



Summer Foundation

Response to the Support Coordination Discussion Paper

September 2020

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INTRODUCTION AND SUMMARY

It is important to begin by recognising that not all Young People in Residential Aged Care (YPIRAC) or young people at risk of RAC admission have access to support coordination. In fact, some don't have access to the National Disability Insurance Scheme (NDIS). While the number of YPIRAC becoming NDIS participants has increased there are still approximately 20 per cent who are not yet in the Scheme. At 31 March 2020, 4,018 were participants with an approved plan – 79% of the 5,113 YPIRAC at this time.

At 30 September 2019, 4,826 YPIRAC NDIS participants had support coordination in their plans (88% of the 5,468 YPIRAC at this time).¹ The average funding was \$13,092 pa, equating to approximately 2.5 hours per week at Level 2 support coordination.

The review of the support coordination service model is an important opportunity to address significant problems people with high and complex needs experience in accessing high quality and effective support coordination. Without effective support coordination, it can be difficult to avoid or exit RAC.

The key problems that we have identified in this submission are:

1. Inadequate support coordination funding including planners failing to fund Specialist Support Coordination
2. Ineffective support coordination in the interface between the NDIS and mainstream health systems
3. A lack of support coordinators who can work with people who require accessible housing solutions and SDA
4. The absence of a fit-for-purpose formal qualification for support coordinators
5. Inadequate training and professional development opportunities for support coordinators, particularly related to supporting people with high and complex needs
6. The challenges in locating and connecting with appropriately skilled and knowledgeable support coordinators
7. A lack of documented best practice approaches
8. Failing to address the conflicts of interests among support coordinators who are not independent providers

¹ Senate Estimates Supplementary Budget Hearings 2019-20 Questions on Notice SQ19-000279

This submission addresses the questions put forward in the Support Coordination Discussion Paper and highlights the need to improve the support coordination service model in a range of areas. These include ensuring access to adequate and timely support coordination; incorporating effective support coordination in the interface between the NDIS and mainstream health systems; support coordinators with specialist knowledge in housing for people with complex needs; easier access for participants to appropriately skilled and experienced support coordinators; encouraging innovation and the development of best practice approaches through training and development opportunities and Communities of Practice; and addressing conflicts of interests.

This submission is informed by our research, training and collaborative practice projects addressing support coordination. These include:

1. *DHHS Leaving Hospital Well: Health Collaboration Project*² - a Victorian initiative to assist in building the capacity of local health networks to interface with the NDIS.
2. *UpSkill* - a support coordination workforce training and peer support program designed to increase capacity of support coordinators and allied health workers. The program includes:
 - a. A series of training modules being rolled out nationally
 - b. Peer network opportunities, a Community of Practice
 - c. A Support Coordination *UpSkill* Directory (See Attachment)
3. Documentation of participants' stories and joint workshops on support coordination in hospital settings as seen from participants' and support coordinators' perspectives.

Our key recommendations are:

1. ***Address the support coordination needs of people who are stuck in hospital:***
 - a. Ensure this group have access to interim plan funding for a Specialist Support Coordinator to work with the discharge planners in hospital to assist the person to return to the community.
 - b. 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.
2. ***Fund the necessary amount of support coordination at the appropriate level:***
 - a. Planners need to approve sufficient hours of support coordination at the right level to enable YPIRAC and other participants with complex support needs to access the support they need to achieve the goals in their NDIS plans.

²Summer Foundation (2020). *Leaving Hospital Well: Health Collaboration Project*, Victoria. Unpublished Project Report.

- b. Planners must be provided with appropriate guidelines that make it clear that people with high and complex needs should be funded for at least 120 hours of Specialist Support Coordination.
- c. The NDIA should report on the level of utilisation of support coordination for YPIRAC to the YPIRAC Joint Agency Taskforce to establish utilisation rates and factors influencing support coordination implementation in RAC.
- d. 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.

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

- a. The NDIA should promote and support the expansion of the *UpSkill* Directory.
- b. The NDIA should put in place strategies that will enable support coordinators to develop skills to work with participants who have complex housing and support needs. The NDIA should promote and support the expansion of the *UpSkill* program – training and Community of Practice.
- c. 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. This qualification should not be mandatory so that participants may opt for a support coordinator who does not have formal qualifications.
- d. The NDIA should support and disseminate the findings of participant-driven research into what makes quality support coordination.
- e. 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.
- f. 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 coordinator workforce to provide quality services to NDIS participants.
- g. The NDIA should develop strategies to make training on supported decision-making available and affordable to support coordinators.
- h. The NDIS 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.

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

- a. The NDIS Quality & Safeguards Commission should undertake 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 the potential participant impact 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.

ABOUT THE SUMMER FOUNDATION

Established in 2006, the Summer Foundation works to change human service policies and practices related to young people (18-64 years old) living in, or at risk of entering residential aged care facilities.

Our Vision is that young people with disability and complex support needs live where and with whom they choose, with access to high quality housing and support options that enhance health, wellbeing and participation.

Our Mission is to create, lead, and demonstrate long-term sustainable systems change that stops young people from being forced to live in aged care because there is nowhere else for them.

The Summer Foundation has worked extensively with people with complex disability support needs to ensure they have access to all the NDIS supports essential to living the life they choose. Access to quality support coordination is critical to achieve the targets of the YPIRAC Action Plan 2025.

