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Department of Health, Disability and Ageing
GPO Box 9848
Canberra ACT 26001

via email: SCCreform@health.gov.au

RE: NDIS Support Coordination and Connection consultation

Thank you for the invitation to make a submission on the proposed changes to the NDIS support coordination role. Motor Neurone Disease (MND) Australia welcomes the opportunity to provide this submission on behalf of its members, the State MND Associations, and people living with MND.

What is MND?

MND Australia is the national peak body for state organisations that support those living with, and impacted by, motor neurone disease (MND). Since 1993, we have been the voice for the MND community. Our national and international networks help increase understanding of the disease and advocate for the needs of those affected.

Motor neurone disease (MND) is the name given to a group of neurological diseases in which motor neurons – the nerve cells that control the movement of voluntary muscles – progressively weaken and die. With no nerves to activate the voluntary muscles, they become progressively weaker to the point that the ability to walk, speak, swallow and ultimately breathe is lost. MND affects each person differently with respect to initial symptoms, rate and pattern of progression and survival time.

Average life expectancy for people living with MND is 27 months from diagnosis. A third of those die within one year and more than half within two years of diagnosis. There are no known causes for MND, apart from the up to 15% per cent of cases which have a genetic basis. There are no effective treatments and there is no cure. There are no remissions and progression of MND is usually rapid and relentless, creating high levels of life-limiting disability, regardless of the age at onset, and a consequent need for a wide range of changing supports based on the person's complex needs. In 2025 there were an estimated 2,752 people with MND in Australia, with 1,018 registered as NDIS participants receiving an average package size of \$302,000.¹

MND is a complex and rapidly degenerative disease requiring specialised multidisciplinary team care. State MND Associations provide services, supports, invaluable expertise and a comprehensive understanding of MND to ensure people living with MND can be supported to navigate the health system and access supports in a timely manner.

Response to the consultation paper

MND Australia appreciates the opportunity to respond to the consultation paper on redefining an NDIS provider. In consultation with our State Associations, who are registered NDIS Providers, we have summarised a few key points, below, which complements the individual responses provided by the MND State Associations

We understand that the changes currently under consideration are intended to increase fiscal accountability, through the separation of the support coordination role from services provision.

In the case of motor neurone disease, in which few clinicians, allied health professionals or other practitioners have familiarity, we argue that it does not make sense to separate out support coordination and service delivery.

The care network for MND care and support is a patchwork, with far fewer options for informed care, particularly in more remote regions of Australia. The MND State Associations currently provide support coordination to many of their clients. This ensures that:

- a. The support coordinator is knowledgeable of MND and its projected pathway.
- b. Needs can be anticipated and the right support is available at the right time.
- c. Local care and support pathways and options are already established. This may include coordination across clinics, hospitals, neurologists, community nurses, palliative care services, and other localised services and agencies.
- d. Equipment can be provided from the MND State Association equipment libraries at the time that they are required.
- e. The embedded support coordination facilitates the collaborative relationship with the MND Priority Access Pathway team, ensuring more seamless support delivery.

The NDIS priority access pathway for MND has been life-changing for people living with MND. It demonstrates that coordinating care for MND, with its rapid degeneration and quickly changing needs, is both necessary and effective. The MND State Associations currently provide the system navigation for accessing these supports. In many cases, they also fill the support gaps. It is the alignment of expertise across support and service provision that is making the critical difference for people living with MND. Disrupting this alignment is likely to degrade the both the quality and responsiveness of service provision.

We are concerned that support coordination that is geographic rather than condition-specific will seriously degrade the quality of service. It will simply not be possible for support coordinators to be across the specifics of MND, its erratic presentation and often rapid progression. Because people living with MND are not concentrated, and a support coordinator could work for years without seeing a case, it will not be possible to upskill the workforce to the level that is required.

The work that our State Associations do is admired and supported by the NDIA staff who work closely with them. With very little government funding and a heavy reliance on charitable giving and local fundraising, they are filling gaps in the care and support system to ensure people living with MND, their carers and families, are connected to and receiving appropriate care. Particularly for NDIS participants, the system is working. **We fear that reallocating the support coordination role to an external, generalist workforce will fracture a system that is currently working nearly seamlessly.**

This is missional for us. The State Associations exist to ensure people living with MND receive the best care that is available. **We therefore request that a carve-out is created**

for people living with MND as part of the priority pathway and that State Associations can continue to provide the best continuity of care for people living with MND as is currently possible.

The state associations are for-purpose agencies who do not make a profit on support coordination; for many, it is a heavily subsidised service.

There is both a community and a fiscal value in supporting specialist agencies, such as the MND State Associations, to continue providing support coordination due to their high level of expertise in the motor neurone disease and its progression.

MND Australia would be happy to provide any further information or to discuss our submission.

We look forward to hearing about the outcome of the consultation process.

Kind Regards,



Clare Sullivan
Chief Executive, MND Australia



¹ MND Australia and Evohealth (2025). *Every moment matters. Addressing the human and economic toll of motor neurone disease in Australia*. Canberra. https://www.mndaustralia.org.au/getmedia/e5df789a-3318-4fb5-89c2-ed4935e3ebae/Every-Moment-Matters-report_MND-Australia.pdf

MND QUEENSLAND SUBMISSION

NDIS Support Coordination and Connection Reform Consultation | September 2026

ABOUT MND QUEENSLAND

MND Queensland supports Queenslanders impacted by motor neurone disease (MND), including people living with MND, their families and carers.

Our work gives MND Queensland direct experience of the challenges people with a rapidly progressive neurological condition face in navigating the NDIS, health services, allied health, assistive technology, community supports and other systems.

MND Queensland is part of Australia's network of State MND Associations. These organisations concentrate knowledge and capability in a rare disease that most generalist health and disability providers encounter infrequently. State MND Associations form part of the network of care for people with MND and provide services including advice, navigation, equipment, allied health services and referrals, carer support, and assistance navigating government funding systems.³

For people with MND, coordination is not simply an administrative function. It is an essential part of ensuring that multiple services and systems can respond quickly and coherently as needs change.

MND Queensland welcomes the opportunity to contribute to the Australian Government's consultation on the proposed Support Coordination and Connection (SCC) service.

EXECUTIVE SUMMARY

MND Queensland supports stronger quality, consistency, accountability and safeguarding in support coordination. However, **standardisation of quality must not result in standardisation of service.**

MND requires a different response.

MND is a rare, progressive and life-limiting neurological disease. Needs change throughout disease progression and can change rapidly, requiring coordinated responses across personal supports, allied health, assistive technology, home modifications, communication support, informal and carer supports, health and palliative care.³

Importantly, **the need for a different response to MND is already recognised by the Australian Government across both disability and aged care systems.**

Within the NDIS, a Priority Pathway has been established for people with MND, supported by a dedicated NDIS team for new applicants with the disease. In 2026, the Australian Government also recognised MND

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as a discrete condition warranting urgent priority for Support at Home because of its particular characteristics and rapid deterioration in physical function. The Government expressly linked the aged care arrangements with the priority pathway available to people with MND in the NDIS.²

Together, these arrangements establish an important principle across Commonwealth disability and aged care policy: people with MND require systems that can respond differently because their needs can change quickly and delays can have significant consequences.

The same principle should inform SCC.

MND Queensland's central recommendation is that the future SCC commissioning framework should include a cohort-specific commissioning pathway for defined disability cohorts where diagnosis or disability type materially affects the expertise, responsiveness and service networks required for effective coordination. For MND, this should allow an appropriately commissioned MND-specific provider to deliver SCC directly to people with MND across geographic boundaries.

This would not require a separate SCC service for every diagnosis. Cohort-specific commissioning should be available where there is a clear case that the characteristics of a condition materially change the coordination response required and where concentrating that capability is more effective than attempting to reproduce it across multiple generalist providers.

MND presents such a case.

For MND, effective coordination is inherently anticipatory. Its value lies not only in responding to a participant's current needs, but in understanding what is likely to be needed next and acting early enough for assessments, equipment, supports and services to be in place as function changes.³

An SCC worker does not need to be a clinical expert in MND. They do, however, need to understand how the disease progresses, anticipate the supports that may be required, recognise when action is time-critical, and know how to connect participants quickly with providers and services that have appropriate MND expertise.

Australia already has an established network of State MND Associations that concentrates this knowledge and capability. Through sustained work with people with MND, these organisations have developed organisational knowledge, referral pathways and relationships across disability, allied health, assistive technology, health, palliative care and community services.³

This capability is not simply the knowledge held by an individual SCC worker. It is an ecosystem of disease knowledge, service networks, referral pathways and organisational experience that can be drawn upon as a person's needs change.

A cohort-specific commissioning pathway would allow this capability to be used directly within the future SCC system rather than requiring people with MND to enter a generalist service and rely on that service recognising when MND expertise is required.

This distinction also matters because **more intensive coordination is not necessarily MND-informed coordination**. A person with MND may need condition-specific coordination even when their circumstances do not warrant the most intensive SCC+ service. SCC+ is proposed for participants with very complex circumstances, including intensive coordination needs, significant safety considerations, complex support environments, multiple interacting systems and heightened risk of disengagement.¹ MND-specific

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coordination addresses a different issue: the type of knowledge required to anticipate and coordinate effectively.

When coordination lacks this knowledge, or does not respond quickly enough, the consequences extend beyond the SCC service. Participants can experience avoidable gaps in support, loss of independence and safety, and increased risk of crisis. Unmet disability needs can also create additional pressure on health and hospital services.

