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‘Hurry Up and Get Me out of Here’: The Experience of People Under 65 Years (Still) Stuck in Aged Care

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ABSTRACT

Following the Royal Commission into Aged Care Quality and Safety, the Australian Government set a target for no-one under 65 years of age to be living in residential aged care (RAC) by 2025. The numbers of young people in residential aged care (YPIRAC) have significantly declined since the start of the targets. However, most of the reduction can be attributed to death and people turning 65 rather than to people moving into better housing. This qualitative study informed by grounded theory methodology explores the intersection between the housing needs, preferences, and the experience of securing adequate funding, housing, and support to transition out of RAC for nine people with disabilities and six close others. Findings showed that despite having access to funding under Australia’s National Disability Insurance Scheme (NDIS), the transition out of RAC was impacted by difficulty securing the right category and amount of funding, unmet housing preferences and inadequate housing and support. The cumulative impact was frustrating, exhausting, limiting, dislocating and ultimately restricting. Policy implications include the need for a skilled workforce to navigate the transition, a responsive approach to housing that considers diverse needs and preferences, and systematic data collection to better inform housing options and supports.

1 | Introduction

The worldwide shift away from institutional living to community living for people with disabilities is reflective of a greater understanding of the harmful impact of living in institutions and the right of people with disabilities to live in non-segregated environments (Committee on the Rights of Persons with Disabilities 2017). Housing choice is considered a fundamental right under article 19 of the United Nations Convention on the Rights of Persons with Disabilities (UNCPRD) (2006) which states that people with disabilities are not obliged to live in a particular living arrangement and have the right to live

independently and be included in the community. As a signatory to the UNCPRD, the Australian government is committed to these rights.

The impact of institutionalisation is nowhere more evident than in the case of young people with disabilities residing in residential aged care, recognised as an inappropriate option for people under 65 years (Commonwealth of Australia 2020). Conversely, individualised housing for people with disabilities is seen as contributing to positive health and wellbeing outcomes including health, social connection, functional skills and community participation (Douglas et al. 2024).

This work was conducted whilst Dr Dearn was employed by Summer Foundation. Dr Dearn is now employed at RMIT and therefore their contact email is RMIT.

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The timely availability of appropriate alternative housing, and inappropriate housing being offered are long-standing barriers to people wishing to move out of RAC and a key structural issue for people wishing to move out of institutional settings (Winkler and Douglas 2023). Alternative housing and support services are viable for many YPIRAC, offering a higher quality of life and better health, wellbeing and social outcomes (Douglas et al. 2024). However, there has historically been little choice for people with severe disabilities under 65 years of age but to move out of institutional forms of housing, including RAC (O'Donovan et al. 2021). There have been significant changes in the policy and funding landscape in Australia since the introduction of the CRPD, notionally creating the levers for people under 65 years to move into individualised housing.

In 2019, the Australian Government responded to the Royal Commission into Aged Care Quality and Safety's interim report, *Neglect* (RCACQS 2019), by announcing targets for reducing the number of younger people residing in RAC facilities. The resulting *Young People in Residential Aged Care Strategy 2019–2025* (YPIRAC strategy) aimed to ensure that no people under the age of 65 would be residing in RAC by 2025, except in exceptional circumstances¹ (Commonwealth of Australia 2020). The YPIRAC strategy primarily focuses on meeting the housing and support needs of this population through the NDIS, Australia's national social insurance scheme (Commonwealth of Australia 2020). In a more recent change, Australia's *Aged Care Act 2024* precludes people under 65 years from entering RAC (Part 1 (s55)).²

