

Emerge Australia submission to: NDIS Support Coordination and Connection (SCC) Consultation

About Emerge Australia

Emerge Australia is the national organisation leading action on myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS), long COVID and overlapping conditions. We work to improve the lives of those impacted through clinical education, policy and advocacy, biomedical research and health and support services.

We provide information, support and advocacy, and we regularly hear from NDIS participants and their families about the barriers they face in accessing appropriate, well-informed support. We welcome the opportunity to respond to the Support Coordination and Connection (SCC) Reform Consultation Paper.

Executive summary

Emerge Australia supports the objectives of a better-governed, more consistent SCC service, and recognises the genuine problems the reform is intended to address, including inconsistent quality, unclear role boundaries, conflicts of interest, and issues with the current fee-for-service model. However, we have significant concerns about how the reform could affect people with ME/CFS and long COVID in practice, in particular:

- the loss of participant choice and control under a single lead-organisation-per-region model;
- the risk that eligibility criteria for SCC and the higher-intensity SCC+ service do not adequately recognise individual functional impairment and the resulting coordination needs, including cognitive and communication impairments and very limited capacity to find, arrange and manage supports;
- the risk that commissioning arrangements could displace independent and small providers who currently hold valuable ME/CFS and long COVID-specific expertise;
- the need to embed virtual and hybrid delivery as standard, equally valid service options, recognising that physical accessibility measures alone will not make SCC accessible to many people with energy-limiting conditions.

Below, we summarise our recommendations and respond to the consultation questions most relevant to our community, drawn from both sections of the Consultation Paper.

Summary of recommendations

- Preserve participant choice and continuity of trusted relationships. Wherever a lead-organisation-per-region model is adopted, require a genuine internal choice of worker, the ability to change workers without service interruption, and an independent escalation pathway.
- Base SCC and SCC+ eligibility and service levels on individual functional impairment and the participant's actual capacity to find, arrange and manage appropriate supports, rather than broad assumptions about a cohort.
- If new framework support needs assessment information is used for SCC decisions, require consideration of the complete assessment record, participant and nominee evidence, relevant clinical evidence and the person's safe and sustainable capacity. Do not rely on I-CAN or any single assessment component and allow participants to review and correct the information used.
- Establish consistent national standards covering clear role boundaries, core support coordination competencies, condition-informed practice and the proactive identification and provision of accessibility adjustments.
- Make virtual, hybrid and home-based service delivery standard, equally valid options for participants whose functional impairments make in-person engagement inaccessible or unsafe.
- Adopt a blended funding model with an adequate base payment, needs-based loadings and flexible capacity to respond immediately to increased coordination needs, including while any required plan variation or reassessment is being considered. Payment and monitoring arrangements should support workforce sustainability, service quality and participants with more complex needs.
- Require commissioned organisations to establish partnerships or subcontracting arrangements with specialist SCC providers where they cannot provide the necessary expertise internally and allow participants to access specialist expertise outside their immediate region, including virtually.
- Define community connection as helping participants identify and access meaningful, safe and sustainable opportunities, including remote, hybrid, home-based and asynchronous options where appropriate.
- Include workforce transition measures, such as recognised prior experience, secondment and preferred subcontracting, to retain existing coordinators with relevant expertise as the market consolidates.
- Require accessible, low-energy complaints and safeguarding mechanisms, including written and asynchronous reporting channels, involvement of a nominee or representative, and a written acknowledgment and outcome for every complaint, so

participants are not required to make repeated phone calls or attend in person to have a concern addressed.

- Support participants through transition with adequate advance notice, a supported handover, and clear written information in accessible formats, so that participants are not required to repeatedly re-explain their disability, functional impairments and accessibility needs to each new worker or organisation.
- Communicate clearly, and consult separately where needed, on how Local Area Coordinators and Early Childhood Partners will support participants not found eligible for SCC.

Part A: What participants want from the new SCC service

Q1. What is working well in support coordination today that you would like to see in the new SCC service?

