Huntington's Australia

Support Coordination and Connection Reform Consultation Submission



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About Huntington's Australia

Huntington's Australia (HA) is the national peak organisation supporting individuals and families impacted by Huntington's disease (HD).

HA provides specialist services nationally, including NDIS Support Coordination, counselling, social work, community programs, education and training. Our work requires extensive coordination and established relationships across disability, neurological and neuropsychiatric services, mental health, acute and primary health, community services, housing, police and justice systems.

Huntington's disease is a rare, inherited, progressive and terminal neurodegenerative condition. Its impacts extend across movement, cognition, behaviour, mental health, communication, swallowing, executive functioning, decision-making capacity and, progressively, a person's ability to live independently.

The Australian Government and NDIA have recently recognised this complexity through the establishment of a NDIS HD Planner Pathway for people with Huntington's disease. The Ministerial material supporting that pathway describes HD as a "rare complex genetic disorder", acknowledges that the condition can progress rapidly and recognises that people with HD require faster, more specialised support delivered with an understanding of the disease.[1]

Huntington's Australia currently provides specialist disease specific NDIS Support Coordination to just over 20% of NDIS participants with Huntington's disease nationally, giving HA substantial direct experience of the needs, risks and service-system challenges experienced by this cohort.

Executive Summary

Huntington's Australia supports the objectives of the proposed Support Coordination and Connection (SCC) reforms, including stronger quality standards, accountability, safeguarding and workforce capability.

However, we are concerned that the NDIA's preferred lead-organisation model may unintentionally reduce access to expert Support Coordination for people living with rare, progressive and highly complex conditions such as Huntington's disease (HD).

Huntington's Australia currently provides disease-specific Support Coordination to just over 20% of NDIS participants with HD nationally. Our experience demonstrates that specialist expertise, continuity of support and established cross-sector networks are critical to participant outcomes and safeguarding.

The NDIA has already recognised the importance of specialist HD expertise through the HD Planner Pathway. We believe that specialist knowledge should remain available not only during planning, but throughout the implementation and coordination of supports.

We recommend a hybrid commissioning model that combines regional SCC providers with a dedicated specialist provider stream for rare and complex conditions. This approach would strengthen quality and accountability while preserving access to proven specialist expertise.

Geography is not expertise. For people living with Huntington's disease, specialist knowledge is itself a safeguard.

1. Huntington's Australia supports reform - but not uniformity

The Consultation Paper identifies legitimate concerns within the current Support Coordination market, including inconsistent participant experiences, variable service quality and workforce capability, conflicts of interest, access difficulties in thin markets and inconsistent oversight.[2]

HA does not seek to preserve the existing system unchanged. We support stronger quality and practice standards; improved workforce capability requirements; effective safeguarding and oversight; appropriate accreditation and registration; stronger conflict-of-interest controls; performance monitoring; greater accountability; and commissioning arrangements that remove demonstrably poor-quality providers.

However, national consistency in quality standards should not mean uniformity in service delivery. Participants have different disabilities, circumstances, risks and levels of complexity. The commissioning model must retain sufficient flexibility to recognise when specialist expertise materially affects participant safety and outcomes.

2. Rare diseases require more than a regional service model

The Consultation Paper identifies two potential approaches: a lead-organisation model and a multi-provider model. Its preferred model, based on early thinking, is one lead organisation per region responsible for providing and/or contracting all required SCC services.[2]

HA questions the assumption that this model will necessarily increase quality or safeguarding for every participant cohort.

For a rare disease such as Huntington's disease, the relevant specialist service market is often national rather than regional. Expertise has developed within specialist organisations precisely because relatively small numbers of participants are geographically dispersed. It is unrealistic to expect every regional SCC organisation across Australia to develop and maintain sufficient HD expertise when it may support relatively few people with the condition. The likely outcome is dilution of expertise rather than expansion of expertise.

This is particularly concerning because the Consultation Paper itself acknowledges the importance of a highly capable workforce, continuity of trusted relationships, tailored support for people with complex and intersecting needs, access for specific cohorts and preservation of participant choice and control.[2]

3. HA supports more than 20% of NDIS participants nationally

Huntington's Australia currently provides expert, disease-specific Support Coordination to just over 20% of NDIS participants with Huntington's disease nationally. As a result, we have extensive experience supporting individuals and families experiencing the complex and progressive impacts of HD.

The proposed lead-organisation model could result in participants being transitioned away from specialist providers and into mainstream regional services with limited knowledge of Huntington's disease.

The key question is simple: how does participant quality, safety or choice improve by moving someone from a trusted specialist provider to a generic provider solely because it holds a regional contract?

