



How to Reform Support Coordination to Meet the Needs of NDIS Participants with High and Complex Needs

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Key Messages

- National Disability Insurance Scheme (NDIS) participants with high and complex needs experience difficulty in accessing high quality and effective support coordination. Without effective support coordination, it can be difficult to avoid or exit residential aged care (RAC).
- Around 4,860 younger people aged under 65 are living in RAC. As at 30 June 2020, 3,708 are participants with an approved National Disability Insurance Scheme (NDIS) plan.
- 301 younger people in residential aged care (YPIRAC) are ineligible for NDIS funding as at 30 September 2020.
 - Funding for Specialist Support Coordination is needed to ensure that younger people at risk of entering RAC are provided with better housing options and supports.
 - There are not enough support coordinators with the necessary skills and knowledge to support people with high and complex needs:
 - Support coordinators are currently ill-equipped to work with matters arising from the complex interface between the health system, housing and the NDIS
 - New support coordinators lack peer and mentorship connections to familiarise them with 'specialist' areas of support coordination like health and housing
 - Support coordinators lack opportunities for professional development. The NDIA should create formal qualifications to support professional development and increase the effectiveness of support coordination.
- Work is needed to ensure that support coordinators avoid and effectively manage conflicts of interest.

The following recommendations have been made:

Recommendation 1: Improve professional development options for support coordinators.

Recommendation 2: Address the support coordination needs of people who are stuck in hospital.

Recommendation 3: Fund the necessary amount of support coordination at the appropriate level.

Recommendation 4: Address the gaps between mainstream health systems and the NDIS.

Recommendation 5: Implement strategies to ensure NDIS participants can access support coordinators with the necessary skills and knowledge as well as suitable attitudes and values.

Recommendation 6: Address the problem of conflict of interest among support coordination providers.

The Problem

It is important to recognise that not all YPIRAC or those at risk of RAC admission have access to support coordination. While the number of YPIRAC becoming NDIS participants has increased there are still many who are not yet in the scheme. As at 30 June 2020, there are 3,708 YPIRAC who are participants with an approved plan – 76% of the 4,860 YPIRAC¹. As at 30 September 2020, 301 YPIRAC are ineligible for NDIS funding².

The Summer Foundation has identified the following key problems:

- 1. Inadequate support coordination funding including planners failing to fund Specialist Support Coordination**
Younger people either in RAC or at risk of admission to RAC aren't receiving funding for support coordination at a level that meets their needs. Significantly, those who require Specialist Support Coordination are either not receiving it or are not receiving it at the appropriate level.
- 2. There is a lack of support coordinators with the right skill sets to work with people who require accessible housing solutions and specialist disability accommodation (SDA)**
YPIRAC or those at risk of admission are facing limited opportunities for exploration of suitable housing that reflects their preferences in supports and living arrangements. This challenge is heightened by difficulties accessing support coordinators who have the necessary skills, knowledge and experience to help younger people navigate an evolving and complex market.
- 3. There is no fit-for-purpose formal qualification for support coordinators**
Support coordination is a role that requires no formal qualification or training and therefore often lacks specialised knowledge for addressing participants' needs for appropriate support and capacity building.
- 4. Inadequate training and professional development opportunities for support coordinators, particularly relating to supporting younger people with high and complex needs in hospitals**
Many support coordinators lack the time and opportunity to regularly undertake professional development. In addition, many are unsure of their roles and responsibilities across the range of service systems they have to navigate. This is increasingly so within hospital settings, where support coordinators struggle to navigate how to best assist people with complex needs to identify support and housing options, and to transition to new/appropriate housing. There is a lack of coordination between the health system and support coordinators, and there are no formalised peer or mentorship programs.
- 5. Challenges in locating and connecting with appropriately skilled and knowledgeable support coordinators**
Younger people with complex disability needs as well as the health services staff working with them struggle to identify or access enough skilled support coordinators.

¹ NDIS Quarterly Report to disability ministers. September 2020

² Senate Estimates. October 2020

6. A lack of documented best practice approaches

The absence of documented and disseminated best practice approaches of support coordination is impacting the quality, ongoing learning and development of support coordination practice. This in turn is impacting outcomes for NDIS participants.

