

12 July 2024



Senate Community Affairs Legislation Committee

Delivered via email: community.affairs.sen@aph.gov.au

Dear Committee

Re: *The National Disability Insurance Scheme Amendment (Getting the NDIS Back on Track No. 1) Bill 2024* and the whole of person issue

Queensland Advocacy for Inclusion works on the front-line supporting people to appeal NDIS decisions at the AAT. We see first-hand how decisions made by government either enhance a person with disability's quality of life or go wrong and deny people with disability access to essential supports.

It is with this experience that we write to you with specific feedback on the most recent Government proposed amendments to the National Disability Insurance Scheme Amendment (Getting the NDIS Back on Track No. 1) Bill 2024 (**the Bill**) to address the 'whole of person' issue (PA112Revised).

An updated version of our substantive submission on the Bill previously provided to the Committee is also attached which references priority matters which are still of concern to us, including accountability associated with the needs assessments (and the ability of a participant to request a replacement).

QAI's response and context

1. Firstly, we maintain our position, as expressed in our original submission, that QAI does not agree to changes which link funding for supports to only those impairment/s which have met the access criteria (i.e. either the 'disability requirements' or the 'early intervention requirements'). In our experience, this approach fails to consider the *whole of person* when determining disability support needs. It is inconsistent with

recommendations made by the Independent Review of the NDIS and it over-medicalises people with disability, evidencing the continued application of the medical model of disability in Australia.

2. Securing access to the scheme and obtaining funding for supports should be separate decision-making processes. The purpose of the access criteria is to ensure that access is restricted to people with a significant disability. The current legislative tests for access are stringent and require substantial evidence such as extensive medical history. Only one impairment needs to meet the access criteria for a person to gain access. Then, funding for supports should be based on a person's need for disability supports as a whole person.
3. Secondly, the Government's proposed amendments do not adequately clarify the intention of the legislature. The location of the amendments as legislative notes makes them difficult to find and their co-existence alongside provisions which continue to explicitly state that supports will only be funded *in relation to impairments which meet the disability or early intervention requirements* may create unnecessary confusion.
4. Notwithstanding, should the Government pursue the changes and legislate that funding for supports must be linked to impairments we seek further modest amendments to provide **transparent and reviewable decision-making process** associated with adding and removal of impairments from a participant's record or file.
5. In our experience:
 - a. There is currently no transparent process for listing and removing conditions / diagnoses or impairments¹ and the legislative amendments have not sufficiently set out a framework for a transparent process.
 - b. Many participants have only one impairment recognised because this is the current legislative requirement for access (and the lists have assisted with a focus

¹ We have used the terms diagnosis / conditions / impairments here as the terms are used interchangeably by the Agency and Participants. The list a and list b used extensively by the Agency has largely referred to conditions rather than impairments. We have further comments on this issue below at paragraph 6.

on one condition or only the conditions on the lists as being an easier pathway to access).

- c. Conditions/diagnoses and/or impairments have been removed or changed on a participant's record without any transparency or notice given to the participant. **This is unacceptable.** Once an impairment is recognised as permanent and meeting the disability requirements, they should not be re-tested against the access criteria again.

Requested further amendments to the Bill

1. Notice of impairments

To ensure transparency for participants and the Agency further amendments are required to subsections 28(2) and 32D(2)(c). The changes we seek are so impairments linked to funding decisions are plain to see within both the participant's access notification and subsequent NDIS plans.

The following changes are required:

Section 28(2) When a person becomes a participant

(2) The CEO must give written notice of the decision to the participant, stating:

(a) the date on which the person became a participant; and

(b) whichever of the following applies:

(i) that the CEO is satisfied the participant meets the early intervention requirements and the impairments it is satisfied meet those requirements;

(ii) that the CEO is satisfied the participant meets the disability requirements and the impairments it is satisfied meet those requirements;

(iii) that the CEO is satisfied the participant meets both the early intervention requirements and the disability requirements and which impairments meet which of those requirements.

Section 32D(2)(c) – Matters that must be included in a participant's plan

having regard to the needs assessment report for the plan, whichever of the following applies:

(i) that the participant meets the disability requirements and the impairments it is satisfied meet those requirements;

(ii) that the participant meets the early intervention requirements and the impairments it is satisfied meet those requirements;

*(iii) that the participant meets both the disability requirements and the early intervention requirements and which impairments meet which requirements;
and*

2. No removal of impairments without process and review

Impairments recognised by the CEO as meeting the disability requirements or the early intervention requirements **should not be removed** without notice and any removal must be a reviewable CEO decision. Further, when a participant undergoes a plan reassessment, impairments which have already been recognised as meeting the access criteria **should not be 'retested'** unless a significant error is identified or there has been a substantial change to the participant's impairments.

Whilst we understand that it may not be the current intention of parliament to 'retest' impairments against the access criteria at each plan review (and to do so would be inefficient and destabilising for participants) the inclusion of note 1 under the proposed 32L(6) and 34(1) could be understood as requiring a retest at these decision making times. Retesting impairments against the access criteria should not ever be necessary given the permanency of any impairment accepted to have met the disability or early intervention requirements has already been determined.

We consider a **new provision and an update to the notes** is required to ensure that recognised impairments are not reconsidered and removed from participant's files except:

- at the time of a decision to approve a statement of participant supports **and** there has been a substantial change to a participant’s impairments, or
- at the request of a participant who makes a change of circumstance application.