There is also a significant impact on families and carers. When emerging needs are not anticipated and coordinated effectively, partners and family members can be left to identify what is needed, navigate services, coordinate providers, pursue assessments and equipment, and advocate for a response, while also providing increasing levels of direct care.

This additional responsibility matters in a disease where the caring burden is already substantial. *Every Moment Matters* estimates that carers of people with MND provided 5.37 million hours of unpaid care in 2025, valued at approximately \$212 million. It reports that carers frequently reduce their working hours or leave employment as the disease progresses, resulting in lost income, superannuation and career progression.³ The 2025 MND Community Survey found that 66% of current and recent carers surveyed were providing more than 40 hours of care each week.⁴

MND Queensland does not suggest that inadequate support coordination causes this broader economic burden. However, poorly informed, delayed or reactive coordination can add avoidable navigation, planning and advocacy responsibilities to families already carrying substantial caring responsibilities.

The future SCC model should therefore recognise MND-specific coordination capability as part of an effective response to a rapidly progressive disease, not simply as desirable additional knowledge.

For rare and rapidly progressive conditions such as MND, diagnosis can be more relevant to effective coordination than geography.

The future SCC architecture should reflect that.

KEY RECOMMENDATIONS

MND Queensland recommends that the future SCC model:

1. **Establish a cohort-specific commissioning pathway within SCC and apply it to MND**, allowing an appropriately commissioned MND-specific provider to deliver SCC directly to people with MND across geographic boundaries where diagnosis materially affects the expertise, responsiveness and service networks required for effective coordination.
2. **Recognise rapid progression, anticipated disease trajectory and the consequences of delay** when determining SCC eligibility, intensity and responsiveness for people with MND.
3. **Distinguish condition-specific coordination from higher-intensity coordination**, recognising that a person may require MND-specific SCC without necessarily requiring SCC+ at all stages of disease progression.

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4. **Preserve meaningful participant choice and control**, including choice between appropriate pathways where possible and practical alternatives where an allocated service or worker is not meeting the participant's needs.
5. **Require generalist SCC services to have formal access to condition-specific expertise** where a participant is not receiving SCC through a cohort-specific pathway.
6. **Make coordination proactive for rapidly progressive conditions**, with response expectations, anticipatory planning, escalation arrangements and capacity to rapidly increase service intensity.
7. **Ensure funding and performance measures assess what SCC can reasonably influence**, including timeliness, responsiveness, anticipatory planning, appropriate connections and avoidance of preventable service gaps and crises.
8. **Manage conflicts of interest through robust and proportionate safeguards**, rather than allowing blanket organisational separation requirements to inadvertently exclude organisations with the condition-specific capability required for cohort-specific commissioning.
9. **Implement active market stewardship and an orderly, flexible transition**, including early identification and commissioning of cohort-specific pathways so that existing knowledge, relationships and workforce capability are not lost before the new system commences.

A. WHAT PARTICIPANTS NEED FROM THE NEW SCC SERVICE

A1. What is working well in support coordination today that you would like to see in the new SCC service?

For people living with MND, some of the strongest features of current support coordination are continuity, trusted relationships, participant choice, flexibility and the ability to choose a provider with knowledge of MND.

These features matter because MND coordination can involve many interconnected elements. Needs can involve personal care and other daily supports, multiple allied health disciplines, assistive technology, home modifications, communication support, transport, informal and carer supports, and coordination across the NDIS, health and palliative care systems.

A support coordinator who understands MND is better placed to anticipate how these needs interact and change as the disease progresses. They can recognise emerging needs earlier, initiate referrals and assessments before needs become urgent, and connect participants with providers who have appropriate MND knowledge.

MND Queensland's current model enables support coordinators to work within an organisation focused on MND. They draw not only on their own knowledge, but on broader organisational expertise, established MND service pathways and relationships across the MND care network.⁵

The important capability to preserve is therefore not simply continuity with an individual support coordinator. It is the ability to receive coordination from within a service that repeatedly supports people with MND and has accumulated knowledge of the disease, its trajectory and the service networks required to respond to it.

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This supports a cohort-specific commissioning approach for MND rather than requiring people with MND to enter a generalist SCC service and rely on that service to identify when MND expertise is required.

A2. What would you most like to see improved in the new SCC service?

MND Queensland supports stronger and more consistent expectations for service quality, workforce capability, safeguarding and accountability.

However, **consistency should not mean generalisation.**

National consistency should apply to quality standards, safeguarding, accountability and participant rights. It should not require every participant to receive the same model of coordination.

A cohort-specific commissioning pathway can operate within a nationally consistent quality framework while allowing the coordination response to reflect the characteristics of particular disabilities.

For MND, improvement is particularly needed in responsiveness to changing circumstances, coordination across disability and health systems, proactive identification of emerging needs and reliable access to MND-specific expertise.

Quality should be consistent. The service required to achieve it will not always be.

A3. When should SCC be a face-to-face service or a virtual service?

The mode of SCC delivery should be participant-led and needs-based rather than prescribed.

Both face-to-face and virtual delivery are important.

Face-to-face support can be particularly important where communication is changing, circumstances are complex, significant changes are occurring, understanding the home environment is necessary, or a relationship needs to be established.

Virtual delivery is also valuable, particularly for rare conditions. It allows scarce expertise to cross geographic boundaries and can improve responsiveness for people in regional, rural and remote communities.

For people with MND, the important question is not whether a service is local or virtual. It is whether the participant can access **the right expertise, at the right time, in the way that best meets their needs.**

Geographic commissioning may be useful for ensuring general SCC coverage, but geographic boundaries should not prevent a participant from accessing an appropriately commissioned cohort-specific service.

For MND, the relevant community of expertise is statewide as well as local. Diagnosis can therefore be more relevant to effective coordination than postcode.

A4. What participant groups will benefit most from the SCC service? What do their needs for connection and coordination of supports look like?

People with rapidly progressive neurological conditions such as MND require explicit consideration within the SCC design.

For MND, complexity cannot be assessed through a snapshot of current circumstances.

A participant's needs at the point of assessment are not a reliable indicator of the coordination they will require over the following months. MND is progressive, and changes in function require supports to be reviewed and adjusted throughout the course of the disease. Effective coordination anticipates these changes rather than waiting for deterioration to create a crisis.³

The Australian Government already recognises the need for a different response to MND through the NDIS Priority Pathway and, since 2026, priority access to Support at Home and immediate priority for Assistive Technology and Home Modifications funding for eligible older people with MND.²

In announcing the aged care changes, the Government expressly linked them to the experience of the NDIS MND pathway, with Minister McAllister stating that the pathway had demonstrated what was possible when a system was designed around how quickly a person's needs can change.²

The significance for SCC is not simply that people with MND need faster service. It demonstrates an established policy principle of adapting pathways where the characteristics of MND require a different response.

MND Queensland recommends applying the same principle to SCC through a cohort-specific commissioned pathway.

SCC eligibility and service intensity for MND should consider:

current need + anticipated trajectory + consequences of delay.

The consequences of delay should include not only the immediate effect on the participant, but the risk of preventable crisis, additional pressure on families and carers, and avoidable demand on health and other service systems.

Not every person with MND will require the highest intensity of coordination at every point. However, this does not mean they do not require MND-specific coordination.

Condition-specificity and intensity are different dimensions of need.

A participant may require an MND-informed coordinator because of the disease trajectory and service knowledge required while needing relatively modest coordination input at one stage, followed by a rapid increase in intensity as their needs change.

A5. What experience, skills and knowledge do you look for in an SCC worker?

An effective SCC worker requires strong coordination and communication skills, sound knowledge of the NDIS and its interfaces with other systems, and the ability to identify emerging risks and changing support requirements.

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When supporting a person with MND, relevant capability includes understanding rapid progression and its implications, anticipating changing functional needs, coordinating across disability and health systems, and recognising the importance of timely access to appropriate allied health, assistive technology and other supports.

The distinction between reactive and anticipatory coordination is particularly important. An SCC worker does not need to provide clinical advice, but they do need sufficient understanding of MND to recognise what may be coming next and begin coordination early enough for the relevant supports to be available when required.

It is neither realistic nor necessary for every SCC worker to become knowledgeable in every rare disability. **That is precisely why the commissioning model should allow cohort-specific SCC arrangements where condition knowledge materially affects coordination.**

For MND, concentrating capability within an MND-specific commissioned service would avoid expecting multiple geographically based generalist services to independently develop and maintain the same depth of condition knowledge and networks.

Where a participant remains within a generalist SCC pathway, workers must understand the limits of their own knowledge and have formal, timely access to appropriate condition-specific expertise.

A6. What would help you feel safe when receiving SCC services and encourage you to report an issue if needed?

Safety requires competent practice and a system in which participants can raise concerns without fearing that doing so will jeopardise their access to coordination.

Participants should receive clear information about service standards, their rights, complaints pathways, conflicts of interest and options where the allocated SCC service is not meeting their needs.

The future model should include accessible and independent complaints mechanisms, clear escalation pathways, transparent provider monitoring and appropriate external auditing.

Choice between pathways is also relevant to safeguarding. Where a participant is eligible for a cohort-specific pathway, they should be clearly informed about that option and, where practicable, retain meaningful choice about whether it meets their needs.

