



# A more inclusive and just society for people with disability

Summer Foundation submission to the  
Disability Royal Commission

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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 make a submission to the Disability Royal Commission (DRC). It is crucial that outcomes of the DRC ensure a more inclusive and just society for all people with disability.

The National Disability Insurance Scheme (NDIS, Scheme) empowers people with disability to live an ordinary life, contributing to Australia's human rights obligations under the [United Nations Convention on the Rights of Persons with Disabilities](#) (UNCRPD). Although there has been positive momentum since the Scheme was created, many people with disability continue to lack many of the rights espoused by the UNCRPD.

The NDIS, health, housing and aged care systems work against younger people with high and complex needs. System inefficiencies have resulted in slow and inaccurate decision-making and NDIS participants (participants) having limited to no choice and control over their supports. This removes their sense of security, safety and independence, placing them at greater risk of experiencing a cycle of violence, abuse, neglect and exploitation.<sup>1</sup>

The Summer Foundation is confident the recommendations in this submission will ensure the National Disability Insurance Agency (NDIA, Agency) and all levels of government are positioned to:

- Prevent and better protect people with disability from experiencing violence, abuse, neglect and exploitation
- Achieve best practice in reporting, investigating and responding to violence, abuse, neglect and exploitation of people with disability
- Promote a more inclusive society that supports people with disability to be independent and live free from violence, abuse, neglect and exploitation

**Recommendation 1:** The DRC's inquiry and Final Report must be informed by the diverse experiences of younger people with high and complex needs to ensure the final recommendations to the Federal Government and resulting policy reforms improve outcomes for this cohort.

**Recommendation 2:** The DRC must instruct and hold the NDIA to account to make timely and accurate decisions on Specialist Disability Accommodation (SDA) funding and housing related supports for eligible participants.

**Recommendation 3:** The DRC must require the NDIA to apply the NDIS legislation in a fair and consistent manner, ensuring appropriate weight is assigned to participants' goals and aspirations when making funding decisions that provide participants with the help they need to pursue these goals and aspirations.

**Recommendation 4:** The DRC must require the NDIA to undertake a demand activation campaign to support awareness among likely SDA-eligible participants, and build the capacity of participants to make informed decisions about their housing options (SDA or other).

**Recommendation 5:** The DRC must facilitate greater innovation in SDA by ensuring the NDIA fosters the development of innovative models of housing and support that are driven by the needs, preferences and a rigorous evidence base about the outcomes of tenants.

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<sup>1</sup> Centre for Evidence and Implementation and Monash University (2021) 'Rapid Evidence Review: Violence, abuse, neglect and exploitation of people with disability'. Link [here](#).

**Recommendation 6:** The DRC must require the NDIA to provide accessible information and guidance regarding participant rights, especially those under the SDA Rules, and make timely and accurate funding decisions that enable and support participants to live in SDA with their families, friends or close others.

**Recommendation 7:** The DRC must ensure state and territory governments deliver disability and social housing strategies that meet the needs of people with disability in their respective state or territory.

**Recommendation 8:** The DRC must require that housing for people with disability is person-centred and structured to meet individual needs, resulting in group homes being redeveloped and reconfigured.

**Recommendation 9:** The DRC must require the NDIA, NDIS Quality and Safeguards Commission (NDIS Commission) and state and territory governments to apply a consistent approach to protecting the rights of all participants who need independent living options and specialised housing. This includes working together to transition participants out of Supported Independent Living (SIL) homes and into SDA or other appropriate housing.

**Recommendation 10:** The DRC must require greater collaboration between the Federal and state and territory governments to improve hospital discharge and safely support participants out of hospital and into appropriate housing.

**Recommendation 11:** The DRC must require the NDIA to work more closely with the sector and all levels of government to address the barriers that disempower younger people in residential aged care (YPIRAC) from establishing a life outside of aged care, and create individualised solutions that allow them to safely adjust to community living in their own time.

**Recommendation 12:** The DRC must require alignment between state residential tenancy legislation and the NDIS Rules and policies to ensure people with disability have the same housing rights and protections as other Australians, regardless of their housing arrangement.

**Recommendation 13:** The DRC must require the NDIS Commission to mandate and enforce a complete separation between the provision of housing and supports.

**Recommendation 14:** The DRC must require the NDIA and Federal Government to build a responsive and capable workforce that provides high quality services for people with disability.

**Recommendation 15:** The DRC must recommend that the NDIS Commission requires all registered and unregistered NDIS providers to undergo appropriate safety screening as a condition of employment.

**Recommendation 16:** The DRC must require the NDIA and all levels of government to fund co-designed, peer-led information for participants to ensure information about their rights and options for support is easy to access and navigate.

**Recommendation 17:** The DRC must require the NDIA, all levels of government and the disability sector to work together to make de-identified data available for independent analysis via the National Disability Data Asset (NDDA), to enable a thorough and system-wide approach to understanding disability in Australia.

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## Introduction

Violence, abuse, neglect and exploitation against younger people with disability who have high and complex needs encompasses a range of behaviours. It often takes the form of limiting or controlling daily activities and a lack of support to engage in their own lives. They are often forced to rely on others to provide their daily needs, which means other people hold power and control over how they can live. They are at a heightened risk of being isolated from loved ones and denied opportunities and support to live well in society.

Key drivers of violence, abuse, neglect and exploitation experienced by this cohort include, but are not limited to:

- Reliance on funding for services and supports
- Reliance on personal care and support from those who could take advantage
- Inadequate or inappropriate care in institutional or group settings
- Barriers and delays to accessing supports
- Inability, or limited ability, to leave situations or make changes
- Inappropriate or insecure housing
- Social isolation and segregation
- Communication barriers and lack of access to information in accessible formats

Efficient and reliable support systems have a profound effect on the health and wellbeing of people with disability. Measures that have been developed with the purpose of increasing individual capacity protect people with disability against violence, abuse, neglect and exploitation. Facilitating social inclusion and independence in daily life helps keep them safe.

# What are the issues?

## Lack of choice and control

### Housing options

People with disability who live in institutional settings, segregated from the wider community, are given limited choice and control over how they live their day-to-day lives. This is a profoundly negative experience that impacts on their health and wellbeing. Being unable to live in the community perpetuates isolation and neglect, which often results in the loss of functionality and difficulty regaining independence and the capacity for self-determination.

Disability housing policy has moved away from traditional institutional settings towards individualised housing options, recognising that the home is important for promoting quality of life.<sup>2</sup> While this move is largely positive, system inefficiencies in the provision of housing and supports have meant young people with disability are still being forced into housing options that emulate institutional culture and practices. They are therefore still at an increased risk of violence, abuse, neglect and exploitation. These housing options are explored in more detail below.

#### **Case Study: Jack\***

In May 2008, Jack moved into shared support accommodation with other people with disability. His support workers are shared and based on a rotational roster.

