Submission

Developing a Not-for-profit Sector Development Blueprint

December 2023

# 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

DANA greatly appreciates the opportunity to speak to the issues raised in the discussion paper and is excited and energised by the willingness of the government and a range of stakeholders to chart out a strong future for the not-for-profit sector.

Our submission is structured in response to the discussion paper and our key recommendations are as follows:

*Our Vision for Disability Advocacy within the Broader Not-for-Profit Sector*

* Increase resourcing and capacity for the disability advocacy sector to help improve the lives of people with a disability.
* The blueprint should include principles relating to:
  + working constructively and respectfully with the community sector;
  + resourcing disability representative and advocacy organisations to meaningfully contribute to policy design, development and implementation;
  + allowing government decision-making, policy and law reform processes to benefit from the extensive expertise, insights and networks the disability advocacy sector holds;
  + valuing and supporting the diversity and grass-roots nature of organisations;
  + investing in funding and focused collaboration with the disability advocacy sector, to ensure it is well-supported, represented and enabled to develop fit for purpose structures and systems for reporting activities and measuring outcomes achieved and the demand and need for advocacy not being met by current capacity; and
  + ensuring cultural safety, and that organisations are child-safe and trauma-informed.

*Measurements of Outcomes and Disability Services*

* Federal, and state and territory governments should unify their reporting processes to assess how programs are operating, as much as possible.
* Funding bodies should recognise that, particularly in the disability advocacy space, objective measurements of outcomes often do not present the whole picture (or otherwise note the extensive benefits of widely available services in preventative and empowerment contexts).
* Cost bases for government programs and funding should incorporate the costs in hiring and employment people with specific knowledge around data knowledge and implementation, rather than leaving it as an additional task for people performing services on the ground.

*Policy, Advocacy, Communications and Engagement*

* Longer-term contracts for the delivery of advocacy services should be in place, particularly where programs are already well-established and effective.
* Clauses in tendering contracts that constrain not for profit organisation’s ability to campaign and comment on political developments in their area of work should not be allowed.
* Suitable funding for the delivery of primary work should be in place, so that resources do not have to be shifted away from broader systemic efforts. The 90-10 split in NDAP funding in particular should be re-considered to be more flexible and account for the needs of Advocacy organisations.
* Strengthen and expand mechanisms that develop and enable independent disability advocacy and representation, such the National Coordination Function and the National Centre for Disability Advocacy.
* The roles of advocacy, representation and leadership by and for people with disability should be embedded across government, service systems and the not-for-profit sector.

*Philanthropy & Volunteering*

* Long-term funding should be provided to allow organisations to develop long-term relationships and self-advocacy skills with their client bases, particularly given the insights gained from the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability (Disability Royal Commission) and effectiveness of Citizen Advocacy organisations.
* A Disability philanthropic foundation should be established that involves people with disability to be involved in the disbursement of charity funds.

*Governance and Legal Environment*

* Systems should be unified between federal and state bodies (where possible) would help improve efficiency (see section 2).
* People with disability and other relevant communities should be playing a leading role in the development of programs and initiatives that affect them.
* Data, in accessible formats, should be published from programs like the National Disability Advocacy Program in a public-facing dashboard to give the community an indication about the capacity of programs and inform public policy about the operation of those services.

*Leadership and Staff Development*

* Support sector-led organisations in areas that have inconsistent or limited opportunities for leadership and staff development to work with organisations and stakeholders to deliver training and share good practice and expertise across sectors, through establishing or strengthening initiatives like the National Centre for Disability Advocacy (NCDA).
* Resource organisations, particularly in regional, rural and remote areas, so that the advocacy workforce can be developed and supported through secure funding, and expertise can be built and retained in the independent disability advocacy sector.
* People with disability should be resourced and supported to take on leadership roles across the disability advocacy sector, and the wider community sector.

*Government Funding Contracting and Tendering*

* Programs should be led by their users, indexation incorporated regularly, compliance costs are considered, and length of contracts are extended to develop skills.
* Resources should be provided to a greater array of providers
* The role of smaller organisations should be maintained, recognising that they are well-positioned to connect and serve the needs of smaller and/or more remote communities.
* The role of place-based services should be recognised, including their deep expertise in their local area.

*Information Technology*

* Reporting services should be consolidated to help minimise overhead, particularly for smaller organisations.
* Options to integrate reporting systems with popular content management systems should be explored, ensuring that organisations can develop methods that work for them when reporting to funding bodies.
* Organisations should be resourced to invest in hardware, software and staff development to increase and maintain IT skills in organisations, particularly small to medium organisations.

*Leveraging Social Assets and Finance*

* Options to benefit organisations with limited assets or financing opportunities should be explored.

# 2. Our vision for disability advocacy within the broader not-for-profit sector

DANA’s vision is of a nation that includes and values people with disability and respects human rights for all. To achieve this aspiration, Australia needs diverse, strong, sustainable, visible and proactive independent disability advocacy organisations as part of the broader not-for-profit community sector, so Australians with disability can be connected to help to defend their rights and interests and to remedy and speak out about discrimination, exclusion and harms they experience.

DANA has long argued that significantly increased levels of resourcing and sector support and coordination would benefit people with disability, individual advocates and organisations, leading to better results and outcomes. Researchers have found that disability advocacy is an excellent investment to make - advocacy provides a benefit-cost ratio of 3.5:1 for each dollar spent.[[1]](#footnote-2) A 2021 review of this 2017 analysis concluded that the original findings were still relevant and the benefit of independent disability is substantial, particularly in reducing unreasonable burdens on people with disability directly.[[2]](#footnote-3) We recently made a pre-Budget Submission calling for a tripling of funding for the independent advocacy sector.[[3]](#footnote-4)

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.
* People with disability can access advocacy support before they are in crisis.
* 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.

## Values to guide the not-for-profit sector development blueprint

DANA is cognisant of the breadth and depth of the work performed by disability advocacy organisations around Australia. There is a diversity of disability advocacy organisations - in terms of size, types of organisations, capacity, location and approaches to disability advocacy provision:

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

DANA sees strength and responsiveness in the diversity and community-driven nature of many of the organisations funded to provide disability advocacy. There are also a range of grass-roots rights-focused organisations that (like advocacy organisations) also guide activities such as peer support, supported decision making, leadership and representation for people with disability. These organisations are people-centred and people-powered and often disability-led or governed and can therefore be incredibly responsive to needs of the local communities they have grown up from.

DANA would strongly endorse a blueprint that would compel government to:

* work constructively and respectfully with the community sector;
* resource disability representative and advocacy organisations to meaningfully contribute to policy design, development and implementation, including with shared decision-making;
* allow government decision-making, policy and law reform processes to benefit from the extensive expertise, insights and networks the disability advocacy sector holds;
* value and support the diversity and grass-roots nature of organisations; and
* invest funding and focused collaboration with the disability advocacy sector, to ensure it is well-supported, represented and enabled to develop fit for purpose structures and systems for reporting activities and measuring outcomes achieved and demand and need for advocacy.

As recent Royal Commissions have highlighted, other important themes for action include improving cultural safety,[[4]](#footnote-5) and ensuring organisations are child safe,[[5]](#footnote-6) and trauma-informed.[[6]](#footnote-7) This is particularly important given that many people with disability may have experienced complex trauma from witnessing repeated physical or emotional harm or neglect in disability (or other) service contexts, including from not-for-profit organisations.

