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Adults With Intellectual Disability Moving out of the Family Home Using the National Disability Insurance Scheme: Family Members' Planning Experiences

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ABSTRACT

For adults with intellectual disability and their families, future planning and moving out of the family home in Australia will increasingly occur within the context of the National Disability Insurance Scheme (NDIS). As a market-based, individualised funding system its impact on this transition remains largely unknown. This paper reports on a qualitative study involving 17 family members who supported an adult with intellectual disability to move out of the family home using the NDIS. For many families, the NDIS provided increased funding opportunities and greater flexibility in housing and living supports than were previously available. However, they also described how navigating the Scheme and achieving desired housing and living goals had a significant impact on their well-being. More research is needed to more fully understand the mental and emotional toll of engaging with the NDIS for significant life course transitions specifically. Additionally, while initiatives such as the Australian Government's proposed 'Navigator' service demonstrate growing recognition of the need to bolster the quality and availability of formal support for those using the Scheme, our results would indicate that this does not yet go far enough in addressing the complex and sometimes long-lasting impact of engaging with such complex bureaucratic processes.

1 | Introduction

Most adults with intellectual disability reside with their parents, who as they get older are increasingly concerned about who will support their adult son or daughter with intellectual disability in the future (Brennan et al. 2018; Taylor et al. 2024). Moving out of the family home is one step in addressing future support needs and preventing crisis transitions when ageing parents can no longer provide care (Brennan et al. 2018; Davys et al. 2015; Lee and Burke 2020). Moving out of the family home is also a rite of passage in Western societies and one which adults with intellectual disability indicate they are desirous of undertaking (Midttun et al. 2024; Salt et al. 2019).

In Australia, where this study was conducted, making plans for moving out of the family home for adults with intellectual disability now increasingly occurs in the context of the National Disability Insurance Scheme (NDIS). Introduced in 2013 and fully implemented by 2020, the NDIS was a major change in the way disability services were funded and delivered (NDIA (National Disability Insurance Agency) 2023a) that followed a growing international trend of individualised funding schemes

(Dickinson et al. 2014; NDIA (National Disability Insurance Agency) 2022a). As a rights-based scheme, the overall aim of the NDIS is to promote greater choice and control by people with disabilities over the services they use (Hummell et al. 2023). Those with access to the Scheme are referred to as NDIS participants. The NDIS showed initial promise in addressing some of the shortcomings of the previous system, but it has faced many challenges since implementation. It has been subjected to much scrutiny through for example an ongoing Joint Standing Committee on the NDIS (Parliament of Australia n.d.) and the Independent Review of the NDIS completed in 2023 (Department of the Prime Minister and Cabinet 2023a). The benefits of the Scheme have been experienced unevenly. Its operationalisation has been confusing, gaining access to it has been difficult, and eligibility criteria have been applied inconsistently (Department of the Prime Minister and Cabinet 2023a). Moreover, it has been limited in its stated aim of ensuring greater choice and control for people with disability (Hamilton et al. 2024; Warr et al. 2017). In 2019, the NDIA predicted the NDIS would cost $31 billion by 2024–25. This was later revised to $41 billion, with a further projected increase to over $59 billion by 2030. This unanticipated cost increase prompted the Australian Government to introduce a number of legislative reforms. While it is anticipated that these changes will address much of the projected increase, the reforms have received widespread criticism for lacking detail, with little clarity regarding how the significant reductions in spending would be achieved (Pennings, n.d.). Consequently, concerns around the NDIS's sustainability remain, and the spending increases threaten to erode the broad-based support it has experienced to date (Pennings, n.d.; Department of the Prime Minister and Cabinet 2023a).

People with intellectual disabilities have had poorer outcomes than other disability groups (Mavromaras et al. 2018), despite being the Scheme's second largest group according to disability type (NDIA (National Disability Insurance Agency) 2023b). Informal supporters, predominantly family members, play a crucial role in supporting adults with intellectual disabilities to engage with the NDIS and establish plans to meet their needs and aspirations (Collings and Dowse 2018; Lakhani et al. 2018; Mavromaras et al. 2018). For example, unpublished data from the NDIA suggest that close to 50% of participants with intellectual disability have a nominee in place to make decisions and act on their behalf. While family support is important to adults with intellectual disability and to families (McCausland and O'Donovan 2023), it has some drawbacks and may be more risk-averse, paternalistic, and harder to monitor than formal support and it is often unregulated. This raises a number of concerns around self-determination, and the exercise of choice and control (Bigby 2021; Bigby and Douglas 2020; Carney et al. 2019; Curryer et al. 2020; Ellem et al. 2019). Additionally, not all adults with intellectual disability have families with access to the resources and education necessary to successfully navigate complex bureaucratic processes. McAuliffe et al. (2025) found for example, that educational attainment and transferable professional skills were crucial for families' ability to manage self-funded plans under the NDIS. Alternatively, some adults with intellectual disability may not have, or may not wish to engage informal support to assist with planning (AIHW (Australian Institute of Health and Welfare) 2024). This then creates diverse barriers to access and to achieving equitable outcomes.