If commissioning substantially reduces the number of available SCC organisations, participants also need a practical remedy when a relationship breaks down. A complaints process is not sufficient if the participant remains effectively dependent on the organisation about which they are complaining.

A7. What else should we consider when designing the future SCC service?

MND Queensland recommends that the SCC architecture include a formal mechanism for **cohort-specific commissioning**.

Under this approach, the NDIA could identify cohorts for which diagnosis or disability type materially affects effective coordination and commission an appropriate organisation or consortium to provide SCC directly to that cohort across one or more geographic commissioning regions.

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This would sit alongside, rather than replace, general SCC services.

MND is well suited to this approach because it is rare, progressive and life-limiting; needs are foreseeable but can change rapidly; coordination crosses disability, health and palliative care systems; and established MND-specific organisations and service networks already exist.³

This would not require a separate SCC service for every diagnosis. Cohort-specific commissioning should be used where there is a demonstrable case that the nature of the condition materially changes the coordination response required and where concentrating that capability provides a more effective response than attempting to reproduce it across generalist services.

For MND, a cohort-specific provider could deliver SCC directly, supported by statewide service networks and virtual and face-to-face delivery as appropriate.

Where the SCC model relies on external condition-specific expertise, the cost of providing that expertise should be recognised within the commissioning model rather than treated as a resource that generalist providers can access without provision for its cost.

For MND, the commissioning unit should be the cohort rather than the postcode.

B. SERVICE PROVIDER MODELS AND APPROACHES

B1. What commissioning arrangements would best balance participant outcomes, quality, sustainability and choice and control?

Of the two commissioning approaches proposed, **MND Queensland sees greater potential in a multi-provider model**, provided it is designed to preserve meaningful participant choice and enable condition-specific providers to operate across geographic boundaries.¹

The consultation paper describes the multi-provider option as allowing providers to pool resources and expertise across or within regions.¹ For MND, this provides greater potential to retain diversity of expertise within the SCC system and reduce the risk that access to condition-specific support is controlled by a single regional organisation.

MND Queensland has greater concerns about a single lead-organisation model. While such a model may provide clearer regional accountability and governance, placing responsibility for an entire region with one organisation risks reducing participant choice and making geography the primary determinant of who coordinates a participant's supports.

These risks are particularly significant for rare conditions such as MND. A regional lead organisation may be highly capable as a general SCC provider but have limited exposure to MND. Requiring people with MND to receive coordination through that organisation, with access to MND expertise dependent on referral or subcontracting decisions made by the lead provider, would not provide the same assurance as direct access to a commissioned MND-specific pathway.

Regardless of whether a lead-organisation or multi-provider model is adopted for general SCC, MND Queensland recommends that the commissioning framework also allow cohort-specific pathways to operate across geographic service areas.

For MND, this should allow an appropriately commissioned MND-specific provider to deliver SCC directly to people with MND across geographic boundaries. Participants should not first have to enter a generalist regional service in order to access condition-specific coordination.

Under a multi-provider model, an MND-specific provider could form part of the commissioned provider network while operating across regions for the MND cohort.

If a lead-organisation model is adopted, the MND-specific pathway should be separately accessible so that a regional lead organisation does not determine whether a person with MND can receive MND-specific coordination.

This would create a commissioning architecture that can use geography where geography is useful and diagnosis where diagnosis is more relevant to effective coordination.

MND Queensland therefore sees greater potential in a multi-provider model, together with a formal cohort-specific commissioning pathway for MND and other cohorts where condition-specific knowledge materially affects effective coordination.

B2. What provider types would be best placed to be a lead organisation? Why do these characteristics matter?

If a lead-organisation model is adopted, MND Queensland does not consider organisational type or scale alone to be an adequate basis for selecting lead organisations.

Lead organisations should be required to demonstrate strong governance and safeguarding systems, coordination capability, workforce capacity, community relationships, established referral pathways and the ability to work genuinely with disability and condition-specific organisations.

A regional lead organisation should also not necessarily hold responsibility for every eligible participant who lives within its geographic boundary.

Where a participant meets the criteria for an appropriately commissioned cohort-specific pathway, they should be able to receive SCC through that pathway instead.

This would allow lead organisations to concentrate on strong general SCC delivery while condition-specific providers concentrate expertise for cohorts where that expertise materially affects coordination.

For participants remaining within general SCC, lead organisations must be able to recognise when required expertise does not reside within their own workforce and access it without unnecessary delay, organisational barriers or geographic restrictions.

B3. What are the advantages and disadvantages of the lead organisation model?

A lead-organisation model could provide clearer accountability, stronger governance, more consistent practice expectations and more reliable responsibility for regional service coverage.

However, it also creates risks of reduced participant choice, market concentration, gatekeeping of condition-specific expertise and dilution of existing disability-specific capability.

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In particular, it could make **location the primary determinant of coordination provider even where disability type is a stronger determinant of the expertise required.**

For rare disabilities, concentrated expertise cannot necessarily be recreated simply by recruiting additional generalist SCC workers. It develops through repeated exposure to the condition, organisational learning, established referral pathways and relationships with relevant providers and services.

If a lead-organisation model is adopted, these risks could be reduced by allowing separately commissioned cohort-specific pathways to operate across regional boundaries, rather than requiring all specialist capability to sit beneath or be accessed through the regional lead organisation.

This would retain the potential accountability and coverage benefits of a lead model without making it the sole route through which participants can access condition-specific SCC.

B4. What would be appropriate regional areas to use for SCC service areas?

MND Queensland does not propose particular geographic boundaries because our principal concern is that **those boundaries should not determine access to MND-specific SCC.**

Geographic regions may be appropriate for commissioning general SCC coverage. Cohort-specific services for rare conditions should be permitted to operate across those boundaries.

For a rare disease such as MND, attempting to duplicate concentrated expertise within every commissioning region would be inefficient and risks diluting rather than improving capability.

A statewide or cross-regional MND-specific pathway could combine concentrated expertise with local service knowledge and face-to-face delivery where required.

Commissioning geography should organise general coverage, not constrain condition-specific pathways.

B5. How might SCC providers manage variable need among the participants they support? Which workforce, caseload and service capacity factors should be considered?

The changing needs of people with MND will not align with organisational timetables, staffing cycles or available service capacity.

Disease progression determines when coordination is required; provider capacity cannot be allowed to determine when that need is met.

Changes in function can occur rapidly and require simultaneous action across personal care and daily supports, multiple allied health disciplines, assistive technology, home modifications, communication support, informal and carer supports, and health and palliative care systems.³

A cohort-specific MND service offers an important advantage here. Workforce capacity, caseload design and service responsiveness can be built around the particular pattern of MND demand, including periods of relative stability followed by rapid increases in coordination intensity.

Caseload measures based primarily on participant numbers will not adequately reflect this workload. They should account for intensity, anticipated trajectory and the potential for rapid changes in need.

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Service standards should include proactive contact, response expectations, escalation and anticipatory planning. Participants who are less able to advocate, communicate or repeatedly seek assistance must not receive less support as a consequence.

This is also important for families. If an SCC service does not anticipate changing needs or respond in a timely way, the coordination work does not disappear. It can fall to partners and family members who are already managing substantial caring responsibilities.

The 2025 MND Community Survey found that being a carer commonly includes acting as an advocate within support systems, and 66% of current and recent carers surveyed reported providing more than 40 hours of care each week.⁴

For MND, effective coordination must be proactive rather than crisis-driven.

B6. Which payment and funding approaches would best support participant outcomes, workforce sustainability and innovation?

Payment arrangements must provide sufficient capacity to respond to differences in participant need, including rapid changes in the intensity of coordination required.

For a cohort-specific MND pathway, funding should recognise that demand is unlikely to be uniform. The service must have sufficient capacity to respond when a participant's needs escalate rather than requiring coordination to fit a fixed pattern of contact.

MND Queensland cautions against payment or performance models that equate successful SCC with improvement in functional capacity.

MND is progressive. A person's function will deteriorate despite excellent coordination.

Service effectiveness should instead be assessed against what SCC can influence: timeliness, responsiveness, anticipatory planning, access to appropriate supports and expertise, avoidance of preventable service gaps and crises, and support for participant choice and independence.

There is also a broader system efficiency argument for getting this right.

In a rapidly progressive condition, delayed coordination can leave disability needs unmet until they become urgent. This can increase pressure on families and carers and may contribute to additional demand on health, hospital and other services.

Effective SCC should therefore be valued partly for its ability to **anticipate foreseeable needs and coordinate an earlier response**, rather than only for activity after a need has become urgent.

The economic context for families is significant. *Every Moment Matters* estimates 5.37 million hours of unpaid MND care in 2025, valued at \$212.02 million, and reports that carers frequently reduce work hours or leave employment as disease progression increases caring demands.³

MND Queensland does not attribute these costs to support coordination. However, a model that transfers avoidable navigation, planning and coordination responsibilities to families risks adding to an already substantial economic and caring burden.

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Where a cohort-specific pathway is commissioned, funding should recognise the infrastructure required to maintain the knowledge, networks, responsiveness and workforce capability on which that service depends.

Where general SCC organisations instead draw on external condition-specific expertise, commissioning should similarly make appropriate provision for that input rather than assuming it will remain available without cost.

B7. What quality, workforce and safeguarding requirements should apply to commissioned SCC organisations?

MND Queensland supports strong and enforceable quality and safeguarding requirements.