Jack feels like he doesn't have control over how he gets his supports. Even if he has a plan and staff know about it, it may not work that way because it may not fit in with others.

*"I do have a life. I had my physiotherapy session and once the session ended, I was left on my bed for 2 hours until a support worker came. This is not ideal. I actually had something to do and they didn't respect it."*

Jack would like to have more choice and control over his life. He wants to live more independently with his partner Melissa\*, who is also a resident, but he doesn't know of other forms of disability housing. He doesn't want to rock the boat for fear of losing the support he's currently being given, and he is scared to ask about other options.

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<sup>2</sup> Summer Foundation (2021) 'Closed setting SIL Homes Policy Position Statement'. Link [here](#).

## Group homes

Group homes are associated with poor outcomes for people with disability.<sup>3</sup> From 1 July to 31 December 2021, 15.6% of accounts of violence, abuse, neglect and exploitation occurred in group homes. The lack of choice and control for people with disability around where they live, who they live with and who provides their support is a central concern.<sup>4</sup> In group homes, schedules are often set, which restricts choices around daily living and community access.

*“We really feel like second class citizens living here. There are all these systems and supposed changes but I don’t think these will bring any improvements to my life because they don’t understand what life is like for people with disability.”*

**Jack - Participant**

## Specialist Disability Accommodation (SDA)

SDA is accommodation funded through the National Disability Insurance Scheme (NDIS, Scheme) for long-term, accessible housing for participants with extreme functional impairment and very high support needs. It was developed to move away from institutional housing settings and designed to encourage investment and growth in individualised housing options for the 6% of NDIS participants (participants) with the greatest needs.

Participants who are eligible for SDA often also receive funding for Supported Independent Living (SIL), which is a separate but related home and living support that provides help and/or supervision to a participant to undertake daily living tasks. Separate funding and delivery of SDA and SIL gives participants the flexibility to reside in housing that is suited to their needs while receiving day-to-day support services of their choice. This enables a change to SIL supports without having to move home.

### *SDA decisions and participants’ needs*

The National Disability Insurance Agency (NDIA, Agency) determines participants’ eligibility for SDA. It allocates funds that align to an SDA type that meets the participant’s needs and preferences and the Agency’s responsibilities under the [NDIS legislation](#). In what appears to be a move to control SIL costs, the Agency is restricting the eligibility and entitlements of participants looking to move into SDA.<sup>5</sup> As a result, many participants are being forced to share their homes and supports with other people with disability they do not know. Yet, data shows that shared SDA and supports do not necessarily represent value for money to the NDIS<sup>6</sup> and for some participants, shared living arrangements often lead to distress, and violence and abuse between residents (encompassing physical assault, verbal abuse and sexual assault),<sup>7</sup> further limiting their ability to live an ordinary life.

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<sup>3</sup> Disability Royal Commission (2020) ‘Overview of responses to Group homes Issues paper’. Link [here](#).

<sup>4</sup> Disability Royal Commission (2022) ‘Fifth Progress Report’. Link [here](#).

<sup>5</sup> Summer Foundation (2021) ‘Moving into new housing designed for people with disability: Evaluation of tenant outcomes’. Link [here](#).

<sup>6</sup> Senate Community Affairs Legislation Committee (2022) ‘Answer to Question on Notice, Social Services Portfolio, Additional Estimates. Question No: NDIA SQ22-000021’ Link [here](#).

<sup>7</sup> Disability Royal Commission (2020) ‘Overview of responses to Group homes Issues paper’. Link [here](#).

There is an increasing trend of SDA determinations that do not align with the needs and preferences of participants or the NDIS legislation. This has led to increased numbers of participant appeals to the Administrative Appeals Tribunal (AAT). Recent analysis highlights that 92% of participants receiving the determination they had originally requested,<sup>8</sup> suggesting that the majority of NDIA Home and Living decisions are fundamentally incorrect.

#### *SDA provider compliance management*

The regulatory environment for SDA is complex and highly dynamic. It encompasses the [NDIS Rules](#) and policies covered in the [SDA Practice Standards](#) and [SDA Pricing Arrangement](#). Compliance management is challenging for SDA providers given the significant variability and unclear interface between these instruments. Further complexity arises as SDA providers' obligations also encompass residential tenancy law, which differs between states and is not aligned with the NDIS Rules or policies.

Research conducted through the Summer Foundation's [Welcome Home](#) project has identified significant confusion among SDA providers regarding their tenancy management responsibilities, including the obligation to manage conflicts, complaints and other serious incidents in an SDA household. This is particularly concerning in light of evidence that poor tenancy management across the disability sector creates ongoing risks for tenants by contributing to unresponsive and unsafe living environments.<sup>9</sup>

#### **Supported Independent Living (SIL) homes**

SIL homes are emerging in the sector, responding to an unmet demand from participants who have SIL but do not have adequate or any SDA funding. In a SIL home, participants are offered housing and support based on their SIL funding package, Commonwealth Rent Assistance and a proportion of their Disability Support Pension.

SIL homes are not held to the same regulatory standards as SDA, with responsibilities falling under the [NDIS Practice Standards and Quality Indicators](#) alone. This results in reduced compliance obligations and associated oversight by the NDIS Quality and Safeguards Commission (NDIS Commission). This effectively leaves SIL home providers to self-regulate their tenancy management practices.

The Summer Foundation's [policy position statement on closed setting SIL homes](#) highlights that 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 support provided. Participants are often too scared, unable to or ignored if they do make a complaint about the housing or support and they are often unable to have additional support services in the home. They are at greater risk of abuse or neglect because 1 provider handles the majority or entirety of their supports.

#### **Lack of separation of housing and support**

Housing, supports and tenancy/property management are 3 or more separate services; however, they can be delivered by 1 provider. Participants who are supported by only 1 service provider often have limited support networks and avenues to raise concern.

The Summer Foundation's [submission to the Joint Standing Committee on the NDIS' inquiry into the NDIS Commission](#) discusses how the NDIS Commission has mandated the

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<sup>8</sup> Public Interest Advocacy Centre and Housing Hub (2022) 'Housing Delayed and Denied: NDIA Decision-Making on Specialist Disability Accommodation Funding'. Link [here](#).

<sup>9</sup> Disability Royal Commission (2020) 'Interim Report'. Link [here](#).



separation of housing and supports yet does not enforce it. This puts participants at an increased risk of violence, abuse, neglect and exploitation because a single provider is able to be in control of all facets of the participant's life and take advantage of the fact that the participant has few options for changing providers or how support is given to them.<sup>10</sup>

### **Social, public and private housing**

The Summer Foundation has conducted extensive research on the housing needs of people with disability living in social, public and private housing. Current housing stock already fails to meet the needs of Australians with disability and demand for accessible housing is anticipated to almost double over the next 40 years.<sup>11</sup> More than a decade ago, the building industry committed to uphold voluntary accessibility standards set by the [Livable Housing Design Guidelines](#) (LHDG) to ensure all new housing being accessible by 2020. But only 5% of new home builds achieved this. Most homes lack adaptability and post-construction home modifications fail to fully meet the accessibility needs of people with disability, especially those with mobility limitations.

