

# Being a pioneer: a qualitative study of moving into individualised housing from the perspective of adults with neurological disability

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## ABSTRACT

**Background.** Despite a move towards individualised models of housing and support for people with disability, there is limited research to inform best practice with people with neurological disability. This study was undertaken to better understand the experience of moving into individualised housing from the perspective of people living with neurological disability. **Methods.** Ten adults with neurological disability (acquired brain injury = 3; cerebral palsy = 4; muscular atrophy = 1; muscular dystrophy = 1; multiple sclerosis = 1) undertook semi-structured interviews at two time points (pre-move and 6–24 months post-move). Interviews explored participants' quality of life, community participation, social connection and support use. Transcripts from 20 interviews were analysed using constructivist grounded theory methods. Analysis moved through a process of data-driven, open and focused coding; identification of emergent themes; and relations between them using the method of constant comparison. **Results.** Two key themes emerged. Participants' lives pre-move were described as '*not a good fit*' with experiences of social isolation, lack of autonomy and limited housing choices. In contrast, life post-move was characterised as '*moving in the right direction*' with experiences of new responsibilities, building a support team and making a home. Transition between the two environments was a challenging period of adjustment in which participants felt like a pioneer navigating new opportunities and responsibilities. **Conclusion.** The findings highlight the value of moving into and living in individualised housing, contributing much needed research evidence from the perspective of people with disability. The move into individualised housing was identified as a transition experience that necessitates the development of transition-specific policy and support models to better prepare and support people during this transition.

**Keywords:** autonomy, individualised housing, independence, lived experience, neurological disability, qualitative, support, transition.

## Introduction

Young adults with neurological disability are a vulnerable cohort who have historically had limited viable housing options following serious injury or illness (Connellan 2015; Wiesel 2015). Unfortunately, the outcome for many is living in housing that is either unsuitable for the person's needs or not the person's preferred long-term housing option (Wiesel 2015). Such arrangements include sharing a house with other people with disability (i.e. group homes, shared supported accommodation), living with parents beyond the age when people would usually leave (often living with ageing parents as carers) or living in residential aged care (RAC) facilities designed for an aging population (Taleporos *et al.* 2013; Connelan 2015). Despite facing multiple barriers to moving due to having high levels of healthcare and support needs, many adults with neurological disability aspire to live as independently as possible in the community (Winkler *et al.* 2007). Additionally, although shared living arrangements are preferred by some, concerns have been raised about the limited choice available to residents regarding with

whom and where they live, inadequate engagement and participation outcomes and limited opportunities to build independence (Wiesel 2011; Mansell *et al.* 2013; Taleporos *et al.* 2013; Oliver *et al.* 2022). In recognition of these factors, there has been a worldwide shift away from shared living towards more individualised models of housing and support (Mansell and Beadle-Brown 2009; Harkes *et al.* 2014). Individualised housing options are life stage appropriate and can be tailored to an individual's needs. They aim to support the human rights of people with disability by offering increased self-determination in housing and support (Fisher *et al.* 2009; Connellan 2015).

The movement towards individualised models of housing has been supported by the shift towards personalised funding for people with disability, such as personalised budgets in the United Kingdom, Ireland and Scandinavia (Department of Health 2012; Spicker 2013; Tøssebro 2016). In the Australian context, personalised funding arrangements designed to increase choice and maximise independence allow people with disability and complex needs to access tailored support packages and individualised housing called 'Specialist Disability Accommodation' (SDA) (Australian Government 2020a). This movement enables people with neurological disability and complex needs to move into more independent living situations that have greater potential to meet individual housing needs and preferences (Australian Government 2020b; Wiesel 2020). These dwellings are mostly designed for single occupancy, are situated close to amenities and public transport, incorporate smart home and communication technology, can be customised according to a person's needs and utilise tailored support arrangements (Wiesel 2020; Aimers *et al.* 2021).

