

Submission

A strong, sustainable future: addressing capacity shortfalls for a strengthened disability advocacy sector



DANA Disability Advocacy
Network Australia

Key Proposals

1. Address immediate funding shortfalls with an urgent injection of funds

2. Create a new grant round for non-National Disability Advocacy Program (NDAP) organisations in urgent need of funding

3. Targeted funding boost for independent disability advocates operating in rural, remote, and very remote areas

4. Further sector capacity building: invest in disaster support, First Nations cultural safety and support for decision making

Key Costings

\$43 million for National Disability Advocacy Program (NDAP) organisations to meet existing advocacy demand until mid-2025

This figure is based on approximate yearly funding allocation as gathered by Disability Advocacy Network Australia (DANA) through extensive manual reconciliation work. As previously established by DANA, the minimum spend required to meet existing unmet demand is twice what is currently being spent on independent disability advocacy nationally. We have doubled existing funding and pro-rated this figure for 18 months to create a proposed funding injection until the end of June 2025. This will allow for increased capacity to service existing clients and meet all current needs, as well as building a clearer picture of advocacy requirements to support future funding allocation.

\$25 million to establish a new grant round for non-National Disability Advocacy Program (NDAP) organisations in need of urgent funds

Many organisations are ineligible for NDAP funding, and without urgent investment, some are at serious risk of closure. DANA recommends an open grant round for existing advocacy organisations in need of funding. DANA suggests an investment of \$25 million allocated for an 18-month period. Current NDAP spending is approximately \$25 million per year and only meets half of existing demand. Increasing the investment will identify and address critical service gaps, allowing more organisations to deliver more advocacy support.

This funding investment should be used to address NDAP eligibility inconsistencies, allow organisations to express interest in joining the NDAP and access support to do so, and to standardise funding for independent disability advocacy nationwide, resulting in simpler grant and funding processes for the next funding cycle.

\$20 million as a dedicated funding boost for independent disability advocates facing increased operating costs in rural, remote, and very remote areas

This proposed figure, pro-rated for 18 months until end of June 2025, should fund at least 70 new advocates working in rural, remote and very remote areas¹, as well as training and support needed to expand the workforce. DANA recommends this investment be used to assess demand and understand work requirements in these areas to allow for adequate rural, remote and very remote funding in the next NDAP funding cycle.

Further sector capacity building: \$5.225 million to be spread across disaster management, First Nations cultural safety training, resources and pilot projects, and awareness of Supported Decision Making

While whole-of-sector funding boosts are critical for the health of independent disability advocacy, there are distinct areas in need of targeted investment to address inequity and disadvantage. These proposals and their costings have been developed in partnership with First Peoples Disability Network and Inclusion Australia, and DANA encourages further dialogue with these peak bodies to further develop this work. Additionally, DANA has drawn on previous disaster management exploration to reiterate the need for discretionary emergency funds for independent disability advocacy organisations to use in times of disaster.

The total proposed investment into independent disability advocacy is \$91.225 million until the end of June 2025

¹ Based on DANA member data, employing one full time independent disability advocate can cost up to \$180,000 per year in rural, remote, or very remote areas due to additional travel, training and resources required to operate in these roles.

Introduction

People with disability, their families and supporters turn to independent disability advocacy organisations to make sure they can access mainstream and disability-focused services and supports that all too often they are shut out of. Together, the different forms of advocacy address inequitable access, unfair decisions, and promote inclusion for people with disability.

Currently, the advocacy sector faces massive challenges from lack of funding to service demand. Approximately half of people with disability who seek support from advocates are turned away due to lack of available advocates – and this number is only indicative of services demanded, not services required overall. This ‘capacity crunch’ has been compounded over time by the growth of the National Disability Insurance Scheme (NDIS) and the reduction of accessible services for people with disability outside the NDIS. The two major recent reforms, the Disability Royal Commission final report and the NDIS Review, both recognise and require a very significant role from disability advocates and organisations. However, there is no dedicated funding allocated to independent disability advocacy to support the change management activities that will be needed and have been flagged under both these major reform processes.

Economic evaluation of disability advocacy has found it an excellent investment, with advocacy returning a benefit of \$3.50 for each \$1 spent (Daly et al, 2017). There is significant financial investment in disability service delivery: in 2022-2023, the NDIS is quoted at a yearly operating cost of \$35.8 billion dollars. It is worth noting that this number only includes the NDIS, which services approximately 10% of Australians with disability. However, investment in advocacy to support service delivery is lacking. The cost of independent disability advocacy is minor in comparison to disability sector operating costs: as of 2022-2023, DANA is aware of approximately \$60 million per year of total advocacy funding spread across federal, state and territory government funding. DANA has estimated a tripling of this funding will begin to meet sector needs and recognises that this increase is both cost-effective and a minor spend compared to the total service delivery across disability and mainstream systems.

Disability advocacy organisations, with strong existing links to marginalised people with disability, including within closed settings, are well placed to support people with disability through the coming changes. Advocates are well positioned to report back to the Australian Government on change progression in the role of an ‘early warning system’. However, this is only possible with additional resources to upscale and sustain the workforce. With approximately 18 months left until the end of the current NDAP funding round, there is a valuable opportunity to understand existing advocacy need and demand, and to ensure future funding reflects operating conditions and complexity of work. Investment undertaken now will clarify the needs of the sector and allow for a stronger and more sustainable NDAP after mid-2025.

In this submission, we ask the Federal Government to immediately invest in the independent disability advocacy sector with a top-up of **at least \$91.225 million** to ensure people with disability can get the support they need, and to navigate the

coming changes across the disability sector. Independent disability advocates are an essential partner in ensuring that reforms are understood, information is disseminated, and service and system transitions are managed appropriately.

Sector influences: context for this submission

The disability advocacy sector is a complex environment and its workload is frequently affected by both proposed and implemented changes made at federal and state levels. In times of change, independent disability advocates support people with disability to access and understand information about new changes or processes across systemic, individual, family and legal levels.