Further comment on impairments and context

6. There is need for a better understanding of impairment within the Agency and the community. An impairment, as described by Justice Mortimer in the Federal Court of Australia, is generally understood as the loss of, or damage to, a physical, sensory or mental function.²
7. The loss generally arises from the impact of a condition / diagnosis or cluster of conditions / diagnoses. However, the Agency practice of accepting only certain conditions/diagnoses as resulting in certain impairments can lead to poor funding decisions when a participant’s conditions/diagnoses and their resulting impairments are not necessarily understood. Impairments that make a listing are often those that appear on the list a or list b. If a participant has other impairments but did not need to demonstrate they met access on those because they also had an impairment on the list a or b then they may not be on the participant’s record.
8. Further examples of the problems associated with the understanding of impairments (as described in the legislation) and the difficulties associated with isolating impacts to a single impairment include:
 - a. A person with severe permanent chronic pain is likely to have cognitive (very poor executive function and decision making), psychosocial (severe depression) and physical (limited mobility) impairments. A listing of chronic pain fails to

² In Mulligan and National Disability Insurance Agency [2015] FCA 544, Mortimer J explained the distinction between disability and impairment at paragraph 51 of the decision: The term “disability” is used in the Act...as a descriptive concept for the overall effect of a person’s impairments on that person’s abilities to participate in all aspects of personal and community life. Threshold provisions such as s 24 operate not on the concept of disability, but on the concept of an impairment, which...is generally understood as involving the loss of or damage to a physical, sensory or mental function.

identify these impairments and we have seen decision makers assume chronic pain is a physical impairment only.

- b. Participants with severe Complex Post Traumatic Stress Disorder (CPTSD) are statistically recognised in numerous longitudinal studies to also experience disability caused from permanent chronic health conditions. However, the Agency frequently refuses to fund supports to meet the physical disability needs of clients with CPTSD on the basis that any physical impairment they may have has not been proven to meet the disability or early intervention requirements. The Agency, in our experience, requires an impossible level of information to demonstrate the physical impairments have been fully treated to be satisfied the impairments are permanent. In requesting this information, the Agency fails to recognise the connection between severe and complex trauma and chronic health conditions. For a participant with CPTSD, the evidentiary burden placed on them by the Agency is too high, and as a result the participant's support needs associated with their physical impairment are disregarded by the Agency.
- c. Where there are a cluster of conditions which typically co-exist as contributing to impairments, the Agency may accept one condition/diagnosis and not the others. This is a recurring and significant problem for many participants. For example, we have clients whose Ehlers-Danlos syndromes (EDS) is accepted but not their Postural Orthostatic Tachycardia Syndrome (POTS). While either condition can exist independently, POTS is a common complication of EDS. When the Agency fails to recognise a participant's POTS, the participant's needs associated with the impairments arising from the POTS (for example loss of balance and falls due to light-headedness) are ignored and left unmet.

Practical improvements and matters for further consideration

Outside this legislative process and for future consideration we note there is significant work to be done to improve Agency processes, understanding of the access criteria and the recognition of impairments, particularly if funded supports will be dependent on which impairments the Agency recognises as meeting access.

In practice and historically, many participants have only had one impairment (or condition /diagnosis) recognised by the Agency as that is all that has been required to gain access to the scheme and become a participant. Whilst we continue to be concerned regarding the Agency’s assessment of participants’ needs based on *a whole of person* approach, the proposed Government amendments to the Bill together with our suggested improvements outlined above will at least provide clarity and transparency to participants which in our experience has been lacking.

Final comment

There are other improvements to the Bill required and we commend the work of our colleagues at the Justice Economic Centre (formerly Public Interest Advocacy Centre (PIAC)) and Villamanta Disability Rights Legal Service who have made and continue to make further submissions in relation to these issues.

The Scheme is here to stay, but things need to change for people with disability and it is vital that the voices of people impacted, and lessons from the past ten years are learned. We know that when the lived experience of people with disability is listened to during law reform processes such as this, we create inclusive communities where all people are equally valued and enjoy human rights.

Yours faithfully,



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Sian Thomas
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Submission by



qai

Queensland
Advocacy
for Inclusion

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

To Senate Community Affairs Legislation Committee

May 2024 (Updated at 12 July 2024)

About Queensland Advocacy for Inclusion

Queensland Advocacy for Inclusion (QAI) is an independent, community-based advocacy organisation and community legal service that provides individual and systems advocacy for people with disability. Our purpose is to advocate for the protection and advancement of the needs, rights, and lives of people with disability in Queensland. QAI's Management Committee is comprised of a majority of persons with disability, whose wisdom and lived experience guides our work and values.

QAI has been engaged in systems advocacy for over thirty years, advocating for change through campaigns directed at attitudinal, law and policy reform.

QAI also provides individual advocacy services in the areas of human rights, disability discrimination, guardianship and administration, involuntary mental health treatment, criminal justice, NDIS access and appeals, and non-legal advocacy for young people with disability including in relation to education. Our individual advocacy experience informs our understanding and prioritisation of systemic advocacy issues.

Since 1 January 2022, QAI has also been funded by the Queensland Government to establish and co-ordinate the Queensland Independent Disability Advocacy Network (QIDAN). QIDAN members work collaboratively to raise the profile of disability advocacy while also working towards attitudinal, policy and legislative change for people with disability in Queensland.

QAI's recommendations

1. The Federal government release a transparent, over-arching plan outlining how the NDIS Review's recommendations will be strategically implemented over time. The plan must be developed in genuine codesign with disabled people across a range of disability types and backgrounds.

[QAI Comment (12/07/2024): The introduction of a reference to co-design in the Bill is acknowledged. Genuine co-design of the legislative rules and future reform is critical to a Scheme which meets its original objectives.]

2. Implement the NDIS Review's intended 'whole person' approach by removing sections 34(1)(aa) and 32L(3) from the Bill and introducing a provision that will ensure disability supports are funded based on a holistic understanding of a person's disability support needs.