INCLUSION OF SUPPORT COORDINATION IN PLANS

Discussion Paper Questions:

1. What factors should be considered when determining if, when and for how long support coordination should be funded in a person's plan?

For people with high and complex support needs, access to the right level and right amount of support coordination is vital to achieve the goals outlined in their plan. Funding for support coordination should be for as long as there is a need for the support, with the aim of building capacity of the person over time. For many people with high and complex needs this is likely to be ongoing, although the level and number of hours may reduce over time. For some people with progressive disability, the need for support coordination may significantly increase over time.

The following factors need to be considered when determining the funding for support coordination:

- Complexity and severity of disability
- Risk to safety and wellbeing and risk of abuse, neglect, violence and exploitation
- The individual's ability and willingness to coordinate and implement their plan
- Availability of informal support/family or trusted others to assist with plan implementation, coordination of services and advocacy
- The life stage of the individual, for example, whether they have a need to transition into a new housing arrangement

The Summer Foundation often works with people who are stuck in hospital because they have acquired a disability and are waiting for an NDIS plan.

Recommendation 1 (a): It is important that this group have access to interim plan funding for a Specialist Support Coordinator to work with the discharge planners in hospital to assist the person to return to the community.

Question:

2. Should the current three level structure of support coordination be retained or changed?

When looking at the entire population of NDIS participants, the three level structure is appropriate and does not need to be changed. However, for YPIRAC and those at risk of RAC admission there is a need for Specialist Support Coordination to be funded more often than is current practice.

The Summer Foundation delivers a Housing Brokerage Service which provides secondary consultation to discharge planners, support coordinators and people in hospital, builds capacity to explore housing needs and preferences, and conducts a comprehensive housing search based on the person's housing needs and preferences. Only 6 out of 71 NDIS participants in hospital using this service were funded for Specialist Support Coordination. Considering the complex needs of this cohort, and the need for specialist knowledge and experience, the funding of Specialist Support Coordination is far less than what is required.

Recommendation 2 (b): Planners must be provided with appropriate guidelines that make it clear that people with high and complex needs should be funded for at least 120 hours of Specialist Support Coordination.

Questions

3. How should support coordination interact with other NDIS supports? For example, local area coordinators, community connectors, liaison officers and recovery coaches?
4. How should support coordination interact and complement existing mainstream services?

A common pathway to admission to RAC of young people 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.

As a state responsibility, health services vary across Australia and have interfaced with the NDIS at different rates and in different modalities. While the Health Liaison Officers have an important role, they are not available across all hospitals or well embedded in all processes. More needs to be done to enable people with disability in hospital to engage with the NDIS as early as possible in order to initiate NDIS planning for supports ready for their discharge. Support coordinators working in the health/NDIS interface have experienced many challenges in carving out a new role working across 2 major systems, which lack a standardised interface. The Summer Foundation delivers the *Leaving Hospital Well* project, funded by the Victorian Department of Health and Human Services. A recent needs analysis found that people with complex disability needs, and the health services staff working with them, could not identify or access enough skilled support coordinators.

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

In hospital settings, many support coordinators were unsure of their roles and responsibilities and how to assist people with complex needs to identify housing options, or where identified, to transition to new housing.

The Summer Foundation has worked extensively with mainstream state health systems and the NDIA to ensure seamless interface processes. The *Leaving Hospital Well* project is an example of successful collaboration focusing on education and training, tool development, operational policies and worker capacity building through peer support. It encompasses:

- a) An in-depth analysis carried out in 20 regional and metro Local Health Networks (LHNs) of problems affecting health services staff in their interaction with the NDIS. The study found that problems experienced in all LHNs were greatly compounded for regional health services.
- b) Development and dissemination of the *Collaborative Health Approach* model
- c) Delivery of an individually tailored education program to each LHN, which included online and face-to-face delivery
- d) Development of NDIS and health resources
- e) Secondary consultation
- f) Health and NDIS Community of Practice

Recommendation 1 (b) The NDIA reviews the findings and resources of the *Leaving Hospital Well* project and, in conjunction with the Summer Foundation, makes them available widely to health systems as an example of best practice in NDIS support coordination in hospital settings.

Question

5. What can or should be done to address the level of utilisation of support coordination in plans: and is this any different to general issues of utilisation?

Difficulty in finding a suitable support coordinator with the necessary skills and qualifications may be a key reason behind low utilisation rates.

To overcome this difficulty, the Summer Foundation established the *UpSkill* Directory that outlines the qualifications, training and experience and areas of expertise of each support coordinator listed. The directory is undergoing a redesign which will provide information in an accessible format to assist participants to choose the best support coordinator to meet their needs. In order to join the directory, the support coordinator needs to have undertaken training with the *UpSkill* program.

Recommendation 2 (c): The NDIA should report on the level of utilisation of support coordination for YPIRAC to the YPIRAC Joint Agency Taskforce to establish utilisation rates and factors influencing support coordination implementation in RAC.

Recommendation 3 (a) The NDIA should promote and support the utilisation and expansion of the *UpSkill* Directory.

UNDERSTANDING THE ROLE OF A SUPPORT COORDINATOR

Question

6. What functions should a support coordinator perform? Are there tasks that a support coordinator should not do?

To support this submission, we spoke with NDIS participants about what they wanted from a support coordinator and this is what one person said:

Sarah* aged 46, living with complex disability needs in the community in non-SDA housing

I use a support coordinator who is not registered with NDIA. They are able to remain impartial in making decisions, and to advocate on your behalf. If you are an NDIS registered support coordinator you are not allowed to use advocacy in your role.

