### **Submission**

# Invest in the experts: ensuring sustainable advocacy funding for specialist NDIS advocacy work



#### Introduction

Independent disability advocacy has always been a critical part of the disability services ecosystem. Advocates, as independent supporters of people with disability, act in the interests of the person with disability and have no connection to government, the NDIA, or to disability service providers, creating a genuine service committed to upholding individual human rights. The advocacy ecosystem involves many different advocacy roles: advocacy at individual, peer, systemic, family, legal and citizen levels all have an impact on wellbeing and outcomes for people with disability.

Under the NDIS, the advocacy workload has increased significantly. Currently, funding for independent disability advocacy work is provided by the Department of Social Services (DSS), as well as state and territory governments. As the NDIS has rolled out across Australia, advocates have begun to take on more specialist advocacy work, developing NDIS-specific knowledge and processes to support people with disability to navigate deeply complex systems, new terms and language, and complicated review and appeal processes, as well as taking on knowledge sharing and change management roles as needed.

People with disability who use the NDIS often also interact with, and need advocacy about other public services, delivered from various governments. The variety of funding reflects the diversity of systems that any one person with disability will encounter, and are best served by advocacy that supports that diversity.

In this submission, we ask the NDIA to acknowledge the advocacy load the NDIS is putting on independent disability advocacy. We also ask for a significant increase in funding to reflect the complexity of this work, along with meeting the increased demand for independent advocacy.

## What are the problems?

# The NDIS has drastically increased the workload of all advocates

Specialist NDIS advocacy has created a whole new layer of expertise required in the advocacy space. Over time, the Scheme has defined its own processes, language, and expectations of people using the NDIS. As the Scheme evolves and changes are made, advocates need to continuously learn about changes to systems, processes, rules and funding usage. Independent disability advocates regularly interpret and disseminate complex information about Scheme changes in accessible and real-world formats, both individually and on a systemic level, and are valuable change management experts for the NDIS as a result.

People with disability and their families also need independent advocacy support to navigate the NDIS. This advocacy workload can begin before a person applies for or enters the Scheme. It is critical that advocacy support is available for those who need it to learn about and access the Scheme, before, during and after engaging with the NDIA and with disability service providers. For people with disability who experience significant and multiple marginalisation, including people who are refugees, people who have been incarcerated or interacted with the justice system, and First Nations people with disability, advocates often play a critical role in providing information about the Scheme, navigating complex systems and environments, supporting evidence gathering and helping to organise Scheme access. This work is often only being done by independent disability advocates and without it, some people with disability may never be able to access or navigate the Scheme, missing out on much needed support.

Across systemic expertise, entering the Scheme, utilising the Scheme, and addressing risks or complaints, advocates take on a wide variety of advocacy roles to ensure the Scheme works well. NDIS-specific advocacy support provided by advocacy organisations includes:

#### Support for Scheme entry:

- NDIS introduction: Understand the NDIS and what support is possible
- Knowledge of supports outside the NDIS: Knowledge of other disability supports available, potentially diverting potential participants from the Scheme if their needs are met elsewhere
- Eligibility expertise: Understand specific eligibility and disability requirements
- Application and evidence support: support to gather evidence and fill in access request documentation
- Follow-up application support: Managing internal and external reviews, appeals and further evidence requirements, including support with complex legal processes

 Outreach and connection: Connecting people who experience multiple or significant marginalisation to the Scheme