7. A lack of support coordinators with expertise to navigate the NDIS and mainstream health systems

The lack of support coordinators working in hospital settings is a result of the many challenges working across multiple systems and the lack of specialised training and support available to both support coordinators and health professionals. There has been a lack of capacity building that minimises the complexities between service systems. Without this, support coordinators will continue to struggle to enter the health service system and to engage effectively.

8. The National Disability Insurance Agency (NDIA) is failing to address the conflicts of interest among support coordinators who are not independent providers

The support coordination workforce is dominated by providers who also provide other NDIS supports including housing and Supported Independent Living. This lack of independence in service delivery makes it less likely that the provider will support the person to explore the full range of housing and support options available – instead only offering them options that are provided by their organisation. This significantly reduces the choice and control of the person, limits capacity building and exploration of needs and preferences. There must be mandated separation of service provision by providers to enable independence of support functions.

Case studies

David* **Name has been changed for privacy*

David is a 67-year-old man who had a stroke 15 years ago. David recently decided his support coordinator was not providing the support and service that he needed. *“Support coordinators need to have more connection with the person. To let us know what’s happening and what’s going on. We don’t know how the NDIS works, and I’ve found out that most coordinators don’t know either. It’s a shot in the dark sometimes.”*

David wasn’t able to get the help he wanted from his support coordinator. He would call the office and have to wait 2-3 days to have his call returned. David was incredibly frustrated – *“there’s no action done”*.

David decided to do some research and found another provider he wanted to deliver his support coordination. When David attempted to change over, his provider told him that if he changed support coordinators he could also lose his key support worker. David had worked with this support worker for more than 3 years and did not want to lose her. The support coordination service failed to manage the conflict of interest that existed as the provider of support workers and of support coordination.

“The NDIS is supposed to be about having choice and control but some providers just want to keep you on their books as their cash cows. They don’t care about you, they just care about the NDIS funds. It’s how much funding have you got and how fast can we get it off you?”

David rang the NDIS to understand what his rights were. They confirmed that he should be able to choose his key support worker and change his support coordinator. *“No advice was given on what I should do though. Just that it shouldn’t happen.”*

Paulene

Paulene is a strong and fiercely independent person who at the age of 23 began her journey as a person with Multiple Sclerosis (MS). Despite her youth, she entered an aged care facility at the age of 44 and spent 6 years there feeling trapped and disempowered, accepting inadequate support coordination because she didn't want to be a burden or make a fuss. She felt like she wasn't getting what she needed through that support, but thought it was better than nothing.

Today, Paulene sits comfortably in her new SDA apartment overlooking the city. *"I feel free, just so beautiful, I feel like I'm on top of the world.... I can make my own decisions now I'm my own person"*.

This freedom is a strange feeling for Paulene.

Although Paulene had a support coordinator, she was never asked whether she wanted to explore housing options outside the nursing home, or what she would like to do.

Once she realised it was possible to change her support coordinator, Paulene's life changed.

She then began working with her current support coordinator who she loves dealing with and is *"on the same page"*. She says: *"We just clicked. I found her very positive. She chatted with me about things I could do, like shopping and swimming."*

Her new support coordinator also told Paulene about other housing options – including her new permanent residence in SDA apartments in Melbourne's CBD. Paulene now has newfound control over her life.

She is ecstatic and understands the important role her support coordinator plays in her life.

Paulene's situation is proof of the huge empowerment, choice and flexibility that comes from working with or simply choosing to change support coordinators. She now feels like *"a little kid in the candy store"*.

Policy Change Must Address Support Coordination Needs

A more effective approach to support coordination is urgently needed for people with high and complex needs to alleviate these issues:

NDIS funds will continue to be wasted

Where support coordinators lack knowledge of the service systems and opportunities for participants, support coordination funding can often be used to pursue inappropriate and unsuitable service and housing arrangements. This leads to the need for additional funding in subsequent plans to improve the situation and implement more suitable supports. Policy change is required to mandate quality provision of support coordination through significant and regular capacity building for support coordinators, mandate understanding of service and support systems and facilitation of best practice learning through Community of Practice or peer-to-peer learning opportunities.