The NDIS, fully implemented since 2020, provides individualised funding for people with significant disability associated with a permanent impairment (Commonwealth of Australia 2013). In addition to a range of support roles targeted directly at YPIRAC, the NDIS introduced supported independent living (SIL) funding, which provides support and supervision with personal care and everyday activities in the person's home, with the goal of building a participant's capacity to live more independently (Andrews 2020; NDIA 2022). Alongside this, specialist disability accommodation (SDA) funding was introduced in 2016 to fund accessible and affordable accommodation for people with an extreme functional impairment or very high support needs. The aim of this policy was to encourage private investment to fund innovative housing for people with disabilities that is designed to foster independence and enable the efficient delivery of support (NDIA 2016). In June 2023, 7925 SDA dwellings were enrolled across Australia, 48.2% of which were 'new build' dwellings designed to enhance accessibility and to facilitate the delivery of safe and efficient support (Aimers et al. 2023). Most of these new builds are single occupancy apartments (Crowe et al. 2024). Taken in conjunction with the Australian government's commitment to the YIRAC targets, opportunities for pathways out of RAC are now available that were previously not achievable.

In December 2023, only 2 years short of the 2025 target, 1469 people under 65 years (excluding First Nations' people aged 50–64) remained in RAC (AIHW 2024). This is an overall reduction of 70% from 4903 people in December 2019, just prior to the start of the YPIRAC strategy in 2020 (AIHW 2024). However, the reduction in YPIRAC numbers overall is largely accounted for by fewer admissions into RAC, and people already in RAC dying

or turning 65 years. Relatively few people have transitioned out of aged care into better accommodation options (AIHW 2023).

When the YPIRAC targets were established, it was believed that the YPIRAC population, who have disabilities and complex needs such as acquired brain injuries, neurodegenerative conditions and spinal cord injuries (Cubie et al. 2020), would require NDIS funding for SDA, support services, capacity building and assistive technology in order to transition out of residential aged care facilities (Brown et al. 2022). Indeed, 1433 YPIRAC do have NDIS funding, and 475 people with an NDIS plan have a goal to move out of RAC formally recognised in their NDIS plan (NDIA 2023). But the administrative data does not show why they continue to live in RAC.

Previous research indicates that obtaining the SDA funding can be a complex and protracted administrative procedure, with many NDIS participants receiving incorrect SDA determinations, experiencing extensive delays and administrative errors (Skipsey et al. 2022; Crowe et al. 2024). People living in RAC with NDIS funding wishing to move rely on support coordinators and NDIA staff who often have limited hours to provide the necessary support (Skipsey et al. 2022). The protracted nature of the SDA process has a significant 'impact on the physical and emotional wellbeing of people with disability' (Crowe et al. 2024, 64).

There is currently no evidence regarding the experiences of people under 65 years who receive NDIS funding and have a goal to transition out of RAC. This study sought to address this gap in evidence by exploring the intersection between the housing needs and preferences of people with disabilities under 65 years and the experience of attempting to secure adequate funding, housing and support to transition out of RAC. The overall aim of the study was to better understand the lived experience of young people with disabilities living in RAC with a goal to move out of RAC.

2 | Methods

This study was informed by a constructivist grounded theory approach using in-depth, semi-structured interviews to capture the lived experience of people under 65 years living in RAC. Charmaz and Belgrave (2012, 347) describe grounded theory as 'a systematic method for constructing a theoretical analysis from data'. Grounded theory is a common method adopted in qualitative analysis and is used to understand social worlds, behaviours and people's interactions with their environments. In grounded theory, the focus of the research emerges 'during the research process, rather than being determined before empirical inquiry begins' (Charmaz and Thornberg 2021, 305). Ethics approval was attained from La Trobe University Human Research Ethics Committee (approval number: 18507).

2.1 | Recruitment

Recruitment occurred from early 2022 until late 2023, with interviews occurring across that time. Three recruitment approaches were implemented: distribution of postcards about

the study to RAC providers, placement of a recruitment advertisement on the Summer Foundation website and external websites, and direct contact by the researcher with professionals working with people living in RAC. Significant barriers were encountered to recruiting participants, which included gatekeeping of service providers and family, limited access of participants to communication technology in RAC (e.g., phones and computers), and the capacity of YPIRAC to consent due to cognitive issues relating to acquired brain injury (ABI).