#### Support while in the Scheme:

- Supporting choice and control: Support people with disability to exercise choice and control with providers, support coordinators and other NDIS supports
- NDIS update management: Ensuring changes to NDIS structure, payments, or reporting are understood
- **Knowledge translation:** Sharing information on operational changes in the Scheme and how they impact on people with disability
- Connection to safeguards: Facilitate access to mainstream safeguarding systems, like the police
- Supporting decision making: Ensures people have access to independent decision support and facilitate involvement of other decision supporters, independent from disability service providers and the NDIA, and instead of substitute decision making
- Managing potential safeguarding conflict: The limited flexibility of NDIS
  funding may divert participants away from natural safeguards, such as trusted
  communities, friends and family, and towards services i advocates can and
  do act to help manage these complex relationships, but the system cannot
  depend on advocates to be the eyes and ears of safeguarding alone
- Disaster support: managing inaccessible disaster information, ensuring continuity of supports, and escalating emergency support needs
- Managing thin market issues: Thin markets can limit access to high-quality and safe services, and render a single service provider responsible for multiple supports - advocates help manage these conflicts and ensure appropriate service delivery
- Human rights education: Provide information and understanding of human rights to inform NDIS engagement for people with disability and disability service providers
- Citizen and Consumer advocacy: Engaging in preventative support and empowering people with disability as citizens and consumers - work within the NDIS Commission's remit but is not currently being undertaken by the Commission
- Independent NDIS advocacy: Providing impartial support for people who may not have access to natural safeguards
- **Specialist advocacy work:** Specialised support with specialised knowledge about specific types of advocacy
- Specialist knowledge: Knowledge of, and connection to, specific types of services and supports for people with disability who experience multiple marginalisation

Supporting safety and addressing concerns:

- Managing risk and harm: Working with people with disability when providers do the wrong thing
- **Complaints management:** Support to make and escalate complaints and understand complaint processes
- **Dispute resolution:** Supporting dispute processes between providers and people with disability
- NDIS decision review support: ensuring people with disability can access reviews of decisions and navigate review processes
- Navigation of appeals and escalation: Providing support to appeal decisions and escalate to the Administrative Appeals Tribunal if required
- Legal specialist expertise: Legal advocacy support and other specialist advocacy expertise relevant to NDIS experiences

Systemic expertise and advocacy:

- Market stewards: Through information provision, one-on-one advocacy, peer support, and systemic advocacy, advocacy groups act as market stewards of the NDIS, facilitating its functioning
- **Systemic advocacy:** Advocates also play a critical role in providing informed and expert advice to government on the NDIS
- Change management: Advocates work to stay up to date on Scheme changes through continuous education, in order to process and respond to Scheme changes, providing valuable interpretation and dissemination of new change and materials

NDIS-specific advocacy support generally does not replace or negate any non-NDIS advocacy support that is needed. Currently, the NDIS accounts for approximately 50% of the advocacy workload across all types of advocacy. DANA research has shown significant unmet advocacy demand, which is widespread across the sector. This means the non-NDIS and NDIS advocacy workloads can be in direct competition, and as workload has increased over time, independent advocates and advocacy organisations must choose which work to prioritise.

It is important to note that most advocacy organisations are aware of a significant population of very marginalised people with disability in their communities who need a great deal of support to access the NDIS. However, the proactive outreach to ensure people with disability are informed about and accessing the NDIS is not available or funded.

While the recent funding increase for appeals is a good start, and brought the total funding closer to the previous peak level, it is only one part of the NDIS advocacy landscape. This funding injection, while welcome, does not recognise the wider NDIS advocacy workload being taken on by independent advocates, which spans much more than just appeals. It also does not recognise the amount of (frequently unpaid)

NDIS-related labour that is now falling on independent advocates and advocacy organisations across Australia.

# Case study: People from refugee backgrounds accessing support for the first time

AMPARO Advocacy first started working with a woman (AA), who is deaf and of Afghan origin to provide advocacy in September 2019. She had only been living in Australia for 6 months and did not speak English and had no pre-existing language, apart from some limited sign language that she had developed with her family, which is not recognized outside of the family home. The women's mother and siblings had been living in Australia for five years before she came to Australia, and her mother had limited English language skills. The family had several barriers which resulted in them needing individual advocacy support to effectively access the NDIS, including:

- 1. No evidence of diagnosis
- 2. Lack of understanding of complex service systems here in Australia
- 3. No knowledge of the rights of persons with disability in regard to the NDIS
- 4. No language and means of communicating for the person with the disability and,
- 5. A need for good interpreters for the family to help them to understand our systems as well as a deaf relay interpreter for AA

Initially the advocate supported AA to access services from Hearing Australia; in order to provide evidence of disability to the NDIS and to assist AA to receive hearing aids. Independent advocacy has meant that AA was successful in accessing the NDIS and for the first time in her life she has received supports for her disability.