In the current environment, change – both proposed and expected – is a crucial factor in advocacy workloads. Current events of significance to this submission include:

- The Disability Royal Commission has just handed down its full report featuring 222 recommendations. These recommendations traverse many areas of the lives of people with disability, including the long-term phase-out of group homes, Australian Disability Enterprises (ADEs), and segregated education. These are historic recommendations with expected huge impacts for people with disability and for independent disability advocates in managing change. Many of these recommendations directly involve disability advocates and organisations playing a larger role in safeguarding, complaints systems and standing with people with disability as they navigate changes to come.
- The Disability Royal Commission has recommended an additional funding commitment of \$16.6 million per annum for the NDAP and an additional \$20.3 million per annum for the National Disability Insurance Scheme Appeals Program (Recommendation 6.21) for 2024-25 and 2025-26. Amounts should be indexed and the Federal Government should ensure long-term and stable funding. While DANA is pleased to see additional funding recommended for the sector, these figures are not adequate to meet current advocacy demand or to do proactive outreach work.
- As part of the Disability Royal Commission, Taylor Fry and the Centre for International Economics were commissioned to report on current disability advocacy funding needs and to predict advocacy demand through 2028. Taylor Fry has reported that 75% of advocacy demand is currently being met, and therefore a 25% increase to existing funding through 2028 is an adequate investment to meet current demand. Taylor Fry also acknowledges a significant amount of unavailable data and reliance on assumptions to complete this work. This project did not involve any independent disability advocacy organisations (as far as DANA is aware). There are strengths in the report and recommendations that DANA endorses, however, the suggested budget stated is inadequate for current needs and does not plan for the future. Based on direct gathered data from independent disability advocates across Australia, DANA estimates that a tripling of existing funding will begin to manage current demand, unmet demand, and to do proactive outreach work to find and address unmet need.
- The NDIS Review is currently in progress and is collecting the experiences of Australians with disability. The Review is projected to hand down its final report by November 2023. It is highly likely that the Review will recommend significant changes to the operation and experience of the NDIS, and that these changes will need to be understood and navigated by people with disability, their families, and their supporters.

What are the problems?

Advocacy is critical, but only half of current demand can be met

Independent disability advocacy is a critical factor in ensuring people with disability have their human rights both respected and upheld. Various approaches to disability advocacy are used 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. Disability advocacy supports people 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.

The need for advocacy is critical, but only half of people with disability who seek support from advocates can receive it. DANA collected data from independent disability advocates in Australia on their capacity to service intake requests using existing allocated funding as part of the Intake Project, commissioned by the Department of Social Services. We measured both unmet demand and unmet need to truly understand the current advocacy environment.

- Approximately **1 in 2** people with disability are not able to access requested advocacy supports when required, referred to as 'unmet demand'.
- Unmet need – which includes people who have not approached an advocacy organisation, but need help with an issue – is difficult to measure, but organisations estimate this is **at least** another 50% of people with disability in addition to unmet demand.

In addition, NDAP advocacy providers were surveyed by Customer Driven on behalf of the Department of Social Services, highlighting critical issues in response time and unmet demand. Of the 69.5% of providers who responded, key insights included:

- 24% of NDAP providers take **more than 4 weeks** to make first contact with clients seeking advocacy assistance (Customer Driven, 2023). This is a significant amount of time when many advocacy matters have limitation dates. It also means people with disability are waiting to receive initial support for issues currently impacting them, and that will continue to impact them into the future.
- **45.45% of NDAP providers have times when they close their books.** Closing books means an organisation is unable to assist or places people on a waiting list until capacity opens up to deliver advocacy support. Although half of organisations say this occurs 'quite rarely', 33% do this quite often or often (Customer Driven, 2023).

When demand is significantly larger than supply, as it currently is, advocates are forced to prioritise the most urgent situations, leaving people with less critical issues unable to receive support. This can lead to people with disability then unnecessarily progressing into crisis, needing more resources to resolve their situation (including mainstream systems and services) and causing distress. Many of these situations occurring are preventable with adequate advocacy funding, including progressing to needing access to the NDIS, or much larger plans for those already receiving NDIS supports.

Adequate, stable funding also prevents people with disability from falling through service gaps by allowing advocates to reach the people who need them using a range of approaches. People with disability who live in rural, remote and very remote areas face particular barriers to accessing independent advocacy services due to a profoundly inadequate funding base. Engagement can happen differently in these areas, with a stronger focus on in-person engagement, outreach and in-reach. However, many organisations are not funded to account for these additional costs and specialist advocacy frequently requires face-to-face engagement, including accessing closed settings such as group homes and hospitals. Accessing these environments can result in additional time needed and funds spent, including travel, parking costs, and regular follow-up engagements. There is a strong need for sufficient advocacy funding that allows for multiple communication and engagement options and that supports the preferred engagement styles of different communities of people with disability. Services should not only be provided by phone or by internet as this is not accessible for many people with disability.

Awareness also plays a significant part in advocacy understanding and uptake. People with disability may not know what they can access, when an advocate can help, or how to find and secure an advocate to support an issue. People with disability may also not be aware of their right to be safe from violence and abuse. Many people with disability, particularly from marginalised communities, are also unaware they have the right to services or to assistance. This can include people with disability living or spending time in closed settings, who may require specialist in-reach work to learn about and access advocacy support. There is a critical need for investment in awareness and education activities across disability and mainstream sectors to ensure Australians with disability can understand and exercise their rights to safety and justice under Australia's Disability Strategy. This should be done in alignment with a funding increase to ensure extra demand can be accommodated.

Outreach can also ensure all people with disability can access the advocacy support they need. Outreach work helps find and support people who may not be able to proactively seek advocacy supports themselves due to various barriers. Proactive outreach is a critical part of safeguarding work for independent disability advocacy, identifying and addressing issues that may otherwise progress to crisis situations. A strong investment in proactive work is required to increase awareness and outreach activities and understand the true extent of unmet need within the sector.

To be able to meet the needs of Australians with disability, independent disability advocacy needs stable and adequate funding, including funding to adapt ways of working to suit community preferences. People with disability, their families, friends and supporters, disability services and the mainstream community all need to be

aware of what advocacy is, what it can do, and how to work with an advocate to address an issue or build capacity. And for Australians with disability who are falling through the cracks in existing systems, funded outreach work means advocates can find and support the people who are most in need, including in times of crisis or natural disaster when other services may be out of action and new supports may be urgently required.

