

Draft National Strategy for the Care and Support Economy

A joint submission from Disability Representative Organisations

June 2023

Introduction

The *Draft National Strategy for the Care and Support Economy* is a welcome investment in prioritising this growing and essential part of our social infrastructure.

This submission has been developed by the Disability Advocacy Network Australia, on behalf of the eight national Disability Representative Organisations (DROs) and contains a recommendations, feedback and expertise from each of the DROs.

In this submission, we use care to refer to informal, unpaid care, and support to refer to paid support work.

The eight national Disability Representative Organisations are:

- Australian Federation of Disability Organisations
- Children and Young People with Disability Australia
- Disability Advocacy Network Australia
- First Peoples Disability Network Australia
- Inclusion Australia
- National Ethnic Disability Alliance
- People with Disability Australia
- Women with Disabilities Australia

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Summary of Recommendations

- Recommendation 1: That the Strategy be revised to recognise that many people with disability and older people are both cared for, and carers and that people with disability work in various paid roles within and outside the care and support economy, including as disability support workers.
- Recommendation 2: That the Horizon 1 Action Plans incorporate other key policy recommendations from the NDIS Review and the Disability Royal Commission.
- Recommendation 3: That Disability Representative Organisations are resourced to co-design Action Plans.
- Recommendation 4: That Disability Representative Organisations are resourced to provide the significant expertise required for co-design of this Strategy and associated Action Plans, including how this intersects with other policy frameworks and strategies.

Who cares?

Everyone needs, and will use, care and support throughout their lives. From the time we are children, to when we get older, every single person will need care.

Everyone will also give care and support – in their families, among their friends and in their communities. Many people are both cared for, and carers. One third of informal carers are people with disability¹.

For many people with disability and our families, care and support is woven into much of our daily lives. Our expertise about what is good support, about how to care for each other and what happens without that care and support, is unmatched.

In addition, over 85% of people with disability will not receive support through the NDIS, and this needs to be recognised in the Strategy.

The artificial separation of those cared for and those caring in this strategy needs to be revised.

The **Australian Federation of Disability Organisations** (AFDO) agrees that there is a lack of recognition that many carers also have disabilities themselves and this will impact the support they will need.

First People with Disability Network (FPDN) wants recognition and support around of the impact of intersectionality for First Nations people with disability, who are aged, are pre-schoolers, and are veterans. Impacts of intersectionality include intergenerational trauma resulting from the Stolen Generations who were separated from family, culture, language and culture. There is a need to promote truth-telling.

Women With Disabilities Australia (WWDA) wants to ensure that the Strategy does not only have a gender and disability lens, but an intersectional gender and disability lens. This includes acknowledging the significant paid and unpaid care and support work that women with disability perform.

Recommendation 1: That the Strategy be revised to recognise that many people with disability and older people are both cared for, and carers and that people with disability work in various paid roles within and outside the care and support economy, including as disability support workers.

¹ <https://www.carersaustralia.com.au/about-carers/who-is-a-carer/>

Action Plans

The draft Strategy contains several proposed Action Plans, including several to be implemented in Horizon 1. It is vital that these Action Plans are coordinated with other policy developments and co-designed with people with disability and their families and supporters.

The initial Action Plans are:

- Regulatory review
- Data standards
- Worker safety

The Regulatory Review Action Plan must incorporate findings from both the NDIS Review and the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability (Disability Royal Commission). There is significant co-design and consultation work currently being undertaken about quality and safeguarding frameworks for people with disability who use the NDIS, including a specific issues paper and consultation by the NDIS Review.²

There is concern about the impact of a regulatory framework that is uniform across all care and support areas, as the needs of people with disability are different to children and older people.

The Data Standards Action Plan needs to incorporate the work being undertaken by the National Disability Data Asset and incorporate likely recommendations from the Disability Royal Commission and the NDIS Review about data collection and use.

The Worker Safety Action Plan needs to be closely co-designed with people with disability, our families and supporters and organisations. This plan needs to also recognise the need for flexibility, choice and control of people with disability, including the dignity of risk.

The other Action Plans in Horizons 2 and 3 need to build on this consultative work and be developed in collaboration with both other policy initiatives, and people with disability.

