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The Transition From Family Home to Alternative Living Arrangements: Experiences of Adults With Intellectual Disabilities and Their Family Members

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ABSTRACT

Background: It is well documented that many adults with intellectual disabilities live with ageing parents, often without concrete plans for transitioning to alternative living arrangements. Little is known about transition experiences once they occur. This study explores the experiences of adults with intellectual disabilities and their family members of this transition through a relational lens.

Method: Semi-structured interviews were conducted with 25 people: 8 adults with intellectual disabilities, 13 parents, and 4 siblings.

Results: Three themes were constructed from the data: 'Gaining independence and letting go', 'negotiating unfamiliar relationships' and 'social inclusion and making new connections.'

Conclusion: Adults with intellectual disabilities discussed numerous benefits associated with moving out of the family home, including increased autonomy and opportunities for new relationships. Family members also described benefits of the transition, but some grappled with needing to 'let go' whilst at the same time retaining some degree of control over their family members' lives.

1 | Introduction

Due to improvements in life expectancy, many adults with intellectual disabilities are outliving their ageing parents with whom they reside. In Australia, where this research was conducted, although there are no firm data, estimates suggest around one-third of adults with intellectual disabilities live in the family home, usually with parents (Commonwealth of Australia 2023). Accordingly, global literature has reported a need for adults with intellectual disabilities to plan for post-parental care life, including transitions to alternative living arrangements (Belperio et al. 2024). Studies have highlighted the perceptions of parents and siblings about personal and systemic barriers associated with moving or making plans to move (Cairns et al. 2013; Grey et al. 2015; Leane 2020; Lee and Burke 2020; Lindahl et al. 2019; Walker and Hutchinson 2018, 2019). However, few studies have explored the experiences of adults with intellectual disabilities or their families, in the period after their transition from the family home. This means there is little knowledge about how to best support adults with intellectual disabilities to successfully transition out of the family home or their families in adjusting to this transition.

Summary

- Moving out of the family home can be beneficial for adults with intellectual disabilities across a range of life areas.
- There is a need, however, for greater recognition of how the move affects the relationship between adults with intellectual disabilities and their family members.
- Helping adults with intellectual disabilities learn skills to build and manage new relationships is important when moving out of the family home.
- Communication between service providers, adults with intellectual disabilities, and family members before and after the move is vital to ensure a positive transition.

Research consistently finds that future planning and transitions, in general, among families where an adult son or daughter has an intellectual disability are complex (McCausland and O'Donovan 2023). For example, a study from New Zealand found a range of factors including individual familial factors as well as systemic issues (such as changing government policy and access to alternative accommodation), likely intersect to impact decision-making and 'future points of transition' (Trip et al. 2019). Studies have also found that some families wish to be supported to age in place with their adult son or daughter with intellectual disability (Chou and Kröger 2022; Kelly et al. 2020). In contrast, some families choose to transition out of the family home for various reasons, such as the changing needs of the family member with an intellectual disability, the needs of older parents, or the desire of the family member with an intellectual disability to become more independent (Grey et al. 2020; Hagan 2024).

In Australia, the National Disability Insurance Scheme (NDIS), introduced in 2013 and fully implemented by 2018, provides reasonable and necessary support for people with disabilities whose needs are not met through other service systems. The scheme is rights-based, with avenues for legal appeal if expressed needs are not met. Under this scheme, disability services are fully marketised and individualised, meaning that funding is allocated and managed by individuals rather than the government (National Disability Insurance Agency (NDIA) 2023). In terms of housing and support options, the NDIS has created opportunities for adults with disabilities to exercise greater choice and control in relation to their living arrangements and access to a more diverse range of home and living options (National Disability Insurance Agency (NDIA) 2023). For example, adults with complex disabilities can use their funding towards Specialist Disability Accommodation (SDA) and do not need to rely on the private market or social housing (Wiesel 2021).

