Building a strong and effective NDIS for participants with complex housing and support needs

Summer Foundation submission to the NDIS Review

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The Summer Foundation acknowledges and thanks all staff and storytellers for their contributions to this submission.

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Executive Summary

The Summer Foundation welcomes the opportunity to contribute to the National Disability Insurance Scheme (NDIS) Review on building a strong, effective NDIS. Improving outcomes for people with disability requires the NDIS to take a lifetime approach to supporting NDIS participants (participants). Participants having choice and control over the supports that help them to achieve their goals and participate in the community improves individual health and wellbeing while positively contributing to the sustainability of the NDIS.

The NDIS seeks to ensure people with disability have the same rights and opportunities as other members of Australian society to live their lives the way they want. Individualised housing and support can make a significant contribution to improved health, wellbeing and independence for people with disability. Immediate action is required to improve National Disability Insurance Agency (NDIA) decision-making on funding for housing and supports to secure better experiences and outcomes for people with complex needs.

What does success look like?

- The needs and preferences of people with disability are at the centre of all NDIS processes and decision-making.
- Participants have the information and support they need to navigate the NDIS and access the Home and Living funding they need to live well in the community.
- Participants are able to secure appropriate housing that meets their needs and preferences. The NDIA is supporting eligible participants to access Specialist Disability Accommodation (SDA) and state and territory governments are ensuring appropriate development of accessible non-SDA housing, particularly social and public housing, for participants who are not eligible for SDA.
- Systems are in place to divert participants away from inappropriate accommodation settings including long stays in hospital, residential aged care (RAC), boarding houses and Supported Independent Living (SIL) homes.²

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² In a SIL home, a SIL provider leases a property to the participant based on their SIL funding package, Commonwealth Rent Assistance and a proportion of their Disability Support Pension. The SIL provider provides both housing and support services to the participant, with the provision of housing being conditional on the participant’s use of the support provided, limiting choice, control and agency of the participant(s).
Background

The NDIS assists participants to live independently by funding home and living supports that provide choice and control over where, how and with whom to live.

Many participants experience difficulties in accessing suitable housing and supports and have lost trust in the delivery of these services. Key concerns include:

- Accessing and navigating the NDIS is difficult, time-consuming and stressful
- Home and Living funding decisions often ignore the preferences of participants
- Unfair, inconsistent, opaque and delayed decision-making

Case Study: Suzie

Suzie is a mother, a writer and lover of the arts. She is determined to not just live an ‘ordinary life’, but hopes it will be ‘extraordinary’. Suzie has lived with an acquired brain injury for the last 25 years. Since joining the NDIS, Suzie is very grateful for the funding that allows her regular access to occupational therapists, psychologists, physiotherapists, podiatrists, and support workers.

The empowerment, choice and independence that Suzie receives via the NDIS is of great benefit. She feels such strength from the opportunity to make personal choices towards living a more independent life that NDIS has provided for her but there are things that could be improved rather than made easier.

The bureaucracy and paperwork involved with accessing the NDIS and getting supports is ‘very annoying’. This is made worse by Suzie’s memory that can make filling in long forms particularly challenging. She laments the rigid structures that sometimes limit the possible services and supports.

Suzie thinks the NDIA needs more staff who understand complex disabilities, and who are better at listening to the needs of participants. She is confident that she is the expert when it comes to her own needs and wants. Suzie knows what she needs but finds it frustrating when the NDIA staff ‘on the end of the phone’ aren’t always listening carefully. She doesn’t want to have to retell her story each time she contacts the NDIA and wants to be treated as an individual with unique needs: ‘I am a person, remember?’

Participants often experience a significant decline in health and wellbeing while they wait for needed housing and supports to be funded. Delays in NDIS decision-making contribute significantly to hospital discharge delays and admissions to RAC.

