Issues paper

Foundational supports and disability advocacy

Key issues and questions

October 2024



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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Introduction

The 2023 NDIS Review called for the introduction of 'foundational supports', a new term for what was known during the design of the scheme as Tier 2 disability supports.

These supports sit between NDIS-funded individual supports, and mainstream services and community supports. As DANA explored through consultation with the sector during the NDIS Review on the topic of 'Mainstream and Tier 2' supports, the 'Information, Linkages and Capacity building' (ILC) and Local Area Coordinators (LAC) programs have not operated or been governed as originally intended, and have inconsistently delivered the supports people with disability need.

The NDIS Review proposed two types of foundational supports: targeted and general. Targeted foundational supports could include home and community supports, personal assistance, early supports for children, and targeted supports for adolescents. General foundational supports could include assistance to navigate the support system, information and advice, peer support and **advocacy** for individuals, families and communities. There is an undertaking that foundational supports will be jointly funded by state/territory and federal governments, though the details of how they will be administered and governed are still to be resolved.

In September 2024, DSS published a consultation paper on 'general supports' as part of the ongoing foundational supports consultation. The preamble notes its focus on information, advice and supports to build capacity and acknowledges "other general supports not covered by this paper", including:

"advocacy (other than self-advocacy) as this type of support is already being dealt with through the National Disability Advocacy Framework 2023-2025."

DANA members, independent disability advocacy organisations, have a range of views about whether advocacy should be included as a general foundational support. Although there is significant uncertainty and guesswork in predicting and evaluating the implications, some members believe advocacy should be included within foundational supports, and some do not.

At DANA, we are interested in hearing from members and representing your views. This paper outlines some of the current issues, challenges and unresolved questions for our members to consider, and to discuss at a future forum.

Individual advocacy and the NDIS

The NDIS Review found that many of the current issues facing people with disability arise from government agencies failing to agree to responsibilities under the Applied Principles and Tables of Support (APTOS) (p.66, NDIS Review Final Report). This makes it essential that advocacy organisations can undertake their work with independence, to hold governments and the NDIS accountable to rectify the existing issues caused by the lack of clarity around roles and responsibilities.

Evidence from advocacy organisations show that demand for independent advocacy substantially increased with the introduction of the NDIS. People with disability needed assistance to access the Scheme, stay in the Scheme and appeal decisions made about their NDIS plans and individual funding.

Whether individual disability advocacy is positioned inside foundational supports or remains outside, if people with disability are not all provided access to independent advocacy support at a time of significant change from the NDIS Review and DRC reforms, **more people with disability will fall through the gaps** of NDIS, mainstream and community support access.

Advocates are often engaged in **safeguarding activities** including risk management and crisis intervention, in prevention of violence, abuse, neglect and exploitation. Although the NDIS Quality and Safeguards Commission is the agency tasked with oversight and monitoring of quality and safety of NDIS providers, a lack of proactive outreach means this function is often falling into the work of disability advocates. Supporting this role for independent advocacy, the Inquiry into the NDIS Commission by the NDIS Joint Standing Committee in 2021 made an explicit recommendation for additional funding to that provided through NDAP to support people with disability to connect with the NDIS Commission (Recommendation 17).

Individual advocacy in a new ecosystem

The NDIS Review recommendations included a new ecosystem of supports for the NDIS (Recommendation 1) and improvements to the interface to mainstream services and supports for people with disability (Recommendation 2). Under Action 1.5 of Recommendation 1, the NDIS Review asserted that National Cabinet should jointly invest in achieving nationally consistent access to individual disability advocacy services, with better coordination across levels of government.

The NDIS Review proposed that individual advocacy could be a foundational support, potentially shifting how individual advocacy is funded. In January 2024, National Cabinet announced that \$11.6 million has been invested into a Foundational Supports Strategy. This followed an agreement brokered in December 2023 that state and territory governments will fund foundational supports in a 50-50 split.

In addition, the Federal Government's response to the Disability Royal Commission in July 2024 announced a new advocacy program, without detail about how funding would be distributed, how it would relate to the Foundational Supports Strategy, or which kinds of advocacy would be included.