I have a support coordinator for 2 hours a fortnight - for me that is enough. I communicate through meetings, emails, text messages and phone calls. They assist me with communication with TAC, and the supports services in my plan - podiatry, physiotherapy, OT, exercise, physiology. My support coordinator helps to gather reports for plan review meetings and with any problems I might incur to get up and running.

Support coordinators must be methodical and able to follow up: able to learn the NDIS system and how that operates for both mainstream participants and protected participants. They need to be able to think outside the box and have great understanding of community resourcing. Connecting people into their communities and making sure they are fully engaged and not just referring them.

**Pseudonym*

Essentially, NDIS participants have told us they want their support coordinator to:

- Be highly aware of their needs and preferences – this means that a support coordinator needs to work with a participant to understand, explore and decide on their needs and preferences
- Have the skills and abilities to help coordinate and implement an NDIS plan, including the negotiation of services, funding under the plan and advocating for any gaps between the needs of the person and the provisions under the plan
- Commit to supporting the person in and through all decision-making
- Demonstrate that they have supported the participant in decision-making to date

Our experience at the Summer Foundation is that when insufficient hours are allocated in plans, only one of the common functions (*connecting the participant with and monitoring NDIS-funded supports*) is addressed by the support coordinator. Other functions, such as *connecting with and/or interfacing 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*, are neglected.

This is a significant risk for the NDIS as it means that a person is not getting access to what they need to live a normal life. Furthermore, the lack of capacity building for the individual means that additional services and support coordination will be needed for a longer term and into the future.

Building a participant's capacity for self-direction and independence demands time and advanced skills of support coordinators.⁴ Ellis et al identified 8 functional areas covering actions of:

- Navigating and informing
- Planning and guiding
- Researching and connecting
- Facilitating and coordinating
- Coaching
- Advocating
- Negotiating and mediating
- Providing technical advice
- Reflecting and developing

Currently many people with complex needs are isolated and have few connections beyond paid support and immediate family.⁵

Living well in the community involves people with complex support needs being active in their communities, experiencing a sense of belonging and maintaining relationships with other community members. Not only is community inclusion vital for a sense of wellbeing, there is significant evidence that connection with people outside the disability sector is an important safeguard.⁶

Support coordination has an important role in conjunction with informal and other paid supports, to assist a person with complex needs to (re)discover their interests and aspirations and find connections in the community. This requires a new focus on relationships and community inclusion and sufficient hours allocated to support coordination to establish and support community and mainstream connections.

Support coordinators who have local knowledge and connections are at an advantage in being aware of the resources of the participant's community and how they can be mobilised.

Recommendation 2 (a): Planners need to approve sufficient hours of support coordination at the right level to enable YPIRAC and other participants with complex disability needs to access the support they need to achieve the goals in their NDIS plans.

⁴ Ellis, L., Fulton, K., B'osher, L. (2017) Support Coordination: A Changing Landscape. Melbourne: Summer Foundation.

<https://www.summerfoundation.org.au/?s=Support+Coordination+A+changing+Landscape>

⁵ IAC, (2019) Enhancing Outcomes from Social and Community Participation

<https://static1.squarespace.com/static/5898f042a5790ab2e0e2056c/t/5f1a5d7408d2690d494526f9/1598500794695/Enhancing+outcomes+from+social+and+community+participation+%28September+2019%29+Paper.pdf>

⁶ Wakler, M Fulton, K, Bonyhady, B (2013), A personalised Approach to Safeguards in the NDIS

<https://www.centreforwelfarereform.org/uploads/attachment/385/a-personalised-approach-to-safeguards-in-the-ndis.pdf>

Question

7. Is there evidence that participants with specific plan goals related to education, accommodation and employment would benefit from more targeted support coordination services to achieve these outcomes?

YPIRAC with specific or potential housing goals have difficulties accessing support coordinators who have the necessary depth of disability housing knowledge and skills. This results in limited opportunities for exploration of suitable housing that reflects their preferences in living arrangement and supports. There is an unmet need for support coordination that is targeted to assisting with housing goals, and support coordinators who have up-to-date knowledge of SDA, SIL, ILO and other housing options in the community.

A common challenge for the Summer Foundation is working with support coordinators who do not see housing as a priority or are unsure if housing is an area that sits within their role. This can be because support coordinators are constrained by funding when they cannot access appropriate support coordination hours to find a suitable house. If they have very large caseloads, they have limited time to support participants with housing goals.

This is one of the reasons why the Summer Foundation has built in a housing module as a core component of the *UpSkill* program. It is critical that support coordinators understand their role in supporting across the expanse of a person's life and are able to establish the importance of a seamless approach to all aspects of support.

Support coordinators have difficulty building the specialist knowledge needed to navigate the health/NDIS interfaces, particularly during a period of hospital admission and discharge. If they do not see housing as their responsibility, they can often pursue the 'easy' or 'known' housing options for the person, rather than the most suitable.

To support this, the Summer Foundation has established the Housing Brokerage Service to work with health and other mainstream services in supporting a person to explore their housing needs and preferences and to conduct a comprehensive housing search. The Housing Brokerage team builds the capacity of support coordinators, through secondary consultation, to understand housing, housing needs and preferences of the person they are working with and the different housing options available through the NDIS and through state and community housing services.

