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RESEARCH ARTICLE

"It's going to be huge": family member experiences of the transition into individualised housing for people with disability

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ABSTRACT

Purpose: To understand the perspectives of family members supporting people with disability moving into individualised housing in the community.

Methods: A constructivist grounded theory analysis of interview transcripts for 12 family members supporting 12 people with neurological disability and complex needs aged 21–53. Family members comprised of nine mothers, one father, one sibling, and one partner. Interviews were conducted during the transition as the person with disability moved from living in group homes, residential aged care, or with family into specialist disability accommodation (SDA) apartments.

Results: Analysis of 12 interview transcripts identified two overarching themes that characterised the transitional experience, from the perspective of family members: (1) "*care transition*" and (2) "*relational transition.*" The first theme describes the practical and emotional transitions of the family members' care role as the person with disability moves to new housing. The second theme describes how this transition affects the relationship between the family member and the person with disability.

Conclusions: The move to SDA apartments has benefits for people with disability and their families, but is also characterised by adjustment challenges and stresses. Our findings illustrate the need for considered planning and support for family members of people with disabilities moving into individualised housing.

> IMPLICATIONS FOR PRACTICE

- Transition planning is critical to people with disability being empowered to manage their support teams when moving into individualised housing.
- Families can have a key role to play in supporting people with disability to identify quality support and to successfully manage a support team that aligns with their needs and preferences and supports their move towards independence.
- Families need emotional and social support to help them adjust to the role and relational changes associated with the move of their family member with disability into more individualised housing.

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Introduction

Housing is a basic human need that can significantly impact a person's quality of life [1]. For people with disability, a growing body of literature affirms the links between a person's housing, and their health, personal relationships, social networks, and independence [2]. However, a substantial number of people with disabilities and high and complex support needs have limited choice in their living arrangements [3]. Under the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD), people with disability are recognised as having the right to live in the community, with choices equal to people without disability [4]. In line with these principles, some governments have introduced funding programs which seek to provide people with disability more control over their lives, including their housing [5]. As a result, more people with disability are choosing to move away from shared living arrangements into more individualised housing [2,3].

In Australia, people with disability and high and complex needs who are participants of the National Disability Insurance Scheme (NDIS) may be eligible to receive funding to live in specialist disability accommodation (SDA) housing. This housing is designed to increase people's independence over time and enable the cost-effective delivery of person-to-person disability support. Demand projections estimate that by 2042 over 36,000 people will be eligible for SDA funding [6]. While there are different types of SDA buildings available, including shared occupancy, and villa, duplex, and townhouses [7], this study focused on a model of individual housing consisting of apartments (often 10) designed for people with disability situated within larger residential apartment developments (e.g., 70 apartments or more) that are centrally located and close to public transport and community amenities [2]. One additional apartment is used as a base for staff who provide 24-h shared onsite support. The co-location of accessible apartments enables people to use a combination of 1:1 support (e.g., personal care, community based activities) with the shared onsite support for unplanned or brief (i.e., less than 30 min) support needs (e.g., preparing a drink, snack or sandwich, assistance with medication, going to the toilet or a dropped phone).

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This support arrangement along with appropriate design and technology likely contributes to increased independence and reduced lifetime care costs [2]. More than 1,700 SDA apartments have been built for NDIS participants since 2016, and more than 1,400 are under construction [8]. As a relatively new housing model in Australia, research is needed on the impact of the "10 + 1 model" for people with disability and those closest to them.

In Australia, individualised housing models, such as 10 + 1, have evolved out of the necessity to provide an alternative to group homes. Group homes are a congregate model of living, where up to six people reside together and share 24-h support [3,9]. Since the closure of disability institutions from the 1970s onwards, group homes have become the predominant model for providing housing paired with 24-h support [10]. However, despite being situated in the community, group homes have been critiqued as being similar to institutional care because residents still experience restricted choice over their lives, including over who they live with, who they are supported by, and how they live their daily lives [3,11].

Early evaluations of the 10 + 1 model of single occupancy apartments have shown promising wellbeing outcomes and increased independence for people with disability (neurological disorder or cerebral palsy) [2,12]. Existing literature highlights the role of family members in the care and wellbeing of the people with disability they support. While family members often desire or feel it necessary to play a central role, this can have a significant impact on their own health and wellbeing [13]. The demands of care provision can result in family members feeling overwhelmed, exhausted, and isolated, with negative impacts on their physical and mental health, reduced freedom and leisure time, and employment and economic sacrifices [14]. Research also examines the perspectives of family members as they support a person with intellectual or learning disabilities transition into individualised housing. Triggers for the move into individualised housing may include unmanageable care needs, the declining health and ageing of family members, and a desire for privacy and greater independence for the person with disability [15]. While family members perceive the move to individualised housing as mutually beneficial for autonomy and independence [15], more often, family members report concerns for the quality of care and wellbeing of the person with disability [15,16]. There are distinctions between this, and the viewpoints of people with disability. While people with disability also report challenges during the transitional stage, pertaining to adjusting to new responsibilities and setting up support [15,17], equally, they report positive experiences, such as greater levels of autonomy, independence, and self-determination over daily life [15,17]. Despite the strength of this scholarship, there is little Australian-based research on the transitional experiences of individuals with neurological disability and complex needs such as brain injury, spinal injury, multiple sclerosis, or cerebral palsy [15,18]. In particular, there is limited insight into the role that family members play throughout this transition and the practices they engage in to support people with disabilities and complex care needs to move into individualised housing. Therefore, this study addresses this evidence gap, by investigating the perspectives of family members supporting a person with disability to transition into SDA apartments.