Recommendation 2: That the Horizon 1 Action Plans incorporate other key policy recommendations from the NDIS Review and the Disability Royal Commission.

Recommendation 3: That Disability Representative Organisations are resourced to co-design Action Plans.

² <https://www.ndisreview.gov.au/resources/paper/ndis-quality-and-safeguarding-framework-issues-paper>

Key common points

Introduction: Care and support in Australia

The introduction to the Strategy sets out the policy and economic landscape that underpins this work, including the very significant growth of support as part of Australia's economy.

People with disability, their families and supporters, and organisations, are an integral part of how this part of our economy has grown and developed, and as such, must be an integral part of how this Strategy unfolds. People with disability have significant expertise about both care and support, and this is vital to a comprehensive and adequate Strategy.

This Strategy also needs to align with Australia's Disability Strategy, its targeted action plans, and outcomes framework.

In the review of the *Disability Services Act* in 2023, Disability Representative Organisations said that:³

'People with disability should be positioned as co-designers of future service models and their regulatory regimes within communities that uphold core citizenship rights. The piecemeal removal of barriers within existing systems will not provide the substantive change required to advance the rights of people with disability.'

'Any attempt at regulatory alignment should make sure that high standards are required, retaining any unique standards based on the type of service, support or provider. Regulatory arrangements should avoid the adoption of lower standards for the sake of alignment.'

We reiterate this statement now in relation to this draft Strategy.

Recommendation 4: That Disability Representative Organisations are resourced to provide the significant expertise required for co-design of this Strategy and associated Action Plans, including how this intersects with other policy frameworks and strategies.

We welcome the increased focus on the contribution of care and support to the wider Australian economy. Investment in life saving and changing support for people with disability and their families through the NDIS has shifted some of the economic impact of serious disability from individuals and families to be shared among the entire community.

This must be considered as part of looking at the economic impact of ensuring people with disability received vital support and services – these costs don't go away if support is cut, but instead are borne by people with disability and their families.

While there may be some benefits of taking a holistic approach to care and support, the specific needs of people with disability must be taken into account. Any move towards a single regulatory framework or qualification requirement needs to be carefully co-designed with people with disability, their families and supporters and organisations. At each life stage, people with disability have distinct requirements for care and support that could be erased or undermined under a single system.

Women with Disabilities Australia (WWDA) emphasises the need for clarity regarding any move towards harmonisation, particularly in relation to existing initiatives, such as the NDIS Review and the NDIS Workforce Strategy. It is also crucial to address the limitations of a

³ <https://www.dana.org.au/wp-content/uploads/2023/02/Disability-Services-Act-Review-DROs-Joint-Submission-Feb-2023-1.pdf>

focus on the NDIS, when most people with disability in Australia do not receive supports through the NDIS.

AFDO agrees, saying although the inquiry notes some similarities, the sectors being defined including early childcare, disability, aged care, and veterans support, encompass diverse populations and supports and are concerned the Strategy may be too broad and not address the specific needs of care and support for people with disability correctly.

FPDN says that trust issues around authority – particularly around the removal of children from First Nations families – is ongoing and linked to intergenerational trauma from Stolen Generations. This is a significant issue in the design of any Strategy.

It is disappointing to see the economic discussion about care and support not acknowledge the significant economic contribution of the NDIS. There are now close to 300,000 jobs directly related to the NDIS, and more people with disability and family members are now in employment⁴.

In addition, there is no discussion about how essential support is for working age people with disability to participate in the workforce.

The draft Strategy notes the impact of support services on the capacity for carers to undertake paid employment. There is currently significant government interest in this area, including the recently announced Parliamentary inquiry into the recognition of unpaid carers.⁵ However, the draft Strategy does not mention that this is already a significant area of investment in the NDIS. In the latest NDIS Quarterly Report, more carers are working.

“Overall, for parents/carers of all participants, there has been a four-percentage point increase [in employment], from 46 per cent to 50 per cent, reaching the 2022–23 target of 50 per cent.

