SUBMISSION TO PARLIAMENT

National Disability Insurance Scheme Amendment (Securing the NDIS for Future Generations) Bill 2026

Submitted by: Emerge Australia

National patient organisation for people living with ME/CFS and long COVID

Informed by: Emerge Australia's Community Advisory Panel Consultation

Position in brief

Emerge Australia supports a sustainable NDIS that provides timely, appropriate and evidence-informed supports to people with permanent and substantially disabling impairments. The Bill must not inadvertently exclude, underfund or penalise people with ME/CFS and long COVID because their disability is fluctuating, poorly understood by assessors, difficult to document through standardised tools, or unsupported by adequate mainstream services.

About Emerge Australia

Emerge Australia is the national patient organisation representing people living with myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) and long COVID. We advocate for access to appropriate healthcare, research funding, and disability supports for a community that experiences high levels of persistent disability yet remains historically underserved by health and social support systems.

ME/CFS affects an estimated 250,000 Australians. Long COVID, which can cause ME/CFS-like illness, has added substantially to this number since 2020, with conservative estimates of 400,000 people affected.

Both conditions are characterised by profound functional impairment, post-exertional malaise (PEM), fluctuating capacity, and a near-complete absence of evidence-based effective treatments. PEM is "an exacerbation of some or all of an individual's ME/CFS symptoms that occurs after physical or cognitive exertion and leads to a reduction in functional ability."[1] These characteristics create specific vulnerabilities under the proposed legislative changes that this submission addresses.

This submission is directly informed by a structured consultation with Emerge Australia's Community Advisory Panel (CAP), conducted in May 2026 in direct response to this Bill. The CAP comprises people with lived experience of ME/CFS and long COVID, including current NDIS participants, carers, and medical practitioners with expertise in these conditions.

Ten (10) CAP members completed a detailed survey covering four areas of the Bill: (1) permanence and treatment requirements; (2) functional capacity assessment; (3) supports outside the NDIS; and (4) overall priorities for this submission. All respondents confirmed consent for their first names and direct quotes to be used.

[1] Committee on the Diagnostic Criteria for Myalgic Encephalomyelitis/Chronic Fatigue Syndrome; Board on the Health of Select Populations; Institute of Medicine. *Beyond Myalgic Encephalomyelitis/Chronic Fatigue Syndrome: Redefining an Illness.* Washington (DC): National Academies Press (US); 2015 Feb 10. 4, Review of the Evidence on Major ME/CFS Symptoms and Manifestations. Available from: https://www.ncbi.nlm.nih.gov/books/NBK284902/

Executive Summary

Emerge Australia welcomes the opportunity to provide this submission on the National Disability Insurance Scheme Amendment (Securing the NDIS for Future Generations) Bill 2026. Our submission is informed by structured consultation with ten members of Emerge Australia's Community Advisory Panel (CAP), including people with lived experience of ME/CFS and long COVID, carers, NDIS participants, and medical practitioners with expertise in these conditions.

The Bill creates two categories of risk for people with ME/CFS and long COVID: immediate risks for existing participants, and future access risks for people seeking to enter the scheme.

Immediate or near-term risks arise from the tightened impairment-support link, restrictions on unscheduled reassessment, ministerial support determinations, automatic plan renewals, and plan suspension for participants deemed uncontactable.

Future access risks arise from provisions commencing on 1 January 2028, particularly the treatment and permanence requirements (s. 25A) and the statutory definition of functional capacity (s. 9B).

Under the NDIS access pathway, a person must first establish that they have a permanent, or likely permanent, impairment before decision-makers consider whether that impairment results in substantially reduced functional capacity. For people with ME/CFS and long COVID, this creates two linked access risks: first, that people may be denied access if they are expected to try treatments that do not exist, are not accessible, or may make them worse; and second, that functional capacity may be underestimated if post-exertional malaise (PEM), delayed deterioration and fluctuating baseline capacity are not properly recognised.

Emerge Australia does not suggest that every person with ME/CFS or long COVID will meet the NDIS access threshold. Rather, our concern is that people with permanent and substantially disabling impairments arising from these conditions, particularly those with severe and very severe functional limitations, must have access to assessment processes that are fair, safe, accurate and clinically appropriate.

Emerge Australia urges the Government to amend the Bill and its Rules so that people with ME/CFS and long COVID are not excluded from access, denied essential supports, or required to undertake clinically inappropriate treatment or assessment processes. The window before the 2028 commencement of the most significant access provisions provides an opportunity to develop the condition-specific guidance this community requires.