[QAI Comment (12/07/2024): See our letter accompanying this updated submission.]

3. Remove the provisions relating to needs assessments until the relevant processes and tools have been codesigned with the disability community and until they are accompanied by sufficient legislative safeguards.

[QAI Comment (12/07/2024): The development, review and replacement of the needs assessments remains of concern to us. See our comments below.]

4. Implement the NDIS Review's recommended trust-based approach. There should be a significant increase in safeguarding measures around exercise of the proposed new Agency powers to limit choice and control, revoke, or suspend a person's plan. The powers should only be available as a last resort, any use should require proper written reasons, and a separate right of review should exist allowing participants to appeal these decisions without triggering a review of funded supports.

5. Delay the operation of 'NDIS supports' in both access and supports criteria until the rules have been codesigned and agreed, and foundational supports established.

[QAI Comment (12/07/2024): Amendments to NDIS supports are acknowledged. We look forward to genuine co-design of the relevant Rules.]

Introduction

Like Medicare, the National Disability Insurance Scheme (NDIS) is an essential public service.¹ It is transforming the lives of people with disability, their families and our communities. When people with disability access individualised disability supports, they enjoy independent, dignified lives that enrich our society. However, there are fundamental problems with how the NDIS is being implemented, as was found during the NDIS Review. These need to be addressed to improve equity and safeguard the NDIS for the future. The *National Disability Insurance Scheme Amendment (Getting the NDIS Back on Track No 1) Bill 2024* (the Bill) is therefore of great importance, as it could represent the first step towards implementing the NDIS Review's landmark recommendations.

The NDIS represents a vision that people with disability should have the same right as other members of Australian society to realise their potential and participate in society. There were three main principles which made the NDIS unique:²

- 1) Participants should receive **individualised support** funding packages that consider their individual circumstances holistically.
- 2) Participants should receive funding to purchase services and equipment where they are **reasonable and necessary supports** related to the individual's disability.
- 3) Participants should have **certainty, choice, and control** regarding their disability supports.

Amendments to the scheme must be considered in the context of whether they bring us closer to these foundational principles, or risk moving us further away.

Given the significance of the Bill, it is vital that it has the support of the disability community. While it contains some welcome changes, such as longer plan periods and increased

¹ Burton, T, 'NDIS is as popular as Medicare, study shows', The Financial Review, 13 March 2024, <https://www.afr.com/politics/federal/ndis-is-as-popular-as-medicare-study-shows-20240312-p5fbv1>

² Commonwealth, *Parliamentary Debates*, House of Representatives, 29 November 2012, 13877 (Julia Gillard, Prime Minister) ('*NDIS Act Second Reading Speech*') <https://parlinfo.aph.gov.au/parlInfo/search/display/display.w3p;query=Id%3A%22chamber%2Fhansard%2F9b96ae59-96ca-4e39-b984-8b520b432ef5%2F0005%22>

flexibility over budget spending, there are several concerning aspects that must be viewed in the context of the objects and principles of the NDIS.

Firstly, it substantially changes the way people with disability will access support and sets the direction for subsequent reforms to the scheme, yet there was no opportunity for the disability community to consult on a draft Bill prior to its introduction into Parliament.

Secondly, it has been introduced in the absence of a transparent, over-arching plan outlining how the NDIS Review's recommendations will be strategically implemented over time. There must be a plan that ensures changes are not made prematurely but are instead made logically and at the appropriate time, preventing people with disability from falling through the gaps and missing out on vital support. This is critical to the successful implementation of the NDIS Review but is either non-existent or not publicly available.

Thirdly, the Bill relies heavily on legislative instruments and rules that have not yet been developed.³ Despite a stated intention to co-design them with the disability community, there are no safeguards that will ensure this occurs, or to what extent. The absence of relevant information makes it impossible to provide an informed response or support such significant changes. It also creates uncertainty for participants and asks people with disability to trust the Agency and NDIS Minister. Unfortunately, trust has been eroded over time, through poor planning decisions and communication. While some of the proposed changes may seem reasonable at first glance, the level of anxiety the Bill is generating within the disability community must be understood within this context.

The proposed changes also assume the scheme is infallible, yet the lived experience of people with disability, their families and advocates prove this isn't true. No system as large as the NDIS can work perfectly at all times. We know that when safeguards aren't built into the NDIS it places people with disability at risk of serious harm and even death. There is a real risk that the new powers could be used punitively and arbitrarily, considering the power imbalance

³ 'Delivering on our commitment to a better NDIS,' Bill Shorten, 14 May 2024 at <https://ministers.dss.gov.au/media-releases/14666>

that exists between participants and the Agency. This is of particular concern given the lack of accountability mechanisms that accompany the proposed changes.

QAI therefore urges the Committee to consider whether the proposed changes will be workable for people who experience the greatest barriers to inclusion. For example, people without informal support, literacy skills or self-advocacy skills.

QAI endorses the analysis provided by other legal experts, such as PIAC and Dr Darren O'Donovan. Our submission will focus on four key areas where we believe the Bill is inconsistent with the NDIS Review and incongruent with the scheme's foundations:

1. The 'whole of person' approach
2. Needs Assessments
3. Agency powers
4. NDIS Supports

1. The 'whole of person' approach

QAI Comment – 12 July 2024: See our letter of today's date provided with this updated submission.

The NDIS Review recommends the basis for setting a budget to a 'whole-of-person level' (see recommendation 3.3) and at page 26 says 'by breaking things down to the smallest level, we have lost sight of the big picture and the whole person'. Recommendation 3.1 provides:

“Once a participant has met access requirements through the new approach following a functional capacity assessment, they would not be required to be reassessed unless there are exceptional circumstances”.

