

Re: Proposed changes to NDIS Act Legislation and Access/Planning

I am writing to express my disagreement and anger at the changes that the NDIA have proposed, which while they are being advertised as improving "fairness" have very little about them that is actually "fair". Almost every section of the changes proposed seem to be aimed at removing key portions of the NDIS Act legislation, and with it to also remove the participant's right to have decisions made about access/funding on a fair assessment of their functional loss. Further, some of the proposed changes are actively discriminatory and violate international laws that Australia is a signatory to and has agreed to abide by.

Change #1 - explicitly banning disability supports that enable people with disability to experience sexual relationships:

*"Under this category, a new rule will make clear that NDIS funding is not to be used to purchase the services of a sex worker or devices solely for sexual stimulation."*¹

*"Changes to the legislation will also make it clear that NDIS funds should not be used to purchase the services of a sex worker or devices solely intended for sexual stimulation and arousal."*²

UN Convention on the Rights of Persons with Disabilities

Article 23 - Respect for home and the family³

1. States Parties shall take effective and appropriate measures to eliminate discrimination against persons with disabilities in all matters relating to marriage, family, parenthood and relationships, on an equal basis with others, so as to ensure that:
 - a) The right of all persons with disabilities who are of marriageable age to marry and to found a family on the basis of free and full consent of the intending spouses is recognized;
 - b) The rights of persons with disabilities to decide freely and responsibly on the number and spacing of their children and to have access to age-appropriate information, reproductive and family planning education are recognized, and the means necessary to enable them to exercise these rights are provided;
 - c) Persons with disabilities, including children, retain their fertility on an equal basis with others.

The NDIS was created on the basis of providing the necessary disability supports for people with disability so that they could live a "normal" life. Part of a "normal" life for most adults includes marriage, sexual relationships, and children. The UN Convention on the Rights of Persons (UN CRPD) with Disabilities states that people with a disability have the **same** rights to intimacy that any other adult has, **and that they be provided the supports required due to their disability in order to exercise these rights.**

It is not possible for people with disability to exercise their rights to parenthood if they are denied the disability supports they require in order to engage in sexual intercourse. Removing these disability supports explicitly contravenes the UN CRPD Article 23.1.b) which states that the means necessary to enable people with disability to exercise these rights be provided. This means that the proposed legislative change to remove access to these disability supports is *illegal* under the international laws that Australia has agreed to abide by, and for which the NDIS was designed to

1 NDIS Reforms DSS Information Paper, "Improving the National Disability Insurance Scheme", 24 November 2020, page 4

2 Source: NDIS Reforms DSS Information Paper, "Improving the National Disability Insurance Scheme", 24 November 2020, page 16

3 UN Convention on the Rights of Persons with Disabilities, available from <https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities/article-23-respect-for-home-and-the-family.html>

provide. Part 2, Section 3 of the National Disability Insurance Scheme Act 2013 states:

Part 2—Objects and principles

3 Objects of Act

(1) The objects of this Act are to:

(a) in conjunction with other laws, **give effect to Australia’s obligations under the Convention on the Rights of Persons with Disabilities** done at New York on 13 December 2006 ([2008] ATS 12); and

(b) provide for the National Disability Insurance Scheme in Australia; and

(c) **support the independence and social and economic participation of people with disability**; and

(d) provide reasonable and necessary supports, including early intervention supports, for participants in the National Disability Insurance Scheme launch; and

(e) enable people with disability to exercise choice and control in the pursuit of their goals and the planning and delivery of their supports; and

(f) facilitate the development of a nationally consistent approach to the access to, and the planning and funding of, supports for people with disability; and

(g) promote the provision of high quality and innovative supports that **enable people with disability to maximise independent lifestyles and full inclusion in the community**; and

(ga) protect and prevent people with disability from experiencing harm arising from poor quality or unsafe supports or services provided under the National Disability Insurance Scheme; and

(h) raise community awareness of the issues that affect the social and economic participation of people with disability, and facilitate greater community inclusion of people with disability; and

(i) in conjunction with other laws, give effect to certain obligations that Australia has as a party to:

(i) the International Covenant on Civil and Political Rights done at New York on 16 December 1966 ([1980] ATS 23); and

(ii) the International Covenant on Economic, Social and Cultural Rights done at New York on 16 December 1966 ([1976] ATS 5); and

(iii) the Convention on the Rights of the Child done at New York on 20 November 1989 ([1991] ATS 4); and

(iv) the Convention on the Elimination of All Forms of Discrimination Against Women done at New York on 18 December 1979 ([1983] ATS 9); and

(v) the International Convention on the Elimination of All Forms of Racial Discrimination done at New York on 21 December 1965 ([1975] ATS 40).

Note: In 2013, the text of a Convention or Covenant in the Australian Treaty Series was accessible through the Australian Treaties Library on the AustLII website (www.austlii.edu.au).

(2) These objects are to be achieved by:

(a) providing the foundation for governments to work together to develop and implement the National Disability Insurance Scheme launch; and

(b) adopting an insurance-based approach, informed by actuarial analysis, to the provision and funding of supports for people with disability; and

(c) establishing a national regulatory framework for persons and entities who provide supports and services to people with disability, including certain supports and services provided outside the National Disability Insurance Scheme.

(3) In giving effect to the objects of the Act, regard is to be had to:

- (a) the progressive implementation of the National Disability Insurance Scheme; and
- (b) the need to ensure the financial sustainability of the National Disability Insurance Scheme; and
- (c) the broad context of disability reform provided for in:
 - (i) the National Disability Strategy 2010-2020 as endorsed by COAG on 13 February 2011; and
 - (ii) the Carer Recognition Act 2010; and
- (d) the provision of services by other agencies, Departments or organisations and the need for interaction between the provision of mainstream services and the provision of supports under the National Disability Insurance Scheme.

