



DANA Disability Advocacy
Network Australia

DANA submission to the Disability Royal Commission into Violence, Abuse, Neglect and Exploitation

Independent Disability Advocacy

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The Disability Advocacy Network of Australia (DANA) is the national peak body for disability advocacy in Australia with a membership comprising 78 organisations that are funded to provide disability advocacy across all jurisdictions. Fifty-nine of these advocacy organisations receive funding from the National Disability Advocacy Program (NDAP) and other funding is received from various state and territory disability programs.

The DANA submission to the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability (the Royal Commission) is informed by the collective knowledge and experience of member organisations. These organisations work directly with people with disability deploying various models and styles of advocacy to support them in upholding their rights and promoting their safety. People with disability are at much higher risk of experiencing violence, abuse, neglect and/or exploitation.

Through consultation with its network of members DANA is able to identify systemic issues faced by people with a very broad spectrum of disabilities whose needs are poorly met by current systems and environments.

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Introduction

At present across Australia, insufficient, fragmented and insecure resourcing severely limits disability advocacy provision and there are major gaps, deficiencies and systemic issues that prevent access to independent advocacy for all people with disability.^{b 2} This carries multiple individual, community, societal and economic costs and poses major risks to people and diminishes the upholding of their human rights.^{3 4}

By contrast, the economic and other benefits of disability advocacy far exceed the economic costs. Advocacy facilitates more efficient communities and government, often playing a constructive or a preventative role, through intervening in situations before they progress to crisis or further harm.^{5 6}

This state of affairs stands in stark contrast to Australia's stated commitments to the human rights of people with disability.

First, the United Nations Declaration of Human Rights and the United Nations Convention on the Rights of Persons with Disabilities (CRPD) - of which Australia is a signatory - enshrine the rights of people with disability to equal citizenship and full and equal enjoyment of all human rights and fundamental freedoms. Australia has international obligations to promote these rights including freedom from all forms of exploitation, violence, neglect and abuse.⁷

Second, Australian governments endeavour to uphold these obligations through a range of legislative measures, policies and funded strategic programs including anti-discrimination legislation, Australia's Disability Strategy 2021-2031(ADS)⁸ and the National Disability Insurance Scheme (NDIS).⁹

Third, at the heart of the ADS is a commitment to create an inclusive community for all people in Australia including those with disability. The ADS recognises, under its Safety, Rights and Justice Outcome that:

“Disability advocacy also supports people with disability to safeguard their rights, experience equality and overcome barriers that can affect their ability to participate in the community.”¹⁰

^b In 2014, the Productivity Commission recommended in relation to the civil justice system that: “*Australian, State and Territory Governments should provide funding for strategic advocacy and law reform activities that seek to identify and remedy systemic issues and so reduce demand for frontline services.*” (See Productivity Commission (2014) *Access to Justice Arrangements Inquiry Report* - Recommendation 21.1, pp705-713.)

Fourth, the National Disability Advocacy Program (NDAP)¹¹ and state and territory disability advocacy programs are guided by the stated objective of the National Disability Advocacy Framework (NDAF):^c

“People with disability access effective disability advocacy that promotes, protects and ensures their full and equal enjoyment of all human rights, enabling full community participation and inclusion.”¹²

Achieving the intended outcomes of the ADS, NDIS and NDAF relies on the reach and effectiveness of advocacy organisations supporting an increased number of people with disability.^d Independent disability advocacy strengthens people’s capacity to manage their lives and reduces the call on government agencies.¹³

^c NDAF is “a shared commitment between Commonwealth, state and territory governments to ensure there is access to advocacy services for all people with disability nationwide.” A new NDAF (2022 - 2025) is currently under development.

^d Although the proportion of people with disability in Australia has remained fairly constant in recent years according to the Australian Bureau of Statistics Survey on Disability, Ageing and Carers (between 17.7% and 18.3%) the Australian population overall is growing.

Importance and value of independent disability advocacy

Independent disability advocacy is integral to fulfilling the “Safety, Rights and Justice” outcome area of the ADS: ***“The rights of people with disability are promoted, upheld and protected, and people with disability feel safe and enjoy equality before the law.”***^{e 14}

The *NDIS Act 2013* specifically acknowledges the role of advocacy.^f

Various approaches to disability advocacy are utilised in different contexts, at different times and for different purposes including the six models of individual advocacy, Citizen Advocacy, legal advocacy, Self Advocacy, family advocacy and systemic advocacy.^{g 15 16}

Disability advocacy supports individuals with disability (and their family and supporters) in a range of ways - to be aware of and assert their rights and to facilitate their access to services and support that enhance their capacity to participate fully in society across multiple domains of life.^{h 17 18 19 20}

- Advocacy operates as an early intervention and safeguarding mechanism particularly for those people with disabilities who are at most risk of harm from violence, abuse, neglect and exploitation.^{21 22 23 24}
- In some contexts, the local advocacy organisation is the only on-the-ground safeguard, due to inconsistent provision and reach of community visitor and a lack of other oversight mechanisms.²⁵
- Individual advocacy is particularly important for those who are not aware of their rights and/or have limited capacity to safeguard themselves against violence, abuse, discrimination and exploitation.^{26 27 28}

“Independent disability advocacy has strengthened people with disabilities’ capacity to manage their lives in their own way while making less call on government agencies (such as police, courts, hospitals, foster care, legal aid, nursing homes, etc.). Independent disability advocacy has improved the life of many thousands of people with disabilities and thereby the wider Australian community.²⁹**”**

^e This role is underlined in the Draft New National Disability Advocacy Framework 2022-25: [The Framework | engage.dss.gov.au](https://engage.dss.gov.au)

^f 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.” [Section 4](#), Subsection 13.

^g For a brief explanation about each of these models of disability advocacy see Attachment C

^h See Attachment D: Case studies, S demonstrating the importance and benefits of independent disability advocacy.

- Advocates can support and assist people to demonstrate eligibility to access services and support such as the NDIS but are currently overstretched and have limited capacity for this work.^{29 30}

Cost benefit analysis has shown that independent disability advocacy delivers a substantial positive net economic benefit to Australia that far exceed its economic costs. A recent DANA study found that every dollar used by Australia’s independent disability advocacy agencies delivers \$3.50 in benefits.³¹

The disability advocacy sector is very efficient in meeting the needs of clients within the constraints of available resources and limited capacity to reach out into the community. There is a diversity of these organisations - in terms of size, types of organisations, capacity, location and approaches to disability advocacy provision.

- Local and regional organisations can be particularly valuable with their detailed local knowledge and networks.
- Specialised disability advocacy organisations provide familiarity and knowledge of specific issues for particular groups of people.

Introduction of the NDIS has seen a significantly increased demand for advocacy to support people in navigating its inherent complexities.^{33 34 35 36 37 38} Recently, Queensland Public Advocate Dr John Chesterman asserted:

“...individual advocacy is more important, now than ever, when we have a service system that is increasingly individually focused. It’s much harder, through the system, to navigate - individual advocates play a crucial role.”³⁹

A range of government consultations, reviews and inquiries have reiterated the importance of independent disability advocacy in relation to quality and safeguarding in the NDIS and other government systems.^{i 40 41 42 43 44 45 46 47 48 49 50 51 52 53 54 55 56 57 58 59 60 61 62}

Self Advocacy can be very empowering for individuals in asserting their rights and maintaining safety.^{63 64 65 66 67 68 69} Supporting individuals to self-advocate is a regular part of the work of individual advocates. Only very limited numbers of people with disability can join a Self Advocacy group or receive training in Self Advocacy, because there are very few organisations funded to facilitate this form of advocacy.^{70 71 72}

Supported decision making is another vital component to ensure people with disability can genuinely exercise their rights and autonomy.^{73 74} Although decision support is distinguishable from advocacy, advocates often support people with decision-making in the course of their work, especially for people with intellectual disability.⁷⁵ Therefore, independent advocacy organisations already possess great expertise in supporting people with disability to make decisions and are well placed to deliver decision support with adequate additional funding.^{76 77}

ⁱ See Attachment E: Previous recommendations from nationally focused inquiries and reviews, concerning advocacy, its role and resourcing

Dr John Chesterman recently reflected:

“...individual advocates strike me as having the capacity to be able to play that role quite well if we ensure that there is that clarification of the distinction between advocate and a [decision] supporter. But there are many ways in which advocates could play that role...”⁷⁸

Through working directly with people with disability, advocacy organisations can identify systemic issues and barriers at all levels to inform needed changes and reforms in the systems and environments impacting people with disability. ^j⁷⁹ One woman with disability highlighted:

“Depending on the exact circumstances, I would probably go to the police with an advocate first. I’d go first to an advocacy organisation and have them go with me... But if it’s an advocate, it’s somebody that knows you as well.”⁸⁰

Given the multiple individual, societal and economic benefits of disability advocacy and the capacity to improve human rights, quality of life and reduce risks of violence, abuse, neglect and exploitation, ensuring access to advocacy for all those who need it needs to be a government priority.

Case study from Amparo Advocacy (2020) *2019-2020 Annual Report*, pp11-12

A young woman from a Middle Eastern background experienced an accident that left her with an Acquired Brain Injury (ABI). She now experienced difficulties managing her home, caring for her children, and accessing the community due to physical and cognitive impairments. Additionally, she had limited proficiency in English and no understanding of the National Disability Insurance Scheme (NDIS) and the support system in Australia.

When she tried to access supports through the NDIS her application was rejected twice, even though she had an outpatient allied health team and social worker assisting her with appropriate information and reports. She also applied for the Disability Support Pension (DSP), again assisted by the outpatient rehabilitation team but her application was rejected.

An advocate was engaged to help navigate these systems, and as a result her NDIS application was accepted, and funding was provided to meet her needs. Additionally, a specialised assessment was arranged to provide additional medical evidence for her to re-apply for the DSP.

The advocacy provided brought opportunities to participate in the local community, build her informal support circle, improve her physical strength, and gain control over her own life.

^j In 2014, the Productivity Commission recommended in relation to the civil justice system that: “Australian, State and Territory Governments should provide funding for strategic advocacy and law reform activities that seek to identify and remedy systemic issues and so reduce demand for frontline services.

Context of disability advocacy in Australia

It is difficult to understand the current situation of disability advocacy in Australia without appreciating some relevant contextual factors that include:

- Growing numbers of people with disability and increasing complexity of individual needs along with greater risks of violence, abuse, neglect and exploitation.
- Specific population groups that are at higher risk of violence, abuse, neglect and exploitation.
- Multiple barriers limit access to services and support for people with disability – for both mainstream and disability services.