In relation to housing specifically, prior to the NDIS, most funding was tied to supported accommodation in the form of group homes for four–six people. For those who were not eligible or did not want to live in this type of housing, there were few alternatives, making moving out of the family home difficult (Wiesel 2021). The NDIS has introduced a number of different funding options with associated housing and living arrangements aimed at supporting individuals with disabilities to have greater choice in where and with whom they live (NDIA (National Disability Insurance Agency) 2023c). Two of the most prominent initiatives are supported independent living (SIL) and specialist disability accommodation (SDA); although they do not necessarily have to be used together. SIL is funding for services to assist people with disabilities who require support in the home, such as with personal care or meal preparation. SDA is housing designed for individuals with high support needs. It is funded through a combination of the NDIS participant's plan and a rental contribution by the participant (NDIA (National Disability Insurance Agency) 2023c). In the first quarter of 2025, close to one tenth of the total NDIS budget of $52.3 billion was spent on these two housing schemes alone (NDIA (National Disability Insurance Agency) 2025a). Another housing initiative introduced under the NDIS is individualised living options (ILO). This funding has considerable flexibility. For example, NDIS participants can choose to live with a host, who provides housing and support (NDIA (National Disability Insurance Agency) 2025b). As of December 2024, a little over 500 people in Australia were utilising this funding stream for their living arrangements, yet recent economic modelling shows significant financial gains for the Australian Government if more people were to choose this type of housing support (Summer Foundation 2025). Despite these policy initiatives and significant financial investment, there continue to be unmet housing needs in Australia for people with disabilities (Wiesel 2021).

The aim of this study was to explore the experiences of families of adults with intellectual disability in planning and supporting the transition of their family member out of the family home in the context of the NDIS. It is part of a larger study exploring the experiences of adults with intellectual disability moving out of their family home, and the perspectives of formal supporters involved in this move.

2 | Methods

2.1 | Study Design

The study used a qualitative methodology and semi-structured interviews to collect data. This approach is suited to the exploration of lived experience perspectives (Roller and Lavrakas 2015). The study received ethics approval from the Flinders University Human Research Ethics Committee (4635).

2.2 | Recruitment

Family who had helped an adult (18+) with intellectual disability move out of the family home since the introduction of the NDIS, and adults (18+) with intellectual disability who had moved out of the family home since the NDIS were invited to participate

in the study. Study participants were recruited through contact with disability service providers in several states and territories across Australia and the professional networks of the research team. Details of the project were shared by email, through organisational newsletters and websites, and through social media sites using a short recruitment video. Those interested in participating were directed to contact the lead author to discuss the project and their eligibility. All potential participants were given an information sheet and consent form which they were required to sign and return prior to being interviewed. All information was provided in Easy Read for adults with intellectual disability. Adults with intellectual disability were also able to provide verbal rather than written consent where this was preferred.

2.3 | Study Participants

This article only reports on data from family members who participated in the study, given the research aim of exploring the role of informal supporters in navigating a transition out of the family home since the introduction of the NDIS. The experiences of the adults with intellectual disability who moved out of the family home as part of this research are captured in a separate article, and therefore their experiences are not included here (Walker et al. 2025). However, Table 1 provides the details of all study participants, and therefore includes details of both family members and adults with intellectual disability. It also provides details of the family member with intellectual disability who moved out of the family home but who did not participate in the study.

Fourteen interviews were conducted with seventeen family members, and included single, dyadic, and triadic interviews (see Table 1). Where participants were part of dyadic or triadic interviews, they have been allocated a shared interview number in Table 1. Thirteen parents ($n=10$ mothers) and four siblings ($n=2$ sisters, $n=2$ brothers) took part. Family members were aged between 43 and 82 years, with an average age of 66 years. Participants were from three states and one territory in Australia. The average length of time since the family member with intellectual disability had moved out was 2 years. All the adults with intellectual disability were NDIS participants. They were aged between 30 and 66 years, with an average age of 42 years. They lived in varied settings, with diverse tenure arrangements. Six lived in privately owned properties purchased by family members. Of these, four lived alone and two with housemates. One adult with intellectual disability lived alone in a private rental property. The remaining seven lived in SDA (see Table 1). All participants had paid disability support, ranging from ad hoc drop-in support for a few hours a week, to 24/7 in-home support. The most common type of support was that funded through the SIL line item.

