surfing.

Issues raised in a submission by DRAS regarding South Australian housing availability is typical of the issues observed nationally. The submission states that “... in July–December 2022, we had 306 clients who sought disability advocacy related to housing”.¹⁴ This includes a myriad of issues of varying complexities from wait times, significant home repairs, and inadequate properties for individuals’ disabilities, through to delays in modifications or removal of pest infestations. One of the common themes, both throughout the report and in advocacy case studies nationally, is the difficulty that people with disability have in communicating with housing providers. This can include insufficient methods of communication and delays in replying. These issues align with the discussions from jurisdictions around Australia. Housing affordability has a significant impact on people with disability as many have low or fixed incomes and are struggling with the rise in the cost of living as rent increases are above what they are able to afford.

DRAS clients have reported a decrease in the quality of rental housing available as people with higher disposable incomes are renting properties that were once affordable to people with disability.¹⁵ This means that housing stock is minimal, and people with disability, often on a fixed income, are settling for properties that have issues that require advocacy to resolve, such as pest control and lack of effective heating and cooling. Some people are avoiding requesting much-needed repairs on their properties for fear that they may lose their tenancy or incur further rent increases if they report maintenance problems.

Housing issues have also been discussed by DANA in response to the Disability Royal Commission (DRC) recommendations in November 2023¹⁶ and the National Housing and Homelessness Plan.¹⁷ These issues include assisting clients:

- to register for social housing, including supporting appropriate clients in accessing priority lists
- to navigate homelessness services that may not be accessible when experiencing insecurity
- in resolving tenancy with landlords, including state housing agencies
- in ensuring their housing is secure and appropriate for their disability
- with NDIS issues, including Supported Independent Living (SIL) and Specialist Disability Accommodation (SDA)

¹⁴ DRAS, no date, [Submission to the Inquiry into South Australian Housing Availability](#).

¹⁵ DRAS, no date, [Submission to the Inquiry into South Australian Housing Availability](#).

¹⁶ DANA, 2023, [Royal Commission: Analysing the recommendations on housing and homelessness](#).

¹⁷ DANA, October 2023, [Submission to National Housing and Homelessness Plan](#).

- with state-based administrative tribunal matters.

a) People living in closed settings

The NCDA has heard concerns from advocates across Australia about their capacity to access and talk to people residing in closed settings, including boarding houses, “group homes”,¹⁸ forensic facilities and prisons. People who live in these settings have their rights of movement restricted and are often not given an opportunity to associate with people outside the service. There are also concerns that people in these environments are at “higher risk of abuse, neglect and exploitation”.¹⁹

During 2023, DANA used some of the funding received through the Engagement and Solution Project to provide small grants to 6 advocacy organisations across Australia to enable them to undertake engagement activities with people from a range of closed environments to gain insight and lived experience of what works, what is wrong and what should be improved with the NDIS.²⁰ Each organisation was required to provide a final report, which DANA was able to use to feed information into the NDIS Review through its Engagement and Solution Project.²¹

The Opening the Door project organisations included:

- Intellectual Disability Rights Service (IDRS) (NSW) – Used links through Justice Advocacy Service to facilitate one-on-one engagement with 8 to 10 people with disability who were released from prison in the past 2 years. The target audience included people with intellectual disability and First Nations peoples. The focus area was on how successfully they linked with accommodation and NDIS support after leaving prison.
- Victorian Advocacy League for Individuals with Disability (VALID) (VIC) – Used links through VALID8 Program to engage with people living in disability group homes in Victoria, including people from culturally and linguistically diverse (CALD) backgrounds, young people, and people from rural/regional communities. The discussion included what participants liked and disliked about where they lived.
- Capricorn Citizen Advocacy (CCA) (QLD) – Used links through Capricornia Correctional Centre to engage NDIS participants, correctional services staff, and Citizen Advocates in one-on-one interviews/focus groups including First Nations peoples, those from CALD backgrounds, young

¹⁸ The Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability defines a “group home” as a form of accommodation where services and supports are provided to 4 to 6 long-term residents with disability as noted in their [Group homes issues paper](#), November 2019.

¹⁹ Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability, November 2019, [Group homes issues paper](#).

²⁰ The small grants were approved as part of DANAs work plan.

²¹ DANA, 2023, [Engagement and Solution Project](#).

people, and people from rural/regional communities. The focus of the discussion was navigating the NDIS following release from prison.