Case study: the impact of proactive outreach

Whilst visiting another client at Mallacoota Foreshore Holiday Park after the Black Summer bushfires, the East Gippsland Bushfire Disability Advocate stopped to talk to a man outside his van. He was a single man, aged in his early 50s, and had been living at the caravan park since his rental property burnt down in Mallacoota. The man had neurological disability and in passing advised that he was struggling to buy food as he was on a Jobseeker allowance. He was refused access to the Disability Support Pension due to insufficient evidence.

Prior to COVID-19, he was doing a TAFE course in Lakes Entrance (attending back and forwards three days a week) and struggled to cover the cost of his travel, food and rent (his current rent is greater than the cost of his rental property in Mallacoota was). He lost his license for six months with lost demerit points but said he would not be able to afford to use his vehicle. He was currently getting around on a push bike.

The man was very motivated to finish the Fabricating Engineering TAFE course and was suffering from isolation in COVID-19. He was a smoker, and this was discussed. Information was given on the Quit Program and contact numbers and referrals made. He mentioned that he would like to join the local Men's Shed but was unable to afford the \$62 membership fee. The Bushfire Disability Advocate made contact with the Men's Shed Mallacoota and, following advocacy, the fee was waived, giving the man greater access to his community.

Further appointments were made with local counsellors with applications in the process of being undertaken for both the NDIS and DSP. The chance meeting between the independent advocate and this man only occurred because of existing proactive disaster outreach activities. Advocates are a valuable tool in finding and getting help for people who are slipping through the cracks of current systems and ensuring they can realise their human rights.

Disability advocacy funding is not equitable across different areas – and is unable to meet existing needs

Independent disability advocacy benefits people with disability, families, supporters, the disability sector, and the wider community. Advocacy supports people to understand and access services and supports, know their rights, and address serious risks, issues or crisis. However, funding for disability advocacy is frequently tied to short-term contracts, allocated through multiple funding streams and rounds including extensions and top-ups, and does not usually take into context the complexity of cases or operating environment.

DANA is aware of at least \$60 million in advocacy funding from various streams and initiatives currently allocated across Australia. To understand current funding sources, DANA has been performing extensive reconciliation of funding data in partnership with its members. Funding data collected for the NDAP indicates that both the Northern Territory and Tasmania receive less than \$1 million in funding each year, with no support from state-based funding pools. This disparity creates additional funding instability and more dependence on the Federal funding cycle, making business planning more complex – from typical organisational management to planning for long term advocacy needs, such as the expected transition away from group homes and segregated employment.

What is it like for areas experiencing extreme funding disadvantage?

The employment of a single full-time advocate, particularly in a rural, remote or very remote area, can cost anywhere up to \$180,000, including wages, superannuation and employee entitlements, plus advocacy and operating environment-specific training, resources, staff support, and other associated costs.

For the Northern Territory, the current total disability advocacy funding pool pays for approximately **three** full time independent disability advocates for the entire state.

This funding is split between multiple independent disability advocacy providers, meaning many advocates are funded on a part time basis, reducing their ability to service caseloads.

In addition, it is likely that funding allocated to the Northern Territory results in less 'active hours' performed than in most other states due to significantly increased training and resourcing required for rural, remote and very remote work.

Current data suggests that there is approximately **twice** as much demand for advocacy in comparison to supply². The Intake Project undertaken by DANA in partnership with the Department of Social Services indicates significant unmet demand and need for advocacy around Australia. Advocacy organisations cannot service all the people seeking advocacy support with current resources; this also includes people seeking NDIS appeals advocacy, despite recent funding injections.

It is clear that a significant increase in funding is required to meet existing advocacy need. To be truly equitable, funding allocated should take into account individual circumstances, including geographic area, experiences of multiple marginalisation, and the required methods of engagement within an organisational caseload. More money is needed to deliver the same quality of service in areas with lower population or more complexity of needs, and to provide in-person/ appropriate services across large service areas, such as the Northern Territory, northern South Australia, western Queensland and north-western Western Australia. Additionally, capacity building work and support to self-advocate is a valuable role performed by advocates. This work requires building trust with the person with disability and

² This estimate factors in potential duplication of advocacy clients across organisational waitlists.

regular engagement over time, requiring stable funding for the duration of the advocacy relationship. DANA endorses the Taylor Fry recommendation that the 'cost per client' be reviewed and include geographic and other demographic data to capture intersectional experiences and ensure complex advocacy clients are funded to receive the level of support they need. It is further recommended that any costing studies or surveys related to independent disability advocacy are completed by, or in consultation with, independent disability advocacy organisations and people with disability. This work should be broad in scope and cover all advocacy organisations and clients, building a clear understanding of different users of advocacy and the different types of specialist expertise and engagement options required to support them. Some independent advocacy organisations focus on specific areas or support people with disability who are not able to access advocacy without a specialist targeted approach and way of working. These organisations are part of the advocacy caseload but exist as a valued pathway to ensure people with disability do not fall through the cracks. This should include understanding the value of existing connections, in-reach and outreach activities.

Additionally, different types of advocacy funding receive different increases at different times, leaving some areas more well-funded than others. This results in 'artificial barriers' around different funding types and makes it more difficult for advocates to support people across multiple areas of concern or with multiple issues. The flow-on effect from this approach creates multiple overlapping needs that cannot be addressed by one advocate in an individualised way, resulting in needs that remain unmet. While DANA welcomes the increased advocacy funding for NDIS Appeals and Disability Representative Organisation (DRO) systemic advocacy in recent announcements, these types of advocacy do not operate alone.

Data from the DANA team: insights into funding allocation and inconsistencies across jurisdictions

Not every state receives state funding for advocacy activities. State-based contributions to individual advocacy vary from millions per year (in larger states) to zero (Northern Territory, Tasmania, Australian Capital Territory). This means some states are fully dependent on NDAP funding for their advocacy work, while others are not.

Funding is not allocated per capita. Under the NDAP, Victoria receives 51% of the funding that New South Wales does. The population difference between New South Wales and Victoria is approximately 20%.

State contributions change the overall effectiveness of national funding allocations significantly. New South Wales receives strong state-based contributions for the highest total advocacy funding pool in Australia.

DANA is only aware of three states receiving state-based systemic funding: New South Wales, Queensland and Western Australia.

The funding environment of independent disability advocacy is complex, adding additional challenges to an environment that is already unable to meet the needs of Australians with disability with its current resourcing³.

