

Survey of support coordinators

Essential features of support coordination assistance for pursuing home and living goals

The National Disability Insurance Scheme (NDIS) aims to provide individualised, person-centred funding and support for participants. In order for people with disability to have choice and control and achieve positive outcomes, they need to be empowered to navigate the Scheme. A high-quality workforce of support coordinators is critical to enable this.

Support coordinators help participants with a range of tasks. These include using the funding in their NDIS plans, accessing services, building capacity and independence, connecting participants with support and housing providers, and assisting with service agreements. In quarter 4 2021/22, \$213m was paid by the NDIA for support coordination.¹

Despite the importance of their work, recent research has shown that support coordinators face poor role definition and guidelines from the NDIA.² As a result, there are workers with varying levels of knowledge and expertise, leading to a variability in the quality of support provided. Therefore, as 1 study asserts, the NDIA should consider:

"Developing clearer guidelines and a framework of practice for the support coordinator role would enable better management of stakeholder expectations ... Without these changes, there is a risk that support coordination continues to be a role that 'every man and his dog thinks they can have a crack at'.³

Support coordinators play an especially critical role in the housing pathway for many NDIS participants with complex needs. Therefore, there is a need for support coordinators to have up-to-date knowledge of housing and support options available under the NDIS, including Specialist Disability Accommodation (SDA), Supported Independent Living (SIL), and Independent Living Options (ILOs).⁴

¹ NDIA (2022). 'NDIS Quarterly Report to Disability Ministers: Q4 2021-2022.' https://www.ndis.gov.au/about-us/publications/quarterly-reports

² Hummell, E., Foster, M., Fisher, K.R., Needham, C., Borg, S.J. and Venning, A. (2022) Challenges and adaptations of an intermediary: an exploration of support coordination in the Australian National Disability Insurance Scheme, *International Journal of Care and Caring*, DOI: 10.1332/239788221X16504513780378

³ Hummell, E., Foster, M., Fisher, K.R., Needham, C., Borg, S.J. and Venning, A. (2022) Challenges and adaptations of an intermediary: an exploration of support coordination in the Australian National Disability Insurance Scheme, *International Journal of Care and Caring*, DOI: 10.1332/239788221X16504513780378, p. 14.

⁴ Communities of practice like UpSkill facilitate best practice learning through peer-to-peer professional development. UpSkill's training program includes modules that build the capacity of support coordinators to determine the necessary components of good housing and address common barriers to good housing for people with disability.

The Summer Foundation Ltd and the Housing Hub work with hundreds of NDIS participants with complex needs who have goals related to housing. Many report 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 participants' preferences in living arrangement and supports.

Based on this, the Summer Foundation is exploring how support coordinators can improve the quality and consistency of guidance provided to NDIS participants seeking funding for home and living supports, including SDA. In July 2022 it conducted a survey of support coordinators who work with participants considering their housing options. Findings from this survey describe the essential features of support coordination enabling NDIS participants to make an informed choice and move into new housing.

What is the problem?

Finding skilled and experienced support coordinators is a particular challenge for NDIS participants with high and complex needs. At present, there is limited understanding of the demands of the role and the skills required for support coordinators, as well as the operating environment in which they work.⁵ For many NDIS participants with high and complex needs, these goals may relate to their housing.

The housing needs of 1000s of NDIS participants are not being met. There are more than 1,400 NDIS participants stuck in hospital awaiting discharge,⁶ and more than 3,000 younger people in residential aged care (RAC).⁷ In order to prevent further admissions of younger people to aged care, and to facilitate timely hospital discharge to suitable housing, these people need adequate funding for support coordination in their plans, as well as access to well-trained support coordinators.

