



Submission to Department of Social Services on Foundational Supports December 2024

ABOUT CARERS AUSTRALIA

Carers Australia is the national peak body representing the diversity of the three million¹ Australians who provide unpaid care and support to family members and friends who live with disability, a chronic condition, mental illness or disorder, a drug or alcohol problem, terminal illness, or who are frail aged.

In collaboration with our members, the peak carer organisations in each state and territory, we collectively form the National Carer Network and are an established infrastructure that represents the views of carers at the national level.

Our vision is an Australia that values and supports all carers, where all carers have the same rights, choices, and opportunities as other Australians to enjoy optimum health, social and economic wellbeing and participate in family, social and community life, employment, and education.

Our carers are diverse and include those who:

- have their own care needs
- are in multiple care relationships
- have employment and/or education commitments
- are under 25 years (young carers)
- are 65 years and over
- identify as Aboriginal and/or Torres Strait Islander
- are from culturally and linguistically diverse backgrounds (CALD)
- identify as Lesbian, Gay, Bisexual, Trans and gender diverse, Intersex, Queer, Questioning and Asexual (LGBTIQ+)
- live in rural and remote Australia,
- are former carers (no longer in a caring role), and
- have a disability.

¹ [Carer's Australia - About Carers - Who is a Carer](#)

Acknowledgment of country

Carers Australia acknowledges Aboriginal and/or Torres Strait Islander peoples and communities as the traditional custodians of the land we work on and pay our respects to Elders past, present and emerging.

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INTRODUCTION

"For me, if you're under the NDIS, that's helpful in a way because you know that they might do something that might be able to help you. If you're not NDIS, there's nowhere that you can go." Carer - 2024 National Carer Strategy Consultation

"I needed help accessing the NDIS to see if I could get funding for my son, but I kept getting conflicting information where in the end I received no help and was told continually that I could not access funding. I then received no help for his condition from other community groups because he was denied funding from NDIS." Carer response to the 2024 Carer Wellbeing Survey

Carers Australia welcomes the introduction of Foundational Supports for people with disability who are NDIS participants, but most significantly, people with disability who do not have access to the NDIS.

These supports will help to fill a very large gap for people with disability and their carers that followed from the introduction of the NDIS. As noted in the NDIS Review Report², the NDIS was never designed to support all people living with disability. It was reserved for people with severe and profound disabilities which were likely to be permanent, although support was added for such things as children with developmental challenges and for people with mental health conditions which might not be permanent but who needed intensive support nevertheless.

It was not assumed at the time of the NDIS’s introduction that disability supports for people who did not meet the stringent eligibility criteria, would struggle to find support which had previously been available to them within their communities. These included people who were considered disabled but not quite disabled enough, or not disabled in the right way, or where it

² Independent Review of the National Disability Insurance Scheme, 2023, Working together to deliver the NDIS [Working together to deliver the NDIS. NDIS Review: Final Report](#)

was often wrongly considered that their needs would be covered by the health system. However, with the introduction of the NDIS, states and territories began to withdraw funding from their services and disability providers turned their attention to providing their services solely to NDIS participants. As the quotes above reflect, a very large number of people living with disability have found themselves confronting a major deficit of support services.

It also has a had a profound effect on their carers as they struggle to fill in the gaps; often with consequences to their own general wellbeing, their emotional and mental health, their employment, their capacity to engage in education and their finances.

The most recent Australian Bureau of Statistics’ (ABS) Survey of Disability, Ageing and Carers (SDAC)³, revealed that that there were an estimated 1,733,700 people living with disability under the age of 65 in Australia who required assistance with daily activities. In the last quarter of the 2023-24 financial year there were 661,267 NDIS participants.⁴ In short, over 60% of people living with disability in need of assistance are not included in the NDIS.

While the published SDAC information does not break down the source of assistance by age group, of the 3.2 million people living with disability who required assistance on a daily basis, 75.7% received support from carers (‘informal assistance’) and only 57.0% received assistance from formal providers. Figure one below shows the breakdown of type of care and support required.