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6 Summer Foundation (2022) ‘A more inclusive and just society for people with disability’. Link [here](#).
7 La Trobe University and Summer Foundation (2022) ‘Evaluating the discharge planning process: Barriers, challenges, and facilitators of timely and effective discharge for people with disability and complex needs’. Link [here](#).
8 Summer Foundation (2021) ‘Hospital discharge of NDIS Participants with high and complex needs’. Link [here](#).
9 Summer Foundation (2022) ‘Current Scheme Implementation and Forecasting for the NDIS’. Link [here](#).
Home and Living Framework

The NDIA is co-designing a new Home and Living Framework (Framework). It is still in the development phase and has not yet been released publicly. A robust Framework should systematically ensure good outcomes for participants, improve policy and process and enable participants and their supporters to easily navigate the NDIS.

The Framework should build the NDIA’s capacity to make funding decisions that align with participant needs and preferences to ensure participants can access the right housing and supports, and avoid RAC and hospital. Home and Living funding should be flexible and tailored to the individual, giving participants choice and control over how their funding is used.

**Recommendation 1:** The NDIA must stick to its core business as a funding body and market steward, rather than getting involved in matching NDIS participants to housing vacancies. There is an inherent conflict of interest with a funding body providing an accommodation matching service or other support services to vulnerable people.

**Recommendation 2:** All participants with a Home and Living goal and complex support needs (e.g. long stay in hospital or living in RAC or boarding house) to have at least 40 hours of level 3 specialist support coordination funding included in their NDIS plan. This will ensure participants can work with an independent transition navigator to better explore and secure Home and Living supports.

**Recommendation 3:** The NDIA to build on and utilise the comprehensive resources that already exist on the Housing Hub rather than reinventing or replicating an information hub for Home and Living resources.

**Recommendation 4:** The NDIA to improve operational and decision-making processes, to build its capacity to consistently make Home and Living funding decisions that align with participants’ needs and preferences within an average of 10 days.
Specialist Disability Accommodation

Demand activation

The NDIA anticipates that approximately 30,000 participants will be eligible for SDA funding.\(^{10}\) Currently only 22,680 participants have SDA in their plans.\(^{11}\) Around 8,000 more participants are likely to be eligible for SDA funding and are yet to be identified. Further, the majority of participants with SDA funding reside in Existing or Legacy SDA\(^ {12}\) and will need information, capacity building and expert support to understand their options and receive the funding to move into New Build SDA that aligns with their needs and preferences. This calls on the NDIA to better shape demand for SDA by working with participants to determine SDA eligibility and allocating appropriate funds in plans.

Many participants who are likely to be eligible for SDA experience barriers to accessing SDA.\(^ {13}\) Participants with complex housing and support needs require skilled support from experts in disability, health and housing who can assist them to submit quality Home and Living requests and secure the housing and supports they require.

"[My son] was lucky to have [a support coordinator] do his SDA application. Knowing the process to gain SDA helped us achieve an SDA allocation."

Emma*\(^ {14}\) - Family member\(^ {15}\)

SDA funding should be used to divert participants who are in hospital awaiting discharge, or living in RAC, SIL homes and other inappropriate or insecure housing. Higher weight in decision-making must be given to the quality of life outcomes achieved as a result of living in SDA that is designed to meet the needs of the individual.\(^ {16}\)

"I moved from a group home to my own SDA apartment in 2019. This has given me more independence, privacy, dignity, peace and quiet, a place to call home, and the space I need to do my work."

Samuel* - Participant

Additionally, demand activation will likely increase utilisation of the SDA vacancies across Australia,\(^ {17}\) providing more certainty and confidence to the market.

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\(^{10}\) Senate Community Affairs Legislation Committee (2021) ‘Answer to Question on Notice, Social Services Portfolio, Additional Estimates. Question No: NDIA SQ21-000118’. Link [here](#).


