

# Response to Consultation on Proposed NDIS Reforms: Planning and Budgets

## NDIS Appeals Advocacy Organisations

<b>Executive Summary and Recommendations</b>	1
<b>Introduction</b>	2
Planning and Independent Assessments	2
Proposed reforms inconsistent with Tune Review recommendations	2
Proposed Changes to definition of “Reasonable and Necessary” Supports and Operational Guidelines	3
Granting of Exemptions from Independent Assessments	4
Trauma and Independent Assessments	5
Environmental factors and associated support need decisions	6
Reliance on Third Party Information	6
Impact on Participants with multiple disabilities	8
<b>Purpose of Planning Meetings and client-centred planning</b>	8
Global Plan Budgets	9
Global Flexibility	9
Periodic release of funding	10
Plan Reassessment, Change of Circumstances and Amendments	11
Check-Ins	12
Reviews and Appeals	12
<b>Signatory Organisations</b>	<b>Error! Bookmark not defined.</b>

# Executive Summary and Recommendations

We call on the National Disability Insurance Agency to:

- Cease progress towards rollout of the proposed reforms to Planning and Budgets until the Tune Review recommendations are relied upon in context, including extensive consultation with participants and the community
- Make clear the mechanisms by which Independent Assessments will be used to generate a Plan funding figure, including any human intervention in this process to prevent support gaps or other dangerous outcomes
- Make clear the mechanisms by which environmental factors and other holistic considerations for the support needs of people with disability will be understood, recorded, and affect funding, and how a change in these factors during the life of a Plan will impact funding
- Ensure that the individualised goals and aspirations of people with disability remain a paramount consideration in the Planning process, and are considered, discussed and agreed between the person with disability and the delegate *before* a Plan budget is created
- Ensure significantly increased, ongoing, high-quality implementation supports are made available to participants to understand and utilise flexible Plan budgets safely and effectively

The signatory organisations to this document provide advocacy support to a broad spectrum of individuals with disability who are overwhelmingly expressing acute fears regarding the risks to their health, wellbeing and access to reasonable and necessary supports raised by the currently proposed NDIS reforms.

The signatory organisations urge the National Disability Insurance Agency to commit to halting the currently proposed reforms and rebuilding them with an end-to-end codesign process directly involving people with disability, in line with Australia's obligations under the UN Convention on the Rights of People with Disability and the objects and principles of the NDIS Act itself.

# Introduction

The NDIS Appeals National Advocacy Network (“the Appeals Network”) serves as a means for Advocacy organisations funded under the NDIS Appeals program to connect and share information regarding developments in the sector.

This submission was produced as a collaboration between several member organisations of the Appeals Network in response to the proposed reforms of the NDIS announced in November 2020 (“the proposed reforms”) but does not constitute an official position of the entire Appeals Network.

Signatory organisations to this document (“the signatories”) have contributed based on the experiences of, and feedback from their clients, representing a very diverse range of individuals and perspectives. As such, individual issues discussed in this document may vary significantly between regions and may not represent all the signatories’ views.

All the signatories have endorsed the recommendations made herein.

The signatories note that many of the proposed reforms cover matters which are most appropriately responded to by specialist or professional organisations, including but not limited to professional associations for Occupational Therapists and other allied health professionals, Early Childhood specialist organisations, and bodies representing demographics with particular needs such as First Nations or Culturally and Linguistically Diverse (CALD) people with disability. The signatories strongly recommend the NDIA pro-actively engage in direct and detailed consultation with these organisations and bodies on the proposed reforms. The NDIA should be prepared to be flexible on their policy based on the consultations.

This consultation paper was developed in a relatively short timeframe, particularly given the brief consultation window which included the Christmas-New Year period. This document therefore only covers critical concerns. It will be supplemented by more comprehensive submissions from individual organisations via other processes.

## Planning and Independent Assessments

### Proposed reforms inconsistent with Tune Review recommendations

In communications to date, the NDIA has implied or directly stated that the proposed reforms around Eligibility and Independent Assessments are consistent with and supported by the Tune Review recommendations.