Prior to receiving NDIS supports, AA spent her time at home and isolated and this was affecting her mental health. The advocate supported her and her family with preplanning, at the planning meeting and then to understand her NDIS plan and access appropriate services. The advocate worked with the family to help them to understand their rights in relation to the NDIS.

There were some unacceptable practices by the Support Worker service and the advocate supported the family to understand that they had the right to find an alternative service, which they did.

Unfortunately, despite advocacy and AMPARO® involvement, the first NDIS Plan was inadequate for a person who has never received supports for their disability before and had no pre-existing language. The advocate worked with the family and Support Coordinator to lodge a review of reviewable decisions with the NDIS for more funding. The outcome of this review was very positive and as a result AA received twice as much funding in her new NDIS. This meant that AA was now able to start learning Auslan with the help of Deaf services, which means she will now be able to communicate with others from the Deaf Community. Her supports have also been increased so that she is able to make links with the deaf community and learn about deaf culture, an I-Pad was purchased to assist AA with learning Auslan and learning to write and also to increase her safety when out in the community. In addition to this, safety devices were purchased and installed in the family home, which included a flashing smoke alarm.

AA is making progress with her Auslan and has connected with another person from her community who is deaf, and that person is proving to be a positive support to her. AA is now able to leave her home with support to explore her community and is learning about life in Australia. This would not have been possible without the support of an advocate to help her to understand her rights and the opportunities and benefits that good support through the NDIS can provide and to effectively access the NDIS.

# Lack of funding to reflect need for independent advocacy despite NDIS workload

Currently, there is no proportionate funding to reflect the large growth in independent disability advocacy workload despite being responsible for approximately half of current advocacy caseloads (DANA Annual Report 21-22). Even with existing targets, there is still much to do: the National Disability Advocacy Program target of 75% of people reporting increased choice and control for decision making has not yet been met (DSS Annual Report 21-22). This indicates a strong need for further investment in disability advocacy to meet current needs and to future-proof existing advocacy systems.

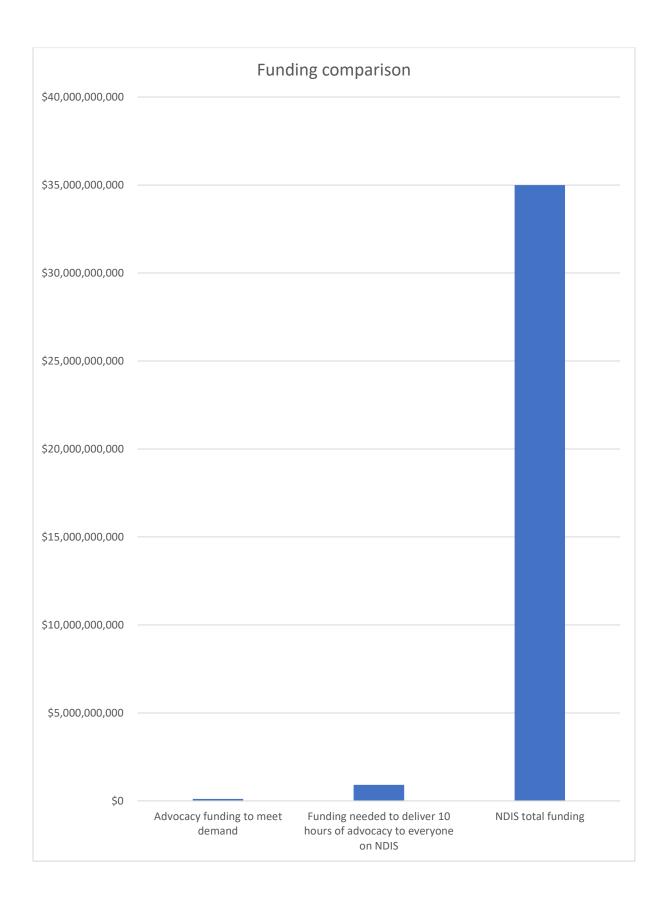
Independent disability advocacy is critical for the wellbeing and human rights of people with disability. Independent advocates take action alongside people with disability to uphold their human rights. It is critical that advocacy exists independently of the NDIA, the government, and disability service provision to be truly personcentred and effective.