Recommendations

Issue	Key Ask
Permanence and Treatment s. 25A	Require that, for people with ME/CFS and long COVID, the benchmark for assessing whether "all appropriate treatment" has been undertaken is a medical assessment by a treating clinician with knowledge of the person's condition, functional impairment and treatment history. This assessment should confirm whether any further treatment is clinically appropriate, accessible, safe, and likely to materially improve functional capacity. Where no evidence-based treatments exist, or where further treatment is unavailable, inappropriate, unsafe, or risks triggering PEM or permanent functional decline, applicants should not be required to undertake additional treatment trials before their impairment can be accepted as permanent. Permanence determinations should be based on clinical evidence and peer-reviewed prognosis data using appropriate diagnostic criteria.
Functional Capacity Assessment s. 9B	NDIS Rules under s. 9B must require functional capacity to be assessed by what a person can do safely, reliably and repeatedly, not what they can perform once. Assessments must identify the person's safe level of activity and must not treat activities that trigger PEM, delayed deterioration or risk of permanent functional decline as evidence of functional capacity. The I-CAN tool should not be used as the sole or primary assessment instrument without validated supplementary processes and specialist clinical input. Assessment processes must be accessible to people who are housebound, bedbound, cognitively impaired, sensory sensitive, isolated, or without a carer or advocate.
Impairment-Support Link s. 34(1)(aa)	The NDIS Rules made under the amended s. 34 should clarify how the impairment-support link applies to multisystem conditions such as ME/CFS and long COVID. Supports should not be excluded simply because every relevant symptom or functional impact was not separately listed, documented or accepted as a distinct impairment at access. Decision-makers should consider the full pattern of disability-related functional limitations arising from the condition, including physical, neurological, cognitive, autonomic and sensory impairments. A transitional provision should protect existing participants from having supports removed at renewal solely on the basis of the amended s. 34(1)(aa), unless a full needs reassessment has first been conducted. Associated guidance, including the Explanatory Memorandum and Operational Guidelines, should provide practical clarification for assessors on how to apply the impairment-support link to complex multisystem presentations, including the common functional limitations such as orthostatic intolerance, cognitive dysfunction and autonomic impairment that form part of ME/CFS and long COVID but may not have been separately documented at access.
Ministerial Support Determinations s. 34A	Support determinations affecting categories relied on by specific cohorts, such as participants with ME/CFS or long COVID, must require prior national patient organisation consultation and a condition-specific impact assessment before taking effect. Participants whose funding is reduced by a support determination should have an automatic right to an unscheduled reassessment to address the gap between their funded and actual support needs, without being required to meet the s. 48A threshold.
Supports Outside the NDIS	Any reduction in NDIS supports must be based on evidence of practical, accessible, and appropriate alternative disability support access for the specific individual. Suitable alternative non-NDIS disability supports must be in place before applying these provisions.
Plan Reassessment	NDIS Rules under s. 48A should explicitly provide that progressive functional decline from cumulative post-exertional deterioration constitutes a "significant and

s. 48A	ongoing" alteration in functional capacity and need not be attributable to a single identifiable event. The 90-day decision period should be suspended where a participant cannot make contact due to severe relapse, until the participant or their nominee can confirm the request. The Government should establish a separate clinically urgent reassessment pathway where treating clinician evidence of urgent need is provided.
Plan Suspension s. 40A	NDIS Rules must require extended and multi-modal contact attempts before suspension is triggered for participants with conditions causing cognitive impairment and activity-limiting fatigue. Allow participants to pre-register relapse protocols including nominated contacts. Require independent review before revocation of participant status.
Automatic Plan Renewals s. 50A	Essential ongoing assistive technology and home modifications should be carried over in automatic renewals. Establish a simplified reapplication process for previously funded equipment, distinct from the full reassessment threshold.
Governance and Automation Governance provisions	Prohibit automated decision-making on eligibility or plan content for participants with poorly understood conditions without mandatory specialist human review. Preserve and strengthen independent review and appeal rights.
Poorly Understood Conditions Relevant to s. 9B and s. 25A	Introduce a standing provision requiring the NDIA to develop condition-specific implementation guidelines for poorly understood conditions before the new provisions apply to those cohorts. The 1 January 2028 commencement for s. 9B and s. 25A provides a window to do so.

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1. Commencement Timeline

The Bill's provisions are staggered across multiple commencement dates. Provisions most directly threatening NDIS access for our community, the permanence requirements (s. 25A) and functional capacity definition (s. 9B), do not commence until 1 January 2028. This creates a window for the Government to develop condition-specific guidance before those provisions take effect. Other provisions take effect much sooner, including the impairment-support link tightening (7 days after assent) and ministerial funding cut powers (1 October 2026).

Although the permanence and functional capacity provisions both commence on 1 January 2028, they operate sequentially in the NDIS access pathway. A person must first establish a permanent, or likely permanent, impairment before decision-makers consider whether that impairment results in substantially reduced functional capacity. For this reason, Emerge Australia addresses permanence and appropriate treatment before functional capacity assessment.

Date	Provisions commencing
7 days after Royal Assent	Plan reassessment restrictions (s. 48A) Impairment-support link tightened (s. 34(1)(aa)) Governance: pricing and automation (Schedules 3–4)
1 October 2026	Ministerial support determinations, funding cuts by instrument (s. 34A) Plan suspension for uncontactable participants (s. 40A)
1 February 2027	Automatic plan renewals, loss of capital funding (s. 50A) Tighter reasonable and necessary test (s. 34)
1 January 2028	Functional capacity definition (s. 9B) Permanence and treatment requirements (s. 25A) Alternative support (compensation scheme) exclusion (s. 25B)

2. Permanence and Treatment Requirements (Schedule 1, Part 8 — ss. 24, 25, 25A)

Permanence is the first major access gateway for people seeking NDIS support. Before a person's functional capacity is assessed, they must establish that they have a permanent, or likely permanent, impairment. This creates an early access risk for people with ME/CFS and long COVID, because there are no evidence-based treatments for these conditions, and some interventions may be inaccessible, inappropriate or harmful where PEM is present.

Schedule 1, Part 8 tightens the meaning of 'permanence' for NDIS access. The Bill reverses the effect of the Federal Court's 2022 decision in NDIA v Davis, which had interpreted 'permanent' as 'enduring rather than irreversible' and found that a treatment must practically cure an impairment to prevent it being classified as permanent. The proposed s. 25A now requires a person to have undertaken all 'appropriate treatment' before an impairment can be treated as permanent.

