



8 November 2021

Committee Secretary
Senate Standing Committees on Community Affairs
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Parliament House
Canberra ACT 2600

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Dear Sir/Madam,

We welcome the opportunity to provide feedback in relation to the Committee's inquiry into the *National Disability Insurance Scheme Amendment (Participant Service Guarantee and Other Measures) Bill 2021*.

Maurice Blackburn Pty Ltd is a plaintiff law firm with 33 permanent offices and 30 visiting offices throughout all mainland States and Territories. The firm specialises in personal injuries, medical negligence, employment and industrial law, dust diseases, superannuation (particularly total and permanent disability claims), negligent financial and other advice, and consumer and commercial class actions. The firm also has a substantial social justice practice.

For 100 years, Maurice Blackburn has worked with Australians who have suffered severe and catastrophic injuries, assisting them to access justice, compensation and support as they attempt to rebuild their lives. We assist them in navigating the law, social insurance schemes and private sector insurance. We engage with their families, friends and carers – as well as service providers – as they rally to assist our clients.

We have been regular contributors to the various inquiries relating to the development of the NDIS since its inception, dating back to the original Productivity Commission inquiry. We have also been advising clients and other stakeholders since the commencement of the Trial sites. All of our submissions are based on the lived experience of our clients, and the observations of Maurice Blackburn staff who work with them.

Many of Maurice Blackburn's clients are also NDIS participants and we have acted in a number of internal review and AAT appeals.

Maurice Blackburn provided a submission to the NDIS Act Review Consultations¹, when DSS released the exposure draft of the Bill, along with the accompanying proposed changes to NDIS Rules, last month.

In that submission, we highlighted two important short-comings in the drafts, specifically in relation to:

1. Variation of a participant's plan by CEO: and
2. Scheme Eligibility

While some adjustments have been made in response to concerns expressed by the disability sector², we remain concerned that the Bill poses significant risks to the health and financial security of participants, and to the integrity of the scheme.

Below, we draw the Committee's attention to our specific concerns, which have not been satisfied through the initial consultation period.

Please note that all references to 'the Act' are references to the *National Disability Insurance Scheme Act 2013*. References to 'the Bill' are references to the *National Disability Insurance Scheme Amendment (Participant Services Guarantee and Other Measures) Bill 2021*.

1. VARIATION OF A PARTICIPANT'S PLAN BY CEO

We refer in this section to the proposed provisions contained in sections 47A and 48 of the Bill.³

We are unable to see where, in the Tune recommendations, the need for this proposed power is drawn from. We are concerned that, without appropriate limitations, this power could be used to unilaterally alter the supports funded in a participant's plan and, by extension, unilaterally define or restrict what supports will be funded across the scheme.

We submit that this power is unnecessary and a justification has not been articulated. Further, if the CEO is to be given this power, three key limitations must be clearly articulated in the legislation:

1. The power can only be used with the consent of the participant, except in exceptional circumstances;
2. Where used in relation to the supports included in a participant's plan, the power must be subject to the 'reasonable and necessary' criteria set out in section 34 of the Act; and
3. Any use of the power must be subject to the internal review/external appeal process set out in sections 99 to 103 of the Act.

The need for these proposed limitations is detailed below.

¹ <https://engage.dss.gov.au/wp-content/uploads/2021/09/participant-service-guarantee-and-other-measures-ed-bill-2021.pdf>

² As detailed in the draft Explanatory Memorandum - https://parlinfo.aph.gov.au/parlInfo/download/legislation/ems/r6806_ems_0b91c1c4-78c6-45c4-814e-7b50fdb6f812/upload_pdf/JC003927.pdf;fileType=application%2Fpdf: p.9

³ https://parlinfo.aph.gov.au/parlInfo/download/legislation/bills/r6806_first-reps/toc_pdf/21154b01.pdf;fileType=application%2Fpdf: p.9

Use of the power only by consent or in exceptional circumstances

Section 47A of the Bill states that:

(1) The CEO may, in writing, vary a participant's plan (except the participant's statement of goals and aspirations) if the variation is:

- (a) a change to the statement of participant supports in the circumstances prescribed by the National Disability Insurance Scheme rules; or*
- (b) a correction of a minor or technical error; or*
- (c) of a kind prescribed by the National Disability Insurance Scheme rules.*

Each variation must be prepared with the participant.

(2) The CEO may vary the participant's plan on request of the 18 participant or on the CEO's own initiative.

