Committee Secretary Senate Standing Committees on Community Affairs PO Box 6100 Parliament House Canberra ACT 2600



**Dear Committee Secretary** 

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

Thank you for this opportunity to make a submission to the consultation process on the National Disability Insurance Scheme Amendment (Getting the NDIS Back on Track No. 1) ("the Bill").

I am Professor of Public Service Research at the Public Service Research Group, University of New South Wales Canberra. I have expertise in policy design and implementation with a particular interest in disability policy and services. I have undertaken several research studies examining the implementation of the NDIS in terms of market stewardship, the role of registration, plan utilisation rates, disability employment, COVID responses and the NDIS, experiences of disabled children and young people within the scheme and the challenges and complexities for formerly incarcerated people in accessing the scheme. I have published 41 peer reviewed journal articles on these topics and broader disability policies and services and many more reports, newspaper columns and articles in publications such as The Conversation and Mandarin. I was also a member of the working party that established the National Disability Research Partnership.

I have a number of concerns relating to the legislation as it currently stands and the belief that it has the potential to detrimentally impact current and future participant experiences of the scheme and the supports that they receive. Moreover, some of these changes may also be counterproductive to the efficiency of the scheme. Some of these changes would put the scheme at odds with the growing international evidence base about what is needed to make individual funding schemes for disability effective and efficient. Below I outline specific concerns alongside recommendations that should mitigate these.

## Co-design of reforms

The NDIS Review states that changes to the NDIS must be genuinely co-designed with people with disability. However, there has yet to be a Government response to either the NDIS Review or the Disability Royal Commission findings. Despite this lack of formal response or the publication of an implementation plan, the Bill suggests that legislative reform has started and the implementation process has begun. This stands in contrast to commitments to co-design of the scheme. This Bill lacked co-design with the disability community and an exposure draft for comment from the sector. Furthermore, the short timeframe of this inquiry means that people with disability, their families and representative organisations need more time to engage and understand these reforms. This is particularly the case for individuals with disability who are significantly marginalised and who often encounter barriers in having their voices heard.

As previous reform efforts within the NDIS have demonstrated, a lack of co-design can lead to changes either not having their intended impacts or having unintended consequences as they do not fully take into consideration all potential factors within the lives of scheme participants. Moreover, co-design efforts should meaningfully engage a broad range of individuals with different impairments, culturally and linguistically diverse populations, those living in rural and remote areas, Aboriginal and Torres Strait Islander people, those from the LGBTQIA+ community and other marginalised groups. Through meaningful co-design process it can be ensured that any changes will have their desired impact and not generate any potential unintended challenges for participants.

**Recommendation 1:** The Bill should be amended to incorporate a requirement that people with disability and their representative organisations are meaningfully involved in codesigning and implementing NDIS reforms. This should also involve adequate time and resourcing and include those groups that are too often unheard.

#### Needs assessment

As outlined in Section 32(IL), those that meet the eligibility criteria will undergo a needs assessment to determine funding in their NDIS Plan. While the move away from reliance on medical diagnoses is welcome, it is important that this is done in a holistic way at a 'whole of person level', drawing on information from a range of sources. This is important to get a holistic picture of an individual's life, and particularly so for individuals with complex or multiple disabilities. It is important that the needs assessment process is flexible and there is not a one-size-fits-all process. Different individuals will need to rely on different sets of evidence so the same sorts will not be able to be sought from each individual. It will be crucial to engage with existing health and allied professionals who often have long and trusted relationships with individuals and understand their lives.

As set out in the Explanatory Memorandum, the needs assessments tool(s) will be highly technical and developed in consultation with the disability community, medical and professional experts, and international learning and best practice. These tools do not currently exist and were a key cause of contention in discussions about the previously shelved Independent Assessment processes. Despite significant research into this issue in Australia and Internationally over the last few decades these tools have not been developed. Neither are any of the existing tools designed to determine appropriate funding. People with disability are a highly diverse group in terms of not only disability but a number of other intersectional issues. Some of the existing tools that do exist are not culturally safe for minority groups and careful consideration will need to be given in terms of how to achieve this. In the UK, the National Audit Office found in a study of the practices of the Department for Work & Pensions, which administers Personal Independence Payments (a benefit to support independent living for disabled people), that "functional health assessments are inherently judgement-based resource-intensive and difficult to administer consistently". This will not be an easy process for the NDIS to get right and will take some time to do well. It cannot be done without the engagement of people with disability, their families and allies and representative organisations.

