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Understanding the Housing and Support Experience of People With Complex Disability in Australia: A Qualitative Analysis of Submissions to the Disability Royal Commission

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ABSTRACT

In 2019, the Australian government established the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability ('Disability Royal Commission', DRC) to investigate widespread mistreatment of people with disability. Nearly 10,000 people with disability, their families and supporters engaged with the DRC. The Commission published 1586 de-identified narratives online, of which 485 focused on the theme of housing. The DRC also released transcripts and exhibits from 33 public hearings, including Public Hearing 3 on living in group homes for people with disability. Despite the Australian government recognising the rights of people with disability to choose where and with whom they live, many Australians with high and complex needs are living in older style group homes, with ageing parents or in residential aged care. This study analysed publicly available submission data from the DRC to better understand the housing and support needs, preferences and experiences of people with complex disability and their supporters. The findings provide critical insights to inform the co-design of user-led housing and support solutions that deliver better outcomes for people with disability.

1 | Introduction

As an original signatory to the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD), Australia has agreed to recognise and uphold the rights of people with disability (Australian Human Rights Commission 2024). Article 19 of the UNCRPD states the rights of people with disability to choose where and with whom they live. Despite these commitments, many of the 1.4 million Australians with a severe or profound disability (AIHW 2024) lack the freedom to choose their living arrangements, remaining in housing that is unsuitable for their needs, unsafe or not their preferred long-term option. These arrangements often include older style group homes, living with ageing parents or in residential aged care (RAC) (Callaway et al. 2021; Douglas et al. 2023). For Australia to fulfil its obligations under the UNCRPD, there is a need to find effective housing and support solutions that prioritise the rights and perspectives of people with disability. A key source of these perspectives is in publicly available data.

In response to widespread evidence of mistreatment and abuse faced by people with disability, in 2019 the Australian government established the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability (or 'Disability Royal Commission', DRC) (CoA 2023a). The DRC examined and exposed these problems in various environments, including workplaces, institutions, care facilities and homes, with the aim of promoting a more inclusive society that supports people with disability to be independent and live free from violence, abuse, neglect and exploitation (CoA 2023a). The DRC had high levels of engagement with nearly 10,000 people sharing their experiences through public hearings, submissions, workshops and

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private sessions. By amplifying the voices of individuals with disability, the DRC aimed to ensure their dignity and rights were upheld in all areas of life.

The DRC's Final Report was delivered to the Australian government in September 2023. It made 222 recommendations on how to improve laws, policies and practices to prevent and better protect people with disabilities from mistreatment and abuse (CoA 2023a). This paper focuses on the recommendations pertaining to housing, and specifically the future of congregate living arrangements. All Commissioners recommended reform in how congregate living arrangements, such as group homes, are delivered, including reviewing mechanisms to transition towards a separation of housing and support provision to ensure authentic choice in support provision, thereby reducing vulnerability to violence, abuse, neglect and exploitation by providers (CoA 2023b). Commissioners also recommended the implementation of models of practice for increased opportunities for social interaction, community participation, and inclusion (recommendation 7.41). However, there was some disagreement amongst the Commissioners on the role and future of group homes. At the time of writing, the Australian government has provided a response to the DRC Final Report (CoA 2023a), but has not specifically addressed the recommendations pertaining to group homes.

Two significant policy changes to the housing and support arrangements of people with disability in Australia have been made in the past 50 years. First, the closure of disability institutions from the 1970s onwards where people with disability were moved into community settings (Beadle-Brown et al. 2007; Bigby and Beadle-Brown 2018). Since then, group homes have become the predominant model of housing and support (Bigby and Beadle-Brown 2018). Group homes consist of up to six people living with shared, extensive support (Bigby and Clement 2009; Wiesel 2015). They have been likened to mini-institutions as residents still have limited or no choice over who they live with, who supports them, and how they spend their days (Mansell et al. 2013; Wiesel 2015; Morgan et al. 2024). Second, the government introduced and commenced implementation of the National Disability Insurance Scheme (NDIS) in 2013. The NDIS replaced state government funding for disability services and moved from block-funding for services to individualised funding for people with 'permanent and significant' disability with the aim of enhancing participants' choice and control (Wiesel 2015). Early research into individualised housing models such as the 10 + 1[1] model shows promising results in well-being, community integration and enhancing residents' control over their housing and support (Douglas et al. 2023, 2024). However, many people with disability and complex support needs are living in institutional or older style group homes where the rhythm of the household is determined by the needs of workers instead of participants (CoAb 2024).

Existing academic literature highlights that while some people with disability prefer congregate arrangements (Carnemolla 2022; Fisher et al. 2021; Iriarte et al. 2021), there are ongoing concerns about the limited choices residents have regarding who they live with and where they live (Mansell et al. 2013; Wiesel 2015; Morgan et al. 2024). In Australia, while scholarship has examined the practices and experiences of staff within congregate settings that share support (Bigby and Beadle-Brown 2018; Quilliam et al. 2017; Spivakovsky 2017), little is known about the circumstances that lead to people with disability and complex support needs moving into and remaining in congregate housing, or their housing and support preferences. Existing literature has mostly included the perspectives of stakeholders, staff and family members; thus, there is an absence of scholarship that centres the voices of people with disability living in congregate arrangements (exceptions include, e.g., Dearn et al. 2022; Iriarte et al. 2016). Similarly, to date, studies that have considered the work and findings of the DRC have focused on supported decision-making for people with disability (Then and Bigby 2024), recommendations about the phasing out of group homes (Bigby 2024), the manner in which disability services are regulated (Hough 2024) and the role of positive behaviour support in addressing the use of restrictive practices (Hayward 2023).

The purpose of this study was to better understand the housing and support experiences and needs of people with complex disability, through a qualitative analysis of the DRC submissions. This article draws on submissions provided to the DRC by people with disability or their family and close friends.