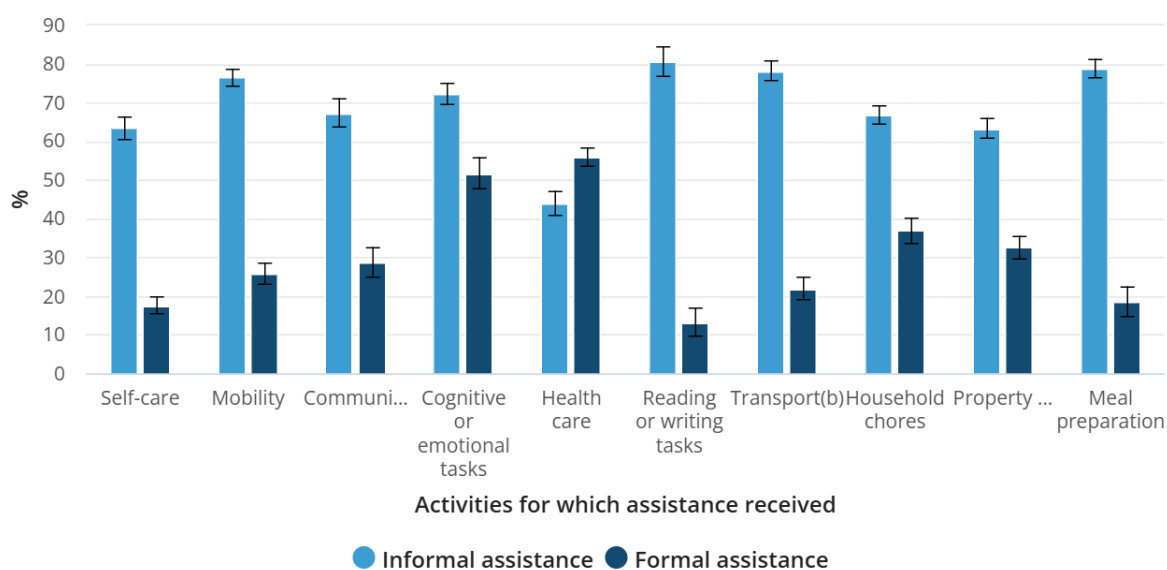


Figure one: Persons with disability who needed assistance with specific activities, assistance received by provider type, 2022⁵

³Australian Bureau of Statistics, 2022, Survey of Disability, Ageing and Carers, [Disability, Ageing and Carers, Australia: Summary of Findings, 2022 | Australian Bureau of Statistics](#)

⁴ National Disability Insurance Scheme website, [Explore data | NDIS](#)

⁵ Op. cit.

While Foundational Supports are described as short-term supports, as opposed to the core supports available under the NDIS which will be ongoing, they promise to make a real contribution to both NDIS participants and those outside the NDIS, and to their carers. They will go some of the way to rectify the oft quoted description of the NDIS as an oasis in a desert.

The NDIS has also had a poor record in delivering support services to carers, including dedicated respite opportunities. It is very welcome that foundational information and referral supports, as well as peer support, are to be carer inclusive, and that capacity building support to help guide carers in decision-making or to help the people they care for to make informed decisions where the circumstances of the person with disability requires this, are included in the Foundational Supports design.

GENERAL SUPPORTS

“If I had those two things sorted - respite and navigation support - I reckon it would be pretty much a walk in the park.” Carer – 2024 National Carer Strategy Consultation

Information and referral

Carers Australia fully supports the services identified under this heading, delivered via different mechanisms (including a single information website, online apps, online chat, phone services, and face-to-face meetings) and that they need to be shaped for the communication requirements of people with different abilities (ensuring methods of communication address the challenges users may have with access).