Where support coordination works well, participants can choose and retain a coordinator who understands their individual functional impairments and helps them implement their NDIS plan with the least possible administrative and cognitive burden. An effective coordinator identifies and compares suitable providers, helps establish services, coordinates communication between providers and other systems, addresses service gaps or breakdowns, and monitors whether supports remain appropriate and effective. A trusted, continuing relationship means the coordinator already understands the participant's circumstances, goals, communication needs and accessibility requirements, reducing the need for the participant to repeatedly explain their disability.

For people with ME/CFS or long COVID, effective coordination also requires knowledge of post-exertional malaise and the difference between completing an activity once and being able to do it safely and sustainably. A knowledgeable coordinator can communicate and organise services in an accessible way, identify providers capable of making necessary adjustments, and screen out approaches that may cause deterioration. The new SCC model should preserve participant choice, continuity of trusted relationships and access to this combination of skilled coordination and condition-informed expertise.

Q2. What would you most like to see improved in the new SCC service?

We would like to see clearer role boundaries so participants understand what SCC can and cannot assist with, noting that the paper confirms SCC will not provide advocacy. We also support consistent national standards for disability and condition-specific knowledge across commissioned organisations, not only individual workers. These standards should require organisations to identify and offer accessibility adjustments proactively, rather than placing the burden on participants to repeatedly request, explain and justify them.

The service and payment model must also be able to respond promptly when a participant's functional capacity and coordination needs increase. For people with ME/CFS or long COVID, a significant crash or episode of post-exertional deterioration may cause a prolonged or permanent reduction in functional capacity, rather than a short-term fluctuation followed by a return to the previous baseline. SCC organisations must be able to increase or adapt coordination promptly when this occurs. Where the deterioration requires a plan variation or reassessment, the SCC worker should support the participant to navigate that process.

The participant should not be left without adequate coordination, or required to manage a complex reassessment process without assistance, while acutely unwell or cognitively impaired.

Q3. When should SCC be a face-to-face service or a virtual service?

Participants should be able to choose the mode of service delivery that is safe and accessible in light of their functional impairments. For many people with ME/CFS or long COVID, travel and in-person meetings consume substantial energy and may trigger post-exertional malaise. Virtual or home-based delivery should therefore be available as a standard, equally valid option, not treated as a lesser form of service. Delivery should also accommodate cognitive, communication and sensory impairments through options such as written or asynchronous communication, flexible scheduling and cancellation, shorter interactions, rest breaks and low-stimulation environments. Face-to-face contact should remain available where the participant chooses it or where it is genuinely necessary, but should not be required merely as a matter of standard procedure. Accessibility should be judged by whether the participant can engage safely and sustainably, not whether they can manage a single appointment at the cost of subsequent deterioration.

Q4. What participant groups will benefit most from the SCC service? What do their needs for connection and coordination of supports look like?

Eligibility for SCC and SCC+ must be determined through individual assessment rather than assumptions based on diagnosis or broad illness severity. NDIS participants with ME/CFS or long COVID generally have substantial functional impairment and may be mostly housebound or bedbound. Their coordination needs vary depending on the nature and extent of their physical, cognitive, communication, sensory and other functional limitations. In particular, cognitive impairment may substantially affect their ability to understand information, communicate with providers, complete administrative tasks, make and implement decisions, and monitor whether supports are working safely. Assessment should examine the person's actual capacity to find, arrange and manage appropriate supports safely, reliably and without worsening their health. Coordination needs may include identifying, comparing and engaging condition-informed providers; coordinating communication between providers and other systems; resolving gaps or breakdowns in services; and arranging supports that assist with essential activities such as obtaining groceries and attending medical appointments. Because participants may be managing daily life within very limited energy and cognitive capacity, interactions must be simple, low-energy and effective, with minimal administrative burden and repetition.

If information from the new framework support needs assessment is used to determine SCC eligibility or service level, decisions must not rely on an I-CAN score or any other single

assessment component. They should consider the complete assessment record, participant and nominee evidence, relevant clinical evidence, and the person's actual capacity to find, arrange and manage supports safely, reliably and sustainably. Participants must also have an accessible opportunity to review and correct the information relied upon before an SCC or SCC+ decision is made.

