29 May 2026

Senator Dorinda Cox
Chair
Senate Community Affairs Legislation Committee
PO Box 6100
Parliament House
Canberra ACT 2600

Dear Committee Chair and Members

We welcome the opportunity for Neurological Alliance Australia and members of the Neurodegenerative, Palliative Care and Rare Diseases Advisory Group of the NDIA (NPRAG) to make a submission to the Senate Community Affairs Legislation Committee's Inquiry on the National Disability Insurance Scheme Amendment (Securing the NDIS for Future Generations) Bill 2026.

Attached is our joint submission for your consideration. As you will note in the submission, we are calling on the Committee to recommend the following:

- Require functional capacity assessments to capture fluctuation, energy limitation, medication effects, treatment-dependent variability and post-exertional impact, using multiple time points and clinical specialist evidence.
- Make the NPRAG testing partnership for the support needs assessment tool substantive, public and binding on deployment, with explicit testing for conditions with fluctuating, episodic, energy-limiting and poorly characterised manifestations.
- Confirm that symptomatic management, including medication and disease-modifying treatments, does not satisfy the permanence test for conditions where no curative treatment exists. Exclude experimental and surgical interventions from the treatment exhaustion requirement where individual clinical grounds exist.
- Restore support coordinator rights to request reassessments on behalf of participants who cannot do so, and set a 21-day decision window for conditions with documented rapid progression.
- Require individual notification and a right of merits review for all support determinations under section 34A. Keep pricing instruments subject to Senate disallowance and establish an independent clinical advisory panel for specialist and rare disease service pricing.
- Prohibit automated decision-making for participants with fluctuating, episodic or energy-limiting conditions. Require that computer-made decision notices include a plain-language explanation of the criteria applied and data used, not merely disclosure of automation. Ensure active assistance for participants with cognitive impairment seeking human review. Require the CEO's annual report to disaggregate substituted decisions by condition type, and mandate an independent clinical review before automated tools are deployed for the conditions covered by this submission.

- Require automatic plan renewals under section 50A to carry forward unspent capital funding for participants with documented progressive conditions. Require NDIA outreach to nominees and carers before suspending or revoking plans under section 40A where there is a documented medical basis for unavailability.
- Include a medical event extension mechanism in the 90-day claim window for participants who experience hospitalisation or acute incapacity during the claim period. Include a capacity-based exemption in the record retention obligation so that participants with documented cognitive impairment are not subject to civil penalties where non-compliance results from that impairment.
- Resolve the NDIS-health system interface before tightening access criteria, and establish an early intervention pathway for conditions with evidence of trajectory modification.
- Legislate the Priority Access Pathway with eligibility based on functional decline trajectory, not solely on proximity to death, and extend it to all conditions with a documented rapid decline trajectory.
- Ensure any proposed restrictions on rights of review and appeal are subject to full public consultation and do not take effect under this Bill.

About the Neurological Alliance Australia

Neurological Alliance Australia (NAA) is a national alliance of around 50 not-for-profit organisations representing the needs of approximately seven million Australians living with neurological and neuromuscular conditions. NAA promotes shared issues and concerns for the improved quality of life for people living with these conditions and funding to support research into treatment and better care management.

About Neurodegenerative, Palliative Care and Rare Diseases Advisory Group of the NDIA

Neurodegenerative, Palliative Care and Rare Diseases Advisory Group was established in May 2024 at the suggestion of the NAA to provide strategic advice to the NDIA on a set of defined issues relating to participants with neurodegenerative, neuromuscular or rare conditions, or those requiring palliative care. The Advisory Group is comprised of members of the NAA together with Rare Voices Australia.

Further information

If you have any questions or require any further information, please contact Olivia Nassaris, Co-chair of the Neurodegenerative, Palliative Care and Rare Diseases Advisory Group of the NDIA at olivia@parkinsons.org.au or NAA Executive Officer at david.ali@NeurologicalAlliance.org.au.

Yours sincerely

Rohan Greenland
Chair
Neurological Alliance Australia

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Submission to the Senate Community Affairs Legislation Committee

NDIS Amendment (Securing the NDIS for Future Generations) Bill 2026

Joint Submission prepared by Olivia Nassaris, Co-chair of the Neurodegenerative, Palliative Care and Rare Diseases Advisory Group of the NDIA.

Submitted on behalf of: Parkinson's Australia | MS Australia | MND Australia | | Dementia Australia Huntington's Australia| Mito Foundation | Angelman Syndrome Australia | Tuberous Sclerosis Australia | Palliative Care Australia | Parent Project Muscular Dystrophy | Muscular Dystrophy Australia | Fragile X Association of Australia | Duchenne Foundation Australia | Leukodystrophy Australia | Neuromuscular WA | Epilepsy Action Australia | Emerge Australia

May 2026

Introduction

This submission is made jointly by organisations representing people living with neurological, neurodegenerative, palliative and rare disease conditions. Together, our communities represent hundreds of thousands of Australians and their families who depend on the NDIS to live with dignity and participate fully in their communities.

We acknowledge the importance of scheme integrity and fiscal sustainability. The NDIS must be well managed, and we support measures that reduce fraud and improve consistency. However, we are deeply concerned that several provisions in the *NDIS Amendment (Securing the NDIS for Future Generations) Bill 2026* (the Bill), taken together, will create substantial new barriers for people with complex, progressive, fluctuating and rare conditions, at precisely the point in their disease course when they can least afford them.

The conditions represented in this submission share a common profile: they are permanent, they worsen over time, they involve a combination of motor, cognitive and non-motor symptoms that interact in highly individual ways, and they are already poorly understood by NDIA assessors. The reforms proposed in this Bill will be felt most acutely by this group.

The impact extends beyond people with disability. Caregivers of people with these conditions frequently reduce or leave the workforce as care demands increase. Approximately 26 per cent of Parkinson's caregivers reduced or gave up work, and 30.4 per cent reported their finances worsened because of caregiving. Unpaid carers of people with Huntington's disease (HD) and mitochondrial disease (mito) already experience significant burnout, and many are themselves at genetic risk of developing the condition. A scheme that reduces or delays support for participants does not eliminate these costs. It transfers them to unpaid carers and ultimately back to health and welfare systems.

We also note that the announcement of projected outcomes — including estimates of 160,000 fewer participants — without accompanying detail on how these reductions will be achieved has generated significant and avoidable concern across our communities. This lack of transparency is contributing to heightened anxiety and scepticism. Our member organisations are managing a significant increase in distress calls and enquiries from people who fear they will lose access to supports that are essential to their safety and wellbeing. The Government

should provide a clear public explanation of how projected participant reductions would be achieved and which populations are affected.

1. Functional Capacity (new section 9B, commencing 1 January 2028)

New section 9B defines functional capacity as a person's ability to undertake daily activities without assistance from other people, assistive technology or modifications, and excluding personal and environmental circumstances as much as possible. This definition is fundamentally incompatible with the nature of the conditions represented in this submission.

A point-in-time, unaided assessment will produce a systematically distorted picture for every condition in our group, for different but equally important reasons.