- Advocacy for Disability Access and Inclusion (SA) – Used links to existing clients in the justice system, including Yatala Labour Prison, to engage with people with disability for face-to-face and phone interviews and facilitate discussion groups.
- Rights & Inclusion Australia (R&IA) (ACT) – Used links to boarding house accommodation in the Southern Highlands region of NSW to engage with up to 30 individuals in one-on-one interviews, discussion or focus groups, including First Nations people with disability and people from diverse ethnic backgrounds, with focus areas being the experience of people living in boarding houses.
- Integrated disAbility Action (IdA) (NT) – Used links to NT Shelter & Disability Housing Futures Working Group to engage in one-on-one interviews with clients. Interviews focused on the housing needs of people with disability living in a range of closed environments across the Northern Territory.

Disability residential services

During the systemic advocacy forums, advocates spoke of their concerns that people living in group homes and boarding houses are not able to exercise their human rights to access independent advocacy that is private and confidential. Often, the sole phone in the house is in an office that is only accessible by staff of the service. When advocates get an opportunity to meet with a client in their home, there is often no privacy, except in their bedroom, which is not an appropriate setting for one-on-one meetings with professionals.

Advocates reported that support workers will sit in on meetings the advocate is having with their clients, saying that they are required to make notes for the client file and report to management any discussions clients have with professionals outside the organisation.²²

Some advocates report that, in the past, they were able to do some outreach into group homes; however, since the introduction of the NDIS, it is harder to know where these types of residential services are located and who is delivering services. Prior to the NDIS, group homes were owned or funded by the state or territory government. Advocates knew which organisations provide accommodation services. They were able to engage with providers and residents.

Since the introduction of the NDIS, a greater range of commercial arrangements has been put in place for the provision of accommodation for people receiving SIL. A concern for advocates is the number of unregistered providers establishing “SIL homes” to deliver 24/7 supports to several individuals in the same house. Advocates raised concerns that in the unregulated market of the NDIS,

²² Discussion during consultations for the establishment of the NCDA in November 2022.

vulnerable people with disability are at a greater risk of abuse, neglect, and exploitation. The concerns of the advocates were brought to public attention in an ABC *Four corners* program aired in September 2023.²³

NCDA engagement with advocates since the *Four corners* episode reveals a lack of surprise at the content of the program but alarm at the response of NDIS Quality and Safeguards Commission (NDIS Commission) featured during the show. The view was that the response lacked true transparency and accountability for serious offences by service providers. There was similar feedback from advocates after the Commission spoke at a NCDA webinar in July 2023 about its complaint-handling process as advocates reported receiving very little feedback from the Commission when complaints are raised about NDIS providers on behalf of people with disability.

Advocates have spoken about their confusion in navigating the complex arrangements that are in place to separate accommodation and supports in disability housing. In December 2023, Villamanta Disability Rights Legal Service and Victoria Legal Aid provided education to advocates in Victoria by presenting at a Disability Advocacy Resource Unit (DARU) Advocacy Sector Conversations forum titled *Protecting the rights of tenants in disability accommodation settings*. The session explained the rights of tenancy and rent agreements and arrangements for SIL housing.²⁴

During the presentation, the difference between an SDA house and a SIL house was explained. A SIL house does not have legal meaning, but the term is used to describe a number of arrangements to enable providers to deliver 24/7 support²⁵ to people living in the same house. The NDIA or NDIS Commission have no way of knowing where SIL houses are located. There is a need for residents to have separate agreements between where they live and the NDIS services they are provided with. The presentation covered how Victorian legislation may be able to be used to protect residents' rights.

Forensic facilities

Advocates raised human rights concerns about people being held indefinitely in forensic facilities. Queensland Health defines Forensic Orders as being made "primarily by the Mental Health Court for individuals charged with a serious offence who are found of unsound mind at the time of an alleged offence or are unfit for trial. People on a Forensic Order may be provided with involuntary treatment and care and, if necessary, detained in an authorised mental health

²³ ABC *Four corners*, 25 September 2023, [Careless: How the NDIS fails to protect our most vulnerable](#).

²⁴ Villamanta Disability Rights Legal Service and Legal Aid Victoria, December 2023, presented at the Disability Advocacy Resource Unit (DARU) [Advocacy Sector Conversations forum series](#) on the topic of [Protecting the rights of tenants in disability accommodation settings](#).