For this cohort, community connection must be understood broadly. It may need to occur remotely, asynchronously or from home, including through online activities in which participants can genuinely engage rather than merely observe. Where participation outside the home is possible, it may require individual assistance, a low-stimulation environment, small numbers of people and careful pacing. The SCC worker's role is to understand these limitations and help the participant identify, access and coordinate safe, appropriate services that reflect how the person can participate.

Q5. What experience, skills and knowledge do you look for in an SCC worker?

We look for SCC workers with strong skills in implementing NDIS plans, identifying and comparing suitable providers, establishing and coordinating services, navigating NDIS and mainstream systems, resolving service gaps or breakdowns, and monitoring whether supports remain appropriate and effective. They should communicate clearly, work collaboratively, respect participant choice and control, and reduce rather than add to the participant's administrative and cognitive burden.

SCC workers must also be able to understand how an individual's physical, cognitive, communication, sensory and other functional impairments affect both their capacity to find, arrange and manage supports, and the types of supports they require. This includes identifying and offering appropriate adjustments proactively, such as written or asynchronous communication, flexible scheduling, shorter interactions, rest breaks, and virtual or home-based engagement.

For participants with ME/CFS or long COVID, workers also need practical knowledge of post-exertional malaise and the difference between completing an activity once and being able to do it safely and sustainably. They should be able to identify condition-informed providers, recognise approaches that risk deterioration, and seek specialist advice when a participant's needs extend beyond their own expertise. They do not need to be clinicians, but they must understand the limits of their role and give appropriate weight to the participant's experience and relevant clinical evidence.

Q6. What would help you feel safe when receiving SCC services and encourage you to report an issue if needed?

Participants should have a genuine ability to change SCC worker or escalate a concern without having to change organisations altogether (see our comments on the lead-

organisation model below). Reporting mechanisms should be available in multiple low-energy formats, including written and asynchronous options, and should allow a nominee or representative to assist where needed. Participants should not be required to make repeated telephone calls, attend an in-person meeting or repeatedly recount their experience to have a concern addressed. They should receive a written acknowledgment, clear information about what will happen next and the outcome of the complaint.

Q7. What else should we consider when designing the future SCC service?

Building on the condition-specific knowledge and coordination skills outlined above, relevant lived experience should be valued in SCC workforce recruitment, training and service design. Participants should have access to an ongoing relationship with a consistent coordinator who understands their circumstances. Continuity should be embedded in routine service delivery as well as protected during transition, with staffing and caseload arrangements that allow coordinators to build and maintain these relationships.

With the participant's consent, the service should also enable collaboration between the coordinator, disability support providers, treating clinicians and other relevant services. This should reduce the participant's burden of relaying information and managing connections between services, while maintaining clear role boundaries.

Part B: Service provider models and approaches

Q1. What commissioning arrangements would best balance participant outcomes, quality, sustainability and choice and control?

Of the two approaches outlined (a single lead organisation per region, or a multi-provider model allowing providers to pool resources and expertise across or within regions), we favour arrangements that preserve genuine participant choice within a region. If a single lead-organisation model is adopted, we recommend the lead organisation be required to offer participants a real choice between at least two workers or sub-contracted specialist partners, with a clear, independent pathway to escalate or change worker where the relationship is not working or the worker lacks relevant condition-specific knowledge. A multi-provider model that allows specialist organisations to hold a role alongside a generalist lead would better protect access to condition-specific expertise for smaller, complex-needs cohorts like ours.

Q3. What are the advantages and disadvantages of the lead organisation model?

The advantage is consistency and simplified oversight. The disadvantage, from our community's perspective, is that if a region's lead organisation does not have staff with ME/CFS or long COVID expertise, participants may have no alternative provider to turn to, unlike today, when they can seek out one of the small number of coordinators nationally who understand the condition, even if that coordinator is outside their immediate region. The paper already identifies partnerships and subcontracting with specialist providers as possible responses in specialist and thin markets. We support this approach and recommend that commissioned organisations be required to establish such arrangements where they cannot provide the necessary condition-specific expertise internally. Participants should also be able to access an appropriate specialist provider outside their immediate region, including virtually, where equivalent expertise is not available locally.

