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The experiences of parents arranging the move of their young adult offspring with intellectual disabilities to 24-hour residential settings; a continuing puzzle

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ABSTRACT

Background: Moving out of the family home is a key transition for people with intellectual disabilities and their families. Yet there has been little research about parents' experiences of planning the move of their young adult offspring to residential settings offering 24-hour support.

Method: Interviews were conducted with eleven parents whose offspring moved to residential settings within the past 5 years (five fathers; six mothers). They consisted of structured questions about planning their offsprings' moves and semi-structured questions about parents' experiences.

Results: Content analysis of the structured questions revealed reasons parents began thinking about the moves and routes to finding information. The thematic analysis highlighted the emotional challenges parents faced.

Conclusions: The findings highlight the need to address this neglected topic and ensure that practical and emotional support is put in place to plan positive futures, rather than relying on families to use their own initiative or waiting until a crisis occurs.

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The move out of the family home, as part of the transition to adulthood, can be seen as important for all emerging adults (Arnett, 2004). For people with intellectual disabilities, this transition can be more complex, as they are likely to remain reliant on support from others as adults, and may have to move into accommodation where they can continue to receive the support that they need (Pallisera et al., 2014). Creating opportunities for people with intellectual disabilities to choose where and how they want to live has been shown to have a positive impact on their quality of life and self-determination (Isaacson et al., 2014). When people with intellectual disabilities move to suitable accommodation, this can also have a positive impact on parents. Reducing the burden of care can create room for parents to lead their own lives as well as enjoying a better relationship with their son or daughter (Chadwick et al., 2013; Chowdhury & Benson, 2011).

Despite the potential benefits of moving on from the family home, previous research indicates that this transition can be difficult for people with intellectual disabilities (Jacobs et al., 2018; Roos & Søndena,

2020; Ryan et al., 2014). For family members, planning long-term care for their offspring with an intellectual disability, including finding a place for them to live, can be a source of significant worry (Chadwick et al., 2013; Davys et al., 2010). For example, parents have reported being unable to find suitable accommodation or residential placements that they feel meet the needs or wants of their offspring (Grey et al., 2015). Family members have also reported that there are limited opportunities to plan a move before the situation reaches a crisis point (McConkey et al., 2018). At the same time, this transition is an emotionally challenging time for parents, and they may experience feelings of guilt because they are unable to continue caring for their offspring (Chadwick et al., 2013). Parents may also be worried about having to trust others to care for their offspring (Chadwick et al., 2013; Ryan et al., 2014; Werner et al., 2009). When it comes to negotiating with care professionals, parents have reported experiencing a lack of transparency from service providers about possible residential options and felt that the care professionals they sought help from tended to lack empathy

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or a willingness to work in a spirit of co-operation, causing further stress (McConkey et al., 2018; Nowak et al., 2013).

Literature focusing on parents supporting their offspring moving out of the family home is sparse. Previous studies concerning a move from the family home have focused on settings in the United Kingdom and Ireland, and often found the lack of available housing to be a considerable barrier (Grey et al., 2015; McConkey et al., 2018). The study reported in this paper was conducted in the Netherlands. It is noteworthy that the Dutch care system differs from other countries, such as Canada, where all large residential institutions have been closed, and the United Kingdom (UK) where the number of adults with intellectual disabilities living in residential settings has decreased, with an increase of supported living arrangements or people living with their families (Gov.UK, 2020; Woittiez et al., 2018). In the Netherlands, support to people with intellectual disabilities is often provided by relatively large service organisations with up to 10,000 service users and staff. The locations of the service organisations mostly concern a specific region, with several locations scattered within this region. The services offer a broad range of support, ranging from day care, respite support, outreach, supported living and 24-hour residential support settings. These services accommodate to the needs of people with disabilities that range from mild to profound (Kersten et al., 2022). In the Netherlands, most people with intellectual disabilities still live in 24-hour residential support settings (Den Draak et al., 2016; Statline, 2023a, 2023b). Therefore, the current study focused specifically on parents whose offspring moved to these settings. In a 24-hour residential support setting, people with intellectual disabilities live within the housing of intellectual disability services, which may either be located in the community or on institutional grounds (National health care institute, 2023), and may consist of group homes or core and clustered care settings with support staff being present in the house or building a fixed number of hours per day, while being able to ask for additional support 24-hours a day. The offspring of the participants included in this study all moved to group homes of around 6–12 residents. The residents were matched to an accommodation based on their needs and the care profile the offspring were assigned.

The study aimed to explore the parents' experiences of searching for suitable accommodation and planning the move of their offspring out of the family home into residential settings. Furthermore, as studies in the UK have found that there is limited available housing (Grey et al., 2015; McConkey et al., 2018), this study

aimed to explore the entire process from when parents started to think about the move out of the family home, until after their offspring had moved out and the parents' experiences with professional support during this process.