The available evidence suggests that meeting an individual's housing needs and preferences is foundational to positive outcomes, including increased self-determination, autonomy, home and community participation, mood, and social relationships (Oliver *et al.* 2022). However, most existing research has investigated the experiences and outcomes for people with intellectual disability living in individualised housing, with limited research focusing on people with neurological disability (Wright *et al.* 2020; Oliver *et al.* 2022). Furthermore, although the transition experience from hospital to home for people with neurological disability is becoming increasingly understood (Turner *et al.* 2008, 2011; Chen *et al.* 2020), there is only limited research into the experience of housing transitions. Sloan *et al.* (2012) examined the outcomes of people with acquired brain injury who transitioned to more home-like housing options (i.e. private homes, including living with parents) to those who remained in disability-specific accommodation settings. The research found that transitions to more independent, home-like situations is possible for people many years post-injury, regardless of injury severity. Home-like settings were also found to be more conducive to flexible support arrangements and were associated with gains in independence and community

participation (Sloan *et al.* 2012). Access to both formal and informal support, financial management, and emotional and behavioural control have previously been found to be common factors in the success of transitioning into more independent living for people with acquired brain injury (McColl *et al.* 1999).

Despite a small body of evidence supporting the successful transition to more independent and individualised housing, recent literature reviews have concluded that existing research is limited in both quality and quantity, making it difficult to determine the efficacy of individualised housing models (Wright *et al.* 2020; Oliver *et al.* 2022). Previous studies have included a number of different housing models and used broad housing classifications (e.g. 'home-like', independent living arrangements) that include a variety of living arrangements (e.g. living with parents, living with friends, living in a private rental, living in social housing). High-quality evidence is needed to evaluate and isolate the efficacy of individualised housing specific for adults living with neurological disability. This is especially important in the Australian context, as it is expected that funding for individualised housing (i.e. SDA dwellings) will grow by approximately \$700 million per year (Australian Government Department of Social Services n.d.). This substantial investment highlights the critical need for evidence to inform best practice.

In recognition of the need for an evidence base surrounding individualised housing, Douglas *et al.* (2023) assessed the change in individual outcomes for people with neurological disability and complex needs after moving into newly built, individualised apartments in the community. Participants reported a significant increase in health, well-being and home participation after living in individualised housing for 6–24 months, following their move from a range of living environments (e.g. group homes, residential aged care, living with parents). This preliminary research provides a starting point to understanding the outcomes of individualised housing options for people with neurological disability. However, the subjective lived experience of moving into and living in individualised housing, from the perspective of people with disability, is essential for the development of relevant policy and best practice guidelines. Accordingly, the aim of the current qualitative investigation was to gain an understanding of the experience of moving into and living in individualised housing for people with neurological disability.

## Methods

### Design

This study was undertaken to inform the development of a larger mixed-methods research project designed to systematically evaluate individual experiences and outcomes of moving to and living in newly built, individualised housing

for people with disability over a 3-year time period. This is one of two studies that have been completed from several of the first participants from the larger study. The first study examined quantitative outcomes for 15 participants (Douglas *et al.* 2023). The current study focused upon the transition experience of moving into individualised housing and reports on qualitative data from interviews conducted pre-move and 6–24 months post-move.

## Methodology

A constructivist grounded theory approach was used to guide data collection and analysis (Charmaz 2006). Grounded theory is well suited to social inquiry when there is a lack of established information available, enabling in-depth analysis of a dynamic social process, such as the transition to a new living environment (Browne 2003). We anticipated that the insider perspective would provide important insights into the impact of individualised housing models on the lives of residents and inform the development of critical policy and practice initiatives.

## Setting

This study was conducted in the context of an individualised housing model in Australia funded by the National Disability Insurance Scheme (NDIS). The NDIS provides SDA payments for people with disability and complex care needs who require housing specifically designed to maximise independence or improve the efficiency of the delivery of person-to-person support (Australian Government 2020b). Non-capital costs, such as day-to-day support and services are funded separately under the NDIS. SDA-funded housing enables individuals to transition from a range of living environments, including group homes, residential aged care and living with ageing parents, to more contemporary models of housing designed for people with disability. For participants in this study, the model of individualised housing comprised a number of apartments (e.g. 6–12) that are designed for people with disability and are peppered throughout a larger residential development (e.g. more than 70 apartments). One additional apartment is used as a base for 24-h onsite support staff, enabling people with high support needs to live in their own apartment with access to a combination of 1:1 and shared 24-h support due to the co-location of apartments. The apartments were designed to maximise the independence of people with disability and incorporate smart home and communications technology. Apartments are co-located within mainstream residential developments that are centrally located and close to accessible public transport and community amenities.