These should include appropriate workforce competency requirements, registration or accreditation, minimum practice standards, external auditing, performance monitoring, accessible complaints processes, transparent governance requirements and effective consequences for serious or repeated non-compliance.

Conflict of interest should also be addressed directly, but a distinction should be made between the existence of a potential conflict and an unmanaged conflict that results in harm or inappropriate provider practices.

This becomes particularly important if cohort-specific commissioning is adopted.

A blanket organisational separation requirement could unintentionally prevent organisations with deep condition-specific knowledge from participating in cohort-specific SCC commissioning simply because they also provide other supports relevant to that cohort.¹

Integrated disability-specific organisations can offer legitimate benefits, including concentrated condition knowledge, continuity, rapid communication and connection with established multidisciplinary and service networks.

MND Queensland therefore recommends that the final framework focus on **identifying and managing conflicts rather than assuming organisational separation is the only effective safeguard**.

Safeguards could include transparent disclosure of related services, genuine presentation of alternative providers, informed participant choice, appropriate separation of referral and service decisions, monitoring of internal referral patterns, independent audit and accessible complaints mechanisms.

Where evidence demonstrates that an integrated model creates unacceptable risk that cannot be appropriately managed, separation may be warranted. However, the framework should not exclude cohort-specific providers solely because related services exist within the same organisation.

The objective should be to prevent conflicts from harming participants while preserving access to the expertise required for effective coordination.

B8. How can the future SCC model attract, build and retain workforce capability, including retaining participant relationships?

The reform creates a workforce challenge well before the new service commences.

Existing support coordination organisations and workers face an extended period of uncertainty about their role in the future system. The consultation paper identifies continuity of participant services, workforce quality and provider readiness as priorities for implementation.¹

Some providers may reduce investment, redeploy staff or leave support coordination before implementation.

For condition-specific organisations, there is an additional risk. Workers leaving support coordination may take with them condition-specific knowledge, service relationships and experience developed through years of concentrated work with particular cohorts.

Retaining generic support coordination capacity elsewhere in the system would not necessarily replace that capability.

Early confirmation that cohort-specific commissioning will form part of the future SCC architecture would allow priority cohorts to be identified and commissioning arrangements developed early enough to reduce unnecessary loss of relevant workforce capability.

This does not mean existing providers should automatically receive future contracts. Cohort-specific services should be commissioned through appropriate and transparent processes against clearly defined capability and quality requirements.

The relevant workforce question is therefore not simply how many support coordinators remain. It is what knowledge, relationships and condition-specific capability remain in the system after reform.

B9. How should local knowledge and community connection be defined and assessed?

Local knowledge should not be defined solely by physical location.

For a person with MND, useful knowledge includes understanding local services while also knowing the disability, health, allied health, assistive technology, palliative care and community pathways relevant to MND.

A provider can be geographically close to a participant while having little experience of MND. Conversely, a statewide MND organisation can have extensive knowledge of providers and pathways throughout Queensland because it repeatedly supports people with the same disease across those locations.

This distinction matters because the coordinator's knowledge and networks can influence which services a participant is connected with. A generalist coordinator may understandably draw first on familiar local providers, but those providers may have limited experience with MND.

The 2025 MND Community Survey demonstrates why this matters. Knowledge of MND and delays were the most prevalent issues reported as affecting access to health professionals. Allied health professionals accessed through MND Clinics and State MND Associations were regarded as more knowledgeable about MND than community providers overall.⁴

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Within Queensland, the survey also found a high reported level of MND knowledge among allied health professionals accessed through MND Queensland. This result was based on a relatively small sample and should be interpreted accordingly. Its relevance here is not that SCC workers should perform allied health functions. Rather, it demonstrates the value of knowing where MND expertise sits within the service system and being able to connect participants with it.⁴

The survey also found that people living with MND reported difficulty finding knowledgeable health professionals locally, with shortages and delays having significant ramifications for care and support.⁴

The relevant question is therefore not simply, "Does the coordinator know providers near this participant?" It is, "Does the coordinator know which providers are appropriate for this participant's disability and changing needs?"

For MND, that is another reason a cohort-specific SCC pathway may provide greater value than relying exclusively on geographic commissioning.

B10. How can the SCC service best support participants in regional, rural and remote areas, or other thin markets?

For rare conditions, local capacity and statewide condition-specific capability should complement one another.

A statewide MND-specific SCC pathway could improve equity for regional participants by ensuring access to concentrated MND knowledge regardless of which geographic commissioning region they live in.

A cohort-specific service would not remove the need for local providers. Rather, it would combine local service delivery with coordination informed by a broader MND-specific network.

Virtual delivery and outreach can make scarce expertise available across large geographic areas, while face-to-face coordination can still be provided where the participant's circumstances require it.

Where a participant remains within general SCC, regional workers should have formal access to MND-specific advice, secondary consultation, education and referral support.

Regional participants should not have to trade access to MND expertise for access to a local SCC service.

B11. 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?

The future definition of complexity should expressly recognise rapidly progressive neurological conditions.

Complexity does not arise only from crisis, disengagement, behavioural complexity or the number of services involved.

For MND, complexity can arise from the speed, progression and interaction of changing needs.

A participant can require coordinated changes across multiple supports and systems within a very short period. The appropriate response is anticipatory planning, flexible service intensity, effective coordination across systems and ready access to MND-specific expertise.

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There is also an important distinction between **SCC+ and cohort-specific SCC**.

SCC+ addresses the intensity or complexity of coordination required. A cohort-specific pathway addresses the type of knowledge required to coordinate effectively. The consultation paper proposes SCC+ for a small proportion of participants with very complex circumstances, including intensive coordination needs, significant safety considerations, complex support environments, multiple interacting service systems and heightened risk of disengagement.¹

A person with MND may require MND-specific coordination even when their circumstances do not currently warrant the highest level of SCC intensity.

Conversely, a person receiving MND-specific SCC may at some stages of disease progression require significantly increased coordination intensity.

The two concepts should therefore be capable of operating together.

A participant could receive MND-specific SCC at the ordinary SCC level and move to greater intensity where their circumstances require it, without losing access to the condition-specific pathway.

SCC+ criteria should not require a person with MND to reach crisis or extreme current complexity before the system recognises the implications of their anticipated trajectory.

The relevant questions are not only **"How complex is this participant today?"** but also **"What is the participant's anticipated trajectory, and what are the consequences if coordination is delayed?"**

B12. What transition arrangements would minimise disruption and support successful implementation?

Transition should be planned, time-limited and flexible at the participant level, with a strong focus on continuity, safe handover and preservation of condition-specific capability.

For people with MND, transition arrangements must recognise that changing SCC workers during a period of rapid disease progression or intensive coordination may create unnecessary risk and disruption. Where critical work is underway, flexibility should allow that work to be completed and a safe handover to occur.

Importantly, cohorts requiring condition-specific commissioning should be identified early.

If decisions about cohort-specific pathways are delayed until after general geographic commissioning arrangements are established, existing MND-specific workforce capability, organisational knowledge and service relationships may already have been lost.

Where an MND-specific SCC pathway is commissioned, transition planning should enable people with MND to move directly into that pathway rather than first transferring to a generalist geographic provider and subsequently transferring again.

Providers need sufficient certainty and lead time to manage workforce changes responsibly. Participants need protection from abrupt or poorly timed transfers.

Market stewardship must also begin well before implementation. The consultation paper recognises the expertise, skills and relationships within the existing workforce and identifies market stewardship as part of the transition.¹ Monitoring should therefore include provider exits, workforce capacity, loss of

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condition-specific capability and emerging service gaps, with contingency arrangements where capacity deteriorates.

The transition objective should be continuity of effective coordination while participants move into the right future service, with particular care where needs are changing rapidly.

CONCLUSION

MND Queensland supports stronger quality, accountability, consistency and safeguarding in support coordination.

Our central recommendation is that **the future SCC model should not rely exclusively on geographically commissioned generalist services. It should include a cohort-specific commissioning pathway for disabilities where diagnosis or disability type materially changes the coordination response required.**

For MND, this should allow an appropriately commissioned MND-specific provider to deliver SCC directly to people with MND across geographic boundaries.

This is not an argument that every diagnosis requires its own SCC service. It is an argument for a commissioning architecture capable of recognising when a generalist model is not the most effective model for a particular cohort.

The Australian Government has already applied this principle to MND in other contexts. The NDIS Priority Pathway recognises the need for a different response to MND, and in 2026 the Government applied the same principle to aged care, giving eligible older people with MND urgent priority for ongoing Support at Home and immediate priority for Assistive Technology and Home Modifications funding.²

SCC reform should follow the same logic.

For MND, effective coordination is anticipatory. It requires understanding what is likely to happen next, acting before foreseeable needs become crises, and connecting people quickly with providers and services that understand the disease.

A geographically local coordinator is not necessarily an MND-informed coordinator.

More intensive coordination is not necessarily MND-informed coordination.

Access to condition-specific advice after a problem arises is not equivalent to having coordination informed by the disease from the outset.

The consequences of getting this wrong extend beyond the SCC service. Participants may experience preventable gaps in support and increased risk of crisis. Families may carry additional navigation, planning and advocacy responsibilities on top of an already substantial caring burden. Unmet disability needs may also create additional pressure elsewhere in health and other service systems.

Conversely, knowledgeable and anticipatory coordination can help ensure foreseeable needs are acted upon early and participants are connected quickly with appropriate services and expertise.

