

Submission

NDIS Provider and Worker Registration and Enrolment

May 2024



DANA Disability Advocacy
Network Australia

About DANA

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

Our Vision

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

Our Purpose

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

We achieve this by

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

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Executive Summary

The NDIS Review proposed a new system of registration for all supports that people with disability use through the NDIS. The uncertainty around what, how and when changes to registration will be made has caused a lot of concern in the disability community, including for independent disability advocacy organisations.

DANA supports the Australian Government's establishment of this NDIS Provider and Worker Registration Taskforce (the Taskforce) to provide advice on the design and implementation of this new system of registration, and particularly the appointment of Natalie Wade as the chair, as disability leadership and representation is deeply important. We welcome this opportunity to provide input to this consultation to inform expert advice to the Australian Government.

A broken system

DANA's network of member organisations work with and advocate for some of the most marginalised Australians with disability, often from population groups that have multiple barriers to having their voices heard or their rights, will and preferences fulfilled. This submission reflects the themes we have heard from disability advocates for many years, and the sector's deep understanding of where systems have been failing to deliver quality, choice or safety to people with disability. These failures have extended across structures for:

- building and guiding Australia's disability supports ecosystem,
- overseeing and responding to complaints about quality, and
- safeguarding against harm, neglect and isolation, the existing systems.

In the current landscape there are significant safeguarding gaps in both registered and unregistered providers.¹ Independent advocacy organisations around the country frequently hear about shocking levels of neglect, exploitation, violence and abuse perpetrated by or within registered providers. There is also no oversight or visibility of unregistered providers, notably including providers delivering supported independent living (SIL) support. There is also a lack of scrutiny of quality, and little emphasis on quality improvement and safeguarding.

The only way for governments to make sure the new registration and quality system works for people with disability is to work closely and collaboratively with people with disability and their representative and advocacy organisations to develop the new model. There has been significant distress, fear and anxiety in the disability community around the potential impacts on choice and control if people with disability are restricted to using registered providers and workers. Many people with disability currently use self-management and direct employment. People with disability also rely on accessing mainstream services and use mainstream outlets. Meaningful consultation and co-design centring people with disability is essential to

¹ See [Section 1 - Existing arrangements and markets failing people with disability](#).

developing mechanisms for how the new model can retain optimal elements of innovation, flexibility and self-direction.

Among DANA's membership of disability advocacy organisations there are diverse and valuable perspectives to contribute to this process. Acknowledging and honouring the diverse perspectives on this issue, our organisation believes that mandating a basic level of enrolment of providers and workers delivering NDIS supports is a necessary step in remedying the low quality, safety and visibility of the status quo, though by no means the whole journey. However, the level of enrolment, and the administrative requirements for that level, must not risk the availability, affordability and choice of disability services for people with disability, particularly in regional, rural, remote and very remote areas. In addition, this basic level needs to be designed so that people with disability do not face barriers to access mainstream supports particularly for goods and consumables. DANA believes that this very basic level may not need worker screening, for example, for accessing mainstream retailers.

Principles to guide reforms

In these needed reforms, we do not want to lose the elements that are working well for many people with disability and their families and are at the heart of the Scheme's design to enable the autonomy and self-direction of people with disability. While there is an unquestionable need for an overhaul of the existing structures, this submission outlines important principles to guide the development of this new model, including principles informed by the need to:

- Improve safety and quality of services and supports for people with disability;
- Preserve and improve choice and control for people with disability; and
- Embed codesign and meaningful consultation with people with disability.²

The risk or decision-making framework, particularly to determine which service or support goes into which category, needs to be individualised, evidence-based and developed by people with disability. The impacts on choice and control must be carefully considered, including the impact on self-management, directly employing support workers and accessing mainstream services like purchasing consumables.

The model will need to be complex and sophisticated to allow flexibility, innovation and self-direction while also effectively identifying and responding to the high levels of risk that arise in certain support contexts. Although the NDIS needs to differentiate between the circumstances and capabilities of each individual and respond to varying levels of risk effectively and with nuance, the design must avoid blunt demarcations that conceptualise people with disability who are identified as experiencing higher levels of risk as less entitled to the freedom and dignity of choice and flexibility, or as needing to be restricted to a smaller market of "extra-regulated" providers. This presents the danger of the scheme treating some people with disability (particularly people with intellectual disability, acquired brain injury, psychosocial disability, and/or complex communication support needs, and those without strong support networks) as a "second class" of NDIS participants, who are limited in their choices and designated to "disability services land", with these distinctions working to

² See: [Section 2 - Principles to guide development of the new model](#)

structurally separate and exclude them from the mainstream, and segregate and isolate them from community involvement and inclusion. We know too well that this paternalistic approach of sheltering “vulnerable people” in disability-specific settings on a rationale of protecting them has historically had the opposite effect. Instead, violence, abuse, neglect, exploitation, discrimination and dehumanisation have thrived in exclusionary and institutional modes of service delivery.³

One piece of the puzzle

Getting the new model for registration and enrolment right is an important and challenging piece of the puzzle of redesigning the NDIS to facilitate the rights of people with disability to access the services they need. However, the design of a model of provider and worker registration and enrolment, no matter how sophisticated and reflective of the principles outlined above, is only one piece in the broader context of the transformative changes needed. Although in this consultation, the Taskforce is focused specifically on the development and delivery of the model proposed in Recommendation 17, this task cannot be separated out from the other crucial components for ensuring people with disability have a choice of quality supports, control over their daily lives and freedom from violence, neglect or exploitation.⁴

Both the Disability Royal Commission and the NDIS Review have outlined key elements of change to the regulatory and safeguarding system that need to be considered alongside the question of registration.

This submission also briefly outlines how this new model will need to exist within a landscape of other essential elements supporting the fulfilment of the rights of Australians with disability, including:

- Improved monitoring and oversight, complaints processes and promotion of best practice;
- Active efforts and investment in promoting the inclusion of people with disability and their connections to family, friends and community;
- Concerted action to dismantle the structures, service models and attitudes that separate, isolate and discriminate against people with disability;
- Access to:
 - Independent disability advocacy;
 - Support for decision making, free from conflicts of interest;
 - Peer-led information and support;
 - Capability and capacity building, including support for self-management; and
- Structures and investment to address gaps in supports, including:
 - Foundational supports;
 - An organisation tasked with and funded to be an independent consumer voice;

³ WWDA, CYDA, FPDN, PWDA, NEDA, AFDO and IA (2020) [Segregation of people with disability is discrimination and must end – Position Paper](#).

⁴ See [Section 3 - Upholding and fulfilling the rights of people with disability](#)

- Provider panels; and
- Provider of last resort schemes.

The new model will need to effectively connect and interact with, and be strengthened by, all of these elements to succeed in its objectives. Developing and implementing regulatory changes to registration and enrolment must be done in concert with co-designing the broader safeguarding and structural reforms needed.

Recommendations

Recommendation 1: That the new enrolment and registration system (in combination with other needed improvements to the NDIS and to quality and safeguarding measures) ensures that people with disability have safer and higher quality services and supports.

Recommendation 2: That the new model is complemented by a range of effective and focused initiatives and mechanisms to improve governance, oversight, service quality and safeguarding that are codesigned with people with disability and their representative organisations.