Independent disability advocacy benefits people with disability, families, supporters, the disability sector, and the wider community. Advocacy, as part of the NDIS ecosystem, supports people to understand, access the Scheme, know their rights, and address serious risks, issues or crisis.

There is robust evidence supporting the economic value of independent disability advocacy. Advocacy provides a benefit-cost ratio of 3.5:1 for each dollar spent (Daly et al, 2017). A 2021 re-review concluded that the original findings were still relevant and the benefit of independent disability remains substantial, particularly in reducing unreasonable burdens on people with disability directly.

Independent disability advocates do not believe that funding should be delivered through the budgets of people with disability who use the NDIS, or directly from the NDIA. This is vital to retain the independence of advocacy and the capacity for advocates to work across the complexity of issues, including the NDIS, that impact on people with disability, and to continue to support people with disability outside the NDIS

However, the disproportionate total funding for the NDIS, compared to independent disability advocacy, creates significant challenges in supporting the vital role advocates play in the success of the NDIS. Even modelling 10 hours of advocacy for every single person with disability who uses NDIS supports (\$915m) does not come close to the total NDIS funding pool.



#### Roles in the advocacy ecosystem

The disability advocacy sector does not just include people who work directly with people with disability on specific cases (individual advocates). The ecosystem needs many roles to function well, including:

- Individual advocates work directly with people with disability to address issues in the NDIS and other public services and systems
- Systemic advocacy understands the NDIS market, its conditions, and advocates to address systemic barriers for people with disability by advancing their rights
- Peer advocacy builds the individual advocacy capacity of people with disability including to take action together
- Citizen advocacy creates advocacy support for people who may have barriers to access the NDIS and other public services, often with volunteers
- Family advocacy supports family relationships and builds the capacity of support people
- Legal advocacy helps people understand and act on their rights in the legal system

There are a range of changes coming to the NDIS, across many parts of the systems. This means that advocates across different forms of advocacy, including legal, systemic and individual advocacy, all have involvement in understanding and communicating these changes, and working through their impacts with people with disability.

Together, the different forms of advocacy address inequitable access, unfair decisions, and ensure better outcomes for people with disability. Advocacy is a key part of market stewardship: there is no other part of the NDIS ecosystem that acts independently on behalf of people with disability to uphold their rights, address injustice, and promote inclusivity and equity of opportunity. Advocacy touches every part of the NDIS landscape and is critical to delivering a safe and effective Scheme.

#### Unmet demand is significant across the sector

Current data suggests that there is approximately **twice** as much demand for advocacy in comparison to supply. A DANA survey and anecdotal reports from DANA members (the Intake Project) indicate significant unmet demand and need for advocacy around Australia. Advocacy organisations cannot service all the people seeking advocacy support with current resources; this also includes people seeking NDIS appeals advocacy, despite recent funding injections.

This is a massive shortfall with serious flow-on effects for people with disability and for mainstream systems. Needs do not disappear when they are not met; an issue left unaddressed can result in progression to crisis situations, needing higher levels of engagement and involvement from the NDIS and mainstream supports, including health, housing, welfare, and justice systems. Without adequate advocacy funding, people with disability remain at unnecessary risk.

In addition to advocacy availability, uptake is also a significant issue. We know that advocacy uptake, even in areas that have received funding injections, is not where it should be. NDIS Appeals advocacy clients stand at around 0.6% of all participants i less than the stated goal of 1% (DSS Annual Report 21-22). Many people with disability cannot access appeals due to the difficulty of the process, and the shortfall in advocacy, which the unmet demand figures reflect. While this is not a clear measure of all appeals - people may choose to go through the appeals on their own without the support of an advocate - it is still an indicator that more work is needed to ensure advocacy can be utilised by the people who need it. It is clear that increasing advocacy available is part of the solution, but awareness and education must also be provisioned as part of ongoing funding.

Advocates and organisations often prioritise by need and urgency of support required. This means acute issues are prioritised, but people with disability facing less urgent immediate issues are less likely to receive support before issues progress to crisis level. The impact of unmet disability advocacy demand is then not just felt in disability and within the NDIS, but in flow-on effects to other sectors. When advocacy need is not met, risks and issues can progress to crisis. Crisis support is then absorbed into other sectors, including health, justice, welfare, and the community sector.