- For people with Parkinson's disease, functional capacity is not stable across the day. On-off medication fluctuations can mean that within a single day the same person walks independently, dresses themselves and holds a conversation in an on state, and is unable to walk, speak, swallow safely or manage their hygiene in an off state. An assessment almost certainly conducted during a relatively functional period will not capture the true level of support required. Freezing of gait, one of the most dangerous features of advanced Parkinson's, is context-dependent and typically absent in clinical settings but present in doorways, crowds and when dual-tasking.
- For people with multiple sclerosis (MS), energy-limiting symptoms and post-exertional deterioration mean that a person who performs adequately in a one-hour assessment may be unable to function for hours or days afterwards. Additionally, most people with MS will experience ongoing periods of relapse and recovery over their lifetime. The NDIA already does not understand MS well, as documented in MS Australia's recent NDIS community survey, and a framework that assesses unaided capacity at a single point will make this worse.
- For people with HD the proposed definition of “functional capacity” in section 9B is particularly concerning because many individuals rely heavily on supervision, prompting, structured environments, and caregiving to function safely in daily life, while anosognosia can impair their ability to recognise or accurately report their own support needs. Many HD participants genuinely cannot recognise or accurately report the extent of their impairments because of the disease’s impact on the brain. In addition, the proposed one-to-three-hour assessment format may itself disadvantage people with HD, as fatigue, cognitive slowing, impaired concentration, anxiety, and speech difficulties often worsen over prolonged interactions, potentially leading to an inaccurate overestimation of functional capacity. As a result, assessments that rely heavily on self-reporting or brief observations risk significantly underestimating support needs and overlooking safeguarding risks. Without proper consideration of carer evidence, clinical reports, cognitive decline, and the progressive nature of HD, participants may be assessed as more independent than they truly are, resulting in inadequate supports and increased risks to their safety and wellbeing.
- For people with mitochondrial disease, energy limitation is often the primary disabling feature, is poorly understood, and will be invisible to an assessment that does not account for the energy cost of activity or post-exertional deterioration.
- For people with Motor Neurone Disease (MND), functional capacity at the time of assessment may not reflect support needs even weeks later given the speed of

progression. Assessing current unaided capacity is of limited value for a condition that changes this quickly.

- For people with Duchenne muscular dystrophy and related dystrophinopathies, functional capacity fluctuates significantly in relation to steroid treatment cycles. During a steroid on period, a person may present with considerably greater mobility and strength than during or after a steroid off period. The condition also involves sudden, irreversible losses of function, including loss of ambulation, which cannot be predicted by assessment of current capacity. The heterogeneity of these conditions means that two people with the same diagnosis and disease duration may have radically different functional profiles.
- For people with young onset dementia unaided "functional capacity" assessed at a single point in time is unreliable. Dementia involves impaired insight, executive dysfunction and communication changes that means people can overstate capacity and under describe risks, particularly if they live alone or attend assessments without an informed support person. In clinical or formal settings people may also "present well", masking functional decline that is evident at home. Functional capacity for young onset dementia must therefore be assessed over time and across settings, and must require consideration of carer/nominee evidence and treating clinician reports to capture typical functioning.

- For people living with progressive neuromuscular conditions including myositis, spinal muscular atrophy, inclusion body myositis and related disorders, fatigue, fluctuating symptoms, progressive loss of mobility and respiratory complications mean that functional capacity at a point in time does not represent the person's genuine support needs. These conditions require flexible and preventative supports, and a static assessment model is not fit for this purpose.
- For people with tuberous sclerosis complex (TSC), functional capacity is significantly affected by seizure frequency, TAND-related behavioural and cognitive factors, and co-occurring psychiatric symptoms. These vary considerably over time and between individuals with the same diagnosis. A static assessment will miss significant impairments that are less visible or intermittent.
- For people with Fragile X-associated Tremor Ataxia Syndrome (FXTAS), a late-onset progressive neurological condition affecting carriers of the Fragile X gene premutation, functional presentation varies significantly across individuals and between genders. The condition is not well understood by most clinicians, let alone NDIA assessors. An assessment of unaided capacity at a single point in time will systematically underestimate support needs for a condition characterised by variable and progressive symptoms.
- For people living with epilepsy, the Bill's reliance on functional capacity assessments risks applying a snapshot view of disability that does not reflect the reality of an episodic condition. Epilepsy is episodic in presentation but continuous in impact. Daily realities — including seizure unpredictability, post-ictal recovery time, fatigue, cognitive effects and the ongoing need for supervision — carry significant functional impacts across communication, social interaction, learning, mobility, self-care and self-management domains that will not be visible in a point-in-time unaided assessment. Not capturing this creates a real risk that people with epilepsy will be under-assessed

or excluded from appropriate supports, with foreseeable consequences for safety and participation.

- For people living with Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS), long COVID and other energy-limiting conditions, functional capacity assessments as currently framed may fail to capture Post-Exertional Malaise (PEM) — a hallmark feature of these conditions in which even modest activity triggers delayed and disproportionate deterioration. A person may be able to complete an assessment task once, but doing so may trigger a significant and prolonged worsening of their condition. Assessments must capture what is safe and sustainable over time, not merely what is possible on the day of assessment. A single unaided assessment will systematically overestimate the functional capacity of people with ME/CFS and similar energy-limiting conditions.
- For people with leukodystrophy conditions and childhood onset mito, the progressive and life-limiting nature of these diseases means that functional capacity can change significantly and rapidly. A single assessment may accurately reflect capacity at a given moment but fail to represent the trajectory of decline that is central to this group's ongoing support needs. The functional capacity framework must account for documented disease trajectory, not only current presentation, to avoid systematic under-assessment of people whose conditions worsen over time.

The above issues are further exacerbated by the fact that many of the symptoms experienced by people living with these conditions are 'invisible' and not immediately obvious to unskilled assessors.

Recommendation: The functional capacity definition must require assessment across multiple time points. For conditions characterised by fluctuation, the assessment must capture worst-state as well as best-state functioning. For conditions involving energy limitation or treatment-dependent variability, the assessment must account for the full range of functional states. Clinical specialist reports must be accepted as determinative evidence of functional capacity range where a single assessment is insufficient.

2. Support Needs Assessment (Schedule 4, sections 32K and 32L)

Schedule 4 clarifies who can conduct support needs assessments and removes broad assessor discretion over what information can be considered. While greater consistency is welcome in principle, the changes create serious problems for conditions that are complex, rare, or poorly characterised.

The direct link requirement, now applied to support needs assessments under amended section 32L, means that needs arising from symptoms that do not independently meet eligibility criteria will be excluded, even where those symptoms are intrinsic to the primary diagnosis. It is critical to get the impairment categories right for multi-system conditions like those covered in this submission.

For Parkinson's disease, depression, anxiety, psychosis, autonomic dysfunction and urinary dysfunction are well-documented clinical features of the disease itself, not separate comorbidities. For HD, impulsivity, apathy, aggression and obsessive behaviours are central to the condition but will score poorly on standardised tools and risk being classified as

secondary. For TSC, the neuropsychiatric manifestations known as TAND, including anxiety, depression, behavioural dysregulation and executive dysfunction, are a major contributor to disability but may be excluded if assessors treat them as distinct from the eligible impairment.

The causal link test creates a particularly acute problem for FXTAS. The symptoms of FXTAS, including tremor, ataxia, balance impairment and cognitive decline, overlap significantly with the symptoms of usual ageing. Many assessors will not understand the distinction between disease-related functional impairment and age-related change, and participants may struggle to prove that their symptoms are caused by the FMR1 premutation rather than ordinary ageing. The Bill does not provide guidance on how this determination should be made, and the risk of misattribution is high.

