



Response to the Independent Review of the National Disability Insurance Scheme - Proposal Paper on NDIS Participant Safeguarding

19 June 2023

Introduction

Carers Australia welcomes the opportunity to provide feedback on the Independent Review of the National Disability Insurance Scheme (NDIS Review) Proposal Paper [NDIS Participant Safeguarding](#) (the 'Paper'). Carers Australia is committed to the rights of people with disability and seeks to work with the NDIS Review to ensure that NDIS participants are safe, empowered and aware of their rights.

We acknowledge the importance of participant-centred responses, and that in-depth responses from organisations focused on disability supports and advocates, as well as individuals with disability, will provide much needed information on participant safeguarding. Please note that this paper may contain references to sensitive issues and may cause distress to some readers.

It is our role as Carers Australia to provide information to the NDIS Review from a carer¹ lens, and recognising that as our focus, we are encouraged to see the Paper identifying that building strong natural safeguards is important.

As identified in the Paper, we are also conscious that terminology can have negative connotations for many people and acknowledge that not everyone's experience is or can be properly captured by terminology. We are supportive of efforts to influence the social narrative around respectful and inclusive language about people with disability, however this must also extend to language related to carers and caring. As such we choose to respectfully use terms in this response, recognising the diversity of carers, care relationships and those receiving care.

We also reiterate that while carers can be providing care to someone with disability, they can also be living with disability themselves and may be a participant of the NDIS. In fact, in 2018 more than one-third (37.4%) of primary carers lived with disability, twice the rate of non-carers (15.3%).²

The relationship between carers and the NDIS is multifaceted and unique. Between the relationship they have with the person they care for, the intensity of care and support provided based on individual circumstances, and the experiences they incur as a carer within the NDIS as a system, the carer's story is one of many voices, but an important one.

"[What I least like] Hate being called "an Informal support" by the NDIS. I am his wife and carer."

– 2022 Carer Wellbeing Survey Response

¹ Carers Australia uses the term 'carer' as defined by the Commonwealth [Carer Recognition Act 2010](#) (the Act), where it should not be used broadly and without context to describe a paid care worker, volunteer, foster carer or a family member or friend who is not a carer. It is also important to distinguish a carer from a parent, where the caring role is different to child-rearing. The terms 'informal carer', 'unpaid carer' or 'family and friend carer' are also often used by organisations, government and the community to describe a carer. Carers Australia may use these terms to assist in providing context and to differentiate between other types of care.

² Australian Bureau of Statistics (ABS), Survey of Disability, Ageing and Carers, (2018), [\[accessed online\]](#).

We want to work with the NDIS Review to embed processes where carers are equally recognised and supported for their role in providing informal (or 'natural') safeguards for people with disability, including to:

1. consider ways that carers can be supported to understand their role in natural safeguarding and build their capacity as advocates,
2. improve knowledge and systems that uphold and promote the rights of people with disability, and
3. assist with engagement opportunities for lived experience carers on proposed supports and mechanisms.

Carers Australia broadly supports the draft proposals for change identified within the paper. We direct the NDIS Review to our [past responses](#) for further guidance on questions around the role of carers in supporting safeguards and supported decision making, including [our submission on Safeguards and Quality](#) to the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability (Disability Royal Commission), [our response on Support for Decision Making](#) to the National Disability Insurance Agency's consultation, and through our involvement as a member of the Disability Representative and Carer Organisations (DRCO). Our response to this Paper is also informed by our members - the state and territory peak advocacy organisation for carers, which collectively form the National Carer Network, as well as information collected through the annual [Carer Wellbeing Survey](#) and individual feedback from carers to Carers Australia.

Response to Proposals Paper

We understand the focus of the NDIS Review is on the NDIS, however we must stress the importance of acknowledging that not all people with disability will meet the requirements to access the NDIS, or may make the decision for various reasons to not engage with the NDIS despite being eligible.