2 | Method

2.1 | Design

This study adopted a qualitative research design, informed by symbolic interactionism that is concerned with the meaning people ascribe to their social situations, and their interactions within these settings (Liamputtong 2020). This approach supported an in-depth exploration of the lived experience of housing and support for people with disabilities, considered within the broader social and political context of the disability service system. The qualitative design supported the analysis of publicly available documents in the form of submissions made to the DRC.

2.2 | Data Sources

Nearly 10,000 individuals with disability, along with their families and supporters, engaged with the DRC. In total, 1586 de-identified submissions ('narratives') were made available on the Commission's website to help inform the public on the experiences of those with disability. This paper is concerned with the homes and accommodation theme, for which there were 485 narratives available. Narratives were not only published online but also as addenda to the DRC Final Report, as 'Volume 1: Voices of people with disability'. In addition, the DRC made available transcripts and exhibits from each of the 33 public hearings they held on different themes or settings. For this study, the authors reviewed transcripts and exhibits from 'Public Hearing 3: The experience of living in a group home for people with disability'.

2.3 | Procedure

This project was granted an ethics exemption by the La Trobe University Human Research Ethics Committee (ref:

EIBX24002), due to the data being publicly available and de-identified.

Initial screening of submissions was conducted by two authors (PM and JS) using the inclusion criteria listed below. Submissions were only included in the final dataset for people with disability who were: (1) aged 18 and over at the time of the submission; (2) living in a congregate living arrangement (group home, institution, residential aged care) or living with ageing parents, a frequently unsustainable arrangement that creates concern for both the person with disability and their family (Carey et al. 2025; Lutz et al. 2011); and (3) required access to 24-h support. The need for access to 24-h support was determined by the description of people with disability or their family members or close friends as documented in the submissions.

The term 'congregate living arrangement' was chosen to capture the following disability housing arrangements:

- Institutions; defined as large residential centres, now predominantly closed
- Group homes; defined as smaller residential environments with shared facilities and often shared support

In the submissions, congregate living arrangements were referred to in a number of ways including 'supported disability housing', 'shared living', 'group homes' and others. To capture this difference in terminology all submission data that described a form of congregate living were included.

After initial screening, there were 134 submissions available for analysis. Of these, 127 were DRC narratives and 7 were excerpts from Public Hearing 3. Where possible, demographic data were extracted from all submissions. The DRC redacted key personal information from submissions to ensure individuals could not be identified. This meant that in some submissions, the disability type, age or location could not be determined.

2.4 | Data Analysis

Two data analysis approaches were used. First, content analysis was conducted on extracted qualitative data by two authors (JS and PM) to understand key characteristics of participants and patterns in their disability type and living arrangement (Krippendorff 2019). Second, qualitative data were analysed using reflexive thematic analysis, underpinned by the principles of symbolic interactionism, to understand how individuals made meaning of their experiences and interactions within social contexts (Braun and Clarke 2006, 2022). Thematic analysis proceeded according to six distinct phases: familiarisation with the data; generating initial codes; searching for themes; reviewing themes; defining and naming themes; and producing the final report (Braun and Clarke 2006). Submission data were read by five of the authorship team (PM, JS, FC, LW and KD), with double coding completed by three authors (KD, FC and LW). Team discussion occurred throughout the analysis to ensure consensus on the meaning of the codes and associated descriptive themes. The team comprised a research assistant with lived experience of disability who is a co-author and was involved in all stages of this project. She contributed valuable insights to the data analysis, informed by her own lived experience.

3 | Results

3.1 | Participants

Submission respondents were primarily family members of people with disability (64.2%) as compared to people with disability (35.8%). Most submissions identified a disability that impacted the person's housing and support needs. The most common disability types identified were intellectual disability (24.6%), autism (22.4%) or cerebral palsy (10.4%). The disability type was not stated for 9.7% of the submissions analysed. See Table 1.

Many submissions captured both the previous living situation (PLS) and current living situation (CLS) of the person with a disability. At the time of the DRC, most lived, or had previously lived, in group homes (PLS = 73.9%, CLS = 56.7%), with ageing parents (PLS = 7.5%, CLS = 11.9%) in residential aged care (PLS = 5.2%, CLS = 0.7%) or in NDIS-funded specialist disability accommodation (SDA) (PLS = 0%, CLS = 6.7%). While there was movement in housing type from PLS to CLS, with a reduction in numbers of people in group homes, residential aged care, institutions and supported residential services (SRS), there was also a number of people remaining in group homes.

3.2 | Thematic Findings

Analysis of the extracted data produced three main themes: (1) The congregate living experience; (2) Moving in and out of congregate living; and (3) Support preferences. Considered together, these themes capture the housing and support experiences and needs of people with complex disabilities, revealing housing instability and movement between housing options. Central to this movement is a lack of choice, autonomy and control in housing and support, and descriptions of experiences of abuse and neglect. The three themes are explored in detail, with use of quotes extracted from the submission data. A summary of the themes and sub-themes is displayed in Table 2. Pseudonyms applied in the DRC submissions have been used.

3.2.1 | Theme 1: The Congregate Living Experience

Analysis of the submission data revealed an overall dissatisfaction with congregate living. While some people valued the potential opportunity of congregate living to create a socially connected and safe environment, this vision was not realised for the majority. Three central experiences characterised congregate living: 'neglect and abuse', 'exclusion of family' and 'complaints mechanisms'.