2.1 The Unique Challenge for ME/CFS and Long COVID

For most disabilities, asking whether a person has pursued appropriate treatment is a reasonable inquiry. For ME/CFS and long COVID, this creates risk because of what the law means by “appropriate”. Under s. 25A (1), treatment is only “appropriate” if it is evidence-based, can reliably

be expected to materially improve the impairment, and is regularly undertaken in Australia. For ME/CFS and long COVID, no treatment currently satisfies all three criteria.

There are no evidence-based treatments that reliably improve, reverse or alleviate the core impairments, particularly post-exertional malaise (PEM) and severe energy limitation. The very absence of effective treatment is, paradoxically, what makes the inquiry so dangerous for this cohort: where the statutory definition of "appropriate treatment" is not met by any available intervention, the question of whether all appropriate treatment has been "undertaken" becomes unanswerable, and applicants risk being held in an indefinite limbo of expected treatment compliance with nothing to comply with.

Treatments historically recommended for ME/CFS, including graded exercise therapy (GET) and cognitive behavioural therapy (CBT) based on deconditioning or illness-belief models, are contested and may be inappropriate or harmful for people who experience PEM. Despite this, Emerge Australia is aware of many NDIS applicants with ME/CFS who have had their applications denied because they had not undertaken these treatments.

> *"If you remove studies using outdated diagnostic criteria … and only look at studies that assess a population diagnosed using more modern criteria in which PEM is mandatory, it is clear that there are zero evidence-based treatments for ME/CFS due to lack of adequate research. It logically follows, then, that no treatment trials of any sort should be required prior to accessing the NDIS."*
>
> **— Dr. Belinda, CAP**

> *"Assessment of appropriate treatment and permanency should be grounded in clinical appropriateness, functional impact, and real-world accessibility, rather than a prescriptive or exhaustive treatment pathway."*
>
> **— Karin, CAP member**

Where clinically appropriate management of ME/CFS and long COVID comorbidities exists for those who experience them (e.g. orthostatic intolerance, migraine, sleep disorders, pain conditions), such management may improve specific symptoms but rarely materially alters the core disabling impairments of ME/CFS and long COVID, particularly post-exertional malaise (PEM) and severe energy limitation. While reasonable treatment of comorbidities may be appropriate, applicants should not be expected to demonstrate extensive and unrealistic treatment histories across overlapping conditions where further treatment is unlikely to result in meaningful functional improvement.

> *"People with severe ME/CFS can't access appropriate medical treatment, so this requirement will definitely disadvantage us. Who determines what is appropriate treatment? Given we don't have current medical guidelines, what will the NDIS rely on?"*
>
> **— Tracey, CAP member**

A further and serious concern arises from s. 25A(2), which provides that treatment may be deemed "appropriate" regardless of whether the person's individual circumstances, including financial circumstances and geographical location, restrict their access to it. For people with ME/CFS and long COVID, this provision creates a specific risk: a person may be told they must undergo a treatment they cannot physically access, cannot afford, or cannot reach, before their impairment is accepted as permanent. This applies even where the treatment is inaccessible due to the severity of the disability itself, for example, a person whose functional impairment prevents them from attending an appointment. The provision effectively requires

people to demonstrate compliance with treatments they are structurally prevented from accessing.

> *"My treatment options living in Alice Springs are greatly reduced compared to someone living in Sydney. How are treatment options determined when the disability is caused by a medically undetermined condition?"*
>
> **— Michelle, CAP member (Alice Springs)**

Requiring people to attempt treatments, including any involving exertion, risks causing permanent harm. PEM can lead to lasting functional decline. Mandating harmful treatment as a precondition for support is contrary to the principle of 'do no harm' and may constitute a systemic risk to participant health.

> *"No-one should have to risk permanent exacerbation of their condition to receive essential support. The irony of course being that doing so would just increase the cost of the support that is needed."*
>
> **— Carly, CAP member**

2.2 Evidence on Permanence

Permanence determinations should be grounded in the best available prognosis evidence. For ME/CFS, that evidence is unambiguous: full recovery is uncommon, particularly in adults with moderate-to-severe illness. Fewer than 10% of people with ME/CFS diagnosed using appropriate criteria (requiring PEM) achieve full recovery. The prognosis is worse for adults and for those with more severe presentations. This evidence base should be referenced explicitly in the Rules made under s. 25A.

> *"Permanence should be understood not as the absence of fluctuation, but as the presence of ongoing, substantially reduced baseline functional capacity despite appropriate management."*
>
> **— Karin, CAP member**

2.3 Recommended Amendments

- The NDIS Rules under s. 25A should explicitly provide that, for conditions where no evidence-based treatments currently exist (including ME/CFS and long COVID as diagnosed using criteria requiring PEM), no treatment exhaustion requirement applies as a precondition for access.
- Where treatment requirements are applied, the Rules must specify that only treatments that are: (a) evidence-based; (b) accessible given the person's location, financial circumstances and functional capacity; and (c) unlikely to cause harm or deterioration can be required. Treatments known to risk PEM and deterioration must be explicitly excluded.
- The rules made under s. 25A(4) should explicitly provide that treatment cannot be required where it is practically inaccessible to the specific individual, regardless of the general availability of that treatment type in Australia.
- Permanence of ME/CFS or long COVID should not depend on exhaustive investigation and treatment of every overlapping or difficult-to-separate comorbidity, particularly where the primary disabling impairment is already established.
- Permanence determinations for ME/CFS and long COVID should draw on peer-reviewed prognosis literature using appropriate diagnostic criteria (i.e., those requiring PEM), not on studies using discredited or outdated criteria.

- The Rules should ensure poorly understood conditions are not disadvantaged simply because they have been under-researched.