## Participants

In this study, we report on the transition experience of 10 adults (5 males; 5 females) with neurological disability who

had moved into SDA-funded apartments. Participants were aged between 30 and 57 years (mean = 38.7 years) with a disability (acquired brain injury = 3; cerebral palsy = 4; muscular atrophy = 1; muscular dystrophy = 1; multiple sclerosis = 1). All participants were NDIS participants living in SDA-funded apartments and were therefore classified as having very high support needs (Australian Government 2020b). Participants had moved from a range of pre-move living environments; four shared supported accommodation (group homes), three RAC and three living with parents. Seven of the 10 participants from this study participated in the quantitative study (Douglas *et al.* 2023).

## Procedure

This study was approved by the La Trobe University Human Ethics Committee (HEC18441). Participants were invited to participate in this study by housing providers. Following informed consent, interviews were conducted at a time and place convenient for participants, either face-to-face or via video conference (Topping *et al.* 2021). Semi-structured interviews were designed to accommodate the cognitive and communication needs of participants with the use of plain language information, verbal and visual prompts, rest breaks, and text-to-speech communication devices (Paterson and Scott-Findlay 2002). Interviews were conducted by skilled research assistants with extensive experience as allied health professionals, working with people with complex needs and communication difficulties. For participants who required assistance to participate in the interview, a close other was present. Two participants completed their first interview less than 6 months before their move. The remaining eight completed their first interview retrospectively, reflecting on their pre-move living environment an average of 5 months after moving (four less than 5 months; four between 6 and 8 months). A close other was present for two of the eight participants who completed retrospective post-move interviews. Guided interviews explored quality of life, community participation, social connection and support use, pre- and post-move for each of the participants. The pre- and post-move interview questions included: (1) How has life been for you, and what are your goals? (2) What do you do inside and outside of your home? (3) Who do you see regularly, and how often do you see them? (4) How much paid support do you receive, and how satisfied are you with your current support arrangements? All interviews were audio recorded. Retrospective interview transcripts were quality checked to ensure appropriate framing was provided to participants regarding the context of their responses, for example 'Please think back to before you moved home and answer the following questions as if you were still living at X' and 'How was life for you before you moved, and what were your goals when living at X?'. Quality checking was conducted by a researcher independent of the data collection. The research assistant

responsible for data collection then reviewed the retrospective transcripts and confirmed that the included participants provided information that was aligned with their retrospective living situation.

## Data analysis

A total of 20 transcripts from interviews conducted with the 10 participants across two time points (pre-move and post-move) were analysed using constructivist grounded theory methods (Charmaz 2006). Interviews were transcribed verbatim to create written transcripts of the participants' narratives. Identifying information (e.g. participant's name, home location) were removed from the transcripts to maintain anonymity and pseudonyms were applied. Two of the authors (S. O. and K. D.) coded all transcripts. The initial 10 transcripts were double coded to ensure consistency of coding across the two authors. Analysis followed two main phases of open and focused coding. Open coding commenced with the development of provisional codes using gerunds to capture the participants' experience. Using a process of constant comparison whereby similarities and differences in participants' experiences were compared, the initial codes became increasingly focused. Axial coding was used to construct linkages between codes and enabled the exploration of associations across participants' experiences and the development of categories and emergent themes. Where discrepancies arose, the researchers returned to the original transcripts and achieved consensus through discussion and comparison across transcripts. This process of data-driven coding and identification of emergent themes was repeated until no new themes were evident and code and theme saturation was apparent (Hennink et al. 2017).

This approach included several strategies designed to maximise the rigour of the analysis. Memo writing was used to provide an audit trail throughout the research process. In addition, coding was conducted independently across two authors and, where differences occurred, original transcripts of interviews, fieldnotes and coding memos were reviewed and the code or theme under consideration was discussed until consensus about meaning was reached. Memos were used to ensure that data analysis decisions were documented, and the process was reviewed across the research team. Finally, to show the reader that the analysis was fully grounded in the participants' accounts of themselves, illustrative quotes from the interviews were presented throughout the results, as shown in Table 1.

