Preventing and better protecting younger people with complex needs from experiencing violence, abuse, neglect and exploitation

Summer Foundation report to the Disability Royal Commission

October 2022
Introduction

The Summer Foundation welcomes the opportunity to provide advice to the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability (DRC) regarding the experiences of people with disability that are not being adequately heard by the DRC. There are many younger people with complex needs living in inappropriate settings such as residential aged care (RAC) and hospitals. To help ensure the DRC is best placed to drive policy reform that will meaningfully improve outcomes for this cohort, this report summarises areas in need of action into 4 main categories:

1. Improved legislated timeframes for decision-making around housing and supports
2. Building the capacity of the National Disability Insurance Scheme (NDIS) to make timely and accurate funding decisions
3. Younger people with complex needs having choice and control over housing
4. Early and supported access to NDIS supports

Recent government inquiries have provided opportunities for defining and measuring progress towards essential reforms.

- The Tune Review was set up to cut red tape and improve the experiences of NDIS participants (participants). An important aim of the Tune Review was to introduce a Participant Service Guarantee (PSG) into legislation. This would clearly define, and keep the National Disability Insurance Agency (NDIA) accountable for response parameters for NDIS planning and approval processes. The recommendations for policy reform were all supported, or supported in principle, by the Federal Government.¹

- The Aged Care Royal Commission’s (ACRC) recommendations and Final Report positively support younger people with disability to live the life they want. In particular, the ACRC recommended that no young person under the age of 65 should live in RAC.² The Federal Government created the Younger People in Residential Aged Care (YPIRAC) Strategy, recognising that the aged care system is not designed for younger people.

Although progress has been made to ensure a more inclusive and just society for people with disability, not all recommendations have been appropriately implemented. More still needs to be done to improve the experiences and outcomes of younger people with complex needs. This report highlights the key recommendations that would bring about the most positive changes in the lives of younger people with complex needs.

Improved legislated time frames for decision-making around housing and supports

Impacts
A key theme that emerged during the DRC’s inquiry is that poor quality service provision puts people with disability at greater risk of violence, abuse, neglect and exploitation.³

Many people with disability depend on NDIS supports and services in order to live an ordinary life. Participants are often left with no support or they are forced to rely on others for their daily support needs, putting participants at high risk of experiencing a cycle of violence, abuse, neglect and exploitation.

“Change the requirement to continually have to prove need and tell the story of disability. The mental burden, administrative burden and time burden is immense. The uncertainty is stressful. Let a satisfactory plan continue until a change of circumstances arises.”

Alex - Participant

“Make it simpler - Stop making participants who already struggle in life have to battle a bureaucracy and system that is complex and exhausting to understand and deal with…”

Sarah - Participant

Service standards that adequately meet the needs of participants
As stated in the Tune Review, time frames in the PSG should be ambitious and consistent with best practice administrative decision-making principles, ensuring the NDIS remains accountable to the people it was designed to support.⁴ Although most of the recommended time frames were adopted by the Federal Government, these time frames do not achieve their intended purpose.

The legislated time frames do not adequately meet the needs of participants with complex needs, who are at greater risk of violence, abuse, neglect and exploitation while waiting for the NDIA to approve essential supports. For example, the NDIA has committed to finalise plan reviews within 50 days, which is far too long for participants with complex needs to be without reasonable and necessary housing and supports. In contrast, the aged care system is able to assess and provide funding for younger people with disability within 3 days in urgent circumstances (in line with Aged Care Assessment Team’s (ACAT) urgent circumstances pathway) and 10 days for many other participants.

The legislated PSG does not work as intended and as such, should be reviewed to account for the risks of long wait times for people with complex needs. Time frames for decision-making processes should be improved to ensure participants are able to access essential supports and services when they need them. This will minimise risk of being forced into precarious circumstances where they are vulnerable to violence, abuse, neglect and exploitation.

**Recommendation 1: Revision of the PSG to be co-designed and driven by participants.**

This ensures the legislated time frames for decision-making achieve best practice outcomes for participants, are achievable and do not create undue risk or harm for participants, particularly those with complex needs.