²⁵ The NDIS Review defines 24/7 living support as participants who require at least 8 hours of active support and/or supervision with activities of daily living and some level of support for the remaining hours of the day while at home, including overnight assistance (whether active or passive). NDIS Review, no date, [Housing and living supports that are fair, consistent and promote choice](#).

service”.²⁶ “Trapped”²⁷ was an ABC *Four corners* report that investigated the treatment of people in forensic facilities. There are an estimated 700 people with intellectual or mental health disability who are on Forensic Orders in Australia. They are being held indefinitely by the state but have never been convicted of a criminal offence. The program highlighted the work of disability advocates, including Queensland Advocacy for Inclusion (QAI), to bring the issue to national and international attention. QAI CEO Matilda Alexander presented evidence at the 15th United Nations Conference of States Parties calling for the end of indefinite detention of forensic patients across Australia.²⁸

Prisons

Advocates have a role to support people with disability who are in prison.

Examples:

- Advocates support people with cognitive disability to understand their rights before the law with regard to their court proceedings. With an increase in the use of video links between court and prison, there is a need for an advocate to sit beside their client in prison during a court hearing.
- Advocates support a person to access housing and NDIS supports once they are released from prison.

Advocates spoke about the difficulties they have in accessing incarcerated clients as there is a process to apply for clearance to enter the correctional centre. Advocates reported it can take 3 months to obtain the appropriate clearance from corrective services. By the time they have the clearance, their client has been released or moved to another facility.

b) Modifications

Advocates have identified an issue with the interface between housing and the NDIS, particularly around eligibility and modifications.

Providing accessible rental housing is an ongoing issue with social²⁹ and private housing markets. Modifications appear to be a personal responsibility with individuals needing to pay for modifications from their NDIS plans. If a person makes modifications to the home, they are required to restore the house to its original condition when they move out. This requires further discussion at both state and federal government levels to provide clarity on responsibilities.

²⁶ Queensland Health, no date, [Mental Health Act 2016 factsheet: Forensic Orders](#).

²⁷ ABC *Four corners*, 16 October 2023, [Trapped: Inside the hidden system locking people up indefinitely](#).

²⁸ Queensland Advocacy for Inclusion, 16 October 2023, [Indefinite detention and solitary confinement – the awful reality of Queensland’s Forensic Disability Service](#).

²⁹ Social housing is defined in the National Housing and Homelessness Agreement as affordable housing provided by government or community sector to assist people who are unable to afford or access suitable accommodation in the private rental market.

c) National construction code and accessible housing

Accessible housing has been an issue for people with disability for some time. A Melbourne Disability Institute study found that 80% of survey respondents could not “visit friends or family because of poor access”.³⁰ To combat this increasing issue, in 2021, a decision was made by federal, state and territory ministers to introduce the Livable Housing Design Guidelines silver level into the National Construction Code. With some exceptions, this would require all new homes, including apartments, to adhere to a minimum set of accessibility standards that would ensure homes would be accessible to people with disability. This includes at least one step-free entrance from the street, wider doorways, hobless showers as well as a host of features designed to ensure housing is accessible for people with physical disability.

Currently, all states except for NSW and WA have agreed to adopt the guidelines as part of the National Construction Code. NSW and WA have cited the increased building costs as the main reason behind their lack of adoption. The Building Better Homes campaign,³¹ which includes a range of advocacy organisations, has created a website to communicate the importance of the standards to governments as well as inform wider society of the value of accessibility for an inclusive society. The campaign also outlines steps individuals can take to show their support. Both the NDIS Review and the DRC recommended all states and territories immediately adopt the code’s new accessibility standards.

d) Waiting times for social housing

During the National Systemic Advocacy Forum, advocates discussed the need to escalate people with disability to priority waiting lists and prove their disability. This level of advocacy work continues to consume sizeable time and resources. There is also an increase in wait times between when people with disability make applications and when they are allocated suitable housing. Many organisations cited extremely long wait times in their geographical area as a significant systemic issue that needs to be addressed; however, without appropriate housing stock, this will continue to be a problem. Wait times vary depending on a range of factors, such as location, available stock, and general demographics of the area.

In areas where there has been a natural disaster, these wait times have risen significantly. A report by the University of New South Wales³² found that the 2022 floods in the Northern Rivers of NSW, “worsened an already strained housing system”. The flood has increased the waiting time for social housing to 10 years or more. Similarly, inappropriate waiting times are spoken of

³⁰ Dr Ilan Wiesel, 22 October 2020, [Living with disability in inaccessible housing: social, health and economic impacts](#), University of Melbourne.

