

Australian Autism Alliance

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

12 July 2024

Committee Secretary
Community Affairs Legislation Committee
Parliament House
Canberra ACT 2600, Australia
c/o community.affairs.sen@aph.gov.au

Dear Community Affairs Legislation Committee,

Thank you for the opportunity to make a submission to the second inquiry of the Senate Community Affairs Legislation Committee ('Committee') inquiry into National Disability Insurance Scheme Amendment (Getting the NDIS Back on Track No. 1) Bill 2024. The Australian Autism Alliance (Alliance), described in Appendix 1, is focussed on Autistic people and their families and has strong interests in matters that affect NDIS. It is well publicised that autism has the largest number of participants in the scheme and over 95% of Autistic people experience one or more co-occurring disabilities and/or health or mental health conditions.

1. OVERVIEW

The Australian Autism Alliance made an original submission.¹ This submission is an additional submission responding to the most recent amendments (Revised Sheet PA 112) that have come before the Parliament since the original inquiry and are intended to be read alongside our original submission. A summary of recommendations is provided in Section 2 with more detailed explanations provided in Section 3.

We would like to reiterate that the fact that the NDIS is under significant pressure is completely recognised. We fully support genuine efforts to eliminate all aspects of fraud, ineffective funding use, and overspending. While we are pleased to see the amendments proposed in Revised Sheet PA 112 to address concerns, there is still more to be done as our community still feels worse off under the proposed legislation given the introduction of a raft of new concepts and removal of established concepts. That is, there are still not sufficient guard rails to safeguard participants who rely on the Scheme and for which the Scheme exists. There is still a need to remove the ambiguity that still exists in some of the legislation amendments so they can be interpreted clearly and not rely on the current Minister or NDIA Leadership. To this end, the following are additional or enhanced recommendations due to the amendments made to date.

¹ Australian Autism Alliance Submission 135

2. SUMMARY OF RECOMMENDATIONS

CEO POWERS INFORMATION GATHERING POWERS

Plan Management Regulations in Section 43 and 46

Recommendation 1: The legislation be amended so that Sections 43 and 46 are better defined. This includes:

- i. a provision of what constitutes “physical mental or financial harm”;
- ii. a specific provision to assess whether the information request can be addressed with decision-making support;
- iii. clarity that a breach of section 46 is only in the event of ‘wilful and repeat non-compliance’.

Information Gathering in Section 30, 30A and 36

Recommendation 2: Amend Sections 30, 30A, and 36 in relation to “other information requests” so that information requests that would be “unduly burdensome” are excluded.

Recommendation 3: Requests for information from participants that does not exist and/or needs to be created is to explicitly be excluded within the legislation.

Appropriate Accountability and Remedy

Recommendation 4: The legislation make provision to reflect:

- a) The rights of the participants if it is identified that the threshold requirements were not met;
- b) The right to review under s99 of the Act of all new CEO Powers;
- c) In the event that the request for information was not appropriate this annuls the CEO’s decision, notwithstanding if the participant complied or did not comply with the information request.

Debt Recovery Powers

Recommendation 5: The legislation makes provision that any debt recovery is on the party or organisation which resulted in the plan not being compliant and explicitly excludes where the participant is an innocent party who was misled, coerced, misrepresented, under duress etc. The onus should be on the CEO to provide reasonable evidence that the participant, whose plan has been impacted, has been complicit. For the avoidance of doubt this is not meant to be interpreted that any 3rd party that is not the participant is protected by this provision.

Recommendation 6: The legislation makes provision to specify that debt recovery powers will ensure that to recover debts from a person or organisation this cannot be funded through other plan funds (same participant’s plan or other plans).

WHOLE OF PERSON

Recommendation 7: The legislation be amended:

- a) to allow people to have additional impairments listed, in addition to the impairments through which they entered the scheme.

b) to include a requirement that:

- i. a person's eligible impairments (and what criteria they met) and when access was provided are identified in a participant's plan under s32D and s33;
- ii. the participant is informed .

c) to make these decisions reviewable.

Recommendation 8: The legislation be amended to make a decision to remove a condition from a person's file reviewable.

Recommendation 9: The legislation includes the relevant contents of the Revised Sheet PA112 legislative note(s) of and explanatory memorandum should be included as part of section 32K to remove ambiguity and for completeness.

Recommendation 10: The legislation includes clarity as to how a degenerative or fluctuating condition is considered for given the stipulation that the assessment is at a point in time.

