



**Submission to the Joint Standing Committee on
the National Disability Insurance Scheme**

**Inquiry into the Capability and Culture of the
National Disability Insurance Agency (NDIA)**

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About Carers Australia

Carers Australia is the national peak body representing the diversity of the 2.65 million Australians who provide unpaid care and support to family members and friends with a disability, chronic condition, mental illness or disorder, 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 represent the views of carers at the national level.

Our vision is an Australia that values and supports all carers, where all carers should 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.

This includes carers:

- Who have their own care needs
- Who are in multiple care relationships
- Who have employment and/or education commitments
- Aged under 25 years (young carers)
- Aged over 65 years, including 'grandparent carers'
- From culturally and linguistically diverse backgrounds
- Who identify as Aboriginal and Torres Strait Islander
- Who identify as lesbian, gay, bisexual, transgender, intersex (LGBTI+)
- Who are living in rural and remote Australia, and
- That are no longer in a caring role (former carers).

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. As an inclusive organisation we celebrate people of all backgrounds, genders, sexualities, cultures, bodies, and abilities.

Introduction

Carers Australia appreciates the opportunity to provide feedback on Capability and Culture of the National Disability Insurance Agency (“the Agency” or “the NDIA”) and wants to work with the Agency, other relevant area of government, people with disability, disability representative organisations (DROs), disabled people’s organisations (DPOs), and advocates to improve the National Disability Insurance Scheme (“the Scheme” or “the NDIS”) for participants, carers, families and the community.

We note the term ‘carer’ should not be used broadly and without context to describe a paid care worker, or a family member or friend who is not, in fact, a carer as defined by the *Carer Recognition Act 2010* (Commonwealth)¹.

This response addresses Terms of Reference items (a) and (b):

The committee will inquire into and report on the implementation, performance, governance, administration and expenditure of the National Disability Insurance Scheme (NDIS), with particular reference to:

- a) the capability and culture of the National Disability Insurance Agency (NDIA), with reference to operational processes and procedures, and nature of staff employment*
- b) the impacts of NDIA capability and culture on the experiences of people with disability and NDIS participants trying to access information, support and services from the Agency.*

Carers Australia has engaged heavily in reform processes focused on the Scheme, including responses to numerous papers from the Agency over several years, submissions to the range of Senate and Joint Select Committee inquiries, as well as submission to inquiries into the disability community, services and supports beyond the Scheme². As such, we are aware of the recent changes, including the introduction of new board representatives and executive staff, as well as ongoing reviews taking place, and commend the Agency for its efforts taken to begin rebuilding trust with the disability community.

Nonetheless, there remains a range of capability and cultural challenges for the Agency, Scheme, and whole of government which negatively impact on Scheme participants, their carer(s) and families, and the broader community. This will require significant work to occur before the Scheme is sufficiently supporting participants and their carer(s) and families to meet their outcome goals.

It is also important to highlight that while primary carers provide care to someone with disability, they can also be living with disability themselves and be a participant of the Scheme. In fact, in 2018 over one-third (37.4%) of primary carers had disability, twice the rate of non-carers (15.3%).³ This linkage is not represented within NDIA reporting and increased efforts to recognise, validate and address the issues faced by carers would increase the capability of the Agency’s services and better inform staff and service providers on lived experience.

Carers Australia remains open for further consultation with both the Agency and other government and parliamentary inquiries and encourages the use of collaboratives efforts to instill changes led by participants, their carer(s) and families.

¹ Australian Government, *Carer Recognition Act 2010*, No.123,2010 [[accessed online](#)]

² Previous submission by Carers Australia can be found on the website www.carersaustralia.com.au

³ Australian Government, Australian Bureau of Statistics (2018). *2018 Survey of Disability, Ageing and Carers – Summary of Findings*. Accessed on 10 October 2022 [[accessed online](#)]

Operational processes and procedures

Carers Australia believes that a lack of carer-inclusive processes and procedures has been detrimental to the capability and culture of the NDIA. Carers are an integral part of society and play large roles in the lives of many NDIS participants in addition to being participants themselves⁴. It is important that carers are supported to participate in economic, social and community life, as recognised by the Statement for Australia's Carers under the *Carer Recognition Act 2010* (Commonwealth)⁵. Current operational processes and procedures used by the Agency work to identify and recognise carers in an ad hoc at best, and often rely on the carer of the participant already identifying as a carer. Even when a carer is identified by the Agency as an informal support for a participant, the carer's role is often acknowledged only superficially, without taking steps to support and enable the carer to best support the participant so that both parties may be sufficiently supported to thrive and participate in the community. Carers Australia suggests the Agency addresses and remedies this identification, recognition and support deficiencies through two mechanisms: increasing use of Carer Impact Statement during application and planning processes, as well as increased transparent data, modelling and forecasting in public documents.