³¹ Building Better Homes, 2024, [Building Better Homes: A national building code for all Australians](#).

³² Dr Ryan van den Nouwelant and Alessia Cibir, October 2022, [The impact of housing vulnerability on climate disaster recovery: The 2022 Northern Rivers Floods](#) University of New South Wales.

throughout the nation when engaging with advocacy organisations. Unfortunately, wait times for social housing will only increase as natural disasters become more prevalent unless more affordable and accessible public and social housing is built.³³

3. Education

a) Suspensions and expulsions

Access to mainstream education by children with disability is seen as an ongoing systemic issue in most states and territories. Suspensions and expulsions of students with disability, including First Nations students, is a significant issue across the country. In Queensland, for example, the Queensland Independent Disability Advocacy Network (QIDAN) hosted an event with multiple state peak bodies. During the morning, conversations consistently returned to the suspension of children with disability in mainstream schooling. It was agreed that further action was required. A collaborative campaign was launched, led by QAI, the Aboriginal and Torres Strait Islander Legal Services, and Peak Care, who initiated a freedom of information request and research paper. The data demonstrated disproportionately high suspension rates for First Nations students, students with disability, and students in out-of-home care. When students are in more than one of these groups, the risk of suspension is even greater. Findings indicate that disability is the most common factor, raising urgent questions as to whether these students are receiving the adjustments and support to which they are entitled.³⁴ The result of this research paper is the launch of the [A Right to Learn](#) campaign, which has 5 main asks from decision makers, including an ultimate focus on increasing support and reducing suspension for students in the identified groups.

b) Inclusive education

Advocates across Australia regularly assist students with disability and their families who are told they are not able to access mainstream school or are forced to be educated in a segregated setting³⁵ without exploring options for inclusive settings. The provision of education is a jurisdiction-based policy. Each state and territory has legislation that provides nuance relevant to its geographic location. Despite the minor jurisdictional differences, the education system in Australia has 2 main streams.

One of the most alarming themes to emerge from the DRC was the suggestion that people in segregated settings are more likely to experience violence, abuse,

³³ DANA, 2023, [Discussion paper – NDIS Review: Fires, floods, and COVID-19](#).

³⁴ Linda Graham, Callula Killingly, Matilda Alexander and Sophie Wiggans, 26 July 2023, [Suspensions in QLD state schools, 2016-2020: overrepresentation, intersectionality and disproportionate risk](#).

³⁵ Segregated schooling or “special/specialist schools”. These can be physically separate schools, co-located education support units within mainstream schools, or “special classes”. All of these are places where students are segregated based on their disability.

neglect, and exploitation.³⁶ The findings from the DRC are significant in that all Commissioners agreed that reforms are required within the education system to minimise the chances of segregation.

Family Advocacy, along with multiple DROs and disability advocacy organisations in NSW, have started the Better Together, Inclusion for All campaign that “aims to ensure people with disability have access to inclusive education, employment, housing and community to create a more inclusive society”.³⁷ The campaign’s goal is to lobby decision makers to create a more inclusive society for all people with disability. It is backed by the evidence and recommendations from the DRC. The campaign has recently written a position statement,³⁸ and it has been forwarded to government ministers imploring them to adopt the recommendations from the DRC.

4. Transport

Transport plays a significant role in the lives of people with disability. The ability to travel to appointments, work, and social activities can either support or hinder the inclusion of people with disability. The effect of transport on individuals can also vary depending on location. The availability of public transport in regional areas is a recurring theme that organisations address in submissions. Systemic issues relating to transport are varied and can take many forms from accessible bus/tram stops to air travel and a range of point-to-point services, including taxi and uber services and private cars.

a) Vehicle modification

Obtaining an accessible motor vehicle under the NDIS has been identified by Developmental Disability Western Australia as a systemic issue.³⁹ The NDIS will pay for modifications to a motor vehicle that meets specific criteria,⁴⁰ including the age of the vehicle and whether the vehicle has a sturdy frame to accommodate the modification. This means that, due to the cost, an accessible personal vehicle is often unachievable for most people with disability. The issue is even more significant for individuals in regional areas where public transport is not as prevalent as it is in metropolitan areas. This means individuals require their own vehicle as distances between locations can be larger, and public transport options are often irregular. Individuals in regional or remote locations who do not have access to their own vehicle will often rely on others to take them to appointments, employment, or social activities.