Significant differences between the current proposal and the Tune Review’s recommendations include (but are not limited to):

- The proposed reforms’ lack of codesign principles and proper consultative processes during their development

- The Tune Review does not recommend any significant changes to the definition of “reasonable and necessary” in the NDIS Act, which would be required to legally support the proposed reforms
- The discretionary nature of Independent Assessment application, including the need for this discretion to be exercised in a manner consistent with the objects and principles of the Act, a human-rights-based approach, and ensuring equity of access
- The key protections recommended including the participant’s right to challenge capacity assessment results, and to a second opinion
- Further, the Tune Review makes specific reference to additional assessments not being required where the participant’s functional capacity is stable

The signatories have extensive issues with the methodology that the NDIA is proposing for the Independent Assessments themselves, which are set out in our separate submission on that topic.

## Proposed Changes to definition of “Reasonable and Necessary” Supports and Operational Guidelines

The signatories note at the outset that we are making comments in a vacuum: the NDIA has indicated that the legislation will be changed, but the new form of the legislation has not been seen. The NDIA have also indicated that “reasonable and necessary” will be redefined in the NDIS Act, but proposals of any updated definitions have also not been seen. This does not represent a genuine consultation.

A significant number of cases at the Administrative Appeals Tribunal have given shape to the current Reasonable and Necessary test currently included in section 34 of the Act. We are beginning to reach a clearer level of understanding about the current operation of the Scheme, which could be dismissed in the event of changes to this section. Notably the cases of *McGarrigle*<sup>1</sup> and *WRMF*<sup>2</sup> at the Federal Court, as well as some 42 published decisions at the Administrative Appeals Tribunal (at time of writing) have offered useful case studies of how the legislation applies to participants.

*WRMF* serves as a useful example of the way in which a person’s rights and requirements can be articulated through the current wording of section 34. The matter demonstrates a participant is able to identify a particular support they require as a starting point. It does not need to be previously approved, considered or encountered by the Agency but only that it be beneficial to their goals and participation, effective and beneficial and the other requirements in the act. Costs are calculated as an endpoint - not as the primary consideration over whether a person’s rights and needs should be met.

Potential changes to the operation of this section threaten to replace the rights-based assessment that allows people to articulate and discuss their particular needs with a flat and more basic assessment of ‘what is typical for your level of disability.’ While the proposed reforms state that

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<sup>1</sup> [2017] FCAFC 132

<sup>2</sup> [2020] FCAFC 79

calculated Plan budgets will not function as typical support packages, it has not been made clear how this is the case.

One of the great strengths of the NDIS in fulfilling our nation's obligations to People with Disability has been its personalised and adapted approach, and this approach should not be done away with because its effective implementation requires ongoing effort.

It is worth noting at this point that many cases regarding reasonable and necessary supports at the Tribunal and in Federal Court have been decided in a manner contrary to the arguments made by the NDIA. Leaving those decisions in the hands of the agency and associated assessors, without specific and support-specific appeal rights, consolidates power with decision makers that have been previously deemed to be acting contrary to the underlying legislation. Notably, in *WRMF*, the Agency was rebuked for their approach and 'hypervigilance' in the matter,<sup>3</sup> and that:

*"The inquiry required of the decision-maker [in deciding whether a support is reasonable and necessary] is therefore a targeted one, but it is not necessarily a complex one. The criteria are straightforward and pragmatic. The decision-maker's approach is also entitled to be of the same kind."*<sup>4</sup>

As with any new scheme, there has been inconsistency as boundaries and edge-cases are explored and argued. Hitting the reset button on this developing area of law (and replacing it with a system, discussed below, which is much less considerate of people's individual needs) risks throwing away the significant progress which has been made. The Agency's assertion that the current legislative scheme leads to inconsistent outcomes is not evidenced. The signatories have observed that inconsistent outcomes are often a result of the Agency's failure to hold policy positions that reflect their underlying legislation; for example, the Agency's public and persistent refusal to fund the full value of Participants' disability-related transport costs despite multiple AAT findings against this.

The Tune Review, NDIS Act Review 2015 and reports from the Joint Standing Committee have all shared concerns about the inconsistent implementation of section 34 by the NDIA. None of these recommendations have suggested re-defining the legislation to the extent that the existing case law may become irrelevant.

Outside of considerations of legislative good practice, many people with disability have expressed dismay at the prospect of changing the definitions of reasonable and necessary at this time, making statements to the effect of "we're finally just learning how to use it the way it's set up, and now we're going to have to start over and learn a whole new system."

## Granting of Exemptions from Independent Assessments

As noted above, the Tune Review recommended independent assessments to be discretionary. The NDIA's proposed process would make such assessments mandatory. The NDIA then proposes a process by which certain individuals can seek an exemption.