4 General principles guiding actions under this Act

- (1) People with disability have the same right as other members of Australian society to realise their potential for physical, social, emotional and intellectual development.**
- (2) People with disability should be supported to participate in and contribute to social and economic life to the extent of their ability.
- (3) People with disability and their families and carers should have certainty that people with disability will receive the care and support they need over their lifetime.
- (4) People with disability should be supported to exercise choice, including in relation to taking reasonable risks, in the pursuit of their goals and the planning and delivery of their supports.
- (5) People with disability should be supported to receive reasonable and necessary supports,** including early intervention supports.
- (6) People with disability have the same right as other members of Australian society to respect for their worth and dignity and to live free from abuse, neglect and exploitation.
- (7) People with disability have the same right as other members of Australian society to pursue any grievance.
- (8) 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.
- (9) People with disability should be supported in all their dealings and communications with the Agency and the Commission so that their capacity to exercise choice and control is maximised in a way that is appropriate to their circumstances and cultural needs.
- (10) People with disability should have their privacy and dignity respected.
- (11) Reasonable and necessary supports for people with disability should:
 - (a) support people with disability to pursue their goals and maximise their independence; and
 - (b) support people with disability to live independently and to be included in the community as fully participating citizens; and**
 - (c) develop and support the capacity of people with disability to undertake activities that enable them to participate in the community** and in employment.
- (12) The role of families, carers and other significant persons in the lives of people with disability is to be acknowledged and respected.**

(13) The role of advocacy in representing the interests of people with disability is to be acknowledged and respected, recognising that advocacy supports people with disability by:

(a) promoting their independence and social and economic participation;
and

(b) promoting choice and control in the pursuit of their goals and the planning and delivery of their supports; and

(c) maximising independent lifestyles of people with disability and their full inclusion in the community.

(14) People with disability should be supported to receive supports outside the National Disability Insurance Scheme, and be assisted to coordinate these supports with the supports provided under the National Disability Insurance Scheme.

(15) Innovation, quality, continuous improvement, contemporary best practice and effectiveness in the provision of supports to people with disability are to be promoted.

(16) **Positive personal and social development of people with disability, including children and young people, is to be promoted.**

(17) It is the intention of the Parliament that the Ministerial Council, the Minister, the Board, the CEO, the Commissioner and any other person or body is to perform functions and exercise powers under this Act in accordance with these principles, having regard to:

(a) the progressive implementation of the National Disability Insurance Scheme; and

(b) the need to ensure the financial sustainability of the National Disability Insurance Scheme.

Denying participants whose level of disability means that disability supports are required in order to facilitate them to engage in sexual intercourse also denies them the right to full participation in the community, particularly in terms of family and parenthood. It shows a complete lack of respect for the role of other significant persons in the lives of participants. This violates the Object and Principles of the NDIS Act 2013 legislation.

The denial of disability supports for those who require supports to be able to engage in sexual intercourse also violates the International Covenant on Civil and Political Rights, Article 23⁴:

Article 23

1. The family is the natural and fundamental group unit of society and is entitled to protection by society and the State.

2. The right of men and women of marriageable age to marry and to found a family shall be recognized.

3. No marriage shall be entered into without the free and full consent of the intending spouses.

4. States Parties to the present Covenant shall take appropriate steps to ensure equality of rights and responsibilities of spouses as to marriage, during marriage and at its dissolution. In the case of dissolution, provision shall be made for the necessary protection of any children.

Removal of those supports represents removal of the participant's rights to found a family and the explicit denial of equality of rights and responsibilities of spouses as to and during marriage. This violates the NDIS Act 2013, Section 3.1.i.i by failing the obligations within the International Covenant on Civil and Political Rights.

4 International Covenant on Civil and Political Rights 1966:
<https://www.ohchr.org/en/professionalinterest/pages/ccpr.aspx>

Article 16 of the Convention on the Elimination of All Forms of Discrimination against Women⁵ states:

Article 16

1. States Parties shall take all appropriate measures to eliminate discrimination against women in all matters relating to marriage and family relations and in particular shall ensure, on a basis of equality of men and women:
 - (a) The same right to enter into marriage;
 - (b) The same right freely to choose a spouse and to enter into marriage only with their free and full consent;
 - (c) The same rights and responsibilities during marriage and at its dissolution;
 - (d) The same rights and responsibilities as parents, irrespective of their marital status, in matters relating to their children; in all cases the interests of the children shall be paramount;
 - (e) The same rights to decide freely and responsibly on the number and spacing of their children and to have access to the information, education and means to enable them to exercise these rights;**
 - (f) The same rights and responsibilities with regard to guardianship, wardship, trusteeship and adoption of children, or similar institutions where these concepts exist in national legislation; in all cases the interests of the children shall be paramount;
 - (g) The same personal rights as husband and wife, including the right to choose a family name, a profession and an occupation;
 - (h) The same rights for both spouses in respect of the ownership, acquisition, management, administration, enjoyment and disposition of property, whether free of charge or for a valuable consideration.

The proposed law that disability supports that enable participants to engage in sexual intercourse be banned from support violates Article 16.1.e) of the Convention on the Elimination of All Forms of Discrimination against Women.

The proposed change to explicitly exclude disability supports if those disability supports are to permit people with disability to have sexual intimacy violates:

- the original intention of the NDIS to be supported to live a normal life
- the UN CRPD Article 23, section 1: "States Parties shall take effective and appropriate measures to eliminate discrimination against persons with disabilities in all matters relating to marriage, family, parenthood and relationships"
- the UN CRPD Article 23, section 1. b): "The rights of persons with disabilities to decide freely and responsibly on the number and spacing of their children...are recognised, and *the means necessary to enable them to exercise these rights are provided.*"
- the International Covenant on Civil and Political Rights, Article 23, parts 2 and 4.
- the Convention on the Elimination of All Forms of Discrimination against Women, Article 16, section 1.e) which states that women have "The same rights to decide freely and responsibly on the number and spacing of their children and to have access to ... the means to enable them to exercise these rights".