For people with MS, the requirement to establish a direct causal link is complicated by the complexity and variability of the condition itself. Fatigue, cognitive dysfunction, mood disorders and bowel and bladder dysfunction are all intrinsic symptoms of MS but are frequently misunderstood by non-specialist assessors as secondary conditions. The NDIA's documented difficulty in understanding MS makes this a live risk under the new framework.

For people with young onset dementia, standardised support needs tools risk systematic under-assessment unless they are validated for progressive cognitive conditions and administered by dementia-capable assessors. Dementia affects cognition, behaviour, communication and physical functioning, with highly variable and fluctuating presentation. The proposed approach also risks relying too heavily on participant self-report despite well-established issues with reduced insight in dementia, meaning those with the greatest support needs may be least able to articulate them.

For people with Angelman syndrome and many other severe rare neurodevelopmental disorders, the long-term functional impact is already extremely well established in clinical literature. People with Angelman syndrome who do not have one of the rarer genetic mechanisms are non-verbal for life, have significant developmental impairment, and require lifelong 24/7 support. Repeated intensive assessments add little new information in these cases while creating significant burden and cost for families and the system. Diagnosis by a specialist, combined with established clinical literature, should be accepted as primary evidence of need without requiring full reassessments.

The requirement to attribute support needs directly to a single eligible impairment creates particular problems for epilepsy, which frequently interacts with cognitive, psychosocial and co-occurring conditions. Epilepsy often co-occurs with anxiety, depression, cognitive impairment, behavioural dysregulation and the consequences of medication side effects — all of which contribute materially to functional limitation but may be classified as separate from the “eligible” impairment. Strict causal attribution risks fragmented supports, inappropriate cost-shifting between systems, and plans that are inadequate to the real complexity of the person’s situation. The same concern applies to ME/CFS, long COVID and other energy-limiting conditions, where fatigue, cognitive dysfunction (often described as “brain fog”) and mood disturbance are intrinsic features of a single pathological process, not separate conditions requiring separate attribution.

Assessor qualifications are a critical concern across all conditions in this submission. Reports indicate that support needs assessments under the new framework may be conducted by APS Level 6 staff where an allied health background is desirable but not mandatory. For conditions as complex as HD, Parkinson's, MS, TSC, mito, FXTAS and young onset dementia, this is

inadequate. The NDIA's existing difficulties in understanding these conditions will be compounded by a framework that does not require or verify specialist knowledge.

We note that the NDIA has agreed to test the new support needs assessment tool in partnership with the Neurodegenerative, Palliative, Rare Diseases Advisory Group (NPRAG). We welcome this commitment and consider it essential that the testing process is genuine, that findings are acted on before the tool is deployed, and that conditions with complex and heterogeneous presentations are adequately represented in the test population.

Recommendation: Assessors must demonstrate specific competency for the condition being assessed. The direct impairment link test must be interpreted to include all symptoms intrinsic to the primary condition, not only those that would independently meet eligibility criteria. For late-onset conditions with presentations that overlap with normal ageing, the assessment framework must include specific guidance on distinguishing disease-related impairment from age-related change. For conditions with well-established and permanent functional profiles documented in clinical literature, specialist diagnosis combined with that literature must be accepted as determinative without requiring repeated full assessments. The NPRAG testing partnership must be substantive, with findings made public and used to modify the tool before full deployment.

3. Permanence and Treatment Requirements (new section 25A, commencing 1 January 2028)

New section 25A states that an impairment is not permanent unless the person has undertaken all appropriate treatment, defined as evidence-based care available in Australia that is reliably expected to materially improve, reverse or alleviate the impairment. The Bill includes a carve-out for degenerative conditions requiring ongoing maintenance treatment, which we acknowledge. Significant concerns remain.

The permanence of the conditions in this submission is not in doubt. Parkinson's disease, MND, HD, MS, mitochondrial disease, Angelman syndrome and TSC are all permanent, incurable conditions. However, the requirement risks being applied ambiguously at the level of individual symptoms and functional impairments.

- For Parkinson's disease, dopaminergic therapy manages symptoms but does not reverse or halt neurodegeneration. An NDIA assessor without specialist knowledge may conflate partial motor improvement on medication with impairment alleviation and incorrectly conclude that the impairment is not permanent. The legislation must explicitly state that symptomatic management does not constitute alleviation for the purposes of the permanence test. Deep brain stimulation for Parkinson's disease is a major surgical procedure, conducted while the patient is awake, with significant eligibility requirements and insufficient public listings to meet current demand. Individual clinical decisions to decline DBS should not affect NDIS access.
- For MS, disease-modifying therapies (DMTs) exist for relapsing-remitting forms but do not work for progressive forms and are not approved under the PBS for this use. Additionally, some people living with MS may have adverse reactions to DMTs and choose to not take them. The requirement creates pressure on participants to attempt treatments that do not work for them and excludes people with progressive forms of

MS. For people with MS whose condition is relapsing-remitting, a relapse may include a new symptom which, with appropriate care, improves or resolves. The permanence requirement does not account well for conditions where presentation changes episodically rather than continuously.

- For mitochondrial disease, there are no curative treatments and the evidence base for symptom management is limited and highly individualised. New therapies are arriving in clinical trial but remain untested. The assumption that all eligible impairments have a set of appropriate treatments to be exhausted fundamentally misunderstands the nature of rare, poorly characterised conditions.
- For MND, there is no treatment that reverses or halts the disease course. The permanence test should be straightforward but the broader requirement that all appropriate treatment options be exhausted before permanence is established creates unnecessary burden for people already facing a terminal prognosis on a very short timeline.
- Similarly, for people living with young onset dementia there are currently no curative treatments. The evidence on emerging disease-modifying therapies is continuing to evolve, but these are not suitable for all people living with dementia and are not currently widely available or subsidised through the Pharmaceutical Benefits Scheme. Dementia remains a progressive and terminal disease. The permanence test should reflect this and seek to minimise unnecessary burden on people with a dementia diagnosis.
- For FXTAS, the condition is late-onset and progressive with no curative treatment. However, the variable presentation of FXTAS and its overlap with usual ageing symptoms create a real risk that the permanence test will be applied inconsistently. There is currently no clarity on whether a late-onset, variable condition will be reliably treated as permanent under the new framework.
- For people with Duchenne muscular dystrophy, emerging treatments including gene therapies may be interpreted as potentially curative, creating a risk that participants will be required to justify declining or awaiting experimental treatments before NDIS access is confirmed. Exon-skipping therapies and other emerging interventions do not benefit all individuals equally, and clinical decisions about whether to pursue them are highly individualised.
- For people living with ME/CFS, long COVID and other poorly understood energy-limiting conditions, the treatment and permanence requirements may create unfair access barriers. There are currently no evidence-based curative or substantially restorative treatments for ME/CFS. The requirement to exhaust “appropriate treatment” before permanence is recognised risks penalising people for not completing treatments that do not exist, are inaccessible, or may cause harm — including graded exercise therapy, which has been demonstrated to worsen outcomes for people with PEM. Permanence for ME/CFS should be recognised on the basis of documented functional impact and disease duration, not on the exhaustion of a treatment pathway that is clinically absent.
- For people living with epilepsy, the proposed permanence settings risk embedding a false assumption that seizure control can be universally achieved. Epilepsy encompasses multiple syndromes with distinct causes and trajectories. While many anti-seizure medications exist, they are not interchangeable, not universally tolerated, and not clinically appropriate for all epilepsy types or individuals. Requiring people to

exhaust sequential or hypothetical treatment options before recognising permanence misrepresents the clinical reality of epilepsy and creates a real risk of delayed, denied or withdrawn supports for people with lifelong disability and ongoing safety risk. Similarly, for people with leukodystrophy conditions, there are no curative treatments for most leukodystrophies. The permanence of disability arising from these conditions should be determined by specialist clinical evidence and the established disease course, not by a treatment exhaustion requirement that has no clinical foundation in this context.