TABLE 1 | Key characteristics of submissions and people with disability.

	n	%
Submission type		
Narrative	127	95%
Exhibit/hearing transcript	7	5%
Respondent		
Person with disability	48	35.8%
Family/friend of person with disability	86	64.2%
Disability type		
Intellectual disability	33	24.6%
Autism	30	22.4%
Cerebral palsy	14	10.4%
Other physical	10	7.5%
Other neurological	10	7.5%
Acquired brain injury	10	7.5%
Down syndrome	7	5.2%
Stroke	2	1.5%
Psychosocial	1	0.7%
Developmental delay	1	0.7%
Spinal cord injury	1	0.7%
Multiple sclerosis	1	0.7%
Vision impairment	1	0.7%
Unknown	13	9.7%
Age of person with disability		
18–19	1	0.7%
20–29	19	10.9%
30–39	22	12.6%
40–49	28	16.1%
50–59	26	14.9%
60–65	10	5.7%
Unknown	28	16.1%
Total	*134*	*100%*

3.2.1.1 | *Neglect and abuse***.** Submissions detailed experiences of abuse from other residents and staff. Alongside descriptions of abuse, submission data emphasised that residents had little or no choice over whom they lived with in congregate settings. For example, 'Kelli didn't get a choice about the people she lived with or where she lived. There just wasn't consultation. It was really – there's a vacancy here, go there' (CoA 2023c, 66). Given the lack of choice, residents described living with other residents with whom they did not get along, while others reported experiencing violence and abuse from co-residents with challenging behaviours. Lack of choice and little consideration for the mix of residents' complex support needs left people feeling uncomfortable and unsafe living with other residents, while some detailed direct experiences of sexual and physical abuse. As Ibrahim's submission described, 'The residents had serious behavioural issues and Ibrahim was bitten repeatedly. Residents also pulled out clumps of his hair, threw things at him and deliberately pushed him into tables and chairs' (CoA 2023c, 754). Another submission captured reflections on the vulnerability of people with complex disability. Lyndal, sister to Syd, said, 'If you're a person in a wheelchair, you could be sharing a house with a person who has high behaviours where they hit, bite, punch, smash things. And [Syd], he cannot move himself … He's 100 per cent vulnerable' (CoA 2023e, 383).

The lack of choice for residents living in congregate living extended to choice of staff. While some residents had funding for some paid 1:1 support provided by independent support workers, congregate living currently operates with the employment of staff by the landlord or support provider chosen by the landlord. Coupled with the lack of choice, submission data detailed instances of staff physically and sexually abusing residents. The following quote captures the despair of a parent in response to the abuse of their child from employed staff in congregate living. Rona, mother to Babette, shared, 'I got in the car and went to the house to try and beat the ambulance, because [Babette] had already been traumatised …What they did is unforgivable. It is unforgivable. You don't treat an animal like that' (CoA 2023e, 14). Submission data also described a lack of staffing, as well as concerns with responsiveness, and staff being unskilled or unqualified to work with people with complex disability. For example, Patsy, Teddy's mother, shared, '[T]he support staff that they employed just didn't have the skills for the job, they didn't have the training for the job, they didn't have very much at all' (CoA 2023d, 836). Submissions reported a disturbingly large number of examples of medical neglect, such as the provision of incorrect medication and restrictive practices, including inappropriate responses to challenging behaviours. Others described instances of inadequate supervision of residents. For example, Samson shared an experience in which he had to wait for an hour for help from the staff. He said, 'I had fallen into that position an hour earlier. It left me in a position where it was impossible to reach the buzzer and here I was vomiting and yelling for one hour' (CoA 2023f, 23). While others shared experiences of disregard for their rights and preferences, such as recognising religious beliefs or cultural practices, or supporting community access and socialisation. As shared by a family member of Kalifa, an NDIS participant, 'The fridge for [her] food was found to have virtually nothing in it aside from pork and veal – in contravention of her halal food plan' (CoA 2023e, 878).

3.2.2 | Exclusion of Family

The submission data details numerous examples of families reporting resistance from staff or housing providers to their involvement and a subsequent exclusion from the life of their family member living in congregate living. Exclusionary practices included staff and providers restricting family access, ignoring the family and providers applying for guardianship. For example, Tilda, family member of Zena, described, 'We will have to ask permission if we want to speak to her, whether

TABLE 2 | Summary of themes, sub-themes, codes and illustrative quotes.

Themes/sub-themes	Codes	Quotes
1. The congregate living experience	Describes the mostly negative experiences of living in congregate arrangements	
Neglect and abuse	Abuse from co-residents and staff; social, medical, religious and cultural neglect; conditions that lead to neglect and abuse including understaffing and underqualified/untrained staff	*'And that went on for two days. It was very abusive. I had workers yelling at me. Like, I'm in a meltdown and they're keeping me in meltdown' (Solene*, CoA 2023e, *250)* *'One time a staff member gave Laurence the wrong medication, which caused significant distress. The staff member claimed they were dyslexic and couldn't read'. (Laurence and Janine*, CoA 2023d, *253)*
Exclusion of family	Practices of providers used to exclude the families from people with disability living in congregate arrangements and family member responses.	*Eveline tried to tell her mum what was going on. 'If I was talking to mum, they'd say, "Hang up the phone right now!"' (Eveline, book 3, p. 278)* *'It's a hard road. A lot of these facilities that run these group homes don't understand where the parents are coming from. I am an advocate for my son and they don't like that. They like to be in control'. (Nikolas and Valery*, CoA 2023c, *33)*
Complaint mechanisms	The challenging process and adverse impacts of making complaints to providers and the NDIS	*'When I tell various people they are shocked at what I have endured. When I complain to NDIS, the department of health, or my member of parliament they just refer me to another organisation. When my partner complained to the guardian about the abusive group home, she was told to complain to the group home. So where does the buck stop?' (Herbert*, CoA 2023j*)* *Ollie told the provider he didn't want to do the work anymore and they threatened him with eviction. The provider's lawyers said they would 'bury' him in legal costs if he ever told anyone what was happening. Ollie reported the provider to the police, but they didn't believe him. He also made a report to the NDIA, who told him that the conduct was in the past and the provider had changed their practices. Ollie made a complaint to the Australian Human Rights Commission but said they passed his complaint back to the provider. Ollie is frustrated no-one has taken any action and feels as though he has not been listened to. (Ollie*, CoA 2023e, *135)*
2. Moving in and out of congregate living	Describes the conditions and rationales for moving into and out of congregate living	
Moving in: 'no other choice'	Conditions that lead to moving into congregate living; insufficient support; regional deficits in supports; insufficient funding and funding delays to support individualised living options; pressure from state bodies	*With her aunt and uncle aging, they could no longer care for Tracyann and placed her in a group home (Tracyann and Moya*, CoA 2023e, *669)* *When he was young, his mum was pressured into placing him in an institution. (Syd and Lyndal*, CoA 2023e, *383)*
Moving out: living with family and individualised options	Rationales and mechanisms that supported the move out of congregate living; the need for safety after inadequate support in congregate living; economic capacity of families; experiencing ongoing precarity living with ageing parents and with uncertain tenure	*This was the final straw for Vern. With no faith in the supported accommodation model he decided to go it alone. 'At our cost, we have built a unit on to our house and now our two sons live happily in the existing house together … assisted by the family and handpicked support workers'. (Raph, Santino and Vern*, CoA 2023k*)* *With the help of an advocate, Sheena sacked the service provider and brought Kia home to live with her. 'You don't do that as a sister if you have another option', Sheena told the Royal Commission. (Kia and Sheena*, CoA 2023e, *28).*