For families and carers of participants aged 0 to 14, the percentage in work tends to improve more the longer the participant has been in the Scheme. For those in the Scheme for two years, the families and carers employment rate increased from 46 per cent to 51 per cent, compared to 42 per cent to 52 per cent for those who have been in the Scheme for both five and six years.”⁶

Inclusion Australia (IA) is also concerned about cuts to essential NDIS supports, and the impact on carers capacity to undertake paid work. IA is hearing from the community about carers having to leave the workforce in response to changes in NDIS supports for people with disability.

⁴ <https://www.ndis.gov.au/about-us/publications/quarterly-reports>

⁵ <https://www.aph.gov.au/UnpaidCarers>

⁶ <https://www.ndis.gov.au/about-us/publications/quarterly-reports>

Goal 1: Quality Care and Support

Quality support is vital to people with disability so they can work, play, get an education and in some cases stay alive. Quality support is also vital in preventing violence and abuse.

The Disability Royal Commission has heard hundreds of stories from people with disability and their families about the impact of poor-quality support, as has the NDIS Quality and Safeguards Commission, including their recent Own Motion report.

Preventing violence and abuse against people with disability must be a core component of this Strategy, which will include coordination with the findings of the Disability Royal Commission.

Regulatory systems must be developed in concert with national, state and territory existing systems, and also address the failures in each of these systems.

The current system puts too much emphasis on people with disability making complaints to activate any safeguarding regime. As the Disability Royal Commission has heard, for many people with disability this is not possible. The Strategy puts a great deal of weight on the capacity for 'consumers' to know when they are receiving good quality care and support, when there has been little to no development of that capacity, nor any infrastructure to support NDIS consumers.

In addition, often these complaints are not acted on in a timely manner, or at all, leaving people with disability in dangerous and at times, life threatening situations. The complaints also rarely lead to any systemic change in the current regulatory environment.

IA argues there should be a significant investment from Government in independent information and resources, which should be delivered by people with disability, including people with an intellectual disability and family members. IA has made specific recommendations to the NDIS Review about the need for independent information and its role in quality services.

IA also says that while it is necessary to build capacity among service participants to build knowledge about their rights and build skills to exercise those rights (and that this must be coupled with access to fully resourced and widely available self-advocacy training and opportunities), Government must also recognise and actively work to address the power imbalance that exists between people and service providers, which makes it both illogical and unjust to place the onus of responsibility on participants to drive safety.

IA reiterates its concern that if Government continues to excessively rely on a complaints-driven approach to safeguarding, it will put the onus on participants to drive quality and safety. That means the power imbalance will be perpetuated, and people with an intellectual disability, especially non-speaking people or people with complex communication needs, will be further disempowered.

Children and Young People with Disability (CYDA) says that the federal systems that influence and should support key aspects of early childhood development are underperforming and must improve. For instance, early learning centres are of inconsistent quality.

Too many do not meet National Quality Standard (NQS). According to National Quality Framework Snapshot June 2020, 17.7 per cent of centres did not meet the NQS, rising to 18.4 per cent for long day care (excluding preschools). Funding high-quality care and

support provision in the early years is an investment for the future, enabling people with disability (and their families and carers) to participate in the workforce and society.

In addition, Australia's Disability Strategy recognises that high quality early childhood education sets children up with the foundations for success and that inclusion must begin from the earliest ages with a focus on access and participation of all children in early childhood support and care.

Workforce

Workforce shortages are not the only factor that impacts on 'poor outcomes for individuals with care and support needs' (p18). Segregated support systems and poor attitudes towards people with disability are significant contributors towards the high rates of abuse and violence that many people with disability experience while receiving support.

The NDIS also takes a narrow approach to what supports they will fund and how to interpret what is reasonable and necessary. This can lead to what the NDIS Review has identified as 'perverse incentives' to provide support via disability support workers, rather than build the capacity and independence of people with disability.

The NDIS Review has identified that:

“...there are perverse incentives for providers to maximise the volume and types of supports they deliver, in order to maximise the total payment they receive. This, in turn, does not reward providers to support participants to be more independent and can place pressure on scheme sustainability.”⁷

The disability support workforce is valuable but is not always deployed in ways that serve people with disability.

People With Disability Australia (PWDA) wants to ensure that the Strategy does not inadvertently create a situation where people (at scale) move out of one part of the Care and Support Economy to the detriment of another part, for example, moving from disability service provision to age care because settings, wages, conditions and incentives are more favourable.