NEEDS ASSESSMENT

Recommendation 11: The rights to further needs assessment (s), if people are unsatisfied with the first needs assessment is included.

Recommendation 12: The re-assessment process is clearly explained in the legislation (as opposed to relegated to the Rules), for people who are unhappy with the first assessment.

Recommendation 13: Insert the relevant contents of the legislative note (Items 6 and 7) and explanatory memorandum relating to this as a part of section 32K.

Recommendation 14: The legislation be amended to capture the rights of draft copies of the assessment and plans, in the preferred format, be provided to people before being formalised so that the person can respond in a reasonable timeframe for consideration prior to the needs assessment process being finalised.

Recommendation 15: The legislation remove reference to the person conducting an assessment consider the financial sustainability of the scheme and provide clearer provision clearly outlining the operation.

SECTION 10 NDIS SUPPORTS

Recommendation 16: The legislation includes an amendment that any exclusion decision is reviewable including for the provision of clinical judgment.

SECTION 10 ASSESSMENT TOOLS

Recommendation 17: There are clear provisions in the legislation that:

- a) appropriate assessment tools need to be developed and validated (reliable, validated by clinical judgement and individualised) before they can come be legislated for use.
- b) assessment tools that have been demonstrated to be ineffective/ inappropriate be excluded. This includes the previously trialled PediCat ASD.

CO-DESIGN AND CONSULTATION COMMITMENT IN THE LEGISLATION

Recommendation 18: That the legislation be amended to clarify that instruments provided to Parliament do not come into effect until the disallowance period passes and the rules and determinations can be viewed by the public.

Recommendation 19: That the legislation be amended to directly include a duty to consult with DROs and the community with reasonable timeframes for response, as opposed to just referring to the Legislation Act.

Recommendation 20: That amendment (18) that inserts new section 211, which prescribes certain information about consultation that must be included in explanatory statement to legislative instruments made under the NDIS Act is extended to include the percentage in total that was agreed or disagreed.

Recommendation 21: That the legislation incorporates all relevant explanatory memorandums relating to Co-Design to remove the ambiguity that currently exists and capture what is intended.

GENERAL

Recommendation 22 That the legislation appropriately incorporates all relevant explanatory memorandums to reduce ambiguity.

Recommendation 23 An independent expert panel is established and funded that has relevant expertise representing the diversity of the participants, particularly during the transition phase.

3. DETAILED RECOMMENDATIONS RESPONSE

3.1 CEO POWERS INFORMATION GATHERING POWERS

Based on Committee recommendations, the Government has introduced amendments regarding how people would be treated when they do not comply with a request for information from the Agency.²

We request more controls exist in the exercise of information request powers. It is our opinion that the following recommendations should be included to address the broad range of information that can be requested and ensure that the information being requested is reasonable (accessible, available, affordable, not invasive).

3.1.1 Plan Management Regulations in Section 43 and 46

The regulation of the type of plan management that a participant can have under section 43 and 46 still needs to be addressed as this impacts choice and control. The issue of when and what is reasonable as a threshold for information request powers is not adequately addressed in the amendments to date. The proposed amendments only limit the risk of a participant facing adverse consequences for non-compliance.

Dr Darren O'Donovan, suggested such controls only be implemented when a threshold of 'wilful, repeat non-compliance' is met, as well as requiring an assessment of whether the

² Government, Amendment Sheet PA112 (Revised) in Senate to *National Disability Insurance Scheme Amendment (Getting the NDIS Back on Track No. 1) Bill 2024*, cl 1-5.

situation could be addressed with decision-making support.³ It is noted that language such as “compliance” can be trauma triggering. What may appear as “non-compliance” may be cultural awareness. It is proposed that ultimately alternative suitable language is identified but for the purpose of the recommendation as been used in this submission.

Recommendation 1:

The legislation be amended so that:

- a) Sections 43 and 46 are better defined. This includes:
 - iv. a provision of what constitutes “physical mental or financial harm”;
 - v. a specific provision to assess whether the information request can be addressed with decision-making support;
 - vi. clarity that a breach of section 46 is only in the event of ‘wilful and repeat non-compliance’.

3.1.2 Information Gathering in Section 30, 30A and 36

The CEO’s extensive powers to request information in proposed sections 30, 30A and 36 are linked to serious consequences for participants who do not comply with these requests.