2.4 | Data Collection

Interviews took place between December 2021 and June 2022. They were conducted over the telephone, via video conferencing, or in-person (at home), depending on participant preference and lasted 60 min on average. All interviews were conducted by the lead author who is experienced in conducting research with people with intellectual disability and families undergoing housing transitions. Families were asked to describe the move of their family member with intellectual disability out of the family home, to talk about the goals they had for the move, to discuss the process of planning and executing the move, including their experiences with the NDIS, and to identify what had worked well and what they would do differently.

2.5 | Analysis

All interviews were audio-recorded and transcribed verbatim by a professional transcription service under a signed confidentiality agreement with Flinders University. Interpretative phenomenological analysis (IPA) guided the data analysis. IPA is suited to small samples as it requires detailed case-by-case analysis of individual transcripts (Smith et al. 2021). Analysis was conducted according to the most recent iteration of IPA following the steps outlined below (Smith et al. 2021). Each interview transcript was printed out and read individually for the purposes of immersion in the data. Notes were then made on the individual transcripts focusing on responses from family members regarding their experiences with the NDIS. These notes were used to create experiential statements which reflect the study participants' experiences or their attempts to make sense of their experiences in relation to the research aim. Experiential statements were constructed for each interview in separate Word documents, printed and cut out, and arranged on a table to enable further analysis and the creation of Personal Experiential Themes (PETs) (see Figure 1). PETs reflect the process of mapping meaningful connections between the experiential statements for each interview. PETs were created for each transcript and typed into separate Word documents. These documents were printed and the PETs cut out and arranged on a table to enable additional analysis to create Group Experiential Themes (GETs). GETs represent commonalities between the PETs and points of interest to the study aim across the entire data set. A table of GETs was compiled, with the title of the GETs, all the related experiential statements, and illustrative quotes. The lead author conducted the analysis, and the GETs document was shared with the second author. The two authors engaged in a workshop refining the GETs and reaching consensus on the final GETs through discussion. The agreed-upon GETs were shared with the remaining authors for comment and feedback. Only minor changes were suggested by the wider research team.

3 | Results

We present the six GETs constructed from the data and illustrate these with interview extracts. Pseudonyms are used to ensure participant anonymity. The GETs are: 'New opportunities' explaining how the NDIS provided opportunities to enable future planning; 'Dealing with something new' explaining study participants' lack of familiarity with the NDIS; 'Finding information and reaching out to others' identifying the importance of informal networks and engaging in information-seeking behaviour; 'A second pair of eyes' describing experiences with formal support services; 'Keeping up the fight' outlining the challenging experiences of finding one's way through bureaucratic

TABLE 1 | Participants and adults with intellectual disability demographic details.

Interview number	Interview type	Family participant (pseudonym)	Relationship to adult with intellectual disability	Age	Employment status (full-time FT; part-time PT)	Adult with intellectual disability (pseudonym)	Age	Housing
1.	Dyad (mother and son)	Robyn	Mother	63	PT	Angus[a]	38	Lives alone, one-bedroom unit; private rental
2.	Dyad (sisters)	Constance	Sister	43	PT	Nicole[a]	30	Lives alone, three-bedroom house; SDA
3.	Dyad (brothers)	David	Brother	61	PT	Chris[a]	52	Lives alone, two-bedroom apartment; privately owned
4.	Triad (father, mother and son)	Jeremy	Father	60	FT	Todd[a]	30	Lives alone, three-bedroom house; privately owned
		Kate	Mother	62	Retired			
5.	Single (mother)	Lucy	Mother	72	Retired	Harry	38	Lives alone, two-bedroom unit; privately owned
6.	Dyad (mother and daughter)	Sue	Mother	75	Retired	Chelsea[a]	45	Lives with one housemate, five-bedroom house; privately owned
7.	Single (mother)	Patricia	Mother	67	Retired	Linda	40	Lives with two housemates, three-bedroom house; SDA
8.	Single (mother)	Karen	Mother	63	Retired	Tina	37	Lives with five housemates, four-bedroom house, with two units attached; SDA
9.	Dyad (father and mother)	Robert	Father	82	Retired	Naomi	37	Lives with three housemates, six-bedroom house; SDA
		Joan	Mother	76	Retired			
10.	Single (mother)	Bethany	Mother	66	PT	Stacey	31	Lives with three housemates, four-bedroom house; SDA
11.	Single (sister)	Barbara	Sister	64	FT	Michael	66	Lives with four housemates, four-bedroom house, with one unit attached; SDA
12.	Dyad (mother and son)	Felicity	Mother	56	FT	Brian[a]	33	Lives with two-housemates who provide support in three-bedroom house; privately owned