1. Increased number of people with disability, and increased complexity of issues and risks

Changing Australian demographics with an ageing population has seen an increase in the numbers of people who live with a disability - currently estimated at 18 per cent of the population.⁸¹ Currently there are 534,655 participants in the NDIS, almost half of whom are under 18 years old. People over 65 are ineligible to be a NDIS participant and currently only 12 per cent of people with disability receive individually funded plans through the NDIS.^k

Across the broad spectrum of types and complexities of disabilities, there is a great diversity of needs and many people with disability experience multiple significant life challenges. Limited life choices and opportunities for participation, reduced access to services and outright discrimination result in social and economic exclusion, diminished quality of life and impairment of human rights.^{82 83 84}

The current situation greatly impacts people's mental health and well-being and carries considerable private and public costs, including overrepresentation in the criminal justice system.^{85 86 87 88}

Multiple studies and inquiries confirm that people with disability are particularly at risk of experiencing violence, abuse, neglect and exploitation.^{89 90 91 92}

There is increasing recognition of the multiplier effects of intersectional disadvantage for people who have disability along with health and/or other issues that influence their well-being - for example, welfare, poverty, housing and justice related issues.^{93 94 95 96 97 98 99}

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^k In the latest NDIS Quarterly Report, the number of current participants in the scheme with approved plans is reported as 534,655: National Disability Insurance Scheme (2022) *Q4 2021-22 - NDIS Quarterly Report to disability ministers*, 30 June 2022, p29. AIHW estimates the number of people with disability as "around 4.4 million": Australian Institute of Health and Welfare (2022) *People with disability in Australia 2022*, catalogue number DIS 72, AIHW, Australian Government, p14.

Regardless of age or eligibility for the NDIS (or the Disability Support Pension), people with disability should be entitled to support for advocacy in the issues impacting their safety and well-being.

The increase in numbers of people with disability in the Australian population, complexity of their needs and heightened risks of violence, abuse, neglect and exploitation carries a proportionate need for increased access to advocacy support.¹⁰¹

2. Groups of people that are at particularly high risk of violence, abuse, neglect and exploitation

People with disability in 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.¹⁰² These include:

- people with intellectual disability;^{103 104 105 106 107 108}
- people with complex communication support needs;^{109 110 111}
- women;^{112 113 114 115 116}
- Aboriginal and Torres Strait Islander people;^{117 118 119 120}
- people from culturally and linguistically diverse (CALD) communities;^{121 122 123}
- LGBTQIA+ people;^{124 125 126 127 128 129 130}
- children and young people;^{131 132 133} and
- people with disability with no informal support networks.^{134 135 136 137}

As many of the Royal Commission issues papers and hearings have confirmed, people in closed settings are also at higher risk - for instance in segregated environments, prison, family or other domestic contexts and residential arrangements.^{138 139 140 141 142 143}

There is also likely underreporting of violence of abuse, neglect and exploitation relating to people with intellectual disability and complex communication. This cohort experience barriers in reporting, obtaining assistance and pursuing prosecution. Particularly for people with intellectual disability, figures are likely underestimates.

People with disability in the community who are at particularly high risk need to be identified and concerted efforts made to ensure they have access to independent advocacy to enable them to receive services and support to uphold their rights and maintain their dignity.

Case study from Rights in Action – See Queensland Independent Disability Advocacy Network (2022) Data Analysis January to June 2022 – Submission to Department of Seniors, Disability Services and Aboriginal and Torres Strait Islander Partnerships, p28

In March 2020, an advocacy organisation began assisting a 19-year-old First Nations woman from the Atherton Tablelands with suspected foetal alcohol spectrum disorder (FASD). The young woman was homeless and at a high risk of physical, emotional, financial and sexual abuse. Despite experiencing significant difficulties, she did not have access to disability supports or a disability support payment due to the lack of a formal diagnosis of her disability.

When advocacy commenced, she underwent specialist tests to obtain the medical evidence needed but missed or terminated many appointments due to her lack of appropriate accommodation, declining mental health and substance abuse. In December 2020, she moved into a Department of Housing unit as a result of close collaboration and advocacy support.

In January 2021, the clinical psychologist at the Aboriginal Medical Centre was engaged through advocacy support and the formal diagnosis of FASD was provided. A private occupational therapist conducted a full functional capacity assessment to identify the young woman's support needs in day-to-day life with funding from a disability support service. In February 2021, a NDIS application was submitted.

3. Multiple barriers limit access to services and support for people with disability (mainstream and disability services)

People with disability require a range of mainstream health and other services, such as GPs, medical specialists and dentists. Many people require multiple types of services and these are often complex systems that are challenging to navigate. Some difficulties experienced in accessing these services, include inadequate information, unacceptable or lengthy waiting times, excessive costs, inaccessibility of buildings, and discrimination by health professionals and other service providers.^{144 145 146 147}

The large national systems and programs established to support people with disability, including Centrelink and the NDIS are complex and difficult to navigate and frequently not responsive to the individual needs of people with disability.^{148 149 150 151 152 153 154 155}

There are also issues of discrimination, unfairness, abuse and exploitation in the NDIS systems and by NDIS registered and unregistered providers.

This is especially the case for those who require support for decision making or communication and/or experience other forms of discrimination or disadvantage.^{156 157 158 159 160 161 162 163}

The processes for people with disability to challenge NDIS decisions, including through appealing decisions about eligibility or supports included in plans to the Administrative

Appeals Tribunal, has been especially problematic.^{164 165 166 167} Advocacy (and legal aid) organisations have been overwhelmed by recent massively increased demand for support.^l

Lack of access to services (mainstream and disability) carries considerable associated costs and unnecessary imposts on government emergency and acute services, health, justice and other human services.¹⁶⁸ It reduces the capacity for people to participate, further contributing to diminished quality of life and results in many people with disability having poorer health and well-being outcomes including earlier death.^{169 170 171}

The barriers to access to health and other mainstream services need to be clearly identified and addressed to enable improved health outcomes and quality of life for people with disability.

4. Inadequate involvement of people with disability in service design, oversight and delivery

People with disability should be able to be actively involved in the design, delivery and governance of organisations and supports to ensure these are appropriate, inclusive and effective.^{m 172 173 174} One of Australia’s Disability Strategy policy priorities is to “increase representation of people with disability in leadership roles”, stating that:

Although there are increasing endeavours to proactively include people with disability in all aspects of service design, delivery and governance, this requires additional targeted resources, especially to facilitate and support the meaningful involvement of people with complex support needs, and this is not yet widespread.^{176 177 178 179 180}

“People with disability are significantly underrepresented on boards, in politics and in other leadership roles in Australian society. Increased inclusion of people with disability in leadership will enable the perspectives of people with disability to be included in decision-making, thereby making decisions more reflective of the community.”¹⁷¹

^l In the 2019-2020 financial year there were 1,780 NDIS appeals applications lodged; followed by 2,160 applications during the 2020-2021 financial year. For the period 1 July 2021 to 30 June 2022, 5,918 applications were lodged leading to a much larger backlog reported in the AAT Caseload Report. For the period of 1 July to 31 October 2022 there were 1,596 applications lodged. See [Statistics | Administrative Appeals Tribunal \(aat.gov.au\)](https://www.aat.gov.au/statistics)

^m As the DRC-commissioned Research Report on changing community attitudes concluded ‘active presence of people with disability’, ‘leadership’ and ‘long-term approaches with adequate resources’ are all key strategies to facilitate attitude change.

Lack of competence in interacting with people with disability (and also outright discrimination) can create a challenging environment for people with disability to feel comfortable in participating and contributing. This is particularly relevant for people with intellectual disability and/or complex communication support needs who may need intensive and ongoing individualised supports to participate meaningfully in co-design and governance activities.¹⁸¹

Support for enhanced involvement of people in disability service design, management and oversight can improve the quality and effectiveness of the supports provided by all organisations and service systems to enhance quality of life and reduce risks of violence, abuse, neglect and exploitation.

Key barriers and challenges in disability advocacy

The following are the key barriers and challenges in disability advocacy that underpin the DANA recommendations.

1. Funding for disability advocacy is fragmented, inadequate and inconsistent.
2. Significant barriers limit access to disability advocacy.
3. Disability advocacy organisations are overstretched, impacted by COVID and other emergencies.
4. The disability advocacy sector varies greatly and has low visibility.
5. Paucity of national data – unknown unmet need and unmet demand, lack of advocacy outcomes data

1. Funding for disability advocacy is fragmented, inadequate and inconsistent

Disability advocacy is funded through a patchwork of Commonwealth and state and territory government programs and contractual arrangements that are fragmented and uncoordinated.ⁿ There has been considerable funding uncertainty and disparity in relation to some state based programs.^{182 183 184}

- National data regarding the funding that is provided is difficult to access – how much, to which organisations and what arrangements and for what activities.
- It is not possible to gain a clear understanding of the quantum of disability advocacy funding available to address the increased need for advocacy support.
- There are reported significant gaps in geographical coverage, leaving some people without access to advocacy organisations at all.¹⁸⁵

According to a recent survey of 364 disability services providers by peak body National Disability Services, only 14% of respondents agreed with the statement that “there is sufficient advocacy for the people we support”, with 73% disagreeing or strongly disagreeing.¹⁸⁶

Commonwealth disability advocacy funding has not kept pace with increased demand and advocacy organisations are inadequately resourced to respond to all people who need advocacy.^o

- Commonwealth funding for disability advocacy has been stagnant or inconsistent for 16 years with unclear correlation with CPI, the growing numbers of people with disability and increasing need.¹⁸⁷

ⁿ Under all three versions of the *Commonwealth State Territory Disability Agreement* (since 1991) all Australian governments are responsible for funding specialist services for people with disabilities, including that “*support for advocacy and print disability is a shared responsibility between the Australian Government and state and territory governments.*” See Department of Social Services (2016) [Commonwealth State Territory Disability Agreement Factsheet](#), accessed 16 November 2022.

^o See Attachment F: Unmet demand for advocacy support

- Funding for NDIS appeals is limited and Disability Royal Commission individual advocacy support funding (to assist with making submissions) terminates in June 2023.

Multiple recommendations for increased investment in and certainty of disability advocacy funding have not been acted upon.^{188 189 190 191 192 193 194 195 196 197 198}

The current funding structure also does not reflect the level and complexity of needs of individuals with disability nor requirements for advocacy organisation sustainability and efficiency.

- No robust funding formula is in place to inform appropriate levels of disability advocacy support
- Current funding only provides for limited disability advocacy hours with no component for developing organisational systems to improve efficiency, client management, consistent data collection, storage and analysis.
- Current funding does not support the provision of all models of advocacy for people with disability (individual advocacy, Citizen Advocacy, legal advocacy, Self Advocacy, family advocacy and systemic advocacy)
- Funding terms are typically short (with 1-2 year extensions); this greatly limits the capacity of organisations to consolidate systems and supports, and to plan ahead.

Despite the significant increase in disability services funding through the NDIS, this has not been met with proportionate additional funding for disability advocacy organisations to deliver the coordinated support people with disability require for the goals of the NDIS to be achieved.¹⁹⁹

- The NDIS Appeals funding allocations only go to 40 of 59 NDAP funded organisations and not to advocacy organisations that are funded from other sources.^P The demand has increased significantly in the past 2 years and many people are unable to access support from an advocate.^{200 201 202}
- Some State funding has stipulations barring funded organisations from providing advocacy on federal issues, such as NDIS and appeals advocacy. This contributes to fragmentation of the support that disability organisations are able to provide.

Coordination and streamlining of funding from Commonwealth and state governments would greatly benefit disability service organisational efficiency and data collection.