For some participants, expert disease-specific Support Coordination has been sought only after generic arrangements failed to adequately identify or respond to escalating needs. Requiring those participants to return to similar service models risks reversing the very outcomes the reforms are intended to achieve.

4. SCC reform should align with the HD Planner Pathway

The NDIA's recently established HD Planner Pathway is directly relevant to SCC reform. In announcing the pathway, the Government recognised that Huntington's disease is a progressive condition requiring timely access to specialised support. Participants are assigned dedicated planners with HD-specific training to improve decision-making, responsiveness and continuity as needs change.[1]

More than 1,100 NDIS participants with HD have already transitioned to the pathway, with planners receiving specialist training through the NDIA, Huntington's Australia and the Royal Melbourne Neuropsychiatry Clinic.[1]

If specialist knowledge of Huntington's disease is required to determine the right supports, it is equally important when those supports are implemented, coordinated and adapted as the disease progresses.

Specialist planning and specialist implementation should be viewed as complementary parts of the same participant journey. A participant's outcomes may be compromised if a plan developed by a specialist HD Planner is subsequently implemented by a provider without comparable understanding of the condition.

Early experience of the HD Specialist Planner Pathway provides clear evidence of the need for disease-specific Support Coordination. HD Pathway Planners are directly referring participants to Huntington's Australia after identifying that their existing mainstream Support Coordination services do not have the specialist expertise required to support the complex and progressive needs of people with HD. These referrals demonstrate that generalist services are not consistently meeting the needs of this highly complex cohort and reinforce the critical importance of preserving continuity between specialist planning and specialist Support Coordination, rather than breaking that connection.

5. HA can demonstrate that specialisation and high quality can coexist

The Consultation Paper appropriately identifies quality, governance, workforce capability and safeguarding as priorities.[2]

HA supports substantially stronger standards. However, there should be no assumption that organisational size or regional scale automatically equates to quality.

Huntington's Australia has recently successfully completed its independent NDIS audit with exceptional results. Auditors identified HA's specialist expertise as exemplary and provided highly positive feedback arising from participant interviews. HA's processes, systems and governance structures were also identified as being among the strongest reviewed by the auditors.

This provides important independent evidence that specialist organisations can deliver the characteristics the new SCC model seeks to achieve specialist expertise, strong governance, effective systems, participant satisfaction, quality and safeguarding.

The correct policy response to variability within the existing market is therefore to establish standards capable of distinguishing excellent providers from inadequate providers. It is not to assume that consolidating services into larger organisations will itself produce quality.

6. For Huntington's disease, expertise is itself a safeguard

The Consultation Paper proposes workforce capability requirements, minimum practice standards, complaints mechanisms, safeguarding requirements, conflict-of-interest controls and performance monitoring.[2]

HA strongly supports these measures. However, for people living with rare and progressive conditions such as Huntington's disease, safeguarding extends beyond governance, compliance and oversight. Disease-specific expertise is itself a safeguard.

HD can impact executive functioning, insight, judgement, behaviour, communication, decision-making and a person's ability to engage consistently with services.

Without specialist knowledge, behaviours associated with neurological decline may be misinterpreted as disengagement, non-compliance or a lack of motivation. Practitioners with HD expertise are more likely to recognise these changes as indicators of increasing risk and deteriorating health.

That distinction matters. It can mean the difference between proactive intervention and crisis response.

7. Inadequate Support Coordination can have serious consequences

HA's concerns regarding safeguarding are not theoretical.

Through our Community Practitioner services, HA has supported individuals whose existing Support Coordination arrangements were not adequately responding to their complexity, changing circumstances or escalating risks. In many cases, significant advocacy was required to secure additional supports, services and intervention.

HA does not suggest that Support Coordination alone determines outcomes for people with HD. However, our experience highlights the profound vulnerability of this cohort and the importance of recognising and responding to deteriorating circumstances before crisis occurs.

For people with Huntington's disease, inadequate coordination may contribute to carer breakdown, unsafe living environments, service disengagement, homelessness, hospitalisation and other serious adverse outcomes. The future SCC model should be designed with these risks firmly in mind.

8. Specialist HD Support Coordination requires cross-system expertise

Effective HD Support Coordination extends beyond knowledge of NDIS providers.

It requires an understanding of neurological, neuropsychiatric, mental health, acute health, disability, housing and community systems, and the ability to navigate intersections between them as participant needs change. It also relies on established relationships with services and clinicians who understand Huntington's disease.

For rare conditions, relevant expertise may not exist within a participant's local region. A future SCC model should therefore recognise the importance of both local networks and national disease-specific expertise.