Training

Training for disability support workers must be co-designed with people with disability, including through the new Jobs and Skills Council. The expertise of people with disability, their families and supporters and organisations is essential to building the appropriate skills for the disability support workforce.

PWDA believes we need to recognise that when training people to work in disability support that people with disability are the experts in what a good service is and should be. There are opportunities to harness the expertise of people with disability in a paid capacity to deliver and co-design that training.

Both PWDA and IA emphasised the importance of the workforce having specific training and understanding of human rights and supported decision-making. PWDA says staff need to have a contemporary view of disability that is underpinned by rights to choice and control. This is underpinned by NDIS Code of Conduct, and important to maintain if there is a move to a single regulatory and qualifications framework. Support for decision making is also important for children and older people.

⁷ https://www.ndisreview.gov.au/sites/default/files/resource/download/pricing-payments_0.pdf

National Ethnic Disability Alliance (NEDA) supports more comprehensive training of support workers to reflect the skills required for direct care, medications, and behaviours of concern management. A Certificate III in disability or aged care or training in individual support does not appear to give sufficient skills in these areas. It is worth investigating a degree qualification for the carer workforce, such as is used for nursing. Care and support work needs to be a specialist field as it is work with people with significant needs and marginalisation covering a wide scope of their lives.

FPDN says that there needs to be funding and access to training for non-Indigenous organisations and service providers around cultural awareness and cultural sensitivity.

First Nations people

FPDN believes that quality care and support is to be led by First Nations people for First Nations people through community-controlled organisations. It is vital that cultural values are to be embedded within the care and support economy.

Accessible resources on the rights and responsibilities of people being cared for must be part of all qualifications, and care is to be culturally safe and meet the holistic needs of those being cared for.

Within prisons and institutions, First Nations people with disability are to have full access to culturally safe care and support.

All care and support services and workers are to be trauma informed.

There needs to be adequate support services in remote, rural and regional communities for First Nations people.

IA also says that services must be psychologically and culturally safe but there is a lack of detail in the draft Strategy about how this will be achieved. First Nations people and organisations must be paid to develop and deliver any training in cultural safety and be at the centre of any strategies in this regard.

Migrant and refugee people

NEDA is concerned that the migrant and refugee, culturally and linguistically diverse workforce does not have employment security, with an increasing amount of casual and gig work. Casualisation and agency rostering are currently leading to poorer outcomes between people with disability and support service agencies. Placement of workers with people with disability needs to lead to safety, less harmful interactions and a more stringent workplace culture that fosters trust.

In addition, diversity and culture needs to be seen as adding value to the multicultural consumers of disability, aged care and early childhood services.

NEDA also wants to ensure that there are more career incentives integrated into the care economy.

There also needs to be clearer immigration rules on skilled migrants in the care and support workforce. This sector should not be seen as a temporary employment transition opportunity to a better job in another sector.

Women

WWDA notes that the under-recognition of care and support work performed by women and people with disability is compounded for women with disability.

WWDA is concerned that the gender lens of the Strategy does not adequately take into account the needs of women with disability who both provide and receive care and support.

WWDA is also concerned about the Strategy's focus on the NDIS, noting that women and girls are under-represented as participants within the Scheme (totalling just over 1/3 or 37%). At present, the NDIS does not have a gender strategy to address the barriers women and girls face to NDIS access, or systemic gender-based violence within the disability services sector.

Navigating care and support systems

The NDIS Review has identified that independent information is a key missing element to support people with disability who use NDIS supports⁸ and also that:

'Participants can find it difficult to compare providers or negotiate prices as they cannot readily access the information they need to make informed decisions. The NDIA has limited visibility of whether the supports participants purchase help to achieve outcomes.

Increased transparency of NDIS transactions – including on prices, volume, quality and outcomes – would support:

- participants to become more informed and empowered consumers
- providers to compete on price and quality and deliver outcomes for participants
- governments, as market stewards, to better monitor pricing and market outcomes, and set prices more effectively⁹

The NDIS myplace portal and the Disability Gateway do not provide accessible, up to date or easy to use independent information that people with disability can use to exercise choice about their supports. There is little Easy Read information available from Government about this, and where it is provided, it can be very difficult to find and navigate to on government websites. Relying on online methods for sharing information with the community means many people, including many people with disability, are excluded.¹⁰

It is also unclear what the relationship is between the Carer and Disability Gateways, and how they recognise the intersection between the two groups.