Changing the NDIS legislation to remove disability supports if those supports are connected with enabling a person with disability the capability to engage in sex is discriminatory. There is *no* valid reason why required disability supports for this *one* aspect of a normal life should be barred from a participant. The Federal Court of Australia has already ruled that these supports can be reasonable

⁵ Convention on the Elimination of All Forms of Discrimination against Women, 1979 : <https://www.ohchr.org/EN/ProfessionalInterest/Pages/CEDAW.aspx>

and necessary disability supports in some circumstances. It is because of this ruling that the government & NDIA are seeking to explicitly ban these supports, for no reason other than that the government feels it is "inappropriate" for people with disability to be enabled to experience this aspect of life. This proposed legislative change violates the Object and Principles of the NDIS Act 2013 legislation, which was created in part to give effect to the international laws that Australia was a signatory to and which are also being violated by this proposed change.

This proposed change should **never** be signed into Australian law.

Change #2: Independent Assessments

The issues with the changes for Independent Assessments as proposed are numerous, but it all comes back to a single critical issue - *the right of the participant to have access to the disability supports they personally require to live a normal life*. There are many procedural injustices proposed in the details for this change that will have the effect of denying the participant access to the disability supports that they require.

a) The right to a fair assessment of functional capacity

It has already been *proven* in multiple AAT cases for the NDIS that medical professionals that undertake assessments of functional capacity do *not* always provide a fair assessment. There can be many reasons for this, such as unfamiliarity with the person's particular conditions that are causing the disability and hence how those conditions affect their functional capacity, misunderstanding things that they are told or have observed, disbelief in the particular causes for the person's disability and hence in the losses of functional capacity it creates, personal theories as to how those conditions "ought" to be treated in terms of minimising impact on functional capacity, beliefs that the person with disability is exaggerating their situation, etc. Two key cases in point are the external AAT review cases on access to the NDIS:

- Arnel and National Disability Insurance Agency [2019] ^{Attachment 1}
- Ray and National Disability Insurance Agency [2020] ^{Attachment 2}

In both of these cases, the applicant was refused access to the NDIS on the basis of *substantial* errors in the independent assessment reports. Both women were assessed by qualified Occupational Therapists. In both cases, the Occupational Therapists misunderstood the functional impacts caused by the prospective participant's conditions, resulting in assessment results that were fundamentally unrepresentative of the person's actual functional capacity. In the Arnel case, this extended to recommending that the prospective participant was perfectly able to drive despite them being unable to feel the position of their right leg, or to control that leg adequately (her accelerator/brake foot!) making driving an extremely dangerous activity both to herself and to any other person on the road at the same time. In both cases, the AAT ended up completely discarding those independent assessments due to the extent and severity of the *errors of fact* in the assessments that meant that the conclusions formed from those assessments were invalid. In both cases, the AAT ruled after examining the rest of the participant's medical evidence that the people involved did indeed qualify for the NDIS under the disability requirements in section 24 of the National Disability Insurance Scheme Act 2013.

These cases highlight how *critical* it is that people with disability have the ability to challenge an assessment if it is substantially incorrect. While it is likely true that *many* assessments will be fair, the consequences of an assessment that is not a fair representation of the participant's functionality are extensive and can cause significant harm to the participant.

The Independent Assessment process that the NDIA is proposing is different to the process that was present in these cases. The assessments undertaken in the proposed process will be significantly reduced in scope, so much so that there have already been protests by multiple medical associations that these assessments are *not* comprehensive enough to be called a "functional capacity" assessment. The NDIA also propose to exclude *any* right to challenge or replace an unfair assessment - during an AAT case people have always had the right to submit contradictory evidence to contest/refute an unfair assessment.

*3.11 Appeal rights and complaints*⁶

We will not be changing the review process. The access decision remains a reviewable decision and the applicant can request an internal review and then appeal the decision at the Administrative Appeals Tribunal (AAT).

Independent assessment results themselves will not be directly reviewable by the AAT. This is because independent assessments are not a decision the delegate makes under the NDIS Act. Instead, the delegate will request that an applicant has an independent assessment for the purposes of informing an access decision under the NDIS Act.

Disagreeing with the results of an otherwise sound and robust independent assessment is not sufficient for the NDIA to fund another assessment. Applicants can only seek a second assessment where the assessment was not consistent with the independent assessment framework, or if the applicant has had a significant change to their functional capacity or circumstances. In the instance where a new assessment is provided, the initial assessment and outcomes are to be considered invalid for all further decision making purposes.

This proposed exclusion is extremely unfair and detrimental to the participant. This means that the participant either:

- Has to take each and every decision made on the basis of a flawed assessment to the AAT for the period of time that the assessment is retained (which can be up to 5 years), OR
- Is deprived of the disability supports that they required and that would have been found to be reasonable and necessary had the assessment had been accurate for the period of time that the assessment is retained (up to 5 years).

This is a denial of procedural fairness - and many of the issues with the Independent Assessment process as currently defined by the NDIA stem from the NDIA's denial of the participant's right to a *fair* assessment in the proposed process.

The Tune Review⁷ that the NDIA are using as part of the justification for independent assessments explicitly stated that it was *essential* that participants had the right to challenge an inaccurate assessment in section 4.34.b):

4.34. The NDIS Act should be amended to support the use of functional capacity assessments as proposed above. However, **there are a number of key protections that need to be embedded as this approach rolls out, including:**

- a) participants having the right to choose which NDIA-approved provider in their area undertakes the functional capacity assessment

6 National Disability Insurance Scheme Consultation Paper: Access and Eligibility Policy with independent assessments, v1.0, November 2020.