Independent disability advocacy is a sound investment in the disability ecosystem

Representing approximately one fifth of the Australian population, 4.4 million people with disability are equal citizens, who use both mainstream and disability systems, services and supports. In the NDIS era, disability funding is often directed to the NDIS without consideration of the support processes that make the NDIS work. This has resulted in the NDIS becoming the ‘oasis in the desert’ where 90% of people with disability miss out on supports, increasing pressure on advocates to balance both NDIS and non-NDIS needs.

The cost of violence, abuse, neglect and exploitation of people with disability is estimated at **\$46.0 billion dollars per year** (Taylor Fry, 2023). This includes both interpersonal maltreatment, where a person experiences the effects of direct maltreatment on their quality of life, and systemic failures, including lost productivity and the impact of inaccessible housing and other systems.

Independent disability advocacy plays a critical role in both facilitating and safeguarding the disability and NDIS ecosystems, including:

- Helping to prevent NDIS exploitation by supporting people with disability to advocate for their rights and to address unfair treatment or plan utilisation by providers.
- Capacity building support so people with disability can better use their NDIS funding and meet their goals.
- Keeping mainstream systems accountable by ensuring they provide equitable access to people with disability, meaning mainstream supports do not need to be unnecessarily duplicated.
- Supporting the Australia’s Disability Strategy (ADS) outcome of Safety, Rights and Justice and ensuring Australia meets its obligations under the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD).
- Advocates work with people with disability to build their own capacity to self-advocate, building trusted relationships over time.

³ DANA has collected the above data through extensive manual reconciliation work. These insights have come from proactive outreach work, engaging independent advocates across the country to understand allocated funding, existing need, and serious risks to organisational health and operation. We acknowledge there may be inconsistencies or missing contributions due to the complexity of funding and reporting requirements, as well as the capacity of smaller organisations to find and contribute data. We provide these insights as a lens into the current funding situation and recommend strong investment in remedial data work to capture the whole picture.

The need for a strong, independent safeguarding and capacity building role is particularly evident within the NDIS environment. The NDIS review process has revealed that the existing 'fee-for-service' support model allows for the possibility of exploitation and over-supporting: increasing support provision is beneficial for providers, even if supports do not improve individual client outcomes (NDIS Review, 2023). Independent disability advocates do not benefit from fee-for-service models: instead, advocates support people with disabilities' wishes and interests. Independent disability advocacy can not only prevent exploitation of people with disability, but provide a valuable safeguard against overutilisation of existing budgets.

Case study: advocacy as safeguarding against misinformation and gatekeeping

Direct transcript from an independent disability advocate:

“What we're seeing at a systemic level now that I've been able to break into some of the Culturally and Linguistically Diverse (CALD) communities is around NDIS and a lot of the CALD communities are being told that it's their responsibility to fund their children or family members and they get instant rejection.

There's been some feedback being told that they can't engage in advocacy services because they're at capacity, which is really concerning, the fact that this has been passed on to some of the CALD communities, and at times we're seeing a lot of push back where they can't speak to someone if they want to make reviews and things like that. So the CALD community is really having problems around ... getting the right information, which is a concern in general.

That's one side of it. The other side that I'm seeing when I go out into the community, is we're seeing a lot of resistance and pushback again with gate keeping and information around Supported Independent Living (SIL). I'm currently working with one person with disability who reached out to us because I was doing some mini networking within another little network where they were not aware that they could access advocacy support and have avenues to possibly follow up on some very serious allegations and what had taken place within a SIL. So it's just my concern and what I'm seeing is the fact that information and gatekeeping behaviour is still prevalent, but it goes beyond the education sector, beyond NDIS. It's actually ... just stopping [indistinct] ... some of the workers who were supporting her child were also told that they can't report these matters as well, and that they have no right to report ... about what they're seeing in the SILs.

The concern is that you've got employees being threatened and those unheard stories would be something ... that is concerning at this stage ... is use of threat against employees trying to talk up about serious matters and issues that they're seeing against people with disabilities.”

The Disability Royal Commission has particularly noted the significant safeguarding role for independent disability advocacy organisations throughout their 222 recommendations. With much of the proposed reforms to safeguarding relying on state and territory governments, disability advocacy organisations will need increased funding to contribute to, manage the change to and support people with disability to engage with the new systems.

Disability advocacy safeguards people with disability, but only those who can secure an advocate benefit

“...There's those sorts of stories which won't get told unless a third party, like an advocacy program, takes it up.”

DANA member advocate

The stable funding of independent disability advocacy is a strong investment in Australia's work to uphold the human rights of people with disability. Australia's Disability Strategy and the National Disability Advocacy Framework (and its associated work plan) both feature strong acknowledgements of the role of advocacy as a critical safeguard and tool for inclusion.

Under its Safety, Rights and Justice outcome, the ADS states:

“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.”

The National Disability Advocacy Framework (NDAF) is guided by the following stated objective:

“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.”

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

In the current system, independent disability advocates are doing a lot of the risk management and crisis intervention work to prevent or address issues of violence, abuse, neglect or exploitation experienced by people with disability. This includes identifying risks, making reports, connecting with organisations, supporting legal or justice processes, and navigating support systems, including the NDIS, as well as its complaints and appeals processes. Accessible information frequently is not created or provided for people with disability. Advocates regularly take on the (unpaid) work of creating, interpreting and disseminating information, updates, and changes. These roles are needed for both disability and mainstream services and programs. Not all this work is funded, and DANA advocates regularly report unpaid hours worked.

Without adequate structural support, advocates are forced to take on broader safeguarding roles. While proactive outreach and safeguarding is technically under the remit of the NDIS Quality and Safeguards Commission, proactive safeguarding work is largely not occurring, and the Commission's work is primarily in responding to reported quality and safety concerns. In the current environment, independent disability advocates are taking on safeguarding work in the absence of other structural supports.