The growth in the support coordination workforce has seen many disability support workers transition into the support coordination role. Many will not possess the necessary skills or knowledge, and without mentoring and supervision will not be able to support people with complex needs. Where support coordinators lack knowledge of the service systems and opportunities for participants, support coordination funding may be used to pursue unsuitable housing arrangements. A lack of training means support coordinators risk pursuing the 'easy' or 'known' housing options rather than the most suitable. This leads to poorer outcomes for NDIS participants. In turn, this leads to the need for additional funding in subsequent plans to improve the situation and implement more suitable supports. Other possible impacts of unskilled or inexperienced support coordinators include delays and wasted plan funds for participants.

https://www.summerfoundation.org.au/wp-content/uploads/2021/03/How-to-reform-support-coordination-to-meet-the-needs-of-NDIS-Participants-with-High-and-Complex-needs.pdf

⁵ La Trobe University and the Summer Foundation are currently addressing this evidence gap with a research project exploring the skills and characteristics of a 'good' support coordinator.

⁶ Gailberger, J. (2022). Hospital patients wait to be discharged in NDIS 'bed block'. *Herald Sun*, 8 August. https://www.heraldsun.com.au/news/victoria/hospital-patients-wait-to-be-discharged-in-ndis-bed-block/news-story/13a 4b76f83c95b25be51df072c377f52

⁷ AIHW GEN Aged Care Data (2022). 'Younger people in residential aged care'. https://www.gen-agedcaredata.gov.au/Resources/Younger-people-in-residential-aged-care

⁸ Adequate training ensures 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

⁹ Summer Foundation Ltd (2021). How to reform support coordination to meet the needs of NDIS participants with high and complex needs.

Survey

The aim of the survey was to get expert input from support coordinators who are supporting NDIS participants to consider housing options and move. Survey respondents were asked to comment on an NDIA-drafted document listing 16 'Essential features of support coordination assistance for pursuing home and living goals.'

The draft document contained the following description:

Overarching principle: Involving the participant within their capacity to make decisions and take on tasks themselves where possible. Who has supported the participant in these decisions? Needs to be linked with the supported decision making project

The survey was conducted in July 2022, and was sent to relevant Summer Foundation professional contacts. In total, 29 support coordinators responded to the survey.

Results: Support coordinator feedback

In the table below, the 16 essential features, as well as 2 additional questions are listed. Beneath each feature are the comments provided by support coordinators in response.

Table 1 – Support coordinator feedback on essential features

Essential Feature 1

Understand current and usual living situation

- Including who they usually live with and may live with
- History of their living situation

"Provision of this background information prior to commencing the assessment would be very helpful to reduce the extensive assessment and report writing time required."

"It is important that this information is accurate and also reflects if there were any barriers, risks, incidents, behaviors that may support determination of building type and or support ratio that a person may be best suited to for sustainability. Evidence and justification as to why specific requests are made."

"Confirm who makes or influences decision-making in the person's life."

"The living situation and history should be recorded or checked at the initial meeting/implementation information by the COS."

"This information should be established at Access and on file and available to COS and can verify any changes."

"Processes need to be easy and the person with a disability or carers should not have to repeat themselves endlessly."

Clarify expected time frame for participant readiness to move

 Are there any priorities or urgencies eg. existing lease expiring, risk at current housing/home?

"Their timeframe may be VERY different to the time frame that NDIA has (i.e. taking months/years in one case to provide adequate SIL decision/funding; and then lack of suitable SIL homes in rural Aus."

"Prompts to emergency strategies via NDIS- change of circumstances, home and living request, for over 55s check Retirement Village rental or supported living options are available if mostly independent."

"SDA assessment provider requires this information at time of referral to determine if the provider can meet any essential time frame considerations."

"It would be great if there was a NDIS process in place that could fast track applications that are urgent due to a participant's risk, notice to vacate etc. As there is currently a housing shortage of affordable housing in the private market it is important that participants are not placed at risk through circumstances that are beyond their control. There should be a bit more flexibility in the determination of the ratio of shared support if the person finds existing vacant SIL accommodation that they are happy with rather than an endless request to have the shared support ratio changed. There appears to be a lot of vacancies in 1 person accommodation yet the NDIS do not determine this support ratio very often."