Often, the Housing Brokerage Service receives referrals when the support coordinators have given up on finding appropriate housing. This is most commonly because of the difficulties that support coordinators have in navigating the NDIS housing systems and understanding the options to fund housing, or it is because they are unsure of where to look for housing, confined to the traditional scope of housing for people with disability which is not at all suitable.

The value of the secondary consultation by the Housing Brokerage Service is significant for support coordinators and enables them to develop capacity to support all the people they work with through the exploration of housing and housing goals. Likewise, the value of the *UpSkill* core training module on housing provides significant insight, guidance and support to understand housing options, NDIS funding and how to build the capacity of a person to explore and consider their housing needs and preferences.

The Housing Brokerage Service could be funded to provide secondary consultation to support coordinators through the Specialist Support Coordination line item. This would enable capacity building for both the person and the support coordinator on housing needs and preferences, housing options and housing search.

Support coordinators who are not engaging with capacity-building for themselves in the area of housing can create major challenges and issues for the participant. Support coordinators play a critical role in the housing pathway. In such circumstances, they may become a barrier and 'gatekeeper' rather than 'enabler'.

Support coordinators need access to specialised disability housing information and training, as well as guidance and mentoring to familiarise themselves with strategies for effective housing support coordination. The *UpSkill* program has successfully enabled knowledge and understanding in the area of housing for the cohort of support coordinators who have participated. This happens through tailored conversation and capacity building to support across several aspects relevant to housing.

In its *UpSkill* program, the Summer Foundation has found training modules focusing on the following areas to be most useful:

- Support coordinators' role in housing
- Searching for housing – through NDIS funding or state and community housing
- SDA – purposes and structure, eligibility for SDA, outcomes of SDA compared to traditional group homes
- SDA and housing
- Discharge from hospital
- Transition planning

Recommendation 2 (d): 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.

Recommendation 3 (b): The NDIA should put in place strategies that will enable support coordinators to develop skills to work with participants who have complex housing and support needs. The NDIA should promote and support the expansion of the *UpSkill* program – training and Community of Practice.

There is risk in funding specific support coordination services, i.e. housing, which may cause conflict in a person's life. Support coordination should look at all the supports a person needs as a whole and manage and balance these to effectively enable and direct supports to create a normal life.

Funding support coordination for one group of supports and separate support coordination for other supports will create barriers, conflict, silos and possibly a tiered systems of support opportunities. Community participation is as essential as housing as is any other support. This is true for all of us and should be enabled as such.

Rather than additional specific support coordination, a model of secondary consultation services to guide, mentor and build capacity of support coordinators on 'specialist' areas should be implemented.

Question

8. How could plan management and support coordination be more closely aligned and what would the potential benefits and risks be?

Support coordination should be aligned closely with the goals of the participant. This would enable a focus on the person's needs and help to determine the hours needed to spend on supporting, exploring, building capacity and strengthening the services and connections in relation to each goal.

Benefits and risks should be defined in terms of the participant's goals and the benefit they will bring to their life. Risk should be documented in terms of, if the support coordination wasn't provided, what risk is there to the goal being achieved. In many ways, this will contribute broadly to plan utilisation across all funded supports and to accountability of goals. Further, this will help to unpack any barriers or adjustments needed in regular plan reviews which should focus on the achievement of goals and addressing gaps in funding or service provision.

QUALITY OF SERVICE AND VALUE FOR MONEY

Question

9. Should there be minimum qualifications requirements or industry accreditation in place for support coordinators? If so, what might be applicable?

We do not support a minimum formal qualification requirement for support coordinators at this time for 2 key reasons.

- Firstly, there is no single formal qualification currently available that would be an appropriate minimum qualification for support coordination.
- Secondly, imposing mandatory qualifications now would severely limit access to support coordinators at this time.

Recommendation 3 (c): 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, support coordinators. This qualification should not be mandatory so that participants may opt for a support coordinator who does not have formal qualifications.

To develop a formal qualification, we need a much better understanding of what people with disabilities 'need' from support coordinators. Participants who have transitioned into SDA housing were surveyed by the Summer Foundation on the skills and qualities that make a good support coordinator. The skill they rated the most highly was a thorough understanding of the NDIS and the ability to translate government language into meaningful language. The second most highly rated skills were strong teamwork, enthusiasm, adaptability, and ability to locate, coordinate, manage and/or facilitate a range of supports and providers. Communication skills, empathy, creativity, ability to connect with mainstream supports, coordinate plans and enable greater independence were also highly rated. Some of these skills could be further developed in a formal qualification. Notwithstanding any qualification, the ability to adapt to the needs and style most appropriate to the person is critical and is a necessity for a quality support coordinator.

Sally* aged 44, living in RAC, says:

I need fun-going people like Lisa (my support worker), and just someone kind and honest is very important – I would rather hear the truth than lip service.

They need to be good at keeping you up to date and listening to me - and fulfilling what you say if it's possible. I'm sitting here and I wouldn't expect them to know everything about me or the system, but they need to learn about the system, be helpful and learn as they go.

They need to learn about each individual they are working with and their needs and they need to be a person that can do that.

J (my support coordinator) is a neuropsychologist and she has been a legend, and I'll need her when I move.