Accepting that a voluntary code for accessible housing does not work, most states and territories have agreed to the inclusion of mandatory minimum accessibility standards in the new [National Construction Code](#) (NCC), which are in line with the Silver level standard specified in the LHDG. But these provisions are yet to be implemented and homes constructed to this standard will not be accessible for people with high and complex needs. People who are dependent on accessibility at the Gold or Platinum level require wider internal spaces and a shower and bedroom on the ground floor, among other improvements.

*"My house is not really accessible for me. But it's just going to have to do because I can't get home modifications done. My kitchen is down a step and for the last few years I haven't been able to get to my kitchen independently."*

Angela\* - Participant

### **Residential aged care (RAC)**

#### *Inadequate quality of care for younger people with disability*

A younger person with complex disability needs highly specialised support, which is vastly different to that of an older person needing end-of-life care. Inappropriately placing younger people with disability into RAC forces them into isolation and inhibits their capacity for independence and community participation. Younger people in residential aged care (YPIRAC) often have their needs neglected because RAC staff lack the capacity, knowledge and training required to provide proper care to younger people with disability.<sup>12</sup> Their quality of life declines as RAC facilities are fundamentally not designed to support younger people with disability who require continued social and emotional support, community participation and development.<sup>13</sup>

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<sup>10</sup> Disability Royal Commission (2020) 'Overview of responses to Group homes Issues paper'. Link [here](#).

<sup>11</sup> 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*, 15 February 2022. Link [here](#).

<sup>12</sup> Oliver S, Gosden-Kaye EZ, Jarman H, Winkler D and Douglas J (2020) 'A scoping review to explore the experiences and outcomes of younger people with disabilities in residential aged care facilities'. *Brain Injury* vol 34(11), 8 September 2020. Link [here](#).

<sup>13</sup> Winkler D, Farnworth L and Sloan S (2006) 'People under 60 living in aged care facilities in Victoria'. *Australian Health Review* vol 30(1) 100-108. Link [here](#).

Younger people with disability are often told that aged care is the only suitable place for them to live given their support needs, despite other suitable housing options being available to them. It is not the lack of appropriate housing options that forces or keeps younger people in RAC, but the lack of access to, and information about, these options. YPIRAC are provided with limited information about alternative models of housing and support and minimal guidance to navigate and explore these options. As a result, they are trapped in isolation in an institutional setting that has lasting negative impacts on health and wellbeing.

*“It’s hell in here – every day is the same. Every day I am isolated in my room, left there by staff. There are people dying all around me. It feels like God’s waiting room. It’s very confronting.”*

*“I have fallen out of bed and waited for people to find me. The staff don’t clean me properly. I had to fight to have a shower every second day. Before, I was only having a shower once a week if I was lucky.”*

**Lisa\* - Participant**

#### *Dual regulatory obligations for RAC providers*

In 2020, RAC providers delivering services to participants automatically became registered NDIS providers to enforce compliance with the NDIS legislation at the same level as registered providers in other settings.<sup>14</sup> Recognising that participants living in RAC are dual participants of the NDIS and aged care systems, RAC providers are subject to the regulation of the Aged Care Quality and Safety Commission and the NDIS Commission. Although this change was implemented to ensure all participants have access to the same level of safeguarding no matter where they live, many RAC providers have found the additional regulatory burden to hinder their already limited capacity to deliver care.

Most RAC providers do their best within the operational constraints of the system, but enabling younger people to continue to live in institutional settings cannot continue. RAC staff have little skill or opportunity to provide individualised supports to people with disability, in addition to their core service.

#### *Inadequate strategies to transition younger people out of RAC*

The Federal Government’s [Younger People in Residential Aged Care \(YPIRAC\) Strategy](#) aims to address the systemic issues and barriers that continue to allow younger people to enter and remain in RAC. The YPIRAC Strategy acknowledges that:

1. The aged care system is unable to meet the basic human needs of younger people with disability
2. Age-appropriate housing options are available to younger people with disability, and they therefore need not live in RAC

RAC being a housing option for younger people with disability is, by nature, a barrier to achieving the YPIRAC Strategy<sup>15</sup> and to younger people living an ordinary life. Many YPIRAC become lost within the system, decreasing their chances of ever leaving.<sup>16</sup> The number of YPIRAC is falling, but mostly not for the right reasons because the drop is mainly

<sup>14</sup> NDIS Quality and Safeguards Commission (2021) ‘NDIS participants in residential aged care.’ Link [here](#).

<sup>15</sup> Royal Commission into Aged Care Quality and Safety (2019) ‘Interim Report: Neglect (Vol. 1)’ p246. Link [here](#).

<sup>16</sup> Winkler, D. (2020) ‘YPIRAC is a wicked problem that can only be solved by working across sectors’. ProBono Australia, 21 October 2020. Link [here](#).

attributed to younger people dying in RAC or ‘ageing out’ of the cohort when they turn 65 years old, meaning they are no longer counted.<sup>17</sup> Natural attrition is not an acceptable way for the Federal Government to meet its targets under the YPIRAC Strategy. A more strategic and collaborative approach is required to achieve good outcomes for younger people with disability currently in, and at risk of entering RAC.

*“Young people with disability do not belong in [RAC] where there is an element of neglect and abuse. More needs to be done to give us the opportunity to live the independent life that able-bodied people take for granted.”*

**Bonnie\* - Participant**

All participants currently living in RAC require NDIS funding for housing and support to safely leave RAC but there are significant delays to this occurring. Only 30 YPIRAC exited into SDA in 2021, while 65 moved into SIL homes, 38 moved to other group residential settings and 66 moved to unknown destinations.<sup>18</sup> Despite SDA being the best housing destination to safely transition participants out of RAC, the majority of participants are exiting RAC into other settings that pose unacceptable risks, some of which could be greater than those in RAC.

It is unacceptable that people with disability are forced to live in institutional settings where by design, they lose independence, capacity and access to loved ones and the community. Younger people with high and complex needs must be better supported to access housing that allows them to live independently in the community. RAC should never be an option.

### Cuts in plan funding

The Agency’s planning decisions predominantly revolve around [value for money](#) considerations to ensure financial sustainability of the Scheme. But recently this has resulted in cuts to participants’ plans despite supports being reasonable and necessary.<sup>19</sup> This prevents people with disability from exercising choice and control in the management of their supports, a fundamental principle under which the NDIS was created.<sup>20</sup>

The Agency states that reasonable and necessary supports should help participants to pursue their goals, increase their independence, increase community and workplace participation and develop their capacity to actively take part in the community.<sup>21</sup> But participants are not able to pursue their goals if their plan funding does not provide for the supports they need. As a result, independence, community engagement, capacity and dignity are lost.

