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NDIS Rules Public Consultation March 2026

EXECUTIVE SUMMARY

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Feedback on NDIS New Framework Planning Rules & Consultation

At Parkinson's Australia, we understand the profound impact that NDIS supports have on the lives of people living with incurable conditions, Parkinson's or Parkinson's Plus (e.g. MSA, PSP, LBD, CBD). Hereafter referred to as PwP or Parkinson's, respectively.

This submission provides critical feedback on the proposed New Framework Planning Rules and the associated transition process for PwP aged 65 and younger, their families, and care partners. While the new framework plans are designed to make NDIS planning clearer and more transparent, specific safeguards are required to address the progressive, neurodegenerative, whole-body and fluctuating nature of Parkinson's or Parkinson's Plus.

Step 1: Preparing for a support needs assessment

- **Information shared:** It is a critical failure in the accessibility of technical documentation, which lacks "Easy Read" formats for this consultation. Also, any information developed to give PwP participating in Step 1 must be easy to read and take into account limited dexterity, voice problems and communication issues.
- **Impairment notices:** If Parkinson's is categorised under "neurological" impairments, the NDIA must consider the holistic interaction of over 40 motor and non-motor symptoms when assessing PwP's functional capacity, especially when a participant seeks to vary their notice due to the progressive nature of their condition.
- **Transition timing:** Participants aged 16 and older will begin transitioning to new framework plans from 1 July 2026. We think this is too soon to bring this in without proper co-design of the process. When it is implemented, clear, trauma-informed communication is essential to support the community through this five-year transition window.

Step 2: Support needs assessment

- **Assessment tool suitability:** There are significant concerns regarding the ability of the I-CAN version 6 tool to accurately capture the support needs of those with progressive and complex neurological conditions like PD, MSA, PSP, CBD & LBD.
- **Assessor expertise:** Assessors must possess specialised knowledge of Parkinson's symptoms, which are episodic ("on/off" periods); a snapshot assessment often fails to capture the "worst-day" functional impact. Training could be gained through the Parkinson's MOOC, and further consultation with the national Peak Body is needed.
- **Transparency:** Participants must have access to raw assessment scores and detailed descriptions of support needs for each sub-domain to understand how their budget will be created.

Step 3: Building the plan

- **Prioritising functional maintenance:** We strongly support rules that allow for funding to be used specifically to "slow the decline" of functional capacity. For PwP, early and consistent access to a multidisciplinary care team with AHPs is a critical intervention.
- **Safeguarding care partners:** Informal support should not be included in the plan. The inclusion of Short-term Respite as a stated support is a vital protection for informal care partners, ensuring they can sustain their support role without reaching burnout.
- **Funding period flexibility:** While funding periods (e.g., 1, 3, or 6 months) are intended to assist with budgeting, they must not restrict access to supports for those with fluctuating or episodic impairments that may progress quickly, like a Parkinson's Plus condition or be an increased administrative burden for PwP and their care partners.

Step 4: Using the plan

- **Responsive variations:** The rules must ensure that plan variations can be processed rapidly in response to a "significant change in support needs," such as a sudden decline in mobility, a change in diagnosis (Parkinson's has no biomarker and can be mistaken for Parkinson's Plus conditions) or other health crisis (e.g. falls, new symptom arises).
- **Implementation support:** We recommend that implementation meetings be prioritised for participants with complex neurological needs to help them navigate their new budgets and create a multidisciplinary care team (e.g. OT, Physio, AEP, specialist nurses, Urologist).

Parkinson's Australia is the national peak body, voice & advocate representing over 150,000 people living with Parkinson's & Parkinson's Plus conditions, their families, carers, researchers, & health professionals. We connect communities & promote awareness to support those affected in living well & independently.

Parkinson's Australia represents one of the most vulnerable groups in NDIS – those diagnosed with Parkinson's or Parkinson's Plus conditions (e.g. MSA, PSP, LBD, CBD). These are progressive, neurodegenerative, incurable conditions that have debilitating motor (slow movement, rigidity, tremor, gait changes) & non-motor symptoms (e.g., sleep, continence, vision, fatigue, apathy) that significantly impact their daily activities.