\(^{12}\) Current as at 31 March 2023. See: National Disability Insurance Agency (2023) ‘SDA Enrolled dwellings and NDIS demand data’. Link [here](#). $353M annualised SDA supports in active plans and 22,680 active participants with SDA supports shows the average amount per plan is $15,564, which is significantly lower than most new build SDA dwelling types and indicates that the majority of participants with SDA funding have it in plans at Existing or Legacy levels.


\(^{14}\) Asterisks indicate pseudonyms used to maintain contributor confidentiality.


\(^{16}\) Douglas J, Winkler D, Oliver S, Lidiccoat S and D’Cruz K (2023) ‘Moving into new housing designed for people with disability: preliminary evaluation of outcomes’. Disability and Rehabilitation, 45:8, pp1370-1378. Link [here](#).

\(^{17}\) Summer Foundation (2023) ‘Improving Outcomes for Younger People in Residential Aged Care’. Link [here](#).
**Recommendation 5:** The NDIA to fund independent support and capacity building opportunities so participants can genuinely explore all housing and support options and navigate NDIS processes.

**Recommendation 6:** The NDIA to prioritise decisions for participants seeking SDA who are stuck in inappropriate settings (including hospital, RAC and SIL homes).

**Optimising the supply of SDA**

While 22,680 participants have SDA in their plans, only 13,189 are receiving SDA payments.\(^{18}\) Approximately 9,000 participants are experiencing barriers to moving into contemporary SDA, including inadequate funding and availability of suitable housing.

To ensure participants can access SDA that meets their needs, there must be an adequate supply of the right kinds of SDA in the right locations. For SDA providers to make informed decisions about the SDA they will build, they need to understand the local demand for SDA as well as the existing and pipeline of supply. As market steward, the NDIA must facilitate the provision of reliable and regular information that informs quality investment decisions aligned to the needs of participants.\(^ {19}\)

**Recommendation 7:** The NDIA to improve demand data collection and develop the systems needed to track and release data in a variety of useful formats for the market.

**Recommendation 8:** The NDIA to publish comprehensive market statements with a 3-5 year outlook, including an analysis of supply and demand data, to enable SDA investors to make decisions that are informed by the future needs and overall shape of the market.

**Supports within the home**

The funded supports within a home are just as important as the housing itself in enabling participants to live well. A participant who has SDA funding in their NDIS plan but does not have adequate funding for in-home supports (SIL, Individualised Living Options (ILO), home modifications and assistive technology) will be restricted in living well in the community.

“Getting adequate funding for adults to live in their own home and with the right and flexible supports to have as ordinary a life as possible...Life changing for the whole family as well as the participant.”

Evan* - Participant\(^ {20}\)

A participant needs housing and supports that work together to create a sustainable and secure environment. To ensure a participant’s NDIS funding best meets their needs, housing and housing supports must be considered together.

**Recommendation 9:** The NDIA to make Home and Living decisions regarding housing and supports (including SIL, ILO, home modifications and assistive technology) at the same time and work together to enable a safe and timely transition to living well in the community.

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Models of shared support

Independent living housing models achieve better outcomes for individuals as well as lower costs than group home settings.\textsuperscript{21,22} One important way to improve the cost effectiveness of the SIL model is to maximise participant independence and account for the lifelong costs and needs of participants through accessible design and collaborative care models.\textsuperscript{23,24}

On-site shared support (OSS) in co-located SDA allows participants to live alone or with family, while having supports available on-site in an emergency and at unscheduled times. A co-designed model of OSS allows individuals to build independence, privacy and control.\textsuperscript{25}

Each participant in a shared support arrangement must be funded for the supports they need. It is critical that the shared supports are sufficient to enable a provider to deliver adequately across the participants sharing supports, meeting the needs of each participant.

**Recommendation 10**: The NDIA to facilitate the development of innovative models of shared support to maximise participant independence and lower costs. This includes greater adoption of shared models of support, including OSS, which enable a combination of 1:1 and shared support, greater flexibility for participants and better value from NDIS funding.

**Recommendation 11**: The NDIA to ensure participants who share supports have the funding to access the supports they individually and collectively need.