To meet immediate advocacy need, disability advocacy organisations require an urgent injection of funding to allow for the hire and training of more independent advocates, to develop more training and support programs to standardise and better utilise advocacy supports in Australia, and to engage in community awareness activities to increase advocacy awareness and uptake.

# Funding continuity and stability is critical to sustain expertise

Most independent disability advocacy organisations run on a contract or limited funding based model, leading to a lack of security for employees across the sector as organisations approach the next ifunding cliffig when funding ends abruptly with no clear extension or path forward. With varying contracts and funding sources currently active, there are several expected upcoming funding cliffs in 2024-25 that leave advocacy sector employees and their expertise at risk.

Specialist expertise in the disability space is highly transferrable across the sector, and advocates whose roles are no longer funded can transition to other funded (non-advocacy) projects or NDIS-focused roles such as support coordination or working for a Local Area Coordinator or Early Childhood Early Intervention provider, among many other options. Some specific wide and deep knowledge applicable to the advocacy landscape includes legal systems, guardianship, and working with people with deep barriers to NDIS access, such as people interacting with the justice system. When advocates transition to other roles, this deep knowledge, particularly of working across multiple complex systems, is often not needed and consequently lost to the sector.

However, the option to transition elsewhere is never available for all at-risk advocates. At the end of June 2023, Disability Royal Commission funding for advocacy and engagement activities ended and many advocatesôcontracts ended. People with these specific focused skillsets are not always be redeployed into other roles by their respective organisations; DANA estimates that 30% of people in roles funded by the Disability Royal Commission were not redeployed, and many of these people have now left the sector or may not have found other work in the space. The NDIS Review currently has a valuable and timely opportunity to examine and address existing workforce instability, but it **must** act quickly in order to secure current existing skilled staff for the future.

# Lack of appropriate investment in areas experiencing multiple marginalisation, including Aboriginal and Torres Strait Islander people with disability

NDIS access figures, plan amounts and plan utilisation are not equitable across Australia. Additionally, some of the earliest Scheme entry areas are still considered top potential thin markets while also having comparatively low total plan budgets (NDIS Market Insights, 2021). It is clear that investment is needed to ensure all Australians have the same opportunities to access and utilise the NDIS, including awareness campaigns and proactive outreach. All investment must be aligned with cultural safety practices and delivered by appropriate organisations. Investment should also account for potential changes in outreach methods and community needs, for example, travel time needed for face-to-face engagements in rural or remote areas, or the need to rent or hire appropriate work spaces.

#### Case study: Kirra's story

Kirra\* is a young 17-year-old Indigenous woman with intellectual disability who lives in a small town in regional Queensland.

In early 2020, Kirra was referred to QAI's Decision Support Pilot by a local psychologist. Kirra had disengaged from school nearly two years ago. She had been living with her father, however he passed away suddenly last year so she had to move back to her mother's house. Kirra suddenly left town and became very hard to track down. QAI's Indigenous Liaison and Referral Officer used her extensive networks to locate Kirra and began to establish a relationship. Kirra had begun couch surfing with friends in a nearby city. Evelyn identified agencies that had a professional relationship with Kirra and was able to obtain relevant reports that would serve as supporting evidence for an NDIA Access Request. The Access Request and supporting documentation was compiled and submitted to the NDIS by the Decision Support Advocate.

Within a fortnight, a delegate from the National Access Team phoned the advocate to discuss Kirra's situation in more detail as part of her decision-making role. When it became clear that there was no more formal supporting evidence that could be provided to support Kirra's Access Request, that delegate sought further information about Kirra directly from the advocate during a detailed phone interview. Later that afternoon, Kirra was granted NDIS access.

Since then, the Decision Support Advocate has been meeting weekly with Kirra to help her to prepare for her NDIS Plan Meeting, by mapping her current supports, helping her to envision a future, determine her goals and become clearer about what supports would be required to achieve those goals. Kirra is now ready to schedule her Plan Meeting and is about to embark upon a new life where she will have access to additional support to achieve her goals and where some of her incredible dreams may now become a reality.