3. Functional Capacity Assessment (Schedule 1, Part 1 — s. 9B)

Once permanency is established, the next critical issue is whether the person's impairment results in substantially reduced functional capacity. For people with ME/CFS and long COVID, this assessment must recognise PEM, fluctuating baseline capacity, delayed deterioration, and the difference between what a person can do once and what they can do safely, reliably and repeatedly.

Schedule 1, Part 1 of the Bill introduces a statutory definition of 'functional capacity' as a person's ability to undertake an activity without assistance and 'in a context that excludes, as far as possible, the impact of the person's environmental and personal circumstances' (proposed s. 9B). This is the issue rated most important by our community, with eight of ten CAP respondents identifying it as their most significant concern.

3.1 The Problem: Single-Point Assessment Misrepresents Capacity and Safety

The proposed definition does not adequately account for the distinctive nature of disability in ME/CFS and long COVID. Functional capacity in these conditions is not a fixed attribute that can be reliably assessed at a single point in time. It is dynamic, highly sensitive to exertion, and subject to delayed deterioration following activity. This is a core clinical feature known as post-exertional malaise (PEM). PEM is "an exacerbation of some or all of an individual's ME/CFS symptoms that occurs after physical or cognitive exertion and leads to a reduction in functional ability."[2]

For people with ME/CFS and long COVID, functional capacity must be assessed through a safety lens. The relevant question is not simply whether a person can perform an activity once, but whether they can do so safely, reliably, repeatedly and without triggering PEM or further functional decline. An assessment approach that records a task as "possible" without considering the consequences of that task will systematically overestimate capacity and underestimate support need.

For this cohort, a person may be physically able to undertake an activity during an assessment, but doing so may result in delayed deterioration, days or weeks of reduced function, or permanent loss of capacity. In this context, support is not only about enabling participation; it is also a safeguard against harm.

Where performing an activity causes PEM, prolonged deterioration, or risk of permanent functional decline, that activity should not be treated as evidence of functional capacity.

> *"It is not always an inability to do something — it's an inability to do something without causing harm (immediate or delayed, temporary or permanent). Unlike a paraplegic who cannot walk, with ME/CFS we can (usually) physically walk — but if we do it will cause significant harm. We are just as disabled, but a functional capacity assessment needs to be able to recognise what is safe for that person to do without worsening their capacity."*
>
> **— Tracey, CAP member**

[2] *Ibid.*

> *"Functional capacity must be assessed based on baseline ability over time, rather than isolated observations, as capacity is both severely limited and highly vulnerable to deterioration."*
>
> **— Karin, CAP member**

This means a functional capacity assessment conducted on a 'good day', or one that requires a person to demonstrate their capacity through physical or cognitive performance, will systematically underestimate the severity of impairment and the need for supports.

> *"Assessing us one day when we don't have PEM may give a falsely 'rosy' picture of our day-to-day capacity."*
>
> **— Fiona, CAP member**

3.2 PEM: A Mechanism That Must Be Explicitly Recognised

Post-exertional malaise is not simply fatigue or a temporary dip in energy. It is a pathological response to physical, cognitive, sensory or emotional exertion that can cause delayed, severe and sometimes permanent reductions in functional capacity. This link between exertion and deterioration is central to disability in ME/CFS and long COVID. A person may be able to perform an activity once, but if doing so triggers PEM, causes days or weeks of reduced function, or risks permanent loss of capacity, that activity is not safe and should not be treated as functional capacity.

Assessments must therefore identify a person's safe level of activity: what they can do safely, reliably and repeatedly without triggering PEM or further functional decline. Current assessment frameworks, including the I-CAN tool, do not adequately capture this relationship between exertion, delayed deterioration, safety and support need.

> *"The I-CAN does not capture dynamic disability, cognitive disability, or sensory disability very well, and does not capture or account for post-exertional malaise (which by definition includes post-exertional functional decline) at all. This makes it an inappropriate tool for assessing the needs of ME/CFS patients."*
>
> **— Dr. Belinda, CAP member**

> *"PEM can lead to a permanent reduction in capacity. Avoiding it isn't lazy, it's protecting your health."*
>
> **— Carly, CAP member**

Assessments that require prolonged conversation, form-filling, travel, phone calls or sustained cognitive processing may themselves reduce the person's functional capacity and distort the result.

> *"The accessibility of that assessment system is also critical. ME[/CFS] and long COVID are conditions that are best understood by a clinician over time. A standardised assessment conducted over a number of hours, presumably by phone, will be inaccessible to a large percentage of people with ME/CFS and long COVID."*
>
> **— Karyn, CAP member**

3.3 Recommended Amendments

- The NDIS Rules made under s. 9B should explicitly require decision-makers to assess functional capacity according to what a person can do safely, reliably and repeatedly, not merely what they can perform once during an assessment.
- Functional capacity assessments must identify the person's safe level of activity, including the level of physical, cognitive, sensory and emotional exertion that can be sustained without triggering PEM, delayed deterioration or further loss of function.

- Where performing an activity causes PEM, prolonged deterioration, or risk of permanent functional decline, that activity should not be treated as evidence of functional capacity.
- Decision-makers must consider functional capacity across multiple time points and varying conditions, including the impact of the assessment process itself on the person's functional capacity.
- Assessment tools used under s. 9B must be validated for dynamic and fluctuating disability, including PEM. The I-CAN tool should not be used as the sole or primary instrument for ME/CFS or long COVID without validated supplementary processes and specialist clinical input.
- NDIS staff conducting assessments must receive mandatory training on ME/CFS, long COVID and PEM, including the difference between what is possible once and what is safe and sustainable.
- Assessment processes must be accessible to people who are housebound, bedbound, severely disabled, cognitively impaired, sensory sensitive, isolated, or without a carer or advocate.

