Submission to the Department of Health, Disability and Ageing
Public Consultation on the NDIS Support Coordination and Connection Reform

Date: 1 October 2026

1. Executive Summary

Parkinson's Australia is the national peak body for the more than 150,000 Australians living with Parkinson's disease and Atypical Parkinsonism. An estimated 13,400 of them are of working age (Mellick, 2024). We welcome the chance to respond to the consultation paper on the proposed NDIS Support Coordination and Connection (SCC) service (Department of Health, Disability and Ageing, 2026).

Our response draws on *Your Voice, Your Needs,* our national community survey (N = 2,649). It heard from 1,692 people living with Parkinson's and 871 carers (Parkinson's Australia, 2026). In that survey, 47.0% of respondents said they need help to find their way through health and disability services. The figure rises to 66.7% among younger respondents and 50.0% among people in regional, rural and remote areas. Help with coordination is one of the most common unmet needs our community reports.

We support the aims of the reform: better quality, more consistent practice and stronger safeguards. Our main concern is that the early design is built around people whose needs are stable and predictable. Parkinson's and Atypical Parkinsonism do not behave that way. Needs can change within a day, shift over a few months and, for some conditions, rise quickly. A service that responds well to this will work for our community. One that does not will leave the people with the greatest need waiting for a crisis before they get more help.

What we are asking for

- Eligibility and service level should be decided on the pattern of a person's needs over time, including fluctuation and expected progression. The paper's factor of "stability and predictability of support needs" must not count against people whose needs are unstable because of their condition.
- People with Atypical Parkinsonism and other rapidly progressive presentations should have timely access to SCC+ without having to show a crisis first and should be able to move between SCC and SCC+ quickly as needs change.
- Commissioning should use a mixed model. Regional lead organisations would deliver general SCC, and a specialist neurological stream would deliver SCC+ across regions. Participants should be able to change provider.
- Where a lead organisation is used, it must be required to keep working links with neurologists, movement disorder specialists, Parkinson's nurses and multidisciplinary clinics.
- SCC workers supporting people with progressive neurological conditions should be trained in motor fluctuation, cognitive fatigue, communication impairment and autonomic dysfunction.

- The transition should protect trusted relationships, give at least three months' notice and funded handover, and avoid any gap in coordination for people whose condition is advancing.
- Face-to-face and virtual delivery should both be available, chosen with the participant. Carer input should be formally recognised.
- Payment should reflect complexity and location and should allow more intensive support at key points of change such as diagnosis, a significant decline or a hospital admission.
- Complaints and safeguarding processes must work for people with speech, cognitive and fatigue-related barriers, and SCC workers must respect existing supported decision-making arrangements.

2. Why Condition-Specific Design Matters

Parkinson's is a progressive neurological condition with motor and non-motor symptoms. Medication effects can wear off between doses, so a person may function well in the morning and struggle by the afternoon (Poewe, 2017). Fatigue, slowed thinking, soft speech and reduced facial expression are common, and they often hide how much a person understands. A person can look fine in a one-hour meeting and be unable to follow through on what was agreed that afternoon.

Atypical Parkinsonism covers four conditions that usually progress faster than Parkinson's and respond poorly to Parkinson's medication. Each creates different coordination work, as the table below shows.

Condition	What it means for coordination
Progressive Supranuclear Palsy (PSP)	Falls, eye movement problems, speech and swallowing difficulty, and changes in thinking and behaviour. Needs can rise quickly and involve several health and disability services at once.
Multiple System Atrophy (MSA)	Blood pressure drops, bladder and bowel problems, speech and swallowing change, and movement symptoms. Needs often move from home support to equipment and care in a short time.
Corticobasal Degeneration (CBD)	Stiffness and loss of use in one limb at first, then wider loss of movement, with speech, language and thinking changes. Equipment and communication supports need frequent review.
Dementia with Lewy Bodies (DLB)	Thinking that varies hour to hour, hallucinations, sleep disturbance and movement symptoms. Decision-making support and carer input are central, and some medications need care.