Method

This study was undertaken to inform the development of a larger ongoing longitudinal mixed-methods research project evaluating the individual experiences and outcomes of moving to and living in newly built, individualised housing for people with a neurological disability and complex needs, henceforth referred to as people with disability. The aim of the study was to explore the experience of moving into SDA apartments for people with disability, from the perspective of a family member.

Participants

Recruitment of family members was nested within the larger mixed-methods research project requiring "primary participants" to be adults with disability who were eligible for SDA funding through the NDIS. The people with disability from the larger study were asked if they could identify a close support person and if they would like to be involved in the study. "Close others" could be family members, friends, or paid support workers. For this paper, we focused on family members only. It is important to make a distinction between the perspective of family members from that of people with disability. Family members can play an important role in the lives of people with disability and make a valuable contribution in understanding the experiences of people with disability [15]. However, at times driven by paternalistic tendencies to protect and ensure support, family member viewpoints can overshadow or contradict that of the person with disability [19]. As such, caution must be shown to ensure family member perspectives do not replace those of people with disability. We mitigate this risk in two ways. First, the larger research project within which this study sits has previously reported on the experience of moving to individualised housing from the perspective of people with disability [2,12]. Second, analysis of the data focused on family member perspectives of their own experience, excluding family member interpretations of the person with disability's experience.

Twelve family members of people with disability were interviewed. Guest et al [20]. argue this sample size is sufficient to reach data saturation in qualitative enquiry when the focus of interviews is on a common or shared experience. As displayed in

Table 1. Participants.

Family member pseudonym	Primary participant pseudonym	Relationship	Primary disability	Pre-move housing
Gary	Dominic	Father	Congenital Neurological	Lived with parents
Donna	Catherine	Sister	Congenital Neurological	Lived with parents
Josie	Paul	Mother	Degenerative Neurological	Lived with parents
Debbie	Bella	Mother	Degenerative Neurological	Lived with parents
Marianna	Ivan	Mother	Acquired Neurological	Group home
Olivia	Mia	Mother	Degenerative Neurological	Lived with parents
Sarah	Janine	Mother	Degenerative Neurological	Lived with parents
Adrianna	Karen	Mother	Congenital Neurological	Lived with parents
Leslie	Tammy	Mother	Congenital Neurological	Lived with parents
Carla	Jay	Mother	Acquired Neurological	Lived with parents
Charlotte	Liam	Mother	Congenital Neurological	Residential aged care
Laura	Matthew	Partner	Degenerative Neurological	Private rental with partner

Table 1, family members included nine mothers; one father; one sister; and one partner. The people with disability were 12 adults (five males; seven females) aged between 21 and 53 years. Their primary disability reflected a number of conditions (Congenital Neurological = 5; Degenerative Neurological = 5; Acquired Neurological = 2). These individuals had moved into SDA from a range of living environments: nine living with parents; one living with a partner; one in a group home; and one in residential aged care (RAC). They had all moved into SDA funded apartments in metropolitan areas of Australia in locations that were close to public transport and community amenities.

Procedure

Ethics approval to conduct this study was obtained from the La Trobe University Human Research Ethics Committee prior to its commencement (HEC18441). Recruitment was supported through a partnership with housing and community service providers. Interviews were held between March 2019 and July 2022, and were completed both in-person and virtually. Interviews were conducted during the transitional period, where the move to new housing was imminent (up to three months prior to moving) or had recently occurred and so people with disability were still in the "settling in" period (up to six months after moving). By focusing on the transitional period our intention was to gain insights into the experiences and challenges unique to this phase of the housing journey.

Interviews with family members explored wellbeing, stress, social support, the role of a caregiver, and the quality of life for the person with disability. The interview questions included: (1) How has life been for you and the person with disability you are supporting – what have you wanted to change or keep the same? (2) Do you have any particular worries or concerns for yourself or the person with disability you are supporting? (3) How much time do you have to yourself? (4) Does the person you are supporting have significant relationships? All interviews were audio recorded, and professionally transcribed. Identifying information was removed from transcripts and pseudonyms were allocated to maintain anonymity of participants.