4. The Impairment-Support Link (Schedule 1, Part 3 — s. 34(1)(aa))

Schedule 1, Part 3 rewrites the requirement for a reasonable and necessary support to have a connection to the participant's eligible impairment. Support needs arising from secondary conditions or impairments that do not independently meet NDIS eligibility criteria may be at risk of exclusion.

This provision commences only 7 days after Royal Assent, far earlier than the more prominent access provisions, and will immediately affect existing participants' plans.

4.1 Impact on People with ME/CFS and Long COVID

People with ME/CFS and long COVID experience a range of impairments and functional limitations including autonomic dysfunction, orthostatic intolerance, chronic pain, cognitive dysfunction and sleep disturbance. In many cases, these impairments do not represent separate disabilities requiring independent eligibility assessment, but form part of the overall functional presentation of ME/CFS and long COVID.

Under the amended s. 34(1)(aa), supports addressing needs arising from impairments intrinsic to ME/CFS and long COVID could be excluded where those impairments are treated as separate issues that did not independently establish eligibility. For example, a participant may require specific functional disability supports due to orthostatic intolerance or pain arising as part of their ME/CFS or long COVID presentation. Once a person has met eligibility for ME/CFS or long COVID, supports responding to these impairments should remain within scope. This is distinct from circumstances where a person seeks supports for a separate impairment requiring consideration in its own right.

Commencement risk:

This change takes effect just 7 days after Royal Assent. Existing participants could have supports removed at their next plan review without any transitional protection. Participants with complex comorbidity profiles should be informed immediately.

The amended s. 32L applies the same direct-link requirement to support needs assessments, meaning the problem enters the system at the assessment stage, not only at the funding decision stage.

4.2 Recommended Amendments

- The NDIS Rules made under the amended s. 34 should clarify how the impairment-support link applies to multisystem conditions such as ME/CFS and long COVID. Supports should not be excluded simply because every relevant symptom or functional impact was not separately listed, documented or accepted as a distinct impairment at access. Decision-makers should consider the full pattern of disability-related functional limitations arising from the condition, including physical, neurological, cognitive, autonomic and sensory impairments.
- A transitional provision should protect existing participants from having supports removed at plan renewal solely on the basis of the amended s. 34(1)(aa) without a full needs reassessment.
- The Explanatory Memorandum, Operational Guidelines, or associated guidance should explicitly clarify how support needs are to be assessed for complex multisystem conditions such as ME/CFS and long COVID, including common impairments and functional limitations that form part of the overall clinical presentation (e.g. orthostatic intolerance, autonomic dysfunction, chronic pain, cognitive dysfunction, sleep disturbance, and sensory sensitivities).

5. Ministerial Support Determinations (Schedule 1, Part 4 — s. 34A)

Schedule 1, Part 4 introduces a new mechanism, 'support determinations' under proposed s. 34A, allowing the Minister to make legislative instruments that reduce the funding available for specified categories of supports by a set percentage. These reductions apply automatically to existing plans without altering the plan text and take effect even if they result in NDIS funding falling below the actual cost of the support.

5.1 Disproportionate Risk for ME/CFS Participants

A support determination takes effect automatically on existing plans without triggering a plan review. Participants have no administrative avenue to challenge or seek adjustment before the reduction takes effect. For participants with ME/CFS and long COVID who depend on core supports for basic safety, a funding reduction that cannot be contested before it is applied creates a direct risk to continuity of care.

People with ME/CFS and long COVID depend overwhelmingly on core supports, particularly assistance with daily living (ADLs), personal care, domestic assistance, and community access, because the nature of their disability prevents them from performing basic self-care tasks independently. Unlike some other conditions where capital items, specialised therapies, or behaviour support represent a significant share of plans, ME/CFS plans are dominated by recurring core supports.

A ministerial support determination targeting core support categories would therefore hit this community disproportionately hard. The Minister is required to 'have regard to participant safety' when making a determination, but this standard is not defined and creates no reviewable obligation.

Participants with severe functional limitations due to their ME/CFS or long COVID face significant difficulty leaving the house and depend on in-home service delivery. This is inherently more

resource-intensive, with increased provider costs arising from travel time and reduced scheduling efficiency. Accordingly, percentage-based reductions to core supports risk creating systemic inequity, as they reduce funding without reflecting the true cost of service delivery for this cohort.

For a participant whose plan consists almost entirely of in-home assistance with eating, dressing, toileting and personal care, a percentage-based reduction to core supports means less care. Unlike participants whose plans include a mix of capital items, therapies and community supports that can absorb a reduction without affecting critical daily living, ME/CFS participants have little or no capacity to redistribute savings.

Participant safety cannot be properly assessed by the Minister if the people most likely to be affected, including participants who rely on in-home core supports and are poorly captured in scheme data, remain largely invisible in the decision-making process.

This mechanism commences on 1 October 2026, ahead of many other provisions, and will affect existing plans that have not yet transitioned to new-framework planning.

5.2 Recommended Amendments

- Any support determination under s. 34A that would reduce funding for a category on which participants with specified conditions depend should require prior consultation with relevant national patient organisations and a condition-specific impact assessment.
- Participants whose funding is reduced by a support determination should have an automatic right to an unscheduled reassessment to address the gap between their funded and actual support needs, without being required to meet the 'significant change' threshold under s. 48A.
- The safety safeguard in s. 34A should be expressed as a substantive requirement, not merely a matter the Minister must 'have regard to' and should be independently reviewable.

