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

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The Neurological Alliance Australia is an alliance of 22 not-for-profit peak or national patient organisations representing adults and children living with progressive neurological or neuromuscular diseases or neurological disorders in Australia. The Alliance was established to promote improved quality of life for people living with these conditions and increased funding to support research. Members of the Alliance are: the Brain Foundation, Brain Injury Australia, the Childhood Dementia Initiative, Dementia Australia, Emerge Australia, Epilepsy Australia, Epilepsy Foundation, Fragile X Association of Australia, Huntington's Australia, Leukodystrophy Australia, Migraine Australia, the Mito Foundation, MJD Foundation, Motor Neurone Disease (MND) Australia, MS Australia, Muscular Dystrophy Australia, Muscular Dystrophy Foundation Australia, Myasthenia Alliance Australia, Parkinson's Australia, Polio Australia, Spinal Muscular Atrophy Australia and the Stroke Foundation.

Some NAA members are providers under the NDIS, offering support coordination, allied health and/or other supports. Most members provide information and navigation services funded through separate sources such as fundraising and philanthropy.

Overseas studies indicate as many as 1 in 3 people live with a neurological condition, the leading cause of illness and disability worldwide¹, with an annual impact on the Australian economy of over \$100 billion².

These conditions represent around 14% of NDIS participants³.

According to the AIHW Australian Burden of Disease Study 2023, neurological conditions are one of the five leading disease groups causing burden in 2023⁴.

¹<https://www.who.int/news/item/14-03-2024-over-1-in-3-people-affected-by-neurological-conditions--the-leading-cause-of-illness-and-disability-worldwide>

² Based on an aggregation of data from organisations who have commissioned economic impact studies

³ Based on an aggregation of neurological 'primary disability groups' in the NDIS quarterly reports

<https://www.ndis.gov.au/about-us/publications/quarterly-reports>

⁴ Retrieved from Australian Burden of Disease Study 2023, About - Australian Institute of Health and Welfare (aihw.gov.au)

Introduction

The Neurological Alliance Australia (NAA) is pleased to provide a submission to the NDIS Amendment (Getting the NDIS Back on Track No. 1) Bill. This submission focusses on the key areas that will impact people affected by the conditions represented by the members of the NAA.

The NAA was established in 2010 to promote improved quality of life, coordinated services and greater research investment in these conditions that have no cure. This group includes adults and children, carers, families, friends and workmates whose lives have been affected by a progressive neurological or neuromuscular condition or a neurological disorder. The impact of neurological disorders and progressive neurological and neuromuscular conditions on individuals and families can undermine their resilience, which is a vital element of their ability to remain purposeful and in control of their lives in addition to preventing or minimising financial and emotional burden.

Progressive neurological and neuromuscular diseases and neurological disorders are a set of complex and disabling conditions often resulting in severe functional impairment. While this broad group contains conditions with various characteristics, different disease trajectories and life expectancy, nearly all are degenerative, all are incurable and few have proven treatments. This results in significant disability and the need for expert information, specialised care and personal assistance which is responsive to individual needs.

Recommendations

The NAA recommends that:

1. A statement be included in the amended Bill to ensure that the new, and any future, NDIS rules will be designed and implemented with extensive consultation and co-design with the disability community.
2. The draft Rules are released for consideration as a matter of urgency.
3. The fundamental aspects of the NDIS such as those related to access, assessment, supports and the early intervention pathway be enshrined in the legislation rather than left to rules and determinations.
4. Any assessment methodology acknowledges the complexity of progressive conditions and incorporates provisions for anticipating future needs.
5. Provision for exemptions to blanket rules for supports, such as those pertaining to standard household appliances, should be made, based on a person's unique needs or specific circumstances.
6. Explore mechanisms that facilitate proactive and responsive adjustments to plans when needed, without imposing undue administrative burdens or delays.
7. Provide clarity regarding the professionals responsible for conducting assessments requested by the NDIA and reassess the feasibility of the 28-day

timeframe for building a new framework plan; consider extending it to allow participants sufficient time to gather and submit requested information without undue pressure.

8. Consider establishing a specialised workforce within the NDIA specifically trained and with significant experience to cater to clients with progressive and rare neurological conditions.

Overall changes

The amended Bill includes the most significant changes to the NDIS since it commenced in 2013. This includes how participants access the Scheme and how their support needs will be assessed, monitored, modified and funded. For example, the amended Bill introduces “needs assessments”, “framework planning” and “flexible” budget-setting and tightens the kinds of supports the NDIS will fund.