Governments need to ensure appropriate funding is allocated, informed by data on unmet demand and unmet need so that people with disabilities can access support to exercise their rights. This should be based on a robust formula that reflects the complexity of individual disability needs, advocacy organisational sustainability and capacity to deliver quality supports.

^P Some other advocacy organisations assist with Internal Reviews but will refer clients to organisations funded through the NDIS Appeals stream if someone is taking an appeal to the AAT.

2. Significant barriers limit access to disability advocacy

Without access to disability advocacy people with disability are at greater risk of violence, abuse, neglect and exploitation and of experiencing entrenched exclusion.

- There are multiple gaps and inconsistencies in the availability and accessibility of disability advocacy supports due to fragmented and inadequate funding for organisations across states and territories.²⁰³
- Organisations are of varying size, focus and capacity for provision of disability advocacy for the increasing numbers of people seeking advocacy support.

Many people with disability miss out due to a range of factors including:

- Lack of knowledge of their rights, lack of proximate or accessible organisations, complexity of the service system and overburdening of the advocacy organisations that exist.²⁰⁴
- Disability support workers and professionals are not always aware of, or educated about, the rights of people with disability, the role or availability of disability advocacy and how or when it is important to refer people with disability to independent advocacy
- In some specific settings including closed, institutional and family settings, people do not have access to independent advocacy, due to lack of awareness, gatekeeping or exploitative practices

Anecdotally, there is limited general community awareness of rights and disability advocacy and where and how to access advocacy supports which is a further constraint on supporting people with disability to exercise their rights.

Some population groups are particularly vulnerable and less likely to be able to access disability advocacy support, including:

- Aboriginal and Torres Strait Islander people's access to culturally appropriate advocacy support.^{205 206}
- LGBTIQ+ people access to responsive and supportive advocacy.^{207 208}
- People with disability living in rural and remote areas are particularly disadvantaged due to the limited services and advocacy support available.^{209 210 211 212 213 214 215 216}
- People with disability from CALD communities have limited access to culturally appropriate and responsive supports even in major metro areas.^{217 218 219}
- There are some youth and children-specialist organisations but advocacy for children and young people is not available everywhere.^{220 221 222 223 224 225}
- People with intellectual disability and complex communication support needs including acquired brain injury and psychosocial disability.^{226 227}

- People living in congregate settings, and especially people with a ‘whole-of-life’ disability supports and accommodation provider may have practically no access to independent advocacy or support to report violence, raise a complaint or request an advocate.^{228 229}

Concerted efforts are needed to improve access to disability advocacy support by reducing the current barriers and expanding access to tailored services for identified populations that are at higher risk of violence, abuse, neglect, and exploitation.

3. Disability advocacy organisations overstretched, impacted by COVID and other emergencies

Organisations are severely stretched and unable to meet existing demand due to insufficient workforce funding and inadequate organisational resources to respond to all those seeking advocacy support.

- Additional supports from advocacy services are required to assist people with disability to navigate the complexities of the NDIS
- Chronic under-funding, exacerbated by the strains created by COVID-19 and other emergencies and the high demand on the NDIS Appeals stream of the National Disability Advocacy Program (NDAP) has contributed to further pressures on advocacy services.^{230 231}
- The COVID pandemic has disproportionately impacted people with disability and contributed to additional challenges of providing advocacy supports and been compounded by significant workforce constraints.^{q 232 233 234 235}

Advocacy organisations have increasingly been forced to prioritise crisis response work over the preventative and developmental work of rights education and awareness raising, capacity building and early stage problem-solving and dispute resolution.

- This in turn has led to increased demand, longer waiting lists and greater strain on organisations.
- DANA members report that advocacy and legal services are overwhelmed and experiencing high levels of staff fatigue and burnout.^{236 237 238 239}

^q As the Disability Royal Commission has found the impact of COVID-19 pandemic on the health, safety and wellbeing people with disability has been profound, including sudden loss of support services, lack of access to basic necessities, and uncertainty about survival in the face of prolonged disruptions to essential care and support - Royal Commission on Violence, Abuse, Neglect and Exploitation of People with Disability (2020) *Report on Public hearing 5: Experiences of people with disability during the COVID-19 pandemic*, p26.

Because services are currently overstretched there is very limited capacity to work towards identification and analysis of systemic issues impacting people with disability and to take action to address these in coalition with others.

The varied funding arrangements carry multiple reporting requirements that create an additional reporting burden for organisations that are already overstretched. Also the need for compliance with multiple audits and regulatory requirements, place disproportionate burdens on smaller advocacy organisations.

“*(There is a) complexity of current client issues - many have been clients for a significant amount of time and their matters requiring significant resources to address. There are few referrals that can be addressed quickly and if this is the case we promote self advocacy and provide information and support rather than taking them on as a client. NDIS Appeals matters are taking a long time to progress through the AAT with some matters commencing in 2020 still not resolved.*”²³⁴

Additional funding is urgently needed to enable disability advocacy organisations to deal adequately with complex issues and systems alongside clients, to service unmet demand and identify additional unmet need. Resources are needed to strengthen organisational capacity to deliver timely and efficient services, meet increasing operational costs and to undertake systemic analysis.

4. The disability advocacy sector varies greatly and has low visibility

The type and approach to disability advocacy varies across the sector with limited training and sector development available and no benchmarking of best practice.

No concerted national promotion of disability advocacy has been undertaken and there is limited awareness of disability advocacy across health, disability and other support services and the community in general.

- This contributes to failure to refer people with disability, exacerbating low access and increased vulnerability of people with disability to violence, abuse, neglect and exploitation without the intervention of independent advocacy.²⁴¹
- However increased visibility and awareness of advocacy support risks creating further increased demand that cannot be met by current levels of disability advocacy funding.

The disability advocacy sector is not currently resourced for up-to-date infrastructure and systems to enable efficient data collection and synthesis. There is also no sector guidance in relation to systematic collection of data to build the evidence base of what is effective in addressing people's needs through advocacy support and to identify specific systemic issues at local, regional and national levels that need to be addressed to improve circumstances for people with disability.

Funding to DANA for the National Centre for Disability Advocacy provides an opportunity to build much needed sector capacity over the next few years through training and building communities of practice.

Enhanced targeted funding to DANA and the National Centre for Disability Advocacy would support greater visibility of disability advocacy, facilitate significant increased sector consistency and capacity to deliver high quality support. This would greatly contribute to prevention of and timely responses to violence, abuse, neglect and exploitation of people with disability.

5. Paucity of national data

There is a paucity of robust national (and regional) data that accurately reflects both the extent, nature and specificity of both unmet demand and unmet need for advocacy support for people with disability. This has been well recognised for some years and not yet addressed.^{242 243}

- Lack of robust aggregated data limits the capacity of governments and services at all levels to appropriately target funds to address unmet need and enhance efforts to reduce risks of violence, abuse, neglect and exploitation.

No systematic data collection systems are in place to monitor unmet demand and to explore unmet need, including among individuals who may find it difficult to access independent disability advocacy.²⁴⁴

- A recent DANA survey and anecdotal reports from DANA members (Intake Project) indicate significant unmet demand and need for advocacy around Australia.[†] Survey respondents reported that 50% of people seeking support had to be turned away due to lack of organisational capacity. For those seeking NDIS appeals advocacy 60% were turned away.²⁴⁵

There is also very limited data on:

- The effectiveness and outcomes from the advocacy that is provided.
- Advocacy service capacity, efficiency, service delivery challenges etc.

[†] See Attachment F: Unmet demand for advocacy support.

Data paucity is compounded by the complexity of funding arrangements from Commonwealth and jurisdictional sources and divergent reporting requirements and systems. There are multiple funding agreements with no standardised and consistent performance indicators to facilitate data collection.

Data gathered for reporting purposes by funded agencies is not generally publicly available, including demographic data and categorisation of the advocacy issues being addressed.^s This in turn limits the research undertaken in the field.

No focused analysis of systemic issues impacting advocacy for people with disability is undertaken that could inform system changes and reforms to improve outcomes for people.

There is an urgent need for nationally consistent, comprehensive systematic data collection mechanisms to monitor disability advocacy activity, service availability and capacity together with outcomes of advocacy. Analysis of the data would identify trends and inform appropriate resourcing, service availability and sector development needs.

^s Except in Queensland – the Queensland Government Department of Seniors, Disability Services and Aboriginal and Torres Strait Islander Partnerships has funded Queensland Advocacy for Inclusion as the Principal Advocate to deliver a central hub, called [Pathways – Disability Advocacy](#) from 2022. This has enabled increased visibility and analysis of disability advocacy data, including the demographic information for specific categories of requests, for instance: [QIDAN data analysis – housing – Pathways](#).

Recommendations

We can envision an Australia in which people with disability have equal access to participating fully in communities and to feel safe and enjoy equality before the law by being able to access independent advocacy when and where they need it. Unfortunately, notwithstanding the Australian Government's stated commitment to upholding the rights of people with disability, the existing under-resourced sector cannot guarantee that this support is in fact available for people across the country.

Commonwealth, state and territory governments need to work collaboratively to establish comprehensive and consistent funding and reporting arrangements to ensure that all Australians with disability have access to advocacy to eliminate their risks of violence, abuse, neglect and exploitation. And to ensure access to the ordinary aspects of life enjoyed by the rest of society that are currently denied to many.

The following DANA recommendations support fulfilling the obligations inherent in the implementation of the purpose and principles of the ADS (2021-2031) and NDAF (2022-2025) to achieve desired outcomes for people with disability throughout Australia. In particular, the recommendations seek to eliminate their risks of experiencing violence, abuse, neglect or exploitation.[†]

1. **ENHANCE DISABILITY ADVOCACY SERVICE CAPACITY:** Increase disability advocacy funding to support service capacity to provide access to all people with disability who require advocacy support to reduce risks of violence, abuse, neglect and exploitation and enhance quality of life
 - a. Provide an immediate injection of additional funds to address the existing crisis in lack of independent advocacy service availability by enhancing the workforce capacity of disability advocacy organisations to meet current demand and to support clients in a timely and consistent manner.
 - b. Address unmet need for disability advocacy by expanding reach through targeted advocacy to increase access and support for identified high risk population groups and to address specific needs including issues arising from intersectionality that impact people with disability i.e. housing, poverty, mental health, justice, abuse, vulnerability
 - c. Strengthen organisational systems and infrastructure to support enhanced administrative efficiency and quality of disability advocacy service delivery
 - d. Undertake collaborative work between state, territory and federal governments with the disability advocacy sector to develop a robust disability advocacy funding model. The model to guide distribution of funding to address client complexity, meet current and unmet advocacy needs and to support organisational responsiveness and sustainability.

[†] See detailed recommendations in Attachment A.

- 2. IMPROVE AND DEVELOP SECTOR QUALITY:** Provide funding to develop the disability advocacy sector to enhance consistency, responsiveness and professionalism of disability advocacy support to facilitate positive outcomes for all people with disability through:
 - a. Workforce training and development to build quality and consistency in disability advocacy practice
 - b. Develop tools, resources and tailored approaches for identified high risk population groups who may find advocacy hard to access
 - c. Promote increased recognition and awareness of the roles and value of disability advocates
 - d. Support implementation of a new disability advocacy service standard
 - e. Enhance systemic data collection processes across organisations nationwide
 - f. Develop approaches to support the inclusion and involvement of people with disability in decision making, co-design and organisational governance.

