



Australian Autism Alliance

Submission to National Disability Insurance Scheme Amendment (Getting the NDIS Back on Track No. 1) Bill 2024 [Provisions]

17 May 2024

The Australian Autism Alliance (Alliance) is focussed on autistic people and their families and has strong interests in matters that affect NDIS.

About the Australian Autism Alliance

www.australianautismalliance.org.au

The Alliance aims to provide 'One United Voice for Autism'. The Alliance was established in 2016 and aims to improve the life chances of autistic people and facilitate collaboration within the autism community. Operating as a cohesive network of organisations with a diverse focus on autism, we have a national reach that brings together key autism organisations representing and led by autistic people, advocacy groups, peak bodies, service providers, and researchers. We reach over half a million people through our communication channels and provide support to people with autism across the lifespan. Most importantly, our work is informed by autistic people and their families and carers.



Acknowledgment:

We acknowledge the First Nations and Traditional Owners of the land, sea and waterways and pay respects to Elders past, present and recognise those whose ongoing effort to protect and promote Aboriginal and Torres Strait Islander cultures will leave a lasting legacy for future Elders and leaders.

We recognise and thank emphatically all the Autistic and disabled people who contributed to this submission. We recognise their vital contribution and value the courage of those who share this unique perspective for the purpose of learning and growing together to achieve better outcomes for all.



1. Overview:

It is understood that:

- the National Disability Insurance Scheme Amendment (Getting the NDIS Back on Track No 1) Bill 2024 is based on the recommendations of the NDIS Review.
- the Bill represents the first tranche of several upcoming amendments to the NDIS Act, to improve the participant experience.
- the Bill provides governments, and the disability community, with a framework to start improving the scheme for NDIS participants. Reforms in the Bill include:
 - taking a whole-person approach to participant support needs
 - improving service quality and safeguards
 - reforming participant pathways onto the NDIS and working towards a unified system of support for people with disability.
- many improvements will not take effect until a suite of changes are made to NDIS Rules and the legislative instruments that outline the detailed operation of the Scheme, which are made with the states and territories.

In this context, several recommendations are made below.

1. Co-Design Commitment in the Legislation

It is recognised that it is represented that it is intended that the Australian Government and NDIA will work with people with disability and the disability community to design rules and to implement legislation, and to design operational guidance and practice.

Given:

- a) how much is yet to be designed, yet there are deep and far-reaching consequences of what is being proposed to be amended;
- b) the significant power this provides to Government; and
- c) that a formal Government response to the NDIS review and DRC recommendations is still pending

Recommendation 1:

A co-design framework is attached to the legislation and tabled to Parliament to embed this commitment through all phases, providing improved transparency and certainty, outlining as a minimum:

- the process of best practice co-design to occur including for those who cannot advocate for themselves and/or are often overlooked;
- how the elements of best practice co-design will be met including respect, equality, diversity, safety, acknowledgement, accessibility, communication, and commitment;
- the resolution process of any contentious issues resulting from co-design with people with disability and the community;
- an outcomes framework including what needs to change in legislation regarding mainstream services to give effect to foundational supports, the measures of success and how a “no wrong door” government accountability framework will operate;
- an evaluation and continuous improvement public process that will operate throughout the process. This includes shorter and more frequent timeframes in relation to design elements as they should be trialled and assessed before being finalised such as the “needs assessment tools & process” and “budget setting



process". With complex disabilities such as autism, including co-occurring conditions and intersectionality issues, this is a must before wide-scale rollout.

- a mechanism to enable current elements identified to be in Rules to be elevated to Primary Legislation, as discovered during the co-design process.
- an undertaking of continued access to supports for people with disability until the State and Territories have practical and accessible alternatives in place for what is no longer intended to be accessed through the NDIS and that a transition of participants to mainstream services will not occur until this has occurred.
- a co-design process to develop the transition to the new planning pathway to ensure people are safeguarded. This needs to include a risk assessment and contingency plans.

Recommendation 2:

A provision is included in legislation that co-designed Primary Legislation and Rules cannot be subsequently unilaterally overruled by the NDIA through their discretionary powers. Any changes need to be co-designed.