Feedback and data from DANA members makes it clear that any changes to systems and processes result in increased advocacy demand, as people with disability can require support to understand, take action, and adjust to new systems, processes, or requirements. These changes may not be within the external environment; in regards to NDIS appeals advocacy specifically, Queensland Advocacy for Inclusion reported a disproportionate spike in cases referred to the Administrative Appeals Tribunal without an accompanying increase in internal review numbers, suggesting a change in NDIA internal review decision making (QAI, 2022). DANA expects advocacy demand to increase significantly in the coming months in response to proposed sector changes. The Disability Royal Commission has made significant and historic recommendations for change in its final report. Some of these recommendations will result in significant life and daily change for many people with disability, including the phase-out of group homes, Australian Disability Enterprises (ADEs), and segregated education. In their work, the Disability Royal Commission has also identified the need for advocacy to support these transitions and manage existing issues, including the guarantee of access to independent advocates to visit group homes and identify new living options (Disability Royal Commission, 2023). Advocates who work with people with disability impacted by these changes – particularly those who are experiencing transitions in multiple life domains – will be disproportionately impacted, with a need for higher intensity support provision to identify new options for living, working and schooling, and to provide valuable change management and transition support. These new recommendations are much needed, but without urgent injections of funds, this new work will compete with existing advocacy needs and dilute an already stretched advocacy pool.

The Disability Royal Commission is not the only major reform process in the disability space. More needed changes are likely to come: the NDIS Review is yet to hand down its final report and recommendations, and it is expected that the NDIS Review will also result in significant changes to the systems and processes of the NDIS. These changes will need to be managed appropriately – including ensuring and maintaining access to advocacy support – to ensure people with disability do not 'slip through the cracks' during the transition.

Independent disability advocates regularly go above and beyond for the people they work with. DANA frequently hears from independent disability advocates who are engaging with different systems and processes outside of their expected scope of work in order to ensure people with disability have the support they need when navigating complex systems and environments.

Direct quotes from DANA member advocates working with people with disability

“... In the end I felt like there was no choice but to go sit beside them in court, which I did.”

“Some of the issues that we see a lot of [in relation to] homelessness. I think, you know, a lot of people stay at different people's places, all that kind of thing, but the most difficulty that we come across is then accessing services for them. So, NDIS ... they certainly will say, ‘they're not in a home, we can't actually put those support services in place for them.’ So we have a lot of issues around that.”

“The advocate tried referring directly to a homeless housing service, but they didn't seem to be able to work with him. Sometimes people with disability are almost blacklisted and classed as too difficult by the housing providers.”

“I've had quite a few people with disability not accessing education and the interface with the NDIS, they do that thing about bouncing back and saying that's the responsibility of the education department. These children are just at home and their parents are working, they've often got siblings caring for them.”

“I agree with what (fellow advocate) was saying to work collaboratively across agencies. It's vital when there's a crisis situation develops.”

Lack of clear, comprehensive data on advocacy funding and its effectiveness

Funding is complex in the independent disability advocacy environment. Independent disability advocates may be funded through many different streams, including through the NDAP, through state advocacy funding, for NDIS-specific work, for cohort specific work (such as the Indigenous Community Advocate Project) and through other grants or discretionary projects. Additionally, there have been top-ups and injections of funding for existing grants or grant rounds, increasing the complexity of data analysis and reporting.

While DANA appreciates the efforts made by Taylor Fry (2023) to understand the current advocacy environment and to predict future advocacy spending, it is evident that there is not enough data to accurately understand the existing environment and predict funding needs for the future. Some assumptions made are deeply concerning, including that advocacy providers will overstate demand in order to secure more funding. DANA rejects this premise. Independent disability advocates support people with disability to navigate issues and realise their human rights; people reporting unmet demand simply want to meet all existing and future demand.

DANA has undertaken considerable work to remediate existing data, including using manual and proactive outreach to individual organisations and advocates, but with the complexity of the environment, some information is not available or inconsistently available to analyse. There is a critical need to remediate all existing data to truly understand the scope of gaps, identify unmet need as well as unmet demand, and inform new, best practice models and funding allocations. DANA strongly recommends that the Federal Government uses existing networks and organisational expertise in upcoming data and evaluation projects to ensure effective data collection, and to invest in the employment and professional expertise of people with disability as both market stewards and consumers.

To properly understand the health and effectiveness of the disability advocacy sector, reliable and consistent data must be made available. This issue is not new, and there is an acknowledgement of the need for consistent data and the complexity of data collection across jurisdictions, culminating in Work Areas 2 and 3 of the National Disability Advocacy Work Plan (Department of Social Services, 2023). DANA is also pleased to see a strong focus on data within the recommendations of the Disability Royal Commission's final report. However, the recommended disability advocacy funding model by Taylor Fry relies on many assumptions made due to lack of available data across many areas of advocacy and DANA is concerned about the use of this model to predict funding until 2028. Working with the disability advocacy sector to gather this data – much of which is being manually collected by DANA and its member organisations in the absence of an existing adequate dataset – would have addressed some data gaps within the report and provided valuable context for the disability advocacy operating environment to support recommendations. DANA hopes that future investigation and modelling will be co-created with people with disability and independent disability advocates.

Additionally, as the report was released prior to the Disability Royal Commission final report, it cannot factor in the implications of the Disability Royal Commission recommendations, including the phase-out of group homes, ADEs, and segregated education settings. These significant changes in the lives of people with disability are likely to result in increased demand on advocates, both in individual case work and in broader systemic or change management activities. Data remains an ongoing concern for the independent disability advocacy sector, and there is a strong need for investment in data remediation before any modelling can adequately predict current and future demand.

What we know: How underfunded are independent disability advocacy services?

DANA has been funded to undertake the Intake Project by the Department of Social Services (DSS), exploring unmet demand for independent disability advocacy across Australia. DANA also does its own manual data reconciliation to understand current demand and accurately represent its members. We present the following insights, including facts and figures from the Disability Royal Commission, to illustrate the current state of independent disability advocates across states and territories.