The amended Bill relies heavily on new NDIS Rules (including detail regarding how participants gain access to the Scheme, what supports the NDIS will fund and how participants can spend their NDIS funding) and a range of legislative instruments made by the Minister (called ‘determinations’) that will determine the method for calculating budgets and how needs assessments are conducted.

This gives the Minister significant power with limited oversight by Parliament.

The Government has not released drafts of these Rules or determinations so the details of what they will include, and the practical impact on participants, remains unknown. It will be essential that they are developed in close consultation with people with disability.

Recommendation

- 1. A statement be included in the amended Bill to ensure that the new, and any future, NDIS rules will be designed and implemented with extensive consultation and co-design with the disability community.**
- 2. The draft Rules are released for consideration as a matter of urgency.**
- 3. The fundamental aspects of the NDIS such as those related to access, assessment, supports and the early invention pathway be enshrined in the legislation rather than left to rules and determinations.**

Planning process including “needs assessments”

The amended Bill will change the existing line-by-line planning process. Previously, planners or Local Area Coordinators would review health care professional’s reports and assess the need for each individual support against the “reasonable and necessary” criteria in the existing legislation (section 34(1)). A dollar amount would be allocated to each support category and create total funding amounts in the plan against Core, Capacity Building and Capital categories.

Under the amended Bill, budgets will be created using a needs assessment and a budget methodology, yet to be developed. The outcome will be called a 'reasonable and necessary budget.'

The amended Bill allows the Minister to determine assessment methodology by legislative instrument (that is, Rules) including:

- assessment tools to be used in undertaking a needs assessment
- requirements for undertaking assessments (such as the skills and qualifications of assessors)
- information that must be included in a needs assessment report, and
- requirements that the needs assessment report must satisfy (including matters that must be set out in the report).

The Explanatory Memorandum says that for the purpose of informing funding decisions, the needs assessment tool (or tools) will be highly technical and developed in consultation with the disability sector and medical and professional experts.

It is not clear how these tools will be validated and whether these will be useful for people with progressive conditions.

Progressive conditions present unique challenges in accurately assessing needs and projecting future support requirements. Unlike static disabilities, the dynamic nature of progressive conditions necessitates a nuanced approach that considers fluctuating levels of functionality over time. It is crucial that any assessment methodology acknowledges this complexity and incorporates provisions for anticipating future needs.

Currently, people with progressive conditions encounter obstacles in accurately identifying their primary disability and articulating their evolving support needs. While medical and allied health reports are submitted during the access request process, there is uncertainty about how these are used by planners or Local Area Coordinators (LACs). This discrepancy between information provided and how it is applied in the planning process is leading to inadequate support allocations and unmet needs.

Without clear guidelines on how assessment tools will be used for people with progressive conditions and account for future support requirements, there is a risk of exacerbating existing challenges. Therefore, it is imperative that the development and validation of these tools prioritise input from people with lived experience of progressive conditions and incorporate mechanisms for ongoing review and adaptation.

Recommendation

- 4. Any assessment methodology acknowledges the complexity of progressive conditions and incorporates provisions for anticipating future needs.**

New framework plan

The amended Bill introduces a new ‘framework plan’. These plans can have two parts:

1. “Flexible supports” (that can be spent on supports of the participant’s choice as long as they are deemed to be within the scope of disability supports relevant to the participant’s impairment and meet the support criteria in Section 10). There will be a funding period set for the use of flexible supports (usually 12 months and this time period can be shorter than the plan itself), unspent funds in this part of the plan can be rolled over to another time period in the same plan. This is to reduce overspending in plans that results in participants running out of funds early.
2. “Stated supports” will generally be higher cost capital items or a class of supports for which a provider can be specified, or for which a quote is needed.

A legislative instrument – or Rules - will further explain how new framework plans will roll out, though these are not yet available.

We are hopeful that this change will lead to greater flexibility for people with progressive neurological conditions. We look forward to working together to ensure this is realised as the Rules and operating procedures are developed.

Flexible and fixed budgets

Under the new framework plans, a person will receive a flexible budget and a fixed budget. These changes aim to dissolve the rigid categories within a budget. For example, a person with plan-managed core consumables funding cannot currently use it on a capacity building support such as physiotherapy. Under the amended Bill, it is expected that flexibility will be extended. There will be limits and exceptions though, for example the NDIA could restrict flexibility where there is risk of harm to the person or if the support is a “stated support”.

We are hopeful that this change will lead to greater flexibility for people with progressive neurological conditions. We look forward to working together to ensure this is realised as the Rules and operating procedures are developed.