9. SCC+ does not replace specialist HD knowledge

The proposed SCC+ model recognises participants with highly complex circumstances, significant safety concerns and multiple interacting support systems. HA welcomes the acknowledgement that SCC+ requires specialist workforce capability.[2]

However, complexity expertise is not the same as condition-specific expertise.

A practitioner may be highly skilled in managing complex cases yet have limited understanding of Huntington's disease. For participants living with HD, effective support requires both expertise in complexity and a deep understanding of the condition, its progression and associated risks.

The future SCC model must ensure access to both capabilities.

10. Participant choice and continuity are safeguarding issues

The Consultation Paper highlights the importance of trusted relationships, participant choice and continuity of support.[2] These considerations are particularly important for people living with HD.

Specialist providers often develop extensive knowledge of a participant's disease progression, communication needs, family circumstances and risk factors. For many families, those relationships are built over many years and often span generations.

Where cognitive capacity is changing, requiring participants and families to repeatedly explain their circumstances to new providers creates an additional burden and may increase risk. Continuity of support should therefore be recognised as a safeguarding mechanism, not merely a participant preference.

This is reflected in HA's recent community survey, where Support Coordination was identified as one of the most valued services provided by Huntington's Australia and a key reason individuals and families engage with the organisation.

11. The lead-organisation model creates market, economic and safeguarding risks

HA recognises the problems associated with a fragmented Support Coordination market. However, replacing fragmentation with a single lead organisation in each region risks concentrating market power rather than resolving it.

Under the proposed model, the lead organisation could determine whether services are delivered internally or subcontracted to a specialist provider. This creates a potential conflict where the organisation deciding whether specialist expertise is required may also have a financial incentive to retain the participant and associated funding within its own service.

There is also an important economic concern. Where specialist services are subcontracted, the lead organisation may effectively become the purchaser and price-setter, potentially determining the rate paid to the specialist provider while retaining a proportion of funding for administration or contract management.

This introduces an additional layer between NDIS funding and the participant. Funding absorbed through intermediary administration or management is funding no longer available for direct participant-facing support. If subcontracting rates do not reflect the genuine cost of maintaining specialist expertise, specialist providers may ultimately be unable to sustainably deliver the quality and intensity of service required.

The lead organisation could therefore potentially control the referral, the decision to subcontract, the provider selected, the price paid and the funding retained for administration. For HA, this is not simply a provider-market issue; it is a participant choice, value-for-money and safeguarding issue.

Where a specialist provider can demonstrate appropriate expertise, quality, governance and safeguarding, the NDIA should retain the ability to commission that provider directly rather than requiring participant funding to pass through an additional intermediary.

12. Subcontracting alone is not sufficient

HA welcomes recognition within the Consultation Paper of the role played by specialist organisations.[2]

However, subcontracting should not become the sole pathway to specialist expertise. Making regional lead organisations the gatekeepers to specialist services could create inconsistent access across Australia and place unnecessary administrative burdens on specialist providers.

Where specialist expertise is required, NDIA planners should be able to refer participants directly to appropriately commissioned specialist providers.

13. Regional, rural, remote and First Nations participants

The Consultation Paper appropriately recognises the need for specialised and culturally safe responses in thin markets and specifically acknowledges the expertise of ACCOs, ACCHOs, Remote Community Connectors and other specialist organisations.[2]

This is particularly important for rare diseases. Rare diseases do not follow regional commissioning boundaries.

A participant in a remote community may require specialist HD expertise located elsewhere in Australia. For Aboriginal and Torres Strait Islander families impacted by HD, effective coordination may additionally depend upon trusted community relationships, culturally appropriate engagement and established connections with Aboriginal health organisations. These relationships cannot simply be replicated through procurement.

14. The downstream economic cost must be considered

Commissioning should not assess efficiency solely by the cost of providing SCC.

Poor coordination of a progressive condition can result in substantially greater downstream expenditure. Failure to anticipate deterioration can contribute to carer breakdown, service failure, emergency presentation, hospitalisation, delayed discharge, accommodation breakdown, emergency supported living arrangements and substantially increased NDIS expenditure.

Costs may also be transferred to State health systems, mental health services, housing, police and justice.

The appropriate measure of efficiency is therefore the whole-of-system outcome produced by effective coordination, not simply the unit cost of the SCC service.

15. The proposed model contains a fundamental policy tension

The Consultation Paper identifies the importance of a capable workforce, continuity of trusted relationships, participant choice and tailored responses for people with complex needs and specific cohorts.[2] It also recognises the value of specialist organisations and the role specialist responses may play within the future SCC system.[2]

However, the preferred lead-organisation model would concentrate responsibility for SCC services within a single organisation in each region.[2]

For rare and progressive conditions such as Huntington's disease, this raises an important policy question: how can specialist expertise, participant choice and continuity of support be preserved if access to services is largely determined by geography rather than capability?