- 3. IMPROVE NATIONAL CO-ORDINATION AND DATA:** Increase government and sector co-ordination to streamline disability advocacy funding and as information and data collection to better inform systemic improvements:
 - a. Establish and facilitate federal and state and territory collaborative mechanisms to coordinate and streamline disability advocacy funding, reporting and administrative systems to enable increased access, efficiency, outcomes and improved data quality and availability
 - b. Strengthen data and information systems to enable systematic collection, analysis and utilisation of high-quality accessible data to build a solid evidence base and to inform systems improvement at all levels
 - c. Support disability advocacy sector coordination through funding of national and state and territory peak and representative organisations.

- 4. ENHANCE SAFEGUARDING MECHANISMS:** Explore potential solutions to ensure access to independent disability advocacy as part of protection and safeguarding of people with disability who are at particular risk of violence, abuse, neglect and exploitation
 - a. Increase awareness of, and access to advocacy for all people with disability
 - b. Introduce new legislation to provide right of entry for disability advocates to closed, congregate or institutional settings
 - c. Establish a mechanism to enable organisations to provide dedicated 'safeguarding advocacy' for people with disability who are identified as experiencing elevated risk of violence, abuse, neglect and exploitation
 - d. Establish an ongoing funding stream for Supported Decision Making.

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 - the International Convention on the Elimination of All Forms of Racial Discrimination
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Attachment A: DANA Submission to Disability Royal Commission – detailed recommendations - December 2022

Recommendation 1. Enhance disability advocacy service capacity

Increase disability advocacy funding to support service capacity and provide access to all people with disability who require advocacy support to reduce risks of violence, abuse, neglect and exploitation and enhance quality of life

Recommendation	Details of recommendations	Benefits & likely outcomes
<p>1.a. Provide an immediate injection of additional funds to address the existing crisis in lack of independent advocacy support availability by enhancing the workforce capacity of disability advocacy organisations to meet current demand and to support clients in a timely and consistent manner.</p>	<ul style="list-style-type: none"> • Additional funding to advocacy services funded by Federal and State and Territory government programs to <u>increase workforce capacity to meet current demand, reduce waiting times and waiting lists.</u> • Include funding allocations to: <ul style="list-style-type: none"> - address complex needs and - address advocacy issues arising from intersectionality that impact people with disability (see 1.b.) • Allocate funding support for staff training and ongoing professional development, supervision and counselling 	<p>More people with disability able to access disability advocacy when needed, resulting in:</p> <ul style="list-style-type: none"> • reduced risk of violence, abuse, neglect and exploitation^{1 2} • improved quality of life, wellbeing, autonomy, community participation and inclusion^{3 4 5 6 7} • stronger human rights protection and access to justice^{8 9} • positive flow-on effects to carers, family members and supporters¹⁰ <p>Improved geographical coverage of rural, regional and remote communities^{11 12}</p> <p>Across disability advocacy sector, increased advocacy staff resourcing results in</p>

Recommendation	Details of recommendations	Benefits & likely outcomes
		<ul style="list-style-type: none"> • prevention of staff burnout and vicarious trauma;^{a b 13} • enhanced staff retention;^{14 15} • strengthened medium and long-term responsiveness and capacity of organisations.
<p>1.b. <u>Address unmet need</u> for advocacy by expanding reach through targeted advocacy to increase access and support for <u>identified high risk population groups</u> and to address specific needs including <u>issues arising from intersectionality</u> that impact people with disability i.e., housing, poverty, mental health, justice, abuse, vulnerability</p>	<ul style="list-style-type: none"> • Provide funding allocations for <u>assertive outreach (and in-reach) and culturally appropriate support</u> for people who are at high risk of violence, abuse, neglect or exploitation and those who may find advocacy hard to access e.g. First Nations people, CALD community members, people with complex communication support needs, socially isolated people, people in closed settings, and rural and remote areas. 	<p>Improved disability advocacy access and support for identified high-risk populations of people with disability results in:</p> <ul style="list-style-type: none"> • improved utilisation of available supports, including government and community services • mitigation of risk of violence, abuse, neglect or exploitation¹⁶ • prevention of crisis situations (avoiding unnecessary costs to governments) <p>Advocacy organisations able to engage in proactive outreach (and in-reach into institutional environments) to:</p>

^a The [Best Practice in Disability Advocacy course](#) created by Disability Advocacy Resource Unit (DARU) in Victoria recognises that “advocates can be highly susceptible to burnout and vicarious trauma.” The final module focuses on “Self Care”.

^b The DARU 2019 Strengthening Disability Advocacy Conference included a facilitated workshop focused on the issues of managing overwhelming workloads: [A Sector at Capacity: Burnout, organisational change and adapting in the face of adversity.](#)

Recommendation	Details of recommendations	Benefits & likely outcomes
		<ul style="list-style-type: none"> • identify people at greater risk of violence, abuse, neglect and exploitation • intervene at an earlier stage to avoid further harm to individuals • allow advocates to engage in more preventative and developmental work to prevent crises developing <p>Focus of advocacy practice shifts from reactive crisis intervention (due to need to prioritise according to urgency of needs) to primary prevention and earlier intervention to prevent harm occurring and promote inclusion, human rights and access to justice.^{17 18}</p>
<p>1.c. <u>Strengthen organisational systems and infrastructure</u> to support administrative efficiency, and quality of advocacy service delivery</p>	<ul style="list-style-type: none"> • Provide <u>consistent funding that is CPI indexed</u> and supports advocacy service continuity and sustainability: <ul style="list-style-type: none"> - 5 year funding grants • Provide additional targeted funding to improve advocacy organisations' systems capacity and support implementation of nationally consistent and compatible CRM systems tailored for advocacy organisations 	<p>Organisational efficiency and sustainability supported through longer-term indexed funding agreements:</p> <ul style="list-style-type: none"> • improved organisational planning and development, • enhanced staff retention (being able to offer stable contracts)¹⁹ • increased efficiency with improved technology infrastructure and streamlined processes²⁰ • reduced administrative burden through use of fit-for-purpose systems

Recommendation	Details of recommendations	Benefits & likely outcomes
		<ul style="list-style-type: none"> increased staff capacity for direct client support or other disability advocacy activities
<p>1.d.Undertake collaborative work between state, territory and federal governments with the advocacy sector to <u>develop a robust disability advocacy funding model. The model to guide distribution of funding</u> to address client complexity, meet current and unmet advocacy needs and to support organisational responsiveness and sustainability</p>	<ul style="list-style-type: none"> Establish an expert taskforce and sector consultation framework to design a disability advocacy funding model that can be applied at federal, state and territory levels. The <u>funding model</u> to take into account: <ul style="list-style-type: none"> equitable, population based allocation that reflects levels of need elements of client complexity prioritised support for people with disability who are at greatest risk provision of face-to-face support for those who need it equitable staff wages for disability advocates service on-costs and related non client direct services e.g., consultation with other service providers (lawyers, educators, therapists etc.) specialist advocacy services for specific cohorts Include allocations to enable organisations to engage in collaboration, expertise-sharing, and training described in (2a) 	<p>Current gaps in coverage identified and rectified</p> <p>Advocacy organisations resourced to advocate effectively for people with disability with complex needs and/or who are experiencing complex situations of discrimination, disadvantage, abuse, neglect, trauma, etc.</p> <p>Face to face support is available to those whose needs cannot be met by phone or internet communication (including some people with intellectual or psychosocial disability or complex communication support needs).</p> <p>Improved staffing and organisational sustainability meets the needs of people with disability at risk of violence, abuse, neglect and exploitation</p>

Recommendation 2. Improve and develop sector quality

Provide funding to develop the disability advocacy sector to enhance consistency, responsiveness and professionalism of advocacy support to facilitate positive outcomes for all people with disability

Recommendation	Detail	Benefits & likely outcomes
2.a <u>Workforce training and development</u> to build quality and consistency in disability advocacy practice	<ul style="list-style-type: none"> • Expand funding for <u>National Centre for Advocacy</u> to work in collaboration with relevant organisations and agencies to develop and deliver training and workforce development to support effective advocacy <ul style="list-style-type: none"> - Consultatively develop nationally <u>consistent professional competencies</u> for disability advocates drawing on current work in development - Support establishment of disability advocacy networks and communities of practice to draw on collective skills, knowledge and expertise and disseminate knowledge and evidence nationally. 	Improved collaboration on workforce training and development and stronger information sharing networks enable: <ul style="list-style-type: none"> • increased sharing of professional expertise across sector • more training opportunities equip advocates to better meet the needs of people with disability Increased profile of the role of independent disability advocates ²¹ Greater clarity around professional competencies and training required for paid professional advocates.
2.b. Develop <u>tools, resources and tailored approaches</u> for identified high risk population groups who may find advocacy hard to access	Provide targeted funding for National Centre for Advocacy to work in collaboration with relevant peaks and specialist advocacy organisations to develop <u>tailored advocacy approaches and tools for:</u> <ul style="list-style-type: none"> • Specific population groups of people with disability <ul style="list-style-type: none"> - First Nations people - CALD people - LGBTIQ+ people - Children and young people 	Advocacy sector effectively meets the needs of individuals from specific groups or demographics. ^{22 23 24 25} e.g. National Centre for Advocacy to facilitate cultural safety training delivered by First Peoples Disability Network to ensure all advocacy organisations are equipped to build relationships with local Aboriginal and Torres Strait Islander organisations, networks and communities and better meet the needs of

Recommendation	Detail	Benefits & likely outcomes
	<ul style="list-style-type: none"> - Older people - Women, girls and non-binary people • Specific cohorts requiring specialist expertise: <ul style="list-style-type: none"> - Specific and/or multiple disabilities (such as people with intellectual disability, people with acquired brain injury, people with autism, people with psychosocial disability or mental illness) - People with disability in segregated settings e.g. group homes, jails, schools etc. - Children and young people with disability, including those in and transitioning out of out-of-home care - Parents and carers with disability - People living in rural and remote areas - People with complex communication support needs - People who may behave in challenging ways when they have unmet needs - People with chronic health conditions • Addressing the impacts of intersectionality through provision of early support and continuing across the lifespan 	<p>First Nations people with disability (and when appropriate and available, refer them to more specialised advocacy supports)^c</p> <p>Government savings, benefits for individuals, and reduced pressures on other systems e.g.</p> <ul style="list-style-type: none"> • Specialist approaches for parents interacting with child protection systems to provide practical and emotional support helping “parents to understand the child protection process and to cope with the requirements placed on them to attend case plan meetings and court hearings” ^{26 27} • The Justice Advocacy Service at Intellectual Disability Rights Service in NSW demonstrated a positive return on investment for government and significant benefits for the individuals supported. ^{28 29}

^c During the Disability Royal Commission First Peoples Disability Network (FPDN) were funded to deliver “Disability Business Training” to organisations funded through the National Disability Advocacy Program: [Disability Business Training - FPDN](#)