## Priorities and consequences of no action

For independent disability advocacy and representation, the most important action is an immediate increase of funding to ensure capacity to meet both unmet demand and need, and the financial viability and effectiveness of the sector. In the short to medium term there needs to be considerable work with the sector and between different levels of government to build and strengthen mechanisms to measure the levels of unmet demand and need for independent advocacy. There is much scope for streamlining processes and building purposeful consistency and guidance for funded advocacy organisations to report to government funders, and also develop a strong sector-owned evidence base to demonstrate outcomes across the sector, which is discussed further below. Please refer to our recent Pre-Budget Submission for more discussion of the immediate need,[[7]](#footnote-8) and earlier submissions for medium to long term needs to develop, support and represent the sector and to strengthen access to and awareness of independent disability advocacy.[[8]](#footnote-9)

With no action to ensure the viability of organisations and sustainability of the independent disability advocacy sector or to ensure that the voices of people with disability and their advocates are listened to through meaningful co-design, the implementation of Australia’s Disability Strategy and recent recommendations from the Disability Royal Commission and the NDIS Review will not be fully realised. It would also mean that the efforts of organisations delivering individual advocacy would need to remain focused on fulfilling vital crisis response and safeguarding functions for people with disability facing immediate harms. This diverts efforts from the more developmental and preventative work of rights education and awareness raising, capacity building and early stage problem-solving and dispute resolution, which in the longer term could work to reduce the currently high level of unmet demand and need.

DANA believes a strong, sustainable future is possible with the right investment, and independent disability advocacy organisations are a critical partner in undertaking this work.[[9]](#footnote-10)

# 3.Measurement, outcomes and quality of services

## The need for consistency

Ensuring that Advocacy programs incorporate the views of people with disability and the organisations that will be deploying them is a key part of the work that should be undertaken when building service mechanisms. This should extend through both the actual intention of how services should be delivered, but also the reporting and data collection efforts that will be required on the back-end.

In assessing outcomes, it is important to consult with people with disability and providers on what goals their programs are seeking to implement.

A segment of the disability advocacy sector has been moving towards an outcomes-focused approach for the past few years. DSS introduced ‘the partnership approach’ (SCORE) which was initially optional and then became a mandatory requirement as part of tendering agreements. One of the issues with this process was that no sector wide guidance was provided on why the data was being captured, what the data was being used for and how to capture the data/ when the data should be captured. Many organisations then had to figure it out themselves which leads to inconsistencies between organisations and limits the utility of the sector-wide data.

## Outcome-based approaches and advocacy

By contrast, some states and territories seek basic outcome data such as ‘outcome met’, and ‘outcome partially met’ etc (which is the case in Queensland), whereas other state and territories only seek output data (Victoria).[[10]](#footnote-11) For organisations that are only state/territory funded, moving to an outcomes approach would be a big change, and significant support would be needed.

There should be a universally accepted outcomes framework that is the same for both national and state/territory disability advocacy, that meets the needs of all models of advocacy.[[11]](#footnote-12) This could mean that there are multiple outcomes areas, but the provider only completes the section relevant to the work.

It is also important to clarify that in advocacy, material or objective outcomes are not always the end goal alone. There should be scope for the greater purpose of independent disability advocacy, specifically ensuring that people with a disability are supported to exercise their rights on a general level, without directly being tied to a particular measurable outcome. This might include supporting someone through a NDIS Appeal through external administrative review, where the ultimate decision that they receive is not changed but they have been supported in the overall goal to ensure that people with a disability to exercise their rights and systemic accountability has been exercised in asking a government agency to defend and express their decision. Subsequent effects of advocacy assistance can also be more diffuse and only apparent beyond the scope of reasonable data collection, such as the prevention of future harms or otherwise supporting people’s self-advocacy, knowledge, decision-making support, or long-term wellbeing.

Additionally, outcome identification is a difficult area of qualitative research. A study from Bodille Arensman notes the extensive reporting difficulties experienced in assessing advocacy effectiveness,[[12]](#footnote-13) and that such efforts are often subjective and inherently variable. As the Centre for Social Impact and Social Ventures Australia note, there “needs to be some sensitivity to the challenges that measuring impact can present – especially when making comparisons across organisations.”[[13]](#footnote-14)

## Making organisations data capable

Specific funding and targeted work needs to exist to integrate those with data management and analysis expertise into the work of independent disability advocacy organisations. Current arrangements place the collection, integration and interpretation of data on the back of teams that are primarily concerned with direct service delivery rather than data collection or analysis. That work is often difficult and requires a substantial uplift on the staff that are otherwise already trained and effective in a very different specialised area.

Additionally, clearer and more regular provision of the data that is collected by governments such as in a dashboard or more regular discussions would be helpful in illustrating the utility of collecting it.

Where programs require particular types of data integration (e.g. DEX for Department of Social Services funded programs) additional efforts could be targeted in ensuring databases and CRMs are fit for purpose. In working with organisations to develop appropriate data formats discussed above, appropriate scope should be given to ensuring that those organisations can develop and integrate a data platform that works for them and their workers.

# 4.Policy, advocacy, communications and engagement

## Embedding the role of advocacy

In July 2022, DANA’s submission on the draft of the *National Disability Advocacy Framework 2022-2025* welcomed the increasing recognition by governments of the vital role that advocacy plays in promoting and protecting the rights, interests and wellbeing of people with disability and in contributing to the proper functioning of systems established to provide services and supports for people with disability.[[14]](#footnote-15) Yet despite the growing acknowledgement of the important role of independent disability advocacy in key legislation,[[15]](#footnote-16) and strategic government documents,[[16]](#footnote-17) and many commissions, inquiries and reviews making strong recommendations in relation to improving its availability and resourcing,[[17]](#footnote-18) this has not yet resulted in the funding security and commitments needed. In fact, disability advocacy organisations have faced a significant cut in funding as the Disability Royal Commission funding increase of 30% expired in June 2023.[[18]](#footnote-19)

Furthermore, over the past decade the introduction of the NDIS has seen a significantly increased demand for advocacy to support people in navigating its inherent complexities. Despite the historic increase in disability services funding through the NDIS, this has not been met with proportionate additional funding for disability advocacy organisations.218F[[19]](#footnote-20) Instead, insufficient, fragmented and insecure resourcing severely limits disability advocacy provision and there are major gaps, deficiencies and systemic issues that prevent access to independent advocacy for all people with disability.

DANA believes that the strong evidence that has emerged from the Disability Royal Commission, and the recognition of individual advocacy as a “foundational support” by the recent NDIS Review,[[20]](#footnote-21) adds pressure on decision-makers to make considerable investment in the short, medium and long-term from both the Federal and state and territory governments. Ambiguity and responsibility-shifting between levels of government should not be permitted to undermine or diffuse the duty of governments to fund vital community supports. As observed in the National Strategy for Volunteering 2023:

*“Shared accountability can become a dilemma when those concerned cannot agree where accountability lies or it is persistently difficult to implement and regulate. However, when done well, shared accountability results in improved performance and increased trust”.[[21]](#footnote-22)*

There are promising indications from the December meeting of National Cabinet[[22]](#footnote-23) of increasing recognition of the need for collaboration and joint contributions from the Australian and state and territory governments to deliver the “foundational supports” needed outside of the NDIS, including individual advocacy, as recommended by the NDIS review panel.[[23]](#footnote-24) For commitments made in policy and legislative frameworks to be fully realised, disability advocacy and representation must have assured funding. As Disability Representative Organisations (including DANA) recommended in a joint submission on the *Disability Services and Inclusion Bill 2023,* laws should include:

*“a commitment that the Australian Government will provide ongoing funding for [Disability Representative Organisations] and advocacy services”.[[24]](#footnote-25)*

Funding agreements must certainly not attempt to constrain advocacy activities or include “gag clauses”[[25]](#footnote-26) that would restrict or prevent “*not-for-profit entities from commenting on, advocating support for or opposing changes to Commonwealth law, policy or practice*”.[[26]](#footnote-27)

We are concerned when we observe government representatives and political leaders displaying frustration with having to listen to a number of diverse voices and receive input from a range of organisations, often out of a desire for clarity and uniformity to inform policy and program development and to eliminate administrative inconvenience. There have been attempts in the past to streamline the National Peaks or Disability Representative Organisations program, and suggestions of pushing organisations into categories that might make sense to bureaucrats but would be a disservice to the people they represent. We are hopeful that Australian governments will develop greater appreciation and understanding of how strong representation, advocacy and involvement of people with disability, including through listening to and considering multiple and nuanced perspectives, ultimately contributes to better design, implementation and oversight of laws and policies.[[27]](#footnote-28)

One of the key limitations in this space is that organisations that may otherwise be capable and eager to participate in systemic advocacy are under resourced to do so. For example, the NDAP program has a 90-10 split of funding – with 90% flagged for direct advocacy supports and 10% for systemic advocacy work. However, in practice, many organisations are unable to meaningfully engage in systemic advocacy in the way that would be most effective for the communities they support.