At page 88 of the NDIS Report it says:

Focusing on the whole person, their circumstances and their support needs would also end the current unhelpful and inappropriate focus on establishing a primary or secondary disability. Budgets will be linked to support need not diagnosis.

Further, the first recommendation of the Joint Standing Committee on the NDIS's inquiry into the Capability and Culture of the NDIA inquiry was that "the NDIA [should] assess people according to the totality of their disabilities".

When QAI appeared before the Joint Standing Committee in 2022 to give evidence on this topic, one of our solicitors who is also a participant of the scheme remarked the following:

"I have been asked at several points to identify...which support needs relate to which specific individual conditions. A lot of the time, that's just not practically possible. I can guess, but it's not something I can say for sure...it's not how disability works, and it's very taxing to ask that of individuals engaging with the scheme."

Given the above recommendations, it is inexplicable then that changes in the Bill do the opposite and instead codifies a process that dissects people with disability by attempting to artificially separate out the impacts of various impairments. In reality, some people with disability have multiple impairments and the impact of the underlying conditions cannot easily be separated. Only assessing support needs or providing supports in relation to certain impairments which have satisfied a very high threshold for access will continue to overmedicalize people with disability by requiring them to revisit the access criteria at every plan review, continuing to 'prove' themselves as deserving of support and subjecting them to needless, repeated, and often dehumanizing and traumatising, assessment processes. It will be burdensome, inefficient and difficult for participants who have multiple diagnoses and impairments.

The specific changes in the Bill (detailed below) tie the "access criteria" to support needs. However, securing access to the scheme and funding of supports must remain separate decision-making steps, for the reasons articulated above and below. The purpose of the access criteria is to ensure that access is restricted to people with a significant disability. The current legislative tests for access are stringent and require substantial evidence such as extensive medical history. Only one impairment needs to meet the access criteria for a person

participant arising from an impairment in relation to which the participant meets the disability requirements or the early intervention requirements”

- **needs assessments:** s32L(3) requires that a ‘needs assessment’ must assess a participant’s need for supports only “in respect of impairments in respect of which the participant meets the disability requirements or the early intervention requirements”.
- **matters included in a plan:** s 32D(2)(c) requires that the plan specifies “having regard to the needs assessment” (which is not the assessment at access) which applies the disability requirements, the early intervention requirements or both.

In our NDIS appeals work this has been a significant issue and arises in many of our cases. The NDIA often refuse to fund supports for a disability that they have not recognised as meeting the access criteria. Clients who cannot leave the house without mobility aids have been refused those aids on the basis that they gained access for Complex Post Traumatic Stress Disorder (CPTSD). For many participants, complex trauma histories and neurodivergence co-exist with complex health histories which contribute to life-long physical disabilities, for example, chronic pain associated with multiple injuries earlier in life.

The NDIS access criteria, particularly permanence of impairment, create insurmountable barriers to these participants to get the supports that they need. The Agency often states that although they acknowledge a *condition* is permanent, there is insufficient evidence to establish that the resulting *impairment* is permanent. Participants can get caught in endless enquiries and arguments about whether certain impairments are permanent or not. This confusion is compounded by the fact that the NDIS Act does not contain a definition of impairment.

A definition of ‘impairment’ would improve the clarity of the access criteria and consistency of decisions. Impairment is currently used inconsistently, sometimes used synonymously with ‘diagnosis’ or ‘condition’, sometimes as a specific symptom, and sometimes as a broad category like ‘physical impairment’ or ‘psychosocial impairment’. This inconsistency and uncertainty will be exacerbated if the proposal to tie the access criteria to support needs is introduced.

We have included **2 case studies at Annexure A** to demonstrate some of our experience with participants who have been refused a support on the basis that it was for a condition or impairment for which they did not allegedly “meet the access criteria.”

Transparency of the reasons and conditions for which a person meets access to the scheme is a welcome change to the current situation where participants have no way of seeing or appealing the impairment/s listed on their profile. However, it does not and will not mitigate the harm and inefficiencies that will continue to be caused if the aforementioned provisions of the Bill are adopted to allow the Agency to continue applying their policy considering people with disability as a collection of impairments, some of which meet the access criteria and some of which do not, rather than as whole people.

QAI Recommendations:

- Delete sections 34(1)(aa) and 32L(3) from the Bill.
- Include amendments to explicitly ensure that supports are funded based on a person’s disability needs as a **whole person** and not on the limiting access criteria which were never designed to be the lynchpin on which support needs would be determined.
- Introduce a **definition of ‘impairment’** into the NDIS Act.
- Reconsider the current interpretation of ‘permanence’ when assessing eligibility for access under the early intervention criteria.

2. Needs assessments

QAI Comment – 12 July 2024: We remain significantly concerned with the lack of detail regarding the needs assessments and the critical role they will have in determining a participant’s budget. We support the submission of the Justice and Equity Centre’s dated 10 July 2024 call for Participant’s to have a right to a replacement review in the legislation.

The needs assessments provisions appear to be implementing Action 3.4 of the NDIS Review.

Action 3.4 states that the NDIA should introduce a new needs assessment process to

consistently determine the level of need for each participant and set budgets on the basis of the needs assessment.

In principle, the concept of a comprehensive needs assessment which considers all the circumstances of a person relevant to their support needs has merit, if:

- they are conducted by people with appropriate training and qualifications, and
- there are sufficient checks and balances in its development, use, and review.

The Bill as currently drafted does not provide this. It states that a needs assessment report will determine a participant's budget. This report will follow a 'needs assessment' which must be undertaken using an 'assessment tool' which is to be determined by the Minister, by legislative instrument. The Minister will also, by legislative instrument, determine the methods by which the Agency quantifies the report into a budget amount for the participant.