(Continues)

TABLE 2 | (Continued)

Themes/sub-themes	Codes	Quotes
3. Identified needs and preferences	Describes housing and support preferences to enable feeling safe and to live like anyone else	
Having choice and control	Choice over who you live with; choosing who supports you and how	*There was limited choice and the houses were disappointing. Most didn't feel like a home and provided limited opportunities for residents to participate in the community. (Lazlo and Philomena*, CoA 2023e, *585)* *The provider has a new CEO who has 'put some time in' getting to know him. She's met with him several times 'to try and help with this issue'. Miguel hopes it will lead to him having more say in his living arrangements. (Miguel*, CoA 2023d, *527)*
Support worker attributes and competencies	Attributes such as caring, respectful, advocacy and including family; supportive of goals and relationships; respecting privacy, confidentiality, and boundaries; Competencies such as understanding complex and individual disability support needs; health, psychosocial, physical support and support for multiple conditions; potential to be taught and adapt	*When there was a change of management, the situation improved. For the next 20 years Valery had a 'very good working relationship' with the new managers. There was good communication, understanding, respect and empathy. (Nikolas & Valery*, CoA 2023c, *34)* *'My son is now served by undertrained staff who are left to manage difficult behaviours from four residents. Their response is frequently to call police or lock themselves in the office. Behaviour management skills are totally missing.' (Newton & Lada*, CoA 2023c, *740)*

or not we can take her out to coffee. It is beyond devastating, and she won't understand' (CoA 2023e, 529). Analysis of the submission data revealed a pattern of active exclusion of families, contributing to the vulnerability of residents, and missed opportunities for maintaining their wellbeing and safety, especially in the context of behavioural management. The following quote captures the reflections of a family member on the restraint of their loved one. Benicio, brother to Sigrid shared, 'Completely contrary to our intention to rehabilitate her … they basically wanted to keep her fully restrained 24/7. We were being obstructed, deliberately prevented from progressing her' (CoA 2023e, 777).

In response to this exclusion, and the vulnerability of their family members, many of the submissions detailed how families engaged in practices to rectify the situation, such as advocating for family members and filling support gaps. However, submission data revealed an overall sense of despair with the lack of ability to protect their family members and to ensure their safety and well-being. This sentiment is captured in the following quote by Viktoria (sister of Stefanie) who says, 'I despair for the lack of truth and the lack of transparency. I despair for the lack of regard for family carers, the lack of respect for family knowledge and the lack of effective communication processes' (CoA 2023i).

3.2.3 | Complaints Mechanisms

Many submissions outlined frustrations with the lack of available complaint mechanisms, and furthermore, the lack of response to complaints. Underpinning this concern is the inherent vulnerability of many people with complex cognitive and communication impairments who are residents of congregate living, and thus the heightened need for accessible complaints processes for residents and their supporters. Submissions detailed the challenges of making complaints both within congregate living, such as to staff or the housing provider, as well as the broader disability sector. For example, one submission detailed how, after a brother, Jarrod, witnessed his sister, Neve, receiving inadequate care in a group home, he:

> made a formal complaint to the NDIS Quality and Safeguards Commission. Jarrod said the process was "totally unsatisfactory". He received a single phone call in three months to ask how it was going. Their parents felt disheartened and felt the commission was "basically a swamp" (CoA 2023c, 319).

Submissions also detailed a lack of response to complaints, and in some cases, people being 'punished' for making complaints. For example, one submission describes, 'One time, Esmae found her [Anisha, Esmae's daughter] with a broken nose and two black eyes. Esmae made a complaint to the NDIS Quality and Safeguards Commission. Nothing came of it so she found another provider' (CoA 2023d, 417). Similarly, when Nii tried to talk to staff about her family member, Ally, and offer suggestions, they ignored her and when she made a complaint, they restricted her visits to a set time each day. Following this, 'Nii made a complaint to the NDIS Quality and Safeguard Commission but is not confident anything will happen' (CoA 2023d, 505–506). Submissions also described residents being 'pushed' out of congregate living to other congregate living, in response to the resident or their supporters making a complaint. Overall, the submissions indicate the complaints mechanism to be an ineffective system, which resulted in exclusion of families, increased vulnerability of residents and further abuse.

3.3 | Theme 2: Moving in and out of Congregate Living

Submission data provided insights into the conditions and rationales for moving into and out of congregate living. While some submissions reported a satisfactory living arrangement, most submissions indicated ongoing precarity and concerns for safety and wellbeing. This consisted of 'Moving in: "no other choice"' and 'Moving out: Living with family and individualised options'.