We acknowledge that there will be circumstances where giving the CEO the power to vary a participant's plan may be appropriate – especially in circumstances where the changes are minor or typographical in nature, or the participant wishes to alter their stated goals and aspirations. However, in these circumstances, there is no reason for the CEO to exercise these powers without the specific consent and agreement of the participant.

Maurice Blackburn believes that the circumstances where the CEO should exercise the power to change a participant's plan without the participant's express consent should be limited to exceptional circumstances – such as when the participant cannot be reached to achieve his/her consent within a reasonable time.

We note the inclusion of the words: “*each variation must be prepared with the participant*”. While this is a welcome addition to the Bill (it did not appear in the exposure draft), it still fails to satisfy our concerns that the power could be used to unilaterally change a participant's plan. Having the variation ‘prepared with the participant’ implies that only consultation is required and does not actually preclude the CEO implementing whatever variations he/she sees fit. Wording such as “each variation must be made with the express and informed consent of the participant” would be more appropriate and allay concerns that this power could be used unilaterally to change a Participant's plan.

Further, clause 47A, as it is currently written, seems to give the CEO the authority to make changes to a participant's plan on his/her own initiative, without the need for a reassessment process. This is inappropriate.

Power subject to ‘reasonable and necessary’ criteria

When being used in relation to the supports in a participant's plan, the power must also be used subject to the ‘reasonable and necessary’ criteria enshrined in the Act.

The Bill as it stands creates an inexplicable inconsistency for participants when it comes to the formulation of their plans:

- Decisions about what supports are funded made by an NDIA planner must be made with reference to the ‘reasonable and necessary criteria’
- Decisions about what supports are funded made by the NDIA CEO can ignore the ‘reasonable and necessary’ criteria.

The 'reasonable and necessary' criteria are the pillar of scheme accountability and transparency. For a CEO to be able to ignore them when making decisions about funding amounts to an unfettered power to decide what supports are funded by the scheme.

Power subject to the internal review/external appeal process

External oversight of NDIA decisions is central to the scheme's credibility. Having legislation which exempts the CEO from that scrutiny is clearly unacceptable, and would undermine participants' trust.

Decisions using the proposed power must therefore be subject to the internal review and external appeal procedures already included in the Act. The most obvious way to do this would be by specifying that any decision made under section 47A and 47B is a reviewable decision listed in section 99 of the Act.

The Bill as currently drafted creates the same unjustifiable inconsistency outlined above:

- Decisions relating to what supports are included in a participant's plan made by a planner are subject to internal review and external appeal
- Decisions relating to what supports are included in a participant's plan made by the CEO are not.

It could be argued that the exercise of this power for any reason that already gives rise a reviewable decision under section 99 of the Act would enliven the review and appeal process. Legally, this is far from clear and would lead to unnecessary uncertainty and confusion. Unless there is a specific intention for the proposed power to not be subject to the review and appeal provisions, there is no reason not to categorise it as a 'reviewable decision' to avoid any doubt about the status of decisions made under the proposed sections 47A and 47B.

Summary

In summary, Maurice Blackburn does not believe that the proposed changes and Rules provide the necessary protection and limitations on the proposed CEO power. Section 47A (6) notes that:

(6) The National Disability Insurance Scheme rules may set out matters to which the CEO must have regard:

(a) in deciding whether to vary a participant's plan on the CEO's own initiative; or

(b) in doing a thing under subsection (4).

On our reading, the relevant draft Rules⁴ (which as far as we know have not been adjusted since the initial consultation process) do not limit the CEO's powers at all and the amendment to require that "each variation must be prepared with the participant" can only be described as a legal platitude.

Without the three limitations outlined above, the proposed changes would give the CEO the power to unilaterally alter Participants' plans. In practice, this would also give the CEO power to make unilateral decisions about what supports will be funded across the scheme. In this sense, there is little to distinguish this amendment from the previously reported proposal to

⁴ <https://engage.dss.gov.au/wp-content/uploads/2021/09/plan-admin-rules.pdf>: Rule 10: p.4

give the Federal Minister power to determine what supports should be funded by the Scheme.