NDIA assessors must read any reports from specialists and other health professionals and accept the information as accurate and faithful to the experiences of the participant. Further, asking participants what treatments are available for an incurable condition only further retraumatises them, following an already traumatic pathway to diagnosis and treatment.

Recommendation: The legislation must explicitly state that symptomatic management, including medication, disease-modifying treatments and other therapies that manage but do not cure the underlying condition, does not constitute alleviation of the underlying impairment for the permanence test. Experimental, investigational and surgical interventions must be excluded from the definition of appropriate treatment where individual clinical grounds exist for declining them. For late-onset and variable conditions, the framework must provide explicit guidance confirming that conditions are assessed as permanent once the degenerative trajectory is established. Specialist clinical evidence must be accepted as determinative for rare conditions. The NDIA must consult with the relevant Disability Representative Organisations to confirm the appropriate treatments for each condition.

4. Plan Reassessment Restrictions (sections 47A, 48, 48A, 49, commencing 7 days after assent)

The Bill restricts unscheduled plan reassessments to situations where there is a significant and ongoing change in functional capacity. The decision timeframe is extended from 21 to 90 days. Support coordinators and providers are banned from requesting reassessments. These changes will cause serious harm to people with conditions that deteriorate rapidly, episodically, or in unpredictable steps.

- For MND, the disease trajectory is continuous decline. A person with MND cannot wait 90 days for a reassessment decision. The focus on functional capability as measured at a point in time also precludes any planning for near-future need, which is clinically essential for a condition that moves this quickly.
- For HD, the disease is episodic by nature and decline can be swift. Prolonging a review process would put our most vulnerable at significant risk. For people impacted by HD, symptomatic and carers, the burden placed on them to decide when a review is required is unreasonable and inappropriate. Dealing with government appointed decision makers can be a delayed process in itself, this may further prolong decision making and responsiveness. In addition, it is rare to have a consistent appointed guardian assigned a person and irregular visibility could result in disease progression being missed. They also may not have the understanding or skillset to recognise a persons decline and when a response is required, putting our most vulnerable at risk.

- For Parkinson's disease, documented acute events including falls with injury, onset of dementia, loss of independent swallowing or significant medication change can produce immediate and permanent step-changes in support needs. The requirement for change to be confirmed as ongoing before a reassessment proceeds means the person is receiving supports calibrated to their pre-event capacity during the waiting period. The consequences, including inadequate personal care, falls risk and avoidable re-hospitalisation, are foreseeable.
- For MS, people may have a relapse that includes a new symptom which, with appropriate care, improves. The requirement to establish ongoing change creates a trap: the change must be permanent to trigger reassessment, but for MS, what appears to be a permanent change may be an acute relapse. Time-limited supports during a relapse can make a significant difference and ultimately save costs, but they will be difficult to access under the new rules. MS Australia has documented that many people with MS are too stressed and frightened to interact with the NDIA directly. Removing the support coordinator's ability to initiate a reassessment removes a critical safety mechanism.
- For TSC, the condition has an unpredictable progression involving new organ involvement or changes in seizure control. Reduced opportunities for reassessment may prevent timely adjustments following acute deteriorations or during key developmental transitions such as the move from school to adulthood.
- For people with progressive neuromuscular conditions, including mito, reassessment is critical at multiple points of decline, including when mobility is lost, when respiratory support becomes necessary and when the need for capital items such as assistive technology or home modifications changes rapidly. The 90-day decision window and the restriction to ongoing change create dangerous delays. There are also ongoing disputes between health services and the NDIS about responsibility for certain supports, and without timely reassessment these disputes leave participants without adequate care.
- For FXTAS, the trajectory is often a period of plateau followed by unpredictable and rapid decline. Reassessments are vital where needs, including for mobility aids and therapies, cannot be predicted on a fixed timeline. The requirement that change be ongoing before reassessment is triggered does not suit a condition with this kind of trajectory.
- For Duchenne muscular dystrophy, the process for initiating reassessment when a second diagnosis is relevant, including when a person loses ambulation or develops cardiac or respiratory complications requiring new supports, is unclear. This uncertainty delays access to appropriate supports during periods of significant clinical change.
- For people with leukodystrophy conditions, the progressive and at times rapidly deteriorating nature of these diseases means that the criteria for unscheduled reassessment — requiring a “significant and ongoing change” in functional capacity — may not be met quickly enough to reflect the real pace of clinical change. Some leukodystrophies progress very rapidly. A participant may have pressing new support needs well before any scheduled reassessment date. Support coordinators, who are currently prohibited from requesting reassessments under the Bill, play a critical role in identifying and responding to this kind of deterioration. Removing this pathway creates

a structural gap that will leave some of the most vulnerable participants without appropriate support at the point of greatest need. Leukodystrophy Australia also holds significant concerns that the tightened criteria will result in loss of further individual funding, as people who do not clearly understand their plan provisions may not utilise supports during the plan period, which is then incorrectly interpreted as a reduced level of need.

- For people with epilepsy, support needs can change rapidly due to changes in seizure frequency, medication adjustments, hospitalisation, life transitions or changes in carer capacity. Tightened reassessment provisions that require change to be demonstrated as "ongoing" before a reassessment is permitted may not reflect the dynamic reality of epilepsy management, where sudden deteriorations require prompt and flexible responses. Delayed reassessment risks inadequate or unsafe support arrangements for people whose condition fluctuates significantly between assessment points. Loss of economic and social participation — which often precedes clinically visible deterioration in epilepsy — may occur before a reassessment threshold is technically met, by which time re-entry to participation is difficult and costly.
- For people with young onset dementia, support needs can escalate rapidly following behavioural changes, hospitalisation, falls or carer burnout, and delays in reassessment can translate directly into avoidable harm and prolonged hospital stays. The requirement to demonstrate "significant and ongoing" change before reassessment occurs creates a risk that people with dementia remain on plans that don't adapt to progressive decline. Many people with dementia also rely heavily on carers or support coordinators to navigate reassessment processes due to impaired insight, memory and executive functioning. Restricting reassessment pathways and extending decision timeframes will disproportionately disadvantage this group.

Recommendation: For progressive and episodic neurological conditions, documented acute events should constitute automatic grounds for reassessment without requiring confirmation of ongoing change. The 90-day decision window must not apply to conditions with documented rapid progression. Support coordinators and 3rd party consent holders must retain the right to request reassessments on behalf of participants who lack the capacity or confidence to do so. The plan suspension provision must include an explicit exemption for medical incapacity. For conditions with plateau-and-decline trajectories, reassessment rights must not be contingent on demonstrating that change is ongoing rather than acute.