Recommendation 3: That the new model adhere to the principles developed by Disability Representative Organisations (listed in Section 2).

Recommendation 4: That people with disability must not lose support during transition, and reports are made public about the implementation of the new model and the impact on people with disability.

Recommendation 5: That the new registration and quality system ensures that people with disability have choice and control over the supports they use, both inside and outside the NDIS.

Recommendation 6: That the new enrolment and registration system allows a new basic level of enrolment that collects simple information through a process that is not onerous, costly, requiring worker screening or likely to constrict the variety and modes of supports available to people with disability.

Recommendation 7: That the new system accommodate options valued by people with disability including "services for one", purchasing supplies from mainstream sources, and direct employment of support workers.

Recommendation 8: That the new model for registration utilises, where possible, existing or future regulatory structures, such as the ABN register and myGovID.

Recommendation 9: That people with disability lead and are central to co-design of a new registration and quality system, reflecting the diversity and individuality of people with disability, including people with intellectual disability and people living in remote and rural areas.

Recommendation 10: That disability representative and advocacy organisations receive specific funding for engaging with major reforms associated with the NDIS Review and Disability Royal Commission recommendations over the next 5 years in order to engage staff, increase capacity, develop consultation mechanisms and deliver on this complex, cross-government liaison and co-design.

Recommendation 11: That the new registration and enrolment system must not have separate systems for different groups of people with disability, and prioritises the goal of living in the community and being connected to a wide range of people and communities.

Recommendation 12: That the people with disability who are at heightened risk of marginalisation, isolation and disadvantage are actively linked with supports to help them to navigate the new system, make decisions about risk and safety, choose quality supports and exercise control over their lives.

Recommendation 13: That issues for people with disability who live in regional, rural and remote areas are included in the development of the new registration and quality system.

Recommendation 14: That the new model be designed and implemented to effectively interact with and be complemented by a raft of other essential components to support access to safe, quality supports for people with disability, including:

- effective oversight and action to deter poor quality and identify and prevent risks to safety;
- accessible and inclusive complaints and reporting processes;
- independent disability advocacy;
- accessible peer-led information and support;
- support for decision-making; and
- structures and investments to address gaps in support.

Recommendation 15: That an individualised evidence-based risk assessment framework is developed with people with disability, including changes to the safeguarding mechanisms to enable this.

Recommendations 16: That there is effective oversight of high risk environments and supports through on-the-ground checks such as unannounced visits, including when advocates report concerns of mistreatment or gatekeeping, or when people with disability are identified as experiencing segregation, isolation or disconnection from natural safeguards.

Recommendation 17: That people with disability can participate, with independent advocacy and/or decision making support if needed, in complaints, feedback and reporting processes that are independent, accessible, inclusive and effective in enhancing the quality and safety of their supports.

Recommendation 18: That the complaints-handling functions are separated from other regulatory functions through the establishment of a trustworthy rights-focused agency or commission, with sophisticated information sharing arrangements facilitating effective linkages.

Recommendation 19: That people with disability are aware of and can access independent disability advocacy from well-developed sector funded to meet demand and need.

Recommendation 20: That governments provide secure and adequate resourcing to the advocacy sector, by immediately increasing funding for independent advocacy organisations who directly support people with disability by \$91 million per annum:

- \$43 million to address immediate funding shortfalls with an urgent injection of funds for the National Disability Advocacy Program (NDAP)
- \$25 million through a new grant round for non-NDAP organisations in urgent need of funding
- \$20 million for rural and remote providers
- \$5.225 million for capacity building in the sector, including for First Nations cultural safety, resourcing, pilot progress and increased awareness of Supported Decision Making.

Recommendation 21: That people with disability, particularly those at risk of service capture or isolation in closed or institutional settings, are aware of their rights to report and complain about poor quality, mistreatment and neglect, and of their right to access independent advocacy support to do so.

Recommendation 22: That people with disability have access to independent capacity building information and support to engage with services and supports.

Recommendation 23: That the accessible information and peer support sectors are supported through secure long-term funding for independent community-driven organisations, allowing them to accumulate knowledge, skills, experienced staff and relationships over time.

Recommendation 24: That national education and awareness initiatives are adequately resourced to inform people with disability, professionals and the general public about human rights, rights to quality services, processes for identifying or reporting violence, neglect and abuse, or making complaints about disability services.

Recommendation 25: That all people with disability who need support for decision making are consulted about the supports they use, with independent support for that decision making that is well-resourced.

Recommendation 26: That the new model of registration and enrolment is designed to work with and is accompanied by a range of other structures for monitoring and intervention in the disability supports ecosystem, including investment to address the gaps in supports for people with disability, such as:

- Foundational Supports;
- independent disability advocacy and information, including a voice promoting consumer rights in the NDIS market; and
- provider panels and 'provider of last resort' schemes.

Section 1 - Existing arrangements and markets failing people with disability

Independent disability advocacy organisations possess extensive insights about what is and, mostly, what is not working well in the existing NDIS Quality and Safeguarding Framework and other Federal, and state and territory mechanisms designed and implemented to promote safety and quality across a range of service systems used by people with disability.⁵ As DANA submitted to the NDIS Review, the existing quality and safeguarding arrangements have been failing Australians with disability – immediate actions and comprehensive reforms are desperately needed.⁶

Years of appalling examples and examination by the DRC and other inquiries have demonstrated that current regulatory, safeguarding and oversight systems are inadequate to address the scale of violence and abuse against people with disability, or to provide consistent, high-quality services available from their NDIS plans. These systems are frequently not accessible and rely on people with disability and their families making complaints in order to activate regulatory mechanisms. There is little proactive or effective work to ensure quality service delivery.

Through our policy work, informed by our engagement with disability advocacy sector, DANA has highlighted a number of persistent issues with the functioning of the NDIA, the market of services and supports available to people with disability and the Quality and Safeguards Commission.⁷ Advocates are increasingly working to remedy consumer-level complaints,⁸ and resolve issues with service provision,⁹ and acting as market stewards.¹⁰ In addition, advocates are strongly concerned about the lack of action from the Quality and Safeguards Commission in response to credible and repeated complaints about violence and abuse against people with disability. Our consultations with both disability advocates and people with disability found the following key concerns:¹¹

- NDIS registered and unregistered services being unsafe;

⁵ Disability Advocacy Network Australia (2022) [Rights, Safety, Quality – Voices of Advocacy](#).

⁶ Disability Advocacy Network Australia (2023) NDIS Review engagement – [Summary Report – Quality and Safety](#);

Disability Advocacy Network Australia (2023) [NDIS Quality and Safeguarding Framework issues paper – DANA Submission to the NDIS Review](#).

⁷ Laura Davy, Molly Saunders and DANA (2023) [Quality and Safety](#) – Discussion paper for NDIS Review engagement. Disability Advocacy Network Australia.

Disability Advocacy Network Australia (2022) [Independent disability advocacy – DANA submission to the Disability Royal Commission](#).

Disability Advocacy Network Australia (2022) [Rights, Safety, Quality – Voices of Advocacy](#).