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. This was also reflected in the Alliance’s first submission.⁴

Hence, Government amendments containing limits should also be extended to these information requests (and not just those where medical assessments are required). This is to prevent requests for information that are unreasonable as they are impractical, unavailable, inaccessible, unaffordable, invasive or puts them at the risk of serious harm. If the CEO requires powers for specific reasons, then these should be specifically carved out.

The Alliance propose that a threshold be adopted to requesting information of not “unduly burdensome” as has been proposed by PIAC.⁵

Recommendation 2:

Amend Sections 30, 30A, and 36 in relation to “other information requests” so that information requests that would be “unduly burdensome” are excluded.

Recommendation 3:

Requests for information from participants that does not exist and/or needs to be created is to explicitly be excluded within the legislation.

³ Dr Darren O’Donovan, Submission no. 56 to Senate Community Affairs Legislation Committee, Parliament of Australia, *Inquiry into National Disability Insurance Scheme Amendment (Getting the NDIS Back on Track No. 1) Bill 2024 [Provisions]*, 30-32.

⁴ Australian Autism Alliance Submission 135

⁵ Public Interest Advocacy Centre, Submission no. 57, to Senate Community Affairs Legislation Committee, Parliament of Australia, *Inquiry into National Disability Insurance Scheme Amendment (Getting the NDIS Back on Track No. 1) Bill 2024 [Provisions]*, 32-33; Supplementary submission at 4-5.

3.1.3 Appropriate Accountability and Remedy

For accountability and to provide an appropriate remedy to participants the legislation should capture the rights of the participants if it is identified that the threshold requirements were not met. There should also be the right to review all the new CEO Powers under s99 of the Act.

Furthermore, if the request for information was not appropriate this should annul the CEO's decision, notwithstanding if the participant complied or did not comply with the information request.

Recommendation 4:

The Legislation make provision to reflect:

- a) The rights of the participants if it is identified that the threshold requirements were not met;
- b) The right to review under s99 of the Act of all new CEO Powers;
- c) In the event that the request for information was not appropriate this annuls the CEO's decision, notwithstanding if the participant complied or did not comply with the information request.

3.1.4 Debt Recovery Powers

The legislation proposes debt recovery powers. It is requested that there is explicit carve outs to protect participants from debt recovery powers where the participant is an innocent party. The legislation needs to be clear that any debt recovery is on the party or organisation which resulted in the plan not being compliant and explicitly excludes where the participant was misled, coerced, misrepresented, under duress etc. The onus should be on the CEO to provide reasonable evidence that the participant, whose plan has been impacted, has been complicit. For the avoidance of doubt this is not meant to be interpreted that any 3rd party that is not the participant is protected by this provision.

The legislation also should make provision that debt recovery powers will ensure that to recover debts from a person or organisation this cannot be funded through other plan funds (same participant's plan or other plans).

Recommendation 5:

The legislation makes provision that any debt recovery is on the party or organisation which resulted in the plan not being compliant and explicitly excludes where the participant is an innocent party who was misled, coerced, misrepresented, under duress etc. The onus should be on the CEO to provide reasonable evidence that the participant, whose plan has been impacted, has been complicit. For the avoidance of doubt this is not meant to be interpreted that any 3rd party that is not the participant is protected by this provision.

Recommendation 6:

The legislation makes provision to specify that debt recovery powers will ensure that to recover debts from a person or organisation this cannot be funded through other plan funds (same participant's plan or other plans).

3.2 WHOLE OF PERSON

The Alliance welcomes the Government's specific acknowledgement in the legislative note(s) Revised Sheet PA112 Items 6-12 and the Explanatory Memorandum⁶ of the impacts of a participant's other impairments upon their support needs, and requirement for the budget setting process to take these into account supporting the concept of 'whole of person' in line with the NDIS Review's recommendation better. This includes:

- Item 7 requiring the Minister, when making a determination about the budget, to be satisfied the determination adequately takes account of the variety of factors that may affect a participant's need for NDIS supports.
- Supplementary Explanatory Memorandum for Revised Sheet PA112 explanation that
 - 'a needs assessment will assess a person holistically, looking at all of their disability related support needs';
 - the Scheme is not prevented from providing funding in a way that accounts for the impact of other impairments or factors impacting upon these needs.

Based on what is proposed there is a need for:

- a) impairments to be recorded and listed in participant plans;
- b) people to have a mechanism to appeal a decision regarding determination of an impairment.