Earlier this year Carers Australia, in partnership with other organisations representing carers, conducted over 55 [consultations](#)⁶ involving 498 carers across all states and territories to gather lived experience input to the National Carer Strategy currently under development. There was extensive commentary on carers’ needs to find accessible information as well as help with engaging with and navigating the systems of supports for those they care for. This included the NDIS and other disability support services. There was a very strong emphasis on the need for identification of local services, as well as culturally friendly and appropriate services.

When asked about where they commonly sourced information, many identified that they relied on informal sources of information as opposed to government websites - where they often found the information difficult to follow and inadequate for their specific needs. Facebook was frequently identified as the most useful source of information, as was word of mouth advice either obtained accidentally or through peer support groups.

We stress that there must not be over-reliance on accessing information and undertaking referrals via the internet. The 2018 Survey of Disability, Ageing and Carers (SDAC) identified

⁶ [National Carer Strategy Carers Australia reports 2024](#)

that, even though very high numbers of people living with disability did access the internet, 1.1 million people living with a disability did not.⁷

While the provision of individual navigators will make a great difference, people still need to know that these navigators are out there and where to find them.

Self-advocacy

Self-advocacy training will make a real difference to the ability and confidence of people with disability and carers to actively and successfully get access to services and advocate for disability friendly communities, as well as to boost their own overall sense of self-agency and confidence to pursue goals.

Strengthening the ability to self-advocate should not only be geared to direct disability support. It is also important that people living with disability and their carers are able to navigate and advocate across Centrelink income support services such as the Disability Support Pension (DSP) and the Carer Payment and Allowance, as well as to remove barriers to access within their communities.

Peer support

Carers need better access to organised peer support networks where they can interact with people in the same situation as themselves, learn from each other and develop social connections within their communities.

We know from our interactions with carers that these peer networks are often the most useful sources of information, as well providing the opportunity to interact with others with whom they can openly share their struggles and who will really understand what they are dealing with.

From the carers' perspective, social isolation is a major negative outcome of caring. Of the 9,000 carers who responded to the [2024 Carer Wellbeing Survey](#)⁸:

- 40.3% identified that they were always or often lonely
- 53.1% said that their caring role always or often impacted negatively on their social life
- 44.33% said that it negatively impacted on their relationships with family and friends.

In many cases peer support can fill in some of these gaps, as it can for people with disability experiencing social isolation.

Capacity building

Capacity building supports will not only have an impact on the ability of people with disability to live independently. It will also remove some of the strain on carers if they are currently

⁷ Australian Bureau of Statistics, 2018, Survey of Disability, Ageing and Carers, [Use of information technology by people with disability, older people and primary carers | Australian Bureau of Statistics](#)

⁸ [Carer Wellbeing Survey - 2024 report](#) – University of Canberra and Carers Australia

responsible for supplying the everyday needs for such things as shopping, cleaning, managing money, access to transport and personal care.

Building the capacity to engage in employment and building social skills to improve engagement in social and recreational activities will also make a great difference if these supports are effective.

Very importantly, it will help address one of the major sources of anxiety and distress which beset carers – what will happen when they are no longer able to care?

Carer Wellbeing Surveys identify that this is an overbearing concern for many carers. The 2024 survey identified that 67.5% of respondents regularly or always feared for the future of the person/people they cared for.⁹

TARGETED SUPPORTS

Home and Community Supports

“NDIS does not cover my son’s diagnosis - it sees it as a medical condition, yet he has an ongoing disability as a result of it. As the disability can’t be confirmed as permanent as yet (despite it being 12 months) he cannot meet the criteria to access funding.” Carer - 2024 National Carer Strategy Consultation

“Trying to access the NDIS without a clear and simple diagnosis is like pulling teeth from a baby sparrow.” Carer response to the 2024 Carer Wellbeing Survey

Supports for people under 65 who are not NDIS participants are particularly welcome. However, the list of supports under this category which we have found identify very limited specific supports: aids and equipment, shopping, property maintenance (presumably cleaning and gardening).¹⁰

Many people with disabilities do not access the NDIS because they have found the process too daunting (and expensive) or because they fall short of meeting the eligibility criteria but are borderline cases, or it has been deemed that they should access support from the health system despite disabilities stemming from a medical condition. In such cases they are likely to need support beyond these important but elementary services including, but not limited to, transport, social and community interaction supports, some personal care needs and assistance with communication.