Data analysis

Analysis was guided by Charmaz's [21] constructivist grounded theory methodology (initial, focused, and axial coding) and was conducted using NVivo. Grounded theory is an apt approach for enquiry where current evidence is limited and new insights and perspectives are needed to better explain a social problem or experience (Flick, 2013), such as understanding the move into individualised housing. Four transcripts were double coded by four members of the research team (FC, EM, KD, and PM) to establish that themes developed from the data were consistent with interrater reliability. The remaining eight transcripts were then double coded by two members of the research team (FC and EM) to ensure consistency between the two team members. Analysis followed two main phases of open and focused coding. Open coding commenced with the development of initial themes noted within the transcripts. As initial themes were compared for similarities and differences, coding moved to focused coding. Axial coding was used to construct links between participant experiences, and focused codes were refined and combined to identify overarching and emergent themes. Regular discussion between the research team ensured consensus, and identification of data saturation. Researcher reflexivity was used *via* memos, field notes, and discussion with other authors, to challenge researcher assumptions, and to critically engage with how the authors' experiences and perceptions informed the analysis, supporting the development of emerging themes [22]. Data collection stopped at the point that no new themes emerged from the analysis of the interview data, indicating data saturation [23].

Results

Analysis of interview transcripts led to the development of two overarching themes that characterised the transitional experience, from the perspective of family members supporting people with disability to move into individualised housing: (1) "care transition" and (2) "relational transition." The first theme describes the transitions from the family members' pre-move care role to their newly formed care role as the person with disability moves into new housing. It also describes the emotional challenges and practices that accompany the physical move. The second theme describes how the change in living environment affects the relationship between the family member and person with disability, their concerns, aspirations, and relational experiences during the transition. See Table 2 for a summary of the themes and sub-themes.

Care transition

Family members described their care roles before and during the transition of the person with disability to new housing. Pre-move, family members' daily lives revolved around the care needs of the person with disability because they provided or facilitated the majority of care. During the transition, the care role was also time intense, primarily consisting of handing over care responsibilities to a paid support team. Family members described practices and challenges that accommodated the move to new housing, highlighting how the move required both physical and psychological changes. Five sub-themes were identified: "old role," "pre-move care strain," "new role," "getting the right staff," and "emotional adjustment."

Old role

The pre-move lives of family members were enmeshed with those of the person with disability. Along with their family role, they also took on formal and informal caring responsibilities. For some, this meant being the sole or primary care provider. Laura provided the "majority" of her partner's care while Sarah said "I did everything." Family members described the incidental caring that occurred due to living with the person with disability. As illustrated by Josie's quote in Table 2, family members often anticipated needs and provided care spontaneously. This care was reactive, personalised, and automatic; they often instinctively understood the needs, wants, and preferences of the person with disability and would proactively initiate care.

Pre-move care strain

Family members experienced extensive physical and psychological strain from their care role. Of note was the impact on their home life, social networks, and paid employment. The constant presence of paid support workers inhibited home life. For Adrianna, sharing her home with her daughter and paid support workers contributed to a lack of privacy and autonomy over her home:

> I just don't have any privacy, any space to myself. I can't get up in the morning and walk around in my underwear to go and make myself a cup of tea.

Table 2. Themes, Sub-themes, codes and illustrative quotes.

