

Joint Standing Committee on the National Disability Insurance Scheme
PO Box 6100
Parliament House
Canberra ACT 2600
ndis.sen@aph.gov.au

Dear members of the Joint Standing Committee on the National Disability Insurance Scheme,

I write in response to the [Current Scheme Implementation and Forecasting for the NDIS Inquiry](#) the Committee is currently undertaking. This Inquiry marks another step towards implementation of recommendations from the 2019 Tune Review, and a reformed National Disability Insurance Scheme (“the Scheme”) that better meets the needs of participants and carers to allow them to thrive in their communities.

As you are aware, Carers Australia represents carers who provide unpaid personal care, support and assistance to family members and friends or other individuals who have a disability, mental illness, chronic condition, terminal illness, an alcohol or other drug issue or who are frail aged, as outlined in the Commonwealth *Carer Recognition Act 2010*. There are over 2.65 million carers in Australia, with around one in 11 carers (235,300 people) under the age of 25. Carers are an integral part of Australia’s health system and are the foundation of our aged, disability, palliative, and community care systems.

I also highlight that Carers Australia has engaged heavily in reform processes focused on the Scheme, including submissions to the Disability Royal Commission and responses to numerous papers from the National Disability Insurance Agency over several years. This has been difficult due to the lack of funding for our organisation to undertake this important work, and the far-reaching impacts of COVID-19. While a more detailed response to this specific Inquiry would have been preferred, I recommend the Committee also considers Carers Australia’s recent advocacy regarding the Scheme, including our response to the [Proposed NDIS legislative improvements and the Participant Service Guarantee](#) consultation. As such, the purpose of this letter is to draw to the Committee’s attention to three specific implementation and forecasting issues of most concern to Scheme participants and their carers. The headings below are taken from the Inquiry’s Terms of Reference.

C. Variations in plan funding between participants with similar needs

Concerns have been raised to Carers Australia regarding participants who have had their plan funds reduced due to having a carer (or carers) providing unpaid support. While the National Disability Insurance Agency (“the Agency” or “the NDIA”) must take into account the participant’s environment and support networks when assessing what measures are ‘reasonable and necessary,’ the mere presence of a carer in a participant’s life does not necessarily negate or reduce the supports required through the Scheme.

Of particular worry to participants and their unpaid carers is the situation where a participant and carer’s relationship has remained the same, however the participant’s core funding is reduced following the annual review process. A carer (who is also a participant) [recently shared her experience of this issue with media](#):

Bethany's "core supports" funding, used to pay for things such as in-home support workers, was slashed dramatically from \$86,234 to \$600 over 12 months ... The NDIA told Scott in a letter that support workers would not be funded because some of the tasks they assisted Bethany with were considered a "parental responsibility".¹

Unfortunately, this participant-carer's experience echoes a range of anecdotes provided by participants and carers to Carers Australia and our network of carer organisations. These purported funding reductions have negative social and economic ramifications, with some carers reporting they need to quit or reduce hours at paid employment in order to meet the care needs of participants whose funding has been reduced. Beyond the impact on individual participants and carers, this raises broader concerns about how the Agency is defining "parental responsibility," as well as its definition of expected responsibilities of participants' carer(s) who are not parents.

While there has been some media coverage of this issue, it would be prudent for the Committee to refer this issue for further investigation given the devastating impact loss of paid support workers can have on the lives of participants and carers.

E. Financial and actuarial modelling and forecasting of the scheme & F. Transparent data, modelling and forecasting in public documents

Carers Australia remains concerned about the lack of data collected by the Agency and the Scheme which differentiates responses from participants and carers. At present, there is likely an undercount on the number of participants with carers as there is no consistent method of collecting this information within the Scheme. It is Carers Australia's view that all new and reformed data collection processes and reporting mechanisms should collect information about carers separate to participants, especially where the carer is also a participant. Noting the Scheme is undergoing significant reforms, the Committee should consider how the Agency might improve its data capture and data sharing processes.

H. Other related matters – Ongoing oversight

While noting the Committee dissolves alongside the current Parliament, Carers Australia identifies the need for ongoing oversight of the Scheme beyond parliamentary cycles. In the spirit of the broader reforms to enable greater community oversight and understanding of the Scheme, I ask the Committee to reflect the need for ongoing bipartisan oversight of the Scheme in the Inquiry's final report.

Acknowledging the tight timeframes for the Committee to report, Carers Australia is more than willing to provide further information on any aspects of the Scheme as it pertains to carers. I thank the Committee members for their role in overseeing and interrogating the implementation, performance and governance of the Scheme. We welcome any future opportunities to ensure the voices of carers are woven through the ongoing reforms to the Scheme.

Yours sincerely



Melanie Cantwell

Acting Chief Executive Officer

¹ Henriques-Gomes, L. (2022). "Wildly unreasonable": agency slashes mother's NDIS funding and then her daughter's, *The Guardian*. Retrieved from: < <https://www.theguardian.com/australia-news/2022/feb/24/wildly-unreasonable-agency-slashes-mothers-ndis-funding-and-then-her-daughters>>.