There is a lack of transparency regarding the proposed needs assessments. A lot remains unknown about the nature of the assessment process, the assessment tools and the method that will translate the assessment report into a budget. This uncertainty, combined with underlying concerns over 'RoboPlanning' is causing significant concern within the disability community. The changes have also not been co-designed (see NDIS Review actions 3.4 and 3.8), despite the NDIS Review intending to put 'people with disability back at the centre' of the scheme.

This amendment is particularly concerning given the legislative instruments can be determined by the Minister alone, without input from states and territories and their stated mandate to consider the financial sustainability of the scheme. The current drafting therefore leaves open the possibility that significant changes will and could be made without proper consultation.

Fundamental details are missing and in the absence of further information and greater safeguards, it is impossible to support their introduction, in their current form.

QAI Recommendations:

- **Safe and qualified:** Needs assessments must be conducted by appropriately qualified, culturally safe, and trauma-informed professionals. Our experience in representing clients for appeals in the AAT indicates that reports prepared by the NDIA or its contractors are too narrowly focused and fail to take into account a person’s life circumstances. Given this experience, we have grave concerns that these reports won’t be appropriately person centric or reflect the individual needs of participants.
- **Preference:** Participants should be able to express a preference regarding who conducts the assessment and how the assessment is conducted. There should be provision for alternatives where exceptional circumstances exist that mean the assessment would cause undue harm to the participant.
- **Individualised:** The reasonable and necessary criteria should remain the framework through which needs are assessed. New tools and methods should be sensitive enough to recognize individual circumstances, have a human rights framework, and deliver individualised supports, as is the intention of the scheme.
- **Cost:** Any additional reports required in the process must be paid for by the NDIS.
- **Given a copy:** Participants must be given a copy of the final needs assessment report. The Bill states that the Agency will receive a copy of the needs assessment report but there is no requirement that participants receive a copy. The NDIS Review explicitly recommended the needs assessment report be provided to the participant before it is finalised, and this step must be contained within the Bill.

QAI Comment 12/07/2024: We welcome the Government amendments to the Bill to require the needs assessment to be given to participants.

- **Review rights:** Participants must be able to seek review of a needs assessment report. The ability to scrutinize, review or challenge the contents of the report is a critical right for participants but is not currently contained within the Bill. Appeal rights are instead limited to a participant’s entire statement of participant supports. This means that if a person wishes to challenge aspects of the needs assessment report or the process by which it was carried out, their entire plan (and therefore funding) will be at risk of changing. We know that some participants don’t appeal decisions that provide

insufficient funding out of fear that their plan could be further reduced. QAI supports the recommendation by PIAC that “if needs assessments are to be used as the basis for setting budgets, legislation must provide clear and straightforward rights for a participant to receive the needs assessment before it is finalised to ensure it accurately reflects their needs and circumstances, and to request a new needs assessment where appropriate.”

- **Right to request replacement:** A participant should be able to request a replacement needs assessment when the existing one is no longer meeting their needs. A decision not to grant a replacement needs assessment should be a reviewable decision.
- **Test automation:** There must be careful review of automated systems used by the NDIA, to include a human rights framework and to **test assumptions** in the systems **which perpetuate bias** in resulting decisions. This review and testing should occur before widespread adoption of new systems.

3. Agency powers

QAI Comment 12/07/2024: QAI welcomes the Government amendments made with respect to providing legislative principals associated with emergency funding, information requests and medical assessments. However, constraint on powers is necessary where significant power imbalance exists between the Agency and a participant and the consequences of exercising powers can be catastrophic. We support calls for further constraints on the powers in line with Justice and Equity Centre’s the submissions.

While the Bill increases a participant’s ability to use their funding flexibly, it also contains numerous provisions that significantly increase the power of the Agency to control and remove choice from a participant’s plan and apply consequences to a participant for failing to comply or provide information.

These powers cover:

- dictating the plan management type,
- controlling when and how the supports or service providers a participant can use,

- restricting funding periods in a plan potentially to as little as a month,
- revoking or suspending a plan where a participant does not respond to a request for information.

While some provisions might seem reasonable at first glance, they are contributing to the erosion of a participant's choice and control, and risk leaving participants without support. Notwithstanding that a key object of the NDIS Act is to '*enable people with disability to exercise choice and control in the pursuit of their goals and the planning and delivery of their supports.*'⁵

Such powers need to be exercised with discretion and within a human rights framework. Increased powers for the Agency in the absence of safeguards can also be dangerous when exercised by delegates who do not understand a person's disability, its impact, or their personal circumstances. In the absence of the correct information, delegates can make assumptions about people with disability based upon unconscious bias, including ableist attitudes and beliefs. This leads to poor decision-making outcomes which could leave people with disability unable to access the supports they need. We regularly hear of decision making which results in a participant having no support, placing avoidable stress on the individual, their family and community, and mainstream systems such as hospitals. The Agency is not reliably quick to respond to urgent issues or mistakes, particularly when a participant doesn't have access to formal advocacy support. The sluggish administrative pace of the Agency increases the risk associated with the proposed powers.

Significantly increasing the power of the Agency to control a participant's plan appears to be at odds with the trust-based approach recommended by the NDIS Review. It also appears to go beyond the intention that such controls are only exercised in situations of 'last resort', as observed by PIAC. Powers should only be exercised as a last resort and there should be a greater emphasis on guidance and support to participants to build their capacity to manage their plans. This would be a more effective and person-centred way of mitigating risk.