Recognising advocacy as critical and foundational

Background

Advocacy is critical and related to many other proposed foundational supports, such as **peer support**, **information** and **capacity building**. Many advocacy organisations also perform these functions, and several have secured ILC grants to enable them to continue or expand such activities, which often overlap with or complement their advocacy work.

Individual advocacy plays a unique role in **enabling supported decision making**, which is critical to enabling independence and choice, as acknowledged by key recommendations in both the Disability Royal Commission and the NDIS Review. This is especially important in safeguarding people with disability against coercion in making decisions about how they live their lives.

Possibilities

The inclusion of individual advocacy as a foundational support has potential to capitalise on the work already being done in communities to support people through individual advocacy. Work in the community includes **peer-led support**, with advocacy led and delivered by people with disability, including those in intersectional groups including First Nations people, LGBTIQA+ and culturally and linguistically diverse (CALD) people. The <u>Disability Royal Commission</u> reflected that for many people with disability and other intersectional groups, there are 'complex, cumulative ways [that] multiple forms of discrimination and oppression are experienced' (p.19). It is therefore important that individual advocacy can be provided in culturally and psychologically safe ways, by the people with the skills, knowledge and lived experience to create such environments.

The DANA Priorities Project heard that advocacy is the 'foundation of foundational supports', central to the delivery of many other services, and the removal of key community barriers. Given the various functions and forms that independent advocacy can take, it is often not possible to delineate clearly between different forms and models of advocacy and advocacy adjacent activities outlined above.

(The complex intersections between individual advocacy and other models are explored in a section below: <u>Situating the different models of advocacy</u>)

Question 1: Do you think the inclusion of advocacy within foundational supports would connect up and strengthen existing work by the sector to build skills, relationships, leadership and representation for individuals and communities?

Securing increased funding and certainty for advocacy

Background

Currently, independent disability advocacy including individual advocacy, is underfunded and has not been able to meet the levels of demand, which outstrips available resourcing. DANA has consistently advocated for funding increases to accommodate demand for independent disability advocacy support. Many disability advocacy organisations are currently struggling

to survive following the cessation of some sources of funding. A joint Statement released by DANA and endorsed by over fifty organisations in July, reflects the reality that many advocacy organisations needing to make drastic staffing and resourcing cuts in this financial year to survive. Independent inquiries including the Disability Royal Commission have made numerous recommendations to increase funding for advocacy.

The **National Disability Advocacy Framework (NDAF)** is "a shared commitment between Commonwealth, state and territory governments to ensure there is access to advocacy services for all people with disability nationwide." Although it commits governments to sharing responsibility for disability advocacy, the NDAF specifies that decisions about development, funding and management of advocacy programs are the responsibility of the relevant government.

In the context of shared responsibility between levels of government this lack of clarity about which level of government is responsible for shortfalls in the capacity of the sector has made it more difficult to hold funding bodies to account.

Possibilities

If individual advocacy were included as a foundational support, then it would be included under all supports funded by the 50:50 split with Commonwealth and state/territory governments as per the <u>agreement brokered</u> between all governments.

This may **enable recognition of and clearer commitment** to equally funding individual advocacy at both state/territory and Commonwealth levels. Improved coordination and clear accountability for coverage across different regions might ultimately contribute to more people with disability having access to individual advocacy, when they need it.

However, there can be advantages in having two levels of government providing separate sources of funding for organisations, in terms of strengthening funding security and organisational independence. In an environment where funding is not enabling appropriate resourcing and staffing to meet demand, keeping individual advocacy separate to foundational supports could **potentially retain more security and clarity**. However, the status quo, including the National Disability Advocacy Framework, has not yet provided funding certainty or adequate resourcing of the sector.

Another possibility is that general foundational supports are only funded and delivered by the Commonwealth, with continuing doubt over state/territory advocacy funding, or the prospect that state and territory advocacy programs might be incorporated into a centrally administered Federal program. The general supports discussion paper notes that it does not cover advocacy (with the exception of self-advocacy, examined as a form of individual capacity building). The phrasing indicates that governments are considering that advocacy is covered by the NDAF and will be technically including advocacy under the umbrella of foundational support yet envisaging little impact on its funding and administration, as a result of this inclusion.

Question 2: How do you think advocacy being included in or sitting outside foundational supports would affect funding levels and security for advocacy organisations?