Themes/ sub-themes	Codes	Participant quotes
1. Care transition	The process of care roles changing through the housing journey	*I think the biggest thing is now it's all about transition from my old role to a new role (Carla)*
Old role	Describes the pre-move care role. Family members providing the majority of care or primary facilitator of care.	*If I had something like appointments, or it could be anything, I left food on Paul's table, just organised everything. But I couldn't leave [the] house like this. I have to prepare everything, put water in a certain position, open the door, all these few things was in my mind. I'm now wondering how I live without this, because it was these little preparations, which was hundreds (Josie)* *when I had Ivan at home he consumed my whole day, but it was never a problem. (Marianna)*
Pre-move care strain	Daily life revolves around PwD; restricting privacy and autonomy at home, employment and social life.	*Interviewer: 'Olivia, back then how much time did you have for yourself?'* *Olivia: 'Well, zero'* *I retired to look after him full time before he went in to the wheelchair (Laura)*
New role	Describes the new care role as PwD moves to new housing. Training new staff; implementing systems and processes; handing over care responsibilities to paid team.	*at the moment I'm trying to go through the thing of putting my – you know, a lead worker in. So, then I'm starting to train them up so I disappear (Carla)* *we had never had to train an entire support team all at once. (Leslie)*
Getting the right staff	Desired qualities and characteristics of paid support staff from the perspective of family members; good communication, forming relationships with PwD; continuity of staff.	*they communicate well. They're understanding what her needs are and things like that now. I can see her getting friendships and that with these carers (Debbie)* *a problem I find with the whole disability thing that they move on and she becomes friends with people, but they do move on. And that has been an issue for Catherine (Donna)*
Emotional adjustment	Struggling to hand over the care role; feeling replaced; remaining close-by to accommodate and compensate for this challenge.	*I'm prepared to stay until [Janine] says okay mum, you can go. (Sarah)* *I still spend a lot of time here, and may or may not put a bed here, I'm not sure yet. (Adrianna)*
2. Relational transition	How the housing journey and the move towards independence shapes the relationship between the family member and PwD.	*We have little arguments. Because he thinks he's right, and I'm his dad… (Gary)*
Relational context	Close pre-move relationships; companionship; the need for greater independence; anticipated loss post-move.	*Karen's life is my life (Adrianna)* *we can talk about everything, yes, and – and now he's not here, and I'm missing this. (Josie)* *And it was time. It was time for her to move out of home. She needed her own space. (Leslie)*
Family member concerns	Concerns for family members' capacity to continue care based on their own ageing and health needs; worried about the unknown future; concerned about quality and reliability of paid support.	*we thought if something happened to us, we need to have her successfully set up [so] that she has learnt to adapt to an environment that is created for her. (Olivia)* *it's the unknown that's [a] frightening thing, But I think once she gets used to it, she'll be fine. (Debbie)*
Establishing boundaries	Supporting the move to independence; encouraging more paid support; reinforcing the need for financial and domestic independence.	*But he's – therefore was saying – waving with his hand, 'You and I are paying for it.' And I said, 'No, you're paying for it.' I'm happy to pay my own [bills] at home now. Because he's so used to that, everything was combined (Carla)*
Family member aspirations	Family members' goals and desires for the future given their newfound autonomy; wanting to remain close to PwD; wanting own life; increase employment and travel.	*I'm going to move closer to where Liam is. And just build our relationship back up, because we haven't really had a lot to do with each other since he's been in permanent care. It's been pretty horrific. (Charlotte)* *I might have a chance to have my own life more, but it seems that that's not happening yet. It's still wrapped around what he's doing. (Gary)* *I think I need to have some time away (Donna)*

The strain of physical and psychological care impacted family members' personal and professional lives. Their all-encompassing care role restricted family members' capacity to pursue their own interests or social life. Paid employment was also affected. Laura stopped working to care for her partner: "I retired to look after him full time before he went into the wheelchair," while Gary missed out on employment opportunities to care for his son:

> I've missed out on jobs in the past, in the distant past, because they know I've got [Dominic] and I'll need time off.

Gary's experience highlighted the prejudice from some workplaces and a lack of flexibility to support families of people with disability. These examples illustrate the multidimensional impact the primary care role can have on the lives of family members.

"New role"

Some people with disability had part, or all their support staff carry over to the new housing, while others needed to set up a new team. Regardless, throughout the transition to new housing, family members continued to play a significant care role, but this took a different form. Care practices supported the transition, unique to each setting. Disability type and living arrangements informed these practices. For example, Carla had previously been living with her son Jay, and played a key role in training and facilitating Jay's existing paid support. Due to Jay's complex care and support needs he did not have the capacity to direct his own support. The housing transition was a chance for Carla to hand over the daily team management to paid staff. Carla explained how she trained the team to ensure they were equipped to properly support Jay. This encompassed a collaborative approach that included communication and sharing practices to ensure continuity of quality support.

For other family members, transitional care roles consisted of training a support team to effectively replace the care they had previously provided. Again, housing and disability contexts were relevant. For example, Leslie and Sarah trained support teams as their adult children moved interstate. While their adult children had significant support needs, both had the capacity to self-manage their paid support. As such, setting up the paid

support team was a joint effort between family members and the person with disability.

With new housing came new daily support routines that were adapted to the living environment. For Leslie and her daughter, Tammy, this process involved video-recording Tammy's support routines and organising shadow shifts to train new support workers. This was an intense and time-consuming process:

> We could start bringing the support workers in to start training them, how to get her out of bed, how to change the machines over, how to toilet her, how to shower her, all those sorts of things because it's those things that if something goes wrong, could have a big impact. So, the actual training has - the first two weeks were pretty crazy. They were pretty intense. I was - I didn't get to bed before midnight, you know, that sort of thing. (Leslie)

These examples illustrate how practices are context specific. For Carla, staff were already providing most of the support for Jay, so training consisted of implementing reliable procedures to ensure the team functioned smoothly without her. For Leslie, building a new support team combined with Tammy's capacity to manage the team, meant transitional care involved training individual staff and developing tools such as video references to demonstrate how to provide daily support.

Getting the right staff

Setting up a support team also included "getting the right staff," according to Charlotte. The right staff could relate in a friend-like manner with the person with disability and had good communication. Family members desired personal interaction between staff and the person with disability. For example, Carla encouraged staff to share details of their personal lives with her son, Jay.