4A. Automatic Plan Renewal and Plan Suspension (new sections 50A and 40A, commencing 1 February 2027 and 1 October 2026)

Two further provisions in the Bill warrant specific attention for the conditions in this submission. New section 50A introduces automatic plan renewal: when an old framework plan reaches its end date, it renews for 12 months by operation of law. The renewal replicates core supports but strips one-off capital funding — such as equipment, assistive technology and home modifications — and does not carry over unspent funds. Plan renewals are not reviewable decisions. New section 40A, commencing earlier on 1 October 2026, allows the NDIA to suspend a plan where a participant is uncontactable after reasonable attempts, and to revoke participant status entirely if there is no re-engagement within 90 days.

- The automatic renewal mechanism will be harmful for participants whose conditions require ongoing capital items that must be specifically requested and justified. For people with progressive neuromuscular conditions including Duchenne muscular dystrophy, MND, HD, mito and spinal muscular atrophy, the need for new or upgraded assistive technology — powered wheelchairs, communication devices, respiratory equipment — arises as function declines and is often time-critical. Under section 50A, capital funding does not carry forward in an automatic renewal. If a participant has not requested a new capital item before the renewal date, they lose the opportunity to roll over any unspent capital funding and must initiate a new request subject to the tighter unscheduled reassessment criteria. For conditions that progress rapidly and unpredictably, this creates a structural gap between need and funding that is not resolved by the automatic renewal mechanism.
- The plan suspension and revocation provision in new section 40A poses a direct risk to participants with cognitive decline, episodic psychiatric symptoms, vision loss due to mito or reduced communication capacity. The provision applies where a participant is uncontactable after reasonable attempts, with revocation of participant status if there is no contact within 90 days. For people with advanced Parkinson's disease involving dementia, for people with HD experiencing paranoia, social withdrawal or executive dysfunction, and for people with late-stage MS or FXTAS, being uncontactable is a direct symptom of the condition and not an indicator of disengagement or non-compliance. The provision as drafted does not distinguish between voluntary disengagement and incapacity-related unavailability. Revocation of participant status at the point of cognitive or neurological crisis is the worst possible outcome for this group: it removes NDIS access precisely when support need is greatest and reinstating access will require a new eligibility process the person is likely unable to navigate independently.
- The expanded compliance powers, including plan suspension and revocation under section 40A, may not adequately account for disability-related barriers experienced by people with epilepsy. These include hospitalisation, post-ictal cognitive impairment, communication barriers and carer crisis — all of which may render a participant temporarily uncontactable or unable to respond to NDIA communications through no fault of their own. The same risk applies to people with ME/CFS and other energy-limiting conditions, for whom an exacerbation may severely restrict their capacity to engage with administrative processes. Suspension or loss of essential supports during these periods would compound harm rather than address it. Proposed approaches to plan utilisation may also incorrectly treat unspent funds as evidence of reduced need. For people with epilepsy, ME/CFS, mito and leukodystrophy, under-utilisation often reflects health instability, hospitalisation, exacerbation or a lack of available services, not a reduced need for support. Unspent funds should not automatically trigger a reduction in future funding.
- For HD, disengagement from services, social withdrawal, executive dysfunction and paranoia toward providers are intrinsic symptoms of the disease. Some people with HD may miss appointments or disengage during periods of deterioration or psychiatric symptoms. The plan suspension provision under new section 40A, which allows plans to be revoked if a participant is uncontactable for 90 days, creates a direct risk that people with HD lose their NDIS status at the point of greatest need. Being uncontactable is a symptom of HD, not non-compliance.

Recommendation: Automatic plan renewals under section 50A must carry forward unspent capital funding where the participant has a documented progressive condition and the capital item remains clinically appropriate. The plan renewal must trigger an outreach obligation to notify participants and their nominees of the loss of capital funding so they can make timely requests. The plan suspension and revocation provisions in section 40A must include an explicit exemption where incapacity or a medical event explains the participant's unavailability; the NDIA should be required to contact the participant's nominee, carer or treating clinician before suspending a plan. Revocation of participant status must not occur where there is a documented medical basis for unavailability. There must be clear agreed guidelines for what constitutes 'reasonable attempts' when contacting a participant and the opportunity to appeal when NDIA staff do not follow these.

5. Ministerial Power, Pricing and Automated Decision-Making (sections 34A, 34B, Schedule 3)

The Bill concentrates significant new power in the Minister across pricing, support determinations and automated decision-making. These changes create material risks for people with complex neurological conditions that are poorly captured by standardised tools.

New section 34A introduces support determinations: legislative instruments that reduce funding for specified categories of support by a set percentage, applied automatically to existing plans without individual review. A participant's funding can be cut mid-plan with no individual notification, no opportunity to make representations, and no right of merits review. The only safeguard is that the Minister must have regard to participant safety, which is a procedural requirement, not a prohibition. For people relying on funded supports for falls prevention, medication management and safe nutrition, a funding cut is not an inconvenience. It is a safety risk.

New section 34B transfers pricing decisions from the NDIA Board to the Minister through legislative instruments. MS Australia is particularly concerned about the impact on Member Organisations that specialise in therapy supports, which cannot plan long-term when pricing is subject to ministerial instruments that may change without warning. Parkinson's-specialist allied health services including physiotherapy, speech pathology and occupational therapy already operate on thin margins and are in short supply, particularly in regional and rural areas. Politically driven pricing decisions introduce volatility that will disproportionately reduce access in areas where no alternative exists. The same concern applies to MND coordinator services, HD specialist services and rare disease providers whose funding viability depends on pricing certainty.

The formalisation of automated decision-making under Schedule 3 is a serious concern for conditions as complex as those in this submission. The aged care system provides a clear warning: the application of automated tools to undertake assessments for complex, heterogeneous populations produces systematic underfunding that is difficult to identify and nearly impossible to reverse at the individual level. For people with HD, automated tools that score impulsivity, apathy and aggression as behavioural concerns rather than neurological symptoms will produce systematically inadequate plans. For people with Parkinson's, MS and FXTAS, automated tools that do not account for fluctuation, on-off medication cycles or the

cognitive profile of the condition will underestimate support needs with foreseeable consequences.

Recommendation: Support determinations under section 34A must include individual notification, a 28-day period for representations and a right of merits review. Pricing instruments must remain subject to Senate disallowance. Pricing decisions must be supported by transparent modelling of the impact on specialist service viability, including for rare disease and neurological condition providers. An independent clinical advisory panel must inform pricing decisions affecting neurological and rare disease participants. Automated decisions must carry a plain-language explanation of how the outcome was reached, with a right to seek human review. Consideration should be given to moving pricing to a more appropriate body such as the Independent Health and Aged Care Pricing Authority (IHACPA).

Automated decision-making (new sections 59B–59E, commencing 7 days after assent)

Schedule 3 of the Bill creates a formal statutory framework for computer programs to make NDIA administrative decisions. New section 59B enables the NDIA CEO to arrange for automated decision-making. Decisions involving evaluative judgement are limited by a standard operating procedure (SOP) instrument to objective criteria only; fully discretionary judgements must remain with human decision-makers. New sections 59C and 59D require that notices disclose when a decision was made by a computer program, and new section 59E requires the CEO to report annually on decisions substituted by human review.

We acknowledge the disclosure and substitution-power safeguards in the Bill. However, the formalisation of automated decision-making without additional participant-facing protections creates serious structural risks for people with the conditions represented in this submission. The aged care sector offers a direct cautionary example with the introduction of the Integrated Assessment Tool (IAG): the application of a algorithmic tool to undertake assessments for complex, heterogeneous populations produced systematic underfunding that was difficult to detect at the individual level and nearly impossible to reverse once embedded in administrative practice. The IAG has caused considerable distress for older Australians and their families and the Office of the Commonwealth Ombudsman has commenced an investigation into the tool. The NDIS faces equivalent risks.