A coordinator who does not know this will find it hard to anticipate what comes next. They will also struggle to tell when a quiet period means stability and when it only means a person is too tired to ask for help.

3. Evidence Base: Your Voice, Your Needs

Your Voice, Your Needs ran nationally between January and March 2026. It received 2,649 responses from people living with Parkinson's, carers, and people who are both (Parkinson's Australia, 2026). The findings below bear directly on the design of SCC.

Impact measure	Survey finding
Access to healthcare difficulty score (0 to 100, where 100 is impossible)	55 / 100
Respondents needing help to find their way through health and disability services	47.0%
Younger respondents with higher mental health, financial and navigation needs	66.7%
Regional, rural and remote respondents needing navigation support, compared with metropolitan respondents	50.0% compared with 46.2%
Carer support needs, women compared with men	44.5% compared with 31.1%
Respondents needing daily living support	59.9%

People described the current system in their own words.

> *"Someone to help with the organisation and application process... patients are too tired to manage this alone."*
>
> *"They didn't tell me what services are available. I found out by chance."*
>
> *"NDIS very difficult to access."*

These comments describe the problems the reform is meant to fix: scattered pathways, uneven quality, and a system that relies on the participant, or an exhausted carer, to hold everything together.

4. Our Position on the Main Proposals

Before answering the consultation questions, we set out where we agree with the paper and where we have concerns.

Proposal in the paper	Parkinson's Australia position
Eligibility factors, including stability and predictability of support needs	We support using several factors. We are concerned that unpredictable need could be read as a reason for a lower level of service. For our community, unpredictability is a reason for more responsive support, not less.
Two service levels: SCC and SCC+	We support two levels. SCC+ must be explicitly open to people with progressive neurological conditions and rapid decline. "A small proportion of participants" should not become a cap that leaves out Atypical Parkinsonism.
Providers manage changes "within their service capacity"	These need defined triggers and timeframes for moving a person between SCC and SCC+. Without them, a provider at capacity has no way to respond.
Preferred lead organisation model	We can support it only with enforceable access to specialist expertise and a right for participants to change provider. We prefer a mixed model with a specialist SCC+ stream.
No funding for support coordination in the plan	We understand the intent. It removes a lever participants now use to choose and change coordinator, so the new model must replace that choice in practice.

Proposal in the paper	Parkinson's Australia position
SCC workers cannot provide other NDIS supports	We support this. Conflicts of interest between coordination and direct service delivery are a real risk for our community.
Move away from hourly fee-for-service payment	We agree hourly payment can under-serve people with complex needs. A flat rate would make this worse for people whose needs rise and fall.
Start date of 1 July 2028	The timeline is workable only if handover is funded and relationships are protected. People with fast-moving conditions cannot wait through a gap.

5. Questions About What Participants Want From the New SCC Service

1. What is working well in support coordination today that you would like to see in the new SCC service?

Support coordination works well for people with Parkinson's when the coordinator understands that the condition is progressive and fluctuating, the needs for support are multidisciplinary for a holistic care team and all modalities need to be engaged. Support coordination cannot be from the sidelines for someone with Parkinson's or Parkinson's +. They need to have built a relationship over many contacts instead of a single assessment. Coordinators who keep in touch with a person's neurologist or movement disorder specialist, and who help a person plan for the next change before it arrives, are valued highly. The new service should keep and formalise these practices instead of starting again from a blank page.

2. What would you most like to see improved in the new SCC service?

The biggest gap is consistent knowledge of the condition. Many people with Parkinson's tell us they have to explain their condition, including the symptoms others cannot see, to a new worker each time something changes. High turnover and hourly billing add to this. Billing by the hour can lead to under-servicing when a person's needs look steady on paper but are not steady in daily life.

We would like the new service to cut the number of times a person must retell their story. Success should be measured by whether support keeps pace with the condition, and not only by whether a set number of hours was delivered.

3. When should SCC be a face-to-face service or a virtual service?

Both matter, and the mix should be agreed with the participant. Face-to-face contact is important at first engagement, at diagnosis, after a major change in condition and for people receiving SCC+. In person, a worker can see how someone moves around their home, notice what has changed and read cues that a video call can miss.