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<sup>3</sup> [183]-[184]

<sup>4</sup> [202]

A discretionary assessment serves as a potential mechanism for individuals who cannot afford evidence of functional impairment to be assisted to access the scheme, it assists the disadvantaged and seeks to address issues of inequity.

A mandatory process, under which those who are at risk from the process or for whom there are no informal supports to assist them can *request* an exemption. This requires those at most risk, with the fewest supports, and least capacity to do so, to undergo this level of interaction with the NDIA.

Even where people with disability are able to request the exemption, it can be refused, and the refusal is not a reviewable decision. This process does not improve equity for either Access or Planning; rather it imposes the greatest burden on those individuals least able to cope with it.

It is evident from the Tune Review and the Joint Standing Committee reports into the NDIS that many participants already experience very high levels of stress, uncertainty and inconsistent decision making when interacting with the NDIA. There are a variety of potential alternative discretionary processes for Independent Assessments that should be explored first as part of a codesign process with people with disability and disability representative organisations instead of resorting to a mandatory/exemption model.

## Trauma and Independent Assessments

Many people with disability report feeling deeply traumatised by their dealings with the NDIA. The signatories have supported a significant number of clients who refuse any further involvement with the NDIA, even where this has been to their detriment, due to unwillingness to expose themselves to further risk of harm. Many people with disability report having had their funded supports significantly reduced, resulting in significant adverse outcomes for them, and have had to fight for months- or years, if they have to go to external appeal- to have necessary supports restored.

People with disability report that the NDIA have not always communicated in the way they have stated that they will. Despite written assurances from the CEO Martin Hoffman that no participant would have their access threatened without a conversation, a number of the signatories continue to receive contact from NDIS Participants who report that they had received a letter dated two weeks prior stating that they would be exited from the scheme if they did not provide additional evidence of their eligibility, and that their supports would be immediately revoked if the evidence was not provided within 28 days. The specific evidence required was not stipulated, and many people with disability received these letters while under COVID-19 lockdown or restrictions. People with disability reported calling the National Contact Centre, who stated that a member of the National Access Team would call the participant back. A significant majority of the people with disability concerned reported that they did not receive callbacks.

These types of experiences have led many people with disability to feel extremely distressed and anxious about requests made by the NDIA. For many people with disability, any request for them to undertake an Independent Assessment is likely to cause a harmful degree of anxiety and distress. It is the signatories' view that the NDIS has a duty of care to avoid further trauma or harm to these individuals.

A discretionary power to seek Independent Assessments, where they will benefit the prospective Participant and support consistent decision making, would be sufficient to improve outcomes. Based on the observed experiences of the signatories in supporting clients, a mandatory process will cause significant harm to many people with disability and will not significantly improve decision making consistency.

## Environmental factors and associated support need decisions

The assessments identified in the proposed reforms do not, in themselves, result in a recommendation for funding or supports; they provide an indicator of functional impairment. The mechanism by which the Independent Assessment is used to inform or calculate a proposed level of support need and funding has not been disclosed to date, and has not been subject to any clear consultative process.

It is not clear how environmental factors captured during the Independent Assessment will impact access or funding decisions, to what extent this data will be captured, or how sensitive this capture will be to the multiple and complex environmental factors which some cohorts can experience.

If the assessment identifies informal supports as being available, it is not clear how differing levels (and appropriateness) of existing support will translate into the assessment's findings and subsequent funding levels. For example, two people may both have live-in carers, but in one case there may be a reciprocal care arrangement as the carer themselves also has a disability, or one carer may be a sibling or extended family member who is not the most appropriate person to provide the intimate care support the person needs. Given the potential for significant decision making on the basis of such data, the process by which assessment data will be translated into Access decisions or plan funding must be made transparent. Further, the accuracy of such a process must be monitored carefully to ensure that inaccurate modelling does not cause significant cohorts of NDIS participants to suddenly lose access to supports and be forced into complaints and appeals processes.

Concerns have also been raised regarding safety mechanisms to address human error such as data input errors, or the failure to attach or consider supporting evidence, which are regularly seen by people with disability under the current process. Given the likelihood that an adverse finding from an Independent Assessment may lead to reduced funding or a participant being exited from the NDIS, many people with disability fear they may suddenly lose access to necessary supports unless further safeguards and quality checks are implemented.

