Submission to National Disability Insurance Agency

NDIS New Framework Planning submission

Emerge Australia

February 2026

Emerge Australia welcomes the opportunity to provide feedback to the National Disability Insurance Agency's proposed New Framework Planning Rules for the National Disability Insurance Scheme.

Emerge Australia is the national patient organisation representing 250,000 Australians with myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS). We also support people with other energy-limiting post-infection diseases, including the growing number of people (estimated to be up-to 400,000 Australians) who experience long COVID, an estimated 45% of all whom meet the diagnostic criteria for ME/CFS.

ME/CFS is a chronic, fluctuating, and often severely disabling condition characterised by post-exertional malaise (PEM), which is a substantial worsening of symptoms and function following physical or cognitive effort. An estimated 25% of the 250,000 Australians estimated to be living with ME/CFS are house or bedbound. Many require NDIS support. However, few have access to the scheme due to poor understanding of the disease.

Emerge Australia recognises the significant amount of work that is being undertaken to reform the NDIS. However, we are concerned that lack of understanding of ME/CFS and long COVID will continue to disadvantage people living with these conditions, unless the system explicitly recognises and accommodates their fluctuating, unpredictable nature and the impact of post-exertional symptom exacerbation on daily functioning.

Step 1 – Preparing for a Support Needs Assessment

A preparation process that relies on standardised communication, short timeframes, or cognitively demanding interactions risks disadvantaging people with ME/CFS and long COVID, whose energy-limiting conditions and cognitive limitations often require considerable time to respond to cognitive tasks.

It is unclear how participants will be supported to prepare for the support needs assessment in a way that captures fluctuating disability. Without tailored guidance, people with ME/CFS may under-report their limitations, particularly if they are assessed on a relatively better day or are unaware that they must describe the impact of delayed symptom exacerbation. This creates a significant risk that support needs will be underestimated.

In addition, while Notice of Impairments have been created for NDIS participants who entered the scheme since January 2025, those Notices have been prepared in conjunction with medical reports which were submitted as part of the participant's access application and which were prepared by clinicians who understand both the participant's functional capacity and their condition. While this process will continue for all new participants, it is unclear how Notices of Impairments will be developed for participants who joined the scheme prior to January 2025, and who may not have recent medical reports. For these participants, there is concern that the **proposed change may see Notices of Impairments being prepared without supporting external medical reports**. Given that ME/CFS and long COVID are frequently misunderstood, there is a significant risk that assessors with little or no knowledge of these conditions may prepare inaccurate or inappropriate Notices of Impairment for these participants, without input from clinicians familiar with the participant's condition.

To ensure equitable outcomes, Step 1 should include:

- Accessible, multi-format information provided well in advance of assessment.
- Explicit guidance on how to describe fluctuating capacity and post-exertional deterioration.
- Adequate timeframes and flexibility in communication.
- Appropriate training for NDIS assessors in energy-limiting conditions such as ME/CFS and long COVID
- Clear assurance that participant-provided medical and functional evidence will be considered when developing the participant's Notice of Impairments.

Step 2 - Support Needs Assessment

The proposed process places significant weight on the assessor's guided conversation and resulting report. If assessors are not specifically trained in ME/CFS and other fluctuating conditions, invisible impairments such as cognitive dysfunction, post-exertional malaise, orthostatic intolerance, and energy limitation may not be fully captured. As in Step 1, an assessment conducted by an assessor untrained in these conditions may result in participants unintentionally understating their needs due to cognitive impairment, communication difficulties, or a tendency to describe what they can do occasionally rather than what they can sustain safely and repeatedly.

Standardised tools, such as the I-CAN, may underestimate support needs for people living with fluctuating conditions when used by assessors without relevant expertise. As functional capacity varies and post-exertional malaise can cause delayed and prolonged symptom exacerbation after physical or cognitive exertion, a single structured assessment is unlikely to capture true support requirements, particularly without explicit consideration of worst-day functioning and delayed deterioration. **There must be flexibility in how the assessment is conducted.** With 25% of people living with ME/CFS being bedbound or housebound, and those in this most severe category the most likely to be NDIS participants, the assessment conversation itself will need to be tailored to accommodate the disability of these participants. A video conference lasting an hour or more will be beyond their capacity.

The proposed process does not clearly outline how participant-provided medical and functional evidence will be integrated into the assessment outcome. For people with ME/CFS, specialist documentation is often critical to explaining symptom patterns and functional impact. The assessment process must ensure that such evidence is given appropriate weight and is not overridden by standardised tools or assessor interpretation alone.

To ensure equitable outcomes, Step 2 should include:

- Mandatory training for assessors in fluctuating and energy-limiting conditions, including ME/CFS and long COVID. Such training should include the use of appropriate standardised tools with this population.
- Explicit guidance requiring assessment of functional capacity over time, including post-exertional deterioration and sustainability of activity.
- Clear processes to incorporate and appropriately weight participant-provided clinical evidence.
- Accessible assessment formats, including flexibility in timing, breaks, written responses, and the option for advocates or support persons.