3.3.1 | Moving in: 'No Other Choice'

Submissions commonly expressed that the move to congregate living was the only option available, or the better of two less than ideal choices. Submissions reported that families were given the option between congregate living, where support was available, or returning to or remaining at home, where families were often overwhelmed by support needs. For example, Aj was hospitalised after acquiring a brain injury. Aj's ex-wife, Renae, said the 'hospital gave the family no choice. It was either the aged care facility or home [...] We couldn't take him home – he needed 24-hour watching' (CoA 2023e, 285). Ewen also said the NDIS provided him with two options. Ewen, now in his early 50s, wanted to move out of his parent's home. He said, 'That's what they [NDIS] said to me. Live at mum and dad's or live in a group home' (CoA 2023d, 885). Insufficient support services in regional and rural areas also meant that families were left without the required support to care for their family members with complex needs. This resulted in moving into congregate living, and for some, relocating to a different town, like Teddy, who had to move several hundred kilometres away from his parents to the closest suitable group home (CoA 2023d, 836).

Some parents felt pressured by state bodies, such as child protection services, to hand over the responsibility of their child with disability. In older cases, this involved parents feeling pressured to move their child with a disability into institutional care. Within the last decade, despite deinstitutionalisation, parents still reported feeling pressured by state systems to relinquish care for their child with disability. For example, Anja, Emile's mother, said that after being hospitalised for a back injury, 'Child [protection] got involved ... they wanted me to sign a form saying that I was neglecting him' (CoA 2023e, 791), leaving her with little choice but to relinquish care. Emile was moved into a group home, and Anja continues to feel shame for handing over the care of her son to the state, saying 'I can tell you it was the worst experience of my life. To this day I struggle to tell people that [Emile] was put in care because I feel like the worst person in the world' (CoA 2023e, 791). Submissions indicate that parents were largely unsupported by both disability and family support services, with little acknowledgment for the care they had provided. Rather than family and disability services working with parents to support the child with disability to remain with the family, submissions suggest these services excluded parents and removed parental choice and control.

Some people were aware of, or were living in individualised housing options, but were pushed into congregate living due to incongruence between the person's housing and support goals and their approved NDIS funding. This incongruence was due to delays in NDIS plan approval, approved NDIS plans not aligning with housing and support preferences and systemic barriers in accessing support services. Anna's (CoA 2023e, 728–729) story encapsulated the bureaucratic process between the NDIS and SDA housing providers. Penny, Anna's daughter, said the NDIS would not approve SDA funding without Anna first being offered an SDA place, but the SDA providers would not offer an SDA place without NDIS funding approval. After a long stay in hospital, Anna had no choice but to be discharged into a group home, preventing her from having choice regarding where and with whom she lived and how services were delivered. Other people with disability had individualised living arrangements, but as their support needs changed, their requests for additional support were rejected. For example, Solene (CoA 2023e, 259) required additional support hours to sustain her independent living arrangement, but the NDIS rejected her request. Solene shared that she became homeless and ultimately moved into a group home after being refused an increase in her funding.

3.3.2 | Moving out: Living With Family and Individualised Options

For some, after years of violence and abuse in congregate living, having the person with disability move back to the family home was considered the only alternative to ensure safety. This was the case for Matilda. Her mother, Yaneke, believed Matilda was safer living at home with her ageing parents than in a group home. Yaneke was resolute, saying, 'I will never send [Matilda] there. I don't trust them because [of] what they did' (CoA 2023c, 277). A shortfall of housing and support that was tailored to the intersection of health, ageing and disability also resulted in people with complex support needs living with family. This was Baker's situation. Baker's congregate housing provider was unable to support his increasing health needs and suggested Baker move to aged care but no aged care home could support Baker's complex disability needs. Katherine, Baker's mother, had no choice but for Baker to move to the family home. Katherine concluded, 'What is needed is a dedicated facility for disabled people as they age, including medical staff who are educated in disability care' (CoA 2023e, 198). Submissions identified the precarity of these arrangements given ageing parents and their own ill health. Families were concerned about how their adult children would be safeguarded when they die. Nathalia, mother of Kaylene, said, 'if all of this is occurring while I'm alive and involved in her care, she's going to end up being another [victim of neglect], she really is, because that's what happens when there's no-one involved' (CoA 2023c, 548).

In a minority of cases, families purchased properties for their adult children with disability. This was considered the only option to ensure safety from violence and abuse, to receive the required support and to experience a decent quality of life. For example, Keely lived in a group home but inadequate staff ratios and living with others caused Keely distress. Unable to get the required NDIS funding, Keely's family 'spent their last dollar', as well as fundraising with family and businesses to purchase a property for her (CoA 2023e, 513). While families emphasised the financial and emotional burden of this arrangement, this was only an option to families who had the required level of economic capital, pointing to the reliance upon individual families to ensure the safety and security of people with complex needs.

Numerous submissions expressed people with disability wanted to live independently with support of their choosing and more autonomy over daily life. However, of those living independently, some arrangements remained precarious. This included living in housing run by providers who may place additional residents within the home, living in the private rental market with weak tenancy protections or feeling pressured by the NDIS to move back to a group home for perceived economic efficiency. For example, Alain lives in a private rental unit with 24/7 support, a combination of support workers and family, but says that the NDIA wants him to move back into a group home 'because it's cheaper' (CoA 2023e, 352). As Alain developed PTSD after a decade of neglect and abuse living in group homes, this prospect raised safety concerns. Sybil, Alain's mother, said, 'He likes his own space. There's currently no real option other than what we're doing for him to be in a safe environment' (CoA 2023e, 352).