⁹ [Carer Wellbeing Survey - 2024 report](#) – University of Canberra and Carers Australia

¹⁰ Independent Review of the National Disability Insurance Scheme, 2023, Working together to deliver the NDIS [Working together to deliver the NDIS. NDIS Review: Final Report](#)

Targeted Supports for People with Psychosocial Disability

“My son has continued psychosocial challenges. He needs daily check ins, reminders to shower, eat, put bins out, clean and do washing. The NDIS has been impossible to navigate. We are at break point and need assistance for him to make and obtain goals. I sometimes think I would be better off dead; then my superannuation could pay for the supports he needs.” Carer response to the 2024 Carer Wellbeing Survey

“The NDIA refused my son’s application due to it being mental health not a physical disability. He still cannot work.” Carer response to the 2024 Carer Wellbeing Survey

Carers Australia in partnership with the University of Canberra, conduct an annual Carer Wellbeing Survey. In 2024 there were over 9,000 survey responses, just under a third of which were from carers for someone with a mental illness/psychosocial disability. Of these carers, 52% reported poor access to the NDIS for those they cared for.

Based on their responses, 37% of these carers were evaluated as having a high probability of serious mental illness themselves, with a further 20% having a moderate probability. Either way, many carers may need psychosocial supports themselves (i.e. non-clinical and recovery-oriented services, delivered in the community and tailored to individual needs¹¹).

We note that the 2024 Final Report to Government prepared by Health Policy Analysis entitled “Analysis of unmet need for psychosocial support outside the National Disability Insurance Scheme”¹² estimated that in 2022–23 there were approximately 230,500 people with severe mental illness aged 12 to 64 years who required psychosocial support but were not receiving it through the NDIS or other government-funded programs. The total hours of psychosocial support required for people with severe mental illness but not provided were estimated to be 14.07 million in 2022–23. The total hours of psychosocial support required for people with moderate mental illness but not provided were estimated to be 2.76 million in 2022–23.

We consider it important that in-person supports should not be supplied on a time-limited or service limited basis. It may take different people different periods of time to benefit from capacity-building services, especially since mental health conditions tend to be episodic and a flare up can delay the time taken to reach goals or may require going back to square one in some instances. In addition, it may take some time over an extended period for people with psychosocial disability to build up a relationship with a support person before they are able to move forward.

¹¹ Department of Health and Aged Care, Health Policy Analysis, August 2024 [Final Report - Analysis of unmet need for psychosocial supports outside of the National Disability Insurance Scheme](#)

¹² Ibid.

FOUNDATIONAL SUPPORT CONCERNS

While we support the rationale for and design elements of Foundational Supports, we have implementation concerns.

Major ones are:

1. Where will the services and the workforce to deliver these services come from?

We hear many reports of providers pulling out of the disability support sector. The 2023 National Disability Services (NDS) State of the Disability Sector Report¹³ identified that:

- 34% of provider respondents to their survey identified that they were running at a loss
- 18% said they were just breaking even
- 67% of not-for profit providers said they worried they would not be able to provide NDIS services at current prices
- 82% of said they could not fulfil service demand and identified:
 - Not enough staff (45%)
 - Not enough qualified staff (21%)
 - Not enough organisational resources or money (15%)

The availability of allied health professionals was described as “low to non-existent”.

An additional challenge will be the increased workforce demand for aged care services for older people living within the community as the baby boomers begin to hit the aged care system.

With respect to addressing workforce problems in thin markets (provider deserts), it has been suggested that carers could be employed to fill some roles such navigation assistance, referral to local services and a number of capacity building tasks. Many carers who themselves have worked their way through health and disability support systems are uniquely well placed to assist others.