Method

Participants

Eleven parents took part in this study; five fathers and six mothers. One parent from each household was interviewed. Research about parents of people with intellectual disabilities has mostly focused on the needs and experiences of mothers (Marsh et al., 2020). Research shows that the needs, wellbeing and experiences of fathers of people with intellectual disabilities can differ significantly from that of mothers (Davys et al., 2017), therefore, it is important to collect their experiences separately to be able to provide mothers and fathers with sufficient support. To do so, this study included both separately. It proved more difficult to recruit fathers. After the fifth father and the sixth mother were recruited, no more participants were included in the study, as no novel information was given by participants about the move. All were parents of adolescents or (young) adults with intellectual disabilities (range 17–26), who had moved to a residential support setting within the past 5 years (2 weeks–5 years). A maximum of 5 years was chosen to ensure the parents could still recall the transition and to ensure that similar regulations and policies were in place. Offspring all moved into accommodation providing 24-hour support.

The socio-demographic characteristics of the parents and their offspring (i.e., four daughters and seven sons) are shown in Table 1. The mean age of the parents was 53.5 years (range 45–60 years). The mean age of the offspring was 22.18 (range 17–26). The level of intellectual disabilities of the offspring ranged from mild to severe. Some offspring had an additional diagnosis.

All offspring received support under the Dutch Long-term Care Act [Dutch: Wet Langdurige Zorg (Wlz)]. This Act provides funding for individuals with long-term care needs. Under this act, a care profile is assigned (3–8) is assigned to an individual, based on their level of functioning and support needs. Once a care profile has been assigned, parents can make an application to a residence of their choice. Care profile 3 means a fixed number of visits/hours of support staff per week, and support staff can be reached 24/7, even though they are not necessarily present at the accommodation at all hours. Care profiles 4–8 means there is 24/7 supervision. From care profile 5, support staff will be present mostly from 7 until 11 p.m. and staff will be available to provide

Table 1. Characteristics participants and offspring with intellectual disabilities.

Pseudonym	Gender Parent	Marital status	Level of education of parent	Age parent	Age offspring	Gender offspring	Time offspring lived in residential facility	Care profile of offspring ^a	Level of intellectual disability offspring	Additional diagnosis offspring
Aaron	M	Married	Secondary vocational education	57	23	F	1 year and 8 months	4: Living with more intensive support and personal care (e.g., support needed with brushing teeth and showering)	Mild	n/a
Barbara	F	Widowed	Secondary vocational education	59	22	M	7 months	3: Living with some daily support and care needs	Mild	n/a
Carol	F	Married	Secondary vocational education	45	20	F	3 years	8: Living with constant nursing care, due to the severity of intellectual disability as well as physical disabilities	Severe	Williams-Beuren syndrome
Daisy	F	Separated	Honours Bachelor degree	48	21	M	1 year, 1 month	4: Living with more intensive support and personal care (e.g., support needed with brushing teeth and showering)	Moderate	n/a
Eve	F	Married	Post-doctoral researcher	55	26	M	5 years	3: Living with some daily support and care needs	Mild	n/a
Brad	M	Married	Honours Bachelor degree	60	25	M	2 weeks	7: Living with individual support, personal care and support for challenging behaviour	Severe	ADNP/Helsmoortel-Van der Aa syndrome
Chris	M	Married	Honours Bachelor degree	52	26	F	5 years	8: Living with constant nursing care, due to the severity of intellectual disability as well as physical disabilities	Mild	Asymmetric spastic tetraparesis
Fiona	F	Married	Secondary vocational education	51	25	F	1 year	8: Living with constant nursing care, due to the severity of intellectual disability as well as physical disabilities	Moderate	n/a
Daniel	M	Separated	Honours Bachelor degree	58	18	M	1 year	5: Living with intensive daily support needs (e.g., support with communication and performing daily activities) and intensive personal care	Severe	autism
Helen	F	Re-married	Honours Bachelor degree	56	21	M	3 months	4: Living with more intensive support and personal care (e.g., support needed with brushing teeth and showering)	Mild	Continuous Spike and Wave in Slow sleep epilepsy
Eric	M	Separated	Secondary vocational education	48	17	M	4 months	8: Living with constant nursing care, due to the severity of intellectual disability as well as physical disabilities	Severe	Pachygyria

^aAll individual receive care under the Long-term Care Act, under this act needs are rated from 3 to 8 with increasing scores reflecting greater support needs.

night care. The higher the care profile the more care is needed for people with intellectual disabilities to perform their daily tasks. The most prevalent care profile

assigned to offspring in the current study was 8, living with constant nursing care, due to the severity of intellectual as well as physical disabilities. Table 1 provides

an overview of the care profile of each offspring. The level of intellectual disabilities was in two cases based on intelligence quotient (IQ) scores (Daisy and Helen) and in nine cases reported as such by the parents themselves.

