



***National Disability Insurance Scheme Amendment  
(Participant Service Guarantee and Other Measures)  
Bill 2021***

***Submission to the Senate Community Affairs Legislation Committee***

***Young People In Nursing Homes National Alliance  
November 2021***

## Introduction

The Young People In Nursing Homes National Alliance is pleased to provide a brief submission to the Inquiry into the NDIS Amendment Bill 2021.

While the Bill details a range of amendments that are important in updating the NDIS Act including references to co-design (S4)(9), board selection criteria (S127, S129), and the importance of quality supports, these amendments are not material to the operation of the NDIS. The timelines for the participant guarantee, while a good discipline, could also be introduced administratively.

The Alliance has serious concerns about the new own motion power that, should the Bill be passed, enables the CEO to vary participant plans unilaterally. This power is inconsistent with the prioritisation of transparency and engagement with participants that must underpin all aspects of a successful lifetime support scheme's operations. Instead, this own motion power opens the door to misuse scheme-wide cost control strategies that are inappropriate in an individualised lifetime support scheme like the NDIS. This was not a Tune Review recommendation and regardless of what rules are applied to it, this power is a hazardous inclusion into the legislation.

Liability and risk management is fundamental to the success of a lifetime support scheme such as the NDIS. While short term cost control through internal work practices is one component of this, there are more sophisticated and effective strategies available that the scheme has shown little appetite to pursue. As example, by consistently ignoring calls to develop interface protocols with other service systems, the scheme has failed to address key risks that exist at its boundaries. Instead, the NDIS has used its control of participant plan funding as its only liability control measure. Far from assisting the scheme to manage its risks and liabilities, the additional CEO power outlined in S47 will only entrench this inward looking strategy and is not supported.

A Bill that empowers the scheme to undertake collaborative funding, risk sharing and shared policy arrangements with other service systems, would have been preferable and more forward looking. However, the thorough review of the NDIS' implementation and governance system that is really needed, is clearly beyond the reach of this amendment Bill.

For these reasons, the Alliance believes the Bill should not proceed in its current form.

## No urgent need for legislative change

From the Alliance's experience, people facing placement in residential aged care at hospital discharge need urgent access to the scheme and its planning decisions. As they are described, the timelines (while a maximum) are too long to be able to proactively impact this group. Again, the NDIA already has capacity to implement cohort-specific administrative targets for groups such as those stuck in hospital or participants requiring urgent plans

without having to resort to legislative amendment. So too can the provision of reasons for decisions (S100)(1) if the NDIA chooses to implement this through its work practices.

Because they have been identified as important, we recommend that the Commonwealth and the scheme work to implement these changes administratively.

The Alliance does understand that the Bill seeks to implement some of the recommendations of the Tune Review and the 2015 Review of the NDIS Act. Poorly commissioned and incomplete, both reviews were narrow and not consistent with the original vision of launch, learn and adapt that was the context for the 2013 legislation. As a result, we are yet to have a thorough review of the operation of the NDIS.

We do believe that some legislative amendments are required to support the scheme's evolution. But, due to its narrow ambition, they are not in this Bill.

These important changes include the repeal of S29(1)(B) that unfairly removes eligibility for participants who enter residential aged care for the first time after the age of 65; and a redrafting of S31(k) that limits service coordination to disability services only and fails to support coordination of services required by participants across service systems. Both these sections result in poor outcomes for participants and should be changed.

The proposed Becoming a Participant rules that require "appropriate treatment" to be exhausted before an individual can apply to become an NDIS participant, is clearly designed to exclude people with disability acquired as a result of a range of adverse health events.

The Alliance sees the proposed change to the Becoming a Participant Rule as a deliberate attempt to unfairly limit scheme access and strongly rejects it. It also creates a new barrier to the NDIS collaborating with health systems to enable concurrent services to be delivered to individuals with complex health and disability needs.

## **Scheme governance review**

Instead of passing this Bill and continuing to prosecute scheme change via minor amendment bills, we suggest a comprehensive review of the NDIS be undertaken by the Productivity Commission to examine the scheme's evolution, governance and practice as a social insurance scheme.

As example, the scheme's governance is an area that requires significant reform to ensure the NDIS can work collaboratively with other service programs and successfully deliver for its funders and for Australians with a disability. The governance arrangements that have been in place to this point were intended to manage the scheme's launch. Now that we are at full scheme, the states and territories should have a greater role in the scheme's governance arrangements to enable the NDIS to not only benefit from joined up initiatives with state and territory programs, but ensure that the scheme's missing 'tier 2' arrangement can be developed and implemented.

Entrenching the current governance arrangements that concentrate power with the Commonwealth, will not establish the scheme for the future but will take us further from the reform that is so greatly needed here. Instead of prioritising collaboration and risk sharing with state and territory programs, the full benefit of an independent NDIS cannot be realised if the scheme is exposed to the political influence of one level of government. The rules suggested in this amendment Bill as category D rules, simply make this problem worse.

## Increased power vested in the CEO

The proposed amendment to s47 that provides for the CEO to unilaterally vary participant plans, is retrograde and must not go forward. This power should not exist in the scheme at all and if, on the very rare occasion a decision of this nature is required, other processes can be activated to address anomalies or mistakes in plans.