Recruitment was arms-length with a third party gauging the interest of the participant and gaining their permission before sending contact details to the researcher. A total of 12 referrals were made to the researcher from the three recruitment approaches: postcards (4 referrals), internal (4 referrals) and external (4 referrals) contacts. Participants were screened by the researcher against the following criteria: (1) under 65 years living in RAC; (2) disability and complex needs; (3) capacity to consent to the research. Two participants were excluded because they could not understand the research question and purpose; therefore, they did not have capacity to consent. One potential participant was unable to be contacted. Participants could be supported by a close other if they either needed or wanted support in the interview and were asked for their consent for a close other to be interviewed independently or concurrently. In all instances, recruitment started with the primary participant.

The primary method of data collection for the study was semi-structured interviews with YPIRAC and participant-nominated close others. Interviews focused on the housing needs and

preferences of YPIRAC and the experience of working towards their housing goals and attaining the appropriate level of NDIS funding to move out. The purpose of interviewing participant-nominated close others was to complete details about which the primary participant may have been unsure rather than to corroborate or compare responses with primary participants.

2.2 | Participants

Primary participants were all under 65 years and living in RAC in four states in Australia: New South Wales ($n=2$), Victoria ($n=2$), South Australia ($n=2$) and Tasmania ($n=3$). All participants were in receipt of NDIS funding and had a goal in their NDIS plan to move out of RAC. All participants were in receipt of SDA funding and/or SIL funding (NDIA 2016). Participants were living with ABI or other neurological impairments, including stroke and neurodegenerative conditions, which reflect the population of YPIRAC as a whole (AIHW 2011). The length of time participants had lived in RAC ranged from 12 months to 10 years. Three close others sat in on the interview with the primary participant to provide support. One of these close others was interviewed in conjunction with the participant interview ($n=1$ support coordinator). Five close others were nominated by the primary participants for follow-up interviews ($n=4$ support coordinators; $n=1$ partner). Participant characteristics are summarised in Table 1.

Participants had lived in a range of housing situations prior to moving into RAC. Some people had lived in public housing; others rented or had lived in their own homes with their

TABLE 1 | Primary participant characteristics.

Primary participant ^a	Gender	Age	Disability	Previous housing type	Time in RAC	Time waiting to move out of RAC	Close other interviewed
Jack	Male	52	Acquired brain injury	Private rental	12 months	6 months	Support coordinator
Magda	Female	56	Neurodegenerative	Private rental	4 years	3 years	No
Ilsa	Female	63	Acquired brain injury	Public housing	3 years	3 years	Support coordinator
Reesha	Female	37	Neurological	Own home (with family)	10 years	4 years	Support coordinator
Meeka	Female	58	Acquired brain injury	Own home (with family)	3 years	3 years	Partner
Fiona	Female	59	Neurological + mental health	Own home (with family)	5 years	5 years	Support coordinator
Maria	Female	55	Neurological	Own home (with family)	4 years	1 year ^b	No
Peter	Male	51	Neurodegenerative	Private rental	6 years	3 years	Support coordinator
Alison	Female	53	Neurological + mental health	Public housing	5 years	5 years	No

^aNote pseudonyms are used to conceal participants' identities.

^bParticipant didn't know it was possible to move out of RAC until she got a new support coordinator in 2023.

partners or family. All participants were living in RAC due to functional impairment related to their disability. This was primarily because their support needs exceeded what they themselves or their families could provide in their previous housing (Table 1).

2.3 | Data Collection

Semi-structured interviews were undertaken with the nine primary participants and six participant-nominated close others. One close other was interviewed with the participant; five close others were interviewed separately. Participants spoke directly to their own experience, except in the case of one participant whose verbal expression was limited. This participant's partner spoke to her experience whilst the participant's dissent or assent was sought by the researcher throughout the interview.

Primary participants were asked about their housing goals, needs and preferences and their NDIS experience. Close others were asked about the participant's NDIS funding, how the person's housing goals were progressing under the NDIS and any barriers to implementation. All interviews were conducted by telephone, audio recorded and transcribed. Transcripts were de-identified to protect the anonymity of the participants.