Research on housing transitions among individuals with intellectual disabilities to date has primarily been concerned with the move from one form of disability accommodation such as an institution or group home to other forms of supported living (Bigby et al. 2017; Iriarte et al. 2021; Linehan et al. 2015). Apart from two recent UK studies (Jacobs et al. 2021; Taylor et al. 2024), research on transitions of adults with intellectual disabilities from the family home to alternative living arrangements has largely focused on younger adults or adolescents (Cahill and Guerin 2023; Roos and Søndenaa 2020; Vereijken et al. 2024) or older adults living with ageing parents (Strnadová 2019). This means there is limited knowledge about the experiences of people beyond adolescence/early adulthood but not yet past middle age transitioning out of the family home after having spent their lives with parents in a family home. This is despite growing interest in and concern for significant numbers of adults with intellectual disabilities who reside with family caregivers who either need or want to make the transition from the family home (Brennan et al. 2020; Garnham et al. 2019).

This study aimed to better understand the experiences of adults with intellectual disabilities and their family members who have made this transition. We were particularly interested in taking a relational lens, focusing on relationship dynamics between adults with intellectual disabilities and their family members, as well as relationships with service providers and paid support staff.

2 | Methods

2.1 | Study Design

As this study sought to explore the lived experience perspectives of people with intellectual disability and their family members about the transition out of the family home, a qualitative methodology using semi-structured interviews and thematic analysis, underpinned by a reflexive approach, was adopted (Braun and Clarke 2021a). Ethical approval for this study was granted by the Flinders University Human Research Ethics Committee on 15 November 2021 (No. 4635). All study participants, including family members and individuals with intellectual disability, gave informed consent prior to the interviews being conducted. All recruitment material, including consent forms, was provided in Easy Read. Additionally, prior to commencing the interview, IB, who conducted all the interviews, discussed the aims of the study and what was involved, including what consent meant with participants with intellectual disability. This allowed participants to ask questions and for IB to ensure that the adults with intellectual disabilities who were being interviewed had understood the research, the significance of their participation, and their rights within the study context.

2.2 | Recruitment

Participants were recruited through disability service providers in several states across Australia and the professional networks of the research team. Adults (aged 18+) with intellectual disabilities who had recently moved out of the family home and/or their parents or other family members who have been involved with this move were eligible to participate. The definition of 'recent' was flexible but aimed to be no more than five years ago.

2.3 | Participants

Fifteen interviews were conducted involving 25 people. As seen in Table 1, interview types included single, dyad and triad interviews. Generally, a parent or sibling responded to the recruitment invitations, and they would then decide among themselves whether the interviews would be conducted together or separately. For example, some parents chose to participate alone, whilst other families preferred to participate together with their family member with an intellectual disability. In 8 of the 15 interviews, the adult with intellectual disability who had moved out was present and took part in the interview (seven with their parent(s) or sibling, one on their own). Thirteen parents (10 mothers) and four siblings (2 sisters, 2 brothers) took part in the interviews either on their own or with their family member with intellectual disability (See Table 1). The average age of the 15 adults with intellectual disabilities who had moved out of home was 42 years (ranging from 30 to 66 years). The average length of time since moving out was two years (ranging from 10 months to five years). As Table 1 shows, 15 adults with intellectual disabilities had moved to a range of settings including three to private rental properties, two of whom were living alone and one with a housemate. Four had moved to live alone in privately owned properties. The remaining seven lived in shared supported disability accommodation; six in SDA defined as 'housing designed for people with extreme functional impairment or very high support needs' (National Disability Insurance Agency (NDIA) 2022) and one in non-SDA accommodation. All had disability support, funded by the NDIS, for a varying number of hours; ranging from drop in staff visiting the house on an ad hoc basis, to 24/7 in-home support. For 11 of the 15 adults, this was their first experience of moving out of the family home. The remaining 4 adults had experienced other out-of-home living arrangements prior to their current arrangements; including a brief period living with siblings or other short-term living arrangements that had not been satisfactory, so moving back home. Prior to the most recent move, however, all 15 were living with their families. All interviews take place between December 2021 and June 2022.