In many cases, the overwhelming demand for direct advocacy support means that any slack capacity is usually taken up by efforts to reduce long waitlists or help more people directly. Additionally, 10% as a proportion of work for organisations that may only employ a couple of direct staff makes it difficult to employ people with specialist skills in the area, or to give appropriate time and scope to develop those tools in-house. There should be greater flexibility in this space to allow organisations to determine the best use of resources for particular needs of their community given some systemic work can be episodic (where there is a media focus or a long-standing issue comes to a head), as well as more substantial funding efforts explicitly for systemic work for them to be effective.

## Mechanisms and resourcing for co-design

As we explored in our submission to the DSS consultation on “A stronger, more diverse and independent community sector”, some good progress has been made in recent years in the development of disability representation and the involvement of people with disability and their representative organisations in co-design of the policies and programs that affect them. [[28]](#footnote-29)

Our fellow peak and representative organisations, such as Inclusion Australia have also highlighted in recent submissions that this is a central endeavour and must be adequately resourced.[[29]](#footnote-30) Women With Disabilities Australia (WWDA) noted significant resourcing challenges and constraints and that there are limited formal mechanisms that give the community sector a strong voice in co-design processes, despite widespread recognition that genuine co-design is the most effective method of ensuring that a strategy of policy and program delivery meets community needs.[[30]](#footnote-31) WWDA also highlighted that genuine co-design involves the sharing of power and that:

*“On-the-ground engagement with members and community is a critical step in ensuring that representative organisations can act as a conduit between community and government. However, consultation and engagement can be resource-intensive.”*

Australians with disability are best represented and supported to contribute to government, service and community decision-making and genuine co-design by a range of representative and advocacy organisations that reflect their plurality and diversity, and their varied needs and priorities. Both cohort-focused and disability-specific organisations need to be adequately funded to drive the transformative change needed and inform the effective development and implementation of recommendations made by the DRC.

DANA sees great potential for the National Centre for Disability Advocacy to play a significant role in proactively promoting, supporting, and facilitating “linkages between individual and systemic advocacy”, particularly if the Centre receives access to advocacy data and sufficient ongoing funding to coordinate collaboration, networking and communities of practice around specific issues and cohorts.

In addition, DANA is currently funded to deliver the National Coordination Function program which provides secretarial and coordination assistance to national Disability Representative Organisations.[[31]](#footnote-32) This program has contributed to improved collaboration between national organisations, and more coordinated input and advice to government, including through facilitating several joint submissions to consultations on key policy and legislation.[[32]](#footnote-33)

Both these roles have increased the capacity of our organisations to work collaboratively and deliver for people with disability, including through 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 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.

## Leadership and involvement of people with disability

The “nothing about us without us” principle is at the heart of the disability rights movement, and we know that enhanced representation and inclusion of lived experience expertise leads to better more responsive, effective and fit for purpose programs and systems.[[33]](#footnote-34)

Yet to genuinely support the inclusion and involvement of people with disability in co-design and decision making (and oversight and governance), resources and development are crucial. In our detailed recommendations to the Disability Royal Commission, we specified the need for “dedicated funding for advocacy and disability representative organisations to support building the capacity of people with disability in:

* Self advocacy and advocacy skills
* leadership and representation
* advisory and decision-making processes, including in community, public and private sectors at local, regional and national levels.”[[34]](#footnote-35)

We know that many of the problems with existing systems and processes examined during the Disability Royal Commission and the NDIS Review has been their inaccessibility and non-responsiveness to the needs, experiences and human rights of people with disability. Both government and not-for-profit policies and programs have been designed and implemented largely by people without disability, leading to poor and sometimes disastrous outcomes and trauma for people with disability.

We hope that much co-design flows from the DRC and NDIS Review recommendations, yet the voices, experiences and perspectives of those who will be most affected by these various reforms will not be able to genuinely inform and lead their development, if the capacity of disability leaders, and representative and advocacy organisations is overstretched by the pace of reform and the disability community continues to be overwhelmed by “consultation fatigue”. Governments engaging in anything less than meaningful, resourced co-design and supporting strong disability leadership and representation would be extremely disheartening given the abundant evidence that the leadership and active presence of people with disability are central to achieving the transformative systemic and cultural change needed.[[35]](#footnote-36)

DANA’s leadership team comprises three people with disability and through our relationships with independent disability advocacy organisations around Australia our organisation has an enduring connection to many marginalised people with disability, including from diverse communities and backgrounds, and who live in closed settings such as group homes and prisons, and do not often have opportunities to have their voices heard about reforms and changes that affect them.

As we recommended previously, that connection between independent disability advocacy organisations and marginalised people with disability needs to be recognised through funding to deliver consultation and co-design and foster strong leadership and advocacy by people with disability. This resourcing must be adequate to facilitate the inclusion and meaningful participation of people with intellectual disability, acquired brain injury or complex communication support needs, through the provision of individualised support, for instance with meeting preparation, and during and after meetings. These supports should be provided by people who are independent and skilled in supporting decision making without influence, (see Voice At The Table project).[[36]](#footnote-37)

## Building an inclusive evidence base

We are pleased that there is being work done to improve the evidence base around the experiences of and outcomes for people with disability by the National Disability Data Asset (NDDA) and the National Disability Research Partnership (NDRP). There is also some measurement of progress through the Outcomes Framework of Australia’s Disability Strategy 2021-2031. It is encouraging that there is increasing recognition from governments and research institutions of the importance of this work to be done in close consultation with, and including the input and leadership of people with disability and their advocates, and when possible to be founded on principles of inclusive research and collaboration. The NDRP initiative to fund research led by and with people with disability is a positive step.[[37]](#footnote-38)

Advocacy and representative organisations often have much insight, experience, community relationships and data to contribute to research, engagement and evidence gathering activities. However, research projects they are invited to take part in are generally driven and directed by universities, academics and individual researchers or consultants rather than informed by what the sector needs. Furthermore, without additional funding, organisations are not generally in a position to initiate, or participate in, research projects. With many already operating on insufficient funding to respond to government-run consultations and co-design processes, there is often an overwhelming volume of invitations to participate in surveys, workshops, focus groups (or to recruit or support people with disability to participate) or otherwise guide or assist research and engagement by academics, research institutions, consultants, service providers, or other advocacy, representative or adjacent organisations.

Though some monetary support or reimbursement for time may be attached to these opportunities, the necessary triaging, monitoring, decision-making and associated administration (even to respond to these requests to seek further information or decline participation due to lack of capacity), can be a significant impost on the time of busy staff, especially for national and state or territory peak organisations. Inclusion Australia has developed Easy Read information for organisations, researchers and consultants, to encourage early planning on how projects will engage with people with intellectual disability,[[38]](#footnote-39) as their involvement and participation should not be an afterthought.

There has also been limited research about and evaluation of the impact of independent disability advocacy on the lives of people with disability. We would like to see the sector being made a priority for research initiatives (with resourcing for organisations to participate effectively).