Defining an NDIS support

The amended Bill creates a definition of an NDIS support which will ultimately determine how the NDIA arrives at a funding amount, how people can spend their packages, whether the NDIS can alter management types or funding periods and who can access the Scheme.

Section 10(a) of the amended Bill⁵ states:

⁵ https://www.aph.gov.au/Parliamentary_Business/Bills_Legislation/Bills_Search_Results/Result?bId=r7181

“a support is an NDIS support for a person who is a participant or prospective participant if:

(a) the support:

(i) is necessary to support the person to live and be included in the community, and to prevent isolation or segregation of the person from the community; or

(ii) will facilitate personal mobility of the person in the manner and at the time of the person’s choice; or

(iii) is a mobility aid or device, or assistive technology, live assistance or intermediaries that will facilitate personal mobility of the person; or

(iv) is a health service that the person needs because of the person’s impairment or because of the interaction of the person’s impairment with various barriers; or

(v) is a habilitation or rehabilitation service; or

(vi) is a service that will assist the person to access a support covered by subparagraph (iv) or (v); or

(vii) will minimise the prospects of the person acquiring a further impairment or prevent the person from acquiring a further impairment; or

(viii) is provided by way of sickness benefits [...].”

Rules to clarify Section 10

Rules are a legislative instrument under an Act that give details about how the law should work in practice. Sections 10(b) and 10(c) of the amended Bill refer to (yet to be designed) Rules that could further clarify NDIS funding and how plans can be spent. It is expected that they will do this by creating a list of “in” and “out” supports that can or cannot be funded or purchased by a person or “class of persons”.

Examples in the Explanatory Memorandum include things like ‘online gambling’, ‘perfume’, ‘standard household appliance and white goods’- which will not qualify as NDIS supports. The Explanatory Memorandum is not legislation, but it does give an idea about the intentions behind the amended Bill. What items make it into the Rules also depends on agreement by the States and Territories. Until the Rules are created, the Applied Principles and Tables of Support (APTOS) will be legislated to name what is most appropriately funded by the NDIS.

The exclusion of “white goods”, for example, will be of concern to the MS community who often rely on air-conditioning to manage their symptoms. 90% of people with MS are heat intolerant and run their air conditioners 15 times more than average households⁶. Some people with mitochondrial disease also have problems regulating body temperature and have an inability to tolerate either hot or cold temperature⁷. The NDIA has often argued that air-conditioning is not a reasonable and necessary support, though this has been successfully challenged by a person with MS at the Administrative Appeals Tribunal⁸, which agreed the

⁶ <https://www.msaustralia.org.au/news/energy-concessions-for-people-living-with-ms/>

⁷ <https://www.mitoaction.org/day-to-day-with-mito/heat-intolerance/>

⁸ <https://www.austlii.edu.au/cgi-bin/viewdoc/au/cases/cth/AATA/2019/3275.html>

replacement of the ducted air-conditioning system in the participant's home met the requirements of a reasonable and necessary support as defined in the NDIS Act.

It is likely that NDIS planners and LACs will be required to follow the new amended Bill and not the AAT decisions relating to the old Act. If specific needs are no longer able to be met by the NDIS, alternative arrangements must be in place to support people who need specific supports.

Our position is that blanket rules, such as those pertaining to "standard household appliances," cannot adequately account for individual circumstances. There may be situations where exceptions to these rules are necessary, based on a person's unique needs or specific circumstances. Decisions regarding such matters should be entrusted to professionals with relevant expertise, such as Occupational Therapists, Allied Health Professionals, and Medical Practitioners. These professionals are best positioned to assess an individual's requirements comprehensively. Their assessments should prioritise the genuine needs of the individual, ensuring that any supports or aids recommended are tailored to their specific circumstances.

Instead, we suggest that the focus is put on establishing mechanisms that prevent the exploitation of the system. This entails ensuring that recommendations from allied health and medical professionals are guided by ethical considerations and a genuine commitment to supporting the individual's well-being, rather than exploiting loopholes for personal gain.

Recommendation

- 5. Provision for exemptions to blanket rules for supports, such as those pertaining to standard household appliances, should be made, based on a person's unique needs or specific circumstances.**

Plan length

The Agency will be able to build plans as long as five years. Funds will be released in periods, meaning a person will not get access to all five years' worth of funding at once. The increased plan length will hopefully reduce the need for people to undertake regular assessment and reassessment. The funding periods also aim to reduce plans being emptied and topped up before they end.