## Reliance on Third Party Information

We refer to section 3.5.12 of the *Consultation paper: Access and Eligibility Policy with independent assessments* which states:

*“Several of the assessment tools can be completed by either the applicant and/or a person who knows them well. One assessment tool (the Vineland) is not self-reported and requires another person to attend to talk with the assessor and provide information. Choosing who else attends the*

*independent assessment is up to the applicant. Where no support person is nominated, we will initiate a process to help identify an appropriate person or persons if requested by the applicant.”*

We understand that the current Independent Assessment trial, which is opt-in, does not allow individuals without a support person to elect to be part of the trial.

This presents problems in the following ways:

- Section 4(8) of the *National Disability Insurance Scheme Act 2013* (Cth) states that “People with disability have the same right as other members of Australian society to be able to determine their own best interests, including the right to exercise choice and control, and to engage as equal partners in decisions that will affect their lives, to the full extent of their capacity.” Requiring others to speak for the participant will present a breach of this principle in many cases.
- Section 4(10) of the *National Disability Insurance Scheme Act 2013* (Cth) states that “People with disability should have their privacy and dignity respected.” A requirement that others attend this assessment and speak on behalf of the participant will present a breach of this principle in many cases.
- The responses to the Independent Assessment pilot were overwhelmingly from carers rather than from participants, meaning the most critical voices in any consultation were not captured

In work with clients accessing or attempting to access the NDIS to date, the signatories have already observed the risks associated with reliance on third parties to speak on behalf of participants, including:

- Carers or family members with vested or conflicting interests giving inaccurate information to the NDIS planning meeting. For example, in one instance, the step-sibling of the participant who had no legal authority to speak on their behalf, was present and the participant was absent. The step-sibling stated that the participant wished to move from the family home, which the planner accepted as their goal. When the participant later engaged with advocacy, they reported they had no such goal, but rather the step-sibling had wanted to remove the participant from the home in order to sell the property. This example represented multiple breaches of the client’s rights under the CRPD.
- Family members who do not support increasing the independence of the participant understating their support need, so as to reduce their access to external supports.
- Family members who do not have capacity to provide the necessary information, for example due to advanced age or disability, giving inaccurate representations as to the participant and their life.
- Service providers with vested or conflicting interests misrepresenting capacity so as to avoid the involvement of other independent parties, such as support co-ordination who might easily identify significant issues with the arrangements in place, or to financially exploit the client’s NDIS Plan.

## Impact on Participants with multiple disabilities

We refer to the relevant section of the Tune Review:

*“4.48 In circumstances where a prospective participant or participant has multiple disabilities, the NDIA has advised the disability causing the greatest impact on functioning will be listed as the primary disability. Where it is unclear which disability results in greater functional impact, further advice is sought from the treating health professional (where consent is provided) or from the participant to determine which should be listed first. The NDIA has also confirmed that holistic assessments of the impact of the person’s functional impairment drives all planning decisions, and the setting of a plan budget occurs independently of how disability type is recorded.”*

The signatories have observed recent trends wherein the NDIA indicate that they will fund supports only where they can be evidenced as relating to a specific disability as opposed to the person with disability’s holistic circumstances, forcing many people with disability, especially those with complex support needs, to go to review and appeal to receive funding for supports which are clearly necessary when taking a “common sense” view of the person’s circumstances.

The proposed process for Independent Assessments indicates that different forms of assessment will be required for different disability types. Where individuals present with multiple disabilities, especially where those disabilities have complex interactions, people with disability report concerns that the Independent Assessment process will not be able to capture their whole-of-life support needs. Greater transparency around the means by which Independent Assessments are used to generate a Plan budget is required to address these concerns.

## Purpose of Planning Meetings and client-centred planning

Clients of the signatories have expressed extreme concern that under the proposed reforms, the individualised goals and aspirations of people with disability appear to be a secondary consideration in the formulation of the Plan, rather than the foundation. The foundational role of individuals’ goals and aspirations is the NDIA’s most powerful tool to give effect to Australia’s responsibilities toward people with disability under the CRPD, the National Disability Strategy, and the National Standards for Disability Services.

We refer to section 3.4 “Planning” in the Consultation Paper:

*“The personalised budget, informed by the independent assessment, will mean that planning will no longer need to focus on the negotiation and agreement of each individual support. Planning will focus on how a participant can best use community and mainstream supports, combined with their NDIS funding to pursue their goals and aspirations and meet their disability-related support needs.”*

Placing the discussion around an individual’s goals and aspirations after the generation of their Plan budget is not consistent with principles of client-centred service, and will necessarily lead to

situations where the goals and aspirations of people with disability will be shaped by the budget made available to them, rather than the other way around. The use of global budgets that exist independent of the person's goals leaves little room for people with disability or their advocates to argue for additional funds where circumstances may warrant them.