There is a risk that these tools could be overly complicated and significant testing needs to be done to ensure that these are accurate, reliable and are accessible to individuals with a wide range of communication, literacy, language and cultural needs. One way to ensure the accuracy of these tools is to provide a copy of this to the individual. There is a proposal in the current Bill that this be given to the NDIA Chief Executive (32L(5)), but not to give a copy to the individual. This undermines both the transparency of the process and also the opportunity to check for accuracy. Providing this opportunity would likely reduce requests to fix errors through appeals once an individual receive a plan. Those involved in assessing needs will need to have not only appropriate qualifications but also the ability to undertake

assessments in a culturally sensitive and informed way. These requirements are not currently stated in the Bill.

The Bill does not state that the decision of the NDIA to rely on a needs assessment report in preparing a statement of supports as a reviewable decision. This means there is also a lack of a mechanism for decisions to be internally reviewed by the Agency (Section 99). There should be a clear provision within the legislation to allow individuals to appeal if a needs assessment has been of poor quality. Without there is a lack of ability to refer to the Administrative Appeals Tribunal for external review.

**Recommendation 2:** Amend subsection 32L(3) to acknowledge that assessment of support needs will be done on a holistic basis.

**Recommendation 3:** Include a legislative requirement for assessment tools to tested with the disability community including disability representative organisations, families and supporters and service providers.

**Recommendation 4:** Amend subsection 32L(5) requiring draft needs assessments to go to individuals and allow them to request changes before this is provided to the Chief Executive.

**Recommendation 5:** Include a statement about the required skills and qualifications of assessors.

**Recommendation 7:** Amend section 99 to include the decision to rely on an individual's needs assessment report to prepare a statement of participants supports as a reviewable decision.

# **NDIS Supports**

The changes to NDIS Supports are being made to allow individuals more flexibility to determine their supports, given that people with disability know their own support needs and are best placed to determine how to meet these needs. But some of the changes to clarify what constitutes permitted supports may serve to reduce flexibility. There is potential that in seeking to provide lists of what is and is not permitted might reduce opportunities for innovation, reduce independence of individuals and increase costs of supports. The Explanatory memo gives examples of items such as whitegoods. Many people with disability rely on different technologies to support them in their lives. It is likely that this will expand, rather than contract in the future. In the absence of being able to purchase these items, individuals may have to rely on support workers to undertake tasks, which has implications for independence and is likely more costly over the long term. Examples of this are provided in a piece I wrote for the Conversation. This issue is not simply restricted to whitegoods but also other examples cited in the explanatory memorandum.

International evidence suggests that the more narrowly that supports are prescribed and the less control afforded to people with disability to identify supports, the more costly and less appropriate supports become. In Control, a UK charity supporting individuals with disability and individualised budgets, has many examples of how creative supports can be more individualised and more efficient. The definition of supports must be sufficiently broad to allow individuals flexibility alongside individual choice and control and not increase costs.

The Applied Principles and Tables of Support (APTOS) are outlined in the new Part 3 (2) and (3) as being used as an interim measure to determine what is an NDIS Support until the new NDIS Rules are developed. These were never designed to be added into legislation and in some places are contradictory to the Bill (e.g. in terms of responsibilities for rehabilitation).

For those individuals with complexities surrounding their lives and support needs there is growing evidence to suggest that confusion over responsibilities for funding of services can lead to individuals having to undertake significant work to establish supports or go without supports (e.g. formerly incarcerated people, children and young people, and people with health needs) This risks individuals falling between gaps with the NDIS and States and Territories not assuming they have responsibility for these supports. This is particularly problematic while Foundational supports are not in place at this stage.

**Recommendation 8:** Amend section 10 to require that NDIS Rules should be sufficiently broad to allow for flexibility and for individuals to assume choice and control, in line with the interpretation of reasonable and necessary in Section 34 of the existing NDIS Act.