7 Review of the National Disability Insurance Scheme Act 2013, by David Tune AO PSM, December 2019: https://www.dss.gov.au/sites/default/files/documents/01_2020/ndis-act-review-final-accessibility-and-prepared-publishing1.pdf

- b) **participants having the right to challenge the results of the functional capacity assessment, including the ability to undertake a second assessment or seek some form of arbitration if, for whatever reason, they are unsatisfied with the assessment**
- c) the NDIA-approved providers being subject to uniform accreditation requirements that are designed and implemented jointly by the NDIA and appropriate disability representative organisations
- d) the NDIA providing clear and accessible publicly available information, including on the NDIS website, on the functional capacity assessments being used by the NDIA and the available panel of providers.

The NDIA's proposal to ban participants from being able to challenge the results of an assessment violates the recommendations from the Tune report, which means that the process that the NDIA are proposing is NOT one supported by the Tune report.

I have already made a submission to the Parliamentary Inquiry into the general functioning of the NDIS regarding this denial of the right to challenge/refute a flawed assessment. Not giving participants the right to challenge a flawed assessment is a shameful abuse of power and a denial of fair process by the NDIA.

A complaints process will be available for applicants who are dissatisfied with an independent assessment, their assessor, or the assessor organisation.⁸

Most complaints made to the NDIS or the NDIS Safeguarding Commission do not appear to result in the complaint actually being addressed as far as the participant is concerned. Having been through the complaints department myself within the NDIA, I have zero confidence that any complaint regarding issues with an independent assessment will result in *meaningful* action being undertaken. People with disability do not *only* deserve "their complaints to be heard" - *they deserve them to be acted upon in the same way that someone without disability has their complaints acted upon*, and in general this does not appear to occur.

Lodging a complaint regarding an assessment that is not a fair representation of the person's functional capacity is *meaningless* if that assessment still continues to be used for the next 5 years for all the person's funding (and/or access) decisions. It provides *nothing* to address the injustice of the situation, or to limit the harm to the person with disability that will occur as a result of a flawed assessment.

b) People with disability will be unfairly expelled from the NDIS due to flawed assessments that they are not permitted to challenge/refute.

3.10 Eligibility reassessments⁹

The NDIS supports people to reach their potential and live and ordinary life. The process we will use for eligibility reassessments is in line with the insurance principles of the NDIS, supporting capacity building of people with disability to live as part of the community.

If the time comes that people do not need NDIS supports anymore, and they no longer meet the residence, disability or early intervention requirements, then the CEO or their delegate may revoke their status as a participant in the NDIS in accordance with

8 National Disability Insurance Scheme Consultation Paper: Access and Eligibility Policy with independent assessments, v1.0, November 2020.

9 National Disability Insurance Scheme Consultation Paper: Access and Eligibility Policy with independent assessments, v1.0, November 2020.

section 30 of the NDIS Act.

Where an independent assessment indicates a significant improvement in functional capacity, a participant may be referred for an eligibility reassessment, consistent with the current provisions of the Act. The information from the independent assessment may then be used to inform an eligibility reassessment decision.

In the event that the participant's functional assessment unreasonably ignores or minimises the extent of the impact of their disability on their functional capacity, they can be ejected from the NDIS on the basis of reported "gains" in functional capacity that don't actually exist and that they have been given no rights to contest. The *same* assessment that triggered the eligibility reassessment process is used to reassess eligibility and eject the participant from the scheme.

There is nothing "fair" in ejecting the participant from the scheme based solely on a *single* assessment completed by a stranger who met them for 1-3 hours with **no other information to support the accuracy of that assessment**. During the first pilot, 28% of the people who responded to the survey explicitly reported that they felt that their assessor *did not understand their disability, and hence the impact of their disability on their functional capacity*. That's a very large segment of people at risk of being ejected from the NDIS on the basis of an assessment that due to lack of understanding ends up erroneously trivializing their actual loss of functional capacity. The complete inability for the participant to contest the conclusions made in the assessment **will** see some people who *do* meet the legislative requirements for access having their access *incorrectly and unfairly* terminated on the basis of a flawed assessment.

While the decision to end access to the scheme is itself a reviewable decision, this review process takes significant time during which the participant will not be receiving any disability supports. The internal review will also compare the decision back to the original flawed assessment, the participant still has no rights to contest the errors in that assessment, and by virtue of those facts the internal review will most likely uphold the original decision to terminate access. By the time the participant gets through an external review at the AAT and finally gets a court decision based on more information than *only* the flawed assessment, the participant will have been without support for the 18-36 months that it took for the case to be heard - all on the basis of an assessment that was *itself* incorrect that the participant had been allowed no ability to contest or refute.

For some participants, that period of time waiting for the AAT review will cause permanent harm, and potentially death due to the total loss of essential disability supports.

This also violates the General Principles guiding actions under the NDIS Act 2013, Section 4.3, which states that

"People with disability and their families and carers should have certainty that people with disability will receive the care and support they need over their lifetime."

The inability to challenge a flawed independent assessment means that the participant will never be able to have "certainty of support", as there is always the risk that their *next* assessment might be one that results in them having *all* supports unfairly terminated. This further increases the stress and distress that will be experienced by participants as a result of the independent assessment process.

c) Averaging support packages for people with the "same level of impairment" ignores their actual support needs.

Level of impairment discounts the reasons for that impairment - but those reasons are often inextricably linked to the type of supports the participant requires. By separating the reasons for impairment from the planning process entirely, some people will end up with more support than they actually need while others will end up with vastly less support. The underfunding for some participants will then result in costing more over their lifetime due to their condition deteriorating due to the lack of required support.