(Continues)

TABLE 1 | (Continued)

Interview number	Interview type	Family participant (pseudonym)	Relationship to adult with intellectual disability	Age	Employment status (full-time FT; part-time PT)	Adult with intellectual disability (pseudonym)	Age	Housing
13.	Triad (father, mother and daughter)	Ralph	Father	76	Retired	Veronica[a]	50	Lives alone in studio unit, attached to a house with two housemates; SDA
		Kelly	Mother	78	Retired			
14.	Single (brother)	William	Brother	64	Retired	Daphne	60	Lives alone in one-bedroom apartment in 10-apartment complex; shareholder

[a]Participated in an interview.

processes; and 'Thinking ahead' concerning longer-term goals and intergenerational transfers of support.

When the interviews were conducted, the NDIS had only been operating for a short period, but despite this, all the adults with intellectual disability had moved out of home using NDIS funding. Their motivations for moving varied but included seeking more independence, and/or family members no longer being able to provide direct support.

3.1 | New Opportunities

Family members acknowledged that the NDIS had enabled them to access a level of funding that had previously been unavailable and had provided alternatives to the traditional group home. These changes allowed families to plan and execute a move out of the family home in a way they believed had not been possible previously. One mother summarized the changes and their impact on the family's planning activities in the following way:

> I mean really it was probably since the NDIS came in, because before NDIS there just wasn't any [housing]—you just couldn't get anything... But then when the NDIS came in and we thought there could be a possibility [to move out of home] and then ILO came in, the independent living options (sic) came in, then we really started moving forward [with planning]
>
> (Felicity, mother).

Barbara indicated that prior to the introduction of the NDIS and the development of SDA, she believed she would eventually be responsible for supporting her brother with intellectual disability, Michael once her parents passed away:

> Yeah, and I thought for a long time, that I would be the one looking after Michael at home because I did not see, ten years ago I didn't see this [SDA] happening in [name of town]. I only seen respite happening okay? So, I thought, well, if mum or dad die, I then have to take over looking after Michael
>
> (Barbara, sister).

Lucy explained that her relationship with her son Harry had begun to deteriorate while he was still living in the family home, but prior to the introduction of the NDIS they had been unable to secure housing and support that were appropriate and adequate. This situation had become a cause of significant stress for them both. The ability to now access SIL funding had allowed for Harry to move into his own unit with the level and quality of support that Lucy and Harry were satisfied with. Lucy described the effect on her as follows:

> And to be honest, if we didn't have the NDIS, I wouldn't be talking to you because I'd be in a loony bin, I think
>
> (Lucy, mother).