2.4 | Data Collection and Analysis

As this was during the COVID-19 pandemic and periods of restricted movement, interviews were conducted using various means including telephone, video conferencing, or in-person at the participant's home, depending on participant preference. Interviews averaged 60 min. All interviews were conducted by one of the researchers (IB) who had considerable expertise in conducting research with adults with intellectual disabilities and families experiencing this transition. Interviews explored post-transition experiences and relationships using a semi-structured schedule, that included questions of the adults with intellectual disabilities such as "How do you feel about where you live now?", "What do you like/not like about where you live?", "What is the best thing about living out of home?", "What is the hardest thing about living out of home?". Similar questions were asked of family members including: "Overall, what worked well in terms of your family member moving out of home?", "How would you describe your role in your family members life now?", "Do you have any concerns about the future?" and "Are you happy with the way things have worked out" (i.e., where and how your family member lives). All interviews were audio-recorded and transcribed verbatim by a professional transcription company under a signed confidentiality agreement with Flinders University.

Data were managed using NVivo software. Transcripts were analysed using reflexive thematic analysis (Braun and Clarke 2021a). This method of analysing data recommends the following stages: familiarisation with the data, coding, and generation and revision of themes in relation to the data. Each transcript was reviewed and coded multiple times before moving on to the next transcript, using an inductive orientation with coding at the manifest (i.e., semantic or descriptive) level (Braun and Clarke 2021b). Two of the researchers (IB, RW) then independently developed and reviewed the initial themes generated from the data, which were then discussed with other team members (CB, FR, CH, IW). This collaborative reflexive approach to theme development ensured a rich interpretation of the data; by acknowledging that the different disciplines and research backgrounds of the researchers, for example, may offer differing insights into participants' accounts. The team comprised members from disciplines of gerontology (RW), social work (CB) and geography (IW) with research expertise in ageing and disability (RW, IB, CH), family quality of life (FR), housing and adults' with intellectual disabilities (IW) and social inclusion of adults with intellectual disabilities (CB, FR).

3 | Results

Three themes were constructed from the data: (1) Gaining independence and letting go, (2) Negotiating unfamiliar relationships, and (3) Social inclusion and making new connections. We use participant quotes to illustrate these themes. Pseudonyms are used throughout to protect participant anonymity.

3.1 | Gaining Independence and Letting Go

This theme addresses the tension between adults with intellectual disabilities who seek independence by moving out of their family homes and family members who struggle to "let go" and wish to retain some oversight of their relatives' lives.

Adults with intellectual disabilities moved out of the family home for various reasons, but the desire to gain independence was often key. This desire was frequently influenced by witnessing friends or siblings moving out of the family home. As David said, "I just wanted my own independence and my own place to call home". Indeed, many described the benefits of moving out as being able to do their own things, as Henry explained:

> I like the house because I can do the things I want to do on the weekends, like I can sleep in on weekends. My weekends start on Thursday night actually, basically.

TABLE 1 | Participant demographics.