Only people having a lifelong condition that causes a need for 24/7 supervision or support are eligible to receive care under the Long-term Care Act (Nursing homes and residential care, 2023). As such, the care and support the offspring needed in residential support settings is not expected to change significantly and the move is not expected to be a stepping-stone to more independent living for the offspring with a care profile of 4–8. Participants in this study with care profile 3, who moved to accommodation offering 24/7 supervision, may be able to eventually move to more independent living arrangements. However, the parents in this sample did not mention this and in some cases expressed more supervision would be preferable for their offspring.

Interviews

Semi-structured interviews were conducted. The aim of the interviews was to get a clear picture of the process these parents went through to find a suitable residence for their offspring, as well as exploring their emotional experience when planning their offsprings' moves from their family homes.

An interview schedule was developed covering four main topics: (1) Thinking about the move from the family home, (2) the search for suitable accommodation, (3) the move out of the family home, and (4) professional support. Questions were formulated for each of the topics relating to (i) the steps undertaken by parents (i.e., how did you start the search for accommodation?; how did you find the accommodation your offspring has moved to? What professional support was provided?) and relating to (ii) the parent's experiences (i.e., what challenges did you experience during the search for suitable accommodation?; what was your experience of dealing with professionals? how did you feel when your offspring moved out of the family home?).

The interview started with questions about the participants' demographic characteristics and at the end of the interview, participants were given the opportunity to raise other points that had not been discussed.

Procedure

Ethical approval was obtained from the Ethics Review Board of Tilburg University (RP-607). A purposive sampling procedure was used. All 15 intellectual

disability services affiliated with the Academic Collaborative Living with an intellectual disability at Tilburg University were asked to help in recruiting participants for this study. All these services offer various types of support for people with intellectual disabilities (i.e., community-based support, respite services, and accommodation providing 24-hour support). Five of these services agreed to assist with recruitment and found participants eligible and willing to participate. A contact person from each of the service providers got in touch with participants who met the inclusion criteria. The first researcher then contacted the participants by phone or via email and informed them about the study. If the participants were willing to take part, then they emailed their signed consent forms to the first researcher. No incentives were offered. Next, an (online) interview was planned by the first researcher at a time that was convenient for the participant.

The interviews took place over a period of 7 months. As both face-to-face interviews and online interviews are likely to provide similar quality data (Braun & Clarke, 2012), the participants were offered the option to conduct the interview face-to-face or via video call. However, a government enforced COVID-19 lockdown came into place in the Netherlands between December 2021 and January 2022. Hence, the five interviews conducted during the lockdown took place through a video call (Microsoft Teams). Six interviews were conducted when restrictions did not apply, four before enforced lockdown and two after lockdown had been lifted. One of these six interviews was conducted face-to-face, the remaining five were conducted through a video call. All interviews were conducted by the first author. The duration of the interviews ranged from 21 min to 60 min ($M = 43$ min and 11 s). The interviews were audiotaped with the participants' informed consent and transcribed verbatim.

Data analysis

The first aim of the study was to get a clear picture of the process the parents went through to find a suitable home for their offspring with intellectual disabilities. As such, four main questions were asked concerning: (1) first thoughts about the move out of the family home, (2) the search for suitable accommodation, (3) the move out of the family home, (4) the nature of professional support. A content analysis was used to analyse the parents' answers to questions about the steps they took to support their offspring to move from the family home (e.g., how did you find information about accommodation?). The second aim of the interviews was to explore parents' emotional experience when planning

their offsprings' move from the family home. A thematic analysis was used to analyse the data concerning the participants' more in-depth responses about their emotional experience during this process (i.e., how did you experience the eventual move out of the family home?).

The content analysis was conducted on the basis of a general inductive approach (Elo & Kyngäs, 2008), no prior assumptions or theories directed the exploration. In the first step, the first author (FV) read the verbatim transcriptions in detail to ensure they were acquainted with the content. Next, data related to the questions about the steps undertaken by parents planning the move of their offspring out of the family home were assigned a code. This included the question about professional support. After initial codes were generated, the types of answers given were collected onto a coding sheet (Dey, 1993). Next, the codes were clustered and a typology of the different responses given by parents related to the topics was produced. The second author (SG) and the whole research team (FV, SG, AJ, PE) reviewed and agreed the typology, and frequencies obtained of the different type of views expressed.

With respect to the thematic analysis, the first researcher (FV) went through all six phases of thematic analysis (Braun & Clarke, 2006). The first researcher again familiarised herself with the data. In the second phase, initial codes were generated inductively, based on the emotional impact of the transition out of the family home. There were no prior assumptions or theories that guided the initial coding phase. During the third phase, all the codes were be grouped together and potential themes were formulated by the first researcher. In the fourth phase, the themes and subthemes were discussed with the second researcher (SG) and the whole research team (FV, SG, AJ, PE), to ensure a sufficient degree of abstraction was achieved and that the themes matched the data. During phase five, the themes were defined and named. This process was recursive, meaning the first researcher moved back and forth between the steps (Braun & Clarke, 2006).

