

Submission

A stronger, more diverse and independent community sector

7 November 2023



DANA Disability Advocacy
Network Australia

About DANA

DANA is the national representative body for a network of independent disability advocacy organisations throughout Australia.

Our Vision

DANA's vision is of a nation that includes and values people with disabilities and respects human rights for all.

Our Purpose

DANA's purpose is to **strengthen, support and provide a collective voice for independent disability advocacy organisations across Australia** that advocates for and with people with disability.

We achieve this by

- promoting the role and value of independent disability advocacy
- providing a collective voice for our members
- providing communication and information sharing between disability advocacy organisations
- providing support and development for members, staff and volunteers of disability advocacy organisations
- building the evidence base to demonstrate the value of disability advocacy
- promoting the human rights, needs, value and diversity of people with disabilities

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Summary of recommendations

Recommendation 1: That funding for coordination roles be continued to ensure people with disability can be heard.

Recommendation 2: That the connection between independent disability advocacy organisations and marginalised people with disability be recognised through funding to deliver consultation and co-design.

Recommendation 3: That grants cover operational and administrative costs of service delivery.

Recommendation 4: That indexation be paid at regular times each year (say within 4 weeks of the Annual Wage Review), and at levels to fully cover costs.

Recommendation 5: That reporting processes be co-designed with people with disability.

Recommendation 6: That compliance costs are fully funded.

Recommendation 7: That grant periods for core advocacy operations be extended to a default position of three to five years, except in exceptional circumstances.

Recommendation 8: That grant funding be extended to a greater diversity of CSOs.

Recommendation 9: That a dedicated funding round focused on supporting smaller and at-risk advocacy organisations and ensuring continuity of advocacy services be established.

Recommendation 10: That funding for a greater diversity of CSOs does not come at the expense of the sustainability of existing organisations, or the disability sector itself.

Recommendation 11: That place-based reforms understand and include the vital role of independent disability advocacy organisations to connect with people with disability.

Independent disability advocacy is a vital part of the community sector

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.

Disability Advocacy Network Australia (DANA) has a membership of nearly 80 independent disability advocacy organisations which operate across Australia, based in a wide range of areas from very remote to metropolitan. Advocacy also is also delivered in a variety of ways to suit different communities of people with disability – individual, systemic, citizen, self, legal and family advocacy all play a vital role in ensuring that people with disability can be included.

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 and the NDIS Review, 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.¹

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 compared to \$35.8 billion for the operating costs of the NDIS alone. DANA estimates a tripling of this funding will begin to meet sector needs, and recognises that this a minor spend compared to the total service delivery across disability and mainstream systems.

¹ Daly A, Barrett G & Williams R (2017), Cost Benefit Analysis of Australian independent disability advocacy agencies, Canberra: Disability Advocacy Network Australia.

Area of focus 1: Giving the sector the voice and respect it deserves through a meaningful working partnership

People with disability and our organisations are now involved in co-design of government programs and activities, and this is a significant part of the existing Disability Representative Organisation program. This represents a welcome shift to a more equal, peer-to-peer relationship between government and the disability sector, in a space that has historically often been characterised by both paternalism and dependence.

The Disability Royal Commission sees specific roles for independent disability advocacy organisations in supporting people with disability to have a meaningful say about key decisions and issues in their lives, such as where they live, how they work and to speak up about violence and abuse they experience.

Volume 6 (Enabling autonomy and access), Chapter 3 of the Disability Royal Commission final report focuses on “Advocacy and informal supports”, and speaks of the positive, enabling, critical and essential role of advocacy and advocates. We are pleased to see that the Disability Royal Commission concludes, as DANA has long argued, that “immediate action is needed to address the shortfall in funding”, as despite the limitations of available data about the levels of demand, the Commissioners “have taken into account the powerful evidence demonstrating the critical role of advocacy for people with disability and the extent of unmet demand for advocacy services”.