SIL homes

SIL homes are emerging in the sector, responding to unmet demand from SIL-funded participants who have inadequate or no SDA funding. SIL homes create a closed setting where the provider can restrict and control a participant’s access to other support services, as the provision of accommodation is conditional on their use of the supports provided.

Many group homes, including SIL homes, are old semi-institutional arrangements that limit the choice and control of people with disability. The Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability has heard evidence that around 17,000 people with disability living in group homes are vulnerable to violence, abuse and neglect.\textsuperscript{26} Similarly, the NDIS Quality and Safeguards Commission has found widespread instances of complaints relating to the abuse and neglect of group home residents.\textsuperscript{27}

The NDIA must work collaboratively with state and territory governments to ensure an adequate supply of appropriate non-SDA housing so participants are not forced to live in SIL homes. Tenancy protections and separation of housing and support must be mandated to ensure participants are not subject to the control of a single provider.

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\textsuperscript{21} Summer Foundation (2019) ‘Joint Standing Committee on the NDIS Inquiry into Supported Independent Living’. Link [here](#).
\textsuperscript{22} Rathbone A, Dwyer H, Winkler D and Mulherin P (2023) ‘Reimaging shared housing and living: Workshop findings and recommendations’. Housing Hub. Link [here](#).
\textsuperscript{23} Summer Foundation (2022) ‘Supported Independent Living costs and impacts’. Link [here](#).
\textsuperscript{24} Douglas J, Winkler D, Oliver S, Liddicoat S and D’Cruz K (2023) ‘Moving into new housing designed for people with disability: preliminary evaluation of outcomes’. Disability and Rehabilitation, 45:8, pp1370-1378. Link [here](#).
\textsuperscript{26} Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability (2020) ‘Public hearing 3: The experience of living in a group home for people with disability’. Link [here](#).
\textsuperscript{27} NDIS Quality and Safeguards Commission (2023) ‘Inquiry report: Own motion inquiry into aspects of supported accommodation’. Link [here](#).
**Recommendation 12:** The NDIA and NDIS Quality and Safeguards Commission to strengthen the approach to protecting the rights of all participants in independent living options and accessible housing. This includes ensuring NDIS practice standards and tenancy protections cover all housing options available to participants.

**Recommendation 13:** The NDIA and NDIS Quality and Safeguards Commission to work together to mandate and enforce a complete separation between the provision of housing, support and support coordination services. This must include ensuring a registered provider does not provide both support and housing to a participant, including through corporate structures that involve multiple companies under the control of the same owners or directors.

**Recommendation 14:** State and territory governments to stimulate adequate supply of affordable non-SDA housing to support participants who are not eligible for SDA to move out of SIL homes and into appropriate housing.

**Residential aged care**

Supporting a younger person to understand what life could be like outside of an institutional setting requires extensive capacity building and guidance. Younger people with disability are not getting the skilled support they need to leave or avoid RAC.

> “I always thought I would live with my parents until they died or could no longer take care of me, then I would go into a nursing home. Now with the NDIS I am able to live independently for the first time in my life.”

Stacey* - Participant

Using level 3 specialist support coordination funding, every participant in and at risk of entering RAC should be supported by independent transition navigators who are experts in disability, health and housing.

The independence of the transition navigator is critical to protect against conflicts of interest that prevent participants from being able to authentically explore all housing and support options available to them. Clear boundaries between the provision of housing, supports and support coordination enable choice for people with disability and increased control over who provides support services to them. Transition navigators would work alongside participants and their existing support team to navigate the NDIS and aged care system, build their capacity, explore housing and support options and transition to living well in the community.

Data on the housing needs and preferences of younger people in residential aged care (YPIRAC) is needed to inform timely and effective responses. The evidence base from the transition navigator program would support the SDA market and state and territory governments to deliver housing that meets the current and future demand of younger people with complex needs. This would also support solutions for participants at risk of lengthy hospital admissions and other insecure housing.