A careful audit process was built into each stage of both the analyses (i.e., content and thematic), involving different members of the research team. At each step, the analysis was discussed with the second researcher (SG). The whole research team (FV, SG, AJ, PE) reviewed and agreed the typology (content analysis), and themes and subthemes (thematic analysis). During the first step of open coding, a third researcher coded 20% of the interviews to provide another perspective. Disagreements were then discussed, and agreement was reached.

The interview transcripts were analysed in Dutch, and the results were then translated into English to discuss within the research team. Quotations were translated into English through a translation-back translation procedure, carried out by one native English and one native Dutch speaker, both independent of this study. This process was repeated until a high level of congruence between the Dutch quotes and the translated quotes was achieved.

Results

Part 1 content analysis

A detailed overview was constructed of the steps parents provided in relation to planning the move of their adult offspring with intellectual disabilities out of the family home. The parents' answers given to the main questions are described below. In some cases, parents presented more than one point of view, therefore the number of views can exceed the number of participants.

Thinking about the move out of the family home

Parents gave a number of reasons for starting to think about planning their offsprings' move from the family home (Table 2). Some related to their offspring getting older, such as leaving school, or other siblings moving out. Others seemed more related to the parents' own needs. For example, wanting to protect family relationships. One father noticed that the care for his daughter with an intellectual disability was proving challenging for their other daughter. Other parents wanted to avoid a crisis situation leading to a sudden, unplanned move from the family home. And some mentioned not wanting the siblings of their offspring with an intellectual disability having to take responsibility for their care.

In some cases, the reasons seemed to be linked to their offsprings' level of intellectual disabilities. Most parents of people with severe intellectual disabilities said that the reason they had begun to plan the move was because the care of their son or daughter had become increasingly demanding over the years. While parents of people with mild intellectual disabilities had become aware that their offspring wanted to become more independent and to live in their own place.

The search for suitable accommodation

All parents were asked about how they arranged the move of their offspring out of the family home. This started with ways that they searched for information about available accommodation (Table 2). It seemed parents used various ways to find information about possible accommodation. Two parents described getting

Table 2. Sub-topics and number of participants mentioning sub-topics within the overarching topics of the move out of the family home.

Overarching topic	Sub-topics	N	
1. Thinking about the move out of the family home	Others (e.g., neighbours, school or support staff) encourage thinking about the move	1	
	Aiming for a certain age	2	
	Offspring leaving school	2	
	Care becoming too demanding	1	
	Offspring becoming older	1	
	Siblings moving out	1	
	Protecting the parent-child relationship	1	
	Protecting the wellbeing of a sibling	1	
	Avoiding a crisis out of home placement	3	
	Avoiding that siblings have to take over care	3	
	Moving seems better for offspring	5	
	2. The search for suitable accommodation	Getting information from network and acquaintances familiar with the care system (i.e., other parents of people with intellectual disabilities met via sport teams or friends of offspring)	6
		Getting information through day-care, respite, or residential services	4
		Getting coincidental information	2
Exploring multiple accommodations and living arrangements		12	
Putting offspring on waitlist		9	
Offspring admitted to accommodation without waitlist		2	
National organisation (that supports people with disabilities and their network) makes overview of possible accommodations		1	
Being referred to national organisation		3	
Contacting national organisation for support		3	
National organisation helped with application Long-term Care Act		3	
3. The move out of the family home	Places opening up sooner than expected	8	
	Residential facility provides administrative support to arrange move out of the family home	5	
	Handing over formal care responsibilities	2	
	Preparing offsprings' room	2	
	Helping offspring move to accommodation	3	

information through chance encounters. For example, one father sold a mattress online and received information about a possible accommodation for his daughter from the buyer. The buyer happened to have a daughter with disabilities himself and was therefore familiar with accommodations in the area.

To explore their options, most parents said they had visited multiple accommodations.

Some also said it had been very helpful to explore different types of living arrangements; they typically explored residential settings run by both large and small service providers, mainly parent-let, organisations. Most parents put their offsprings' name on a waiting list. Only two parents said their offspring had not been put on a waiting list for the accommodation they moved to.

All parents were specifically asked about professional support they had received during the process of arranging a suitable home for their offspring (Table 2). One parent said a national organisation that helps families of people with disabilities with questions on all domains of life (i.e., MEE NL), helped to provide an overview of possible accommodation. Others seemed to get information through their own informal support networks, or day-care, respite, or residential services.

All parents had to apply for the Dutch Long-term Care Act for their offspring to be able to move to accommodation that provides 24-hour residential support. All parents of offspring with intellectual disabilities moving

out of the family home were entitled to support under the Long-term care Act. However, it seemed that information about who was eligible to apply for support under the Act did not get to all parents easily. For example, one parent said it took a long time for her to find out that her son was eligible to receive care under this Act. As a result, she did not know how to get the necessary funding assigned for her son to be able to get the (residential) support he needed.