FDPN believes that the Disability Gateway needs to provide accessible resources to people with disability and carers around key support needs. For example, within the disability sector, create a hub with information about specific disability and support needs, such as intellectual disability, psychosocial disability, autism, and the d/Deaf community so that supports are tailored and effective.

⁸ 'See discussion paper on *The role of pricing and payment approaches in improving participant outcomes and scheme sustainability*'.

⁹ https://www.ndisreview.gov.au/sites/default/files/resource/download/pricing-payments_0.pdf

¹⁰ https://www.lloydsbank.com/assets/media/pdfs/banking_with_us/whats-happening/210923-lb-essential-digital-skills-2021-report.pdf
https://h3e6r2c4.rocketcdn.me/wp-content/uploads/2021/10/ADII_2021_Summary-report_V1.pdf /
<https://www.digitalinclusionindex.org.au/digital-inclusion-the-australian-context-in-2021/>

WWDA also believes that supports need to be informed by key support needs in concert with a person-centred approach and these resources will contribute to that.

Goal 2: Decent jobs

People with disability, their families and supporters value and want a high-quality workforce more than anyone else, and we understand the value of this work is also tied to attitudes towards people with disability.

People with disability have long advocated for choice and control over their supports so that they can have an ordinary life, going to work, school, and being included in the community. This flexibility is vital to ensure that people with disability can fully participate in all aspects of their lives.

Worker security and flexibility for people with disability can co-exist and must co-exist to make our support systems work for everyone.

Innovative ideas that contribute to this dual goal of security and flexibility, like portable entitlements and training, need to be explored.

Having choice and control means people with disability need a range of options for using support funding, including using unregistered providers and self-employed providers under the NDIS.¹¹

When developing the Priority Workforce Initiatives Action Plan, people with disability, their families, supporters and organisations must be consulted and listened to.

FPDN wants to see a focus on creating decent and ongoing jobs for First Nations people in remote, regional and rural communities. In addition, on-the-job training is to be prioritised through First Nations community-controlled organisations and ensure adequate funding is available for the community-controlled organisations.

¹¹ <https://newsroom.unsw.edu.au/news/social-affairs/unregistered-ndis-providers-are-firing-line-%E2%80%93-lots-participants-have-good>

Goal 3: Productive and sustainable

The NDIS Review discussion paper on *'The role of pricing and payment approaches in improving participant outcomes and scheme sustainability'* has been clear about the problems with the current market system for delivering disability support. The paper has found that:

'The NDIS market, however, is not yet working for all participants.

An over-reliance on competition has seen some participants face persistent service gaps (including those in remote and First Nations communities) and a loss of social capital.

Competition in the NDIS market will not always be possible. For some NDIS services, participants and communities, contestable arrangements could better support access while ensuring providers are responsive to the needs of participants.

Poor market outcomes are also being driven by a lack of accessible and timely information coupled with difficulties in navigating and coordinating supports. The effectiveness of market intermediaries is unclear. Poor market design also means the incentives for providers are not aligned to participants' and governments' interests.

Governments cannot manage government-funded 'social markets' – such as the NDIS – in the same way as they would manage 'private markets'. For social markets to function well, governments need to monitor and, when necessary, intervene using a mix of market-based tools. In the NDIS, however, only a very limited number of market-based tools are currently actively used by governments.'¹²

It is essential that this draft Strategy engages with the work of the NDIS Review, and the Disability Royal Commission, about the large range of problems occurring within the market system for the NDIS.

The policy goal of this section, that 'a care and support economy that has functioning markets, sustainable funding and generates productivity gains', is out of step with the evidence about what is happening in the NDIS market. We urge this Strategy to coordinate with the NDIS Review and the Disability Royal Commission, as well as with Disability Representative Organisations.

There is also a great deal of work going on about market regulation and delivering safeguarding for people with disability who use NDIS supports. Again, this Strategy needs to align with that existing work and the very specific issues for people with disability.