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<sup>17</sup> Winkler D and Mulherin P (2022) ‘Younger people in aged care is a problem: will the government keep its stated commitment?’ Pro Bono Australia, 4 May 2022. Link [here](#).

<sup>18</sup> Senate Community Affairs Legislation Committee (2022) ‘Answer to Question on Notice, Social Services Portfolio, Additional Estimates. Question No: NDIA SQ22-000011’ Link [here](#).

<sup>19</sup> The NDIA denies ongoing cuts to funding, but it reduced participants’ plan funding by nearly 4% in 2021. The average plan budget for SIL also fell by 1.6% during this time. See: Senate Community Affairs Legislation Committee (2022) ‘Senate Estimates - Additional Estimates, 17 February 2022’. Link [here](#).

<sup>20</sup> [National Disability Insurance Scheme Act 2013 \(Cth\)](#) and [National Disability Insurance Scheme \(Support for Participants\) Rules 2013 \(Cth\)](#).

<sup>21</sup> National Disability Insurance Agency (2019) ‘Reasonable and necessary supports’. Link [here](#).

## Human rights

The [United Nations Convention on the Rights of Persons with Disabilities](#) (UNCRPD) recognises the importance of an ordinary life and requires that systems be developed to ensure people with disability are supported to build their capacity for independence and live well in the community on an equal basis to others. The UNCRPD's human rights indicators establish an inclusive society for people with disability,<sup>22</sup> and should form the basis for Australia's disability framework.

Many people with disability need assistance to live an ordinary life but current systems across disability, health, housing and aged care sectors fail to provide them with the housing and supports they need in a timely manner. Poor understanding of the complex and diverse needs of people with disability have resulted in a society that systematically excludes them. Rather than building capacity for independent living, government decision-making processes and models of care often have the effect of forcing people with disability into isolation, away from the rest of the community. This contributes to lost functionality and capacity for independence and increased dependence on others for support.

Further work is required to design and deliver societal systems that reflect the needs and preferences of people with disability and ensure their rights are upheld. A person-centric approach must be utilised by the NDIA, all levels of government and everyone who provides support to people with disability, to ensure people with disability are at the centre of all policies and solutions. Empowering people with disability so they are included in society is the most effective safeguard against instances of violence, abuse, neglect and exploitation.

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<sup>22</sup> For examples, see UNCRPD Articles [5](#), [12](#), [16](#), [19](#), [26](#) and [28](#).

## What is needed from the DRC to protect people with disability?

### A voice for younger people with high and complex needs

The DRC's Final Report must duly consider the experiences and outcomes of all people with disability yet younger people with high and complex needs are not having their voices adequately heard by the DRC. Without understanding the diverse experiences of younger people with high and complex needs, the DRC will be unable to enact meaningful and positive change for this especially vulnerable cohort.

The DRC should encourage private and public consultations and proactive engagement with younger people currently in or at risk of entering inappropriate and unsafe accommodation settings including RAC, boarding houses and supported residential services. This will assist the DRC to achieve a similar level of success as the Aged Care Royal Commission, which recognised that the most vulnerable people needed active support and encouragement to contribute. It will also ensure that the DRC is able to prevent and better protect this cohort from experiencing violence, abuse, neglect and exploitation.

**Recommendation 1: The DRC's inquiry and Final Report must be informed by the diverse experiences of younger people with high and complex needs to ensure the final recommendations to the Federal Government and resulting policy reforms improve outcomes for this cohort.**

Younger people with high and complex needs currently in, or at risk of entering these inappropriate and unsafe settings have unique experiences of violence, abuse, neglect and exploitation that appear to be largely unknown by the DRC. The DRC must create space for younger people with high and complex needs to share their stories and be heard, otherwise the DRC's inquiry and Final Report will be incomplete and this cohort will continue to experience violence, abuse, neglect and exploitation.

### Enable people with disability to live an ordinary life

Younger people with disability want the same opportunities as anyone else. They do not want to worry about whether they have enough plan funding to meet their support needs or if their support workers actually know how to support them. They want to be able to focus on the things in life that matter to them; visiting friends and family, going out into the community, shopping, learning and working. They want options on how they can live their own life.

*"My own disability is only part of my identity, but it takes up a disproportionately large part of my life. I want to contribute more to society but I am being held back by an insecure disability workforce and insecure NDIS funding."*

Angela - Participant

## Accessible housing for all participants

The NDIS provides an opportunity to put into practice a range of adaptive housing models for people with disability, recognising that each individual will have different needs and wants for their housing and supports, which may also change over time. Accessible housing that is designed for independent living can both foster greater autonomy and reduce costs.

### NDIA decision-making time frames

The Public Interest Advocacy Centre and Housing Hub's [Housing Delayed and Denied report](#) highlights that NDIA Home and Living decisions can take up to **18 months**. During this time participants experience a significant decline in their health and wellbeing and increase in vulnerability and dependence on others. Delays have flow-on effects on family and friends who may be required to provide urgent unpaid care. The NDIA must match the efficiency of the aged care system to ensure better outcomes for participants and prevent admissions of younger people with disability to RAC.

This requires timely and accurate decisions on the level of SDA funding and housing related supports within **10 days**. Decision timeframes should commence on receipt of all required evidence to inform a Home and Living determination.

**Recommendation 2: The DRC must instruct and hold the NDIA to account to make timely and accurate decisions on funding for SDA and housing related supports.**

The Summer Foundation's [Pre Budget Submission 2022](#) explains that timely and adequate funding for housing and support achieves better outcomes for participants. This will reduce the violence, abuse, neglect and exploitation they may otherwise experience when support goes unfunded and they are reliant on others for support.

### NDIA decision-making criteria

The Agency's planning decisions are based on a short sighted view of value for money, resulting in Home and Living decisions that often are not aligned to participants' needs and preferences.<sup>23</sup> The NDIA has committed to improving administrative processes relating to home and living supports to improve outcomes for participants.<sup>24</sup> In order to achieve this, the Agency must recognise the longer term benefits and efficiencies of building participants' capacity for independent decision-making and make funding decisions in line with their needs and preferences so they are able to achieve their goals.

It is essential that the NDIA and Federal Government collaborate with the sector to ensure the NDIS produces better outcomes for all participants, in line with the NDIS legislation. Participants, their families and close others are best placed to advise on what are reasonable and necessary supports for them to live an ordinary life. The NDIA needs to understand participants' needs and goals and ensure funding decisions actively enable choice and control.

*"If [a participant] needs it, they should have it. It's really important to respect people's choices."*

**Angela - Participant**

<sup>23</sup> Public Interest Advocacy Centre and Housing Hub (2022) 'Housing Delayed and Denied: NDIA Decision-Making on Specialist Disability Accommodation Funding'. Link [here](#).