2.4 | Data Analysis

Data analysis occurred concurrently with interviews and consisted of steps consistent with constructivist grounded theory (Charmaz 2014). An inductive approach was employed throughout the analysis. Initial line-by-line coding of the interview transcripts was undertaken by the first author. Transcripts were then double-coded by two other researchers (KD & MB) to check the consistency of categories and ideas. Memos were written by the researchers following the line-by-line coding and used as the basis for analytical discussions and reflexive thinking around emergent themes. Analysis went from initial coding to focused coding, with the lead researcher conducting axial and theoretical coding of the transcripts to consolidate emerging ideas across the transcripts, informing the development of broader theoretical themes.

Primary participant transcripts were analysed first, and close other transcripts were analysed second. Where close other data was collected in the interview with the primary participant, the transcript was analysed first for the participant voice and second for the close other voice. Themes emerging from close other interviews were checked against primary participant data.

The four themes reported in the results section are based on the analysis of both primary participant and close other transcripts. Quotes from both primary participants and close others are drawn on to explore the intersection between the housing needs and preferences of adults with disabilities living in aged care, and the experience of securing adequate funding, housing and support to transition out of RAC.

QSR NVivo qualitative software was used to code and sort data at all stages of the data analysis. The analysis revealed no new

emerging themes after the ninth primary participant and six close others; hence the sample size was deemed sufficient as data saturation had been reached (Vasileiou et al. 2018).

3 | Results

Four key themes were developed from analysis of the interview data which are outlined in the following sections. The first three themes describe the structural barriers to moving out of RAC. These themes are: Difficulty securing the right funding, unmet housing choices and inadequate housing and support. The fourth and final theme captures the impact of the barriers to moving out on participants' experience. This theme exists in relationship with the other themes and is grounded in the lived experience of participants.

3.1 | Difficulty Securing the Right Funding

Funding for disability housing and funding for support is sought through the NDIS planning process, which consists of annual individualised planning meetings with participants to secure funding aligned with their housing and support needs. Funding for SDA and SIL is provided where it is considered a reasonable and necessary support to enhance the participant's independence, community inclusion and quality of life (Andrews 2020; NDIA 2022). Eligibility for SDA and SIL is determined based on evidence from medical and allied health assessments.

The participants interviewed for this study shared their frustration with not getting funding in their NDIS plan that aligned with their housing needs and preferences. Most people experienced administrative delays in obtaining the appropriate type and level of funding aligned with their support and access needs before they could move out, finding themselves stuck in a frustrating cycle and elongated process of assessment, review and waiting for NDIS decisions. Reflecting upon her experience, Maria said, 'I don't know. I've just got a message from [support coordinator] that she doesn't know whether I've got enough funding for it. So, we might have to go back to the Tribunal' (Maria). A shortage of occupational therapists (OTs) in rural areas meant that participants were waiting up to a year for their functional capacity, support and housing design needs to be assessed. These assessments are a baseline requirement under the NDIS and thus an essential part of the NDIS funding process. Ilsa's support coordinator shared her frustration with the delays, 'the OTs are about six months behind at the moment, we're kind of on a standstill, but we've started the process' (Support coordinator, Ilsa).

Before actioning their goal to move, participants needed their housing goal documented in their NDIS plan. However, for two people the goal to move out was incorrectly documented in their NDIS plan as a medium-term rather than a short-term goal, as described by Magda:

■ The goals that are on my plan are incorrect. I actually changed them, but they don't change them. The goals

they've got here are what I had three years ago...I've changed my goals twice since then, but they haven't changed it in my plan.