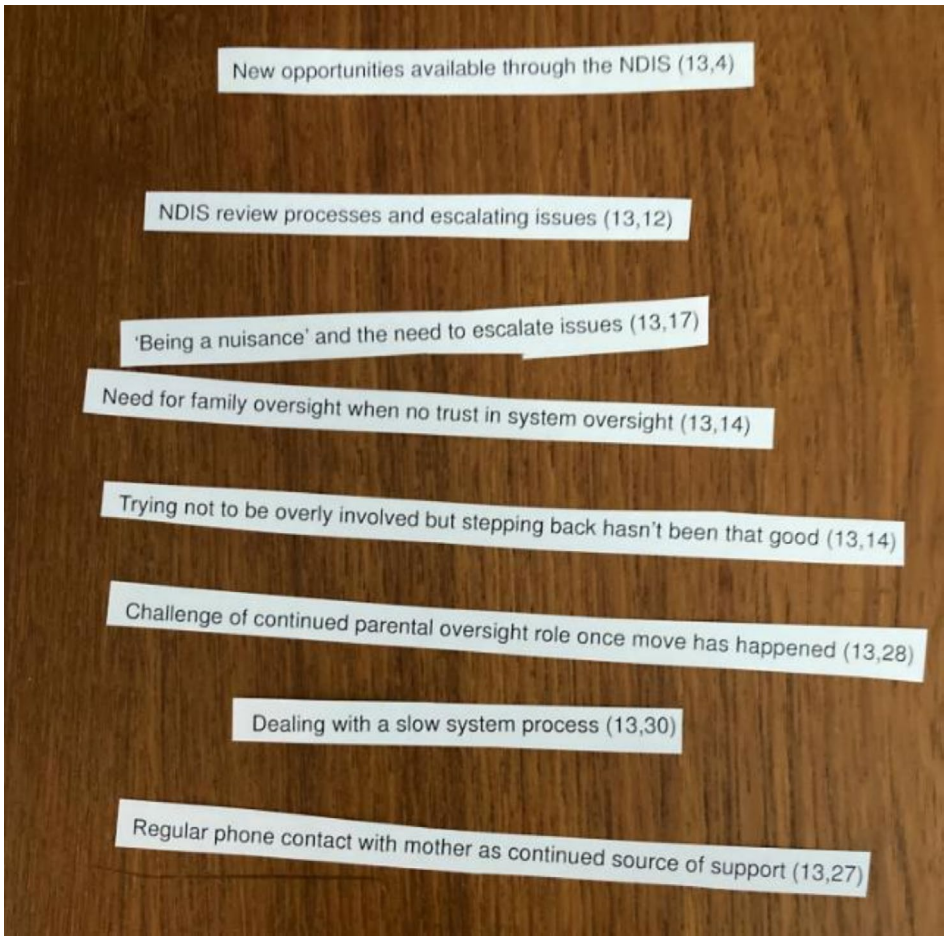

FIGURE 1 | Example of personal experiential theme process.

3.2 | Dealing With Something New

While families acknowledged the increased funding and housing options available to them with the introduction of the NDIS, they also faced challenges utilising a new funding scheme which had not been adequately communicated to them. Families felt they had been thrust into a situation for which they had not been adequately prepared by government and disability services. They discussed the emotional and psychological toll this took on them:

> I came so close to having a nervous breakdown. It was appalling. I didn't have the foggiest idea
>
> (Karen, mother).

Karen suggested that the confusion around processes for securing funding under the NDIS, led to numerous mistakes during her daughter's transition from the family home. She believed some of these errors would have long-term repercussions for her daughter's living arrangements and support:

> But it was totally unsuccessful as well. The next year, we still had the same planner. We had funding for an OT [Occupational Therapy] assessment. We had that done. It was as—I didn't know at the time—you learn along the way. For an OT assessment that was specifically to help get SDA funding, it might as well have been toilet paper. And the planner submitted it. And that has been to our detriment ever since
>
> (Karen, mother).

In other cases, families indicated that the newness of the funding Scheme and the difficulty accessing information about it, left them and their family member with intellectual disabilities feeling uncertain about how to set and achieve goals and use their plans, leading to missed opportunities. This was not just in relation to housing but regarding accessing services and supports using the NDIS more generally. David provided the following example:

> So, the first plan we thought we'd try and cope with it ourselves. And then I had no idea really how to access all the different things... But I probably wasn't getting the best out of the plan, because I just was unaware of what was out there
>
> (David, brother).

3.3 | Finding Information and Reaching out to Others

Given the newness of the Scheme, and the confusion surrounding it, accessing resources and opportunities offered by the NDIS was only possible after considerable effort on participants'

behalf to understand how it worked. Almost half of all participants spoke about the importance of attending seminars and workshops about the NDIS and using the internet to research the Scheme more broadly, or to search for disability service providers who could assist with the transition and/or provide disability accommodation. They also spoke about the benefits of having previously established relationships with other families who had a family member with a disability and of connecting with a range of different disability service providers:

> And so that's—often in the network of—in the disability field, there's a big network and you get to know other parents, but you also get to know other services. So, there's a lot of communication and information sharing
>
> (Sue, mother).

For some families, the connection with disability services and other families with a family member with disabilities had been cultivated over many years, preparing for the time when their family member with intellectual disability would move out of the family home:

> We realised fairly early in life that she would one day need permanent care... She used [name of disability service provider] since she was 10 or 12 to get used to being reliant on others and learning to live with others. After moving down to [name of area] 17 years ago, we joined some groups eager to build houses for disabled by raising money and support
>
> (Robert, father).

Several study participants believed they were able to secure the housing they wanted because of the networks they had built over time. In one case, the eventual move out of the family home began with a family member's connection to a disability services provider delivering short-term accommodation. Through this connection and the use of their short-term accommodation, the family were able to secure long-term housing with the same provider:

> So, I had the connections there with them [disability service provider] and I just said to mum, 'Look, [Michael] needs to go into respite'
>
> (Barbara, sister).

Some of the difficulty in understanding and navigating the Scheme, the impetus to engage in information-seeking behaviour, and the importance of having already established formal and informal networks, was a result of poor direct communication between the NDIA and informal supporters. One mother described her frustration in trying to communicate with the Agency in the following way:

> Look, where the NDIS (sic) themselves are concerned, they're probably about the closest thing to communism that you'll ever know... really there was almost no point in ringing them [NDIA] because they had no interest in communicating with me... You never get beyond the person who answers the phone... They never call you back or email you back... And it's a one-sided conversation. They only have contact with you if and when they choose to. That's why I'm saying it's like communism. You have no say in anything. You can't have a discussion because there's no one to discuss it with
>
> (Karen, mother).