Pseudonym	Interview type	Age (years)	Marital status	Employment status (full-time FT or part-time PT)	New living arrangement	Length of current arrangement
David	Dyad—David and mother interviewed	Mother—63 David—38	Married Single	Both employed PT	Lives alone in private 1-bedroom unit attached to larger dwelling (renting)	4 years 4 months
Rose	Dyad—Rose and sister interviewed	Sister—43 Rose—30	Single Single	Employed PT N/A	SDA[a] Lives alone in 3-bedroom house	2 years 2 months
Ryan	Dyad—Ryan and brother interviewed	Brother—61 Ryan—52	Married Single	Employed PT N/A	Lives alone in private 2-bedroom apartment in a private/secure complex (purchased)	18 months
Henry	Triad—Henry and parents interviewed	Father—60 Mother—62 Henry—30	Married Married Single	Employed FT Retired Employed PT	Private 3-bedroom home in small private complex (purchased)	5 months
Monica	Triad—Monica and parents interviewed	Mother—76 Father—78 Monica—50	Married Married Single	Retired Retired Finished PT work due to COVID	SDA Studio granny flat next to larger house with 2 other residents	2 months
Frank	Single—Frank interviewed	Frank—35	Single	Employed PT	Community housing Complex with 15 one-bedroom units	6 months
Stephen	Single—mother interviewed	Mother—72 Stephen—38	Married Single	Retired Casual employment	Lives alone in private 2-bedroom unit (purchased)	4 years
Emily	Dyad—mother and Emily interviewed	Mother—75 Emily—45	Married Single	Retired Day options	Lives with one housemate in private 5-bedroom house (purchased)	1 year
Eva	Single—mother interviewed	Mother—67 Eva—40	Widow Single	Retired Day options	SDA—3-bedrooms—filled	2.5 years
Michelle	Single—mother interviewed	Mother—63 Michelle—37	Married Boyfriend	Retired Supported employment	SDA—4 bedroom and 2 attached units	1 month
Catherine	Dyad—parents interviewed	Father—82 Mother—76 Catherine—37	Married Single	Retired Day options	SDA—6 bedrooms—4 filled	9 months

(Continues)

TABLE 1 | (Continued)

Pseudonym	Interview type	Age (years)	Marital status	Employment status (full-time FT or part-time PT)	New living arrangement	Length of current arrangement
Louise	Single—mother interviewed	Mother—66 Louise—31	Married Single	Employed PT Supported employment & day options	SDA—4 bedrooms—filled	4 months
Terry	Single—sister interviewed	Sister—64 Terry—66	Divorced Single	Employed FT Day options	SDA—4 bedroom & 1 attached unit—filled	15 months
Sean	Dyad—Sean and mother interviewed	Mother—56 Sean—33	sMarried Single	Employed FT Day options	Private 3-bedroom house (purchased)—has 2 co-residents	5 months
Elizabeth	Single-brother interviewed	Brother—64 Elizabeth60	Married Single	Retired N/A	Lives in private 10 room complex (shareholder)	4 years

[a]SDA = specialist disability accommodation.

Whilst many participants, both adults and their families described the move out of home favourably, some family members wrestled with how to handle facilitating their family member's independence but also retaining oversight of their lives. This often arose from their lack of confidence or trust in paid staff or accommodation service providers to deliver good support which had become evident, for example, by their family member gaining weight, or 'misusing' alcohol since moving out,

> Henry's mother: [speaking to Henry] You're also – you're kind of learning how to be more careful about those sorts of things [speaking to interviewer] He's learning about when it's okay to have a few drinks and not to be drinking too much at certain times and bits and pieces.

> Henry's father: Yeah, that was a bit of a hiccup, wasn't it, partway through when he was drinking during the week.

This sense of needing to retain control over the life of their family member with intellectual disability, yet realising the need to 'let go', is illustrated in the following quote from the mother of Stephen, who has moved out to live alone in a privately owned home, with staff support:

> I mean now Stephen's got his own house, he can do his Nintendo as much as he likes, it's driving them [staff] nuts and we're trying to control it. I think I might have to buy a set of noise cancelling headphones for the house. But they're conscious it's his house. And you've got that balance of what's best for him. For him to make his own choices, but what is best for him.

Some family members spoke about experiencing their own 'transition' from being a primary carer in the same household, to a new form of caring from a distance. Some felt they needed to 'take a leap of faith' and step back, for the benefit of their family member:

> Yeah, look I think it's a risk to do this [person with intellectual disability to move out of home]. But it's a worthwhile risk for the benefits I think that I'm seeing in Ryan's life.
>
> (Ryan's brother)

Other family members spoke about slowly 'letting go', which one parent described as relinquishing some but not all her caregiving roles:

> I haven't changed her address or anything like that. I've kept that because I've still got her Medicare card and I still take her to the doctor. I'm not quite ready for that sort of independence yet, so if there's appointments, I still take her to those. I haven't let go that much yet.
>
> (Louise's mother)

Several family members, however, were resolute that they needed to retain control of caregiving for the time, at least, due to their lack of trust in paid staff and/or accommodation providers. Sean's mother, who is describing her need to be heavily involved in co-ordinating her son's paid supports, emphasised that her concerns were not only an issue with individual support workers, but with the oversight of co-ordinators/managers:

> Well, I was trying to not be overly involved, because we've only been doing this for six months with Sean moving out. But as I've taken my hands off, it's just gone really bad. So I'm back in there now with both hands and really railroading everybody to pull their finger out and do their jobs properly. Because stepping back hasn't been that great.