DANA plays a vital role as the advocate for the advocates, coordinating and supporting this essential role of independent disability advocacy organisations across the country.

In addition, DANA is funded to deliver the National Coordination Function program which provides secretarial and coordination assistance to the national Disability Representative Organisations.

Both these roles have increased the capacity of our organisations to work collaboratively and deliver for people with disability, including interfacing with government. This has been a practical investment in building capability and connections between people with disability, families, supporters, organisations and government processes.

We urge the Federal Government, through this review, to continue and develop this approach further, building on the strengths of people with disability and our organisations to partner more strongly as equals on the reform journey to come.

People with disability from marginalised communities, and who live in closed settings such as group homes and prisons, do not often have opportunities to have their voices heard about reforms and changes that affect them. DANA, through our members organisations of independent disability advocacy organisations, has a unique and enduring connection to many marginalised people with disability.

In the recent NDIS Review², we worked with six of our organisations to hear from people with disability about key aspects of how to ensure the Scheme delivers for them. This feedback was important for the NDIS Review Panel to understand as they consider how to improve the NDIS.

² <https://www.dana.org.au/current-work/ndis-review/>

Recommendation 1: That funding for coordination roles be continued to ensure people with disability can be heard.

Recommendation 2: That the connection between independent disability advocacy organisations and marginalised people with disability be recognised through funding to deliver consultation and co-design.

Area of focus 2: Providing grants that reflect the real cost of delivering quality services

The current grants and funding for independent disability advocacy services are not meeting the costs of delivering quality services, and this is detrimental to people with disability.

Unmet need and demand

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, 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.

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 unfair 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.

Not covering costs

DANA member organisations surveyed for this submission are clear about the wide range of areas where the current grants are not sufficient. This includes project and other funding that explicitly does not cover organisational running costs which has a disproportionate impact on small organisations.

The following administrative and overhead costs are significant:

- Remote travel, intake, business support, evaluation of programs, recruitment and on-boarding of First Nations advocates.
- Administration, human resources, payroll management, insurances, audit fees.
- Leadership and management costs associated with compliance and with providing support and leadership to staff.
- Corporate capacity, governance and compliance costs, including HR, finance, risk systems and quality systems, professional training and development of advocacy staff, in rural/ regional areas travel time and travel costs, recruitment costs, connection between individual advocacy and systemic advocacy and related policy development.
- Inclusive governance for people with disability including intellectual disability.

- Insurance costs.
- Staff wages.
- Investments in systems, processes, procedures to ensure compliance with grant conditions and general regulation, OHS etc.

Rising operational costs are significant across the independent disability advocacy sector, with specific issues for remote service delivery, small organisations and insecure project-based funding.

DANA members have raised strong concerns about the Information, Linkages and Capacity Building grants, recently extended but without an increase to meet both demand and rising costs. Other members have seen long-standing programs administered for decades have funding removed, leading to “an existential crisis due to significant funding cuts ... highlighting to us how little funding there is for operational and administrative costs”.

Disability advocacy organisations say that current advocacy targets are creating huge pressure on sustainability and leaving them:

“With completely inadequate resources to pay for admin, compliance costs and for leadership and management of the organisations. We could only become sustainable under current funding if we withdrew significant resources from frontline advocacy and we are reluctant to do this given current demand.”

This lack of funding for operational costs has:

“Diminished our capacity to meet rising demand to the point of long waitlists, closing books to new clients. They put significant pressure on Board and management around solvency threats, systems that are not adequate to manage organisational risks, staff risk burnout and damaged morale in this environment, and there is a constant fear of letting clients down, or denying access to those who need our service.”

For another advocacy organisation, the ongoing lack of investment in operational costs has meant:

“We are dipping into our reserves to pay staff wages this year. There is a lot that goes into the running of the program, and we are also keen to expand so have increased some staff hours to cover the cost of this. Rent, bills, subscriptions have increased for us due to inflation. We have to pay a considerable amount of money every 18 months for a Quality Assurance audit to meet our reporting requirements.”