6. Supports Outside the NDIS (Schedule 1, Part 9)

Schedule 1, Part 9 includes provisions allowing eligibility or plan content to be affected by whether a person's needs can be met through services or supports outside the NDIS. In principle, Emerge Australia supports a joined-up system of care. In practice, for people with ME/CFS and long COVID, the supports envisioned by this provision do not exist.

The critical question is what the Bill means when it provides that needs 'can be met' by supports outside the NDIS. The Bill does not require those supports to be actually available, accessible to the specific individual, or appropriate for their condition. Theoretical availability of a service type risks being treated as sufficient. This is a gap that will fall hardest on people with ME/CFS and long COVID, where no mainstream service system provides equivalent support.

6.1 Current Reality: A System of Gaps

Every CAP member who addressed this question reported the same finding: mainstream health and community service systems do not meet their needs.

> *"In practice, the NDIS often represents the primary and only reliable mechanism to ensure safety, continuity of care, and quality of life for people with severe and very severe ME/CFS and long COVID."*
>
> **— Karin, CAP member**

> *"I have been unable to access any supports outside the NDIS from any tier of government. I slip through the cracks everywhere and have had to drain family resources and relationships to support my basic needs."*
>
> **— Andrea, CAP member**

> *"I'm not aware of any current and appropriate ongoing community supports for ME/CFS. Often it's practical support with ADLs and assistive technology via core funding that's required, and I don't know any community-based free services that offer this."*
>
> **— Erin, CAP member**

> *"In my community, once the NDIS started, funding for other community supports was withdrawn. NGOs now operate using a business model, with funding coming through NDIS participants. This has led to gaps in choice for participants and holes in services for people who aren't part of the scheme."*
>
> **— Carly, CAP member**

There is also a sequencing risk the Bill does not address: supports may be reduced on the basis that alternatives exist before those alternatives are accessible to the individual. For participants whose safety depends on continuity of in-home support, a gap of even days or weeks between NDIS funding reduction and alternative support commencement raises significant safety concerns.

The picture is especially stark for people with severe and very severe presentations and for those in rural and regional areas. Karin, a CAP member with direct experience of these gaps, described the barriers in detail:

> *"For individuals who are bedbound with profound, multi-domain functional impairment, access barriers are significant. Many services require in-person attendance, which is not feasible due to mobility limitations, sensory sensitivities, and post-exertional malaise, and telehealth is not consistently accessible or appropriate. Specialist services are often geographically distant, decline complex cases, or are not equipped to manage very severe ME/CFS, resulting in substantial gaps in care. Many essential supports — such as 24/7 personal care, environmental modifications, assistive communication, and coordinated care management — are not available through mainstream service systems. As a result, individuals frequently rely on informal carers who provide high-intensity, complex care with little to no access to formal training or condition-specific clinical guidance, creating significant and sustained carer burden alongside risks to both the individual and the carer."*
>
> **— Karin, CAP member**

Shifting care to unpaid family members and informal carers is not a sustainable or appropriate alternative to funded supports. It carries significant risks for both participants and carers.

> *"Pushing care onto unpaid informal caretakers is illogical — it does not improve patient or caretaker quality of life, it brings worse health outcomes, creates risk of patient abandonment due to carer burnout, fosters patient exploitation and abuse, creates unhealthy codependency dynamics, removes ablebodied people from the workplace and society, and negatively impacts whole families financially."*
>
> **— Dr. Belinda, CAP member**

6.2 Systemic Cost Argument

People who cannot access NDIS supports and for whom no alternative exists frequently present to acute healthcare settings at dramatically higher cost to the Commonwealth and state governments. Dr. Belinda (CAP member) noted that NDIS-eligible patients sometimes remain in hospital for extended periods simply because the home supports required for safe discharge do not exist, at costs far exceeding what NDIS-funded home support would have required.

6.3 Recommended Amendments

- Any determination that a person's needs 'can be met' by supports outside the NDIS must be based on evidence that those supports are actually available, accessible, including given the person's functional capacity and geographic location, and appropriate for their specific condition.
- Theoretical availability of a service type is not sufficient. Decision-makers should be required to confirm that a specific, accessible, appropriate service is practically available to the individual before reducing NDIS supports on this basis.
- Emerge Australia recommends that Government make a parallel commitment to establish the non-NDIS disability service infrastructure necessary to appropriately support people with ME/CFS and long COVID who experience substantial functional impairment but are unable to access the NDIS, including those awaiting diagnosis or eligibility determination and those deemed ineligible for the scheme.

7. Access to Plan Reassessment (Schedule 1, Part 2 — s. 48A)

7.1 The Threshold and How It Operates

Schedule 1, Part 2 limits unscheduled plan reassessments. Under proposed s. 48A, the NDIA will only conduct an unscheduled reassessment where there is a 'significant change' in support needs: specifically, a substantial reduction in the ability to perform daily activities arising from the eligible impairment, or an unanticipated and ongoing change in living, education, work, or informal support arrangements. The decision timeframe extends from 21 days to 90 days.

The threshold operates through three compounding conditions under s. 48A(1)–(2): there must be a significant change to ongoing support needs; that change must result from an alteration in functional capacity or personal circumstances; and, where functional capacity is the basis, the alteration must be significant and ongoing, must directly relate to a change in an existing impairment or arise from a new impairment, and the participant must have experienced a substantial reduction in their ability to perform daily activities. All three limbs must be satisfied concurrently.