## Results

The findings of this study provide insights into the transition experience of moving into and living in newly built individualised apartments, informed by people with neurological disability. Two key themes emerged: (1) *Pre-move: Not a*

*good fit* and (2) *Post-move: Being a pioneer*. The first theme describes the experience of participants before they moved and was characterised by feelings of hopelessness and dissatisfaction with their housing; the second theme describes the transition experience during the first 24 months of living in their new home in which participants had an overall sense of moving in the right direction. See Table 1 for a summary of the themes and sub-themes.

### Theme 1. Pre-move: not a good fit

Participants described their pre-move housing as largely unsuitable and not reflective of their unique needs and preferences. Participants who had moved from congregated living, such as RAC or a group home, described feeling stuck in their pre-move environment. While those who were living in private homes shared concerns about having a lack of opportunities for independence and being a burden upon family. For many participants, their pre-move housing experience was accompanied by feelings of hopelessness and a lack of control over their future. Three sub-themes were identified: (1) *lack of autonomy and opportunity in everyday life*, (2) *missing meaningful social relationships* and (3) *having limited housing choices*. Although each of these sub-themes provide insights into key experiences for the participants, the sub-themes overlap and co-exist, capturing an overall dissatisfaction and frustration with their pre-move housing.

#### Lacking autonomy and opportunity in everyday life

Participants who were living in RAC or group homes experienced limited autonomy in everyday activities, such as the selection of carers/support workers, meals and their daily routine. Participants described having routines that were either rigid or not in their control. For example, Darren shared, 'They put you on a timetable. And your time to have a shower is at 8.30...you've got to have a shower then otherwise you don't get a shower at all.' Having limited privacy was also a concern of participants, with examples provided of carers/support workers entering their bedroom or bathroom without permission. Those living with parents described experiencing restricted routines and challenges navigating support arrangements, as explained by Marcus, 'If I go out late, I have to make sure that the carers arrive just when I arrive so that, if Mum is in bed, then they can meet me and put me to bed ...We disturb Mum if it is too late. So, that's always a bit of a difficulty.'

#### Missing meaningful social relationships

This sub-theme describes the impact of the pre-move home environment upon access to social relationships, such as friendships, romantic relationships and family relationships. Participants who lived in RAC or group homes spoke about either being unable to have visitors or not wanting visitors to come due to feelings of shame or



**Table 1.** Themes, sub-themes, codes and illustrative quotes.

Themes/sub-themes	Codes	Participant quotes
1. Pre-move: not a good fit	Feeling very unsatisfied with housing arrangement; feeling worthless; feeling life was meaningless; feeling frustrated	[Aged care] it's not a really nice way to live (Susan)
Lacking autonomy and opportunity in everyday life	Having limited activities; experiencing loss of autonomy in daily routine; having a rigid routine; having limited opportunities for exercise; having limited privacy; lacking everyday choices	They put you on a timetable. And your time to have a shower is at 8:30...and then you've got to have a shower then otherwise you don't get a shower at all (Darren)  If I go out late, I have to make sure that the carers arrive just when I arrive so that, if Mum is in bed, then they can meet me and put me to bed ...We disturb Mum if it is too late. So, that's always a bit of a difficulty (Marcus)
Missing meaningful social relationships	Experiencing difficulties maintaining friendships; having limited social interaction; feeling socially isolated from family and friends; housing restricting relationships	It was very difficult to have like any sort of relationship with somebody whilst you're living in aged care (Peter)  I guess the point is more, not so much about my routine but about the relationship – our relationship [having partner visit] being constrained by routine [in aged care] (Marcus)
Having limited housing choices	Having no other choice; feeling stuck; worrying about not accepting vacancy; disliking not having choice regarding housemates; experiencing difficulties with congregate setting	What I don't like about that is I'm – I'm required to share with somebody not known to me, not of my choice (Susan)  We both knew that, sooner or later, we'd have to look at nursing homes which, at that stage, was the only option. There was no other option (Mary)
2. Post-move: being a pioneer	Navigating new and complex policy; feeling unprepared; experiencing a positive change in outlook; grabbing an opportunity; expressing desire for more independence	My mood has been completely uplifted... Living here now I'm the happiest I've ever been (Andrew)  There were some transition issues in there, but they're always going to – the problems I was having, they're always going to be there, but I didn't feel very supported in that (Kara)
Building a support team	Having a team of familiar support workers; enjoying being able to hire and dismiss staff; having support workers that are invested; recruiting support workers who reflect own preferences; enjoying stability with support arrangements; having trouble with support roster	We do have our own team of workers so everyone's got their own team and different times they come in. I have a really great team...You know, because we're within our rights to say if we don't want that person, we can choose to dismiss them (Mary)  My support arrangements are more settled, but it would be reasonable to say that it's always evolving and always fluctuating (Kara)
Navigating new responsibilities	Finding responsibilities hard; experiencing maintenance issues; experiencing challenges settling in; feeling busy; feeling encouraged to become more independent; enjoying independence	It's allowed me to grow. Like with confidence, and you know, being able to manage things. I feel like I can do a lot more for myself (Sammy)  Just being aware of like with the funding side of it, I need to learn better, I'd love to learn better because I need to know what I can and can't do more than someone telling me what I can and can't do (Lisa)
Making a home	Enjoying autonomy; choosing own things; choosing meals; having choice in lifestyle; having a good routine; enjoying time alone; enjoying hobbies at home; feeling safe in building; building community connections	I like to be able to set it all up myself and then I can do what I need to do and there's no-one stopping me from doing it (Kara)  I feel like I'm having more time to myself, which is really what I enjoy (Sammy)