³⁶ Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability, March 2022, [Overview of the responses to the Violence and Abuse of People with Disability at Home issues paper](#).

³⁷ Family Advocacy, no date, [Better together, inclusion for all](#).

³⁸ Family Advocacy, 20 December 2023, [Joint Position Statement on Inclusive Education and the Disability Royal Commission Final Report Recommendations](#).

³⁹ Developmental Disability WA, July 2023, Member issues register, unpublished.

⁴⁰ National Disability Insurance Agency, 19 April 2023, [Vehicle modifications and driving supports](#).

b) Air travel

Air travel has been problematic for people with disability for some time and has been identified as an area of interest for advocates. In November 2022, the DRC held 2 online workshops to engage people with disability about their experiences related to air travel.⁴¹ The workshops highlighted a range of significant issues of personal concern around discrimination, humiliation, violation of privacy and dignity, as well as cases of personal injury and property damage to mobility devices. These issues can be attributed to inconsistent policies and procedures implemented by different airlines due to a lack of accountability within airports in Australia. To address these concerns, Public Interest Advocacy Centre (PIAC), which is a leading social justice law and policy centre, along with 14 organisations (including multiple NDAP providers) made a submission to the Australian Government⁴² regarding air travel. The submission comes at a time when the federal government is setting the direction for the Australian aviation industry over the coming decades. The submission cites 7 recommendations but 2 are highlighted for government.

- Develop a set of disability standards to govern air travel, which outline detailed minimum standards for disability access at all stages of an air travel journey from booking a ticket, to boarding an aircraft, to disembarking at the destination.
- Give the Australian Human Rights Commission power to proactively monitor airports and airlines and enforce those standards as a regulator.

While it has been identified that significant work is needed to regulate the aviation industry in Australia, adoption of the recommendations of this collaborative effort would be the start of a more positive experience with air travel for people with disability.

c) Accessible point-to-point transport

The deregulation of point-to-point transport services in several states has had an impact on the viability, availability, and quality of accessible services. Advocacy organisations have cited a need for governments to examine solutions regarding the viability of this service, given the higher costs in providing the service to people with disability. In NSW, Spinal Cord Injury Australia (SCIA) and Physical Disability Council of NSW (PDCN) met with the NSW Minister for Transport and provided a briefing paper⁴³ outlining issues they had identified with the wheelchair accessible taxis (WAT) service and the Taxi Transport Subsidy Scheme (TTSS). Examples of issues identified in the paper:

⁴¹ Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability, September 2023, [Realising the human rights of people with disability – Final report, volume 4](#), p. 340.

⁴² Public Interest Advocacy Centre, 30 November 2023, [Submission to the Aviation Green Paper](#).

⁴³ Physical Disability Council of NSW & Spinal Cord Injury Australia, 2023, [Briefing paper: Wheelchair Accessible Taxis and Taxi Transport Subsidy Scheme](#).

- Complications with booking WAT in Sydney occur due to the use of a tier booking system. In 2021, the NSW government contracted SCIA to manage a new wheelchair booking service. To access these bookings, taxi operators must have a secondary app running parallel to their main booking system. This app notifies drivers of the need for an accessible taxi; however, due to complication of the secondary app and it not being integrated with the main booking system, drivers are overlooking bookings leading to long waits or users not receiving a service.
- Operators of WAT are either overlooking or refusing to pick up wheelchair users because they can make more money transporting groups of people.
- Since COVID 19, there has been a reduction in the number of WAT on the road at any one time. This is partly due to skilled drivers leaving the industry during the pandemic and not returning. Another reason is the increased number of alternative point-to-point options where passengers can book directly with the driver. This lack of reliable wheelchair taxi transport is causing people with disability to have anxiety if they are significant delays in receiving a service to attend an appointment, as these appointments often incur cancellation fees if they are missed.
- A large proportion of drivers are refusing to use a new TTSS card as there is a fee associated. Drivers have claimed they did not see an issue with the previous system and would prefer to use a paper version.

The issues are widespread throughout Australia and have been noted by state networks in meetings. Queensland advocacy services have identified similar difficulties. During the National Systemic Advocacy Forum, members of QIDAN spoke of the lack of transport options for people who use wheelchairs; they specifically cited the lack of access to WAT as there has not been an increase in the number of wheelchair taxi stock for a decade.

d) Public transport

Advocacy organisations like Disability Resource Centre have been advocating for improved access to public transport for the past 40 years. Since the introduction of the Disability Standards for Accessible Public Transport 2002, there has been significant progress; however, disability advocates argue that there is much more to be done as the public transport system is still inaccessible.