**Pseudonym*

Denise* aged 50, living in RAC, says:

I was with (another agency) and shit, they were bad, didn't organise my new wheelchair. The support coordinator wanted me to sign something \$4,000, and he was here no more than an hour. So, I rang M (Summer Foundation) so she got me onto (a new provider). When I spoke to them, they ceased (the first agency). I fired all of them it was great. They were a rip off. I rang M and thanked her so much because N (my new support coordinator) rang and I got \$4,000 back. We are on the same page.

*I like my support coordinator to have lots of ambition and looking out for my welfare, looking at your interests and what you want to do – not what **they** want to do. My support coordinator always says: 'what would **you** want to do?'– that is good. You know what drive you have and what you want to do. They need to be kind and understanding of your needs.*

She (N) is good on the phone and knows how to deal with issues had problems. She'll get on the phone and rectify the problem straight away. She's smart and cluey, a problem solver.

Support coordinators need to know about managing people like myself, people with disability, to know what we need and what we want someone to understand, and they can handle the situation. If there is a problem and something is not working out, they can find a solution. They can take on responsibility and say let me worry about it, to have confidence in fixing things and fixing problems.

**Pseudonym*

The growth in the support coordination workforce has seen many disability support workers transition into the support coordination role without the necessary skills or knowledge and without mentoring/supervision to support people with complex needs. Often the culture and skills mix of these practitioners differs from what is required by the support coordinator function. Ellis et al identified the essential personal values and core competencies necessary to the role.⁷ Ranging from ability to design individual solutions, excellent communication skills and high-level problem-solving skills, they emphasise the breadth of capabilities required.

There is anecdotal information about poor quality support coordination services and therefore wasted funds for NDIS participants. This is the result of a lack of clarity of required skills and competencies for support coordinators and lack of professional development opportunities that align service and function with the needs of participants and improve service quality.

The Summer Foundation's *UpSkill* program has a Community of Practice for support coordinators which offers opportunity for professional development, peer-to-peer learning, shared capacity building, collaborative problem solving and collaborative approaches. This is an effective way for support coordinators to actively engage in development and seek out or share effective approaches.

Support coordinators at all levels need at least an understanding of the social model of disability, experience working directly with people with disability, as well as practical knowledge and skills and preferably lived experience.

There is potential for the *UpSkill* program to become accredited training or relevant qualification for support coordinators. With a current comprehensive package of 7 training modules and focus on shaping quality support coordination practices, it provides significant development for all levels of support coordinators.

Question

10. How can the effectiveness of support coordination be measured and demonstrated?

Evidence on how to build the capacity of the workforce of support coordinators is lacking.

There is limited literature on:

1. What makes a good support coordinator?
2. What are the key challenges and barriers faced by support coordinators?
3. What resources might support coordinators need to be more effective in their role?

The Summer Foundation is conducting research to investigate these questions. The research program consists of a scoping review exploring the literature on the components of effective support coordination as well a qualitative investigation. Those invited to participate in the qualitative investigation include NDIS participants who receive support coordination (n = 15), support coordinators with experience working with people with disability and complex needs (n = 15) and family members of NDIS participants with complex needs (n = 15). The insights derived from this research will inform the development of training and resources to build the capacity of support coordinators to support people with disability and complex needs.

⁷ Ellis et al (2017) p17.

Publication of results is expected in June 2021 (subject to the effects of the COVID-19 pandemic).

There is opportunity to contribute to the scope and application of this research. The Summer Foundation would be happy to have a further conversation with NDIA about the research.

Recommendation 3 (d): The NDIA should support and disseminate the findings of participant-driven research into what makes quality support coordination.

Question

11. Are there emerging examples of good practice and innovation in support coordination?

Lack of professional support and capacity development is a major barrier to the provision of quality support coordination. As a new role, support coordination lacks the industry and workforce associations of more mature professions. While they may relate to professional bodies for social workers or occupational therapists, support coordinators working with complex disability needs are unlikely to find the support and professional development needed from these affiliations.

Under-investment in training and development was identified by Ellis et al⁸ as one of the problems leading to poor quality support coordination. If professional development is enabled, such as the training workshops provided by the Summer Foundation's *UpSkill* program and related Community of Practice, support coordinators must often either seek financial support from their employing organisation or self-fund in order to participate. Currently, *UpSkill* is offering subsidised training in Victoria and New South Wales through philanthropic funding. There are however constant requests for *UpSkill* to be made available across the country. Support coordinators often are self-employed or employed in small organisations. Relying on individual organisations to develop internal training and professional capacity building is inefficient and leaves room for immense variation between organisations. Likewise, there are limited opportunities for peer support and peer-to-peer learning for support coordinators outside of *UpSkill*.

The Summer Foundation's *UpSkill* program and associated Community of Practice provide examples of best practice for quality support coordination for participants with complex needs. *UpSkill* provides a multi-pronged approach to support coordination capacity-building. Currently being rolled out nationally, it aims to:

- Document a model of support coordination good practice
- Build capability of support coordinators through a series of 7 training modules
- Grow the support coordination workforce and diversify the skills base
- Assist support coordination organisations to implement efficient systems to ensure sustainability
- Build the capacity of people with disability to choose an appropriate support coordinator

The Support Coordination Community of Practice enables enhanced networking and peer support in a facilitated environment.

⁸ Ellis et al (2017) p12.

For support coordinators working with people in hospital, the Summer Foundation's Collaborative Discharge Approach planning resource⁹ provides another example of best practice for people with complex needs. It describes how support coordinators in mainstream health settings can work with health staff and contains a detailed process mapping of NDIS and health roles and processes to ensure quality support coordination in the NDIS/health interface.