Recommendation 7:

The legislation be amended:

- a) to allow people to have additional impairments listed, in addition to the impairments through which they entered the scheme.
- b) to include a requirement that:
 - iii. a person's eligible impairments (and what criteria they met) and when access was provided are identified in a participant's plan under s32D and s33;
 - iv. the participant is informed.
- d) to make these decisions reviewable.

Recommendation 8:

The legislation be amended to make a decision to remove a condition from a person's file reviewable.

Recommendation 9:

The legislation includes the relevant contents of the Revised Sheet PA112 legislative note(s) of and explanatory memorandum should be included as part of section 32K to remove ambiguity and for completeness.

⁶ Government, Amendment Sheet PA112 (Revised) to National Disability Insurance Scheme Amendment (Getting the NDIS Back on Track No. 1) Bill 2024, items 6-12 and Supplementary Explanatory Memorandum relating to amendment sheet PA112 (revised), 6

It has been stipulated that the needs assessment is at a point in time. It is unclear how planning is to occur for a degenerative or fluctuating condition. Further clarity is required.

Recommendation 10:

The legislation includes clarity as to how a degenerative or fluctuating condition is considered for given the stipulation that the assessment is at a point in time.

3.3 NEEDS ASSESSMENT

The Government has clarified that there is scope for further needs assessments to be made through the internal and external review processes.⁷ It is still not clear, however, what criteria would trigger a replacement needs reassessment for a person, noting this is deferred to the rules.

Given how fundamental assessments are to be complete and accurate as it derives a person's NDIS plan for up to 5 years this right and process for each NDIS plan needs to be in the legislation. That is, there should be provision to provide people with draft copies of the needs assessment report and the plans that are developed for each NDIS plan, in their preferred format, before being finalised, so that there is visibility and common understanding.

People should then have the opportunity to review and respond in a reasonable period for consideration into the needs assessment process. 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 the necessary independent information. The lessons learnt to date have highlighted this critical step in the process to amend errors and reduce the need for reviews /re-assessments/ change in circumstances requests. This needs to be explicit.

Recommendation 11:

The rights to further needs assessment (s), if people are unsatisfied with the first needs assessment is included.

Recommendation 12:

The re-assessment process is clearly explained in the legislation (as opposed to relegated to the Rules), for people who are unhappy with the first assessment.

Recommendation 13:

Insert the relevant contents of the legislative note (Items 6 and 7) and explanatory memorandum relating to this as a part of section 32K.

Recommendation 14:

The legislation be amended to capture the rights of draft copies of the assessment and plans, in the preferred format, be provided to people before being formalised so that the person can respond in a reasonable timeframe for consideration prior to the needs assessment process being finalised.

⁷ Government, Amendment Sheet PA110 in House to *National Disability Insurance Scheme Amendment (Getting the NDIS Back on Track No. 1) Bill 2024*, cl 1.

As per the Alliance's original submission⁸, we are still concerned that Section 32L (10)(b) is asking that the person conducting an assessment consider the financial sustainability of the scheme.⁹ This is not in the scope of practice of an assessor. The focus of an assessor should be on the person's needs.

Recommendation 15:

The legislation remove reference to the person conducting an assessment consider the financial sustainability of the scheme and provide clearer provision clearly outlining the operation.

3.4 SECTION 10 NDIS SUPPORTS

The Government has made amendments to recognise that section 10 'NDIS supports' will be defined entirely by NDIS Rules to be made after the Bill passes and will engage with the disability community to develop the Rules defining an 'NDIS support'.

It is recommended that any exclusion list is reviewable to provide for clinical judgment to inform independently. This is similar to the needs assessment tool (or tools)¹⁰ where it is recognised that many circumstances will be highly technical and require medical and professional experts in their scope of practice.

Recommendation 16:

The legislation includes an amendment that any exclusion decision is reviewable including for the provision of clinical judgment.

3.5 SECTION 10 ASSESSMENT TOOLS

As recognised the needs assessment tool (or tools)¹¹ will be highly technical and developed in consultation with the disability sector and medical and professional experts, as well as relying on international learning and best practice. These instruments will be evidence based and it is expected the instruments will need to be changed and updated in accordance with experience from their use and other updates such as medical standards and advice.