#### What are the solutions?

#### Creating a stronger disability advocacy sector and future

DANA believes that, for a strong future, an overarching Disability Inclusion Agency (DIA) should coordinate and lead government engagement with people with disability. This would concentrate all disability-focused knowledge and projects into one agency, including the ILC and other Tier 2 projects, and disability advocacy funding.

In order for the disability sector to meet the needs of the 20% of Australians with disability, there must be a significant increase in the total pool of advocacy funding. Disability advocates are taking on these roles, frequently in unpaid hours, and have developed deep specialist knowledge and skill as a result that is rarely applicable outside these roles. There needs to be a proportionate increase in funding to directly respond to the increase in workload, but also to do more outreach and preventative work.

We acknowledge the increased funding for NDIS Appeals advocacy, and this is a welcome investment in ensuring Australians with disability can speak up, navigate complex systems, and make sure the NDIS is meeting their needs. However, funding is still much lower than is needed to meet current advocacy demand. Additionally, appeals are only one part of the broader NDIS advocacy ecosystem; for an effective disability sector that meets the needs of people with disability, all levels of support must be equally and sufficiently funded to meet current and future needs.

The disability advocacy sector is in need of immediate support to address an insufficient workforce and inability to provide proactive outreach and other navigation support. Without an immediate injection of funds to at least double advocacy capability, advocacy organisations will not be able to meet the current demand.

Inflation and Consumer Price Index (CPI) are also critical factors in sustainable disability advocacy funding. Funding provided for the disability advocacy sector **must** be tied to CPI to ensure funding increases align with inflation and service delivery remains sustainable and consistent over time.

We ask that there is an increased annual contribution of \$115 million AUD to the advocacy funding pool, adjusted for CPI and inflation over time. This number factors in current grant funding provided by DSS and other funding sources, increases needed to meet unmet demand, and allows for proactive outreach and resource development to better reach and support people who have barriers to accessing both the Scheme and disability advocacy services.

DANA is aware of **at least** \$60 million in advocacy funding from various streams and initiatives currently allocated across Australia. This number has been conservatively adjusted to \$75 million to include other funding not yet accounted for across different administrative areas. Doubling the current pool of funding will allow current advocacy demand to be met across the country, but will not support people with disability who are not engaged with or requesting advocacy support, nor will it consider future

demand on advocacy services. To allow for proactive outreach to people with disability in need of advocacy support, particularly people with disability experiencing significant or multiple marginalisation, current advocacy funding must be tripled. This will ensure advocacy demand is not only met, but well supported into the future. The stated figure is prorated at 50% of total advocacy funding needs to represent the proportion of NDIS-specific advocacy work undertaken.

Scheme running costs for FY22-23 have been quoted at \$35.8 billion. The proposed investment, is a tiny fraction of what is spent on the Scheme each year. Money spent on disability advocacy is a sound investment: proactive support allows issues to be addressed before they progress to crisis level, and may also redirect potential participants to non-NDIS supports that meet their needs. Additionally, many people with disability are employed as disability advocates, and this ongoing commitment will help to build a strong lived experience workforce and increase economic opportunity for people with disability. Reframing independent disability advocacy as specialist expertise and a valuable employment pathway for people with disability adds another critical layer to the NDIS ecosystem.

Again, DANA is firmly opposed to advocacy funding being tied to the budgets of people with disability, or delivered via line item funding. We also do not believe the NDIA should fund advocacy directly, but that funding is increased to reflect the NDIS related workload, while not being only used for NDIS case work.

Funding given to the advocacy sector should be split across the different levels of advocacy. We propose a four-tiered model, as outlined below.

#### 1. Contribution to the broader advocacy funding pool

Advocacy is critical to the disability advocacy landscape. Systemic advocates represent people with disability as a broad group, provide information and knowledge translation to people with disability and the wider community, and navigate changes to the sector and the NDIS. Systemic advocates are a valuable source of change management expertise for the NDIS and have contributed significantly to the success of the Scheme.