3.4 | A Second Pair of Eyes

Over half of study participants spoke about the importance of having formal support to help plan the housing transition and to secure funding. Formal support included NDIS planners, support coordinators, and/or other staff at disability service providers. Support coordinators were identified as having significant influence over plans. Support coordination is a funded component of an individual's NDIS plan and is only for those who require additional assistance to navigate plans and connect with services (NDIA (National Disability Insurance Agency) 2022b). Family members spoke about the valuable role that support coordinators played in assisting them and their family member with intellectual disability to navigate an unfamiliar system during this time of transition:

> Well, I think there were definitely some of the family members didn't think it [moving out of the family home] was going to work. And thought, you know, Chris's going to be in terrible trouble. What happens if this happens? What happens if that happens? So, I think the support coordination with the NDIS and that all helped to make this happen a bit easier
>
> (David, brother).

One mother described the emotional support from her support coordinator in the following way:

> And she [support coordinator] was there for support if I needed it. And she came to the meetings with me. And she was always there for me
>
> (Patricia, mother).

Another family member indicated that not only was formal support needed to help navigate the system to ensure the correct funding and support arrangements were in place, but that it was helpful when professionals and disability service staff understood and supported the adult with intellectual disability and family's vision for moving out of home:

> We're very fortunate, we've got a very close group of disability workers, and the support coordinator is a woman I've known since Harry went into day programs at the age of 19. So, we've got people who've been with us for the long haul, and there's people who understand what I've done
>
> (Lucy, mother).

Frequent changes in personnel, bureaucratic inefficiencies, and instability in the disability sector as it transitioned to market-based service provision under the NDIS negatively impacted some families' in their attempts to secure formal support:

> We got a support coordinator who began the process of what she needed... They began the process and then they went out of business about halfway through
>
> (Constance, sister).

Barbara felt the responsibility for planning and the onus to support her brother with intellectual disability, Michael, achieve his housing goals rested with her. This was partly a result of her perception of support coordination services as being limited to administrative and compliance matters. When asked who else was involved in the planning process aside from Michael, she responded:

> Yeah. Well, yes. It wasn't even the support coordinator. It was probably me—me, myself. I—the support coordinator, when I went to the meetings and that, I—she got an email and I got an email and she'd email me, 'Do you want me to come?' And I'd say, 'Yes, if you can' to keep her up to scratch with it. But support coordinators, they're pretty tightly managed by the NDIS and stuff. They have to report every day and stuff... and I thought... I needed this to happen and the only way I thought, if this is to happen, I'm to be in charge
>
> (Barbara, sister).

3.5 | Keeping Up the Fight

Participants described a sense of having to constantly 'prove' their need for support funding with one mother declaring 'hurdles had to be jumped through' (*Patricia, mother*). Additionally, almost half of all participants described their attempts to plan and execute a move out of the family home with funding from the NDIS in combative terms, using words like 'escalate', 'fighting', 'blocks'. Four families who had not been able to resolve funding disputes with the NDIA, had either approached their local member of parliament to assist them, initiated a formal review, or in one case did both:

> Just after Christmas the person from [name of organisation] who was coordinating things... she said to me, 'Bethany, I think it's time that you intervened, and you have to do this.' She said, 'If it was me, I would be contacting my local MP [member of parliament], and I would be putting in a complaint to the NDIA.' I did both of those things with a supporting letter saying that it was so difficult...
>
> (Bethany, mother).

For some, the need to persist became an obstacle to achieving their desired outcomes:

> And if I wanted to, I just felt like I couldn't ask anything or say anything because I felt like I was being a nuisance
>
> (Felicity, mother).

For this parent, the experience had significant repercussions on her well-being:

> Like I feel like a butterfly flaps its wings and I can have a meltdown. I just feel so stressed, and I've had a big fight with the NDIS (sic) this week again about something else, and it's just the sense of being on edge all the time that it's going to take us a long time to recover
>
> (Felicity, mother).

For one family, repeated delays in relation to plans and funding led to the move out of the family home taking longer than anticipated, with significant consequences on the family member's health:

> I had serious burnout, but I was really depressed. Even after she moved out, I had to go on antidepressant medication just so it would get me back
>
> (Constance, sister).

For others, obstacles were 'just part of the process':

> And that's the big thing is the process that you have to go through, finding your way through the process is difficult. There are places to go but it's a progression you need to work through and there are blocks along the way
>
> (William, brother).