The prospect of extended plan durations is a welcome development, especially since many find the review process burdensome, time-consuming, and costly. However, amidst this positive shift, it is crucial to acknowledge the unique challenges faced by people with progressive conditions.

For people with progressive conditions, timely access to vital supports is paramount, yet the extended intervals between plan reviews may inadvertently hinder their ability to adapt to evolving needs. There is a genuine concern that prolonged plan durations could lead to critical supports being overlooked or

delayed, potentially exacerbating health outcomes and quality of life for this group.

Ensuring equitable access to necessary supports necessitates a balance between the benefits of longer plan durations and the imperative for timely reviews.

Recommendation

6. Explore mechanisms that facilitate proactive and responsive adjustments to plans when needed, without imposing undue administrative burdens or delays.

Plan management

The default position remains that people can tell the NDIA how they wish to manage their plan, but the NDIA can override the preference for a management type in those plans developed under the new planning method if:

- a) A person would likely otherwise suffer physical, mental or financial harm;
- b) funds have not been spent in line with a participant's plan; and
- c) other criteria are met in the (yet to be determined) Rules.

These powers are broad and unbalanced. There is no requirement in the amended Bill for the NDIA to build capacity or put support for decision-making in place where they identify a misuse (or misunderstanding) of funds.

New information gathering powers for the NDIA in relation to preparing a plan

In preparing new framework plans, the NDIA can ask for "information that is reasonably necessary" for the purpose of building the plan. The NDIA will also get new powers to request an assessment by a professional to assist them in building a new plan. If a person does not comply within 28 days or convince the NDIA they have a good reason, their current and future plans will be suspended until they follow the Agency's request.

Further clarification is needed regarding the professionals responsible for conducting assessments requested by the NDIA. Will they be professionals employed directly by the NDIS, or will they be sourced from the community? Understanding this aspect is crucial for participants to comprehend the process and ensure transparency.

Additionally, the mandated 28-day timeframe for compliance raises concerns. Obtaining necessary information, especially from therapists or doctors, often involves scheduling appointments that can take weeks to arrange. This compressed timeline adds unnecessary stress and financial strain to participants, detracting from the intended goal of streamlining the planning process.

It is therefore imperative to reassess the feasibility of the 28-day timeframe and consider extending it to allow participants sufficient time to gather and submit requested information without undue pressure.

Recommendation

- 7. Provide clarity regarding the professionals responsible for conducting assessments requested by the NDIA and reassess the feasibility of the 28-day timeframe for building a new framework plan; consider extending it to allow participants sufficient time to gather and submit requested information without undue pressure.**

Reviewing a needs assessment

In line with the recommendation of the NDIS Review, the amended Bill indicates that future NDIS plans will be developed through a needs assessment. If a participant's needs are not accurately captured in the needs assessment, then their funding package will likely be insufficient. There is no clear power in the amended Bill for a participant to seek an internal review of their needs assessment.

There is a new power in the amended Bill for the NDIA to order a replacement needs assessment. What remains unclear is: a) under what circumstance a replacement assessment can be ordered; and b) whether the NDIA's refusal to order a replacement assessment will be reviewable. The government has indicated there are more Rules to come.

Once again, it is crucial to consider who is responsible for conducting these assessments and what qualifications they possess. Particularly for individuals with progressive diseases, there is a need for forward-thinking in planning to ensure their evolving needs are met in a timely manner.

One solution could be establishing a specialised workforce within the NDIA specifically trained to cater to clients with progressive and rare neurological conditions. These planners would require significant experience in understanding the unique challenges and evolving needs of this demographic. Technical errors in plans, such as accidental changes to agency management instead of plan management, are far too common and can severely impact the timely support individuals require.

Furthermore, there is a valid question regarding the purpose of regular assessments for people with progressive conditions, given some of these have a predictable trajectory. For others progression is expected but the exact pattern and pace of this is less certain. Instead of frequent reassessments, there should be a focus on proactive planning and anticipating future needs based on the known progression of the condition.

Recommendation

- 8. Consider establishing a specialised workforce within the NDIA specifically trained and with significant experience to cater to clients with progressive and rare neurological conditions.**

Early Intervention

To be eligible for the Early Intervention pathway, the existing Act says that a person must be likely to benefit from an “early intervention support.” The amended Bill defines an “early intervention support” as an ‘NDIS support’- as per Section 10.

Under the amended Bill, health care professionals writing NDIS reports to support access applications will need to understand Section 10 and provide evidence about whether a person will be likely to benefit from the supports that match the criteria described in Section 10.