<sup>24</sup> National Disability Insurance Agency (2022) 'Government Improving Home and Living Supports for NDIS Participants, Including SIL.' Link [here](#).

*“We need to go back to basics and support participants. [The NDIA] is more focused on the cost side of things, not individual needs and what people with disability say they need to live their life.”*

**Bonnie - Participant**

**Recommendation 3: The DRC must require the NDIA to apply the NDIS legislation in a fair and consistent manner, ensuring appropriate weight is assigned to participants' goals and aspirations when making funding decisions that provide participants with the help they need to pursue these goals and aspirations.**

NDIS funding decisions that align with participants' needs and preferences help protect them against violence, abuse, neglect and exploitation. Participants remain in control over where, how and with whom they live and are empowered and supported to change their living situation if they so wish.

### **Specialist Disability Accommodation**

SDA is the greatest opportunity within the social impact investment space that exists in Australia today. It has the potential to significantly improve the lives of tenants when it enables them to transition from a range of unsuitable and unsafe living environments to more contemporary models of housing designed for people with disability.

The NDIA holds responsibility for the stewardship of the SDA market. SDA investors and market players have signalled to the NDIA the changes that are needed to ensure opportunity for continuing growth and innovation in the SDA market. More can be done to increase awareness of SDA eligibility. Many participants expected to be eligible for SDA funding remain uninformed about their housing options, meaning that significant potential demand remains inactivated. There is a strong likelihood that thousands of participants are unaware of the existence of SDA, or if they are aware of it, have not fully engaged with the NDIS and explored their eligibility for SDA funding.<sup>25</sup>

**Recommendation 4: The DRC must require the NDIA to undertake a demand activation campaign to support awareness among likely SDA-eligible participants, and build the capacity of participants to make informed decisions about their housing options (SDA or other).**

Wellbeing, community integration and health are key areas of improvement for people who live in housing that is designed for and around their needs, to best support the development of capacity, independence and confidence.

### *Innovation in SDA*

However, low-quality SDA, including existing and legacy stock<sup>26</sup> that do not meet current design standards for SDA, will neither help tenants live independently nor adequately reduce vulnerability because tenants will remain dependent on in-home support. High-quality SDA

<sup>25</sup> Summer Foundation (2021) 'Specialist Disability Accommodation (SDA) Investor Think Tank: Findings and Recommendations'. Link [here](#).

<sup>26</sup> Different types of SDA are defined in the [National Disability Insurance Scheme \(Specialist Disability Accommodation\) Rules 2016](#).

ensures better quality of life and increased independence and is a more effective safeguard against violence, abuse, neglect and exploitation.<sup>27</sup>

The development of any contemporary housing model must utilise a [Tenant Outcomes Framework](#)<sup>28</sup> to ensure the innovation scaled in the SDA market is informed by the needs, preferences, experiences and outcomes of SDA tenants.<sup>29</sup> This fosters effective SDA that meets the specific needs of people with disability.

**Recommendation 5: The DRC must facilitate greater innovation in SDA by ensuring the NDIA fosters the development of innovative models of housing and support that are driven by the needs, preferences and a rigorous evidence base about the outcomes of tenants.**

High quality SDA helps participants build their capacity for independence over time, meaning they are less reliant on others for support over time. They will be safer from, and more likely to report, instances of violence, abuse, neglect and exploitation.

#### *Living with family in SDA*

In 2020, the [National Disability Insurance Scheme \(Specialist Disability Accommodation\) Rules 2016](#) (SDA Rules) was updated to allow a participant to live with the people they want to, including people who are not participants. This provision allows participants to have greater choice and control to live how they wish and keeps family units together. However, participants who are eligible for SDA often have difficulty in accessing funding that is appropriate for their housing and support needs.<sup>30</sup>

Participants have found it difficult to access funding for SDA that allows them to live with the people they choose. This may be due to the lack of guidance on how this should be addressed in Home and Living applications. The lack of understanding and consistent application among NDIS planners and the Home and Living Panel of this change to the SDA Rules is also a likely barrier.

**Recommendation 6: The DRC must require the NDIA to provide accessible information and guidance regarding participant rights, especially those under the SDA Rules, and make timely and accurate funding decisions that enable and support participants to live in SDA with their families, friends or close others.**

Measures encouraging families to stay together will protect participants against isolation, which is a key driver of violence and abuse. These measures will also ensure participants are no longer forced to live with others they did not choose and who are likely to put them at risk of violence and abuse.

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<sup>27</sup> Summer Foundation (2021) 'Moving into new housing designed for people with disability: Evaluation of tenant outcomes'. Link [here](#).

<sup>28</sup> A Tenants Outcome Framework captures the following outcomes: The subjective lived experience, quality of life, wellbeing, community participation, social connection, environmental impact, autonomy, quality and cost of support, and housing and health care costs.

<sup>29</sup> Summer Foundation (2021) 'Moving into new housing designed for people with disability: Evaluation of tenant outcomes'. Link [here](#); and Summer Foundation (2022) 'Support in Specialist Disability Accommodation (SDA) Apartments'. Link [here](#).

<sup>30</sup> Kennedy and National Disability Insurance Agency [2022] AATA 265 (18 February 2022). Link [here](#).



## Improving housing accessibility

Inaccessible housing negatively impacts social inclusion, health and wellbeing. Housing accessibility is best achieved by incorporating accessible design features in the construction of new dwellings.<sup>31</sup> A thriving SDA and accessible housing market will address accessibility needs now and into the future. Post-construction modifications are less likely to meet accessibility requirements, creating challenges and risks for participants while increasing costs.<sup>3233</sup>

*“Our homes need to be made to fit our personal needs. My home needs to be ready for me to move in straight away without needing any modifications otherwise there is nowhere safe for me to live.”*

**Bonnie - Participant**

Every state and territory must commit to implementing the new NCC to support accessible housing for all Australians with disability. The states and territories that have committed to these mandatory accessibility standards have the opportunity to influence the rest of the country, including the building industry, and demonstrate that universal design can be both cost-effective and improve the quality and accessibility of housing for all users.

However, implementing the new NCC is not enough on its own to improve housing accessibility for people with disability. State and territory governments must lead the way for social, public and private housing to better accommodate the varied accessibility needs of people with disability. By mandating the proportion of homes that need to be constructed in line with LHDG Silver, Gold and Platinum Level standards, the needs of people with disability who have complex needs will be addressed. Social and public housing that is required to support the 94% of participants who are not eligible for SDA funding, and other people with disability, should be constructed in line with LHDG Gold level at a minimum. This will improve choices and ensure accessibility for people with disability who face significant affordability barriers to purchase or rent an accessible home.<sup>34</sup>

**Recommendation 7: The DRC must ensure state and territory governments deliver disability and social housing strategies that meet the needs of people with disability in their respective state or territory.**

Providing more accessible housing options gives people with disability more choice and less risk when they need to make a housing change. Participants who are living in inaccessible housing, which makes them vulnerable to neglect, will no longer be forced to remain in high-risk settings because there will be alternatives available to them.