⁵ *National Disability Insurance Scheme Act 2013* (Cth), section 3(1)(e)

The provisions also require enhanced participant safeguards. For example, the Bill should include a right for participants to review a decision regarding their plan management or other restrictions placed on a plan as a separate right to review, i.e. not as part of a single review process that looks at the entire statement of participant supports.

We also have concerns regarding the provisions relating to reconsideration and revocation of a participant's status. The Agency has always had the capacity to revoke a participant's status, however the Bill introduces a formal process and framework for making revocation decisions. The Bill also creates new powers to request information or compel a participant to undergo an assessment for the Agency to then determine whether their status should be revoked, in circumstances that will be prescribed by new Rules.

While increased transparency around the revocation process is welcome, the content of the new Rules is unknown. The process could increase certainty in the long-term, but the lack of clarity at this stage increases uncertainty for participants. Further, the provisions appear to foreshadow a more active review of participant status. This is of particular concern given the inaccessibility of mainstream systems and lack of foundational supports in existence would mean that people with disability removed from the scheme could be left without alternative sources of support.

The consequences of failing to comply with processes, such as being removed from the scheme if certain information is not provided within a set period of time, are unnecessarily severe and are inappropriate for a scheme that is providing vital supports to people with significant and lifelong disabilities.

Requesting information or requiring a person to undergo an assessment might sound simple but in reality, it could see the Agency requesting a person's confidential notes from a treating specialist or compelling a person to undergo an unnecessary and inappropriate assessment simply to satisfy a bureaucratic process. Forcing people with disability to undergo unnecessary and inappropriate assessments is traumatic. It is a continued application of the medical model of disability which forces people who have already satisfied the high threshold for access and demonstrated their need for lifelong support to choose between experiencing further trauma, or having their disability supports withdrawn.

The powers go beyond what is appropriate and necessary and should be curtailed to avoid further entrenching the power imbalance between the Agency and participants. If a person's status as a participant is going to be revoked, there should be a requirement for the Agency to work collaboratively with the person to ensure that alternative support arrangements are not only available but are actively in place. This should include requiring the Agency to take all reasonable steps to ensure the wellbeing of the participant in the event that the participant does not respond or provide the requested information. A person's status as a participant should also not be removed until the appeal process is complete if the participant indicates an intention to appeal the decision to revoke their status. A punitive approach will be traumatizing and will lead to negative outcomes for people with disability and their families.

These provisions could also be used by the Agency to prevent a participant from accessing supports from their preferred service provider.

QAI Recommendations:

- **Trust-based approach:** The trust-based approach recommended by the NDIS Review should be adopted, with the Agency focusing on building capacity of participants to manage their plans, and supporting them to do so (e.g. through the provision of functional budgeting tools or resources in the NDIS portal).
- **Last resort:** If implemented, the proposed powers must be a last resort, and must include further limitations on how the Agency can use them (similar to existing restriction of plan management decisions under s 43 NDIS Act) and protections for participants.
- **Realistic and flexible funding periods:** Funding periods must be realistic and should not be less than 12 months without exceptional circumstances. S 32F(3)(a) of the Bill requires that funding periods are 'no more than 12 months'. Flexibility must be allowed to adjust across periods to account for invoicing delays, fluctuating impairments, and minor crises that temporarily impact on support levels without requiring a plan reassessment.
- **Proper written reasons:** Where a decision is made to restrict a funding period to less than 12 months or restrict allowable service providers, the Agency must provide the

participant with proper written reasons which demonstrate the genuine need for these restrictions to be applied to the participant's plan. Failure to provide quality written reasons has been a persistent issue for the Agency, and the concern was addressed by the AAT in [Sharp](#) on 25 May 2023 where the Member said:

*'It is a matter of concern that an Agency of the Commonwealth with responsibility for administering the NDIS appears to have failed to adhere to the requirements of the legislation it administers, as well as the basic tenets of contemporary procedural fairness and administrative decision-making, which requires an administrative decision-maker provide reasons for a decision to a person whose rights, entitlements or reasonable expectations are adversely affected by it.'*⁶

- **Separate right of review:** A new right of review must be added to the Bill for decisions regarding administrative restrictions such as funding periods, plan management type, and other restrictions. These reviews should be separate from a review of participant supports so that participants are not prevented from requesting a review of administrative restrictions by fear that their supports may be reduced.
- **Agency obligation to assist:** No participant should have their plan suspended or revoked without all steps being taken to engage with a participant. An explicit obligation for the Agency to engage with and assist a participant must be introduced as the 28 days in s 36(3) of the Bill for suspension, or 90 days in s 30(5) for revocation, without such an obligation is wholly insufficient. In our experience, it is often impossible to arrange and undertake an unexpected assessment or examination and receive the professional's report within a tight timeframe, even when the participant is available and actively engaging. The Agency should be required to take all reasonable steps to ensure the wellbeing of the participant and assist them to provide requested information.
- **Alternative supports:** Where a decision is made to revoke or suspend access, NDIS supports should not be withdrawn until any appeal has concluded. Where revocation

⁶ Paragraph 35 in [Sharp and National Disability Insurance Agency \[2023\] AATA 1323 \(25 May 2023\)](#)

or suspension of supports is appropriate, the Agency must be required to ensure alternative supports are in place before ceasing or suspending NDIS supports.

5. NDIS Supports

QAI Comment – 12/07/2024: QAI welcomes the amendments to the definition of NDIS supports and the reliance on APTOS. However, we remain cautious and concerned regarding the use of Rules to inappropriately rule out disability supports which are necessary for a person to live a life of their own choosing.