Maurice Blackburn would prefer that Rule 10 clearly state that:

- The exercise of the power generally be limited to circumstances where the participant has given consent;
- The exercise of the power to vary a participant's plan on the CEO's initiative without consent should be limited to very specific circumstances (and list those circumstances);
- The exercise of this power (insofar as it is exercised to approve/deny funding for supports in a particular case) should still be subject to the 'reasonable and necessary' criteria; and
- The exercise of the power is a 'reviewable decision' for the purpose of section 99 of the Act.

Immediately following the 2019 Federal election outcome, the Prime Minister said:⁵

Every single Australian with a disability needs a bespoke approach, their challenges are different and they must be recognised as different. You can't take a cookie-cutter approach to this....and we need to have a system that can address that.

The Prime Minister's statement is an articulation of something fundamental to our clients and all people with disabilities. The draft legislation, in its current form would permit of the NDIA making decisions, in pursuit of economies, which foster higher numbers of formulaic and minimalist outcomes for participants. Those outcomes are entirely inconsistent with the principles espoused by the Prime Minister.

2. SCHEME ELIGIBILITY

Maurice Blackburn notes the stated purposes underpinning the proposed changes to eligibility criteria:⁶

The changes to the National Disability Insurance Scheme (Becoming a Participant) Rule 2016 will clarify when a person's impairments are, or likely to be permanent, for the purposes of the disability or early intervention access requirements. The Rule will ensure people with psychosocial disabilities are supported to access and test their eligibility for individually funded supports under the NDIS, by recognising that some psychosocial conditions may be episodic and fluctuating in nature. The revised Rule will also reflect best practice drafting standards.

Maurice Blackburn applauds the intention of providing greater clarity around how NDIS eligibility criteria are interpreted and put into practice.

⁵ <https://www.pm.gov.au/media/press-conference-canberra-3>

⁶ <https://engage.dss.gov.au/proposed-ndis-legislative-improvements-and-the-participant-service-guarantee/changes-to-the-becoming-a-participant-rule/>

We are concerned, however, that the provisions currently contained within the draft *National Disability Insurance Scheme (Becoming a Participant) Rules 2021*⁷ may actually reduce clarity. More importantly, in practice, they could also further restrict eligibility and access.

Disabilities other than psychosocial

The draft Rules propose to replicate the current Rules relating to permanency, which state that an impairment can only be considered permanent if:

...there are no known, available, and appropriate evidence-based clinical, medical or other treatments that would be likely to remedy the impairment.

Maurice Blackburn has significant reservations about the construction of the current Rules and, by extension, about the proposed Rules. Our experience is that the interpretation of 'permanency' by the Agency at times is inconsistent, unfair and simply wrong, and is the source of significant disputes in both internal review and the AAT.

Our experience appears to be reflected in the wider disability community. We note that the Joint Standing Committee on the NDIS discussed the issues around permanency in its General Issues report of December 2020.⁸ The Committee reported that:

*The committee heard that there are a number of concerns relating to how the definition of 'permanent' impairment is applied in access processes. Evidence also indicated that people living with particular disability types are experiencing difficulties accessing the scheme, as the NDIA considers that their condition requires medical intervention, not disability support.*⁹

We also note that the Committee also heard significant evidence¹⁰ around the inappropriateness of independent assessment processes for people with neurological conditions.

Given the issues highlighted in our submission, to simply replicate the current Rules for all disabilities other than psychosocial will do nothing to improve clarity, certainty and fairness for NDIS applicants.

A key problem is that none of the relevant terms is currently defined in the Act or Rules, nor are they defined in Section 6 of the proposed Rules. This leaves them open to interpretation and dispute. More importantly, we also believe that the construction of this Rule can be used to unfairly restrict access to the scheme and even force applicants to undergo medical treatment that they otherwise would not in order to access the scheme.

We detail our concerns below:

Requirement to undergo treatment

The Rules can effectively force some applicants to undergo treatment in order to satisfy the permanency and reduced functional capacity requirements.

⁷ <https://engage.dss.gov.au/wp-content/uploads/2021/09/becoming-participant-rules-final-0.pdf>

⁸ https://www.aph.gov.au/Parliamentary_Business/Committees/Joint/National_Disability_Insurance_Scheme/GeneralIssues/Interim_Report: see from 6.5, p.121

⁹ Ibid: paragraph 6.19, p.125

¹⁰ See for example:

https://parlinfo.aph.gov.au/parlInfo/download/committees/reportjnt/024622/toc_pdf/IndependentAssessments.pdf;fileType=application%2Fpdf: paragraph 6.41, p.103

Both the current and proposed Rules state that an impairment can only be considered permanent if:

...there are no known, available, and appropriate evidence-based clinical, medical or other treatments that would be likely to remedy the impairment.