Safeguarding is equally important to those with disability outside of the NDIS, and for mainstream services that *anyone* living with disability may be accessing - health care, aged care, mental health care and social services need to also understand that 'everyone has a role to play in supporting participants to be safe.'³

Recommendation: Establish efforts for capacity building for carers within the Participant Safeguarding Strategy

We believe it is imperative that a NDIS-wide Participants Safeguarding Strategy is developed, and that it must recognise carers for the integral role they have in prevention, intervention, and support of safeguards for people with disability.

The role of natural safeguards is very well recognised through the Paper and carers are recognised for the responsibility they may have as safeguards for an individual. In addition, the Paper notes that family members and carers observe that the complexity of processes can impact upon their capacity to support participants.

³ NDIS Review Proposal Paper 'NDIS Participant Safeguarding' p. 3.

“[What I least like] The hurdles to jump to access support, a lot of support is superficial or doesn’t suit the individual needs. The stress of NDIS under constant threat and the rules/policies surrounding NDIS constantly changing. NDIS having ridged cookie cutter ideas around disability support needs. Constantly fearing paperwork, administration and research around NDIS planning. Worrying about the future and supports being further reduced. Worrying about what will happen to the people I care for if I die.”

– 2022 Carer Wellbeing Survey Response

While we support all efforts directed at capacity building for participants, we also believe that carers are well placed to support the physical, psychological and financial safety of participants and this will only be supported if they have their own rights met as well.

As an example, we highlight the current Carer Impact Statement which can be completed during the NDIS planning process, allowing carers to outline what they do, and the impact caring has on them. A Care Impact Statement provides an opportunity to capture valuable and extensive information about the carer and their understanding and use of resources and support systems within their role.

Despite the value these Carer Impact Statements could have, they are encouraged to strengthen funding for the applicant but are not required. We have made representations on many occasions that where one is provided, little is done with the information collected beyond the application and planning stages, and there is no closing the circle on any issues identified that would help the carer in their role. Proper use of this information would at the very least see carers being referred to Carer Gateway, greater conversation and reporting on carer wellbeing and greater understanding of all parties involved under the NDIS.

“[What I least like] Not having the support I need personally and having to fight and advocate so much with institutions (NDIS/school) to try to ensure my children receive the support they need. The system considering my children as numbers rather than individuals and the stress that causes me.”

– 2022 Carer Wellbeing Survey Response

Inclusion of carers in the Participant Safeguarding Strategy would support development of tailored resources that:

- Illustrate what ‘caring’ is in a way that enables participant decision-making and dignity of exercising choice (including the right to make poor choices) and taking risks.
- Increase awareness of disability advocacy services for carers, including when it may be appropriate to have an independent advocate.
- Support and enable self-advocacy capacity building for participants including developing their skills, independence and confidence with the support of their carer.
- Increase awareness of specific supports for carers who have disability to assist in them continuing to provide care.

Recommendation: Consistent and accurate recognition of carers

The long history of carers not being appropriately identified or their needs addressed across government has not translated into effective or sustainable long-term outcomes for carers or the person receiving care, where successive reform across settings and sectors, while well intentioned, has the potential to further fragment the provision of supports and services.

*“[What I least like] Not knowing how to negotiate the NDIS review and accessing new services.
Feeling like I am never going to be on the radar of LAC...”*

– 2022 Carer Wellbeing Survey Response

While we are pleased to see carers recognised in this Paper by the NDIS Review, it is important to raise the inconsistency of this approach with respect to broader disability-focused policy. As examples of the current policy landscape and reform processes that intersect with the NDIS Review’s work:

- there is carer representation on the National Disability Insurance Agency’s Disability Representative and Carer Organisations (DRCO’s) group to engage, discuss, collaborate and co-design the NDIS, as outlined in the [NDIA Engagement Framework](#),
- there is not however carer representation on the Department of Social Services Disability Representative Organisations (DRO’s) group, despite policy priority 3 of the [Australia’s Disability Strategy 2021-2031](#) focused on the role of informal support, and the Strategy’s Outcome Framework including a [measure for carer satisfaction with support](#),
- the [NDIS Family and Carer Outcomes Report](#) surveys measure the outcomes for participants and their families and carers who are part of the NDIS, however it groups together ‘families and carers’,
- the [ECIA National Guidelines on Best Practice in Early Childhood Intervention \(2016\)](#) to support the successful delivery of early intervention services, both inside and outside the NDIS, uses the term ‘caregivers’ as in ‘parents or other key caregivers’ which also includes child care staff. This is also important when you consider the early childhood early intervention (ECEI) context as opposed to Early Childhood and Care (ECEC), and
- the ECIA Guidelines are monitored under [The Early Childhood Targeted Action Plan](#), where Objective 2 of the Action Plan is to strengthen the capability and capacity of key services and systems to support parents and carers to make informed choices about their child. Caring does not equal parenting – a carer may be the parent of the person with disability, but equally may not be. Similarly, the parent may be the carer, or the carer may be another family member or friend. We often have representation that carers of adult children with disability fall through the cracks of support for ‘parents’ as their child is an adult.

A carer’s role is distinctly different from generalised familial support or parenting and as such the information needs are different, especially as it relates to safeguarding for participants.

Although caring roles are most often filled by close family members or friends it is important to acknowledge the distinction between family and parents with carers, as defined in the [Carer Recognition Act \(2010\)](#). Caring roles may involve ongoing and high intensity care and support of many aspects of participants’ lives, can involve activities that paid ‘formal’ roles might offer if they were available, accessible and affordable, and is done most often without adequate access to respite or other supports.

To this end we note the announcement of an [Inquiry into the recognition of unpaid carers](#) by the House of Representatives Standing Committee on Social Policy and Legal Affairs on 14 June 2023. As highlighted in our [media release](#), Carers Australia is pleased to see that the new Inquiry’s Terms of Reference are broader than simply a definition of ‘who is a carer’, and includes developments in the policy landscape at a Commonwealth level since the Carer Recognition Act’s original passage in 2010, and the Government’s broad agenda in relation to the care and support economy.

“[What I like least] Responsible for the ‘admin’ aspects of being a carer, i.e. dealing with NDIS, Centrelink, My Aged Care (I care for both an NDIS participant and an elderly parent). Worry about whether I have remembered to do all those admin things, preparing for meetings, reading information, finding and coordinating services, managing their health needs including COVID-19 vaccinations and safety, etc, etc. Also worry about who would do all those things if I couldn’t.”

– 2022 Carer Wellbeing Survey Response

Activities that would increase recognition of carers to ultimately benefit NDIS participants include:

- increased efforts to identify whether a participant has a carer and the amount of care that is provided, or if the participant is a carer themselves,
- accurate information for carers with consistent terminology related to the NDIS, and broader disability policy,
- appropriate and consistent representation of carers and their role, and how this may differ from parenting, and the informal supports provided from family or other sources, and
- carer representation consistency across government and processes related to disability policy.

Recommendation: Identify gaps in research related to safeguarding that includes carers

Under no circumstance is abuse or neglect ever acceptable.

We support that the research agenda for the National Disability Research Partnership will also look at a range of issues linked to this topic, including research into how capacity for self-advocacy can be further developed among people with disability.

However, research is also needed on risk factors for abuse or neglect of people with disability perpetrated by family, friends, parents and carers, the impacts of community supports and services that aim to strengthen the relationships between carers and the people they care for, the impacts of lack of recognition or understanding of a carers, and the role of carers as reporters and preventers of abuse or barriers for doing so.

It must also be recognised that carers can be at risk of being abused by the person they care for which is also an under-researched and reported on area that deserves attention. We also highlight that there is no individual independent advocacy mechanism for carers in Australia.

“Carer Burnout is an awful reality, especially when there seems to be no easy way out. Keeping one’s ‘head above water’ is a full time job. Current bureaucratic practices are very responsible for a massive extra load on carers. Everything has to be done twice or more, always needs to be checked up on and waiting is a very big given. The gaps in information are just ignored or left to be filled in or understood by ‘others’. It is very much a do-it-yourself society and even more so for carers. Nothing is straight forward, and trying to sort out issues is the most exhausting part especially for a carer who adopts a positive advocacy role, despite skills in this area.”

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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.

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