The Disability Resource Centre is currently campaigning for accessible tram stops. At present, there are no accessible tram stops for a 5.5 kilometre stretch along Sydney Road between Brunswick Road and Bakers Road (a busy inner-Melbourne route). In 2 years time, the Upfield train line will be closed both to remove the Brunswick Road level crossing and build the Melbourne Sky Rail. During the approximately 18 months that this work will take to be completed, there will be no accessible transport for many people in the community. This includes people with disability, parents with prams, and older people. A

meeting is being planned in February 2024 to build public support for this campaign.⁴⁴

During the National Systemic Advocacy Forum, Southwest Advocacy Association (SWAA) raised the issues of accessible public transport in regional Victoria. In particular, the Port Perry train service, which does not always have an accessible carriage. V/Line will pay for a taxi to transport passengers between Warrnambool and Melbourne rather than ensure there is an assessable carriage on every train. SWAA has raised the issues at consultations held on behalf of V/Line as part of the development of its Accessibility Action Plan 2022 to 2025.⁴⁵

As previously discussed, The Advocacy Collaborative in WA had concerns that the Morley-Ellenbrook Line rail project currently under construction may not meet the Disability Standards for Accessible Public Transport 2002. As a result of their concerns, Metronet, which is managing the project, established community advisory groups for each station along the route to oversee the planning in the surrounding areas. Each member organisation of the alliance has been allocated an advisory group to attend to ensure access issues are addressed. The work is informed by a survey undertaken by People with Disability WA as part of its submission to the review of the standards.⁴⁶

Examples of issues raised by the alliance:

- Information and signage in and around the stations must be accessible to people with diverse disability. Signage must be legible, easy to understand, and available in braille.
- There must be a continuous path of travel in and around the station and precinct ensuring people are able to alight easily from a train onto the platforms and move to other transport links, including buses.
- People identified difficulties getting on and off trains as heights of rolling stock and infrastructure differ across the Perth network. This discrepancy in heights between transport and platforms is dangerous to people with disability. This is a continued conversation, with consistency required to ensure accessibility is ensured for people with disability.

5. Accessible communities and facilities

a) Local access committees

Many advocacy organisations participate in their local government access advisory committees. These committees involve a group meeting together regularly to discuss access issues in the community. Some local councils use the committees to obtain feedback on new developments, refurbished facilities, and other council-regulated amenities/facilities.

⁴⁴ Disability Resource Centre, 2023, [Campaign for a public transport system that works for everyone](#).

⁴⁵ V/Line, no date, [V/Line Accessibility Action Plan 2022 to 2025](#).

⁴⁶ People with Disability Western Australia, August 2023, [Review of the Disability Standards for Accessible Public Transport](#).

Many advocates are able to provide professional comments on the council's access and/or inclusion plans. A research project undertaken by Victorian Rural Advocacy Network (VicRAN) found most local government in regional Victoria does not have current access and/or inclusion plans that meet state and Commonwealth legislative requirements, including the *Disability Discrimination Act 1992* and the Australian Disability Strategy.

b) Human rights and guardianship

Guardianship and financial administration are common issues faced by people with disability in Australia. This is a process that begins when there are concerns that an individual does not have the capacity to make decisions about their own life. These decisions can relate to accommodation, health-care treatments, support or (in the case of administration) financial decisions. If it is determined the individual does not have the capacity to make their own decisions, either temporarily or permanently, a substitute decision maker will be appointed to act on behalf of the individual. At its inception, this process was designed to protect individuals but, as time has progressed, it has been used to rob people of their choices, rights, and personhood.

A sizeable portion of an advocate's work can involve advocating for individuals in the guardianship or administrative process, either through the application or in trying to have a person's voice heard in a decision being made on their behalf. The continued difficulty is the inability of people on guardianship or administrative orders to share their stories. Due to multiple states' confidentiality ("gag") laws, people under guardianship orders are often prohibited from speaking with media outlets to share their concerns about their lack of autonomy. A number of individuals and advocates, including Advocacy Tasmania, VALID and Inclusion Australia, raised their concerns in an ABC *Four corners* program that aired in March 2023.⁴⁷

This legislation varies according to jurisdiction and is a matter for states and territories to determine. The concern for advocates is these decisions tend to remove the person from the situation and negate the human rights framework that advocates work within. With the work of advocates, some states are attempting to operate within a supported decision-making model and use tools for individuals to voice their preference when choices are being made.

