

NDIS Act Review Consultations
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Dear NDIS Consultation team,

I write in response to the *Proposed NDIS legislative improvements and the Participant Service Guarantee* consultation listed on the DSS Engage website.

I welcome the opportunity to provide feedback on *the National Disability Insurance Scheme Amendment (Participant Service Guarantee and Other Measures) Bill 2021* (“the Bill”) alongside the introduction of the Participant Service Guarantee Rule and Plan Administration Rules, and updates to the Children, Nominee, and Specialist Disability Accommodation Rules. This consultation marks another step towards the full implementation of recommendations from the 2019 Tune Review, and a reformed National Disability Insurance Scheme (“the Scheme”) which better meets the needs of participants and carers to allow them to thrive in their communities.

Carers Australia represents the almost 2.8 million carers in Australia who provide unpaid care and support to family members and friends who have a disability, mental illness, chronic condition, terminal illness, an alcohol or other drug issue, or who are frail aged. Carers are often a significant part of the lives of people with disability, as family and friends and loved ones, and as carers who can provide personal and physical care, emotional support and assistance with everyday domestic, social and other tasks.

Given the short consultation period, this brief submission addresses only the key issues in the proposed reforms which will likely or certainly affect carers of participants. Carers Australia has previously expressed our concern that the brevity of this consultation period will limit the breadth and depth of feedback received, particularly during an ongoing major COVID-19 outbreak as well as ongoing consultation fatigue. The limited consultation period for the proposed legislative changes will unlikely capture and respond to the interests of *all* stakeholder groups, which could have negative on flow if the changes are not suitable for *all* participants.

Overview

Carers Australia supports a number of the proposed amendments in the Bill and Rules, however these reforms could be further strengthened to ensure greater carer inclusion and support for carers and the people they care for.

It is critical that any policy and operational reforms to the National Disability Insurance Agency (“the Agency”) consider and promote the inclusion of carers. It is important that carers are supported to participate in economic, social and community life, as recognised by the *Carer Recognition Act 2010* (the Act). Within the Act, the *Statement for Australia’s Carers* notes all carers should have the same rights, choices and opportunities as other Australians, and that carers should be acknowledged as individuals with their own needs within and beyond the caring role. Through this lens, Carers Australia provides feedback on the range of proposed amendments to the Scheme.

Schedule 1

All review processes, regardless of who prompted the review, have time and/or financial impact on participants and carers, often alongside increased stress and worry about losing plan funding. Carers often are the ones responsible for either wholly or partially collecting evidence and other requirements based on an information request. In light of this, where a carer is significantly involved in a participant's review process there must be some recognition of the critical role carers play. This may be in the form of accessible and engaging resources which upskill on the Scheme's jargon and processes, improving digital literacy, access to carer peer workers and/or carer connection groups, or introducing a frontline role specifically trained in supporting carers to best support participants. A combination of these solutions could enable carers to more clearly understand how the Scheme works and the evidence or information required. If implemented correctly, these changes could see a future where carers can support the participant to provide required information back to the Agency with the best chance it meets the Agency's requirements. Where an information request can be resolved the first time, this minimises the need for additional information requests from the Agency, and in turn, improves the efficiency and sustainability of the overall Scheme.

Schedule 2

The insertion of "the relationship between people with disability and their families and carers is to be recognised and respected" at 12A, and "where relevant, recognise and respect the relationship between their families and carers" at 31(c)(ca) are welcome additions to the *National Disability Insurance Scheme Act 2013*.

However, the Scheme needs to go beyond having 'regard for' carers; the Agency must actively work with the carer to best understand their needs are met so they can continue providing care to the participant(s). While Carer Statements can be provided as part of access and planning processes, there is currently no mechanism which requires the Scheme or the Agency to respond to any support needs for the carer. While outside the scope of this current consultation, Carers Australia will continue to advocate for genuine engagement with carers through a carer assessment process.