(Magda)

Before actioning their goal to move, people also needed to have the correct level of SDA funding available in their NDIS plan. However, the funding stated in the NDIS plan did not always reflect the person's housing and support needs. One participant was first allocated a lower level of SDA funding and only later received the higher funding that matched their significant physical support needs:

... originally, we were classified as fully, fully accessible, which wasn't the right classification. So, we had to do a review. And myself and 'Meeka's' support coordinator was getting advice from (name of organisation) on how to put in a review, what documents to send

(Husband, Meeka)

In many situations the funding specified a type of housing arrangement that the participant was unwilling to accept. Most people were offered shared accommodation despite their preference to live alone, necessitating a cycle of review and assessment. For example, Ilsa's support coordinator described the experience of her client being offered a group home, which was not reflective of her housing preference. She said, '... [NDIS participant] had put in her last plan that she would like to live with people more her own age, which was interpreted as a group home ... definitely that's not what she wanted, so we had to change her goal' (Support coordinator, Ilsa).

3.2 | Unmet Housing Choices

A goal to live in their own home rather than share a dwelling with other people with disabilities was the goal of eight out of nine participants. Most people also expressed a clear preference for remaining in their own community close to family and friends. However, most participants received NDIS funding for shared housing, regardless of factors that might have contributed to their goal of independent housing, such as age, disability, history of independence, work, or family, as Maria's situation illustrates:

We started January this year with change of circumstances with the NDIS, which came through very quickly, I have to say. We were quite surprised. But then the plan they had for me they decided on the evidence, I didn't have enough evidence to show that I need to live alone... I'm not sharing at the age of 55. I refuse to. I want my own place.

(Maria)

Participants, such as Peter and Ilsa were looking for housing that could accommodate their family. Peter shared, 'Well, I was looking – like, we was looking at probably at least a three bedroom and garage or a four-bedroom home because, basically, these days I've still got all the family living together'. While Ilsa

said, 'and I've got a grandson that's 14 years of age that just wants me to get me own place so he can come for sleepovers. And that we can cook together'.

Although most participants expressed a clear desire to live alone, most participants also wanted to live in a familiar geographical location or somewhere close to family, friends and established networks. However, it was a common experience, especially for people living in rural and regional areas, to be offered SDA or other shared disability accommodation out of their local area:

The options that have been presented to me are, as I said. They're all houses with three and four bedrooms, or units, and that's given to me – offered to me in a place of (name of city), which is a half hour away from where I actually live and I know people.

(Magda)

The participants noted that a frequent barrier to living in their preferred location was a shortage of available housing. This was particularly the case for people living in regional and rural areas. Ilsa shared, 'well, there's not much accommodation in [name of rural town]. That's the thing, love'. And as Fiona's support coordinator noted, 'the main thing has been accommodation and the lack of appropriate accommodation in the area that she wants to live'.

In cases where housing was being constructed to match locational preferences, it did not always align with the demand for individualised units or houses:

There are two houses that have been built in the area that he wants to live in at the moment. If he did move out into those houses, he'd potentially have to move in with other people.

(Support coordinator, Peter)

3.3 | Inadequate Housing and Support Options

The level of funding allocated in NDIS plans for housing and support was insufficient to address specific levels of impairment and associated complexity in some people's experience. Most participants experienced complex disabilities including physical, psychosocial, sensory issues or dual disabilities and health issues. Participants either were not sufficiently supported to understand how they could live well in current models with their high support needs, or offers were made for housing that did not address their complex needs.

Some participants identified concerns about receiving adequate monitoring for their health needs if living in the available models of housing. For example, Peter's support coordinator shared, 'In a nursing home you've got a, you know, RN and ENs and, you know, basically doctors coming in and out most days through the week. So – so the care, in that respect, is, sort of, there if it's needed' (Support coordinator, Peter). One participant with dual disabilities was funded to live in a group home with shared support to gain the level of staff support and monitoring she

needed. And while the house met her accessibility needs, the support coordinator reported that the staff in this setting did not have the qualifications that would enable them to dispense her medication:

..and then we had issues with that particular company not being able to look after her needs due to her high support needs and requiring S8 drug – drugs to be administered.