Building universal access to advocacy

Background

Achieving access to quality and independent advocacy for all people with disability, regardless of where they live, is one of the outcomes embedded in the NDAF, to which all governments have agreed. Advocacy programs are generally intended to be available to all people with disability, regardless of whether someone can demonstrate meeting criteria for NDIS access or eligibility for the Disability Support Pensions. Many people need support to navigate to and access such government supports so advocacy should be freely available to anyone identifying as a person with disability. Disability advocacy doesn't require someone to prove they have a disability, and at times, organisations help people who have a disability but may not identify as a 'disabled person'.

Some organisations are focused on specific populations such as people from culturally and linguistically diverse backgrounds, or contexts like justice and employment, or specialise in providing support for a specific category of disability.

However, a number of factors currently limit access:

- lack of awareness or warm referrals to advocacy when it is needed;
- restricted or no access from closed, institutional or family settings when people encounter gatekeeping or isolation; and
- insufficient targeted outreach to provide tailored and responsive support to marginalised populations experiencing intersectional disadvantage.

Given the high level of demand, many organisations currently need to triage matters according to urgency, close their waiting lists and often cannot engage in the more proactive and preventative outreach work that in the longer term would reduce the numbers of people with disability needing advocacy. Organisations operating in rural and remote areas are under particular pressure, and people living in these areas have limited or inconsistent access to effective advocacy, particularly if face to face support is needed.

Some state governments have restricted their advocacy programs to be directed only towards areas under state responsibility, limiting their work in relation to the NDIS or other Commonwealth government systems. This is an impractical limitation, as people with disability often approach organisations with multiple and often overlapping issues relating to a range of inaccessible systems and their interactions.

Possibilities

While it is unclear how access will be decided for foundational supports, neither general or targeted supports are yet guaranteed to be universally available to all people with disability.

The consultation paper indicates that general foundational supports will be intended inform and build the capacity of all people with disability; asserting that "once fully implemented, supports will be available nationally, fully accessible and where appropriate, tailored to meet the needs of diverse communities." They are being designed for people with disability under 65 years of age, but not to exclude people over 65 and their supporters from accessing and benefiting from general information.

Some advocates have expressed concern that if individual advocacy were funded as a foundational support access might be limited to certain categories of people with disability, or

require people to meet certain eligibility requirements, reducing the general (though practically limited) access that currently exists.

Question 3: How do you think advocacy being included in or sitting outside foundational supports would impact on its availability, including how readily and consistently people with disability could access an independent advocate when needed?

Valuing independence and managing conflicts

Background

The need to advocate with independence, free of conflicts of interest, has been an important principle and value driving the work of the disability advocacy sector. Advocates need to be on the side of the person with disability only, so that the interests of governments, service providers or carers and family members do not take precedence or obscure the rights, preferences and wellbeing of the individual.

The current funding situation has included advocacy organisations sometimes receiving ILC project grants (from the NDIA and then from DSS), for project work adjacent to their advocacy work in building information, relationships, referral networks and building peer support, leadership development, self-advocacy and representation capabilities.

Given the sector's strong rights-driven focus on prioritising the voices of people with disability over other concerns, organisations are generally equipped to manage the inherent conflict in being reliant on funding from government departments, which in some cases may be the very agencies they need to interact with in their advocacy work to seek outcomes for people with disability. Organisations delivering the advocacy adjacent activities of educating the community about human rights and accessibility and supporting the development of peer support, decision making skills and disability leadership have generally been complementary to their funded advocacy work.

Possibilities

Some advocacy organisations are concerned that the inclusion of individual advocacy as a foundational support will **reduce their ability for independence and autonomy**. This flows from concerns with being tied to other services or supports delivered through the same Foundational Supports Strategy under which individual advocacy organisations would also receive their funding. There are worries that funding agreements might place restrictions on advocating for people with disability in relation to other providers of foundational supports, meaning that advocacy organisations may be wary of implications for their ongoing funding. A real or perceived threat to organisational viability may restrict how vigorously or fiercely advocates can defend the rights and interests of individuals with disability seeking recognition, outcomes and remedies in these contexts.

Some believe advocacy organisations need to maintain distance and separation from other parts of the disability supports ecosystem to avoid conflicts of interest that might impede or undermine their advocacy.