Over recent years, Advocacy Tasmania⁴⁸ has focused a large portion of its systemic activity on working to abolish the Tasmanian Government's outdated guardianship and administration legislation and systems. It wants to shift the power and focus more on supporting the choices and personhood of individuals

⁴⁷ ABC *Four corners*, 14 March 2022, [Guardianship: Life under the hidden control of the Public Trustee system revealed](#).

⁴⁸ Advocacy Tasmania, October 2023, [Guardianship & Administration Campaign](#).

in this process. Advocacy Tasmania was recognised for this work in 2023 when it won the Australian Human Rights Commission's Human Rights Award.⁴⁹

c) Funding for systemic advocacy

This report has identified the variety of systemic activities that advocacy organisations are involved with in Australia. During 2023, the NCDA has had discussions with organisations about the value all levels of government place on systemic advocacy. Most advocacy organisations have limited capacity to participate in systemic advocacy due to low levels of funding. The NDAP Operational Guidelines state that no more than 10% of the funding can be allocated to systemic advocacy activities.⁵⁰ One organisation based in regional Australia said that, based on the level of funding they receive for systemic advocacy, they would spend less than half a day per week on systemic issues.⁵¹ In this context, many organisations report that much of their systemic work is ad hoc and often done "off the side of the desk" with little planning involved. They also note that most of their systemic activity is focused on local issues.

When Advocacy Tasmania won the Community Award (2023 Australian Human Rights Awards), CEO Leanne Groombridge said, "So much of the work has been undertaken by employees volunteering their time and hearts, as we are not funded for systemic work of this scale. But it has been worth all the sleepless nights fighting for the rights of people who have been ignored and harmed by these systems for far too long".⁵²

The NCDA is aware of a small number of NDAP organisations across the country that currently have individual arrangements for undertaking systemic advocacy that exceeds the 10% funding allocation; however, in 2025, these organisations will be required to utilise no more than 10% of their funding for this purpose. The overarching case being made by DSS (as the funding body for NDAP) is that they provide funding to DROs to undertake systemic advocacy and believe there is a danger of a duplication of work. DSS believes there is an opportunity to reallocate funding to increase the capacity of NDAP organisations to provide individual advocacy. This reallocation of funding, however, would result in a loss of specialist skill sets at both an organisational and sector level that have been developed by systemic advocates. It could also be argued the current mechanisms in reporting between advocacy organisations and DROs would need refinement, to ensure DROs respond to the data being provided by the advocacy organisations.

Advocacy organisations also assert that federal, state and territory governments do not understand the long-term benefits of systemic advocacy activities. Some state governments have used funding labelled for systemic advocacy to fund

⁴⁹ Australian Human Rights Commission, 8 December 2023, [Australia's human rights champions put social justice and equality centre stage](#).

⁵⁰ DSS, December 2023, [Operational Guidelines for the National Disability Advocacy Program](#), p. 5.

⁵¹ Discussion during National Systemic Advocacy Forum, September 2023.

⁵² Advocacy Tasmania, October 2023, [Guardianship & Administration Campaign](#).

projects that may address systemic change. While advocates see some of these projects as beneficial, they are often short term and provide only temporary alleviation of issues. They do not consider these projects to be systemic advocacy. Governments argue the difficulty in funding systemic advocacy is that it is hard to measure outcomes in the same way that results can be measured through individual advocacy or projects.

Advocates reported dealing with similar individual issues repeatedly. They see the need to address the systemic cause of these issues but are limited in the systemic work they can undertake due to their prescribed systemic allocation of 10%. As a result, important systemic work that would ease the burden on organisations and increase their capacity is sometimes overlooked. One organisation gave the example of Centrelink previously employing more social workers in their offices. The social worker role was to assist people with Disability Support Pension applications and other Centrelink issues. This function would alleviate portions of work that advocates do in an ad hoc inquiry role, such as paperwork and advice. As this work is often prioritised lower due to limited systemic allocation of resources, the social worker resource has been reduced in recent years, and the burden of these tasks has shifted to advocates. Advocates believe this is a systemic issue which, if addressed, would see Centrelink once again offer support to individuals. This would increase advocacy capacity.