3.4 | Theme 3: Identified Needs and Preferences

Submissions expressed a range of housing preferences. Some people wanted to live in individualised arrangements or with family, while others preferred to live in congregate arrangements. Despite negative experiences in congregate housing, numerous submissions did not identify an explicit preference to live in an alternative arrangement. Rather, submissions centred around finding a safe and secure congregate environment with the required support. Across these different types of housing arrangements, submissions highlighted common desired living and support qualities. Underpinning these qualities was the need to feel safe and to live like anyone else. For example, Talulla explained why she preferred to live in a group home with two other women, saying, 'I like living with other people. I feel safer. Being alone would not do me any good' (CoA 2023e, 589). Additionally, it was important to be supported to live a life where, as Jamal said, they 'feel normal' and are supported to 'still enjoy things I want to enjoy' (CoA 2023c, 71) or, as Zaria said, to not be treated 'any different from someone else' (CoA 2023c, 142). Submissions highlight factors that can contribute to the conditions that enable people with disability to feel safe and 'normal': having choice and control, and support worker attributes and competencies.

3.5 | Having Choice and Control

People with disability wanted choice over who they lived with. For those in congregate arrangements, having choice was important to ensure a preferred social dynamic, including having commonality with other residents, and feeling like a family or community. Submissions reported living happily with two to three other people, like Carlo, who for 10 years 'lived happily in supported accommodation with two other men' (CoA 2023c, 485). Submissions suggest that smaller, more personalised arrangements with people of the same gender may be preferable over larger, mixed-gendered congregate circumstances. Submissions also communicated a sense of disempowerment and unfairness when this choice was removed. Having choice was seen as a mechanism for ensuring safety. As Derrick said, people with disability should, 'have choices with whom they live with, in a safe friendly home environment free from abuse' (CoA 2023c, 787).

Having choice extended to people with disability choosing their own support. People with disability and their families preferred to handpick their own support staff based on their individual needs and preferences. As Layla said, choosing her own support workers 'puts the power into my hands where it should be' (CoA 2023f, 440). Control pertained to having autonomy over daily life, often in the context of living in restrictive congregate environments. As Raelene said, 'It would be nice to have my own place and be able to do what I want, when I want and with who I want, once again' (CoA 2023e, 747). Having autonomy also meant Raelene could live an 'interesting and satisfying life' (CoA 2023e, 747) by pursuing interests and activities of choice. Sarina, who lived in a group home, noted numerous aspects of her life where she wanted more autonomy. For example, Sarina said she wanted 'my [own] goals' and to determine her own bedtime rather than having to adhere to the 9:30 PM bedtime set by support staff (CoA 2023c, 707).

3.6 | Support Worker Attributes and Competencies

Submissions identified preferred support staff attributes and competencies. Attributes included being caring and respectful, having a readiness to include family in order to learn the support needs and preferences of the people they are supporting and a willingness to advocate for the people they support. Further, people with disability wanted dignified treatment that upheld human rights, and where staff were supportive of goals, relationships and external social networks and community participation. For example, Tony's family moved him to a group home where they felt, 'his rights were protected and he is treated well' (CoA 2023g), or Callan, whose current group home had a responsive complaints system (CoA 2023c, 247). Callan's mother, Kelly, explained, 'If you ring up and have a complaint, it's fixed that day, and they get back to you. If there's a problem with the carer, they're gone straight away. They don't muck about' (CoA 2023c, 247). Respect for privacy and confidentiality was paramount and could be shown with practices such as knocking before entering a bedroom and by support staff not discussing residents in shared spaces where they could be overheard. Acknowledging the boundaries of the support worker role was also important, such as not being involved in life domains not relevant to the role. For example, Jaylen, who reported the staff at his group home restricted his access to family and community, said, 'I don't want [the service provider] to interfere with my life anymore' (CoA 2023d, 196).

Competencies included staff being adequately trained. To this end, people with disability wanted support workers who understood the complex and individual nature of disability and support needs, and who could then apply that knowledge to the individual person. Given the complexity and diversity of peoples' support needs, submissions highlighted the need for different competencies within any housing arrangement, whether congregate or individualised. This included supporting both disability and health needs (in response to the vast accounts of neglect within group homes), and a combination of physical and psychosocial supports, recognising the prevalence of people with disability living with multiple conditions. Submissions identified different priorities. Some valued attributes over competencies, believing staff character was most important, whereas the skill could be taught. This was the case for Patsy, mother of Teddy, who said, 'I've handpicked all the staff … None of them have certificate three or certificate four or any certificate whatsoever. They are just decent, caring people who I can train. We can do any training and education they require' (CoA 2023d, 837). Others prioritised staff qualifications and expertise, such as Brenda, who said her son, Tristan was being supported by a 'core of the highly experienced and qualified (e.g., ex-psychiatric nurses)' support staff. Brenda emphasised how important this was as, 'continuing to give people like [Tristan] a worthwhile life is challenging – it's not just taking people out for coffees, ice-cream and shopping trips' (CoA 2023h). These varying priorities reinforce the diverse and individual needs and preferences of people with disability, informed by support needs and past experiences.

4 | Discussion

This study explored the experiences, needs and preferences of people with disability and complex support needs in congregate living, through the lens of lived experience. Our analysis illustrates how the intersection of multiple systems creates the conditions where experiences of neglect and abuse can occur. This includes an insufficient and underqualified workforce, questionable provider practices and ineffective complaint mechanisms. Further, there is an incongruence between people with disability's support and living needs and preferences, their funding arrangements and organisational structures that limit or remove individual choice. In response, people with disability and complex needs experienced forced movement into, out of, and between congregate arrangements. While some submissions indicated some people with disability are living in preferred and safe living arrangements, many remain in unsafe and precarious situations.