I'll use my own experiences here to provide an example. I have an autoimmune condition that has caused my immune system to attack and severely damage parts of my nervous system. It is progressive and untreatable. I can manage moving around indoors barefoot most of the time with rest breaks between rooms. Outdoors (or anywhere where I need to wear shoes) I can manage to walk about 20m with crutches on an average day, requiring at least an hours rest afterwards before I can walk any further. For mobility outside the home, I need to use an electric wheelchair. Due to the cause for my substantial loss of mobility being autoimmune, there are no treatments or therapies available to me to slow or stop the progression of the nerve damage and further loss of mobility. I need home assistance for tasks I can no longer do - cleaning, gardening, cooking, some personal care tasks (particularly showering). Any task that requires standing for any period of time, or applying pressure through my hands (e.g. cutting raw vegetables with a knife, scrubbing the bathroom, etc) is one I am no longer able to do myself. I am married, so my husband is assisting with the personal care tasks and some meal preparation - but due to his own chronic health conditions he's significantly limited in what he can do. Most of the time we use microwave meals from the supermarket because neither of us are physically capable of cooking that day, and we have NDIS assistance for cleaning/gardening because there is no-one in the household or elsewhere that can provide informal support for those tasks.

I've spoken with another participant who also has access to the NDIS. Their level of mobility, and the list of tasks that they cannot do, is roughly equivalent to mine. In their case, they have a condition where their joints are calcifying, so in order to maintain what mobility they have left they require physical manipulation of the joints and stretching by a trained physiotherapist 3 times per week. Without this therapy their joints will become fused/unable to be moved. They've already lost a lot of their mobility this year as a result of Covid and inability to access the physical therapy they needed due to isolation and closure of in-person supports. They need the same daily/core supports at home - cleaning, gardening, meal prep, personal care - but they live alone without any informal supports that they can access for assistance so they need formal assistance in all of those areas.

Giving us a package determined by our assessed level of functional loss means that one of the following will occur:

- If the funding package is suitable for someone with the other participant's support requirements, I will end up grossly overfunded due to having funding for therapy 3 times per week when I do not need/cannot use therapy supports, plus the supports for personal care that my husband currently supplies. That funding would be far better provided to someone who needs it rather than as an excessive amount provided to me.
- If the funding package is suitable for someone with my support requirements, the other person will be severely underfunded and unable to maintain the physical therapy that is essential to maintain what mobility they had left. This would cause them to be completely bedridden within a year or two. Their lifetime support requirements would become much higher, and overall they will end up costing a lot MORE for NDIS supports over their lifetime than they would have if they had been properly supported now. This actually violates the NDIS Act 2013 Objective in section 3.2.b)

"adopting an insurance-based approach, informed by actuarial analysis, to the provision and funding of supports for people with disability"

The benefits from early intervention in terms of limiting the long-term need for funding was one of the primary reasons for the creation of the NDIS in the first place. This situation is exactly how the old funding models for disability support were failing people with disability, and in turn due to the increased need for funding over a person's lifetime as a result of *avoidable* deterioration from lack of required supports to maintain function was failing Australian tax-payers as a whole!

- If the funding package is somewhat averaged between what we need, I *still* end up overfunded and the other person *still* ends up deteriorating due to inability to access an adequate level of support.

In *none* of the potential scenarios above has the amount of funding actually been *equitable* or *fair*.

This proposal is a return to the funding model from prior to the creation of the NDIS. It removes the heart of what the NDIS was supposed to be, which is *equitable* funding so that people got the personalised disability supports that *they* needed to be able to live a "normal" life. By reverting to the old funding models which are *already known* to have worse and more expensive outcomes overall, the NDIA are proposing to destroy the cornerstone of the NDIS.

Packages based on an assessment of functional capacity may provide some "consistency", but they DO NOT provide *fairness*.

I believe that the NDIA would achieve better results by giving their planning staff and the Local Area Coordinators better training in the legislation. The ANAO audit "Decision-making Controls for NDIS Participant Plans recently reported¹⁰:

2.39 As at 30 June 2020, NDIA data showed that there were 1147 planners who had commenced between July 2018 and April 2020. **The reasonable and necessary module of the NSP (NDIA new starter program) course had been completed by 832 of these planning staff (73 per cent).**

The main conclusion in "Section 3: Oversight of reasonable and necessary supports" of the report was:

The NDIA does not yet have appropriate oversight mechanisms in place to ensure the supports in participant plans are reasonable and necessary. The NDIA has established some frameworks for oversight and control of decision-making for participant plans; however, to date, this is not systematically leading to enterprise wide actions for improvement and compliance in decision-making.

Planners and LACs making decisions that are not supported by or are directly violating the NDIS legislation is where many of the inconsistencies and unfairness of the current system is coming from. The ANAO's report demonstrated an *abysmal* level of compliance with the legislation on part of the NDIA, and this lack of compliance has caused an enormous amount of stress and exhaustion for people with disabilities and their families/carers and advocates to deal with the continual fight to get the supports that they were supposed to be able to access under the NDIS legislation.

People with disability deserve better from the NDIA. They deserve that the people who are assessing their funding are actually doing so within the framework of the NDIS legislation.

10 <https://www.anao.gov.au/work/performance-audit/decision-making-controls-ndis-participant-plans>

d) Changing from "Reasonable and Necessary" rules in Section 34 to packages determined by "level of assessed functional capacity" appears to be an attempt to circumvent the requirement that Reasonable and Necessary disability supports will be funded.