⁸ Gerard Brody, (2023) [Consumer policy response to NDIS Review “What we have heard” report](#). Disability Advocacy Network Australia.

⁹ Disability Advocacy Network Australia (2022) [Independent disability advocacy – DANA submission to the Disability Royal Commission](#).

¹⁰ Celia Green, Gemma Carey & Eleanor Malbon (2022): Advocacy as market stewardship in social care quasi-markets, *Public Management Review*.

¹¹ Disability Advocacy Network Australia (2023) NDIS Review engagement – [Summary Report – Quality and Safety](#)

- reporting issues to complaint bodies is too convoluted and difficult;
- people with disability face barriers to accessing advocacy support;¹²
- raising an issue or lodging a complaint does not lead to action or change;
- mainstream supports (like the legal system) are not accessible for people with disability; and
- no specific support for people with disability about what a quality and safe service looks like.

The Disability Royal Commission and the NDIS Review have both recommended significant changes to governance, safeguarding and accountability to get action on the key reforms outlined by both major reports. They both outline failures of the current fragmented and inaccessible complaints system to stop neglect, violence and abuse against people with disability. Their reports provided strong evidence, consistent with the observations and insights of advocates, that the existing Quality and Safeguards Commission is not fit-for-purpose, nor presently capable of managing complaints effectively.¹³ Both processes concluded that the current regulatory and complaints systems are not fit-for-purpose and discuss the impact of a lack of governance and oversight.

The NDIS Review flagged improving quality and safety as a key reason for the need for changing the current system of registration, including:

- Lack of visibility of payments to unregistered providers.
- Reliance on individuals to assess risk and quality.
- The Quality and Safeguards Commission cannot monitor market or take regulatory action.
- Need for oversight of unregistered providers, particularly those providing home and living supports.
- Current worker screening not working well to provide quality services and safety.
- The Quality and Safeguards Commission not effectively addressing ‘conflicts of interest and client capture, sharp practices (including unfair service agreements), transparency and duties of care.’

The recommendations from the Disability Royal Commission and the NDIS Review both contemplate major reforms to this body and its multiple functions, and DANA believes this is urgently needed.¹⁴ The complex challenges of improving the quality and safety of NDIS supports and the strong and varied perspectives on the changes to registration and enrolment described in Recommendation 17, must not cause leaders and policymakers to

¹² Disability Advocacy Network Australia (2022) [Independent disability advocacy – DANA submission to the Disability Royal Commission](#).

Disability Advocacy Network Australia (2023) [Intake Project Summary Report](#), Commissioned by Department of Social Services

See also [DANA website](#) for extent of unmet demand in NDIS Appeals program, in recent years.

¹³ Complaint processes are discussed further in Section 3: [Accessible and inclusive complaints and reporting processes](#).

¹⁴ Royal Commission into Violence, Abuse, Neglect and Exploitation (2023) [Final Report - Volume 10, Disability services](#) Part B, p245-433.

NDIS Review Panel (2023) *Working together to deliver the NDIS – Independent Review in the National Disability Insurance Scheme*, particularly Recommendations 12, 16, 17, 18 and 19.

relegate this area to 'the too hard basket'. Without transformative changes to mainstream and disability services, people with disability, especially those who are most disadvantaged and marginalised, will continue to suffer neglect and violence and be left with poor choices of low quality supports or no supports.

Recommendation 1: That the new enrolment and registration system (in combination with other needed improvements to the NDIS and to quality and safeguarding measures) ensures that people with disability have safer and higher quality services and supports.

Recommendation 2: That the new model is complemented by a range of effective and focused initiatives and mechanisms to improve governance, oversight, service quality and safeguarding that are codesigned with people with disability and their representative organisations.

Section 2 - Principles to guide development of the new model

With the introduction of a new regulatory framework, there are key principles we believe must be central to the reform process. Developed with other Disability Representative Organisations, the following key principles should guide the development and implementation of the new model.¹⁵

1. People with disability must have choice and control over the supports they use, both inside and outside the NDIS – for example, people with disability can use mainstream services, and purchase consumables from mainstream outlets.
2. People with disability need to have safer and higher quality services and supports.
3. People with disability need to be involved in co-design of a new registration and quality system.
4. People with disability who need support for decision making need to be consulted about the supports they use, with independent support for that decision making.
5. People with disability need to have access to capacity building information and support to engage with services and supports – for example, independent, accessible, peer led information and support to build skills and knowledge about what is a good quality service.
6. An individualised evidence-based risk assessment framework is developed with people with disability, including changes to the safeguards mechanism to enable this.
7. Issues for people with disability who live in regional, rural and remote areas are considered.

Implementation must be carefully planned so it does not interfere with the continuity of supports for people with disability during the transition to the new model.

Recommendation 3: That the new model adhere to the principles developed by Disability Representative Organisations.

Recommendation 4: That people with disability must not lose support during transition, and reports are made public about the implementation of the new model and the impact on people with disability.

¹⁵ See: A joint submission from Disability Representative Organisations to the NDIS Provider and Worker Registration Taskforce – 1 May (2024)

Retaining and enhancing choice of and control over supports

Though ‘safety’ and ‘choice and control’ are often framed as principles requiring a careful “balancing act” or as pulling in opposing directions, our discussions with advocates have underlined that this is often practically not the case. The values of independence, choice and control for people with disability are largely not in tension with promoting the right to live in freedom from violence, abuse, neglect and exploitation. Rather, these values strengthen one another.

Generally, efforts to uphold independence, choice and control in service contexts contribute to the quality of life of people with disability.¹⁶ As discussed in Section 3 of this submission, implementing safeguards like ensuring access to independent advocacy and the provision of navigation supports, capacity building, training in human rights, supported decision making and self advocacy for people with disability, will all contribute to independence, self-direction and the realisation of control and choice for people with disability.

To preserve the flexibility and innovation that has driven and enabled many people with disability finding unique and responsive ways to access supports in ways that work for them, the Taskforce must develop a sophisticated and considered model. More than the four categories described by the NDIS Review in Recommendation 17, are needed to allow for a nuanced, responsive approach. The following modes of receiving support are extremely valued by people with disability:

- Services for One;¹⁷
- Purchasing consumables from mainstream services; and
- People with disability directly employing disability support workers.

These options need to be retained and incorporated effectively into the new model of enrolment and registration, so they are practically workable and not financially or administratively burdensome, or inhibiting market development and growth. The model also needs to be sophisticated in how it engages with the complexity of risk while also considering how to maximise clarity and ease of navigation in determining what level of regulation is necessary. Where appropriate, current regulatory burdens can be reduced, and processes streamlined and made more effective and targeted to the highest risk supports.

The Taskforce should consider how to efficiently align new processes with other regulatory structures or useful exemplars in other contexts such as the ABN register and existing government systems and processes for verifying business identity, such as myGovID. In the imposition of universal enrolment as a baseline, there need to be careful thinking and design to craft fit-for-purpose categories of enrolment that are not costly or burdensome but can simply allow for the collection of the basic information needed to provide visibility of the NDIS market. As discussed below in Section 3, this must be accompanied by other measures to support and empower people with disability to confidently exercise their rights as consumers

¹⁶ Carli Friedman and Laura VanPuymbrouck, (2019) ‘The impact of people with disabilities choosing their services on quality of life outcomes’, *Disability and Health Journal*, Volume 12, Issue 2, Pages 187-194.