- **The number of people living with Parkinson's is projected to more than double by 2050, driven primarily by population ageing. (1)**
- **There are more than 1,100 Aussies under 65 who develop young onset each year. Only 16% of all those living with YOP have an NDIS approved plan. (2)**
- **Parkinson's impacts our economy and healthcare systems at a cost of over $10 billion each year. (3)**
- **The mean annual cost per person to the health care system was $32,556 AUD. The burden to society was an additional $45,000 per annum per person with Parkinson's. (4)**
- **Early intervention strategies have been shown to reduce costs in the long-term for people living with Parkinson's.**

We are concerned that the new rules will not accommodate the needs of people managing complex conditions such as incurable, neurodegenerative, progressive, whole-body disorders like Parkinson's and the much faster progressing Parkinson's Plus conditions.

Introduction

There are an estimated 30,000 people under the age of 65 living with Parkinson's in Australia. (5) Though they are living with a life-limiting disability, less than 10% are on NDIS as of 2021, according to the NDIS report. (2) In 2022, 39.4% of people with disabilities aged under 65 reported needing more formal assistance than they were receiving. This highlights a significant barrier to access schemes like the NDIS. (8)

Drawing on peer-reviewed literature, lived experience, and insights from Parkinson's Australia and the Young Onset Parkinson's Exchange, we show that access to NDIS is not only clinically beneficial but also cost-effective over time. NDIS will help PwP maintain independence, reduce long-term care costs and carer burden, and improve overall quality of life.

Understanding Parkinson's

Over 150,000 people are living with Parkinson's in Australia. Fifty Australians are diagnosed every day. Young Onset Parkinson's makes up to 20% of all people living with Parkinson's (i.e. being diagnosed in their 20s to 50s). (5)

Parkinson's is a progressive, whole-body, neurodegenerative condition that affects not only movement, but also mood, sleep, voice, vision, and both the gastrointestinal and autonomic systems.

The pathophysiology of Parkinson's is complex and involves multiple chemical messengers (neurotransmitters), resulting in many changes to a person's normal functioning and everyday life (6).

Many Parkinson's symptoms are caused by the loss of neurons that produce chemical messengers in the brain. The main messenger involved is called dopamine, which regulates mood and movement.

Decreased dopamine leads to irregular brain activity. When 60% to 80% of these dopaminergic neurons are lost, this causes the hallmark movement symptoms of slowness, rigidity, and one-sided tremor.

People with Parkinson's also lose a chemical messenger called norepinephrine that controls many automatic body functions, such as blood pressure, continence and temperature regulation (7).

While no biomarker currently exists for this suite of conditions, early signs of Parkinson's include a reduced or loss of sense of smell, unexplained depression, apathy and/or anxiety, sleep issues, chronic constipation and handwriting changes years before movement difficulties.

Step 1: Preparing for the support

"Easy Read" formats of supporting documents are missing from the consultation and should be an integral part of the information presented to PwP starting this process. They are highly technical and not suitable for PwP as is.

The new process changes how NDIS needs are assessed, how budgets are calculated, and how flexibility and restrictions are applied to the supports you are determined eligible for.

There is also a lack of transparency from the NDIA about how the agency determines what category or categories the participant meets (i.e. intellectual, cognitive, neurological, sensory, physical, psychosocial).

Parkinson's impacts at least 31 unique functional domains, including impacts to movement, cognitive impairment, mood changes (depression, anxiety, apathy), vision, speech and sleep issues, and autonomic dysfunction (blood pressure changes, inability to regulate temperature). However, every PwP has a different constellation of symptoms with no two people progressing in the same way or at the same rate.

Parkinson's Australia argues that this holistic approach must be the default from the very first Step 1 assessment, ensuring that the "unpredictable," "unique" and "progressive" nature of these conditions are fully captured in the initial impairment categories and flow through choice and control of supports.

Also, the assessor must be aware of Parkinson's "on/off" fluctuations. If an assessor met someone for just one hour, critical support needs would likely be missed if the PwP was in an "on" (medication working phase). PwP would be more communicative (less word-finding and more animation in their face), have less tremor (if they have them at all, as only 70% have a resting tremor).