3.2 | Negotiating Unfamiliar Relationships

This theme focuses on the ways in which adults with intellectual disabilities and their family members spoke about experiences forming new relationships during or since the transition out of the family home. These included relationships with paid staff, housemates, and intimate partners.

Relationships with staff were generally positive from the perspective of most of the adults with intellectual disabilities, who were also satisfied with the support they provided. Two adults expressed some concerns about aspects of these relationships. For example, David, who lived on his own, felt overwhelmed by the staff:

> Well, now I've got support workers coming most days of the week helping me to get up and get showered and get dressed and stuff...I find that a bit overwhelming sometimes, but I know what to do...I know what to do myself, how to wash myself and all that, and do my own cleaning and chores and household stuff so - I guess just coming into my personal space [feels overwhelming]

Having a consistent group of staff with whom relationships could be formed was important for Monica. She wanted staff whom she knew and who knew her, as she found it unsettling having to get to know new staff and repeat the same information about her support need, as she explains:

> Some staff I'm happy with. And sometimes, other staff are a bit unnerving. It's because they're new, and that's why I get unnerved. It's like I have to tell them – it's like – how do you say it? The Grand Canyon – if you know – you know where the Grand Canyon is? like if you call out towards the Grand Canyon, it will repeat back what you're saying. So in a way, it's kind of like that, with new staff – and I get really frustrated.

Managing relationships with paid staff was often an area family members felt they needed to control or manage. For example, Emily's mother felt that configuring support staff in Emily's new living arrangement based on pre-existing relationships had been central to its success:

> Well because everybody that are her support workers, we knew them prior to leaving home, they've all gone out of their way to create this lovely environment in this large home and they've made it really possible by not expecting the full hourly rate. But they're all known to Emily and to us. So we didn't have to go through getting to know a new worker, all those sort of things, so it was a very smooth transition.

Finding, and choosing housemates was important for those who had moved into shared living arrangements and was something they had become accustomed to. Monica spoke about how it was important for her to have had a chance to meet her potential housemates beforehand and how she was gradually building connections:

> We had to have a meeting so that we get to know the people that I live with.

> They kind of sit around the table in the dining room... they seemed nice, but... There's some people that I connect with and some people I don't connect with straightaway. Well, how do I say it? I step by step with [housemate's name], when – first time I met him. But now I've connected with him straightaway after that. Because sometimes we like the same things. So yeah, in that way I've connected with him. And sometimes he might give me high fives, and gives me a side hug. And even though he doesn't know me very well, he still does it.

Similarly, Sean described how he had been careful about who he lived with. He explained that when he and his family were exploring options for shared accommodation, some situations were not suitable such as when one potential housemate had turned up his music and was not very welcoming, which had influenced his decision to live alone:

> One guy had his bloody music up [loud], and it was terrible.

Frank expressed a similar sentiment, choosing to live alone because:

> I have always preferred more to have my own space and not moving in with a bunch of strangers.

Opportunities for forming intimate relationships for the first time were perceived as one of the positives of moving out of home by some of the adults with intellectual disabilities, as Henry described:

> I just want to live by myself for a little while and find someone to live with me. Boy or a girl. There's a very important thing here, if a girl wants to move in with me, build a friendship with her and maybe down the track, a bit more than friends, like boyfriend and girlfriend.