The solutions to these challenges - which will be complex, multifaceted and expensive –are fundamental to successfully providing services to a much expanded range of people with disability.

Part of the solution will come via additional funding from state and territory governments and, as the NDS would have it, higher pricing. The workforce challenges may be more difficult to address.

¹³ National Disability Services, State of the Disability Sector Report 2023
[State_of_the_Disability_Sector_Report_2023.docx](#)

2. Geographical equity of access to these supports

While states and territories have agreed to increase their contributions to disability supports and especially to Foundational Supports, there are likely to be variations across jurisdictions as to how much support will be provided.

And then there is the matter of thin geographical markets. While the NDIS Review refers to addressing gaps in thin markets and the need to establish providers of last resort, the fact remains that despite years of aged care and NDIS reforms the thin market problem has not been resolved.

SUMMARY

Foundational Supports have the potential to address many inequities and gaps in Australia's current disability support system.

However, at the moment it is a high-level model which will require a lot of implementation detail and investment to fulfil its promise.

We appreciate that it is still early days in the journey to bring it to fruition and look forward to being involved in its development.

We recommend that Carers Australia has the opportunity to provide direct input into the co-design of supports, to ensure they meet the needs of carers.

A SNAPSHOT OF AUSTRALIA'S CARERS

There are three million^[1] carers in Australia, with almost two thirds caring for someone under the age of 65⁵. Women make up 54% of all carers and nearly 67%⁵ of primary carers. Carers can be any age, 13% of carers are under the age of 25⁵, and 25% of carers are 65 years and older⁵. Just over 14% of the Aboriginal and Torres Strait Islander population identify as carers^[2] and more than 27% of carers were born overseas¹. In 2022, approximately 39% of primary carers identified as living with a disability⁵. The LGBTIQ+ community is 3.4%¹ of the caring population and just over 24% of carers live in an area of most socio-economic disadvantage¹.

Being a carer is a constrained choice that impacts many aspects of a carer's life. To better understand and quantify the impact on carers, both Carers Australia, in conjunction with the University of Canberra, and Carers NSW, together with State and Territory Carer Organisations, undertake detailed surveys.

Carer's Australia's conducts an annual [Caring for others and yourself:2024 Carer Wellbeing Survey \(Survey\)](#)^[3]. This year's survey had 9,000 respondents. Some key findings identified that compared to the average Australian, carers were 2.5 times as likely to report low wellbeing, are twice as likely to have psychological distress, half as likely to be in good health, and are three times more likely to experience significant financial distress.

More than 10,000 carers responded to Carers NSW 2024 biennial [National Carer Survey](#)^[4]. Preliminary findings from this survey have identified most carers felt they were not recognised or valued by government, and nearly one in two felt they are not recognised or valued by their community. Most noted they are not asked by service providers about their own needs as a carer and more than six in ten carers feel socially isolated.

While only 13% of Australians rely on a government pension or allowance, 40% of primary carers and 28% of non-primary carers rely on a government pension or allowance as their main source of income⁵. In 2020, a Deloitte Access Economics report on the value of informal care^[5], identified the economic value provided by carers in 2020 would be \$77.9 billion. The estimated earnings foregone for primary and non-primary carers at \$15.2 billion (\$11.4 billion primary carers, \$3.8 billion secondary carers). In 2022 Australian Bureau of Statistics¹ (ABS) identifies that approximately three in five (60.5%) of the 5.3 million people living with disability in Australia receive assistance with at least one activity of daily living, with 71.6% receiving assistance from informal carers^[6], with 42.2% receiving formal assistance daily.

^[1] Australian Bureau of Statistics, Survey of Disability, Ageing and Carers (SDAC) 2022

^[2] Australian Bureau of Statistics, Census 2021

^[3] Carers Australia [Caring for others and yourself:2024 Carer Wellbeing Survey](#)

^[4] Carers NSW 2024 [National Carer Survey](#)

^[5] Deloitte Access Economics (2020), The value of informal care

^[6] Australian Bureau of Statistics 2022