The future SCC architecture should therefore be flexible enough to organise general service coverage geographically while commissioning around diagnosis or disability cohort where the evidence supports a different response.

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For MND, the cohort, not the postcode, should determine the appropriate coordination pathway.

Quality should be standardised. The service response should not.

Time lost waiting for systems to respond cannot be recovered.

Motor neurone disease doesn't wait. Until there's a cure, there's care, and the systems supporting that care must be able to move at the pace of MND.

REFERENCES

1. Australian Government Department of Health, Disability and Ageing, *NDIS Support Coordination and Connection Reform: Consultation Paper*, September 2026.
2. Australian Government Department of Health, Disability and Ageing, *Priority aged care support for Australians with MND*, 3 June 2026. This source confirms the priority pathway available to people with MND in the NDIS, the dedicated NDIS team established in 2024 for new MND applicants, and the 2026 priority Support at Home arrangements.
3. MND Australia, *Every Moment Matters: Addressing the human and economic toll of motor neurone disease in Australia*, 2025. This report addresses MND progression, multidisciplinary care and coordination, the role of State MND Associations, unpaid care and the economic impacts experienced by carers.
4. ACIL Allen, *MND Community Survey: Final Report*, 2025, prepared for MND Australia and FightMND. Relevant findings include the intensity of unpaid caring, carers' advocacy role, access to health professionals with MND knowledge, and experiences of State MND Association allied health services.
5. MND Queensland, *Advice and Support Coordination* service information. MND Queensland's service material describes MND Advisors as working exclusively with people diagnosed with MND and also providing NDIS Support Coordination, drawing on knowledge of MND and connections with relevant providers.

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24/09/2026

Department of Health, Disability and Ageing

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via email: SCCreform@health.gov.au

RE: NDIS Support Coordination and Connection consultation

Thank you for the opportunity to provide feedback on the NDIS Support Coordination and Connection (SCC) paper. Motor Neurone Disease Association of Victoria (MND Victoria) welcomes the opportunity to provide this submission on behalf of association staff and people living with MND, their family and carers.

Motor neurone disease (MND)

Motor neurone disease (MND) is a rapidly progressive and terminal neurological condition that causes the gradual loss of voluntary muscle function. Over time, the muscles weaken and waste away as the nerve cells (motor neurones) controlling movement deteriorate.

Key features of MND include:

- Progressive muscle weakness and wasting, leading to loss of voluntary movement affecting mobility, speech, breathing, and swallowing.
- Average life expectancy of approximately 27 months from diagnosis, though the rate of progression varies greatly between individuals.
- High levels of disability and impairment, with no known cure currently available.
- Functional deterioration in MND is both inevitable and predominantly rapid. This condition will significantly impact all mobility, daily activities, communication, nutrition, respiratory function, cognition, and psychosocial wellbeing.
- People living with MND typically require up to 30 different pieces of equipment throughout the course of the disease, essential for safety, independence, comfort, and quality of life. This may include (but is not limited to): electric beds, power and manual wheelchairs, commodes, hoists, and walkers.
- MND is a complex and rapidly degenerative disease requiring specialised multidisciplinary and coordinated care.





About MND Victoria

MND Victoria, is the only not-for-profit organisation providing comprehensive care and support to all Victorians living with motor neurone disease. Since 1981, we've delivered services that improve the lives of every Victorian impacted by MND.

MND Victoria is part of Australia's network of State MND Associations. These organisations concentrate knowledge and capability in a rare disease that most generalist health and disability providers encounter infrequently. We provide services, supports, invaluable expertise and a comprehensive understanding of MND to ensure people living with MND can be supported to navigate service system and access supports in a timely manner in line with their disease progression.

For people with MND, Support Coordination is not simply an administrative function. It is an essential part of ensuring the multiple services and systems can respond quickly and coherently as needs change.

MND Victoria currently supports 650 people living with MND across Victoria and Tasmania to ensure no one faces MND alone, including 307 NDIS participants who access Support Coordination and/or equipment through our assistive technology equipment loan program.

Our Equipment Loan Library is designed specifically to meet the rapidly changing and complex needs of people living with MND. Every incidence of MND will follow a different path of progression, and people living with MND typically require up to 30 different pieces of assistive equipment over the course of the disease. The Equipment Bundle provides an efficient, flexible, and cost-effective way to access essential assistive technology in a timely manner. Instead of buying equipment item-by-item and running the risk of the items not being fit-for-purpose on arrival, clients subscribe to a bundled service that provides delivery of assistive technology, collection when equipment is no longer required, ongoing maintenance and repairs and access to equipment exchanges as needs change.

MND Victoria's sole focus on supporting people living with MND has enabled us to develop deep knowledge of the disease, including an understanding of how needs are likely to change over time. It has also strengthened our referral pathways and relationships across disability, health, allied health, assistive technology, palliative care, and community services.

Response to the consultation paper

MND Victoria welcomes changes that improve quality and service consistency, innovation and responsiveness but does not believe the proposed commissioning model is fit for purpose for people living with MND. The proposed changes to the SCC commissioning model threaten to





destabilise the coordinated, skilled and reputable provision of Support Coordination currently delivered to 307 vulnerable clients living with MND across Victoria and Tasmania.

The proposal to deliver SCC within defined geographical areas would diminish the expertise offered by State MND Associations, which has proven to be highly beneficial for this cohort, and places people living with MND at risk of being supported by a generalist workforce.

We would request that a carve-out is created for people living with MND and that State MND Associations can continue to offer and provide the best continuity of highly skilled care for people living with MND through a cohort-specific commissioning model. We endorse the joint statement submitted by MND Australia and strongly urge the NDIA to retain the option of State MND Associations to provide SCC.

The need for a different response to MND is already recognised by the Australian Government across both disability and aged care systems. The NDIS MND Priority Pathway already recognises the need for a specialist workforce that can respond to the complex and rapidly changing needs of people living with MND. This recognition confirms that a generalist approach is inadequate, and that coordinated, specialist care is essential for people with a rapidly progressive condition. Continuing Support Coordination through the State MND Associations would complement the MND Priority Pathway and safeguard timely, responsive and skilled service provision.

In MND Victoria's most recent Annual Client (Participant) Quality Survey undertaken in August 2026, Support Coordination received high satisfaction ratings and was identified by our Lived Experience Committee as the organisation's most valued service.

Losing the specialist knowledge and Support Coordination capability of the State MND Associations would have a devastating impact on people living with MND, their carers and their families. People living with MND need coordination delivered by a skilled workforce specifically trained to understand the condition's complexity and rapid progression, coupled with ongoing access to our extensive equipment loans program.

MND Australia's 2025 report, *Every Moment Matters*, highlights that a holistic, coordinated and multidisciplinary approach provides the best possible quality of life for people living with MND. Applying the proposed commissioning model to this cohort risks undermining that approach.

What Participants want from the new SCC Service-

A1. What is working well and support coordination today that you would like to see in the new SCC Service

For people living with MND, what matters most is the ability to choose a provider with specialist knowledge of the condition and its broader support ecosystem. This expertise is essential to understanding, anticipating, and responding appropriately to the changing needs of someone living with a rapidly progressive condition.





A support coordinator trained and immersed in MND is better placed to anticipate the disease progression, recognise emerging needs, initiate referrals and assessments before needs become urgent. The current models offered by the State MND Associations ensure Support Coordination is delivered by a workforce focused on MND with established networks across the MND care network, including health, allied health, palliative care and community support.

Support Coordination delivered within State MND Associations also supports continuity and trust at a devastating time, when people are coming to terms with a terminal diagnosis, as State MND Associations commence support from diagnosis.

A3. When should SCC to be a face-to-face service or virtual service?

The model of SCC delivery should be person-centered and not prescribed. Both face-to-face and virtual delivery are important features when responding to a cohort experiencing rapid change and progression. Understanding the home environment, witnessing symptom decline and building relationships require an element of face-to-face service provision. This is particularly important when someone living with MND is unable to communicate verbally.

A4. What participant group will benefit most from the SCC Service. What do their needs for connection and coordination of supports look like.

People with rapidly progressive neurological conditions such as MND require explicit consideration within the SCC design.

The Australian Government already recognises the need for a different response to MND through the NDIS Priority Pathway and, since 2026, priority access to Support at Home and immediate priority for Assistive Technology and Home Modifications funding for eligible older people with MND.

The needs of people living with MND are multi-faceted and continually changing. MND is progressive, and changes in function require support to be reviewed and adjusted throughout the course of the disease. Effective coordination anticipates these changes rather than waiting for deterioration to create a crisis.

A5. What experience, skills and knowledge do you look for in a SCC worker.

When supporting a person with MND, knowledge and capability in understanding MND, its rapid progression, future needs, and requirements are fundamental.

Empathy, compassion, strong communication, and interpersonal skills are paramount when working with people living with terminal conditions like MND.



A7. What else should we consider when designing the future SCC service?

MND Victoria recommends that the future SCC model adopt a cohort-specific commissioning approach for people living with MND. This would align with the Australian Government's existing recognition that MND requires an individualised, timely and skilled response as seen via the NDIS and Support at Home pathways.

Conclusion-

MND Victoria welcomes the opportunity to discuss this submission further and collaborate to ensure that the needs and experiences of people living with MND are fully understood and appropriately reflected in the design and implementation of the Support Coordination and Connection model. MND Victoria and the broader MND community strongly advocate for people living with MND to have the choice to receive skilled, experienced Support Coordination from the State MND Associations under a cohort-specific commissioning model delivered by the leading experts in MND care and support.