Recommendation 3 (e): the NDIA should fund industry development strategies 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.

Questions

12. Are the levels and relativities in the NDIA price limits across different services including support coordination working effectively in the interests of participants and a sustainable innovative market?

Price limits need to factor in the importance of allowing time for training, coaching and knowledge development work for the support coordinator workforce to provide quality services to NDIS participants.

Recommendation 3 (f): 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 coordinator workforce to provide quality services to NDIS participants.

13. Should support coordination pricing be determined at least in part, based on progression of participant goals and outcomes, and how might this work?

This would be challenging to quantify in a transparent and meaningful way. Achievement of goals is also influenced by service availability, appropriateness and timeliness of funding and accurate description of goals.

BUILDING CAPACITY FOR DECISION-MAKING

Question

14. How can a support coordinator assist a participant to make informed decision and choices about their disability supports? What are the challenges?

People with complex disability support needs who live in RAC or other restrictive environments have had limited opportunity for choice and control over their lives. People denied choice and control, especially over long periods, may need additional support to uncover and (re)discover

⁹ Collaborative Discharge Approach Summer Foundation (2019)
<https://www.summerfoundation.org.au/?s=Collaborative+discharge>

their ‘voice’, goals and aspirations. A support coordinator’s role may involve assisting a person to imagine, experience and explore a range of options in order to make an informed decision. A support coordinator must create and enable new opportunities.

It is important that support coordinators are aware and follow the principles of supported decisions such as: Principles for supported decision-making [Western Australia’s Individualised Services](#)

- Understand my preferences
- Assume I can
- Who are the right people to assist?
- What are the right supports to assist?
- Opportunities to experience and explore all options
- Decision is up to the person
- They can change their mind

Support coordinators may have a role in assisting a person to bring in family and trusted others to assist and support their decision-making, but they also have a responsibility to make sure that the NDIS participant is central to the decisions about their life. To do this effectively, support coordinators may require additional training.

Recommendation 3 (g): The NDIA should develop strategies to make training on supported decision-making available and affordable to support coordinators.

Question

15. How does a support coordinator build a participant’s independence rather than reliance? Should support coordination pricing be determined, at least in part, based on building a participant’s capacity for decision-making to become more independent?

‘Capacity building is acknowledged as an important part of support coordination, but due to the amount of time required to problem-solve and implement foundational support, as well as the level of unmet need and lack of quality in NDIS plans, support coordinators often have trouble getting around to implementing effective capacity building activities with participants.’¹⁰

Ellis et al found that many support coordinators had poor understanding of what capacity-building strategies look like, and how they could measure success. As a consequence, they had unclear expectations of the lynchpin of the NDIS - capacity building.¹¹ The broad scope of NDIS-set aspirations for participants in regard to their improved participation as active citizens in economic, social and cultural life, adds significant demands to the support coordination role.

Where there are unclear expectations of what to do, how to do it and how to measure whether it has been achieved, support coordinators can do the ‘easy’ part of their role at the expense of functions such as ‘building a participant’s capacity for self-direction and

¹⁰ Ellis et al (2017) p13

¹¹ Op cit p12

independence'. In addition, addressing adaptive barriers with participants requires long-term support, which may be hampered by insufficient plan funding.

Developing high level skills and knowledge for quality capacity building in support coordination practice requires ongoing learning and professional support such as participation in Communities of Practice that offer facilitated peer support.

The support coordinator requires a thorough grounding in a person-centred approach in order to be consistently focused on the participant's direction. This involves a capacity to develop trust and an enabling relationship with participants.

A support coordinator is a key contributor to building the capacity of a participant, but is not the only contributor. Services, environment, and also the community all play a role, as these factors contribute to the capacity of any person. It would be unfair to attribute capacity building to one function.

Furthermore, without clear guidance and capacity building for support coordinators, pricing should not be determined through the successful capacity building on a participant. Likewise, without an established and tailored approach to measuring capacity of a participant, the effectiveness of a support coordinator to contribute to the progression of a participant's capacity is not measurable.

Recommendation 3 (h): The NDIS 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.

Question

16. How can a support coordinator assist a participant in need of advocacy without acting outside the parameters of the role? What are the appropriate parameters of their role? What are the appropriate parameters of the personal advocacy role and the support coordination role?

The roles of support coordinators and advocates differ. Where a person has an advocate, a support coordinator and advocate should work closely together to ensure a participant is able to access the NDIS funding and opportunities which they need. Support coordinators must always ensure that the person is at the centre of all decision-making and that their voice is heard. An advocate can further assist with this and enable the person to access further opportunities which the support coordinator does not have scope to support, or is not funded to support.

If a person does not have an advocate, a support coordinator may support the person to find an appropriate advocate if needed.

CONFLICT OF INTEREST

Questions

17. In what circumstances is it more or less appropriate for a participant to receive multiple supports from a single provider?
18. Should the IAC recommendation for the NDIA to enforce an 'independence requirement between intermediary and other funded supports at the participant level' be adopted?
19. What impacts would stricter conflict of interest requirements have on NDIS participants and the NDIS market?

Conflict of interest issues are particularly prevalent in the provision of housing, SIL and support coordination. The role of support coordinators is to help participants navigate the market and choose a support provider. When the support coordinator is employed by an agency providing other NDIS supports such as core supports, and/or disability housing or SDA, there is an inherent conflict of interest.