One way of navigating the planning process and of achieving desired aims was finding the 'right' people and the 'right' way:

> It was just talking to the right people—getting down the right channels—so that was the process, and it was long, it was frustrating
>
> (Bethany, mother).

3.6 | Thinking Ahead

Over half of study participants discussed planning for or thinking about longer-term issues such as aging and changed support needs for the adult with intellectual disability. For some families it was possible to address these issues in the initial planning of the move:

> We needed a SDA house if we wanted Nicole to stay here because eventually Nicole—Nicole's disease is degenerative, so she's only going to get less able. And eventually she won't be able to walk and at that point

> she'll need lifters. We really wanted a house that was set-up for ongoing stuff, which this one was
>
> (Constance, sister).

For other families, it was only once the adult with intellectual disability had moved into the new home that the longevity of arrangements was considered and the potential need for a further stage of planning:

> So, we've established models which we're now trying to work out, how do we make this sustainable into the future? And I haven't quite worked that out yet
>
> (Lucy, mother).

Longer-term considerations and planning also involved discussion of intergenerational transfers of support. Parents differed in terms of the roles they envisaged for their other children in the future life of the adult with intellectual disability. Some parents were clear that they did not want siblings to take on significant support roles and planned accordingly:

> I mean it's always been the plan, yeah [for Brian to move out], because we knew we weren't going to live forever, and we don't expect his sisters to take on that responsibility. They've got their own families
>
> (Felicity, mother).

Other parents saw siblings as reassuring them that some oversight of the support received by the adult with intellectual disability would continue once they had passed away:

> And we have said to our other children that they always need to check-up on [Naomi] and make sure that she's—if something happens to us and we're not here anymore that they're safe. They [support workers] like you to ring up and say you're coming. But you don't always have to let them know. Just drop-in because then they don't know you're coming
>
> (Joan, mother).

For one sibling, there was discussion of how his and his siblings' ageing would affect the role his children, nieces, and nephews would take in their uncle with intellectual disability's support. His move out of the family home involved future planning with these considerations:

> Also, it [Chris moving out of the family home] was something for the future... I'm not going to be here forever. I'm ten years older than Chris. And my older brother and sisters, they've all had important parts in his life as well... And we've all got children, but we don't want to lay that on them to be the caregivers and have responsibility. Maybe some of them will help, maybe not
>
> (David, brother).

For a number of study participants longer-term considerations included making legal and financial provisions for their family member with intellectual disability and other children or siblings. This was considered separately from the NDIS planning process and not seen as urgent in planning the housing transition:

> Yeah, because they're [family members] in the wills and that sort of thing. And you've just got to—it's got to be sorted at some point
>
> (Ralph, father).

4 | Discussion

This research explored family members' experiences in planning and facilitating the transition of a relative with intellectual disability from the family home to alternative living arrangements in the context of the newly established NDIS. Study participants noted that the Scheme enabled them to start planning and facilitated transitions out of the family home by providing opportunities for housing and support that were previously unavailable. This alleviated the stress of many family members. The increased benefits and opportunities presented by the Scheme have also been reported in other studies involving families and adults with intellectual disability using the NDIS (Lloyd et al. 2021; Perry et al. 2019).

For many participants in our study, the experience of using the NDIS was also stressful and took a significant psychological and emotional toll, and for a number of these participants, this impact was perceived to be long-lasting. Family members had to proactively seek information and use their own informal networks. They found communication around the Scheme limited and confusing, had stressful communication experiences with the NDIA, and required significant assistance and formal support to plan and use funding and services. For many families, their experiences with the NDIA were adversarial, with study participants feeling pressured to constantly 'prove' their family member's need for funding and services. Consequently, one of the distinguishing features of successful transitions was how well families were able to persevere and overcome the obstacles they encountered in this process. Indeed, this is consistent with findings from the Independent Review of the NDIS which reported barriers to access and difficulties with planning as the most raised problems by participants and their informal supporters (Department of the Prime Minister and Cabinet 2023a). It is an experience which has likewise been echoed in the academic literature investigating planning more generally within the NDIS (Carey et al. 2021; Lloyd et al. 2021; Loadsman and Donelly 2021; Russo et al. 2021). This experience of strain may be indicative of what Carey et al. (2021) describe as state constructions of burden. They suggest that individualised funding schemes based on market provision of services contain within them points of strain, for example, due to their level of bureaucratic complexity. Consequently, the differential capacity of people to engage with these schemes is illustrated by their inequitable outcomes, where those with more resources do

better (Carey et al. 2018; Dickinson and Yates 2023; Mavromaras et al. 2018; McAuliffe et al. 2025).