Reference

MND Australia, *Every Moment Matters: Addressing the human and economic toll of motor neurone disease in Australia*, 2025. This report addresses MND progression, multidisciplinary care and coordination, the role of State MND Associations, unpaid care and the economic impacts experienced by carers.

Sincerely,

A handwritten signature in blue ink, appearing to read 'Jo Whitehouse'.

Jo Whitehouse

General Manager Support Services

A handwritten signature in blue ink, appearing to read 'Kim Hamilton'.

Kim Hamilton

Senior Manager MND Advisor and Support
Coordinator Service





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Motor Neurone Disease Association of Western Australia Submission

NDIS Support Coordination and Connection Reform Consultation | September 2026

WESTERN AUSTRALIA PERSPECTIVE: PRESERVING SPECIALIST SUPPORT COORDINATION

The Motor Neurone Disease Association of Western Australia (MNDAWA) supports the NDIA's proposition to ensure Support Coordination is standardised in the future. However, this should not be at the detriment of people living with Motor Neurone Disease (MND). We know that NDIA recognises that MND requires an individualised approach through the priority pathway. This pathway has seen great outcomes for people living with MND and making significant changes to the coordination aspects of this pathway poses a significant risk.

MNDAWA is uniquely positioned to support people living with MND and their families. Our specialist knowledge, multidisciplinary team and established relationships across the health, disability, aged care and palliative care sectors enable us to provide coordinated, responsive and highly specialised support. Western Australia's vast geography and limited access to MND expertise in regional and remote communities make this model particularly important. For many people living with MND, MNDAWA is the consistent point of connection between their NDIS supports, clinical services, equipment needs and broader support network. MNDAWA has and will always advocate for people living with MND who reside in Western Australia to ensure that these systems continue to meet their needs.

MND specialist Support Coordination is fundamentally different from generalist coordination. Receiving MND training is not enough to understand the progression and variability of MND, recognise changing functional needs and anticipating the supports required before a situation becomes urgent. MNDAWA Support Coordinators work within an association that has dedicated its existence to understanding and supporting people living with MND for over 40 years. They work directly with our specialist multidisciplinary team and established service networks to ensure people receive the right support, at the right time, engaging providers who understand their condition.

This specialist, integrated approach delivers meaningful outcomes, including:

- Earlier identification of changing needs and proactive intervention.
- More timely access to NDIS supports, equipment and assistive technology.
- Better coordination between NDIS, health, aged care and palliative care services.
- Reduced fragmentation, duplication and delays.
- Continuity of care throughout a rapidly progressing disease.
- Reduced burden on people living with MND and their families.

If Support Coordination is removed from State MND Associations, participants risk losing access to the very expertise that enables these outcomes. A generalist Support Coordinator or the services they engage, will lack MND knowledge and as such may not recognise the significance of rapid changes or understand how to anticipate the supports required. Established relationships with MND clinics, specialist clinicians, palliative care teams and local providers may also be lost, increasing the risk of delayed supports, fragmented care and greater reliance on families to navigate the system on their own.

For people living with MND, delays can have profound consequences. A support that is appropriate today may be essential tomorrow. MNDAWA understands MND, its progression and its impact on individuals and families better than any generalist service. Our specialist expertise is not an optional addition to Support Coordination, it is what makes timely, effective and person-centred coordination possible.

MNDAWA endorses the joint statement submitted by MND Australia. From a Western Australian perspective, we strongly urge the NDIA to retain the option for State MND Associations to provide NDIS Support Coordination alongside other NDIS supports. Any future reforms must preserve specialist, integrated models that protect continuity, support timely intervention and deliver the best possible outcomes for people living with MND.

Kind Regards,

A handwritten signature in cursive script, appearing to read 'Audino'.

Jessica Audino
Manager Support Services
Motor Neurone Disease Association of Western Australia

29 September 2026

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via email: SCCreform@health.gov.au

NDIS Support Coordination and Connection (SCC) Reform Consultation

About MND NSW

Motor Neurone Disease New South Wales (MND NSW) supports people living with motor neurone disease (MND), their families and carers throughout New South Wales and the Australian Capital Territory. As a specialist organisation dedicated exclusively to MND, we provide information, support, advocacy, equipment services, education and assistance navigating complex health, disability and aged care systems.

MND NSW is part of Australia's network of State MND Associations, which have developed extensive expertise in supporting people living with a rare, rapidly progressive and terminal neurological condition. Through our direct work with individuals and families affected by MND, we have a deep understanding of the challenges associated with accessing timely supports, coordinating multiple service systems and responding to rapidly changing needs.

Executive Summary

MND NSW supports reforms that strengthen quality, consistency, accountability and safeguards within Support Coordination and Connection services. However, we are concerned that a geographically based commissioning model may unintentionally reduce access to the specialist expertise that people living with MND rely upon to navigate a rapidly changing and highly complex support environment.

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Supported by NSW Health
NDIS registered provider 4050003523



MND is a progressive and life-limiting neurological disease with an average life expectancy of approximately 27 months following diagnosis. Changes in function can occur quickly and often require coordinated responses across disability supports, health services, allied health, assistive technology, home modifications, palliative care and informal support networks. Effective support coordination for people living with MND is therefore fundamentally proactive and anticipatory, rather than reactive.

The Australian Government has already recognised the unique needs of people living with MND through the NDIS MND Priority Pathway and, more recently, priority arrangements within the Support at Home program. These initiatives acknowledge that standard service pathways are often not sufficient for a condition characterised by rapid progression and changing support needs.

MND NSW believes the future SCC framework should recognise the importance of condition-specific expertise and allow specialist MND services to continue delivering support coordination and connection services to people living with MND. This would ensure participants continue to receive timely, informed and responsive coordination delivered by organisations with established expertise, clinical knowledge, referral pathways and relationships across the MND care network.

Why MND Requires a Different Approach

For people living with MND, support coordination is not simply an administrative service. It is a critical component of ensuring that changing needs are anticipated, equipment and services are accessed in time, and participants remain connected to the most appropriate providers throughout the progression of their disease.

Unlike many disability cohorts, people living with MND often require multiple changes to supports over relatively short periods of time. Delays in obtaining assistive technology, allied health services, home modifications or personal care supports can have significant consequences for safety, independence, quality of life and carer wellbeing.

The expertise required to effectively coordinate supports for people living with MND is developed through sustained exposure to the disease, understanding of disease progression, established relationships with specialist providers and knowledge of emerging support needs. This capability cannot easily be replicated across a geographically dispersed generalist workforce that may encounter very few MND participants.

Key Recommendations

MND NSW recommends that the future SCC model:

1. Maintains access to specialist MND support coordination through a cohort-specific commissioning pathway or equivalent mechanism.
2. Recognises rapid disease progression and anticipated future need when determining SCC eligibility and intensity.

3. Preserves participant choice and control, including the ability to access specialist MND providers.
4. Ensures generalist SCC providers have formal pathways to access condition-specific expertise where required.
5. Supports proactive, anticipatory coordination models that minimise crises and prevent avoidable support gaps.
6. Recognises the value of specialist organisations that combine condition knowledge, service networks and coordination expertise.
7. Ensures commissioning and funding arrangements consider the complexity and changing nature of MND rather than relying solely on participant numbers or geographic location.

Conclusion

MND NSW supports reforms that improve quality, accountability and participant outcomes within the Support Coordination and Connection framework. However, these reforms must preserve access to specialist expertise for people living with rare and rapidly progressive conditions such as MND.

People living with MND require coordination that understands the disease trajectory, anticipates future needs and responds quickly when circumstances change. A commissioning model that relies solely on geographic service delivery risks weakening the established specialist capability currently provided through State MND Associations and may result in poorer outcomes for participants, families and carers. MND NSW therefore supports the continued provision of specialist MND support coordination through a cohort-specific approach that recognises diagnosis, expertise and responsiveness as critical determinants of effective coordination.

MND NSW also wishes to formally acknowledge and support the submissions made by our colleagues at MND Australia, MND Queensland, MND Victoria and MND WA. MND NSW agrees with the key recommendations advanced by these organisations regarding the need for specialist, cohort-specific support coordination pathways for people living with MND and endorses their collective advocacy to ensure people affected by MND continue to receive timely, expert and coordinated support throughout their disease journey.

Yours sincerely

A handwritten signature in black ink, appearing to read 'Liam O'Meara', with a stylized, flowing script.

Liam O'Meara
Chief Executive Officer

MNDSA submission on the future Support Coordination and Connection service

Motor Neurone Disease Association of South Australia | September 2026

Executive summary

Motor Neurone Disease Association of SA (MNDSA) supports a multi-provider SCC model that preserves participant choice and includes a directly accessible, funded pathway for cohort-specific SCC. Regional commissioning can strengthen local coverage, but geographic boundaries must not restrict access to MND-specific expertise.