According to section 3.3 of the Consultation Paper,

*“A change to the draft budget will only be made in specific circumstances, including where:*

- *a participant has extensive and/or complex support needs (for example where a participant has substantial behavioural support needs, a plan is expected to be of extreme high value, or a participant requires increased temporary support in response to an emergency)*
- *there are additional high-cost supports required that are not accounted for in the independent assessment. These supports include Specialist Disability Accommodation, high-cost or complex assistive technology and home modifications.”*

This model leaves no clear mechanism for identifying or addressing the needs of individuals at risk of service failure, loss of informal support, justice or child safety system involvement, or other risk factors.

## Global Plan Budgets

### Global Flexibility

Many people with disability already struggle to understand Plan flexibility: Historically, people with disability have generally asked for more guidance on how the supports in their Plan were intended to be used (e.g. a particular budget having been calculated on the basis of 20 hours of therapy assistance, 15 hours of OT, etc). Based on the experiences of clients of the signatories, issues with Plan budgets being “too prescriptive” have generally arisen out of providers’ unwillingness to use a Plan flexibly when a person with disability needs to make adjustments to the originally intended use. While the signatories recognise that greater flexibility between core and capacity building funding may be warranted based on the recommendations of the Tune Review, this should only be implemented with significantly increased support for individuals to understand, implement, and adjust their flexible funding allocations over time. Such implementation should employ a co-design approach directly involving people with disability.

We refer to the relevant section of the Tune Review which states:

*“7.14. The NDIA’s work to reform how plan budgets are constructed is welcomed to the extent the participant knows which supports are intended to be funded and the outcomes those supports are intended to achieve. However, consultation feedback suggests many participants already do not know what supports have been funded in their plan or how they can use their funding. Therefore, any move to collapse budget categories, while giving participants more flexibility in implementing their plan, may still create confusion for*

*participants. It may also weaken the NDIA's ability to ensure the funds are spent on the specific purpose they were provided for."*

People with disability frequently report that, under current NDIS processes, they do not receive adequate support to understand and implement their Plan. Even in regions where Plan handover discussions have theoretically been rolled out, and regular LAC check-ins are outlined in policy, clients of the signatories report that in reality these implementation supports frequently do not occur at all.

For proposed reforms towards greater flexibility in Plan budgets to avoid causing harm and increasing confusion, the availability and quality of support for Plan implementation from Plan delegates, Support Coordinators, Local Area Coordinators and other sources must be vastly increased.

We refer to section 3.2 of the Consultation Paper, "Personalised budgets", which states:

*"The funding provided in a personalised budget will be informed by the participant's individual circumstances, such as their age and where they live, and their functional capacity, including any relevant environmental factors, such as available informal supports. The outcomes of the participant's independent assessment will inform their personalised budget.*

*This means that in the future, a participant's plan will no longer be based on individual decisions about each and every support based on the current reasonable and necessary criteria of Section 34 of the NDIS Act."*

The use of an overall budget not calculated based on individual supports does not provide the participant with sufficient information to determine whether their Plan budget will be able to meet their reasonable and necessary support needs. An overwhelming majority of NDIS Participants will lack the capacity to undertake complex budgeting calculations to determine whether a flexible global budget is sufficient to provide the supports they personally determine to be reasonable and necessary, making it extremely difficult to effectively appeal NDIS budget decisions. In order to prove that a total Plan budget is insufficient, participants will be required to provide evidence to establish a comprehensive list of their specific needs across every category of funding.

## Periodic release of funding

We refer to section 3.6.1 of the Consultation Paper:

### *"3.6.1 Release of funds*

*While plans will be up to 5 years long, funds will be allocated into the plan for participants to purchase supports on a scheduled basis. Funds will be released in monthly or quarterly intervals. This is a decision a delegate makes during or after the planning meeting and once options have been discussed with the participant. "*

Pro-rata release of funding relies on the Plan package itself being an appropriate size, and on a participant's support needs remaining relatively stable across the lifetime of the Plan. However, many people with disability report that their support needs vary significantly across the lifetime of even a one- or two-year Plan due to circumstantial factors (anticipated or unanticipated, such as during school holidays, or where a primary carer may be hospitalised for a period), raising concerns around how additional funds may be utilised during periods of increased need.