**Increased NDIA accountability to improve participant experiences**

The Tune Review recommended that the National Disability Insurance Scheme Act 2013 (Cth) be amended to reflect that an NDIS plan must be facilitated and approved in accordance with the timeframes outlined in a PSG.\(^5\) This was achieved through the enactment of the *NDIS Amendment (Participant Service Guarantee and Other Measures) Act 2022* (Cth) in early 2022.

However, not all PSG recommendations, particularly around time frames for decision-making, were adopted in the new legislation. This runs contrary to the NDIA’s own engagement principles, particularly around transparency and responsiveness.\(^6\)

**Recommendation 2: Home and Living determinations to be made within 10 days (from receipt of a complete application).**

This supports participants to leave hospital, RAC and other inappropriate and unsafe settings in a timely manner, with the housing and supports they need to live well in the community.

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Building the capacity of the NDIA to make timely and accurate funding decisions

Impacts

The DRC has acknowledged that there is a need for more capacity, training and expertise in the workforce supporting people with disability.⁷ A lack of skills and understanding about disability can increase risks of violence, abuse, neglect and exploitation.⁸,⁹ A lack of training and expertise within the NDIS can also create excessive delays in decision-making and increase the likelihood of inaccurate decisions, creating the need for reviews and appeals that contribute to further delays and risks to participants.

The NDIA must commit resources to building the capacity of its staff to consistently make funding decisions that align with participants’ needs and preferences as well as the NDIS legislation. Specialised education and training is required to ensure better outcomes for all participants, and particularly those with complex needs.

Capacity to consistently make fair decisions for participants

Requests for Home and Living supports rely on the reports and functional capacity assessments of allied health professionals (AHPs). It is important that AHPs have sufficient guidance so that their reports include the information required for the Home and Living Panel (Panel) to make an accurate decision. At present there is little publicly available guidance regarding the specific evidence needed by the Home and Living Panel to make a decision about housing and support.

In addition, it is critical that Panel staff have the clinical expertise and training required to assess these reports, understand participants' disability and support needs and make funding decisions that allow participants to live an ordinary life. This will enable the NDIA to make fair and accurate decisions about housing and support that appropriately meet the needs and preferences of participants while also aligning with the NDIS legislation.

The Tune Review proposed engagement principles and service standards to measure success under the PSG. These include ensuring “staff have a high level of training in disability, including psychosocial disability and other complex conditions, and understand the impact of disability on people’s lives.”¹⁰ These engagement principles and service standards were incorporated into the Participant Service Charter, which forms part of the PSG. Although the NDIA has committed to making sure its staff are “trained to understand the impact of different disabilities on people’s lives”,¹¹ Home and Living Panel staff do not any specialised training for their role on the Panel.¹² Instead, the Panel is composed of staff who are generally more senior than those making other planning decisions.¹³

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¹² Public Interest Advocacy Centre and Housing Hub (2022) ‘Housing Delayed and Denied: NDIA Decision-Making on Specialist Disability Accommodation Funding’ p16. Link here.
Recommendation 3: The NDIA to provide specialised training to NDIS planners and Home and Living Panel staff to improve their capacity to make timely and accurate funding decisions.

This should involve training on the NDIS legislation and how to use the evidence provided by participants, and their needs and preferences, to make appropriate decisions. This will help reduce administrative errors and cases progressing through internal and external review processes.

Recommendation 4: The Home and Living Panel to be made up of expert skill sets, including AHPs.

This will ensure there is better clinical understanding within the Panel of participants’ disabilities, support needs and the evidence provided.

NDIA commitments to increase its capacity to support participants

The NDIA recently committed to increasing the number of Home and Living Panels and the number of Panel staff to process requests, to improve overall timeframes for Home and Living decisions. However, increasing numbers will not adequately improve the capacity and consistency of the Home and Living Panel if staff do not have the skills and experience needed to make complex funding decisions in a timely and accurate way. Decisions that do not reflect participants' needs and preferences, or the NDIS legislation, may still be made. This puts participants at risk of harm and increases risks of complaints, reviews and appeals.

Recommendation 5: Administrative and procedural measures to be adopted to improve the quality and consistency of the evidence submitted by participants.

- The provision of written advice or guidelines regarding the specific evidence needed for a timely Home and Living decision, targeted towards different stakeholders including participants, support coordinators and AHPs
- The development of template reports, which clearly outline the legislated eligibility criteria and word limits to assist AHPs to provide more concise and rigorous reports for the Home and Living Panel
- Specialised NDIS/Home and Living training for AHPs completing evidence.