To that end, we ask for the following investments:

#### Stability and retention of skilled and specialist expertise

In order to provide stability for advocacy organisations, funding should be extended and longer contracts should be offered - ideally, contract duration should be at least three years. This continuity of funding should be announced at least six months before funding is due to end. This ensures advocacy employees are able to ensure ongoing work and the sector does not lose valuable skills and experience to advocates  $\tilde{\eta}$ umping shipòbefore funding ends.

Ensure systemic advocacy funding is adequate to maintain and support NDIS systemic advocacy through periods of change (acknowledge change management role in systemic advocacy)

Systemic advocacy plays a vital role in reducing load on individual advocates, disability services, the NDIA and other systems during periods of NDIS change. Systemic advocates are briefed on changes, interpret and disseminate information, and provide opportunities for community collaboration and understanding of changes and updates. It is recommended that change management be included as a critical role in systemic advocacy and funded appropriately.

#### 2. Fund advocacy streams

Independent disability advocacy is a specialist field, including individual, citizen, peer, legal, family, and systemic advocacy. Advocates who work with people accessing the NDIS develop specialised knowledge over time that is often not transferable to other parts of the disability sector or to non-disability work. In order to retain this expertise, the sector must be stabilised and well-funded to avoid retain drainà

We ask for the following urgent investments:

# Immediate and significant injection of funding to increase overall numbers and capacity of disability advocates

Individual advocates across Australia are unable to meet current demand. An immediate doubling of ongoing individual advocacy funding, at minimum, would allow for the recruitment and training of individual advocates to meet unmet demand. We also ask that, in line with the proposed investment in systemic advocacy, advocacy contracts are extended to **at least** three yearsôduration with a minimum six month notice period of funding renewal or end.

Additionally, funding should include specific money for non-service delivery activities, including professional development, supervision, counselling and support, and outreach and inreach work. Including specific funding for all organisational activities will create a more sustainable workload and sector.

# Increase funding of non-NDIS Appeals advocacy work in line with new Appeals advocacy funding

While the funding injection for NDIS appeals is a welcome investment, advocacy needs to be adequately funded across all areas and stages. Adequate funding for non-appeals advocacy work helps to reduce potential bottlenecks at appeal level and to ensure support is available to resolve issues before Administrative Appeals Tribunal escalation is required.

#### Targeted funding investment by need, not just per capita funding investment

Many funding injections are allocated by population, resulting in the most funding being allocated to the densest population areas. While broad spectrum funding like this works well for many areas, it does not recognise the impact of thin markets and significant barriers to access for many people with disability. Specific and targeted levels of independent advocacy funding should also be directed to areas with low plan budgets and known potential thin districts.

Specific and targeted investment is needed in areas with low NDIS uptake, plan budget, or plan utilisation to ensure Scheme access is equitable for all Australians. Funding injections can take different forms: it is suggested that funding allocated takes into account population and complexity of needs in targeted areas and populations, allowing for comprehensive advocacy support when required.

# Support the development of a community-controlled advocacy service by and for Aboriginal and Torres Strait Islander people with disability

First Peoples Disability Network have developed the <u>National Disability Footprint</u> to ensure that First Nations people with disability are adequately and appropriately represented across systems and processes. As part of this work, FPDN have identified four key φillarsô

- 3 Building capacity of peak bodies
- 3 Building the capacity of Aboriginal and Torres Strait Islander communitycontrolled organisations
- 3 Growing the Aboriginal and Torres Strait Islander disability workforce, and
- 3 Supporting the capacity of peak bodies to engage with governments.

To this end, we recommend the NDIS make a targeted financial investment in First Peoples Disability Network to carry out the work of the Footprint as a commitment to creating a more equitable Scheme.

# Fund Supported Decision Making training and resources for independent advocates

DANA has identified a lack of understanding of Supported Decision Making among individual advocates and organisations. To ensure people with an intellectual disability have equal access to disability advocacy support, funding should be allocated to an appropriate peak body to develop training and resources for individual advocates and organisations. Outreach funding should also be included to allow Supported Decision Making experts to engage directly with advocates and organisations in a non-training capacity and to ensure SDM practice is entrenched on an ongoing basis. The recent Supported Decision Making pilot needs to be built on and given ongoing resources.