Step 3 – Building a Plan

The proposed planning process does not clearly explain how assessed needs will translate into specific funding allocations. Without transparency in how support needs are weighted and costed, there is a risk that invisible and episodic impairments will be averaged or minimised in the budgeting process. This is of particular concern for people with ME/CFS and long COVID, whose support requirements often centre on energy conservation, assistance with daily living, and reducing exertion to prevent deterioration.

A plan based on a single assessment conversation may fail to account for worst-day functioning, delayed symptom exacerbation, and the need for additional supports during periods of relapse.

While flexible funding is proposed to form a substantial component of plans, it is unclear whether this flexibility will adequately accommodate highly variable support needs. People with ME/CFS may require intermittent increases in in-home support, support coordination, assistive technology, or therapeutic input depending on symptom severity. Plans must be responsive to such variability.

To ensure equitable outcomes, Step 3 should include:

- Transparent methodology linking assessed needs to funding allocations.
- Explicit consideration of fluctuating and episodic disability when setting budgets.
- Sufficiently flexible funding categories to accommodate unpredictable changes in support needs.
- Meaningful participant involvement in reviewing and confirming draft plans before approval.
- Clear and accessible mechanisms for plan variation where funding proves inadequate.

Step 4 – Using a Plan

A single implementation meeting may be insufficient to ensure participants fully understand and can operationalise their plan, particularly where cognitive fatigue affects comprehension, processing speed and decision-making. Implementation processes must be flexible in format, allow written follow-up, provide adequate time, and support the involvement of advocates or support persons.

The proposed plan variation mechanisms appear to focus on urgent or minor changes. However, people with ME/CFS frequently experience non-emergency but significant fluctuations in functional capacity, including relapses that may require temporary increases in in-home support or coordination. If plan variation pathways are narrowly defined, participants may be forced into full reassessment or formal review processes simply to adjust supports in line with genuine health changes. This represents an avoidable use of time and resources for all parties involved.

The expectation that participants will navigate provider markets, service agreements and claiming systems may also disproportionately disadvantage people with ME/CFS and long COVID due to persistent cognitive impairment and energy limitations. Without adequate implementation and coordination support, there is a risk that allocated funding will not translate into effective, usable supports.

To ensure equitable outcomes, Step 4 should include:

- Flexible implementation processes, including shorter or written options and remote engagement.
- Clear, low-burden pathways for plan variation to address non-emergency fluctuations in capacity.
- Proactive access to support coordination or implementation assistance for participants with cognitive and energy-limiting impairments.
- Regular, tailored check-ins that accommodate fluctuating symptoms and minimise risk of exacerbation.

Final Step – Reviews and Appeals

While internal and external review rights are retained under the new framework, there are significant concerns about their practical accessibility and effectiveness for people with ME/CFS and long COVID.

If plan budgets are tightly linked to standardised assessment tools or fixed budgeting methodologies, the scope for meaningful adjustment on review may be limited. For poorly understood conditions such as ME/CFS and long COVID, this creates a risk that underfunded plans will be difficult to correct. The restriction of the Administrative Review Tribunal's powers to amend plans will also likely leave vulnerable participants with no path for redress.

The administrative burden of pursuing internal review or external appeal is also likely to disproportionately impact people with ME/CFS and long COVID. Preparing documentation, meeting deadlines and engaging in review processes requires sustained cognitive and physical effort that many participants cannot safely manage without exacerbating symptoms.

In addition, if plan variation rules are restrictive, participants may be compelled to pursue formal review pathways for changes that are foreseeable consequences of fluctuating disability rather than errors in decision-making. Such rules risk embedding systemic disadvantage for people whose conditions do not fit stable or easily measurable impairment models.

To ensure fairness, the review and appeals framework should:

- Allow meaningful reconsideration of funding amounts where fluctuating disability was not adequately captured.
- Provide accessible, low-burden processes for participants with cognitive and energy limitations.
- Provide external review mechanisms with authority to meaningfully remedy underfunded plans, not merely return decisions to the NDIA for reconsideration.
- Plan variation pathways that accommodate non-emergency but material changes in functional capacity.
- Recognition of cognitive and energy limitations, including allowance for advocate involvement and simplified evidentiary requirements.

Summary

People living with ME/CFS and long COVID, who experience severe, fluctuating, and often disabling symptoms including post-exertional malaise, cognitive dysfunction, and energy limitations, may face difficulties under the proposed NDIS planning framework if their needs remain misunderstood or not appropriately accommodated. Clearer guidance, improved assessor training, consideration of participant-provided medical evidence, and more flexible assessment and planning processes would help ensure that individual support needs are identified accurately and reflected fairly in plans. Without these measures, the new framework is unlikely to capture the day-to-day variability of these conditions, which could lead to unmet support needs across all stages of the planning process.