Where a localised period of increased need occurs early in the life of a Plan, the person with disability may be subjected to stressful bureaucratic processes to seek access to increased funding at a time when their capacity to participate in such processes is definitionally decreased. Conversely, where a period of increased need may happen later in the life of a Plan, people with disability have expressed concerns that a capped periodic roll-over of unspent Plan funds will not allow them to "save up" Plan funds as they currently do to account for these circumstances, instead resulting in the person running out of funding at a critical time.

To date, where a Plan has been produced that does not contain adequate funding that must be appealed, many clients of the signatories report electing to "overspend" and pay for supports at the required rate in order to maintain safety and functional capacity while they appeal the Plan. This has most commonly been observed where individuals have very high intensity support needs, such as 24/7 care. Under a pro-rata release model, this option will not be available: the decision to release additional funding will rely on the same evidence that produced the original inadequate Plan, and therefore will most likely result in the rejection of requests for release of additional funding.

People with disability report that pro-rated release of Plan funding with capped funding rollover between periods reinforces the "use it or lose it" mindset, which undermines appropriate and cost-effective utilisation of funded supports.

The mechanisms by which an NDIS Participant may apply for an additional release of funding to account for a change of circumstances are not clear, and the criteria for decision making in this regard have not been articulated. If periodic pro-rated release of Plan funding is implemented, it is critical that the decision to grant, or not grant, an additional release of funds is made a reviewable decision with full appeal rights.

## Plan Reassessment, Change of Circumstances and Amendments

The proposed reforms indicate that the intended length of Plans will be up to 5 years. Even where an individual's disability and functional capacity are very stable, it is likely that a number of significant changes of circumstances may arise in that time period that necessitate changes to Plan funding.

There is insufficient information in the proposed reforms about what will happen in the event of a change of circumstances, and where a change of circumstances review versus a Plan amendment or adjustment to pro-rated funding release will be utilised.

## Check-Ins

While the signatories support the use of regular check-ins to support Plan implementation for clients, significant concerns exist regarding the form and implementation of this measure. As previously discussed, many people with disability report that current check-in and safeguarding mechanisms are at best ineffective, often non-existent, and at times are even reported to be harmful where a check-in has resulted in the NDIA taking an inaccurate view of an individual's circumstances.

Where LAC partners have, in recent history, been responsible for check-in mechanisms, people with disability report feeling that the LACs have too many other responsibilities and are too overstretched to appropriately and effectively undertake check-ins. People with disability have reported check-ins to date occurring through unexpected cold calls, brief 5-minute conversations where the person with disability was not supported to engage or communicate, with a new LAC who was unknown to the person and had no understanding of their history or circumstances, or where the purpose of the check-in contact itself was not communicated to the person with disability. Many people with disability report these check-ins doing more harm than good through increased stress or confusion.

Further clarification is required on the intended form and purpose of check-ins under the proposed reforms. If these are intended to function as a safeguard, it is especially critical that the design and implementation of check-in processes are codesigned with participants, and that they are flexible to account for the widely varying communication needs and preferences of people with disability.

Many people with disability report that increased utilisation of high-quality funded Support Coordination, and reduced reliance on LACs, would increase the ability of individuals to utilise flexibility in their Plan budgets to respond to changing needs and circumstances over the life of the Plan, while also providing a safeguarding factor where needed.

## Reviews and Appeals

As discussed previously, the use of Independent Assessments to generate holistic Plan budgets prior to discussion of the participant's goals and aspirations, extended Plan lifespans of up to 5 years, pro-rated release of funding in periodic blocks, and the use of non-reviewable amendments rather than fully reviewable Plan funding decisions all present challenges to the right of people with disability to review and appeal decisions made by the NDIA.

See the signatories' other submission on Access and Independent Assessments for a more in-depth discussion of the effect of Independent Assessments on appeal rights.

The signatories express deep concerns that the proposed reforms will lead to a significant increase in the rate of requests for internal and external review of NDIA decisions, which risks collapse in many of the already-overextended services and supports which assist participants in appeals, such as advocacy organisations, community health services, schools, service providers and informal supports.

We urge the federal government and the NDIS to implement reforms in line with the Tune Review's recommendations in their full context rather than in the currently proposed form, and ensure there are appropriate services available to support prospective participants to have full and equitable access to exercise their rights to appeal decisions made by the NDIA.

# Signatory Organisations