The interpersonal aspect of care provision, such as joking, talking, and laughing, were valued for supporting the settling-in process. Family members identified a shift beyond the paid support role to forming friendships with the person with disability. As Marianna said, her son "gets on really well" and has built "really good rapport" with his support team, and will "sometimes even go to the pub for a beer afterwards."

Having a reliable support team to journey with people with disability through the housing transition was also valued. Having quality staff carry over to the new living environment or return after a period of personal leave was regarded as "stabilising" and "lovely" (Carla), fostered "trust" (Charlotte), and was "exciting" for the person with disability (Donna). Some family members expressed their confidence in the reliability of their paid support team. For example, Donna felt assured in her sister, Catherine's support team that "someone will pick up the slack if I'm not around I'm sure, and she's pretty well sorted with care." In contrast, family members observed the impact when continuity and reliability was absent. Family members noted staff turnover as a challenge that impacted negatively on the person with disability. As Donna explained, her sister Catherine would sometimes become friends with her workers, but in the end they would "move on."

Emotional adjustment

Family members emotionally adjusted as people with disability moved into SDA apartments. Often family members felt responsible for monitoring staff and reported challenges in handing over to paid support knowing they will not be living with the person with disability in the SDA apartment. Perceiving paid support as inadequate fuelled this anxiety. Perceptions of inadequacy were related to not understanding people with disability, and insufficient effort to rectify this. Carla and Gary provided examples:

> And it was sort of like pulling a whip out on the workers. I was saying, 'You must be doing this' … And they'd say, '[Jay]'s not interested in it'. It would drive me mental. But there's different ways you can work with [Jay] and you can get results. (Carla)

> there are people that don't listen to him and fight – They say 'I can't understand him.' I said, 'Well, you're not trying hard enough.' (Gary)

During the transition, family members described the shift in the perception of their role. Caring was not what they did, it was who they were. As such, the shift in care role required family members to let go of their long-held identity. Debbie illustrated this process:

> My nose was put out of joint because someone else is helping my daughter and not me …

> I've done it all her life and then all of a sudden other people - all of a sudden, hey, you don't - you're not needed at this point.

Some family members engaged in practices to compensate for their diminishing control over care. This included making back-up plans in anticipation of, or to avoid, possible issues that could arise from the transition. For example, Leslie rented an apartment in the same complex as her daughter. Leslie explained "I've actually got everything here. So, I can literally just pick up my handbag, get on a plane and come." Another back-up plan was having a spare bed at the apartment so family members could continue to provide ongoing informal support. Often this plan was not needed, and the bed was used for more age-appropriate plans such as friends staying over. Josie said:

> Actually, we bought a bed for me, because I thought that I will stay there for the first few weeks, I will stay overnight. … Yeah, his friends sometimes stay there, which is good. Yeah, they stay there watching – watching movies, and then friends stay over.

Relational transition

The second theme relates to the family or relational changes between the family member and the person with disability. This theme was marked with emotional contradictions. Fear of losing the person with disability's companionship was paired with acknowledging the need for age-appropriate independence, and establishing boundaries to support this. Family members expressed concerns and aspirations inherent to their role. They were concerned for their capacity to continue caring for the person with disability, while also being concerned for the adequacy of paid support in SDA. Family members also described hopes and desires for the future that pertained to maintaining or minimising their care role. Four sub-themes were identified: "*relational context*," "*family member concerns*," "*establishing boundaries*," "*family member aspirations*."

Relational context

Family members described their relationships with the person with disability as close. Indeed, the previous section examined how intertwined their lives were through daily care routines. This closeness prefaced the anticipated magnitude of the housing move and its impact on the relationship. Often, the pre-move household consisted of just the family member and the person with disability. In these cases, the angst connected to living separately was most acute. For example, Debbie described the dynamic of her relationship with her daughter as "just the two

of us" and reflected on the change ahead as "it's going to be huge." Similarly, Gary, whose partner had passed away more than a decade prior, described the relationship with his son as one of close "companionship over the years." Gary continued to discuss the anticipated loss the move would have on their relationship: "He will miss me, because I'll miss him." For those who had already moved, family members reflected on the sense of loss from the person with disability moving out of the family home. Josie noted how she was missing the closeness of the relationship with her son. She said, "we can talk about everything, yes, and – and now he's not here, and I'm missing this."

Despite this relational loss, family members acknowledged the readiness of the people with disability to have independence. As Leslie said: "It was time for [Tammy] to move out of home. She needed her own space." For some, this was also mutually desired. As Marianna said: "we both thought he was ready for this next major step." For others, the family member instigated the move into SDA, but it was embraced by the person with disability. Josie provided an example of this: "he is able to understand that he doesn't need Mummy to control him. And it's not that I control, but it was the circumstances like this. We've been together." These narratives highlight the readiness for independence while also acknowledging the enormity of the transition and associated anticipated loss.