Furthermore, it seemed there was no clear process for parents to apply for funding under the Act. Some parents received help from a national organisation that provides social workers to help people with disabilities and their relatives to arrange the care needed. The national organisation only becomes involved when parents turn to the organisation to ask for professional support. As such, some conducted the application mainly by themselves, while others received support from support workers at a national organisation. Three parents said they contacted the national organisation for support when applying for the Long-term Care Act for their offspring.

The move out of the family home

In most cases, the move took place within 4 months after parents had accepted the accommodation. After the residential placement had been accepted by the parents, some parents found that the residential facility provided helpful support in arranging the transfer of care.

Three parents wanted to transfer all legal responsibilities for their offspring, to reduce the demands placed on them. This included medical care, such as making medical appointments and arranging medication; control of the care budget and ensuring all residential service and personal costs are paid. However, not all parents wanted to sign over the care of their offspring completely to the service provider. For example, one mother reported that she wanted to remain in control of her son's finances. Both parents who wanted to retain some formal responsibility for the care of their offspring referred to the management of the care budget of their offspring. It cannot be drawn from the data which characteristics of parents, or their offspring, made it more or less likely for parents wanting to keep some formal responsibilities.

Part 2 thematic analysis

From the thematic analysis five themes relating to emotional aspects associated with the move emerged: (1) a parent's journey, (2) an unstructured process, (3) advantages and challenges of the move for offspring, (4) acknowledging the needs and role of parents, (5) finding the right place: a continuing process.

A parent's journey

Becoming used to the idea of their offspring moving out of the family home was emotional for parents. For example, one father explained that when his daughter stayed at a respite service during the weekends, as an intermediary step to moving out, it first felt like he was sending her away. However, despite some parents initially expressing these kinds of feelings, they eventually felt that moving out would be best for their offspring.

During the search for suitable accommodation, some parents said they noticed their own preferences (e.g., other residents of a similar age to that of their offspring or the way support was offered) played an important role in searching for accommodation. Others also stated that the ability of the accommodation to meet their offspring's needs was more important than their own personal preferences. For example, two fathers said that even though the accommodation was a long drive away, and they would have preferred a place closer to home, their offspring's wellbeing was the most important factor. Most parents talked about the involvement of their offspring in choosing their accommodation. The extent to which offspring were able to voice their preference depended on their level of ability. Offspring with mild to moderate intellectual disabilities all visited potential residences and told their parents what they

thought. When they liked somewhere, then their parents would discuss a possible move with the service. For those with more severe intellectual disabilities, parents looked for residential settings that met their offspring's needs. For example, one father knew his son greatly valued his daycare. Consequently, he looked for somewhere he could live near to the daycare service. Parents would visit potential residences with their sons and daughters on a few occasions, to allow them to become acquainted with their new surroundings and to gauge their reactions to being there, before deciding on a possible move.

Parents noticed that once a place opened up, they worried about what would happen if their offspring would be unhappy in their new home. Some worried that initiating the move had been a mistake. This was especially the case for parents of offspring with moderate to severe intellectual disabilities, and if they had difficulty expressing their feelings about the move. In contrast, parents of individuals with mild to moderate intellectual disabilities, who were able to voice their preferences, could be confident in knowing what their son or daughter felt about the choice of accommodation.

Parents described the move as being an emotional time. However, they said that this was similar to how they had felt when their other offspring without intellectual disabilities had moved out of the family home. One mother said she had felt lost when she returned home, after leaving her son at his new accommodation for the first time.

Despite these initial worries, most parents were reassured when they began to see that their offspring were doing well and felt happy at their new residence.

Then, of course, you have doubts: have I made the right choice, have I understood her properly, was she ready to move out? But when you see how she's flourished, then I'm like, yes, it's been the right choice. (Carol)

The move out of the family home was also the start of a new phase in the parents' lives. A number of parents said that the move created space for them to reflect on the care they had provided the past years. Others indicated that they struggled when their offspring first moved out because after providing years of intensive support to their loved ones, a gap was left in their lives that they did not readily know how to fill. They missed their offspring's presence and realised that, as well as their caring responsibilities, they had valued the time spent together. A father described this as follows "all of the sudden, it falls away [full time care responsibilities], and perhaps I found that harder than my son, I don't know. But I missed it [caring for son], and still do actually" (Daniel).

Most parents felt nothing significant had changed in the relationship with their offspring after the move. They said they remained close and were there for their offspring, to protect their wellbeing and to be the mainstay of their support. One mother said that the bond between her and her son had become even closer. The majority of the offspring continued to return to the family home on a regular basis, usually every weekend, and parents regularly visited their offspring in their new home. The only exception was the son of a father who needed specialist aids at home. As the aids had been moved to his son's new accommodation, his son could not come home and his father had to visit him at his accommodation. Parents appreciated when the service was flexible about when parents could visit and when their offspring could stay at the family home and enjoyed time spent together "when my son comes home on Fridays and pops his head around the door, oh I love that moment. Lovely, he's back again [...] with his bits and pieces, how lovely" (Helen).