<sup>31</sup> Summer Foundation (2021) ‘Accessible design, hospital discharge and ageing in place: A national survey of occupational therapists’. Link [here](#).

<sup>32</sup> Melbourne Disability Institute and Summer Foundation (2020) ‘Accessible Housing - The Way Forward: Response to the Australian Building Codes Board Consultation RIS’. Link [here](#).

<sup>33</sup> Summer Foundation (2021) ‘Accessible design, hospital discharge and ageing in place: A national survey of occupational therapists’. Link [here](#).

<sup>34</sup> Melbourne Disability Institute and Summer Foundation (2020) ‘Accessible Housing - The Way Forward: Response to the Australian Building Codes Board Consultation RIS’. Link [here](#).

## Reconfiguring group homes

Few people with disability who need support to live independently in the community want to live in a group home. The DRC has heard evidence that the group home model breaches residents' human rights and is fundamentally flawed.<sup>35</sup> Research points to smaller dwellings being better than larger ones as residents in larger group homes typically receive less 1-to-1 support and poorer care due to the higher number of residents,<sup>36</sup> whereas residents in smaller group homes are less likely to have their needs neglected.

People with disability must be supported to find and live in homes suited to their needs, whether on their own, with their family, or with others. Large group homes that remove control over environment, supports and the people around you drastically increase the likelihood of dangerous occurrences, including violence and abuse from housemates, as well as neglect from carers expected to address the needs of numerous people on a tight schedule. It is essential that group homes are reconfigured to ensure a person-centred approach to support provision.

**Recommendation 8: The DRC must require that housing for people with disability is person-centred and structured to meet individual needs, resulting in group homes being redeveloped and reconfigured.**

Larger group homes currently pose unacceptable risks of violence, abuse and neglect because quality of care for each resident cannot be guaranteed. Redesigning group homes to ensure they foster choice and control around daily living and make certain that residents are given quality care is crucial to improving outcomes for people with disability while reflecting a contemporary approach to housing.

## Reducing the demand for SIL homes

People with disability living in situations where abuse and neglect are a risk need support to move into safer, more appropriate housing. Nearly 27,000 participants are currently receiving SIL funding. Of these, 17,693 also receive SDA funding yet only 15,035 are living in SDA.<sup>37</sup> SDA and SIL were designed to work together to enable participants to live independently in appropriate housing. As articulated above, participants who are receiving SIL-only funding are likely living in substandard accommodation that does not afford them any rights.

The NDIA must take action to ensure that participants are adequately funded for their housing and support needs and there are a variety of available options for secure and appropriate housing and support. It must work collaboratively with state and territory governments to increase accessible and social housing to transition participants out of SIL homes, particularly for those who are not eligible for SDA.

The NDIS Commission must undertake a quality audit of existing SIL homes and implement a regulatory framework in collaboration with state and territory governments to ensure all participants have tenancy and other rights. It is also essential that SIL homes are not a rebranded institutional group home.

<sup>35</sup> Disability Royal Commission (2020) 'Overview of responses to Group homes Issues paper'. Link [here](#).

<sup>36</sup> National Disability Services (2020) 'Submission to the Royal Commission on the group homes issues paper'. Link [here](#).

<sup>37</sup> Figures current as at 31 March 2022. See: National Disability Insurance Agency (2022) 'NDIS Quarterly Report to disability ministers (31 March 2022)'. Link [here](#).

**Recommendation 9: The DRC must require the NDIA, NDIS Commission and state and territory governments to apply a consistent approach to protecting the rights of all participants who need independent living options and specialised housing. This includes working together to transition participants out of SIL homes and into SDA or other appropriate housing.**

The Summer Foundation's [policy position statement on closed setting SIL homes](#) highlights that providing adequate supports to participants and ensuring Home and Living decisions reflect the true housing and support needs and preferences of participants will protect them against the risks of abuse and neglect in residential settings.

### Improving hospital discharge

Participants in hospital must have funding available to enable them to move into appropriate housing as soon as they are medically fit for discharge. They should not be forced to sit in a hospital bed for months while they wait for the NDIA to make a decision about their housing and supports. Nor should they be admitted to RAC or other unsafe housing options while their health and wellbeing continue to decline.

The transition from hospital to home comes with additional challenges, requiring a coordinated health and NDIS interface to improve health outcomes for participants while also preventing new admissions of younger people into RAC.

The Federal Government should invest \$54 million in:

- Specialist services to assist hospital staff to identify suitable disability housing
- Capacity building for hospital discharge planners and support coordinators
- New flags in hospital systems for the early identification of new participants and patients with disability that need intensive discharge planning
- Developing and piloting an evidence-based approach to streamline the allocation of funding for new participants leaving inpatient rehabilitation

**Recommendation 10: The DRC must require greater collaboration between the Federal and state and territory governments to improve hospital discharge and safely support participants out of hospital and into appropriate housing.**

This should include timely and accurate decision-making regarding housing and supports to facilitate discharge, and increasing options for housing to ensure that participants are not stuck in hospital due to housing barriers.

The Summer Foundation's [policy position statement on hospital discharge](#) and [Pre Budget Submission 2022](#) highlight that effective discharge planning improves health outcomes for participants while also removing the risk of admission to unsafe accommodation settings that make them more vulnerable to a cycle of violence, abuse and neglect.

## Empowering younger people to transition out of RAC

Many YPIRAC and their families/supporters are not aware of the housing and support options that exist outside of RAC. The NDIA does not support YPIRAC to understand what life outside of RAC could be.

As at 30 June 2021, only 886 of 3,232 YPIRAC answered ‘yes’ when asked by a YPIRAC planner if they wanted to leave RAC.<sup>38</sup> Questions about life in RAC and housing goals are asked by YPIRAC planners in a closed manner that does not allow an open discussion about goals and opportunities. Little attention is paid to the individual barriers to leaving RAC, resulting in YPIRAC and close others believing that leaving RAC is too difficult or undesirable. A change of environment and loss of support from trusted support workers are considered to be destabilising, and this is seen as a major barrier to moving out of RAC.

YPIRAC need independent and skilled support to document their housing needs and preferences and realise a life outside of aged care. The NDIA must work with the sector to provide independent information and expert capacity building for YPIRAC.<sup>39</sup> It is essential that the NDIA:

- Skill up YPIRAC planners and implement specialist housing support coordinators to have open and safe conversations with YPIRAC about housing options and life outside of RAC
- Make Home and Living determinations for all participants in RAC, with adequate funding for housing exploration so participants are able to develop their own transition plans and explore a life outside of RAC safely and in their own time
- Collaborate with advocacy organisations within the sector that are experienced in working with YPIRAC and that have the trust of YPIRAC, to support them to navigate housing options and identify the steps needed to ensure a safe exit from RAC
- Work with all levels of government to create practical solutions to support YPIRAC who are not eligible for the NDIS to safely transition out of RAC.