- For people with Huntington's disease, the core behavioural and psychiatric features of the condition — impulsivity, apathy, aggression, obsessive-compulsive behaviours and social disinhibition — are neurological symptoms caused by striatal degeneration, not character traits or conduct choices. Automated tools trained on population-wide patterns are unlikely to distinguish HD-related neurological behaviour from conduct that genuinely reduces assessed need. The predictable result is that automated assessments will systematically understate the support requirements of people with HD, particularly for personal care, supervision and behaviour support, and that this error will be invisible in aggregate data.
- For people with Parkinson's disease and MS, automated tools that score a single input data point will be unable to detect the on-off medication fluctuation and relapsing-remitting profiles that define these conditions' support requirements. A person with Parkinson's who provides data during a medicated "on" period will appear far more capable than their actual daily functional range. An automated system that accepts this

data as representative will produce a plan calibrated to best-case function, not real-world need.

- For people with MND, the lack of a predictive capability in the assessment process coupled with automation means a participant's imminent needs are not part of their support plan or funding package. These needs can be anticipated by a human assessor with expert knowledge of MND but will be completely missed by a focus on functional capability coupled with an automated assessment process.
- For people with young onset dementia the risk of adverse outcomes from automated administrative decisions is significant. Recent experience of the aged care Integrated Assessment Tool for people living with dementia has highlighted that needs may not be accurately captured or reflected in funding decisions. Dementia Australia have received numerous reports of people being assessed as needing less support despite clinician identification of disease progression and increasing support needs.
- For people with FXTAS, mitochondrial disease, rare neuromuscular conditions and other conditions underrepresented in large clinical datasets, automated tools will be trained on populations that do not include sufficient examples of these conditions. The SOP instrument requirement — that automated decisions involving evaluative judgement be limited to objective criteria — provides limited protection where the underlying data inputs themselves fail to capture the condition's functional profile.
- The disclosure obligation (that notices must state when a computer made the decision) is welcome but insufficient. A participant or their representative must be told not merely that a computer was involved, but what criteria the automated system applied and what input data it used. Without this level of transparency, the right to seek human review is effectively unexercisable: the participant cannot identify the error if they do not know how the decision was reached. For participants with cognitive impairment, executive dysfunction or communication difficulties — a significant proportion of people in this submission — even a clear explanation may be insufficient without active support to navigate the review process.
- For people with epilepsy, increased reliance on automation and standardised planning tools creates a particular risk of poor outcomes. Epilepsy is not well-captured by standardised assessments: seizure unpredictability, post-ictal states, recovery periods, medication side effects and the episodic but continuous nature of impact are features that automated tools are unlikely to model accurately. Decisions for people with epilepsy that rely on automated processing of standardised data are likely to produce plans that are systematically inadequate. This is especially concerning given that functional and participation decline in epilepsy often precedes clinically measurable deterioration, meaning automated tools may not flag the need for intervention until significant harm has already occurred.

Recommendation: Automated decision-making must be prohibited for any decision that requires assessment of fluctuating, episodic or energy-limiting functional profiles, or where the participant has a documented diagnosis from the conditions represented in this submission. Notices disclosing computer-made decisions must include a plain-language explanation of the criteria applied and the input data used, not merely disclosure that automation occurred. The right to seek human review must be supported by active assistance for participants with cognitive impairment or communication difficulties. The CEO's annual report on substituted decisions must disaggregate outcomes by condition type, so that

systematic errors affecting specific diagnostic groups are detectable. An independent clinical review must be conducted before any automated decision-making tools are deployed for the conditions covered by this submission.

6. Reasonable and Necessary Supports (section 34, commencing 1 February 2027)

The Bill embeds stricter criteria for reasonable and necessary supports directly into the Act, including a requirement to prioritise published peer-reviewed evidence when assessing whether a support is effective, an explicit presumption that informal supports will be maintained, and financial sustainability as a scheme object that applies to every planning decision.

- For Parkinson's disease, speech pathology using LSVT LOUD, physiotherapy using LSVT BIG and targeted exercise physiology programs have strong clinical evidence and are well-established in specialist practice. However, the evidence for individualised adaptations of these approaches and for many non-motor symptom management strategies is less developed. An over-rigid application of the published evidence requirement risks defunding clinically effective and individually appropriate supports.
- For mitochondrial disease, physiotherapy, occupational therapy and energy management programs are evidence-based and reduce acute episodes and hospitalisations, but the evidence base is limited relative to more common conditions. The requirement that published peer-reviewed evidence be prioritised will disadvantage rare conditions where the volume of research cannot match that for common conditions.
- For young onset dementia, reasonable and necessary supports must explicitly recognise maintenance, adaptation and quality of life outcomes, not only measurable functional gains. Allied health and therapeutic supports , including but not limited to occupational therapy, speech pathology, physiotherapy, psychology are essential across the dementia trajectory to maintain function as long as possible.
- For progressive neuromuscular conditions, preventative and early intervention supports including physiotherapy, respiratory management, and assistive technology are essential to managing progressive decline and avoiding costly acute hospitalisations. These supports must not be treated as discretionary under a financially driven reasonable and necessary test.
- The presumption that informal supports will be maintained rather than replaced is a serious concern across all conditions in this submission. The reasonable and necessary test already allows the NDIA to reduce supports by reference to what families can reasonably be expected to provide. HD caregiving is intensive, intergenerational and long-term, and many HD carers are already at risk of burnout or are themselves pre-symptomatic for the condition. MS caregivers face similar pressures. The Bill strengthens the NDIA's hand in treating caregiver capacity as a reason to reduce funded support, transferring the burden further onto families who are already at their limit.
- Support coordination is critical for people with cognitive impairment, including people with advanced Parkinson's, HD, late-stage MS and FXTAS. If support coordination is

subject to a ministerial support determination reducing funding in this category, participants with cognitive impairment will be directly and foreseeably harmed.

- Social and community participation funding is critically important for people with leukodystrophy and other progressive life-limiting conditions. Proposals to reduce budgets for Social and Community Participation supports are deeply concerning for this group: participation in community activities greatly improves quality of life and reduces isolation, which is a documented risk for people with progressive neurological conditions. Reduced funding in this category will likely lead to less time in the community and an increased sense of isolation, with corresponding impacts on mental health and wellbeing. The progressive and life-limiting nature of these conditions means that Social and Community Participation should be viewed as a core, not discretionary, support.
- Support coordination and plan management funding are similarly at risk of reduction in ways that will disproportionately harm people with complex conditions such as leukodystrophy, ME/CFS and epilepsy. The NDIS system is complex to navigate, particularly for people who are very unwell, exhausted and overwhelmed. Support coordination assists people to understand their plans, access their funded supports and manage their plan provisions. Loss of access to this support creates a serious risk that participants will not utilise supports they are entitled to, compounding the under-utilisation problem that is already observable in this group. Leukodystrophy Australia notes that clients who lose access to support coordination may not clearly understand their funding components, which in turn leads to under-utilisation and subsequent inappropriate funding reductions. Plan management serves a similar function in enabling access for people who cannot independently manage the administrative demands of NDIS self-management.
- Changes to provider regulation, pricing and compliance settings may disproportionately impact smaller and specialist providers, placing condition-specific supports at risk. Services such as epilepsy-specific seizure management training, education programs, navigation support and community capacity building are frequently delivered by small, specialist or regional providers that are particularly vulnerable to market exit under an unstable regulatory and pricing environment. The same risk applies to leukodystrophy, ME/CFS and rare disease providers. If specialist providers exit the market due to pricing or regulatory pressure, participants in these communities may lose access to supports that cannot be provided by generalist services. Market sustainability for thin and specialist markets requires specific consideration that is currently absent from the Bill.