34 Reasonable and necessary supports

(1) For the purposes of specifying, in a statement of participant supports, the general supports that will be provided, and the reasonable and necessary supports that **will be funded**, the CEO must be satisfied of all of the following in relation to the funding or provision of each such support:

(a) the support will assist the participant to pursue the goals, objectives and aspirations included in the participant's statement of goals and aspirations;

(b) the support will assist the participant to undertake activities, so as to facilitate the participant's social and economic participation;

(c) the support represents value for money in that the costs of the support are reasonable, relative to both the benefits achieved and the cost of alternative support;

(d) the support will be, or is likely to be, effective and beneficial for the participant, having regard to current good practice;

(e) the funding or provision of the support takes account of what it is reasonable to expect families, carers, informal networks and the community to provide;

(f) the support is most appropriately funded or provided through the National Disability Insurance Scheme, and is not more appropriately funded or provided through other general systems of service delivery or support services offered by a person, agency or body, or systems of service delivery or support services offered:

(i) as part of a universal service obligation; or

(ii) in accordance with reasonable adjustments required under a law dealing with discrimination on the basis of disability.

(2) The National Disability Insurance Scheme rules may prescribe methods or criteria to be applied, or matters to which the CEO is to have regard, in deciding whether or not he or she is satisfied as mentioned in any of paragraphs (1)(a) to (f).

Part of the requirements in the legislation inside Section 34 of the NDIS Act 2013 legislation is that reasonable and necessary disability supports *will be funded*. This was clarified by the Federal Court Case "McGarrigle v National Disability Insurance Agency [2017]"^{Attachment 3} that the wording here meant to be *fully* funded, not solely a "contribution" to funding.

By dropping Section 34 of the NDIS Act for planning the provision of disability support funding, the NDIA appear to be also seeking to remove the requirement that Reasonable and Necessary disability supports must be fully funded.

This is being advertised to participants as a benefit - but changing the legislation to justify being able to underfund people's disability supports is in no way beneficial to participants.

e) "Spending flexible funding flexibly" does not overcome inadequacy of funding.

Every time I have heard the NDIA speak about "spending flexible funding flexibly" it has been as an attempt to excuse an inadequate total amount of funding for a participant's reasonable and necessary disability supports. This is something that the NDIA have already been reprimanded for in court (AAT cases "David and National Disability Insurance Agency [2018]"^{Attachment 4} paragraph 74 and "Medcalf and National Disability Insurance Agency [2018]"^{Attachment 5} paragraphs 95-96). There is a lot of talk in the discussion papers about how people will be able to use all their non-fixed funds flexibly. While the blending of funding across the current 15 categories into simply "flexible" and "fixed" is a good step in the right direction, having an inadequate funding package based on level of

impairment rather than level of disability support actually needed will *not* be "fixed" by having the ability to spend what funds they receive flexibly. If someone has a need for therapy 3 hours per week at Physiotherapy rates, it puts their therapy needs at roughly \$30,000/year at current NDIS Price Guide Physiotherapy rates. Being given a package that is allowed to vary between \$12,000 to \$20,000 for their assessed level of impairment means that no matter how flexible their funds are they cannot be made to stretch to cover both the participant's required core supports and their required therapy needs.

f) Drip-feeding funding unfairly impacts people whose support needs are not constant during the year, and destroys flexibility.

There are some participants where their disability is episodic, or they need more support at certain times of the year - e.g. winter, school holidays, etc.

The plan to change funding to monthly or quarterly means that these people are unable to access the funding that they *have* been allocated according to their level of support needs at the time.

It precludes being able to use supports in intermittent bursts - e.g. spring cleaning windows, or being supported to attend a special public event, due to the inability to access an increased portion of their supports for these intermittent types of need.

If someone has funding for participation in interstate sporting events twice per year, having that funding spread by drip-feed over 12 monthly periods, or 4 quarterly periods, means that the funding is not going to be available to the participant when the interstate sporting events actually occur (see AAT Case Decision in "David and National Disability Insurance Agency [2018]" Attachment 4).

This change is not required, is not helpful for most participants, and it unfairly punishes people whose needs are not constant or who have intermittent life events requiring support by withholding the funding *that they have been allocated and should have had access to* from them at times when it is *needed*.

It also restricts the participant's ability to exercise choice and control over the delivery of their supports, by restricting their access to the funding for those supports. *Changing the funding so that it is limited to monthly or quarterly accessibility IS a Restrictive Practice that the NDIA are seeking to impose on every single NDIS participant, and will be done outside of any Behaviour Support Plan.*

Will the NDIA be reporting their unauthorized Restrictive Practice applied to every single NDIS participant regardless of the participant's capabilities to the NDIS Quality and Safeguards Commission?

g) Removing reports from the person's therapists is also an attempt to remove the NDIA's requirement to properly fund recommended therapy needs

In the AAT case "Castledine and National Disability Insurance Agency [2019]" Attachment 6, the NDIA were informed that planners and LACs with no medical experience or knowledge of the participant should not override the assessment of therapy needs from a trained medical professional that has medically assessed the participant:

292. The NDIA did not call any expert evidence from a speech therapist or occupational therapist providing an alternative opinion, based on a professional assessment of Mr Castledine, as to what therapy was appropriate for him and how many hours were

reasonable and necessary in his circumstances.

293. Ms Parsons, a senior employee of the NDIA, who admittedly holds impressive qualifications and has had significant work experience in the disability sector, expressed a view about what was appropriate for Mr Castledine as part of proposing an integrated MDT support. However, the Tribunal does not accept Ms Parsons' evidence as it relates to how many hours of speech therapy or occupational therapy are required by Mr Castledine, primarily, because she is neither a speech pathologist or occupational therapist, and also because she has never had the opportunity of making direct observations of Mr Castledine and his present ability to communicate with others and to undertake activities of daily living.

294. The NDIA complained of Ms Cohen only having been present with Mr Castledine on 10 to 20 occasions before making her recommendations and that Ms Greiner had only had seven sessions with him. However, by comparison, Ms Parsons had not ever been present with Mr Castledine before making her recommendations about therapeutic interventions that should be regarded as reasonable and necessary supports.