# 5.Philanthropy and volunteering

The independent disability advocacy sector is one of the sections of the not-for-profit sector which is almost wholly reliant on the provision of government funding to deliver free independent support to community members. Most organisations providing independent advocacy are not also operating as service providers within a market model. Although DANA is keen to see and encourage philanthropic giving and support for additional projects in the realm of advocacy, peer support, leadership and representation, ensuring advocacy organisations are equipped with adequate core funding must primarily remain the responsibility of governments.

Recent years have seen some positive and innovative instances of philanthropic support for advocacy and leadership programs, inclusive volunteering programs,[[39]](#footnote-40) or volunteering programs to safeguard rights of people with disability and improve their lives.[[40]](#footnote-41)

## Safeguarding through community connections

A strong theme to emerge from the Disability Royal Commission and previous inquiries is the need for improved safeguarding of isolated people with disability, and especially those only interacting with services providers or living in closed settings with limited external oversight. As we noted in one of our submissions to the Disability Royal Commission,[[41]](#footnote-42) the volunteer model of Citizen Advocacy has great potential to initiate and guide long term supportive relationships for isolated people with disability. This model of advocacy seeks to support people with a disability (also called protégés) by matching them with volunteers. Some of the matches made may last for life. Through Citizen Advocacy:

* people with disability who are isolated with no family or community supports or networks are sought out;
* volunteers are encouraged to represent the interests of a person with a disability as if they were their own and be free from conflict of interest;
* volunteers are recruited, trained and supported by a coordinator who manages the work of the Citizen Advocacy agency.[[42]](#footnote-43)

Strong relationships and community connections reduce a person’s risk of experiencing abuse, violence, neglect and exploitation and provide support and guidance to remedy abuse when it occurs. Unfortunately, Citizen Advocacy organisations are inadequately and inconsistently funded throughout Australia, with Citizen Advocacy programs completely absent from the ACT and NT jurisdictions and many regions around Australia.

In addition to peer support, self advocacy groups, representation and leadership development there are other forms of individual and community capacity building that often rely on voluntary relationships. These can be especially relevant to people with disability who lack informal networks and community connections, and/or need additional support.

* **Circles of support** – a group of people who volunteer to meet with a participant on a regular and ongoing basis to help with the thinking, planning and implementation of their personal goals.
* **Microboards** – a small group of people, typically committed family and friends of a person who experiences challenges in life. That group of people form an incorporated association for the benefit of that person. Depending on a person’s particular needs, a Microboard’s role can include assisting with coordinating support services, finding and keeping employment, facilitating friendships and social community.
* **Social role valorisation activities** – ensuring the individual assumes a valued social role in their community.[[43]](#footnote-44) This sometimes occurs through customised employment, setting up a microbusiness, inclusive volunteering programs or other formats.

Such activities build intentional relationships and provide support for decision making by listening to the person’s ideas, supporting their choices, identifying their goals and aspirations and planning to make things happen.

## Inclusive volunteering and the National Strategy

One of the strategic objectives of the *National Strategy for Volunteering 2023-2033* is to “make volunteering inclusive and accessible”. Many people with disability participate in meaningful voluntary work, and otherwise make valuable contributions or assume valued social roles in their local or online communities, including through programs run by disability advocacy organisations.[[44]](#footnote-45) As noted in a joint submission on the Draft National Strategy for the Care and Support Economy by eight of the National Disability Representative Organisations,[[45]](#footnote-46) one third of informal carers are people with disability. Yet despite the existing and potential unpaid work and valuable contributions of people with disability there can be barriers, inaccessibility and ableism making it difficult for people with disability to participate in volunteering programs.[[46]](#footnote-47) This is recognised by the *National Strategy*, which also highlights the need for other government initiatives such *as Australia’s Disability Strategy 2021-2031* to incorporate planning for the sizeable volunteer workforce that already exists in disability-focused not-for-profit activities, and the research gap around volunteering and inclusion of people with disability.

## A philanthropic foundation

Consideration should also be given to the establishment of a disability philanthropic foundation, focused on strengthening the capacity of people with disability to work with charitable organisations and centring the experiences of people with disability when undertaking grants and program construction. A similar recommendation was made in a recent draft report from the productivity commission relating to a proposed Aboriginal and Torres Strait Islander Foundation,[[47]](#footnote-48) which we also endorse.

Ensuring that the foundation is led and designed by people with disability is crucial to ensuring that we do not return to outdated and harmful beliefs about people with disability, particularly the former charity or medical models. Ensuring that the power to determine appropriate priorities places the power in the hands of the communities that the funds will impact, which minimises concerns about non-disabled people or funding bodies exercising control over people with disability whose support needs are determined and dictated by external forces. It also ensures an appropriate focus on empowerment, rather than reinforcing negative stereotypes or stemming from a place of sympathy, guilt or pity.[[48]](#footnote-49)

Establishing a foundation that can assist in coalescing and co-ordinating investments can assist in the delivery of services in the ways that are most effective that are described above and in the discussion paper. This includes regular and consistent funding arrangements as opposed to one-off interventions and meaningful integration of communities benefitting from such services. There are strong arguments for encouraging philanthropic support of systemic advocacy,[[49]](#footnote-50) given its potential to drive powerful long-lasting improvements in the lives of people with disability.

# 6.Governance, organisation and legal environment

One of Australia’s Disability Strategy policy priorities is to “increase representation of people with disability in leadership roles”, stating that: “*People with disability are significantly underrepresented on boards, in politics and in other leadership roles in Australian society. Increased inclusion of people with disability in leadership will enable the perspectives of people with disability to be included in decision-making, thereby making decisions more reflective of the community.”*

As we explored above in Section 4, people with disability should have opportunities and support to be actively involved in the design, delivery, leadership and governance of organisations and programs to ensure these are appropriate, inclusive and effective.12F[[50]](#footnote-51) Although there are increasing endeavours (especially by disability advocacy and other rights-focused organisations) to proactively promote and appoint people with disability to leadership positions and to involve people with disability in all aspects of service design, delivery and governance, [[51]](#footnote-52) this requires additional targeted resources, especially to facilitate and support the meaningful involvement of people with complex support needs.[[52]](#footnote-53) Although there are pockets of excellence and increasing prominence of Disabled Peoples Organisations,[[53]](#footnote-54) and a number of leaders with disability working in disability advocacy and representation, there is considerable scope for improvement to truly reflect the sector’s aspirations for improved disability leadership and governance and the diversity of Australia’s disability community.98F199

## Frameworks within the Federation

As is discussed above, ensuring that there are shared areas of assessment and unified reporting tools between state and federal funding bodies would help minimise the complexity that comes with integrating multiple sources of funding. When asked to report in different ways across different funding streams, there is a substantial administrative overhead that can often be difficult to manage.

## Board composition

As the DRC-commissioned Research Report on changing community attitudes concluded, ‘active presence of people with disability’, ‘leadership’ and ‘long-term approaches with adequate resources’ are all key strategies to facilitate attitude change.[[54]](#footnote-55) People with disability should be able to be actively involved in the design, delivery and governance of organisations and supports to ensure these are appropriate, inclusive and effective. 12FSee further discussion in our submission on “A stronger, more diverse and independent community sector”[[55]](#footnote-56) and our Independent Disability Advocacy submission to the Disability Royal Commission.[[56]](#footnote-57) 1O

## Publicising data

Greater publicity and accessible dashboards for important data about the work undertaken in programs is crucial to informing public debate and civil society. As an example, most public and community housing statistics are gathered and fed into programs such as the Australian Institute of Health and Welfare (AIHW) to detail the scale of housing shortages in Australia.[[57]](#footnote-58) In the advocacy example, a greater sense of the total number of people needing assistance at any one time (particularly if that included waitlist data or the number of organisations whose books had closed) could offer a useful systemic idea of the amount of barriers people with disability are experiencing at a given time.