- Approximately **one in two** people with disability who approach an advocate are turned away or waitlisted.
- This number does not include unmet need – people with disability who are in need of support but have not approached an advocacy provider. DANA estimates this at an **additional 50%** of current advocacy workloads. People counted under ‘unmet need’ may require proactive outreach by advocates to access support.
- Breaking down allocated advocacy funding shows a wide inequity of funding per capita across different states. Funding ranges from \$6.77 per person (Tasmania) to \$54.89 (New South Wales). Percentages of state and territory populations with disability vary from 16.9% (New South Wales) to 26.8% (Tasmania) (Australian Bureau of Statistics, 2018).
- State funding is a significant boost in NSW, contributing nearly twice the amount of allocated national advocacy funding. However, other states – like the Northern Territory and the Australian Capital Territory – receive zero state funding, creating further inequity.
- Taylor Fry and the Centre for International Economics suggest that 75% of advocacy demand is currently being met (Taylor Fry, 2023). However, DANA data suggests that only 50% of demand is being met.
- Following from the work of Taylor Fry, the Disability Royal Commission has recommended additional commitments of \$16.6 million per annum for the NDAP and \$20.3 million (Disability Royal Commission, 2023). Based on direct gathered data from independent disability advocates across Australia, DANA estimates that a tripling of existing funding is what is needed to begin to manage current demand; meet unmet demand; and to do proactive outreach work to find and address unmet need. This recommendation from the Disability Royal Commission is far below what is needed simply to address current unmet demand without factoring in proactive outreach and unmet need.
- Taylor Fry acknowledges the ‘high uncertainty’ of estimates and inputs into its funding model, and therefore recommends a review of the ‘cost per client’ in partnership with disability advocacy providers and clients, as well as acknowledging intersectional identities as a factor on service delivery costs (Taylor Fry, 2023). DANA supports this recommendation.
- Both DANA and Taylor Fry call for increased public reporting on advocacy supply and demand going forward.

Looking forward: what could a well-resourced advocacy sector look like for people with disability?

Due to recent data-gathering efforts such as the Disability Royal Commission, there is a wealth of current information on the critical issues experienced by people with disability, and the needed changes to the services and systems that support them. Moreover, many of the recommendations in the Disability Royal Commission rely on a strong and secure disability advocacy sector for their efficacy. The understanding of need has never been greater, and now is the time to make a strong investment in disability advocacy.

DANA believes that an increased level of funding benefits people with disability, individual advocates and organisations, leading to better results and a stronger sector. We know advocacy is an excellent investment to make: advocacy provides a benefit-cost ratio of 3.5:1 for each dollar spent (Daly et al, 2017). A 2021 re-review concluded that the original findings were still relevant and the benefit of independent disability remains substantial, particularly in reducing unreasonable burdens on people with disability directly. In addition to the financial value, investing in independent disability advocacy has many benefits, including:

- More people – within the disability space and in mainstream systems - know about independent disability advocates, what they do, and when to seek advocacy support.
- More people with disability who approach an advocacy service can receive the support they need.
- Organisations working with people with disability who have complex advocacy needs are funded in a way that recognises specialist expertise and service delivery.
- Investment in culturally safe and accessible distinct advocacy services and supports for First Nations people with disability, people with disability from culturally and linguistically diverse backgrounds and LGBTQIA+ people with disability means people can receive advocacy support that is safe and relevant to their lived experience.
- Stable funding creates stable jobs. Advocates will enjoy more stable employment and be adequately funded to perform advocacy activities.
- Advocacy organisations will have increased resources for service delivery and to access training, development, supervision and support.
- The overall disability advocacy sector will be strengthened, with standards, training, data and research all coordinated for a solid sector knowledge base.
- With the right investment, rural, remote and very remote disability advocates will be better able to service their communities in safe and culturally appropriate ways.

DANA believes this strong future is possible with the right investment, and independent disability advocates are a critical partner in undertaking this work. We make several recommendations to help realise this future for independent disability advocacy.

What are the solutions?

Create a stronger disability advocacy sector and future

DANA believes that, for a strong future, an overarching Disability Inclusion Agency should coordinate and lead government engagement with people with disability. This would concentrate all disability-focused knowledge and projects into one agency, including disability advocacy and other Tier 2 projects including Information, Linkages and Capacity Building funding. Our work and recommendations factor in the idea of a proposed agency and its projects.

With reports and recommendations being handed down from the Disability Royal Commission and the NDIS Review in progress, there is a wealth of knowledge and lived experience currently available on the value of – and urgent need for – independent disability advocacy supports. We urge the Federal Government to act on the evidence gathered from the disability community and to implement the recommendations of the Disability Royal Commission immediately. Investing in the independent disability advocacy sector is a strong safeguard that ensures Australians with disability have equitable access to services, safety, and justice.

DANA is a national organisation with a strong member base and extensive experience gathering data in complex operating environments. DANA and its members are in a strong position to coordinate vital projects to address service availability, data quality, and safeguarding needs. Many of the solutions in this submission are designed to occur together for maximum efficiency; for example, investing in awareness of advocacy supports data remediation by allowing for better measurement of unmet need. We hope the Federal Government will consider this approach to support remediation of the sector and invest in a strong, inclusive future for independent disability advocacy.

We ask for the following investments:

1. Address immediate funding shortfalls with an urgent injection of funds

In order for the disability sector to meet the needs of the 20% of Australians with disability, there must be a significant increase in the total pool of advocacy funding available. In particular, there needs to be a proportionate increase in funding to directly respond to current unmet demand, but also to increase outreach and preventative work. The Disability Royal Commission has made many recommendations to address violence, abuse, neglect and exploitation. DANA recommends the Federal Government invest in the implementation of these recommendations in partnership with people with disability and with the independent advocacy sector. Independent disability advocates across Australia have the expertise, connections and knowledge to support this vital work.

Currently, NDAP funding ends in June 2025. This is one of several approaching funding 'cliffs', creating instability for many advocacy organisations as future funding may not be guaranteed. In addition to an uncertain future, current funding estimates do not allow independent disability advocates to meet all requested service demand; it is estimated that approximately one in two people with disability are unable to access their requested advocacy support. To meet immediate advocacy need, independent disability advocacy organisations require an urgent injection of funding to increase numbers by hiring and training more independent advocates, to develop more training and support programs to standardise and better utilise advocacy supports in Australia, and to engage in community awareness activities to increase advocacy awareness and uptake. Funding should include specific money for non-service delivery activities, including professional development, supervision, counselling and support, and outreach and in-reach work. Including specific funding for all organisational activities will create a more sustainable workload and sector.

The Federal Government must also acknowledge the additional work that will be required to support people with disability through changes resulting from the Disability Royal Commission recommendations. Advocates will also be focusing on areas identified by the Disability Royal Commission, including education advocacy and complaints management and addressing and preventing violence in supported accommodation. This work will require proactive outreach to identify people with disability in need of support in addition to the provision of independent advocacy services.