Indexation and supplementation

Most surveyed members were mostly positive about receiving indexation payments for their existing grants, but raised significant concerns with both the time that it took for indexation to come through, and that it did not cover all the increased costs.

Some of the areas that indexation did not cover were IT, cybersecurity, travel, utilities and wages for non-frontline staff.

The uncertainty of the timing of indexation was a major issue, with budget planning made very difficult which then leads to challenges with recruitment, loss of skilled staff and less project impact.

Streamlined reporting

Disability advocacy organisations often receive a range of different funding from different levels of governments, and through different programs. These all have different reporting timelines and requirements, putting a significant administrative and management burden on organisations, particularly smaller ones.

DANA members surveyed suggested a co-design process with government about grant reporting processes so government could better understand the challenges of these systems on organisations. They also believe that the costs of compliance should be funded properly.

Members were also concerned that some of the complexity of disability advocacy is not reported on in the current system, such as how organisations work with people with disability with complex support needs. Reporting also often takes a deficit frame, rather than the strengths-based language that advocates use about people with disability.

Disability advocacy organisations also raised concerns about how difficult it can be to fit specific activities and outcomes into a standard reporting template, saying government needs to:

“Align reporting requirements to match the nature of the activity undertaken - too often a generic reporting structure is used and actual activity has to be shoe-horned into an inappropriate structure. There is no question governments should get performance information, but it must be appropriate to the activity, not generic across all activities it funds.”

For organisations in areas that have moved to outcome-based reporting for advocacy organisations, they report that this is a much better model.

Recommendation 3: That grants cover operational and administrative costs of service delivery.

Recommendation 4: That indexation be paid at regular times each year (say within four weeks of the Annual Wage Review), and at levels to fully cover costs.

Recommendation 5: That reporting processes be co-designed with people with disability.

Recommendation 6: That compliance costs are fully funded.

Area of focus 3: Providing longer grant agreement terms

All the DANA member organisations surveyed agreed that longer grant terms would be significantly beneficial, with suggestions of three to five years. Most responded suggesting five-year terms.

Their suggestions included:

- Five years minimum however a built-in system to review funding amounts by bi-annually to ensure the amount is appropriate for cost of operation.
- Minimum of five years, with meaningful indexation, and/or capacity to renegotiate if demand exceeds projections at application.
- Three – five years would be ideal.
- Four – five years would give much needed stability and certainty.
- Minimum five years.
- Five years would be helpful. Where project funding is granted, it should be considered as a pilot with the possibility of ongoing funding where positive impact is demonstrated and discerned by external evaluators. A great deal of money is wasted on short-term projects. For many people with intellectual disability, there is no substitute for ongoing, skilled engagement or facilitation/ support of freely given engagement.
- Five years (not three).
- Three years minimum to allow for relevant planning, resourcing and outcomes.
- Longevity is vital if governments expect providers to adhere to quality standards - such standards cannot be maintained if there is too high turnover in staff, and quality staff won't be attracted and can't be retained without certainty.
- Three years has been the ideal for us.
- Five years.

Recommendation 7: That grant periods for core advocacy operations be extended to a default position of three to five years, except in exceptional circumstances.

Area of focus 4: Ensuring grant funding flows to a greater diversity of CSOs

Independent disability advocacy organisations are a very diverse group that serves a wide range of people with disability across Australia. One of the key strengths of the disability advocacy sector is this diversity of approaches to advocacy, ensuring that the different needs of people with disability can be met.

However, the current grant funding programs exclude some advocacy organisations and can be inequitable and inconsistent in their application.

DANA has interviewed our member organisations across the country to examine in detail the gaps and challenges with existing grant programs to support disability advocacy. We have found that organisations that are not included in the National Disability Advocacy Program, and are delivering essential independent disability advocacy, often for significantly marginalised communities of people with disability, are severely impacted by this inequity.