¹⁷ See: Inclusion Australia website: [A Service for One Project \(inclusionaustralia.org.au\)](https://www.inclusionaustralia.org.au)

and citizens and make informed assessments about quality and safety, both within and outside the NDIS.¹⁸

Recommendation 5: That the new registration and quality system ensures that people with disability have choice and control over the supports they use, both inside and outside the NDIS.

Recommendation 6: That the new enrolment and registration system allows a new basic level of enrolment that collects simple information through a process that is not onerous, costly, requiring worker screening or likely to constrict the variety and modes of supports available to people with disability.

Recommendation 7: That the new system accommodate options valued by people with disability including "services for one", purchasing supplies from mainstream sources, and direct employment of support workers.

Recommendation 8: That the new model for registration utilises, where possible, existing or future regulatory structures, such as the ABN register and myGovID.

Co-design for the diversity of people with disability

Co-design with people with disability and their representative organisations to develop and implement the new model is essential, as all reforms must be guided by the "nothing about us without us" principle at the heart of the disability rights movement.¹⁹

The ability to exercise choice and control of providers is particularly important for intersectional communities of people with disability both inside and outside the NDIS. These communities face additional and unique barriers to accessing safe and quality supports. The impacts on First Nations, Culturally and Linguistically Diverse (CALD), LGBTQIA+SB, and other diverse communities need to be examined and considered carefully throughout the NDIS reform process. People with disability, their families and organisations representing different communities must be involved in designing and testing improvements to provider registration and enrolment to ensure they work well for everyone.

Groups most impacted by limited availability and accessibility of services and supports also need to be central in codesign processes. People with disability who live in regional, rural and remote Australia need to be included in the consultation and codesign through resourced engagement with representative, advocacy and peer support organisations and networks operating in local communities. We also strongly support Inclusion Australia's call for the inclusion of people with intellectual disability in this co-design process.²⁰

¹⁸ Gerard Brody, (2023) [Consumer policy response to NDIS Review "What we have heard" report](#). Disability Advocacy Network Australia.

¹⁹ See further discussion in Disability Advocacy Network Australia (2024) The Australian Government response to the Royal Commission into Violence, Abuse, Neglect and Exploitation.

²⁰ Inclusion Australia (2024), [NDIS Worker and Provider Registration](#) Position statement.

To support meaningful co-design and consultation, the advocacy sector needs to be resourced or this engagement will run the risk of being tokenistic and inauthentic, and of perpetuating exclusion without properly incorporating or reflecting the diverse needs and perspectives of people with disability. Disability representative and advocacy organisations must receive additional systemic advocacy funding for the next five years to engage and lead on reforms from the Disability Royal Commission and the NDIS Review.²¹

Recommendation 9: That people with disability lead and are central to co-design of a new registration and quality system, reflecting the diversity and individuality of people with disability, including people with intellectual disability and people living in remote and rural areas.

Recommendation 10: That disability representative and advocacy organisations receive specific funding for engaging with major reforms associated with the NDIS Review and Disability Royal Commission recommendations over the next 5 years in order to engage staff, increase capacity, develop consultation mechanisms and deliver on this complex, cross-government liaison and co-design.

Inclusive and responsive to individuals

As we've seen through many tragic cases leading up to, during and since the Disability Royal Commission, there is higher risk of violence, abuse, neglect and exploitation when people are segregated and/or isolated from others in the community (such as family, friends, advocates, community visitors, or other professionals playing a safeguarding role). This risk is very high for people with disability living in closed residential settings such as prisons, group homes or boarding houses, or experiencing domestic violence, neglect or service capture.²² The new Provider Risk Framework needs to identify and evaluate the risk profile of different types of supports and providers, while also reflecting the centrality of individual contexts and circumstances in the process for determining the level of regulatory barriers and oversight imposed by the scheme.

However, the design of this model must be nuanced and carefully considered so that the NDIA's processes for distinguishing between the capabilities and confidence of some individuals with disability, and others likely to experience greater risk does not inadvertently perpetuate inequity and segregation. There is a danger of entrenching a deeply problematic conception that sharply divides people with disability into two groups:

²¹ See [Disability Royal Commission Response Consultation – A joint submission from Disability Representative Organisations](#). (January 2024). Disability Advocacy Network Australia (2024) [The Australian Government response to the Royal Commission into Violence, Abuse, Neglect and Exploitation](#).

²² The phrase "service capture" or whole-of-life service provision, has been used to describe where someone has a single service provider delivering both accommodation and all other supports. Laura Davy, Molly Saunders and DANA (2023) [Quality and Safety](#) – Discussion paper for NDIS Review engagement. Disability Advocacy Network Australia. (See discussion of how it can affect people with intellectual disability: Inclusion Australia (2022) [Capability and Culture of the NDIA](#): Submission to the Joint Standing Committee on the NDIS)

- savvy consumers, connected to community and skilled in choosing high quality supports and exercising control over their lives;
- at risk and “vulnerable” to harm because they have not demonstrated these capabilities and skills.

Disability advocates know well that this type of distinction does not reflect the uniqueness, diversity and complexity of the lives people with disability. A system that treated one group of people with disability as qualifying as “skilled enough” or “supported and connected enough” to safely choose their providers and live in the community, would therefore deem those who don’t meet the criteria as “less able” to choose safe, quality supports and less entitled to the dignity of risk. People with disability excluded from these privileges would be restricted in their choices to the “extra-regulated” providers, further designating and separating them out of the mainstream and the community. This binary approach would likely exacerbate existing inequities, and potentially push some people towards or further into congregate models of support, living, employment and recreation that do not promote their community inclusion or connection outside of disability services.

Recommendation 11: That the new registration and enrolment system must not have separate systems for different groups of people with disability, and prioritises the goal of living in the community and being connected to a wide range of people and communities.

Recommendation 12: That the people with disability who are at heightened risk of marginalisation, isolation and disadvantage are actively linked with supports to help them to navigate the new system, make decisions about risk and safety, choose quality supports and exercise control over their lives.²³

Avoiding negative impacts in regional, rural and remote communities

There have been gaps in service provision that pre-date the introduction of the NDIS.²⁴ Since its implementation people with disability in rural and remote areas have continued to experience very different access to disability supports to those living in urban areas. Generally, there is less choice in who can provide services, and some areas completely lack large swathes of any crucial services.²⁵ Many organisations face increased difficulty in hiring

²³ The roles of independent supported decision making, information and advocacy are discussed further below in Section 3.

²⁴ Angela Dew, Kim Bulkeley, Craig Veitch, Anita Bundy, Michelle Lincoln, Jennie Brentnall, Gisselle Gallego, and Scott Griffiths (2013) "Carer and service providers' experiences of individual funding models for children with a disability in rural and remote areas." *Health & Social Care in the Community* 21, no. 4 (2013): 432-441

Stuart Wark, Rafat Hussain, and Helen Edwards. "Rural and remote area service provision for people aging with intellectual disability." *Journal of Policy and Practice in Intellectual Disabilities* 10, no. 1 (2013): p62-70.