#### 3. Invest in the advocacy ecosystem

DANA, as the peak body for systemic and individual advocacy organisations across Australia, is the national voice for disability advocacy. DANAs remit includes systemic advocacy, training, support, mapping and knowledge gathering and administration of the National Centre for Disability Advocacy (NCDA).

To support DANA's work, investment is needed to:

# Contribute to funding for state and territory peak bodies, as well as state and territory advocacy networks

Both peak bodies and advocacy networks have critical roles to play in the advocacy sphere. Peak bodies and advocacy networks both have strong involvement with the

NDIS; peak bodies represent people with disability, and support the navigation of the Scheme, while advocacy networks support self, family and peer advocates to self-advocate and fight for change. Both types of organisations provide valuable knowledge and insights on a local level and have the opportunity to do focused engagement. As the NDIS remains a significant factor in the advocacy of both peak bodies and advocacy networks, an investment in the ongoing operations of both types of organisations would provide stabilised funding and opportunities for growth.

# Expand DANA's functions to include the role of an independent citizenship and consumer advocacy organisation

The NDIS is a major consumer market in the disability space. Typically, consumer advocacy organisations are important custodians of service safety and quality, highlighting risk and ensuring consumers are informed and connected. As Australia®s peak body for disability advocacy, DANA is a key leader of quality and safeguarding across advocacy and the broader disability sector. Expanding organisational remit to include independent citizenship and consumer advocacy is a natural complement to DANA® existing work and focuses, while also utilising DANA® existing honest broker role and data gathering expertise. Targeted funding to ensure DANA can perform NDIS-focused consumer advocacy work alongside people with disability will contribute to effective NDIS market stewardship and entrench consumer advocacy as a critical part of the Scheme. [Please also see the paper submitted to the Review from the Consumer Federation of Australia and DANA about a proposed citizenship and consumer body.]

#### 4. Enhance funding for the National Centre for Disability Advocacy

The National Centre for Disability Advocacy is a centre established by DANA to support sector development by working directly with advocacy organisations, identifying unmet demand, and advocating on behalf of advocates across Australia.

There are several immediate actions that can be taken to strengthen NCDAss position and further support the development of the disability advocacy sector. We make the following immediate recommendations to help address urgent needs and ensure proactive outreach and support can be delivered.

# Specific, targeted funding for NCDA to invest in developing best-practice NDIS advocacy models and training for advocates across Australia

With current funding models and contracts creating a highly complex market space, overall sector development is limited, sporadic and largely responsive. Specific funding to develop both a best practice NDIS advocacy model and subsequent NDIS-focused training offerings for disability advocates and organisations will allow for a unified approach to the sector, and simplify the user experience of those seeking advocacy support.

Invest in an NDIS advocacy awareness campaign to bridge the gaps between the advocacy sector, people with disability, mainstream organisations and disability services An investment of \$200,000 will allow NCDA to develop a detailed advocacy awareness campaign on disability advocacy, covering an introduction to disability advocacy for mainstream organisations, the role of disability advocacy in the NDIS, the different kinds of NDIS advocacy supports people use, how to find and access NDIS advocacy services for different issues, frequently asked questions (FAQs), and stories told by people with disability who have used advocacy support. Currently there are very little to no widely available resources for people new to independent disability advocacy, whether they be mainstream organisations, disability services, or people with disability seeking the support of an advocate. The proposed approach will address advocacy knowledge gaps by combining outreach and communications strategy with freely available resources for all target markets, and is in line with existing NDIA video resource production and communications strategies.

# Invest in strong data collaboration by funding citizen science and data gathering

The NDIS employs a Scheme Actuary to understand NDIS expenditure and financial investment. At present, similar quality data for the advocacy sector is lacking and largely responsive rather than proactive. An ongoing commitment to investment is needed to understand service gaps and community benefits. DANA believes the best approach is to move towards co-creation of a knowledge base in a similar model to the CSIRO Citizen Science Principles (CSIRO, 2020) or the European Citizen Science Association Model (ECSA, 2015). While the lack of data is currently concerning, there is also a unique opportunity to address data gaps by doing things differently.

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