In our 2024 pre-Budget submission, we are proposing a new grant round to specifically address these issues, open only to independent disability advocacy organisations who currently receive state and territory disability funding. 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). The flow of grant funds to a greater diversity of CSOs should not come at the expense of the sustainability of organisations that are currently funded, nor the sector itself.

DANA recommends a targeted investment of **\$25 million AUD** 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 outreach, information, and support to make applications for organisations who may need.

In addition, our pre-Budget submission calls for a significant increase for organisations funded under the National Disability Advocacy Program and specific funding for rural, remote and very remote disability advocacy.

DANA members who were surveyed said the following about the impact of this inequity in funding opportunities and what would support smaller organisations:

- Having a government grants person being proactive by working with organisations to identify and apply for funding.
- Redesign application process with an easy/ simple two step application - first being an basic EOI. This could save time on big applications if they don't get through the first step.
- The current DRO grant applications are open to national organisations only, and only for two years. There is no representation from WA in the DRO program, and minimal to no engagement with WA people with disability. The National Disability Advocacy Program has been a closed grant round for years, with no new applicants able to apply. The government needs to open these grant opportunities to smaller organisations who are likely to give greater 'bang for buck' and raise issues which larger organisations may not be aware of. Particular emphasis on regional and remote based organisations, which tend to go unnoticed by government but are vitally important to their local communities.

- They should recognise that advocacy services by nature are generally small and locally based and so we do not get the economies of scale that the large disability organisations get. Funding agreements should explicitly build in extra funding for leadership, management and compliance.
- Make the application process simple and low doc, provide expert support to organisations wishing to make an application, which in working with the organisation can also build capacity for making applications in terms of design of proposals, budgeting etc.
- Create a collegial culture. Simplify the process for non-competitive tenders. Being mindful of the time of year funding submissions are sought. For example, a short time frame at Christmas is unhelpful. Identify needs and invite solutions that will be funded if they have merit – rather than prescribing parameters that organisations need to fit. Notifying organisations about funding opportunities rather than requiring them to find them. Allowing longer for drafting funding application. Providing guidance about outcomes sought from funding. Not expect not for profit organisations to operate in a situation of ongoing need. Provide enough funding to allow for known demands like reporting and completing funding applications. Revisit funding with a contemporary lens. For organisations deemed to have merit, look at what it takes to run an organisation in terms of basic recurring costs such as insurance, rent, audits, equipment, utilities, admin and HR support. Consider the area covered. Consider any specialisation impacting on funding. Recognise additional costs related to time, travel, resources, training etc.
- Provide information and support on how to apply for grants, what projects would be appropriate in the current landscape and how you resource researching this, where to look etc.
- Minimise the number of times organisations have to apply (i.e. longer grants). Don't artificially 'tender' for services when it is clear there is an established set of organisations who do the service in the manner the government has prescribed (e.g. to a set quality standard, for a specified client base, with a specified process). Recognise that organisations may ONLY do that service - too often governments act as if the organisation is fully self-sustaining entity that just happens to offer that service, when in fact many are specialised to that service (and should be so, to prevent conflicts of interest, for example) and so rely on that funding. And yet the government won't fund anything that preserves that organisations capacity to function outside the strict conditions of the grant - as if all the overhead, the accounting, HR, IT, compliance etc (which are all expected to be conducted to a professional standard) somehow happen by magic.
- More organisation capacity building grants.

Recommendation 8: That grant funding be extended to a greater diversity of CSOs.

Recommendation 9: That a dedicated funding round focused on supporting smaller and at-risk advocacy organisations and ensuring continuity of advocacy services be established.

Recommendation 10: That funding for a greater diversity of CSOs does not come at the expense of the sustainability of existing organisations, or the disability sector itself.