2. Principles and/or Intent Captured in the Legislation

While it is recognised that the Government may have not wanted to draft Rules in anticipation as this would not demonstrate good principles of co-design the current drafting of the Bill does not capture the NDIS Recommendations and/or intent that has been relayed publicly to the disability community.

For example, currently, Section 32L (3) of the Bill outlines that the assessment must assess the NDIS participants' need for supports only related to the impairments that meet the eligibility criteria for gaining access to the NDIS. This does not reflect the NDIS Review, which recommended that a person's disability be looked at holistically. This is also inconsistent with the representations of moving away from a medical model and changing the narrative and yet there is language used such as "impairment".

Another example is the NDIS Review Final Report recommended the creation of a unified system where all parts work cohesively together to support people living with disability. Yet the definition of NDIS Supports is being proposed without the context of what is captured in "Functional Supports".

Recommendation 3:

That the intent and examples of the rules proposed that have been provided to date be embedded into the primary legislation, to provide confidence and a level of certainty to the disability community.

3. Flexible budgets

While we support in principle for whole-of-person budgeting and a flexible budget to be set that reduces complexity, this core element should be in the primary legislation (the Bill). We do not support that this is relegated to the instruments and a Ministerial determination be created about how budgets are calculated and when supports should be stated.



Recommendation 4:

That the flexible budget element should be retained in the Bill and a co-design approach be applied to develop a fit-for-purpose 'reasonable and necessary' best practice budget approach for the NDIS.

4. Assessing participants support needs

While we support in principle a new approach to needs assessment that will create a fairer, and consistent approach to ensure that people with disability have access to the supports they need, this core element should be in the primary legislation (the Bill). We do not support that this is relegated to the instruments and a Ministerial determination be created.

The Disability Royal Commission report stated that meeting individualised support needs of participants, and taking a whole of person approach, is:

- a) vital to achieving numerous positive life outcomes, including independence, inclusion and good health and mental health; and
- b) provides vast social and economic benefits to communities and governments.

Recommendation 5:

The needs assessment element should be retained in the Bill and a co-design best practice approach be applied and the results be robustly trialled prior to being rolled out to develop a whole-of-person approach safely which reflects the participant's well-being, life circumstances and life span and is consistent with any independent expert opinions.

This would be in line with what was articulated by the disability community when the Government considered independent assessments in 2021. This would also reflect avoiding going down the same path as what currently exists where there are unqualified, non-specific disability assessors making determinations regarding needs and typical support packages.

It is also unclear how the current proposed approach would account for intersectionality issues and decouple co-occurring conditions.

There is further concern that Section 32L (10)(b) is asking that the person conducting an assessment consider the financial sustainability of the scheme. This is not in the scope of practice of an assessor. The focus of an assessor should be on the person's needs.

Recommendation 6:

The participant receives a draft copy of the needs assessment for review in a reasonable timeframe and also a final copy of the needs assessment.

This would capture the learnings to date so that errors can be rectified, and additional evidence considered without the need for a review to address issues that should have been considered in the first place. Furthermore, this would provide some equity in the process with reciprocal rights, which is currently lacking in this Bill proposed.



There need to be reasonable time frames to enable the individual and/or their supports, to engage with supported decision-making in the process and provide necessary independent information.

Recommendation 7:

That there is a resolution process built into this section including for a participant to have the ability to seek a second independent review. This should also include an onus on the NDIA to provide transparency in their decision-making.

Recommendation 8:

For the avoidance of doubt state clearly in this section that assessments and additional information are not at the individual applicant's cost.

5. Definition of 'NDIS supports'

It is identified that the legislation will define 'NDIS support' (s10) setting out what NDIS funding can and cannot be spent on and will be supported by the development of further rules.