Family members were more cautious, expressing views that exploring and forming new intimate relationships, often for the first time, needed to be carefully navigated and well supported. For example, when describing some of the things Ryan had experienced since moving out of home, his brother described a situation where a woman from Ryan's day options groups had stayed for a 'sleepover' which had ended abruptly because, as Ryan's brother perceived it, "I think it got a bit heavy too soon sort of thing":

> Ryan's brother: – got a bit scary for you I think in the end and you sort of –

> Ryan: Yeah. Got little bit scary and upset...Somebody slammed the gate.

> Ryan's brother: She had a disability as well...I think she opened Ryan's eyes a little bit to what happens in a relationship I think.

Elizabeth's brother shared a similar instance of his sister needing support to negotiate an intimate relationship since moving out of home. He described the 'living together charter' that provided guidelines or expectations about interacting with other homeowners/residents was part of the housing model where Elizabeth had moved. The charter included a dispute resolution process which, as he explained, he had recently supported Elizabeth to go through:

> It was just one of the guys had taken a bit of a fancy to Elizabeth. So, there was – and there was not an issue there, it was just Elizabeth was uncomfortable, and she liked him as a friend but didn't want anything further than that, which we got sorted.

3.3 | Social Inclusion and Making New Connections

This theme describes the extent to which adults with intellectual disability were forging connections or being included in their broader community since moving out of the family home.

For some of the adults with intellectual disabilities, making new social connections and relationships outside of the home was another important experience of moving out of home. Several people spoke about forming connections with their immediate neighbours. For example, Ryan had bonded with his neighbours over shared interests in the local football teams:

> Yeah. Because I – yeah, I know next door neighbours, they barrack for Power.

> And the others barrack for the Crows.

Sean had instigated a relationship with his neighbours which his mother also described as being important for him as well as beneficial for her:

> And interestingly, Sean has met his neighbours at his house as well, because one of the neighbours he cuts their lawn for them – when he cuts his little bit of lawn, he cuts theirs as well. So, they have a nice relationship. And then the [neighbours on the] other side, they always say hello and they've given me their phone number and – you know, if anything happens. So, Sean also met his neighbours by himself, which is good.
>
> (Sean's mother)

Terry's sister described the profoundly improved opportunities for socialising and connecting with the broader community Terry had experienced since moving out of home. She also reflected that such opportunities would not have been possible if he was still living at home:

> And when Terry was living at home, he wasn't getting out – nowhere near as much as what he is in the house and Terry became accustomed to that also. But because my parents were getting older, they couldn't get him out and all that sort of stuff. And I had the weekends, but I was busy doing their housework and getting everything ready to start back at work Monday and cooking foods and all that. And one of the guys [who] is a carer at the house, he's got – he has membership tickets for the [Football League] down in [town] and Terry goes to the footy every week and the guy that takes him, he's got a son that plays footy and he's been going to the footy for years and, so – and he knows everyone and everyone comes up to talk to him. All those sorts of things that never ever would've happened if I was caring for Terry at home.
>
> (Terry's sister)

Not everyone made new social connections and some family members suggested that since moving out of home their relative had experienced a degree of social isolation. David's mother expressed concerns that he may be lonely largely due to living alone and the type of neighbourhood he was living in:

> David's mother: "He gets very lonely, very lonely". There isn't anybody his age around here, they're all working or mums with young kids -

> David: Yeah.

> David's mother: He really doesn't see any neighbours.

> David: No.

> David's mother: Not even on the main street, so he's isolated.

In several cases, family members noted some downsides to relying on support staff to provide social opportunities for their relatives with intellectual disability, as described by Ryan's brother:

> Like we had [one support worker] that was taking him to the pictures all the time. And going to see something like The Matrix, and Ryan had no idea what was going on in the movie really. And maybe they thought it was nice. There was another guy that'd just take him fishing every time. You know, and that guy loved his fishing. Which is fine, but I'm not sure that Ryan was that keen on fishing.