7.2 Structural Problems for People with ME/CFS and Long COVID

Emerge Australia understands the rationale for reducing unnecessary reassessments. However, for people with ME/CFS and long COVID, whose functional capacity can deteriorate permanently and unpredictably following a health event, the ability to request an unscheduled reassessment is a safeguard against serious harm.

> *"Understanding that PEM can result in permanent reduction in capacity, and we all, including government, need to do everything possible to prevent this."*
>
> **— Tracey, CAP member**

The threshold creates a specific structural problem for this cohort. Functional deterioration triggered by PEM is often neither attributable to a single identifiable event nor clearly separable from the person's fluctuating baseline. A participant may experience a significant and lasting decline in

capacity following a period of cumulative overexertion but that decline may be difficult to document as a discrete change with a clear onset, because it has developed progressively over time rather than as an acute episode. The requirement that the alteration be "significant and ongoing" and that it "directly relate to a change in an existing impairment" may not accommodate the reality of PEM-driven deterioration, where the underlying impairment has not changed but its functional consequences have worsened irreversibly.

There is also a practical access problem. Episodic severe relapse, which may leave a participant unable to communicate, use a telephone or computer, or self-advocate for days or weeks, makes it impossible to lodge a reassessment request during the period when the need for reassessment is most acute. The 90-day decision timeframe compounds this: a participant who cannot initiate contact during a relapse may lose weeks of that window before the NDIA is even aware a reassessment is needed.

PEM can cause permanent reductions in functional capacity. A participant who was managing under an existing plan may, following a significant relapse, require fundamentally different supports. Limiting their ability to access timely reassessment in these circumstances is clinically inappropriate and potentially dangerous.

7.3 Recommended Amendments

Emerge Australia recommends that the Rules made under s. 48A explicitly provide for unscheduled reassessment on clinical grounds where there is medical evidence of a significant change in functional capacity, including PEM-related deterioration, regardless of the time elapsed since the previous plan review. The 90-day decision timeframe is also a concern for people experiencing urgent functional decline, and a faster pathway for clinically urgent cases should be established.

The NDIS Rules made under s. 48A should also explicitly provide that:

- Progressive functional decline resulting from cumulative post-exertional deterioration constitutes a "significant and ongoing" alteration in functional capacity for the purposes of s. 48A(2)(a), and is not required to be attributable to a single identifiable event or onset date.

Separately, the Government should establish a clinically urgent reassessment pathway, separate from the s. 48A threshold process, available where a treating clinician provides medical evidence that a participant's functional capacity has deteriorated to a degree requiring immediate plan variation. Where a participant's condition, including ME/CFS or long COVID, is characterised by episodic severe relapse causing temporary inability to communicate or self-advocate, the 90-day decision period under s. 48 should be suspended until the participant or their nominee has been able to make contact and confirm the request.

8. Plan Suspension for Uncontactable Participants (Schedule 1, Part 7 — s. 40A)

Schedule 1, Part 7 introduces new s. 40A, allowing the NDIA to suspend a participant's plan if they are uncontactable after reasonable attempts. If the participant does not re-engage within 90 days of suspension, the CEO can revoke their NDIS participant status entirely. The suspension decision is reviewable, but the revocation of participant status is a severe outcome with lasting consequences.

8.1 Uncontactability as a Symptom, Not Disengagement

For many people with ME/CFS and long COVID, uncontactability during a relapse is a direct and predictable consequence of the condition, not evidence of disengagement. Cognitive dysfunction ('brain fog'), extreme fatigue, and post-exertional malaise 'crashes' following any activity, including

correspondence, mean that a severely disabled person in relapse may be genuinely unable to respond to NDIA contact for extended periods. This may be a consequence of profound, enduring functional impairment.

Therefore, the suspension mechanism penalises participants specifically for experiencing a severe manifestation of the impairment for which they receive support. A participant who cannot respond to contact attempts because they are in a severe relapse is not evading the NDIA; they are experiencing a medical crisis. Suspension in those circumstances removes support from the person who most urgently needs it.

Critical risk:

A plan suspension triggered by uncontactability will most often occur precisely when a participant's disability is most acute and they are least able to respond. The 90-day revocation window could result in an eligible participant losing NDIS access entirely during a severe relapse, removing their supports at the moment of greatest need.

> *"People with ME/CFS and long COVID also experience higher rates of isolation than other people who are severely impacted by disability, and are more likely to not have carers who can advocate for them and undertake such assessments on their behalf."*
>
> **— Karyn, CAP member**

8.2 Recommended Amendments

- The NDIS Rules under s. 40A should prescribe that, for participants with conditions characterised by cognitive impairment and activity-limiting fatigue (including ME/CFS and long COVID), 'reasonable attempts' to contact must include multiple modalities and extended timeframes before suspension is triggered.
- Participants should be able to register 'relapse protocols' with the NDIA in advance, including nominated contacts and agreed procedures for periods when they may be unable to communicate, without requiring a formal nominee arrangement.
- The 90-day window before revocation should be extended, and revocation should require an independent review before taking effect for participants with a diagnosis associated with episodic severe impairment.
- Where a participant's plan has been suspended or revoked in circumstances consistent with a severe relapse, reinstatement should be available without requiring a full new access application.

9. Automatic Plan Renewals and Loss of Capital Funding (Schedule 1, Part 5 — s. 50A)

Schedule 1, Part 5 introduces automatic plan renewals under proposed s. 50A. When an old-framework plan reaches its end date, it renews automatically for 12 months. The renewed plan replicates core supports but does not include one-off capital funding such as assistive technology, equipment, or home modifications that was in the previous plan. Unspent funds are not carried over. The renewal is not a reviewable decision.