The Explanatory Memorandum says the Rules will allow the NDIA to provide clarity about eligibility for early intervention in the NDIS, or whether supports should be sought from programs outside the NDIS. There is no indication as to whether that early intervention pathway will or could accommodate collaboration or coordination with other programs used by people applying for early intervention. It is also not clear whether the amendments will seek to impose, or otherwise assume, the obligations of non-NDIS systems or programs of support.

There is no indication in the amended Bill about what target groups are eligible for the early intervention pathway (for example, children or adults) or whether a person can move from the early intervention pathway to being a participant with lifelong disability status or vice versa. Section 32 does enable the NDIA CEO to specify in a participant’s plan whether the participant meets the requirements for early intervention, lifelong disability or both.

Whether someone meets disability requirements or Early Intervention, or both, will appear in a participant’s Statement of Participant Supports. New Access Rules, yet to be created with states and territories, will further clarify access and Early Intervention tests and set the thresholds applicants need to reach to get into the NDIS.

NDIS powers to revoke participant status

The amended Bill gives the NDIA the power to request information or reports to assess a participant’s ongoing eligibility, including an examination by an appropriately qualified person. The Explanatory Memorandum says a person can choose the professional who completes the examination or assessment, so long as the information is in the form requested by the NDIA. If a participant does not comply with the request, after 90 days, the NDIA CEO may choose to revoke their status. This applies unless the CEO determines it was reasonable for the person not to have complied within that timeframe.

Accessing supports that relate to a new or multiple impairments

The NDIA will inform a person if they meet access to the NDIS via Early Intervention or the disability requirements, or both. This will be recorded in the participant's Statement of Participant Supports. In plans developed through the new planning system, a person will only be assessed – and a budget built – based on their impairments that met the access or Early Intervention criteria for the NDIS.

For plans developed under the current planning model, a new criterion will be added into the current reasonable and necessary criteria, saying: “the support is necessary to address needs of the participant arising from an impairment in relation to which the participant meets the disability requirements or the early intervention requirements”.

What is not clear is how new or multiple impairments will be treated and if new needs assessments will be required as new or multiple impairments arise - a particular concern for participants that live with multiple impairments and complex needs.

The uncertainty surrounding the treatment of multiple impairments and the potential need for new assessments poses significant challenges for people with chronic and progressive neurological conditions. These conditions often manifest in complex symptoms that impact various aspects of daily functioning, not necessarily tied to a single diagnosis. Consequently, attempting to categorise people based on a singular condition overlooks the nuanced and individualized nature of their needs.

This ambiguity also underscores the ongoing reliance on repetitive assessments, which can be burdensome for individuals with progressive conditions. When we know the trajectory of the condition the person has, we know the person will require increasingly intensive supports as their condition progresses. However, the current system lacks adequate pathways to address the multifaceted needs of those with progressive illnesses.

Moreover, there is often overlap between healthcare and NDIS supports. Rather than passing the responsibility between organisations, there is a pressing need for collaboration to ensure holistic support for the participant. It is imperative that both entities work together seamlessly to address the diverse and evolving needs of participants, thereby providing comprehensive and effective support that truly enhances their quality of life.

Conclusion

Much of the detail in the amended Bill is left to Rules and administrative arrangements that will be created after the Bill is passed by Parliament, including arrangements for access, assessment, NDIS supports, plan structure and the early intervention pathway. The Explanatory Memorandum contains no indication as to the timing or process for how these Rules will be developed.

It is therefore difficult to understand the full impact of the Bill and the changes it proposes. For example, the power to make Rules specifying the supports the NDIS will fund means the public does not know how the Government will limit what is funded under the NDIS and what will be funded by states and territories through foundational supports.

The significant reliance in the amended Bill on rules and determinations for fundamental aspects of the NDIS, such as access and assessment, should be included in the primary legislation. At the very least the draft Rules should be made available for further scrutiny.

The Explanatory Memorandum states that “the new NDIS rules will be designed and implemented with extensive consultation and co-design with the disability community”, though this is yet to occur. This statement should be included in the amended Bill to guarantee a co-design process now and into the future and provide reassurance to the disability community.

The insufficient information provided makes it challenging to offer ongoing feedback effectively. We have significant concerns regarding this lack of clarity and its potential ramifications, particularly for people with progressive neurological conditions. It is crucial to delve into why the current system and processes are inadequate, especially concerning individuals with progressive neurological conditions. Additionally, the impact of delays on these individuals' well-being must be carefully considered.

For more information about this submission and the work of the Neurological Alliance Australia please contact:

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