Younger people with complex needs having choice and control over housing

Impacts

The DRC has recognised that Australia has a lack of accessible and safe housing for people with disability. This can force people with disability to live in congregate living arrangements that deny them the right to choose where, how and with whom they live. Many younger people with complex needs are being forced into institutional settings including RAC, or are stuck in hospital because of significant challenges and delays in accessing individualised housing and supports in the community.

Empowering people with disability to have control over their housing and supports is a critical safeguard against violence, abuse, neglect and exploitation. A person's home should be one they have chosen for themselves, and it should make them feel safe, secure, and supported.

“I've got the freedom to do what I want. It's amazing to have my own choice now. We take for granted the freedom to choose, it was very confronting to have that taken away in the nursing home.”

Hayley - Participant

“Everyone is different. It's about drawing out what the individual needs and wants.”

Emma - Family member

Recommendation 6: Widespread awareness and understanding of appropriate housing options for younger people with disability, focussing on independent community living.

Coordinated service offerings that offer capacity building and independent community living need to be better understood and offered to younger people currently in, and at risk of entering, RAC. Younger people with complex needs must be supported to fully consider and explore these options before being referred to an ACAT.

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Recommendation 7: The NDIA, and all levels of government, to fund co-designed, peer-led information for younger people with complex needs.

This will ensure information about rights and options for housing and support is easy to access and navigate.

SDA approvals and a diverse SDA market

In order for people with disability to have choice and control over their housing, they must be informed of and able to access all housing that meets their needs, which can include SDA or private, public or social housing. The NDIA anticipates that approximately 30,000 participants will be eligible for SDA funding. However, only 19,358 participants currently have SDA in their plans and 11,405 participants are receiving SDA payments. Additionally, approximately 70% of SDA is Legacy or Old Stock which will soon expire as SDA or no longer be fit for purpose. This suggests that the NDIA’s market stewardship function to activate demand for SDA is lagging considerably.

Demand activation is made possible by ensuring participants have the right funding for housing and support to meet their needs and preferences. This in turn, is essential for informing the market about the housing that is needed into the long term, enabling the right housing to be built in the right location, at the right SDA level and with the right features to meet the needs of participants. The Summer Foundation’s SDA Investor Think Tank identified a lack of demand activation and demand data as a significant barrier to a thriving SDA market. It identified the need for a forecast of total expected demand for SDA, including housing types and design categories. This will ensure housing is fit for purpose, sustainable in the long term and provides for choice and control for participants over their housing and support.

To ensure SDA-eligible participants are able to secure the right housing as soon as their SDA funding is granted, there needs to be an adequate supply of the right kind of SDA in participants’ desired location. Supply of SDA is growing across all states and territories; however, it does not always align with participant preferences and a number of thin markets do exist. Critically, the NDIA needs to collect real data on housing needs and preferences of NDIS participants as part of their demand activation strategy.

Recommendation 8: The NDIA to release a quarterly demand activation SDA Market Statement to provide guidance that supports informed decision-making by market players.

These statements should provide an analysis of recent market activity, and demand data including the number of current and future SDA tenants and what types of SDA match their needs (including the SDA's housing type, design category and location) and information on anticipated future market conditions. To be most effective this market outlook would offer commentary on consistent themes with a medium-term outlook (i.e. 3+ years).

Recommendation 9: The NDIA to develop and publish an annual national plan for SDA that sets out priority locations and proposed responses to thin or underdeveloped markets.

This should be a companion piece to the SDA Market Statements, to improve market engagement and signalling.

Residential aged care

Aged care is, by definition, not an appropriate setting for younger people to live. However, false perceptions continue to be held that RAC is an appropriate option for younger people with disability to live. It is not often understood that the needs and preferences of younger people with complex needs can be better met outside of RAC.

“The problem isn't really the staff. The problem is that young people should not be put in nursing homes. They're built for old people, not young people.”