As current, a Carer Impact Statement can be completed during the NDIS planning process, allowing carers to outline what they do, and the impact caring has on them. This statement is also known as an Impact Statement – further confusing the purpose of the document. A Carer Impact Statement provides opportunity to capture valuable and extensive information about the carer and their understanding and use resources and support systems within their role. This is not required however is encouraged to strengthen the funding applicant. As with many parts of the application and planning processes, there is currently no standardised template provided by the Agency; this gap is filled with community sector organisations providing tips and ideas. While not suggesting the Agency moves to a model where Carer Impact Statements are mandatory, or written in a strictly prescribed template, the lack of official advice leaves many carers confused about the legitimacy and purpose of this document.

Despite the value of these statements, where one is provided, little is done with the information collected beyond the application and planning stages of the Scheme. Proper utilisation of this information would see carers being referred to Carer Gateway, greater conversation and reporting on carer wellbeing and greater understanding of all parties involved under the NDIS. This lack of initiative taken to recognise the complete picture of the carer support system deprives the system of fully understanding what is reasonable and necessary as required by the NDIS funding criteria. The development of a fuller population picture would enable the NDIS to better tailor services for participants, as well as provide the reasonable and necessary support required to allow carers to increase participation in the workforce (Family and Carers Outcome) while primarily supporting the participant's needs.

Carers Australia continues to advocate for new and reformed data collection processes and reporting mechanisms to better capture information about carers separate from participants in the Scheme. This issue has been previously identified in Carers Australia's response of February 2022 to the Joint Standing Committee on the National Disability Insurance Scheme⁶ and we continue to believe that there is likely an ongoing undercount on the number of participants with carers due to the inconsistencies in collecting information through the Scheme. Most prominently, there is inadequate identification of

⁴ *Ibid*

⁵ *Op.Cit(1)*.

⁶ Carers Australia (2022), *Letter to Joint Standing Committee on the National Disability Insurance Scheme*. Accessed on 10 October 2022 [[accessed online](#)]

carers within current survey models. As of current, all NDIS reporting on carers is done through the NDIS Family and Carer Outcomes Report, which groups together families and carers. Although caring roles are most often filled by close family members or friends it is important to acknowledge the distinction between family members and carers, as defined in the *Carer Recognition Act*⁷. Caring roles involve the ongoing management of many aspects of one's lives and is done in place of paid care roles most often without adequate access to respite. Caring roles are extensive, time consuming and are distinctively different from generalised familial support. Proactive steps taken to differentiate between these two groups would enable better identification of carers and the impact that caring has on their livelihood.

To note Carers Australia has previously engaged with the Agency's Scheme Actuary to build positive relationships; however, the reporting outcomes are beholden to the way the data is collected and analysed. Carers Australia understands that the Agency is undergoing reviews and broader reform to address this issue however, we have not been consulted to provide feedback on how to improve its data capture and data sharing processes in the roll out of the new system. Without adequate consultation we fear that this issue will not be resolved and will continue to impact the Agency's performance and inclusivity of carers, which in turn negatively impacts participants by under considering their true situation.

Nature of staff employment

While the Agency is commended for its achievement of employing high rates of people with disability in its staffing suite, Carers Australia recommends the Agency continues this culture of imbedding people with lived experience of disability and extend this to carers. The Agency has an opportunity to work towards being a more carer inclusive workplace, where the unique expertise and skills of carers are recognised and uplifted. Carers Australia would love the opportunity to work with the Agency as an employer to move towards being more carer inclusive. This similarly extends to positions and organisations contracted by the NDIA in the community such as Local Area Coordinators, who will also benefit from upskilling to be more carer-inclusive employees.

Access to information, support and services

Carers Australia believes that proper acknowledgement of carers experiences with the NDIS is integral to improving the capability and culture of the Agency. Carers are often system navigators for participants within the Scheme and are heavily involved in the decision-making process due to lack of coordinated efforts with information sequencing within the Scheme. The responsibility of this coordination in addition to all the other caring responsibilities makes these participants more likely to become dependent on information and assistance provided directly by service providers as these providers are proactive in finding participants with little regard as the appropriateness of them to the participants needs.

We draw your attention to the results of the 2022 Carer Wellbeing Survey⁸ revealed that when asked to rate the extent to which the person or people they care for had good access to a range of types of support, less than half (41.4%) stated good access to the NDIS, with 47.9% reporting 'poor access'. In addition, the most common barriers experience in the past 12-months prior to March 2022 in accessing supports for the person the care for included:

⁷ *Op.Cit(1)*

⁸ University of Canberra, 'Caring for others and yourself: 2022 Carer Wellbeing Survey Full data report' (2022), prepared for Carers Australia [[accessed online](#)]

- difficulty finding high quality services (69.3%),
- a complicated application process (69.5%),
- lack of funding through NDIS or My Aged Care (65.9%), and
- staff turnover amongst service providers (63%).

Conclusion

Carers Australia thanks the committee for its work through the Inquiry into the Capability and Culture of the NDIA. We remain eager to see the growth and evolution of the Agency, Scheme and broader government to become more inclusive and accommodating of Scheme participants. In order to achieve this growth and evolution the Agency must work closely with all parties involved including participants, carers, family and friends to ensure the policies and procedures align both best practice and practicality, within a supportive and proactive framework.

We look forward to continuing involvement with this inquiry to ensure the voice of carers is included in the ongoing reforms of the NDIS.