Virtual contact can save a person with fatigue or mobility problems a long trip, which matters most in regional and rural areas. It should be offered as a real choice and should never be used to cut contact time. It should not be the default for a first meeting or for a person whose condition has just changed.

4. What participant groups will benefit most from the SCC service? What do their needs for connection and coordination of supports look like?

- People with Atypical Parkinsonism (PSP, MSA, CBD and DLB) usually progress faster than people with Parkinson's. They need SCC+ to keep pace with changes in mobility, communication, swallowing and thinking.

- People with young onset Parkinson's need coordination that supports work, study and family roles as well as care needs. Our survey found younger respondents had the highest navigation needs.
- People in regional, rural and remote areas need a coordinator who can link them to distant specialists and cover the gaps between appointments.
- People with cognitive or communication impairment need a coordinator who works with the person and their support network together and does not assume the person can direct every conversation alone.
- Carers, who currently do much of the coordinating, need their knowledge recognised and their own limits respected.

5. What experience, skills and knowledge do you look for in an SCC worker?

Our community wants workers who understand that Parkinson's is more than a movement disorder. That means practical knowledge of medication timing and "on/off" periods, and awareness of cognitive fatigue, autonomic problems and communication impairment. It also means patience with a person whose speech, processing speed or facial expression does not reflect what they understand.

Workers also need to know when to ask for specialist advice and who to ask, including neurologists, movement disorder specialists and Parkinson's nurses. Generalist workers will do well when they have reliable access to that advice.

6. What would help you feel safe when receiving SCC services and encourage you to report an issue if needed?

Clear conflict-of-interest rules matter to our community because of past experience with organisations that provided both coordination and direct services. People also need complaints processes that do not rely on strong speech or same-day recall. These include written options, the ability to raise a concern through a carer or support person, and enough time to think and respond.

Continuity also supports safety. A person is more likely to raise a worry with someone they already trust. Participants need to be told plainly that raising a concern will not put their supports at risk.

7. What else should we consider when designing the future SCC service?

The paper is clear that SCC workers will not replace supported decision-making arrangements, and we support that. For people with executive dysfunction or reduced insight, particularly those with DLB, workers will need practical guidance on how this works day to day, so that supported decision-making is respected and not worked around.

We also ask that people with lived experience of Parkinson's and Atypical Parkinsonism, and their carers, are involved in co-designing the service standards and the SCC+ eligibility criteria. Parkinson's Australia is ready to help arrange that.

6. Questions About Service Provider Models & Approaches

1. What commissioning arrangements would best balance participant outcomes, quality, sustainability and choice and control?

We support a mixed model. Regional lead organisations would deliver general SCC. A specialist stream would deliver SCC+ for people with progressive neurological conditions across several regions, with the right to refer in and out.

Parkinson's is common across the country but Atypical Parkinsonism is rare in any one region. A single regional provider may see only a handful of people with PSP or MSA a year and will struggle to build expertise. A specialist stream can pool that experience. Participants should also be able to change provider if the service is not working for them.

Selection criteria should give demonstrated quality and condition-specific capability at least as much weight as price. A cost-driven process risks choosing generalist providers over those with specialist links who get better results.

2. What provider types would be best placed to be a lead organisation? Why do these characteristics matter?

Lead organisations should have strong governance, a record in support coordination at scale and sound safeguarding. They should also be able to show working referral relationships with neurology and movement disorder services, and experience with complex, fluctuating conditions. These matter because for our community the quality of coordination depends on working alongside a person's clinical team as well as their disability supports.

Lead organisations should also be able to recognise when a person needs specialist input and have a clear route to arrange it.

3. What are the advantages and disadvantages of the lead organisation model?

A single lead organisation per region can make accountability clearer, improve consistency and make oversight easier. These are real benefits and match what the paper aims to achieve.