Participants begin transitioning to the new framework plans from 1 July 2026 without proper co-design of the process and documents. Key details around timelines for notification and when participants would join the phased rollout are unclear.

When it is implemented, clear, trauma-informed communication is essential to support the community through this five-year transition window.

Lived Experiences

"While I may primarily be viewed as "Neurological," the bradykinesia and rigidity are Physical, the fatigue and executive dysfunction are Cognitive, and the anxiety and depression I experience are Psychosocial. As my disease progresses, NDIS must consider my functional capacity holistically, looking at how these different impairments interact rather than assessing each new symptom in isolation."
— Man living with YOP

My husband didn't have the bandwidth to take the online survey, but I did. I have a master's degree, and the information was either too technical or just lacking for me to fully understand the proposed process enough to make valuable critiques. I found it very frustrating to get through. Overall, the process seems similar to the current one, but the lumping of people into impairment categories seems fraught.
— Care partner of a Man living with YOP

Step 2: The support needs assessment

We are not confident at all in the suitability of the I-CAN tool or the level of assessor expertise needed to correctly identify the complex supports for someone living with a fluctuating and progressive condition like Parkinson's, and, therefore, that either would be able to assign the support needed for early intervention.

Assessors must possess specialised knowledge of Parkinson's symptoms, which are episodic ("on/off" periods); a snapshot assessment often fails to capture the "worst-day" functional impact.

When you're newly diagnosed or new to the NDIS, it's very common not to know what supports you need. Parkinson's changes over time, and you may not yet have the experience to confidently identify what will help day-to-day. The NDIS should allow space for a participant to explore their needs with the help of clinicians, allied health providers, peer groups and lived experience organisations. When a participant isn't yet sure what types or frequency of supports are required, the NDIA should take into account best-practice clinical recommendations. Early plans need flexibility, review points and guidance so people can figure out what will genuinely help them live well.

There also needs to be space for existing participants to outline the supports that genuinely make daily life manageable. This practical, lived experience should carry more weight than a standardised test and be heavily weighed by NDIA assessors.

Participants must have access to raw assessment scores and detailed descriptions of support needs for each sub-domain to understand how their budget will be created.

Lived Experiences

"Support offered through our LAC was abysmal. They had no understanding of all the areas of daily life affected by living with Parkinson's, let alone the basic non-motor symptoms. My husband was also "on" at the time of the planning meeting, so appeared fit, well and was feeling positive. Both these things meant that our plan was sorely undercalculated, and we ran out of core support five months before the next plan rolled over. I am worried about the lack of expertise by NDIS Assessors, and doubtful that a standardised tool can manage the complexities of a condition like Parkinson's."
— Care partner of a Man living with YOP

"Having an AEP on my care team provides me with a tailored, early intervention exercise program that addresses my particular symptoms and one-sidedness. It helps me achieve my goals for physical fitness and mobility while reducing pain, stiffness and bradykinesia."
— Man living with YOP

"The AEP takes some of the mental load off me by programming appropriate workouts and tracking my progress... I struggle with fatigue and apathy... but I strive to make that appointment, whether I feel motivated to go or not."
— Woman living with YOP

Step 3: Building a plan

Parkinson's disease is a progressive, incurable, multisystemic, neurological condition. It is characterised by the permanent and progressive degeneration of dopamine-producing neurons. For the over 150,000 Australians living with Parkinson's, symptoms are heterogeneous and fluctuate hourly, often described as "on/off" periods. For PwP, no change in symptoms over time is a superior outcome, as the condition inherently progresses toward greater disability as symptom severity increases or more symptoms arise.

Using a plan while trying to navigate this stage of life with Parkinson's (i.e. maintaining a career, kids, ageing parents, your relationship and social life) is very difficult if the care team services are not near you or do not fit around accessing out-of-work hours.

The planning rules should not count on unpaid carers when working out a person's budget. Living with Parkinson's often means support needs change over time, and it is not fair to assume that family or friends can always step in. Relying on informal care as the default puts too much strain on households, leads to exhaustion, affects people's health, relationships and can limit their ability to stay in work or school.