Nick - Participant

Amendments to Aged Care Assessment Guidelines made in 2021 provide safeguards to prevent younger people from unnecessarily entering RAC. All identified participants must first be referred to the NDIA YPIRAC Planners and Accommodation Team for support and guidance to explore alternative accommodation. This has significantly improved hospital discharge planning processes for participants with complex needs, who are now less likely to be referred to an ACAT before all appropriate housing options have been properly explored.
In 2021, the Federal Government invested more than $10 million to create a national network of System Coordinators to help YPIRAC find age-appropriate housing and support. An additional $16 million was invested in late 2021. System Coordinators work with YPIRAC who are not participants. However, younger people who are not participants continue to be admitted to RAC:

- Younger people requiring palliative care services are often referred to RAC where their support needs cannot be met at home. This is despite the existence of supports and services that are appropriate to their age and palliative care needs.
- Younger people with complex needs who are not Australian residents are at an increased risk of entering RAC because of their ineligibility for the NDIS and other support services. Without dedicated support and interventions, they will continue to be bounced between the health, disability and aged care systems.

**Recommendation 10: All levels of government to work together to establish a package of wrap-around supports for younger people with complex needs who are not Australian residents, to address all of their housing and support needs and eliminate risks of entering RAC.**

It is critical that the housing and support needs of non-residents are properly understood and addressed. Without dedicated support and interventions, they will continue to be bounced between the health, disability and aged care systems.
Early and supported access to NDIS supports

Impacts

The DRC has acknowledged that people with disability face challenges in accessing the NDIS. While the NDIS is designed to facilitate inclusion, people with disability are required to submit to ‘rigorous application processes’, which further contributes to their exclusion from society.\(^\text{24}\) Research has found that NDIS bureaucracy can be so challenging that it deters participants from even asking for supports to which they are entitled.\(^\text{25}\)

The DRC has also heard from various sources that better coordination of care for patients with complex needs is required to fix the currently fractured health system.\(^\text{26,27}\) This involves sufficient levels of expertise and training for those providing support to people with disability within these settings. Early and supported access to the NDIS will drastically improve outcomes for people with disability, reducing risks of neglect when needed supports and services are not provided.

“I am very grateful for the NDIS and what it does. Although it is working well for me personally, I am appalled at how complex, time-consuming and sophisticated I had to be to get what I have.”

James - Participant

“The funding has been difficult to continue to fight for each year, having to prove lifelong disability that will never improve. However the funds received and the flexibility of using the funds has been so important…”

Susan - Participant

Measures to simplify the hospital discharge process

Minister for the NDIS, the Hon Bill Shorten MP, recently announced the Hospital Discharge Operational Plan, which requires the NDIA to contact a participant within 4 days of being made aware that they are medically ready for discharge, and to have a plan in place within 15-30 days.\(^\text{28}\) To be successful, the Operational Plan must ensure participants are funded for long-term housing and support that meets their needs and preferences and must receive adequate funding and support to transition to appropriate long-term housing. In addition, health and NDIS responsibilities must be clear, discharge planning must be effectively coordinated and the accompanying reporting framework must be transparent and robust.


\(^\text{25}\) Olney S, Mills A & Fallon L (2022) ‘The Tier 2 tipping point: access to support for working-age Australians with disability without individual NDIS funding’ Melbourne Disability Institute, University of Melbourne. Link here.


\(^\text{28}\) The Hon Bill Shorten MP, Media Release 14 September 2022. Link here.
Granting automatic NDIS eligibility status for younger people who are admitted to hospital with a severe acquired disability will improve efficiency and reduce unnecessary delays in the current discharge process. State health systems and the NDIS need to work together to understand the permanent and significant disabilities that would warrant eligibility for the NDIS, identify the people who are admitted to hospital with these disabilities and grant automatic NDIS eligibility status and an NDIS plan to allow for a supported discharge process when medically ready.

“They need to have a fast track possible for people who have had a catastrophic accident happen to them…Once you start thinking about that NDIS support, I start to think maybe other things are possible too.”

Nicole - Family member

In all cases, the NDIA should grant funding as soon as NDIS eligibility has been confirmed. Participants should be funded adequately, through early planning processes, so they can access urgent supports that will enable a more timely discharge from hospital.

These measures will allow the planning process for participants' housing and support needs to begin immediately, reducing the number of unnecessary days in hospital as well as the stress of going through a 'rigorous application process'.