Family member concerns

The move into an SDA apartment was rationalised, in part, by concern for the future of the person with disability considering the family member's health and wellbeing. Both parties identified the need to set up a more secure and sustainable housing and support option given the family member's own mortality. Parents wanted to see their adult children "comfortable" (Olivia) or "successfully set up" (Debbie) taking into account their own ageing. As Debbie said: "that's my main focus, that she is right, because, you know, I'm getting older too." Fears for undesired alternatives such as group homes also underpinned this motivation. As Gary reflected: "me getting old is why – one of the reasons why he wanted to move out …he doesn't want something to happen to me and he'd be shoved into a group home."

The need to move to independent living was coupled with concerns surrounding the adequacy of the SDA environment and the person with disability receiving a sufficient level of support. For example, Debbie was concerned about whether the equipment would meet her daughter's needs. Gary had trepidations connected to support, as he had previously provided the bulk of his son's care and was worried about the reliability of paid support. He said, "what if – someone's supposed to go there and they don't, and he's in bed, how's he going to call anybody else?" Marianna, whose son had previously lived in a group home, had safety concerns related to increased independence and the reduction in onsite support hours after moving into the apartment. Marianna shared a story from when her son "took his new-found independence to a new level and got himself out of bed and made himself a cup of tea, and spilt the boiling hot water in his lap." While her son received medical treatment and the living environment was rectified to prevent future incidents, Marianna reflected on her concerns for safety with independent living. Marianna said, "Him going and living on his own, as opposed to being in that share house; yeah, look, it did worry me." These contradictory concerns draw attention to the angst connected with the housing transition. The concern about the dependence of the person with disability on ageing family members and their living environment was paired with concerns for the person with disability receiving a sufficient level of support when living independently.

Establishing boundaries

Family members engaged in boundary-setting routines in response to care and household management to support and reinforce the transition to independent living. These consisted of family members prompting and reminding people with disability of their new responsibilities and setting limits on care provision. In doing so, family members provided insight into aspects of the transitional process that people with disability may find difficult. Carla noted the challenge of changing care routines for both parties but had established a time boundary for her son to contact her:

> It's very hard to break a pattern that I'm so used to getting up at quarter to six every morning from – with Jay. And I've now got him that he doesn't ring me until at least seven.

Family members reminded people with disability of their responsibility to arrange their own support or increase their paid support rather than continue to be reliant on the family member to fill in the gaps. Sarah, who travelled with her daughter Janine interstate to support the settlement process was still filling in on Janine's support team roster. Sarah prompted Janine, "You've got to start getting people [rostered] on in the afternoons," but reported that Janine said she was not ready yet. This illustrates how the transition from having a family member as the primary or sole carer to paid support requires an adjustment period. As such, as seen with Sarah, family members practised flexibility in establishing boundaries to support the housing and care transition.

Family members also engaged in establishing boundaries for household management outside of care, such as paying bills and buying groceries. Again, this included reminding people with disability of their responsibilities or encouraging them to engage in dimensions of independent living. For example, Carla reminded her son of the financial implications for utilities when costs were no longer shared, and the need to be aware of and make consumption adjustments in consideration for this.

Josie reflected on the benefits she was already seeing in their new independent living arrangement. Paul had already transitioned from his pre-move behaviour of avoiding contributing to the household, to now shopping for groceries for himself. Establishing and maintaining boundaries for care and household management point to the important aspects of adapting and building capacity in independent living skills.

Family member aspirations

Family members identified relational aspirations, as well as aspirations for more autonomy over their own lives. Relational aspirations related to re-establishing a relationship after institutional care or maintaining a close relationship with the person with disability once living separately. For example, Charlotte, who had had restricted contact with her son since he moved into RAC, planned to move closer to her son's new home to rebuild their relationship.

Those who had lived with the person with disability pre-move also identified wanting to maintain their "family unit" (Olivia), and a sense of "home" (Adrianna). For some family members, this also included relocating closer to the person with disability's new home. For example, Adrianna, who had been living with her daughter pre-move, moved at the same time as her daughter to retain physical and emotional proximity. She said:

> [Karen]'s got a degenerative condition; I don't want her separate to me. I don't want her living in a house that is run by support workers and I'm a visitor. I need to be close by, I want to keep her close by, I want to be able to come home to her.

Adrianna aspired to retain a home-like quality to their living environment as opposed to becoming a "visitor" in a house run by staff, cultivating a sense of continued emotional closeness, belonging, and familiarity. Adrianna contextualised this to Karen's degenerative condition. Practices such as relocating to ensure an ongoing family relationship illustrate the ongoing care and family role through the housing transition.