Consent to go through a plan review/reassessment is important. But when it cannot be obtained through direct engagement with the participant, then another avenue must be found.

Issues remain with the scheme dealing with participants requiring supported decision making and include participants' ability to negotiate and execute service agreements with providers. These must be resolved and mechanisms implemented to ensure all participants have an active role in provider and the scheme decisions.

Through the Alliance's recent work with younger people living in aged care, a number of individuals have indicated that they do not see themselves as decision makers; are highly anxious when confronted by NDIS planners asking them if they would consider alternative housing and support options; and are likely to say no. Far from being a true indication of their preferences, these responses reveal that these scheme participants require much more support to consider their options and resolve any questions. For people in this situation, the scheme's ability to change their plan without consultation would not only be alarming, it would do nothing to build their capacity or improve their confidence to engage in decision making about their own lives.

The fact that the rules for S47 and S48 are proposed as Category D rules adds to our concerns that, vested in the CEO, this increased power could be used to address the NDIS' business or strategic interests under the imprimatur of 'improving' participant plans.

Rather than implementing a unilateral power for the CEO to vary plans, work to support participants in their decision making and participation in the marketplace offers the opportunity for the NDIS to comprehensively realise its goals of choice and control for all its participants.

## The influence of internal scheme culture

The Alliance is aware of situations where scheme by managers and planners make pronouncements to participants or their representatives about scheme funding policy that are not supported by the legislation or the rules. Examples of this include:

- Participants in aged care and SDA providers being told that NDIS participants over 65 won't be considered for SDA, despite there being nothing in the legislation that precludes this.
- There is no corporate strategy to cut plan funding, yet anecdotal evidence abounds where this occurs. One recent case highlighted by the media in Western Australia, quoted an NDIS spokesperson who confirmed that 'almost 30% of Huntington's [Disease] sufferers on the NDIS had their funding decreased over the last 12 months.'<sup>1</sup>
- Participants and advocates being advised that the NDIS will not fund additional personal support for Younger People In Residential Aged Care, despite the existence of specific work practices enabling planners to build this support into plans.
- SDA panel outcomes that are inconsistent with participant goals or the detailed recommendations of an occupational therapist. Most commonly this occurs where a participant needs to live alone, has a goal to live alone and has this recommended in their functional assessment, but is approved instead for a shared group home.

Given this experience of scheme administration, we believe there is a real risk that this additional power to vary plans may be used to legitimise and entrench detrimental scheme practices that are not only inconsistent with the legislation, but are designed to deliver cost savings and support work practices based on the business needs of the scheme, rather than the needs of participants.

## Investment in managing relationships

The currency of a lifetime support scheme like the NDIS is the relationships it develops with its participants. Core business for these schemes is thus the development of their ongoing engagement with participants, families, supporters and their providers. From these relationships and their sometimes complex dilemmas and difficult conversations, come the goals, funding outcomes and life chances the scheme is there to deliver. It is critical that an investment in the capacity of the NDIS to support these relationships and prioritise transparency, respect and good communication with its stakeholders is undertaken. Similar schemes in Australia and New Zealand have already shown that this can be done successfully.

The key here is for the scheme to proactively manage complexity and build capacity to deal with conflict and competing priorities – such as managing scheme liability and participant needs – not try to eliminate them. Where successful schemes understand that maintaining

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<sup>1</sup> Ison, S, "NDIS cut to plans- Home care under threat", *The West Australian*, 23 September 2021.

good relationships with their participants is a key liability management strategy, the NDIS seems to short cut the discipline and work required to maintain its relationships, preferring instead the 'set and forget' systems more often used in capped government welfare programs.

## Finally...

The Alliance rejects the use of the term 'reassessment' that is used in this Bill for variations to plans. Understanding the limitations of language here and given that there are already two types of plan review in the Act, we would counsel against using this term outside its recognised usage by a health professional. Younger people in aged care are subject to many (re)assessments and bureaucratic decisions that affect their lives, with aged care assessments, functional OT assessments, mobility assessments and others, and their choices and ultimately their quality of life is tied to the decisions of others. This is debilitating for many people who value their independence and don't want to be institutionalised. Having plan variations called 'reassessments' simply compounds this sense of powerlessness and reinforces for these individuals that their life is not their own. If it is needed, "plan variations" is more appropriate terminology.

The NDIS is a justifiably lauded social insurance scheme. But despite its social insurance imperative, a pull factor exists to make the scheme more predictable, more standardised and more compartmentalised... more like a capped government welfare program.

Barely out of its trial phase, the NDIS is a young scheme still. As it matures, it will develop the confidence in its future and its positive impact on both its participants' lives and on the Australian community, that it currently lacks. At this critical juncture, attention must be given to the NDIS' continuing evolution and to its governance arrangements if the scheme's functionality is to improve.

Unfortunately, this Bill does not take the NDIS down this path.

More deliberative work must be undertaken if the scheme is to emerge from its infancy and grow into the successful social insurance institution it is meant to be.

## Further contact

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