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28 Summer Foundation (2021) ‘Storytellers with lived experience strengthening opportunities for people with disability to live independently’. Link [here](#).


30 Summer Foundation (2023), ‘Improving Outcomes for Younger People in Residential Aged Care’ p2-3. Link [here](#).

Recommendation 15: The NDIA to collaborate with the sector on the development and scaling of a skilled national workforce of transition navigators who can provide participants with expert, patient and independent support to build their capacity and confidence, explore housing options and make informed decisions about moving out of, or avoiding RAC.\textsuperscript{32}

The disability sector, particularly the Summer Foundation and Housing Hub, holds a great deal of expertise around housing and support options for YPIRAC and the transition and long-term support needs of the person. Active collaboration with the sector is critical for improving participant outcomes.\textsuperscript{33}

Recommendation 16: The NDIA to collaborate with the Summer Foundation, Housing Hub and the wider disability sector to support YPIRAC to navigate housing and support options and have true choice and control over where, how and with whom to live.

Medium Term Accommodation

People with complex needs can get stuck in MTA waiting on a Home and Living decision.\textsuperscript{34} To limit the need for MTA, the NDIA must ensure participants are funded to access appropriate long-term housing and supports within 10 days.

However, along with timely and accurate decisions on long-term housing and support, MTA can be part of a larger solution that supports participants to have choice and control. MTA should be used for the provision of flexible funding for medium-term, high-quality housing for participants awaiting their long-term housing solution. This will help divert participants away from hospital, RAC and other inappropriate settings.\textsuperscript{35}

Recommendation 17: The NDIA to provide MTA funding to transition participants out of, or prevent entry to RAC, where no appropriate long-term housing can be immediately found.

Home modifications

People with disability are at greater risk of being admitted to hospital or RAC if they cannot live safely at home. A sustainable approach to home modification requires a long-term view of the participant’s housing and support needs, to ensure funding for home modifications is fit-for-purpose. Most homes lack adaptability and post-build home modifications often fail to fully meet the accessibility needs of people with complex disability.

Features that make a home more adaptable to a person’s changing needs over time include step-free home entry and level access throughout the home, and wider internal corridors and doors.\textsuperscript{36} These features are easy to incorporate at the design stage of new builds but cost more and take longer to install post-build, if they are even possible.

\textsuperscript{32} Summer Foundation (2023) ‘Solving the issue of YPIRAC: Summer Foundation Pre Budget Submission’. Link \textsuperscript{here}.
\textsuperscript{33} Summer Foundation (2023) ‘Solving the issue of YPIRAC: Summer Foundation Pre Budget Submission’. Link \textsuperscript{here}.
\textsuperscript{34} Summer Foundation (2020) ‘Transitional housing and support in Australia for people with disability: Environmental scan’. Link \textsuperscript{here}.
\textsuperscript{35} Summer Foundation (2023) ‘Improving Medium Term Accommodation’. Link \textsuperscript{here}.
\textsuperscript{36} Wellecke C, D’Cruz K, Winkler D, Douglas J, Goodwin I, Davis E and Mulherin P (2022) ‘Accessible design features and home modifications to improve physical housing accessibility: A mixed-methods survey of occupational therapists’. Disability and Health Journal. Link \textsuperscript{here}.
If home modifications are unlikely to meet the participant’s long-term needs, the participant is likely to be eligible for SDA. In all cases, the NDIA should support participants to have their Home and Living needs assessed fully to negate the need for repeated requests and reduce wasted funds, also reducing costs to the NDIS. This support should include the provision of adequate funding so the participant can access quality independent support.

**Recommendation 18:** The NDIA to streamline its approach to approving home modification funding, adopting a long-term view of individual housing and support needs to ensure home modifications can meet the participant’s needs over time.