(Support coordinator, Fiona)

Some people had specific accommodation needs that did not align with the SDA stock that was available. For example, one participant had unique design requirements related to her disability that could not be met by the existing SDA models. She described her challenges as follows:

It's actually been really, really limiting. Because I have chemical sensitivities I can't – I need a home with cross-ventilation or a lot of air so like higher apartments get a lot of air so that would work for me. I can't live anywhere that's got vinyl flooring...– there is no way of pursuing that or figuring it out.

(Reesha)

Two participants had been offered group homes but each time, the house did not meet their access needs. Alison shared her experience:

They said there's no houses that can – can take a person my size, but they don't even know what my actual weight is here because there's nothing to weigh me properly...now I need for – the lifter – they reckon the lifter should be on the roof [sic].

(Alison)

One support coordinator noted that the participant's individual needs would need a tailored design solution and that if he had sufficient funding and opportunity, he may have been able to work with an SDA provider to come up with a solution:

Look, something that I tried with Peter, and I think would be really handy is having a purpose-built house...They would have worked with (participant) and an architect to work out what it—what he needed, based on what he wanted, his requirements, his disability, his everything. It would have been what his needs were and what he felt he needed, rather than what is already around, which would have been fantastic.

(Support coordinator, Peter)

Another person required customised support tailored to their specific level of emotional, psychological and physical needs. Her support coordinator described their need for a family-like environment:

I think what she really needs is a family like environment and so... someone that was set up in a fully accessible house, just, you know – and – and they wouldn't have to provide all the supports but if you could just find the right person.

(Support coordinator, Fiona)

3.4 | Impact of Barriers to Moving out on Participants' Experience

The final theme captures the impact of the structural barriers to moving out of RAC on the experience of participants. The combined effect of waiting to get the right funding, not being able to secure housing consistent with their locational and size preferences, and shortages of housing to meet needs relating to their disability was shown by participants and their close others to be frustrating, exhausting, limiting, dislocating and ultimately restricting.

Securing adequate funding proved to be a source of frustration and exhaustion, and most participants encountered difficulties while exploring alternatives to RAC. They found themselves having to argue to make the case to gain funding aligned with their needs. Magda described the frustration as 'like hitting my head against a brick wall'. Participants emphasised the hard work and challenges involved in gaining the correct funding and described the experience as fighting to get the support they needed:

So that just – yeah, that takes months and is exhausting if you're disabled to try and fight that. And then we had to fight – I had one bedroom. I think we then fought to get two-bedroom funding which I did get in the end, so I got the two-bedroom high physical support apartment funding with OOA³ but my most recent plan dropped off the OOA for no reason you know nothing in my circumstances had changed. So, we're doing a review to fight that at the moment which [has sapped up] my energy.

(Reesha)

Participants discussed the challenging nature of the process, expressing a sense of isolation and being offered limited assistance. Magda recounted her endeavours of trying to secure accommodation and support interstate without the support she needed. She shared, 'I've been doing, doing it all. NDIS haven't helped me at all. They've just given me a phone number and the name. So, I've had to handle it all, which I shouldn't have to do' (Magda). One support coordinator bemoaned the constant need for self-advocacy, particularly for participants already coping with a chronic condition, describing it as exhausting:

So, you've got those – you've got time and anxiety, complexity and then the person who's ultimately the driver of the resolve and decision making, lives with

her conditions which anxiety are symptoms of and – and, you know, horribly poor energy.

(Support coordinator, Reesha)

Prolonged delays resulted in people living in RAC longer than desired or necessary. Alison, who had been striving to move back into the community since her admission to RAC expressed her frustration at the length of time it was taking. She said, ‘I come in here when I – just before I was 48. I’m 53 now. How – how much longer does – do I have to beg and grovel?’ (Alison). Unmet housing preferences in relation to location and size were found to be dislocating and limiting. In Magda’s case, the only available option was a shared house if she wished to remain close to friends. Her strong preference for living alone ultimately led her to accept geographical dislocation, choosing to move interstate into a unit of her own. This highlights the trade-off she made between competing priorities in the context of limited housing options. She shared, ‘... So, I’ve decided that they were stressing me out so much, it was affecting me mentally and physically in some ways because of that. So, I’ve asked them to find me a unit up near my son’ (Magda).