²⁵ Cherry Baylous and Demi Woods (2022) *The Aussie Battlers: Life with a disability in regional, rural and remote NSW*, Disability Advocacy NSW Scoping Research Report: [Disability Advocacy NSW website \(da.org.au\)](https://www.da.org.au). Accessed 4 November 2022.

and attracting workers with the right qualifications,²⁶ as well as higher operating costs resulting from additional travel expenses.²⁷ Many therapy and other capacity building services have to be delivered via telehealth methods which aren't suitable or effective for all people or all therapy types. There is also an additional administrative burden on the back of rural and remote participants who often have to request additional amounts to ensure that services are affordable.

Where choice and control are not practically available to people - as is very commonly the case in rural and remote areas - there is a high risk of abuse, neglect, and exploitation. As we recently argued to the Joint Standing Committee on the NDIS, people with disability should not have to choose between getting the services they need and being safe while doing so.²⁸

In response to the NDIS Review's recommendation, people with disability and their supporters and advocates are particularly concerned that a new system of registration and enrolment must avoid unintended negative effects on the availability and cost of supports in regional, rural and remote communities:

- People with disability who live in regional, rural and remote communities already face profound challenges with access and cost effectiveness of supports;
- Many locations currently have no, or a very small number of, registered providers, or providers that provide a small proportion of NDIS supports compared with other services;
- People with disability fear the proposed changes disincentivise local providers from providing supports, and increase the challenges faced by people with disability in regional, rural and remote communities.

More broadly, many of the recommendations that have been made by the NDIS Review and the DRC have great potential to strengthen the local supports and service systems to meet the needs of people with disability in rural, regional and remote communities, both within and outside of the NDIS. Effective, locally adapted and responsive implementation of a range of proposed improvements to market monitoring and stewardship,²⁹ safeguarding, equity and accessibility could potentially have profound impacts in the lives of some of the most disadvantaged and marginalised Australians.

²⁶ Gilroy, J., Veli-Gold, S., Wright, W., Dew, A., Jensen, H., Bulkeley, K., & Lincoln, M. (2023). Disability workforce and the NDIS planning process in regional, rural and remote regions of Australia: Scoping review. *Australian Journal of Rural Health*, 31(5), 839-854.

Monica Cuskelly (2022) Challenges for the National Disability Insurance Scheme in regional, rural, and remote areas. *Research and Practice in Intellectual and Developmental Disabilities*, p1-10.

²⁷ Disability Advocacy Service (Alice Spring, NT) input about advocacy in central Australia, 2023 (received by DANA February 2024). Rights In Action Inc. (Cairns, QLD) input (received by DANA February 2024).

²⁸ Disability Advocacy Network Australia (2023) [NDIS participant experience in rural, regional and remote Australia](#).

²⁹ Gemma Carey, Eleanor Malbon, Axelle Marjolin, Daniel Reeders (2018) *NDIS Markets: Market stewardship actions for the NDIS*, Centre for Social Impact.

An improved and active effort to assess and detail market shortages specific to local areas is crucial to give policy makers and the community understanding about the problem. Local communities often rely on their own networks to address gaps in support, and there are not currently effective mechanisms for identifying where interventions are needed to guide the market or address shortfalls in the options people with disability, through alternative commissioning or provider panel arrangements.³⁰

While we and others have noted the lack of support availability generally, the Disability Royal Commission specifically highlighted the lack of availability of Positive Behaviour Support Practitioners in regional and remote areas with thin markets and recommended providing additional incentives for providers, creating a publicly accessible list and other measure to address shortages.³¹

Recommendation 13: That issues for people with disability who live in regional, rural and remote areas are included in the development of the new registration and quality system.

³⁰ NDIS Review Panel (2023) Working together to deliver the NDIS – Independent Review of the National Disability Insurance Scheme Supporting Analysis, p772.

³¹ Disability Royal Commission Final Report, Vol 10, Rec 10.24.

Section 3 - Upholding and fulfilling the rights of people with disability

In the questions to guide submissions to this consultation, the Taskforce has listed a number of human rights, including the rights to live independently, be included in the community, be free from violence, abuse, neglect and exploitation, and have an adequate standard of living and economic and social participation. The enjoyment of these rights by people with disability all depend on Australia developing a well-functioning ecosystem of disability and mainstream supports to meet the diverse needs of people with disability. While all stakeholders see this as the goal, how to best achieve this outcome is now the contentious challenge for the Taskforce and government to consider and formulate the needed reforms, with meaningful co-design with and leadership by the disability community.

Currently many people with disability in the NDIS can exercise the right to choose an unregistered provider or worker. However, for many people with disability other rights remain unfulfilled as their opportunities to choose from a range of quality supports, or control how they receive supports and participate in their community are limited or even non-existent. As the Disability Royal Commission heartbreakingly demonstrated in both registered and unregistered service provision contexts, the right to freedom from violence, abuse, neglect or exploitation has been poorly defended by existing safeguarding and quality assurance mechanisms. These systemic failures and dysfunction, and the resulting neglect, mistreatment and exploitation have been particularly acute for the multiply disadvantaged and marginalised people with disability who advocacy organisations often work with and speak up for, and who may also face the most practical difficulties in accessing advocacy support – including:

- people with intellectual disability, acquired brain injury, psychosocial disability, and/or complex communication support needs;
- those without strong support networks, such as family, friends or other supporters to help them navigate complex systems, speak up, make complaints or otherwise defend their rights;
- people experiencing intersectional disadvantage due to their identity, including
 - First Nations people
 - CALD people
 - LGBTIQ+SB people
 - Children and young people
 - Older people
 - Women, girls and non-binary people
- People with disability who are separated from mainstream community participation and isolated, whether in the community or in closed or institutional settings, such as group homes, boarding houses, jails, schools etc; and/or
- Children and young people with disability, including those in and transitioning from out-of-home care.

As noted above, while developing the new model of enrolment and registration is a complex and crucial challenge, alone it does not have the scope to address or solve fundamental problems, including support gaps and the victimisation, exploitation and neglect that has

thrived despite the operation of the NDIS Quality and Safeguarding Framework. While the specific remit for this consultation and the advice of the Taskforce is focused on Recommendation 17, effective functioning of a new system for registration and enrolment will necessarily be supported by and reliant on other components of reform.

Both the NDIS Review and the Disability Royal Commission recommended that far more effective safeguarding measures and protections, along with sophisticated mechanisms for market shaping, stewardship and intervention, need to be implemented. As discussed above in Section 2, enhanced measures across the preventative, developmental and corrective domains of safeguarding need not be inimical to people enjoying expanded control over how they receive their supports. Overall, flexibility and self-direction for people with disability and their supporters, supported by individual and sector capacity-building, and independent information, advocacy and decision making support, all contribute to the prevention of violence, abuse, neglect and exploitation and can help to drive improvements to the quality of supports and market innovation.³²

Recommendation 14: That the new model be designed and implemented to effectively interact with and be complemented by a raft of other essential components to support access to safe, quality supports for people with disability, including:

- effective oversight and action to deter poor quality and identify and prevent risks to safety;
- accessible and inclusive complaints and reporting processes;
- independent disability advocacy;
- accessible peer-led information and support;
- support for decision-making; and
- structures and investments to address gaps in support.