The construction of the Rule focuses only on the *availability* of treatments in determining whether an impairment is permanent and does not consider the applicant's wishes. It would therefore allow the Agency to deny access even if the applicant did not wish to undergo the treatment in question. Put another way, applicants could be forced or pressured to undergo treatment they otherwise would not in order to access the scheme. Anecdotally, we have seen this occur in practice and it is an entirely unacceptable situation.

It could be argued that an applicant would not be *forced* to undergo treatment because they could simply elect not to enter the scheme. We suggest that this is an unreasonable distinction, particularly given care and supports can be absolutely essential for people living with disabilities and the scheme is the only source of funding.

Decisions relating to the appropriateness of any treatment, and whether they wish to undergo that treatment, must only be made by an individual on advice from an appropriately qualified medical professional (most appropriately the applicant's own treating doctors). The freedom to control one's own health and body, and the freedom from interference, are basic human rights.

'Likely to remedy the impairment'

This phrase is central to the construction of the Rule but 'likely' and 'remedy' are not defined.

Is, for example, improvement in an impairment such that is now defined or named differently mean that the original impairment has been 'remedied' even if there is still a residual impairment?

There is also no timeframe specified in which the remedy should take place. The Rules allow the Agency to deny access until any treatment has been exhausted but, for some conditions, it can take years for rehabilitation to finish and the true nature and impact of the condition to become known (for example, following a stroke). It would be grossly inequitable to deny such people access to the scheme in these circumstances.

Further, the use of the word 'impairment' to assess permanency, rather than the illness or disability itself, is problematic. The ordinary meaning of 'impairment' in this context is the practical impact of an injury, disability or illness on an applicant's functional capacity. We submit that this is clearly different from the underlying injury, illness and/or disability itself.

This distinction between functional impairment and the underlying disability or illness seems to be confused by the Rules (see, for example, the description of Alzheimer's disease as an 'impairment'¹¹). However the distinction is crucial, particularly in the context of degenerative and/or fluctuating conditions. Such conditions are often characterised by transient 'attacks' where symptoms and functional impairments are exacerbated. These transient attacks (and the resulting impairment) *may* be temporarily remedied through treatment, meaning they would not meet the permanency criteria in the proposed Rules. For example, a relapse in Multiple Sclerosis symptoms (and by extension the associated *impairment*) is treatable, Multiple Sclerosis itself is incurable.

¹¹ <https://engage.dss.gov.au/wp-content/uploads/2021/09/consultation-becoming-participant-explanatory-statement-1.pdf> at page 7

It would be inappropriate to deny such people access to the scheme as supports are required to manage the impact of their impairments, even if fluctuating, particularly given the underlying disability or illness (as opposed to the impairment) is invariably incurable and degenerative. The concept of 'permanency' must allow for flare-ups, fluctuations, periods of stability, and periods of decline. Support needs are not linear, and the nature of the condition establishes over time – but this does not mean that permanency should be seen as questionable.

Denying people with these degenerative conditions access to the scheme in the early stages of their illness, when the functional impairment could improve with treatment, may also mean that they do not satisfy the permanency requirements until their condition progresses and more permanent and severe impairments emerge, at which point they risk not being eligible due to the age criteria.

We acknowledge that there have been some protections inserted to ensure that people with conditions involving fluctuating symptoms can still access the scheme (for example, section 24(2) of the Act). However, these protections do not guarantee access for people with incurable degenerative conditions.

The likelihood of a particular treatment succeeding (*'likely to remedy the impairment'*) is also a crucial part of the proposed criteria but 'likely' is not defined. This phrase invokes the legal test of 'balance of probabilities', which asks whether a certain outcome is 'more likely than not' or, put another way, whether there is a 51% chance or greater. Without clarification in the Rules or Act, it would seem reasonable to assume that the Agency or subsequent Tribunal/Court would adopt this construction.

The consequence of this would be that the availability of treatments whose efficacy may be barely more than a 50/50 would be enough for the Agency to conclude that an impairment is not permanent and deny access to the scheme. In practice, this could force people to undergo treatment with limited efficacy, treatment that comes with its own risks and complications, in order to access the scheme.