**Recommendation 11: Grant automatic NDIS eligibility status for younger people who are admitted to hospital with a severe acquired disability.**

Make early eligibility decisions and allocate interim NDIS participant status, which would allow for a 6 or 12 month NDIS plan that funds specialised discharge and transitional planning supports. State and territory governments and the NDIA to work together to determine criteria, identify and support eligible participants to access NDIS funding.

**Recommendation 12: The NDIA to determine NDIS eligibility and approve initial plans with flexible funding to accommodate rehabilitation needs and home and living supports, in the one process.**

The NDIA and state governments will need a transparent process to allocate costs to the appropriate health or NDIS funding source. This should not impact participants' discharge from hospital or adjustment to disability and health needs.
YPIRAC Planners

In late 2021, the NDIA implemented YPIRAC Planners to deliver specialist planning for participants who are in or at risk of entering RAC. YPIRAC Planners should work closely with participants and close others to develop their NDIS plan to support achievement of the participant’s goals, including exploring and transitioning to alternative housing.

However, most often younger people are not adequately supported by YPIRAC Planners to understand the different housing and support options that are available to them. The NDIA has stated that it supports YPIRAC to remain living in RAC unless they have expressed an intention to leave. As at 30 June 2022, only 652 participants in RAC (25%) had a goal to leave aged care. More younger people have entered RAC in the last 6 weeks than those who moved out of RAC into appropriate accommodation such as SDA, in the 2021/22 financial year. This suggests that there is a lack of a proactive and committed approach within the NDIA to supporting participants to consider a life outside of RAC.

Specialist Support Coordination

Every participant who has been identified as being in or at risk of RAC (e.g. currently living in hospital or other inappropriate settings) should have Specialist Support Coordination funding included in their NDIS plans. This will enable them to explore and request the Home and Living supports they require. Though 652 participants in RAC have a goal to leave, only 38 moved last year which demonstrates a significant gap in the workforce of Specialist Support Coordinators who are skilled in navigating home and living supports and identifying housing options which meet the needs and preferences of participants.

It is essential that these Specialist Support Coordinators are trained in Home and Living supports and processes. Without the appropriate skills and experience required to submit quality Home and Living requests, participants may not get access the housing and supports they need to live well in the community.

Participants who are exploring housing options require Specialist Support Coordination with skills targeted towards housing and living independently. The NDIS provides for Specialist Support Coordination (Level 3); however, getting the required hours funded to explore housing can be difficult for a participant. Even when the right funding is provided, accessing a Specialist Support Coordinator who is skilled in housing is challenging. Many support coordinators are unskilled in this space so are unable to adequately support participants.

“Young people don’t really need to go into a nursing home if you’ve got the funding. When this first happened we didn’t know what to do, there was no one there. There needs to be more support for young people in hospital and for families to make decisions.”

Robert - Family member

Recommendation 13: The NDIA to fund at least 40 hours of Level 3 Specialist Support Coordination for all participants in or at risk of RAC or stuck in hospital

Specialist Support Coordinators must work alongside YPIRAC Planners, Health Liaison Officers (HLOs), hospital teams and other supporters (including generalist support coordinators) to build participants’ capacity to explore the housing options that will adequately meet their needs and assist participants to submit Home and Living applications.
About the Summer Foundation

The Summer Foundation was established in 2006 and exists to permanently stop young people with disability from being forced into residential aged care (RAC), 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 a central feature of 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 RAC.

We focus on unique, high impact interventions that complement the efforts of government, relevant sectors, markets and other organisations. We use a range of tools including:

| EVIDENCE BASE | Our research informs the development and evaluation of potential solutions, resources and tools. |
| EXPERT KNOWLEDGE FROM LIVED EXPERIENCE | We build on the expert knowledge from those with lived experience of the issue of young people in aged care to inform, co-design and evaluate our resources, tools and interventions. |
| KNOWLEDGE OF GOVERNMENT AGENDA AND DRIVERS | We leverage our knowledge of government drivers to establish best practice policy, to facilitate understanding and implementation of policy and inform government agenda. |
| CLINICAL EXPERIENCE | We use clinical experience that tells us what is happening on the ground to develop and share resources and tools designed to build the capacity of the system and market users. |
| DEMONSTRATION PROJECTS OR SOCIAL ENTERPRISES | We design, test, evaluate and improve potential solutions and market interventions to develop social enterprises. |