# 7. Leadership and staff development

DANA concurs with observations and research cited in the Issues paper and notes the particular applicability in the disability advocacy sector, with its leadership often “being proactive in developing and implementing organisational diversity and inclusion strategies” but also being constrained in “the capacity to meet its own aspirations and meet the needs of communities”. DANA members report that advocacy and legal services are overwhelmed and experiencing high levels of staff fatigue and burnout,[[58]](#footnote-59) and this is not uncommon across the broader community and social sector workforce.[[59]](#footnote-60)

## Insecure and challenging work

People who work in disability advocacy and representation are often motivated by values and purpose, meaning the workforce has strong drive and dedication to their work – yet there are often staffing challenges, especially in regional, rural and remote areas. This is due to overstretched funding allocations to meet demand and need – organisations also face the real risk of advocacy workers burning out and being affected by vicarious trauma and limited job security.

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.

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 of supporting communities located across vast distances. For example, in the Northern Territory, the current total disability advocacy funding pool allows for approximately three full time independent disability advocates for the entire jurisdiction. This funding is split between several 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.

As noted in the issues paper, the fixed-term nature of funding for specific purposes or projects (like the Disability Royal Commission,[[60]](#footnote-61) or Information Linkages and Capacity building[[61]](#footnote-62)) often results in expertise, skills and experience being frequently lost from the advocacy sector when contracts end. Even when there are late extensions or renewals of funding, staff may have already moved on due to lack of certainty.

It is very challenging for the disability advocacy sector to attract, develop and retain leaders and staff when funding is inadequate and insecure. Across the disability advocacy sector, increased advocacy staff resourcing and support would enhance staff retention and prevent staff strain, burnout and vicarious trauma.[[62]](#footnote-63) This would enable organisations to build up expertise and skills and allow for improved development and support of staff, including people with disability with leadership potential,[[63]](#footnote-64) young people with disability,[[64]](#footnote-65) and women, girls, feminine identifying and non-binary people with disability.[[65]](#footnote-66) Inclusive workplace cultures foster stronger team performance and wellbeing,[[66]](#footnote-67) and organisational staffing should ideally reflect the diversity and intersectional identities of the communities they support.

## The National Centre for Disability Advocacy

Relevant to the topic of staff development and support in the disability advocacy sector is the establishment of the National Centre for Disability Advocacy (NCDA) during the last couple of years. This is an initiative of DANA, funded by the Department of Social Services. The aim is to improve access to and quality of the independent disability advocacy sector with a focus on the National Disability Advocacy Program (NDAP) funded organisations. The NCDA has three core functions.

* Capacity building
* Identifying and addressing unmet demand and unmet need
* Identifying and elevating systemic advocacy issues

When the NCDA received funding in 2022, the first task was to undertake consultations in each jurisdiction to find out how the NCDA could assist the advocacy sector. Online and face-to-face consultation forums were held between October 2022 to February 2023, with 140 people and 52 advocacy organisations participating. A consistent theme received in the consultations, was a need for the sector to receive training and resources that would enable advocates and managers to undertake good practice. The team’s first focus was to coordinate a program of activities that would deliver advocacy support, resources and capacity building for the sector.

An expansion of funding for the National Centre for Disability Advocacy, to work in collaboration with relevant organisations and agencies to develop and deliver training and workforce development would have a number of benefits:

* Improved collaboration on workforce training and development and stronger information sharing networks enable:
* increased sharing of professional expertise across the disability advocacy sector
* more training opportunities equip advocates to better meet the needs of people with disability
* stronger disability advocacy networks and communities of practice to draw on collective skills, knowledge and expertise and disseminate knowledge and evidence nationally.

A broader ambit to support organisations that are not currently funded through NDAP, would also be beneficial, to ensure efforts towards sector development and consistency are directed and shared across the whole sector, regardless of the source of funding.

There is also a need for increased technological skills and experience, and as discussed above in Section 3, outcomes measurement and data analysis expertise in the sector. There are potential solutions to address these gaps through the sharing of data specialists between organisations or equipping DANA or the NCDA with a team of data specialists to conduct some of this work for organisations, especially smaller ones.

# 8.Government funding, contracting and tendering

## Funding and contracting principles

Many of the same principles that we discussed in our recent submission are relevant when discussing the role that government plays when funding services.[[67]](#footnote-68) Some of the relevant recommendations included:

* That grants cover operational and administrative costs of service delivery.
* 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.
* That reporting processes be co-designed with people with disability.
* That compliance costs are fully funded.
* That grant periods for core advocacy operations be extended to a default position of three to five years, except in exceptional circumstances.
* That grant funding be extended to a greater diversity of advocacy and community sector organisations.
* That a dedicated funding round focused on supporting smaller and at-risk advocacy organisations and ensuring continuity of advocacy services be established.
* That funding for a greater diversity of does not come at the expense of the sustainability of existing organisations, or the disability sector itself.
* That place-based reforms understand and include the vital role of independent disability advocacy organisations to connect with people with disability.

While most of these recommendations were in the context of the National Disability Advocacy Program, the more general principles are relevant to the not-for-profit sector. organisations are most effective when grants are provided for longer periods and have clear and accounted standards for the type of information that they need to gather. This approach serves a number of purposes discussed in this paper, including providing for appropriate time for skill and expertise to develop, building institutional and systemic knowledge to feedback to decision makers, as well as suitable to get programs and procedures up and running effectively.

More relevantly to other areas discussed in this paper, government bodies should consider the particular costs that arise from things like data analytics and collection when designing programs. The institutional value and strength of the government as a funding body is unique in their ability to co-ordinate and consolidate funding in this way, and we would encourage those departments to consider how best to use that power when making funding decisions. Additionally, given the extra focus on integrating data and outcome analysis in the work of not-for-profit organisations, consideration should be given on how those organisations can employ or commission that expertise and appropriately integrate them into their work when building cost models for programs.

## Data and collaboration

Provided data and feedback is accurate, relevant to program needs and not an additional barrier to implementing those services, using that data to determine effective programs and what is working best in the scheme is highly beneficial to ensuring public funds are used appropriately and responsibly. It is also important to resist efforts against consolidation as a means of efficiency – a great part of many disability organisations is their very close connection to the community. This proximity is usually because they are relatively small, and only operate in a small area. Whatever the approach is going forward, preserving the ability for local grassroots organisations to participate in tendering and contracting processes with government is crucial to effective services.

That said, given the difficulty experienced by many disability related not-for-profit organisations, it is hard to imagine how effective competition can drive things forward when the provision of services is often marginal and leaves substantial unmet need.[[68]](#footnote-69) Collaboration is a hallmark of the disability advocacy sector, with advocates working together across states, and across the country, to ensure that people with disability have access to the best support and information.

# 9. Information technology, communication and marketing

The disability advocacy sector is not currently resourced for maintaining up-to-date infrastructure and systems, with (generally) the smaller organisations being poorly equipped in terms of communications and information technology. We have previously outlined that “current funding only provides for limited disability advocacy hours with no component for developing organisational systems to improve efficiency, client management, consistent data collection, storage and analysis.”[[69]](#footnote-70)

As is discussed elsewhere in our submission, the need for a clear and integrated system of data reporting is clear. This could extend across a number of different areas, but of primary concern for the disability advocacy sector is joining up different reporting mechanisms between funding bodies where possible, ensuring that the data collected is fed back into the community and has clear purposes and standards, providing resources to work with experienced data analysis personnel when receiving grants, as well as exploring options with the sector about integrating effective and efficient reporting systems within popular Content Management Systems and client databases.

# 10.Leveraging assets and social finance

The models of financing detailed in the discussion paper are common experiences for many organisations working in the advocacy sector. Bar a few examples of organisations which have some measure of land-holdings or other substantial assets, many organisations operate on a rolling basis between funding agreements, grants, and the variable costs of leases and other expenses. As such, there is a limited amount of insight DANA can offer on these issues but note the positive need for re-thinking the use of such assets. The primary concern of many organisations is the limited support and funds available to address community needs generally, and that more direct investment is the simpler and more productive pathway to enabling organisations of all sizes to continue doing good work.