Q5. How might SCC providers manage variable need among the participants it supports? Which workforce, caseload, and service capacity factors should be considered?

Caseload and capacity models built around an assumed average level of contact will not work for participants whose need for coordination can change suddenly and significantly. For people with ME/CFS or long COVID, a crash or period of post-exertional deterioration can require a rapid, substantial increase in coordination support that has little relationship to that participant's coordination needs a week earlier. Workforce and caseload planning should therefore build in genuine headroom, rather than assuming that every participant's needs are stable enough to be averaged across a caseload, and should ensure a worker's overall caseload does not prevent them responding promptly when an individual participant's needs increase. We support capacity and performance monitoring that looks at whether organisations can actually flex to meet acute increases in need, not only at average contact levels or aggregate caseload size.

Q6. Which payment and funding approaches would best support participant outcomes, workforce sustainability and innovation?

We support moving away from a pure hourly fee-for-service model, which can create incentives for both over- and under-servicing. However, any replacement model must recognise substantial differences in participants' functional impairments and support coordination needs. A participant with severe cognitive or communication impairment may require substantial assistance to understand information, compare providers, make and implement decisions, establish services and monitor whether supports are effective and safe. Additional coordination time may also be required where appropriate providers are scarce, services have broken down, or multiple providers and systems must work together.

We recommend a blended funding model comprising an adequate base payment, needs-based loadings and access to additional flexible capacity when a participant's circumstances or functional capacity change. Funding should reflect the participant's actual coordination requirements and the work necessary to achieve effective outcomes, rather than an assumed standard level of contact. The model must give SCC organisations sufficient flexible capacity to respond immediately to increased coordination needs, including while any required plan variation or reassessment is being considered. Where a formal change is required, the SCC worker should support the participant to navigate the process, and adequate coordination should continue while a decision is pending.

Workforce sustainability requires funding that supports manageable workloads, appropriate supervision, professional development and the retention of workers with relevant expertise. Payment arrangements should also support accessible and innovative delivery, including digital and asynchronous communication, without discounting virtual services or using technology as a substitute for the human assistance a participant requires. Performance monitoring should examine participant outcomes, unmet need and service quality so commissioned organisations are not rewarded for limiting contact or avoiding participants with more complex coordination needs.

Q8. How can the future SCC model attract, build and retain workforce capability, including retaining participant relationships?

Independent support coordinators and small businesses currently hold a disproportionate share of Australia's ME/CFS and long COVID-literate coordination expertise, built up over years of working with our community. Many stand to lose their livelihoods or face substantial pay cuts if required to move into employment with a small number of commissioned organisations. We ask that transition and procurement processes include specific measures, such as recognised prior experience, secondment arrangements or preferred sub-contracting status, to retain this expertise within the new system rather than losing it as the market consolidates. We note the paper confirms Psychosocial Recovery Coaches will potentially transition into SCC roles for participants with psychosocial disability; we ask that an equivalent, explicit transition pathway be considered for coordinators with deep condition-specific expertise in complex chronic illness.

Q9. How should local knowledge and community connection be defined and assessed?

Local knowledge should mean more than familiarity with nearby services and venues. It should include knowledge of which mainstream and disability providers are safe, appropriate and accessible for a participant's particular functional impairments. For people with ME/CFS or long COVID, an accessible service may need to provide remote or home-

based delivery, written or asynchronous communication, flexible scheduling and cancellation, shorter interactions and rest breaks, and low-stimulation environments. Accessibility should be judged by whether the person can use the service safely and sustainably, not simply whether they can attend or complete an interaction once. SCC workers must also know which providers understand post-exertional malaise and severe energy limitation and avoid approaches that risk deterioration. Where suitable expertise is unavailable locally, they should be able to identify appropriate services outside the participant's region, including services delivered virtually.

For the purposes of SCC, community connection should mean helping a participant identify and access meaningful and sustainable opportunities for participation, not simply directing them to a nearby venue. Depending on the participant's functional capacity, an SCC worker may need to connect them with remote, hybrid, home-based or asynchronous options. These may include online peer groups, activities in which remote participants can genuinely contribute, or services that provide individual assistance with essential and social activities. The suitability of a connection should be assessed by whether the participant can access and sustain it within their energy, cognitive and sensory limits without causing harm.