People with disability are best served when their support coordinator is independent and free of any conflict of interest. We know that support coordinators who also provide housing and SIL may be less likely to support the person to explore the full range of housing options available - instead 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.

We also know that having multiple providers and people in a person's life is an important safeguard against abuse and neglect. This is particularly true for people living in group homes and other congregate settings or on their own. Feedback from young people in RAC indicates that independent support coordinators are often of a higher calibre than those employed by a multi-NDIS support provider agency.

In the housing area there is a lack of understanding by some SDA providers of the fundamental support coordination role to support participant-driven goal setting and goal attainment, or outright negligence in failing to adhere to the *NDIS Act 2013*, Rules and Code of Conduct, which specify the requirements for support coordinators to be impartial and independent in supporting a participant to choose other providers.

The Summer Foundation has been made aware of examples of providers advertising a 'support coordination' position where the key role was to recruit participants as tenants for the provider's SDA units. In a recent position description for a support coordinator, their core responsibilities were defined as: *'Find new participants for our SDA properties' (and) 'Bring participants onboard immediately'*.

In another example, a disability housing website owned by an SDA provider informed Summer Foundation staff that they had become a support coordination organisation in order to access the Summer Foundation's Housing Hub, our tenancy matching site, using NDIS funding. As a result, the Housing Hub team is monitoring the site closely and investigates postings that indicate potential conflict of interest practices by SDA providers.

These examples of blatant conflict of interest demonstrate the harmful impacts on participants when their support coordinators are employed by SDA providers. The Code of Conduct specifies that they need to have accurate information on service availability and on any (real or perceived) provider conflict of interest, and to be free of inducements or pressure in making their own choices. In these situations of single SDA support coordination provider, participants are regarded as 'commodities' rather than decision-makers.

Close monitoring of existing and prospective providers that combine SDA and support coordination provision must be carried out by the NDIS Quality & Safeguards Commission on the grounds that this combination involves inherent risks. Where investigation fails to establish clear benefits to participants that they cannot otherwise access, and publication of measures to reduce conflict of interest impacts, registration must be removed or denied.

Recommendation 4 (a): The NDIS Quality & Safeguards Commission should undertake analysis of existing provider registration details to identify organisations offering both support coordination and housing. These providers should be monitored closely.

Recommendation 4(b): The NDIS Quality & Safeguards Commission should require providers of support coordination and other NDIS supports to lodge a 'conflict of interest' statement defining the potential participant impact 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.

Recommendation 4 (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.

GENERAL

Question

20. What would you identify now as the current critical issues around support coordination?

For participants with complex disability support needs the critical issues around support coordination are:

1. Inadequate support coordination funding and planners failing to fund Specialist Support Coordination
2. Ineffective support coordination in the interface between the NDIS and mainstream health systems
3. A lack of support coordinators who can work with people who require accessible housing solutions and SDA
4. The absence of a fit-for-purpose formal qualification for support coordinators
5. Inadequate training and professional development opportunities for support coordinators, particularly related to supporting people with high and complex needs
6. The challenges in locating and connecting with appropriately skilled and knowledgeable support coordinators
7. A lack of documented best practice approaches
8. Failure to address the conflicts of interests among support coordinators who are not independent providers

Question

21. What are the priority actions the NDIA might take to grow an innovative and effective support coordination market in the interests of participants?

1. **Address the support coordination needs of people who are stuck in hospital**

Our recommendations prioritise access for people in hospital to interim plan funding for specialist support coordination so that they can work with discharge planners as early as possible. This will facilitate planning and implementation of supports to ensure efficient and effective discharge to housing of participant's choice.

The NDIA should work with the Summer Foundation to enable wide distribution to health systems of the findings and resources of the *Leaving Hospital Well* project as an example of best practice in NDIS support coordination in hospital settings.

2. **Fund the necessary amount of support coordination at the appropriate level**

The NDIA must prioritise access for participants with complex support needs to sufficient hours of support coordination at the right levels to enable them to achieve the goals in their NDIS plans. Planners must be provided with appropriate guidelines to specify that people with high and complex needs should be funded for at least 120 hours of Specialist Support Coordination.

The NDIA should prioritise 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.

Plan utilisation rates for support coordination for YPIRAC should be reported to the Joint Agency Taskforce to facilitate its understanding of the factors influencing support coordination implementation in RAC.

3. **Implement strategies to ensure that NDIS participants can access support coordinators with the necessary skills and knowledge as well as suitable attitudes and values**

The NDIA, in conjunction with the Summer Foundation, should prioritise the expansion of the *UpSkill* program – training and Community of Practice, in order to ensure that there is an adequate supply of support coordinators with the required values, skill and knowledge base to provide quality services to participants with complex support needs.

The *UpSkill* program offers a key opportunity to further the recommendations above as it covers:

- Skill development for work with participants who have complex housing and support needs
- Increased participant-driven choice of support coordinator via its *UpSkill* Directory
- The potential to deliver accredited training and/or formal fit-for-purpose qualification for support coordinators.

The NDIA should fund the Housing Brokerage Service as Specialist Support Coordination for people with disability. This would build the capacity of both the person and their support coordinator (through the provision of secondary consultation) around housing.

4. Address the problem of conflict of interest among support coordination providers

A priority for the NDIA is to undertake analysis of existing provider registration details to identify organisations offering both support coordination and housing.