embarrassment associated with their 'depressing' environment. Others described unsuitable support arrangements and inflexible routines that restricted social opportunities. For example, Marcus shared, 'I had to worry about things like going to the toilet when I had a partner or even a casual acquaintance over...I guess the point is more, not so much

about my routine, but about the relationship – our relationship being constrained by routine.' The emotional toll of not having meaningful social relationships was also discussed. Considering his experience, Peter reflected, 'I struggled a lot. I think while I was in aged care my friend came once – one friend once...and that I felt really awkward about it.'

### Having limited housing choices

For many participants, their pre-move housing environment was their only option at the time. Participants spoke about not being aware of more suitable housing options and making the decision to move to their pre-move house in the absence of other options. Indeed, participants described being ‘placed’ where there was a vacancy and feeling pressure to accept this placement due to worry about having nowhere to live. Kara, for instance, spoke about accepting a housing offer because of her concerns about potential negative outcomes in the future if the offer was not accepted. Coinciding with having limited housing options was having limited choice regarding where and with whom participants lived. Susan shared, ‘What I don’t like about that is I’m – I’m required to share with somebody not known to me, not of my choice.’ Other participants spoke of the trajectory of living with parents and knowing that their living environment was not a suitable long-term option, as captured by Mary: ‘We both knew that, sooner or later, we’d have to look at nursing homes which, at that stage, was the only option. There was no other option.’

## Theme 2. Post-move: being a pioneer

The second theme relates to participants’ experiences during the first 24 months of living in their new homes, which was characterised by a period of adjustment and feeling like a pioneer. Central to the experience of ‘being a pioneer’ was navigating new and complex information regarding funding, housing and support arrangements. Additionally, although participants described the move into their new individualised homes as a valued opportunity, many felt unprepared and insufficiently supported for the transition. Despite the challenges, participants described an overall sense of ‘*moving in the right direction*’. For some participants, this included feeling encouraged to become more independent in their new home, an increase in confidence, and having an uplifted mood and feeling as though ‘life has opened up’. Others described looking forward to the opportunity of building confidence and growing in independence over time. Three sub-themes were identified: (1) *building a support team*, (2) *navigating new responsibilities* and (3) *making a home*.