4 | Discussion

This paper has reported on the perceptions of both adults with intellectual disability and their family members regarding moving out of the family home to alternative living arrangements, particularly focusing on changing relationships. What is clear from this research is that whilst adults with intellectual disabilities and their family members spoke about many benefits associated with the transition (including becoming more independent and in some cases, more socially connected), family members emphasised needing to retain some degree of control over their family members life, post-transition.

This apparent tension has been reported previously in research exploring the role of family in decision-making and self-determination of adults with intellectual disabilities (e.g., Bigby et al. 2022; Curryer et al. 2018, 2020a, 2020b). This research has shown that whilst adults with intellectual disabilities often strive for greater independence and autonomy, parents may find it challenging to balance supporting their independence with providing protection. Taken together, these previous findings and data from our study suggest that key concepts from family systems theory (Bowen 1966) may enhance understanding of how family dynamics shape life transitions for adults with intellectual disabilities (Hayden and Hastings 2022). Understanding post-transition relationships using family systems approaches recognises that the person with intellectual disability continues to be part of the family system, whether they are living at home or not (Knox and Bigby 2007). In relation to the current study, it could be argued that moving out of the family home affects and is affected by the entire family unit. Furthermore, this transition not only represents a shift towards independence for the individual with intellectual disability but also reflects a sense of *interdependence* whereby family members are shifting from caring in a 'hands-on' role but are still caring 'from a distance'. Therefore, post-transition experiences should acknowledge the centrality and interconnectedness of the family system, which can act both as a barrier and a facilitator to autonomy, self-determination and independence (Curryer et al. 2018, 2020a, 2020b; Taylor et al. 2019).

Research by Taylor et al. (2024) involving five adults with intellectual disabilities who had either moved out of the family home or were about to, also affirms the value of taking a family systems approach. This study described how some parents felt pressured by accommodation service providers to let go and that their continuing involvement in their family member's life was in some cases actively discouraged by service providers. They suggest that moving out of the parental home be acknowledged as a 'family experience', and an important part of the life course trajectory of adults with intellectual disabilities and their family members. They further argue that rather than being dismissed or discouraged from retaining involvement in their family members' lives, involvement of family members pre- and post-transition should be actively encouraged. This speaks to the need for accommodation service providers to allow family members to continue to be involved, where this is desired. Furthermore, our findings echo the work of Jacobs et al. (2021) and others (Boer et al. 2024; Taylor et al. 2019) which have found family caregivers potentially require support from and collaboration with service providers to assist in negotiating this complex period of the life course, including coping with the separation and shift in their life-long carer role.

Importantly, within the current study, family members' descriptions of needing to retain oversight of their family member with intellectual disability's life post-transition were often linked to a lack of trust in the service providers/staff; an issue which has similarly been reported in recent international studies. In Jacobs et al. (2021) case study of three adults with severe intellectual disabilities who had transitioned or were in the process of transitioning out of home, parents described feeling the need to retain oversight of the new arrangement, often related to high turnover of paid support staff which they felt led to communication issues and lack of consideration of their concerns (Jacobs et al. 2021). Similarly, a Dutch study involving the transition of 11 young adults with intellectual disabilities from the family home to 24-h residential care settings found that parents struggled to let go when they did not trust paid staff (Vereijken et al. 2024). Likewise, parents in an Irish study focusing on the transition of 17 adults with intellectual disabilities from group homes to more 'personalised accommodation' (defined as "rented houses or apartments where people lived alone, with one or two partners of their choosing"), (Iriarte et al. 2021, 478) noticed benefits for their family member with intellectual disability on the one hand while also expressing concern over the capacity of paid support staff (related to high staff turnover or a lack of support hours) and risks of loneliness for their family member in the new accommodation setting. Taylor et al.'s (2024) research, mentioned previously, also found such tension lay in family members' struggle with the 'policy context' of the accommodation service around promotion of choice and independence which could potentially lead to their family member making (what they felt) were 'unhealthy' choices, around food for example.

Taken together these findings emphasise the importance of acknowledging the complex relational context, in this case relationships between paid staff/accommodation service providers, family members and the person with intellectual disability, and its potential influence on the transition experience. They highlight the need for ways to enhance a collaborative partnership both before and after transitions occur, and indeed further research into how to foster effective collaborations between these key stakeholders (Bigby et al. 2022).