9.1 Assistive Technology in ME/CFS

People with ME/CFS and long COVID frequently depend on specific assistive technology and home modifications to manage their condition safely: shower chairs, commodes, hospital-grade adjustable beds, reclining chairs, grab rails, and sensory aids. These items are often one-off capital purchases in a plan. Under s. 50A, they will be stripped from the renewed plan and must be re-applied for under the new strict reassessment criteria.

For a participant who is too disabled to successfully navigate a reassessment request (see Section 7 above on plan reassessment thresholds), the loss of capital funding on automatic renewal could leave them without essential equipment with no effective remedy. If the participant cannot meet the 'significant change' threshold under s. 48A, because their situation has not changed, they simply need the equipment replaced or repurchased, there may be no pathway to reinstate that funding.

9.2 Recommended Amendments

- The NDIS Rules under s. 50A should provide that assistive technology and home modifications that are ongoing and essential to a participant's safety and daily functioning are carried over in automatic renewals, rather than being treated as one-off capital items subject to removal.
- Where one-off capital items are not carried over, a simplified reapplication process distinct from the full unscheduled reassessment process under s. 48A should be available for equipment that was previously funded and remains clinically appropriate.

10. Governance, Automation and Review Rights (Schedule 3)

Schedule 3 introduces a statutory framework for automated administrative decision-making and moves pricing decisions to the Minister. Several CAP members raised strong concerns about automation, particularly given the frequency of errors in NDIS decision-making and the complexity of ME/CFS presentations.

10.1 Risks for ME/CFS and Long COVID

> *"Plans to reduce avenues for decision reviews and external legal appeals is very alarming given how frequently incorrect and harmful decisions are made by NDIS' unqualified staff. AI must be incorporated in a very careful way — not making any decisions but simply doing mundane basic work that involves no nuance or experienced interpretation. We cannot have another robodebt situation in Australia."*
>
> **— Dr. Belinda, CAP member**

Decisions about eligibility, plan content, and suspension for participants with ME/CFS and long COVID inherently involve evaluative judgement: they require assessment of fluctuating, dynamic, and poorly understood presentations that do not map cleanly onto standardised criteria. These are precisely the decisions that the Bill's own framework acknowledges cannot be safely automated. Automated systems trained on scheme-wide data will systematically underweight the needs of small, poorly-captured cohorts.

The Bill does provide that decisions involving 'evaluative judgement' require a standard operating procedure instrument, and that notices must disclose when a decision was made by computer. These are baseline protections. Emerge Australia endorses them but considers them insufficient for complex, fluctuating, and poorly understood conditions.

10.2 Recommended Amendments

- Automated decision-making tools must not be used to make or confirm eligibility, plan content, or suspension decisions for participants with ME/CFS, long COVID, or other poorly understood conditions without mandatory human review by a person with appropriate clinical training.
- Any reduction in avenues for internal review, AAT review, or judicial review must be accompanied by an independent mechanism for correction of errors that is accessible to people with significant functional limitations, including those who cannot participate in formal legal processes.
- Accountability frameworks for automated decisions must be established before deployment, not retrospectively.

11. Broader Recommendation: Provision for Poorly Understood Conditions

11.1 Recommendation

A theme running through every aspect of this submission is that legislation and policy written primarily in the context of well-defined, well-researched conditions will systematically disadvantage people with ME/CFS and long COVID, unless the NDIA uses condition-specific guidance and disability-focused language that reflects permanent impairment, substantially reduced functional capacity and multi-domain support needs.

> *"Every component of the legislation and implementation policies and procedures needs to consider whether it is appropriate for these poorly understood conditions."*
>
> **— Tracey, CAP member**

The window between now and 1 January 2028 is not long. Developing condition-specific guidelines requires NDIA engagement with clinical experts, national patient organisations, and people with lived experience. Emerge Australia urges the Committee to recommend that the Government commit to a specific timeline for the development of ME/CFS and long COVID guidelines under any standing provision, and that those guidelines be finalised and published before the commencement of ss. 9B and 25A.

Conclusion

Emerge Australia supports the stated intent of this Bill to secure the NDIS for future generations. A sustainable, well-governed scheme serves the interests of all Australians with disability, including the ME/CFS and long COVID communities we represent.

However, sustainability cannot be achieved by creating a scheme that is inaccessible to people with permanent and substantially disabling impairments arising from complex and poorly understood conditions. The measures proposed in this Bill, as currently drafted, risk doing exactly that: imposing treatment requirements that cannot be met, assessment processes that will systematically underestimate need, funding cut mechanisms that disproportionately affect those who rely on core supports, suspension provisions that penalise relapse, and governance changes that reduce the safeguards people depend on when errors occur.

Many of the most damaging provisions take effect far sooner than the access and assessment changes: the impairment-support link tightens within days of Royal Assent; ministerial funding cuts and plan suspension powers activate in October 2026; plan renewals that strip capital funding commence in February 2027. The community cannot wait until 2028 to begin advocacy on those provisions.

With the amendments recommended in this submission, we believe the Bill can achieve its objectives while also being just, evidence-based, and workable for people with ME/CFS and long COVID, including those with severe and very severe functional impairment. We welcome the opportunity to provide further evidence, facilitate direct engagement with our Community Advisory Panel, or assist the Committee in any other way.

> *"Emerge Australia's leadership is vital in ensuring that reforms recognise not only the clinical and functional realities of ME/CFS and long COVID, but also the systemic gaps in service access, particularly in regional areas. Without this, individuals with profound disability — and the families who support them — will continue to carry an unsustainable burden in the absence of appropriate, accessible supports."*
>
> **— Karin, CAP member**