295. The Tribunal prefers the evidence of Ms Cohen, Ms Greiner and Ms Killmier, as they are each qualified and practising therapists who have met and interacted with Mr Castledine and his carers. There are better placed to make recommendations as to his need given that they were in a position to undertake a professional assessment of him. There is evidence that each of them have at least a reasonable understanding of his therapeutic history. Accordingly, the Tribunal is not prepared to dismiss Ms Cohen's and Ms Greiner's recommendations for the reasons contended by the NDIA, in preference for Ms Parsons' recommendations.

In removing the requirement for people to submit reports from their therapists and basing plans on the independent assessment only, the NDIA are also removing the *evidence* that participants were providing for what level of therapy *they actually need*. The benefit to the NDIA in doing this is that it also removes the requirement for that therapy to be properly funded - if there is no medical recommendation, there is nothing being overridden when the NDIA reduces the participant's allocated funding.

The NDIA are marketing this to participants as a "simpler" form of planning, but it also appears to be an attempt to evade the legislated requirement to properly fund those reasonable and necessary therapies that are required due to the person's disability.

People with Disability want consistency and fairness - but the proposed method WILL NOT achieve this.

One of the major hurdles with the NDIS is actually dealing with NDIA Planners and LACs **who make decisions that frequently violate the NDIS legislation**. This then results in people with disability not getting funding for the reasonable and necessary supports that they needed and that under the legislation were entitled to, and hence requesting a review of their plan. I've seen decisions being made such as not funding one support because they believe it will be covered by another support - but then not funding the other support either (so the required supports were denied based on the existence of a support that did not exist in the plan).

Other such decisions include ones for psychology as a disability support - NDIA Planners and LACs **routinely** specify that a participant must use the Mental Health Plan *for disability functional*

capacity building/daily living supports prior to being able to get support through the NDIS. This violates the NDIS legislation by:

1. Requiring the participant to pay a "gap", as the Mental Health Plan assistance from Medicare does not fully fund the appointment. This violates the NDIS Act section 34.1¹¹ legislation that specifies that reasonable and necessary disability supports must be fully funded, and the Federal Court Case McGarrigle v National Disability Insurance Agency [2017] Attachment 3.
2. Violates the NDIS Supports for Participants Rules 2013 legislation, Section 7.6-7.7¹², which *explicitly* states that disability functional support IS supposed to be funded by the NDIS:
Mental health

7.6 The NDIS will be responsible for supports that are not clinical in nature and that focus on a person's functional ability, including supports that enable a person with a mental illness or psychiatric condition to undertake activities of daily living and participate in the community and social and economic life.

7.7 The NDIS will not be responsible for:

- (a) supports related to mental health that are clinical in nature, including acute, ambulatory and continuing care, rehabilitation/recovery; or
 - (b) early intervention supports related to mental health that are clinical in nature, including supports that are clinical in nature and that are for child and adolescent developmental needs; or
 - (c) any residential care where the primary purpose is for inpatient treatment or clinical rehabilitation, or where the services model primarily employs clinical staff; or
 - (d) supports relating to a co-morbidity with a psychiatric condition where the co-morbidity is clearly the responsibility of another service system (eg treatment for a drug or alcohol issue).
3. Violates the NDIA's Planning Operational Guidelines, Section 10.8.2¹³ which not only states that it is supposed to be funded by the NDIS but that the supports should be fully funded by the NDIS:
10.8.2 Mental Health

The responsibility for which respective general system of service delivery is to take responsibility for different aspects of mental health support is subject to agreement between governments.

The NDIS will be responsible for supports that are not clinical in nature and that focus on a person's functional ability, including supports that enable a person with a mental illness or psychiatric condition to undertake activities of daily living and participate in the community and social and economic life (rule 7.6 of the Supports for Participants Rules).

11 <https://www.legislation.gov.au/Details/C2020C00378>

12 https://www.legislation.gov.au/Details/F2013L01063/Html/Text#_Toc358793045

13 <https://www.ndis.gov.au/about-us/operational-guidelines/planning-operational-guideline/planning-operational-guideline-deciding-include-supports-participants-plan>

NDIA plans are developed and approved to cover the full cost of supports (e.g. psychology services) where these are considered Reasonable and Necessary for the participant. The decision as to what capacity building supports or therapy would be deemed reasonable and necessary takes into account the responsibilities of the health system and services already available to the participant.

Once supports are approved in a plan the participant is able to use those supports as described in the plan. Therapy may be described generally (e.g. “Therapy up to the value of \$X”) in a budget so supports can be used flexibly within that budget or may be described specifically (for example, 1 session of psychology/therapy per week).

4. Violates the conditions of the Mental Health Plan. The Mental Health Plan is specifically for use for clinical treatment of mental illness, NOT for disability related functional capacity building.¹⁴

Mental health treatment plans

If you have a mental health disorder, you and your doctor can create a plan to treat it. Your mental health treatment plan will have goals agreed by you and your doctor. It’ll also have:

- * treatment options
- * support services available.

Keep in mind your health information and treatment plan will be private. Doctors can’t share your information unless you agree to it.

Mental health professional support

Your doctor can refer you to mental health professionals including:

- * psychiatrists
- * psychologists
- * counsellors
- * social workers.

You can read about the different types of mental health professionals on the healthdirect website.

You can also use their find a health service tool to find one near you.

Help with costs

A mental health treatment plan lets you claim up to 20 sessions with a mental health professional each calendar year.

To start with, your doctor or psychiatrist will refer you for up to 6 sessions at a time. If you need more, they can refer you for further sessions. Health professionals set their own fees, so we may only cover some of the cost. Ask how much you’ll pay and what you’ll get back from us when you make your appointment. If they bulk bill, you won’t have to pay anything. If you have private health insurance, you may be able to get some money back. You can check with your insurer.