In Peter’s case, whilst he held out some hope of finding an accessible house suitable for him and his family, he had made the choice to remain in RAC until his preferences (and health and medical needs) could be met. His support coordinator described the impact of him remaining away from his family:

Peter just wants to live with his family. He loves them so much. He’s got a big family. He wants to live with them. He’s so lonely, he just wants his family. He spends his whole day communicating with his family and his wife comes and sits with him all day and he just loves them... We aren’t just individuals. We like to – we-we’re social beings. We don’t want to live by ourselves, we don’t want – we’re – we don’t want to live with just support workers.

(Support coordinator, Peter)

Insufficient housing and support options tailored to meet the specific needs of participants were found to hinder the ability to transition out of RAC, ultimately constraining people’s life choices. Fiona’s support coordinator described the impact:

... she’s been there for some time now, trying to find a way out and to find a better life but, you know, the impact on day-to-day life is really significant...She’s got so much potential. If she could get into a place where she – she felt safe and secure and – and cared for, then I think like a lot of her other issues, if she had a busy full social, you know, calendar and things like that, you know, she’s got the potential to live quite a happy life.

(Support coordinator, Fiona)

With the average length of time attempting to transition out of RAC being 3 years, as detailed in Table 1, there was a prevailing sense that the process was excessively prolonged. In the words

of Ilsa, cited in the title of this article, there was an urgent plea, ‘Hurry up and get me out of here’. One support coordinator expressed the impact of assisting the person she was supporting to transition out of RAC, stating that ‘it keeps me awake at night’. Reesha recounted her own experience, noting that the majority of ‘my time is pretty much dedicated to trying to get out of here and that has been for the last four years’.

4 | Discussion

Despite having access to NDIS funding and considerable efforts to advocate for their rights, participants in this study encountered numerous challenges when trying to transition out of RAC. These challenges included getting the right support, securing the necessary funding and finding housing options aligned with their needs and preferences. Unlike the experience of long-term institutionalisation, which was found to result in low expectations, a sense of hopelessness, or resignation (Goffman 1961; Barton 1976), very few participants in this study were resigned to living in RAC. Instead, most people maintained their determination to move out, expressing frustration and impatience that it was taking so long and that they were provided with inadequate support and housing options to do so.

Participants emphasised the immense effort and difficulties they faced in securing the appropriate funding and described the experience as ‘fighting’ to get what they needed. The need for high quality transition planning, coordination and ongoing support for people moving out of institutional settings into the community is supported by evidence showing that intensive support is a key feature of successful transitions (Callaway et al. 2015; Douglas et al. 2024).

Participants faced critical challenges in securing the right housing to meet their needs and preferences. Issues included thin markets, particularly in rural and regional areas, as well as being offered housing that did not align with their preferences or disability-related needs, or the preference to live in housing located in their community and close to networks of support. Most participants were initially offered or considered for shared housing rather than their preference for individualised housing, and in an unsuitable location. This finding is supported by previous research which found that many NDIS participants receive SDA funding decisions that do not align with their needs and preferences, with most applications to live alone being rejected, even when the need for an individual dwelling was supported by evidence (Skipsey et al. 2022; Crowe et al. 2024).

Some preferences (e.g., for a purpose-built house, family home) were not deliverable in the current funding landscape. While the NDIS is ostensibly designed to be person-centred, the allocation of resources often reflects system constraints and administrative priorities rather than being a transparent negotiation within system limits. Given the government’s stated priority to transition people out of RAC, prioritisation frameworks must consider the intensity and complexity of individual support needs within this inherently diverse and high-needs cohort.

In 2020, the NDIA introduced individualised living options (ILO) as an alternative to group homes in an effort to broaden the availability of housing and living support options (NDIA 2019). This funding pays for in-home support, host living arrangements or living alone with support from community, friends and family. While ILO may have supported the needs of some participants in this study, there has been poor uptake of this scheme with the implementation of this policy at a national level compared to the promising outcomes expected (Commonwealth of Australia 2023).