An unstructured process

The overall process of finding a suitable accommodation was described by most parents as unstructured and characterised by a lack of information. A few parents mentioned that they found the number of available options overwhelming. "Then you end up in [city] where there are a thousand different options. How are you supposed to find what you're looking for? I really struggled and have felt very lost" (Helen).

As a result, some parents felt that they might not have known all the available options for accommodation and worried that they might have missed a more suitable place for their offspring. "Look, when I call people or organisations, they give you information, but I then have to put the pieces together. But the thing is, I don't know how many pieces there are" (Barbara).

The majority of the parents who put their offspring on a waiting list for a particular service or house, said they had prepared themselves for a long wait. However, most parents found that the wait was shorter than they had expected it to be. Once a place became available, it took an average of 5 months from the moment a place was accepted to their offspring moving in. Some parents did notice the residential facility wanted an answer relatively quickly (i.e., within a few weeks) whether they accepted the accommodation. Most parents acknowledged and sympathised that this was due to financial reasons (i.e., the accommodation losing money when a room is not filled). Parents very much appreciated that after the move, offspring were able to go home during the weekend and stay at the family home if

they wished to do so. By doing so, both the wishes of the families and the residential facilities were met.

It was notable that parents were surprised by the short wait. Most had counted on a wait of at least 2 years, but most accommodations were available within 4 months. This caused some parents to feel the move was happening too quickly. Two parents said they had declined the first offer of accommodation because they felt that it happened too quickly. One parent said she accepted the first offer, as she worried if she turned it down, she'd have to wait several years before another place opened up.

A number of parents did not feel they had received sufficient support during the application process for the Long-term Care Act. Three parents mentioned they had struggled during the application process. These three participants experienced additional difficulties, as they had to apply for continuing statutory support through the Long-Term Care Act when their offspring turned 18 years of age. Parents experienced a lack of information about the Long-Term Care Act and the application process, causing uncertainty and worries related to the need for continuing support for their offspring. Despite this being a crucial transition in the care for people with intellectual disabilities, all these parents said they felt they had to rely on their own resources (i.e., knowledge of the system, ability to get information) to complete the application process. Reflecting on these experiences, the parents thought that the process could be even more difficult for other parents who may have been less familiar with the care system or less able to seek expert help, if needed. Consequently, they thought that accessible information should be available about different types of accommodation and services, and sufficient support should be offered during the application process.

Advantages and challenges of the move for offspring

Once their offspring had moved out, some parents noticed the positive impact the move had on their offspring. Three parents explicitly described how moving to their new home had made their offspring more independent. For example, a mother said that when her daughter was still living at home, she would help her daughter when she performed tasks and often tended to take over. At her daughter's new home, support staff encouraged her daughter to do things for herself.

On the other hand, two mothers of offspring with mild intellectual disabilities described the struggle their sons had experienced since they had moved out. Both mothers described their sons wished to become less dependent on support of others. However, the

mothers felt that their sons would need continuing support with everyday tasks (i.e., cleaning the apartment) and handling finances. They wanted the support staff to support their sons to manage their daily lives. The mothers expressed they wanted to be able to enjoy a parent-child relationship and relinquish this part of their caregiving role to avoid confrontation. Furthermore, they felt it would be more pleasant for their sons if someone else took over this role. "At a certain age, you do not want your mother to tell you how to do things. It is better when other people can help you" (Barbara).

Acknowledging the needs and role of parents

Parents greatly valued when staff at the accommodation were considerate of the parents' feelings and expressed they understood this was an important transition. For example, parents found it helpful when staff consulted them about financial considerations with regards to their offsprings' move and the transfer of budgets to the new service. This more collaborative approach gave time for the parents to adjust, as well as for their offspring.

For all parents, the move was easier when they had good contact with support staff about the care and needs of their offspring. The parents felt that when support staff were open to their views and valued their input and knowledge, they felt more at ease with their offsprings' moves out of their family homes. Furthermore, parents appreciated when support staff valued family relationships and made sure these were supported and acknowledged.

What's really helped us since our son's moved out is the contact we've had with support staff. Right from day one, they've sent us pictures and video called us and they've really made an effort to preserve our bond. (Brad)

This acknowledgment also helped parents to feel that their offspring was receiving sufficient care and support.

Finding the right place: A continuing process

Two fathers had moved their offspring from the first placement they had been given, and one mother expressed doubts about the accommodation her son had moved to and had put him on a waiting list for a different place. One of the fathers was worried that his daughter was not receiving the mental stimulation she required. He knew she needed tailored support and noticed it was difficult for some services to provide that support. Worries about her wellbeing and development caused him considerable distress, "when you know your child's not in the right place, it drives you crazy.