Family members also aspired to have more autonomy over their own lives. This response reflected a desire for a reduction or shift away from the predominant care roles and routines that characterised their lives pre-move. Family members spoke about general or non-specific desires such as having "more balance" (Charlotte), or "some time away" (Donna). Gary noted that this was a slow process. He said, "I might have a chance to have my own life more, but it seems that that's not happening yet. It's still wrapped around what he's doing." The non-specific and unrealised nature of these aspirations suggests family members were still situated within their care roles and perceived desired autonomy to be a distant possibility.

Others had developed more specific leisure and employment goals for themselves. The two family members with employment aspirations centred this around working in the disability sector. Sarah's aspirations captured this:

> I've got a bit of a plan. I'll go home and I'll work as much as I can. I do disability work as well. So, there should be a lot of work at home. And I just want to work as much as I can. Save as much money as I can. And in the meantime, coming down to visit [Janine] regularly.

Sarah continued,

> then, I want to go and travel for a little while in Europe for, you know, three – three to six months. However long my money lasts.

Like Carla and Gary, Sarah was in the early stages of the post-move process but had already formed concrete goals for her future, while for Carla and Gary, daily life still heavily revolved around the needs of the person with disability. This points to the individual and gradual nature of the transitional process. While there are common themes between family members, the timeframes of these transitions vary (Table 2).

Discussion

Family members play a significant role in the lives of people with disability, both relationally and with care provision. Their perspectives of the move into SDA housing for the people with disability, provide valuable insights about the transition towards independence, the challenges they faced and the practices that assist their move. The findings also point to the need for additional support that may better assist in the transition to individualised housing.

This study captured family members' transition from their "old to new role." In the "old role" the daily routines of family members and people with disability were enmeshed, often revolving around the care needs of the person with disability. Family members highlighted the physical, social, and emotional strain of their pre-move arrangement, heightened by the family members' own health needs, sometimes due to ageing. Their experiences reflect the multidimensional nature of care provision and caregiver burden [14].

The importance of building a support team at home has been highlighted in existing literature [24]. This can be seen in the practices that family members engaged in as they transitioned to their "new role," whereby care tasks changed to include training paid staff, handing over the management of support teams, and encouraging the person with disability to take a greater role in this process. Our findings show how family members implement context-specific tools and procedures to support this transition. These practices reflect the multi-system model of quality support described by Topping et al. [24,25]. Topping et al.'s model notes that close others play a central role in building and coordinating a support team, appointing a trusted key support worker for team oversight, as well as instigating team communication mechanisms. This study builds on this knowledge by providing insights into family member practices' specific to the housing transition.

The relational transition provoked mixed emotions for family members, characterised by a close relationship that both acknowledged the need for independence and a sense of loss as the person with disability moved to the SDA apartment. This sense of loss was paired with anxieties about paid support, namely about insufficient or inadequate paid support, and discomfort from the family member due to the impact of their changing care role on their identity. Such anxieties have been reported elsewhere [14,15]. Our research supports Mansell and Wilson's connection between perceptions of paid support inadequacies and desired care qualities [18]. Paid support characteristics desired by family members replicated the support provided by family, such as being friend-like and getting along, communicative, as well as having continuity in service provision. People with disability living in individualised housing also value interpersonal factors such as respect and kindness because it fosters a good relationship with paid support, but equally value paid support that enables independence and self-determination (Ashley et al. 2019; Douglas et al. 2024; Rubio-Jimenez & Kershner, 2021). Family-like paid support can provide assurances to family members as people with disabilities transition to independent living but paid support must primarily centre the needs and preferences of people with disability and support their independence.

The transition towards independence occurred slowly and was not delineated by the physical move. The idea of a gradual transition was also found by Salmon et al. [26] where people with disability utilised formal support to acquire the necessary independent living skills. Our study builds on this by identifying how family members implemented adaptive practices over the first six months post-move to support this gradual process. Adaptations consisted of compensatory practices for no longer cohabitating with the person with disability, such as having a spare bed at the person's dwelling or renting an apartment nearby. These practices were used to reduce the unease of handing the care role over to paid staff and provided reassurances, to both family and people with disability, during the transition process. Family members also established boundaries to support the shift to greater independence for both parties by putting limits on their care tasks, scaffolding independence, and reminding people with disability of their responsibilities. Notably, setting limits was practised with flexibility. Family members still made up the shortfall in support rosters so that the people with disability could transition to independence at their own pace. While other research identified unreliability or inadequacies in paid support as a reason for family members to continue to fill in on support rosters [14,15], in our study this was, in part, a response to the resistance of the people with disability to more paid support and their need to build support over time. These compensatory and support practices suggest both parties need time to adjust to their new living and

support arrangements. Further, this finding highlights the need for paid support to be delivered with flexibility, at a pace set by the person with disability, and in ways that build their confidence and comfort, as this support is often involved in intimate aspects of the person with disability's daily life.