Effective oversight and action to deter poor quality and identify and prevent risks to safety

In response to appalling failures of safeguarding that have come into the spotlight in recent years, there has been an increasing focus on assessing the risks faced by people with disability at the NDIA, its partners, and other government agencies. The Quality and Safeguards Commission has also initiated a number of own motion inquiries on systemic issues. However, since the early implementation of the Scheme, advocates have expressed concern that the Agency does not appear to have adequate processes for identifying people with disability most in need of connections with community, building natural safeguards or additional support, including from an advocacy organisation who is independent of government or service provision.³³ There have been limited numbers of civil

³² Davy, L., Robinson, S., Idle, J., & valentine, kylie. (2024). Regulating vulnerability: policy approaches for preventing violence and abuse of people with disability in Australian service provision settings. *Disability & Society*, 1–22.

³³ Disability Advocacy Network Australia (2022) [Rights, Safety, Quality – Voices of Advocacy](#).

enforcement actions or other actions like registration revocations or infringement notices by the Quality and Safeguard Commission.³⁴ This is consistent with dissatisfaction we have heard over many years from disability advocates in relation how this body has been functioning to oversee compliance with relevant service standards of quality and safety.

Recurrent experiences and concerns included:

- Inadequate oversight and monitoring;
- Lack of action on systemic issues identified and reported by advocacy organisations;
- Lack of measurement of people's rights and wellbeing; and
- Disconnect between glossy organisational brochures and registered policies and reality "on the ground" within group homes.³⁵

A regulatory focus on compliance with process or paperwork has not been effective in ensuring registered providers are actually delivering high quality supports, nor has it fostered approaches focused on improving the experiences of people with disability.³⁶ Unannounced visits through community visitors schemes,³⁷ and other mechanisms (including proactively connecting people experiencing risk to disability advocates)³⁸ are needed to identify where there are large gaps between what is promised in an organisation's policies, indicated in their reporting or demonstrated during audits, and the true on-the-ground experiences of people with disability when the service provider is not aware of external scrutiny. The operations and structure of the Quality and Safeguards Commission needs to be addressed as a vital part of any changes to the registration system.

Recommendation 15: That an individualised evidence-based risk assessment framework is developed with people with disability, including changes to the safeguarding mechanisms to enable this.

Recommendations 16: That there is effective oversight of high risk environments and supports through on-the-ground checks such as unannounced visits, including when advocates report concerns of mistreatment or gatekeeping, or when people with disability are identified as experiencing segregation, isolation or disconnection from natural safeguards.

Disability Advocacy Network Australia (2022) [Independent disability advocacy – DANA submission to the Disability Royal Commission](#).

Celia Green, Gemma Carey & Eleanor Malbon (2022) Market shaping: Understanding the role of non-government actors in social care quasi-market stewardship, *Social Policy and Administration* 56 (7) 1138-1155.

³⁴ Gerard Brody, (2023) [Consumer policy response to NDIS Review "What we have heard" report](#). Disability Advocacy Network Australia.

³⁵ See [Advocates on Quality and Safeguarding – April 2021](#), pages 5- 9.

³⁶ McEwen, J., Bigby, C., & Douglas, J. (2021). How leaders in day service organisations understand service quality. *Research and Practice in Intellectual and Developmental Disabilities*, 8(2), 126–134. <https://doi.org/10.1080/23297018.2021.1951619>

³⁷ See: [Analysing the recommendations on community visitors | Disability Advocacy Network Australia \(dana.org.au\)](#)

³⁸ Disability Advocacy Network Australia (2022) [Independent disability advocacy – DANA submission to the Disability Royal Commission](#).

Accessible and inclusive complaints and reporting processes

The current complex landscape is fragmented and often inaccessible and ineffective for people with disability seeking remedies, recognition or resolution of their complaints or negative experiences with disability supports. The burden of this complexity falls on people with disability, their families and supporters, who then often turn to independent advocacy organisations to support them to navigate that system. Research for DANA's NDIS Review submission found that 'Inadequate mainstream and NDIS complaints mechanisms have a negative impact on both people with disability that use the NDIS and other people with disability, failing to provide consistent access to quality services or sufficient remedies and redress for breaches of rights.'³⁹

Over several years and throughout our engagements with advocates during the Disability Royal Commission and the NDIS Review, consistent themes and frustrations emerged strongly in advocates' commentary about pursuing complaints with the NDIS Quality and Safeguards Commission. Recurrent experiences and concerns included:

- Complaints go nowhere;
- Lack of outcomes for complainants;
- Lack of enforcement or consequences for providers;
- Reputation as "toothless";
- Bureaucratic and technical;
- Risk of power imbalance; and
- Overly trusting of service providers who can "control the narrative".⁴⁰

Both the NDIS Review and Disability Royal Commission highlighted how the current complaints system is not working, is not accessible and is not delivering safer or improved quality services. Issues with the information systems and data linkage and analysis capabilities in the Quality and Safeguards Commission have remained present, even after a report of the Joint Standing Committee on the NDIS in 2021 noted significant concerns in the administration's ability to follow up complaints and gain a complete understanding of a matter's history when reviewing their system.⁴¹ A particular submission from the Community and Public Sector Union noted multiple instances where staff had to manage spreadsheets individually to manage their caseloads.⁴² DANA believes that the complaints system at the Quality and Safeguards Commission is broken, requiring very significant data and digital changes to be functional and responsive to the likely increase in complaints during this time of transition.

³⁹ Laura Davy, Molly Saunders and DANA (2023) [Quality and Safety](#) – Discussion paper for NDIS Review engagement. Disability Advocacy Network Australia.

⁴⁰ See [Advocates on Quality and Safeguarding – April 2021](#), pages 2- 5.

⁴¹ Joint Standing Committee on the National Disability Insurance Scheme, [NDIS Quality and Safeguards Commission](#), Chapter 9 (Australian Parliament).

⁴² Community and Public Sector Union (202) Inquiry into the NDIS Quality and Safeguards Commission – Submission to Joint Standing Committee on the National Disability Insurance Scheme, p10.

Government needs to take on this systemic complexity and undertake reform that ensures that people with disability can access timely, effective and adequate mechanisms to address violence, abuse, neglect and exploitation. A research report commissioned by the Disability Royal Commission found that an independent, trustworthy and effective complaint processes is needed.⁴³ Analysis that DANA commissioned for the NDIS Review found that ‘It is common in other markets for the responsibility for complaints resolution to be housed in a different agency to the agency responsibility for setting standards and ensuring compliance with standards. Complaints handling and compliance activities are related but separate activities.’⁴⁴

Sophisticated information sharing arrangements (in both legislative authorisation and technological infrastructure) must enable these mechanisms to feed in to and be informed by the operation of the new enrolment and registration system. However, we believe that an ideal structure would be to separate the complaints function to an independent entity, to overcome the conflicts between fulfilling multiple functions that have emerged with other regulatory and quality assurance and promotion functions in the current model of the Quality and Safeguards Commission.⁴⁵ There should be potential for repeated complaints to prompt further monitoring or oversight, trigger unannounced visits or lead to reviews of registration or enrolment status.⁴⁶

Recommendation 17: That people with disability can participate, with independent advocacy and/or decision making support if needed, in complaints, feedback and reporting processes that are independent, accessible, inclusive and effective in enhancing the quality and safety of their supports.