'Appropriate evidence-based treatments'

The Rules do not articulate who decides what is appropriate treatment, nor what evidence they must use to justify that decision. If decisions on the appropriateness and availability of treatments are to be made by the NDIA, it would create a situation where untrained public servants can undermine or overrule the advice of medical professionals.

Maurice Blackburn has seen numerous examples of Agency planners, few of whom are medically trained, making ill-informed and wrong decisions about the availability of treatment and denying access on that basis.

This is an area of significant dispute and inequitable outcomes and we submit that it is inappropriate to simply replicate the old Rule in the new.

It would be incorrect to suggest that such occurrences are rare, or could be remedied through the appeal and review process. Participants find the review and appeal process inaccessible and one-sided. Many do not pursue their rights, regardless of how wrong an Agency decision is.

It cannot be seen as an effective remedy to poor Agency decision making and the source legislation and Rules must be carefully drafted to minimise the risk of incorrect decisions.

Psychosocial disabilities

In relation to psychosocial disabilities, the draft Rules state:

- (2) *The impairment may be considered permanent, or likely to be permanent, only if:*
- (a) *both:*
- (i) *the person is undergoing, or has undergone, appropriate treatment for the purpose of managing the person's mental, behavioural or emotional condition; and*
 - (ii) *the treatment has not led to a substantial improvement in the person's functional capacity, after a period of time that is reasonable considering the nature of the impairment (and in particular considering whether the impairment is episodic or fluctuates); or*
- (b) *no appropriate treatment for the purpose of managing the person's mental, behavioural or emotional condition is reasonably available to the person.*

'Substantial Improvement'

The Rules do not articulate what is meant by 'substantial improvement'.

The Rules do not describe any way of measuring 'improvement', let alone 'substantial'. Is, for example, moving from 'acute' to 'significant' impairment a substantial improvement?

Further, while the Rules purport to set a timeframe over which this improvement will be assessed, we submit that the use of the 'reasonable' is vague and uncertain and open to interpretation. For many psychosocial conditions, treatment can be a lengthy process, requiring different approaches before improvement is seen. In these circumstances, applicants could be denied supports in the meantime, regardless of the severity of their impairment. Greater certainty about the relevant timeframe is therefore required.

'Appropriate Treatments'

The Rules do not articulate who decides what is appropriate treatment, nor what evidence they must use to justify that decision. There is nothing that ensures that the applicant's views or wishes should be considered.

If decisions on the appropriateness of treatments are to be made by the NDIA, it would create a situation where public servants are undermining the advice of medical professionals. This is obviously an unacceptable outcome and is particularly relevant to many psychosocial disabilities, for which there may be a number of different treatment options, some of which carry the risk of significant side effects.

To illustrate this point, it is helpful to consider the example of Electroconvulsive Therapy (ECT). This is a widely available and appropriate form of treatment for some psychosocial illnesses. It is also one that carries the risk of a number of complications, including memory loss and brain injury. Under the proposed Rules, the Agency could arguably conclude that the permanency requirement had not been satisfied because ECT is an available and appropriate treatment, regardless of whether the applicant wanted to undergo that treatment.

As we have outlined above, decisions about the appropriateness of treatment must only be made by the individual on the advice of an appropriately qualified medical professional, most appropriately the person's treating doctors.

The eligibility criteria should not lead to circumstances where a participant is coerced to undertake an NDIS prescribed treatment in order to gain access to the scheme. This, in our view, would be contrary to the choice and control philosophy that forms the basis of the NDIS and is contrary to well-established human rights principles.

Other matters

On a side issue, we note that one of the concerns expressed during the initial consultation process¹² was:

There was concern that the four week consultation period was insufficient.

Maurice Blackburn submits that the short time frame that has been allocated for this Committee to properly assess and consult on the draft legislation not only reinforces the concerns expressed to DSS, but is highly disrespectful to people with disability and the sector which supports them. It falls well short of displaying a genuine commitment to consultation and the principles of co-design.

Please do not hesitate to contact me and my colleagues on _____ or at _____
if we can further assist with the Committee's
important work.

Yours faithfully,

Principal Lawyer
MAURICE BLACKBURN



¹² As detailed in the draft Explanatory Memorandum - https://parlinfo.aph.gov.au/parlInfo/download/legislation/ems/r6806_ems_0b91c1c4-78c6-45c4-814e-7b50fdb6f812/upload_pdf/JC003927.pdf;fileType=application%2Fpdf: p.9