Participants will continue to experience poor outcomes

The current support coordination workforce lacks the specialist knowledge needed to navigate the NDIS, housing and health systems, particularly during a period of hospital admission and discharge. Too often, a lack of training means support coordinators pursue the 'easy' or 'known' housing options rather than the most suitable. This is leading to poorer outcomes for NDIS participants.

Inadequate support coordination leads to neglect in key areas such as connecting with mainstream services (such as housing and health), supporting participants to understand and implement other funded supports and building a participant's capacity for self-direction and independence. The NDIA should strongly encourage support coordinators to participate in peer-to-peer learning with high quality capability development, as seen with [UpSkill](#).

NDIS participants continue to needlessly take up beds in hospital and in RAC

An ineffective support coordination workforce is resulting in younger people both entering and staying in RAC for longer periods of time. A common pathway to admission of younger people into RAC is triggered by a hospital admission resulting in discharge to RAC. This process, often crisis driven, can be quite swift, with an impending hospital discharge and no suitable housing and limited supports available³.

Timely and effective support coordination is vital to prevent RAC admission. Furthermore, people with high and complex support needs are stuck in hospital without interim funding for skilled support coordination to help them discharge when they are relatively stable. The NDIA must develop capacity building for hospitals to work with support coordinators to ensure better outcomes for people with disability.

³ Barry, S., Knox, I., Douglas, J. (2018) 'Time's up': the experience entering aged care for young people with acquired neurological disorders and their families

Conflict of interest restricting NDIS participants' choice and control

Without urgent intervention, participants will continue to have their options restricted by a support coordinator workforce that lacks independence. This situation will become worse over time as conflicted providers become more dominant over smaller independent providers. The NDIS Quality and Safeguards Commission must monitor conflicts of interest with a view to transition to a separated support model.

Without these changes, the Federal Government will not achieve the targets outlined in the *Younger People in Residential Aged Care Strategy 2020-2025*

The strategy demonstrates a dedicated effort by the Australian government to ensure that:

- No people under the age of 65 entering residential aged care by 2022
- No people under the age of 45 living in residential aged care by 2022
- No people under the age of 65 living in residential aged care by 2025

Immediate support and development of the support coordination workforce is essential to achieve these goals. The support coordination workforce must be properly equipped to meet the needs of younger people and ensure that no younger person, aged under 65, is stuck in RAC by 2025.

Current State of Support Coordination and a Future Desired State

This table compares the current state of support coordination with what support coordination needs to look like for people who have high and complex needs.

DOMINANT PRACTICE	FUTURE DESIRED STATE
<p>Younger people aren't having their needs for Specialist Support Coordination funding met</p> <ul style="list-style-type: none"> • NDIS participants are not receiving adequate funding for support coordination • People in hospital, especially those with complex and high support needs, are not receiving adequate funding for Specialist Support Coordination • Capacity around finding and transitioning into suitable housing is negatively affected 	<p>People receive dedicated funding for Specialist Support Coordination at appropriate levels</p> <p>The NDIS ensures funding at appropriate levels and prioritises access for people:</p> <ul style="list-style-type: none"> • With complex and high support needs, ensuring funding for at least 120 hours of Specialist Support Coordination • In hospital, to receive an interim plan with funding for Specialist Support Coordination who will work with discharge planners as early as possible
<p>A lack of support coordinators with the right skill sets for people requiring housing solutions and SDA</p> <ul style="list-style-type: none"> • Many support coordinators lack specialised knowledge of the housing market resulting in reduced choice and control for people • A common pathway into RAC is because of the inability to connect with or find appropriate housing solutions 	<p>Availability of and access to support coordinators with the right skill sets</p> <ul style="list-style-type: none"> • NDIS participants have easy access to high quality support coordinators with specialised knowledge of support and housing options resulting in wider choice and preferred housing for people • Support coordinators and people have knowledge around housing options
<p>Support coordinators lack fit-for-purpose and formal qualifications</p> <ul style="list-style-type: none"> • Those entering the support coordination workforce lack a specialised formal or informal qualification which impacts both their professional development and learning opportunities 	<p>Support coordinators have access to co-designed fit-for-purpose qualifications</p> <ul style="list-style-type: none"> • Support coordinators have specialised formal qualifications co-designed by participants • Fit-for-purpose qualifications and training ensure that support coordination extends beyond common functions (such as connecting with mainstream services) and addresses more comprehensive supports such as health, housing, capacity building, goal setting and independence