Unsurprisingly, for many families in our study, support coordinators provided much needed assistance, from emotional support to identifying opportunities that would have otherwise been missed. However, this experience was not consistent amongst participants. For some, support coordinators provided little additional help and for others, delays in accessing services due to barriers with support coordination had repercussions not just on the adult with intellectual disability moving out of the family home but on family members' well-being. The academic literature points to support for families to navigate individualised planning systems as increasingly important (McCausland and O'Donovan 2023). The Independent Review of the NDIS has similarly identified the need for greater formal support for participants and their informal supporters, and it has noted inconsistency in the quality of current support coordination. Consequently, it recommends the introduction of a 'Navigator' service to improve accessibility to the scheme, to better support the decision-making capabilities of participants and their informal supporters, and to ensure greater consistency and quality in formal support services (Department of the Prime Minister and Cabinet 2023b).

The recommended Navigator service also includes a 'Housing and Living Navigator' which provides targeted support to participants and their informal supporters in relation to housing. This initiative acknowledges the basic human right to housing and the centrality of housing to quality of life (Department of the Prime Minister and Cabinet 2023a, 2023b). Casale et al. (2021) in their study of the experiences of siblings in future planning with a sibling with intellectual disability, found that of all the future planning domains, making future plans in relation to housing was the most emotive. In our study, particularly when discussing longer-term considerations around housing and support, families often discussed the roles and needs of other family members as well, especially regarding intergenerational transfers of support. This may be one reason for the more emotive nature of planning for housing transitions identified by Casale et al. (2021) but also speaks to the complexity within families of planning for significant life transitions. In reshaping the support coordination role into the Navigator service, more consideration may need to be given to life transitions, which may be more affected by family dynamics, not just as they relate to decision-making. Specific consideration of the complex and interconnected nature of families, their needs, goals, and plans, and the influence of family members on each other may be useful (Sutherland et al. 2023).

It must be acknowledged that this study was conducted at a point in time and reflects the experiences of individuals engaging with a new system as it was being introduced. Problems with the implementation of the scheme have been well documented, such as a changeable and volatile operating environment; challenges developing the market; and workforce issues, including poor training, and difficulty with staff retention (Alcorso and Stamet 2024; Carey et al. 2022; Dickinson and Yates 2023). Additionally, there is some evidence to suggest that adults with intellectual disability and their supporters become more satisfied with the choice and control they have through the NDIS over time and that they get better at planning (Mavromaras et al. 2018; Warr et al. 2017). However, a number of participants in this study discussed how the impacts of engaging with the Scheme may be long lasting for them. More longitudinal research of participants and their supporters using the Scheme over longer periods of time may be necessary to more fully understand the Scheme's stressors and how these may be more usefully mitigated.

5 | Strengths and Limitations

This study examines planning for and executing housing transitions using the NDIS by a specific population, namely families of adults with intellectual disability. As such, it provides important insight for policymakers looking to better assist participants and their supporters to achieve their planning goals using individualised funding models. While adults with intellectual disability were interviewed as part of the wider study, we did not seek to garner their experiences using the NDIS. Attention to the voices of adults with intellectual disability who are NDIS participants is an important research area which requires further investigation. More research is also needed with adults with intellectual disability who do not have or choose not to engage informal supporters. Finally, we have not distinguished between the experiences of parents and siblings planning in this study. The experiences of these groups may include important differences which require closer examination.

6 | Conclusion

The introduction of the NDIS has been a watershed moment in the history of disability policy, service provision, and funding in Australia. For many of the families in this study it represented an opportunity to plan, particularly in relation to housing in a way that had not been possible previously. However, the process also had significant repercussions on families' well-being, and for some this impact would continue into the future. Moreover, it required mental, emotional, and physical fortitude to achieve desired housing aims. The proposed Navigator service seeks to address issues around consistency and quality of formal support provision and therefore may begin to address some of the challenges highlighted in this study. However, given the burden experienced by some families and the fact that the limited longitudinal data on the Scheme reflects changing experiences with it over time, far more research is needed to understand and address the issues of administrative burden and inequitable outcomes being created.

Author Contributions

I. Belperio: conceptualisation, methodology, data curation, analysis, writing – original draft, writing and reviewing and editing, project administration; **R. Walker:** conceptualisation, methodology, analysis, writing – reviewing and editing, project administration, funding acquisition; **C. Bigby:** conceptualisation, methodology, writing – reviewing and editing, funding acquisition; **I. Wiesel:** conceptualisation, methodology, writing – reviewing and editing, funding acquisition; **F. Rillotta:** conceptualisation, methodology, writing – reviewing and editing, funding acquisition; **C. Hutchinson:** conceptualisation, methodology, writing – reviewing and editing, funding acquisition.

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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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