**Recommendation 9:** Do not use APTOS tables as an interim measure and develop more appropriate provisions while the NDIS Rules are being developed.

### Changes to budgets

As well as sending needs assessments to individuals to check for inaccuracies, there is a need to send a draft budget to the individual. There is no requirement in the Bill for this process to take place. This is likely to lead to higher volumes of requests for internal and external reviews of decisions.

The Bill outlines that there is to be more flexibility in spending of budgets, that do not fall under stated supports. While this is welcome, some constraints set out in Section 32 may constrain flexibility. As outlined in 32F(2) and 32G(3) there will be funding periods introduced, meaning that total funding over the period of the plan will be assigned to defined periods. This is explained as needed to add safeguards if there are concerns around an individual's safety and to deal with 'intraplan inflation', where an individual requires additional funding before the end of their plan having exhausted this. In many international individual funding plans, exhausting plans before their end is typically seen as indicative of an insufficient budget being assigned in the first place (see international study of <a href="Utilisation rates study">Utilisation rates study</a>). Furthermore, individuals do not always experience disability in a consistent way and there may be episodic aspects to their experience. This may mean that participants have good reasons to need some elements of funding at some times and less at others. This could put some participants at risk.

Section 32(H) sets out further restrictions on requirements for spending. These may include receiving services from particular providers or meeting specific procedural criteria before funds can be used. This may restrict flexibility and have particular implications in areas where there are thin markets, such as in regional or remote areas. The issues that this section addresses could instead be dealt with through allocation of stated supports.

It is essential that to ensure that budget approaches are effective and do not have unintended consequences that the method is developed and tested with a broad range of people with disability.

**Recommendation 10:** Add a provision to the Bill to require the NDIA to send a draft budget to an individual before it is finalised. There also needs to be mechanism that allows for this to be changed if it has incorrect or inaccurate information.

Recommendation 11: Amend Section 32 to allow for greater flexibility in spending.

Recommendation 12: Remove Section 32(H).

**Recommendation 13:** The budget approach is developed and tested with a broad range of diverse people with disability.

New powers for the NDIA

The Bill sets out a number of new plans that give the Chief Executive of the NDIA to make decisions about plan management preferences and to revoke NDIS status. In both cases there is a lack of clarity about the situations in which these decisions might be taken.

Subsections 443(2A), (2B), 2(C) and 2(D) allow for the Chief Executive not to comply with an individual's plan management requests for new framework plans. This is explained as being needed to safeguard participants, but it may potentially have adverse impacts for some if used inappropriately. The proposed circumstances are outlines in 43(2C), but the Bill lacks clarity over these circumstances and the tests for determining these. This allows significant discretion to the Chief Executive that potentially removes opportunities for choice and control over plan management. While I appreciate the need for safeguarding, the Bill would benefit from more clarity over how these criteria will be tested.

Subsections 30 and 30(A) allows the NDIA to demand information from an individual or require them to undergo a health assessment if they are considering removing them from the scheme. If this information is not provided in 90 days the Chief Executive may revoke their status, should they not be satisfied that it was reasonable the request was not complied with. There is risk that an individual might not be able to access this information in time and may lose NDIS supports. We have seen examples of individuals experiencing harm when NDIS supports have been cut off, such as happened in the case of <a href="David Harris">David Harris</a> who died when payments were cut off. Greater clarity over what comprises reasonable grounds would help in providing certainty to participants over the circumstances in which these powers may be enacted.

**Recommendation 14:** Detail what test will be used to determine whether the criteria have not been complied with and what non-compliance with section 46 entails.

**Recommendation 15:** Amend 30A to clarify what comprises reasonable grounds for an individual not complying with the Chief Executive's request for information.

As outlined above, I am concerned about a number of elements of the Bill and believe it could restrict the choice and control of individuals, which has always been a core component of the scheme. This seem short-sighted given the evidence base that suggests choice and control is essential for individuals to enable flexibility to individual circumstances and aspirations, to allow for innovation and importantly to manage costs within the scheme. Securing a clear commitment to the co-design of any these changes with people with disability, their families and disability representative organisations should ensure that they operate in intended ways that will not be detrimental to the well being of NDIS participants.

I welcome the opportunity to provide any further assistance or input going forward.

Yours sincerely,



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