1. Daly A, Barrett G & Williams R (2017), Cost Benefit Analysis of Australian independent disability advocacy agencies, Canberra: Disability Advocacy Network Australia. [↑](#footnote-ref-2)
2. See Appendix B, Every Australian Counts and Disability Advocacy Network Australia, (2022) ‘Unreasonable and unnecessary’: How the NDIS and the people who represent it could immediately improve the experiences of people with disability and supporters by meeting their model litigant obligations, [↑](#footnote-ref-3)
3. Disability Advocacy Network Australia (2023) [A strong sustainable future: addressing capacity shortfalls for a strengthened disability advocacy sector](https://www.dana.org.au/wp-content/uploads/2023/11/Pre-Budget-Submission-from-the-Disability-Advocacy-Sector_14-Nov-2023.pdf). [↑](#footnote-ref-4)
4. See Recommendation 6.23, Royal Commission into Violence, Abuse, Neglect and Exploitation (2023) [Final Report – Volume 6: Enabling autonomy and access](https://disability.royalcommission.gov.au/publications/final-report-volume-6-enabling-autonomy-and-access), pp293-301; [Royal Commission: Analysing the recommendations on independent disability advocacy;](https://www.dana.org.au/royal-commission-analysing-the-recommendations-about-independent-disability-advocacy/) During the Disability Royal Commission First Peoples Disability Network (FPDN) were funded to deliver “Disability Business Training” to organisations funded through the National Disability Advocacy Program: [Disability Business Training - FPDN](https://fpdn.org.au/disabilitybusinesstraining/). [↑](#footnote-ref-5)
5. [Child Safe Organisations Project Report - CYDA](https://cyda.org.au/child-safe-organisations-project-report/). [↑](#footnote-ref-6)
6. Dr Cathy Kezelman AM and Julie Dombrowski (2021) [Disability Guidelines for Trauma-Informed Practice – Supporting people with disability who have experienced complex trauma](https://blueknot.org.au/resources/news/disability-guidelines/), Blue Knot Foundation. [↑](#footnote-ref-7)
7. Disability Advocacy Network Australia (2023) [A strong sustainable future: addressing capacity shortfalls for a strengthened disability advocacy sector](https://www.dana.org.au/wp-content/uploads/2023/11/Pre-Budget-Submission-from-the-Disability-Advocacy-Sector_14-Nov-2023.pdf). [↑](#footnote-ref-8)
8. Disability Advocacy Network Australia (2022) [Independent disability advocacy – DANA submission to the Disability Royal Commission](https://www.dana.org.au/advocacy-sub-to-drc/); Disability Advocacy Network Australia (2022) [Submission on the National Disability Advocacy Framework](https://www.dana.org.au/ndafsub/) [↑](#footnote-ref-9)
9. Disability Advocacy Network Australia (2023) [A strong sustainable future: addressing capacity shortfalls for a strengthened disability advocacy sector](https://www.dana.org.au/wp-content/uploads/2023/11/Pre-Budget-Submission-from-the-Disability-Advocacy-Sector_14-Nov-2023.pdf). [↑](#footnote-ref-10)
10. Disability Advocacy Resource Unit (2017) [Disability Advocacy By The Numbers: Statistics form July 2012 to June 2016](https://www.daru.org.au/disability-advocacy-by-the-numbers-data-integrity-supplementary-report), Victorian Office for Disability Advocacy Program Quarterly Data Collection and Data Integrity Supplementary Report. [↑](#footnote-ref-11)
11. See explanation of the six models of advocacy: [What is advocacy? - Disability Advocacy Network Australia (dana.org.au)](https://www.dana.org.au/how-to-advocate/) [↑](#footnote-ref-12)
12. Bodille Arensman, (2020) Advocacy Outcomes Are Not Self-Evident: The Quest for Outcome Identification, *American Journal of Evaluation* 41 (2) pp216-233. [↑](#footnote-ref-13)
13. Social Ventures Australia and the Centre for Social Impact (2022) *Paying what it takes: funding indirect cost to create long-term impact.* Social Ventures Australia., page 34. [↑](#footnote-ref-14)
14. Disability Advocacy Network Australia (2022) [Submission on the National Disability Advocacy Framework](https://www.dana.org.au/ndafsub/) [↑](#footnote-ref-15)
15. For instance the National Disability Insurance Scheme Act: The “role of advocacy in representing the interests of people with disability is to be acknowledged and respected, recognising that advocacy supports people with disability by: (a) promoting their independence and social and economic participation; and (b) promoting choice and control in the pursuit of their goals and the planning and delivery of their supports; and (c) maximising independent lifestyles of people with disability and their full inclusion in the community.” Section 4, Subsection 13. [↑](#footnote-ref-16)
16. For example, under Australia’s Disability Strategy 2021-2031: Safety Targeted Action Plan, Action 3.3 on p9, and Action 5.3 on p11. See [Safety Targeted Action Plan | Disability Gateway](https://www.disabilitygateway.gov.au/document/3176) [↑](#footnote-ref-17)
17. See list of previous recommendations in Attachment E, Disability Advocacy Network Australia (2022) [Independent disability advocacy – DANA submission to the Disability Royal Commission](https://www.dana.org.au/advocacy-sub-to-drc/) [↑](#footnote-ref-18)
18. See media release: [Free counselling, advocacy and legal support critical to supporting people with disability - National Legal Aid](https://www.nationallegalaid.org/resources/media-ysdls/) and ABC radio story: [Advocates concerned as funding for support services set up during Disability Royal Commission set to end - ABC listen](https://www.abc.net.au/listen/programs/am/concern-funding-disability-royal-commission-set-to-end/102222300). [↑](#footnote-ref-19)
19. Joint Standing Committee on the National Disability Insurance Scheme, Parliament of Australia (2020a) op. cit. pp xxii, 134-141. [↑](#footnote-ref-20)
20. NDIS Review Panel (2023) Working together to deliver the NDIS – Independent Review in the National Disability Insurance Scheme, p57. [↑](#footnote-ref-21)
21. [National Strategy for Volunteering 2023-2033](https://www.volunteeringaustralia.org/wp-content/uploads/National-Strategy-for-Volunteering-2023-2033.pdf), pp58-59. [↑](#footnote-ref-22)
22. See [Meeting of National Cabinet – the Federation working for Australia | Prime Minister of Australia (pm.gov.au)](https://www.pm.gov.au/media/meeting-national-cabinet-federation-working-australia) [↑](#footnote-ref-23)
23. NDIS Review Panel (2023) Working together to deliver the NDIS – Independent Review in the National Disability Insurance Scheme, p61. [↑](#footnote-ref-24)
24. Disability Services and Inclusion Bill 2023 (for the Community Affairs Legislation Committee) September 2023 – See “Endorsed and Joint Submissions” section of our [Submissions](https://www.dana.org.au/current-work/our-submissions/) page. [↑](#footnote-ref-25)
25. See discussion of “gag clauses” under previous Australian governments: Gemma Edgar (2008) Agreeing to Disagree: Maintaining dissent in the NGO sector, The Australia Institute. [↑](#footnote-ref-26)
26. [Not-For-Proft Sector Freedom to Advocate Act 2013](https://www.legislation.gov.au/Details/C2013A00056) (Cth). [↑](#footnote-ref-27)
27. See discussion of co-design and best practice principles for involving people with disability in evaluation in [CYDA's response to the consultation papers for Australia's Disability Strategy: A Guide to the Guiding Principles and A Guide to involving people with disability in evaluation - CYDA](https://cyda.org.au/cydas-response-to-the-consultation-papers-for-australias-disability-strategy-a-guide-to-the-guiding-principles-and-a-guide-to-involving-people-with-disability-in-evaluation/), pp20-24. [↑](#footnote-ref-28)