A support plan should be built on what the person actually needs, not on the idea that those around them can provide ongoing care for free. Paid supports must be properly funded so PwP can stay safe, have stable and reliable help, and avoid placing extra pressure on those close to them. Formal supports also create more sustainable arrangements in the long run.

Lived Experiences

"Support offered through allied health has improved my quality of life, and I believe allowed me to retain independence and confidence as a mother, social worker and community member."
— Woman living with YOP

"The EP takes some of the mental load off me by programming appropriate workouts and tracking my progress... I struggle with fatigue and apathy... but I strive to make that appointment, whether I feel motivated to go or not."
— Woman living with YOP

"Having extra support around the house is invaluable. It keeps me employed full-time and reduces my caregiver burden. With two kids and a husband with Parkinson's, there's always a lot to do, keeping up with appointments, logistics, medications, laundry and housework. Having someone able to come in and mop the floors is such a big help."
— Care partner of a Man living with YOP

Step 4: Using a plan

We strongly support rules that allow for funding to be used specifically to "slow the decline" of functional capacity. For PwP, early and consistent access to a multidisciplinary care team with AHPs is a critical intervention.

The inclusion of Short-term Respite as a stated support is a vital protection for informal care partners, ensuring they can sustain their support role without reaching burnout.

While funding periods (e.g., 1, 3, or 6 months) are intended to assist with budgeting, they must not restrict access to supports for those with fluctuating or episodic impairments that may progress quickly, like a Parkinson's Plus condition or be an increased administrative burden for PwP and their care partners.

There is also a need for rapid variations and specialised navigation, which is often due to the recognisable Parkinsonisms (i.e. motor symptoms like tremors, rigidity, and bradykinesia) worsening or causing falls.

We recommend that implementation meetings be built-in and prioritised for participants with complex neurological needs to help them navigate their new budgets and create a multidisciplinary care team (e.g. OT, Physio, AEP, specialist nurses, Urologist). (18, 19)

One size does not fit all. NDIS access, plans and goals should be carefully prescribed for each individual with Parkinson's or Parkinson's Plus conditions, taking their impairments, disease severity, family situation, fall risk and goals into account. As an individual's symptoms progress or get added over time, their plan will need to be reviewed and updated to meet their changing needs and ensure their safety. (20)

Lived Experiences

"The results of my ongoing Exercise Physiology sessions with (my AEP) have been truly life-changing:

- My strength, agility, balance, and coordination have returned.
- My cognition, multitasking, and daily function have dramatically improved.
- My painful spasmodic episodes are now minimal.
- My blood pressure and cardiovascular symptoms are more stable and closely monitored.
- My confidence, mood, and independence have all improved.

As a direct result, I have remained safely at home, avoided further hospital admissions, and maintained my independence — key goals of both my NDIS plan and my personal wellbeing."
— Woman living with YOP

"The Plan Manager is supposed to lift the administrative burden on me and my wife, who would otherwise have to organise these things. However, we are finding that cross-checking for accuracy and the additional 'asks' from the PM make it just as burdensome as if we were doing it ourselves."
— Man living with YOP

These testimonials highlight how the process must take into account lived experience and be patient-centred from the start.

Responses to Consultation Questions

Step 1: Preparing for the Assessment
Q: Is there additional information you think participants should receive during Step 1?

- **Response:** Participants must receive clear guidance on how the NDIS accounts for fluctuating symptoms and episodic impairment. In PD, mobility can change hourly based on medication cycles ("on/off" periods). A "worst-day" baseline is required for accurate funding.
- **Evidence:** Research confirms that motor function and speech are highly variable and sensitive to environmental stressors, needing a long-term view rather than a clinical snapshot.

Step 2: The Support Needs Assessment
Q: What additional information is important to include in the report?

- **Response:** We strongly recommend including raw assessment scores and a description of support needs for each sub-domain.
- **Circumstances for a Replacement Assessment:** An assessment must be replaced if it failed to capture non-motor symptoms (e.g., fatigue, cognitive load) or if the assessor lacked expert neurological knowledge.
- **Evidence:** Successful integrated care for Parkinson's requires expert knowledge as a primary facilitating factor. Without it, subtle but disabling symptoms like hypomimia (facial masking), fatigue or "internal" slowness are frequently missed.