While the move to individualised housing is primarily for the independence and quality of life of people with disability, the housing and support transition can also be beneficial for family members by increasing their autonomy [27]. Family members reflected on what the move meant for them and their own futures, informed by their changing role and increased autonomy. This included aspirations to live nearby to sustain the relationship, and in one case, rebuild the relationship after separation due to institutional care. Parallels can be drawn between the desire to relocate for physical and emotional proximity and the concerns about the support sufficiency and anticipated loss of companionship. Just as family members put in place compensatory plans to ease concerns during the transition, the desire to relocate was a more permanent response to these concerns. This provided the capacity to step back into the old role if required, and a mechanism to sustain the family relationship. Moreover, family members' desire for more time for themselves was contextualised with the dominance of their care role, where daily life revolved around the people with disability and required family members to make sacrifices. Thus, the transition to independence of people with disability equated to family members considering what they could make of their own changing life. Family members varied on realising these desires. Some relocation plans were underway, others had specific employment and recreational plans, while for some family members, relocating or having time to self was an abstract concept. This continuum of actualising aspirations points to the individual and gradual nature of embracing newfound independence.

Implications

This study demonstrates the need for proactive planning and support for family members of people with disabilities moving into individualised housing. Clarity of roles, such as family members as informal carers and the transition to formal support arrangements, is critical during the transition into individualised housing. Family members need to empower people with disability to direct and coordinate their own support team, ensuring their needs and preferences are met within these arrangements. The findings of this study suggest the value in investing time and attention in supporting family members to document the daily tasks they undertake in the caring role to ensure these tasks will be completed by formal support after the move. Examples include establishing a daily support record of what informal support is being delivered, and, if required, an incremental plan for transferring this to paid support. In addition, video recordings of family care interactions could be used to demonstrate the preferences of people with disability. By helping people with disability to manage their own support, family members play a crucial role in empowering people with disability to identify the features of quality support. Family members are encouraged to have open discussions with the person with disability about what comprises good quality paid support. Likewise, people with disability need support to identify and express personal preferences and boundaries for paid support. Exploring these needs and trialling this communication of needs in a safe environment with family members provides an opportunity to practise communication, self-advocacy and directing their own support programs. Family members also need to ensure they are aware of their own emotional needs during the transition process. Developing skills to navigate the relational changes and anxiety that can arise during moving would be beneficial for family members to ensure they are supported during the transition. This could include establishing peer and professional support for the family transition to promote social, emotional, and relational health.

Strengths, limitations, and recommendations for further research

This study utilised a rigorous qualitative methodology to generate unique and novel insights into the experiences of family members supporting people with disability moving into individualised housing. The findings highlight the physical, emotional and social impacts on family members and the transitional experience of shifting care to a formalised model. A strength of the study was that it focussed on the experience of family members of people with disability, complementing previous research on the need for holistic management when supporting people with disabilities during the transition into individualised housing models [2]. Limitations should also be addressed. Our findings show that family members played an important role in supporting the transition to individualised housing. However, this kind of support is not available to all people with disability. For some, the family relationships of people with disability are fraught with conflict, and in some cases, abuse [28]. This can, among other things, lead to people with disability instead developing and leaning on close relationships with a chosen family, that is, a family-like bond with non-related persons [28]. While strained and chosen families were beyond the scope of this study, further research that examines the transitional experience for these family types could advance this field of enquiry and aid the development of more nuanced formal support provision. Recruitment for this study focused within Australian metropolitan cities where people with disability were moving into individualised housing. Thus, the results are particular to this group with limited generalisability to experiences across wider geographical locations within Australia. As the study is nested within a larger study focusing on the experiences of NDIS participants within Australia, there was not a recruitment focus on individuals from culturally and linguistically diverse backgrounds. Indeed, participants' cultural and linguistic identity was not recorded in the pilot stage. Additionally, the study design is limited to people with the capacity to communicate in English. Further studies exploring the experience of culturally and linguistically diverse families, including First Nation peoples, would support further guidelines and recommendations for families. Finally, this study captured the experience of the transitional stage. Further longitudinal research that examines the family dynamic and support needs across time is needed to inform support programs to better assist families as people with disability settle into and live in individualised housing.

Conclusion

Our qualitative study highlights the care and relational transition family members make as people with disability move into individualised housing. While early findings suggest benefits for people with disability and their families, this transition was also characterised by adjustment challenges and stresses. In response, family members engaged in physical and emotional compensatory practices throughout the transitional process. Our findings point to the need for education and support from housing providers

and support services to assist and empower families as they and people with disability embark on this significant life change. This study informed the longitudinal study that aims to provide a much needed evidence base in the transitional experience and longer-term outcomes of people with disability living in new SDA.

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