For those with the option, family played a pivotal role in advocacy and safeguarding people with disability. The movement between and out of congregate arrangements often involved families making complaints to housing or support providers, to the NDIS and to the NDIS Quality and Safeguards Commission. However, some providers and their staff responded by restricting family visiting, ignoring family knowledge and applying for guardianship. These actions excluded families and limited their capacity to ensure safety and better outcomes for the person with disability. The challenges of family advocating for the housing and support needs of people with disability is reported elsewhere (Baily et al. 2024; Barry et al. 2019; McIntyre et al. 2017). As with previous studies, families had to endure a high social and emotional toll from this process. However, in congregate arrangements, there were also experiences of 'punishment', such as the family potentially losing guardianship, barriers to social contact and increased incidents of violence and abuse for the person with disability.

Family capital, or lack thereof, also shaped the housing and support experiences of people with disability. Globally, evidence shows that families with children with disability experience greater financial hardship than families with children without disability (Davis et al. 2009; Isa et al. 2016; Nimbalkar et al. 2014; Xiong et al. 2011). Within this cohort, McConnell et al. (2014) identified how families with high levels of social support and low levels of financial hardship had better experiences and outcomes than those in reverse circumstances. Submissions to the DRC were consistent with this finding. Social and economic pressures on households were associated with relinquishing care that led to people moving into congregate arrangements at a young age. Conversely, some families with the economic capacity to do so purchased properties to ensure the safety and well-being of a family member with a disability. Purchasing an additional property was at significant sacrifice to household wealth, along with social and emotional stress. As a last resort option, people with disability moved back into the family home. The reliance on families to ensure the rights and safety of people with disability raises concerns for those without family to fulfil this role. Further, this highlights inequitable opportunities to realise housing and support needs and preferences when so often this was enabled by family advocacy and financial assistance. The NDIS was expected to address widespread inequities experienced by people with disability, but our findings suggest it is currently not functioning as intended. Recommendations from the DRC have the potential to address this inequity, such as connecting participants who want to move out of group homes with independent advocacy, support and advice (7.42, 7.43), paired with investment and innovation in co-designed alternative housing (7.43). We add to this by emphasising the importance of collaboration between independent support and family (when available) to ensure family knowledge is utilised.

The concept of choice was prominent throughout submissions and across the three themes. Often, choice was expressed as being absent and restricted in past and current circumstances, while the desire for choice shaped support and housing preferences. Feeling a diminished sense of choice, or no choice, in housing and/or support was a dominant experience of people with disability. Contributing factors included structures that prioritised organisational systems over participant needs and preferences, such as housing and support delivered by the same provider, or cost-saving measures and staff rosters. Systemic barriers included inadequate NDIS funding and inadequate complaint mechanisms, and a perceived lack of alternative options to congregate arrangements. In these circumstances, people with disability and their supporters emphasised feeling like they had no other choice but to be pushed into inappropriate housing and support arrangements. These experiences fall short of Australia's commitment to recognising and supporting the choices of people with disability (Australian Human Rights Commission 2024) and undermine the intentions of the NDIS to ensure people with disability have choice and control over their lives (NDIS 2024). There is an urgent need to invest in alternative housing and support models where choice is foundational. Specialist Disability Accommodation (SDA), funded through the NDIS, is one example of an alternative model with early results showing promising tenant experiences (Douglas et al. 2023, 2024). However, a complex application process and inconsistent funding outcomes for participants can make SDA inequitable and inaccessible, limiting choice and control (Crowe et al. 2024). Individualised Living Arrangements (ILAs) are another housing option where people with disability live in the community, in regular homes with community members (Bennett and Orban 2024). As such, ILAs can enable independent living and provide choice in who to live with (Bennett and Orban 2024). ILAs have reported success in Australia (Cocks and Boaden 2011) and overseas (Kilroy et al. 2015; Stancliffe et al. 2011), but little is known about the utilisation or delivery of ILAs since the introduction of the NDIS. Further research is needed into both models. Additionally, given the potential for group homes of up to three residents to remain for the foreseeable future, as indicated in the DRC recommendations, it is imperative to embed participant choice within housing and support options. Without redesigning the way support is delivered within disability housing, there is a risk that smaller group homes will remain institutional environments where people with disability continue to be just as vulnerable.

While the DRC was not explicitly focused on housing and support preferences, noted as a missed opportunity by Bigby (2024), many submissions made by those living in congregate arrangements provided insight into their preferences. Housing preferences included living alone, living with family, partners and/or children, or living with unrelated adults in shared arrangements. For those preferring shared arrangements, the number of co-residents and social dynamics mattered. This included houses with up to three residents, choosing housemates of the same gender and with shared interests. Regardless of housing type, people wanted homelike qualities including autonomy over space, the personalisation of shared space, privacy in bedrooms and the ability to choose their own staff. These preferences are consistent with other research with people with intellectual disability (Chinn et al. 2024) and NDIS participants with disability living in SDA (Douglas et al. 2024; Winkler et al. 2022). Furthermore, these preferences reflect normative ideals of home within Western societies (Easthope 2004; Mallet 2004), highlighting an intrinsic need to achieve conditions of ‘home’ that extends well beyond just placing a group of people with disability together in one dwelling.