Recommendation: The published evidence requirement must not be applied in a way that disadvantages rare conditions or individualised clinical approaches. Specialist clinical endorsement must be accepted as meeting the evidence standard for condition-specific programs. The presumption in favour of informal supports must not be applied where carers are at risk of burnout or are themselves managing a health condition. Support coordination must be explicitly protected for participants with documented cognitive impairment. . The NDIA must consult with the relevant Disability Representative Organisations to determine the appropriate published evidence for each condition.

7. Early Intervention and the Gap Outside the NDIS

One of the most significant problems in this Bill is the absence of any meaningful early intervention framework for conditions where timely, evidence-based support demonstrably changes functional trajectory.

The evidence base for early intervention in Parkinson's disease is among the strongest in neurology. Exercise commenced early in the disease course has been shown to slow motor progression, preserve cognitive function, reduce falls risk and delay the onset of significant disability. Speech pathology intervention before dysarthria and dysphagia become entrenched is substantially more effective than after. Yet people with Young Onset Parkinson's who are still working and managing their own households will not meet NDIS access criteria under either the current or proposed frameworks. For people living with young onset dementia, many people in earlier stages of dementia may not meet increasingly restrictive access thresholds despite clear evidence of the benefits of early access to supports to maintain function and wellbeing for as long as possible.

For people with mitochondrial disease, physiotherapy and energy management programs delivered early reduce acute episodes and hospitalisations. For people with TSC, early intervention during developmental transitions is essential for managing unpredictable progression. For people with progressive neuromuscular conditions, early access to physiotherapy, respiratory management and assistive technology is essential to preventing unnecessary loss of function and costly acute care episodes. For people with Duchenne muscular dystrophy, the window during which exercise and allied health intervention can maintain function and delay loss of ambulation is time-limited and must be supported proactively.

The Bill does not resolve the gap between the health system, which covers episodic acute care, and the NDIS, which requires significant and permanent disability. The proposed Foundational Supports framework is not designed or resourced to provide the intensity and specialisation required by these conditions. Palliative Care Australia notes that the $6 billion earmarked for states and territories for Foundational Supports is unlikely to be sufficient to meet the broader level of population need outside the NDIS, and that work to clarify the interface between the NDIS and the mainstream health system is long overdue.

The National Health Reform Agreement Addendum 2026 acknowledges the need for further work on roles and responsibilities for people with complex health conditions, but this work is not reflected in the Bill's commencement arrangements. There is currently no clarity on what supports will be available for people who do not yet meet NDIS access criteria but whose conditions are on a clear trajectory toward significant disability.

Assumptions embedded in the Bill that NDIS supports will be met by alternative mainstream and community services are unsafe for people with ME/CFS, long COVID, epilepsy, mito and leukodystrophy conditions. Mainstream and community supports for these conditions are limited or, in many cases, absent. NDIS support funding should not be reduced unless alternative supports are actually available, accessible and appropriate for the individual — not theoretically available in the system or assumed to be provided by the health system. People already living with these conditions frequently report significant fragmentation across health, disability, education and community services. Tightening NDIS access before this fragmentation is addressed will increase unmet need and push costs onto informal carers and acute health systems. The Bill assumes alternative systems will meet the needs of those

outside the NDIS, despite these people already experiencing significant gaps across health, disability, education and community supports. These gaps result in unmet need and increased reliance on informal carers who are often themselves under significant strain, supporting multiple family members and/or impacted by conditions themselves.

Recommendation: The Bill must include explicit provisions for early intervention access for conditions with established evidence of trajectory modification. The interface between the NDIS, health systems and Foundational Supports must be resolved before access criteria are tightened, so that no one falls through the gap. The NDIS-health system boundary must be formally negotiated with specialist clinical input before Schedule 1 changes take effect. The Foundational Supports framework must be co-designed with the palliative, neurological and rare disease sectors to ensure it can meet the intensity and specialisation these conditions require.

8. Priority Access Pathway

The Priority Access Pathway introduced in 2024 provides eligibility decisions within seven business days and a first plan within one month for people with rapidly deteriorating conditions. For people with MND, advanced Parkinson's, Atypical Parkinsonism including Progressive Supranuclear Palsy, Multiple System Atrophy, Dementia with Lewy Bodies and Corticobasal Syndrome, these timelines are clinically meaningful. The condition does not wait for administrative processes.

The Bill does not legislate or guarantee this pathway. It exists only as an administrative mechanism and can be altered or discontinued without parliamentary scrutiny. The new framework planning processes and the 90-day decision window introduced by this Bill are not designed with urgency in mind. If the Priority Access Pathway is not embedded in primary legislation, the progress achieved since 2024 is vulnerable to being undone as the new administrative infrastructure takes effect.

There is a related concern across palliative and life-limiting conditions. The concept of permanency has previously been applied by the NDIA to refuse access to people with terminal diagnoses on the basis that their life expectancy is short. The Priority Access Pathway addressed this for a defined cohort. The new permanence requirements in section 25A and the new functional capacity definition in section 9B create fresh risks of re-introducing barriers for people with conditions that are both permanent and terminal. Palliative Care Australia notes that it is not yet clear what the removal of diagnosis-based access lists will mean in practice for the eligibility of people with functional support needs caused by a life-limiting condition, and that the threshold and assessment process under the new framework are yet to be developed.

Recommendation: The Priority Access Pathway must be enshrined in primary legislation, with eligibility defined by documented functional decline trajectory, not solely by proximity to death. The pathway must explicitly extend to all conditions with a documented rapid decline trajectory, not only those already named in administrative guidance. The permanence provisions must not create new barriers for people with life-limiting conditions who have historically been eligible for the NDIS. The lessons of the Priority Access Pathway must be explicitly preserved in the design of the new assessment and planning framework.

9. Rights of Review and Appeal

In his speech at the National Press Club on 22 April, the Minister indicated that court and tribunal decisions have restricted the Agency's ability to implement scheme changes, and that further restrictions on review rights are likely. No specific changes have yet been announced. However, given the provisions already in this Bill that reduce or remove merits review for support determinations, and the history of incorrect decisions affecting people with complex conditions, we are deeply concerned about any further limitation of review rights.

For people with MS, Parkinson's disease, young onset dementia, HD, FXTAS and rare conditions, incorrect NDIA decisions are not uncommon. The NDIA's documented difficulty in understanding these conditions means that administrative errors are a genuine and recurring risk. The Administrative Review Tribunal and the courts have provided an essential corrective mechanism. Restricting access to these mechanisms will not reduce incorrect decisions. It will reduce the ability to identify and correct them.

The proposed changes to review and appeal processes — particularly the extended decision timeframes of up to 90 days — are unreasonable for participants managing inadequate or inappropriate plans. Expecting individuals and their support networks to endure up to 90 days under a plan that does not reflect their actual needs places undue strain on the wellbeing of participants and their carers, and creates foreseeable risks to safety and health. For people with rapidly progressing conditions such as MND, or with episodic conditions where support needs can change suddenly, a 90-day waiting period for a review decision is not a minor administrative inconvenience. It is a gap in essential support that carries real consequences. This concern has been raised by Neuromuscular WA and reflects the experience of people across our broader membership.