It was expected that SDA housing would have an impact on the number of people living in RAC. However, as shown earlier in this paper, most people moving out of RAC are not moving into SDA (NDIA 2023), but are moving into standard disability housing options such as 'shared living arrangements using SIL funding or to other group residential settings' (NDIA 2023, 17). These are likely to be the kinds of closed settings identified in recent reports that put people with disabilities at risk of abuse, neglect, violence and exploitation (McVilly et al. 2022). The experience of participants in this study illustrates the ways in which the SDA market is not working effectively and is unable to offer what is needed.

While the YPIRAC strategy called for the construction of a more diverse range of housing options, including more options for people who wish to live with family and partners, there remain limited options to meet the range of needs of people wanting to move out of RAC. Within this study, people who expressed the choice to live with family members encountered limited options to do so, with the expectations of participants being at odds with the housing stock available. In some cases, accessible social or public housing may be better able to meet the needs of people with specific needs and preferences, for example where a larger dwelling is needed to accommodate family.

5 | Limitations

Whereas most information about NDIS participants in RAC originates from administrative data maintained by the NDIA, this study sought direct insights from participants. The participant pool was inherently self-selecting, based on either their personal interest in transitioning out of RAC or the advocacy of their supporters. This limits the study in that it primarily captures the experiences of those who, despite facing significant barriers, still possess a strong desire to transition and are willing to share their experiences. Consequently, it is likely that we heard less from those who may have become disillusioned and resigned to remaining in RAC. Conversely, the data underscores the magnitude of challenges faced even by those most motivated to leave RAC. Whilst the sample size was small, the findings offer valuable understanding of the perspectives of those currently residing in RAC and their aspirations to leave, thereby contributing to a deeper appreciation of the individual and systemic challenges involved. These insights address a critical gap in knowledge, where, despite the challenge of recruiting participants residing in RAC, there is a need for further research to build our understanding of opportunities and barriers for YPIRAC to move out of aged care.

6 | Conclusion

Overall, the YPIRAC initiative has resulted in poor outcomes because the NDIS scheme and market are failing to deliver sufficient housing and support options for people with complex disabilities and health needs. Policy solutions are needed to address the challenges faced by YPIRAC in finding housing options aligned with their needs and preferences. A first step would be to collect systematic data on the housing needs and preferences of YPIRAC to inform timely and effective responses. A second would be for all levels of government to collaborate on expanding diverse and affordable housing options that align with the needs and preferences of people wishing to leave RAC. The third is for the implementation of the new role recommended in the NDIS review, specialist navigation, to work alongside NDIS participants and their existing support team to navigate the NDIS and support the transition out of RAC (Commonwealth of Australia 2023). Further research is necessary to evaluate, from multiple perspectives and across the disability, housing and aged care systems, what kinds of support result in good outcomes for people with disabilities who want to exercise their right to move out of RAC.

Author Contributions

Elroy Dearn: writing – original draft, writing – review and editing, formal analysis, project administration, methodology, investigation, data curation. **Kate D'Cruz:** methodology, writing – review and editing, formal analysis, data curation, supervision. **Mark Brown:** writing – review and editing, formal analysis. **Jacinta Douglas:** conceptualization, writing – review and editing, supervision. **Dianne Winkler:** conceptualization, writing – review and editing, resources, supervision, funding acquisition.

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Conflicts of Interest

The authors declare no conflicts of interest.

Endnotes

- ¹ The YPIRAC strategy allows people with certain conditions or circumstances to remain in RAC, including those with health-related conditions, as well as First Nations people and people experiencing homelessness if that is their preference (see AIHW 2023).
- ² The *Aged Care Act 2024* specifies that approval may be given to people aged 50 or over when the person has a history of homelessness or is from an Aboriginal or Torres Strait Islander background (Section 55).
- ³ OOA = Onsite overnight assistance.

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