Then you could say, why not take her home, but that's no solution either" (Chris).

The other father also reported that his son had not received appropriate support. He felt that the staff had failed to properly grasp his way of communicating. On several occasions, when he had taken his son back to his residence, his son had refused to get out of the car.

[...] He refused to get out of the car, he never does that. [...] But there [at son's accommodation] he would shut the door and refuse to get out, it was horrible to see him like that and to leave him [at the accommodation]. Daniel

One mother reported that the care which had been promised for her son had not been delivered. She had been promised that someone would be available 24/7, but quickly found out staff were often unavailable. Furthermore, concerns about the fire safety of her son's room had not been addressed in a timely manner. Her son's main support worker had also failed to put a support plan in place for him. All of this had left the mother concerned about her son's wellbeing and the quality of his support.

When parents felt that the accommodation was unsuitable or causing their offspring distress, they wanted to find another place where their offspring could be happy and could stay long-term. It was not an option for them to let their offspring remain where they were.

Discussion

This study examined the steps taken by parents when planning the move of their adult offspring with intellectual disabilities out of the family home, as well as their emotional experiences during this process. A content analysis was conducted concerning the steps undertaken during this process and a thematic analysis concerning their more in-depth emotional experiences during this period. The results of the content analysis showed that all parents initiated the search for suitable accommodation when their offspring was reaching adulthood ((+/-)18 years old). In line with Grey et al. (2015), they supported and encouraged the move of their offspring out of the family home. Parents presented several reasons for beginning this process, such as offspring wanting to move out, protecting the parent-child relationship, and avoiding other siblings having to take over the care of their offspring with an intellectual disability. In line with previous research, parents in the current study wanted to achieve a better quality of life for both their offspring (Schwartz, 2005) and themselves (Grey et al., 2015).

In the current study, parents did not find that there was a lack of available housing, as highlighted in studies

from other countries (e.g., Chadwick et al., 2013; Grey et al., 2015), or within the Netherlands for people with intellectual disabilities who do present challenging behaviour (Den Boer et al., submitted). However, there did not seem to be a structured process to support the person's move out of the family home. All parents had managed to find accommodation for their offspring, but some parents found that there was a lack of information and professional support during the search for suitable accommodation. This is in line with findings from Grey et al. (2015) and Roos and Søndena (2020), who observed that parents had difficulties collaborating with housing staff and that there was a lack of information regarding waiting lists and available housing. In the current study, most parents had expected a longer wait and were surprised by how quickly places opened up. As a result, some parents felt that the move happened too quickly. Furthermore, parents were not always able to find suitable accommodation near the family home, resulting in their offspring having to move a considerable distance away. This was especially difficult, as parents wanted to have their offspring live close to the family home. Lastly, some parents found the application for the Long-term Care Act was time-consuming and experienced a lack of support and timely information. In sum, these results are in line with previous studies, which have shown that parents face barriers during times of transition due a lack of information and support (Brown et al., 2020; Roos & Søndena, 2020).

All parents in this study played a leading role in arranging their offspring's moves out of their family homes, but there were differences as well, depending on the person's level of intellectual disability. For example, most of the offspring with mild to moderate intellectual disabilities indicated they wanted to move out themselves. Whilst parents of offspring with more severe intellectual disabilities said they started the search because the burden of care was becoming too intense. Furthermore, parents of offspring who were able to voice their own preferences said their offspring's input to choosing the accommodation reassured them that they were making the right decision. Parents of offspring who were less able to express their wishes experienced more uncertainty during this process. The different needs of offspring and resulting challenges for parents are an important consideration. There is a balance to be achieved between parents' own wishes with a need to respect the autonomy of their offspring (Vereijken et al., 2022).

Results from the thematic analysis highlighted that, in line with previous research, their offspring's move from the family home in most cases enriched the lives of both the parents and their offspring, with

opportunities for the parents to enjoy their newfound relief from caring duties (Seltzer et al., 2001), and opportunities for the individuals with intellectual disabilities to become more autonomous (Midjo & Aune, 2018). However, in the current study, not all parents expressed an overarching feeling of wanting to let go of all care responsibilities. In some cases, a desire to maintain a key role in the support for their offspring was highlighted. This was reflected, for example, by the decision of some parents to keep some of the formal care responsibilities. Furthermore, besides stating they valued the relief from the burden of care, they also said they missed caring for their offspring. This study adds to existing literature, by highlighting the varying wishes and needs of parents related to their desired place in the support for their offspring. This is a valuable insight for future research exploring the roles parents continue to play in the care for their offspring once they have moved out and how this need can be met.