"Urgent avenues for Home and Living assessment should be created for homeless participants."

"It would be good to be able to have an email or phone contact for the home and living team to touch base."

"We can't see if the application is even being looked at and people that are sitting within a crisis, months is too long to wait without hearing a word."

"Fast track decisions path needs to be recognised in degenerative conditions."

"Risk factors should be identified in advance, if possible, and a plan of action discussed with the person with a disability and carers."

"Crisis situations need immediate action."

"Time frames are woeful and give the participant absolutely zero sense of choice and control."

Assist participant to identify preferred housing arrangement and location/s they would like to move to and why and clarify who supported them to make this decision

"I think Coaches could be used for this period of time."

"If the OT assessment shows exactly what's needed then the Coach can help the participant to make the appropriate decisions after they work together to find places to live."

"It is important to know where the participant would be happy to live and there may be specific reasons for this choice. They may need to be closer to family, public transport, hospitals, shopping centers. Or they may prefer to live in more remote areas. The individual choices of locations do attract different dollar amounts particularly with SDA housing."

"Frequently preferred options/locations are not available, identifying preferred locations sets everyone up to fail when they do not materialise."

"May not be suitable SDA in preferred location. Mostly on urban fringe."

"Explain to participant, the Agency's expectation that unpaid and mainstream supports will be sustainable."

"Finding it hard to get location required."

"The housing crisis impacts greatly on this question in relation to what is realistic."

"Participants need to be informed of the possible impact of changes. Established and trusted supports are a problem with a move; as the same support workers may not be able to work in the new area."

"Funding for provider travel is also an issue depending on the area & needs to be factored into the Core Support funds."

"So few locations available that participants are just as likely to accept anything they can get."

Identify the presence of informal supports in new location

- In home
- In community

"This should be fully disclosed in the referral?"

"This is not clear. Are you asking that there are valued community facilities accessible to the participant? This might be addressed in the preferred location question."

"Informal supports in SIL? Family and friends welcomed? Involved?"

"Available places are not in the person's preferred area. Available places don't have informal supports (family and community) which are important to the person. This is preventing the move and person continues in unsuitable accommodation."

"I believe it is important to discuss with the participants' families that any informal support provided must be sustainable and reliable. Families can most often start off with good intentions but then get busy and cannot continue to commit to provide the ongoing support. In this case there may not be enough funding for staff to replace informal supports or it uses irregular support funds quickly."

"Legal issues need to be taken into account more in this area."

"Some informal supports need to take a step back and reduce the amount of support they are providing to their friend/loved one. NDIS should take this into account as well rather than relying on them since they have always been around."

"Investigated at time of confirming area."

"Clarify both presence, frequency and type of support these informal supports can offer."

"No one seems to understand where informal supports lie. Some people are told that they can't have their spouse live with them."

Detail what housing options have been considered and why preferred/not preferred

"Preference has posed little impact with my participants - it's more about applications being rejected by mainstream/private rentals; years long wait list public housing; applications for youth refuges or housing support services exiting them as 'too hard'; 1/2 SIL funding approved as required (in several instances, therefore SIL providers won't take them)."

"The person wants to live with her child and not to share. This is proving very difficult to achieve. Options are available but not in preferred location and away from family, friends and regular trusted supports. Housing offered an unsuitable option in an unsuitable area. The person needs a high physical needs setting."

"Again, provision of this type of information at the time of referral can reduce the very significant SDA assessment and report writing time and help expedite the process overall."

"Psychologist/OT recommendations to be at the forefront of decisions."

"There is a severe shortage of adequate housing in Townsville, especially robust SDA (there are a number of high support needs SDA available). Even if accommodation options are identified, unless there is adequate housing we can't actually house participants."

"ATSI participants require special consideration - i.e living on or off land."

"Including risks associated with accom options that are not preferred."

"Aged care facility recommended for aging participant but then ACAT need to be involved, defeating the purpose of NDIS. Participant has dementia and is not offered fair and necessary options."

"I don't think that this is necessary to locating and finding new accommodation."