The Bill proposes ‘an enabling architecture for rules and future reforms to restore the original intent, integrity, consistency, and transparency of the scheme.’⁷ The Bill introduces a new concept of ‘NDIS supports’ (see clause 10) which is used both at access and when determining what supports should be funded. The Bill’s definition of ‘NDIS supports’ introduces a number of new concepts which require further clarification. This clarification should occur **before** legislative change. Rules do not receive the same scrutiny as legislation, and the proposed rules would have such significant power to fundamentally change the NDIS that more detail should be provided before these legislative changes are made.

The main result of the introduction of the ‘NDIS supports’ definition is to further restrict the disability related supports participants can access by adding criteria to the existing reasonable and necessary criteria. At present the six reasonable and necessary criteria in section 34(1) provide a principled framework for supports, which can and do allow flexibility to meet the needs of people with diverse disabilities and intersecting identities.

The Bill replaces the existing requirement that the support is most appropriately funded through the NDIS with a requirement that ‘the support is a NDIS support for the participant’. It further provides a definition of ‘NDIS support’, which includes a provision for Rules which

⁷ Commonwealth, *Parliamentary Debates*, House of Representatives, 27 March 2024, 19 (Bill Shorten, NDIS Minister) (‘*NDIS Amendments Second Reading Speech*’)
<https://parlinfo.aph.gov.au/parlInfo/search/display/display.w3p;query=Id%3A%22chamber%2Fhansard%2F27626%2F0059%22>

list supports which can be funded and those that cannot. These rules have not yet been drafted.

The temptation in creating a hard list of supports that will not be funded is to include items which from a non-disabled person's perspective could be seen as a mainstream 'luxury' item when in some circumstances the item is an essential, cost effective, disability support. The ability to consider these nuances is one of the core benefits of individualised support packages. The existing reasonable and necessary support criteria already manage sustainability or floodgates concerns.

Although the Rules have not yet been drafted, the explanatory memorandum provides an indication of the intent, stating:

'things such as holidays, groceries, payment of utility bills, online gambling, perfume, cosmetics, standard household appliances and whitegoods will not qualify as NDIS supports.'

Some of these examples raise concerns as excluding broad categories of items could exclude some supports which are disability related for certain participants. These costs would **not** be disability related for **most** participants. However, the existing reasonable and necessary support rules under s34(1) are responsive to individual circumstances. This inconsistency is not a flaw of the system, but a strength of truly individualized supports.

The inconsistency that should be targeted is primarily an issue of NDIA decision-making, where participants with reduced capacity to advocate for themselves receive insufficient support for their needs. This issue could be substantially improved without legislative reform, for example, by improving training of NDIA staff, and by implementing a system to update operational guidelines to reflect decisions made by the AAT and Federal Court relating to section 34(1) and the Participant Support Rules. Decisions such as Milburn,⁸ in which it was noted by the Tribunal in relation to a request for funding for a gym membership that while it

⁸ Milburn and National Disability Insurance Agency [2018] AATA 4928 (20 December 2018)

is in the nature of discretionary spending for those who do not suffer from a disability, it was attributable to the participant's support needs.

A shallow understanding of disability could lead to things, which provide significant disability support, being on the list of exclusions. In our work we commonly see quick dismissal of items which might fall into this category, but when they are carefully considered for the person, they provide cost effective and efficient support for a person with disability.

Assistance animals, automatic blinds and cooking tools are just some of the supports which can be very effective, beneficial and cost effective through a reduced need for person-to-person support but which may get caught by these types of exclusionary lists.

An example is motorised blinds. A person with a physical disability who cannot manually open or close their blinds could seek funding to motorize the blinds to increase their independence and reliance on others. The NDIA has in the past declined to fund these, on the basis that it is an everyday expense and suggested a support worker should complete the task instead. When, overtime, the funding for the blinds could reduce the need for person-to-person support and give the participant more independence such items have real cost saving potential for the Scheme.

In the short term the 'NDIS supports' definition will add confusion that is not quickly resolved, given the lack of Rules to support the definition and the reliance on the not fit for purpose *Applied Principles and Tables of Support*⁹ (APTOS). Until the Rules are written, the Bill says the NDIA will use APTOS as an interim measure. Further, the removal of 34(f) seems to also imply that Schedule 1 of the NDIS (Supporting Participant) Rules which sets out the rules regarding the responsibilities of other services systems (e.g. health) will no longer apply. Whilst we have existing concerns with this Schedule, it is premature given that currently the APTOS agreed by the States is very out of date and needs urgent update, review and agreement by the States and Territories.

⁹ <https://www.dss.gov.au/disability-and-carers-programs-services-government-international-disability-reform-ministerial-council-reports-and-publications/the-applied-principles-and-tables-of-support-to-determine-the-responsibilities-of-the-ndis-and-other-service-systems>

In our experience, this is likely to leave individuals with unmet needs for prolonged periods while they try to find a system to fund something, and each system trying to push the responsibility elsewhere. For example, an individual who needs feeding tube supplies might have the NDIA say that while they acknowledge the supplies are necessary, they are a health system responsibility, while the health system agrees the supplies are necessary but states they are a NDIS responsibility. The pressure to resolve this dispute must be on government departments and agencies, not on people with disability and their families. Making the proposed amendments before APTOS has been updated and rules drafted, increases the risk of people being left unsupported.

The transition to the NDIS created a vacuum which has been painstakingly transformed into an oasis in the desert over the last decade. Implementing these amendments before the Rules are designed and APTOS is updated would unnecessarily create a fresh vacuum, substantially increasing uncertainty for people with disability and exposing some to substantial risk. Implementation without genuine and robust codesign also risks removing choice and control from people with disability, and could amount to removing the scheme's core value of providing individualized support packages that people with disability can use to cover the additional disability related expenses resulting from reasonable and necessary supports.

