Submission

Building on solid foundations

Investing in local, community-driven disability advocacy organisations

January 2025



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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Executive summary and recommendations

At this time of reform across disability and NDIS policy, independent disability advocacy organisations continue to play a critical role including through helping to prevent NDIS exploitation by supporting people with disability to advocate for their rights and keeping mainstream systems accountable. With ongoing changes to the NDIS, people with disability need the promises of intergovernmental commitments to 'Foundational Supports' to be fulfilled to make sure that nobody is left behind.

Presently, there are vital challenges ahead to design, deliver and monitor Foundational Supports and many disability advocacy organisations face an uncertain future, with the rollover of the new advocacy program until 2026. States and territories and the Commonwealth have made a substantial commitment to Foundational Supports, and the spending of these monies must be both accountable and effective. This submission presents solutions to address each of these imperatives – both separately and holistically – recommending interim actions to:

Brian had tried to get his local housing department to listen to him for two years. His public housing flat wasn't accessible anymore, and he was often stuck inside for weeks at a time. An advocate used their local contacts to organise a transfer within two weeks. Brian is active in the community again, going to the local shops and swimming pool. [Advocacy organisation, Victoria]

- build on existing infrastructure; and
- · harness existing expertise

Recommendations

Recommendation 1: That the Federal government immediately provide bridging funding of at least 10% of Foundational Supports budget allocation to disability advocacy and representative organisations to deliver information, peer support, capacity building and self-advocacy while Foundational Supports are not in place.

Recommendation 2: That this interim funding be to 1 July 2026 (and extended if Foundational Supports are still in development).

Recommendation 3: That the interim funding should include:

- a) At least 12 months of additional funding to continue current ILC funding for existing programs due to cease on 30 June 2025;
- b) New funding for peer support and capacity building programs that previously received Information Linkages and Capacity Building funding, and did not receive ILC or NDIA grants in 2024;
- c) New funding for innovation in peer support and capacity building to support the development of new initiatives and approaches.

What is independent disability advocacy?

Advocates support or work on behalf of a person with disability or a group of people to help them to improve their lives, solve problems, avoid or work through crises, and defend their interests. Effective disability advocacy helps to enhance the wellbeing of people with disability, promoting, protecting and supporting their human rights.

Independent disability advocacy organisations work in every part of Australia, city and country, with some of the most marginalised people with disability.

Disability advocacy organisations are funded by state, territory and Federal Governments as a critical component of support for people with disability. Their role, and critical underfunding, was recognised by the Disability Royal Commission and NDIS Review.

Economic evaluation of disability advocacy has found it an excellent investment, with advocacy returning a benefit of \$3.50 for each \$1 spent. But that is only part of the picture. Every day, independent disability advocacy organisations assist people to defend their rights and wellbeing.

Independent disability advocacy is a critical factor in ensuring people with disability have their human rights both respected and upheld. Various approaches to disability advocacy are used in different contexts, at different times and for different purposes including the six models of individual advocacy, citizen advocacy, legal advocacy, self-advocacy, family advocacy and systemic advocacy.

Disability advocacy supports people with disability (and their family and supporters) in a range of ways - to be aware of and assert their rights and to facilitate their access to services and support that enhance their capacity to participate fully in society.

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

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

Crucial challenges ahead

People with disability know that 2025 and beyond will bring a great deal of change - change to their essential supports, change to how they access the community and change to the tide of violence and abuse that has been inflicted by people and systems.

The Disability Royal Commission and the National Disability Insurance Scheme Review finished in 2023, and 2024 saw responses to both from a variety of governments, agencies and departments, including a very welcome increase to advocacy funding of \$39.7m over four years.

Now, in 2025, the work begins to implement many of the life changing and lifesaving recommendations that will ensure that people with disability are genuinely included across the whole community.

In December 2023, the NDIS Review recommended establishing Foundational Supports across Australia for people with disability and families, outside the individualised support through the NDIS. These services and supports will be a vital part of our social infrastructure, due to start on 1 July 2025.

However, this start date is ambitious, and people with disability are rightly worried about the looming gulf between a narrower availability of NDIS supports, and Foundational Supports. Commitments to equity and leaving no one behind must guide these reforms. Otherwise there is a high risk more people will fall through gaps into neglect and escalating crisis.

Sally is legally blind and relies on audible announcements on the train to let her know which stop is her station and when there are platform changes. After a protracted attempt to catch the train home from a visit to the city due to missing and incorrect announcements, Sally worked with her disability advocate to lodge a disability discrimination complaint with the Australian Human Rights Commission, prompting focused attention on how the state government system should be meeting accessibility obligations. [Advocacy organisation, Victoria]

The underpinnings of these changes for people with disability include our own disability advocacy organisations, firmly planted in local communities with long histories of delivering independent support, by and for us.

Disability advocacy organisations across Australia have worked to deliver peer support, information, a range of advocacy and capacity building over many years. This support has traversed the time before the NDIS, as the scheme has unfolded, and through the Information, Linkages and Capacity Building grants program; however, some are now facing a very uncertain future.

Jane had just left hospital and wanted to go back to her primary school. But the school said Jane couldn't eat lunch with her friends or even move around the school on her own. The principal wouldn't listen to Jane, her family or her doctor and said Jane would scare the other children. An advocate worked with Jane and her family so they understood their rights, including to an education, and how to action them.

[Advocacy organisation,
Queensland]

Solutions already embedded in community

Disability advocacy organisations already exist in local communities and are often driven, led or governed by people with disability and their families. They work with some of the most marginalised people with disability to make sure they can access the same public services as other Australians.