Recommendation	Detail	Benefits & likely outcomes
2.c. Promote increased <u>recognition and awareness of the roles and value</u> of disability advocates	<ul style="list-style-type: none"> Promote increased recognition and awareness of the roles and value of disability advocates through strategic education and awareness-raising activities <p>See further under 4a.</p>	Enhanced understanding of disability advocacy in the broader general public and more targeted referrals due to increased recognition of when people with disability need the support of an independent disability advocate
2.d Support implementation of a new disability advocacy service standard	<ul style="list-style-type: none"> Implement the proposed new National Disability and Older Persons Advocacy Standard (currently being developed by OPAN, DANA with Standards Australia facilitating the technical committee) 	<p>A consistent and specific Advocacy Standard implemented that measures quality for multiple types of advocacy and</p> <ul style="list-style-type: none"> a more in-depth and meaningful auditing process. a set of advocacy-specific criteria (as opposed to a set of general service standards) allows for a more appropriate, contextualised and fit-for-purpose measure of quality specific to the disability and aged-care advocacy sectors.
2.e. Enhance <u>systemic data collection processes</u> across advocacy organisations nationwide	<p>Provide additional targeted funding to enable advocacy organisations (with DANA acting as a conduit) to:</p> <ul style="list-style-type: none"> Flag systemic issues at local, regional, state and territory and national levels Participate in opportunities for intersectoral liaison and awareness raising and broader systemic advocacy activities 	<p>Advocacy organisations able to gather and contribute on-the-ground information and collaborate on identified systemic issues</p> <p>Streamlined information-sharing, coordination and collaboration on systemic issues identified by on-the-ground advocacy organisations.</p>

Recommendation	Detail	Benefits & likely outcomes
		Tangible changes in key systemic issues through a more streamlined approach and greater co-operation on systemic issues (informing policy development and law reform)
2.f. Develop approaches to <u>support the inclusion and involvement of people with disability in decision making, co-design and organisational governance</u>	<ul style="list-style-type: none"> • Provide dedicated funding for advocacy and disability representative organisations to support building the capacity of people with disability in: <ul style="list-style-type: none"> - Self advocacy and advocacy skills - leadership and representation - advisory and decision-making processes, including in community, public and private sectors at local, regional and national levels • Provide funding to support advocacy organisations include meaningful participation of people with disability in organisational decision-making processes and program co-design <ul style="list-style-type: none"> - Include resourcing for individualised support to facilitate participation of people with intellectual 	<p>People with disability access training and support to be able to contribute to co-design processes³⁰</p> <p>More people with disability are active in effective Self Advocacy, representation and leadership, enhancing human rights and reducing risk of violence, abuse, neglect and exploitation^{31 32 33 34 35}</p> <p>The ‘Nothing About Us Without Us’ ideal of the CRPD is more fully realised through enhanced representation and inclusion of lived experience expertise and peer advocacy insights within and beyond the disability advocacy sector^{d e 36 37}</p>

^d See relevant training and resources in ‘Voice At The Table’ project by Self Advocacy Resource Unit - [Voice at the Table - State Government funded training with resources for Government and Peer Advisors.](#)

^e Inclusion Australia has produced a number of useful resources for Service Providers as part of their [Your Service Your Rights](#) project, including a guide for [Setting up an Advisory Group in Your Service](#) and for including people with an intellectual disability in the audit process.

Recommendation	Detail	Benefits & likely outcomes
	<p>disability, acquired brain injury or other cognitive impairment</p> <ul style="list-style-type: none"> • Provide DANA with funds to collaboratively develop models of peer and lived experience advocacy training, qualifications and support mechanisms 	<p>Improved planning and service structures at all levels more effectively meet the needs of people with disability (consistent with international human rights norms and CRPD principles) ^{38 39 40 41}</p> <p>Voices of people with disability heard and amplified through support of local networks ^{42 43 44 45}</p> <p>Successful approaches from the health and mental health sectors usefully guide development of models to meet the needs of different disability types ^{f g 46 47 48 49 50}</p>

^f Lived Experience Australia has developed online training modules for mental health consumers: [Training - Advocacy Skills for Consumers and Carers | Lived Experience Australia](#)

^g See resources created by the Lived Experience Leadership and Advocacy Network, the independent peak body for people with lived experience of mental distress, social issues or injustice in South Australia: [LELAN | SA Lived Experience Leadership & Advocacy Network](#)

Recommendation 3: improve national co-ordination and data

Increase government and sector co-ordination to streamline disability advocacy funding and information and data collection to better inform systemic improvements

Recommendation	Detail	Benefits & likely outcomes
<p>3.a. Establish and facilitate <u>federal and state and territory collaborative mechanisms</u> to coordinate and streamline disability advocacy funding, reporting and administrative systems to enable greater organisational efficiency, improved access and outcomes</p>	<p>Establish a national series of roundtables focused on disability advocacy including federal and state and territory funders, representative organisations, peaks and other key stakeholders (including people with disability who have accessed advocacy support) overseen by the disability reform ministers.</p> <p>The roundtable agendas to:</p> <ul style="list-style-type: none"> • Identify and establish agreed mechanisms to streamline funding and reporting to reduce administrative and compliance burden on advocacy organisations to free up more time for direct advocacy support • Review current barriers and identified gaps and systemic issues for people with disability requiring advocacy • Develop a comprehensive collaborative strategy to address barriers and fragmentation in access to disability advocacy support to reflect population demographics 	<p>Widespread investment and commitment by all key stakeholders nationally to addressing key issues in disability advocacy</p> <p>Comprehensive collective understanding of the range of issues and needs for disability advocacy support across all areas and regions and all levels of government.</p> <p>A strong evidence-base available to guide resource allocation to address unmet demand and unmet need for advocacy among people with disability. Gaps in access addressed</p> <p>Increase in direct advocacy time available through reduced administrative and reporting burden for organisations</p>

Recommendation	Detail	Benefits & likely outcomes
<p>3.b. <u>Strengthen data and information systems</u> to enable systematic collection, analysis and utilisation of high-quality accessible data</p>	<p>Establish a National Disability Advocacy Data Taskforce with relevant expertise to:</p> <ul style="list-style-type: none"> • Developed agreed national and jurisdictional data collection systems to: <ul style="list-style-type: none"> - Define agreed priority data sets - Develop an optimal approach for outcomes measurement across the sector - Increase efficiency and consistency of data collection - Implement agreed processes for data release and protection of confidentiality - Enable transparency and public sharing of high-level information - Support building an evidence base of effective disability advocacy models, approaches and systems • Incorporate mechanism for collecting and disseminating data at federal, state and territory levels on systemic issues that adequately reflects on-the-ground experience 	<p>Consistent, streamlined data collection and analysis provides a solid evidence base to inform systems improvement at all levels</p> <p>Evidence-based data more clearly outline the causes and solutions of unmet demand</p> <p>Improved data quality and availability with potential for aggregation, cross-system data linkages and systemic analysis⁵¹</p> <p>Evidence of effective disability advocacy models and documented outcomes</p>
<p>3.c. Support <u>disability advocacy sector coordination</u> through funding of national and state and territory peak and representative organisations</p>	<ul style="list-style-type: none"> • Enhance sector capacity to engage in systemic advocacy and representation activities: <ul style="list-style-type: none"> - Funding for both cohort-focused and disability-specific national disability representative organisations and other organisations with specific expertise 	<p>Streamlined elevation of systemic issues for all people with disability</p> <p>Consistent representation and voices of lived experience of specific groups of people with disability are reflected in systemic advocacy</p> <p>More action taken in response to systemic issues for specific cohorts of people</p>

Recommendation	Detail	Benefits & likely outcomes
	<ul style="list-style-type: none"> • Consultation and collaboration to support the development of resources, training and communities of practice to support relevant tailored advocacy approaches 	Fit-for-purpose information and resources meet the needs of specific cohorts through inclusion of voices of lived experience expertise

Recommendation 4. Enhance safeguarding mechanisms

Explore potential solutions to ensure access to independent advocacy as part of protection and safeguarding of people who are at particular risk of violence, abuse, neglect and exploitation

Recommendation	Detail	Benefit
4.a. Increase <u>awareness of, and access to advocacy</u> for all people with disability across sector, cross-sector, government and the broader community	<p>Disability sector and cross-sector awareness</p> <ul style="list-style-type: none"> Establish an information and awareness program for disability and other service providers and related professionals (including local area coordinators, support coordinators and plan managers) to raise awareness and understanding of the importance of advocacy for people with disability, roles of advocates, types of advocacy, advocacy services and benefits of advocacy. Include surrounding sectors such as health, mental health and allied health, community legal sector, domestic and family violence services, financial counsellors, education, justice, transport, employment, housing 	<p>Reduced risk of people with disability being subject to violence, abuse, neglect and exploitation</p> <p>Increased referrals of people in need of advocacy</p> <p>Increased access of people with disability to appropriate advocacy</p> <p>Improved communication and coordination across sectors</p>
	<p>Government agency awareness</p> <ul style="list-style-type: none"> Include specific information in all relevant government-produced or government-funded information resources for people with disability, their families and supporters about disability advocacy services, rights to advocacy, roles of advocates and benefits of access to independent advocacy Strengthen awareness of the right to independent advocacy among all staff within the NDIA, Services Australia, and other government 	<p>Clearer information and increased referrals⁵²</p> <p>Increased access to justice support for people with disability</p> <p>Increased timely referrals to advocacy organisations when they can play a preventative, developmental and/or corrective safeguarding role⁵³</p>

Recommendation	Detail	Benefit
	<p>agencies including at the State and Territory level e.g. Public Guardians/Advocates, Child protection, Justice, community visitor schemes</p> <ul style="list-style-type: none"> • Strengthen organisational policies and processes for referral to independent advocacy from relevant staff within government agencies • Promote recognition of the protective role of disability advocates with all safeguarding institutions, including the NDIS Commission, Human Rights, Anti-Discrimination and Complaints Commission 	
	<p>Community awareness raising</p> <ul style="list-style-type: none"> • Establish a national public information and awareness raising campaign about advocacy support for people with disability that <ul style="list-style-type: none"> - clearly articulates the links with upholding human rights - emphasises that anyone with disability can access advocacy support, whether or not eligible for or receiving Disability Support Pension or NDIS supports - highlights the need for community support for people who are seeking to self-advocate - explains conflict of interest and when an independent advocate is needed - is widely available in accessible formats, Plain English, diverse languages - highlights the role of independent disability advocacy in abuse prevention and response, 	<p>Increased community awareness of advocacy, its function and role in upholding human rights</p> <p>Increased awareness of rights and entitlement of people with disability to access advocacy support</p> <p>More accessible information about advocacy available for people with disability⁵⁴</p> <p>Increased knowledge of service systems and how to navigate them⁵⁵</p> <p>Increased early intervention prevents risks for people with disability</p> <p>Stronger networks of support, information, exchange and community connectedness</p>

Recommendation	Detail	Benefit
	<p>including potential for earlier intervention in high risk situations</p> <ul style="list-style-type: none"> • Provide community information about different models of independent advocacy, including Citizen Advocacy, (and the opportunity to volunteer and train as a Citizen Advocate), legal advocacy, Self Advocacy groups and family advocacy supports 	
<p>4.b. Introduce <u>new legislation to provide right of entry for disability advocates</u> to closed, congregate or institutional settings</p>	<ul style="list-style-type: none"> • Consider and draft legislative reforms to enable advocates to enter group homes and other high risk settings without exclusion by gatekeepers 	<p>Greater safety for people in closed settings, by ensuring people have meaningful access to independent disability advocacy⁵⁶</p>
<p>4.c. Establish a mechanism to enable organisations to provide <u>dedicated ‘safeguarding advocacy’ for people with disability</u> who are identified as experiencing elevated risk of violence, abuse, neglect and exploitation</p>	<ul style="list-style-type: none"> • Develop mechanisms for people with disability who are at particularly high risk to be allocated a designated independent advocate supported by adequate funding, for instance: <ul style="list-style-type: none"> - people under guardianship - children with disability in out of home care - people with intellectual disability - people with complex communication support needs - people without family or informal support 	<p>Greater frequency of people being identified and referred by government agencies and community services to receive general or specialist advocacy support e.g.</p> <ul style="list-style-type: none"> • Parents with intellectual disability interacting with the child protection system^{h 57 58} • Early intervention diverting people away from the court system, resulting in

^h A three year evaluation by researchers at RMIT recommended that Independent Family Advocacy and Support (IFAS), an early intervention non-legal child protection advocacy and support pilot at Victoria Legal Aid, be expanded, and include an automatic referral system for eligible people (which included families where one or both primary carers have an intellectual disability.)