Assist participant to articulate their long term plan for living situation eg. is this a short term option, does participant intend to move into own home in the future, what is the transition between existing and future homes? etc

"I've found this challenging, particularly with participants with autism, intellectual disability, or those with trauma/chaotic backgrounds - many of them live day to day and either can't imagine a better future or live day to day."

"A lot of emotional support needed to consider the move. Challenge for CoS is mobilising the transition due to person's fear/reticence for change and firm preferences that can't be met."

"Participant wishes always need to be considered."

"I believe all of the above would be very helpful information to have, especially including a transition plan. A transition plan may also help to identify that home modifications, assistive technology, capacity building of skills for greater independence may be required to make it a sustainable arrangement and value for money if and when a person purchases their own home."

"Not all participants are verbal, and there are hugely differing needs for those people who are in wheelchairs and those with disabilities such as autism. Therefore, to assist participants to articulate long term (or even short term plans) is not always possible."

"Feel plans are not taken into consideration when building a plan. NDIS are more about here and now, not what might be."

"Transition may be lengthy, for some people building capacity with a lot of support may run over several years."

"Refer back to essential feature 3 around who supports the participant to plan and make decisions."

"It would be so helpful if we could have medium term accommodation approved in a plan while we are waiting for the Home and Living team to make their final decision. That way participants aren't stuck waiting in limbo for months."

"Participants with dementia or similar cognitive impairment rely on spouse or informal supports to articulate for them but still are not given a fair and equitable hearing. Support coordination needs to be increased for supporting this to occur."

Confirm whether existing core supports provider will continue?

"Most accommodation providers seem to be saying their chosen daily living provider has to be used."

"This is entirely dependent on the participants choice to provide this information. For eligibility purposes for SIL or SDA I do not believe this information is necessary. Once the suitable accommodation or provider has been chosen then NDIA are notified."

"The Participant needs to be informed of any possible change in their supports. Keeping the supports who understand and respect the Participant's ways is important and a change of supports needs to be introduced as part of the transition Plan."

"Core supports should be encouraged to build relationships with participants. Regulations need to be in place to ensure that participants who are vulnerable are not left when they are moved on."

"If they move to SIL accommodations, the existing core support provider doesn't need to continue their support."

Essential Feature 8

If current support provider continues clarify:

- Does the participant needs a new support team?
 - o If so, time frame to complete
- Does the participant need any additional supports for the transition eg. training of new provider for disability specific needs eg. DRHS

"I believe there should be an inclusion of funding for training of a new disability support team to ensure that all of the clients care needs are provided and it is a smooth transition to a new support provider."

"Again, the shortage of suitably qualified support workers needs to be considered."

"Ensure staff are trained and have extensive knowledge of the disability to ensure participant is supported in the best way."

[&]quot;Yes, participants will need all these."

If participant needs a new support provider:

- Confirm likelihood of finding a new provider in preferred location?
- Assist them to identify likely providers
- Assist them to make contact
- Consider how long it will take to engage a new provider?
- Consider the likely time frame to staff a full roster
- "All of this takes HOURS and often there's not enough funded SC hours or workload is so enormous, where do we find the time for all this?"
- "All very difficult to achieve due to a variety of factors specific needs of participants, lack of availability of supports in preferred locations. Timeframe to achieve this would be approx 1-3 months."
- "This is part of the role of a SC who is supporting a participant to explore housing option."
- "There is a lack of good service providers who are willing to train and support their staff (support workers) as necessary, particularly with participants who have complex needs and severe and challenging behaviours."
- "Considerations of area and availability of support."
- "Would it be suitable to consider a question relating to the frequency of staff/agency change and reasons for? (le. inexperience, complexities, COVID etc, sustainability of staff)."
- "Consider the experience of the provider and seek testimonials and feedback from service users and others familiar with the provider."
- "With Covid making its way around everywhere again it is extremely hard to engage a new provider with complex participants, especially those requiring hoist transfers."
- "New providers of quality and availability are extremely difficult to find or recruit."
- "New service providers in regional areas are very difficult to attain. Even through organisations such as Hire Up travel is a prime consideration of support workers & a barrier."
- "At times the Participant 'makes do'- due to limited choices."