The main risks for our community are loss of specialist knowledge held by smaller providers, reduced choice if only one organisation operates in a region and added paperwork for subcontracted specialists. Any lead organisation model should therefore include three protections:

1. an enforceable requirement to keep access to specialist expertise for people with complex neurological conditions;
2. a right for participants to change provider or worker without losing support; and
3. reporting requirements for subcontractors that are proportionate and do not repeat existing NDIS Quality and Safeguards Commission requirements.

4. What would be appropriate regional areas to use for SCC service areas?

We have no strong view between Primary Health Network, Local Hospital Network and SA4 boundaries. Whichever is chosen should line up with the health services that SCC workers need to work with. Regions should also be tested against where neurologists and movement disorder specialists actually are. They are unevenly spread and concentrated in cities, so a region that looks sensible on population may still leave a person a long way from the specialist their worker needs to contact.

Boundaries should not stop a person from using a specialist provider based outside their region.

5. How might SCC providers manage variable need among the participants it supports? Which workforce, caseload and service capacity factors should be considered?

Caseloads and capacity should be planned around changing need and not a fixed average. A caseload set from a person's needs on assessment day will understate what they need a few months later.

We suggest clear review triggers, such as a fall, a hospital admission, a change in medication regime, a new swallowing or communication difficulty, or the loss of a carer. When a trigger

occurs, the provider should be able to increase contact within a set number of days and not wait for a formal reassessment. A person should keep receiving support while a move from SCC to SCC+ is being decided.

6. Which payment and funding approaches would best support participant outcomes, workforce sustainability and innovation?

We agree that hourly billing has weaknesses. We would support a per-person payment, provided it is set at a realistic price and includes:

- a higher rate for SCC+ than for SCC, reflecting the greater intensity and skill involved;
- loadings for regional, rural and remote delivery, including travel and outreach;
- the ability to draw additional support at key points of change, such as diagnosis, significant decline or a hospital admission; and
- funding for supervision, training and quality assurance.

The model should be tested against one risk shown in our survey data. People who are too tired or unwell to speak up for themselves are the most likely to be under-served by a flat rate.

7. What quality, workforce and safeguarding requirements should apply to commissioned SCC organisations?

Commissioned organisations should meet the same quality and safeguarding requirements as other registered NDIS providers, with extra requirements for SCC+. We ask for:

- condition-specific training for workers supporting people with progressive neurological conditions, covering motor fluctuation, cognitive fatigue, communication impairment and autonomic dysfunction;
- clear and enforced conflict-of-interest controls;
- regular supervision and access to specialist advice for workers; and
- performance reporting that includes continuity of relationship, speed of response when needs change, participant experience and complaint trends, as well as volume of contact.

8. How can the future SCC model attract, build and retain workforce capability, including retaining participant relationships?

Providers need certainty about funding, regions and participant numbers before they can recruit and keep staff. Experienced support coordinators should have a clear route into SCC worker roles, so that hard-won knowledge of the condition and of participants stays in the workforce.

Partnerships with condition-specific organisations can build capability without every SCC provider having to start from nothing. Parkinson's Australia and Parkinson's nurses can contribute training and advice, and we would welcome discussing how.

9. How should local knowledge and community connection be defined and assessed?

For our community, local knowledge should include working referral pathways with neurologists, movement disorder specialists, Parkinson's nurses and multidisciplinary clinics, as well as the community and mainstream connections described in the paper. We suggest assessing it through evidence of past service in the area or nearby, letters of support from local clinical and community partners, and participant feedback. The quality of relationships matters more than how many a provider can list.

For specialist providers working across several regions, local knowledge should be assessed alongside their specialist expertise.

10. How can the SCC service best support participants in regional, rural and remote areas, or other thin markets, where support options may be limited?

Properly funded partnerships with telehealth-enabled specialist providers can extend condition-specific knowledge into thin markets. These must be built into the funding and not left as an optional extra. They should be combined with visits in person when a person's situation or risk requires it.

This is an access issue for our community. Our survey found people in regional, rural and remote areas report lower confidence in local GP understanding of Parkinson's and higher navigation needs than people in cities. A person should not receive a weaker service because of where they live.

11. How can the SCC service best support participants who face additional barriers, including those experiencing complex and overlapping support needs or requiring decision-making support?