Recommendation	Detail	Benefit
	<ul style="list-style-type: none"> - people living in closed or segregated settings 	<p>considerable savings for government.^{i 59 60}</p> <ul style="list-style-type: none"> • Throughout NDIS planning process people without informal support networks consistently identified and referred to independent disability advocacy
<p>4.d. Establish an <u>ongoing funding stream for Supported Decision Making</u></p>	<ul style="list-style-type: none"> • Strengthen the oversight and capacity-building role of independent advocacy organisations to: <ul style="list-style-type: none"> - Deliver decision support to people with disability - Provide training on supported decision making practice - Play a supportive and linking role in ensuring access to decision support 	<p>Increased safeguarding of the rights of people with disability to make decisions with support, according to their own will and preferences.^{61 62}</p> <p>Knowledge and skill building for people with disability to make decisions with support, increasing self-determination and improving quality of life.^{63 64 65 66 67 68 69}</p> <p>Reduced reliance on guardianship and other forms of substitute decision making, including formal and informal denial of the rights of people with disability to exert their autonomy, will and preference.^{j 70 71 72 73 74}</p>

ⁱ The evaluation team found IFAS diverted 20% of referred clients away from court, resulting in an estimated return on investment of \$3.52 (\$2.52 in savings) for every dollar spent.

^j As explored at Public hearing 30 and throughout the Royal Commission, the removal of a person's right to make decisions about their life through the imposition of a guardianship or administration order frequently disempowers individuals, reduces their quality of life and places them at greater risk of violence, abuse, neglect and/or exploitation.

Recommendation	Detail	Benefit
		<p>Improved access and connection to decision support, through advocacy organisations providing information and linkages.</p> <p>Advocacy organisations well positioned to play these roles, given:</p> <ul style="list-style-type: none"> • independence from service provision • human rights focus • existing quality assurance structures • expertise in supporting people with complex communication support needs; and • experience supporting and assisting people to make decisions in the course of advocacy work.^{75 76 77}

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Attachment B: DANA Membership 2022-23

[ACT Disability Aged and Carer Advocacy Service](#) (ADACAS)

[Advocacy for Inclusion](#) (AFI)

[Women with Disabilities ACT](#) (WWDACT)

[Self Advocacy Sydney Inc](#)

[Family Advocacy](#)

[DAISI Services Ltd](#) (formerly Disability Aged Information Service Inc).

[Side By Side Advocacy Inc.](#)

[Intellectual Disability Rights Service Inc.](#)

[People With Disability Australia Ltd.](#)

[Disability Advocacy NSW](#) (Advocacy Law Alliance Inc.)

[IDEAS \(Information, Disability Education and Awareness Service\)](#)

[Synapse](#)

[Illawarra Advocacy Inc.](#)

[Rights & Inclusion Australia](#)

[Newell Advocacy Inc.](#)

[Australian Centre for Disability Law](#)

[The Physical Disability Council of NSW](#) (PDCN)

[Multicultural Disability Advocacy Association of NSW Inc.](#)

[Action for People with Disability Inc.](#)

[Spinal Cord Injury Australia](#)

[Darwin Community Legal Service](#)

[Disability Advocacy Service](#)

[Integrated disAbility Action Inc.](#)

[Ngaanyatjarra Pitjantjatara Yankunytjatjara \(NPY\) Women's Council](#)

[Aged & Disability Advocacy](#) (formerly Queensland Aged & Disability Advocacy)

[Independent Advocacy North Queensland](#)

[Speaking Up For You Inc.](#)

[Amparo Advocacy Inc.](#)

[Queensland Advocacy for Inclusion.](#) (QAI)

[Mackay Advocacy Inc.](#)

[Queenslanders with Disability Network \(QDN\)](#)

[Capricorn Citizen Advocacy](#)

[Rights in Action](#)

[Sunshine Coast Citizen Advocacy](#)

[TASC - QLD Social Justice Centre](#)

[Independent Advocacy SA Inc.](#)

[Advocacy for Disability Access and Inclusion \(ADAI\)](#)

[Disability Advocacy & Complaints Service of South Australia \(DACSSA\)](#)

[Brain Injury SA](#)

[Citizen Advocacy South Australia Inc.](#)

[Disability Rights Advocacy Service Inc.](#)

[Association for Children with Disability \(Tas\) Inc.](#)

[Your Say Advocacy Tasmania Inc.](#)

[Citizen Advocacy Launceston](#)

[Speak Out Association of Tasmania](#)

[Gippsland Disability Advocacy Inc.](#)

[Rights Information and Advocacy Centre Inc.](#)

[Citizen Advocacy Sunbury & Districts Inc.](#)

[STAR Victoria Inc.](#)

[Grampians disAbility Advocacy Association](#)

[Barwon Disability Resource Council](#)

[Regional Disability Advocacy Service Ltd. \(RDAS\)](#)

[North-East Citizen Advocacy \(NECA\)](#)

[Leadership Plus](#)

[Melbourne East Disability Advocacy \(MEDA\)](#)

[Association of Employees with Disability Inc \(AED Legal\)](#)

[Association for Children with a Disability \(VIC\) Inc.](#)

[Disability Resources Centre \(DRC Advocacy\)](#)

[Southern Disability Advocacy](#)

[Victorian Advocacy League for Individuals with Disability Inc \(VALID\)](#)

[Action on Disability within Ethnic Communities Inc. \(ADEC\)](#)

[Youth Disability Advocacy Service](#) (part of Youth Affairs Council of Victoria)

[Action for More Independence and Dignity in Accommodation](#) (AMIDA)

[Colac Otway Region Advocacy Service](#)

[Disability Justice Australia Inc.](#)

[Women with Disabilities Victoria Inc.](#)

[Southwest Advocacy Association](#)

[Villamanta Disability Rights Legal Service](#)

[Victorian Mental Illness Awareness Council](#) (VMIAC)

[Citizen Advocacy Perth West](#)

[Midland Information Debt & Legal Advocacy Service](#) (MIDLAS)

[Sussex Street Community Law Services Inc.](#)

[Developmental Disability WA Inc.](#)

[People with Disabilities WA Inc.](#)

[Advocacy WA](#)

[Kin - Disability Advocacy for Diverse Communities](#)

[Explorability Inc.](#)

[Uniting WA](#)

Attachment C: Models of Advocacy

Effective disability advocacy promotes, protects and supports a person's, or a group's, full and equal human rights.

Advocates support or work on behalf of a person with disability or a group of people to help them to speak out and defend their rights and interests.

There are six main models of advocacy:

- Self advocacy
- Family advocacy
- Citizen advocacy
- Individual advocacy
- Legal advocacy
- Systemic advocacy.

Self advocacy

Self advocacy is when people advocate for themselves. This does not mean that the person is alone. Disability advocacy agencies help people to learn how to express themselves and to stand up for their rights as well as provide advice and support.

Being a self advocate means the person can make their own decisions and make sure that others respect their choices. The person is in charge of the advocacy process and can ask for support from other people. But the individual decides what support they need.

[Watch Self Advocacy video](#)

Family advocacy

Family advocacy is when a family member of a person with disability advocates for that person to help them get what they need to live a full and equal life.

Advocacy agencies can support families to learn how to advocate for their family member and how to speak out on their behalf.

Family members usually know the person better than anyone else and are often best placed to promote their views and wishes.

[Watch Family Advocacy video](#)

Citizen advocacy

Citizen advocacy is when a member of the community offers their time to work with a person with disability to advocate for them. A citizen advocacy agency will match the community person with a person with disability and support them to learn how to advocate on behalf of that person with disability.

The community person develops a relationship with the person with disability and supports them to have their voice heard.

[Watch citizen advocacy video](#)

Individual advocacy

Individual advocacy is when a professional advocate supports a person with a particular problem. An individual advocate either supports a person one-to-one or supports them to advocate for themselves.

The advocate will support someone with an issue they've not been able to solve on their own.

An individual advocate must be independent, and only be on the side of the person with disability, and only represent their interests.

[Watch individual advocacy video](#)

Legal advocacy

Legal advocacy is when a professional advocate with legal experience helps a person with disability with a legal issue. The advocate can help the person through the justice system and to understand their legal rights. They can also stand up for a person if they are being discriminated against, abused or neglected.

Legal advocacy can also help make changes in the law so it works better for people with disabilities.

[Watch legal advocacy video](#)

Systemic advocacy

Systemic advocacy works to solve an issue that affects a large group of people with disability. The sorts of issues this advocacy addresses are often a problem with the system, meaning that a lot of people are experiencing the same problem.

[Watch systemic advocacy video](#)

Attachment D: Case studies

The importance of independent disability advocacy in preventing violence, abuse, neglect and/or exploitation of people with disability

Below is a sample of case studies that demonstrate the types of issues and reasons for which people with disability seek advocacy, as well as the effectiveness, impact and support that independent disability advocacy can provide. Recurring themes of systemic power imbalance, multiple client issues and navigating several complex systems simultaneously are highlighted through various areas of focus. Further barriers can be experienced and can be particularly challenging for some specific groups in the community (e.g., First Nations and CALD communities).

Systems complexity case studies

A man originally from Hong Kong was referred to an advocacy organisation in Queensland for support with NDIS access as his previous application had not been successful due to a poorly completed access request being submitted by his GP.

Following an operation relating to a rare progressive disease several years ago, he had suffered a stroke resulting in a cognitive impairment, including difficulty with memory and executive function, severe hemiplegia to his left side, with very limited use of his left arm and hand and restricted mobility and endurance. This also impacted his vision, speech, and hearing.