The introduction of automated decision-making compounds this concern. If automated tools produce systematically incorrect outcomes for complex conditions, and the right to challenge those outcomes is reduced, the harm is not isolated to individual cases. It is structural.

Recommendation: Any proposed changes to rights of review and appeal should be subject to full public consultation before introduction. Changes that reduce or remove merits review rights for decisions affecting people with disability must be accompanied by independent oversight mechanisms and transparent reporting on decision accuracy. The Bill should not be read as authority to limit review rights without further specific legislation. Additionally, a greater focus on improving the NDIA's workforce and administrative processes, would significantly reduce the need for review and improve outcomes for participants.

10. Fraud Measure Impacts on Participants with Cognitive Impairment (Schedule 2, sections 45A, 45B and 46)

Schedule 2 of the Bill introduces measures primarily directed at providers, including expanded NDIA enforcement powers, a requirement to retain records for seven years (providers) or three to five years (participants making claims), and a reduction in the claim lodgement window from two years to 90 days. These changes take effect 7 days after assent, with the 90-day claim timeframe commencing 1 December 2026. While the fraud measures serve a legitimate purpose, their application to self-managing participants with progressive neurological conditions raises concerns that have not been addressed elsewhere in this submission.

- The 90-day claim lodgement window creates a compliance burden that will disproportionately affect participants with cognitive impairment, executive dysfunction, or hospitalisation. Self-managing participants with advanced Parkinson's disease, HD, late-stage MS, mito or FXTAS may not have the cognitive capacity to track and lodge claims within 90 days without active support. People who experience hospitalisation, acute medical events or psychiatric episodes during the 90-day window may miss the deadline through no fault of their own. The previous two-year window provided reasonable tolerance for these circumstances; the 90-day window does not. Late claims will simply not be paid, meaning the participant loses funding for supports that were legitimately received.
- The mandatory record retention obligation under new sections 45A and 45B requires participants who make claims directly to retain records for three to five years. Failure to do so is a new civil penalty and can result in recovery of paid amounts as a debt. For self-managing participants with progressive cognitive decline, the administrative burden of maintaining compliant records over a multi-year period is not trivial. The risk is that participants who are managing their own plans — often a positive indicator of independence and agency — are exposed to enforcement action or debt recovery based on an inability to satisfy record retention requirements, rather than any fraudulent intent. This is a particularly acute concern for participants with HD or advanced Parkinson's who chose to self-manage when cognitively capable but whose capacity to maintain records has since declined.

Recommendation: The 90-day claim window must include an extension mechanism for participants who experience a medical event, hospitalisation or acute incapacity during the claim period, with a minimum extension of 90 days upon documented application. The record retention obligation must include a capacity-based exemption, so that participants with documented cognitive impairment are not subject to civil penalties or debt recovery where non-compliance results from that impairment rather than deliberate conduct. The NDIA should provide active record-keeping support to self-managing participants with progressive cognitive conditions, rather than treating compliance failure as an enforcement matter.

Conclusion

The conditions represented in this submission share a defining characteristic: they do not plateau. They progress. People who rely on the NDIS with Parkinson's disease, MND, HD, MS, mitochondrial disease, Angelman syndrome, TSC, FXTAS, Duchenne muscular dystrophy and related progressive neuromuscular conditions are, by definition, managing disability that will increase in severity over time. The NDIS has provided many of these Australians with something no other system has offered: support that can move with them as their condition changes.

The Bill, as drafted, risks dismantling the features that make the scheme work for this group. Tighter reassessment criteria will leave people receiving supports calibrated to their pre-crisis capacity for months after a significant change. A functional capacity assessment that cannot capture fluctuation, energy limitation, medication cycles or rapid progression will systematically underestimate need. Ministerial funding instruments with no right of review will cut plans without individual consideration. The Priority Access Pathway, which has genuinely improved outcomes for people with rapidly deteriorating conditions, has no legislative protection.

We support a sustainable and well-managed NDIS. But we are opposed to a scheme that achieves sustainability by systematically excluding and under-supporting the people with the most complex, least understood and most rapidly changing conditions in Australia. Sustainability built on this foundation is not genuine sustainability. It is cost transfer to unpaid carers, health systems and families.

We call on the Committee to recommend the following:

- Require functional capacity assessments to capture fluctuation, energy limitation, medication effects, treatment-dependent variability and post-exertional impact, using multiple time points and clinical specialist evidence.
- Make the NPRAG testing partnership for the support needs assessment tool substantive, public and binding on deployment, with explicit testing for conditions with fluctuating, episodic, energy-limiting and poorly characterised manifestations.
- Confirm that symptomatic management, including medication and disease-modifying treatments, does not satisfy the permanence test for conditions where no curative treatment exists. Exclude experimental and surgical interventions from the treatment exhaustion requirement where individual clinical grounds exist.
- Restore support coordinator rights to request reassessments on behalf of participants who cannot do so, and set a 21-day decision window for conditions with documented rapid progression.
- Require individual notification and a right of merits review for all support determinations under section 34A. Keep pricing instruments subject to Senate disallowance and establish an independent clinical advisory panel for specialist and rare disease service pricing.
- Prohibit automated decision-making for participants with fluctuating, episodic or energy-limiting conditions. Require that computer-made decision notices include a plain-language explanation of the criteria applied and data used, not merely disclosure of automation. Ensure active assistance for participants with cognitive impairment seeking human review. Require the CEO's annual report to disaggregate substituted decisions by condition type, and mandate an independent clinical review before automated tools are deployed for the conditions covered by this submission.
- Require automatic plan renewals under section 50A to carry forward unspent capital funding for participants with documented progressive conditions. Require NDIA outreach to nominees and carers before suspending or revoking plans under section 40A where there is a documented medical basis for unavailability.
- Include a medical event extension mechanism in the 90-day claim window for participants who experience hospitalisation or acute incapacity during the claim period. Include a capacity-based exemption in the record retention obligation so that participants with documented cognitive impairment are not subject to civil penalties where non-compliance results from that impairment.
- Resolve the NDIS-health system interface before tightening access criteria, and establish an early intervention pathway for conditions with evidence of trajectory modification.

- Legislate the Priority Access Pathway with eligibility based on functional decline trajectory, not solely on proximity to death, and extend it to all conditions with a documented rapid decline trajectory.
- Ensure any proposed restrictions on rights of review and appeal are subject to full public consultation and do not take effect under this Bill.

We are available to provide oral evidence and to meet with the Committee and officials. We welcome the opportunity to work constructively toward a scheme that is both financially sustainable and genuinely fit for the people it was designed to serve.

Prepared by Olivia Nassaris, Co-chair of the Neurodegenerative, Palliative Care and Rare Diseases Advisory Group of the NDIA.

Contributions from Parkinson's Australia | MS Australia | MND Australia | Dementia Australia Huntington's Australia | Mito Foundation | Angelman Syndrome Australia Tuberous Sclerosis Australia | Palliative Care Australia | Parent Project Muscular Dystrophy |Muscular Dystrophy Australia | Fragile X Association of Australia Duchenne Foundation Australia | Leukodystrophy Australia | Neuromuscular WA Epilepsy Action Australia | Emerge Australia