### Building a support team

This sub-theme describes participants’ experiences of recruiting support workers based on their own preferences and needs. Participants felt empowered to make decisions about the recruitment of their support workers, including hiring and dismissing staff. Mary spoke about developing her support team: ‘We do have our own team of workers so everyone’s got their own team and different times they come in. I have a really great team...You know, because we’re within our rights to say if we don’t want that person, we can choose to dismiss them.’ Participants also spoke about the

value of having a familiar team with whom they felt comfortable and working collaboratively with support workers who are invested in their care. Susan shared, ‘I’m feeling valued. Rather than just a job or a chore to be done. I feel like these people who are helping me get ready, are invested in the fact that I feel ready to go out. And it changes your outlook on facing the day.’ Although participants valued the opportunity to build an individualised support team, they also experienced difficulties managing their support. Common challenges included creating and coordinating a large team of support, training support workers and maintaining a roster of support. Participants highlighted that getting support arrangements right takes considerable energy and effort and requires ongoing monitoring, as captured by Kara’s comment: ‘My support arrangements are more settled, but it would be reasonable to say that it’s always evolving and always fluctuating.’

The participants’ experience of building their own support team was also impacted by positive and negative experiences associated with onsite support arrangements. Mostly, it was highlighted that living with 24/7 onsite shared support allowed participants increased privacy and more targeted use of individual support hours. However, participants also spoke about the onsite support model being different to what they had anticipated. Common concerns included experiencing delays with the onsite support responses, having limited choice about who provides the onsite support and changes to onsite support being beyond the tenant’s control.

### Navigating new responsibilities

This sub-theme captures the everyday responsibilities and adjustments involved in moving into and living in an individualised home. Participants spoke about the challenges of keeping on top of bills, the time required to plan meals and addressing maintenance issues. Participants spoke about feeling overwhelmed at times, and although life was better, it was also more complex. For some participants, this was their first experience of living on their own with no prior opportunity to develop skills of independent living. Nonetheless, participants valued the increased freedom and control that came with their new responsibilities, as shared by Kara, ‘If we want maintenance done, we organise it...I don’t have to wait for somebody else to do it or their approval to do it.’ Participants were enjoying transitioning into a period of increased independence and were thinking about the next stage of adjustment. Some participants described feeling more confident as a consequence of managing everyday responsibilities, as shared by Sammy, ‘It’s allowed me to grow. Like with confidence, and you know, being able to manage things. I feel like I can do a lot more for myself.’ Others reflected upon the role of their support workers in encouraging their independence. For example, Andrew shared, ‘He [support worker] goes ‘well we’ll go and buy something and you can cook it.’ However, some required a

slower pace of transition, looking forward to more responsibilities and independence over time. As pointed out by Susan, 'That's what I want to do, moving in here. I want to be able to grow in independence, and not need so much help. I'm looking forward to, you know, just that next step of being able to be a bit more independent.' Part of the settling-in process also included making changes to the physical environment to further individualise their homes (e.g. accessible placement of appliances). For Sammy, this involved applying for funding to install automatic blinds. These adjustments were important, as they allowed for even further independence and self-management of responsibilities.

### Making a home

This sub-theme describes participants' experiences of having their own space and setting up this space to feel like a home. Having an individual space allowed for new experiences, such as choosing the set-up of the apartment (e.g. choice and placement of furniture), selecting their own belongings and getting a pet. Participants enjoyed the increased autonomy in daily activities, as captured in this quote from Kara: 'I like to be able to set it all up myself and then I can do what I need to do and there's no-one stopping me from doing it.' Some participants spoke about the challenges of setting up their new home and that settling in was taking longer than expected. Susan reflected, 'I still don't feel completely settled. I've still got boxes of stuff that I can't find homes for...those kinds of things overwhelm me...Settling in is a continuation, which has surprised me. It's still ongoing.' Participants were enjoying having flexibility, freedom and control over their routine. Some participants described the positive impact of this freedom upon their social life and relationships, as it allowed them to better plan social activities. Participants also enjoyed going out more and were starting to build connections in their local community, for example going to the local shops, cafes and starting to get to know people, such as shopkeepers and baristas. Lisa shared her experience of connecting with other residents in the apartment building: 'I'm a very private person and I find it hard to get to know people, but I know some of the people that live in the building, and I had a coffee with one of them.' Appreciating the increased privacy and being able to spend time alone were also common experiences among participants. Sammy said, 'I feel like I'm having more time to myself, which is really what I enjoy.' Participants also described feeling safe due to the design of the building, having 24/7 onsite support and having support workers who are concerned about their safety, which contributed to feeling more comfortable in their new home.