MNDSA recommends that the future SCC model:

- establish a formal cohort-specific SCC commissioning pathway;
- preserve direct participant choice of specialist providers;
- assess the need for specialist expertise separately from coordination intensity;
- enable specialist delivery across geographic boundaries;
- fund proactive coordination, specialist consultation and cross-system work; and
- protect participant relationships and specialist workforce capability during transition;
- permit specialist organisations to provide SCC alongside therapy and other NDIS supports where appropriate governance and conflict-of-interest safeguards exist;
- recognise that integrated specialist service models can improve participant outcomes, continuity and responsiveness for low-prevalence and rapidly progressive conditions such as MND.
- allow specialist disability organisations to deliver Support Coordination and other NDIS-funded supports where appropriate safeguards are in place. Blanket service separation requirements should not prevent participants from accessing integrated, condition-specific expertise that improves coordination, responsiveness, continuity and outcomes. Conflicts of interest should be managed through robust governance, transparency and participant choice rather than organisational service separation.

Definition: Cohort-specific SCC is coordination delivered by organisations with demonstrated expertise in a defined disability cohort where that expertise significantly affects the quality, timeliness or outcomes of coordination.

Specialist expertise and service intensity are distinct. SCC+ reflects when intensive coordination must be delivered; cohort-specific SCC reflects the knowledge required to coordinate effectively. A person with MND may need cohort-specific SCC before meeting SCC+ criteria and may later require both.

MNDSA context and position

MNDSA is a not-for-profit organisation with 40 years of experience providing specialist support and care statewide to people living with Motor Neurone Disease (MND). MND is progressive and life-limiting, and support needs can change rapidly. MNDSA combines condition-specific expertise, statewide community-provider networks and an established relationship with the MND Clinic multidisciplinary team at Flinders Medical Centre. MNDSA's position is that regional coverage should complement—not replace—direct access to specialist MND coordination.

Motor Neurone Disease Association of Australia (MNDA) have also submitted a response. We have included that as an attachment to our email and support it.

A1. What is working well in support coordination today that you would like to see in the new SCC service?

For people living with MND, the strongest features of the current support coordination model are continuity, trusted relationships, participant choice and flexibility—including the ability to select a provider with specialist knowledge of MND.

An additional strength is the ability for participants to access support coordination alongside specialist therapy and advisory services within the same organisation. This model enables faster information sharing, coordinated planning, reduced duplication, and earlier identification of emerging support needs. Participants benefit from having a coordinated team with shared MND expertise rather than navigating multiple disconnected providers.

MNDSA recommends retaining the strongest features of the current support coordination model:

- participant choice and continuity with trusted support coordinators;
- access to disability-specific expertise
- flexible, responsive and proactive coordination
- strong links across disability, health, aged care and palliative care
- collaboration with families and carers.

These features allow coordinators to anticipate rapid change by drawing on individual expertise, organisational knowledge and established MND service networks. They should be preserved through a cohort-specific commissioning pathway.

For people living with MND, support coordination must anticipate rapid change and draw on specialist organisational knowledge and established service networks—not simply administer a plan.

A2. What would you most like to see improved in the new SCC service?

The new SCC service should improve:

- responsiveness when needs change;
- early planning and intervention rather than crisis response;
- coordination across service systems;
- national quality and workforce standards;
- recognition of specialist expertise;
- participant choice and continuity; and
- assessment of complexity beyond diagnosis or plan value.

The model must provide timely access to specialist advice, proactive monitoring and coordinated delivery across disability, health, aged care and palliative care. It must also allow support to escalate rapidly as a person's needs change.

A3. When should SCC be a face-to-face service or a virtual service?

SCC should use a blended model, with the delivery method determined by participant needs, preferences and circumstances.

- **Face-to-face delivery** is essential when circumstances are complex or changing, a home assessment is needed, a new relationship is being established, or communication and decision-making are best supported in person.
- **Virtual delivery** can provide rapid access to specialist expertise regardless of location. It is appropriate when preferred by the participant, when specialist expertise is unavailable locally, or when routine monitoring and coordination can be delivered effectively at a distance.

A blended model combines personal engagement with timely, equitable access to specialist MND expertise.

A4. What participant groups will benefit most from the SCC service? What do their needs for connection and coordination of supports look like?

SCC will particularly benefit people with progressive neurological conditions like MND, as well as those with complex or overlapping needs, communication or decision-

making support needs, limited informal supports, significant life transitions, safeguarding concerns, and those in thin markets.

For these groups, needs include timely access to services, coordination of allied health and equipment, navigation across systems, proactive planning, engagement with families, and access to specialist networks.

For MND, complexity is shaped by the speed and likely trajectory of change—not only current circumstances. Eligibility and service intensity should account for anticipated progression and the consequences of delay. Condition-specific expertise may be essential even when high-intensity coordination is not yet required.

A5. What experience, skills and knowledge do you look for in an SCC worker?

SCC workers should have:

- strong knowledge of the NDIS and its interfaces with health, aged care, housing, community and palliative care;
- excellent communication, engagement and relationship-building skills;
- capability in assessment, safeguarding, advocacy and problem-solving;
- experience coordinating complex, changing circumstances; and
- a person-centred, strengths-based approach.

SCC workers need not be experts in every rare disability, but they must recognise the limits of their knowledge and obtain specialist advice promptly. Coordination needs to be anticipatory rather than merely reactive. For MND, they must understand—or quickly access expertise about—disease progression and changing equipment, communication, care and clinical needs.

A6. What would help you feel safe when receiving SCC services and encourage you to report an issue if needed?

Participants are more likely to feel safe and report concerns when services provide:

- clear information about rights, standards and complaints;
- accessible, independent reporting channels and timely feedback;
- strong governance, safeguarding, supervision and quality assurance;
- transparent management of conflicts of interest;
- trusted, respectful relationships; and
- practical options to change coordinators or providers without losing support.

Competent practice, effective complaints processes and genuine provider choice are essential. If provider numbers are reduced, participants must retain practical options to change coordinators or providers without losing support.

A7. What else should we consider when designing the future SCC service?

The future model should:

- preserve participant choice, continuity of relationships and access to specialist providers;
- formally recognise specialist expertise and enable direct participation by specialist organisations;
- fund proactive, preventative coordination;
- assess the need for specialist expertise separately from service intensity;
- support workforce development, capability building and sustainable caseloads;
- enable flexible service delivery across regional and geographic boundaries;
- manage potential conflicts of interest through proportionate safeguards rather than blanket service separation; and
- implement a staged, participant-centred transition that minimises disruptions to participants.

The NDIA should establish a formal cohort-specific commissioning mechanism. It should directly commission organisations with demonstrated condition-specific capability to deliver SCC across geographic boundaries where that expertise materially affects coordination outcomes. This pathway should complement general SCC services.

National consistency must not produce a one-size-fits-all model. Commissioning criteria and funding should explicitly recognise the specialist knowledge, clinical and community networks, responsiveness and infrastructure required to support rare and rapidly progressive conditions.

The NDIA should avoid adopting a blanket prohibition on SCC providers delivering other NDIS supports. While conflicts of interest must be appropriately managed, an across-the-board service separation requirement would disproportionately affect specialist disability organisations supporting low-volume cohorts such as MND. For many participants, integrated access to support coordination, specialist allied health, equipment advice, education and service navigation improves responsiveness and reduces fragmentation. Effective safeguards should focus on participant choice, transparency and governance arrangements rather than preventing specialist organisations from delivering multiple supports.

B1. What commissioning arrangements would best balance participant outcomes, quality, sustainability and choice and control?

MNDSA supports a multi-provider model with regional coverage and a directly accessible, funded cohort-specific SCC pathway.

The framework should:

- commission regional providers to ensure local coverage, community connections and place-based knowledge;
- establish a dedicated, funded cohort-specific SCC commissioning pathway;
- permit direct participant referral and specialist delivery across geographic boundaries;
- preserve genuine participant choice and control in selecting providers;
- fund referral, consultation and partnership arrangements between generalist and specialist services; and
- allow participants to access specialist coordination when needed, without first having to demonstrate that a generalist service is unable to meet their needs.

This approach balances governance, quality and sustainability requirements with timely access to specialist MND expertise. It also reduces the risk of access to specialised support being controlled by a single regional provider. Importantly, it enables direct access to MND-specific coordination, ensuring participants receive support that is aligned with their diagnosis, needs and circumstances, rather than being determined solely by their geographic location.

B2. What provider types would be best placed to be a lead organisation? Why do these characteristics matter?

If a lead organisation model is adopted, organisations should be selected on demonstrated capability—not type or scale alone. Criteria should include governance, financial sustainability, safeguarding, coordination capability, workforce capacity, service quality, accessibility, regional reach, cross-system knowledge and established local relationships.

Lead organisations should also maintain clear referral pathways and formal, funded partnerships with specialist organisations, recognising that specialist expertise cannot always be replicated internally. Participants whose condition or circumstances warrant access to cohort-specific support, such as MND-specific SCC, should be able to access that pathway directly. This would allow lead organisations to focus on the delivery of general SCC services, while specialist providers concentrate expertise where condition-specific knowledge materially influences coordination outcomes.

Specialist organisations frequently deliver a combination of coordination, capacity-building and therapeutic services because condition-specific expertise is concentrated within a small workforce. Requiring complete organisational separation of these functions risks fragmenting care, reducing efficiency and weakening access to specialist knowledge. Commissioning arrangements should therefore permit integrated

service models where providers demonstrate robust conflict-management processes and participants retain genuine choice.

These safeguards would align support with participant needs rather than organisational structure or location.

B3. What are the advantages and disadvantages of the lead organisation model?

Advantages include a single point of responsibility, clearer accountability, improved communication between providers, consistent standards, coordinated referrals and stronger regional coverage.