As with housing, people with disability had diverse preferences in paid support. For some, staff qualifications were most important, while for others, the personal attributes of staff mattered more. This finding is consistent with earlier research (Topping et al. 2022a) and demonstrates the need for people with disability to have choice. However, systemic barriers restricted people with disability having choice over their support and realising their preferences, consistent with prior research (Douglas et al. 2024; Oliver et al. 2020; Topping et al. 2022b). Moreover, the broader remuneration and training of support staff was identified in the DRC findings as a perceived barrier to people receiving the required quality of support, with staff in congregate living not sufficiently skilled to work with people with complex needs. Similar constraints were reported by Topping et al. (2024), emphasising the need for good working conditions, such as fair remuneration and professional development, to attract and retain a quality workforce that can provide meaningful choice in supports for people with disability. For people living in congregate arrangements, this is twofold. First, as Topping et al. (2024) argue, ensuring a quality workforce from which to choose, and second, having mechanisms within shared living arrangements that enable informed resident choice and control over how supports are provided and by whom. The DRC recommended a review of mechanisms to transition away from the same provider providing both support and housing services (7.41). Having the one organisation being both the landlord and the service provider was identified as a major contributor to the neglect, abuse, and disempowerment of people with disability. While there is a growing body of literature in the co-design of housing for people with disability (e.g., see D'Cruz et al. 2021; Jamwal et al. 2025; Tucker et al. 2022), our findings draw attention to the need for co-design for individual and shared support mechanisms that enable residents to exercise choice and control over the service delivered. This is in line with the recommendations from the NDIS Review and DRC on the need for co-design of services with and for people with disability (Australian Government 2023; CoA 2023a). People with disability have the right to be involved in the design and development of services for them and offer valuable insights that are critical to designing practical solutions. Co-design is crucial to developing disability services that better meet the needs and preferences of people with disability and deliver better outcomes (Dobe et al. 2022; Marier-Deschênes et al. 2021).

Several practical implications to inform housing and support for people with disability have emerged from this study (see Table 3). Critically, these implications are grounded in the lived experience of people with disability and their supporters and underscore the importance of partnering with people with lived experience in the design and implementation of housing and support innovation (Morgan et al. 2024). This includes designing housing options that are homelike, reflect the needs and preferences of residents and have an inclusive culture for the involvement of families and friends. Furthermore, people with disability and their supporters need independent advocacy, support and advice regarding housing and support options. This includes increasing the awareness of people with disability and their supporters of housing choices, and to ensure that people with disability are making, or involved in making, informed decisions about their housing and support.

Mechanisms are also needed to hold service providers accountable for ensuring support staff are competent to fulfil assigned roles, including training in working with people with complex disability, and cognitive, communication and behavioural needs (Topping et al. 2022b). There is also a need for improved safeguarding and regulation in congregate settings, with active involvement of people with disability in the design and implementation of safeguarding arrangements such as formal audit processes and peer support. Community visitor schemes for people residing in congregate settings offer another approach to a regulatory system that upholds choice for people with disability. Furthermore, accessible and transparent feedback and complaints mechanisms with in-built accountability must be available to people with disability and their supporters to ensure that experiences of violence,

TABLE 3 | Housing and support in congregate living: Factors that help or hinder.

Factors supporting independence and the right to live free from violence, abuse and neglect	
Support	Choice in support, including 1:1 and shared
	Sufficient support
	Support worker attributes: caring; respectful; inclusive of family; to learn individual support needs; dignified treatment; uphold human rights; supportive of goals, relationships, social networks and community participation; respect for privacy, confidentiality and boundaries of the support worker role
	Support worker competencies: adequate training; understanding complex disability and support needs; able to advocate; physical and psychosocial support for co-conditions
Housing	Choice regarding where and with who you live
	Congregate environment that has commonality between residents; family or community-like feeling; smaller numbers; personalisation; the same gender; a home-like environment
	Safe and secure environment
	Family and friends are welcomed
Systems	Accessible and responsive complaint system – timely responses and addressing issues
	Housing and support that considers the intersection of disability, health, and ageing
Factors hindering independence and the right to live free from violence, abuse, and neglect	
Support	Restricted choice or consultation regarding 1:1 and shared support
	Insufficient support
	Staff not trying to understand individual support needs, or seek information from family and specialists
	Tension between making profit and providing adequate support
Housing	Restricted choice or consultation regarding where and with who you live
	Lack of consideration to the mix of residents and their needs
	Unsafe environment
	Family excluded—restricted access, ignoring family knowledge and experience
Systems	Inaccessible or unresponsive complaints system
	Lack of housing options in mainstream and disability housing markets

abuse and neglect, as outlined in the DRC submissions, are not tolerated.

5 | Conclusion

This study analysed publicly available submissions from the DRC to better understand the housing and support needs, preferences and experiences of people with complex disability and their supporters. In line with obligations to the UNCRPD, people with disability have the right to choice in housing and support. The findings of the DRC highlight the failings of the disability housing and support system in upholding the rights of people with disability and safeguarding from violence and abuse. Submission data indicated several factors contributing to the abuse, namely a culture of disempowerment for residents and their families or supporters, and inadequate oversight by staff, associated with a lack of staff skills in caring for residents with complex cognitive, communication and behavioural needs. The findings provide critical insights to inform the development of effective housing and support solutions that prioritise the rights and perspective of people with disability. Disability housing and support is a complex issue, with intersecting systems and policies, and an absolute need for people with disability and their families to be engaged in the co-design, trial and evaluation of solutions. This paper honours the time and emotional investment of people with disability and their families in sharing their experiences through submissions to the DRC. By analysing and considering the perspectives captured in the submissions, we better understand the conditions required for people with disability to exercise genuine choice and control over their housing and support.

Author Contributions

Kate D'Cruz: formal analysis, writing – original draft, writing – review and editing, project administration, methodology. **Fiona Carey:** formal analysis, writing – original draft, writing – review and editing, data curation, project administration, methodology. **Libby Witts:** formal analysis, writing – review and editing. **Jessie Spence:** formal analysis, writing – original draft, writing – review and editing, data curation. **Peter Mulherin:** formal analysis, writing – original draft, writing – review and editing, data curation, project administration. **Megan Topping:** writing – original draft, writing – review and editing. **Di Winkler:** conceptualization, writing – review and editing, methodology. **Jacinta Douglas:** conceptualization, writing – review and editing, methodology.

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Conflicts of Interest

The authors declare no conflicts of interest.

Endnotes

[1] The 10 + 1 model consists of approximately 10 apartments designed for people with disability peppered throughout a larger apartment complex plus one additional apartment used as a base for 24-h onsite support staff.

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