## Discussion

This qualitative study aimed to capture the experience of moving into and living in newly built, well located and

appropriately designed housing for people with neurological disability and complex needs. As outlined in the key themes, the findings suggest that moving into a single occupancy dwelling is a positive shift in the right direction. Participants described their pre-move housing as largely unsuitable and not suited to their needs and preferences. These experiences echo previous research that has highlighted the negative impact that having limited choice in living arrangements has on quality of life and wellbeing (Taleporos *et al.* 2013; Tichá *et al.* 2013; Salmon *et al.* 2019; Oliver *et al.* 2022). Participants talked in-depth about their experiences of moving into individualised housing and highlighted the challenging, but valued, transition process involved in moving into a built environment that offered more choice and independence. These findings build upon similar positive outcomes from the quantitative study that reported improved wellbeing, health and community participation (Douglas *et al.* 2023). Findings from the current study provide insights into the factors that can make moving into individualised housing challenging, as well as the factors that contribute to increased wellbeing and autonomy. The findings also emphasise the importance of having a good team of support and the complexity of the participants' support needs. Moving house is considered a highly stressful life event even without the added complexities for people with disability (Haslam *et al.* 2021). It is therefore not surprising that the challenges involved in this experience were highlighted in the current project.

Exploring the experience of the first 24 months of living in individualised housing from the perspective of people with disability provides valuable insights into the transition period of moving home. This transition period was a time of significant adjustment for participants, with the experience likened to being a pioneer. Although participants valued the experience of increased choice and autonomy in their daily lives, participants described a significant increase in responsibilities with limited preparation and guidance on how to best manage these new roles. Participants described a skill or experience gap between their pre-move living arrangements and their new individualised home. Many participants spoke about feeling unprepared to navigate the support arrangements and household responsibilities in their new individualised housing, describing feeling busy and at times overwhelmed by the experience. Previous research investigating the transition period from hospital into the community following acquired brain injury has found that feeling prepared for discharge from hospital and being linked with appropriate support services post-discharge are important elements that contribute to the transition experience (Turner *et al.* 2008). Findings from the present study suggest that there is scope to better support people with disability during the transition period of moving into individualised housing. Increased transition planning and assistance with navigating policy, support, and household responsibilities will assist in bridging the gap that currently exists between the housing arrangements.

Findings also emphasise the importance of having a good team of disability support workers. In this study, having a quality team of support workers was perceived as vital to wellbeing during the transition period. For many participants, building a high-quality support team was necessary to feel settled in their new home and to participate in the community. The findings also indicated that participants experienced a broad range of support needs, highlighting the importance of the individualisation of housing arrangements. Individualised support has previously been found to contribute to more positive outcomes for people with disability (Topping *et al.* 2022). Indeed, meeting an individual's needs and preferences, as well as the right to choose and have control over one's own life, are foundational to the United Nations Convention on the Rights of Persons with Disabilities (CRPD) (UN General Assembly 2007) and reflected in the policy underpinning the NDIS in Australia (Australian Government 2020a). Despite the importance of having high-quality support, participants in the current study described experiencing significant challenges in building a suitable support team and establishing a structure that suited their personal needs and preferences. Challenges regarding accessing and utilising supports have previously been reported by people with acquired brain injury during their transition from hospital to the community (Turner *et al.* 2011). Additionally, there is currently limited knowledge surrounding what constitutes quality support for people with disability (Topping *et al.* 2022). More assistance to develop a reliable support team, in conjunction with further research to better understand what contributes to quality support, is needed to ensure the transitional support needs of people who move into individualised housing are met.