Clarify whether the participant needs to change or engage a new support coordinator or capacity building providers and confirm:

- Who is organising?
- Likely time frame to engage required providers and new SC

"Could continue with current CoS."

"Any participant in shared living arrangements should have an independent person who can check in - a coach, a support coordinator to ensure there are no conflicts of interest and quality of service is maintained - including complaint follow ups."

"It is a participant's choice to choose providers of their own choice. Participants often like to have SC that are local so they have greater opportunity to meet with them face to face or be supported to explore vacancies available. Having a local SC also gives greater knowledge to the supports available in the community network."

"There is a lack of good service providers who are willing to train and support their staff (support workers) as necessary, particularly with participants who have complex needs and severe and challenging behaviours."

"Clarify roles. E.g. what is support coordinator's role, LAC? What is the guardian's role if there is a guardian?"

"The NDIS should be responsible for the sourcing of a new COS and there should be forward planning so the Participant is covered at whatever point of their transition. It is important for a handover and all information to be available to a new COS; as again the Participant does not need to repeat themselves."

Essential Feature 11

Confirm whether the participant has sufficient supports confirmed to continue at a safe level in new home?

"They might not have but can't find anyone else to work with them, or they don't want more."

"More clarification to question- is this referring to funding supports or everything including informal supports, support team, advocacy or guardianship of required? Rather than to CONTINUE at a safe level would PROCEED be a better term?"

"New supports would be needed."

"Often left to providers."

"Clearly this is very important to ensure that a participant is supported adequately to minimize risks to client wherever, whenever possible. It is also important that adequate funding is available to ensure that adequate staff are available to assist participants care needs to maintain safety for the client."

"Planners are not skilled enough to identify the risks of sufficient or type of support as they don't know the participant and don't read the reports."

"As per essential feature 9, seek feedback about the provider."

"A lot of the time if a participant is transferring out of the hospital setting, or into a new home in general. There is an increase of supports required for them to get settled into their new home. The step down support model can work a treat for this situation if NDIS allows the extra funding."

"Sufficient supports is usually an issue with bad funding outcomes in the plan."

"NDIS should provide back up funds to be accessed to transition to a new home or any other unknown event that can cause distress and anxiety."

Essential Feature 12

Clarify who the participant will live with (if anyone)

- If this is another PWD, clarify whether there are opportunities for shared care

"Superfluous if funded for shared care 1:2, 1:3 etc and therefore entering SIL."

"Participant wants to live with a family member."

"If the person or the family wishes are to live on their own then this should be considered."

"A participant's inability to share their accommodation is consistently one of the most challenging criteria to satisfy for NDIA approval. Any preliminary information by way of the participant's history and details regarding reasoning for their inability (if that is the case) to share their accommodation will help expedite the process as ultimately, this is a question that can require considerable exploration."

"The level of support needed (1:1, 1:2, 1:4) is one thing; finding suitably qualified workers and staff is another."

"Transitions to other living arrangements need to be considered in plans."

"If flatmates without disability what services will they provide to the participant."

"Clarify shared goals, dreams or common interests of other residents."

"Challenge finding a person without disability to engage with an ILO with a PWD."

Determine if the contents of the new home has been organised eg. furniture, white goods, utility connection?

- If not, confirm who is organising this

"Determine who is responsible for this where there is no engaged decision-maker or family member."

"If the person or their family cannot afford to purchase household goods, where would they go for assistance?"

"Unnecessary unless NDIS plan on funding the provision of these items in clients plans.

Specific equipment required re persons disability needs definitely would be required."

"This will be difficult for people living on their own to afford. Suggest NDIS assists with furniture and whitegoods in this instance."

"This may be too far in the future for the participant to consider. i.e. if they are waiting for a property to be built."