28. Disability Advocacy Network Australia (2023) [A stronger, more diverse and independent community sector](https://www.dana.org.au/wp-content/uploads/2023/11/A-stronger-more-diverse-and-independent-community-sector-Submission-DANA.pdf). [↑](#footnote-ref-29)
29. Inclusion Australia (2023) [Submission to the Department of Social Services re: A Stronger, More Diverse and Independent Community Sector](https://www.inclusionaustralia.org.au/submission/a-stronger-more-diverse-and-independent-community-sector/): *Recommendation 1*: Place people and communities who use community services at the centre of all planning, design, management and governance of the community sector, *Recommendation 2*: Remunerate and sustainably resources community sector organisations for ongoing engagement on public advisory groups, bodies and other authorities, and properly acknowledge and value expertise and capabilities [↑](#footnote-ref-30)
30. Women With Disabilities Australia (2023) Response to the ‘A stronger, more diverse and independent community sector’ issues paper. [↑](#footnote-ref-31)
31. See [National Coordination Function (NCF) - Disability Advocacy Network Australia (dana.org.au)](https://www.dana.org.au/current-work/national-coordination-function-ncf/) [↑](#footnote-ref-32)
32. See for example: [A New Act to Replace the Disability Services Act 1986: A joint submission from Disability Representative Organisations](https://www.dana.org.au/a-new-act/) (February 2023) and [Draft National Strategy for the Care and Support Economy – A joint submission from Disability Representative Organisations](https://www.dana.org.au/wp-content/uploads/2023/09/230626-Draft-National-Strategy-for-the-Care-and-Support-Economy-Joint-submission-final-for-submission.pdf) (June 2023) [↑](#footnote-ref-33)
33. Jennifer Smith-Merry (2020) Evidence-based policy, knowledge from experience and validity., *Evidence & Policy*, vol 16, no 2, 305–316; Laufey Love, Rannveig Traustadottir, Gerard Quinn and James Rice (2017) ‘The Inclusion of the Lived Experience of Disability in Policymaking’, *Laws:* 6 (33). Patsie Frawley & Christina Bigby (2011) ‘Inclusion in political and public life: The experiences of people with intellectual disability on government disability advisory bodies in Australia’, in *Journal of Intellectual and Developmental Disability*, 36:1, 27-38. [↑](#footnote-ref-34)
34. Disability Advocacy Network Australia (2022) [Independent disability advocacy – DANA submission to the Disability Royal Commission](https://www.dana.org.au/advocacy-sub-to-drc/), pp29-30. [↑](#footnote-ref-35)
35. Jan Idle, Gianfranco Giuntoli, Karen Fisher, Sally Robinson, Christiane Purcal, Christy Newman, Kathleen Reedy (2022) *Research Report – Changing community attitudes to improve inclusion of people with disability.* Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability, University of New South Wales, pp53-58. [↑](#footnote-ref-36)
36. See training and resources from Voice At The Table project: [Voice at the Table - State Government funded training with resources for Government and Peer Advisors](https://voiceatthetable.com.au/) [↑](#footnote-ref-37)
37. See the NDRP commitment to inclusive research discussed: University of Melbourne (2022). [National Disability Research Partnership, Learnings and Recommendations](https://www.ndrp.org.au/post/a-step-closer-to-inclusive-disability-research), pp20-35. [↑](#footnote-ref-38)
38. See resources: [Engagement and consultation with people with an intellectual disability – Inclusion Australia](https://www.inclusionaustralia.org.au/resource/engagement-and-consultation-with-people-with-an-intellectual-disability/) [↑](#footnote-ref-39)
39. See resources: [Inclusive Volunteering Program - VolunteeringACT](https://www.volunteeringact.org.au/services/inclusive-volunteering-program/); [Inclusive Volunteering Pathways to Employment Program - The Centre for Volunteering](https://www.volunteering.com.au/join-us/inclusive-volunteering-pathways-to-employment-program/); [Building an inclusive volunteer program - Volunteering Victoria](https://www.volunteeringvictoria.org.au/leading-volunteers/building-an-inclusive-volunteer-program/); [Inclusive Volunteering - Volunteering Tasmania](https://volunteeringtas.org.au/for-volunteers/inclusive-volunteering/) [↑](#footnote-ref-40)
40. For example, Intellectual Disability Rights Service [About Justice Advocacy Service (JAS) - IDRS](https://idrs.org.au/jas/about-jas/), and TAD ACT. [↑](#footnote-ref-41)
41. Disability Advocacy Network Australia (2022) [Rights, Safety and Quality – Voices of advocacy – Submission to the Disability Royal Commission](https://www.dana.org.au/rights-safety-quality/). See discussions in Section 5 and Section 10. [↑](#footnote-ref-42)
42. See further information on Citizen Advocacy Trust of Australia website:[What is Citizen Advocacy? - Citizen Advocacy Trust of Australia](https://citizenadvocacytrust.com.au/what-is-citizen-advocacy/) [↑](#footnote-ref-43)
43. Social role valorization (SRV) is a relationship theory of empirical knowledge for the design and rendering of formal and informal services and relationships to people with any need or condition, especially those who are devalued or are at risk. This theory often informs the activities, training and projects of Citizen Advocacy organisations and also some family advocacy organisations, see e.g. [Roles-Based Recruitment | A Resource About Support (imaginemore.org.au)](https://imaginemore.org.au/resources/support/roles-based-recruitment/) [↑](#footnote-ref-44)
44. The 2022 ANUpoll survey and the 2019 and 2020 General Social Surveys all indicate that people with disability volunteer at a similar rate to the general population of Australia. See [National Strategy for Volunteering 2023-2033](https://www.volunteeringaustralia.org/wp-content/uploads/National-Strategy-for-Volunteering-2023-2033.pdf), p65. [↑](#footnote-ref-45)
45. Draft National Strategy for the Care and Support Economy – A joint submission from Disability Representative Organisations (June 2023) - See Endorsed and Joint Submissions: [Submissions - Disability Advocacy Network Australia (dana.org.au)](https://www.dana.org.au/current-work/our-submissions/) [↑](#footnote-ref-46)
46. This is recognised by the [National Strategy for Volunteering 2023-2033](https://www.volunteeringaustralia.org/wp-content/uploads/National-Strategy-for-Volunteering-2023-2033.pdf), p44. [↑](#footnote-ref-47)
47. Productivity Commission (2023) [Philanthropy and the role of government – Draft Report](https://www.pc.gov.au/inquiries/current/philanthropy/draft), see Recommendation 10.1, p335. [↑](#footnote-ref-48)
48. The Achieve Foundation and the Australian Centre for Philanthropy and Nonprofit Studies (2021) [Disability philanthropy in Australia – The case of the Missing Foundations](https://www.theachievefoundation.org.au/resources/philanthropy-for-people-with-disability); Williamson, A. and C. Parker. 2021. [Philanthropy for people with disability in Australia: Actors and insights](https://eprints.qut.edu.au/227152/1/Philanthropy_for_People_wiith_Disability_ACPNS_Report_2021.pdf). Brisbane: Australian Centre for Philanthropy and Nonprofit Studies (ACPNS), Queensland University of Technology. [↑](#footnote-ref-49)
49. Philanthropy Australia (2018) [The Power of Advocacy: Making the Case for Philanthropic Support for Advocacy](https://apo.org.au/node/132686), pp2, 10. [↑](#footnote-ref-50)