Parental relationships with care staff in their offspring's new home were also crucial to the perceived success of the move. Parents felt more at ease with the move of their offspring when support staff acknowledged their needs (e.g., keeping them informed, being easy to reach) and their continuing role in the lives of their offspring. However, as has been raised in previous studies (Bright et al., 2018; Jansen et al., 2017; McKenzie et al., 2018), parents also reported negative experiences with support staff, such as a lack of effective communication and lack of trust in the care provided. Signs that their offspring were not receiving sufficient support caused parents anxiety about the wellbeing of their offspring and made it difficult for them to step back. Even though some parents reported worries about their offspring's wellbeing due to a lack of appropriate support, in contrast to previous studies (Chou et al., 2009; Taggart et al., 2012) the parents in this study did not mention abuse or neglect related concerns for their offspring. However, this may be because this topic was not explicitly addressed during the interviews.

In line with other studies, lack of trust and communication with support staff increased parents' sense of responsibility for their offspring, in contrast to what they might have expected to happen after their offspring's move (Bright et al., 2018). A study by Vereijken et al. (2022) showed that a history of service concerns, continued difficulties to establish genuine partnership, and dissatisfaction about the support for their offspring living outside the family home caused parents to struggle to find their place in the care for their offspring after they had moved out. The experiences of parents with support staff and the residential facility their offspring moves to are important as this

may impact how parents adjust after the move of their offspring out of the family home.

This study highlights the practical and emotional challenges of arranging the move from the family home. Moreover, the study suggests a disconnect between services' wish to take responsibility for the care for their offspring and the parents' wish to remain involved in their offsprings' care. Current research into the experiences of parents planning the move of their offspring out of the family home has highlighted important challenges related to the lack of available and suitable housing (Chadwick et al., 2013; Grey et al., 2015). This study adds to existing literature, by showing the need to explore the desired role of parents in the lives of their offspring after they have moved out.

Furthermore, the study highlights the importance of professionals considering that the move out of the family home is an emotional process for parents. More awareness of the impact of this process and the experiences of parents after their offspring has moved out is important to support parents and provide them with the necessary information for them to be able to sufficiently support their offspring. Sufficient support and information may help parents be less hesitant to arrange future care (Taggart et al., 2012). Future research in other countries and other living arrangements should explore the needs of parents further, to support a satisfactory transition for all involved and support future planning.

The findings from this study have a number of implications for practice and research. Firstly, to allow parents and their offspring, regardless of the level of intellectual disabilities, to be involved in the move, it is important that parents know what planning this move entails, what accommodation is suitable for their offspring, how waiting lists work, and where they can find adequate information and support. Isaacson et al. (2014) found that gradual preparation and clarity about the planning of the move helps to support the involvement of people with intellectual disabilities, whereas uncertainty impedes the inclusion of people with intellectual disabilities in the planning process of moving out. In this respect, it is important to explore how to include people with intellectual disabilities in planning their move out of the family home. Previous research has shown that even though people with (mild) intellectual disabilities have indicated that they want to be involved in the search for a suitable accommodation (Cahill & Guerin, 2023; Isaacson et al., 2014) only a minority of people with intellectual disabilities are actually involved (Leonard et al., 2016).

Lastly, it is important to recognise the needs and role of parents. Difficulties in establishing genuine

partnership with support organisations and dissatisfaction about the support that their offspring receive in their new homes, strengthened parents' resolve to remain involved in their offsprings' care and can shape the role parents continue to play in the life of their relative with intellectual disability (Bright et al., 2018; Vereijken et al., 2022).

This study makes an important contribution to our knowledge about the move of a person with intellectual disabilities out of the family home. Specifically, it provides insight into parents' experiences of planning the move of their offspring from the family home. Nevertheless, consideration should be given to some limitations. First, all parents in this study were well-educated, which limits the relevance of the findings. Therefore, future research on the move out of the family home should include parents from more diverse backgrounds. This is important, as previous research indicates that people occupying lower socioeconomic positions may have more difficulty accessing the information and support they need, especially at times of transition (Brown et al., 2020; Emerson & Hatton, 2009). Second, this study only includes the perspective of parents. As research has shown the importance of including people with intellectual disabilities in decision making about where and with whom they live (Cahill & Guerin, 2023), future studies should also include the perspective of people with intellectual disabilities. Finally, this study has focused on the transition to accommodation that provides 24-hour care. Future studies should examine the transition to different types of accommodation (e.g., parent-led organisations, community living) to explore possible differences in the experiences of parents and people with intellectual disability regarding the move to different types of accommodation.

To conclude, parents encounter challenges when supporting their offspring moving out of the family home. Participating parents planned the move out of the family home for a better quality of life for their offspring and for themselves. The process of moving out seemed to be unstructured, with parents experiencing varying levels of information and support. Finding suitable accommodation had a positive impact on both the parents and their offspring. However, disappointing experiences with support staff or the residential facility left some parents feeling uncertain and worried about their offsprings' wellbeing, and in some cases led to moving their offspring on to a different setting. The current findings highlight the need for parents to receive timely information and continuing support through this complex and emotionally challenging process.

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