SCC+ should be the main pathway for people with complex and overlapping needs, delivered by workers with the right specialist skills and, where needed, lower caseloads. Workers need training to recognise when reduced insight or executive dysfunction is affecting a person's engagement. They should work alongside existing supported decision-making arrangements and carers and avoid both overriding them and leaving the person without effective help.

Information about the service, including how to complain, should be offered in formats that suit people with speech, vision, cognitive or fatigue-related barriers.

12. What transition arrangements would minimise disruption and support successful implementation?

Continuity of trusted relationships should be the first principle. Where a current coordinator has an established relationship with a participant and can move into an SCC worker role, the participant should be supported to stay with them wherever possible.

We also ask for:

- at least three months between announcing successful providers and handover;
- funded time for current coordinators to prepare handover summaries and meet the new provider with the participant;
- earlier and more careful handover for people with SCC+-level needs, including confirmation that essential supports are in place before the transfer is treated as complete;
- eligibility decisions made early enough that no one is left without coordination while they wait; and
- plain, accessible communication about what is changing, in formats suited to people with cognitive or communication impairment.

People with fast-moving conditions can change a great deal in a year. Handover must be quick enough that the plan on paper still matches the person.

7. Consolidated Recommendations

1. Assess eligibility and service level on the pattern of need over time, including fluctuation and expected progression, and remove any effect of the "stability and predictability" factor against people with unstable conditions.
2. Give people with Atypical Parkinsonism and other rapidly progressive conditions timely access to SCC+ without requiring a crisis.

3. Set defined review triggers and timeframes for moving between SCC and SCC+, with support continuing while decisions are made.
4. Commission a mixed model: regional lead organisations for general SCC and a specialist neurological stream for SCC+, with a right for participants to change provider.
5. Require lead organisations to keep working links with neurologists, movement disorder specialists, Parkinson's nurses and multidisciplinary clinics, through enforceable partnership or subcontracting arrangements.
6. Require condition-specific training for SCC workers supporting people with progressive neurological conditions.
7. Preserve trusted relationships through the transition, with at least three months' notice, funded handover and a pathway for current coordinators into SCC worker roles.
8. Offer a participant-led choice between face-to-face and virtual delivery, with face-to-face contact protected for first engagement and major changes in condition.
9. Formally recognise carer input in SCC processes.
10. Pay for SCC through a per-person model with SCC+ and regional loadings, and allow extra support at key points of change.
11. Report on continuity of relationship, speed of response to change and participant experience, as well as volume of contact.
12. Test proposed SCC regions against the location of specialist neurology and movement disorder services.
13. Fund telehealth partnerships to extend specialist expertise into regional, rural and remote areas.
14. Make complaints and safeguarding processes accessible to people with communication and cognitive impairment, using written, verbal and supported options.
15. Give SCC workers clear guidance on working alongside supported decision-making arrangements, particularly where reduced insight or executive dysfunction is present.
16. Involve people with lived experience of Parkinson's and Atypical Parkinsonism, and carers, in co-designing standards and SCC+ eligibility criteria.

Conclusion

Parkinson's Australia supports the intent of the Support Coordination and Connection reform: a more consistent, higher-quality and better-safeguarded service. For our community to benefit, the service must be designed for conditions that fluctuate and progress, delivered by workers who understand them, and introduced in a way that protects the relationships people already rely on.

We thank the Department for the opportunity to contribute and would welcome the chance to discuss this submission further.

Yours sincerely,

Olivia Nassaris, CEO
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References

Department of Health, Disability and Ageing. (2026). *NDIS Support Coordination and Connection Reform: Consultation paper*. Australian Government.

Mellick, G. D. (2024). *Ecosystem of Parkinson's in Australia project*. Parkinson's Australia.

Parkinson's Australia. (2026). *Your voice, your needs: National survey data analysis report*. Parkinson's Australia.

Poewe, W. (2017). Levodopa-related "wearing off" in Parkinson's disease: Current therapeutic options. *EMJ Neurology, 5*(Suppl 1), 2 to 8.