To address the immediate funding shortfall, DANA proposes an immediate funding injection of **\$43 million** to allow disability advocacy organisations currently funded by the NDAP to meet existing demand until June 2025. This is an approximate doubling of existing funds adjusted for an 18-month investment period. During the next 18 months, efforts should be made to remediate existing data and understand sector needs to allow for adequate funding allocations after June 2025.

2. Create a new grant round for non-National Disability Advocacy Program (NDAP) organisations in urgent need of funding

DANA is aware of advocacy organisations operating with very low amounts of targeted funding. Evidence from DANA members show some organisations are operating on the equivalent of less than one full time role to meet demand in their catchment areas. This is a significant risk to operational sustainability and has left some advocacy organisations at serious risk of closure. This is compounded by existing nationwide issues of unmet demand.

To address this issue, it is recommended that a new grant round be established for organisations in urgent need of immediate funding. This grant round should be open to organisations who perform independent disability advocacy work, but not to include existing organisations funded through the NDAP who will receive a funding increase outlined in part 1. This will allow for smaller organisations to access equitable development opportunities, create a broader pool of advocates across the country, and allow organisations to be supported to apply and gain experience with the grants process (when applicable).

DANA recommends a targeted investment of **\$25 million** in a funding round focused on supporting smaller and at-risk advocacy organisations and ensuring continuity of advocacy services. This total includes some funding for governance, outreach, information, and support to make applications for organisations in need.

3. Targeted funding boost for independent disability advocates operating in rural, remote, and very remote areas

In order for independent disability advocates to provide equitable service in rural, remote and very remote areas, there must be a significant boost to funding to support the increased complexity of remote engagement. The NDIS uses an established maximum price loading of 40%/ 50% for rural/remote and very remote service delivery using the Modified Monash Model, and it is recommended that the same model is applied to independent disability advocates operating in rural, remote and very remote areas with some additions.

Many NDIS providers, registered or unregistered, operate in a for-profit model, meaning their income from service provision is taxable. This allows providers to subsidise and 'write off' assets and expenditures, including vehicles, maintenance, fuel, travel, training, and other costs related to running a business. Most, if not all, independent disability advocacy services are registered not-for-profits or charities and do not have these privileges; instead, many organisations have access to salary packaging, which benefits employees directly but does not subsidise assets and everyday expenditure. This means that vehicles, training and employee support, travel and accommodation and other necessary expenditures are paid in full by independent disability advocates. For advocates operating in rural, remote or very remote areas, these costs are significantly increased.

The NDIS market also has many large providers who can apply economies of scale to both the services they offer in rural and remote areas and the resources they have available; in contrast, many disability advocates are very small organisations with small amounts of funding and small staff teams, some of whom are unsure of the future of their organisation beyond the next funding 'cliff'. Organisations operating in remote areas are subject to additional costs, including safe vehicles for rural and remote travel, travel costs, accommodation, and training (which can include driving on dirt roads, first aid, advanced first aid, and cultural safety practices).

In addition to the suggested application of loading for rural, remote and very remote work, we propose two potential solutions to address the extra resourcing required by independent disability advocates operating in rural, remote and very remote environments:

1. That the Australian Tax Office implements a 'write-off' scheme allowing non-profit independent disability advocates to access the same cost reductions as for-profit providers to improve service sustainability, or
2. That an **additional** 50% funding loading is applied to all independent disability advocacy organisations operating in rural and remote areas to allow for vehicle purchase and maintenance, travel and accommodation, additional staffing and resources, and the additional training and safety requirements of rural and remote work.

Together, these additional loadings address disproportionate costs experienced by advocates operating in rural, remote and very remote areas.

DANA recommends an additional investment of **\$20 million** into supporting regional, rural and remote advocacy work. This investment will ensure independent disability advocates can do their jobs safely and people with disability can access equitable advocacy support – no matter where they live.

4. Further sector capacity building: invest in disaster support, First Nations cultural safety and support for decision making

In addition to the requested immediate funding boosts needed, DANA has identified critical areas for targeted investment including simpler support for advocacy during disasters, investment in culturally safe resources, training and projects for First Nations people with disability, and a stronger investment into awareness and outreach to extend Supported Decision Making practice across disability and mainstream sectors. We encourage investment in specific projects to address historic systemic gaps.

Establish a Disability Disaster Management Fund to ensure timely and adequate support during disasters

The impact of disasters is often disproportionately felt by people with disability, from planning to relief options to recovery efforts. Advocates are frequently on the front-line during disasters and in affected areas; as trusted members of communities and individual support networks, they can be called upon to navigate changes, advocate for extra resources, and report serious issues arising from disaster situations. DANA member advocates report coordinating informal relief efforts, managing major changes in support capacity and availability, and advocating directly to government agencies during times of crisis. There is a need to establish a specific funding stream that supports advocacy organisations during times of disaster. This pool of funding should be made up of 50% federal government contribution and 50% state government contribution.

The need for support when disaster strikes is immediate, and government response and support allocation can take days or weeks, causing serious risk to safety for people with disability. When a disaster is activated, all advocacy groups responsible for supporting that LGA should receive a boost to their funding (of, say, 20%) to undertake disaster relief work. To address this issue, DANA recommends at least **\$2,000,000** be provisioned in a Disability Disaster Management Fund for advocacy organisations to draw from to provide high-intensity emergency supports and additional human resourcing during disasters. At the end of the current funding cycle in mid-2025, this approach should be reviewed and a permanent measure to support people with disability in disaster situations should be enshrined in future disaster response plans.

Advocacy organisations should also receive specific funding for preventative disaster responses in their local communities, working with other local organisations and people with disability to prepare and plan in advance.

Invest in culturally safe resources, training and projects for First Nations people with disability

The Disability Royal Commission has collected a wealth of knowledge from First Nations people with disability. In its final report, the Commission has acknowledged the 'unique marginalisation' faced by Aboriginal and Torres Strait Islanders with disability (Disability Royal Commission, 2023) and the critical need for culturally safe and appropriate services and safeguards, as well as First Nations-led development and delivery of services, supports and advocacy. The Commission recommendations include changes to NDIS structure and documents to include cultural life and safety, as well as the stronger representation of First Nations people with disability by establishing a First Nations Disability Forum.