*“Change can be scary, especially if you’ve been in an institutional setting for what feels like your whole life. YPIRAC planners need to do everything they can to address the barriers [to leaving RAC] and let [YPIRAC] know that they actually can leave. They may not know it now but life is better outside of RAC.”*

Angela - Participant

**Recommendation 11: The DRC must require the NDIA to work more closely with the sector and all levels of government to address the barriers that disempower YPIRAC from establishing a life outside of aged care and create individualised solutions that allow them to safely adjust to community living in their own time.**

Understanding how the NDIA and disability sector can work together to assist YPIRAC to explore their housing and support options and build their knowledge and skills so they can make informed choices and reconnect with their community, are essential safeguards against violence, abuse and neglect of institutionalised people with disability.

<sup>38</sup> Senate Community Affairs Legislation Committee (2021) ‘Answer to Question on Notice, Social Services Portfolio, Additional Estimates. Question No: NDIA SQ21-000180’ Link [here](#).

<sup>39</sup> Winkler D and Mulherin P (2022) ‘Younger people in aged care is a problem: will the government keep its stated commitment?’ Pro Bono Australia, 4 May 2022. Link [here](#).

## Regulated rights and safeguards for participants

### Equal residential tenancy rights under law

The NDIS Commission must collaborate with state and territory governments to afford all tenants with the same residential tenancy rights regardless of whether they are living in social, public or private housing. People with disability who live in SDA or other NDIS-funded settings must have the same rights and protections within the home as those who live in rentals that are already covered in state residential tenancy legislation. Legislation must be immediately reviewed to be complementary to the [NDIS Rules](#). To clarify rights and responsibilities for SDA tenants and providers/landlords, residential tenancy law must also align with the [SDA Pricing Arrangement](#) and [SDA Practice Standards](#).

**Recommendation 12: The DRC must require alignment between state residential tenancy legislation and the NDIS Rules and policies to ensure people with disability have the same housing rights and protections as other Australians, regardless of their housing arrangement.**

There must be fair and consistent oversight in social, public and private housing and all NDIS-funded accommodation settings to better ensure no person with disability experiences violence, abuse, neglect or exploitation at home.

### Enforced separation of providers

Interaction with several providers increases opportunities for intervention where violence and abuse, neglect and exploitation committed by 1 provider are identified.<sup>40</sup> Clear boundaries between the provision of housing and supports enable choice for people with disability and increased control over who comes into their home to provide care services. It also increases the likelihood of having people on hand without conflicts of interest if issues arise.

As recommended in the Summer Foundation's consultation paper on [Improving Outcomes for Participants who Require SIL](#) and [Submission to the NDIA Consultation on Supports for Decision Making](#), the NDIS Commission must address the necessary separation of housing and supports, avoid conflicts of interest and provide more meaningful choice and control for participants.

**Recommendation 13: The DRC must require the NDIS Commission to mandate and enforce a complete separation between the provision of housing and supports.**

These changes must be in line with the [Tune review](#) and include:

- Safeguards against referrals to 'preferred partners'
- Implementing a strategy to support the achievement of full separation
- Requiring all support coordinators to be independent of other service provision
- Closely monitoring existing providers that combine housing and support provision
- Independent service agreements so one can be changed or ended without impacting another

A clear separation of housing and supports protects participants against violence, abuse, neglect and exploitation by ensuring no single provider has too much power over them.

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<sup>40</sup> Disability Royal Commission (2020) 'Overview of responses to Group homes Issues paper'. Link [here](#).

## Strengthened NDIS workforce standards

### *Ensuring a highly skilled workforce*

People with disability are more likely to experience abuse and neglect from support providers who do not have the skills or experience to provide quality disability care.<sup>41</sup> Support workers' preconceived ideas and attitudes often impact the approach they take to support provision, which affects experiences and outcomes for the participant. Flow-on effects include participants feeling 'stuck' with support workers they no longer want to work with, as they fear being unable to find a better worker or are tired of hiring and training.<sup>42</sup>

The production and use of [participant-led training videos](#) has the potential to improve the delivery of support and maximise support outcomes for people with disability. These enable people with cognitive and communication impairments to have increased choice and control, set their own goals and direct their supports. They can also facilitate changes in support practice, imparting readily applied practical knowledge about what to do and how to do it effectively in the context of the expressed needs of the person with disability.<sup>43</sup> The burden that people with disability and their family members experience as a result of overseeing, training and retraining support workers is likely to reduce over time.

The NDIS workforce must be strengthened through preventative safeguards and fit-for-purpose training and qualifications. These serve to improve quality of care for participants including understanding of and responses to violence, abuse, neglect and exploitation, while strengthening the sector through career development. The Federal Government must commit to appropriately resourcing the NDIA and delivering fair remuneration, job security and career development opportunities for the disability workforce. Additionally, investing in NDIS-focused education within tertiary settings ensures more skilled workers and a more formalised workforce. It also ensures participants are better supported and have greater access to experienced and dedicated disability workers.

**Recommendation 14: The DRC must require the NDIA and Federal Government to build a responsive and capable workforce that provides high quality services for people with disability.**

Increasing the effectiveness of the NDIS workforce must be done by:

- Attracting students into careers in the disability workforce
- Increasing the supply of disability workers and allied health professionals
- Creating formal qualifications and training to support professional development

Coordinated supply-side government investment and innovative ways to grow a quality workforce are critical to address current disability workforce growth issues that contribute to violence, abuse, neglect and exploitation of people with disability.

<sup>41</sup> Disability Royal Commission (2020) 'Overview of responses to Group homes Issues paper'. Link [here](#).

<sup>42</sup> Topping M, Douglas J and Winkler D (2022) "They treat you like a person, they ask you what you want": a grounded theory study of quality paid disability support for adults with acquired neurological disability'. Disability and Rehabilitation, 21 June 2022. Link [here](#).

<sup>43</sup> La Trobe University (2018) 'Participant Led Training Videos' Link [here](#).

### Safety screening of NDIS workers

The NDIS Commission must mandate proper screening of all NDIS workers. Unregistered providers and self-managed participants can choose to ask workers to apply for a Worker Screening Check and obtain an NDIS Worker Screening clearance, though this is not mandatory.<sup>44</sup> There is no inherent issue with unregistered providers or participants managing their own funds and services and in fact, these have benefits including access to a larger network of services to help meet participants' needs particularly where there might not be any suitable registered providers in their location. However, inadequate safety screening to ensure people who should be precluded from providing care services to vulnerable people with disability are restricted from doing so, pose unacceptable risks to participants.<sup>45</sup>

**Recommendation 15: The DRC must recommend that the NDIS Commission requires all registered and unregistered NDIS providers to undergo appropriate safety screening as a condition of employment.**

Until this becomes mandatory for all providers, participants must be informed if their support workers do not have an NDIS Worker Screening clearance. This will give them the opportunity to ask that their support workers undertake NDIS worker screening.