There is also reference that "assessment tools" will be determined by the Minister, "additional assessment tools" may be taken into account and a contingency that the appropriate safeguards and assessment tools may not be in place.

That is under:

a) subsection 32C(1)¹² signals the end of 5 years all participants are expected to have transitioned to a new framework plan. A contingency exists where if this timeframe is too short or too long it states the Minister may, by legislative instrument, extend or condense the overall timeframe for transition where organisational capacity may dictate the necessity to extend timeframes to protect participants from automatically transitioning to a new framework plan without appropriate safeguards and assessment tools in place.

⁸ Australian Autism Alliance Submission 135

⁹ Explanatory Memorandum, Back on Track Bill, 21-22.

¹⁰ Explanatory Memorandum, Back on Track Bill, 13,

¹¹ Explanatory Memorandum, Back on Track Bill, 13,

¹² Explanatory Memorandum, Back on Track Bill, 13, 23-24.

b) subsection 32K(5) outlines that it may take into account additional assessment tools relevant to the particular participant.

c) subsection 32L(8) allows the Minister, by legislative instrument, to determine the following:

- assessment tools to be used in undertaking needs assessments.
- requirements for undertaking assessments (such as a requirement for a person undertaking the needs assessment to have certain skills or qualifications).

Recommendation 17: There are clear provisions in the legislation that:

- a) appropriate assessment tools need to be developed and validated (reliable, validated by clinical judgement and individualised before they can come be legislated for use
- b) assessment tools that have been demonstrated to be ineffective/ inappropriate be excluded. This includes the previously trialled PediCat ASD.

3.6 CO-DESIGN AND CONSULTATION COMMITMENT IN THE LEGISLATION

There have been amendments relating to consultation requiring the Minister to detail their consultation with groups when lodging legislative instruments to ensure appropriate consultation occurs on disallowable legislative instruments as well as transparency over the consultation process.¹³

It is recognised that the Minister is already required to provide information about consultation undertaken on legislative instruments under paragraph 15J(2)(d) of the Legislation Act 2003.

This amendment now clarifies and strengthens this requirement in relation to legislative instruments made under the NDIS Act. That is, explanatory statements to all legislative instruments made under the NDIS Act will be required to meet the following requirements:

- describe the nature of the consultation
- describe in general terms the persons, bodies or organisations who were consulted
- contain a summary of the views expressed by those persons, bodies or organisations.

It is requested to further strengthen this consultation commitment that further recommendations are incorporated.

Recommendation 18: That the legislation be amended to clarify that instruments provided to Parliament do not come into effect until the disallowance period passes and the rules and determinations can be viewed by the public.

Recommendation 19: That the legislation be amended to directly include a duty to consult with DROs and the community with reasonable timeframes for response, as opposed to just referring to the Legislation Act.

Recommendation 20:

That amendment (18) that inserts new section 211, which prescribes certain information about consultation that must be included in explanatory statement to legislative instruments made under the NDIS Act is extended to include the percentage in total that was agreed or disagreed.

¹³ Government, Amendment Sheet PA112 (Revised) in Senate to *National Disability Insurance Scheme Amendment (Getting the NDIS Back on Track No. 1) Bill 2024*, cl 18.

Recommendation 21: That the legislation incorporates all relevant explanatory memorandums relating to Co-Design to remove the ambiguity that currently exists and capture what is intended.

For instance, it was stated that “Government is committed to ensuring the design and implementation of changes will include extensive consultation and co-design with the disability community and that this will be achieved through working together with the disability community to design and implement legislative instruments to ensure people with disability remain at the centre of the Scheme”.

3.7 GENERAL

Recommendation 22

That the legislation appropriately incorporates all relevant explanatory memorandums to reduce ambiguity.

Recommendation 23

An independent expert panel is established and funded that has relevant expertise representing the diversity of the participants, particularly during the transition phase.

We thank the Committee for the opportunity to provide this submission. The Alliance provides permission to publish this submission. Please do not hesitate to contact us with any queries or requests for further information to assist the Committee's inquiry into the Bill.

and would be pleased to provide any additional information.

We are committed to working in partnership with the Australian Government for many more years to achieve an inclusive society supported by a co-ordinated and integrated whole of government ecosystem for all people with disability, including Autistic people, to thrive.

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Appendix 1: 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. As of 1st July 2024, the Alliance is a funded Disability Representative Organisation. The members represent a cohesive national network of key organisations with a diverse focus on autism – that is 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.