Priorities for the NDIS Quality & Safeguards Commission include:

- Requiring providers of support coordination and other NDIS supports to lodge a 'conflict of interest' statement defining the potential participant impact 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.
- Adopting and enforcing 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.

ATTACHMENT 1

UpSkill | Summer Foundation

August 2020

UpSkill was launched as the Summer Foundation's Support Coordination Flagship Program in September 2018. *UpSkill* was originally created as a training initiative with the main objective of building the capacity of support coordinators so that all young people in residential aged care (RAC), and at risk of RAC entry, have access to a highly-skilled support coordinator. The program audience was later expanded to include training and resource provision for private NDIS allied health professionals.

The program is currently funded through fee-for-service training, philanthropy and government grant funding. *UpSkill* is a recipient of the DHHS [Victorian Regional Readiness](#) grant funding as well as a recipient of the [Gandel Philanthropy Major grant](#) funding.

Working Vision Statement

UpSkill aims to enable Young People in Residential Aged Care (YPIRAC), and those at risk, access to NDIS support coordinators and allied health professionals who are delivering evidence-based practice to support them to live well in the community with a mix of NDIS and mainstream supports.

UpSkill's vision is for a workforce of NDIS professionals delivering quality services to empower young people to have independence, choice and control over their lives and the supports they choose to access. Furthermore, to develop a highly capable workforce to ensure that no NDIS-eligible people under 65 are admitted to RAC by 2025.

Need for the *UpSkill* Program

Finding skilled and experienced support coordinators who can work with people with complex needs has been identified as a current challenge by people with disability, their families, hospital staff, RAC staff and by the NDIA itself.

The Summer Foundation has focused its *UpSkill* program on 4 priority activity streams:

1. Develop and deliver training and resources to assist support coordinators and allied health professionals to improve their skills and knowledge.
2. Research and understand the skills that define quality support coordination.
3. Develop a database of support coordinators and NDIS allied health staff for NDIS participants to find suitably skilled professionals.
4. Facilitate the sharing of knowledge and expertise among support coordinators and NDIS allied health professionals through a dedicated Community of Practice.

Program Achievements

Training and Resources

As of July 2020, the program has delivered over 65 training events to 1000+ support coordinators, health services workers and participants covering various topics including but not limited to:

- Evidence for SDA outcomes (formerly 'How to Write a Housing Plan')
- Working with people in the hospital setting
- Working with younger people in aged care
- Working with people living in RAC
- Working with people with complex needs

Several resources have been developed for support coordinators and allied health professionals including, but not limited to:

- [How to write a Housing Plan](#)
- [My Housing Preferences](#)
- [Participant Housing Statement template and guide](#)
- [Sample NDIS Plans](#)
- [Looking for somewhere to live](#)
- [SDA Payments Guide](#)
- [Mainstream Housing Options](#)
- [Living More Independently](#)
- [Allied Health Housing Assessments](#)
- [NDIS Housing Pathway](#)
- [Using SDA to buy your own property](#)

A [suite of webinars and podcasts](#) has recently been produced in collaboration with the Victorian Regional Readiness Fund consortium partners as part of the project deliverables including:

- *UpSkill* Fundamentals Part 1
- *UpSkill* Fundamentals Part 2
- *UpSkill* Fundamentals Part 3
- Using teach back to improve understanding
- Cultural understandings of disability
- Working with interpreters
- Support coordination vs. great support coordination
- Running a support coordination business
- Working efficiently with templates and systems

Training Evaluation

Pre and post surveys are conducted via the live polling application, Slido, for all training sessions to ensure learning expectations are met and that knowledge gaps are understood. Face-to-face workshops consistently achieve high satisfaction ratings, demonstrating an increased confidence in achieving good outcomes for their clients. When asked about what information was most useful in the workshops, responses included:

“I was able to understand SDA on another level and got some great resources to learn more about the SDA housing plan and eventually write one.”

A formal evaluation plan for the program as a whole is currently being established to ensure the program continues to meet the needs of the audience.

Journey Mapping

A number of training modules have been informed by the experience and preferences of people with disability through journey mapping. To date it has included the exploration of:

- The barriers preventing people with complex needs from leaving aged care
- The skills required to make a ‘good’ support coordinator
- How the workforce can support participants to transition into SDA
- How the workforce could support participants to live well in the community

The journey mapping has allowed the program to capture the lived experience of NDIS participants (and their families) and provide a structured forum to:

- Formally reflect, share and document their experiences with support coordinators
- Share their expectations of the support coordinator role and identify common pain points associated with the milestones shared by people living in aged care
- Share ideas about the support coordinator role in supporting young people with complex needs to live well in the community

UpSkill Directory

The [UpSkill Directory](#) has been piloted and is used by Summer Foundation staff to refer people with disability and/or close others to support coordinators and NDIS allied health professionals working in their area. Approximately 40 support coordinators have joined the pilot directory. While the pilot has limited functionality and scope, funding has been secured to scale this work; a web developer has been engaged to complete this by the end of December 2020.

Community of Practice

The [UpSkill Community of Practice \(CoP\)](#) provides a platform to showcase best practice for working with people with high and complex support needs. The CoP provides a foundation for the workforce to ‘think together’ to create positive outcomes for people with complex disability by identifying and disseminating ‘best practice’ approaches; sharing learnings to generate new knowledge; and documenting improvements in participant outcomes.

More information

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