QAI recommendations:

- **Delay effect:** If 'NDIS supports' is included in the Act, a further provision must be added deferring its application until APTOS has been updated, the rules have been developed, and foundational supports rolled out. To do otherwise creates an avoidable vacuum, resulting in dangerous uncertainty for people with disability. These rules will be Category A rules so will at least have input and agreement from all states and territories, but the importance of codesigning these rules cannot be overstated.
- **Genuine codesign:** Rules must go through genuine codesign with disabled people across a range of disability types and backgrounds. Superficial consultation is not sufficient. These rules are likely to significantly reduce what the NDIS will fund, and have the potential to undermine or eliminate the founding objectives of the NDIS:

individualised support packages developed by considering people with disability holistically and providing reasonable and necessary disability supports in a way that gives individuals certainty, choice, and control.

- **Retain flexibility:** The rules must not be too prescriptive or narrow, they should be non-exhaustive and allow for exceptional circumstances.
- **Improve decision making:** Our experience is that the main cause of confusion about and inconsistency in NDIS funded supports is poor decision making and communication by the Agency. We recommend that the Agency invests in better training of staff, stronger systems (including a system to ensure operational guidelines are updated to reflect AAT and Federal Court decisions), and more transparency (such as through publishing anonymised summaries of settled AAT appeals).

Conclusion

QAI thanks the Senate Standing Committee on Community Affairs for the opportunity to contribute to this inquiry. We are happy to provide further information or clarification of any of the matters raised in this submission upon request.

ANNEXURE A – QAI Case Studies

These case studies demonstrate why linking access criteria to supports doesn't work for many people with disability.

*Case studies have been de-identified and may combine different stories.

1. Fails to fully understand the impact of disability

In her mid-50s, **Vivian*** has complete medical deafness in both ears (she wears cochlear implants). She struggles with communication and only recently started learning Auslan. She also experiences anxiety, depression and lifelong physical impairments stemming from hip dysplasia. Despite these challenges she had been able to work in aged care for many years, until being discharged because of the decline in her continual pain and reduced mobility.

Vivian met access to the scheme for her hearing impairment. She needs a combination of supports including psychology and support worker assistance primarily to help her navigate communication and a small amount of help around the house and garden. She cannot communicate by telephone and finds she misses significant parts of in-person meetings. Her difficulties communicating affected her mood, self-confidence and social isolation. All of this was exacerbated by her pain.

The NDIA argue that no support should be provided to her unless it is directly related to her hearing impairment. Whilst her physical impairments and her anxiety and depression are both significant and impact her, on their own and viewed in isolation, they are unlikely to meet the access criteria.

The NDIA refused psychological support or help in the home on this basis. This doesn't make sense, nor does it give Vivian the support she needs to engage in the community to increase her confidence.

2. Changing needs, extreme and never ending need for more reports, failing support

QAI has supported a number of clients who over time their support needs have changed and the Agency has refused to provide supports for those changing needs, without extensive new medical evidence from costly specialists, appeals to the AAT and arguments that not all medical interventions have been tried.

Joanne* is a 62-year-old woman living in her home whose primary disability listed by the Agency was cerebral palsy. Joanne had for most of her life mobilised with minimum support, she did have regular falls and, as is common with older people with cerebral palsy, she had osteoarthritis. She also had kyphosis. Over time her mobility significantly reduced and especially so after a significant fall which caused substantial damage to her knee. She consulted a surgeon who advised against surgery due to the complications that could occur due to her gait and regular falls, caused by her cerebral palsy.

She applied to the Agency for a powered wheelchair (PWC) and increased support worker hours. They were refused on the grounds that she had not explored all treatment options (the surgery) and the knee, osteoarthritis and kyphosis were all separate conditions which needed to meet the access criteria.

As part of the refusal the NDIA sought reports from orthopaedic surgeons about her knee and refused to holistically consider her other disabilities that meant surgery wasn't available to her. The arguments went on for 2 years.

Over this whole time and during the period of plan review and internal review, for Joanne to mobilise in her home, she was confined to a shower commode which she struggled to manoeuvre with her feet. Due to her osteoarthritis and carpal tunnel she wasn't able to independently use a manual wheelchair without support. She required support for all transfers, the burden of which primarily fell to her husband. Due to the pressure on her abdominal region due to using unsuitable equipment over a long period of time she became bladder incontinent.

The process, and the way Joanne lived through this period was exhausting, exacerbated her bipolar, contributed to further disability and caused her extreme distress.

It is worth considering how the Agency lawyers approached the matter which demonstrates the burden that will be placed on participants to 'prove' that each impairment meets the access criteria. During the process, the Agency lawyers sought answers to close to 70 questions from various medical and allied health professionals.

An example of 5 of those questions are below:

A report by the Applicant's treating orthopaedic surgeon, providing further details in respect of the following:

- Please confirm what condition this support is directly related to (e.g. osteoarthritis, cerebral palsy or other).
- Please confirm the likely cause of the Applicant's osteoarthritis (such as age, cerebral palsy or other). Please provide clinical justifications and refer to academic literature, where applicable.
- Please address how this support is directly related to the Applicant's diagnosis of cerebral palsy, including clinical justifications.
- Please provide details of the Applicant's osteoarthritis has manifested.
- Please provide details of the treatments that have been trialled in respect of the Applicant's osteoarthritis (including details of progress and outcomes and how these have been measured).

Ultimately, through the AAT process with the support of QAI, the NDIA recognised that her mobility was related to her cerebral palsy, and she was funded for additional support. The practice of splitting conditions / impairment, is unhelpful and the introduction of s34(1)(aa) to the Bill will hard wire this damaging practice. Had Joanne's secondary conditions been considered appropriately in the context of her cerebral palsy this battle should not have occurred.