Issues with this are:

- a. It is too premature to determine a new definition of 'NDIS supports' before Foundation Supports is agreed.
- b. Utilising the 'Applied Principles and Tables of Support' (APTOS) is not a fit-for-purpose approach during the transition phase. The NDIS Review stated this document is based on a flawed assumption of clearly demarcated systems, "has failed", and has "led to seemingly endless arguments about who does what and who pays for it" (pages 35-36 and 66).
- c. White goods are provided as an example in the explanatory memorandum of items that are likely to be ruled out through the operation of this new definition. This approach does not align with assessing functional needs as this may capture items that are disability-related support needs, particularly as technology advances and provides for enhancing people's independence in ways that have not even been imagined. An example now would be a robot vacuum cleaner resulting in increased independence, privacy and reduced costs of needing a support worker. An example in the future may be commercialised wearable body suits that detect bruising (safeguarding) or health condition alerts (reducing the need for support workers). Hence there should also be provision for exceptions to be outlined. For instance, where there is a clear correlation where the allowance will enable a reduction of costs in the long term and improve life outcomes.
- d. In-home supports are limited to mobility supports. This is not contemporary and reflective of other life-long conditions that exist besides physical disability such as autism.
- e. It is unclear why only certain CRPD principles have been included.



Recommendation 9: The new definition of 'NDIS supports' is co-designed after or in parallel to Foundational Supports, hence delaying legislating related provisions until this work is completed. There should also be a provision for exceptions to be outlined.

Recommendation 10: Add a provision stating that a) rules cannot be made eliminating certain supports from the NDIS with the intention that they are to be provided through 'Foundational Supports' unless they are confirmed to be practically and sustainably available, accessible and affordable and b) that the current NDIS framework applying to plans continues.

Recommendation 11: Reject provisions referring to APTOS for transition.

Recommendation 12: Ensure in any transition phase there are adequate independent advocacy support services available who already understand the existence and operation of mainstream supports and ensure a person is assigned to prevent people from falling between the cracks and being left without supports.

Recommendation 13: A broad ban on white goods and appliances and in-house supports being limited to mobility supports should not form part of the Rules. The Rules should focus on Principles capturing what is intended to be avoided. An example may be "items not to be included are white goods that do not demonstrate the direct application of addressing disability-related support needs.

Recommendation 14: CRPD principles should be implemented in full, so they are read in complete context.

6. Information gathering for eligibility reassessment

NDIA will be able to request further information or assessments for the purposes of deciding whether a person continues to meet the access criteria. It further states where a participant chooses not to comply with a request, the NDIA will be able to revoke a participant's status if a participant repeatedly refuses to engage with the NDIA without a reasonable excuse and following repeated attempts.

Notwithstanding the intent, as currently written the NDIA has open-ended power while the participant has stated requirements that are onerous. There needs to be a more reciprocal reflection of responsibilities and obligations with certainty provided to participants given the experiences to date that are well documented in the NDIS Review.

For instance, the current Sections 30 and 36 proposed is inadequate.

- a) As mentioned above there is no provision for a participant to receive a draft copy of the needs assessment for review and a copy of the final assessment. Refer to Recommendation 5.
- b) Requests for information need to be substantiated and need to pass a reasonableness test. Some information is private and not relevant to the assessment



of supports such as how many partners a person has had which has been reported experiences to date.

- c) NDIA requests and decisions require the onus on the NDIA to provide sufficient substantiation, particularly involving an independent specialist report rather than the onus being on the participant to challenge and provide further evidence.
- d) The NDIA has the power to suspend a person's status as a participant or the development of their plan if the participant doesn't provide that information within a timeframe. Timeframes to respond need to be reasonable (28 days is not reasonable) with mechanisms for reasonable extensions to apply, particularly for reasons outside of the participant's control. There should also be a clear safeguarded pathway if this was exercised as a last resort. Exclusions can exist to carve out evidence of fraudulent practices.
- e) The NDIS does not have the reciprocal obligations to meet stated timeframes. If not met there should not be negative consequences to the participant.

Recommendation 15: As a minimum address the shortfalls as stated above in a, b, c and d in Sections 30 and 36 by co-design.

We thank you for the opportunity to respond and are committed to working with the Australian Government to achieve all people with disability, including Autistic people, thriving in an inclusive society.

Please do not hesitate to contact us with any queries or requests for further information.

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