Q10. How can the SCC service best support participants in regional, rural and remote areas, or other thin markets, where support options may be limited?

Condition-informed ME/CFS and long COVID support coordination expertise is a thin market nationally, regardless of geography. A person with ME/CFS or long COVID in a capital city may have as much difficulty finding a knowledgeable coordinator as someone in a regional area. We recommend that the SCC model recognise condition-specific expertise as a specialist thin-market need and use partnership, subcontracting and virtual delivery arrangements to ensure participants are not limited to the expertise available within their immediate geographic region.

Q11. How can the SCC service best support participants who face additional barriers, including those experiencing complex and overlapping support needs or requiring decision-making support?

SCC and SCC+ criteria should recognise that complexity can arise from the interaction of multiple functional impairments, not only from involvement with multiple service systems, unstable supports or heightened safety risks. A NDIS participant with ME/CFS or long COVID may experience severe physical, cognitive, communication, autonomic and sensory impairments simultaneously. They may be housebound or bedbound, have very limited capacity to communicate with providers or complete administrative tasks, and face a scarcity of services that understand their disability and can provide support safely. These

barriers compound one another even where the participant's overall level of impairment and support arrangements are relatively stable. Eligibility and service level should therefore be based on an individual assessment of the person's actual capacity to find, arrange, and manage appropriate supports, together with the complexity of the service environment they must navigate. Stable circumstances should not be treated as evidence that coordination needs are simple or low. Within their coordination role, SCC workers should help participants communicate their support needs accurately and seek clarification where a NDIA decision or service arrangement appears inconsistent with the participant's functional limitations or relevant evidence.

Participants may also require increased and responsive coordination when they need to navigate health, housing or another service system. For example, a hospital admission may require an SCC worker to coordinate with the hospital, the NDIA and existing providers; clarify and arrange disability-related supports; support discharge planning; and help the participant navigate any necessary plan variation or reassessment. This coordination may be particularly important where the participant has substantial cognitive or communication impairment or experiences a reduction in functional capacity during or following the admission. The SCC service and its payment model should provide flexible capacity to mobilise additional coordination at these times, without requiring the participant to manage complex arrangements while acutely unwell.

Where a participant requires decision-making support, SCC workers should recognise and work within existing supported decision-making arrangements, consistent with the paper's confirmation that SCC will not make decisions on behalf of participants or replace supported decision-making arrangements. This means enabling a nominee or representative to be involved on the participant's terms, giving information and options in a form the participant can genuinely understand and act on, and allowing extra time and repetition where cognitive or communication impairment affects decision-making, rather than treating the presence of a nominee as a reason to communicate primarily with that nominee instead of the participant.

Q12. What transition arrangements would minimise disruption and support successful implementation?

Continuity of relationship should be prioritised wherever a participant currently has a coordinator with relevant expertise, even where that coordinator's business does not become a commissioned lead organisation, for example through subcontracting, secondment or grandfathering arrangements during transition. Participants should be consulted before their coordinator or service arrangements change and receive adequate notice, a supported handover and clear written information in accessible formats. Communication should be available through multiple channels and allow involvement from a nominee or representative. Participants should not have to repeatedly explain their

disability, functional impairments and accessibility needs to each new worker or organisation. We also ask that the separate reforms affecting Local Area Coordinators and Early Childhood Partners, who will support participants not eligible for SCC, be clearly communicated and, where they affect service design, opened to consultation in their own right, given the significant number of participants likely to rely on them.

Conclusion

Emerge Australia supports the broad objectives of the SCC reform and welcomes the opportunity to contribute to its design. Our overarching concern is that a model built around consistency and safeguarding at a regional level must not lose the ability for participants with complex, poorly understood conditions like ME/CFS and long COVID to access coordinators who genuinely understand their illness and functional capacity limitations. We would welcome the opportunity to discuss this submission further, including how Emerge Australia's expertise could support the design and delivery of the SCC service for people with ME/CFS, long COVID and associated energy limiting conditions.