Health, transport, education and housing are just a few of the systems with barriers to people with disability being treated equally. Advocates are experts in inclusion, often because they are people with disability themselves.²

While the additional advocacy funding announced in the Federal response to the Disability Royal Commission will support organisations delivering individual advocacy through the National Disability Advocacy Program, all other disability advocacy organisations, and non-advocacy programs are at very real risk of ending altogether. Some have already had to close their doors.

Emi meets regularly with friends with a similar kind of disability in her regional town. Together, they have shared experiences about their lives and worked with an advocate to work on getting more into the community. Emi and her peers found that many people in their community didn't know about people with disability and felt nervous about talking with them. They worked with their advocate to develop speaking engagements across the town that built understanding and inclusion. [Advocacy organisation, New South Wales]

The decades of expertise, experience and knowledge in these organisations are both essential to the changes coming but will be lost without urgent action. The new system cannot be built without them.

Significant investment in advocacy and representative organisations to continue and expand information, peer support and capacity building is needed. This funding would leverage, strengthen and build upon the community structures, networks and expertise that already exist, to make sure disability reforms are constructed on a solid basis and do not fail. If the bedrock crumbles and the reforms do not deliver, many people with disability will fall through chasms in other systems.

Build on existing infrastructure

Given the uncertainty around the timing of the rollout of Foundational Supports, there is an opportunity to build on existing organisations and expertise. As disability advocacy organisations are already delivering Foundational Support-type services, the Federal government can leverage the extensive expertise of these organisations deliver on the promise of improved and expanded disability information, advice and referral and capacity building activities to meet the needs of Australians with disability.

This approach would help provide a practical and workable bridge while we await the full roll-out of Foundational Supports. This approach would also ensure that people with disability are not left without supports but rather have local sources of information and capacity building that they already trust and recognise.

The interim funding should be provided to 1 July 2026, (and longer if Foundational Supports are still not in place by then).

Due to his disabilities, James finds interactions with the police or legal hearings, stressful and confusing. A specialist advocate helps him to understand what is going on, make decisions and participate effectively. Feeling supported and informed helps him to remain calm, avoiding expressions of distress that would likely disrupt, delay and prolong his involvement with the justice system, preventing more stress and poor outcomes.

[Advocacy organisation, NSW]

The Grattan Institute³ estimates that the existing spending on Information, Linkages and Capacity Building grants and Partners in the Community is about \$255 million per year for 'general foundational support-equivalent services'. The NDIS Review estimated the total ILC funding for 2023 was \$135m⁴. National Cabinet committed to jointly fund additional Foundational Support services, acknowledging the significant under-investment that the ILC program represents compared to the need of people with disability⁵.

At least this amount needs to continue after 30 June 2025, growing as a percentage of the total spent on the NDIS. DANA's analysis with Associate Professor Sue Olney for the NDIS Review estimated that the total investment in Foundational Supports (Tier 2) needed to be closer to \$1.7b per year, a ten-fold increase⁶ to meet the needs of people with disability.

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Harness existing expertise

Many disability advocacy organisations also deliver vital programs through the Information, Linkages and Capacity Building (ILC) grants, and addition peer support and capacity building funding. These programs will all end on June 2025, and there is a significant risk of losing expertise and experience, including of people with disability, in the period leading into deliver of Foundational Supports.

The inadequacy and uncertainty of funding for these essential organisations drives a loss of expertise, knowledge and relationships, that would need to be rebuilt if not preserved and strengthened now. Although there was a welcome funding lifeline granted for a number of advocacy, peer support and capacity building organisations, announced in December 2024,

these and other vital organisations require security through increased funding and longer-term contracts beyond 30 June 2025.⁷

Increasing funding for advocacy organisations to continue and expand upon their existing programs would ensure people with disability have trusted, reliable, local services to draw on. This interim resourcing must span multiple funding programs in order to be effective and is particularly vital for organisations existing outside the National Disability Advocacy Program, who have been reliant on other sources of funding, such as ILC grants or State and Territory funding.

Kate was upset at the prospect that her newborn child may be removed from her care, and is distrustful of child protection workers. A specialist advocate talked with Kate to develop options to address safety concerns, access parenting supports and aided effective communication with community services, enabling Kate to leave hospital with her baby. Ongoing contact has supported Kate to avoid crises and cooperate with plans to keep her child safe in her care. [Advocacy organisation, Victoria]

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Endnotes

¹ Australian Government Department of Social Services (2024) Foundational Supports - <u>General Support Consultation Paper</u>, p5, see also Appendix B.

²See DANA's previous pre-Budget submission for greater explanation of the varied functions, value, benefits and unmet demand and need: Disability Advocacy Network Australia (2023) <u>A strong</u> sustainable future: addressing capacity shortfalls for a strengthened disability advocacy sector.

³ https://grattan.edu.au/wp-content/uploads/2024/12/Strong-foundations-Grattan-Institute-Submission-to-DSS.pdf

⁴ https://www.ndisreview.gov.au/sites/default/files/resource/download/NDIS-Review-Supporting-Analysis.pdf

⁵ https://disability.unimelb.edu.au/home/projects/support-outside-ndis

⁶ https://www.dana.org.au/media-release-watering-ndis-desert/

⁷ 22 community based organisations share in \$11.1million to continue activities under the Individual Capacity Building or Social and Community Participation streams of ILC - <u>Media release on information</u>, inclusion and connection for people with disability | <u>Department of Social Services</u> Ministers