Area of focus 5: Partnering with trusted community organisations with strong local links

The National Disability Advocacy Program is an example of an existing place-based program, with independent disability advocacy organisations funded to deliver advocacy to people with disability via geographic regions.

A key strength of independent disability advocacy organisations is their connection to their local communities, working in partnership to solve individual and systemic barriers for people with disability.

They often also play a vital role in adding local knowledge and capacity to national systems, such as the NDIS. Research has found that local disability advocacy organisations are essential market stewards³ due to their intimate knowledge and understanding of gaps and capacities within local NDIS service provision:

“Advocacy organisations are uniquely positioned to be able to provide information to the NDIA on what is happening at the local, on the ground level, from an independent participant (rather than provider) focused point of view. This is instrumental for good market stewardship and functioning of the system.”⁴

In addition, the current reforms recommended by the Disability Royal Commission and the NDIS Review⁵ will require deepening these local connections and relationships to ensure that there is increased access for people with disability to inclusive mainstream public services and the community.

DANA members surveyed for this submission value their role in the local community and believe this is an essential component to delivering effective advocacy with people with disability. There is also recognition of specialist skills that may not be locally based, but are equally important. They say the benefits and experience with working in a local area are:

- Local relationship. Knowledge of local community, solid local networks. Knowledge of delivery environment. Knowledge of local issues/ priority areas/ service gaps.
- Relevant, local knowledge and expertise. We are often contacted by both the Disability Gateway and the Carer Gateway staff seeking advice and support for people living all over WA. This is because the centralised services are based in the eastern states with no understanding of the geographic distances in WA and the services available on a local level.
- Advocacy services are generally small and place-based grassroots organisations. This is much more conducive to being controlled by people with lived-experience of disability. It also means that we have strong links to our local communities and understand local issues. We also have stronger ties and working relationships with the local service providers who are best placed to help resolve issues being experienced by people with disability. Local services are generally also trusted more by local people with disability.

³ Celia Green, Gemma Carey & Eleanor Malbon (2022): Advocacy as market stewardship in social care quasi-markets, Public Management Review, DOI: 10.1080/14719037.2022.2084771

⁴ As above

⁵ <https://www.dana.org.au/discussion-paper-mainstream-tier-2/>

- Enormous benefits from reaching and working with people in their local lives and contexts. It makes the work, and associated referrals as relevant and accessible to clients as possible. It ensures people can be reached across the digital divide and in modes and terms that respect their needs and circumstances. It makes services attuned to barriers and able to advocate for systemic policy and service reforms that address them.
- Every area has its own culture and way of doing things and it is vital that organisations know what this is. We see a number of city-based organisations with contracts for country regions that are never serviced. People with disability want to see local people they know and trust deliver their services.
- Local knowledge can help us know who is doing what, organisational specialisations and projects. It can help us be known and develop a relationship of trust with vulnerable people in the local area. This can result in more trauma informed, impactful advocacy. It can also help us build relationships of trust with service providers so that referrals are more likely to be made. At the moment, poor quality search engines (Ask Izzy), and poor dissemination about who is doing what make local knowledge imperative to make appropriate referrals.
- By being 'place-based' we are linked with organisations and services that provide services to our client group, which allows positive relationships at the service level, and so is helpful for assisting our clients. It also allows our services to be known by word of mouth, and so reach a wide client group.
- The benefit is that we live in and know the community well, which means we have networks to reach out to some of the most vulnerable people in our community to help them by seeking an advocate to support and assist them.
- Entirely dependent on the nature of the service - at least as often it is more important that organisation has skills in a specialist area, or with a particular cohort, which are available to a wider geography than it is important to be local.
- Indigenous advocate has local connections. Face to face service delivery. Long term client relationships. Local area isn't only about geography, but also consider closed environments.

Recommendation 11: That place-based reforms understand and include the vital role of independent disability advocacy organisations to connect with people with disability.