Advocates present a strong argument for increased investment in both individual and systemic advocacy. Many organisations argue that they should not need to reduce their valuable systemic advocacy (for instance to the 10% specified in NDAP agreements) in order to address the high demand for individual advocacy, with strong consensus reiterated across the sector that funding needs to be increased for advocacy models directed at both the individual and systemic level. Many advocacy organisations contributed their perspectives and insights to a DANA submission to the DRC⁵³ and a Pre-Budget submission⁵⁴ calling for an immediate injection of funding for the advocacy sector to meet the current unmet demand for services, particularly in rural, remote, and very remote communities. Recognition of the present shortfall in funding and capacity across the sector is reflected in the recommendations from the DRC and the NDIS Review, which clearly call for additional resourcing for the advocacy sector short and long term.

d) Resourcing systemic advocacy work in the sector

The NCDA has heard from advocates about how they can be supported to build their capacity to be effective in their systemic advocacy work.

Ways in which the NCDA can assist:

⁵³ DANA, 2022, [Independent disability advocacy – DANA submission to the DRC](#).

⁵⁴ DANA, November 2023, [A strong, sustainable future: addressing capacity shortfalls for a strengthened disability advocacy sector](#).

- Develop, with the sector, a framework around best practice systemic advocacy. The framework should include a clear definition of what systemic advocacy is and how disability advocacy organisations can be effective in their advocacy work. This framework should also give clear pathways for identifying and elevating systemic issues to ensure organisations, no matter their size, can escalate pressing issues as informed by their individual work.

The framework should outline how systemic advocacy is informed by individual advocacy work and create an opportunity for best practice systemic advocacy.

- Assist in workforce development. This includes building the capability of individuals in the unique skill sets required to undertake systemic advocacy. The NCDCA can deliver webinars and training to enable advocates to develop systemic advocacy skills.
- Facilitate opportunities for collaboration, such as giving advocacy organisations an online platform where people from smaller groups with specific expertise can contribute to larger systemic issues and activities. The NCDCA can assist by developing a database on a portal where organisations can share systemic advocacy examples and case studies from their individual advocacy work. The NCDCA will also continue to host forums to foster discussion across organisations.
- Continue to deliver insight reports that are informed by the advocacy sector and that identify emerging systemic issues and associated activities. These reports can be elevated to appropriate parties, including the DANA policy team, to ensure a clear pathway of escalation for identified grassroots issues.

Conclusion

This report presents a small sample of the systemic advocacy work that disability advocacy organisations – despite limited resources – have been engaged with over the past 12 months.

Individual advocacy work has been used to inform systemic work.

- QAI's work representing people on Forensic Orders at the Queensland Mental Health Review Tribunal led to a presentation at the United Nations Conference of State Parties.
- DRAS used case examples from its individual work to highlight issues in its submission to the Inquiry into South Australian Housing Availability.
- SWAA provided case examples at a V/Line consultation highlighting instances where people were required to travel by taxi between Warrnambool and Melbourne due to a lack of accessible options on the rail network.

Where organisations have worked in collaboration, the collective voice and effort has achieved more equitable outcomes for people with disability.

- Advocacy organisations contributed to DANA summary papers for the NDIS Review. This included collection of information from people living in closed environments. The issues raised featured strongly in the final report of the review.
- NDIS Appeals Program advocates identified the need to create an opportunity for open dialogue between themselves, the NDIA, and the AAT. They established the National NDIs Appeals Network. Network members report seeing more consistent decisions for people with disability as a result of these discussions.
- QIDAN members and peak organisations work cooperatively on the A Right to Learn campaign to address the number of students with disability being suspended from school.
- The Advocacy Collaboration members in WA are working together to attend advisory committees to advocate for improved access on the Perth rail network.

The significant effort the sector has spent on preparing submissions to the DRC and the NDIS Review in 2023 should be acknowledged. There is great anticipation within the sector that these 2 large pieces of work will bring about significant reform to improve the quality of life for people with disability. It is crucial organisations continue to advocate systemically to ensure the recommendations from this work are implemented. Future insight reports will monitor activities identified in this report as well as emerging issues.

Overall, the NCDA believes the greatest systemic outcomes are informed through the work of individual advocacy activities. The ability to monitor trends and emerging issues through the data collected by organisations is invaluable in prioritising systemic improvements. The NCDA will distribute this report and is open to communicating further with any sector that has queries and would like to partner with organisations to achieve greater outcomes. The NCDA contact details are on the back cover.

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