



**MND Australia Submission to the Community Affairs  
Legislation Committee for inquiry on the National Disability  
Insurance Scheme Amendment (Getting the NDIS Back on  
Track No. 1) Bill 2024**

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## **Introduction**

Motor Neurone Disease (MND) Australia is pleased to provide this submission on the new draft legislation NDIS Act 2024 – getting the NDIS on track, the Joint Standing Committee on the Community and Legal Affairs on behalf of its members the State MND Associations, and people living with MND.

MND Australia provided a submission to the Independent Review of the NDIS. MND Australia supports the commitment of the Federal Government to ensure the NDIS remains sustainable into the future and that it serves the needs of NDIS participants as a matter of principle. However, we have some concerns on some aspects of schedule 1 of the new legislation and seek further investigation and clarification from the Committee.

### **Issues with the new legislation:**

- A new definition of NDIS Supports
- Access via disability
- Reassessment criteria and processes for a participant to remain on the Scheme
- Flexibility on new framework plans for people with complex needs

### **New definition of NDIS Supports**

MND Australia seeks clarification on what “NDIS Supports” will be, noting that the new definition *“also includes a power to make new NDIS rules to identify supports that are and are not appropriately funded by the NDIS for participants individually or as a group”*.

People with MND have needs that increase with complexity as the condition progresses and as such require assurance that supports and services will be available within their plans as their needs change. Disabilities that have health related needs may require supports that fall outside of a rigid definition of disability supports and services. MND Australia seeks clarification regarding this section of the draft legislation to ensure that people with MND will not be disadvantaged or prevented from accessing MND specific supports.

### **Access via disability**

The new legislation appears to re-track access to the Scheme via two avenues 1) early intervention 2) total and permanent disability. Currently, under the present legislation *NDIS Act 2013*, there are two categories for access via disability Category A and Category B. These were established as temporary criteria to support transition into the scheme for participants as the scheme rolled out, MND is currently a Category B listed condition.

MND is a total and permanently disabling condition, once diagnosed a person with MND will progressively require ongoing disability supports and services. To this end, access to the scheme based on total and permanent disability should include criteria of conditions that should get automatic entry to the scheme and this criterion should include MND.

MND Australia requests that the Committee amend the draft legislation to include these automatic entry criteria.

### **Reassessment criteria and processes for a participant to remain on the Scheme.**

Under the new draft legislation there is provision for reassessment to ascertain ongoing eligibility of access to the scheme. MND Australia understands that this reassessment will be based on

functional needs and will be undertaken by a professional of choice by the person with disability. MND is an unrelentingly progressive and degenerative condition leading to total and permanent disability. MND Australia requests that the Committee consider a guarantee that people with life limiting progressive conditions should be exempt from such a redundant reassessment process which will needlessly consume resources and cause unnecessary distress. Reassessment of a person with MND is redundant as function will always decline. Additionally, such reassessment could cause significant re-traumatisation to the person with MND and their family.

The draft legislation states the needs assessment tool(s) will be highly technical and developed in consultation with the disability sector, medical and professional experts. This raises the question about how the tools will be validated and whether these tools will be useful for people with progressive condition, like MND. Peak bodies should be consulted on this.

### **Flexibility on new framework plans for people with complex needs.**

The new draft legislation posits that plans will be referred to as “framework plans” and that “*New framework plans will include a flexible budget and/or budget for stated supports (including a total funding amount for each) and will be developed following a needs assessment.*” This means that a plan will be developed via a functional needs assessment and budgeted for “appropriate NDIS supports” to a total funded amount.

Additionally, framework plans will be increased in duration to between 3 – 5 years. This would mean that people with MND could potentially be assessed for a plan length of 3 years or longer with fixed funding capped at annual increments. This could seriously limit the supports and services that people with MND might need to access across the duration of their plans, given that MND is a rapidly and progressively degenerative condition.

MND Australia requests that the Committee investigate the definition of “Flexible budget” as stated in the draft legislation and seek assurances that people with very complex needs such as MND will not be unnecessarily disadvantaged by having capped plans. It is imperative that people with MND have flexibility within their plans as inevitably their support needs will increase and this is likely to happen rapidly.

### **Additional Note**

MND Australia notes that the new draft legislation openly states that part of its purpose is to see the realisation of and harmonisation with the United Nation Convention on the Rights of Persons with Disabilities (CRPD). It should be noted that the CRPD Article 1 states:

*The purpose of the present Convention is to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity.*

People with MND have a fundamental right to access disability supports and services and that these services ought not to be arbitrary nor insufficient based on legislation designed to impose fiscal priorities, as this would be disrespectful of the inherent dignity of people with MND and their families.

### **Further Information**

MND Australia welcomes the opportunity to provide further information or to appear at the public hearings regarding the Bill and the information contained in this submission. Please contact Clare Sullivan, CEO of MND Australia, on \_\_\_\_\_ or \_\_\_\_\_.