50. United Nations Special Rapporteur on the rights of persons with disabilities, delivered to Human Rights Council at its 31st Session, 4 March 2016: [OHCHR | A/HRC/31/62: *Report on the rights of persons with* *disabilities to participate in decision-making*](https://www.ohchr.org/en/documents/thematic-reports/ahrc3162-report-rights-persons-disabilities-participate-decision-making), pp8-22; Damian Mellifont and Jennifer Smith-Merry (2016) ‘Laying or delaying the groundwork? A critical framing analysis of Australia’s National Disability Strategy from an implementation planning perspective’, *Disability & Society*, 31:7, 929-94; Jan Idle, Gianfranco Giuntoli, Karen Fisher, Sally Robinson, Christiane Purcal, Christy Newman, Kathleen Reedy (2022) *Research Report – Changing community attitudes to improve inclusion of people with disability.* Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability, University of New South Wales, pp53-58. [↑](#footnote-ref-51)
51. Patsie Frawley and Christina Bigby (2011) ‘Inclusion in political and public life: The experiences of people with intellectual disability on government disability advisory bodies in Australia’, in *Journal of Intellectual and Developmental Disability*, 36:1, 27-38; Diane Craig and Christine Bigby (2015) “She's been involved in everything as far as I can see”: Supporting the active participation of people with intellectual disability in community groups, *Journal of Intellectual and Developmental Disability*, 40:1, 12-25; Laufey Love, Rannveig Traustadottir, Gerard Quinn and James Rice (2017) ‘The Inclusion of the Lived Experience of Disability in Policymaking’, *Laws:* 6 (33). [↑](#footnote-ref-52)
52. Inclusion Australia has produced a number of useful resources for Service Providers as part of their [Your Service Your Rights](https://www.inclusionaustralia.org.au/project/your-service-your-rights/) project, including a guide for [Setting up an Advisory Group in Your Service](https://www.inclusionaustralia.org.au/wp-content/uploads/2022/06/YSYR-Advisory-Group-Guide_FINAL.pdf) and for including people with an intellectual disability in the audit process. [↑](#footnote-ref-53)
53. A Disabled People’s Organisation is an organisation that is controlled by people with disability (at least 51% people with disability at the board and membership levels). A DPO is different to other disability sector organisations because it is ‘for us, by us’. See [Disabled People’s Organisations - People with Disability Australia (pwd.org.au)](https://pwd.org.au/about-us/about-disability/disabled-peoples-organisations/) [↑](#footnote-ref-54)
54. Jan Idle, Gianfranco Giuntoli, Karen Fisher, Sally Robinson, Christiane Purcal, Christy Newman, Kathleen Reedy (2022) *Research Report – Changing community attitudes to improve inclusion of people with disability.* Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability, University of New South Wales, pp53-58. [↑](#footnote-ref-55)
55. Disability Advocacy Network Australia (2023) [A stronger, more diverse and independent community sector](https://www.dana.org.au/wp-content/uploads/2023/11/A-stronger-more-diverse-and-independent-community-sector-Submission-DANA.pdf), p5. [↑](#footnote-ref-56)
56. Disability Advocacy Network Australia (2022) [Independent disability advocacy – DANA submission to the Disability Royal Commission](https://www.dana.org.au/advocacy-sub-to-drc/) [↑](#footnote-ref-57)
57. See [Housing data dashboard](https://www.housingdata.gov.au/) – Australian Government, Australian Institute of Health and Welfare. [↑](#footnote-ref-58)
58. Royal Commission into Violence Abuse, Neglect and Exploitation against People with Disability - Transcripts, Fiona Downing, Public Hearing 5, 18 August 2020, p69; Kirsten Deane, Public hearing 5, 19 August 2020, p141. Eleanor Gibbs, Public hearing 5, 18 August 2020, p71. [↑](#footnote-ref-59)
59. Natasha Cortis, and Megan Blaxland, (2022) Carrying the costs of the crisis: Australia’s community sector through the Delta outbreak. Sydney: ACOSS, p12, 54, and 57; Megan Blaxland, and Natasha Cortis, (2021) Valuing Australia’s community sector: Better contracting for capacity, sustainability and impact. Sydney: ACOSS, 23-25; Natasha Cortis, & Megan Blaxland (2020): Australia’s community sector and COVID-19: Supporting communities through the crisis. Sydney: ACOSS, 71; and The XFactor Collective (2020) RESET 2020 – National Impact and Need Research Study – Phase 2 – September 2020 Survey Interval, p9,10, 32-33, 39 and 47. [↑](#footnote-ref-60)
60. See January 2023 submission on the discontinuation of funding: [DANA and AFDO call for continuity of funding in short Pre-Budget Submission - Disability Advocacy Network Australia](https://www.dana.org.au/pre-budget-23-24/) [↑](#footnote-ref-61)
61. Wilson, E., Qian-Khoo, J., Campain, R., Brown, C., Kelly, J. & Kamstra, P. (2021). Overview of results: Informing investment design, ILC Research Activity, Hawthorn: Centre for Social Impact, Swinburne University of Technology, pp46-47. [↑](#footnote-ref-62)
62. The [Best Practice in Disability Advocacy course](https://www.daru.org.au/course/best-practice-in-disability-advocacy) created by Disability Advocacy Resource Unit (DARU) in Victoria recognises that *“advocates can be highly susceptible to burnout and vicarious trauma.”* The final module focuses on “Self Care”; The DARU 2019 Strengthening Disability Advocacy Conference included a facilitated workshop focused on the issues of managing overwhelming workloads: [*A Sector at Capacity: Burnout, organisational change and adapting in the face of adversity.*](https://www.daru.org.au/conference-session/a-sector-at-capacity-burnout-organisational-change-and-adapting-in-the-face-of-adversity) Natasha Cortis, and Megan Blaxland, (2022) *Carrying the costs of the crisis: Australia’s community sector through the Delta outbreak*. Sydney: ACOSS. InSync Surveys (2014) *Employee retention in community services organisations*, accessed 6 December 2022. [↑](#footnote-ref-63)
63. See [Disability Leadership Institute | Develop Your People](https://disabilityleaders.com.au/organisations/develop-your-people/) and [Building diversity and inclusion - Diversity Council Australia (dca.org.au)](https://www.dca.org.au/research/building-inclusion-evidence-based-model-inclusive-leadership). [↑](#footnote-ref-64)
64. For instance, there are a range of leadership programs and training for young people with disability including: [Young Leaders Program - CYDA](https://cyda.org.au/youth-hub/young-leaders/), [Youth Disablity Advocacy Service | Young Leaders Program (yacvic.org.au)](https://www.yacvic.org.au/ydas/get-involved/youngleaders/) and [WWDA Youth Network - Women With Disabilities Australia](https://wwda.org.au/campaign/wwda-youth/). [↑](#footnote-ref-65)
65. [Lead . Engage . Activate . Drive - Women With Disabilities Australia (wwda.org.au)](https://wwda.org.au/project/lead/) [↑](#footnote-ref-66)
66. [The Case for Inclusion@Work - Diversity Council Australia (dca.org.au)](https://www.dca.org.au/research/case-for-inclusion-at-work) [↑](#footnote-ref-67)
67. Disability Advocacy Network Australia (2023) [A stronger, more diverse and independent community sector](https://www.dana.org.au/wp-content/uploads/2023/11/A-stronger-more-diverse-and-independent-community-sector-Submission-DANA.pdf). [↑](#footnote-ref-68)
68. Disability Advocacy Network Australia (2023) [A strong sustainable future: addressing capacity shortfalls for a strengthened disability advocacy sector](https://www.dana.org.au/wp-content/uploads/2023/11/Pre-Budget-Submission-from-the-Disability-Advocacy-Sector_14-Nov-2023.pdf). [↑](#footnote-ref-69)
69. Disability Advocacy Network Australia (2022) [Independent disability advocacy – DANA submission to the Disability Royal Commission](https://www.dana.org.au/advocacy-sub-to-drc/). [↑](#footnote-ref-70)