DANA is working with First Peoples Disability Network (FPDN), the peak body for First Nations peoples with disability, as they move to becoming an accredited NDAP provider. FPDN is developing their community-controlled NDAP services, with a specific focus on First Nations people with disability with significant marginalisation and complex support needs. FPDN is already working with very marginalised First Nations people with disability, particularly people who are homeless and not able to access culturally appropriate disability services, but this work is severely underfunded. FPDN advocates work with communities, taking the time to develop the trusted relationships and flexible service delivery that quality advocacy relies on. DANA recommends a strong investment in FPDN to understand First Nations-specific advocacy needs and to develop resources, training and pilot offerings. DANA also strongly recommends funding specialised advocates to work with First Nations people with disability. This work should also engage First Nations people with disability living in rural, remote and very remote areas, and allow for in-person, place-based outreach and training development and delivery. This approach aligns with the Disability Royal Commission recommendation on remote workforce development and strengthens the employment of First Nations people with disability. This work also aligns with the Strengthening a Culturally and Disability Inclusive Workforce element of the [National Disability Footprint](#).

Explore First Nations workforce upscaling with a dedicated scoping project

There is a critical need for more advocates who work in culturally safe ways and who can perform on-the-ground outreach to First Nations people with disability. Current funded advocates are working with extremely limited resourcing, and many do not have access to staff vehicles for travel, facilities to work from, or supervision and other typical work supports. Creating a specialised network of First Nations advocates will help disseminate knowledge of services and systems, address underutilisation of available supports such as the NDIS, and increase community safeguarding against maltreatment. It is recommended that **\$200,000** is invested in a scoping project to understand current operating conditions and to build a workforce upscaling plan to enable more advocates to be funded from June 2025.

Develop training resources for National Disability Advocacy Program (NDAP) organisations on working with First Nations people with disability

FPDN already has strong connections with NDAP advocates across Australia and is a regular source of guidance and expertise on culturally safe practice for advocates working with First Nations people with disability. However, there is a lack of resourcing available to develop training offerings and materials to standardise and formalise this work. It is recommended that **\$100,000** is invested in developing a suite of videos on working with First Nations people with disability for all NDAP organisations. Once this work is completed, the National Centre for Disability Advocacy (NCDA) will work with FPDN to roll out training offerings nationally.

Culturally safe resource development

To support First Nations people with disability, advocates need culturally safe and accessible resources on advocacy, services and supports to share. Currently, adequate resources are severely lacking outside of targeted projects such as NDIS access. It is proposed that FPDN addresses information disadvantage by developing a new suite of resources for First Nations people with disability to be disseminated to independent disability advocates around Australia. DANA recommends an investment of **\$25,000** to develop resources about disability advocacy, including culturally safe resources in Braille, Easy Read and Auslan.

Pilot a new Community Hub in Far North Queensland

FPDN has identified a proposed pilot site to continue the work currently occurring at its [Paterson Street Hub](#) in Tennant Creek. The proposed Cairns Hub will be a 'one-stop shop', community-controlled advocacy service with disability, legal and financial advocacy available, and will service the Torres Strait Islands in addition to Far North Queensland. As part of the establishment of the Community Hub, advocates will also develop a Systems Community of Practice to explore the interactions of First Nations people with disability with government systems such as housing, income support and Centrelink, the NDIS, justice, and child protection, with the goal of increasing collaboration between advocates and government services and streamlining access pathways. DANA recommends an investment of **\$900,000** to establish and run the pilot Cairns Hub until June 2025. The Hub pilot will produce an interim project report by end of 2024 to support Pre-Budget advocacy service planning.

Understanding First Nations advocacy needs: preparing for 2025 and beyond

There is a strong need to understand what advocacy supports are needed by First Nations people with disability, what capacity the sector currently has to deliver these supports, and how supports should best be delivered to ensure cultural safety and accessibility. To this end, DANA recommends an investment of **\$1.5 million** into mapping the First Nations disability advocacy sector in preparation for new advocacy funding arrangements after mid-2025. This project will produce an interim report by end of 2024 to support Pre-Budget advocacy service planning.

DANA, in partnership with FPDN, recommends a total investment of **\$2.725 million** for FPDN over the period to end of June 2025. To better define this work, DANA recommends further engagement and discussion with FPDN on needed projects, project scope and potential costings. We also call for a strong investment in culturally safe advocacy and resources for First Nations people with disability. This investment is not costed in this submission but, rather, needs to be devised in collaboration with First Nations people with disability.

Increase awareness and usage of Supported Decision Making in disability and mainstream environments

The NDIA's Supported Decision Making Policy has created wider knowledge of Supported Decision Making in the NDIS space, and this has helped ensure people can learn about and have access to the support to make their own decisions and move away from substitute decision making processes. Specialist advocacy organisations have been providing support for decision making for many years and work to uplift the human rights of people with disability. However, there is still significant education needed, particularly for non-NDIS and mainstream cohorts, to ensure that substitute decision making does not remain the default approach for those uninformed or underinformed about support for decision making.

It is therefore recommended that to expand on current existing project work about Supported Decision Making and existing sector expertise, the Federal Government funds Supported Decision Making awareness and outreach work done by people with lived experience of using Supported Decision Making. This work will involve proactive outreach activities to mainstream and disability organisations, and the development and delivery of Supported Decision Making-specific training for organisations on the role of decision supporters, who can be a decision supporter, and how to work effectively with decision makers and decision supporters in partnership. Outreach funding should also be included to allow Supported Decision Making experts to engage directly with advocates and organisations in a non-training capacity and to ensure Supported Decision Making practice is entrenched on an ongoing basis. This work will be done by Inclusion Australia and its member organisations who have the appropriate expertise, working in partnership with people with an intellectual disability.

DANA, in partnership with Inclusion Australia, recommends an investment of \$500,000 to undertake the rollout of Supported Decision Making outreach and awareness. Furthermore, we recommend consultation with Inclusion Australia, its members and other organisations run by and for people with an intellectual disability to identify other pathways to the wide implementation of Supported Decision Making, as well as understanding adequate funding requirements for this work.

In total, DANA recommends an investment of **\$5.225 million** split across the appropriate organisations to complete these projects.

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