Ultimately, worker screening is critical to minimise harm to vulnerable people with disability and ensure the workers who come into contact with them do not pose unacceptable risks of violence, abuse, neglect and exploitation.

## Improve access to information

### Improved accessibility of resources for participants

People with disability who experience violence, abuse, neglect and exploitation often do not have access to information about where and how to seek support.<sup>46,47</sup> They must be able to access information in their preferred manner. Despite easy English explainers, many people with disability still find information regarding the NDIS, their housing and support options and their rights and protections to be inaccessible and far too complex.

*“Putting something in easy English doesn’t automatically mean it’s accessible. I remember reading something from the NDIA. The easy English version was actually harder to understand than the harder version. I don’t use easy English versions anymore because they don’t make sense.”*

*“I get information from other people with similar disability; people who have been there and done that.”*

**Angela\* - Participant**

People with disability can be better supported if they are more informed on their rights, the services available to support them in making decisions and the implications of those

<sup>44</sup> NDIS Quality and Safeguards Commission (2021) ‘NDIS Worker Screening Check: What unregistered NDIS providers need to know. Link [here](#).

<sup>45</sup> Davis A (25 March 2022) ‘NDIS-funded support workers not automatically screened, says mother of abuse victim’ ABC South West WA. Link [here](#).

<sup>46</sup> Disability Royal Commission (2020) ‘Overview of responses to Group homes Issues paper’. Link [here](#).

<sup>47</sup> Summer Foundation (2021) ‘Submission to the NDIA on Home and Living’. Link [here](#).

decisions.<sup>48</sup> Participant-led videos are an innovative way for people with disability to understand complex information.<sup>49</sup> Importantly, they are created by people with disability, for people with disability.

**Recommendation 16: The DRC must require the NDIA and all levels of government to fund co-designed, peer-led information for participants to ensure information about their rights and options for support is easy to access and navigate.**

This is crucial to ensure participants are fully informed of their rights and support options, and able to exercise true choice and control over all aspects of their lives.

### Effective data modelling

Access to complete data is critical to understanding the experiences of people with disability and monitoring system effectiveness in ensuring good outcomes. However, there is a general lack of useful and nationally consistent data on the extent of violence, abuse, neglect and exploitation of people with disability.<sup>50</sup> The data that does exist is not transparent enough to support sector responses that address risks.

The 18-month National Disability Data Asset (NDDA) pilot aims to give a more complete picture of the life experiences of people with disability. With the help of the NDDA:

- People with disability can access better information to understand what supports and services may be right for them
- NDIS providers can access information to help them deliver better quality supports and services to people with disability<sup>51</sup>

Investment in the NDDA must be maximised to better understand the life experiences of people with disability, including the key drivers of violence, abuse, neglect and exploitation in different settings. The current 18-month investment in the NDDA is insufficient as it does not allow for longitudinal data or the assessment of medium to longer term outcomes. A longer investment in the NDDA will make it possible to monitor the impact of the NDIS and obtain an evidence base about how to ensure mainstream systems better meet the needs of all people with disability over time.

**Recommendation 17: The DRC must require the NDIA, all levels of government and the disability sector to work together to make de-identified data available for independent analysis via the NDDA, to enable a thorough and system-wide approach to understanding disability in Australia.**

A clear and complete data set is required to understand what is and is not working and make informed decisions about what is needed to achieve an ordinary life for all people with disability. Without such system-wide data collection, it is impossible to ascertain the extent to which people with disability experience violence, abuse, neglect and exploitation, or otherwise thrive in different systems and areas of community life.

<sup>48</sup> Summer Foundation (2021) 'Submission to the NDIA on Support for Decision Making'. Link [here](#).

<sup>49</sup> La Trobe University (2018) 'Participant Led Training Videos'. Link [here](#).

<sup>50</sup> Royal Commission into Aged Care Quality and Safety (2019) 'Interim Report: Neglect (Vol. 1)' p246. Link [here](#).

<sup>51</sup> National Disability Data Asset (2022) 'The NDDA for different users'. Link [here](#).



## Call to action

With the DRC's Final Report due to be presented to the Governor-General by 29 September 2023, there is limited time for the DRC to hear the unique experiences of younger people currently in, or at risk of entering RAC, boarding houses and supported residential services. The DRC's inquiry is yet to adequately explore the violence, abuse, neglect and exploitation this cohort continues to experience. If these are not prominently placed within the DRC's inquiry in the coming months, the DRC will miss the opportunity to drive policy reform that will meaningfully improve outcomes for this cohort.

**1. The DRC must invite younger people who are currently in, or at risk of entering inappropriate and unsafe accommodation settings including RAC, boarding houses and supported residential services, to make submissions to the DRC.**

The DRC's [Terms of Reference](#) requires that the DRC have regard to the extent of violence, abuse, neglect and exploitation experienced by people with disability in all settings and contexts. Yet the DRC's [public hearing schedule](#) has failed to address the unique issues experienced by younger people who are currently in, or at risk of entering RAC, boarding houses and supported residential services. The DRC must ensure that they are encouraged and supported to give evidence about the violence, abuse, neglect and exploitation they experience.

**2. The DRC must work with key advocacy organisations to ensure the DRC achieves good outcomes in line with the diverse and wide ranging needs of people with disability.**

The Summer Foundation operates with a strong evidence base to promote more independent living options for people with disability to live an ordinary life free from violence, abuse, neglect and exploitation. The DRC must engage with organisations including the Summer Foundation and take advantage of the knowledge and expertise that currently exists in the sector as it considers its Final Report and recommendations to the Federal Government. In doing so, the DRC will ensure lived experience and evidence drives, informs and shapes its policy influence.

## Conclusion

Immediate action is needed to improve outcomes for people with disability. Despite state, national and international mandates, many people with disability with high and complex needs are still not afforded their rights. They are often denied the opportunity to live where, how and with whom they want.

Young people with disability want to have more choice and control over how they can use their NDIS plan funding and how support is given to them. They want to feel safe at home, have confidence that the people and systems that they rely on will understand and support them, and uphold and protect their rights and interests. They want to set goals for their lives and be able to achieve them, with support if required.

Targeted intervention across the disability and mainstream sectors and all levels of government is required. Significant reforms to the NDIS and health and housing interface systems are needed to uphold participants' choice and control over their own lives and break the cycle of violence, abuse, neglect and exploitation when they are dependent on supports provided by others. Greater investment into person-centred decision-making is essential to ensure that participants can exercise their right to an ordinary life.

## About the Summer Foundation

The Summer Foundation exists to permanently stop young people with disability from being forced into residential 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 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. We use a range of tools including our:



### 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.