National Disability Insurance Scheme (Participant Service Guarantee) Rules 2021

Engagement principles

The engagement principles and service standards provide useful guides for the Agency to model their behaviour, and set out the behaviour participants and carers can expect from the Agency. Carers Australia is pleased to see the principles of responsiveness, respect, and connectedness expressly include reference to carers. Similar to above, this needs to go beyond changes to words but rather be supported by an implementation plan with sufficient retraining and re-education where standards are currently falling short. Carers Australia would be delighted to work with the Agency on how to best implement these updated principles.

We affirm the responsiveness principle's service standards (g)(i)-(g)(iv) requiring the Agency, CEO and other responsible persons to "provide an effective single point of contact so that: ... participants, their families and carers ... only have to tell their story once and are able to build productive relationships under the NDIS." With transition and roll out now completed in all jurisdictions, some participants and carers have felt they are lost in a large, complex system. Ensuring a single point of contact is provided to participants, their families, and carers will help to remedy these concerns, and potentially result in better engagement.

Under the principle of empowerment, 4(e) states “empower participants to request to see a draft plan in advance of: (i) final planning discussions; and (ii) the approval of the statement of participant supports to be included in the plan.” To enable best-practice whole-of-person care and planning for a participant, this provision should more clearly set out that the participant *or their nominee* can request to see a draft.

Timeframes

We have heard many participants and their carers have been confused by inconsistent timeframes and actions experienced in the current Scheme. Clarifying timing expectations through *Part 3 – Timeframes and related obligations* will assist participants and carers to manage their expectations and better understand the processes which underpin access to and participation in the Scheme.

The 90-day time period for responding to the Agency’s request for information following an access request is a significant improvement for carers who support their participants to apply. This change may be particularly impactful on carers who live in regional, rural and remote areas, or those who are in financial distress, as many can find it challenging to meet the current timeframes given the waitlist length for professionals, particularly so in the public health systems.

For time periods imposed on the Agency, there must be a specific implementation plan which facilitates these time periods. While timeframe clarity is useful on paper, if the Scheme’s frontline workforce are not in a position or have capacity to adhere to these timelines, it is unlikely the timeframes regulating response times from the Agency will change for the participant or carers. If timeframes are updated and provided to participants (prospective and current) without implementing the infrastructure on the ground, participants and carers may become further frustrated with and feeling let down by the Scheme.

National Disability Insurance Scheme (Becoming a Participant) Rule 2021

Mental Health Carers Australia estimates there are 240,000 carers¹ of people living with mental illness and/or psychosocial disability, which accounts for at least 10% of Australian carers. Updating the language and clarifying the rules around psychosocial disability will better support people with psychosocial disability to access the Scheme and receive necessary supports, which in turn can improve the wellbeing of the carer(s) in the prospective participant’s life.

Data and reporting

There are several clarifications of reporting requirements throughout the suite of proposed changes. The changes to the Commonwealth Ombudsman’s powers to monitor the Agency’s performance could provide useful oversight and increased transparency. In the operationalising of this change, it would be beneficial for the Ombudsmen to expressly clarify if carers can provide complaints the Ombudsman, or if it will only be a mechanism for participants.

Carers Australia remains extremely concerned about the lack of data collected by the Agency and the Scheme which differentiates responses from participants and carers. Reflecting the updates to the engagement principle, all new and reformed data collection processes and reporting mechanisms should collect information about carers separate to participants, even where the carer is also a participant.

¹ Mental Health Carers Australia. *Mental health carers – webpage*. Accessed on 7 October 2021 from <<https://www.mentalhealthcarersaustralia.org.au/>>.

Overall, the amendments to the legislation, new Rules, and amended Rules should improve access to the Scheme, along with improving understanding of how plans should be managed, and what a plan can be used to fund. Carers Australia commends these beginning steps in implementing the Tune Review's recommendations to reform the Scheme to better meet the needs of participants, and their carer(s).

I welcome further opportunities to work with both the Department of Social Services and the National Disability Insurance Agency to ensure the voice of carers is woven through the ongoing reforms to the Scheme.

Yours Sincerely

A handwritten signature in blue ink, appearing to read 'Liz Callaghan', followed by a period.

Liz Callaghan

Chief Executive Officer

Carers Australia