Moving out of home for many adults with intellectual disabilities in this research also meant being exposed to new types of relationships, for example, with paid support workers, housemates/co-residents with intellectual disabilities, and potential intimate partners. Our findings regarding some of the challenges inherent in adjusting to these new relationships suggest a potential need for capacity building in this area for both adults with intellectual disabilities and their family members. This could involve skill-building workshops to raise awareness about the new relationships that may develop during the transition out of home, which aim to build the capacity of the individual with intellectual disability in terms of self-advocacy and decision-making (Bigby 2022).

There was also evidence that some adults with intellectual disabilities were making new connections within the broader community since moving out of the family home; however, some barriers to being actively involved in community life were highlighted (albeit primarily by family members). One example of a challenge in this area was that high staff turnover in supported accommodation can result in a lack of opportunities for staff to facilitate social inclusion and 'convivial encounters' for adults with intellectual disabilities or enabling relationships which build community connections (Bigby and Wiesel 2019). This vulnerability to a 'narrowness' of relationships has also been mentioned in the research by Jacobs et al. (2021) who pointed out both positives but also negatives to social relationships post-transition where these are largely dependent on paid staff. Where on the one hand paid staff took on some of the advocacy roles and social connection previously offered by family members, they noted that such relationships may also be vulnerable to being 'cut-off' or discontinued due to factors in the service provision context such as availability of staff, or changes to funding within the service (Jacobs et al. 2021).

5 | Strengths and Limitations

To conclude, a strength of this research is that it involved the perspectives of people with intellectual disability living in a range of different living arrangements (e.g., in private rental market, and in disability-specific accommodation); with differing levels of support needs, and that the average age of the sample was older (40+), unlike previous research which has tended to focus on younger adults/adolescents. A limitation was that the perspectives of family members did tend to dominate the interviews and despite our best intentions for adults with intellectual disability who were present at the interview ($n = 8$) to actively contribute, this did not always occur. This may have been because family members were typically responsible for leading a lot of the planning, organising, and administrating the transition out of home and therefore had many things to say about all these areas and their experiences doing these things. For this reason, the data arguably reveals more about their needs and experiences as well as their perspectives of the needs and experiences of their family member with intellectual disability, as opposed to adults with intellectual disabilities perceptions per se. We also acknowledge that interviewing family members and individuals with intellectual disability together (as occurred in eight cases) might have led to a reticence to speak freely in order to preserve the relationship and/or avoid conflict. Further research in this area should therefore aim to better capture the direct perspectives of people with intellectual disability about moving out of the family home, including those with communication difficulties (Jacobs et al. 2021). Another limitation of our study was that the perspectives of parents and siblings were analysed together, rather than separately. This was due to the small number of siblings who participated ($n = 4$). Future research should distinguish between the perspectives of siblings and parents, as they are likely to be quite different. Nevertheless, given the relatively limited extant literature specifically asking adults with intellectual disability about their new living arrangement since moving out of the family home, this study offers some important understandings. It reveals what is important once the move out of home occurs, and what adults with intellectual disabilities and their families value about this new living arrangement, including where capacity building might be needed, particularly in terms of navigating changing relationships.

Author Contributions

Conceptualisation of the study, R.W., C.B., I.W., F.R. and C.H. Data collection and analysis, R.W. and I.B. Writing original draft, R.W. Review and editing subsequent drafts R.W., I.B., C.B., I.W., F.R. and C.H. All authors have read and agreed to the published version of the manuscript.

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Ethics Statement

Institutional Review Board Statement: The study was approved by the Human Research Ethics Committee of Flinders University (project number 4635; date of approval 15 November 2021).

Consent

Informed consent was obtained from all participants involved in the study.

Conflicts of Interest

The authors declare no conflicts of interest.

Data Availability Statement

The data that support the findings of this study are available from the corresponding author upon reasonable request.

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