Findings from the current study underscore the overall value of living in individualised housing for people with neurological disability. Although the experience of moving involved challenges, namely managing support and navigating new roles and responsibilities, participants emphasised that these challenges were worthwhile due to the highly valued increase in independence and autonomy gained in their new homes. These findings echo previous research in the context of intellectual disability (Marlow and Walker 2015; McConkey *et al.* 2018; Salmon *et al.* 2019) and support the worldwide shift away from shared living to individualised models of housing (Spicker 2013; Tøssebro 2016). Furthermore, the experience-based findings from the current study, when considered together with the quantitative findings (Douglas *et al.* 2023), provide compelling evidence of positive outcomes for people with neurological disability moving into individualised housing. In the current study, the initial 24-month period of living in an apartment was clearly a transition period, with participants settling into their homes and beginning to participate in their community. It is likely that, in the larger longitudinal study in which this smaller study is situated, we will find that living

in individualised housing presents ongoing benefits and challenges once people have settled into their home and start to participate more fully in their community. Indeed, participants in the current study, when reflecting upon their own lived experience, highlighted that living with a complex disability involves unexpected fluctuations in health. Therefore, there is a need to investigate the ongoing trajectory of people with complex disability who live in individualised housing to ensure appropriate long-term support and services are available, potentially both during and beyond the initial transition period.

The findings of the present study have important practical implications. Although previous research has emphasised the need to acknowledge transition as a distinct phase within the rehabilitation continuum (Turner *et al.* 2008), the results of the present study highlight the move into individualised housing as a transition experience that necessitates the development of transition-specific policy and support models. A gradual move approach, including support for skill acquisition to live independently, has previously been utilised by people with intellectual disability (Salmon *et al.* 2019). Our findings indicate that a similar graded transition would likely be valuable for people with neurological disability who move into individualised homes. Findings also suggest that there is a need to assist people in developing a reliable and high-quality disability support team that is suited to their personal needs.

Furthermore, although research about the housing transition experience regarding living arrangements for people with neurological disability now exists, little is documented about the preferred home design and location (Callaway *et al.* 2021). Participants in the current study discussed the benefits of location and, to a lesser extent, the benefits of tailoring the environment to suit their personal needs. This intersection between people and preferred living spaces thus warrants further investigation from the perspectives of people with disability.

This study has a number of strengths, including the collection of interview data at two time points, capturing pre- and post-move experiences, as well as the completion of data collection by skilled allied health professionals experienced in working with people with complex disability. Additionally, as findings pertain to one type of individualised housing environment (apartments integrated into new mainstream housing with availability of onsite support) for participants who qualified for SDA funding within the rules of the Australian NDIS, appropriate comparisons are made between experiences. However, this study is not without limitations. The sample used in this study is relatively small and reflects the perspectives of people with disability who were among the first to move into individualised housing in Australia. Although code and meaning saturation was evident within the data, it needs to be emphasised that the experiences revealed through this inquiry were particular to this group of participants. Thus, the transferability of the



findings needs to be considered in this light. Additionally, although there was no evidence of differences in themes for the participants who completed retrospective pre-move interviews and those who did not, it is possible that the use of retrospective interviews may have influenced reflections shared. However, there was clear evidence in the interviews that participants were actively comparing distinct pre- and post-move experiences. Finally, the current findings contribute to a limited evidence base that has investigated the experience of people with disability after moving into individualised living arrangements. Despite the findings providing valuable insights into the transition period of moving, it is important to acknowledge that these results reflect the first two time points of a 3-year longitudinal study. The longitudinal project will provide much needed insights into how people continue to adjust and the ongoing benefits and challenges of living in individualised housing.

The current study highlights the value of moving into and living in individualised housing from the perspective of people with neurological disability. Pre-move housing arrangements did not suit participants personal needs and preferences and were accompanied by feelings of hopelessness. Despite the challenges involved in moving, the experience of living in individualised housing was highly valued due to an increase in independence and autonomy. Participants gained more control over everyday living choices (e.g. sleep and wake times, meals), as well as more complex choices (e.g. support arrangements). Findings draw attention to the broad range of experiences and support needs of this cohort and, in conjunction with the quantitative study findings (Douglas *et al.* 2023), highlight the importance of the individualisation of housing arrangements. Findings support the development of personalised funding arrangements that allow people with complex disability to access tailored support packages and individualised housing. Policies and housing payments that foster the development of more contemporary and individualised housing options, such as SDA, are aligned with the human rights principles of the CRPD (UN General Assembly 2007). The challenges experienced by people with disability moving into individualised housing highlight a need for transition-specific policy and support models, including services that assist with the development of an individualised support team.

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