At the time of the referral the organisation was able to advocate for an assessment from the Specialist Disability Services Assessment and Outreach Team in the Department of Communities – a much needed service that provided free assessments for NDIS access for those without the required evidence of disability and functional impairment. Following a psychiatric and functional assessment by his psychiatrist and mental health nurse he was granted access to the NDIS. The advocate supported him with pre-planning, attending his planning meeting and to connect with a good support coordinator and support workers who speak his language. He also received NDIS funding for assistive technology, including a specialised bed and scooter. The latter has been vital in allowing him to access the shops and bring groceries home independently. The advocate both requested or organised for an interpreter to be present at each stage of the NDIS process.

Often it may take a couple of years of intense advocacy to achieve these outcomes for someone, however this man was very lucky to have access to the Department of Communities team to complete the much-needed assessment for the NDIS.

Currently there is no such access to free assessments and so many who should be eligible for the NDIS are unable to get access due to a lack of acceptable evidence.

A 12-year-old boy with a rare medical condition and disability that impacts his mobility and cognition has been supported by an advocate through an Administrative Appeals Tribunal (AAT) process. He uses a powered wheelchair which goes in the back of the family car, and until recently the parents have lifted and carried him into the family car so they can travel to school or out and about. Due to his size and weight and the parents' deteriorating musculo-skeletal condition it is no longer possible for them to transfer him into the car.

His therapy team recommended a modified vehicle where he could stay in his wheelchair as the safest option for him. These modifications were requested through the NDIS and initially rejected, then rejected again in the internal review process. Advocacy support was engaged to support the family with an external appeal through the AAT. The original decision was eventually overturned after some months, and the modifications accepted as reasonable and necessary. Unfortunately, there is now a 6 month wait for a car, and a further 4-month wait for vehicle modifications which was not the case 18 months ago.

The family requested a modified hire vehicle in the interim as there is no alternative transport for him. This young boy has experienced a decrease in his functional capacity and has been house bound since the start of 2022. He has been unable to go to school or participate fully in community activities.

The NDIS was in the process of rejecting this request until at conciliation, the AAT agreed to fund a hire vehicle until the modified vehicle is available.

LGBTIQA+ case studies

A young person with down syndrome and their carer met with a NDIS planner. The person used keyword sign to communicate, however their carer was the interpreter for the meeting.

As the session continued the young person became more and more agitated as their carer appeared to not be listening or communicating anything they were saying. The carer also mentioned that the young person was intersex and made casual comments about the medical interventions which were made without the person's consent when they were born, including having "picked wrong" concerning their assigned sex.

The planner had no knowledge of intersex issues at the time and didn't have access to impartial interpreting services, so was unable to discuss what the client wanted directly with them. As the planner lacked knowledge, they were unable to offer appropriate supports to put in place for the client.

A young adult who has autism, sought advocacy support after they had been blocked from accessing medical gender transition. This person explained to an advocacy organisation that they had seen a letter on the computer at the medical clinic that contained their formal gender dysphoria diagnosis. The letter also indicated that the clinic believed this young adult did not have capacity to make the decision to transition and was refusing to provide them with a copy of the letter.

An advocate helped the young person to understand the AusPATH standards of care for gender transition and their rights with medical services. When the advocate obtained a copy of the letter from the clinic, the advocacy client noted that it was a different letter than the original they had seen, as it contained no mention about their decision-making capacity. The advocate helped them to identify another pathway for medical support, and they were able to progress their transition.

First Nations case study

In October 2020, an advocacy organisation in Queensland received a referral from the Indigenous Consumer Assistance Network (ICAN) to advocate on behalf of a vulnerable and financially disadvantaged First Nations man with end-stage chronic inflammatory lung disease. He experienced severe shortness of breath, fatigue, difficulty walking and a high rate of hospitalisations due to frequent lung infections. He was receiving the Job Seeker payment and struggling to comply with the Disability Employment Service's (DES) program of support and mutual obligations during a time that was exceedingly difficult for him and his family.

Two years earlier he had made enquiries at the local Centrelink office about receiving the Disability Support Pension (DSP) but was told he wouldn't qualify. His GP at the Aboriginal Medical Centre had been assisting with medical certificates, but he was still required to attend meetings with the DES provider.

Through vigorous advocacy support in collaboration with ICAN and the Aboriginal Medical Centre, medical evidence was provided, and a Centrelink DSP application submitted. In December 2020, he was approved for the DSP. He was then assisted to create an Enduring Power of Attorney document so he could identify who will make decisions about his health and welfare if he becomes incapacitated in the future. A referral was also sent to ICAN who helped him gain early access to his superannuation funds.

CALD case studies

A Muslim woman who had a mental illness, intellectual disability and hearing impairment had contacted a to obtain help to be transferred to another service provider for her support with her daily living, as she felt she was being mistreated with her then service provider. Once her current service provider found out about her intention to change, the provider began threatening to start proceedings for them to gain guardianship over the woman. This caused the woman to be fearful of making any formal complaint.

A guardianship order – that is loss of legal personhood – was used coercively to prevent decision making, choice and complaint. This example also highlights some of the potential barriers faced by people from culturally and linguistically diverse backgrounds with disability, particularly where information on rights is not available in a range of community contexts.

A mother from a non-English speaking background who has a son with autism sought help from her Local Area Coordinator (LAC) to organise a social trainer for her son for two to three hours a week. As her English was limited the LAC had difficulty communicating with her and did not access an interpreter. The LAC told the mother she is too demanding, and no help is available for her.

After seeking help from a CALD disability advocacy organisation, the advocacy officer got in touch with the LAC and referred the client back to the LAC which then organised a social trainer for the son. The LAC told the client that she shouldn't have complained to the advocacy organisation. The incident caused the mother to be initially fearful of returning to the advocacy organisation, and after advising them of the incident she felt too intimidated to make a formal complaint.

Attachment E: Previous recommendations from Nationally focused inquiries and reviews concerning advocacy, its role and resourcing

Australian Human Rights Commission

Australian Human Rights Commission (2014) *Equal Before the Law: Towards Disability Justice Strategies*.

Action 4.3.3:

Provide access to advocacy and legal services with disability expertise regardless of place of residence or geographical location.

Action 4.3.6:

Establish as a matter of urgency a national Aboriginal and Torres Strait Island disability individual advocacy program.

Productivity Commission

Productivity Commission (2014) *Access to Justice Arrangements Inquiry Report*

Recommendation 21.1:

“Australian, State and Territory Governments should provide funding for strategic advocacy and law reform activities that seek to identify and remedy systemic issues and so reduce demand for frontline services.”

Productivity Commission (2017) *National Disability Insurance Scheme (NDIS) Costs Study Report*

Recommendation 10.4

“The Australian, State and Territory Governments should continue to fund disability advocacy organisations. State and Territory Governments should fund disability advocacy to 2019-20 by an amount that at least matches the per capita contribution of disability advocacy funding announced by the Australian Government.

The Australian, State and Territory Governments should also collect data from funded disability advocacy organisations about people with disability who use their services, and their outcomes. This data should be in a format that can be linked with data held by the National Disability Insurance Agency, and be made publicly available. The Department of Social Services should undertake an independent evaluation of advocacy funding at the beginning of 2020 to inform future funding arrangements, and thereafter periodically evaluate disability advocacy. These reports should be made public.”

Productivity Commission (2019) Review of the National Disability Agreement Study Report.

Recommendation 3.4

“The new National Disability Agreement should set out the responsibilities of the Australian, State and Territory Governments to provide disability services outside the National Disability Insurance Scheme (noting that these could be provided through mainstream systems), in particular where there is lack of clarity including for:

- *services to people with psychosocial disability*
- *advocacy services, including systemic, individual, legal and self-advocacy*
- *carer services, in particular respite services*
- *community access and inclusion programs.”*

Productivity Commission (2020) *Mental Health Inquiry Report*

Action 21.9 – Individual non-legal advocacy services:

“Non-legal advocates can help support individuals subject to involuntary detention under mental health legislation.

Start later

State and Territory Governments should ensure individual non-legal advocacy services are available for any individual detained under mental health legislation. In particular, services should:

- *focus on facilitating supported decision making by individuals*
- *be adequately resourced to provide assistance to individuals who require it*
- *not replace legal advocacy services.*

Where an individual is detained under mental health legislation, or agrees to mental health treatment in lieu of being detained under mental health legislation, the treating facility should notify non-legal advocacy services and the individual’s family or carer.”

Action 22.4 – Enhancing consumer and carer participation:

“Consumers and carers should have the opportunity to participate in the design of policies and programs that affect their lives.

Start now

- *The Australian, State and Territory Governments should establish a clear, ongoing role for consumers and carers to participate in all aspects of mental healthcare system planning, design, monitoring and evaluation and seek involvement from people with lived experience from the beginning of these processes.*
- *The National Mental Health Commission should report annually on the state of systemic advocacy in mental health in Australia at a State, Territory and national level.*
- *The Australian Government should facilitate a process through Mental Health Australia to establish peak bodies that are able to represent the separate views of*

mental health consumers, and of carers and families, at the national level. It should provide sufficient funding to cover the development, establishment and ongoing functions of these peak bodies.

Start later

- *Mental Health Australia should create formal mechanisms to bring the new peak bodies together regularly to progress issues of mutual interest and develop common policy positions and advice.*

The Australian, State and Territory Governments should extend the funding cycle length for their relevant peak bodies to at least five years.”

Joint Standing Committee on the NDIS:

Joint Standing Committee on the National Disability Insurance Scheme, Parliament of Australia (2014) *Progress report on the implementation and administration of the National Disability Insurance Scheme.*

Recommendation 6:

“The Committee notes the importance of the role of advocacy services in ensuring quality plans and supporting participants in the planning process. The committee recommends that certainty regarding the role and support for advocacy services in the NDIS be urgently resolved through the Ministerial Disability Reform Council.”

Joint Standing Committee on the National Disability Insurance Scheme, Parliament of Australia (2017) *Provision of services under the NDIS for people with psychosocial disabilities related to a mental health condition.*

Recommendation 8:

“The committee recommends the Department of Social Services and the NDIA collaboratively develop a plan outlining how advocacy and assertive outreach services will be delivered beyond the transition arrangements to ensure people with a psychosocial disability and those who are hard-to-reach can effectively engage with the NDIS and/or other support programs”

Joint Standing Committee on the National Disability Insurance Scheme, Parliament of Australia (2018) *Transitional arrangements for the NDIS.*

Recommendation 19:

“The committee recommends the Council of Australian Governments (COAG) Disability Reform Council work with the Department of Social Services to address the expected funding shortfalls for advocacy services beyond transition.”

Joint Standing Committee on the National Disability Insurance Scheme, Parliament of Australia (2020) *Supported Independent Living.*

Recommendation 40:

“The committee recommends that the Commonwealth, states and territories, through the Disability Reform Council, progress work to understand and address gaps in the availability of advocacy and decision support services as a matter of urgency”

Recommendation 41:

“The committee recommends that the National Disability Insurance Agency, working with the Australian Government, publish and distribute additional information on the availability of advocacy and decision support services.”

Recommendation 42:

“The committee recommends that the Australian Government increase funding for advocacy and decision support initiatives, to ensure that these initiatives reach the broadest range of people who require these services.”