Many of the capacity building activities that are envisaged to be funded through general foundational supports are functions that the advocacy sector has frequently performed, including supporting self-advocacy, rights awareness, supported decision making, peer support and leadership development. This work has sometimes been unfunded or

underfunded through specific advocacy or information programs or philanthropy, or in recent years funded inconsistently through ILC projects or other time-limited grants from Federal or state/territory governments.

This existing complexity raises questions and challenges as to the rationale and **practicality of separating individual advocacy programs** from these other related supports, which are expected to fit within a Foundational Supports Strategy. There may be conflicts that need to be managed if an organisation receiving funding through an advocacy program and is concurrently also delivering capacity building supports through a separate grant under the Foundational Supports Strategy. Conflict may also arise if funding arrangements, either expressly or indirectly, constrain how organisations can direct their advocacy towards decision-makers or other government funded supports.

Funded disability advocacy organisations are often well-equipped to effectively manage conflicts. The strong understanding across funded disability advocacy organisations of the need for an advocate to only be on the side of the person with disability, and represent their interests and rights, has been evidenced by the uncompromising integrity and willingness to 'speak truth to power' displayed across the sector, at both individual and systemic levels.

Question 4: How do you think advocacy being included in or remaining separate from foundational supports would affect the independence of your organisation to advocate, only on the side of the person with disability?

Questions 5: Have you observed any impacts or problems in advocacy delivered by your or other organisations, also receiving Information, Linkages and Capacity Building grants?

Questions 6: What is needed in funding arrangements and sector support structures to ensure organisations can identify and manage potential conflicts of interest that may affect how they perform advocacy at individual and systemic levels?

Evidencing unmet demand

Background

Unmet demand is where a person with disability requires advocacy support but cannot access it due to a lack of supply. It is already known that there is a significant level of unmet demand.

Currently, unmet demand is difficult to ascertain and evidence, due to inconsistent reporting across levels of government in relation to individual advocacy provided. Data collected through QIDAN and surveys by DANA suggest that only half of demand is being met and there is likely considerable unmet need which is more difficult to quantify. However, complexities and challenges in data quality and consistency undermine its evidentiary strength to influence the allocation of additional funding. Making this case is particularly difficult in the context of many fiscal pressures on government decision makers, meaning that even irrefutable evidence may have no impact on budgetary allocations.

Possibilities

A cohesive central administration of individual disability advocacy funding and reporting might allow for stronger, more persuasive evidence of the levels of unmet demand to present to the decision makers allocating funding.

However, if funding for the sector were not increased, became more insecure or access were restricted in new funding arrangements, unmet demand would likely worsen, despite the sector being able to evidence long waiting lists of people requesting and needing advocacy.

Question 7: How do you think advocacy being included in or outside foundational supports would affect the clear measurement of the extent of unmet demand for independent advocacy?

Question 8: Do you think more robust consistent evidence demonstrating unmet demand for advocacy would compel funding bodies to provide the needed increases and adjustments in funding to meet demand, in the medium and longer term?

Situating the different models of advocacy

There are **six models of advocacy** currently funded within the National Disability Advocacy Program. These models frequently overlap practically and theoretically, and can also function to strengthen each other, and other related capacity building and safeguarding supports in a myriad of ways.

At this stage it is not clear what is envisaged for different forms of advocacy aimed at assisting individuals, such as family, legal, self and citizen, - nor is the role of systemic advocacy, directed at changing the systems to better include, support and empower people with disability.

Under the six models individual advocacy has referred to advocacy performed by paid advocates employed at independent advocacy organisation working one on one to advocate for a person with disability. The current version of the NDAF includes a definition of individual advocacy that is broad enough to encompass advocacy at an individual level relatives (and supported by family advocacy organisations) and by volunteers (who citizen advocacy organisations train and support). It also includes definitions of legal advocacy and self advocacy. Self advocates are often initially focused on learning how to speak up for their individual rights and needs but are also frequently focused on representing a group of people - engaging in advocacy directed at improving systems, educating people about rights or developing leadership skills. This is one example of how a model of advocacy can straddle the individual and systemic levels.