National consistency should mean consistent quality, safeguarding and accountability. It should not require every participant to receive support through the same service model or provider structure.

The future SCC model should be capable of delivering both consistency and specialisation, particularly where disease-specific expertise has a direct impact on participant outcomes and safeguarding.

A hybrid commissioned model

HA does not recommend preserving the current market unchanged. Instead, we recommend that the NDIA establish two complementary commissioning streams.

Regional SCC Stream: Regional organisations would provide SCC and SCC+ services for participants whose needs can appropriately and safely be met through mainstream regional capability.

Specialist SCC Stream: National and/or jurisdictional specialist organisations would be separately commissioned or accredited for defined rare, progressive or highly complex cohorts where condition-specific expertise materially affects participant outcomes or safeguarding.

For Huntington's disease, this would enable:

NDIA HD Planner Pathway → Specialist HD Planner → Specialist HD SCC Provider

This approach maintains continuity of specialist expertise across the participant journey while preserving access to mainstream regional services where appropriate. It delivers the benefits of commissioning and quality assurance without unnecessarily reducing access to proven specialist providers.

Recommendations

1. Adopt a hybrid commissioning model that combines regional SCC providers with a dedicated specialist provider stream for rare, progressive and highly complex conditions, rather than a single lead-provider model.
2. Recognise Huntington's disease and similar rare conditions as cohorts requiring access to disease-specific expertise to support participant outcomes, safeguarding and quality service delivery.
3. Align SCC reform with the HD Planner Pathway by enabling continuity of specialist expertise across planning, implementation and ongoing coordination, including direct referral pathways to specialist providers where required.
4. Preserve participant choice, continuity and existing specialist relationships, recognising trusted relationships and disease-specific expertise as important safeguarding mechanisms.
5. Ensure SCC and SCC+ models provide access to condition-specific expertise, in addition to generic complexity and coordination capability.
6. Commission and evaluate providers based on demonstrated quality, including governance, workforce capability, participant outcomes, independent audit results and participant experience, supported by appropriate registration and quality assurance requirements.
7. Enable specialist providers to operate across geographic boundaries and maintain national cross-sector networks that support people with rare and complex conditions.
8. Undertake further consultation, evaluation and risk assessment to ensure the final model effectively meets the needs of rare disease cohorts and does not create unintended risks through consolidation or loss of specialist expertise.

Conclusion

Huntington's Australia supports stronger standards, improved quality, enhanced safeguarding and greater accountability across Support Coordination services. However, reform should strengthen what is working well rather than inadvertently dismantle proven specialist capability.

Through the HD Planner Pathway, the NDIA has already recognised that people with HD require specialised knowledge and support. That principle should extend beyond planning and remain available through implementation and ongoing coordination.

As Australia's national peak body for Huntington's disease, HA provides disease-specific Support Coordination to more than 20% of NDIS participants with HD nationally. Our experience demonstrates that for rare, progressive and highly complex conditions, expertise is itself a safeguard.

HA supports a hybrid commissioning model that combines regional SCC providers with a dedicated specialist provider stream for rare and complex cohorts. This approach would strengthen quality and accountability while maintaining access to proven specialist expertise.

Reform should improve participant outcomes without forcing vulnerable participants away from trusted relationships and disease-specific support. Quality and specialisation are not competing objectives. The future SCC model should preserve both.

References

[1] Senator the Hon Jenny McAllister, Minister for the National Disability Insurance Scheme, draft media release, “Priority NDIS Pathway for People with Huntington's Disease”, 2026, pp. 1-2. The release describes HD as a rare complex disorder, notes the need for faster and more specialised support, outlines the dedicated trained planner model, records specialist planner training, and states that more than 1,100 participants with HD have moved to the Priority Pathway.

[2] National Disability Insurance Agency (NDIA), Support Coordination and Connection Reform Consultation Paper, 2026. Cited throughout for the proposed lead-organisation and multi-provider commissioning models; stated reform objectives; workforce, quality and safeguarding requirements; specialist/thin-market responses; participant choice and continuity; SCC+; and transition considerations.

Note: Statements regarding Huntington's Australia's current market share, current referrals from NDIA Specialist HD Pathway Planners, independent NDIS audit findings, and HA's Community Practitioner experience are based on Huntington's Australia's organisational and operational evidence. Supporting internal records and audit documentation can be provided or cited separately if required.