Recommendation 18: That the complaints-handling functions are separated from other regulatory functions through the establishment of a trustworthy rights-focused agency or commission, with sophisticated information sharing arrangements facilitating effective linkages.

⁴³ [Disability complaints processes need major overhaul - The University of Sydney](#) - Dinesh Wadiwel, Claire Spivakovsky, Linda Steele (2022) *Complaint mechanisms: Reporting pathways for violence, abuse, neglect and exploitation* - Research Report commissioned by the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability.

⁴⁴ Gerard Brody, (2023) [Consumer policy response to NDIS Review “What we have heard” report](#). Disability Advocacy Network Australia.

⁴⁵ Gerard Brody, (2023) [Consumer policy response to NDIS Review “What we have heard” report](#). Disability Advocacy Network Australia.

Disability Advocacy Network Australia (2023) [NDIS Quality and Safeguarding Framework issues paper – DANA Submission to the NDIS Review](#).

⁴⁶ Despite the Quality and Safeguarding Commission housing the multiple functions of registration, monitoring restrictive practices and adherence to practice standards and the code of conduct, safeguarding, complaints and reportable incidents, there has not been effective information sharing internally between the different arms of the Commission. There would greater benefit in these functions being separated to independently focus on their task, with effective linkages working to raise alerts for needed interventions and guide systemic improvements in each other’s work.

Independent disability advocacy

As we argue in our pre-Budget submission⁴⁷ (and heard throughout the DRC hearings),⁴⁸ independent disability advocacy plays a critical role in both facilitating and safeguarding Australia's disability and NDIS ecosystems, including through:

- helping to prevent NDIS exploitation by supporting people with disability to advocate for their rights and to address unfair treatment or plan utilisation by providers;
- building capacity, understanding and confidence so people with disability can better use their NDIS funding and meet their goals;
- keeping mainstream systems accountable for providing equitable access to people with disability;
- helping people to navigate and engage with safeguarding and complaints processes;
- preventing and solving problems through education and building skills, sometimes intervening before situations escalate to crisis;
- working to fix barriers in local, state and national systems and frameworks; and
- working with people with disability to build their own capacity to self-advocate, building trusted relationships over time.

Unfortunately, years of inadequate funding levels, opaque and inconsistent data collection and lack of sector support and investment means that meaningful access to disability advocacy is not currently the reality for many Australians with disability, especially those living outside of metropolitan regions.⁴⁹ DANA expects advocacy demand to increase significantly in the coming months in response to proposed sector changes arising from both the DRC and the NDIS Review. That is why our member organisations united in calling for significantly higher injections of funding in this year's Federal budget.⁵⁰

Recommendation 19: That people with disability are aware of and can access independent disability advocacy from well-developed sector funded to meet demand and need.

Recommendation 20: That governments provide secure and adequate resourcing to the advocacy sector, by immediately increasing funding for independent advocacy organisations who directly support people with disability by \$91 million per annum:

- \$43 million to address immediate funding shortfalls with an urgent injection of funds for the National Disability Advocacy Program (NDAP)
- \$25 million through a new grant round for non-NDAP organisations in urgent need of funding

⁴⁷ Disability Advocacy Network Australia (2023) [A strong sustainable future: addressing capacity shortfalls for a strengthened disability advocacy sector](#).

⁴⁸ See: [Spotlight on Advocacy | Disability Advocacy Network Australia \(dana.org.au\)](#)

⁴⁹ Disability Advocacy Network Australia (2022) [Independent disability advocacy – DANA submission to the Disability Royal Commission](#).

Disability Advocacy Network Australia (2023) [A strong sustainable future: addressing capacity shortfalls for a strengthened disability advocacy sector](#).

Disability Advocacy Service (Alice Spring, NT) input about advocacy in central Australia, 2023 (received by DANA February 2024).

⁵⁰ See sector campaign: [SPEAK UP for independent advocacy \(speakupadvocacy.com.au\)](#)

- \$20 million for rural and remote providers
- \$5.225 million for capacity building in the sector, including for First Nations cultural safety, resourcing, pilot progress and increased awareness of Supported Decision Making.

In theory, registered NDIS providers have an obligation to allow a person with disability to receive support from advocates during a complaints process.⁵¹ Services covered under the Disability Services and Inclusion Act 2023 also have obligations to provide information about access to independent advocates following incidents, or support to make complaints.⁵² However, people with disability may:

- experience fear or hesitation to voice complaints;
- lack awareness of their rights to complain;
- lack trust or confidence in complaints mechanisms; and/or
- be segregated or isolated without support to speak up;

In practice, advocates have observed providers who engage in ‘gatekeeping’ and little indication that there is meaningful access to advocacy facilitated by many providers.

The Taskforce should consider whether advanced registration for high risk supports delivered in closed settings where people may be isolated, segregated or unaware of their right to request an advocate, should include an additional obligation to facilitate access. DANA has previously argued that these types of providers should be required not only to arrange access to independent advocates once a person with disability has made a complaint, but to also ensure that independent advocacy is meaningfully accessible for people with disability who may need support to voice their complaint (or to report abuse or mistreatment) in the first place.⁵³

Recommendation 21: That people with disability, particularly those at risk of service capture or isolation in closed or institutional settings, are aware of their rights to report and complain about poor quality, mistreatment and neglect, and of their right to access independent advocacy support to do so.

Accessible peer-led information and support

Accessible information about the NDIS and the wider landscape of disability supports has long been recognised as a crucial component of how the scheme should work.⁵⁴ This includes information sharing through peer support organisations or networks and disability

⁵¹ See *National Disability Insurance Scheme Act 2013*, s73Z on Reportable incidents and s73W on complaints management and resolution or [NDIS practice standards | NDIS Quality and Safeguards Commission \(ndiscommission.gov.au\)](#). These standards include three indicators that mention the right to access advocates under the outcome headings of ‘Independence and informed choice’, ‘Violence, Abuse, Neglect, Exploitation and Discrimination’, and ‘Feedback and Complaints Management’, including some mention of providing information about that right.

⁵² Disability Services and Inclusion (Complaints and Incidents Management) Rules 2023

⁵³ Disability Advocacy Network Australia (2022) [Rights, Safety, Quality – Voices of Advocacy](#).

⁵⁴ Christine Regan (2013) *The importance of Independent Advocacy and Independent Information in a Person-Centred World* – Presentation to Carers NSW Conference, 15 March 2013.

representative and advocacy organisations who are independent of government and service provision. Recent research has also demonstrated how information sharing can contribute to valuable market stewardship of the NDIS.⁵⁵

One of the Discussion Papers that DANA commissioned for the NDIS Review concluded that although there is extensive information online about services and activities open to people with disability, including dedicated resources and databases created and designed to help people with disability find services and support, crucial details are often missing, inaccurate or outdated. The time and effort involved in navigating and sifting the volume of information online can be overwhelming and frustrating.⁵⁶

Since 2016, the Information, Linkages and Capacity Building (ILC) program has been providing fixed-term grants to organisations to deliver projects in the community to “benefit all Australians with disability, their carers and families”. With less than one percent of the overall investment in the NDIS, much fantastic work in accessible information and peer networking and support has been funded through this program, including activities delivered by advocacy organisations in specific jurisdictions or local areas. However there has been a lack of strategy, measurement and evaluation and/or leveraging on previous work given the project-based time limited nature of the funding.⁵⁷

As highlighted by the NDIS Review, navigation and greater equity must be supported by accessible information in a range of formats. The information accessibility sector has been under-resourced and poorly acknowledged.⁵⁸ This has been exacerbated by the scattershot approach of ILC funding.