Individual advocacy is needed alongside self advocacy

The funding of individual advocacy as a foundational support would acknowledge **the unique expertise and skills of individual advocates** to navigate systems and provide support to people with disability in overcoming barriers for access and participation.

Individual advocacy is not a replacement for building self advocacy skills but rather a support that needs to exist alongside. One type of support does not replicate the other; both individual advocacy and self advocacy programs can help a person with disability build the skills to self-advocate, however there are matters including NDIS appeals that require specialist knowledge of professional advocates and are rarely able to be effectively navigated by a person with disability on their own.

The <u>Disability Royal Commission</u> acknowledged this:

"In many public hearings, we heard about the importance of self-advocacy in preventing violence against, and abuse, neglect and exploitation of, people with disability. However, some people with disability may have limited capability to self-advocate. Their personal circumstances or high support needs may mean they require independent advocacy support" (p.75).

Maintaining effective self advocacy networks and training, especially for people with intellectual disability and/or complex communication support needs often requires ongoing and sometimes intensive support to enable them to stand up for and assert their rights.

'Self-advocacy' is cited in the discussion paper by DSS as one of the types of individual capacity building within general foundational supports. However, there is no detail as to whether or how this component would be connected to or distinguished from existing programs delivering self advocacy or the broader advocacy sector in work at individual, group and systemic levels.

Question 9: How would the inclusion of all or some self advocacy activities within foundational supports affect the functioning of advocacy organisations and the strong complementary connections and overlap between individual and self advocacy?

Systemic advocacy and individual advocacy strengthen each other

The advocacy sector includes both individual and systemic advocacy; individual advocacy can support the role of systemic advocacy by providing rich evidence of trends and data to support advocacy at all levels of government, and across all public facing systems including the NDIS. Effective systemic advocacy effects positive change, to reduce the demand from people with disability needing individual advocacy support.

Advocacy organisations are funded to deliver systemic advocacy, as well as other models of advocacy. There are clear advantages in having **strong connections between advocacy directed at an individual level and systemic advocacy efforts** directed at changing systems, culture and attitudes.

Many organisations have argued for flexible funding agreements that allow them freedom to respond to local, place-based circumstances (including determining the proportion of funding to be directed to providing the different models of advocacy). The standard NDAP agreement stipulates only 10% of total funding for systemic, though some legacy arrangements have existed for organisations engaging in a higher proportion of systemic advocacy in their work.

It is unclear whether such flexibility and connections are more likely to be maintained if individual advocacy remains outside foundational supports. Currently systemic advocacy also takes place outside the NDAP program, with some organisations receiving funding through state and territory advocacy programs and disability representative organisations operating through the DRO program (via DSS) and the DRCO program (via NDIA), or other sources providing project and/or philanthropic funding.

Question 10: If individual advocacy were to be included within foundational supports, how would the separate funding and administration of systemic advocacy and representation affect the important overlap, connection and information flow between advocacy at individual and systemic levels?

All questions

Question 1: Do you think the inclusion of advocacy within foundational supports would connect up and strengthen existing work by the sector to build skills, relationships, leadership and representation for individuals and communities?

Question 2: How do you think advocacy being included in or sitting outside foundational supports would affect funding levels and security for advocacy organisations?

Question 3: How do you think advocacy being included in or sitting outside foundational supports would impact on its availability, including how readily and consistently people with disability could access an independent advocate when needed?

Question 4: How do you think advocacy being included in or remaining separate from foundational supports would affect the independence of your organisation to advocate, only on the side of the person with disability?

Questions 5: Have you observed any impacts or problems in advocacy delivered by your or other organisations, also receiving Information, Linkages and Capacity Building grants?

Questions 6: What is needed in funding arrangements and sector support structures to ensure organisations can identify and manage potential conflicts of interest that may affect how they perform advocacy at individual and systemic levels?

Question 7: How do you think advocacy being included in or outside foundational supports would affect the clear measurement of the extent of unmet demand for independent advocacy?

Question 8: Do you think more robust consistent evidence demonstrating unmet demand for advocacy would compel funding bodies to provide the needed increases and adjustments in funding to meet demand, in the medium and longer term?

Question 9: How would the inclusion of all or some self advocacy activities within foundational supports affect the functioning of advocacy organisations and the strong complementary connections and overlap between individual and self advocacy?

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