Risks include reduced choice, geographic gatekeeping, marginalisation of specialist providers, disrupted relationships and loss of specialist capability.

A further risk is the loss of integrated specialist service models if SCC providers are prevented from delivering other NDIS supports. This may result in fragmented communication, duplication of assessments, delayed responses to changing needs, increased burden on participants and carers, and reduced access to specialist expertise.

If adopted, the model should guarantee participant choice and direct, funded access to specialist providers. People with MND should not have to demonstrate failure of a generalist service before receiving MND-informed coordination.

Conflict-of-interest risks should be managed through transparent disclosure, participant consent, independent oversight, clear separation of decision-making where required, and participant freedom to choose alternative providers. These safeguards are more proportionate and effective than blanket service separation, which could unintentionally reduce access to specialist expertise and disrupt established models of care.

B4. What would be appropriate regional areas to use for SCC service areas?

Regional boundaries should support service planning and accountability, but must not restrict participant access to statewide specialist providers. In South Australia, planning could distinguish metropolitan Adelaide, regional centres, rural communities, and remote or very remote locations to reflect different markets, workforce capacity, travel requirements and access barriers.

Specialist organisations should be commissioned to work across regions through face-to-face, virtual and outreach delivery. Participants should have access to both local knowledge and the specialist expertise relevant to their disability.

B5. How might SCC providers manage variable need among the participants they support? Which workforce, caseload and service capacity factors should be considered?

Providers should allocate resources according to changing complexity and intensity, with regular review, rapid escalation and proactive planning.

- **Workforce:** appropriate remuneration, supervision, professional development, specialist capability and arrangements for urgent responses.
- **Caseloads:** weighting for complexity, cross-system work, communication and advocacy needs, progression, safeguarding risk and multidisciplinary coordination—not participant numbers alone.
- **Capacity:** surge capacity, flexible delivery, clear escalation pathways and funding for proactive work and crisis prevention.

For MND, coordination intensity may increase within weeks due to changes in mobility, communication, swallowing, respiratory function, hospitalisation or informal support capacity. Participant need—not a standard caseload or static annual allocation—must drive the response.

B6. Which payment and funding approaches would best support participant outcomes, workforce sustainability and innovation?

Because MND is progressive, funding must support anticipatory planning and timely responses even when functional decline continues despite effective coordination.

MNDSA supports a funding model that combines participant-based allocations with:

- complexity and specialist capability loadings;
- mechanisms for rapid escalation of funding and support when needs change;
- recognition of anticipated disease progression and future support requirements;
- payment for essential indirect activities, including case conferences, discharge planning, service liaison, safeguarding, and crisis prevention;
- funding for supervision, workforce development, training, and sustainable caseloads; and
- support for specialist consultation, hybrid service delivery, partnership arrangements, and outreach activities.

This approach would support responsive services, sustainable workforces and proactive intervention before issues become crises.

Commissioning arrangements must pay specialist organisations for consultation, referral and partnership work provided to general SCC services.

Cohort-specific funding should also cover the infrastructure needed to maintain specialist knowledge, professional networks, workforce capability and service responsiveness.

B7. What quality, workforce and safeguarding requirements should apply to commissioned SCC organisations?

Commissioned organisations should meet enforceable requirements for:

- **Quality:** governance, national standards, continuous improvement, accessible complaints, transparent conflict management and outcome measures such as responsiveness, continuity and timely implementation.
- **Workforce:** appropriate recruitment, induction, supervision, development, manageable complexity-weighted caseloads, staff wellbeing and access to specialist advice.
- **Safeguarding:** risk identification and escalation, incident and whistleblower systems, independent monitoring, and protection from retaliation or service loss.

Compliance should be tested through audits, service review, participant feedback and measurable outcomes. Conflicts of interest should be managed through proportionate safeguards including disclosure requirements, participant choice protections, governance controls, independent complaints mechanisms and regular oversight. Blanket organisational service separation between SCC and other NDIS supports should not be required where specialist providers can demonstrate that integrated service delivery improves participant outcomes while maintaining appropriate safeguards.

Safeguards should protect participants from harm and inappropriate provider practices while preserving access to condition-specific expertise.

B8. How can the future SCC model attract, build and retain workforce capability, including retaining participant relationships?

Workforce capability is at risk before implementation begins. Prolonged uncertainty may cause providers to reduce investment, redeploy staff or exit support coordination, resulting in the loss of experienced workers, participant relationships and specialist knowledge that cannot be quickly rebuilt.

The model should recognise SCC as skilled professional work and fund competitive remuneration, manageable caseloads, structured induction, supervision, mentoring,

professional development and career pathways. Early clarity about cohort-specific commissioning is essential to minimise attrition and support readiness.

Transition arrangements should preserve trusted coordinators and specialist organisational knowledge wherever practical. When transfers are unavoidable, comprehensive handovers should be mandatory. Cohort-specific pathways should be commissioned through transparent processes with defined capability and quality criteria.

B9. How should local knowledge and community connection be defined and assessed?

Local knowledge should extend beyond physical proximity and include:

- an understanding of local services, workforce capacity, wait times, service gaps, and community and cultural contexts;
- the ability to identify and connect participants with the disability-specific expertise most relevant to their needs;
- established relationships with community organisations, government agencies, health services, and other providers;
- effective referral pathways and strong participant engagement practices; and
- connections with specialist organisations and broader cross-sector networks.

Assessment should test demonstrated knowledge of local and specialist service systems, awareness of service gaps, established networks, coordination outcomes and participant feedback. Geographic knowledge and disability-specific expertise should be assessed as distinct, complementary capabilities.

For people with MND, proximity alone is insufficient. Commissioning should ensure access to coordinators who understand MND pathways, networks and service systems.

B10. How can the SCC service best support participants in regional, rural and remote areas, or other thin markets?

The model should:

- preserve choice regardless of location;
- enable specialist delivery across regions;
- combine face-to-face, virtual, outreach and hybrid services;
- fund travel, outreach and the additional coordination needed in thin markets;
- provide escalation pathways when essential services are unavailable; and
- formalise partnerships between local and specialist providers.

Regional participants should not have to choose between local knowledge and specialist MND expertise. Recruitment and retention strategies are also needed to build sustainable local capacity.

B11. 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?

The future definition of complexity should recognise rapidly progressive neurological conditions such as MND. Complexity is not defined solely by crisis, behavioural issues or the number of services involved. For people with MND, it often arises from the speed and progression of changing needs across disability, health, communication, housing and care systems. Effective SCC should therefore provide anticipatory planning, flexible support intensity, cross-system coordination and timely access to MND-specific expertise, recognising both current circumstances and anticipated trajectory.

There is also an important distinction between SCC+ and cohort-specific SCC. SCC+ reflects the intensity of coordination required, while cohort-specific SCC reflects the specialist knowledge needed to coordinate effectively for a particular population. A person with MND may require condition-specific coordination before they meet SCC+ criteria and may later require both. Participants should be able to move between levels of coordination intensity without losing access to MND-specific expertise. Eligibility should not depend on reaching crisis point; consideration should also be given to the likely consequences of delayed coordination, including avoidable crises, reduced quality of life and increased pressure on families and carers.

For people living with MND, coordination is most effective when informed by current clinical, functional and service-delivery knowledge. Integrated specialist service models allow support coordinators to work closely with therapists and other specialist staff, resulting in earlier identification of changing needs, more timely equipment and service responses, and improved continuity for participants and families. Future SCC arrangements should protect access to these collaborative models.

B12. What transition arrangements would minimise disruption and support successful implementation?

Transition should be gradual, participant-centred and designed around continuity. It should:

- retain existing coordinators where appropriate;
- use clear timelines, adequate notice and phased implementation;
- provide individual transition plans and comprehensive handovers;

- avoid transferring participants during rapid deterioration, hospitalisation, end-of-life care or other high-risk periods unless requested or necessary;
- protect specialist workforce capability and monitor emerging gaps; and
- provide accessible information about changes, choices, support and complaints.

For participants with MND, continuity and preservation of specialist relationships are critical to avoiding delays, duplication and distress.

MNDSA's priority recommendations

1. Allow specialist disability organisations to deliver Support Coordination and other NDIS-funded supports where appropriate safeguards are in place. Blanket service separation requirements should not prevent participants from accessing integrated, condition-specific expertise that improves coordination, responsiveness, continuity and outcomes. Conflicts of interest should be managed through robust governance, transparency and participant choice rather than organisational service separation.
2. Permit specialist organisations to deliver SCC alongside therapy and other NDIS services where robust conflict-of-interest safeguards exist, recognising that integrated specialist service models improve continuity, responsiveness and participant outcomes for people living with MND.
3. Establish a formal, funded cohort-specific SCC pathway for disability cohorts where specialist expertise materially affects outcomes.
4. Preserve participant choice and permit direct access to specialist providers without requiring a generalist service to fail first.
5. Assess specialist knowledge requirements separately from SCC+ service intensity.
6. Use regional boundaries for planning and accountability, not as barriers to statewide specialist delivery.
7. Fund proactive coordination, rapid escalation, indirect coordination activities, travel, outreach and specialist consultation.
8. Apply enforceable quality, workforce and safeguarding standards with proportionate conflict-of-interest controls.
9. Implement a staged transition that protects trusted relationships, specialist workforce capability and continuity of support.

These measures would combine local accountability with equitable access to the specialist expertise required by people living with MND.