Step 3: Building a Plan
Q: Do you have any concerns or questions about the examples of the types of stated supports?

- **Response:** We strongly support Short-term Respite as a stated support to prevent caregiver burnout, which research shows increases over time even if the patient's clinical state is stable.
- **Sustainability of Informal Supports:** Budget rules should not reduce funding based on informal care. Instead, they should "strengthen the sustainability of informal supports" by building the capacity of the carer.
- **Maintenance Funding:** We support restrictions on flexible funding if they mandate access to therapies that "slow the decline" of functional capacity.
- **Evidence:** Intensive, high-amplitude protocols (like LSVT BIG) have been proven to "recalibrate" movement patterns, allowing participants to dress 18 seconds faster and improving balance significantly more than general care.

Step 4: Using a Plan
Q: Is there additional information you think participants should receive during Step 4?

- **Response:** Participants require a "Roadmap of Services". Given the complexity of Parkinson's, an implementation meeting should be mandatory to connect participants with a multidisciplinary care team.
- **Evidence:** Integrated care models involving a single point of coordination (e.g., a specialist nurse, social worker or care coordinator) reduce patient depression and improve resource access.

FINAL SUMMARY: Parkinson's Australia Submission to the NDIS Rules Public Consultation

There is a concern that the NDIS's 4-step process will not capture the unique challenges of a progressive, multisystemic, and fluctuating condition like Parkinson's or Parkinson's Plus conditions (hereafter Parkinson's), and whether the "Notice of Impairments" accurately captures the breadth of neurodegenerative conditions.

For PwP aged 65 and younger, the NDIS must shift its evaluative framework to suit progressive, neurodegenerative, and incurable conditions. Standard disability models often prioritise "improvement" to reduce long-term support. However, in Parkinson's and Parkinson's Plus conditions, scientific research states that no change in symptoms over time is a "great outcome" and a primary goal of intervention.

Parkinson's is a multisystemic condition impacting at least 31 unique functional impairments across five distinct domains:

- **Neurological/Physical:** Bradykinesia ("moving through sludge"), rigidity, tremors, and freezing of gait.
- **Cognitive:** Declines in executive function, attention, cognitive fatigue, and mental flexibility.
- **Psychosocial:** Depression, anxiety, and apathy affect over 90% of the Parkinson's community.
- **Autonomic/Self-Care:** Dysphagia (swallowing), continence, sialorrhea (drooling), loss of temperature regulation, orthostatic hypotension, lack of fine motor skills, and severe fatigue are also impacts of PD.
- **Communication:** Up to 90% of PwP experience reduced vocal loudness and imprecise articulation. Word-finding is another cognitive impact.

Articulating how NDIS Assessors will deal with the breadth of symptomology in the impairment notices and the need for someone to understand the complexity of these conditions is integral to having a true representation of support needs.

Recommendations & Key Action Items

1. **Meaningful Co-Design:** The NDIA must engage in true co-design with PwP and the neurological sector before implementing the New Framework in mid-2026.
2. **Specialised Training:** Mandatory training for NDIA Assessors and Delegates on progressive neurological conditions, specifically focusing on symptom fluctuation and the "maintenance" model of care; or assessments must be conducted by professionals with expert neurological knowledge.
3. **Transparency:** Participants must receive raw assessment scores (e.g., I-CAN) and a copy of the draft support needs assessment report to review for errors before it is finalised.
4. **Maintenance as success:** Rules must explicitly recognise that supports intended to "slow the decline" or maintain functional capacity are reasonable and necessary, even in the absence of "improvement".
5. **Accessible information:** Consolidate all technical rules and explanatory materials into a single, easy-read, plain-language guide.
6. **Safeguarding care:** Informal supports must not be used to justify budget reductions; they should be treated as an optional contribution to ensure carers' wellbeing. As is including Short-term Respite as a stated support in the plan.
7. **Responsive variations:** Plan variations must be processed rapidly in response to a "significant change in support needs," such as a sudden decline in mobility, a change in diagnosis or other health crisis.
8. **Implementation support:** Implementation meetings must be prioritised for PwP to help them navigate their new budgets and establish a multidisciplinary care team.

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