**Recommendation 19:** The NDIA to support participants to secure appropriate funding for housing and supports that will allow them to continue to live well at home. This should include testing participants’ eligibility for SDA and working with state and territory governments to ensure participant access to appropriate non-SDA housing as needed.

### Access to housing other than SDA

Participants who are not eligible for SDA are often forced to rely on public and social housing. Yet public and social housing encompasses only 6% of the Australian market and much of the existing stock is not suitably designed or well located for people with disability. Living in a built environment that is not adaptable to the needs of people with disability diminishes choice and control while increasing daily support costs. Public and social housing have few inherent drivers to foster independence and reduce support needs over time. The majority of state and territory governments have commitments to improve public and social housing but targets to ensure accessibility for people with disability are lacking.

There is a need to reimagine public and social housing to enable people with disability living in these settings to develop skills, become independent and live well. OSS in co-located SDA was developed to enable people with high support needs to be able to live in their own apartment but be co-located to enable cost-effective provision of support. These models present a significant opportunity for people with disability living in a shared/group setting to increase control over their housing and support options while lowering the overall cost of their support.

The NDIA holds data on the housing and support needs of participants who are not eligible for SDA. This should be shared with state and territory governments to enable the development of accessible non-SDA housing, particularly social and public housing. This will improve housing options and ensure accessibility for people with disability.

**Recommendation 20:** The NDIA to collate Home and Living data on participants’ housing and support needs and preferences and share this data with state and territory governments to support the growth of public and social housing stock that will meet the needs of people with complex disability.

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38 Wiesel I (2020) Living with disability in inaccessible housing: Social, health and economic impacts. University of Melbourne. Link [here](#).

Conclusion

Many people with disability depend on the NDIS to live an ordinary life. The NDIS must strengthen the rights and choices of participants and build participants’ capacity to live well in the community. The provision of NDIS supports and services must directly align with the needs and preferences of participants.

Access to appropriate housing and supports is a critical issue for many participants. The NDIA, state and territory governments and the disability sector need to work together to streamline processes and ensure good outcomes for people with disability. Shorter wait times and increased access to appropriate housing and supports will enable a greater quality of life, independence and connection to community.
About the Summer Foundation

The Summer Foundation was established in 2006 and exists to permanently stop young people with disability being forced into aged care, ensuring people with disability have access to the support required to be in control of where, how and with whom they live.

The Summer Foundation works to support people with disability who have high and complex disability support needs. It has a strong focus on supporting people with disability to access quality housing, which meets their needs and preferences, and enables them to live well in the community.

The Summer Foundation has established a number of social enterprises, including the Housing Hub and UpSkill. Capacity building of people with disability, their close others, support coordinators, allied health professionals and other key supporters is central to the work of the Summer Foundation.

The Summer Foundation works to influence, challenge and build capacity of the systems, policies and markets that need to change; to permanently eliminate the need for young people with disability to live in aged care.

We focus on unique, high impact interventions that complement the efforts of government, relevant sectors, markets and other organisations.
About the Housing Hub

The Housing Hub was created by the Summer Foundation as a pilot project in 2017 with funding from the Department of Social Services (DSS) Sector Development Fund. This online platform currently has over 3,000 listings for a range of housing including existing Specialist Disability Accommodation (SDA), new SDA builds, non-SDA supported accommodation, private rental and properties for sale.

In addition to advertising properties, the Housing Hub hosts a library of over 150 resources, runs free events every week and an NDIS Housing Advice Line to help people with disability consider housing options and plan their move. The platform is free for both housing seekers and housing providers. The Housing Hub is Australia’s leading disability housing online platform with over half a million visitors since it commenced. In the last five years the Housing Hub team supported over 950 people to find new SDA housing and seek home and living funding.

The Housing Hub is currently auspiced by the Summer Foundation. However, in 2023-24, the Housing Hub will become a separate charity and a Disabled Persons Organisation with more than 50% of board members with lived experience of disability. The Housing Hub team already has 40% of employees with lived experience of disability.