Regulatory frameworks must not impact on the choice and control for people with disability who use the NDIS. Registered providers under the NDIS do not always offer what people with disability and their families want in terms of services and supports. People with disability cannot be forced to use only NDIS registered providers for their support. This is counter to the aims of the NDIS to further community inclusion and independence of people with disability.

¹² https://www.ndisreview.gov.au/sites/default/files/resource/download/pricing-payments_0.pdf

Research has found¹³ a variety of “push and pull” factors that inform using unregistered providers by people with disability. These are:

‘Push factors included negative experiences with or perceptions of registered providers. These often related to services they had received in the “bad old days” of pre-NDIS block-funded services, where they had little or no choice in service provision and coordinators acted as gatekeepers. Interviewees described bad behaviour by some registered providers, incompatible “deficit” culture (where people with disability are framed around what they can’t do, not what they can), invasive scrutiny of their lives, inflexibility, “price gouging”, and distrust of large organisations.

Pull factors included perceptions of better, more person-centred service, flexibility, innovation, choice, empowerment, social inclusion, and improved cost-effectiveness associated with using unregistered providers. Contrary to public perception, many of the participants we spoke to said using unregistered providers allowed them to be more cost-savvy with purchases.’

The need for people with disability to be in control and have choice over their supports is fundamental to building quality supports. Any regulatory change needs to prioritise this choice and control and provide appropriate and effective safeguarding mechanisms.

Regulatory frameworks also need to be linked to the findings of the Disability Royal Commission, and the work being done through the NDIS Review on quality and safeguarding. Any moves towards ‘harmonisation’ must lead to action that eliminates violence and abuse towards people with disability, including forms of violence that remain lawful and legitimised, such as forced treatment and restrictive practices.

CYDA says that the service systems that relate to early childhood development – including childcare, preschool, child health, family support, the NDIS early childhood approach and child protection – are disconnected. Policy, process and programs for these systems span federal and state/territory governments, and a mix of ministries and departments within governments. This complexity is confusing for families and caregivers to navigate and children risk falling between the gaps of a fragmented system. Regulatory reform needs to take this into account.

FPDN says that sustainable funding needs to be ensured for First Nations carers without the systemic barriers to accessing funding. Funding also has to recognise the cultural and family care structure of First Nations communities and provide financial support to First Nations carers. There also needs to be a look beyond fiscal and productivity markers to ensure that success markers from the care and support community are recognised. For example, a care economy needs to be rich in culture, community and connection. There also needs to be ongoing and stable funding to existing First Nations advocacy, early childhood, aged care, veterans’ affairs and disability services to expand their scope in creating and supporting a community-controlled sector.

CYDA says that there should be investment and subsidisation of (without compromising on workers salaries) Australia’s early learning centres which are some of the most expensive in Organisation for Economic Co-operation and Development (OECD) countries. According to the Household, Income and Labour Dynamics in Australia (HILDA) Survey, approximately 27

¹³ <https://www.unsw.adfa.edu.au/newsroom/news/conversation-unregistered-ndis-providers-are-firing-line-lots-participants-have-good-reasons-using-them>

per cent of household income is absorbed by childcare. These costs have more than doubled since 2002.

Disability Representative Organisations strongly reject any move toward consumer co-contributions for disability care and support.

Disability support is significantly more expensive than other support systems, and people with disability and their families are significantly more likely¹⁴ to live in poverty than other communities. Many people with disability rely on income support, including the Disability Support Pension.

Research found that:

'people with a disability need to increase their adult-equivalent disposable income by 50% (in the short-run) to achieve the same standard of living as those without a disability. This figure varies considerably according to the severity of the disability, ranging from 19% for people without work-related limitations to 102% for people with severe limitations. Further, the average cost of disability in the long-run is higher and it is 63% of the adult-equivalent disposable income.'¹⁵

In other jurisdictions, such as the UK and the USA, means testing and co-contributions have led to significant unintended consequences in terms of employment participation and overall rates of poverty.

¹⁴ <https://www.aihw.gov.au/reports/disability/people-with-disability-in-australia/contents/income-and-finance/income>

¹⁵ <https://thehealtheconomist.biomedcentral.com/articles/10.1186/s13561-020-00264-1>