Joint Standing Committee on the National Disability Insurance Scheme, Parliament of Australia (2020) *NDIS Planning*.

Recommendation 33:

“The committee recommends that the Australian Government review the amount of funding that it provides to advocacy organisations through the NDIS Appeals program and ensure that these organisations are sufficiently funded to support participants throughout the Administrative Appeals Tribunal process.”

Joint Standing Committee on the National Disability Insurance Scheme, Parliament of Australia (2021) *General issues around the implementation and performance of the NDIS*

Recommendation 1:

“The committee recommends that the Australian Government reconsider its responses to particular recommendations in the committee’s previous reports.” (This includes “Whether funding for advocacy services is sufficient”)

Joint Standing Committee on the National Disability Insurance Scheme, Parliament of Australia (2021) *NDIS Quality and Safeguards Commission*

Recommendation 17:

“The committee recommends that the Australian Government allocate specific funding to advocacy organisations to assist complainants in their dealings with the NDIS Quality and Safeguards Commission. This funding should be in addition to existing funding provided through the National Disability Advocacy Program.”

Recommendation 18:

“The committee recommends that the Commission establish appropriate referral pathways with advocacy organisations, Community Legal Centres and State and Territory Legal Aid Commissions to ensure participants who are particularly vulnerable are supported through complaint and investigation processes. This process should be developed through a co-design process with people with disability, their families and representative bodies and advocacy organisations.”

Senate Community Affairs References Committee, Parliament of Australia

Senate Community Affairs References Committee, Parliament of Australia (2015) *Violence, abuse and neglect against people with disability in institutional and residential settings, including the gender and age related dimensions, and the particular situation of Aboriginal and Torres Strait Islander people with disability, and culturally and linguistically diverse people with disability.*

Recommendation 15:

“The committee recommends all levels of government acknowledge the vital role that formal and informal advocacy plays in addressing violence, abuse and neglect of people with disability, by considering:

- *increased training for people with disability to recognise violence, abuse and neglect so they can self-report;*
- *government service contracts to include provisions to enforce access to facilities for advocates, requirement for self-advocacy programs;*
- *further consideration of the Victorian Self Advocacy Resource Unit, with a view to roll out across other states and territories;*
- *funded advocacy programs to include training for informal advocates;*
- *States and Territories not to reduce advocacy funding with the rollout of the NDIS.”*

Recommendation 16:

“The committee recommends the National Disability Advocacy Program implement the following recommendations:

- *significant investment to National Disability Advocacy Program funded advocates, to deliver equitable access and representation of issues and to match the increased demand for advocacy anticipated under the NDIS;*
- *undertake a review to ensure delivered advocacy is appropriately spread across service types and complaint types, to ensure the most vulnerable are receiving advocacy;*
- *increase funding for self-advocacy programs;*
- *ensure that current model of funding peak bodies does not inadvertently result in the closure of smaller specialist or local advocacy organisations.*
- *Improved coordination between the National Disability Advocacy Program and the National Aged Care Advocacy Program.*

Recommendation 17:

The committee recommends of the Government consider the following when rolling out the National Disability Insurance Scheme (NDIS):

- *an urgent roll out of capacity-building and advocacy support for individuals undertaking negotiations for self-directed disability support;*
- *increased training for NDIS planners around intellectual impairment and guidelines on when to require decision-making support;*
- *further investigation of whether the current NDIS unit pricing will have an impact on incidents of violence, abuse or neglect.*
- *NDIS quality and safeguarding framework must ensure a zero-tolerance approach to restrictive practice, and be tied to the National Framework for Reducing and Eliminating the Use of Restrictive Practices in the Disability Service Sector; and*
- *amendment of the Quality and Safeguarding Framework to include advocacy as a key component to reduce and address incidents of violence, abuse and neglect.*

Senate Community Affairs References Committee, Parliament of Australia (2015) *Impact on service quality, efficiency and sustainability of recent Commonwealth community service tendering processes by the Department of Social Services.*

Recommendations 7:

“The committee recommends that advocacy support be considered a vital component of community services in future funding arrangements and is given appropriate weighting in funding assessments.”

Recommendation 12:

“The committee recommends that the Auditor-General conduct its own review into the tendering process, including examining:

- *The Department of Social Services' work pre-tender in identifying service needs by region;*
- *The extent to which successful tenderers have sub-contracted their work to local and regional providers, job losses that have resulted from the tendering process and outcomes, and the extent to which Department of Social Services has oversight over these subcontracts;*
- *The extent to which the capacity for community-based service delivery (particularly the capacity to provide services to CALD and indigenous communities) was factored into the tender selection process;*
- *The impact on service delivery, advocacy and the support available to vulnerable people and communities”*

Senate Community Affairs References Committee, Parliament of Australia (2022) *Purpose, intent and adequacy of the Disability Support Pension*

Recommendation 15:

“The committee recommends that the Australian Government provides additional funding to advocacy groups and community legal services to support Disability Support Pension claimants.”

Recommendation 17:

“The committee recommends that the Australian Government increases funding for First Nation’s advocacy services and Aboriginal community controlled health organisations to allow these organisations to better support their clients through the Disability Support Pension claims process.”

Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability

Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability (2020) *Public Hearing Report: Public hearing 5 – Experiences of people with disability during the ongoing COVID-19 Pandemic*

Recommendation 12:

The Australian Government should immediately commit to providing supplementary funding to disability representative organisations for individual advocacy should there be a significant resurgence of COVID-19 in Australia.

Recommendation 13:

The Australian Government should commit to providing supplementary funding to disability representative organisations for individual and systemic advocacy whenever a new pandemic or major emergency (such as a natural disaster) occurs. The commitment should include establishing an emergency fund that can be drawn upon as soon as the need arises.

Attachment F: Increased demand for disability advocacy and insufficient capacity of disability advocacy organisations to meet demand

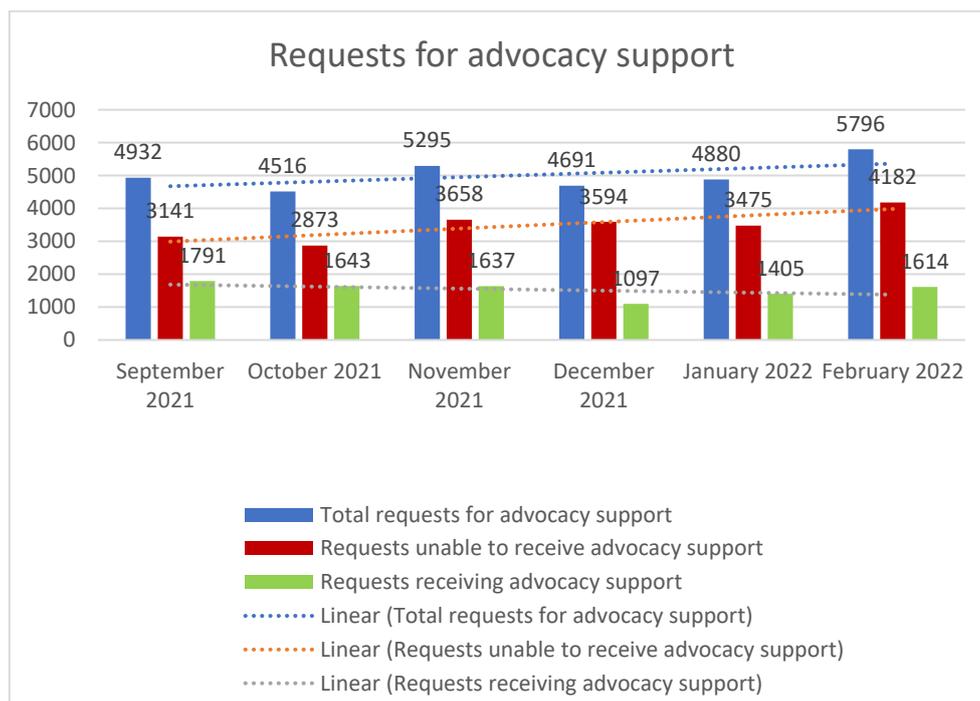
DANA Intake Survey - unmet demand

During the period September 2021- February 2022 DANA conducted a survey with the disability advocacy sector to gather data to provide a picture of unmet demand for disability advocacy nationally. There had been a sense for some time of growing unmet demand for disability advocacy throughout the sector but no data on the scope of the issue or how to address it. The survey was developed in consultation with the sector and the project was also an opportunity to garner preliminary insights into sector capacity. During this period the disability advocacy sector reduced from 80 organisations to 78.

Through the DANA Intake survey period, responding organisations provided monthly data on intake, waitlists, and capacity. Thirty-nine organisations, or just over 50% of the disability advocacy sector nation-wide, provided full data sets for the 6-month period. The respondent sample included organisations from each state and territory across Australia, as well as the different types of advocacy organisations (size, general or specialist service etc.) and provided a representative snapshot of the sector.

The Intake survey provided valuable indicative data on demand, and a rich source of information to better understand areas in the sector for further investigative work.

The types of advocacy requests and capacity of organisations to meet demand are summarised in **Graph 1 – Requests for advocacy assistance** below:



Requests for Advocacy

The types of assistance people with disability are requesting from advocacy organisations includes but is not limited to:

- information (resources, services, as well as what advocacy is and how it can help),
- advocacy assistance
- support but not advocacy, for example, coordination of services.

Sometimes people requesting advocacy are aware they need assistance but are unsure of the type of assistance or where to find it. The number and type of contact with advocacy organisations are shown in **Table 1** below.

Table 1: Requests for advocacy assistance breakdown:

Month	Requests receiving advocacy support	Requests unable to receive advocacy support	Requests receiving information in lieu of advocacy support	Total requests for advocacy
Sep-21	1791 (36%)	3141 (64%)	1291 (26%)	4932
Oct-21	1643 (36%)	2873 (64%)	1274 (28%)	4516
Nov-21	1637 (31%)	3658 (69%)	1508 (28%)	5295
Dec-21	1097 (23%)	3594 (77%)	1292 (28%)	4691
Jan-22	1405 (29%)	3475 (71%)	1395 (29%)	4880
Feb-22	1614 (28%)	4182 (72%)	1647 (28%)	5796
TOTAL	9,187 (31%)	20,923 (69%)	8,407 (28%)	30,110

Graph 1 and Table 1 summary:

- Requests for advocacy support ranged between 4,500 and 5,800 per month over the 6-month survey period.
- Generally, the advocacy organisations participating in the survey had collective capacity to intake just over 1,000 advocacy clients each month, with a range between 1,097 and 1,791. This means advocacy organisations only had capacity to provide advocacy for 31% to 36% of total requests for support.
- Over the 6 months, an average of 28% of total requests for advocacy were provided information even though they did not become an advocacy client. This indicates that a considerable part of an advocate's role is providing information, and that this is being done in lieu of having the capacity to take on more advocacy clients. Anecdotal evidence from advocates indicates enquiries and information provision are necessary and important aspects of their work and can be very time consuming.

Survey results trends

The data were analysed independently by two project officers and three significant trends emerged:

1. An increase in requests for disability advocacy
2. An increase in the number of people not receiving advocacy support, and,
3. An increase in the total number of days organisations closed their books to new clients.