5. Denies participants access to Medicare supports for the clinical treatment of mental illness during the year because they have been forced to misuse the Mental Health Plan for disability supports instead that were *legally the responsibility of the NDIS*. The NDIS does not fund supports for clinical treatment - but NDIA planners and LACs are frequently demanding that people use up their clinical treatment supports to provide disability functional capacity building rather than funding those reasonable and necessary disability

¹⁴ <https://www.servicesaustralia.gov.au/individuals/subjects/whats-covered-medicare/mental-health-care-and-medicare>

supports as legislated. *This means that a participant ends up having less access to standard Medicare supports for clinical treatment of mental illness than someone without a disability.*

It is decisions like these to sometimes fund disability supports, and sometimes refuse those same supports - even to the same participant from one year to the next - where **the NDIA are failing participants by failing to manage the NDIS according to legislated requirements.** The issue here rests *solely* in the inaccuracies and errors routinely made by planners and LACs in the NDIA. ***Independent Assessments will not change this.***

NDIA planners and LACs also frequently do not properly read documentation that is provided. As such, it is commonplace that requested supports are refused on the basis of the planner *not having read the reports/evidence provided where those supports were explicitly stated as essential due to the person's disability by medical professionals.*

Instead of promoting fairness in any way, the NDIA's proposals will:

- Deny People with Disability their rights under the UN Convention of the Rights of Persons With Disabilities.
- Deny People with Disability their rights under the International Covenant on Civil and Political Rights.
- Deny Women with Disability their rights under the Convention on the Elimination of All Forms of Discrimination against Women.
- Violate the Objectives and Principles of the NDIS Act 2013.
- Deny People with Disability their right to have their funding to be based on their actual disability support needs.
- Deny People with Disability their right to fair process in terms of an assessment that does not fairly reflect their actual capability.
- Deny People with Disability adequate funding for their disability support needs.
- Deny People with Disability access to funding that they have been approved for at the times of the year when they need it.
- Require People with Disability to take plans to the AAT in order to get any fairness *at all* if an independent assessment is inaccurate/flawed - increasing pressure on the AAT.
- Result in some People with Disability being denied any funding at all for 18 months to 3 years until their access termination external review is ruled on by the AAT on the basis of a functional assessment that *incorrectly* assessed that person as no longer meeting the requirements for NDIS access.
- Reset disability funding to what existed *prior* to the NDIS, destroying the NDIS in all but name.

These changes **do not** improve fairness for the participant. They are an attempt to gut the NDIS legislation and return to the older forms of funding which have already been shown to be more expensive long-term due to avoidable deterioration from inadequate levels of support. The proposed changes will see the end of what the NDIS was *supposed* to be.

What participants want is for **decisions to be fairly made based on the NDIS legislation.** Not on invented rules such as "if a disability support occurs at home instead of at the normal clinic/salon/gym/etc, it is no longer related to your disability in any way and therefore cannot be funded" (as I received recently). Not requirements to abuse Medicare Mental and Allied Health Plans for functional capacity building supports that are legislatively supposed to be funded by the NDIS. Not putting ALL supports in the category of "parental responsibility" even when they're far in excess of normal parental responsibility (e.g. what "normal" parent spends more than \$200 in fuel every week transporting their child to therapy appointments?). Not having recommended/required therapy supports denied on the basis of "no normal child

needs that much therapy" (no normal child qualifies for the NDIS either!). Not having recommended supports denied as "double funding" due to another support - but then not funding the other support either (so "no" funding rather than "double" funding, at which point the initial support ought to have been re-examined). Not having supports denied on the basis that the planner feels the person and their children should have to move out of the house that they have lived in for 20 years to get "cheaper access" to support. Not having mainstream supports denied - when more expensive services that exactly duplicate the mainstream support are approved instead (there is a **lot** of money wastage that occurs due to the NDIA enforcing "supports which are specifically disability supports" as opposed to "supports which are specifically required due to someone's disability" - the second is what the NDIS legislation requires and it *permits* the use of mainstream supports if those supports are specifically required due to the participant's disability, and which are generally less expensive than "disability-specific supports"!)). Not having supports denied based solely on prejudice and discrimination - that the planner believes that people with disability don't *deserve* to be supported to live a normal life, that consenting adults should be required to remain celibate if they require disability supports to engage in physical intimacy, that married couples are required to have separate single beds instead of sharing a double/queen sized bed due to disability needs. For the clarifications on the legislation as put forth by the AAT and the Federal Court to *actually be obeyed/used to inform decision making in other people's plans* (e.g. what constitutes an "everyday cost of living", transportation funding to be full funding not just a "contribution", requirement that someone with no medical training and who has never met or assessed the person with disability should not override the therapy recommendations of qualified medical professionals). For planners to actually *fully read* the reports/evidence that have been submitted in support of the participant's support needs.

If decisions were properly made based on the NDIS legislation and employed the results from past review decisions/AAT rulings/Federal Court rulings, many/most of the inconsistencies of one person being properly funded for a support while another with the same need and same level of evidence for the need was refused funding for the same support should be resolved.

I do agree that there **is** a valid use case for Independent Assessments in establishing functional loss for access - the reports required for NDIS access are extremely expensive to obtain, not all medical professionals are aware of what the NDIA require in order to be able to assess access, and not everyone can freely access someone to do a functional assessment. However, if someone has *already* had an assessment, why should it be required to be repeated?

The participant MUST have the right to refute an assessment with other evidence if that assessment is inaccurate/flawed - a right that the NDIA are proposing to explicitly deny.

Having your life for the next 5 years determined by a stranger you met for 1-3 hours and who did not assess your functional capacity fairly and whose assessment you cannot challenge or refute with other evidence, is an abuse of power and denial of any control over your own life.

The NDIA is proposing to deny participants the right for them to have their access and funding decisions to be based on a fair assessment of their functional capacity and their actual disability support needs. The proposed assessments are NOT full functional assessments, and will NOT provide the "holistic" view of the participant that the NDIA is claiming. This proposed process is procedurally UNFAIR.