Inadequate training and professional development opportunities, particularly within hospitals

- Many disability support workers transition into support coordination roles without the necessary skills or knowledge to support people with complex and high needs
- The culture and skills mix of support coordinators often differ from what is required by the support coordinator function when working with a diverse range of people

Support coordinators have opportunities to connect with peer and mentorship networks to improve supports for people with high and complex needs, particularly in hospitals

- There is active engagement with Communities of Practice for support coordinators to share ideas and build their capacity to work with clients who have complex needs
- High quality professional development is available and accessible to support coordinators throughout Australia. These courses include skills and knowledge to work with people who have high and complex needs

New skills and training for support coordinators are not considered billable hours

Support coordinators have little time to pursue training and professional development when these are non-billable hours

Support coordinators are required to regularly undertake professional development

The NDIA ensures that support coordinators are able to undertake a certain number of professional development hours every year:

- The number of hours and how this is mandated is up to the NDIA

Younger people needlessly take up beds in hospital and in RAC

- Younger people both enter and stay in RAC for long periods of time due to ineffective support coordination
- Hospital admission, especially when crisis driven, often results in discharge to RAC for younger people

Younger people have timely and effective support coordination to prevent extended hospital stays and admission to RAC

- Younger people being admitted to hospitals receive appropriate support coordination and are discharged into appropriate housing instead of RAC
- Younger people do not enter or stay in RAC except under exceptional circumstances or by their own choice

Support coordinators lack documented best practice approaches

The NDIS lacks documented and implemented best practice approaches for support coordinators around:

- Training and peer/mentorship
- Connecting and communicating with healthcare systems and within hospital settings
- Quality support for people with complex and high support needs

Support coordinators operate with best practice approaches around quality, ongoing learning and development of support coordination practices

The NDIS documents and implements best practice approaches as seen in:

- The *UpSkill Community of Practice* for people with high and complex support needs
- Summer Foundation's *Collaborative Discharge Approach* planning resource⁴ around people with complex needs
- The Hospital Liaison Officer (HLO) pilot's demonstrated best practice around hospital admissions and discharge

⁴ Collaborative Discharge Approach Summer Foundation (2019)
<https://www.summerfoundation.org.au/?s=Collaborative+discharge>

NDIS participants and support coordinators struggle to navigate the NDIS and mainstream health systems without HLOs

- HLOs are not available in all hospitals
- There is a lack of training and support for support coordinators working with the health system

National implementation of HLOs to work with support coordinators in navigating the NDIS and mainstream health systems

- HLOs are implemented nationwide to work with support coordinators within hospital settings
- HLOs build collaborative relationships with hospital staff to connect participants and their carers with support coordinators, community organisations and the disability housing and support service market⁵
- Specialist training is available across Australia to build the capacity of support coordinators to work with the health system

Failure to address conflict of interest is significantly reducing choice and control

Within the housing area there is:

- A lack of understanding by many SDA providers of the fundamental support coordination role to support participant-driven goal setting and goal attainment
- A failure by providers to adhere to the NDIS Quality & Safeguarding Practice Standards, which require support coordinators to be impartial and independent in supporting a participant to choose other providers

Strict guidelines, monitoring and consequences for conflict of interest among support coordinators who are not independent providers

- Clear separation between providers of support coordination and other NDIS supports
- Close monitoring of existing and prospective providers that combine SDA and support coordination provision. This is carried out by the NDIS Quality & Safeguards Commission on the grounds that this combination involves inherent risks. Registration is to be removed from or denied to providers when investigations fail to establish clear benefits to participants that they cannot otherwise access, as well as when there is no publication of measures to reduce the impacts of conflicts of interest

⁵ NDIS. Supplementary Budget Estimates 2019-20. Update: Younger People in Residential Aged Care

The Way Forward

To deliver positive outcomes for NDIS participants with complex needs, we recommend the following:

1. Recommendation 1: Improve professional development options for support coordinators

- a) Support coordinators must have access to professional development opportunities and information resources to support them to deliver high quality support coordination.
- b) The NDIA should put in place strategies that will enable support coordinators to develop the necessary skills and knowledge to work with participants who have complex housing and support needs.
- c) The NDIA should mandate a minimum number of hours a year for support coordinators to undertake professional development.
- d) The NDIA should fund industry development measures, including access to training and resources and membership of Communities of Practice (delivered through UpSkill). Delivery of training and resources should be available in face-to-face and online formats to enable access from all locations.
- e) The NDIA should invest in the development of a formal qualification for the practice of support coordination. This qualification must be co-designed by NDIS participants and support coordinators. Co-design will provide insight into what quality support coordination means to a wide range of participants. This qualification should not be mandatory so participants may opt for a support coordinator who does not have formal qualifications.
- f) The NDIA should support and disseminate the findings of participant-driven research to develop a wider understanding of expectations and good practice within the Australian disability sector.

2. Recommendation 2: Address the support coordination needs of people who are stuck in hospital

- a) Ensure that people stuck in hospital have access to interim plan funding for a Specialist Support Coordinator to work with the discharge planners in hospitals to assist the person to return to the community.
- b) The NDIA should review the findings and resources of the Leaving Hospital Well project and, in conjunction with the Summer Foundation, make them available widely to health systems as an example of best practice in NDIS support coordination in hospital settings.
- c) The NDIA should build the capacity of hospitals and discharge planners to understand the role of support coordinators (specialist or other) and how best to work with them to maximise outcomes for people.

3. Recommendation 3: Fund the necessary amount of support coordination at the appropriate level

- a) Sufficient hours of support coordination at the right level should be included in a participant's plan to enable YPIRAC and those at risk of admission as well as other participants with complex support needs to access the support they need to achieve the goals in their NDIS plans. Additionally, planners must be provided with clear and appropriate guidelines to determine the support coordination needs of people with high and complex needs i.e. should be funded for at least 120 hours of Specialist Support Coordination.
- b) The NDIA should report on the level of utilisation of support coordination by YPIRAC to the YPIRAC Joint Agency Taskforce to establish utilisation rates and factors influencing support coordination implementation in RAC.
- c) The NDIA should provide targeted support coordination funding for exploring housing options and to support transition into suitable housing. This should cover secondary consultation for support coordinators, encompassing comprehensive housing search and mentoring.

4. Recommendation 4: Address the gaps between mainstream health systems and the NDIS

- a) The NDIA should utilise the Summer Foundation's Collaborative Discharge Approach planning resource as an example of best practice for coordinators working with people with complex needs in hospital.

5. Recommendation 5: Implement strategies to ensure NDIS participants can access support coordinators with the necessary skills and knowledge as well as suitable attitudes and values

- a) The NDIA must provide support coordinators with the essential tools and strategies to accomplish meaningful results with a diverse range of people.
- b) The NDIA should develop strategies to make training on supported decision-making available and affordable to support coordinators.
- c) The NDIA should collate data on effective capacity building strategies and timescales to expand the understanding of what is required, and address access for support coordinators to peer support for ongoing learning opportunities.
- d) The NDIA should reassess price limits. Price limits need to factor in the importance of allowing time for training, coaching and knowledge development work for the support coordination workforce to provide quality services to NDIS participants.

6. Recommendation 6: Address the problem of conflict of interest among support coordination providers

- a) The NDIS Quality & Safeguards Commission should undertake an analysis of existing provider registration details to identify organisations offering both support coordination and housing. These providers should be monitored closely.
- b) The NDIS Quality & Safeguards Commission should require providers of support coordination and other NDIS supports to lodge a 'conflict of interest' statement defining potential participant impacts and the measures they have adopted to reduce or eliminate any negative impacts of real or perceived conflict of interest on participant choice and control.
- c) The NDIS Quality & Safeguards Commission to adopt and enforce an 'Independence requirement between intermediary and other funded supports at the participant level' in regard to SDA providers. Stricter conflict of interest requirements for providers of both SDA and support coordination must be put in place to refuse or remove registration unless conflict of interest issues can be managed.