"Part of the Plan of action."

Essential Feature 14

If participant is moving in with others

- Assist the participant to be involved in the choice of housemates
- Confirm who supported the participant in this choice
- Confirm that the housemates are identified
- Clarify who is organising connections between housemates?
- Confirm how long will it take the household to be organised
- Determine what additional assistance is required to organise this?

"Again, HUGE workload in all this. I totally understand it's so important for the participant to have a safe, happy environment to live with people that get along, there are just so many variables, i.e. whether the SDA or SIL provider is helpful with this, or the other Support Coordinators, other families etc."

"Confirm what supports, if any, the housemates will be supplying."

"Confirm steps if co-tenants break down and impact on tenancy."

"If the participant is non-verbal and does not have capacity for these decisions, what other actions have taken place to ensure supported decision-making has taken place and is this aligned with the observed and identified needs of the participant."

Identify who is setting up the house rules – needs all tenants involved.

"One experience of setting up a brand new SIL is the provider tried really hard with the families to do this, with varying degrees of success, then the landlord (family of one resident) just did what they wanted to do in the end."

"Consider risk to self and others; Choice and control; Consensus decision-making; Reasonable expectations within a household. E.g. no smoking indoors."

"All residents to be involved and support to be there to answer any queries."

"SIL providers will setting up the house rules."

Essential Feature 16

Prepare discharge plan from home and living support coordination services including check in after in place

"Not enough great SCs on the ground so may be same SC all along - needing to be a Jill of all trades in country areas. Speaking of discharge plans, does this guideline also deal with exiting hospital into new living arrangements - my experience with HLOs are they are variable, one has done nothing in 9 months."

"Why would a discharge be needed? Should not the care be overseen by an independent person to ensure services are of a high quality and complaints and feedback are dealt with in a timely manner instead of leaving a participant 'hanging' for an indefinite amount of time and to have someone assist them out of that accommodation without too many dramas if they decide they can no longer live there."

"I believe it is important to continue monitoring how a participant is settling into the new accommodation to ensure it is fully meeting a person's needs."

"Does a discharge plan already exist or is it yet to be developed?"

"Support Coordination support needs to be continued after they move to new accommodations."

Is there anything missing from the Essential Features list?

"This is a good list."

"Gathering of evidence?"

"Managing emergency housing needs that are not planned e.g. risk, Domestic Violence, early end of lease, financial issues. This immediately impacts SC budget and some guidance documents would be extremely valuable."

"No, very good, something that is long overdue."

"Consistency being required in processing of eligibility and notification of outcome of the approved SIL /SDA and levels."

"Ensuring that there is also consideration of those with complex disabilities and severe and challenging behaviours."

"There is no mention of ensuring that appropriate funding is available if client moves to a location away from informal supports or needs additional support to access activities already established (eg support to negotiate public transport etc)."

"Resources."

"Bringing out points of supported decision-making, aligning the risk assessment and documenting the safeguards or mitigating circumstances."

"Confirm who makes or influences decision-making in the person's life."

Is there anything listed in the Essential Features which you do not think is part of the role of support coordinators?

"How comprehensive this can be done depends on the abilities of the person and also the time available. The opportunity to assess every potential SIL vacancy for instance will not be funded. Requires coordination with informal supports(family for example) to assist is present, or support workers to facilitate visits also. Priorities based on essential physical requirements of home and compatibility indications with co tenants. House rules may not be necessary. A SIL provider should do this. Discharge is only if this exercise is part of planned EHO not responding to emergency, changes of circumstances for which new housing need arises, amongst other support changes."

"Often a support coordinator is not included in the process of matching co-tenants. This tends to be completed by the provider themselves or determined through family meetings."

"All the essential features could be part of the SC role but it is unlikely that funding would be made available to ensure that all of these tasks have been completed appropriately."

"Medication and PBS conversation."

"Selection of replacement COS."

"No, it is all the role of the COS."

"All were what I thought were the role of the Support coordinator."