As a stronger community-driven sector of accessible and peer led information and support for people with disability is developed, there should be a particular focus on providing the support participants need to make decisions about NDIS supports and processes and undertake key tasks to participate knowledgeably and confidently in planning and review. There also needs to be clear accessible information about consumer rights, laws and remedies when supports are of poor quality or safety.⁵⁹

Recommendation 22: That people with disability have access to independent capacity building information and support to engage with services and supports.

⁵⁵ Carey, G., E. Malbon. (2020) “Information Sharing as Market Stewardship in the NDIS [Internet].” Centre for Social Impact, UNSW Sydney.

⁵⁶ Sue Olney and DANA (2023). [NDIS Review: Mainstream and Tier 2](#)—Discussion paper for NDIS Review engagement. Disability Advocacy Network Australia.

⁵⁷ Productivity Commission (2017), [National Disability Insurance Scheme \(NDIS\) Costs, Canberra](#); Olney S, Mills, A & Fallon L (2022) *The Tier 2 tipping point: access to support for working-age Australians with disability without individual NDIS funding*. Melbourne Disability Institute, University of Melbourne.

⁵⁸ Meltzer, A., Barnes, E. and Wehbe, A. (2024) Better acknowledging and resourcing the information accessibility sector in Australia: Final Report. Centre for Social Impact, UNSW Sydney

⁵⁹ Gerard Brody, (2023) [Consumer policy response to NDIS Review “What we have heard” report](#). Disability Advocacy Network Australia.

Recommendation 23: That the accessible information and peer support sectors are supported through secure long-term funding for independent community-driven organisations, allowing them to accumulate knowledge, skills, experienced staff and relationships over time.

Recommendation 24: That national education and awareness initiatives are adequately resourced to inform people with disability, professionals and the general public about human rights, rights to quality services, processes for identifying or reporting violence, neglect and abuse, or making complaints about disability services.

Support for decision making

The NDIS Review recognised in Recommendation 5 that many people with disability, (particularly those with cognitive disability and complex communication support needs) deserve better support to make decisions about their lives.⁶⁰ Specialist advocacy organisations have been providing support for decision making by people with disability for many years and work to uplift the human rights of people with disability. During our NDIS Review Engagement and Solutions Project, we heard about the need for disability advocacy funding for supported decision making for people with disability both in and outside the NDIS, including:

- delivery of supported decision making capacity building for people with disability and their families and supporters;
- resources, training and ongoing capacity to support an expanded role for advocacy organisations in supported decision making; and
- capacity building, resources and training for decision supporters, disability services and providers, NDIA staff and planners and intermediaries.⁶¹

Independent advocates have a long and proud tradition of supporting people with a disability to express, defend and assert their will and preference. It is a role that may come under increased demand as people with disability want to make more of their own decisions. For people who need decision making support to effectively exercise their rights to choose their disability supports, take informed risks and assess what level registration or enrolment they want their providers to have, they must access to independent support for decision making that meets their particular needs.

Recommendation 25: That all people with disability who need support for decision making are consulted about the supports they use, with independent support for that decision making that is well-resourced.

⁶⁰ NDIS Review Panel (2023) Working together to deliver the NDIS – Independent Review of the National Disability Insurance Scheme, pp107-115

⁶¹ Disability Advocacy Network Australia (2023) [NDIS Review Summary Report - Advocates and supported decision making for people with disability](#).

Structures and investment to address gaps in supports

Understandably, many people with disability, carers and advocates are deeply worried that mandating registration will further constrict already thin or failing markets. In practical terms, the development of the NDIS has left some people worse off. In the 'Aussie Battlers' report from Disability Advocacy NSW, a case study details the difficulty experienced in both obtaining an NDIS plan and then having to seek out supports that may not actually exist in the area.⁶² The practical supports the person with disability received were also reported to be a step below what was available through general block-funded services pre-NDIS.⁶³

These problems have been identified and explored by NDIS Review and Disability Royal Commission. The NDIS Review recommended improved market monitoring,⁶⁴ the introduction of provider panels⁶⁵ and ensuring providers of last resort in market failure.⁶⁶ There is potential that greater visibility of market functioning, and the availability or absence of supports, may open up and guide more market stewardship and interventions, particularly in areas of particular need – for instance alternative commissioning approaches in remote and First Nations communities have been proposed.⁶⁷

Reforms to registration and enrolment requirements must be complemented by a range of structures including significant market monitoring and interventions to address dysfunctions in the NDIS market and other service systems, (like health, transport and education) that are currently failing to meet the needs of people with disability. These include:

- establishing effective 'Foundational Supports' to respond to community needs including specific local gaps,⁶⁸
- an organisation funded to be an independent consumer voice;⁶⁹
- provider panels;⁷⁰ and
- 'provider of last resort' schemes.⁷¹

The new model will need to effectively connect and interact with, and be strengthened by, all of these elements to succeed in its objectives. Developing and implementing regulatory

⁶² Cherry Baylous and Demi Woods (2022) *ibid*, p5.

⁶³ Cherry Baylous and Demi Woods (2022) *ibid*, p6.

⁶⁴ NDIS Review Panel (2023) *Working together to deliver the NDIS – Independent Review of the National Disability Insurance Scheme* pp178-182.

⁶⁵ NDIS Review Panel (2023) *ibid*, pp183-184.

⁶⁶ NDIS Review Panel (2023) *ibid*, p185.

⁶⁷ NDIS Review Panel (2023) *ibid*, p187-190.

⁶⁸ See proposed actions and insights gathered through consultations for recently published [Priorities Project Report](#). May 2024.

⁶⁹ 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. Refer to this the paper submitted to the Review from the Consumer Federation of Australia and DANA about a proposed citizenship and consumer body: Gerard Brody, (2023) [Consumer policy response to NDIS Review "What we have heard" report](#). Disability Advocacy Network Australia.

⁷⁰ See further discussion: Disability Advocacy Network Australia (2024) *NDIS participant experience in rural, regional and remote Australia* - Submission to the Joint Standing Committee on the NDIS.

⁷¹ *Ibid*.

changes to registration and enrolment must be done in concert with co-designing the broader safeguarding and structural reforms needed.

Recommendation 26: That the new model of registration and enrolment is designed to work with and is accompanied by a range of other structures for monitoring and intervention in the disability supports ecosystem, including investment to address the gaps in supports for people with disability, such as:

- Foundational Supports;
- independent disability advocacy and information, including a voice promoting consumer rights in the NDIS market; and
- provider panels and 'provider of last resort' schemes.